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SHELTERED WORK AND INTELLECTUAL DISABILITY EQUALITY: CAN THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES TACKLE THIS FORM OF SEGREGATION?

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IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

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Abstract

This thesis is a theoretical study that addresses the enduring segregation of people with intellectual disabilities in sheltered work environments. Having identified that many people with intellectual disabilities remain in such institutions, the study addresses this problematic practice by reviewing the available literature on the subject. This review finds that sheltered work is an approach to employing people with disabilities that is replicated across the globe in some shape or form. Although strict definitions of sheltered work are difficult to agree on, these typically function as a type of institution and serve to exclude certain groups from participating fully in society. It is argued, therefore, that due to its segregated nature, sheltered work possibly constitutes a form of discrimination on the basis of disability that perpetuates intellectual disability inequality.

Having identified continuing concerns with the practice of sheltered work, this thesis investigates how, from an equality perspective, the subject has remained largely unchallenged. The research finds that this lacuna is rooted in the common perception that most persons in sheltered work are regarded as fundamentally unequal. By exploring the liberal tradition of equality, which assumes that only eligible persons have an equal right to liberty, and by applying Rawlsian thought to the governance of societies, this research considers how members of society enjoy citizenship and rights. It is argued that people with intellectual disabilities are considered unequal, as they are incapable of engaging in the implicit social contract. Despite the evolution of the concept of equality over time, subsequent approaches to equality have failed to adequately embrace intellectual disability.

It was envisaged that the UN Convention on the Rights of Persons with Disabilities (CRPD) would help rectify the many persistent inequalities faced by people with disabilities. This study then explores its potential to achieve intellectual disability equality and examines its impact on sheltered work. The future of these work settings is considered by exploring how the CRPD can be interpreted in regard to sheltered work, using three pivotal sources: the travaux préparatoires, the State Reports, and a General Comment prepared by the Committee on the Rights of Persons with Disabilities (CmRPD). This analysis has revealed that, despite its noble intentions, the CRPD is nevertheless a product of law and exists within the confines of existing binary tensions - between international and domestic levels, civil and political and socio-economic rights, and rights and protection. As a result, the CRPD's ability to effectively challenge the practice of sheltered work is potentially limited. This is because the concept of equality it operationalises is not sensitive enough to specifically target segregation in sheltered work as a form of discrimination. Furthermore, the CmRPD has not sufficiently clarified its interpretation of the CRPD in relation to its application for sheltered work. This thesis proposes a more appropriate, intellectual disability-sensitive, model of equality that is based on a human rights model of disability.

Statement of Original Authorship

The work contained in this thesis has not been previously submitted to meet the requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Signature: _____

Date: _____

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Thank you.

'People with cognitive disabilities are equal citizens and the law ought to show respect for them as full equal citizens. Now we must take the most controversial step of all, giving people with disabilities, [...] rights on the basis of genuine equality, [...]. Let the debate begin'.[1]

[1] Martha C. Nussbaum, 'The Capabilities of People with Cognitive Disabilities', (2009) 40(3) *Metaphilosophy,* 331-351.

Chapter 1: Introduction and Methodology

1.1 INTRODUCTION

Many people with intellectual disabilities remain segregated in sheltered work settings. As a result, they experience social exclusion and discrimination, amongst numerous other negative effects of such placements. Sheltered work, not only, presents as a barrier to inclusion, and distorts the enjoyment of rights on an equal basis with others, but also fundamentally constitutes a persistent form of inequality and must be confronted. This argument is, however, not straightforward. Firstly, as an institution serving multiple roles, the sheltered workshop is difficult to define and differentiate from other services. Secondly, approaching the concerns surrounding intellectual disability by using an equality framework is notoriously difficult; this is due to an inadequate theorisation of equality as it relates to this group.[2] Indeed, this thesis recognises that it is their very exemption from any equality debates that has caused their segregation in sheltered workshops to remain largely unchallenged. This discussion therefore introduces the UN Convention on the Rights of Persons with Disabilities, (CRPD) to this debate and assesses its ability to tackle segregation in sheltered work settings, and as a result, its potential to effect change in the lives of people with intellectual disabilities. Specifically, this thesis explores whether, unlike previous equality models, the CRPD's vision of equality can categorically frame segregation in sheltered work as a form of discrimination and satisfactorily formulate intellectual disability equality.

Mounting this challenge of sheltered work policies is long overdue. These measures have historically placed people with disabilities on a 'side track' and are no longer acceptable in light of cultural, ideological and legislative changes in disability policy.[3] Sheltered work must be examined in terms of its compatibility with the aims of modern disability policy that increasingly implements a rights-based approach to service provision.[4] While some call for legal clarity for persons with disabilities working in the sheltered sector, this thesis seeks legal clarity over the legitimacy of the sheltered work

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[2] Also noted by leading scholars, for a discussion see: Eva Feder Kittay and Licia Carlson, (eds.), *Cognitive Disability and Its Challenge to Moral Philosophy,* (Wiley-Blackwell 2010).

[3] Kai Leichsenring and Charlotte Strümpel, 'Employment policies for people with disabilities in Austria, Vienna', (European Centre for Social Welfare Policy and Research, 1995), cited in Martin, T. & Associates, 'Review of Sheltered Employment: A Review of the Literature', (2001), 40.

[4] Erik Samoy and Lina Waterplas, 'Sheltered Employment in the European Community', (Katholieke Universtieit Leuven & Hoger Instituut voor de Arbeid, 1992), 40.

sector as a whole, using the CRPD.[5] This study identifies that there is indeed little legal commentary addressing sheltered work and the CRPD, specifically its Article 27, on work and employment. As a result, multiple interpretations of the CRPD's position as either endorsing or condoning sheltered work have surfaced. By addressing this lacuna, this thesis finally clarifies the CRPD's impact on the subject and assesses whether its revised equality compass can truly effect change for all people with disabilities by protecting them from discrimination in all forms of employment, as promised in Article 27.

Overall, this thesis maps the widespread use of sheltered work policies and critically examines their impact on achieving intellectual disability equality. It calls into question the continued use of such measures and examines their legitimacy in an era where the segregation of people with intellectual disabilities is beginning to be systematically criticised. Having identified that this form of inequality remains unchallenged due to, in part, and inadequate theorization of equality in the context of intellectual disability, a solution is offered. A key contribution of this research is then the new model for inclusion that is presented in the penultimate chapter. This model is sensitive of the difference of intellectual disability and targets the justification of segregation as part of this experience. The proposed inclusion model for intellectual disability equality increases our knowledge of equality and expands the concept to include one of the most marginalised groups in its scope.

1.2   THESIS OUTLINE

This research is divided into 3 Sections, each with a specific focus. The first section introduces the reader to sheltered work, its history and the problems it presents. Section 2 explores the evolution of equality in the context of intellectual disability to understand how such segregated policies have remained so popular. Section 3 introduces the CRPD and considers its impact on challenging segregation by exploring its consequence for the practice of sheltered work. On the basis of some identified limitations present in the CRPD, Chapter 8 then suggests a new, more appropriate Inclusion Model to achieve intellectual disability equality, before concluding the study. First, however, this chapter will continue to introduce this thesis and proceed to present a vignette of a typical experience of a sheltered worker in 'Francesca's story', followed by a discussion of the methodology used.

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[5] European Association of Service providers for Persons with Disabilities, 'EASPD Employment Declaration', (2014). Important to note here, is that this thesis switches between the phrases: 'people with disabilities' where a group is referred to and 'persons with disabilities' where individuals with a disability are implied.

1.2.1. What is sheltered work and why is it problematic?

Section 1 will be comprised of two chapters that provide an overview of sheltered work on the basis of an extensive literature review. This section will lay the foundation for our understanding of the term 'sheltered work/workshops', which will prove vital in establishing a common definition used in this study. Chapter 2 will look at the origins of the practice and the history of institutions for people with intellectual disabilities in general. With the help of the literature review, which draws on international research findings, Chapter 3 will distil some of the common concerns intrinsic to the practice of sheltered work. As a central theme of this research, the differential treatment of people with intellectual disabilities occurring in sheltered workshops is highlighted. Section 1 therefore concludes that sheltered work practices are problematic but remain a popular policy implemented in most Western states. This section establishes, however, that sheltered work potentially constitutes human rights violations, based on the resulting experiences of segregation and exclusion which must be recognised and challenged as a form of inequality experienced predominantly by people with intellectual disabilities.

1.2.2. Equality and intellectual disability: The manifestation of segregation

Section 2 aims to understand how policies that effectively keep people segregated from others, such as sheltered work services, have remained largely uncontested from a rights perspective. This discussion identifies that this is largely based on the position of people with intellectual disabilities in society. Section 2 comprises 2 chapters that guide the reader through the related discourses, familiarising them with the seminal discussions around the intersections of intellectual disability, equality, discrimination and segregation. Chapter 4 begins by exploring how Western democratic society has generated a notion of rights that is rooted in liberal ideals of justice. An essential component of this philosophy is the assumed ability of all members of society to act according to a social contract. Understanding how liberal theory and social contract theory influence our modern conception of equality is then pivotal when considering intellectual disability. An exploration of Rawlsian thought reveals that only people who are able and willing to cooperate and who, therefore are viewed as reciprocators, are included as worthy participants in the social contract and become eligible for rights. Those unable to demonstrate cooperation and the ability to enter into the hypothetical bargaining that takes place as part of this, are excluded.

Chapter 5 then considers how these criteria, required to benefit from laws, underpin the design of equality models that are applied to regulate society and social relationships. A discussion on the evolution of these models reveals that they are largely unable to include people with intellectual disabilities in their scope. Despite their aim

of rectifying past transgressions and reversing certain persons' ineligibility for rights, the 'difference' of intellectual disability presents as being too difficult to be overcome using existing equality tools. I argue that this is because these tools are influenced by the liberal ideals that favour certain capable individuals, as well as hegemonic notions of merit and adaptability. As a result, this group's underlying ineligibility for rights is upheld and their unequal treatment is sanctioned. Moreover, this failure of traditional models to include people with intellectual disabilities, has maintained their segregation and exclusion from shared spaces such as the open labour market. The unchallenged nature of sheltered work practices is then arguably a result of a failure to recognise intellectual disability inequality. Moreover, based on the concerns listed in Section 1, segregation in sheltered work is arguably a moral failing, considering the negative repercussions attributed to such placements. Indeed, paired with the findings from Section 2, sheltered work is potentially a form of inequality, which, as discussed in Chapter 5, has persisted as a policy measure because people with intellectual disabilities are still fundamentally regarded as unequal compared to non-disabled persons.

1.2.3.   What version of equality is embedded in the CRPD and what is its impact on sheltered work?

Section 3 of this thesis is dedicated to understanding the impact of the CRPD on the issue of sheltered work, thereby estimating its ability to effect change for people with intellectual disabilities. As a product of lengthy and concentrated negotiations, the treaty represents possibly the most pronounced manifestation of a consensus on equality, in terms of its meaning and implications, available at an international level. Chapter 6 explores the vision of equality pursued in the CRPD, considers this in relation to achieving intellectual disability equality and its potential to combat segregation as form of discrimination. The wording of the treaty is considered in more detail with specific attention to Article 27, on work and employment, as the topic of sheltered work is primarily discussed in relation to this article. The CRPD's negotiation archives offer some insight into the omission of any reference to sheltered work throughout Article 27 and the entire CRPD.

Chapter 7 draws upon jurisprudence by the Committee on the Rights of Persons with Disabilities (CmRPD) as vital interpretative sources to clarify the meaning of the CRPD in relation to sheltered work. In the Concluding Observations and General Comment No. 6 on equality and non-discrimination the CmRPD specifically identify the problematic issue of sheltered work and apply the CRPD's equality tools to the debate. This chapter discusses the fact that these interpretations are not unproblematic and reveal limitations of this new rights framework in achieving intellectual disability equality. This section concludes by questioning whether the CRPD's equality dimensions are able to meaningfully challenge sheltered work practices as a form of discrimination. This examination of the CRPD ultimately supports the arguments that existing equality concepts need to be revisited in light of their relevance in securing the

rights of people with intellectual disabilities to lead self-directed, autonomous lives of equal concern and respect. [6]

Chapter 8 rounds off this thesis by introducing a new Inclusion Model for intellectual disability equality. Having explored the roots of exclusion, the limits of traditional and current equality theories, as well as that pursued in the CRPD, this study finds that a specific model that is sensitive to the intricacies and experience of intellectual disability is required. This chapter devises an equality approach that satisfactorily includes people with intellectual disabilities by referring to the basic promise of human rights in general, which lies in ensuring dignity. A seminal argument made here, is that segregation in sheltered work arguably violates people's dignity. Inclusion is then framed as a remedy if harnessed correctly. A similar approach is also reflected in the recent General Comment No. 6 on equality and non-discrimination, in which the CmRPD introduce 'inclusive equality'.[7] However, my Inclusion Model goes further by suggesting that inclusion is both a right *and* a method of equality and I present a 4-pronged approach to formulating intellectual disability equality.

The concluding chapter of this thesis reiterates the most important findings from each of the three sections. Chapter 9 also lists some of the research limitations before indicating future research avenues based on the findings. Next, this chapter contextualizes the research by contemplating its overall contribution to disability rights research, followed by some important policy recommendations. Lastly, the take-away message for the reader is offered in some closing words.

1.3   'FRANCESCA'S STORY'- A VIGNETTE

A vignette, as a written illustration of a research issue, is typically used in psychological and sociological experiments and, more recently, in socio-legal research.[8] Vignettes often comprise a narrative depiction of a hypothetical or real-life situation preceding the presentation of research to contextualise the subject matter. Here, a vignette was identified as a useful tool to provide an unobtrusive depiction of a problematic experience. An exposé of the research problem in this manner offers a descriptive overview of the lived experiences of a sheltered worker. In this instance, a personal motivation behind the research also contributed to the decision to include her sister's experience as a template. Francesca's story is presented as a vignette for this research

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[6] It is important to note that I is indeed aware of the many effective and innovative inclusive employment programmes sprouting across many States. Certainly, a multitude of projects are underway that operate on the basis of supporting people with intellectual disabilities into open employment on the supply side, and on creating more inclusive labour markets on the demand side. However, as will be discussed herein, these are far from becoming the mainstream, default approaches to disability employment/social policy adopted by States and remain in their infancy and related projects rarely develop past the pilot stages.

[7] UN Committee on the Rights of Persons with Disabilities (CRPD), General comment No. 6, (2018), Article 5: Equality and Non-Discrimination, 26 April 2018, (CRPD/C/GC/6).

[8] Paul Lavrakas, 'Vignette Question', in Paul Lavrakas, (ed.), *Encyclopaedia of Survey Research Methods,* (Sage, 2008).

and is used here to symbolically represent the segregation in sheltered work typically experienced by people with intellectual disabilities across the globe.[9]

My research interest in this topic stems from personal and professional experience of sheltered workshop practices, both as a social worker and as the twin sister of a sheltered worker. Francesca works in a sheltered workshop in Germany, which she has attended daily since the age of 18. Francesca works from 8am to 4pm, 5 days a week, and conducts assembly line labour that is contracted into her workshop (run by a large charity with religious foundations) by commercial companies such as IKEA and other local industries.[10] The sheltered 'workshop' has recently been renamed a 'studio' to update its brand and dissociate it from the negative connotations attached to the former. The 'studio' prides itself on its ability to provide employment for a range of people with different needs and on how closely its working conditions emulate those of any regular work environment.[11] As a participant in the sheltered workshop programme Francesca works under the direction of and is accountable to a supervisor who oversees production. Holidays must be requested in advance and are granted at the discretion of her supervisor and under consideration of the impending workload as, after all, targets must be met. A doctor's note is required after an absence from the workshop of more than 3 days and participants must collectively elect a representative to the workshop's governing council, similar to processes under which labour and trade unions operate.

Although these working conditions emulate those of a regular, fully-fledged employee, a sheltered worker's legal status under German social law differs considerably. Sheltered workshop activity is not recognised as an employment relationship and is excluded from the statutory minimum wage. Instead, the sheltered worker is employed under a contract of rehabilitation and different rights and obligations govern this relationship, regardless of the fact that the duties are almost identical and the commercial nature of work. Perhaps the most drastic disparity between these two statuses lies in the payments received. Regardless of her productivity and the economic value of her work, Francesca's monthly payslip never exceeds €180.[12] This is because the amount of remuneration is stipulated in the rehabilitation contract which all sheltered work placements are subject to, and is considered a form of compensation rather than a wage. Disability advocates fed up with this form of institutional discrimination have queried the legal status of workshop participants compared with other workers and

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[9] Consent was obtained to include Francesca's story herein, (see Appendix A).
[10] The German sheltered workshop system is very well established with over 700 separate companies set up as charities or non-profit organisations across 3000 individual sites. These employ over 300,000 people, 75% of whom have an intellectual disability. Bundesarbeitsgemeinschaft Werkstaetten fuer behinderte Menschen e.V., 'The System and Services of Sheltered Workshops in Germany', (2018), 5. (Federal Working Group for Workshops for Disabled People, translation by Author).
[11] For more information see: Evangelisches Johanneswerk, 'Studijo, work and qualifications', (2019), [online], available at: <https://www.johanneswerk.de/angebote/menschen-mit-behinderung/studjo-arbeit-und-qualifizierung/> (accessed 14 August 2019).
[12] n 10, 12.

challenged the lawfulness of their differential treatment in terms of pay. These attempts have however been quashed in the labour courts.[13]

Besides highlighting the institutional discrimination that determines the working lives of many adults with intellectual disabilities, Francesca's story shows how the experience of segregation pervades every aspect of their lives. Often, an entire system of entangled services for people with intellectual disabilities is offered via separate institutions that exist in parallel to mainstream service provision. Education, residential and day services are highly segregated and run in close cooperation with the sheltered workshop programme. In Francesca's case, the segregated school she attended operated as a direct pipeline of former pupils into the sheltered workshop, with no alternative options available. On graduating from 'special school', Francesca was immediately placed in the nearest sheltered workshop, irrespective of possible alternatives and without any attempt to reflect on Francesca's wishes, explore any career aspirations or any broader ambitions for life.

Once placed in the sheltered workshop, the likelihood of finding employment in the open labour market is low. Despite many placements being initially made under the pretence of being a temporary measure to train individuals and make them 'job ready', participants rarely leave the sheltered workshop. Instead, they are stuck in an endless loop of rehabilitation and training although effectively contributing to the workshop's commercial output. Challenging this aspect of sheltered work in particular, the complainant in the case noted above claimed that after more than 10 years of doing the same tasks he could now be considered rehabilitated and his work recognised as such.[14] In Francesca's case she was offered a 2-year training course during which she participated in various work placements at different stations throughout the workshop. This training programme was intended to support Francesca in finding out which skills she could develop for the benefit of the institution. The training took place entirely within the confines of the sheltered institution: in its kitchen, cleaning unit, and carpentry and gardening teams. No alternative training, outside of the workshop was offered with no individual skills coaching or transition plan into employment on the open labour market since.

The supervisor overseeing the commercial contracts outsourced to her working group explains that, in fact, a mandate has been imposed on the sheltered workshop by regional authorities to integrate workers into the open labour market. An annual quota to transition 10% of sheltered workers into open employment has been set.[15]

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[13] ArbG Kiel, 19.06.2015 - 2 Ca 165 a/15.
[14] Ibid, para. 2.
[15] Deutsches Institut fuer Menschenrechte und Susanne Krowosh, 'Analyse: Menschen mit Behinderungen in Nordrhein-Westfalen: Zur Umsetzung der UN-Behindertenrechtskonvention in den Bereichen Wohnen, Mobilität, Bildung und Arbeit, (2018), (German Institute for Human Rights, 'Analysis: People with Disabilities in North-rhine Westphalia: Implementing the UN Convention in the areas of Living, Education and Work', translation by the Author), [online] available at:

Regrettably, this quota is never met as the workshop receives no extra staff or resources to support this endeavour. Moreover, the sheltered workshop is keen to retain its best, most productive workers to fulfil their contracts and maintain the facilities. Therefore, those most likely to transition successfully are held back in the interest of preserving the workshop, ensuring production rates and maintaining the institution. Additionally, the sheltered workshop receives a public grant on a per capita basis, which is a vital source of funding besides contracted work. As a particularly adept and quick learner, Francesca is an efficient worker of particular economic value to the workshop and her supervisor declares that, 'Francesca runs the place, so we cannot afford to lose her'.[16]

Besides very limited supports and programmes geared to finding employment on the open labour market, other factors also operate as pull factors in retaining the workshop population. In the German social welfare system, benefit and income support payments to individuals with intellectual disabilities are enmeshed with sheltered workshop placements and are conditional on workshop attendance. As a result, many are reluctant to pursue mainstream forms of training or open employment for fear of losing their entitlement to these payments. Effectively, the social service system and related income packages for people with intellectual disabilities operate to keep people dependent on segregated institutions. The concern that Francesca would no longer be eligible for the package of benefits, along with her wish to stay amongst friends from school, were the principal factors in her decision to take up the placement.

Francesca has now been in the sheltered workshop for 15 years and is fully immersed in the institution's economic and productive system, including its social dimensions, every aspect of which operates and exists alongside but is never part of mainstream society. As a result, workers in the sheltered workshop have formed their own sub-culture. As a result of their institutionalisation, the sheltered workers are part of a separate community and lead separate lives. Even the public bus that takes them to their isolated factory on the outskirts of town is branded by townspeople as the 'Sheltered Workshop Bus', crudely marking its otherness. Painfully aware of their difference and the ascribed label, Francesca and her and co-workers have begun to refer to themselves as the 'special workers' on the 'disabled bus'. Reports of bullying and harassment by non-disabled commuters on the public transport systems used by sheltered workers are not uncommon. Together, these factors have an undeniably negative impact on the lives of persons with intellectual disabilities, affecting their mental health and well-being. It is not surprising then that last year saw the second suicide by a fellow sheltered worker during Francesca's time there.[17]

<https://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/Publikationen/ANALYSE/Analyse_Menschen_mit_Behinderungen_in_NRW.pdf> (accessed 20 January 2020).

[16] Personal correspondence with foreman Dirk H.

[17] A young man had hung himself in the workshop kitchen.

Francesca lives with our mother, who had reservations accepting the placement in the workshop on Francesca's behalf (a guardians' approval to enter into the rehabilitation contract is required). These reservations were based on her dislike of an institution that gathered anyone labelled as having a disability under one roof with little access to non-disabled communities and mainstream environments. After all, the only characteristic that unites all workshop workers is that they have a medically assessed limitation to function. In all other aspects this is an entirely heterogeneous group with different characters, wishes and interests. In fact, if it were applied to any other group, this practice of sorting out and organising persons according to a shared characteristic that constitutes a minimal part of a person's identity would be seen as an archaic practice. Undeniably, this form of segregation of people along the lines of any other aggregate, such as sex, religion, social class or ethnicity, and their subsequent placement in a confined institution such as the workshop, would be unthinkable.[18] A delegation from New Zealand, during the CRPD treaty negotiations even compared the 'expulsion' of people with intellectual disabilities to sheltered workshops with the anti-semitic ghettoization of the Jewish population in Poland under the German National Socialist regime of the late 1930s.[19]

You may be wondering why so much detail about my sister's experience is provided, conveying my subjective motives for this research. Indeed, I would have previously baulked at the idea of inserting herself in the research. However, as I began to research the general concept of sheltered workshops with increased vigour, the similarities of the practices across the globe were striking. Amongst the analysis, reviews and research on sheltered work policies on a global scale it appears that Francesca's experiences seemed somewhat interchangeable with those of other individuals with intellectual disabilities. In other words, Francesca's story somewhat depicts the average experience of people with intellectual disabilities in sheltered workshops worldwide. Francesca's story, therefore, describes a typical profile of a sheltered career, representative of most individual sheltered workers' experiences.

Francesca's story has inspired this research project. Not only is hers a typical story, but it perfectly depicts the way in which people with intellectual disabilities are expelled to the margins of societies and subjected to cultural and economic poverty. More importantly however, Francesca's story describes how people with intellectual disabilities are routinely cast off and deprived of their rights owing to a widespread denial of their recognition as equal members of society. Francesca's is only one example of a career that is encapsulated in the specialised disability service system, is denied opportunities and is therefore wholly defined by the ascribed label of intellectual

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[18] Self-segregation of groups is an exemption here but by definition this is a free choice, not imposed by law, financially or because no other alternatives exist.

[19] United Nations Enable, 'Daily Summary of Discussion at the Fifth Session 3 February 2005, UN Convention on the Human Rights of People with Disabilities Ad Hoc Committee—Daily Summaries a Service Brought to You by RI', (Rehabilitation International), (2005), Vol. 6, #9; United Nations Enable, 'Daily Summary of Discussion at the Sixth Session 08 August 2005, UN Convention on the Human Rights of People with Disabilities Ad Hoc Committee - Daily Summaries, A Service Brought to You by RI (Rehabilitation International)' (2005), Volume 7, #5.

disability. Her story, then, perfectly highlights how some lives are ensnared in a fundamentally discriminatory system that operates on the basis of systemic and unchallenged inequality. This research, therefore, attempts to pick away at the largely undisputed discrimination experienced by persons with intellectual disabilities through challenging their segregation in sheltered workshops.

1.4   RATIONALE

My involvement and personal experience in sheltered workshops matched with the research findings have led to the realisation that whilst there are arguments in support of retaining disability services that support people with specifically higher support needs in separate day services and that their work is commendable, the ideology of segregation requires scrutiny. Not only do clear distinctions between occupational day services and work settings need to be made but the default placement of groups of individuals therein must be challenged: otherwise a fundamental disservice is done to a large number of people with disabilities who find themselves trapped in a system that is preoccupied with rehabilitative philosophies and commercial pressures. This is arguably the result of the homogenised (catch all) policy design and the failure to offer individualised and flexible service options that have prevailed in the disability services sector. Too often, the diversity amongst people with intellectual disabilities is ignored. This heterogenic group with differing abilities and needs is subject to one-dimensional policies with singular objectives based on low expectations concerning the abilities of individuals: as a result their yearning to hold valid and respected social roles and make meaningful contributions to society is ignored.[20]

1.5   RESEARCH DESIGN AND METHODOLOGY

As a desk-based study, the primary methodology for this research applied socio-legal research theories and methods. As a sociological phenomenon, the practice of sheltered work was analysed using primary and secondary sources of law and policy to explore the equality implications thereof. Interdisciplinary research like this is becoming increasingly popular, with a growing awareness that law is part and product of its society. As an instrument created by society, law is used to regulate the relationship and conduct between individuals, groups and institutions. Legal research aims to understand these relationships and determine the impact and effectiveness of laws and policies. Due to a growing awareness of this social contingence, legal researchers increasingly adopt research methods borrowed from other disciplines to conduct their examination. Posner identifies that in relation to research, law 'is not a field with a

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[20] Paul Milner and Berni Kelly, 'Community Participation and Inclusion: People with Disabilities Defining Their Place', (2009) 24(1) *Disability & Society*, 47-62.

distinct methodology, but an amalgam of applied logic, rhetoric, economics, and familiarity with a specialized vocabulary and a particular body of texts, practices, and institutions, (...)'.[21]

This thesis primarily employed a documentary research methodology for each section, which involves using existing documents as sources to support its analysis. This methodology is popular amongst the disciplines of history and contemporary social sciences, including legal studies. Forgoing the practice of generating primary data through interviews, statistics or other qualitative and quantitative methods, documentary methods include the categorisation, investigation and interpretation of written documents.[22] Used in law, this analysis relies on documents available in the public domain, such as state archives, case notes, judicial decisions, and legislation or government policy. Documents constitute a valuable type of data in and of themselves. They are a record of time and context, with vital information of that era and institution. Newspapers, articles, policy records, minutes and case law all constitute materials that represent ideas and ideologies of the social context from which they emanated.

Similar to Posner's account, this research draws upon specifically chosen texts and documents for each of its three sections. Section 1 aims to provide a global snapshot of the practice of sheltered work and comprises a literature review based on international research studies addressing sheltered work selected based on their relevance. Therefore, the documents used in this section consist of historic and descriptive documents, as well as research studies (both qualitative and quantitative) with an international scope. Chapter 2 also draws on the work of the prominent sociologist Foucault, who researched the use of power in regulatory systems and discussed the emergence of institutions as an outcome. Foucault's work provides a unique sociological perspective, commonly used in critical disability theory to examine disability policy.[23] His perspective on the ways in which power is exerted in institutions is still relevant today. Based on how he describes legitimised forms of oppression, his insights are unique and can be applied in the context of this research to explain the continued use of sheltered work practices. Considered in combination with the previously noted sources of literature, these works were assessed to understand the shared concerns and problematic issues associated with sheltered work. The literature used in this section was then primarily sourced from academic journals found on social science research databases. Access to these was gained through the James Hardiman Library web portal at NUI, Galway.

The scope of the literature review in Section 1 was determined by the main research focus of this section which was to provide an overview of sheltered work. For an overview of the current state of play of sheltered work, a review of the literature was

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[21] Richard Posner, 'Conventionalism: The Key to Law as an Autonomous Discipline', (1988) 38(4) *University of Toronto Law Review*, 333-354.
[22] Geoff Payne and Judy Payne, *Key Concepts in Social Research*, (Sage Publications, 2004).
[23] Shelley Tremain, (ed.), *Foucault and the Government of Disability*, (University of Michigan Press, 2005).

conducted by searching for research that addressed the topic of 'sheltered work/shops' with an international or comparative element. An initial search using the databases EBSCO host, JSTOR, PubMed and Web of Science revealed that there were very limited international or comparative studies that matched this category. Therefore, a further search was conducted that included national studies, revealing a number of research reports conducted in the U.S in particular, which are referenced in Section 1. Another reason for the limited research found is possibly the use of terminology. As discussed throughout this study, sheltered work is not only context specific and difficult to define, but it is also an outdated term, making it hard to identify research that addresses such policies and practices. However, some early discussions and dated studies of sheltered work across Europe was found and included in this overview. Although dated, these studies were included, as when matched with more recent reports, similar issues remain relevant. This is also reflected by looking at reports from international bodies such as the International Labour Organisation (ILO)_and the Organisation for Economic Co-operation and Development (OECD) in which the same issues are reported over reports from different years.

Chapter 3 also uses a collection of literature gathered from various sources and mainly focuses on the subjective experience of sheltered work. This Chapter, therefore, includes reports from self-advocates and their representative organisations found in online reports and pivotally centres the voice of people with intellectual disabilities in a direct manner. Newspaper reports are also referenced here, to give a topical and current overview of the current debates on sheltered workshops. A further source of literature used in this section saw the inclusion of journal articles discussing the purpose of institutions in the care of persons with disabilities from political and historic perspectives. Some case-law is also included where cases by sheltered workers are discussed in courts in German, Austria and Denmark. Official, national reports, where these discuss the status of sheltered workers in the U.S and the UK are also referenced to highlight some problematic issues with making this determination.

Section 2 offers a theoretical discussion of equality, to understand the ways in which laws and rights have been created and operate to categorically exclude people with intellectual disabilities from equality discourses. The intention, then, is to construe a critical, sociological understanding of the concepts of equality by tracing its development over time, using the work of equality scholars and discussing the influence of liberalist thinking on the regulation of society. Most reference materials used to compile information were sought from the reference library within the Centre for Disability Law and Policy (CDLP) at NUI, Galway. This unique collection of materials has been a critical source of information and texts. Indeed, a theoretical discussion of equality and intellectual disability is a specific sub-category within disability research that requires a tailored collection of documents. Moreover, the theoretical framework set forth in this section is grounded in human rights law and has, therefore, also fundamentally been shaped by my personal experiences and those gained working in disability advocacy and as part of the CDLP.

The third section of this thesis utilizes a further set of specific documents. Due to the focus on the CRPD, the materials published in relation to its creation, interpretation and implementation are considered. The treaty negotiation archives provided an important behind the scenes look into the discussions during the drafting of the CRPD. The Concluding Observations and General Comments published by the Committee on the Rights of Persons with Disabilities, (CmPRD) are further important sources of data on the interpretation of the CRPD and its application in practice.

The scope of this part of the document analysis was comprehensive. The treaty was drafted over the course of 4 years during 8 concentrated sessions. Each entry into the treaty negotiation archives was considered, as part of this review, along with additional supporting documents for these discussions which included position papers and statements lodged by individual States and delegates. The review of CmRPD commentary was also broad as a complex reporting process is involved. The Concluding Observations issued by the Committee are the outcome of an exchange of information and documents circulated between the State and the CmRPD. States are required to send an initial report to CmRPD upon which it reviews these and responds with a List of Issues (LOI) for further elaboration of specified issues by the State party. Only once a response to these has been re-issued to the CmRPD, does it finalise its recommendations to States in the form of Concluding Observations. As part of this process any parallel and shadow reports submitted to the CmRPD are also considered. The document analysis in Section 3 therefore, assessed each of the documents submitted under the State reporting process which is specified in Article 35 CRPD, such as the initial State reports, the LOIs and shadow reports by civil society groups. In total, the review included all the documents tracing the developments across 17 Committee sessions (4th session at which the first State report was considered held in 2010 to the 21st session held in 2019), involving the reporting cycles of 53 States, conducted between 2010 and 2019.[24]

1.5.1 Methodology- International Human Rights Law

This thesis is modelled on a human rights approach to disability. The rights-based approach identifies people with disabilities as rights holders and subjects of human rights law on an equal basis with others. It recognizes and respects a person's disability as an element of natural human diversity, similar to race or gender. This approach addresses disability-specific prejudices, attitudes, and identifies barriers to the enjoyment of human rights. Moreover, the approach places the responsibility on society and governments to ensure that the political, legal, social, and physical environments support the human rights and full inclusion and participation of people with disabilities.

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[24] For a list of which States reports were included please see the bibliograpahy.

This thesis assumes that people with intellectual disabilities are equal citizens and are, therefore, deserving of an equal recognition of and respect for their rights. Moreover, this study does not question if or why people with intellectual disabilities are deserving of the same balance of rights and protections as others. Instead, it takes for granted that as members of democratic societies and based on our shared humanity everyone is entitled to an equal concern for and respect of their rights. It is assumed that Western, liberal societies subscribe to these principles of human rights with a striving ambition to act according to the moral imperative of achieving just and equal societies. Therefore, this research postulates that States have an obligation to each and every citizen under these basic tenents of human rights law and acknowledges that the CRPD is a further impetus towards this achievement.

The UN Office of the High Commissioner for Human Rights (OHCHR) has provided a helpful analysis of the rights-based approach, stressing that the approach is comprised of two fundamental elements.[25] First, a human rights approach asks what the long-term or underlying reasons are that cause a particular group within society to experience marginalisation or discrimination. Second, the human rights approach provides strategies based on international human rights law to address these root causes of discrimination. According to this logic, this discussion, having identified the problematic aspects of sheltered work, will proceed according to this process outlined by the OHCHR. First, it will uncover the underlying reasons why people with intellectual disabilities are marginalised in society and second, assess the effectiveness of international law, (the CRPD) to address this root cause.[26]

The CRPD was chosen as a useful instrument, because, as a product of international human rights law this treaty provides a framework for an international debate on equality. The pitfalls and strengths of international law and related human rights systems are well established. Indeed, extensive literary debates questioning the effectiveness, validity and legitimacy of international human rights systems exist. As a result, the UN treaty system is subject to much international criticism.[27] Otto identifies a Western, even European, bias in human rights law and questions its general universality.[28] Hafner-Burton claims that human rights treaties fail to take effect where they matter most, and as such, bear only on stable, consolidated democracies with an

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[25] Office of the High Commissioner for Human Rights, 'What is the OHCHR methodology for developing human rights indicators?', (2019) [online], available at:
<https://www.ohchr.org/EN/Issues/Disability/Pages/EUAndOHCHRProjectBridgingGapIFAQ.aspx> (accessed 21 January 2020); see also Office of the High Commissioner for Human Rights, 'Human Rights Indicators: A Guide to Measurement and Implementation', (United Nations, 2012).

[26] Janet Lord, Katherine Guernsey, Joelle Balfe, Valerie Karr, Alison Flowers, 'Human Rights. YES! Action and Advocacy on the Rights of Persons with Disabilities', (University of Minnesota, 2012).

[27] Emilie M. Hafner-Burton and Kiyoteru Tsutsui, 'Human Rights in a Globalizing World: The Paradox of Empty Promises', (2005) 110(5) *American Journal of Sociology,* 1373-1411.

[28] Dianne Otto, 'Rethinking the "Universality" of Human Rights Law', (1997) 29(1) *Columbia Human Rights Law Review,* 1-46. For a general discussion see: Jack Donnelly, *Universal Human Rights in Theory and Practice,* (3rd ed.), (Cornell University Press, 2013).

already functioning civil society network.[29] Despite these reasoned arguments elaborating valid criticisms of human rights instruments, this research does, however, identify their potential. The CPRD, and the wider UN treaty system, do have an impact on States, making it a powerful tool for social change.

One benefit of discussions of international human rights law is that they require a negotiated, if not agreed, understanding of shared values to achieve shared goals, like equality. Once agreed, these become universal objectives and the collective aspiration of achieving these, ideally, surpasses problematic aspects of validity or applicability. States that accede to these agreed principles engage in an on-going, shared exercise of promoting and safeguarding rights. In other words, the collective attempt of ensuring equal human dignity has a unifying quality. International instruments are thus not only an important diplomatic tool but also establish commonalities and shared values between States.[30] Despite being pluralistic in nature, the process of treaty implementation has the potential to transcend differences.[31] At minimum, the concession of States to international human rights frameworks demonstrates a political choice made by governments, signalling a willingness to accept and ascribe to international human rights norms.

This consensus on universal human rights norms is then perhaps one important way in which international human rights law impacts upon the lives of people with disabilities. As a persuasive tool, then, international treaties can be used to socialize and influence States to respect and protect the rights of people with disabilities. The popular strategy of 'naming and shaming' to enforce human rights norms and laws does carry weight, making it the international treaty system's wielded axe.[32] Without questioning their sovereignty, the UN system can hold States to account in an international forum. Human rights are, thus, as much about politics as they are about achieving justice.[33] By researching the implications of the CRPD and its application then, we learn how its norms are and, ideally should be, embedded into domestic practices, improving rights internally and internationally.[34]

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[29] Emilie M. Hafner-Burton and Kiyoteru Tsutsui, 'Justice Lost! The Failure of International Human Rights Law to Matter Where Needed Most', (2007) 44(4) *Journal of Peace Research,* 407-425.

[30] For more on international relations see: David P. Forsythe, *Human Rights in International Relations,* (4th ed.), (Cambridge University Press, 2017); For more on activism see: Sally Engle Merry, 'Transnational Human Rights and Local Activism: Mapping the Middle', (2006) 108(1) *American Anthropologist,* 38-51; Ryan Goodman and Jinks Derek, 'How to Influence States: Socialization and International Human Rights Law', (2004) 54(3) *Duke Law Journal,* 621-703.

[31] Paolo G. Carozza, 'Uses and Misuses of Comparative Law in International Human Rights: Some Reflections on the Jurisprudence of the European Court of Human Rights', (1998) 73(4) *Notre Dame Law Review,* 1217-1238, 1236.

[32] For a discussion of the politics behind naming and shaming techniques see: Emilie M. Hafner-Burton, 'Sticks and Stones: Naming and Shaming the Human Rights Enforcement Problem', (2008) 62(4) *International Organization,* 689-716.

[33] Anthony J. Langlois, *The Politics of Justice and Human Rights: Southeast Asia and Universalist Theory,* (Cambridge University Press, 2001).

[34] Thomas Risse and Kathryn Sikkink, 'The Socialization of International Human Rights Norms into Domestic Practices: Introduction' in Thomas Risse, Stephen Ropp and Kathryn Sikkink, (eds.), *The Power of Human Rights: International and Domestic Change,* (Cambridge University Press, 1999).

This research recognises the potential of the CRPD to achieve disability equality, and its impact is worthy of investigation. The CRPD offers a template for change, presenting a concrete framework within which to manage reform processes. Since its adoption, the CRPD has spurred widespread activism on disability rights. The extent to which this reform process has impacted upon the lives of people with intellectual disabilities is, however, difficult to measure. Nevertheless, its most tangible effects undeniably derive from its re-envisioning of disability equality. The CRPD, therefore, must be examined for its potential to contribute towards intellectual disability equality specifically, testing whether it can help frame segregation as a form of inequality. If harnessed correctly, the CRPD could be a powerful instrument in the realisation of the universal promise of international human rights law.

1.5.2 Research limitations

This research does not generate its own original data based on an empirical investigation, which possibly constitutes one of its main weaknesses. Initially, the research process was designed to include a qualitative element based on interviews with people in sheltered work settings. The choice to ultimately refrain from this approach was, however, a purposeful and well-reasoned one, made after deliberations with the research supervisor Professor Gerard Quinn. Over the course of the initial scoping exercise for the literature review now incorporated into Section 1 of this thesis, I soon realised that a multitude of research papers and reports examining the lives of people with intellectual disabilities already exists, with valuable data readily available. Consequently, there was no need to conduct a further study, as an examination of existing research would suffice in depicting the experiences of sheltered workers.

A further factor influencing the decision to refrain from collecting data empirically stems from a concern with the research population itself. As perhaps one of the most researched groups in society, owing not only to a medical but also a sociological interest in the lives of 'others', people with intellectual disabilities have been subject to much 'poking and prodding' in the name of science. In fact, Clark identifies a so-called 'research fatigue' among disabled groups as a result.[35] Subsequently, research 'about' people with intellectual disabilities, (albeit not 'with'), exists in abundance. Given this saturation of available data then, it was decided that a further investigation was superfluous. Rather, a secondary analysis using documentary research methods, in place of a qualitative investigation, was considered more suitable and potentially more effective given that the intention was to apply an equality lens to the discussion of sheltered work.

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[35] Tom Clark, 'We are Over-researched here!'- Exploring Accounts of Research Fatigue within Qualitative Research Engagements', (2008) 42(5) Sociology, 953-970; Teresa Iacano, 'Ethical Challenges and Complexities of Including People with Intellectual Disabilities in Research', (2006) 31(3) *Journal of Intellectual and Developmental Disability,* 173–179; Rob Kitchin, 'The Researched Opinions on Research: Disabled People and Disability Research', (2000) 15(1) *Disability and Society*, 25–47.

Needless to say, the researcher is aware that people with intellectual disabilities have struggled to have their voices heard. This has culminated in significant levels of activism calling for more meaningful participation and consultation of people with disabilities in all aspects of life, including research activities. As a researcher, I am cognisant that any social change can only be achieved with and by people with disabilities. The CRPD, as an example of an inclusive and consultative process itself, is demonstrative of the participation required in disability rights research and also an appropriate source used for this discussion.[36] Indeed, the CRPD is a 'living' document that represents how, for the first time, a minority group was able to exert considerable influence on an international stage, advocating for disability equality.

Further arguments for the chosen methodology, and the decision to refrain from using qualitative techniques, were also based on the realisation that a qualitative approach would be beyond the practical remits of this research endeavour. Not only did the collection of literature and the discussion of relevant equality theory require significant attention, but the identification of relevant human rights documents and data sources, as well as their analysis, commanded a serious devotion in its own right. Furthermore, the research reveals that the *prima facie* inequalities enshrined in policy and practice are sufficient evidence to mount a challenge thereof. While an individual experience of discrimination and inequality in a sheltered workshop illustrates the points to be made, it is not essential for this argument. Using the vignette elaborating on Francesca's case as an exemplary experience suffices in demonstrating the impact of segregation in sheltered work.

1.6 'INTELLECTUAL DISABILITY' TERMINOLOGY

Of the 1 billion people with a disability globally, it is estimated that 2% have an intellectual disability, although exact figures are hard to determine based on the inconsistencies in reporting and definitions.[37] Before proceeding with this discussion it is, therefore, important to reflect on my understanding of the term 'intellectual disability'. Like the term 'disability', 'intellectual disability', is considered to be a construct, produced and determined by the society it is born of.[38] Pfeiffer compares the use of the term 'disability' with the arbitrary construction of the term 'race'. Accordingly, both terms have no common scientific definition, yet are frequently used.

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[36] During the treaty negotiations, State delegations, government representatives and most importantly, Disabled People's Organizations (DPOs) embarked on a remarkable diplomatic process of treaty drafting. An unprecedented collection of disability stakeholders came together, forming alliances and collectively representing the voices of persons with disabilities with unparalleled vigour. For a political evaluation of this process see: Arlene Kanter, 'The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities', (2007) 34(2) *Syracuse Journal of International Law and Commerce,* 287-322.

[37] Others suggest that globally the figure of people with intellectual disabilities is 200 million however; some inconsistencies in reporting on these figures exist based on its indefinite label. World Health Organization, 'World Report on Disability', (2011).

[38] Michael Oliver, *The Politics of Disablement,* (Macmillan, 1990).

Bickenbach continues this thought, and explains that viewed scientifically, no innate or comprehensive delineation of human ability exists. Rather, ability-disability is a continuum which each of us finds ourselves on at varying points and at various stages of our lives. In fact, to Bickenbach, the 'complete absence of disability, like the complete absence of ability, is a limiting case of theoretical interest only'.[39]

Braddock and Hatton identify that the term has an institutional history, and that, beyond medical and psychological aspects, intellectual disability is commonly understood as referring to a homogenous group of people that are intellectually impaired and, thus, perceived as inferior.[40] Moreover, the implications of the label of intellectual disability, and its measurement, vary considerably between countries.[41] Commonly, a classification system, which is heavily influenced by the medical profession and usually involves an intelligence test, is applied to ascertain type and degree of intellectual disability. This is because the modern conceptualisation of intellectual disability, according to Hatton, rests on a deficit of intelligence and adaptive behaviour. The effects of these deficits are then believed to impact on intellectual functioning, leading to behaviours deemed random and irrational. Both factors have, in turn, led to the categorisation of people as 'different' and 'vulnerable'.[42]

Rioux also establishes that the definition of intellectual disability is closely tied to ideas of intelligence and thus also of 'worth'. She concludes that biological determinism and scientific positivism have sought to categorise difference (both biologically and rationally) and ultimately justify the differential treatment of certain people based on IQ.[43] In this way, 'worth' has been assigned to individuals and groups by using intelligence tests, which purport to provide 'objective' standards in the form of a scale and, thereby, inadvertently creating an intelligence hierarchy. Those presenting on the lower end of the scale and, thus, the intelligence hierarchy, are classified as intellectually inferior. These forms of 'objective' classification tests are still widely used today and serve to qualify laws and policies that exclude or to treat those so designated, differently.[44]

As a result of its classification, the experience of intellectual disability becomes a distinct issue, worthy of discussion and scholarly attention as the label has generated specialised policy responses. Most noticeably, the concept of intellectual disability has evoked responses aimed at primarily 'caring' and 'protecting' this group, prompting the

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[39] Jerome E. Bickenbach, 'Minority Rights or Universal Participation,' in Melinda Jones and Lee Ann Basser, (eds.), *Disability, Diversability and Legal Change- International Studies in Human Rights,* (Martinus Nijhoff, 1999), 112.
[40] Chris Hatton, 'Intellectual Disabilities: Epidemiology and Causes' in Eric Emerson, Chris Hatton, Kate Dickson, Rupa Gone, Amanda Caine and Jo Bromley, (eds.), *Clinical Psychology and Persons with Intellectual Disabilities*, (Wiley, 1998).
[41] David Braddock, 'An Institutional History of Intellectual Disability' in Susan Parish and David Braddock, (eds.), *The State of the States: Public policy toward Disability at the dawn of the 21st century,* (American Association on Mental Retardation, 2002).
[42] n 35.
[43] Marcia Rioux, 'Towards a Concept of Equality of Well-Being: Overcoming the Social and Legal Construction of Inequality' in Marcia Rioux and Michael Bach, (eds.), *Disability is Not Measles: New Research Paradigms,* (L'Institute Roeher, 1994), 71.
[44] Ibid.

development of institutions. For the purposes of this investigation then, the term 'intellectual disability' is understood as a broad term and one that it intrinsically linked to institutions. Many researchers agree, regardless of the exact label used, 'intellectual disability' describes an experience that is linked to segregation, indicative of a group that is heavily stigmatised and marginalised which face additional barriers and limited recourse to their rights.[45]

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[45] Katrina Scior, Aseel Hamid, Richard Hastings, Shirli Werner, Catherine Belton, Adebisi Laniyan, Maya Patel, Nora Groce, Maria Kett, 'Consigned to the Margins: A Call for Global Action to Challenge Intellectual Disability Stigma', (2016) 4(5) *Global Health,* 294-295.

SECTION 1: SHELTERED WORK - AN INTRODUCTION

Section 1 of this thesis provides a detailed overview of the topic of sheltered work. Chapter 2 establishes the context of the practice of sheltered work and discusses its background. The experience of exclusion from society, which many people with intellectual disabilities experience, is linked to early forms of institutionalisation. Next, the development of sheltered workshops in a national context, as well as the current prevalence of sheltered workshops, are explored. Chapter 2 also highlights some problems with agreeing on a definition of the term 'sheltered work' and, thus, introduces a working definition for the purposes of this research. Chapter 3 highlights some common concerns associated with sheltered work identified in the literature. The main concerns are outlined and subsequently addressed in the following order: servitude in the workshop, uncertain legal status of sheltered workers, remuneration, low transition rates, the dichotomy of sheltered work, and proponents of sheltered work.

Chapter 2: What is Sheltered Work?

This chapter introduces the concept of sheltered work and employment and describes related practices. This chapter will begin by exploring the foundations of sheltered work by delving into the history of institutionalisation and exclusion, and briefly offer a sociological perspective based on the work of Michel Foucault, the French philosopher and social theorist. Next, this chapter will trace the practice of sheltered work in an Irish context to provide a national example of the development of sheltered work services, before moving on to discuss the prevalence of sheltered work on a global scale. This introduction to sheltered work will then conclude by explaining how such practices are an embedded feature of many welfare states, and remain a popular employment policy targeted at people with disabilities. Next, this chapter addresses the significant difficulties in arriving at a general, all-inclusive definition of sheltered work and proceeds to formulate a working definition for the purposes of this study.

2.1   A HISTORY OF EXCLUSION AND INSTITUTIONALISATION

Any discussion of sheltered work must trace its formation and consider what thinking rationalised it in the past. Undeniably, this requires an understanding of the widespread, historical practice of institutionalising people with disabilities. The practice of systematically herding the 'physically disabled', the 'indigent', the 'feeble-minded' and 'lunatics' into asylums began as early as the 1700's across Europe, and was at first not an attempt to ameliorate suffering and poverty, but intended simply to remove people from the streets and ultimately, the public domain. The dominant and ideological response to dealing with the unemployed and vagrant members of society was to remove the impotent and the afflicted from the discomforted public eye and confine such individuals in excluded places.[1] Banishing this group to 'mad houses', lunatic asylums and hospitals would become the basic template for the treatment of disabled people over time.[2] Gradually, the intention of these institutions would become charitable and 'include helping the poor, protecting communities from the menace of deviants, protecting inmates from being taken advantage of by others, and when possible, rehabilitating inmates'.[3]

The resulting exclusion of certain groups as part of this institutionalisation finds its roots in the Middle Ages, coinciding with the emergence of social institutions generally.

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[1] Deirdre Lindsay, 'The Sick and Indigent Roomkeepers' Society', in David Dickenson, (ed.), *The Gorgeous Mask: Dublin 1700-1850*, (Trinity History Workshop, 1987), 132.
[2] Patrick McDonnell, *Disability and Society, Ideological and Historical Dimensions*, (Blackhall, 2007), 22.
[3] Rachel L. Nunley, 'Workshops for the Handicapped in the United States. A Historical and Developmental Perspective', (1972) 52(2) *Physical Therapy*, 601.

As the foremost charitable organisation of that time, the Church sought to provide religious protection, save souls and offer spiritual redemption to the poor and those inflicted with a disability.[4] Schools, hospitals, asylums and workhouses all share these traceable, historic roots.[5] Some argue that remnants of these institutions and traces of their underlying ideologies still influence disability services today.[6] Exploring the ideological and institutional roots of exclusion, McDonnell finds that the practice of segregating people with disabilities remains a dominant threat for disabled people in Western societies, stemming from these 'early modern, political, social and cultural responses to poverty'.[7]

Sheltered workshops, as a specific institution, directly evolved from the era in which privately run 'mad houses' and workhouses for the impoverished were set up in the 19th century in Britain and Ireland and proliferated, based on the absence of state intervention.[8] With the emergence of charitable services offered in specific institutions during the Victorian era, the idea of rehabilitative work that focuses on the concept of work as therapy began to consolidate. Therapeutic work regimes applied in psychiatric hospitals, it was believed, could stabilise distracted or traumatised minds and offer regularity and focus. Across Europe then, particularly after the First and Second World Wars the provision of predominantly physical work to 'emotionally disturbed' soldiers and civilians with mental health problems was prescribed for its rehabilitative effects.[9]

Sheltered workshops also emerged in America during the 19th century, but numbers rocketed after World War II, when honourable soldiers with disabilities were placed in these.[10] In fact most sheltered workshops were established after World War II, a time when disability service provision expanded generally, as a response to the needs of injured war veterans.[11] For example, between 1948 and 1976, the number of sheltered workshops in the U.S. increased from 85 to about 3000.[12] This expansion in service provision also saw increases in the services available for adults with intellectual

[4] Jacob ten Broek. 'The Character and Function of Sheltered Workshops', (National Federation of the Blind, 1995), available at: <http://www.disabled-world.com/definitions/sheltered.php> (accessed on 10 February 2016). Ten Broek was a famous American academic and disability rights activist. For more of his work see: Jacob ten Broek, *Equal under Law*, (Collier Books, 1965).

[5] Carlson provides a brief overview of the institutional history of mental retardation, which some historians divide into three eras: 'A period of optimistic institution-building 1850-1880; a shift from education to custodialism, reflective of the professional view that' deviants' needed to be sheltered from society, 1880-1900; and finally, an attempt through social programmes and institutional restrictions to protect society from the menace of feeblemindedness, 1900-1920', Licia Carlson, 'Docile Bodies, Docile Minds: Foucauldian Reflections on Mental Retardation', in Shelley Tremain, (ed.) *Foucault and the Government of Disability*, (The University of Michigan Press, 2005), 150.

[6] Ten Broek, n 4.

[7] McDonnell, n 2.

[8] Roy Porter, *Madmen: A Social History of Mad-Houses, Mad-Doctors and Lunatics*, (Tempus, 2004).

[9] Dustin Galer, 'A Place to Work Like Any Other?' Sheltered Workshops in Canada, 1970-1985', 3(2) *Canadian Journal of Disability Studies*, (2014).

[10] Selden Biggs and Lelia B Helms, *The Practice of American Public Policymaking*, (Taylor and Francis, 2014).

[11] The first workshop in the United States was the Perkins Institute, opened in 1837 for individuals with 'visual handicap'. This workshop was typical of the categorical workshops that were established during this time to serve people with particular disabilities. , Coombe, 'Sheltered Workshops and Transition: Old Bottles, New Wine?' (The American Council on Rural Special Education (ACRES), Rural America: Where All Innovations Begin, 1993).

[12] According to figures provided by the U.S. Department of Labor. Alberto Migliore, 'Sheltered Workshops', (International Encyclopedia of Rehabilitation. Centre of international Rehabilitation Research Information and Exchange, 2010), [online], available at: <http://cirrie.buffalo.edu/encyclopedia/en/article/136/> (accessed 15 February 2016).

disabilities, as individuals with disabilities and parents joined forces to advocate for more services for their children.[13] The subsequent Civil Rights Movement would constitute a further pivotal moment that would change the landscape of the disability service system, beginning particularly with the independently living movement at the University of California, Berkeley.[14]

In their research on sheltered work and employment and its development as a service for people with intellectual disabilities, in the European Community (now European Union), Waterplas and Samoy also look to recent history.[15] These researchers similarly trace the evolution of workshops to archaic institutions that primarily provided medical and residential services for impoverished groups, including people with disabilities. Those deemed incapable of economically productive work were segregated further and often accommodated in large institutions that provided therapy and care. Persons capable of contributing to the upkeep of the institution were tasked with a variety of jobs, including cleaning, cooking, agriculture and horticulture. Often, alongside these domestic tasks, economically productive work units were also set up which gradually evolved to become sheltered workshops for people with intellectual disabilities. Abbas also notes that a gendered perspective of the work conducted is apparent.[16] Women in the institutions often take on traditional female roles, such as cleaning and cooking or taking care of other workers. A further gendered aspect noteworthy at this junction is that reportedly more men take up the opportunities to transition out of workshops, compared to women.[17]

The development and the purpose of work within such institutions has since been the subject of some debate as it has been ascribed varying roles and importance over time.[18] While at first labour by the residents was necessary to run the institution, later shifts saw the role of this work framed in terms of its therapeutic functions. Abbas also observes this shift and considers that the objectives of work changed in respect to how the labour conducted by 'inmates' was framed according to the trajectory of the institution.[19]

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[13] Commenting on practices in the 70s Fernald claims that the most obvious aim of education and training in American institutions was the 'instruction in industrial occupations and manual labour'. Walter Fernald, 'Description of American Institutions', in Marvin Rosen, Gerard Clark and Marvin Kivitz, (eds.), *The History of Mental Retardation: Collected Papers Vol I,* (University Park Press, 1976).

[14] Doris Zames Fleischer and Frieda Zames, *The Disability Rights Movement: From Charity to Confrontation,* (Temple University Press, 2001); Richard Scotch, 'Politics and Policy in the History of the Disability Rights Movement', (1989) 67(2)*The Millbank Quarterly*, 380-400.

[15] Erik Samoy and Lina Waterplas, 'Sheltered Employment in the European Community', (Katholieke Universtieit Leuven & Hoger Instituut voor de Arbeid 1992).

[16] Jihan Abbas, 'A Legacy of Exploitation: Intellectual Disability, Unpaid Labor and Disability Services, (2012)14(1) *New Politics*.

[17] Employability Galway for example report that every year on average 65% of the applicants are men. Pauline O'Dwyer, 'Employability Galway, Employment Services- Emerging Examples and Pinpointing the Values to Be Achieved', (Conference: Spending Socially- Achieving Social Value through Public Procurement, National University of Ireland, Galway, 15 June 2015).

[18] Rannveig Traustadóttir, and Kelley Johnson, *Deinstitutionalisation and People with Intellectual Disabilities: In and Out of Institutions,* (Jessica Kingsley Press, 2005).

[19] Abbas, n 16.

From the 1960s onwards, residential facilities and accompanying work centres became increasingly detached, following the belief that work and home life should be separated, leading to a further expansion of segregated services. Kliewer and Drake note that this resulted in an ever-increasing 'base of power, privilege and authority' which promoted the creation of various professions linked to the institution and with the control of people with disabilities.[20] Social and medical care were increasingly being offered as distinct services, (separate from vocational rehabilitation or training centre and sheltered workshops), and depending on the design, these were often referred to as 'day centres', 'occupational centres', 'therapeutic centres', or 'educational centres', primarily for people with intellectual disabilities where, initially, no work of commercial value took place. Rather, the focus was on providing therapy and occupation. However, Waterplas and Samoy reveal, that even in the early stages some activities and therapies showed a 'remarkable resemblance to the routine work characteristic of the sheltered workshop' that would eventually emerge.[21] Indeed, this intermingling of therapy, rehabilitation and work continues to obscure the debate over sheltered workshops today, and will be addressed in more detail below.

2.1.1 A Foucauldian explanation of institutions

The 20th century sociologist Foucault wrote extensively on the emergence of institutions in Europe and founded the critical discipline. He traced the roots of the phenomenon of institutions and segregation back to the need to control society and manage deviants. The very description of certain phenomena in society as requiring management is a consequence of liberalism in governance, a framework that developed and began to describe people that were different as 'problems'.[22] He notes that with the development of political rationality, an emerging strategic movement of managing the 'problems' faced by governments gave birth to a vast apparatus of control, created to secure the well-being of the general population. The 19th century then saw the growing compartmentalisation of society based on an increase in the medical dissection and examination of the body. An, initially, rather undifferentiated mass of people was ordered into categories and classified as 'mad or sane, sick or healthy, criminal or good'. In response to this codification, groups were managed and their social abnormalities controlled in institutions according to their characteristics, (deaf, physically impaired, insane, etc.). Foucault refers to this phenomenon as 'dividing practices', which saw an increase in the segregation and social exclusion of certain groups in asylums and prisons.

To Foucault, institutions for the 'feeble-minded', in particular, developed to separate and treat 'idiots' and 'were significant insofar as, for the first time, causes, definitions,

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[20] Christopher Kliewer and Stephen Drake, 'Disability, Eugenics and the Current Ideology of Segregation: A Modern Moral Tale' (1998) 13(1) *Disability & Society*, 95–111.
[21] Samoy and Waterplas, n 15, 10.
[22] Foucault came to this conclusion in his writings on 'The Birth of Bio-politics', which were part of a lecture series held between 1978 and 1979. Since published by Picador in 2004.

descriptions, and treatments were discussed and practiced within an organised institutional structure'.[23] The existence of these institutions spurred the production of knowledge on treatment and its application. Foucault's treatise on the discursive formation of institutions, therefore, highlighted how, in line with the production of new scientific and medical knowledge, distinctly new categories of individuals were produced. With this objectification certain terms and labels were born and with them the possibility of naming, categorising and generalising disability as inferior.[24] Foucauldians believe this extensive, institutional apparatus of control is still in operation today and includes residential facilities and sheltered workshops. As a result, these settings continue to frame people with disabilities as deviant, 'other', in need of treatment; relying heavily on an approach otherwise known as the 'medical model of disability'.[25]

2.2   THE DEVELOPMENT OF THE SHELTERED WORKSHOP IN A NATIONAL CONTEXT: IRELAND

In the 19th century, the development of the Irish health and social service sector was, for the most part, influenced by the English model of the Victorian workhouse. Based on the tyranny of English rule, the number of workhouses rose to meet the demand of an increasingly impoverished community, and by the mid-19th century over 150 workhouses existed throughout Ireland.[26] These were asylums where the poor were catered for and accommodated, provided they worked and, thus, 'paid their way'. Where previously it had made economic sense to respond to the destitution among large populations and house all of those in one institution, there was a growing recognition of the need to differentiate between the large groups placed in these, based on their needs.

Thus, according to the Poor Laws of the late 19th century, adults with disabilities in these asylums were further separated and segregated in hospitals operating in conjunction with the workhouse.[27] These hospital-like residential services constituted the early beginnings of institutional care, becoming the first services to develop for people with disabilities in Ireland. The Daughters of Charity were the first publicly funded organisation that provided specialist services specifically to people with intellectual disabilities. The organisation undertook to clothe, maintain and educate its wards, becoming the first disability day service offering 'wrap around care', resembling

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[23] Licia Carlson, 'Docile Bodies, Docile Minds: Foucauldian Reflections on Mental Retardation', in Shelley Tremain, (ed.), *Foucault and the Government of Disability* (The University of Michigan Press, 2005), 137.
[24] Shelley Tremain (ed.), *Foucault and the Government of Disability* (University of Michigan Press, 2005), 5.
[25] Ibid, 6.
[26] Carol Linehan, Shiobhan O'Doherty, Mark Tatlow-Golden, Susan Craig, Mary Kerr, Carol Lynch, Roy McConkey, and Alan Staines, 'Mapping the National Disability Policy Landscape', (School of Social Work and Social Policy, Trinity College Dublin, 2014).
[27] Based on a report by a Royal Commission on the Poorer Classes in Ireland, the Irish Poor Law Act of 1838 as issued with instructions on how to manage the poor and set up institutions for them. Fiona Dukelow and Mairead Considine, *Irish Social Policy: A Critical Introduction, 2nd ed.*, (Gill & Macmillan, 2009), 9.

those that still exist today.[28] Notably, these services enjoyed little accountability, and were minimally monitored, with limited oversight of their operation by government bodies.[29]

Developing into a powerful establishment these hospitals and their ancillary services became a stronghold of society that fulfilled many functions, such as observation, teaching, research and treatment.[30] As a charitable foundation and legitimised by its altruistic status, it became the linchpin institution from which other specialised institutions evolved. This is largely based on the recognition that although their responsibility was largely custodial, there was a need to occupy those in hospitals. This led to a basic programme of simple activities being offered, as well as an educational programme. Based on the institution's eminent status and religious influence, it came to provide a particular type of education and training that would dominate the field of disability services for future centuries.[31] Special schools then emerged as more differentiated administrative categories were established to direct people into more appropriate settings based on their characteristics.[32]

Along with the hospitals, asylums and workhouses, the special school became the most significant institution for disabled people that developed during the mid 19th century. The first school for deaf children was established in Dublin in 1816, and by 1850 nine such schools existed across Ireland. In 1860, seven institutions provided, specifically, 'literary and industrial education for the blind', and in 1869 one of the first institutions for people with learning disabilities was opened - the 'Stewart Institution for the Idiotic and Imbecile Children'.[33] These special schools provided accommodation, and religious and industrial training and were run in a manner similar to the other main institution of the time, the hospital. The special school also developed based on the idea that it made economic sense to house all 'feeble-minded' children in one place so as to prevent them from becoming a burden to society, 'engaging the anxious attention of every social reformer'.[34]

Besides such economic purposes, a shift in moral sensibilities, identified by McDonnell, also greatly influenced societal responses to people with disabilities and impacted on

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[28] Kliewer and Drake report that these segregated classrooms did not emphasise expectations of achievement, nor a vision that the student would ever belong in the larger community. Instead, special education was viewed as a `way stop' on the road to the institution. The curriculum of segregated special education was ultimately a curriculum of control. n 20.
Health Service Executive, 'New Directions, Review of HSE Day Services and Implementation Plan 2012-2016', (2012), 34; Department of Health, 'Value for Money and Policy Review of Disability Services in Ireland', (Department of Health, 2012), 13.
[29] Colin Bates-Harris, 'NDN Webinar: The State of Sheltered Workshops', (Presentation, 19 August 2014), [online], available at: <http://ddi.wayne.edu/pdf/ndrn_sheltered_workshop_webinar_transcript.pdf> (accessed 7 July 2016).
[30] Roy Porter, 'The Eighteenth Century', in Lawrence Conrad, (ed.), *The Western Medical Tradition: 800 BC to AD 1800, Vol. I*, (Cambridge University Press, 1995), 371.
[31] According to McDonnell, such was the hegemony of the hospital that 'captive social groups', including people with disabilities, housed in these were exploited in a number of ways, justified on the grounds that it was ultimately for the benefit of the individual. n 2, 51.
[32] McDonnell, n 2, 92.
[33] Ibid.
[34] Matthew Russell, 'The Irish Monthly: A Magazine of General Literature Founded by the Rev. Matthew Russell', (1917), 641.

the development of services. Generated as part of the distribution of charity, concepts of the 'deserving' and 'undeserving' poor became central to welfare provision throughout this period.[35] To receive charitable services, people had to show how impoverished and impaired they were to prove worthy of alms. This ideology of charity that favoured and supported only the most deserving groups, fuelled the emergence of disability as a specific category and a predominantly medical issue, requiring medical responses. Like the sick, recipients with disabilities had to exaggerate their impairments and present as helpless, tragic cases, highly dependent and uniquely deserving.[36] Once in receipt of care, recipients had to continue demonstrating their worthiness through learning, work and devoutness.

Individual institutions had to compete for patronage to secure revenue and were eager to report on how they contributed towards making patients and pupils less of a burden to society.[37] Therefore, a large focus was placed on showing how children at schools were driven hard to study and conduct domestic labour. For example, the National Institution for the Education of Deaf and Dumb Children emphasised, in its report of 1820 that as a school of industry 'the time of all the pupils is nearly equally divided between study and labour of domestic work, (…) and any person examining the quantity of various labours performed, (…) by the pupils, (…) will acknowledge that they have not been allowed to eat the bread of idleness'.[38] Besides fulfilling the requirement of 'earning their keep', specialist schools began to expand and develop into places of work, spurred by the need to occupy older students moving on from these schools.[39]

Residential, institutional care run by charitable and voluntary organisations of the church in receipt of government funding became the primary services for people with intellectual disabilities. These included sheltered workshops, which became prominent in the 1960s and 1970s when, besides government subsidies, these began to actively seek out commercial contracts. Funding from the European Union, via its European Social Fund, also contributed significantly towards the upkeep of these workshops, under the pretence that these offered training.[40] However, in a later report, the European Commission would come to note that, worryingly, none of the trainees managed to graduate from the programme or transitioned into work.[41] In Ireland, a review of community workshops by its Health Board also commented on the sector's failure. The Health Board in 1986, found that in some centres the range of activities and the opportunities for vocational training offered were so limited that these, in fact, 'limited

[35] Virginia Crossman, 'The Poor Law in Ireland, 1838-1948', (2008) [online], available at:
<http://www.history.ac.uk/ihr/Focus/welfare/articles/index.html> (accessed 11 July 2016).
[36] McDonnell, n 2, 99.
[37] Peter McVerry, 'Making Ireland a Caring Society', (2011) 100(397), *Studies: An Irish Quarterly Review,* 7-16.
[38] National Institution for the Education of Deaf and Dumb Children of the Poor in Ireland, Fourth Annual Report, (1820), 18.
[39] NAHMI (now Inclusion Ireland), cited in Tom Martin and Associates, 'Review of Sheltered Employment: A Review of the Literature', (2008), 28.
[40] Patricia Thornton and Neil Lunt, 'Employment Policies for Disabled People in Eighteen Countries a Review', (Cornell University ILR School, 1997).
[41] Christy Lynch, 'An Audience with Christy Lynch, European and National Disability Policy-Making', (Seminar, Centre for Disability Law and Policy, National University of Ireland, Galway, June 2, 2017); European Commission, 'The European Social Fund and Disability', (2010), 33.

the overall long-term vocational development of the disabled person'.[42] In 2017, the Health Research Board would go on, however, to report that over 2,600 people with disabilities were still in government-funded sheltered work centres.[43] Moreover, other forms of employment services for people with intellectual disabilities are still, largely, offered in institutional settings.[44]

2.3 PREVALENCE OF SHELTERED WORKSHOPS

Obtaining figures of sheltered workshop attendance on a global scale is difficult because there are significant variations in the provision of sheltered work services between countries. However, a study in 2000, covering 15 EU Member States, Australia and the United States, concluded that sheltered employment is a major source of employment for people with disabilities in these countries.[45] Across Europe, it is estimated that between 2 and 3 million people work in sheltered workshops.[46] Therefore, with the growing competencies of the European Union, the institution has taken an interest in the area of sheltered work and employment. This has led to 2 significant scoping reviews conducted in 1992 and 2015, which provide a snapshot of the provision of sheltered work across EU Member States.[47] These two studies will be referenced throughout this section. However, it is also noteworthy that the EU itself, as a policy-making instrument, funding agent and political influencer, has also shaped the provision of sheltered work and employment in Member States. By creating exemptions and specific provisions for sheltered workshops in EU Public Procurement

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[42] The Steering Committee for Community Workshops Research Project, Eastern Health Board, 'Appendices to Community Workshops Research Project', (1986), 20.

[43] Anne Doyle, Sarah Hourigan, and Sarah Fanagan, 'Annual Report of the National Intellectual Disability Database Committee 2016', (Health Research Board, 2017).

[44] For more details on these figures and developments see: Charlotte May-Simera, 'Is the Irish (Republic of) Comprehensive Employment Strategy Fit for Purpose in Promoting the Employment of People with Intellectual Disabilities in the Open Labour Market? A Discussion Using Evidence from the National Intellectual Disability Database', (2018) 15(4) *Journal of Policy and Practice in Intellectual Disabilities*.

[45] International Labour Organisation, 'Draft UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, Chair's Text 7 October 2005 Provisions on Work and Employment, ILO Technical Advisory Note', (2006).

[46] European Association of Service Providers for Persons with Disabilities, 'Key Challenges for Sheltered Workshops in the Future' (2015), [online], available at: <http://eurodiaconia.org/wordpress/wp-content/uploads/2015/09/9_ferraina_sheltered-workshops.pdf> (accessed 13 June 2016); Fidesz EU, 'Sheltered workshops, New Approach Needed', (Press Release, 2013), [online], available at: <http://fidesz-eu.hu/print/sheltered_workshops_new_approach_needed> (accessed 13 June 2016).
Aichele of the German Institute for Human Rights for example reported that in Germany sheltered workshops were on the rise, contrary to CRPD Committee recommendations that these be shut down. Valentine Aichele, 'Germany: Civil Society and the Institute', (Conference Presentation, 8th International Disability Law Summer School, Galway 22 June 2016); Gelashvili et al. also report how popular sheltered employment centers are in Spain; Vera Gelashvili, Maria Camacho-Minano, Marsia Segovia-Vargas, 'The Profitability of Socially Responsible Companies: Public Subsidies for Sheltered Employment Centres', 6(1) *Ramon Llull Journal of Applied Ethics*, (2015), 111.

[47] Waterplas and Samoy n 15; European Parliament, Directorate General for Internal Policies, Policy Department A, Economic and Scientific Policy, Employment and Social Affairs, (Jacqueline Mallender, Quentin Liger, Rory Tierney, Daniel Beresford, James Eager, Stefan Speckesser and Vahé Nafilyan), 'Reasonable Accommodation and Sheltered Workshops for People with Disabilities: Costs and Returns of Investments- Study for the EMPL Committee, (IP/A/EMPL/2013-03, 2015).

and State Aid regulations, these have been granted a favourable status and financial benefits, thereby enabling their development.[48]

In the 1980s, the European Community provided training grants for sheltered workshops directly. Moreover, in a Recommendation adopted by the Council of the European Union, government ministers from each EU country agreed that sheltered employment as a source of employment for disabled people should be reviewed and improved.[49] Although the European Commission is more reluctant to endorse the sheltered workshop system today, as already indicated, the EU continues to support the upkeep of the sheltered work sector, most notably through regulations that benefit any public contracts granted to sheltered workshops. Effectively, sheltered workshops also continue to receive indirect support via EU funding towards the upkeep of large residential institutions, of which they are often a subsidiary service.[50]

On the occasion of drafting the CRPD, the ILO provided a list of figures from around the globe on the number of persons counted in sheltered work settings:

- Germany 2004: 236,000 in state-registered sheltered workplaces
- Poland 2002: 190,000 in registered sheltered workplaces
- United States 2004: 140,000 in supported employment
- Japan 2000: 130,061 in sheltered workshops
- France 2002: 16,651 in sheltered workshops; 96,651 in Centres d'aide par le travail
- Sweden 1999: 33,000 in sheltered workshops; 50,000 in subsidised employment
- Spain 2010: 39,329 in sheltered employment and 59,185 workers in special employment centres
- Italy 1997: 17,000 in social enterprises
- Australia 2001: 14,872 in supported employment
- Flanders (Belgium) 2004: 14,477 in sheltered workshops
- Norway 2004: 8,308 in sheltered workplaces
- New Zealand 2001: 5,400 in sheltered workshops
- Finland 2004: 2,681 in sheltered workplaces
- Indonesia 2002: 68,000 in sheltered workshops or welfare factories.[51]

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[48] For more information on State Aid and Public Procurement rules and how these support sheltered workshops, please see my reports written in the *European Yearbook of Disability Law, Volumes 3-5*; Directive 2014/24/EU of the European Parliament and of the Council of 26 February 2014 on public procurement (repealing Directive 2004/18/EC), [2014] OJ L 94, 138; Commission Regulation (EU) No. 651/2014 of 17 June 2014 declaring certain categories of aid compatible with the internal market in application of Articles 107 and 108 of the Treaty, [2014] OJ L 187, 1. Other international bodies such as the Council of Europe, also endorse sheltered workshops. Recommendation No. (92)6, of the Committee of Ministers to Member States on a Coherent Policy for People with disabilities, (adopted by the Committee of Ministers on 9 April 1992 at the 474th meeting of the Ministers' Deputies).

[49] 86/379/EEC: Council Recommendation of 24 July 1986 on the employment of disabled people in the Community [1986] OJ L 225, p 43–47.

[50] For more details see: 'Community Living for All: Structural Funds Watch', (2018), available at: <https://communitylivingforeurope.org> (accessed 19 June 2018).

[51] International Labour Organization, 'The State of Application of the Provisions for Social Security of the International Treaties on Social Rights', (ILO Technical Note, 2016); Tim de Meyer, 'International and National Law Concerning Employment of People with Disabilities in Indonesia', (presented at the Multi-Stakeholders Workshop on People with Disabilities in Indonesia: Access to Employment and Justice ILO Sub-regional Office for East Asia, 2011).

Although dated, this list not only provides a snapshot of the figures in sheltered work but also enumerates the different types and terms that exist. The 2015 review of sheltered workshops in the EU Member States, mentioned above, provides more recent figures. These, equally, show that a high number of people are still placed in these services, which indicates a high prevalence of sheltered work. The review reports that Belgium counted 67 legal entities providing sheltered workshops services, which employed 16,000 people with disabilities; in Germany 682 workshops employed 306,000 people with disabilities.[52] Sweden employed 20,000 people with disabilities in 370 sheltered workshops, and 92 workshops operated in the Netherlands, whereas France counted 1345 related work settings.[53] Moreover, a report on community living in States of South East Europe describes the large number of sheltered workshops, with few alternatives available, as causing the phenomenon of 'over-institutionalization'.[54]

This brief survey of figures collected over time indicates that the sheltered workshop system is not only a popular service across the globe that counts many participants but also that there is great variation among sheltered settings. This popular, yet multifaceted, system of sheltered work and employment continues to receive widespread support and remains as relevant as ever. Cohen and Kramer even identify that, in spite of a growing number of community work initiatives, the vast majority of individuals remain in segregated settings such as sheltered workshops.[55] Broad, international discussions of these settings are however, limited by the variations and differences in their provision. Indeed, this is a factor that will impact on any discussions of sheltered work and will be addressed after an appraisal of sheltered work as an approach to disability services.

2.3.1 An out-dated, yet popular, approach

Of importance to note here are the negative connotations associated with the term 'sheltered workshops'. This undoubtedly has had an impact on the provision of these and requires, albeit brief, attention. Indeed, the term has become synonymous with poor (and sometimes exploitative) pay, and few opportunities for real learning, training or progression towards the open labour market.[56] Specific conditions of sheltered work, discussed in more detail in Chapter 3, have given rise to much criticism of sheltered

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[52] Johannes Bungart, 'A Labour Market for All? A Comparative Assessment of National Job Strategies for Workers with Disabilities, the German System of Supported Employment', (Conference Presentation, Annual Conference on the Rights of Persons with Disabilities, European Rights Academy, Trier, 2015).
[53] European Parliament, Directorate General for Internal Policies, n 47, 23.
[54] Here, people with intellectual disabilities are largely deprived of their legal capacity, are placed under plenary guardianship and can only be gainfully employed if their guardian agrees. Disability Monitoring Initiative, 'Right to live in the Community: Making it happen for People with Intellectual Disabilities in Bosnia and Herzegovina, Montenegro, Serbia and Kosovo', (2008) [online], available at:
<http://www.fotoart.ba/hisee/userfiles/file/community_living_english.pdf> (accessed 8 July 2016).
[55] Allison Cohen Hall and John Kramer, 'Social Capital Through Workplace Connections: Opportunities for Workers with Intellectual Disabilities' (2009) 8(3) *Journal of Social Work in Disability & Rehabilitation* 146-170.
[56] Steven J. Taylor, 'Workers with Disabilities Deserve Real Choices, Real Jobs', (2001) [online], available at: <http://www.accessiblesociety.org/topics/economics-employment/shelteredwksps.html> (accessed on 14 March 2016).

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workshops in some countries.[57] The ILO finds that increasingly, and particularly in developed countries, sheltered workshops have fallen out of favour and are deemed old fashioned and segregationist.[58] Therefore, the term 'sheltered workshop' is considered out-dated in the UK, Ireland, the U.S., and Australia.[59] In theory then, these settings have been replaced or progressively refocused towards more integrated practices.[60]

The World Report on Disability released by the World Health Organization in 2011 marked one of the first instances in which the controversy of sheltered employment was captured on a global scale.[61] The report remarked that the segregation of people with disabilities was unacceptable as it was based on a disability policy grounded in archaic models and an ethos of charity rather than rights. Increasingly, sheltered work is regarded as 'inappropriate' and in need of being replaced.[62] Through lobbying, litigation and condemnation of the large amounts of public funding geared towards sheltered workshops, disability rights activists in the U.S. and Europe have sought to abolish the system outright.[63] This surge of advocacy that has as its aim greater community inclusion has been regarded as the next wave of America's civil rights movement.[64]

Despite these efforts, and a growing understanding that the practice is out-dated, much research still points to the fact that the employment of people in separate settings is widespread. Research on sheltered employment in Europe during the 90s, for example, revealed that besides quota systems, sheltered employment, in all its formats, was the most widely used employment measure for people with disabilities. More recent research, in fact, revealed a growth in segregated day programmes and work centre

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[57] Organization for Economic Co-operation and Development, 'Employment Policy for People with Disabilities', (Labour Market and Social Policy Occasional Papers No. 8, 1992), 34.

[58] Tony Powers, and ILO, 'Recognizing Ability: The Skills and Productivity of Persons with Disabilities- Literature Review', (Employment Working Paper No.3, 2008), 16.

[59] Yani Hasenfeld, 'Human Services as Complex Organizations', (Content Technologies Inc., 2014). In Australia sheltered workshops have undergone a process of rebranding and become 'business enterprises'; Karen Soldatic and Anne Chapman, 'Surviving the Assault? The Australian Disability Movement and the Neoliberal Workfare State', (2010) 9(2) *Social Movement Studies,* 139-154.

[60] In the U.S. Department of Labour describes for example, that while sheltered workshop provided rehabilitation, treatment, training, and/or employment opportunities to individuals with disabilities, the term now commonly used is 'work center.' However, despite renouncing the term 'sheltered workshop', these work centres still operate much the same as before and are still eligible for wage certificates under Section 14(c) of the Fair Labor Standards Act, which certifies the payment of subminimum wages. United States Department of Labor, Wage and Hour Division, Field Operations Handbook, Employment of Workers with Disabilities at Special Minimum Wages under Section 14(c), Fair Labour Standards Act Chapter 8, Title 26 of the United States Code.

[61] World Health Organization, 'World Report on Disability' (2011), 243.

[62] Organization for Economic Cooperation and Development, 'Transforming Disability into Ability: Policies to Promote Work and Income Security for Disabled People', (2003), 10.

[63] Steven J. Taylor, n 56. The U.S. has a long-standing advocacy movement that originally began campaigning for the right to services for people with disabilities in the 1960. These campaigns have been successful in securing the right of Americans with Disabilities to community living and as a result strong deinstitutionalization movement has been underway since. Michael Waterstone, 'Backlash, Courts and Disability Rights', (2015), 95 *Boston University Law Review,* 833.

[64] Chris Kardish, 'Hidden or Unemployed: America's Failure to Get Disabled People Jobs', (*Governing the States and Localities*, 15 June 2015) [online], available at: <http://www.governing.com/topics/mgmt/gov-american-disabilities-act-compliance.html> (accessed 29 June 2016).

participation in America, Germany,[65] and Spain.[66] Reports from Ireland revealed that sheltered work remains the second most popular day service for people with intellectual disabilities since data collection began.[67] In 2012, 75% of people with intellectual and developmental disabilities in the U.S. remained in segregated, sheltered work or day programmes despite some movements towards community-based employment.[68] A rigorous statistical analysis of employment data by the OECD also showed that, 'empirically the protected sector remains as important as ever'.[69] Overall, providing employment in segregated settings is still widely accepted and a popular policy across the globe, warranting their investigation.[70]

2.4 A PROBLEM WITH DEFINITION

Any discussion of 'sheltered work', must consider the definition of the term and what it connotes. This is however not a straightforward task because 'sheltered work' and 'sheltered workshop' are not fixed terms.[71] In fact, these may be used to refer to a variety of different methods, programmes and structures that can exist, usually in Western societies, to provide work or work-like activities for people with disabilities.[72] Perhaps one of the most problematic issues with discussing sheltered work is determining whether these are medical, therapeutic or rehabilitative interventions or places of work and employment. Often, sheltered work amalgamates these functions, making a clear-cut definition difficult. As a result, many different terms exist that denote the method of employing or occupying people in separate, protected environments, usually by specialist services providers or organisations.[73] Elsewhere, in comparative literature the

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[65] Isilda Shima, Eszter Zolyomi, and Asghar Zaidi, 'The Labour Market Situation of People with Disabilities in EU25', (European Centre, 2008).

[66] In Spanish sheltered employment centres, disabled people have a 'special employment relationship', which is reflected in their employment contract. For example, some sheltered workers may not be granted employee status in the terms of their employment contract in recognition of their limited capacity to work; European Parliament, Directorate General for Internal Policies n 47, 200; Noelia Flores, Cristina Jenaro, M. Begoña Orgaz, and M. Victoria Martín, 'Understanding Quality of Working Life of Workers with Intellectual Disabilities', (2011) 24(4) *Journal of Applied Research in Intellectual Disabilities*, 133-141.

[67] Caraiosa Kelly, 'Annual Report of the National Intellectual Disability Database Committee 2014: Main Findings', (Health Research Board, 2015), 15.

[68] Bryan Dague, 'Sheltered Employment, Sheltered Lives: Family Perspectives of Conversion to Community-based Employment', (2012) 37(1) *Journal of Vocational Rehabilitation*, 1; Paul Wehman, W. Grant Revell, and Valerie Brooke, 'Competitive Employment: Has It Become the 'First Choice' Yet?', (2003) 14(3) *Journal of Disability Policy Studies*, 163-173.

[69] Organisation for Economic Cooperation and Development, n 62 122.

[70] Sarah Parker Harris, Randall Owen, and Robert Gould, 'Equality through Difference: Policy Values, Human Rights and Social Justice in the Employment Participation of People with Disabilities', in Matthew Wappett, and Katrina Arndt, (eds.) *Emerging Perspectives on Disability Studies,* (Palgrave Macmillan, 2013), 163.

[71] This thesis will at times refer to sheltered work as a type of practice and to sheltered workshops as the place of that practice.

[72] Erwin Seyfried and Thibault Lambert, 'Semi-sheltered employment for the disabled in the Member States of the EEC', (European Centre for the Development of Vocational Training, 1990), 44. It is interesting to note here that according to Samoy and Waterplas, day centres and occupational services are very distinct to sheltered workshops. In other words, their pan European comparison of services and sheltered workshops reveals that there are clear distinctions. The researchers explain that the common factor that sheltered workshops share is that, unlike day centres, occupational and therapeutic centres, they function like companies- i.e. their prime objective is to produce goods or services; Samoy and Waterplas, n 15, 16.

[73] Other terms used, amongst others: adapted work settings, special work centers, special industries, industrial workshops, affirmative industries, training workshops, vocational workshops, business services, and rehabilitation

term 'sheltered work/shops' is a catch-all term used to denote the various services that may have a combination of functions comprising training, therapy and work.[74]

Largely, the difficulty with a definition stems from differing and divergent understandings of the concepts, objectives and purposes of the workshop. Visier refers to the different and often contrasting objectives in his global comparison and explains that, broadly, sheltered work/shops are part of a fluid labour market continuum.[75] As a result, varying definitions and understandings of sheltered work/shops are in operation not only across but also within departments and between different levels of governance, policy makers and their stakeholders. A scoping study in Ireland revealed that a spectrum of different forms of sheltered work and employment existed, their focus ranging from therapeutic to commercial.[76] These multiple functions can impact upon employers and employees understanding sheltered work/shops, and are reported to cause confusion, with adverse ramifications.[77] The European Disability Forum, for example explains that where sheltered workshops are considered as therapeutic interventions and not labour orientated, 'there is a great uncertainty, in terms of status and rights'.[78]

Despite the variations of facilities, the focus on work in these is a common defining feature. For its reporting mechanisms, the organisation categorises that sheltered workshops fall under 'integration/activation' measures along with: 'Accommodated work, subsidised work, supported work, reserved work and vocational rehabilitation'.[79] The problematic aspect, however, is that these establishments vary with respect to administrative structure, financing, target groups, salaries, and productivity, amongst other characteristics, and the branding of sheltered work as solely an employment measure is not always straight-forward or correct.

Although, sheltered work/shops go by a variety of different names, Bates-Harries declares that, often, the connotation is the same.[80] Indeed, a few distinctive characteristics can be highlighted. For example, as is evident from the name, the term

workshops. Previously in the UK, these have been titled, Adult Training Centres; Lee Anderson Humber, 'Social Inclusion through Employment: The Marketization of Employment Support for People with Learning Disabilities in the United Kingdom', (2014) 29(2) *Disability & Society*, 275-289. Samoy and Waterplas consider the terminology used to refer to 'sheltered employment' by different European Member States can range from 'social', to 'special' to 'centre' to 'companies for social employment provision' (The Netherlands) to 'work aid centres', (France and Luxembourg); Samoy and Waterplas, n 15, 17.

[74] Samoy and Waterplas, n 15, 38.

[75] Laurent Visier, 'Sheltered Employment for Persons with Disabilities', (1998), 137 (3) *International Labour Review*, 363.

[76] Health Service Executive, 'New Directions: Review of HSE Day Services and Implementation Plan 2012-2016, (HSE, 2012). For a discussion of these see: Charlotte May-Simera, 'Is the Irish (Republic of) Comprehensive Employment Strategy Fit for Purpose in Promoting the Employment of People with Intellectual Disabilities in the Open Labour Market? A Discussion Using Evidence from the National Intellectual Disability Database', (2018) 15(4) *Journal of Policy and Practice in Intellectual Disabilities*.

[77] Inclusion Ireland, 'A Chance to Work: A Discussion Paper on Work & Employment Services & Supports Available to People with an Intellectual Disability', (Inclusion Ireland, 2007). Inclusion Ireland state that this confusion particularly relates to the status of workers with intellectual disabilities in workshops in Ireland.

[78] Simona Girratano, 'Article 27 and beyond: A Rights Based Approach to Workers' (Dis)abilities', (Annual Conference on the Rights of Workers with Disabilities-Empowering Workers with Disabilities on the EU Labour Market: Legal Tools, Challenges and Best Practices, Academy of European Law, 2015).

[79] Organisation for Economic Cooperation and Development, n 63, 20.

[80] Bates-Harries, n 29.

sheltered workshop refers to a range of facilities, institutions and practices that are 'sheltered'. Generally, the term signifies settings and services that are organised and administered entirely separately from mainstream work settings, and sometimes even geographically located in sequestered places. The OECD prepared a report comparing employment policies across different countries and concluded that, broadly, the term 'sheltered workshops' covered a wide range of facilities but that these typically provided jobs for people with disabilities in 'sheltered environments alongside other disabled people'.[81]

Commonly, within these sheltered spaces, services offered are largely aimed at providing work, occupation and employment that might not otherwise exist in the open labour market for people with disabilities.[82] The simple work activities undertaken can range from clerical activities to, assembling, packing, woodworking, manufacturing, servicing, sewing, or sheet metal work.[83] The OECD report that, with a few exceptions, sheltered work and employment almost always comprises a manufacturing industry, often on a sub-contract basis, and involves the employment of persons without disabilities to support production and regulate the working environment.[84]

Attendance at these settings is typically captured and quantified according to different categories of disability, which have changed over time. Originally, sheltered workshops were set up to provide employment opportunities for the blind, or more generally, for people with sensory and/or physical disabilities, and war veterans. Nowadays, however, as more recent figures reveal, sheltered workshops in Europe almost exclusively comprise people with intellectual disabilities, and to a lesser extent, people with psycho-social disabilities.[85] Others explain that, broadly, sheltered workshops are set up for all people that have generally been categorised as unemployable.[86] In Germany, France and other EU countries, for example, this decision is based on measurement of ability, whereby a percentage of functionality is ascribed to individuals following tests.[87] In their dated study, Gefton and Lersuny identify that sheltered workshops provide paid industrial activity geared towards the 'needs of vocationally handicapped individuals who cannot compete in a normal employment situation'.[88] Overall, this description has remained relevant, as many identify the non-competitive nature of sheltered work. Bell,

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[81] Organization for Economic Co-operation and Development, n 57.

[82] Samoy and Waterplas, n 15, 17; European Parliament, Directorate General for Internal Policies, n 47, 19. The numbers of people attending sheltered workshops can be broken down into different types of categories such as psycho-social, sensory, physical or intellectual disability.

[83] Visier, n 75, 351.

[84] Organisation for Economic Cooperation and Development, n 57, 32.

[85] Mark Bell, 'Workers On the Margins: People with Intellectual Disabilities and Labour Law', (2019), 4, unpublished available at: <https://soc.kuleuven.be/ceso/wo/erlm/irec/docs/markbell-leuven-irec-2018-mark-bell.pdf> (accessed 17 July 2019); International Labour Office, 'Decent Work for Persons with Disabilities: Promoting Rights in the Global Development Agenda', (ILO, 2015), 73.

[86] Abbas, n 16, 53.

[87] For a comparative study on these assessments see: Working group on the assessment of person-related criteria for allowances and personal assistance for people with disabilities, *Assessing Disability in Europe: Similarities and Differences: Integration of People with Disabilities,* (Council of Europe, 2002).

[88] Carl Gersuny and Mark Lefton, 'Service and Servitude in the Sheltered Workshop', (1970), 15(3) *Social Work,* 74.

for example, describes that recruitment to sheltered settings is typically not competitive but follows an assessment of capacity to work.[89]

While the term 'sheltered workshops' typically describes the setting, 'sheltered work' refers, broadly, to any form of work that takes place in sheltered workshops or under separate conditions. Usually, sheltered work is not protected by employment legislation, although some form of compensation or other type of payment may be received in some instances. Sheltered employment, on the other hand, describes waged or salaried employment that usually takes place within separate enclaves, including sheltered workshops, but can also describe an employment relationship that exists in other settings, separate units, or divisions within mainstream factories on the open labour market. Elsewhere, the workers may be originally from a workshop but working in an enclave in an open setting. Seyfried and Lambert explain, for example, that 'persons employed in such so-called 'enclaves'' are, in formal terms, not employees of the company in which they work. Rather, they are members of a workshop, from which they receive their pay, while that workshop bills the company for the total of the employment services rendered.[90] This type of employment may or may not be subject to employment legislation.

Perhaps a useful clarification at this point is a brief definition of the term 'open labour market'. As it is used in this dissertation, the phrase is perhaps the antithesis of our definition of sheltered work practices and settings. When referring to the open labour market in this discussion, what is implied is the mainstream labour market that is readily accessible to all people, especially those without disabilities, and where work (services and production) and employment are the overarching objective. An open labour market, by definition, is one that is subject to relevant, well-established rules and regulations and where individual and collective rights of workers are safeguarded. Employee-employer relationships are kept in check by independent bodies with extensive equality provisions established through case law. Employment on the open labour market is referred to herein as 'open employment'. This form of employment is subject to the relevant and widely applicable labour laws and regulations. The open labour market arguably constitutes the direct opposite of closed settings, which are typically sheltered from all aspects of the mainstream economy.

2.4.1 The divergent purposes of sheltered work

Whilst sheltered workshops are often part of state's employment measures, as the OECD suggest, in some instances, particularly in eastern EU Member States these operate singularly to provide rehabilitation and medical interventions.[91] The ILO

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[89] Bell, n 85.
[90] Seyfried and Lambert, n 72.
[91] Significant concerns with the system in operation in Hungary have been reported. Here, a high number of individuals are placed in sheltered workshops and as a result people with disabilities remains largely segregated in Hungarian society. European Parliament, Directorate General for Internal Policies, n 47, 183.

highlights this as a concern, using the example of Croatia where, 'many, instead of working, end in day centres for rehabilitation and occupational activities – which are a part of social welfare system and make people attending them a client instead of an employee'.[92] Indeed, most of the literature reviewed referred to this dichotomy of a dual purpose that sheltered work/shops often embody: the rehabilitative, therapeutic function on the one hand, and the work and training function on the other.[93]

As noted above, tracing the history of these institutions reveals that largely sheltered work settings have evolved from institutions run according to an ethos of charity and medical treatment. As a result, sheltered workshops ultimately stem from therapeutic and rehabilitative work and training provisions. Where a workshop's primary focus is to provide vocational training and education, participants either learn life skills or receive vocational training. However, this does not preclude workshops from having a commercial orientation, with a focus on production.[94] Researchers studying sheltered employment in the European Community found that rehabilitative and vocational training played a major part in almost every workshop.[95] A similar study also highlighted the importance of training in almost all sheltered workshops, although the length of this training could be unusually long and it is not 'always clear whether this is designed to lead to open employment'.[96]

The distinction between work, training and rehabilitation, in terms of the tasks and activities conducted in sheltered workshops then makes a legal analysis of these settings complex. Moreover, the term itself can be a legal concept or a loose definition of a rehabilitative programme, the determination of which is subject to national or regional characteristics of the welfare, training or employment systems. Similar to the variations in employment and welfare structures and policies in each EU Member State, provisions for people with disabilities vary too, specifically affecting the organisation and definition of sheltered work/shops.[97] This not only makes a holistic definition impossible but makes strict comparisons of sheltered workshops between states and jurisdictions impossible.[98] Fenger et al. also address these complexities and find that the various ways in which sheltered work is framed, as either a rehabilitative or a concrete employment facility, also reflects political ideologies.[99]

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[92] Vojmir Franičević, 'Decent Work Country Report- Croatia' (ILO, 2008), 21.

[93] Marjolein Peters, Martin von der Ende, Sabine Desczka and Thijs Viertelhauzen, 'Benefit systems and their interaction with active labour market policies (ALMPs) in the new Member States- Final report', (2008), 323.

[94] The International Labour Organization describes vocational training as 'any form of training by means of which technical or trade knowledge can be acquired or developed, whether the training is given at school or at the place of work.' International Labor Organization, Vocational Training Recommendation No. 57, (1939), Part I(a).

[95] Samoy and Waterplas, n 15. Although dated, this research has frequently been cited and has therefore been influential.

[96] Ecotec Research and Consulting Ltd., 'Benchmarking Employment Policies for People with Disabilities, A study prepared for the European Commission Directorate-General for Employment and Social Affairs Unit EMPL/E/4', (2000).

[97] Ibid., 226.

[98] Patricia Thornton and Neil Lunt, 'Employment Policies for Disabled People in Eighteen Countries: A Review', (Social Policy Research Unit, University of York, 1997), 397.

[99] Linda Ware, (ed.), *Political Ideologies of (in)Exclusion*, (Peter Lang Publishing, 2004); Fenger et al. believe that vested interests, political strategy and or public preference can determine the development of social (sheltered) policies; Menno Fenger, Martijn van der Steen and Lieske van der Torre, *The Responsiveness of Social Policies in Europe*, (Policy Press, 2013), 192.

In their EU study, Samoy and Waterplas similarly note the weighting of political choice over the running of sheltered workshops that influences the numbers of placements. These figures also reflect the ideologies of Member States, whether to integrate or separate people with disabilities. The numbers of placements are further determined by the 'acceptance or the rejection of disabled employees by industry, the importance given to labour, the acceptance of a workless life living off benefits, etc'.[100] In the comparative study by the European Parliament it found that, to a large extent, sheltered workshops are influenced by the legal and cultural environments of each Member State, which determines the definitions, activities and legal frameworks of sheltered work/shops. Across the EU a significant variation in these existed, which stem predominantly from differing views as to their purpose.[101] These discrepancies profoundly affect those occupied therein, primarily due to fluctuating levels of, and the importance placed on inclusion and rights. Overall, Pendo succinctly summarizes that the problem with defining sheltered work lies in the dichotomies the term embodies. These raise unresolved questions over the status of individuals, the purpose of the setting and role of the institution generally. She illustrates this issue by asking: 'disabled or worker, work or therapy, independence or assistance, integration or segregation, protection or exploitation, rights or benefits'?[102]

2.5   A WORKING DEFINITION

Judging by their frequency and prevalence across the globe, sheltered workshops and sheltered work practices are evidently an embedded feature of states' employment, education, welfare and rehabilitation programmes. There are, however, vast discrepancies within the operation of these, which makes a distinct definition of sheltered work/shops impossible. The ILO has also identified the issue of definition as problematic and applies a wide-ranging connotation, referring to these generally as alternative work settings.[103] Broadly, the ILO explains that these denote the practice of employing and training people with disabilities separately from others and under separate terms and conditions. Indeed, this review of the international literature and research reveals that sheltered workshops are largely designed to be places of work, often attempting to simulate work environments found in the open labour market, as closely as possible. Having noted the ancillary functions these fulfil, for the purposes of this investigation sheltered work settings will nonetheless also be considered as places of work or where work-like activities take place.

Although, the conceptual boundaries of the sheltered workshop are blurred, there are, however, some features of workshops that warrant, and indeed justify, an

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[100] Samoy and Waterplas, n 15, 38.
[101] European Parliament, Directorate General for Internal Policies, n 47, 31.
[102] Elizabeth Pendo, 'Hidden from View; Disability, Segregation and Work' in Marion Crain, Winifred Poster and Miriam Cherry (eds.), *Invisible Labor: Hidden Work in the Contemporary World,* (University of California Press, 2016), 122.
[103] International Labour Organisation, 'Decent Work for Persons with Disabilities: Promoting Rights in the Global Development Agenda', (ILO, 2015).

understanding of these as primarily work-related settings. Often, including in the case of Francesca, these settings are designed to mimic 'normal' work environments as precisely as possible and, generally, form part of state policies aimed at providing employment to all, regardless of where this takes place. In Germany, for example, sheltered work and employment make up the 'secondary employment market' that co-exists and feeds into the open labour market.[104] Moreover, a review of sheltered workshops in Ireland describes these as purposely emulating the conditions of a well-managed commercial concern where the work conducted was of a semi-skilled or unskilled nature.[105] Therefore, the workshop is described as a quasi 'halfway house' between medical care and competitive employment, implementing the notion that 'rehabilitation can best occur in a situation of real work with a degree of protection from some of the stresses of an actual work situation'.[106] Further, research also highlights this focus on work in sheltered work settings and describes these as 'facility-based day programs attended by adults with disabilities as an alternative to working in the open labour market'.[107] With the exception of some educational and leisure programmes on offer, work is usually the main focus in many sheltered workshops.

Whilst I have clarified how sheltered work settings are defined for the purpose of this discussion, there are significant problematic aspects involved in arriving at a more conclusive and complete definition. This is because these settings can rarely be categorised as exclusively an employment measure, contrary to the approach taken by organisations such as the ILO and OECD. In some instances, sheltered work settings have a heavy industrial focus, whereas elsewhere production may play a lesser role. The setting is therefore notorious for its intermingling of work *and* rehabilitative functions, which in turn impacts upon the application of labour standards and regulations, as well as clarity over the legal status of participants (ranging from patient to employee).[108]

Mindful of this intermingling of functions the working definition for this thesis will interchangeably refer to 'sheltered work settings', 'sheltered work' or 'sheltered workshops'. These are utilised to denote a broad concept rather than a definitive place or practice. This concept comprises two main features central to sheltered work settings and their design. The first aspect is the importance placed on 'work', in whatever form, whether this is for rehabilitative, training or economic purposes. The second vital marker for the choice of terms used here focuses on the segregated, closed nature of the setting or practice, whether this is purposeful or an inevitable consequence thereof. Indeed, by default, the sheltered workshop is a setting that segregates certain groups, primarily people with intellectual disabilities, from others.[109]

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[104] Institut der Deutschen Wirtschaft Koeln, 'Zweiter Arbeitsmarkt', (Trnsl. 'second labour market'), (2018) [online], available at: <https://www.rehadat-bildung.de/de/lexikon/Lex-Zweiter-Arbeitsmarkt/> (accessed 17 July 2019).
[105] The work was either commissioned into the workshop on a subcontract basis or some centres manufactured the products from start to finish. The Steering Committee Community Workshops Research Project, Eastern Health Board, 'Appendices to Community Workshops Research Project', (1986), 13.
[106] Gersuny and Lefton, n 86, 74.
[107] Migliore, n 12.
[108] Ten Broek, n 4, Steven Taylor, n 56, Soldatic and Chapman, n 59, Hasenfeld, n 59.
[109] Pendo, n 102, 127.

This very aspect makes it vulnerable to the criticism that through its very existence the sheltered workshop acts as a deterrent to including people with disabilities in the open labour market.

2.6 **CONCLUSION**

This chapter has introduced the concept of sheltered work and offered an insight into the current provision of it. The chapter began by briefly tracing the emergence of sheltered work, which coincided with the evolution of institutions for people with disabilities generally, before offering a national example. Moreover, the chapter has demonstrated how popular sheltered work settings are based on the figures provided as captured by the ILO. The chapter proceeded to show how its institutional past still pervades the sheltered workshop debate today, blurring the boundaries between rehabilitation and work. As a result, strict definitions of the terms sheltered workshop, sheltered work and sheltered employment are difficult to agree on. In response to this difficulty, this chapter introduces working definitions for this thesis to facilitate a shared understanding of the terms. As they are used in this discussion, the terms broadly denote varied practices that similarly provide work and work-like activities for the purposes of employing, training or occupying people with intellectual disabilities. Besides the centrality of work, one of the most common and distinctive features across these settings and programmes is that these are premised on segregating people with disabilities, especially intellectual disabilities, in specialised settings, subject to separate conditions of work.[110] Numerous criticisms of the sheltered workshop exist. These controversies have negatively impacted on the provision of these in some countries and continue to dominate much of the discourse on the topic today. To complete this introduction to sheltered work, further insight into the practice addressing these criticisms, is offered in the next chapter.

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[110] Jillian Guilfoyle, 'Coming Out of the Shadows of Sheltered Workshops and Subminimum Wage: Exploring the Exploitation of Disabled Workers Under Section 214(c) of the Fair Labor Standards Act', (2015) Paper 53 *Louis Jackson National Student Writing Competition*, 1–30.

Chapter 3: Common Concerns and Problems with Sheltered Work

The topic of sheltered work is often the subject of lively but oversimplified debate. This typically results in a categorisation of sheltered workshops as either 'good' or 'bad'. Ardent opponents describe workshops as 'warehouses' or 'ghettos', where disabled people are hidden away and segregated and experience institutional abuse and exploitation.[1] Proponents regard the sheltered workshop as a practical and necessary service that occupies and employs people who otherwise might not find employment.[2] Others agree that the workshop debate is often not a question of 'either/or' because people with disabilities are a highly heterogeneous group.[3] Evidently, the subject of sheltered work is far more complex, beyond arriving at a common definition, and multiple factors must be considered in any discussion. This chapter lists some of these factors, which, because of their effects, are largely described as problematic. These concerns are distilled from international literature and comparative studies on sheltered work and employment. Based on common findings across this research, the exploitative potential of sheltered workshop practices is highlighted. Listing these areas of concern clarifies why the area of debate is steeped in controversy. Moreover, enumerating these problems shows not only how the CRPD and its new human rights focus might impact on future debate but also what precise aspects of sheltered work are in conflict with its principles.

3.1 SERVITUDE IN THE WORKSHOP

As a result of their institutional past, many sheltered workshops are often affiliated with church-run organisations, originally established to treat and house those regarded as impoverished and delinquent.[4] Persons engaged with these services were often treated as patients, primarily requiring care.[5] Workshops with strong religious roots exercised strong control over their patients that extended beyond the realm of work into diverse aspects of their lives. This intervention was, and still is, largely evident in the many rules and regulations that govern the day to day operation of the sheltered workshop. For example, workers in workshops were

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[1] Erik Samoy and Lina Waterplas, 'Sheltered Employment in the European Community', Katholieke Universtieit Leuven & Hoger Instituut voor de Arbeid, 1992), 37.

[2] Feminist equality Scholar Colker has written extensively on why she defends certain segregated practices. Ruth Colker, *When is Separate Unequal? A Disability Perspective*, (Cambridge University Press, 2009).

[3] Robert Weathers and David Wittenburg, 'Employment' in Andrew Houtenville, David Stapleton, Robert Weathers and Richard Burkhauser, (eds.), *Counting Working-Age People with Disabilities, What Current Data Tells Us and Options for Improvement*, (W.E. Upjohn Institute for Employment Research, 2009).

[4] In the U.S., the Goodwill industries, became the most successful of all the church sponsored workshop chains. Other large religious associates such as the Salvation Army, Volunteers of America and St. Vincent de Paul Society also set up commercial sheltered workshops.

[5] Taylor and Bogdan describe how people with intellectual disabilities are excluded from the mainstream of our society and, 'subjected to the worst kinds of treatments in institutional settings'. Robert Bogdan, and Steven Taylor, 'Relationships with Severely Disabled People: The Social Construction of Humanness', (1989) 36(2) *Current Social Problems*, 135–148.

compelled to regularly attend religious masses for all occasions, and remnants of this practice are still reported today.[6] In the case of Francesca, for instance, a priest regularly visits the workshop, and religious occasions are celebrated, accompanied by a religious service held in a local church.

A further aspect determining the experience of sheltered work is shaped by the ideology underpinning its establishment, described by some as that of a puritan work ethic. In a society that labelled disabled people as deviants, the only means of redemption was to work and be occupied.[7] The workshops thus offered its wards a chance 'to earn money and feel useful'.[8] The workshops were then not only a place to put 'deviants' to work but also a further extension of the institution that exercised complete control over its patients. Researchers have therefore declared that people with disabilities were subject to conditions of servitude in sheltered workshops, as illustrated by the following statement:

> We began our day of work with church services. I have nothing against religious services, but we were all preached at as though we had something to be ashamed of because of our handicaps- that because of our affliction we were sinners. I might add that, unless we attended these services, we were docked one-half hour on the pay-check.[9]

Referring to the position of workers in workshops for the blind, ten Broek describes that they were virtually in the position of wards, without legal rights or recourse to same, and reduced to an abject dependency upon the good will and discretion of their employers'.[10] Researchers Gersuny and Lefton also identify a problematic relationship between organisations offering a service and its clients and workers receiving the service. They note that dependency becomes a lever of organisational control introducing an element of servitude into the social relations of service organisations.[11] Others add that it is because of their conditions that adults with disabilities are automatically dependent on the workshop and subordinate to its staff, introducing a power imbalance.[12] Therefore researchers note, the greater the client's disability the greater their dependency and, therefore, the more servile their status.[13] Haggstrom identifies that the status of clienthood entails an aspect of servitude in every instance: 'When a powerful service organisation establishes a connection with powerless clients, the power of the former rushes into the power vacuum of the latter'.[14] Mittler, notes that, generally, disability services are characterised by power imbalances between those with and those without disabilities and a

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[6] For example, the workshops run in Germany by the religious organisations 'Johannes Werk e.V.' suggests that before every annual Christmas fest all attendees attend a church service.

[7] Sheerin beholds the historical factors of labeling people with intellectual disabilities as deviants, largely ascribed based on the difference this inhibited and imposed upon individuals by the majority or ruling segment of society that value this difference negatively; Fintan Sheerin, 'Incapacity and People with Intellectual Disabilities, A Social Construction?', (Conference of the Law Reform Commission Dublin, 2011).

[8] Carl Gersuny and Mark Lefton, 'Service and Servitude in the Sheltered Workshop', (1970) 15(3) *Social Work*, 74.

[9] Gersuny & Lefton, 76.

[10] Jacob ten Broek, 'The Character and Function of Sheltered Workshops', (National Federation of the Blind, 1995), [online] available at: <http://www.blind.net/resources/employment/the-character-and-function-of-sheltered-workshops.html> (accessed on 10 February 2016).

[11] Gersuny and Lefton, n8, 75.

[12] Alberto Migliore, David Mank, Tara Gross and Peter Rogan, 'Integrated Employment or Sheltered Workshops: Preferences of Adults with Intellectual Disabilities, their Families and Staff', (2007) 26(1) *Journal of Vocational Rehabilitation*, 5.

[13] Gersuny and Lefton, n 8, 75.

[14] Gersuny and Lefton, n 8, 80.

lack of forming natural relationships. Both circumstances are augmented by the act of segregation.[15]

Other social theorists such as Gill and Abbas analyse the social constructs that make up the sheltered workshop setting and the relationships therein.[16] Gill also believes that disabled workers are forced into a subordinate role which, however, is part of a bargaining process.[17] The workshop is then a 'tangible sign' of a social contract that governs a liberal society. It provides a 'vocation in exchange for an attempt to become self-sufficient contributors of society'.[18] As part of this contract, sheltered workers give up their claim to a meaningful occupation and their right to a place in the community in exchange for shelter, food and the illusion of having a purposeful job. This is an implied agreement that sees a society that will readily fund segregated spaces for disabled people as long as these jobs are located in isolation, and deny fair wages and equal treatment. Gill, therefore, describes such a place as a 'location of isolation and forced docility'.[19] To Gill, the sheltered workshop remains problematic because it embodies a silent agreement that justifies the segregation of people with disabilities who are subject to the pervasive nature of this separation, which also strips them of their rights, and treats them as powerless clients and subordinates.

3.1.1 Types, experiences and consequences of sheltered work

Sheltered work and its corresponding practices have been the subject of much controversy. This chapter will now refer to empirical, quantitative and qualitative research and international reports to distil the criticisms of these settings based not only on their institutional legacies, out-dated practices and treatment of people with intellectual disabilities but also because of the types of work activities on offer. Moreover, the specific experience of segregation as a prevailing consequence of sheltered work will be considered, as will its effects.

Nettelbeck describes how sheltered workshops have operated historically according to the notion of 'dull work for dull minds' notion - a view that is based on an understanding that the workshop setting itself represented its clients' limitations in terms of their potential.[20] Constraints imposed by the sheltered work programme were therefore not assumed to be detrimental but a natural consequence of disability.[21] Tasks were, therefore, simple and

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[15] Peter Mittler, 'Preparing for Self-Advocacy' in Barry Carpenter, Rob Ashdown and Keith Bovair (eds.), *Enabling Access: Effective Teaching and Learning for Pupils with Learning Difficulties.* (Routledge, 2012), 280.

[16] Jihan Abbas, 'A Legacy of Exploitation: Intellectual Disability, unpaid labour, & Disability services', (2012) 14(1) *New Politics,* 53.

[17] Professor Michael Gill of the University of Illinois in Chicago also comments on the power relationships at work and that come to fore in the sheltered workshop. Gill describes workshops as places where the 'contractualisation of disability' takes place. Drawing on Foucauldian notions of the social creation and the resulting control through confinement of mad men in society, Gill explores the coming into existence of sheltered workshops. Gill claims these are a result of societal social obligations to control, constrict and therefore, house mad men. According to Gill it is in these separate places of society that conscribed members of society negotiate the label of disability. Michael Gill, 'The Myth of Transition: Contractualizing Disability in the Sheltered Workshop', (2005), 20(6) *Disability & Society*, 613-623.

[18] Ibid, 617.

[19] Ibid.

[20] Theodore Nettelbeck, 'A Skills Approach to the Vocational Training of Mildly Retarded Workers', (1977) 4(7) *Australian Journal of Mental Retardation*, 7-10.

[21] Marvin Rosen, Albert Bussone, Peter Dakunchak, and John Cramp, Jr, 'Sheltered Employment and the Second Generation Workshop', (1993) 59(1) *Journal of Rehabilitation*, 30; Colin Bates-Harris, 'NDN Webinar: The State of Sheltered Workshops',

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repetitive, with a short operation cycle.[22] This is because, as Dines explains, some workshops were designed as interventions for adults with disabilities to merely 'help keep them busy', doing work consisting of repetitive – motion tasks. Much empirical research exists that characterises sheltered work as being highly routinised with little variation.[23] In a report by the OECD, besides criticising the poor working conditions in sheltered work settings, the organisation condemned the unchallenging and repetitive nature of the 'inappropriate' work conducted in these.[24]

Indeed, many people with disabilities have shared their experiences of sheltered work and describe this as repetitive to the point of being punitive. Self-advocate Ellerby, for example, refers to his time in a sheltered workshop as an 'appalling experience'.[25] Placed in the workshop by an employment advisor, Ellerby quickly became bored of the routinised work that was so mundane and repetitive it required high levels of stamina. He contemplates that the whole system and function of the workshop in fact seemed to have a disciplining effect rather than a therapeutic or rehabilitative one.[26] Another worker in a Vocational Rehabilitation Centre in the State of Georgia reports that he was ordered to place a plastic cover on two bottles eight hours a day for three weeks to demonstrate his 'readiness to work'. Upon showing signs of resistance, he suffered negative consequences at the hands of supervisors.[27] Davister et al. also describe how sheltered work measures are often intended to (re)socialise people with 'social problems', -former convicts, drug addicts - and those with a 'mental handicap' as it is thought that through work, its structures, and rules they could be (re)habilitated.[28] Along with the first-hand accounts, this description is reminiscent of the traditional punitive functions of the institution prevalent in the Victorian era, as described above.

Abbas considers that in Canada's sheltered work settings there is still clear emphasis on tedious, monotonous, labour-intensive tasks such as collating and sorting materials.[29] The example of Francesca also shows that there has been no significant change in the types of tasks conducted in sheltered work settings. Further research by Li indicates that sheltered workers feel bored and lament that they don't learn new things.[30] Having experienced the sheltered workshop system, Martin, who is now a member of the CmRPD, describes this as a type of institution that

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(Presentation, 19 August 2014), available at: <http://ddi.wayne.edu/pdf/ndrn_sheltered_workshop_webinar_transcript.pdf> (accessed 7 July 2016).

[22] The Steering Committee Community Workshops Research Project, Eastern Health Board, 'Appendices to Community Workshops Research Project', (1986), 28.

[23] Francisco Borja, Jordan de Urries and Miguel Angel Verdugo, 'Sheltered Employment Centres: Characteristics and users' perception', (2011) 38(1) *Work*, 1.

[24] Organization for Economic Co-operation and Development, 'Employment policy for People with Disabilities', (Labour Market and Social Policy Occasional Papers No. 8, 1992), 34.

[25] Mark Ellerby, *Stages of Schizophrenia*, (Chipmunk Publishing, 2006).

[26] Ibid, 30.

[27] A supervisor concluded that he 'didn't really want to work'. Susan Stefan, 'Beyond Residential Segregation: The Application of Olmstead to Segregated Employment Settings', (2010), 26(3) *Georgia State University Law Review*, 875.

[28] Catherine Davister, Jacques Defourney and Oliver Gregoire, 'Work Integration Social Enterprises in the European Union: An Overview of Existing Models', (2004), [online] available at:
<http://www.joseacontreras.net/econom/Economia/Economia_Social_CIES/pdf/economiasocial/investigacion/PERSE%20Work%20Integration.pdf> (accessed 5 July 2016).

[29] Abbas, n 16, 53.

[30] E. P.-Y. Li, 'Vocational Aspirations of Sheltered Workshop Workers with Intellectual Disability in Hong Kong' (2002) 42(3) *Journal of Intellectual Disability Research*, 208-217, 212.

functions as a glorified babysitter.[31] Today, sheltered work settings continue to be places that offer simple, 'limited-skill work' such as sorting, assembling and packaging, and are described as lacking any purpose or self-fulfilment.[32]

Unsurprisingly, not much value is ascribed to the work conducted in sheltered workshops, which has a negative impact on people with disabilities.[33] In fact, in some instances, the work of persons with disabilities in sheltered work settings goes wholly unrecognised. Besides the simple tasks described above, it is also therefore important to mention the other types of work performed by sheltered workers. These include tasks such as cooking, cleaning and gardening which contribute to the upkeep of the institution. However, these often go unacknowledged, as labour and the significance of this work is often overlooked.[34] Abbas refers to this work as the 'invisible labour' of people with intellectual disabilities.[35] As important economic contributions that support the running of the institutions, outside of the sheltered work setting these activities would undoubtedly be classified as work. Besides their significant economic value to the work setting, the fulfilment of these tasks fundamentally reveals a capacity for productive work on the part of those conducting them. Indeed, this very fact is indicative of an inherent flaw of the institution which will be revisited further below.[36]

3.1.2 The effects of segregation in sheltered work settings

A significant amount of empirical research into the experiences of sheltered workshop attendees has also been conducted.[37] The majority of these studies further consolidate the perception of the negative effects of the placements and tasks, but also allude to the adverse effects of being segregated. A statistical analysis of self-reported well-being by Petrovski and Gleeson, for example, revealed that many participants in sheltered work programmes felt stigmatised and lonely as compared to those in open employment. A significant number of sheltered workers reported feeling 'different' and left out, and nearly half reported that they wanted to work

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[31] Robert Martin, 'The Convention: Drafting Opportunities, Challenges and the Committee's interpretations', (Robert Martin, CRPD Committee Member, New Zealand, speaking at the 11th International Disability Law Summer School, 17-21 June 2019).
[32] M Dines, 'Are Sheltered Workshops a Thing of the Past', (Social Work Helper Blog, 9 September 2014), [online] available at: <https://www.socialworkhelper.com/2014/10/09/sheltered-workshops-thing-past/> (accessed 15 March 2016).
[33] Keith Storey, 'Why Employment in Integrated Workshop setting of People with Disabilities', (2000) 23(1) *Journal of Rehabilitation Research*, 103-110.
[34] Important to note however that in other instances tasks such as these have been officially recognised as work. In *Steymann v Staatssecretaris van Justitie* the European Court of Justice determined that activities conducted by a member of a Bagwhan commune, which included the running of a bar and a launderette, in return for board and lodging did constitute a commercial activity and Steyman could be considered a worker under EU law. Case 196/87 *Udo Steymann v Staatssecretaris van Justitie* [1988] ECR 06159.
[35] Abbas, n. 16.
[36] Abbas also reviews the everyday experiences of those rehabilitation and training programs, both inside and outside of the institution's walls, and uncovers that nature of this labour is entrenched and a central and necessary function within the delivery of disability services for adults with intellectual disabilities, n 16.
[37] Domingo Garcia-Villamisar, Paul Wehman and Maria Diaz Navarro, 'Changes in the Quality of Autistic People's Life That Work in Supported and Sheltered Employment. A 5-Year Follow-up Study', (2002) 17(4) *Journal of Vocational Rehabilitation,* 309-312; Cristóbal Miralles Jose Pedro, García-Sabater, Carlos Andrés and Manuel Cardos, 'Advantages of Assembly Lines in Sheltered Work Centres for Disabled. A Case Study', (2007) 110(1) *International Journal of Production Economics,* 187-197.

somewhere else: this was for different reasons such as 'getting bored', 'doing the same thing over and over again', 'wanting to do more' and 'wanting to do something better'.[38]

Considerable evidence points to the fact that people with disabilities want to be integrated, independent, part of the open labour market and earning more.[39] In addition to research that highlights the negative effects in a material sense, people with intellectual disabilities in sheltered workshops also reported lower levels of self-esteem compared to those on the open labour market.[40] Kober and Eggleton also found a statistically significant lower quality of life scores among people placed in sheltered employment compared to those in open employment.[41] A further study assessed, specifically, the quality of working life in sheltered workshops and noted high levels of dependency between sheltered workers and their supervisors, as previously discussed.[42] Koh speaks of uneven power relationships that generally exist in services and shape the unequal treatment of people with intellectual disabilities.[43] Accordingly, supervisors in sheltered workshops could be overprotective and imposing, effectively stifling the development and limiting the opportunities of sheltered workers.[44]

Disability advocacy groups have been increasingly vocal about condemning sheltered workshops, highlighting the negative consequences of placements.[45] Advocates depict workshops as places of damaging isolation, financial exploitation and poverty and report that placements deny them the opportunity to earn a good wage, including the chance to live a life of dignity.[46] Inclusion International, a leading advocacy group, illustrates that the exclusion of persons with intellectual disabilities in workshops reinforces the negative stereotypes, 'as to our value, in the minds of others'.[47] Along with 'very little pay', these represent a lack of opportunity

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[38] P Petrovski and G Gleeson, 'The Relationship between Job Satisfaction and Psychological Health in People with Intellectual Disability in Competitive Employment', 22(3) *Journal of Intellectual and Developmental Disability,* (1997), 199-211

[39] Tanja Burchardt, 'Enduring Economic Exclusion – Disabled People, Income and Work', (Joseph Rowntree Foundation, 2000); James Dudley and Mona Schatz, 'The Missing Link in Evaluating Sheltered Workshop Programs: The Clients' Input', (1985) 23(5) *Mental Retardation*, 235–240; Steven T. Murphy and Patricia Rogan, *Closing the Shop: Conversion from Sheltered to Integrated Work*, (Paul H. Brookes Publishing Co., 1995); Libby Kumin and Lisa Schoenbrodt, 'Employment in Adults with Down Syndrome in the United States: Results from a National Survey', (2016) 29(4) *Journal of Applied Research in Intellectual Disabilities*, 330-345, 337.

[40] David Griffin, Howard Rosenberg, Wendy Cheyney, 'A Comparison of Self-Esteem and Job Satisfaction of Adults with Mild Mental Retardation in Sheltered Workshops and Supported Employment', (1996), 21(2) *Education & Training in Mental Retardation & Developmental Disabilities*, 9.

[41] Ralph Kober and Ian Eggleton, 'The Effect of Different Types of Employment on Quality of Life', (2005) 49(10) *Journal of Intellectual Disability Research*, 756 – 760. Comparing specifically people with intellectual disabilities in different forms of employment, Eggleton et al. found that those in open employment were happiest. Robinson adds that particularly paid employment impacted positively on self-esteem and quality of life. Ian Eggleton, Sue Robertson, Justine Ryan, and Ralph Kober, 'The Impact on the quality of Life of People with an Intellectual Disability', (1999) 13(1) *Journal of Vocational Rehabilitation*, 95-107; Jill Robinson, 'Access to Employment for People with Disabilities: Findings of a Consumer-led Project', (2000) 22(5) *Disability and Rehabilitation: An International Multidisciplinary Journal*, 246-253.

[42] Noelia Flores, Christina Jenaro, M. Begona Orgaz, and M. Victoria Martín, 'Understanding Quality of Life of Workers with Intellectual Disabilities', (2011) 24(1) *Journal of Applied Research in Intellectual Disabilities*, 133-144.

[43] Harold Hongju Koh, 'Different but Equal: The Human Rights of Persons with Intellectual Disabilities', (2004) 63(1) *Maryland Law Review*, 1-19.

[44] Bryan Farris and Roger Stancliffe, 'The Co-worker training model: Outcomes of an Open Employment Pilot Project', (2001) 26(1) *Journal of Intellectual & Developmental Disability*, 145-161.

[45] Brian Dague, 'Sheltered Employment, Sheltered lives: Family perspectives of conversion to community-based employment', (2012) 37 *Journal of Vocational Rehabilitation*, 1.

[46] Jennifer Richards, 'Too Many Disabled People Work in Shelters Instead of the Community Advocates Say', (*The Columbus Dispatch*, 23 May 2011).

[47] Inclusion International, 'The United Nations Convention on the Rights of Persons with Disabilities' (2012) [online], available at: <http://www.ii-livinginthecommunity.org/UN%20brochure%20screen.pdf> (accessed 16 March 2015).

and lock 'many of us into poverty'.[48] Others add that sheltered settings generally, allow attitudes of fear and misconceptions about disability to fester.

As a substitute for real employment, sheltered work is premised on the assumption that disabled workers cannot compete successfully in the general labour market and instead require separate settings to be productive. As a result of this segregation, misperceptions of the abilities of people with disabilities go unchallenged, and people with disabilities continue to be categorised as incapable, second-class citizens.[49] Subsequently, a sweeping generalisation that people with disabilities are incapable of carrying out any meaningful or economically productive work is affirmed. This approach is sustained by the notion that therefore, they are 'better off' in these protected environments.[50]

There is much research on the negative effects of segregation on many groups, including children, the elderly, and people with intellectual disabilities.[51] This has even been recognised internationally by the European Court of Human Rights in a judgment condemning the segregation of Roma children in education. In its judgement, the Court reported that segregation caused emotional and psychological harm in Roma children, lowering their self-esteem and self-respect, and causing problems in the development of their identity.[52]

Indeed, research indicates that people with intellectual disabilities benefit from being included, as opposed to segregated in sheltered work settings and enjoy access to wider social networks that are otherwise restricted to family, carers and paid staff.[53] Institutions effectively, remove people with disabilities from their communities, cutting ties to natural social networks that develop throughout an individual's lifetime. With no connection to structures such as school, work, neighbourhood and other parts of community life, people with disabilities are unable to engage in the organic process of social learning so instrumental in fostering participation and inclusion. Arstein-Kerslake explains that, among the many effects of segregation and longstanding exposure to institutional authority, a process of de-skilling within the individual occurs as autonomy, choice and natural supports are typically removed.[54]

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[48] Ibid.

[49] the Un reports that employers often resist employing a person with disabilities based on the belief that they are unable to perform their roles and/or that it would be too expensive. UN Enable, 'International Day of Disabled Persons, 'Decent Work for Persons with Disabilities', (Press Release, 3 December 2007) [online], available at:
<http://www.un.org/disabilities/default.asp?id=110> (accessed 13 July 2016).

[50] Marco Fasciglione, 'Article 27 of the CRPD and the Right of Inclusive Employment of People with Autism', in Valentina Della Fina and Rachele Cera, (eds.) *Protecting the Rights of People with Autism in the Fields of Education and Employment*, (2015), 146.

[51] Anne E Berens and Charles A Nelson, 'The Science of Early Adversity: Is There a Role for Large Institutions in the Care of Vulnerable Children?', (2015) 386 (9991) *The Lancet,* 388-398.

[52] ECtHR, Application No. 15766/03, *Oršuš and Others v. Croatia*, judgment (Chamber – First Section) of 17 July 2008 and judgment (Grand Chamber – First Section) (final) of 16 March 2010, para.53.; Croatian Constitutional Court (Ustavni sud Republike Hrvatske), U-III-3138/2002, judgment of 7 February 2000, Official Gazette (Narodne Novine) 22/2007.

[53] Allison Cohen Hall and John Kramer, 'Social Capital Through Workplace Connections: Opportunities for Workers with Intellectual Disabilities' (2009) 8(3) *Journal of Social Work in Disability & Rehabilitation*, 146-170, 148.

[54] Anna Arstein-Kerslake, *Restoring Voice to People with Cognitive Disabilities: Realizing the Right to Equal Recognition before the Law,* (Cambridge University Press, 2017), 196; Jim Mansell, 'Deinstitutionalisation and community living: Progress, problems and priorities', (2006) 31(2) *Journal of Intellectual and Developmental Disability* 65-76; Christine Bigby, Marie Knox, Julie Beadle-Brown, Tim Clement, Jim Mansell, 'Uncovering Dimensions of Culture in Underperforming Group Homes for People with Severe Intellectual Disability', (2012) 50(6) *Intellectual and Developmental Disabilities,* 452-467.

Beyond arguing that segregating people with disabilities under the guise of protectionism is fundamentally wrong, disability rights advocates suggest that a far more impervious barrier to employment is the low expectations society has of people with disabilities along with the assumption that they are unemployable.[55] Abbas declares that, people with disabilities are not expected to perform, to have wishes, hopes or dreams of their own. Further, their contributions are simply not valued.[56] The effect of low expectations leading to low self-esteem is perhaps best illustrated by the following statement of a sheltered worker: 'I consider that I don't have the work abilities for open employment even though I perform quite well at the workshop, (...)'.[57]

The constraints imposed on people in sheltered work settings, including their productive capacities is often argued to be in their 'best interests' and the safest option of learning 'without the normal pressures of mainstream employment'.[58] Evidently, the workshop is often underpinned by the idea that people with disabilities primarily need to be protected.[59] Undeniably, however, the protection paradigm in disability policy has a bad track record and has failed to prepare people with disabilities for real work.[60] The Office of the High Commission for Human Rights also recognises that, indeed, the training, which mostly takes place in separate settings, rarely concerns itself with the skills required on the open labour market and, is rather, 'guided by low expectations in terms of what persons with disabilities can do'.[61] Accordingly, CmRPD member Martin describes institutions are about more than just the bricks and mortar of a building but about the ingrained thoughts, feelings and actions towards people with disabilities.[62]

As has been shown so far, many describe the work in sheltered workshops as monotonous and unengaging. Moreover, sheltered workshop placements are associated with numerous other adverse effects as a result of segregation. Besides excluding people with disabilities, segregated spaces reinforce the negative labels of disability and are often based on a presumption of incapacity, which further justifies the sweeping denial of rights. As a form of ostracisation then, the sheltered workshop does little more than preserve systems that isolate, and in some instances, even exploit people. This chapter will address this exploitation in more detail by addressing the status of sheltered workers and their remuneration.

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[55] Maureen Gormley, 'Workplace Stigma towards Employees with Intellectual Disability: A Descriptive Study', (2015) 43(3) *Journal of Vocational Rehabilitation*, (2015), 249-258.
[56] Abbas, n 16.
[57] 57 E. P.-Y. Li, 'Vocational Aspirations of Sheltered Workshop Workers with Intellectual Disability in Hong Kong' (2002) 42(3) *Journal of Intellectual Disability Research*, 208-217, 213.
[58] International Labour Organization, 'Recognizing Ability: The Skills and Productivity of Persons with disabilities- Literature Review', (Employment Working Paper No.3, 2008), 15.
[59] David Mont, The World Bank, Human Development Network Social Protection Unit, 'Disability Employment Policy', (Social Protection Discussion Paper Series, 2004), 29.
[60] Annie Ryan, *Walls of Silence: Ireland's Policy towards People with a Mental Disability*, (Red Lion Press, 1999).
[61] Office of the United Nations Office of the High Commissioner for Human Rights, 'Thematic Study on the Work and Employment of Persons with Disabilities' (2012), (A/HRC/22/25), 12.
[62] Robert Martin, 'The Convention: Drafting Opportunities, Challenges and the Committee's interpretations', (Robert Martin, CRPD Committee Member, New Zealand, speaking at the 11th International Disability Law Summer School, 17-21 June 2019).

3.2 THE UNCERTAIN STATUS OF SHELTERED WORKERS

Much of the research on sheltered workshops reviewed commented on the problematic issues related to determining the status of participants in sheltered settings. Given the different methods of funding and the varying objectives of the workshops, (ranging from rehabilitation to commercial work), some ambiguities exist over whether people with disabilities occupied therein are to be considered as workers and employees.[63] More often they are not. Comparative research addressing the legal status of workers in sheltered work settings in Europe found stark contrasts. These ranged from some workers in sheltered workplaces being fully fledged employees receiving proper wages to others not having an employment contract and with only a small allowance, especially where attendees were treated more as 'clients' than 'employees'.[64] In some eastern European countries sheltered workers even embody a hybrid status. Accordingly, sheltered workers are officially classed as productive workers; however, their employment is largely regarded as part of a rehabilitation programme.[65]

Indeed, a common characteristic of those in sheltered work is that often, they are not considered to be workers in a legal sense. Some argue that this is because the nature of work in a sheltered workshop is not typical of most employment situations and no true employment relationship is present. Bell, for example, notes that this type of employment differs from normal employment as, typically, recruitment processes are very different.[66] Moreover, the sheltered system is set up by welfare states as a 'token economy' for those who cannot compete in an exclusive, capitalist labour market, with workers earning 'symbolic' rather than 'real' wages'.[67] Concerns particularly arise where sheltered work settings largely operate as businesses, in which case, disability advocates have warned of financial exploitation of workers.[68]

Having evolved from medical and religious, voluntary associations, historically, sheltered work settings have not been required to adhere to the requirements of labour legislation. Visier even notes that doing so might in fact 'jeopardize the very survival of such establishments'.[69] It is then that the therapeutic or rehabilitative aim of the sheltered setting represents a dichotomy. As Visier describes it, the work setting 'stands in its own way'; on the one hand intended to rehabilitate, train and make people labour market ready or 'employ' the 'unemployable'; yet, on the other hand, it is unable to offer proper employment subject to protections enjoyed on the open labour market.

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[63] Laurent Visier, 'Sheltered Employment for Persons with Disabilities' 137 (3) *International Labour Review*, (1998), 363. In his global comparison of sheltered work setting Visier assessed the structures and legal personality of these and found that 4 typologies existed: The therapeutic model (protection vs employee status), The intermediate model (the disabled worker as 'quasi-employee'), the mixed (dual model), the wage employment model (protection and labour legislation).

[64] Samoy and Waterplas, n 1, 20.

[65] International Labour Organisation, 'Employment Prospects of disabled People in transition countries', (1996).

[66] Mark Bell, 'Workers On the Margins: People with Intellectual Disabilities and Labour Law', (2019) unpublished, available at: <https://soc.kuleuven.be/ceso/wo/erlm/irec/docs/markbell-leuven-irec-2018-mark-bell.pdf> (accessed 22 July 2019).

[67] David Galer, 'A Place to Work Like any Other? Sheltered Workshop in Canada, 1970-1985', 3(2) *Canadian Journal of Disability Studies*, (2014); Maria Ventegodt-Liisberg, *Disability and Employment- A Contemporary Disability Human Rights Approach Applied to Danish, Swedish and EU Law and Policy*, (Intersentia, 2011), 312.

[68] Elizabeth Pendo, 'Hidden from View; Disability, Segregation and Work' in Marion Crain, Winifred Poster and Miriam Cherry (eds.), *Invisible Labor: Hidden Work in the Contemporary World,* (University of California Press, 2016), 117.

[69] Visier, n 63, 364.

3.2.1 Worker status in case-law

Historically, the sheltered work setting has operated outside of the remit of normal industry and has evaded certain obligations. Regarded as a 'non-work' setting, it has then also remained outside the scope of labour law, further impacting on those occupied therein. Indeed, often the sheltered work setting is considered as rehabilitative in nature, and the setting is exempt from the legal protections that apply on the open labour market, with unique regulations of its own.[70] Either entirely different acts apply to the sheltered work sector, as is the case in Germany, or exemptions in law are made for 'special facilities', removing these from the general equality obligations, as is the case in Ireland.[71]

Even where the very question of workplace classification for the purposes of non-discrimination law has been tested, these settings have failed to be recognised as places of work and remain outside the material scope of such laws. This is illustrated in a Danish case, *Revacenter Horsens v. A*.[72] In 2009, the Western High Court in Denmark was required to rule on whether an individual with an intellectual disability who worked in sheltered employment was protected from disability discrimination under national and EU law. A central aspect of this case was the question of whether the occupation within the sheltered workshop amounted to employment or not. The Court found that sheltered workshop was a social measure and not a workplace, so the activities therein did not amount to employment. As a result, the work in a sheltered workshop was not included in the scope of disability non-discrimination law. Less favourable treatment of disabled individuals 'employed' in sheltered workshops was therefore permitted as, 'according to the Danish court, this was excluded from the material scope of non-discrimination law' and not protected by it.[73] In a similar judgement by the Eastern High Court of Denmark, it was also concluded that sheltered work could not constitute real work and, therefore, no right to a work contract or to subsequent protections could be granted.[74]

According to research by the European Association of Service Providers, most sheltered workshops in EU Member States are not party to national labour codes, and attendees are not considered to be workers or employees.[75] As a result, most people in these settings do not enjoy employee status.[76] From a legal perspective then, those in sheltered settings are often in precarious positions because ordinary employment legislation and standards do not apply.[77]

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[70] Sozialgesetzbuch (SGB) Neuntes Buch (IX) - Rehabilitation und Teilhabe behinderter Menschen - (Artikel 1 des Gesetzes v. 19.6.2001, BGBl. I S. 1046).

[71] In Ireland, provisions are made in the Employment Equality Acts 1998-2011 relieving special work settings from the obligation to not discriminate against persons with disabilities in terms of pay. See Section 35, Employment Equality Acts (1998-2011). For more details see: Centre for Disability Law and Policy, 'Submission to Department of Justice and Equality on the General Scheme of the Equality/Disability (Miscellaneous Provisions) Bill' (2016), 7.

[72] *Revacenter Horsens v. A*, Western High Court, *Weekly Law Journal*, 23 September 2009, (U2010.93VL) cited in Lisa Waddington, 'Fine-Tuning Non-Discrimination Law: Exceptions and Justifications Allowing for Differential Treatment on the Ground of Disability' (2015) 15(1) *International Journal of Discrimination and the Law,* 11-37, 19.

[73] Lisa Waddington, 'Fine-Tuning Non-Discrimination Law: Exceptions and Justifications Allowing for Differential Treatment on the Ground of Disability' (2015) 15(1) *International Journal of Discrimination and the Law* 11-37, 19.

[74] Pia Justesen, 'Report on Measures to Combat Discrimination, Directives 2000/43/EC and 2000/78/EC, Country Report 2013, Denmark', (2013), [online] available at: <https://www.equalitylaw.eu/country/denmark> (accessed on 25 January 2019).

[75] European Parliament, Directorate General for Internal Policies, Policy Department A, Economic and Scientific Policy, Employment and Social Affairs, 'Reasonable Accommodation and Sheltered Workshops for People with Disabilities: Costs and Returns of Investments- Study for the EMPL Committee, (IP/A/EMPL/2013-03, 2015), 23.

[76] European Association of Service Providers of Persons with Disabilities, 'Sheltered workshops in the EU: Factsheet', (2012).

[77] Visier, n 63, 364.

Even when workers in a sheltered workshop are defined as employees, exceptions may still apply. For example, sheltered employees may enjoy some labour rights, such as being member of trade unions or electing their representatives, but their remuneration being below minimum wage may still be lawful.[78] This is the case in France and Germany, where workers in sheltered employment are legally classified as employees, but separate rules apply and they do not receive equal remuneration.

People with disabilities have a right to employment under the German Social Code (Sozial Gesetzbuch IX), provided they fulfil the requirement to be able to deliver a minimum amount of 'economically usable work with no extraordinary care needs'.[79] Sheltered employees in Germany are entitled to elect a representative body to represent their interests and are protected from unfair dismissals.[80] However, sheltered employees are paid only a small refund for their work, (€180 a month) rather than the national minimum wage.[81] Overall, in Germany, sheltered work is exempt from national employment legislation and constitutes a unique relationship.

These exemptions were even upheld when challenged in court. A labour court of the federal region Schleswig-Holstein was the first German court to address the issue of whether or not a worker in a sheltered workshop could be considered as an employee and thus entitled to the national minimum wage. The court quashed the claims brought forward by a worker in a sheltered work setting, stating that they were not entitled to a minimum wage because they are contractually bound by a legally distinct workshop-employee relationship, despite proof that they conducted 'proper work' (of economic value) and regardless of the length of time they had spent training or working in the work setting.[82]

In an Austrian case, a worker employed as a seamstress in a sheltered work setting earned €411 a month for a 38-hour work week, sought a similar recognition of worker status and an entitlement to back pay, arguing that she fulfilled the necessary conditions to receive the same remuneration as other workers in the same sector.[83] The respondent, a sheltered workshop, run by a non-profit agency, argued that an employee-employment relationship did not exist and neither the labour code nor any collective agreements applied because the purpose of the work was therapeutic and the workshop was a project with social objectives. Further, the applicants' work capacity ('Arbeitsleistung') was only a fraction of that of a 'healthy' employee and the working hours were also used for social activities.[84] The respondent further argued that the

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[78] In Germany and the U.S., for example. European Parliament, Directorate General for Internal Policies, n 75.

[79] § 39 Sozial Gesetzbuch IX.

[80] Martin Kock, 'Disability Law in Germany: An Overview of Employment, Education and Access Rights', (2004) 5(11) *German Law Journal*, 1374-1394.

[81] Michael Scheer, 'Working opportunities for disabled persons in Germany: Laws, practices and experiences. Report within the framework of the EU project 'Chance for better opportunity' (Without borders – Component 2)', (2013, Project No. BG051PO001-7.0.07-0127-C0001); Elisa Fiala, 'A New Hierarchy of Social Exclusion? The Implementation of the right to Work and Employment (UN CRPD) in the national context of Germany', (Paris, France Conference Presentation, 4th Annual Conference of Alter-ESDR, 3 July 2015); In sheltered workshops in Greece, Ireland, Italy and Portugal, people are similarly granted employee status but do not enjoy the same access to rights as other, non-disabled employees. In Belgium and the UK, sheltered workshop employees have the right to earn the minimum wage. European Parliament, Directorate General for Internal Policies, n 75, 23.

[82] ArbG Kiel, (Az 2 Ca 165 a/15, Urteil vom 19.06.2015).

[83] Republik Oesterreich, Oberster Gerichtshof, 26. Januar 2010, (9 ObA 105/09w).

[84] Ibid.

'participants' were employed permanently regardless of work performance and no sanctions were applied where the work conducted was insufficient, thus missing the competitive element of a typical work relationship, as indicated by Bell.[85]

In this case, the Regional Court decided that despite the rehabilitative focus of the setting, the working conditions and the activities of the complainant therein, did meet the essential criteria to be defined as employment. Therefore, the question of remuneration must primarily refer to the relevant collective agreement in place for that sector.[86] An appeal by the agency, was, however, successful and this decision was overturned on the grounds that no prevailing case-law clarifying the legal nature of sheltered employment in a sheltered workshop existed. This decision of the Appellate Court was upheld by the High Court, ultimately quashing the applicant's claim for backpay. Interestingly, Austria and Germany ratified the CRPD in 2008 and 2009, respectively. The CRPD was, however, not mentioned in either case despite the focus on disability, non-discrimination and equality principles in both. This signals that at the domestic level, the CRPD has so far not had any impact on jurisprudence concerning sheltered work.[87]

More importantly, however, these court cases illustrate the challenging issue of status and objectives of the sheltered work setting. Indeed, this problem area is identified at governmental level and has also featured in States' official guidance for policy implementers and enforcing agents. The Department for Trade and Labour in the UK, for example, comments on the uncertain legal status of certain workers in 'therapeutic work settings'. The Department explains that it will always be difficult to establish the 'employment position of people who are not in the general labour market or who are being gradually introduced to it'.[88] Indeed, Bell declares that in the sheltered work setting it is difficult to 'draw a neat boundary between non-work activities and those that should enjoy the recognition of labour law', because as noted in Chapter 2.5, work and non-work activities may sometimes be blended together, making a clear distinction between the two difficult.[89] In the U.S., the Department for Social Security explains that the matter over whether an individual in a sheltered workshop is an employee or not is largely a 'question of fact to be determined from the facts and circumstances in each individual case'.[90] The Department even warns officials to be aware of the differing interests between sheltered workers and employers, as problems in the determination of worker status can arise as a result of conflicting interpretations and confusion.

These brief examples highlight not only the unusual situation of sheltered workers, which requires separate consideration, but alludes to the precariousness that arises from the uncertainty over status. Overwhelmingly, however, persons placed in sheltered settings are

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[85] Ibid.
[86] Oberlandesgericht Linz, 10. Maerz 2009, (GZ 12 Ra 5/09f-31); Landesgericht Ried im Innkreis, 27 Juni 2008, (GZ 14 Cga 123/07p-23).
[87] Surprisingly, the UNCRPD was also not referred to in a case before the CJEU that sought to determine whether a worker in a work rehabilitation centre was to be determined a worker for the benefit of EU labour law protections. For a discussion see: Mark Bell, 'Disability, Rehabilitation and the Status of Worker in EU Law: Fenoll' (2016) 53 *Common Market Law Review*, 197-208.
[88] Department of Trade and Industry, 'National Minimum Wage Information Note, The Minimum Wage and "Therapeutic Work"', (2003), para. 12.
[89] Bell, 66.
[90] USA Social Security Administration, 'Program Operations Manual System (POMS), RS 02101.270 Services for Sheltered Workshops', (2012).

denied employee or worker status, constituting, as Bell describes it, legal 'grey zones' because ordinary employment legislation and standards do not apply.[91] Undoubtedly, one of the most problematic issues when discussing sheltered work is the concern around worker status. The reason why the issue of worker status is of such importance is that this can have further knock-on effects, impacting on the levels of remuneration.

3.3 REMUNERATION IN SHELTERED WORK SETTINGS

The topic of sheltered work also concerns questions concerning wages and pay and their interrelationship with benefits, which are further contentious issues. Indeed, most studies address the low remuneration received by those in sheltered work. Quantitative studies have revealed that many workers in sheltered workshops are dissatisfied with their low wages.[92] The amount and types of payments received are often contingent on the status ascribed to workshop participants. Where they are regarded as workers, some may receive full and proper wages pursuant to common regulations. Where those in workshops are considered to be trainees or patients, payments may consist of a discretionary allowance. The type and level of activities conducted does not necessarily factor in the decision of payments. In Ireland, for example, people in either sheltered work or rehabilitative training, regardless of whether they 'may produce goods with a commercial value', are regarded as trainees and receive a training allowance of €31.80 per week.[93] Other sheltered work settings paid their workers on a sliding scale, according to their productivity, usually at the discretion of the setting in question.[94]

A comparison between 20 OECD countries also noted that wage levels in the sheltered work environments varied noticeably, 'both between and within countries, ranging from programmes that offer merely symbolic remuneration to jobs that give full social security and pay regular, sector specific minimum wages, often through wage subsidies'.[95] Between these two extremes, many other arrangements exist, variations of which can be found not only between states, but even within the same work setting. In other words, the amount of pay received is often based on individual productivity and ability and is subject to a measurement thereof.[96] According to Bach, the corresponding tests are highly discriminatory and based on an archaic assumption

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[91] Bell, n 66.

[92] Jordán de Urríes and Miquel Verdugo, 'Sheltered Employment Centers: A study of their characteristics and way in which they are perceived by those who use them', (2011) 38(2) *Work*, 155.

[93] Mark Coughlan, *Sheltered Workshops- An Investigation,* (RTÉ- Prime Time, 2013); Citizens Information Board, 'Rehabilitation and training services for people with disabilities', (2014) [online], available at:
<http://www.citizensinformation.ie/en/health/health_services_for_people_with_disabilities/rehabilitation_and_training_services _for_people_with_disabilities.html> (accessed on 10 August 2015).

[94] Some workers received 13 EUR a week, with some centres paying as little as 3 EUR a week. Few workers, whose productivity was higher, earned up to 95 EUR a week. The National Disability Authority report: 'Work where the weekly remuneration is less than what would be earned at the minimum wage in two hours does not constitute employment in the usual sense of earning a living. Indeed, on average these earnings represent a drop in income from the €31.80 a week participants receive as a training allowance, in addition to their Disability Allowance'. National Disability Authority, 'Disability and Work: The picture we learn from official statistics', (2006), 20.

[95] Organisation for Economic Cooperation and Development, n 24, 34.

[96] For example, where different employment or social institutes existed (e.g. France), each utilize a different status and a different remuneration system for employees. The legal status and pay can also vary within the same workshop (e.g. in Belgium). The wages or allowances can vary depending on performance, seniority, or type of contract (training contract, employment contract, etc.). Samoy and Waterplas, n 1, 20.

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that 'if you've got a disability, primarily an intellectual disability, you're not going to be able to be as economically productive'.[97]

Advocacy organisations report that even where sheltered workers are considered as employees, they may still only receive a small weekly allowance.[98] Arguably then, in situations where workers with disabilities do in fact engage in work of economic value, the payment of subminimum wages is exploitative, yet it is not regarded as such. In fact, it can be lawful to pay sheltered workers subminimum wages, as is the case in the U.S., Canada and Germany, to name a few states.[99] A review of the quantitative data available on adults in sheltered workshops across the U.S. revealed that, on average, workers (of 5,000 individuals counted), earned $101 per month for approximately 74 hours of work per month.[100] A further investigation conducted in 2013, revealed that 13 workshops across 10 U.S. states paid their workers less than 22 cents an hour.[101] Moreover, wages of sheltered workers in some settings in the U.S. are determined using 'time studies'. These tests consist of a calculation of an employee's salary using a stopwatch. The recorded time it takes a worker with a disability to do a task is compared with the time it would take a non-disabled worker to complete the same task.[102]

Low wages are also a characteristic of sheltered work settings beyond the U.S. and indeed a persistent feature of sheltered work on a global scale. Canada also has exemptions in its provincial labour laws which allow providers of workshops to pay an 'honorarium' or 'stipend' rather than a minimum wage.[103] Concerns over this issue were even been bought to the ILO in 2009 when a complaint was heard against Japan's 'welfare factories', alleging that workers engaged in 'welfare work' received very low wages, in breach of the relevant ILO Conventions.[104] A Committee was set up to examine this case which noted that it was unable to ascertain how the distinction is made between work under an employment relationship and other work operates in practice. It noted that work performed by men and women with disabilities in sheltered production workshops with a view to vocational rehabilitation, irrespective of whether it is performed under an employment relationship, should meet certain minimum standards in line with the with the principles of the Convention, including the principle of

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[97] Teuila Fuatai, 'From Exploitation to Employment: Undoing Canada's Sheltered Workshop System', (*Rabble News*. 12 April 2016).

[98] Inclusion Ireland, 'A Chance to Work', (2007), 40; Disability Rights Network, 'Segregated and Exploited: A Call to Action, the Failure of the Disability Service System to Provide Quality Work', (2011), [online] available at:
<http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Segregated-and-Exploited.pdf> (accessed 5 July 2016).

[99] According to the Fair Labour Standards Act 1938. There was no minimum guarantee in a Work Activity Centre (renamed from sheltered workshops) only the requirement that a commensurate wage be paid.

[100] Alberto Miglioire, 'Sheltered Workshops' in J. H. Stone and M Blouin, (eds.), *International Encyclopedia of Rehabilitation*, (Centre of international Rehabilitation Research Information and Exchange, 2010), [online] available at:
<http://cirrie.buffalo.edu/encyclopedia/en/article/136/> (accessed 15 February 2016); Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services, 'National Core Indicators, Employment data, phase IX final report', (2008).

[101] Freedom of Information Act (FOIA), 5 U.S.C. § 552. Reporters referred to an alleged abuse of a legal loophole on part of Goodwill Industries in the application of the Fair Labor Standards Act (FLSA), which was passed in 1938. Section 14(c) of the FLSA allows employing organisations to apply for special certificates from the Department of Labor. These certify that employers have the right to pay disabled workers below minimum wage and according to their abilities, with no bottom limit to the wage. Anna Schecter, Monica Alba, and Mark Schone, 'More Disabled Workers Paid Just Pennies an Hour', (NBC News, 10 August 2013).

[102] A formula is then applied to ascertain the difference and justify the rate of pay. Ibid.

[103] Picard reports that the Ottawa-Carleton Association for Persons with Developmental Disabilities operates a sheltered workshop, where its clients get work experience and are paid an 'honorarium' that amounts to $1.15 an hour. Andre Picard, 'You Don't Help Disabled Workers by Hiding Them', (*The Globe and Mail*, 12 March 2018).

[104] Report of the Committee set up to examine the representation alleging non-observance by Japan of the Vocational Rehabilitation and Employment (Disabled Persons) Convention, 1983 (No. 159), made under article 24 of the ILO Constitution by the National Union of Welfare and Childcare Workers.

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equality of opportunity and treatment (Article 4).[105] With regard to the particularly low level of pay received by some sheltered workers, the Committee commended the Government's acknowledgement that workshop pay is too low and its Five-Year Plan to Double Workshop Pay. The Committee hoped that progress would continue to be made to bring workshop pay to an adequate level and requested that further information be provided in this regard.[106]

Despite national minimum wage regulations, sheltered workshops are usually exempt from these as they are largely not regarded as being typical work environment.[107] Low remuneration, and even no payments, is therefore often the direct consequence of denying workers in sheltered workshops employee status. There are, however, opponents to the idea of paying workers in the sheltered sector appropriate or, at least, the minimum wage. Opponents argue that it would not be profitable to do so as sheltered work settings are not profit-making businesses.[108] In fact, some run at a loss and are heavily reliant on state subsidies and grants. Others argue that the discussions over whether people receive low remuneration or not are moot as the payments received are not comparable to a wage, rather they are top-up payments. O'Reilly explains that, in many cases, sheltered workers are paid less than the minimum wage because their payments are merely an addition to their normal disability benefit.[109] This view is, however, problematic when we consider that some of the work conducted may in fact amount to economically valuable work.

Besides wages and allowances, sheltered work payments may include disability benefits. As with every other variable of sheltered work, payment packages differ between states. Broadly, these can be made up of a combination of an allowance based on a training contract, wages based on an employment contract, or income supplements and benefits (especially disability benefits and unemployment benefits), and other forms of remuneration (basic pay and/or performance-related pay).[110] In his global comparison, Visier also reports on payments-in-kind received that may consist of meal and transport subsidies and even accommodation, as part of the sheltered work provision.[111] The relationship between payments and benefits is unique to the sheltered work setting and is often highly interdependent.

Benefit payments as part of social security payments can become major factors in the decision on whether to stay or leave sheltered settings. The risk of losing vital income from social benefits that are tied to the placement can be a major deterrent for persons with disabilities when considering entering the open labour market.[112] When deciding whether to take up formal

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[105] Vocational Rehabilitation and Employment (Disabled Persons) Convention, 1983 (No. 159).
[106] ILO, n 104, para. 70-78.
[107] Miglioire, n 100.
[108] Campbell discusses how Congress believed that low wages would encourage hiring as a reason for minimum wage exemptions in workshops. Alexia Fernandez Campbell, 'A loop hole in Federal Law allows companies to pay disabled workers $1 an hour', (*VOX*, 2 May 2018) [online], available at: <https://www.vox.com/2018/5/3/17307098/workers-disabilities-minimum-wage-waiver-rock-river-valley-self-help> (accessed 22 January 2020); Henderson and Bryan believe sheltered work is primarily about dignity and reject the criticism that it receives. George Henderson and Willie Bryan, *Psychological Aspects of Disability*, 4th Ed., (Charles Thomas, 2011), 204.
[109] Arthur O'Reilly, 'The Right to Decent Work of Persons with Disabilities', (International Labour Organization, 2007).
[110] Samoy and Waterplas, n 1, 16.
[111] Visier, n 63, 364.
[112] Fenger at al. even suggest that the design of benefit payments can be politically motivated and intended to direct persons into institutions. Menno Fenger, Martjn van der Steen and Lieske van der Torre, *The Responsiveness of Social Policies in Europe*, (Policy Press, 2013), 192. Many people in sheltered workshops in the U.S. do not know of the work incentive programmes available. This

employment, people with disabilities have to weigh up the financial consequences.[113] This is particularly the case where the transition from unemployment or sheltered work to employment on the open labour market infers a loss of entitlements. Inclusion Ireland refers to this as the so-called 'benefit-trap', which is a major reason for the low progression rates from sheltered to real employment. Even the loss of secondary benefits (such as entitlement to free medical care or transport services) inhibits the transition out of sheltered workshops, and important employment opportunities are missed.[114] The benefit-trap is commented upon in almost all the research cited herein and also features in Francesca's story.[115]

3.4 LOW TRANSITION RATES OUT OF SHELTERED WORK

Despite a growing number of supported employment initiatives and pilot projects, aiming to increase the employment of people with disabilities in open employment, the number of people moving from sheltered to open work settings, i.e. the 'transition rate', remains low.[116] Indeed, concerns about transition rates are well chronicled, leading to a widespread belief that wherever they exist, in whatever shape or format, sheltered work settings largely fail to facilitate the transition of adults with disabilities into 'real' work.[117] The literature and international reviews signal that whilst this is often not explicit, sheltered work settings themselves operate to retain people with disabilities and, therefore, embody a conflict of interest. Indeed, the topic of transition from sheltered to open employment is complex and political, involving varying parties and oppositional voices with interests at stake.[118]

Only limited comprehensive figures are available, but where transition rates are documented, these usually hover between less than 1% to (rarely over) 5%.[119] Even where the transition from

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situation in the UK and Ireland is similar, where the 'Make-Work-Pay' Incentives aim to make work more rewarding than welfare payments. However, these are not specifically targeted at people in receipt of disability allowances or those in sheltered work. Ne'man reports of an 'understandable confusion as to how to navigate the fairly complex rules' of benefit payments. Arie Ne'man, 'Sometimes a Lion: (Almost) everything you need to know about Sheltered Workshops: Part 2 of 2', (26 September 2016) [online], available at: <http://arineeman.com/2015/09/26/sheltered-workshops-part-2/> (accessed 20 April 2016).

[113] Erwin Seyfried and Thibault Lambert, 'Semi-sheltered employment for the disabled in the Member States of the EEC', (European Centre for the Development of Vocational Training, 1990).

[114] Inclusion Ireland, 'Protecting Human Rights in Austerity', (Presentation, FLAC Conference: Protecting Human Rights in Austerity, Dublin, 14 May 2015).

[115] A report by the Citizens Information Board (CIB), Ireland in 2013, revealed that a series of welfare traps were in operation and put people at risk of poverty as many people refused to enter employment for fear that they would no longer be eligible for certain supports. Citizens Information Board, 'Social Policy Quarterly Report, 1 January-31 March 2013', (2013).

[116] Bent Greve and Academic Network of European Disability Experts, 'The labour market situation of disabled people in European countries and implementation of employment policies: A Summary of evidence from country reports and research studies', (2009), 15.

[117] Douglas Biklen, James Knoll, 'The disabled minority' in Steven J. Taylor, Douglas Bilken, and James Knoll, (eds.), *Community integration for people with severe disabilities*, (New York: Teachers College, 1987); Steven J. Taylor, 'Caught in the continuum: A critical analysis of the principle of the least restrictive environment', (2004), 29(4) *Research & Practice for Persons with Severe Disabilities*, 218.

[118] Arie Ne'man, 'Sometimes a Lion, (Almost) Everything you need to Know about Sheltered Workshops', (20 September 2015), available at: <http://arineeman.com/2015/09/20/sheltered-workshops-part-1/> (accessed 20 April 2016).

[119] Dutch researchers claim that in the Netherlands for example, on average just 5% of those who leave the workshops find competitive employment; Harry Michon and others, 'Accessibility of Government-Run Sheltered Workshops to People with Psychiatric Histories', (1998) 33(6) *Social Psychiatry & Psychiatric Epidemiology*, 252-259. An EU study in 2000, reviewed employment policies for people with disabilities in the EU and signalled that data on transfers from sheltered to open employment was either unavailable or transferral were negligible. Ecotec Research and Consulting Ltd., 'Benchmarking Employment Policies for People with Disabilities, A study prepared for the European Commission Directorate-General for Employment and Social Affairs Unit EMPL/E/4', (2000), 217.

sheltered to open employment is an identified goal, many studies continue to report remarkably low transition rates.[120] International research by the OECD even shows that low transition rates have remained a constant feature of sheltered work over time. Studies on sheltered work by the organisation in 1992, 2003 and 2010 commented on similar problematic issues in each report, amongst which a primary issue was that of transition rates.[121]

Often designed to be a transitional step, sheltered workshops largely fail to provide 'meaningful work experience' or prepare people for the competitive work force.[122] Even where work is the main focus, the work environment in a sheltered setting will be different from mainstream businesses and unable to adequately represent the requirements needed elsewhere.[123] Sheltered work settings fail to prepare people, as the training received therein is of little relevance for real employment. Moreover, where the workshop has a competitive focus, the tasks and skills practised will vary according to the contract secured rather than training needs or interests of the individual.[124] In these instances, the scope of learning is dictated by the contractual obligations of the workshop. In fact, the more involved the workshop is with its local economy, the more criticisms arise that outside companies take advantage of cheap labour in the workshop, freed from any obligation to directly employ workers with disabilities.[125] Even sheltered facilities without commercial pressures interfere with the goal of competitive employment, according to Bond.[126]

In his global comparative study, Visier concludes that the whole, sheltered work rarely meets any legal or social requirements of a proper working environment, and often cannot provide proper training. Indeed, as a training facility, the sheltered workshop is largely unsuccessful. Numerous studies show that upon completing training in a sheltered workshop, individuals are more likely to remain in sheltered work than progress into open, integrated employment.[127] Where the sheltered workshop is purported to have a training function, people with disabilities can often find themselves stuck in an endless cycle of training with no progression. Advertised as temporary or transitional steps then, sheltered training placements are often, in fact, a 'disguised form of permanent employment' and thus referred to by Taylor as 'dead-end placements'.[128] Pendo similarly notes that although characterised as a training programme, sheltered work rather functions as, 'long-term and isolating alternatives to competitive employment'.[129]

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[120] Fenger et al., n 109, 141.
[121] Overall, sheltered employment 'was and still is widely used in many countries'. Organization for Economic Co-operation and Development, n 24; Organization for Economic Co-Operation and Development, 'Transforming Disability into Ability: Policies to Promote Work and Income Security for Disabled People', (2003); Organization for Economic Co-operation and Development, 'Sickness, Disability and Work: Breaking the Barriers', (2010), 146.
[122] Pendo, n 69, 117.
[123] Alberto Migliore, 'Sheltered Workshops' in J. H. Stone and M Blouin, (eds.) International Encyclopedia of Rehabilitation, (Centre of international Rehabilitation Research Information and Exchange, 2010), available at:
<http://cirrie.buffalo.edu/encyclopedia/en/article/136/> (accessed 15 February 2016).
[124] Storey, n 33.
[125] Seyfried and Lambert, n113, 55.
[126] Gary Bond, 'Supported Employment: Evidenced for an Evidence-Based Practice' (2004) 27(4) *Psychiatric Rehabilitation Journal*, 345-359.
[127] European Social Fund Programme Evaluation Unit (ESFPEU), 'Training for People with Disabilities', (Dublin: European Social Fund Programme Evaluation Unit, 1995).
[128] Stephan Taylor, 'Workers with Disabilities Deserve Real Choices, real Jobs', (2001), [online] available at:
<http://www.accessiblesociety.org/topics/economics-employment/shelteredwksps.html> (accessed on 14 March 2016).
[129] Pendo, n 69, 116.

Comparing employment outcomes, Cimera finds that people with disabilities did not fare better or worse where they attended a sheltered workshop. In fact, those never placed in a workshop were more likely to earn and work more hours than those that had, suggesting that the sheltered placement has an insignificant, and potentially adverse, effect in preparing and training people for open employment.[130] On the other hand, a longitudinal study into adaptive skills accumulated in different types of employment (sheltered, supported and competitive) suggest that competitive work on the open labour market correlated positively with enhanced adaptive skills for people with intellectual disabilities and greatly improved community participation.[131]

Besides, the low transition rates, the ineffectiveness of sheltered work to prepare people with disabilities for any other type of employment, is well established.[132] However, there are other reasons for the inability of the sheltered work systems to progress people with disabilities into proper employment. In fact, although a common symptom, the root causes for the low transition rates may differ significantly, according to the design and objectives of the workshop. For example, some sheltered workshops simply do not aim to facilitate a transition or purport to have a training or rehabilitative purpose. In these instances, the sheltered workshop system functions as a secondary economy that feeds into and exists alongside the general labour market. This type of sheltered economy is well established in Germany and is referred to as 'Der Zweite Arbeitsmarkt', (the second labour market).[133] As a fixture within many production cycles, the second labour market is relied upon by other industries, and most placements therein are permanent. This is because sheltered work settings are designed to be part of the equality measures implemented to improve the employment of people with disabilities. According to the German Social Code all public and private companies with a minimum of 20 employees are required to meet a quota of employees with disabilities, (5%).[134] Where this quota is not met, a levy must be paid (called 'equalisation levy') of €320 per month, per unfilled workplace. This levy further funds the sheltered work setting or businesses can choose to contract work out to the sheltered work setting, to reduce impending charges.[135]

Further reasons for a low rate of transitions can be monetary. In Norway and Sweden, for example, employment in a sheltered enterprise is attractive, based on the relatively high wages and benefits workers are entitled to. Some workshops, Fenger et al. found, even paid wages equal to those on the open labour market and, consequentially, there were no real incentives to move out of the sheltered sector.[136] This particularly contributed to the low transition rates in

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[130] Robert Cimera, 'Does being in Sheltered Workshops Improve the Employment Outcomes of Supported Employees with Intellectual Disabilities? 35(1) *Journal of Vocational Rehabilitation,* (2011), 21-27.

[131] D. Dodder, M. Collins, and R. Dodder, 'A longitudinal study of employment skills acquisition among individuals with developmental disabilities', (2005) 26(5) *Research in Developmental Disabilities*, 469-486.

[132] Bond, n 126.

[133] Scheer, n 81.

[134] Comprehensive legislation on rehabilitation and participation of disabled persons. Consolidates the previous laws on Severely Handicapped Persons. Sozialgesetzbuch (SGB) - Neuntes Buch (IX) - Rehabilitation und Teilhabe behinderter Menschen, (Social Code - Book IX - Rehabilitation and Participation of Disabled Persons), (2001), (Bundesgesetzblatt, Part I, 2001-06-22), No. 27, p. 1044-1139.

[135] Bundesarbeitsgemainschaft Werkstaetten fuer behinderte Menschen e.V., (Association of sheltered workshops for people with disabilities), 'The system and services of sheltered workshops in Germany', (2018) [online], available at:
<https://www.bagwfbm.de/file/1168> (accessed on 24 July 2019).

[136] Fenger et al., n 112, 143.

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counties with relatively high overall spending on employment measures and subsidies to support sheltered work. Interestingly, these countries also counted the highest number of sheltered work settings.[137] This is perhaps because, besides becoming an economy itself, the sheltered sector also feeds an industry of welfare services. In other words, countries with highly developed and generous welfare structures have a robust care infrastructure that relies on institutions as a workplace for disabled as well as non-disabled people. The sheltered workshop then remains an integral part of social welfare policy both geographically and by design. Key gatekeepers such as case workers and teachers, as part of this system then endorse the sheltered work placement, enforcing the need for their own roles.

The role of sheltered work staff in counteracting transition processes has also been researched. Reportedly, staff can feel antagonistic toward employment initiatives where these phase out segregated placements, enforce change, or threaten their jobs. In practice then, staff can become all-powerful gatekeepers to the outside world, frequently declaring that workers are not yet 'job ready'.[138] This is largely the case where they seek to maintain their purpose as, without its wards, the need for the institution would be diminished. Migliore et al. conclude from their survey that staff working in sheltered workshops were largely in favour of maintaining workshops. This was despite recognising that a high percentage of adults with intellectual disabilities preferred open employment and were deemed capable of working on the open labour market if supported adequately (78%).[139] Thus, acting in the interest of the workshop, supervisors sacrifice individual aspirations and goals to ensure the continued functioning and purpose of their employer, the sheltered setting.

Particularly where sheltered work settings produce goods, function like industries or, are part of a larger production cycle, an eagerness to keep their workers surfaces, so as to meet the demands of the contracted work and generate sufficient revenues. Indeed, where a strong focus is placed on production in the work setting, there is a tendency to hold on to the 'best', i.e. most productive, workers.[140] This tendency is also reflected in the example case of Francesca, where her supervisor openly declares that Francesca 'practically runs the place'.[141] In a study of sheltered work programmes in Sweden, Skedinger and Widerstedt refer to this practise as 'cream skimming', whereby the more productive and capable workers are kept in the program for various reasons.[142] In fact, in more labour intensive work settings, the focus on fulfilling contracts takes precedence over developing strategies for transition. The sheltered work setting is, then, often preoccupied with both maintaining itself and with the search for funding at the expense of efforts to transition its workers into the regular labour market.[143]

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[137] Organisation for Economic Co-operation and Development, 'Sickness, Disability and Work: Breaking the Barriers', (2010), 146.
[138] Roy McConkey and Felice Mezza, 'Employment Aspirations of People with Learning Disabilities Attending Day Centres', (2001) 5(4) *Journal of Learning Disabilities*, 310.
[139] Migliore et al., n 12, 15.
[140] Daniel Mont, 'Employment Policy Approaches and Multisectoral Implementation in Low- and Middle-Income Countries' in Jody Heymann, Michael Ashley Stein and Gonzalo Moreno, (eds.), *Disability and Equity at Work,* (Oxford University Press, 2014).
[141] See Chapter 1.
[142] Per Skedinger, and Barbro Widerstedt, 'Cream Skimming in Employment Programmes for the Disabled? Evidence from Sweden', (2007) 28(8) *International Journal of Manpower,* 694–714.
[143] Indeed, the funding systems in place can also play a part in this logic. Especially, where grants are calculated on a per capita basis, sheltered work settings are also keen to maintain their numbers. Organization for Economic Co-operation and Development, 'Sickness, Disability and Work: Breaking the Barriers', (2010), 146

The wishes of family members can also play a critical role in the transition process. As indicated in Francesca's story, her mother was keen to maintain access to the disability benefits that automatically transferred from the segregated school to the segregated work setting. Families are also eager to see their loved ones in 'safe and familiar environments' with access to a suite of benefits, and they encourage the taking up of sheltered work run by a trusted service.[144] Research also shows that families certainly play a critical role and factor highly in the transition process.[145] West et al. found in their statistical study that 37% of families were not in favour of open employment options.[146] Migliore reported that even where families supported placements outside the workshop and believed their relative would be as able to adjust to this, they remained reluctant to facilitate the transition.[147]

Researchers have noted further factors that contribute to the low transition rates out of sheltered work are a result of the negative connotations associated with the setting. Empirical research by Dague, for example, revealed that working in a 'reclusive', sheltered workshop brought with it an added stigma.[148] Employers are reported to be resistant to hiring someone from a sheltered work setting, based on the assumption and labels attached to them as unable and unproductive workers.[149] In fact, numerous reports explain how sheltered work contributes to the prejudices experienced by people with disabilities who reportedly feel stigmatised and unable to find work elsewhere once having been placed in sheltered work.[150] Further research by Bunzel links the practice of sheltered work with labels and views of people with intellectual disabilities as dependent and incapable, and an unproductive group.[151]

3.5 THE SHELTERED WORK SETTING AS A DICHOTOMY IN ITSELF

A review of the literature and studies available similarly indicates that workshops, which often function like businesses, have a vested interested in keeping their most productive workers, revealing a fundamental systematic flaw in the system. Its hybrid, overlapping and ambiguous objectives as a rehabilitative, educational and employment facility becomes its inherent flaw. Measuring a setting's success in one of these focus areas will sacrifice that of the other. As a rehabilitative and training service the workshop is, in theory, tasked with helping workers prepare for an open work environment. However, an 'in-built incentive' within its structure

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[144] Organisation for Economic Cooperation and Development, n 24, 35.
[145] Migliore et al., n 12, 8.
[146] Michael West, Grant Revell, and Paul Wehman, 'Conversion from Segregated Services to Supported Employment: A Continuing Challenge to the VR Service System', (1998) 33(3) *Education and Training in Mental Retardation and Developmental Disabilities*, 239–247.
[147] Migliore et al., n 12, 14.
[148] Brian Dague, 'Sheltered Employment, Sheltered Lives: Family Perspectives of Conversion to Community-Based Employment', (Presentation, 11th European Union of Supported Employment Conference, 2013).
[149] Gail Fawcet, 'Living with Disability in Canada: An Economic Portrait', (Canadian Council on Social Development, Office for Disability Issues, 1996)
[150] Jed Boardman, 'Work, Employment and Psychiatric Disability', (2003) 9(5) *Advances in Psychiatric Treatment*, 327-334; James Dudley, 'Confronting Stigma in the Service System', (2000) 45(4) *Social Work*, 449-545.
[151] Dirk Bunzel, 'Rehabilitation Through Work? Disability and the Productivist Road to Participation in the East of Germany' (2007) 20(3) *Journal of Historical Sociology*, 362-383.

prevents its most productive workers from transitioning to open employment. Supervisors are most loath to part with those most likely to thrive in the open labour market as the workshop depends on their work.[152] As an employer, the workshop, like any other business, has little interest in losing its most productive employees or in the costs associated with minimum wage requirements and, therefore, often opposes the introduction of general labour regulations. As a powerful institution, a strong lobby of sheltered work organisations in the U.S. was indeed successful in advocating the retention of an exemption in labour law permitting the payment of sub-minimum wages to sheltered workers.[153] Others argue that despite operating as non-profit organisations, sheltered work settings are essentially businesses and, like any other, will aim to 'maximize their profits and economic viability'.[154] The interests and aspirations of workers, thus, stands in direct contrast with the commercial interests of the workshop. Integration and inclusion in mainstream society are of secondary importance.

Quite critically, Gill refers to a system that is targeted to train individuals for open employment but relies on skilled workers as 'faulty', with transition being merely a 'myth', 'perpetuated only to appeal to socially conscious donors at fundraisers over wine and cheese'.[155] Indeed, the sheltered workshop receives much criticism for its ambiguous roles. Taylor refers to the institution as ironic; although set up to improve their lives, it seldom serves people with the most severe disabilities.[156] In fact, it may have an opposite effect. Rather than facilitating inclusion and participation, a placement in these affirms the stigma and label of being unproductive. As a result, people with intellectual disabilities in sheltered workshops are less likely to take on meaningful roles and be part of their communities.

Instead of undoing the stereotype that workers with disabilities cannot work in open settings, this perception persists because those most likely to succeed in competitive employment rarely graduate from the workshop.[157] Bach considers that everything about the sheltered workshop system paints its employees as dependent and encourages segregated labour markets based on disability.[158] Visier describes this dichotomy and finds that, regardless of their focus, whether it be treatment, education or employment, disability is construed as a form of 'incapacity which

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[152] Mark Hyde, 'Sheltered and Supported Employment in the 1990s: The experiences of disabled workers in the UK', (1998) 13(2) *Disability & Society*, 199.

[153] Goodwill Industries along with other large, traditional organisations vehemently lobby to preserve this legal entitlement and the special wage certificates system under the FLSA Section 14(c). In addition to this, lobby organisations that represent disability service providers have also worked to maintain the exemption. Goodwill Industries International, 'Employment of People with Disabilities through FLSA Section 14(c)', (Position Paper, 2013), available at: <http://msnbcmedia.msn.com/i/MSNBC/Components/Photo/_new/130619-Final-14c-position-paper.pdf> (accessed 19 March 2016); Anna Schecter, 'Disabled Workers Paid just Pennies an Hour- and its Legal', (NBC News, 25 June 2013). For further discussion on the FLSA exemption please see: Peter Blanck, Helen A Schartz and Kevin M. Schartz, 'Labor Force Participation and Income of Individuals with Disabilities in Sheltered and Competitive Employment: Cross-Sectional and Longitudinal Analyses of Seven States during the 1980s and 1990s', (2003) 44(3) *William and Mary Law Review*, 1029-1108.

[154] Ne'man, n 118.

[155] Gill, n 17, 613.

[156] Steven J. Taylor, 'Workers with Disabilities Deserve Real Choices, Real Jobs', (2001) [online], available at: <http://www.accessiblesociety.org/topics/economics-employment/shelteredwksps.html> (accessed on 14 March 2016).

[157] National Disability Rights Network, 'Segregated and Exploited: The failure of the disability service system to provide quality work', (2012) 36(1) *Journal of Vocational Rehabilitation*.

[158] Bach explains that workplace research shows that people with disabilities can be productive and dependable workers, are more loyal and reliable with lower rates of absenteeism compared to others. Michael Bach cited in Fuatai n 97.

then, far from being remedied by an environment supposedly intended to do so, is in fact fostered by the structure itself'.[159]

Even where the aim is to provide an educational or employment service, 'disability' remains the operative focus of the institution. As opposed to breaking down the barriers created by society and create disabling experiences then, the sheltered workshop itself represents a barrier to participation, inclusion and, ultimately, the equal enjoyment of rights. The sheltered work setting is an institution that creates a separate space reserved only for people with disabilities and in which separate standards and regulations apply. This form of segregation, not only marginalises people with intellectual disabilities but symbolises a further shackle placed on them: It is much harder to get out of the segregated system than it is to get in. Those who wish to move on from the institution must prove their worthiness, willingness and ability to leave it by withstanding a standard of scrutiny that is arguably far greater than that required of other groups. Consequently, the sheltered system as a whole is afflicted with conflicting interests but fundamentally represents a separate standard functioning as a barrier to inclusion reserved only for persons with disabilities.[160] Besides being inherently flawed, the sheltered work system, which brings work into a facility that is organised to train people to leave it and find integrated employment, has also been described as, quite simply, counterintuitive.[161]

3.6   PROPONENTS OF SHELTERED WORK SETTINGS

Having outlined some of the most apparent concerns and flaws of the institution, it is useful to address the views of proponents of the sheltered workshop. Not all users condemn or experience these as negative and some may favour a sheltered workshop placement. Committed supporters of sheltered work, for example, defend these as practical options that grant people more opportunities to develop than do open employment settings. Sheltered settings may be less demanding than open work environments and, therefore, more suited to the requirements of individuals with disabilities. Proponents thus argue that they are a 'necessary evil' and 'a fact of life' as it is impossible to ever 'fully incorporate all disabled employees in the normal production cycle'.[162] Consequently, sheltered workshops are revered for their flexibility to offer jobs and are a practical alternative to formal employment even in times of economic crisis.[163]

The debates regarding the benefits of sheltered work settings arises particularly at times where the closure of these facilities is imminent. These instances typically generate two camps pitted against each other, arguing feverishly for or against the change. Protective parents express fear, anger and concern and are often the most reluctant to embrace transitions. Amongst others,

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[159] Visier, n 63, 364.
[160] World Health Organization, 'World Report on Disability', (2011), 6.
[161] Colin Bates-Harris, C., 'NDN Webinar: The State of Sheltered Workshops', (Presentation, 19 August 2014), [online] available at: <http://ddi.wayne.edu/pdf/ndrn_sheltered_workshop_webinar_transcript.pdf> (accessed 7 July 2016).
[162] Samoy and Waterplas, n 1, 37.
[163] Numbers of sheltered employment centres rose as a direct result of the economic crises resulting from the events in the global market in 2008. Vera Gelashvili, Maria del Mar Camacho-Minano, Maria Jesus Segovia-Vargas, 'The Profitability of Socially Responsible Companies: Public Subsidies for Sheltered Employment Centres', (2011) 6(1) *Ramon Llull Journal of Applied Ethics*, 111; Fenger et al., n 112, 141.

researchers Rogan and Rinne, in fact, determine that it is families who are most likely to resist change and, thus, pose one of the major barriers that people with disabilities face in accessing open employment.[164] As an influential party in the change process, family-run campaigns can adopt an antagonistic stance towards de-institutionalisation processes generally.[165] Describing particularly the effects of disability policy reform in the U.S., family organisations refer to the gradual move away from sheltered work as a 'dangerous push towards community settings for all'.[166] In fact, in New Jersey, after months of petitioning the state legislature and other state officials, families of individuals and operators of sheltered workshops successfully stopped a process of defunding sheltered employment.[167] In Australia, family organisations have campaigned to directly undermine the disability movement's claims for 'industrial justice' by supporting increased development of sheltered employment using productivity-based wage assessments.[168]

Common arguments from parent-run organisations typically challenge the dissolution of the sheltered work system for its detrimental impact on those who require higher levels of care, leaving them unprotected. Sheltered settings are deemed safer than open employment settings and vital in protecting vulnerable people with disabilities from harassment. Disability rights organisations, on the other hand, highlight the fact that it is precisely in these institutions or 'prisons of protection', seemingly set up to protect people with disabilities, where serious violations occur, ranging from exploitation and degrading treatment to all forms of harassment.[169] Moreover, individuals in sheltered work settings are often stripped of numerous other rights, such as the right to participation and to self-determination, something which families seem willing to forego in favour of protection.

Family approaches to sheltered work settings do have a large impact on them, and their support must be regarded in context with the roles that these play. A source of charity and relief, these institutions are, themselves, born out of community-orientated measures and are a steadfast fixture of most care and service landscapes. Families come to rely on the sheltered settings as these are often part of the limited services offering support and where parents and carers receive respite.[170] As an integral part of a long-established network of trusted services and institutions, these play a significant role in many lives making debates over their closures emotive. Additionally, as a social institution, the sheltered work settings may be regarded as a fun place where people meet other people with disabilities, creating a supportive community.[171] This is

[164] Patricia Rogan and Susan Rinne, 'National Call for Organizational Change from Sheltered to Integrated Employment', (2011) 49(4), *Intellectual and Developmental Disabilities*, 248-260.
[165] Murphy and Rogan, n 39.
[166] Rita Price, 'Families Fight to Keep Institutions, Sheltered Workshops Open', *The Coloumbus Dispatch*, (15 April 2016).
[167] Pendo, n 69, 118.
[168] Karen Soldatic and Anne Chapman, 'Surviving the Assault? The Australian Disability Movement and the Neoliberal Workfare State' (2010) 9(2) *Social Movement Studies* 139-154.
[169] Rick Cohen, 'Are People with Disabilities Exploited in Sheltered Workshops?', (*Nonprofit Quarterly*, 14 April 2014); Michelle Diament, 'Sheltered Workshops NO Better than Institutions Report Finds', (*Disability Scoop*, 19 January 2011); Kitty Holland, 'Sheltered Work Locations under Investigation', (*The Irish Times*, Dublin, 27 August 2007); Beverley Burrell, and Henrietta Trip, 'Reform and Community Care: Has De-Institutionalisation Delivered for People with Intellectual Disability?', (2011) 18(2) *Nursing Inquiry*, 174–183.
[170] Dague, n 45, 1.
[171] David Sommerstein, Advocates Fight to Keep Sheltered Workshops for Disabled Workers, (*NPR*, 14 April 2015)[online], (available) at: <https://www.npr.org/2015/04/14/395287097/advocates-fight-to-keep-sheltered-workshops-for-disabled-workers> (accessed 22 January 2020).

also evident in the example of Francesca, as she describes enjoying seeing her friends and the security of her workshop. Armsby considers that, as a consistent, omnipresent structure, the workshop offers protection and routine, as well as a sense of belonging.[172]

Many people with intellectual disabilities themselves choose the sheltered workshop over other opportunities. Reportedly, sheltered facilities are favoured and popular amongst disabled people themselves. A significant amount of research reports that although, generally, people wanted to find proper employment, many workers did also enjoy attending their workshop.[173] In Migliore's study, for example, 30% of the respondents in sheltered workshops across the U.S. said that they 'liked their workshop because of the network of friends that they had developed there'.[174] Therefore, many choose to stay in sheltered workshops despite aspiring to work on the open labour market. This is largely because these offered a safe haven, away from the mainstream, unwelcoming environments. Francesca, also fearful of the 'outside world', prefers to stay in sheltered work despite offers to transition. Increasingly, then, people in sheltered settings identify more with others in the same institution than with those outside of it, even where the only common characteristic between them is that they have a disability.[175] Subsequently a sub-culture and a 'social identity' is formed (both internally as well as through interaction with external perceptions) that is entangled with all aspects of life in the workshop and the institution itself.[176]

Considering the role of institutions in the lives of people with disabilities, it is evident that meaningful relationships and attachments are formed therein. As result, a close, insular community of its own is generated, further impacting transition rates. People with disabilities, particularly those that have grown up in an institution, choose to stay in the sheltered workshop over a placement in an open position, demonstrating what some analysts have called the effects of the 'institutionalised mind'.[177] While the psychological, neurological effects of segregation and institutionalisation on the brain has not been meaningfully researched, activists have argued that attending these for years on end can mean alternatives to institutional life, are difficult to fathom. Attendees identify with the institution and their behaviour becomes institutionalised, with participants choosing to stay segregated in the face of the unknown.[178] Based on their long-standing roles and their entanglement in the lives of all those involved, the eradication of sheltered work settings causes disruption and distress. Families, and even

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[172] J Gardener Armsby, 'The War on Sheltered Workshops: Will ADA Title II Discrimination Lawsuits Terminate and Employment Option for Adults with Disabilities', (2015) 31(2) *Georgia State University Law Review*, 443.

[173] Mark Hyde, 'Fifty Years of Failure: Employment Services for Disabled People in the UK', 10(4) *Work, Employment & Society*, (1996), 683.

[174] Migliore, A., 'Sheltered Workshops and Individuals Employment; Perspectives of Consumers, Families and Staff Members', (PhD Thesis, School of Education, Department of Curriculum and Instructions, Division of Special Education Indiana University, 2006), 133.

[175] Gerard Quinn, Grainne de Burca, Lisa Waddington, Mark Bell, Anna Lawson, Michael Stein, Titti Mattsson, Luke Clements, 'Legal Memo: Segregation and segregated facilities as a *prima facie* form of discrimination. The Impermissibility of using the ESIF to invest in monies in long term care residential institutions for persons with disabilities', (2018),8, [online], available at: <https://enil.eu/news/segregation-and-segregated-facilities-as-a-prima-facie-form-of-discrimination/> (accessed 16 August 2019).

[176] For more on this see: Douglas S. Massey, 'Segregation and Stratification: A Biosocial Perspective' (2004) 1(1) *Du Bois Review: Social Science Research on Race*, 7-25.

[177] Migliore et al., n 12, 5.

[178] Teodor Mladenov, 'Institutional Woes of Participation: Bulgarian Disabled People's Organisations and Policy-making', (2009) 24(1) *Disability & Society*, 33–45.

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attendees, therefore, overtly resist the disbanding of these institutions.[179]

Listing proponents' views of the positive aspects of sheltered work is indeed useful as it helps to frame these as either good or bad and to draw conclusions for their future. Discussing these also helps to delineate the position of the author clearly. This discussion does not argue for the outright closure of all sheltered settings. I do not presume that all people necessarily want to be included in the open labour market. Rather, the intention is to challenge what has gone unchallenged for too long by highlighting certain practises and their adverse effects. The aim is to show how the system and ideology of the sheltered work system is fundamentally flawed and, by design, a contradiction in itself.

3.7 **CONCLUSION**

This chapter provides an overview of some of the most problematic issues associated with sheltered work. The alarmingly low transition rates out of sheltered work settings and into the open labour market indicate that these fail to either (re-)habilitate, train or prepare people for meaningful work. Broadly, a review of the literature and research supports the finding that sheltered work settings are systemically ineffective in achieving any of their objectives. Moreover, as this chapter has shown, sheltered work placements are in many ways unfavourable, leaving individuals with disabilities segregated in an institution and, effectively, stripped of their rights. Furthermore, sheltered workshops are widely associated with poor conditions, low status and, sometimes, exploitative pay. One of the main findings of this chapter, and what has remained unaddressed in any previous study, is that the entire sheltered system is trapped in a self-perpetuating cycle. Although tasked to prepare people for open employment, it broadly fails to do so and, instead, relies on people with intellectual disabilities to sustain the institution, who, as a result, remain in the sheltered workshop, often against their will.

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[179] Disability advocate Arie Ne'man explains that the sheltered workshop debate has divided many advocates working in the developmental disability advocacy community. Progress on transitioning people with disabilities out of sheltered work and into integrated employment is politically difficult and faces opposition from very well intentioned families and agencies, explains Ne'man. Ne'man, n 118.

SECTION 1: CONCLUSION

The purpose of this section was to comprehensively introduce the topic of sheltered work to the reader. Besides discussing the history of the institution of sheltered work, this section clarified its definition and highlighted some concerns associated with the practice. Sheltered work settings impact on the lives of people with intellectual disabilities in complex ways. As an intrinsic and inevitable feature of sheltered work and, indeed, the root of many associated problems with it, the aspect of segregation requires a closer examination. As a result of their segregation in sheltered work settings people with intellectual disabilities remain excluded and marginalised and the problems listed above remain unaddressed. The next section of this thesis will go on to explore how the practice of sheltered work, identified here as a major cause of inequality, has remained unchallenged to date. It will highlight the fact that despite its expanding scope, equality remains elusive for people with intellectual disabilities. As a result of their unequal status in society, people with an intellectual disability remain unprotected from discrimination and their segregation in sheltered workshops is not considered problematic. It is argued herein that discussions of equality have yet to consider the sheltered work setting in terms of its discriminatory potential.

SECTION 2: EQUALITY THEORY

Based on the findings from the previous section, it is evident that people with intellectual disabilities are subjected to institutional and societal treatment that enforces their dependency, and renders them, 'highly invisible both on the streets and as the focus of scholarly attention'.[1] Indeed, much disability scholarship now identifies how the lives and life experiences of people with intellectual disabilities are invisible to the nondisabled community. This transfers to the workplace, where people with intellectual disabilities, 'remain unseen, unacknowledged, or simply not present'.[2] As a result, the experience of exclusion permeates the lives of many people with intellectual disabilities, who remain outside of the participatory mainstream and are one of the most marginalised populations in Western society. Their invisibility and exclusion from social spaces, it will be argued herein, is a result of the tendency for this group to not be regarded as equal members of society. In turn, this renders them more likely to face discrimination on an individual, social, and institutional level, experiencing 'abjection, and abuse, fewer options in education and employment, limited freedom, less choices, and a lack of control over the key decisions that affect their lives'.[3]

Over the course of the next two chapters, this section will reveal how deeply entrenched the exclusion of people with intellectual disabilities is. It will begin by exploring, in Chapter 4, how people with intellectual disabilities have generally not been regarded as fully-fledged members of society, exemplified in the ways in which their rights have been negated. A central aim of this chapter is to understand the position of people with intellectual disabilities in society and explore the liberal framework of rights as part of this. Only by addressing how this group has been exempt from wider debates of equality generally can their widespread segregation in institutions such as sheltered workshops be tackled specifically. Chapter 5 further consolidates the findings made in Chapter 4 by addressing how, even throughout the evolution of equality and revised approaches, most equality models have continued to fail to include people with intellectual disabilities.[4]

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[1] Edward Hall, 'Social Geographies of Learning Disability: Narratives of Exclusion and Inclusion', (2004) 36(3) *Area,* 298-306.

[2] Elizabeth Pendo, 'Hidden from View; Disability, Segregation and Work' in Marion Crain, Winifred Poster and Miriam Cherry, (eds.), *Invisible Labor: Hidden Work in the Contemporary World,* (University of California Press, 2016), 125.

[3] Edward Hall, 'The Entangled Geographies of Social Exclusion/Inclusion for People with Learning Disabilities', (2005) 11(2) *Health & Place,* 107-115.

[4] Before launching into a theoretical discussion, however, one thing is of note. Throughout this discussion, this thesis refers to human rights and at times refers to equality law or rights frameworks. There are, however, distinct differences and in traditional legal scholarship these are conceptualised separately. In simple terms, the difference between human and personal rights is why you have them. Human rights, (comprised of civil and political rights, and socio-economic rights) arise simply by being human, and personal (or actionable) rights, on the other hand, arise only by virtue of a legal grant of that right, such as the rights imparted via citizenship of a state or non-discrimination laws. Human rights, by design, are universal in all countries, thanks largely to the UDHR and the subsequent legal instruments of the UN system. Actionable rights, however, vary greatly from one state to the next based largely on the different constitutions and/or legal systems. This section switches imprudently between both levels of rights, which is unusual. It does so, however, for two reasons: first, because it is understood that individualised, actionable rights stem from human rights, i.e. there is no actionable right that is not also a human right, and thus they are interlinked; second, because although

Chapter 4: Equality and Intellectual Disability - An Unhappy Alliance

To understand the unequal position of people with intellectual disabilities in society and before the law it is imperative to first understand how equality is bestowed upon people, generally. This chapter will therefore begin its examination of equality and intellectual disability by describing the liberal values that have shaped the development of equality, as pursued in western democratic societies. According to the liberal ideal, equality and rights are a fundamental part of the collective and social lives of communities. Within these structures, rights are an expression of the liberty and freedom granted to individuals to enjoy rational, free, choice while not impinging on the rights of others. People with intellectual disabilities, who do not 'fit' into this scheme, are simply omitted.[5] Therefore, the unique position of people with intellectual disabilities as, (non-) rights holders warrants specific consideration and instigates a moral debate on the ways in which liberal society functions, the beliefs and convictions it holds and, ultimately, its understanding of equality.[6]

Within a liberal understanding of society, equality is part of a system of governance in operation that delicately balances individual and communal interests. This relationship is widely described according to social contract theory as devised by the renowned legal philosopher of the 20th century, John Rawls. Often used to explain how western societies function, social contract theory is rooted in liberalism and explains how individuals and institutions relate to one another. This theory is introduced in this chapter to illustrate how rights bearers in society are recognised as eligible or deemed ineligible. Besides, uncovering how the equal status of individuals is established, understanding the nature of equality in operation today requires an understanding of the underlying social agreement. Disability ethicist Hans Reinders explains how these implicit agreements have become rules that determine the experience of liberal equality and specifically considers 'intellectual disability' in light of these.

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human rights are interrelated, interdependent and indivisible, people with intellectual disabilities are at risk of being denied rights on both levels, and excluded from both concepts of rights.

[5] Damon A. Young and Ruth Quibell, 'Why Rights Are Never Enough: Rights, Intellectual Disability and Understanding', (2000) 15(5) *Disability & Society,* 747-764; John Stuart Mills, *Utilitarianism, Liberty, and Representative Government,* (J M Dent and Sons, 1947).

[6] Hans Reinders, *The Future of the Disabled in Liberal Society: An Ethical Analysis,* (University of Notre Dame Press, 2000), 21.

4.1 EQUALITY AND LIBERALISM

Equality is a central principle of liberalist thought. Locke, regarded as the founder of liberalism, describes the enjoyment of equal liberty as a natural right, or what is referred to as a human right today.[7] Donnelly outlines the foundations of liberal thought to discuss the link between liberal theory and human rights. Liberal thought places the individual at the centre of its politics. Within the liberal construct, the most important tenet is that qualified individuals possess an inherent right to freedom that entails the right to 'govern' themselves, make their own life choices and have these respected, provided these do not interfere with the recognition of equal liberties and opportunities of others. Individual autonomy and the liberty to exercise this autonomy, however, is held to stand in contrast with the interests of society, the state or other institutional actors. The relationship between these agents thus requires regulation via a social contract comprised of a type of moral code for societies and has become an inherent feature of the liberal ideal. Held declares that 'contemporary Western society is in the grip of contractual thinking'.[8] Indeed, contractual thinking can be used to understand and form models to describe a variety of relationships in western, democratic societies.[9]

Social contract theory explains how communities live together and regulate access to that society, which guarantees the protection of individuals' interests who are bound by a moral contract. However, inclusion in this society is not automatic. Individuals must be able to act as moral agents according to agreed rules. Only once their eligibility is established are individuals worthy of inclusion and considered as equal. In the 20th century, Rawls used social contract theory to develop a concept of justice that could be accepted by citizens and adopted by institutions to govern society. Accordingly, this theory stipulates that an ideal society consists of an agreement that requires a legitimate political authority, regulated and delivered by institutions and which is grounded in the consent of the governed.[10]

Although social contract theory is not a new philosophy used to explain society, its application to human rights law is fairly recent and can almost singularly be traced back to the work of Rawls. Indeed, Rawls' theories are often used to understand western law, how societies are formed, and who is a participant therein. Rawls is credited with further developing the liberal idea that the right to act freely and engage in the social contract is only bestowed upon persons that are deemed eligible and, therefore, considered as 'equal persons'. Eligibility requires the presence of moral powers set forth

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[7] John Locke, Second Treatise of Civil Government, (Awnsham Churchill, 1689). Other theorists, such as Aristotle and Rousseau, also concerned themselves itself with explaining the natural order of societies. They focused on explaining the concepts of sovereignty, legitimacy and the governance of societies so as to find the most just forms of society and on what grounds rights should be based. For a detailed discussion of Foucault see: Paul Rainbow, (ed.), *The Foucault Reader: An Introduction to Foucault's Thought,* (Penguin, 1991).

[8] Virginia Held, *Feminist Morality: Transforming Culture, Society and Politics,* (The Chicago University Press, 1993), 193.

[9] Modern moral and political philosophers, such as Hobbes, Locke and Rousseau expanded on the ideas of social contract theory (Hobbs referred to the contract as 'Civill Amenity' [*sic*]) to inform theories that explain how subjects in society are formed and related to one another. To Hobbes, rationality of man was the most important good: 'In all deliberations and in all pleadings the faculty of solid reasoning is necessary', something that Rawls would also believe. Thomas Hobbes, *Leviathan,* (1651), (C. B. MacPherson ed., Penguin 1985), 717.

[10] John Rawls, *A Theory of Justice,* (Revised Edition, Harvard University Press, 1999).

in what is now known as 'Rawlsian social contract theory'.[11] According to Rawls' thinking, which has significantly influenced the underlying theory of justice pursued in human rights law, persons must demonstrate a capacity to negotiate and cooperate as part of a social contract. Besides the fundamental tenet of protecting the interests of the individual then, liberalist equality, as it is understood today, is also shaped by social contract theory to determine who is an eligible individual.

Understanding the interplay between the individual and society is fundamental as ideas of 'the competent actor' and the social contract are two pivotal components that shape the modern conception of equality. Using Rawlsian social contract theory, this relationship will be discussed further in the next section to show how people with intellectual disabilities are discounted as eligible persons and ultimately denied recognition as rights bearers. This argument will be followed by a discussion of Reinders' 5 fundamental tenets of equality according to the liberal tradition in operation that enforces their exclusion. Aware that numerous models and theories exist that conceptualise disability equality, these two perspectives are chosen based on their overall influence on subsequent disability theories and models.

4.1.1 Rawlsian social contract theory and the eligibility criteria

Recognising the centrality and influence of Rawlsian thought within current western legal systems, it is important to explore the basis of Rawls' theory and how equal status is bestowed upon individuals therein. This helps us understand the unique position of people with intellectual disabilities within this construct. Moreover, many disability theories work off the basis of Rawlsian social contract theory to debate the systematic exclusion of people with disabilities in law.[12]

As previously noted, Rawlsian social contract theory holds a pre-eminent position in western liberal democratic thought. Developed alongside international efforts to establish a treaty that would ensure lasting peace in the aftermath of the Second World War, Rawls' theories have had a lasting impact on human rights law today.[13] The coherence between the Universal Declaration of Human Rights and Rawls' early texts prove how influential his theory was, making it an important determinant of western liberal politics and its conception of equality.[14] In line with the liberal tradition, both

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[11] Henry S. Richardson, 'Rawlsian Social-Contract Theory and the Severely Disabled', (2007) 10(4) *The Journal of Ethics*, 419-462.

[12] Harry Brighouse, 'Can Justice as Fairness Accommodate the Disabled?', (2001), 27(4) *Social Theory and Practice*, 537; 560; Martha Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership,* (Harvard University Press, 2006).

[13] Rawls served as a soldier during the Second World War and witnessed the atrocities directly associated with the effects of war including the injustices and abuses by totalitarian regimes. With these experiences in mind, Rawls aimed to devise a framework that enabled different worldviews to exist alongside each other whilst focusing on the fundamental needs of equal and fair societies.

[14] This theory has however not gone unchallenged. Feminist and critical race theorists have criticised social contract theory, arguing that it supports patriarchal relationships and relies on a 'liberal individual' who is purported to represent an abstract, generalised person based on a norm. *See for example,* Carol Pateman, *The Sexual Contract,* (Stanford

focus on protecting the individual who has consented to be governed by a sovereign state via a bargaining process. This process, in turn, is an inherent part of the social contract in operation that enables societies to live cooperatively and safely according to agreed rules. In this way, modern human rights law, exemplified in the International Bill of Human Rights, has evolved on the basis of Rawlsian theories of justice and assumed a liberal democratic tradition that relies on the ability of individuals to demonstrate their eligibility to enter into the so-called social contract.

In his most influential publication, *A Theory of Justice,* Rawls began his analysis from the standpoint that 'the moral and political point of view is discovered via impartiality'.[15] Rawls' ideas were heavily influenced by Kant and based on the belief that (nearly) every person had the capacity to reason and, therefore, possess a moral capacity to judge between what is right and wrong in a neutral, impartial manner. This imagined impartiality was the foundation of a peaceful and just society and, therefore, an important aspect underpinning the social contract.

The social contract represents a hypothetical agreement between capable, impartial persons who have agreed on a set of moral principles of governance. These agreements are arrived at through a process of bargaining. It is through the ability to exercise moral powers and rationality that citizenship is bestowed upon individuals who then enjoy rights, freedoms and responsibilities as equal members of society. The participants in this process are imagined to be free and equal citizens and, therefore, able to establish what is fair. Moreover, being counted as a participating agent in Rawls' theory relies heavily on the basic notion that an individual possesses two moral powers: a capacity for a sense of justice, including the conception of what is 'good', and the power of reason. This preoccupation with rationality is reflective of wider philosophical debates looking to define the essence of 'humanness' that favour the ability to reason, think, understand and remember as definitive markers thereof.[16]

The two moral powers manifest themselves via social cooperation. Demonstrating a commitment to reciprocity through rational behaviour and understanding 'the good' forms the basis of justice contained in Rawls' social contract theory. The pre-eminence of impartiality and having the moral powers, 'to a requisite minimum degree to be fully cooperating, members of society', is what, according to Rawls, makes persons capable of the social contract and, therefore, equal and worthy of justice.[17] In this way, as Fletcher has described it, people with intellectual disabilities who are seemingly unable to act according to the social contract's requirements are defined as non-persons and denied many aspects of their humanity, most notably equal status.[18]

University Press, 2006); Charles Wade Mills, *The Racial Contract* (Cornell University Press, 1997), here Mills criticizes specifically the history of social contract theory.

[15] Celeste Friend, 'Social Contract Theory: Internet Encyclopaedia of Philosophy', (2004) [online], available at: <http://www.iep.utm.edu/soc-cont/#SH4a> (accessed 7 October 2016).

[16] Robert Bogdan, and Steven Taylor. 'Relationships with Severely Disabled People: The Social Construction of Humanness', (1989) 36(2) *Current Social Problems*, 135–148.

[17] John Rawls, *Political Liberalism,* (Columbia University Press, 1993), 18.

[18] Joseph Fletcher, *Humanhood: Essays in Biomedical Ethics,* (Prometheus Books, 1979).

Rawls' ideas bind individuals' membership in a 'just' society to a contingent set of abilities and rational reasoning.[19] However, moral philosophers are increasingly at odds with Rawlsian thought and challenge the traditional criterions of equality. Not only is the dominance of impartiality therein criticised particularly by feminist critics, as this relies on a patriarchal account of what 'impartiality' is, but also the idealisation of rational behaviour is questioned. Rawls principles of justice are also criticised for ignoring the special status of people with disabilities.[20] Specifically, the focus on co-operation, and a demonstration thereof, as a condition for equality is criticised. Because, accordingly, individuals seemingly lacking the ability to 'cooperate' fall outside the range of normal human functioning and are discounted as eligible members of society. Stipulating an ideal actor in this way is biased and problematic. When people with intellectual disabilities present with atypical and challenging behaviours, distinguishing between cooperating and non-cooperating behaviour is difficult, leaving people at risk of being disregarded. In fact, Wong determines that such distinctions are moot as all citizens are located somewhere along a developmental pathway between non-cooperating and fully cooperating citizens.[21]

Silver and Francis find further criticisms of Rawlsian social contract theory and how it has shaped modern equality frameworks.[22] They take issue with the premise of equality that determines eligibility based on the demonstration of moral powers. Thereunder, people with intellectual disabilities, who are often presumed to be incapable of reason and rationality, are regarded as unable to understand what is right and good. As a result, the perceived inability to exercise the two moral powers serves as a justification for the exclusion from citizenship, or 'moral personhood'. Essentially then, Rawls's theory implies that people with severe mental impairments, and who are unable to demonstrate the moral capacities required to cooperate in the social contract, automatically fail to qualify as equal persons.[23]

As a fundamental flaw of social contract theory, the focus on morality, like impartiality, is problematic as these are not unbiased values. Besides being heavily influenced by the ruling norms, conceptions of the good and an understanding of justice are never formed in a vacuum, nor do individuals alone conceive them but, rather, they are 'socially scripted and interactively developed'.[24] Ideas and knowledge, too, are formed interdependently and may be expressed in different ways. People with intellectual disabilities who display their comprehension and who communicate in alternative ways are then at risk of being unduly disregarded. Moreover, by being mostly segregated in

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[19] John Rawls, n 17, 18; John Rawls, *Justice as Fairness: A Restatement,* (The Belknap Press, 2001), 19.
[20] Brighouse, n 8, 560.
[21] Silvia I. Wong, 'Duties of Justice to Citizens with Cognitive Disabilities', in Eva Kittay and Licia Carlson, (eds.), *Cognitive Disability and its Challenge to Moral Philosophy,* (Wiley-Blackwell, 2010), 127; Cynthia Stark, 'How to Include the Severely Disabled in a Contractarian Theory of Justice', (2007) 15(2) *Journal of Political Philosophy*, 127-145.
[22] Anita Silvers and Leslie Francis, 'Thinking About the Good: Reconfiguring Liberal Metaphysics (or Not) for People with Cognitive Disabilities', (2009) 40(3) *Metaphilosophy*, 485.
[23] Nussbaum, n 8, 166.
[24] Silvers and Francis, n 18.

institutions, for the most part, this group is prevented from experiencing and learning the rules of society and what is accepted as 'the good'. Instead, interactions with natural, social environments enjoyed by others are replaced with confined, artificial ones.

Disability advocates have sought to dispel the myth arising from Rawlsian thought, that people with intellectual disabilities are incapable of conceiving the 'good'. It is argued that although some people may need support to formulate and express the 'good', they do have individualised and subjective accounts thereof, and posses an innate capacity to learn.[25] Moreover, according to Wong, excluding people with disabilities is quite simply 'morally wrong', as they are owed the same duties of justice as other citizens. Rather, people with intellectual disabilities must be assisted to become cooperating members and able to engage in the social contract, through 'enabling conditions'.[26]

4.1.2 Reinders' liberal tenets and intellectual disability

Reinders' work builds on social contract theory as the basis for current liberal ideals and discusses its influence on equality for people with intellectual disabilities. On the basis of identified convictions and beliefs, Reinders lists 5 constituent elements that shape a common understanding of equality and how these operate to exclude people with intellectual disabilities.[27]

The first liberal tradition identified by Reinders that underpins the vision of equality in operation today is based on the principal moral value of free choice, which permits individuals to act according to their own preferences, provided these actions do not interfere with the equal freedom of others. This tenet can be broken down into three elements comprised of an individual that is recognised as an eligible agent, the free choice of that individual that is acknowledged based on the recognition of the former, and their interaction with others. People with intellectual disabilities are excluded from all three parameters of this tenet. This is because, as shown by applying Rawls' contractarian thought, their recognition as free agents is not automatic. Instead, individuals must first show their entitlement, as agents capable of making choices and having these respected, by proving a capacity for the required moral powers. Absent of the required moral powers, many people with intellectual disabilities are regarded as incapable and dependent agents. The moral value of free choice is, then, not bestowed upon uncounted and unprotected persons.

The second tradition of liberal equality which Reinders lists, builds on this understanding of eligible individuals' freedom of choice and postulates that this is

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[25] Hardeep Aiden and Andrea McCarthy, 'Current Attitudes towards Disabled People', (Scope, 2014).
[26] Wong interprets Rawlsian social contract theory to contain a duty of justice as the notion of two moral powers anticipates that each individual possesses the innate potential to develop a conception of the good and a sense of justice, albeit with support. Wong, n 17, 127.
[27] Reinders, n 2.

universal and should be respected. The extent to which this freedom of choice is respected is broad and, itself, enjoys a layer of protection, in that it may not be infringed upon. Accordingly, the choices made by individuals should not be unduly influenced or subject to appraisal. In other words, choices made by eligible individuals should be free of external evaluations and not be interfered with. Dimopoulos clarifies this second premise and explains that 'once it is accepted that people have the right to choose for themselves the kind of life they prefer, the value of those choices and their lives cannot be measured by external standards. The life one leads is valuable by the mere fact that one is capable of valuing it at all'.[28] However, people with intellectual disabilities have not enjoyed this protection from external judgements. Rather, such judgements have served to categorise acceptable variations of functioning into 'normal' and 'abnormal', on the basis of which people with disabilities are ascribed an inferior status.[29] The extent of external judgements for this group is so far reaching that ideas of what a life should look like are imposed upon people with intellectual disabilities, and, as a result, decisions of what constitutes a 'good' life are made on their behalf.[30]

This leads us to the third convention, characteristic of liberal equality as pursued in western, democratic societies, which lies in the belief that the status of persons is of primary moral concern. However, persons only become full moral agents with rights and responsibilities when they are deemed capable making rational choices and acting rationally upon their preferences. For people with intellectual disabilities, this is perhaps the most challenging attribute of a society preoccupied with liberalist thought because it assumes an actor that is a well-adjusted and abled-bodied individual, and one that is capable of acting independently, demonstrating 'powers of reason and free will'.[31] Similar to Rawls' moral powers, to be recognised as a moral agent, rational thinking and an ability to communicate that thinking is imperative. The importance of demonstrating rationality is so pervasive that the perceived lack of this ability has justified the categorical denial of moral agency to certain groups through time.[32] As a characteristic, 'intellectual disability' is often readily equated with an inability to act rationally due to a diminished capacity for moral agency. Essentially, Rawls's theory implies that people with severe mental impairments who are unable to demonstrate the moral capacities required, to demonstrate an understanding of the 'good', cannot cooperate in the social contract, and thus fail to qualify as equal persons.[33] The resulting denial of moral agency is regarded as legitimate. According to Arstein-Kerslake, this

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[28] Andreas Dimopoulos, *Issues in the Human Rights Protection of Intellectually Disabled Persons,* (Ashgate, 2010), 28.
[29] Ronald Amundson, 'Against Normal Function', (2000) 31(1) *Studies in History and Philosophy of Biological and Biomedical Sciences,* 33-53.
[30] The value of leading a so-called 'normal life' has then been so influential that it has largely shaped Scandinavian and American disability policy and services since the inception of the so called 'Normalization principles' by Wolfensberger and colleagues in the late 1960s. The work of Wolfensberger was groundbreaking at the time and did enable a radical reform in the provision of residential services for people with intellectual disabilities. For more information see: Wolf Wolfensberger, 'The Principles of Normalization in Human Services', (National Institute of Mental Retardation, 1972).
[31] Dimopoulos, n 28.
[32] Historically, inferior groups were denied the recognition of their moral agency, based on a belief in their innate inability to act rationally. Women, generally held to be emotionally unstable and prone to hysteria, were denied the right to make decisions without their husband's acquiescence. Robert Bartholomew, 'Why Are Females Prone to Mass Hysteria', (*Psychology Today* blog, 2018) [online], available at: <https://www.psychologytoday.com/us/blog/its-catching/201703/why-are-females-prone-mass-hysteria> (accessed 26 October 2018).
[33] Nussbaum, n 8, 166.

leaves people with intellectual disabilities, 'disenfranchised and without protection from state interference with individual liberty. This is discriminatory and disempowering and does not comport with the tenets of a free and equal society'.[34]

Democratic debates of what constitutes 'free and equal societies' bring us to the fourth liberal convention identified by Reinders. Political and social equality are such highly valued tenets of liberal society and have prompted multiple theories of how they can be achieved. The on-going deliberations regarding the meaning of an 'ideal society' and how this should be structured is, itself, an aspect of the liberal convention.[35] In other words, the very act of continuing discussions and (re-) negotiations of what justice and equality are is, itself, the fundament of an equal society. As a result of these debates, theories are developed and constantly updated to formulate new approaches that underpin the development of new theories and models, as demonstrated in Chapter 5. Arguably, however, these discussions to date have still largely presumed that most individuals possess equal abilities to contribute to these discussions and have their voices heard. This convention is premised on the existence of a status of social equilibrium, where each member of society relates to one another via a centrifugal force of normalcy.[36] People with intellectual disabilities, who are not 'normal', are rarely able to engage in these debates and thus, remain unheard, as equality is negotiated without them.

The final stipulation of the liberal covenant that underpins our modern understanding of equality identified by Reinders is that of public morality. Public morality is made up of the ethical standards in a society and, according to Reinders, should not concern itself with assessing and determining what is 'good'. Because the concept of 'good' is a relative value with different conceptions, it cannot be used to regulate or police citizens. In other words, the 'goal of the state is not to promote a particular end in life, but to secure equal opportunities of its citizens to realize their own ends under the rule of law'.[37] Similar to the second liberal tenet, according to which life choices made by eligible individuals enjoy a degree of immunity from external judgement, ideas of what is right and proper cannot be forced on another, as to do so would be to consider them lesser moral agents. States are required to respect the dignity and worth of individuals, which includes the respect of their liberties and choices, regardless of their preferences and, therefore, also their differences. After all, the demonstration of an equal concern and an equal respect towards individuals is a fundamental political principle that underpins international human rights law and must equally apply to those that are 'different' and those who do not ascribe to common notions of the 'good'.[38] This fifth

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[34] Anna Arstein-Kerslake, *Restoring Voice to People with Cognitive Disabilities: Realizing the Right to Equal Recognition before the Law,* (Cambridge University Press, 2017).

[35] Social Contract theory according to Rawls is perhaps the most pronounced of these theories in the area of equality and liberalism.

[36] For a discussion on the institutionalization of normalcy see: Tanya Titchkosky and Rod Michalko, (eds.), *Rethinking Normalcy: A Disability Studies Reader,* (Canadian Scholars' Press Inc, 2009).

[37] Donnelley similarly writes that individuals are 'entitled to make fundamental choices about what constitutes a good life (for them), and with whom they associate'. Jack Donnelly, *Universal Human Rights in Theory and Practice, 3rd ed.,* (Cornell University Press, 2013), 63; Dimopoulos, n 28, 28.

[38] Most fundamentally, this relates to the Universal Declaration of Human Rights. Donnelly, n 28, 63.

stipulation however, has underpinned public thinking and approaches to disability, fuelling the idea that people with intellectual disabilities are better off segregated.

Rights have developed, according to a liberal theory of equality based on the social contract, which extends eligibility to participating subjects with flexibility. The extent to which variations in thinking and acting are accepted, however, is limited. Observably different people and groups are presumed to be equal provided they are able to act according to the requirements of the contract and possess the moral powers.[39] However, serious impairments distort the requirements of the social agreement and individuals with disabilities are customarily conceptualised as 'irremediably unequal'.[40] The insurmountable difference of cognitive impairment is indeed fostered in the liberal tradition of rights in operation that relies on the social contract, as elaborated on above.

4.2   THE DIFFERENCE OF INTELLECTUAL DISABILITY

Historically, to receive welfare payments and charity, persons with disabilities have had to claim their difference and demonstrate how they are disadvantaged by this to obtain support, thereby establishing a category of the deserving poor. This gave rise to the development of specialised disability services founded on the idea that its subjects were unequal, inferior persons. I argue that, today, institutions and sheltered workshops continue to operate on the basis of these assumptions and frame intellectual disability as an intrinsic inequality.[41] As Gill identifies above at 3.1., the workshop is an institution that is part of the social contract and serves to regulate society by containing its deviants, further consolidating their inferiority. Work towards unpicking these assumptions has been gradual, and with only moderate success. Undeniably, as a characteristic, 'intellectual disability' does encompass some very real implications, and impairments in cognitive functioning do impact on individuals' abilities as compared to others'. Intellectual disability as a characteristic therefore poses quite a specific challenge to equality, which is why it must be addressed in more detail here.[42]

Arguments for equality for other groups draw heavily on pluralist political philosophy and encompass the fight for the accommodation of their differences.[43] Accordingly, the

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[39] Joan Scott, 'Deconstructing Equality vs Difference' in Marianne Hirsch and Evelyn Fox Keller, (eds.), *Conflicts in Feminism,* (Routledge, 1990), 142.

[40] Anita Silvers, 'Reconciling Equality to Difference: Caring (F)or Justice for People with Disabilities', (1995) 10(1) *Hypatia,* 30-55.

[41] Where no distinction is made between intrinsic inequality (where the fundamental values and principles in society impact) and extrinsic inequality (the result of the difference, ie an inability of a subject) material inequalities as the result of 'extrinsic factors such as income, employment, housing and services are presumed to arise because of factors intrinsic to the individual'. Marcia Rioux, 'Towards a Concept of Equality of Well-Being: Overcoming the Social and Legal Construction of Inequality' in Marcia Rioux and Michael Bach (eds.), *Disability is Not Measles: New Research Paradigms,* (L'Institute Roeher, 1994), 81.

[42] 'Whether or not people with severe disabilities will be treated as human beings or persons is not a matter of their physical or mental condition. It is a matter of definition'. Bogdan and Taylor, n 12.

[43] Generally speaking, Quinlivan regards that others have been 'slow to realize that, arguably, the same arguments that apply to gender and racial discrimination also apply to disability discrimination'. Shivaun Quinlivan cited in Office of

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advancement of the 'different but equal' adage is now recognised as a key moral value in western, democratic societies.[44] Discussions over the ethics of difference, as utilised in feminist debates for example, have been an effective remedy in addressing the inequalities experienced by other marginalised groups but have remained ineffective in their application to people with intellectual disabilities.[45] The unalterable nature of cognitive disability, as the very determinant and the root of all problems associated with that difference, is regarded as insurmountable.[46]

Unlike other differences between groups that equality models have sought to overcome, intellectual disability is fundamentally separate. While the differences presented by other groups are accommodated because these are conditional and external (biological, religious or class related, for example) and do not confute the moral agency of the person or group in question, the difference of intellectual disability is considered too great. Over time, enabled by medical and charitable paradigms, as well as the manifestation of the liberal conventions, intellectual disability is equated with an inferior moral status. According to Silvers, this thinking is based on a fixation on standardised behaviours and a preoccupation with what afflicts all rational moral systems, namely that reasons for action must not be 'opaque to normal adults'.[47] The parameters for acceptable behaviour, ability and rationale become the dicta of entitlement to equal treatment, per the moral powers and the structures of liberal equality suggested by Rawls.

Measured against these benchmarks, people with intellectual disabilities seemingly display irrational behaviour and limited cognitive functioning making them 'too different' for equality. Intellectual disability tests the very limits of equality approaches because, as Silvers declares, the existence of so-called 'defective agents' frustrates the levelling tendencies of even more the progressive social agreements; this is because the liberal tradition of equality and its requirements are rooted in the social contract. Accordingly, mental competence and ability are the most esteemed values and necessary standards for eligibility for equal treatment and underpin the creation of current rights framework, including international human rights law.[48]

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the High Commissioner for Human Rights, 'Sub-Regional Meeting on Disability Legislation: Decent Work for Persons with Disabilities in Asia', (Organised by the ILO and OHCHR funded by the Government of Ireland, 2008), 15.

[44] Koh describes that this as, essentially, meaning that 'however different people with disabilities may be, they are nevertheless born free and equal in dignity and rights and, hence, are entitled to equality and respect, even if that equality does not entail identical treatment under all circumstances'. Harold H. Koh, 'Different but Equal: The Human Rights of Persons with Intellectual Disabilities', (2004) 63(1) *Maryland Law Review*, 1-19.

[45] Silvers, n 36.

[46] Martha Minow, 'When Difference Has Its Home: Group Home for the Mentally Retarded, Equal Protection and Legal Treatment of Difference', (1987) 22(1) *Harvard Civil Rights-Civil Liberties Law Review*, 111-189.

[47] Anita Silvers, '(In)Equality, (Ab)Normality and the Americans with Disabilities Act' in Hilde Lindemann Nelson, (ed.), *Meaning and Medicine: A Reader in the Philosophy of Health Care*, (Routledge, 1999), 35.

[48] David Pfeiffer, 'The Philosophical Foundations of Disability Studies', (2002) 22(2) *Disability Studies Quarterly*, 3-23; Luke Clements and Janet Read, 'Life Disability and the Pursuit of Human Rights', in Luke Clements and Janet Read, (eds.) *Disabled People and the Right to Life: The Protection and Violation of Disabled People's most Basic Human Rights*, (Routledge, 2008), 4; Adrienne Asch, 'Disability Bioethics and Human Rights' in Gary Albrecht, Katherine Seelman and Michael Bury, (eds.), *Handbook of Disability Studies*, (Sage, 2001), 297.

As a unique character trait, which is defined by its very variation in cognitive functioning, intellectual disability represents an ultimate challenge to equality. It evokes deliberations over which theory of justice is best placed to offset the inequalities and marginalisation experienced as a result of intellectual disability. Moreover, intellectual disability sheds a distinct light on the criteria that shape the principles of equality models and tools currently in place, which will be discussed in more detail below. But most of all intellectual disability brings into question which version of equality is able, if at all, to bridge every, or even major disparities. By doing so, we are compelled to reflect on the ways in which people are valued in society, which is largely based on merit-worthy traits, behaviours and abilities. As a result, we have ended up with a framework for equality that is premised on establishing equivalence between the 'intellectually disabled' and the 'mentally competent', effectively assessing one's worth over the other.[49] However, making comparisons only serves to reify a material definition of difference. Instead, what is required is a framework of equality that incorporates diversity and defies the difference of intellectual disability.

4.3 EQUALITY, INTELLECTUAL DISABILITY AND INSTITUTIONS

Fully comprehending the unique situation of people with disabilities in society today in the context of equality requires not only considering the individual, in relation to their capacity to exercise moral reasoning and rationale, but also the social structures that have developed, and gradually enveloped, intellectual disability. Ignoring the socio-political context and its impact on this group neglects a large part of the experience of disability and is, arguably, the reason why the medical model of disability, along with paternalistic, protectionist and segregationist thinking still dominate disability law and policy today.[50]

Institutionalisation is indeed a pervasive experience in the lives of people with intellectual disabilities and requires some attention. Sheltering and shielding undesirable people, including those with disabilities, in separate places began as early as the thirteenth century.[51] As a result, the very concept of intellectual disability has evolved along with the development of medicine and related institutions.[52] Disability, as Stone claims, is then as much a product of institutionalisation and part of a political and economic system as it is about real differences between people. As places that isolate and marginalise certain groups, institutions continue to fuel a construct of

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[49] Martha Minow, 'When Difference has its Home: Group Homes for the Mentally Retarded, Equal Protection and Legal treatment of Difference', (1987) 22(1) *Civil Liberties Law Review*, 111-189.

[50] The medical model of disability conceptualizes disability as a personal, medical problem, requiring an individualised medical solution. According to this model and its influence on disability policy, the individual is treated as the locus of the problem, usually dependent and lacking capacity. For a more detailed discussion of its application in law see: Bradley Areheart, 'When Disability Isn't "Just Right": The Entrenchment of the Medical Model of Disability and the *Goldilocks* Dilemma', (2008) 83(1) *Indiana Law Journal*, 181-232.

[51] Heather E. Keith and Kenneth D. Keith, (eds.), Intellectual Disability: History and Evolution of Definitions, (John Wiley and Sons, 2013).

[52] Stone also believes that disability is largely a socially created category that has a distinct history. Deborah Stone, *The Disabled State,* (Temple University Press, 1984).

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disability not only socially but also spatially, and almost always entail removing autonomy from the individual.[53] Accordingly, an industry of care has grown which is founded on the idea that caring for people with intellectual disabilities in specially tailored places protects and is a greater benefit to them, than ensuring their equal treatment.[54]

Whilst most historically segregated groups have emancipated themselves from the institution, for people with intellectual disabilities their institutionalisation continues as a legitimised form of inequality. Some sociologists observe that this is because of the way legislation, including welfare law, has developed in western liberal societies relies on a contractual basis.[55] Reminiscent of Rawlsian social contract theory as explored above, this involves a reciprocal relationship. The entitlement to economic and social benefits is then subject to social conformity and the adjustment of the individual to the existing social system.

Looking inward, Silvers draws on this process of conformity that occurs inside institutions which involves an act of 'indulging the disabled' because they are disadvantaged. For the disabled participant, on the other hand, submissiveness remains the price of good treatment. Silvers clarifies this by stating that if,

> forbearance for subordinates, rather than respect for equals, motivates moral conduct toward the disabled, their abandoning the compliant behaviour that marks them as subordinate inevitably will dissolve or at least weaken the moral bonds that link others to them.[56]

In other words, the institutionalisation of people with disabilities further compounds the perception of this group by others as, fundamentally, 'other'. Research indicates that segregationist planning communicates to people with intellectual disabilities: 'you are out of place', 'you are different'; and with this, landscapes of exclusion are maintained. In fact, the pervasiveness of segregation as an inevitable consequence of intellectual disability is so commonplace that disabled people who do live or work independently are considered as heroes, 'defying their impairment and natural selection'.[57]

Similar to Silvers view, social theorist Gill comments on this quasi, inexplicit, bargaining process in institutions as applied to the example of sheltered workshops. He

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[53] Rob Kitchin, '"Out of Place", "Knowing One's Place": Space, Power and the Exclusion of Disabled People', (1998) 13(3) *Disability & Society,* 343-356; Ball further elucidates the discrepancy between institutions and autonomy and cannot imagine who would opt to attend and institution. Ball contemplates this and considers that 'if given the choice, most of us would opt for having our needs satisfied outside of such institutions because they are unlikely to respect our autonomy and individuality, (…)'. Carlos A. Ball, 'Autonomy, Justice and Disability', (2000) 47(3) *UCLA Law Review,* 599-651.
[54] Clearly there are several problems with this underlying rational from a human rights perspective. However, I will first discuss address the dichotomy between the seemingly contrasting paradigms of care and equal treatment.
[55] Alan Roulstone, 'Disability, Dependency and the New Deal for Disabled People', (2000) 15(3) *Disability & Society,* 427-443.
[56] Silvers, n 36.
[57] Kitchin, n 53.

explains that disabled workers are forced into subordinate roles. In exchange for shelter, food and the illusion of having a purposeful job, sheltered workers give up their claim to a meaningful occupation and their right to a place in the community as part of a social contract. In other words, 'the workshop is a tangible sign of the social contract that was created: a vocation in exchange for an attempt to become self-sufficient contributors of society'.[58]

As a result of the implicit contract entered into, of which the sheltered workshop is representative, groups become subject to state control in exchange for state benefits and support. This creates an imbalance of power in favour of the ruling parties who determine the eligibility and conditions to be met, as well as the parameters of action and expectable behaviour in order to receive supports.[59] In this way, state paternalism becomes manifest in institutions as individuals lose their autonomy and accept inferior treatment as a compromise for care. Gill is concerned that minimal social obligations or pressures to change this treatment of people with intellectual disabilities are evident, largely because institutions are also seen to be working to rehabilitate persons.[60] Because of this role, the debate on social justice, including the meaning of equality, is circumvented and becomes unnecessary.

The segregation of persons with intellectual disabilities in institutions is commonplace. The sheltered workshop is one such institution that contributes to the disproportionate exclusion of people with intellectual disabilities. Despite, the known negative effects thereof, placements in sheltered workshops continue. The provision of institutions thrives, even where clear arguments challenging these exist. Theorists have argued that the reason why these institutions retain their legitimacy is because individuals therein are treated as wards of the state, exchanging their citizenship for the price of care, as part of a social contract. Equality is evaded because subjects therein are ineligible and therefore unworthy of moral personhood and citizenship rights. The sheltered workshop, thus, represents a further factor in the social contract model that disregards and excludes people with intellectual disabilities, embodying a legitimate form of discrimination. This is particularly the case where sheltered workshops 'unnecessarily' segregate people with disabilities, keeping them 'marginalised and hidden, creating opportunities of abuse, neglect and exploitation'.[61] The experience of institutionalisation for people with intellectual disabilities is so prevalent that Barnes declares that it constitutes a form of discrimination that has become part of the 'very fabric of British society'.[62]

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[58] Michael Gill, 'The Myth of Transition: Contractualizing Disability in the Sheltered Workshop', (2005) 20(6) *Disability & Society,* 617.

[59] Bo Rothstein, *Just Institutions Matter: The Moral and Political Logic of the Universal Welfare State,* (Cambridge University Press, 1998).

[60] Colin Barnes, 'Institutional Discrimination against Disabled People', (The British Council of Organisations of Disabled People, 1991).

[61] Pendo, n 2, 117.

[62] Colin Barnes and Mike Oliver, 'Disability Rights: Rhetoric and Reality in the UK', (1995) 10(1) *Disability and Society,* 111-119.

4.4 CONCLUSION

This chapter has offered a theoretical discussion of equality and identified that liberalist thought has prompted a framework of rights that prioritises the protection of select, eligible individuals. Social contract theory offers a model to explain how individuals are recognised as rights bearers according to the liberal tradition and is the theory most famously pursued in modern times by Rawls. This theory sets forth that individuals are bound to each other by a set of moral obligations, via a hypothetical social contract, as the foundation of communal living. Citizenship and rights then hinge on the ability to enter into the social contract.[63] The mastery of two moral powers is required to become a participant in the social contract and eligible for equal status. These powers entail a demonstrable capacity for a sense of justice, including the conception of what is good, and for displaying the ability to reason. To be regarded as equal in moral status and as a full, social and political actor, an individual must possess these qualifying markers. Those deemed unable to make decisions regarding what is 'good', based on a perceived inability to contemplate, communicate or otherwise demonstrate a rational ability to make 'good' choices, lack the moral powers required to enter into the social contract and to be regarded as equal.[64]

Next, this chapter addresses further principles of equality developed as an expression of the liberal ideal. Using Reinders' discussion of the 5 tenets of liberal equality, it explores the operation and tangible impact of equality based on the foundations of Rawlsian social contract theory. This chapter shows that people with intellectual disabilities are not only excluded from most considerations of equality on the basis of their unequal status but also by the ways in which the principles operate. A further confounding factor for equality in the context of intellectual disability is also addressed in this chapter, namely the difference posed by the trait. This difference of intellectual disability is widely held to be insurmountable, and, therefore, equality for this group is unattainable.

While the main object of this thesis is not to discuss political liberalism or critique Rawlsian theories of justice, elaborating on these theories has, however, been helpful in a) understanding the liberal ideas which underpin current concepts of equality and which have shaped human rights law, and, b) in determining how intellectual disability poses a distinct set of challenges to the concept of equality, impacting upon claims to rights. As a result, the segregation of people with disabilities in institutions is regarded as unproblematic, and an inevitable consequence of their difference, and even part of the social contract process. Overall, this chapter has revealed that our framework of rights as it exists today is based on a belief system that envisions free and rational

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[63] John Rawls, *Political Liberalism* (Columbia University Press, 1993), 18; John Rawls, *Justice as Fairness: A Restatement* (The Belknap Press, 2001), 19. Although the intention here is not to provide an in-depth discussion of Rawlsian theory, it is important to appreciate how influential his thoughts were. Particularly his revival of Social Contract Theory is of note as it has been one of the most dominant theories in the aftermath of the Second World War.
[64] Ashley Taylor, '"Lives Worth Living": Theorizing Moral Status and Expression of Human Life', (2013) 33(4) *Disability Studies Quarterly*.

agents. Further, this system of rights operates in a way that prevents the inclusion of those deemed unable to act accordingly. People with intellectual disabilities are effectively classed as ineligible for the same balance of rights as other groups. As a result, their segregation in sheltered workshops has not, to date, been meaningfully challenged.

Chapter 5: Existing Equality Models and Intellectual Disability

This chapter builds on the findings from Chapter 4 and further explores the evolution of equality through various models. The chapter will first address traditional equality models and discuss how people with intellectual disabilities typically fare in formal and substantive approaches. Next, more modern, evolved models of equality, which have developed in response to criticisms of the impact of previous ones, will be explored. It will be seen that these models are more sensitive of the impact of normative frameworks on the formulation of equality approaches. This is particularly true of the newest model, coined 'inclusive equality', introduced here. Distilling the unique perspective of intellectual disability amidst equality debates in this way not only generates a strong understanding of equality theory generally, but also offers insight into the new vision of equality embraced by the CRPD and its implications for sheltered work. Lastly, this chapter also considers some theoretical and practical impediments facing claims to equality by people with intellectual disabilities.

5.1 TRADITIONAL EQUALITY MODELS

The principle of equality has become 'fundamental to the notion of governance', in western societies today.[1] This is not least because it is derived from a common understanding of humanity and based on shared beliefs of human dignity, spurred largely by liberalist ideals of social justice and protection of individual liberties.[2] As an entrenched feature of the International Bill of Human Rights, equality is a central ideal and the root of contemporary human rights law. The doctrine of equality and the standards put forward in the 'controlling documents of international law' have now become the moral touchstone influencing economic and political institutions, internationally and domestically.[3] The role of equality is so fundamental in modern liberalist thinking that it is often assumed that we have a shared and intuitive understanding of what equality means. However, little, and often conflicting, guidance is available as to how to achieve equality and, as Fredman explains, the closer we look at the principle the more its meaning shifts.[4] So much so that investigations and debates into its meaning and implications are on-going and constantly evolving.[5]

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[1] Marcia Rioux and Christopher Riddle, 'Values in Disability Policy and Law: Equality' in Maria Rioux, Lee Ann Basser and Melinda Jones, (eds.), *Critical Perspectives on Human Rights and Disability Law,* (Nijhoff, 2011), 37.
[2] David Miller, 'Deliberative Democracy and Social Choice', (1992) 40(1) *Political Studies,* 54-67.
[3] Charls R. Beitz, 'Human Rights as a Common Concern', (2001) 95(2) *American Journal of Political Science Review,* 269-282.
[4] Sandra Fredman, *Discrimination Law, 2nd Edition,* (Oxford University Press, 2011).
[5] This was particularly highlighted by Amartaya Sen's Tanner Lecture entitled 'Equality of What?' given in 1979, see also: George Cohen, 'Equality of What? Welfare, Goods and Capabilities', (1990) 56(3) *Louvain Economic Review,* 357-382.

We must begin this discussion then by exploring the purpose of equality. In practical terms, equality is a concept aimed at ensuring individuals' right to participate in their own societies. Furthermore, equality is often understood as a tool to ensure that individuals and groups of individuals are treated equally and no less favourably than other individuals.[6] Elsewhere, equality is explained as 'ensuring that every individual has an equal opportunity to make the most of their lives and talents and believing that no one should have poorer life chances because of where, what or whom, they were born, what they believe, or whether they have a disability'.[7] Phrased in this manner, equality, it seems, is a straightforward tool to achieve a more equal society; however, a deeper consideration of how liberal thought shapes equality, presented above, reveals that its application is more obscure and that eligibility for equal treatment is not automatic.

In Rawls' influential egalitarian theory, to be considered as a member in society, and, therefore, included in equality debates, individuals had to demonstrate the capability to act rationally and make morally sound judgments. In other words, individuals must first prove their eligibility to be considered as equal.[8] People with intellectual disabilities, traditionally regarded as lacking these abilities, were thus found to be ineligible from the outset, failing to even meet the threshold to be regarded, let alone treated, as equal. Consequently, their ineligibility as members in society and their non-status were self-evident. Years on from Rawls' impact on legal and political ideologies of western nation states', access to full citizenship is still unattainable for people with intellectual disabilities, who remain institutionalised and excluded, with their rights and dignity not respected. The ineligibility of people with intellectual disabilities to be counted as members in society has manifested itself within the different equality models over time. This has had the effect that these do not apply to, or include, people with intellectual disabilities; this is a situation which, so far, no model has satisfactorily rectified. The following will highlight this further.

5.1.1 Formal equality

The formal equality model is also referred to as the sameness or symmetrical approach and rests on a seemingly straightforward and morally irrefutable comparison between two persons or situations.[9] Transposed into law, this principle has manifested itself as the rule of equal

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[6] Irish Human Rights and Equality Commission, 'Equality', (2014) [online], available at: <http://www.ihrec.ie/your-rights/what-is-equality.html> (accessed 13 September 2016).
[7] UK Equality and Human Rights Commission, 'Understanding Equality', (2016), [online] available at:
<https://www.equalityhumanrights.com/en/secondary-education-resources/useful-information/understanding-equality>
(accessed 13 September 2016).
[8] Nussbaum explains that under liberal regimes of rights that is based social contract theory, the notion of rights and their contractual conditionality presupposes that individuals enter into these because of a mutual advantage. Traditionally, contracting individuals are imagined as free, equal and independent, according to Locke's notion of man in society. Nussbaum explains that for people with intellectual disabilities this conception fails as it regards only 'rough equals, none able to dominate the others, and none asymmetrically dependent upon the others'. Martha Nussbaum, 'Capabilities as Fundamental Entitlements: Sen and Social Justice', (2003) 9(3) *Feminist Economics,* 33-59.
[9] Oddney M. Arnardóttir, 'Non-Discrimination in International and European Law: Towards Substantive Models', (2007) 25(2) *Nordic Journal of Human Rights,* 140-157.

Existing Equality Models and Intellectual Disability

treatment, and 'treating like cases as like', according to the Aristotelian maxim.[10] In this model, single standard rules are adopted, ensuring the equal treatment of all persons before the law, anticipating that all subjects can perform according to the same rules and standards as the dominant class. The fact that laws may have an unequal impact upon different groups is of little relevance as long as the rule of equal treatment is applied in each case.

Equality of treatment according to the formal approach relies on the principle of justice that in turn relies on the moral virtue of fairness and the consistent application of the logic, to 'treat similars [*sic*] similarly'.[11] As a definition of justice, however, this view fails immediately. This is because treating two similar persons dissimilarly may not necessarily be prohibited, depending on whether the process or the outcome of that rule is measured. Where anti-discrimination law is structured using the principal of equal treatment often a comparator is required to establish dissimilar, and therefore unequal, treatment. This is where a significant number of claims by persons with intellectual disabilities fail early on, as they are unable to find non-disabled comparators due to the fact that they inhabit very different social and public spaces.[12] A sheltered worker, for example, will have difficulty finding a non-disabled worker working in such a setting. Unequal treatment, therefore, cannot be proven as no non-disabled comparator can be found working in a sheltered workshop, nor can a sheltered worker find a comparator on the open labour market as their employment (situation) cannot be compared.[13] Evidently, singularly relying on equal treatment devised on a formal conception of equality is of no benefit to people with intellectual disabilities.[14]

An example of the effects of this is provided by Shriner et al. who explain that in the U.S., until recently, the right to vote of persons in institutions was denied, regardless of their ability to exercise the right.[15] This exclusion was justified on the proposition that all persons in institutions were denied the right to vote and were therefore being treated equally. In that regard people who were similarly situated were being treated equally. In this case the comparator was another person in the institution rather than a non-institutionalised person, and the denial of the right to vote was therefore seen as justified. However, the people who were being treated alike in this instance were being denied their vote on the basis of an incorrect assumption, i.e. that because they were in an institution they were automatically incapable of voting. Rioux warns that when the individual is understood as the source of the inequality in this way 'there is a ready rationale for social inequality and for limiting social entitlement'.[16] As

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[10] Jenny E. Goldschmidt, 'New Perspectives on Equality: Towards Transformative Justice through the Disability Convention?', (2017) 35(1) *Nordic Journal of Human Rights*, 1–14.

[11] Daniel Lyons, 'The Weakness of Formal Equality', (1966) 76(2) *Ethics*, 146-148.

[12] Harold Hongju Koh, 'Different but Equal: The Human Rights of Persons with Intellectual Disabilities', (2004) 63(1) *Maryland Law Review*, 1-19.

[13] Denise Réaume, 'Dignity, Equality and Comparison' in Deborah Hellman and Sophia Moreau, (eds.), *Philosophical Foundations of Discrimination Law,* (Oxford University Press, 2013).

[14] Peter Western, 'The Empty Idea of Equality' (1982) 95(3) *Harvard Law Review,* 537.

[15] Kay Shriner, Lisa Ochs and Todd Shields, 'The Last Suffrage Movement: Voting Rights for Persons with Cognitive and Emotional Disabilities', (1997) 27(3) *Publius,* 75-96.

[16] Marcia Rioux, 'Towards a Concept of Equality of Well-Being: Overcoming the Social and Legal Construction of Inequality' in Marcia Rioux and Michael Bach, (eds.), *Disability is Not Measles: New Research Paradigms* (L'Institute Roeher, 1994), 73.

a result, institutionalised persons have generally been regarded as inherently unequal to non-institutionalised persons.[17]

Young and Quibell agree that where what is 'just' is determined by law on the basis of formal equality, the automatic exclusion of institutionalised persons is not recognised as unjust.[18] As a result, a cascade of rights denials sanctioned by unfavourable laws and regulations has unfolded. However, while the principle of equal treatment laid down the foundation for equality law, its meaning and scope have gradually developed. Over time and through case law, the principle of equal treatment now reflects a more sophisticated vision of equality that captures the diversity in society, human relations and delicate characteristics that can lead to disadvantage by embracing substantive inferences. Beyond the limitations of formal equality then, evolved models are based on an awareness that for full and effective equality, different treatment is necessary.[19]

5.1.2 Substantive equality models

More recent interpretations of equality have moved on from merely 'linear' conceptions of the principle of equal treatment to more analytical ones in terms of its impact. Whilst under the formal model differences led to the exclusion of unqualified persons, substantive approaches embrace these and recognise that they must be acted upon to include more members of society and achieve *de facto* equality.[20] Substantive equality models, based on 'the difference approach', thus aim to accommodate differences amongst groups and individuals via specific measures. In practice, approaches under this model utilise a 'permissive interpretation' of equality (i.e. certain unequal actions are permitted) to increase, through laws and policy, the participation of traditionally disadvantaged groups to achieve more equal societies. In accordance with substantive models of equality, which are typically underpinned by progressive theories of distributive justice, a host of methods are employed with the aim of equalising opportunities, redistributing resources or alleviating disadvantage to achieve a more applicable and substantive conception of equality.[21]

5.1.2.1 Equality of opportunity

'Equality of opportunity' models introduce substantive elements to equality frameworks and adopt approaches that aim to equalise life chances.[22] Thereunder, targeted measures, such as

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[17] White describes how people with without intellectual disability but with Hansons Disease where institutionalised and as a result, denied the right to vote in: Neil White, *A Sanctuary of Outcasts: A Memoir,* (Murdoch Books, 2009).
[18] Damon A. Young and Ruth Quibell, 'Why Rights Are Never Enough: Rights, Intellectual Disability and Understanding', (2000) 15(5) *Disability & Society*, 747-764.
[19] Equal Rights Trust, 'Declaration on the Principles of Equality', (2008).
[20] Oddney M. Arnardóttir, 'A Future for Multidimensional Disadvantage Equality?' in Oddny M. Arnardóttir and Gerard Quinn, (eds.), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives,* (Martinus Nijhoff, 2009), 50.
[21] Fredman would add that the neo-liberal goal of market or contractual equality and the political goal of access to decision-making processes are further central elements of redistributive justice. Fredman, n 4, 3.
[22] S. J. D. Green, 'Is Equality of Opportunity a False Ideal for Society?', (1998) 39(1) *The British Journal of Sociology*, 1–27.

positive action or reasonable accommodation, are adopted to equalize the opportunities between individuals and between groups.[23] This approach attempts to account for characteristics such as sex, gender, race, age, religion or disability and rectify the disadvantages experienced by groups that fall under these categories. This model is particularly reflective of the impact of laws and policies and acknowledges that, while these may purport to be equal, in reality they can have an unequal effect on certain groups.[24] Unlike the narrow, and arguably biased, white, male-centric reach of formal equality, this concept is based on a model of redistributive justice that ensures that groups with different proverbial 'starting points' have equal chances, regardless of their characteristics. Using a similar adage, Cooray explains that 'equality of opportunity provides in a sense that all start the race of life at the same time'.[25]

Equality of opportunity measures are recognised as addressing some of the limitations of formal equality by considering the wider conditions that lead to substantive inequalities between advantaged and disadvantaged groups.[26] However, these measures have been criticised for contributing little towards dismantling the pervasive liberal ideals according to which equality is still formulated, remaining problematic for intellectual disability equality. In the context of work, for example, mainstream environments effectively remain biased towards non-disabled, 'able-bodied', norms, with little attention paid to changing the organisational context in which the work is conducted for the benefit of workers with disabilities.[27] Thus, although aimed at providing favourable treatment for targeted groups, people with intellectual disabilities rarely benefit from equality of opportunity measures, unable to attain the standard at which to be considered worthy of participation in the first place.[28] The resulting exclusion is largely based on the unchallenged hegemony of normativity and ableism that prevails, argue some theorists.[29] Meyers therefore, concludes that equality of opportunity models are superficial remedies that fail to address the relative disadvantage faced by people with intellectual disabilities.[30]

5.1.2.2 Equality of outcome

Equality of outcomes is another approach under the substantive model of equality. Aware of certain gaps that other equality measures fail to bridge, the outcome approach considers equality from the reverse perspective, i.e. in terms of the outcomes sought. Equality of outcomes, also referred to as equality of results, is therefore considered as an alternative conception of equality as it focuses on limiting the material inequalities between individuals or

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[23] Equal Rights Trust, 'The Ideas of Equality and Non-Discrimination: Formal and Substantive Equality', (Equal Rights Trust, 2007).

[24] Christopher McCrudden, 'The New Concept of Equality', (European Rights Academy, 2003).

[25] Mark Cooray, 'The Australian Achievement: From Bondage to Freedom; Equality of Opportunity and Equality of Outcome', (1996) [online], available at: <https://www.ourcivilisation.com/cooray/btof/chap20.htm> (accessed 30 August 2019).

[26] Goldschmidt, n 10; Fiona Myers Alastair Ager, Patricia Kerr and Susan Myles, 'Outside Looking In? Studies of the Community Integration of People with Learning Disabilities', (1998) 13(3) Disability & Society, 389-413.

[27] Pearl Buhariwala, Robert Wilton and Joshua Evans, 'Social Enterprises as Enabling Workplaces for People with Psychiatric Disabilities', (2015) 30(6) *Disability & Society,* 865-879.

[28] The reasons for this have been discussed above in Chapter 4.

[29] Goodley believes that dominance and ableism are such prevailing forces that 'compulsory able-bodiedness functions by covering over, with the appearance of choice, a system in which there actually is no choice. Dan Goodley, 'Dis/Entangling Critical Disability Studies', (2013) 28(5) *Disability & Society,* 631-644.

[30] Myers et al., n 26.

groups and 'equalising where people end up rather than where or how they start'.[31] Approaches under this model may involve directly redistributing wealth between groups or implementing other measures to equalise material outcomes. Specifically, this model necessitates a re-evaluative element, prompting a reflection on the goals of equality. By instigating a deeper consideration of the moral principles of social redistribution in society it injects a little more substance into the concept of equality.

Equality of outcome is, however, regarded as a controversial concept because of the noted difficulty in achieving a consensus on its objectives and measurability. After all, a focus on outcomes and results immediately presents further questions over what should be equalised? (Income? Happiness? Welfare?). Sen poignantly summarizes this dilemma with the infamous question 'Equality of What?' in his influential treatise on the subject. Indeed, the possibilities and combinations of outcomes measured are vast, making equality of outcome a difficult model to translate into concrete policy. This complexity is further impacted, in the context of disability, due to specific requirements attributed to impairment and health conditions. These individual factors must be weighed up and accommodated when pursuing means to achieve equal wealth or well-being, as compared to others who do not have additional needs.[32] Furthermore, the experience of well-being or wealth is grounded in the subjective, adding a further dynamic to this conception of equality. The measurement of equality of outcome in the context of intellectual disability therefore requires a deep philosophical deliberation and has fuelled much continuing debate.[33] Overall, Rioux remains sceptical of this approach as, once again, it is rooted in liberal ideals and fails to address the historically constituted relations of power and privilege associated with these.[34] Most of all, the substantive models mentioned so far build on the assumption that any form of equality and social progress can be achieved without challenging the liberal thinking they are based on.

Essentially, existing equality measures do little to change the structures of inequality or 'create an adjustment to permanent differences, (real or imagined) between [different] groups'.[35] Therefore, while these may be adept in dealing with direct discrimination, their reliance on merit-worthy attributes and adaptability of the individual renders these insufficient in addressing the 'complexities of indirect, or culturally-entrenched discrimination', affecting people with intellectual disabilities the most.[36] Therefore, traditional equality models are subject to the general criticism that they merely offer restorative justice and fail to combat the root of the disadvantage, unlike newer approaches. In other words, they operate by correcting

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[31] Anne Phillips 'Defending Equality of Outcome', (2004) 12(1) *Journal of Political Philosophy*, 1-19.
[32] Amartya Sen referred to the two economic problems associated with disability: '1. the person – or family – with a disability will find it harder to get rich; 2. even if they make money (from a job) they will probably have to spend a proportion of it on their extra needs'. John Cullinan, 'The Economic Costs of Disability', (Frontline, The Irish Voice of Intellectual Disability, 2016), [online], available at: <http://frontline-ireland.com/economic-costs-disability-families/> (accessed 12 December 2016).
[33] Leanne Dowse, 'Some People Are Never Going to Be Able to Do That'. Challenges for People with Intellectual Disability in the 21st Century', (2009) 25(5) *Disability & Society*, 571–584.
[34] Marcia H. Rioux, 'Towards a Concept of Equality of Well-Being: Overcoming the Social and Legal Construction of Inequality' (1994) 7(1) *Canadian Journal of Law & Jurisprudence*, 127-147, 142.
[35] Wendy Williams, 'The Equality Crisis: Some Reflections on Culture, Courts and Feminism', (1982) 7(3) *Women's Rights Law Reporter*, 175-201. Important to note is that equality enforcement measures are also an important type of equality measure typically established in secondary legislation. For a discussion of these in the context of the Irish Employment Equality Act 1998, please see: Lucy-Ann Buckley, 'The Employment Equality Act 1998 (Ireland)', (2000) 29 *Industrial Law Journal*, 273-279.
[36] Young and Quibell, n 18.

the discriminatory impact or unjust results but do not, however, encourage any wide-scale reform of structures that, explicitly or implicitly, favour some groups over others.[37]

5.2 MODERN EQUALITY MODELS

Having introduced formal and substantive models of equality and addressed some of their limitations, it becomes apparent that broader approaches are required to conceptualise equality for people with intellectual disabilities. Newer models of equality therefore focus less on assimilating groups, as did traditional models, and more on the formal recognition of differences. Accordingly, 'diversity' is increasingly considered, a valuable norm.[38] Newer equality models, therefore, formalise this recognition by determining that outcomes and situations outside of normative constructs are equal. Moreover, the aim is to tackle the root of inequality by challenging the dominant hegemony that has oppressed minorities.

5.2.1 Anti-subordination

As a group-based theory of equality, anti-subordination theory states that laws may not 'aggravate or perpetuate' the subordinate status of disadvantaged groups.[39] Practices and policies that by intent or effect enforce the secondary social status of minority groups must be challenged.[40] This approach tackles the problem of inequality in a proactive rather than a re-active manner, suggesting intervention at earlier stages than previous models. Actions under this model target policies and practises in order to redress entrenched structures of inequality, anticipating law reform and, ultimately, the achievement of a society that does not subordinate.[41]

The anti-subordination approach is perhaps better known in the U.S., where it was originally developed to ensure equal protection in law regardless of race, religion or gender. Based on the diverse nature of society in the U.S., made up of many immigrant, and therefore subordinate, groups this approach was developed to ensure equal citizenship and to tackle subjugation.[42] As a distinct model, the anti-subordination approach developed particularly as a product of the American Civil Rights movement in response to the rigid and narrow application of equality

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[37] Bhiku Parekh, 'A Case for Positive Discrimination' in Bob Hepple and Eva Szyszcak, (eds.), *Discrimination the Limits of the Law,* (Mansell, 1993).
[38] Creating what some consider, a society built on 'pluralist egalitarianism'. Alan Carter, 'Value-Pluralist Egalitarianism', (2002) 99(11) *The Journal of Philosophy,* 577-599.
[39] Ruth Colker, 'Anti-Subordination above All: Sex, Race and Equal Protection', (1986) 61 *New York University Law Review,* 1-54.
[40] See generally: See generally Owen M. Fiss, 'Groups and the Equal Protection Clause', (1976) 5(2) *Philosophy and Public Affairs,* 107-177.
[41] Therefore, it is referred to by Barry as the 'unicorn' to chase. Kevin Barry, 'Chasing the Unicorn: Anti-Subordination and the ADAAA', (2015) 14(2) *Connecticut Public Interest Law Review*, 207–241.
[42] Raquel Aldana, 'Introduction: The Subordination and Anti- Subordination Story of the U.S. Immigrant Experience in the 21st Century', (2007) 7 *Nevada Law Journal,* 713–35.

principles by courts, especially after the landmark ruling in *Brown v. Board of Education* addressing racial segregation in the education system.[43]

The most prominent anti-subordination theorist who applies this theory in the formulation of disability equality is Colker.[44] Colker, however, applies anti-subordination to denounce the idea that segregating people on the basis of disability is unequal. Instead, she argues, the status of being segregated and receiving care in specialised services should be revered as a new source of equality reserved especially for people with intellectual disabilities. By enjoying their segregation, this group, defies the pressures of norms and standards; after all, she asserts, some people are simply better served in an institutional setting. Accordingly, the full inclusion of all people with disabilities in society as a goal and a measure of equality is questionable anyway.[45] Arguably, this is a false application of anti-subordination theory. Colker's thinking, rather than tackling systems of oppression (and segregation), enforces them and perpetuates the exclusion of subordinates.

A significant problematic issue with the anti-subordination approach, from the perspective of intellectual disability, is establishing *who* is defining the problem and *how* it will be tackled using this approach. Inevitably we arrive at a situation where equality sought using the anti-subordination model similarly requires the presence of certain intellectual abilities, resources and collective efforts of individuals and groups of persons with disabilities. So while the anti-subordination model is a little more radical than previous approaches it may not help people with intellectual disabilities in their attempt to challenge the very structures and institutions that oppress them. Additionally, persons with intellectual disabilities are more likely to experience social isolation which negatively impacts on their opportunities to band together and tackle systems of subordination. Moreover, due to a situation of under-theorising on the subject of intellectual disability equality more generally, certain process of subordination are simply not addressed or regarded as problematic. As a result, topics such as power, institutionalisation and segregation are rarely considered as processes of harmful subordination, aside from the context of race.

5.2.2 Transformative equality

While the anti-subordination approach promotes a group-based perspective that facilitates an understanding of the way in which certain groups have been historically treated unequally, it is limited in its ability to fundamentally dispel hierarchies between people with and without disabilities.[46] Two further models of equality have then been developed and applied by theorists Fredman and Degener, specifically, in addressing the equality measures required to achieve

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[43] Jack Balkin and Reva Siegel, 'The American Civil Rights Tradition: Anticlassification or Antisubordination?" (2003) 58 *University of Miami Law Review*, 9–34. Subsequent proponents, such as McKinnon have, famously, also applied the principles in gender discrimination contexts. See generally: Catherine MacKinnon, *Feminism Unmodified: Discourses on Life and Law,* (Harvard University Press, 1988).

[44] Ruth Colker, *When is Separate Unequal? A Disability Perspective*, (Cambridge University Press, 2009).

[45] Ibid. 7,

[46] Sheila I. Velez Martinez, 'Towards an Outcrit Pedagogy of Anti-Subordination in the Classroom', (2015) 90(2) *Chicago-Kent Law Review*, 585-614.

disability equality. The first, and markedly new, model embraces an approach to equality that not only challenges dominant structures and concepts but re-engineers them, and is thus labelled as 'transformative'.[47] Based on this model's approach to difference and the recognition of intersectional dimensions of discrimination requiring multidimensional responses, it is also known, variously, as the 'proactive model', the 'multidimensional disadvantage model', and the 'diversity equality model'. [48]

Transformative equality is, in essence, analogous to anti-subordination theory and targets the structures of inequality, albeit originating from a more international source as a by-product of CEDAW (Convention on the Elimination of All Forms of Discrimination Against Women) jurisprudence.[49] Focusing on the position of women and how they have structurally been disadvantaged based on their inferior status, this approach understands that the magnitude of change required to achieve equality must be nothing short of 'transformative'. Decidedly, this is where the transformative approach distinguishes itself from the anti-subordination model of equality, as the latter is said to be merely a further means to restore justice by redressing disadvantages only once they have occurred and been argued, in line with the substantive approaches.[50] The transformative model then requires more critical reflection. It more accurately identifies the source of much disadvantage to lie in the conflicts different groups have with over-bearing normative frameworks, of which subordination is only a symptom. Bernadini and Giolo speak of an 'implicit political anthropology' that still dominates and regulates which persons are eligible for equality and rights, which a transformative approach to relational equality must overcome.[51]

The transformative model addresses the societal power-relationships and sees the need for a shift. It builds on the idea that equality and difference have traditionally been regarded as antagonistic concepts.[52] Rather than considering them as opponents, the transformative model contends that the right to equality is more effectively enforced when it is framed in context, which may necessitate a multi-dimensional approach. In other words, the conception of equality in operation must be a dialogue with different aspects of identity and flexible enough to respond adequately to the situations of those who are 'disadvantaged, demeaned, excluded, or ignored'.[53] The transformative model then requires considering the lives of individuals and groups in a 'contextual' way and the adoption of measures that effect the "*real* transformation' of opportunities, institutions and systems so that they are no longer grounded in

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[47] Degener refers to it as a 'modern equality concept'. Theresia Degener, 'Disability in a Human Rights Context', (2016) 5(3) *Laws*, 35–59.

[48] The term 'intersectionality' was coined by Kimberlé Williams Crenshaw, in 1989, and refers to an interdisciplinary field of studies which explores how structures of disadvantage associated with race, religion, gender, age, disability, sexual orientation, class etc. impact and influence one another.

[49] Minkowitz refers particularly to the General Recommendation No. 25 (paras. 7-10) adopted by the Committee on the Elimination of Discrimination Against Women at its Thirtieth session (2004), Tina Minkowitz, 'CRPD and Transformative Equality', (2017) 13(1) *International Journal of Law in Context*, 77–86.

[50] Donna Cooker, 'Transformative Justice: Anti-Subordination Processes in Cases of Domestic Violence', in Heather Strang and John Braithwaite, (eds.), *Restorative Justice and Family Violence*, (University of Miami, 2002), 128.

[51] Maria Giulia Bernardini and Orsetta Giolo, 'Relational Equality before Power(s): Towards the Shifting Parameter', (2016) 7(1) Comparative Law Review, 1-16.

[52] Ibid, at 15.

[53] Sandra Fredman, 'Substantive Equality Revisited', (2016) 14(3) *International Journal of Constitutional Law,* 712–738.

predetermined, historical (male, non-disabled) paradigms of power and life patterns'.[54] Therefore transformative equality distinguishes itself from its anti-subordination counterpart by highlighting that, besides addressing the structures of inequality, dominant and pervasive determinates of 'normality', must also be actively problematised.

Transformative equality is particularly adept in tackling disability inequality because it is non-hierarchical, affects interpersonal relationships, and is therefore perhaps more democratic than previous approaches.[55] Moreover, it addresses 'barriers' and focuses on 'inclusion' and other positive measures to initiate 'real' changes focusing specifically on addressing hierarchical power relations.[56] Because of its focus on the power relations, Minkowitz deems that the transformative approach can help promote a deeper understanding of the position of people with disabilities in society. Specifically, she believes, that it will help address urgent, heretofore unchallenged, problems and tensions in the relationships between individuals and their family members, medical professionals, as well as institutions of all kind.[57]

Fredman, the scholar most associated with the evolution of transformative equality, recognises that the meaning of equality, and particularly substantive equality, is still deeply disputed. Fredman fundamentally regards equality as a tool for social change in which the main tenet of substantive equality is more concerned with equality of results than equal treatment.[58] The essence of Fredman's understanding of transformative equality is its unique handling of the complex relationship between equality and, what is often framed as its negative counterpart, difference. Indeed, negative judgements of 'the other' have justified differential treatment of groups perceived as different, and therefore under the norms of hegemony, as inferior. Fredman believes, however, that the role of equality, 'far from suppressing difference, should accommodate and even celebrate it'.[59] Fredman identifies four different but overlapping approaches to the concept of equality that have evolved, and she incorporates these into a four-dimensional model she comprises to achieve social change. Accordingly, laws and policies must be designed to work on a number of levels: redress disadvantage; counter stigma, prejudice, humiliation and violence; transform social and institutional structures; and facilitate political participation and social inclusion.[60]

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[54] General Recommendation No. 25 adopted by the Committee on the Elimination of Discrimination Against Women at its Thirtieth Session (2004), 'General recommendation No. 25: Article 4, paragraph 1, of the Convention (temporary special measures), para. 10.

[55] Raphaele Xenidis, 'Shaking the Normative Foundations of EU Equality Law: Evolution and Hierarchy between Market Integration and Human Rights Rationales', (Working Paper, EUI LAW, 2017/04, European Regulatory Private Law Project (ERPL)).

[56] Sandra Fredman, 'Beyond the Dichotomy of Formal and Substantive Equality: Towards a New Definition of Equal Rights' in Ineke Boerefijn, Fons Coomans, Jenny Goldschmidt, Riki Holtmaat, and Ria Wolleswinkel, (eds.), *Temporary Special Measures: Accelerating De Facto Equality of Women under Article 4 (1) UN Convention on the Elimination of All Forms of Discrimination Against Women,* (Intersentia, 2003), 115.

[57] Minkowitz, n 49.

[58] In her more recent writings Fredman applies her the four-dimensional approach to substantive equality against the commitment to equality as purported by international human rights law. According to Fredman, the framework of equality applied needs to evolve in unison which is why the concept of equality of outcome is important in addressing disadvantage and discrimination faced by different groups. This is a particularly the case if we concede with Fredman's view that 'equality, far from suppressing difference, should accommodate and even celebrate it'; Fredman, n 4, 3.

[59] Fredman, n 4, 3.

[60] Actions to remedy this describe the aim of achieving social inclusion which improves the ability, opportunity, and dignity of those disadvantaged on the basis of their identity, from an economic, social and cultural perspective. Fredman has written extensively on the subject of formal versus substantive equality. See, for example: Sandra Fredman, 'Making Equality Effective: The Role of Proactive Measures', (European Network of Legal Experts in the Field of Gender Equality, 2009). Fredman explains that, 'drawing attention to all the dimensions and insisting on building complementarities can move us positively towards furthering substantive equality. Conflicts should be addressed by referring to the whole framework, to create a synthesis rather than prioritizing. It is thus not a definition, but an analytic framework to assess and assist in modifying laws, policies and practices to better achieve substantive equality'; Sandra Fredman, 'Substantive Equality Revisited', (2016) 14(3) *International Journal of Constitutional Law,* 712–738.

As a comparably new model of equality, transformative equality is somewhat underdeveloped, yet its potential to transcend the limitations of other models is promising, although some have expressed doubt and see this models' transformative potential as finite.[61] According to Wilkes, relying on law and policy to amend existing social structures is possibly one of the 'obvious weaknesses' of the transformative approach.[62] Certainly, it is questionable how much social engineering can be achieved and to what extent group differences can be absorbed by law and policy. Indeed, it remains to be seen in how far the obligation to transform entire societies and their structures is actionable, using approaches that rely on traditional legal approaches to achieve such a transformation. [63]

5.2.3 Inclusive equality

Similar to transformative equality, inclusive equality is also a transformative approach, rather than merely a corrective one, and requires the reshaping of normative values by identifying and tackling practices that might otherwise be widely regard as 'unobjectionable, and even virtuous'.[64] Inclusive equality, thus, also focuses on changing both systemic and structural processes of inequality, but it adds a distinct awareness of the impact of inclusion and exclusion as a part of this. Sheppard identifies that inclusive equality is premised on a commitment to inclusion of specifically those that have been historically and structurally excluded.[65] Poignantly, under this model, inclusion and exclusion are recognised as outcomes produced through interactions between individuals and structures, with exclusion framed as a marker of inequality. Inclusive equality, therefore, envisages equality achieved through inclusion and a widening of the participation and access to mainstream settings, including goods and services.

Indeed, in a fashion that is perhaps more reflective of the specific disability characteristic, inclusive equality rejects the automatic stigmatization associated with many experiences of disability. Inclusive equality is then more of an ecological model. As described by Solanke in her discussion of equality and the 'anti-stigma principle', inclusive equality engages in a process that shifts the focus from individual attributes and behavioural deficits to the social context of production of discrimination through social meanings and discourses.[66] This vision of inclusion is based on recognising rather than oppressing, rethinking rules instead of making exceptions and negotiating (rather than imposing) redistributive principles.[67] Sheppard believes that, in a

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[61] For a discussion see: Tina Minkowitz, n 49.

[62] Robert Wilks, 'Transformative Equality', (*North of the Stupid Line: To Signify an Individual of Subnormal Intelligence and General Social Ignorance*, blog, 2017) [online], available at: <http://www.robwilks.com/2017/08/08/transformative-equality/> (accessed on 17 September 2018).

[63] So far, as Wilks explains, much focus is placed on how this model distinguishes itself from formal and other substantive equality models without realising that a robust equality framework incorporates all principles. Ibid.

[64] Hester Lessard, 'Book Review: Inclusive Equality: Relational Dimensions of Systemic Discrimination in Canada, by Colleen Sheppard', (2011) 49(1) *Osgoode Hall Law Journal*, 159–165.

[65] Colleen Sheppard, *Towards Inclusive Equality: The Relational Dimensions of Systemic Discrimination in Canada*, (McGill University Press, 2010), 147.

[66] Iyiola Solanke, *Discrimination as Stigma: A Theory of Anti-Discimination Law*, (Hart, 2017), 102.

[67] Marta Carneiro, 'Book Review: Inclusive Equality: A Vision for Social Justice by Sally Witcher', (2014) 16(4) *European Journal of Social Security,* 404–406.

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way, inclusive equality is an approach that combines the insights of all models preceding it. It builds on substantive equality approaches but also recognises that systemic discrimination, highlighted by anti-subordination models, must be tackled.[68]

According to Witcher, measures of success under inclusive equality are framed as both 'material and non-material', which involves 'having' as well as 'being able to do'.[69] Due to these alternative objectives, rooted in the subjective, inclusive equality as a model, is able to flexibly accommodate the differences inherent in the intellectual disability characteristic. Indeed, an inclusive model of equality does not presume certain levels of adaptability or ability on the part of the individual, thereby ruling out ineligible persons. Rather, inclusive equality seeks to include even those that may not meet the standards of ability and self-sufficiency previously required. Beyond its flexibility, inclusive equality is an approach according to which means and needs must be understood in the context of their socio-cultural determinants, making this approach perhaps more theoretical than practicable. Theorists, thus, also refer to inclusive equality as a definition of social justice, as it redefines an ideology that societies should collectively strive towards, stipulating greater social cohesion as a predetermined outcome.[70] Therefore, it has been claimed that inclusive equality suggests a new 'bottom line' for redistributive justice, prompting a fundamental re-evaluation of societal values, citizenship, and entitlement to rights.

5.2.3.1. Inclusive equality and the CRPD

Degener determines that the vision of equality pursued in the CRPD is based on inclusive equality as the treaty drastically re-engineers a vision of equality to achieve justice for people with disabilities.[71] Specifically, this vision is boosted by the human rights model of disability upon which the CRPD is based on (discussed further below). The CRPD, then, primarily aims to include all people with disabilities in all life situations within the same rights framework that others enjoy, thereby restoring their fundamental human rights.

Still a relatively new model, inclusive equality, was first introduced to theorise the CRPD's approach to equality in the latest General Comment interpreting Article 5, CRPD, on equality and non-discrimination. Besides referencing inclusion as a principle component therein, the CmRPD identify that preserving dignity is a central purpose of equality utilised in the CRPD. With the help of Fredman's model of transformative justice, the CmRPD illustrate that the CRPD's aim is to tackle inequality using multiple approaches:

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[68] Sheppard, n 65, 146.

[69] Sally Witcher, *Inclusive Equality: A Vision for Social Justice,* (Policy Press, 2013), 123.

[70] As a result, this approach overcomes a prevalent dichotomy of current equality approaches that target either groups or individuals with the potential of the interest of one negating that of the other. According to an inclusive model of equality, however, 'it is possible to universalise *and* individualise'. Marta Carneiro, 'Book Review: Inclusive Equality: A Vision for Social Justice by Sally Witcher', (2014) 16(4) *European Journal of Social Security,* 404–406. See generally: Sally Witcher, *Inclusive Equality: A Vision for Social Justice,* (Policy Press, 2013).

[71] Theresia Degner, 'A Human Rights Model of Disability' in Peter Blanck and Eilionoir Flynn, (eds.), *Routledge Handbook of Disability Law and Human Rights,* (Routledge, 2016).

(a) a fair redistributive dimension to address socioeconomic disadvantages;

(b) a recognition dimension to combat stigma, stereotyping, prejudice and violence, and to recognize the dignity of human beings and their intersectionality;

(c) a participative dimension to reaffirm the social nature of people as members of social groups and the full recognition of humanity through inclusion in society; and

(d) an accommodating dimension to make space for difference as a matter of human dignity.[72]

There is no doubt that both Fredman and Degener, in formulating their equality models, were influenced by the work of Nancy Fraser, who maintains that any theory of justice and subsequent equality model must be three-dimensional. This includes an economic dimension (redistribution of resources), a cultural dimension (recognition of rights of diverse oppressed groups), and a political dimension (entailing representation and democratic voice recognition).[73]

The inclusive equality approach identifies inclusion as a major principle in human rights law. Although it is a broad concept, inclusion is a valuable marker of equality and particularly applicable for people with disabilities, who so readily experience exclusion. Yet, whether or not all these elements translate into real change and are able to formulate intellectual disability equality remains to be seen. Moreover, the impact of this approach is further limited by whether or not States that were originally involved in drafting the CRPD, are convinced of the CmRPD's 'better' theory of equality compared to that in operation during treaty negotiations. Undeniably, as with any international instrument, there is an underlying question of jurisdictional legitimacy of the CmRPD's capacity to superimpose their views of equality upon States. Indeed, there are limits of law and legal imagination, but it is, nevertheless, important to explore the current understanding of the concept of equality utilised in the CRPD as it is a living document. Afterall, it is only through discussions, its interpretations and its implementation by certain actors, that the treaty is given meaning and becomes valuable. In fact, this will be discussed further in Section 3 of this thesis, where the CRPD's vision of equality and its impact on combating segregation in sheltered work are examined.

5.3 THEORETICAL LIMITATIONS OF EQUALITY MODELS IN ADDRESSING INTELLECTUAL DISABILITY

As described in the previous chapter, the main tenet of equality sought in the models briefly described above clearly reflects the liberal ideologies that underpin current human rights frameworks. This is evident in the way these models presuppose an interventionist state and

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[72] Theresia Degener and Marine Uldry, 'Towards Inclusive Equality: 10 Years Committee on the Rights of Persons with Disabilities', (2018) [online], available at:
<http://www.anffas.net/dld/files/rapporto_10anni_attività_comitato_onu_sui_diritti_delle_persone_con_disabilita_4sett_18.pdf>
(accessed on 19 September 2018).
[73] Nancy Fraser, *Redistribution or Recognition: A Political-philosophical Exchange*, (Verso, 2003).

the (recognised) autonomy of the individual to act.[74] In fact, equality law in the western, liberal tradition largely focuses on its subjects as independent individuals and the protection of their autonomy from state interference. However, equality measures that require recipients to be autonomous, self-reliant and self-efficient individuals effectually determine that people with intellectual disabilities are ineligible from the outset. People with intellectual disabilities, who are often denied the recognition of their capacity and the support to become active citizens, thus rendering them unable to act within these frameworks, are simply overlooked.

Moreover, traditional equality mechanisms have all, to an extent, encouraged a degree of conformity. The right to the protection of individual freedoms (e.g., of religion or sexuality) is based largely on a process of assimilation and compliant behaviour. A certain threshold of uniformity (in ability) must be demonstrated, to be accorded the right to deviate and be different and yet be considered equal. In brief, the right to be equal in our differences and have these respected clearly demands certain actions and levels of ability, reflective of the requirements of the social contract. Equality models based on this premise are then rigged in favour of a select, 'capable' few. Equality measures applied as a means to redress discrimination and other inequalities may then be beneficial in race, gender and physical disability cases but are ineffective in promoting equality for people with intellectual disabilities. Because they are deemed too different, or as Kliewer and Drake explain, because of their 'human variation', people with intellectual disabilities have been disregarded and treated as unequal and warehoused in institutions.[75] Undeniably, the road to respect for the difference of intellectual disability has been arduous. Minow refers to this struggle as the 'dilemma of difference', and some question, in light of such a strong requirement of conformity, to what extent people with intellectual disabilities will ever be considered equal.[76]

Besides the pressures of conformity, the equality mechanisms in operation present further limitations from an intellectual disability perspective.[77] Almost all existing models are fundamentally modelled around ability and an expectation of adaptability on the part of the individual. The use of affirmative action, for example, relies heavily on a normative framework, and particularly one that is centred on ability. Equality approaches thereunder then hinge upon traditional, value-laden accounts of 'merit' that are formulated based on intelligence and standards of achievement. Consequently, qualification for affirmative action, 'like qualifying for other socially-valued goods, is based on measurements of individual, technical competence, according to the normative meritocratic criteria of educational credentials and standardised testing'.[78]

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[74] The application of this conception of equality is not uncontested. Scrutiny from classical liberalism maintains that the distributive justice theory is contrary to liberal democratic thought as it imposes too high a burden on both actors. William A. Galston, *Liberal Purposes: Goods, Virtues, and Diversity in the Liberal State,* (Cambridge University Press, 1991). See Chapter 3 on 'Contemporary critics of liberalism'.

[75] Christopher Kliewer and Stephen Drake, 'Disability, Eugenics and the Current Ideology of Segregation: A Modern Moral Tale', (1998) 13(1) *Disability & Society*, 95–111.

[76] Martha Minow, *Making All the Difference: Inclusion, Exclusion and American Law*, (Cornell University Press, 1990); Jonathan Wolff, 'Cognitive Disability in a Society of Equals' in Eva Feder Kittay and Licia Carlson, (eds.), *Cognitive Disability and its Challenge to Moral Philosophy,* (Wiley-Blackwell, 2010).

[77] Brendan Pooran and Cara Wilkie, 'Failing to Achieve Equality: Disability Rights in Australia, Canada, and the United States', (2005) 20(1) *Journal of Law and Social Policy,* 1-34.

[78] Rioux, n 16, 82.

Operationalising equality through an entitlement based on merit, however, risks entirely omitting people with intellectual disabilities from the scope of the equality measure.[79] The pre-eminence accorded to merit in most equality models and the impossibility of qualifying that this creates for people with intellectual disabilities is recognised by Thornton. She describes that there is 'virtually no way that the intellectually impaired and the intellectually normal can ever be said to be similarly situated in respect of either employment or education'.[80] This is particularly the case where attaining merit-worthy attributes is, in fact, itself a matter of inequity, not least because the idea of merit is a loaded concept.[81]

A reliance on merit as the basis for achieving equality in this way enforces competitive individualisation, while serving the notion that power and positions should be vested in individuals according to their ability, measured intelligence, education and talent.[82] This runs the risk that only certain 'merit worthy' disadvantaged groups benefit from the preferential treatment of substantive equality models.[83] Effectively, these equality measures operate selectively, neglecting certain disadvantaged groups who remain largely excluded.[84] Subsequently, most equality approaches reproduce the existing hegemony, benefitting only those that demonstrate certain intellectual abilities.

Besides the limits of conformity and merit, a third major limitation of existing equality approaches, in the context of intellectual disability, stems from the design of instruments employed. Reasonable accommodation, for example, is an equality tool that is utilised particularly in employment and work-related contexts but presupposes a certain level of adaptability on the part of the individual to the 'normal' work process. As a highly individualised measure, it entails a tailored, reactive approach applicable to a specific situation.[85] Thereunder, individuals must be accommodated in a setting according to the notion that inequalities can be removed in this way. In practice, however, equalising the opportunities for people with intellectual disabilities in the workforce often requires substantive changes beyond those achieved thorough reasonable accommodation. Despite being a popular equality provision,

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[79] Wilton and Hall refer to this as the 'social and spatial organisation of work under capitalism' that is based on a non-disabled norm with the consequence that 'mainstream labour processes, work environments and organisational cultures privilege certain types of bodies and minds over others'. Edward Hall and Robert Wilton, 'Alternative Spaces of "work" and Inclusion for Disabled People', (2011) 26(7) *Disability & Society,* 867-880, 872.

[80] Margaret Thornton, *The Liberal Promise: Anti-Discrimination Legislation in Australia,* (Oxford University Press, 1990), 22.

[81] Rioux claims that this is because many equality approaches are still exercised on the basis of two traditional assumptions, making these unsuitable for people with intellectual disabilities. First, these assume that support in accessing status, wealth and position, as well as participation in the labour market should be conditional and based on merit. The second false assumption Rioux identifies is that this reliance on merit as a concept is impartial, and value natural, when it actually is anything but. Rather, decisions of merit are largely market driven and based on competency in terms of economic productivity and success. Rioux, n 16.

[82] Carol Bacchi, 'Policy and Discourse: Challenging the Construction of Affirmative Action as Preferential Treatment', (2004) 11(1) *Journal of European Public Policy,* 128-146; Craig Lerner, "Accommodations' for the Learning Disabled: A Level Playing Field or Affirmative Action for Elites', (2004) 57(3) *Vanderbilt Law Review,* 1043-1122.

[83] Bacchi, n 82.

[84] Cawley et al. have conducted an insightful study into the effect and impact of ability and meritocracy in economic terms. John Cawley, James Heckman, Lanc Lochner and Edward Vytlacil, 'Understanding the Role of Cognitive Ability in Accounting for the Recent Rise in Economic Return to Education' in Kenneth Joseph Arrow, Samuel Bowles and Steven N. Durlauf, (eds.), Meritocracy and Economic Inequality, (Princeton University Press, 2000). Rioux declares that the 'goals that are to be achieved in the individual-employer relationship must be rethought if the individual and extrinsic circumstances render the achievement of typical goals difficult. Often this means redefining the goal of work in ways that are foreign to market economy notions of work'. Marcia Rioux, n 16, 83.

[85] Peter Blanck, *Disability Rights,* (Ashgate, 2005).

reasonable accommodation has therefore had little bearing on the practical and systemic changes required, to include workers with intellectual disabilities in the open labour market.[86]

Owing to the requirements inherent in the social contract that underpin many legal frameworks, existing concepts of equality effectively associate worth with conformity, merit-worthy attributes and adaptability. As a result, equality measures remain 'founded in the nature of discrimination rather than in the ethical imperative of equality as a valued end in itself'.[87] Undeniably laws and policies have developed on the bases of these equality models to address obvious inequities, bringing some groups or individuals up to a 'perceived minimum standard'.[88] It can also be said that methods applied under substantive models of equality have generally contributed to the development of a rights-based approach to disability policies. However, their practical effectiveness in understanding the nature of intellectual disability specifically, and tackling the segregation of people with intellectual disabilities is limited. As a result, people with intellectual disabilities largely remain excluded on the margins of society.

Appreciating that people with intellectual disabilities might never fit into the meritocratic normative framework is, therefore, a first step in perhaps truly recognising the difference that intellectual disability poses and a fundamental argument for a new approach to equality. Reflective of this requirement and the need to formulate a more definitive approach to tackling the persistent inequalities that perpetuate the segregation of people with intellectual disabilities, in Chapter 8, this thesis devises a new intellectual disability equality model.

5.4 PRACTICAL IMPEDIMENTS TO EQUALITY

Throughout the evolution of equality, the conceptual shifts between formal and substantive approaches have failed to reflect on the intricacies of intellectual disability, deepening the material chasm in differences between the 'intellectual disabled' and the 'mentally competent'.[89] Besides the theoretical limitations of existing equality models, there are further limitations of a practical nature that warrant mentioning. These help us gain a full understanding of the experience of intellectual disability and how their segregation and exclusion have remained unaddressed by any wider societal mechanism (until now).[90]

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[86] Some projects have begun to address this. These are however sporadic and in their infancy. The range of reasonable accommodations available for particularly employees with intellectual disabilities is being thrashed out in the U.S.. Here, the Equal Employment Opportunity Commission are advising employers to look beyond the 'normally accepted and well-practiced ADA accommodations' to include accommodations more relevant for persons with intellectual disabilities specifically. Timothy Lindsay, 'Accommodating the Intellectually Disabled', (HR Professionals Magazine, 2016) [online], available at: <http://hrprofessionalsmagazine.com/accommodating-the-intellectually-disabled-2/> (accessed 23 September 2016). Rosemary Lysaght, Helene Ouellette-Kuntz and Lin Cheng-Jung, 'Untapped Potential: Perspectives on the Employment of People with Intellectual Disability', (2012) 41(4) *Work,* 409-422.

[87] Rioux, n 16, 85.

[88] Young and Quibell, n 18.

[89] Rioux, n 16, 81.

[90] Mike Oliver, 'Disability and Dependency: A Creation of Industrial Societies' in Len Barton, (ed.), *Disability and Dependency,* (Routledge, 1989).

Munyi explains that the reason for the on-going inattention paid to the intellectual disabilities characteristic in equality matters is largely because of the way disability is perceived.[91] All too readily, and rather than regarded as a product of economic, political and social conditions, when it comes to intellectual disability the values and assumptions underpinning law and policy still derive from perspectives that approach disability from a medical model perspective which emphasise individual pathologies and responses to combat these. Indeed, intellectual disability presents very specific challenges and barriers, both internally and externally, that impact on the equality claims of this group. Procedurally, for example, Minow describes that intellectual disability aggravates and distorts the straightforward application of equality principles to such an extent that courts have been reluctant to take on such cases.[92] Such hesitancy has resulted in a dearth of precedent-setting legal cases where aspects of intellectual disability equality are explored.[93] Rioux, on the other hand, declares that this dearth is rooted in the belief that people with intellectual disabilities have fewer needs and abilities essential for citizenship and the exercise of legal rights and, subsequently have no entitlement to equality claims.[94]

According to the principle of equal treatment, which underpins most equality and non-discrimination frameworks, people with intellectual disabilities can only establish such claims to the extent that they can approximate other citizens. As a result, there have been few, if any, cases where a person with an intellectual disability has bought a claim of wrongful discrimination in employment on the basis of disability where the comparator has been a non-disabled counterpart. Additionally, individuals with intellectual disabilities are often not in a position to make a claim, lacking support and the resources to do so. As a result, the concept of equality from an intellectual disability perspective (i.e. intellectual disability equality) largely fails to reach any legal arenas and is, thus rarely, thrashed out in these.[95]

Further causes of a practical nature have resulted in the limited bearing in the formulation of equality concepts by people with intellectual disabilities. Unquestionably, this group have had little influence over the development of equality because of the limited platforms on which they have been able to advocate for their equal rights. Again, the limited resources and supports available to this group play a role, but other factors also interfere here. In fact, disability advocacy has not always benefitted all people with disabilities equally. Rather, disability activism has generated internal, political struggles between groups, with some victories gained at the expense of others negatively impacting upon their rights claims. For example, people with

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[91] Chomba Wa Munyi, 'Past and Present Perceptions Towards Disability: A Historical Perspective', (2012) 32(2) *Disability Studies Quarterly*.

[92] Minow, n 76.

[93] Rioux and Riddle, n 1, 54; A general scoping exercise of cases involving persons with intellectual disabilities, found that often these fail based on the inadmissibility and concerns of the credibility of claimants. Constantin Cojocariu, 'Handicapping Rules: The Overly Restrictive Application of Admissibility Criteria by the European Court of Human Rights to Complaints Concerning Disabled People', (2011) 6 *European Human Rights Law Review*, 686-699; Eilionóir Flynn, 'Making Human Rights Meaningful for People with Disabilities: Advocacy, Access to Justice and Equality before the Law', (2013) 17(4) *The International Journal of Human Rights*, 491-510.

[94] Rioux, n 16, 68.

[95] Indeed, equality principles and their application in protecting other disadvantaged groups from discrimination in employment have been extensively interpreted and expanded upon by a bulk of case law on the subject. Comparatively few cases involving workers with intellectual disabilities are available. The only cases bought forward in Ireland, for example, involved claimants in sheltered workshops. Anecdotal evidence points to the fact that these were never adjudicated upon but instead withdrawn due to the claimants' lack of resources, Personal communication in an email with Niall Crowley former equality tribunal member.

physical disabilities' early advocacy work required claiming their equal rights by challenging false assumptions and dispelling the stigma of cognitive incompetence readily associated with disability at the time.[96] Clifford describes that early disability equality movements first needed to cast intellectual disability as a 'true' insufficiency to establish a contrast and a differentiation within the disability category.[97] In other words, the interests of one sub-group suppresses those of the other, inadvertently casting down those with intellectual disabilities in an effort by the physically disabled to set themselves apart from those that are 'truly different' and genuinely 'less equal'.

Further impediments to the equality claims by people with intellectual disabilities are tied to external, relational and political forces, similar to those experienced by all oppressed groups.[98] This is because the fight for equality as a form of social change has always been met with opposition. Just as there are proponents in favour of tackling the segregation of people with intellectual disabilities based on equality arguments, there are also opponents to this idea. Kliewer and Drake, for example, identify a so-called 'science of segregation' behind institutionalisation that originated with eugenics. This had the effect of imposing a 'technical rationalism' and 'professionally designed techniques' in disability services to control for difference. Accordingly, segregation in institutions such as sheltered workshops is seen as serving an important purpose of protecting wider society from social deviants, and acts to 'stigmatise, contain and eliminate [them] from the community'.[99] Challenges to this manner of control are considered anti-professional and, because professions are purportedly based on science, anti-scientific'.[100]

As noted above in Section 1, other voices, such as those with vested, industrial interests in the disability service sector, also campaign to preserve the segregated service system maintaining the exclusion of people with intellectual disabilities.[101] As part of a political and economic system, institutions contain built-in pressures for expansion. Substantial industrial and medical lobbies therefore argue for the continuation of segregated service provision by emphasising the dependency and protection needs of their clients. Arguments in favour of segregation are often underpinned by medical-model perspectives of disability as a condition that must be fixed, and economic concerns. These typically maintain the position that people with intellectual disabilities are inferior and that full desegregation is unrealistic.[102] According to this thinking,

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[96] For a discussion of disability movement politics see: Colin Barnes and Geof Mercer, (eds.), Exploring the Divide: Illness and Disability, (The Disability Press, 1996); Richard Scotch, 'Disability as the Basis for a Social Movement: Advocacy and the Politics of Definition', (1988) 44(1) *Journal of Social Issues*, 159-172.

[97] Stacy Clifford, 'The Capacity Contract: Locke, Disability, and the Political Exclusion of "Idiots"', (2014) 2(1) *Politics, Groups, and Identities,* 90-103.

[98] See, for example: Kathleen Lynch, 'Equality Studies, the Academy and the Role of Research in Emancipatory Social Change' (1999) 30(1) *Economic and Social Review,* 41-69; Rosemarie Garland-Thomson, 'Integrating Disability, Transforming Feminist Theory', (2002) 14(3) *Feminist Formations,* 1-32;

[99] Kliewer and Drake, n 75.

[100] Ibid.

[101] Hatton explains that, 'alongside discourses on human rights and self-determination for/by people with learning disabilities, there are still powerful, parallel discourses on segregated services' voiced by physicians and other professionals that 'know better'. Chris Hatton, 'If It looks like a Duck and Walks like a Duck... Winterbourne View and Institutions Redux', (*Chris Hatton's Blog*, 2013) [online], available at: <https://chrishatton.blogspot.com/search?q=segregated> (accessed 9 November 2018).

[102] Christie Hartley, 'Justice for the Disabled: A Contractualist Approach', (2009) 40(1) *Journal of Social Philosophy,* 17-36; David J. Connor and Beth A. Ferri, 'The Conflict within: Resistance to Inclusion and Other Paradoxes in Special Education', (2007) 22(1) *Disability & Society,* 63-77; David J Connor and Beth A. Ferri, 'Integration vs Inclusion- A Troubling Nexus: Race, Disability and Special Education', (2005) 90(1) *Journal of African American History,* 107-127.

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equality arguments applied to the topic of intellectual disability equality are simply irrelevant because full inclusion in society is undesirable and unnecessary given that entire industries (including institutions, sheltered workshops and day centres) are charged with their care.

In the fields of work and education, where equality has been debated the most, the matter of intellectual disability and inclusion even sparks controversy. According to opponents, the unsuitability of equality measures and the resulting exclusion of certain groups is not regarded as objectionable, based on the view that their inclusion may negatively impact upon others. The inclusion of workers with intellectual disabilities in the open labour market, for example, may pose health and safety risks for other workers. The inclusion of children with disabilities in mainstream education, it is feared, may disrupt the learning of other students.[103] More extreme opponents consider that including people with intellectual disabilities within the scope of existing equality measures would even have an adverse effect on justice, sacrificing one group's interests for the sake of another.[104] Accordingly, the right to inclusive education and the right of students without impairments to the best education possible collide and are framed as mutually exclusive.[105] These concerns, which have practical as well as, ideological ramifications, have yet to be comprehensively resolved but significantly undermine the formulation of intellectual disability equality.

Evidently, equality and intellectual disability do not easily coalesce. Adversaries query the relevance of equality considerations from an intellectual disability perspective on not only economic but also scientific grounds. In these cases, the difference of intellectual disability is emphasised and portrayed as insurmountable and potentially damaging to others, making the pursuit of equality through inclusion even less popular. The views of sceptics manifest themselves in a myriad of ways, whether overtly or subliminally, but have generally been successful in maintaining a status quo: the widespread segregation of people with intellectual disabilities in segregated (work) settings remains unchallenged.

5.5 CONCLUSION

Considerations of what is fair and just play a large part in the regulation of societies and are the foundation of any democracy.[106] This involves safeguarding the rights and freedoms of individuals on an equal basis, defining citizenship and who are rights bearers within this construct. Discourses in human rights law thus focus, to a great extent, on determining the meaning of equality. As a fluid concept, meanings attached to equality and its objectives have developed over time, shaped, in large part by social structures and related public debates. People with intellectual disabilities have not played any major part in this evolution, with their

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[103] Karen Burke and Candra Sutherland, 'Attitudes Toward Inclusion: Knowledge vs. Experience', (2004) 125(2) *Education*, 163-172.
[104] Rioux and Riddle highlight this example by referring to reports of complaints over allowing students with disabilities extra time in exams, a reasonable accommodation which arguably degrades the schooling system, disadvantaging non-disabled students. Rioux and Riddle, n 1, 54.
[105] John-Stewart Gordon, 'Is Inclusive Education a Human Right?', (2013) 41(4) *The Journal of Law, Medicine & Ethics*, 754-767.
[106] Jerome Shestack, 'The Philosophic Foundations of Human Rights', in Robert McCorquodale, (ed.), *Human Rights*, (Routledge, 2003).

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concerns rarely recognised as an issue for rights. Resulting equality instruments have been created in the absence of any awareness of the intricacies of the experience of intellectual disability.

While it has been relatively straightforward to show how formal equality so consumed with procedural equality is ineffective in achieving equality for people with intellectual disabilities, showing the limitations of substantive approaches requires more attention. Whilst substantive equality models do cast their net a little wider in terms of their scope and tangible ramifications, these approaches still contain inherent flaws, making their impact on the inequalities faced by people with intellectual disabilities negligible. Despite a range of instruments adopted under substantive equality models, people with intellectual disabilities remain ineligible and equality still elusive.

This chapter proceeded to introduce newer models that offer alternative concepts of equality, built on the premise that the very structures that cause inequality need to be dismantled. Anti-subordination theory, as one approach developed under this line of thought, tackles inequality by dismantling the social hierarchies between groups. Accordingly, equality cannot be achieved without challenging the oppressive structures that enforce the secondary social status of historically oppressed groups. Although this approach goes some way in identifying the disadvantages people with intellectual disabilities collectively face, an anti-subordination approach is largely ineffective in determining different outcomes. Aware of these limits, Fredman has designed an equality approach that is literally transformative. Fredman's 4-dimensional model of equality envisages multiple, varied tools to achieve equality and tackle systemic inequalities.

In interpreting the CRPD's equality implications, the CmRPD applies Fredman's transformative equality but adds an inclusive dimension. As a new and somewhat subversive model, inclusive equality is particularly relevant in determining an equality approach that includes people with intellectual disabilities. It is, therefore, of compelling interest in this thesis as, by its very definition, it aims to include people with disabilities within its remit, framing inclusion as a fundamental human rights principle. Despite this promising development, this chapter addresses impediments of a theoretical and practical nature that impact upon the formulation of equality for this group. These very real limitations must be addressed in any future intellectual disability equality model.

SECTION 2: CONCLUSION

Over the course of the previous 2 chapters, the intersections of intellectual disability, rights and equality have been explored. As part of this endeavour, I have traced the ways in which people with intellectual disabilities have been singled out and set apart from other citizens, beginning with their very eligibility for rights. The aim has, then, been to determine the origins of social segregation of people with intellectual disabilities by addressing their position in society. Overall, this section has revealed that the exclusion of people with disabilities is pervasive and deeply rooted in our modern, liberal conception of equality. As a result, certain groups are held to be fundamentally unequal and ineligible for equal treatment.

Despite promising developments, which see a widening of the conceptual foundations of equality, significant theoretical and practical barriers to formulating intellectual disability equality remain. Most models still expect a certain level of competency and functioning in the individual, to qualify for equality, and the models, are, thus, inconsequential for people with intellectual disability. As a result, existing approaches continue to neglect the specific experiences of inequality unique to the intellectual disability characteristic. Their segregation and exclusion in specialised services remain unaddressed from an equality perspective. As the CRPD purportedly operates according to the new model of equality, which is premised on inclusion, assessing its ability to rectify this, and to achieve intellectual disability equality is imperative. The next section will, therefore, consider the CRPD's vision of equality and its impact on people with intellectual disabilities in more detail, before examining its handling of, arguably, one of the most persistent and insidious forms of intellectual disability inequality: the practice of sheltered work.

SECTION 3: THE CRPD

Section 3 of this thesis is dedicated to understanding the approach to equality envisaged in the CRPD and its impact on people with intellectual disabilities. Chapter 6 finds that the extent to which the segregation and institutionalisation of people with intellectual disabilities can be tackled using the CRPD will ultimately determine its impact on the lives of persons with intellectual disabilities. Chapters 6 and 7 therefore proceed to explore the CRPDs position on sheltered work, as type of institution, using 3 resources, the negotiation achieves, the Concluding Observations adopted by the CmRPD and its General Comments.

Chapter 6: The CRPD and Sheltered Work

This chapter introduces the United Nations Convention on the Rights of Persons with Disabilities (2006), (hereafter, 'CRPD'), and considers how it instrumentalises equality to achieve its aims. Next, this chapter reflects on its impact on achieving intellectual disability equality. Having identified that the CRPD's true worth will lie in its ability to tackle segregation, the following part of this chapter begins to unpack its position on sheltered work as a prime example of insidious segregation. The chapter proceeds to introduce Article 27, on work and employment, as sheltered work is often discussed thereunder. Further, the impact of the CRPD's failure to specifically address sheltered work practices in the treaty text is examined, as well as the reasons behind this. These different strands of investigation are worthwhile as they reveal conflicting positions on the role of sheltered work settings, which ultimately impacts upon the CRPD's equality implications vis-à-vis sheltered work.

6.1   INTRODUCTION TO AND OVERVIEW OF THE CRPD

On December 13, 2006, the CRPD was adopted by the UN General Assembly by general consensus and came into effect in 2008 as the latest international human rights instrument.[1] It is said to be the fastest UN treaty ever negotiated and the first legally enforceable UN instrument geared toward the rights of people with disabilities, thus finally empowering the world's 'largest minority'.[2] The treaty draws on the landmark Universal Declaration of Human Rights (UDHR), as well as the most important UN human rights treaties, to re-formulate key provisions provided for within these, consequently making them applicable to people with disabilities.[3] Thus, the CRPD does not create any new rights, as in theory, all existing human rights instruments apply to all people, including people with disabilities. Instead, it interprets existing law and universal human rights documents from a disability perspective, reformulating existing international human rights norms using 'disability' language.[4]

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[1] UN General Assembly, Convention on the Rights of Persons with Disabilities, (13 December 2006), (A/RES/61/106), Annex I.
[2] Michael L. Perlin, ''There Must Be Some Way Out of Here'': Why the Convention on the Rights of Persons With Disabilities Is Potentially the Best Weapon in the Fight Against Sanism', (2013) 20(3) *Psychiatry, Psychology and Law,* 462-476.
[3] UN General Assembly, Universal Declaration of Human Rights, (10 December 1948), 217 A (III).
[4] Beauftragter der Bundesregierung für die Belange behinderter Menschen, ´UN-Behindertenrechtskonventions Koordinierungsstelle: Inklusionsbeirat und Fachausschüsse zur Umsetzung der UN-Behindertenrechtskonvention´, (Bundesministerium für Arbeit und Soziales 2010).

There is much debate on whether or not the creation of a disability convention was necessary, given the existing, expansive human rights system. After all, most human rights documents assert that all people are to be regarded as equal and that the specific rights set forth therein shall apply to all citizens, without discrimination of any kind.[5] As such, all three documents that comprise the International Bill of Human Rights (UDHR, 1948; International Covenant on Civil and Political Rights, 1966, (ICCPR); and the International Covenant on Economic, Social and Cultural Rights, 1966, (ICESCR)) are all applicable to people with disabilities, even in the absence of any specific references to disability.[6] This has been reaffirmed within the jurisprudence of most treaty bodies, and reporting on disability has become an inherent part of the universal periodic review system, whereby the implementation of all human rights obligations by States Parties is assessed at the Human Rights Council.[7]

However, while the legally binding UN treaties that preceded the CRPD may have included people with disabilities in their scope, this inclusion was subject to varying and inconsistent interpretation, determined on a case-by-case basis. As a result, only limited disability-related human rights claims had been acknowledged using these treaties.[8] Kayess and French emphasize this further by stating that not one of the three instruments comprising the International Bill of Human Rights recognised that the central concept of equality necessitates a specific consideration in the case of disability. When the CRPD was eventually adopted, it would be termed the harbinger of change, primarily because of its unique approach to (disability) equality.[9]

6.1.1 Vision of equality pursued in the CRPD

What spurred the development of equality in the context of the CRPD, most significantly, was a general consensus amongst the international disability community over a lack of protections afforded to people with disabilities at an international level. The Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, for example, noted that before the CRPD, compared to other vulnerable groups such as refugees, women and migrant workers, who all have an international legal instrument and treaty bodies dedicated to their protection, persons with disabilities were at a legal disadvantage.[10] This was because, there was no specific

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[5] See, for example: Preamble and Article 1, UDHR n 3.

[6] Article 25 UDHR does indeed mention disability, which provides that everyone has the right to an adequate standard of living and security in the event of disability.

[7] Common Wealth Forum of National Human Rights Institutions, 'The Universal Periodic Reporting Process: A Guide for National Human Rights Institutions', (2016), [online] available at: <https://www.upr-info.org/sites/default/files/general-document/pdf/nihrc_an_nhri_approach_to_the_upr_process.pdf> (accessed 31 January 2019).

[8] For further discussion of this see: Anna Lawson, 'The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?', (2007) 34(2) *Syracuse Journal of International Law and Commerce,* 563-619; Michael Stein, 'A Quick Overview of the United Nations Convention on the Rights of Persons with Disabilities', (2007) 31 *Mental and Physical Disability Law Repository,* 679-683.

[9] For more on this opinion see: Gerard Quinn, Lisa Waddington and Eilionoir Flynn, *European Yearbook of Disability Law*, Vol. 1-5), (Intersentia, 2009-2015).

[10] Theresia Degener and Yolan Koster-Dreese, (eds.), *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments,* (Martinus Nijhoff Publishers, 1995), 7.

body in charge of monitoring the respect for the human rights of disabled persons and acting, whether confidentially or publicly, when particular violations occurred.[11] Indeed, it is the very recognition that this was one of the inequalities and disadvantages that people with disabilities experienced that led to a general agreement that a disability specific instrument that employs a tailored vision of equality must be formulated and enforced at international level. This acknowledgement led to the sea change culminating in the adoption of the CRPD, prompting a new approach to disability policy.

Besides marking a paradigm shift in the way that disability is conceptualised, the CRPD marks a change in the way equality is framed at the international level in human rights law, and has been the subject of much scholarly debate. To Arnadóttir, the CRPD marks a definitive move away from a concept of formal equality to one that embraces a substantive, intersectional approach, which she terms, 'multidimensional disadvantage equality'.[12] Waddington on the other hand describes that rather than 'moving on' from a formal equality approach, the CRPD 'embraces both a formal approach to equality and a more substantive approach', based on how it utilises elements from both camps, (i.e. 'equal before and under the law' and substantive instruments such as reasonable accommodation and positive action).[13]

Considering the provisions that are listed therein in more detail then, the CRPD arguably utilises the most refined and tailored form of equality of all of the UN instruments. This is evident in the way equality is applied in all of its formats throughout the treaty, embracing broad, philosophical notions of autonomy, independence and respect for difference. Furthermore, the CRPD presupposes procedural equality, expressly refers to equality of opportunity and anticipates equality of results by aiming for participation and inclusion. Further evidence of the multiple facets of equality employed throughout the CRPD can be found in nearly every article which reiterates the requirement that the rights therein can be enjoyed 'on an equal basis with others', focusing on accessibility and participation as supporting mechanisms. Besides being principally addressed in its own, separate article, Article 5, Waddington illustrates that further references to equality and its mechanisms are 'sprinkled liberally' throughout the entire CRPD.[14]

The Convention repeatedly refers to the principle of equality in its Preamble, as well as its introductory Article 1 stating that its purpose is to ensure the full and equal enjoyment of all human rights by people with disabilities and promote their respect of their inherent dignity. A closer look at Article 3 reveals how the CRPD embraces

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[11] ILO, 'Decent Work for Persons with Disabilities: Promoting Global Rights in the Global Development Agenda' (2015), 38.
[12] Oddney Mjoll Arnardóttir, 'A Future for Multidimensional Disadvantage Equality?' in Oddny Mjoll Arnardottir and Gerard Quinn (eds.), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff, 2009), 41.
[13] Lisa Waddington, 'Breaking New Ground: The Implications of Ratification of the UN Convention on the Rights of Persons with Disabilities for the European Community', in Oddný Mjöll Arnardóttir and Gerard Quinn, (eds.) The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives, (Brill, 2008).
[14] Ibid.

perhaps the most novel, modern and dynamic conception of equality available at treaty level. Article 3 lists the general principles of the CRPD, illustrating the values and ideology of the treaty which include equality between men and women, equality of opportunity and other additional fundamental equality concepts such as (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; (b) Non-discrimination; (c) Full and effective participation and inclusion in society; (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; (f) Accessibility, (...).[15] Indeed, the CRPD embraces multiple approaches to achieve its equality mandate. Besides the broad principles listed in Article 3, the treaty also explicitly refers to practical policy tools to assist in achieving equality, such as reasonable accommodation, affirmative action, and other 'specific measures', laid out it its prescriptive Article 5 on equality and non-discrimination.

Article 5 of the Convention clarifies how equality for people with disabilities shall be achieved by clarifying States Parties obligations thereunder. First, the Article outlines that it is of fundamental importance that all persons are held to be equal. Article 5(1) declares that all persons are 'equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law'.[16] In fact, this aspect of equal recognition and treatment before the law is so essential that this is addressed in greater detail in Article 12, addressing equal recognition before the law. Next, Article 5 declares that States Parties must prohibit any form of discrimination on the basis of disability and guarantee all persons with disabilities equal and effective legal protection against discrimination on all grounds. This aspect of Article 5 must be cross-read with the CRPD's definition of discrimination. This definition is elaborated on in Article 2 and determines that any such definition must now expand to include, 'any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation'.[17]

Further equality provisions are outlined in Article 5(3) wherein it is specified that to promote equality and eliminate discrimination, certain tools and 'appropriate steps' must be taken, including the provision of 'reasonable accommodation'. In conjunction with such steps, Article 5(4) also clarifies that any actions taken, or specific measures adopted, are permitted where these aim to accelerate or achieve de facto equality of persons with disabilities, and are not considered as discrimination under the terms of the CRPD. The CmRPD has stated that such actions may 'imply a preferential treatment of persons with disabilities over others to address historic and/or systematic/systemic

[15] Article 3, UNCRPD, n 1.
[16] Article 5(1), UNCRPD, n 1.
[17] Article 2, UN CRPD, n 1.

exclusion from the benefits of exercising rights'.[18] Here, again it is important to cross-reference this section of Article 5 with the Article 2 definition of discrimination, wherein any actions targeted specifically at people with disability, while permitted in terms of their specificity, in their consequence however, may not lead to further exclusion on the basis of disability.

As is evident from this brief overview, the CRPD pursues equality by centrally addressing the concept of discrimination and suggesting substantive expansions and changes in anti-discrimination laws to ensure comprehensive protections for people with disabilities. The treaty pivotally broadens the concept of discrimination thereby expanding the protections granted to this group, in the context of international human rights law. As a result of wider changes to rights frameworks also spurred by the treaty, we see an emerging era marking a novel approach to disability. The CRPD has indeed encouraged the development of a new model of disability which, due to its conceptualisation in international human rights law, is referred to as the human rights model of disability. Degener, therefore, considers that the concept of equality in the CRPD is specifically moulded by, but also prompts the new human rights model of disability.[19]

6.1.2 The human rights model of disability

Throughout the CRPD negotiation, a social model view of disability became the consensus generating mantra, as most could agree on the increased onus that needed to be placed on society in ending the disenfranchisement of persons with disabilities.[20] As a result, many scholars describe that the CRPD is rooted in the social model of disability.[21] Degener however, identifies that the CRPD in fact goes further, and embraces a human rights approach to disability. This is not only because it introduces central aspects of human rights law to the subject of disability, but also because the CRPD is itself a legally binding document, unequivocally linking disability and human rights as subject areas. Degener elaborates on the human rights elements in the CRPD and examines these further.

First, Degener describes how in Article 3, the CRPD places disability upon the spectrum of human variation, rather than framing it as a deficit. In this light, ability and disability are to be regarded as fluid, social constructs. By recognising disability as an integral aspect of human diversity, the CRPD prompts a much deeper ideological shift in our

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[18] UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 6, (2018), Article 5: Equality and Non-Discrimination, 26 April 2018, (CRPD/C/GC/6), para. 25(c).
[19] As a current member of the CmRPD on the Rights of Persons with Disabilities and a legal scholar, Degener's commentary is considered the most relevant and authoritative interpretation of equality in the CRPD and provides the basis for further discussion. Theresia Degener, 'The New General Comment No. 6 of the UNCRPD on Discrimination', (Workshop Presentation, Berkeley Comparative Equality & Anti-Discrimination Law Study Group, 16 May 2018).
[20] Although not everybody at the negotiating table might have understood the theory behind the social model, it was nevertheless a popular approach as it provided an easy way to conceptualise disability as a social construct, thus setting the scene for the emergence of a rights-based approach.
[21] See, for example: Rosemary Kayess and Philipp French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities', (2008) 8(1) *Human Rights Law Review*, 1-34;

conception of humanity towards acknowledging that disability is a fundamental part of 'what it means to be human'.[22] The human rights model of disability then goes beyond the social model view of disability. While the latter is a theoretical construct, entirely focused on assessing external forces and their disabling effects, impacting on the individual, the former implies an actionable approach. Moreover, the human rights model of disability incorporates the experience of impairment, with all of its facets such as pain, fatigue, reduced life expectancy, and weaves this in to its construct. The human rights model is therefore, arguably, a truer, more holistic representation of impairment *and* disability.

A second aspect indicating the CRPD's incorporation of a human rights-based approach to disability is its recognition that disability may be only one of several layers of identity. Albeit timidly, the CRPD moves towards an acknowledgment of the effects of multiple discrimination and the need to address all aspects of individual identity. Degener laments that the CRPD only touches on the intersectionality dimension of discrimination in its Articles 6 and 7, where it addresses women and children with disabilities. Unfortunately, other cross-sectional characteristics, such as religion, sexuality and gender, are not explicitly addressed.[23] Indeed, intersectionality as an emerging theme in international human rights law is increasingly making ground as part of any comprehensive approach to protect and promote human rights effectively.[24]

A third indicator that the CRPD embodies a human rights model of disability is its unique recognition of the interdependence, interrelatedness, indivisibility and universality of rights, 'the extent of which has never been seen in a binding human rights instrument before'.[25] The CRPD acknowledges that for people with disabilities the enjoyment of rights may require added accommodation and supports but that all persons are inherently entitled to human rights. Stein explains, therefore, that some articles, 'at first blush, might look like newly created rights, but, in fact, are included for the purpose of clarifying the means through which other rights are culminated', to ensure all persons can equally enjoy these.[26] Access to supports, for example, thus becomes a rights issue and a bridge to the equal enjoyment of rights. The right to supports is essential for disability equality. Without this right one of the underlying

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[22] Bickenbach explains that 'we are all abnormal, disabled, impaired, deformed and functionally limited, because, truth be told, that is what it means to be a human being. Kudlik discusses disability and 'humanness' further: Christine Kudlik, 'Disability History: We need another 'Other', in Rod Michalko and Tanya Titchkosky, (eds.), *Rethinking Normalcy: A Disability Studies Reader*, (Canadian Scholar's Press, 2009), 31; Jerome Bickenbach, 'Minority Rights or Universal Participation: The Politics of Disablement', in Melinda Jones and Lee Ann Basser, (eds.), *Disability, Diversability and Change*, (Martinus Nijhoff, 1999), 114.

[23] Degener explains that the CRPD is one of the first international human rights instruments that specifically acknowledges intersectional discrimination, albeit predominantly with respect to gender.

[24] For more on intersectionality see: Gauthier de Beco, 'Protecting the Invisible: An Intersectional Approach to International Human Rights Law', (2017) 17(4) *Human Rights Law Review*, 633-663.

[25] Arstein-Kerslake poetically illustrates this interdependence of rights with the following metaphor: 'There is an acknowledgement that the protection of the individual within the colossal institutional legal and societal structures can only occur if there is a living, breathing arterial network connecting the rights and evermore pumping lifeblood between the rights in order to allow them to grow simultaneously – feeding off each other and providing nutrients to each other. Within this structure, each right nourishes the other, but simultaneously is struggling against the others for access to nourishment. The balance of the rights is an eternal war that is both confounding and essential to the growth of each right'. Anna Arstein-Kerslake, *Restoring Voice to People with Cognitive Disabilities: Realizing the Right to Equal Recognition Before the Law*, (Cambridge University Press 2017),15.

[26] Stein, n 8.

challenges in disability law and policy, cannot be combatted, and this challenge is the 'legacy perception' that impairment, impedes human rights agency.[27] The CRPD, then, impresses upon States Parties that human rights agency does not require the absence of impairment, nor is it premised on a certain ability to be afforded full human rights; instead, supports become an instrumental aspect of rights. This gives further effect to the universality principle of human rights, according to which these cannot be gained or taken away from individuals, or groups, based on their characteristics or social status, because human rights are universal.[28]

A fourth indicator that the CRPD is firmly rooted in the traditional principles of human rights law is its instrumentalisation of equality and non-discrimination principles. Indeed, Degener explains that it focuses specifically on these doctrines of human rights law because of a general consensus amongst negotiators that the new convention should not create new rights or 'special' rights for people with disabilities but, rather, reinforce existing rights and ensure that these can be enjoyed on an equal basis with the general population. The CRPD, therefore, places a strong emphasis on equality and non-discrimination as well-established, core elements of international human rights law, and enumerates almost all of its rights with reference to these principles.[29]

6.1.3 The CRPD – a typography of rights

Regarded in comparison with other UN treaties, the CRPDs most striking and novel feature is perhaps its comprehensive approach as it merges within it 'civil and political rights provided by anti-discrimination legislation with the full spectrum of social, cultural, and economic measures bestowed through equality measures'.[30] The effect of this combination of types of rights indicates an approach that is holistic: addressing issues typically regarded as 'secondary' to civil rights laws and placing these on a par with each other illustrates an understanding of how indivisible and intertwined rights are. While the idea that these rights are interlinked in this way is not necessarily new, the CRPD is, however, the first instance in which this idea is incorporated into a human rights document. The CRPD is, thus, famous for its merging of rights, creating articles that formulate 'hybrid rights' comprising civil, cultural and social elements, (such as Article 27 discussed below). This contingent relationship is particularly important for people with disabilities, and specifically for people with intellectual disabilities, who often require additional supports, such as accessible information or personal assistance, to exercise their civil rights.[31] In this way the CRPD reflects a vision of seeing the person, in their entirety, at the centre of any provision, indicating the realisation of the need to

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[27] Degener, n 19.
[28] For more in the universality principle in human rights law see: Dianne Otto, 'Rethinking the "Universality" of Human Rights Law' (1997) 29(1) *Columbia Human Rights Law Review*, 1-48.
[29] Degener, n 19.
[30] Stein, n 8, 680.
[31] For example, a civil right, such as the right to vote, cannot be enjoyed if other socio-economic rights are not fulfilled, such as the right to education or to accessibility, to be able to understand and participate in voting procedures.

be both protected from discrimination but also supported through affirmative action towards participation.[32]

Degener argues that this understanding that both sets of human rights (economic, social and cultural rights, and civil and political rights) are interrelated and indivisible is a novel feature of the CRPD's equality vision.[33] Perlin agrees that, indeed, this combination of rights is required to achieve 'authentic equality'.[34] Assessing whether this amalgamation and complex layering of rights works to achieve equality for all people with disabilities, will be assessed herein by considering the CRPD's impact on the problem of sheltered work.[35]

6.2   IMPACT OF THE CRPD

Since its entry into force in May, 2008, the CRPD has generated major discussions at international and national level about the impact it will have on States Parties and ultimately, on the lives of people with disabilities.[36] Despite being adopted over 13 years ago and the fact that the number of ratifications are rising steadily, the CRPD is still a relatively new introduction onto the legal landscape of many States Parties. Its long-term implications are yet to be identified.[37] Fully grasping the CRPDs' impact is, in fact, a topic worth investigating itself, as many different opinions exist regarding its legal significance for States Parties and its bearing on domestic legislation.[38] Ideally, legal scholars wish to see the legal provisions of an instrument like the CRPD seamlessly transposed upon the domestic legal order of states and interpreted correctly, resulting in solid, unambiguous and autonomous meaning. However, legal norms and their clarity are less peremptory when we set aside the existing international framework of well-established norms, such as the prohibition against torture or slavery, and enter the realm of more fluid constructs, such as that of socio-economic rights. Indeed, the CRPD mixes rights that are subject to immediate and progressive realisation with both negative and positive duties for States Parties, making an evaluation of its impact even more compelling.

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[32] Frédéric Mégret, 'The Disabilities Convention: Towards a Holistic Concept of Rights', (2008) 12(2) *The International Journal of Human Rights*, 261-278.

[33] Degener, n 19.

[34] Perlin, n 1.

[35] Arnardóttir, n 12, 66.

[36] At the time of writing, 177 States or regional bodies had ratified the Convention. For up to date information, see: <https://www.un.org/development/desa/disabilities/> (accessed 2 September 2019).

[37] Raymond Lang, Maria Kett, Nora Groce and Jean Francois Trani, 'Implementing the United Nations Convention on the Rights of Persons with Disabilities: Principles, Implications, Practice and Limitations' (2011) 5(3) *European Journal of Disability Research,* 207-220. Steinert et al. also identify a paucity of research about any achievements of the CRPD as much scholarship is still focused on providing an overview and its meaning. Christoph Steinert, Tilman Steinert, Erich Flammer and Susanne Jaeger, 'Impact of the UN Convention on the Rights of Persons with Disabilities (UN-CRPD) on Mental Health Care Research - A Systematic Review', (2016) 16(1) *BMC Psychiatry.*

[38] Some are optimistic as the CRPD's potential to create change while others are less convinced. Harpur is confident it will spark a new rights discourse, whereas West and Basser are less complimentary. Paul Harpur, 'Embracing the New Disability Rights Paradigm: The Importance of the Convention on the Rights of Persons with Disabilities' (2012) 27(1) *Disability & Society,* 1-14. Raelene West, Paul Ramcharan and Lee Ann Basser, 'Apparently We Have Human Rights to Health? Health and Human Rights Frameworks of People with Disabilities in Victoria', (2017) 23(1) *Australian Journal of Human Rights,* 24-41.

Importantly, the CRPD places general obligations on States Parties set out in Article 4, to repeal inconsistent laws and policies (Article 4(1)(b)), to enact new laws and policies where needed to give effect to the CRPD (Article 4(1)(a), to refrain from any action inconsistent with the CRPD (Article 4(1)(d)), to take all measures to eliminate discrimination (Article 4(1)(e)), and to mainstream disability (Article 4(1)(c)). All of these actions signify the dynamic change required by States Parties to give the CRPD meaning, suggesting practical processes of law and policy, beyond 'a passive genuflection of the CRPD's abstract principles'.[39] Exploring how progress towards achieving intellectual disability equality within the framework of the CRPD is envisaged warrants further attention.

6.2.1 Limitations of achieving equality 'on an equal basis with others'

At first glance, the CRPD is a human rights treaty that, in theory, applies to all people with disabilities, encompassing all types of disabilities. Article 1, for example, includes a comprehensive definition of 'persons with disabilities' that includes those who have 'long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.[40] While on paper, then, all the CRPD's provisions may include people with intellectual disabilities, covering many aspects and life situations, the practicality of this, however, warrants further attention.

As the most marginalised group within the disability family and, arguably, the most 'socially devalued minority group' *per se*, people with intellectual disabilities face many additional barriers to inclusion and participation.[41] These barriers interact to create particularly volatile situations and an increased risk of experiencing discrimination and disadvantage. Evans considers that while people with intellectual disabilities may be entitled to benefit from the CRPD, they are, however, 'frequently not well placed to gain from' it.[42] This is due not only to the nature of intellectual disability but, as I argue, also the ubiquitous institutionalisation and segregation of many people which present considerable, often unidentified, obstacles to inclusion and the enjoyment of rights. Closer scrutiny of the CRPD does indeed reveal that it was largely drafted with people

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[39] Gerard Quinn, Grainne de Burca, Lisa Waddington, Mark Bell, Anna Lawson, Michael Stein, Titti Mattsson, Luke Clements, 'Legal Memo: Segregation and segregated facilities as a *prima facie* form of discrimination. The Impermissibility of using the ESIF to invest in monies in long term care residential institutions for persons with disabilities', (2018) [online], available at: <https://enil.eu/news/segregation-and-segregated-facilities-as-a-prima-facie-form-of-discrimination/> (accessed 16 August 2019).

[40] Article 1, UNCRPD, n 1.

[41] Christopher Bennett and Adrian Coyle, 'A Minority with a Minority: Experiences of Gay Men with Intellectual Disabilities' in Victoria Clarke and Elizabeth Peel, (eds.), *Out in psychology: lesbian, gay, bisexual, trans and queer perspectives,* (John Wiley & Sons, 2007), 125.

[42] International Labour Organisation, 'Promoting Training and Employment Opportunities for People with Intellectual Disabilities: International Experience', (International Labour Organization, Employment Working Paper No 103, 2011), iii.

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with physical disabilities in mind.[43] This becomes evident when we consider that the leading phrase that runs through the CRPD, and underpins its human rights claims, is that these are to be provided to people with disabilities 'on an equal basis with others'.[44] At first reading, this phrase may seem undiscerning, except 'difficult interpretive questions' in the operationalisation of this dictum in relation to persons with intellectual disabilities arise.[45]

First, this implies that any and all promotion of human rights and the enjoyment of these must only be pursued to the level that they are granted to the wider population. In other words, if certain rights are denied to others on the basis of this comparative legal statute, denying these to people with disabilities is legitimate and will not be considered evasive. In fact, Quinn labels this 'conditional element of equality', which is heavily relied on in the CRPD, as a double-edged sword that is premised on a liberal understanding of rights. In other words, this element of equality presupposes that all persons are recognised as eligible, autonomous actors. On the one hand, this principle of equality may be interpreted progressively to ensure that people with disabilities have access to the same rights as the rest of the population; but, on the other hand, it may be interpreted conservatively so as to evade any obligations towards people with disabilities, where these do not exist for the general population.[46]

Secondly, the promise to ensure rights 'on an equal basis' with others suggests an inbuilt and predetermined limit on the efforts adopted and the necessary changes required to achieve this. States Parties may then interpret this phrase as referring to the efforts adopted in respect of disability equality that need only match those adopted for other groups. However, having examined the specific case of intellectual disability in relation to equality claims, we find that the difference it poses requires more than ensuring access, 'on an equal basis' to the same rights, but rather, a specific acknowledgment of the differences and the corresponding support required to achieve equality. Moreover, an acknowledgment is required both of the liberal ideals that underpin the construction of human rights frameworks and of how these need to be either rejected or redesigned for the specific purpose of achieving intellectual disability equality.

The CRPD is very much a product of its time, indeed, a response to the need to encourage the evolution of our interpretation and adaption of human rights. Our system of human rights protection has evolved considerably over time, in the realm of disability this is perhaps based on universalist approaches to the concept of equality.

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[43] Permitted that important Articles like Article 12 and Article 19, which address legal capacity and institutionalization- do cover important topics for persons with intellectual disabilities.

[44] The CRPDs focus on physical disability is perhaps most evident in Article 9 on the right to accessibility, for example. Thereunder, people with disabilities are entitled to access, on an equal basis with others, the physical environment, transportation and information and communications. A long list of means to achieve accessibility is listed out but omits any specific consideration of the multiple, alternative ways in which communication and information is processed and produced, besides promoting, 'other appropriate forms of assistance and support'. Article 9(2)(f), UNCRPD, n 1.

[45] Andreas Dimopoulos, *Issues in the Human Rights Protection of Intellectually Disabled Persons,* (Routledge, 2010), 67.

[46] Gerard Quinn, 'Centering People Over Their Own Lives, From Paper Rules to Action', (Summer School Centre for Disability Law and Policy, NUI Galway & Harvard Project on Disability, National University of Ireland, Galway, 2011).

Just as it would have been unthinkable that one day gay men would no longer face conviction and castration, a fate from which not even Britain's code-breaking war hero Alan Turing was exempt, so too was it unthinkable that the 'feeble-minded' might one day lay claim to the equal enjoyment of rights, formulate a right not to be segregated and demand the right to work on an equal basis with others.

However, I argue that simply an evolution of the concept of equality in theory is not enough. It must go hand in hand with a resolute cognisance of oppressive forces that have served to create the label and experience of intellectual disability. If the protections, rights and freedoms of the CRPD are applied without a realisation of the unique situation of people with intellectual disabilities, the interpretation of the fundamental phrase, 'on an equal basis with others' may do little to challenge the existing exclusionary practices. If States fail to unpack and comprehend the new vision of equality suggested within the CRPD by demonstrating an awareness of the harms of segregation, they may even use, or as Quinn claims 'abuse', the CRPD to rationalise existing exclusionary practices including segregated employment.[47] To Quinn, interpreting the phrase correctly will require an acknowledgment of reckonable differences between persons with disabilities, but runs the risk of invoking an objective interpretation of inequality akin to the Aristotelian conception of equality which requires that 'like persons be treated alike and that unlike persons be treated unlike'. Herein lies the biggest threat when it comes to States' interpretation of the CRPD. A robust understanding of equality as it is underpinned by liberal thought of the modern, western academy is pivotal to frame this discussion.

In fact, according to Reinders (discussed above), who connects liberalism and intellectual disability, the liberal convention attributes such a high value to social and political equality that it is often taken for granted and assumed to be a universal concept enjoyed and applied equally. As a result, however, Dimopoulos believes that often States, in their well-intentioned disability policies, are quick to over simplify what equality is, particularly in the case of intellectual disability. Presented with the difference and diversity of intellectual disability in terms of the cognitive skills and abilities presented Dimopoulos asks how then should the unlike be treated on a similar basis? Agreeing with Quinn, Dimopoulos is concerned that there is a real danger that the ratification process of the CRPD falls short of fully embracing the radical version of equality as suggested in the Convention and might more resemble 'putting new wine into old wineskins'.[48] A comprehensive and systematic review of the how the CRPD has been interpreted and has influenced policies and rights impacting people with intellectual disabilities, as a focus for a further study, would be of compelling interest.

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[47] Gerard Quinn, 'Resisting the Temptation of Elegance: Can the Convention on the Rights of Persons with Disabilities Socialise States to the Right Behaviour' in Gerard Quinn and Oddny Mjdll Arnardottir (eds.), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff, 2009).
[48] Dimopoulos, n 45, 35.

6.2.2 Identifying and combating segregation as a form of discrimination

Ensuring equality by achieving rights on an equal basis with others does indeed throw up important interpretive questions. Therefore, I suggest that a more appropriate means to consider the equality impact of the CRPD for people with intellectual disabilities lies in its ability to challenge their segregation, given the pervasiveness of this experience in their lives.

There is some evidence that the CRPD addresses the specific situation of intellectual disability using its equality tools. Most notably, its Article 12 on legal capacity and its Article 19 on independent living in the community directly address issues that people with intellectual disabilities struggle with specifically, namely the denial of their legal capacity and their institutionalisation in large group homes. These Articles poignantly address the power, control and protection paradigms that have been at the forefront of disability policy and recognise how these have operated to deny persons with intellectual disabilities a host of rights. Moreover, these Articles lay out the specific requirements needed to secure the rights of persons with intellectual disabilities, which signals that not only a different kind of equality is pursued in the CRPD but one that is built specifically on inclusion and participation. However, the issue of sheltered work is not explicitly addressed, risking the impact of the treaty in challenging the on-going practice of segregation. Indeed, while Article 19 has instigated a global de-institutionalisation movement we are yet to see any clear legal arguments that equates segregation in *all* types of institutions with discrimination.

Considered through the prism of the human rights model of disability, as outlined, above, the practice of sheltered work contradicts many principles embedded in the ideology distilled from international human rights law. This is further clarified when assessing the practice using the human rights model of disability. Segregated work practices represent a fundamental, ideological failure to accommodate human diversity and make all areas of human activity and life accessible to people with disabilities, who are, instead, removed from their communities. Rather than accepting disability as a natural variation of human functioning, it is treated as an anomaly to be contained via the artificial practice of segregation in professionalised services. Moreover, besides interfering with the universality principle of human rights law, and failing to ensure that every person has the same rights regardless of their characteristics, this form of segregation disproportionately affects people with intellectual disabilities and is, therefore, representative of how this group is held to be fundamentally less equal than others. Not only does segregation thus interfere with access to rights, but it also contradicts the principle of a shared, common human dignity and the right to an equal concern, and respect thereof, which is essential if these are to be enjoyed 'on an equal basis with others', as promised in the CRPD.

The matter of segregation is of further interest when considering that the CRPD possesses important tools to combat segregated practices such as sheltered work. Identifying and evaluating these are, therefore, essential when contemplating the impact of the CRPD on intellectual disability equality. For example, Article 2 of the

CRPD determines that any distinction and exclusion on the basis of disability that has the effect of nullifying or otherwise interfering with the rights enjoyment of persons with disabilities is to be regarded as a form of discrimination. As this discussion has already revealed, segregated practices such as sheltered work are distinctly designed and reserved for people with intellectual disabilities and are one of the direct causes of their exclusion and marginalisation, along with other serious repercussions (reports of exploitation and abuse are higher in segregated, institutional settings).[49] Therefore, there is an argument to be made that sheltered work potentially fulfils the definition of discrimination for the purposes of the CRPD.

Elsewhere, I argue that the segregation of people with disabilities is erroneously disregarded as a form of discrimination and, instead, framed as an inevitable consequence of disability, and remains largely unchallenged.[50] Indeed, Solis declares that segregation is a complex phenomenon that requires a multi-layered analysis that conceptualises and theorizes segregation as unjust and unfair.[51] After all, a caring and civilised society should be based on support and inclusion and not on marginalisation, exclusion, and segregation. I would add that especially in a society in which the CRPD exists, an ideological, systematic and legal challenge to segregation is overdue. Framing practices and policies that segregate and, effectively, exclude people on the basis of their intellectual disability as a form of discrimination is then perhaps one of the most important ways in which the CRPD might effect change in the lives of this group. After all, the CRPD is uniquely placed to encourage States Parties to reform and develop their domestic disability discrimination laws, acting as a signpost for the right direction in which these need to be headed.[52]

Many are enthusiastic about the 'ground-breaking' CRPD, also coined a 'declaration of independence for persons with disabilities throughout the world' by Quinn.[53] It will undoubtedly effect widespread reform, revolutionising disability policy across the globe, securing the rights of people with disabilities with unprecedented vigour.[54] Whether people with intellectual disabilities will, equally, reap the benefits and enjoy the fruits of this flagship initiative, in quite a literal sense, is subject to debate and perhaps not so easily determined. Dimopoulos, for example, is apprehensive and considers that 'it remains to be seen whether it will make a significant difference in the human rights protection of this group'.[55] Any assessment will require a look at the very

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[49] James A. Rosenthal, Janet Mot, Dorothy Edmonson and Victor Groze, 'A Descriptive Study of Abuse and Neglect in Out-of-Home-Placement', (1991) 15(3) *Child Abuse & Neglect,* 249-260; Ann Macfarlane, 'Subtle Forms of Abuse and Their Long Term Effects', (1994) 9(1) *Disability & Society*, 85-88, 85.

[50] Charlotte May-Simera, 'Reconsidering Sheltered Workshops in Light of the United Nations Convention on the Rights of Persons with Disabilities (2006)', (2018) 7(1) *Laws.*

[51] Santiago Solis, 'I'm "Coming Out" as Disabled, but I'm "Staying in" to Rest: Reflecting on Elected and Imposed Segregation', (2006) 39(2) *Equity & Excellence in Education,* 146-153.

[52] Dick Thornburgh, 'Globalizing a Response to Disability Discrimination', (2008) 83 *Washington Law Review,* 439-448; Charles Szymanski, 'The Globalization of Disability Rights Law - From The Americans with Disabilities Act to the UN Convention on The Rights of Persons with Disabilities', (2009) 2(1) *Baltic Journal of Law & Politics,* 18-34.

[53] Gerard Quinn, 'Closing: Next Steps- Towards a United Nations Treaty on the Rights of Persons with Disabilities' in Peter Blanck, (ed.), *Disability Rights,* 2nd edition, (Routledge, 2016), 519.

[54] See, for example: Arlene Kanter, 'The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities', (2007) 34(2) *Syracuse Journal of International Law and Commerce,* 287-322.

[55] Dimopoulos, n 45, 79.

practical changes the CRPD instigates, particularly ones that can be felt in the everyday lives of people with intellectual disabilities, making its impact tangible. Here, I have discussed how the practice of segregation in sheltered work contradicts the human rights model of disability envisaged in the CRPD. Framing the CRPD's impact in terms of its ability to tackle segregation is, therefore, a particularly apt means to assess its equality implications for people with intellectual disabilities. As a worthy exercise, the following will closely scrutinise the CRPD's bearing on sheltered work.

6.3   ARTICLE 27 ON WORK AND EMPLOYMENT

Little legal commentary or research that spans equality, sheltered work, and the CRPD exists, a fact that this study aims to rectify. Where academic literature linking these subject areas does exist, this is usually addressed in relation to Article 27, on work and employment. It is thus important to introduce Article 27 CRPD and discuss this article in terms of its implications for sheltered work and employment. In this respect, and for reasons that will become clear, it is equally important to look at what the CRPD has to say in this regard, and what it does not say.

Like other rights enumerated in the CRPD, Article 27 is not a new addition to the international human rights arsenal and it reflects many elements of existing international law on the right to work. Indeed, Article 27 is often referred to as a hybrid right as it utilizes both typologies of rights to promote and protect the rights of people with disabilities in work and employment.[56] Article 27 also amalgamates, and is therefore exemplary of how the CRPD generally, innovatively spans, civil and political rights with socio-economic rights. The use of both categories of rights already appears in the chapeau. Article 27 opens by obliging States Parties to recognise the right of people with disabilities to work, on an equal basis with others, in the same vein as the civil and political rights tradition.

The second main purpose of Article 27 is, then, to facilitate the interpretation of the right to work from a disability perspective and enable a more applicable formulation of its protections and benefits. The Article also articulates the equal right of persons with disabilities to the 'opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities', which is to be achieved progressively by adopting 'appropriate steps'.[57] Indeed, Article 27 is illustrative of how the CRPD imposes negative and positive rights duties to secure a solid rights framework for people with disabilities using a mixture of legal tools. Ventegodt summarizes and describes it thus:

> While the full realisation of equality or opportunities and the creation of a
> labour market that is open, inclusive and accessible is subject to progressive

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[56] Article 27(2), UNCRPD, n 1.
[57] Article 27, UNCPRD, n 1.

realization, the prohibition against discrimination on the grounds of disability is a civil and political right with immediate effect.[58]

Overall, the Article comprises 2 sections and 11 subsections and constitutes one of the most detailed provisions of the entire CRPD, establishing a legal framework of State obligations in relation to work and employment that is 'robust'.[59] Moreover, the Article is particularly prescriptive in how the right to work is to be guaranteed for people with disabilities, listing in its subsections the obligations that cover all aspects of working life and employment situations.[60] The first of these obliges States Parties to 'prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, (...)'.[61] Article 27 further urges States Parties to 'protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, and ensure workers with disabilities are able to 'exercise their labour and trade union right on an equal basis with others'.[62] States Parties must also enable access to technical and vocational programmes, and placements and training; promote employment opportunities in the labour market and assistance in finding obtaining, maintaining and returning to employment, as well as self-employment opportunities.[63]

Article 27 also clarifies that the right of persons with disabilities to work implies an obligation on States Parties to create enabling and conducive environments for employment in both the public and private sectors. This is of particular consequence considering that private-sector employers constitute the main provider of jobs in any market economy and have a responsibility to create a working environment that welcomes people with disabilities as employees. Article 27(i) provides that States must ensure that reasonable accommodation is provided in the workplace. Article 27(j) also urges States Parties to promote work experience on the open labour market, as well as 'vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.[64] Section 2 of the Article compels States Parties to 'ensure that persons with disabilities are not held in slavery or servitude and are protected, on an equal basis with others, from forced or compulsory labour',

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[58] Maria Ventegodt-Liisberg, 'Article 27 Work and Employment', in Valentina Della Fina, Rachele Cera and Giuseppe Palmisano, (eds.), The United Nations Convention on the Rights of Persons with Disabilities: A Commentary, (Springer, 2017), 502.
[59] Mario Fasciglione, 'Article 27 of the CRPD and the Right of Inclusive Employment of People with Autism', in Valentina Della Fina and Rachele Cera, (eds.), *Protecting the Rights of People with Autism in the Fields of Education and Employment*, (Springer, 2015), 146.
[60] The right to work has been codified in several international legal instruments, of which Article 27, on work and employment, is the most recent and comprehensive international standard. The right to work is made up of several interrelated rights; it is considered a fundamental human right chiefly because it ensures the individuals sustenance, dignity and well-being. Office of the United Nations Office of the High Commissioner for Human Rights, 'Thematic Study on the Work and Employment of Persons with Disabilities', (2012), (A/HRC/22/25), 5.
[61] Article 27(a), UNCRPD, n 1.
[62] Article 27(1)(c), UNCRPD, n 1.
[63] Article 27(1)(d-f), UNCRPD, n 1.
[64] Article 27(1)(j)-(k), UNCRPD, n 1.

evocative of the wording found in the ICCPR, specifically its Article 8 on slavery and forced or compulsory labour.[65]

6.3.1 Article 27 and sheltered work settings

As already noted, where sheltered work and the CRPD are discussed, this is typically in relation to Article 27, despite the fact that that the article fails to establish a clear link connecting its rights and protections with the practice of sheltered work. As a result of this omission a complex relationship between the two has developed which will be discussed further below. Besides, a failure to explicitly mention sheltered work or employment in the article, no reference to the practice can be found anywhere else in the CRPD. This is surprising given how prevalent sheltered work and employment is, and how established the rights to, and at, work are in existing international law.[66] However, as a discussion of the drafting sessions further below will reveal, it is clear that those who drafted Article 27 were aware of the controversies surrounding sheltered work and employment from an equality perspective. An awareness of this problematic is not only apparent in the discussions during the negotiations, but it is also evident if we pay closer attention to the wording of the treaty text.

Although Article 27 does not mention sheltered work, it is purposely broad in its scope. Notably, nowhere throughout its text does it specify that the suite of rights rely on the status of being defined as an employee or worker, (no reference is made to workers or employees with disabilities).[67] The only broad, guiding factor the CRPD provides for the interpretation is that the same rights must apply equally to people with and without disabilities and that discrimination must be prohibited with regard to, 'all matters concerning all forms of employment'. This is of particular interest in reference to sheltered work settings, where, often, participants are not regarded as workers or employees for the purposes of labour law and are subject to separate conditions with limited rights or means of redress. By design, Article 27 includes a broad spectrum of work settings under its protections. However, as a complex topic, the issue of rights in sheltered work settings is not as straightforward as merely declaring that these apply.

Further subtle indicators found in the treaty text are evident in the contrast envisioned by Article 27 between 'closed' and 'open' employment settings and the central role of inclusion. For example, States Parties must support the creation of a labour market that

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[65] Ilias Bantekas, Stefan Tromel and Facundo Pennilas, 'Article 27 Work and Employment' in Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou, (eds.), *The UN Convention on the Rights of Persons with Disabilities: A Commentary*, (Oxford University Press, 2018), 770. In this report, Bantekas et al. mistakenly refer to Article 9 ICCPR.
[66] GC No 5 by the CESCR, issued in 1994, already, in relation to the ICESCR in fact, quite starkly denounces the use of sheltered workshops as a meaningful employment option and raises serious human rights concerns in relation to their usage. UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 5: Persons with Disabilities, (9 December 1994, E/1995/22).
[67] Theresia Degener and Andrew Begg, 'From Invisible Citizens to Agents of Change: A Short History of the Struggle for the Recognition of the Rights of Persons with Disabilities at the United Nations' in Valentina Della Fina, Rachele Cera and Giuseppe Palmisano, (eds.), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, (Springer, 2017), 41.

is 'open, inclusive and accessible', ensure access to 'general' or 'mainstream' vocational training and promote the acquisition of work experience in the 'open labour market'. These small references are considered by Bantekas et al. as indicative of the type of employment envisaged by the drafters. [68] Therefore, while not leading to an explicit prohibition of sheltered work and employment, the text of Article 27 implies a preference for employment in open settings, as opposed to that occurring in 'closed' settings. Thus, researchers conclude that sheltered work, in fact, contradicts the principles of the CRPD and should no longer be promoted.[69] Interestingly, this is only one interpretation of Article 27 by academics in the field. On other occasions, the opposite has been stated, with others asserting that the CRPD does, in fact provide a legal basis in support of sheltered work and employment.[70]

Unlike Bantekas et al., who believe they have detected the drafters true intentions embedded in the text of Article 27, Dhanda considers that the drafters remained decidedly neutral on the subjectof sheltered work. Dhanda further explains that, as a result of this decision not to take a 'stand for or against' sheltered workshops, a 'host of other options' has been created in the absence of any legal clarity, advice or guidance.[71]

6.3.2 Different interpretations of Article 27 for sheltered work

Undeniably, as a result of not mentioning sheltered work in the CRPD, conflicting interpretations of its position on this have arisen. The European Disability Forum (EDF), for example, interprets that in a 'strict sense' sheltered work settings are not entirely abrogated by the CRPD. However, where these settings are, 'not transitory, but rather exist as workplaces where people work forever, then they are violations'.[72] Further, EDF explains that sheltered work settings themselves are not to be regarded as violations. Rather, the negative consequences for individual workers that result from placement therein, i.e. the lived experience of being in a sheltered workshop, where this amounts to isolation and segregation, is to be considered as contrary to the principles of equality, inclusion and participation of the wider CRPD. In other words, clarifications are required into whether sheltered work settings operate as transitional work environments that offer training and rehabilitation leading to open employment,

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[68] Bantekas et al., n 65, 772.

[69] Ibid.

[70] See, for example this report commissioned by the European Parliament where sheltered workshops are framed as a reasonable accommodation, as envisaged by the CRPD. European Parliament, Directorate General for Internal Policies, Policy Department A, Economic and Scientific Policy, Employment and Social Affairs, (Jacqueline Mallender, Quentin Liger, Rory Tierney, Daniel Beresford, James Eager, Stefan Speckesser and Vahé Nafilyan), 'Reasonable Accommodation and Sheltered Workshops for People with Disabilities: Costs and Returns of Investments - Study for the EMPL Committee, (IP/A/EMPL/2013-03, 2015).

[71] Office of the High Commissioner for Human Rights, 'Sub-Regional Meeting on Disability Legislation: Decent Work for Persons with Disabilities in Asia', (Organised by the ILO and OHCHR funded by the Government of Ireland, 2008), 14.

[72] Simona Girratano, 'Article 27 and beyond: A Rights Based Approach to Workers' (Dis)abilities' (Annual Conference on the Rights of Workers with Disabilities-Empowering Workers with Disabilities on the EU Labour Market: Legal Tools, Challenges and Best Practices, Academy of European Law, 2015).

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or whether these are permanent forms of work. Only in the case of the former is sheltered work not in violation of the CRPD.[73]

A further interpretation offered by the European Association of Service Providers for Persons with Disabilities (EASPD), links Article 27 rights with those listed in Article 26 on habilitation and rehabilitation. In their legal analysis, the EASPD identify that sheltered work settings present a challenge from a rights perspective. This is because sheltered work settings often fulfil more than one function for people with disabilities. Besides being a place of work and employment, these also offer rehabilitation services and serve some Article 26 objectives. This makes the question of their compliance with the CRPD a particularly sensitive issue, claims EASPD. The EASPD laments that all too often, however, sheltered work settings are solely discussed in relation to Article 27 rights, which neglects the fact that such structures have multiple functions and offer various types of support to workers.

Another interpretation of the CRPD by legal researchers reporting to the European Parliament regards that it 'provides a legal basis for sheltered workshops'.[74] In a report on 'Reasonable Accommodation and Sheltered Workshops for People with Disabilities', this research group interprets that sheltered work provides one means to fulfil the right to reasonable accommodation in the workplace, in accordance with the duties and obligations of the CRPD. This clear misinterpretation as to the purpose and legal concept of reasonable accommodation is illustrative of the numerous uncertainties and heterogeneous interpretations of the CRPD's vision of equality in practice.

Quinn and others elaborate on this problematic interpretation of equality in the CRPD and explain that, often, misinterpretations such as this one arise because it is thought that because people with intellectual disabilities have high support needs, they are, in fact, materially different relative to others. States are then thought to be obligated to respond to that difference by providing separate treatment or institutionalisation. This is, however, wrong-headed and a misleading interpretation based on orthodox discrimination law and theory which is surpassed by the CRPD, explains Quinn.[75] He argues that equality based on these views are, then, more likely to justify the creation of 'gilded cages' that entomb people forever, as often special treatment is absent of any dynamic toward real inclusion. Even if only temporary, special treatment in segregated settings can never be regarded as a reasonable accommodation because it does not address a particular functional need or provide the learning required for community inclusion. This follows the arguments, presented above, that the segregated service system is fundamentally flawed and unable to provide appropriate training or to adequately prepare people for 'open' work settings. Acutely aware of the use of this

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[73] Ibid.

[74] European Parliament, Directorate General for Internal Policies, Policy Department A, n 70.

[75] Gerard Quinn, Grainne de Burca, Lisa Waddington, Mark Bell, Anna Lawson, Michael Stein, Titti Mattsson, Luke Clements, 'Legal Memo: Segregation and segregated facilities as a *prima facie* form of discrimination. The Impermissibility of using the ESIF to invest in monies in long term care residential institutions for persons with disabilities', (2018), 8, [online], available at: <https://enil.eu/news/segregation-and-segregated-facilities-as-a-prima-facie-form-of-discrimination/> (accessed 16 August 2019).

rationale to justify institutions, the CmRPD address this frequent misinterpretation in a separate General Comment, which will be discussed in more detail below.

Ventegodt also provides an interpretation of the CRPD in relation to sheltered work. Because States Parties have immediate obligations under Article 27 1(a) to eliminate discrimination on the basis of disability in all matters and forms of employment, she notes that States Parties must immediately modify or repeal laws, policies or practices that discriminate on the basis of disability in the field of employment, whether intentionally or unintentionally.[76] Notably, this obligation to prohibit discrimination on the basis of disability affects 'all matters concerning all forms of employment'; this is an intentionally broad definition purposefully chosen to encompass all types of employment, including, according to Ventegodt, employment in sheltered workshops.[77] Ventegodt, therefore, concludes that the CRPD obliges States Parties to eliminate discrimination in employment, which includes discrimination in sheltered employment. Unclear here is whether this obligation is understood to apply *in* or *to* sheltered work settings, i.e. if States Parties must merely ensure non-discrimination in the sheltered work setting, or consider the work setting *itself* as a form of discrimination.

Clearly, the omission of any reference to sheltered work settings in Article 27 has resulted in different interpretations of the CRPD's text and, thus, its impact on sheltered work settings. However, the following discussion will explain that this was, in fact, a purposeful decision.

6.3.3 The use of silence in the CRPD

Considering that, as shown in Chapter 2, sheltered workshops and sheltered employment are popular policy, it is remarkable that Article 27 does not refer to them. However, it is even more surprising that neither are mentioned anywhere in the CRPD, especially considering the extent to which sheltered work and employment are addressed in other legal texts. Indeed, sheltered work and employment feature in a number of other international legal instruments, e.g. the European Social Charter, (revised version),[78] and ILO Conventions and Recommendations, and even in the UN Standard Rules on the Equalization of Opportunities of Persons with Disabilities, which is widely considered as the CRPD's predecessor.[79] Sheltered work and employment have

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[76] Ilias Bantekas, n 65, 770.

[77] Elsewhere Ventegodt classifies sheltered work as a form of affirmative action to promote employment equality. However, this should not lead to segregation and impose any limitations on persons with disabilities on the labour market. As has been discussed in Section 1, however, it almost always does. Ventegodt, n 58, 506.

[78] The European Social Charter is a Council of Europe treaty focused on economic and social rights which complements the European Convention on Human Rights' focus on civil and political rights. The original Charter, adopted in 1961, was revised in 1996. Article 15 discusses the right of persons with disabilities to independence, social integration and participation in the life of the community. Thereunder, Parties are to promote their access to employment through all measures, including by 'arranging for or creating sheltered employment according to the level of disability, (...)', (Article 15(2), European Social Charter (Revised) ETS. 163 3.V.1996.

[79] ILO Convention concerning the Vocational Rehabilitation and Employment, (Disabled Persons), 1983 (No. 159), which establishes Recommendations that, 'appropriate government support for the establishment of various types of sheltered

even been mentioned in international jurisprudence issued by other treaty bodies since the introduction of the CRPD. The latest General Comment by the Committee on Economic Social and Cultural Rights, (GC No. 23), for example, clarifies how the right to just and favourable conditions of work in Article 7 of the ICESCR applies to workers with disabilities. It states that while this group may require specific measures to enjoy Article 7 rights on an equal basis with others, under no circumstances, however, did that imply their segregation in sheltered workshops. [80]

According to Dhanda, the omission of sheltered work in the text of the CRPD is, however, purposeful, and it is therefore just as important to look at what is explicitly stated in the CRPD as well as what is not.[81] Indeed, it is important to appreciate the use of silence in international law generally as a deliberate tool often used to achieve an international consensus. In the case of the CRPD, where it became evident during its drafting that it would not be feasible to definitively ban the use of certain practices, for practical or political reasons, the text omitted any reference to sheltered workshops. This was to ensure that a consensus over the text could be reached and that disagreements over certain matters would not block its overall progress or even jeopardise the entire project.[82]

Dhanda asserts that the restraint in issuing any definitive stances or overly prescriptive versions of rights has in fact been beneficial in the 'transition phase' of the CRPD. Silences have created 'positive opportunities', and guaranteed a somewhat smooth and flexible adoption, allowing the CRPD to be tailored to domestic specificities. Of importance to note here, however, is that other scholars are less convinced of this more 'relaxed' approach to implementing the CRPD and argue that its silences have created a vague and toothless instrument of little legal consequence.[83]

Certainly, the interplay between silence and the text of the CRPD identified by legal scholars prompts a flexible application of the CRPD's reform proposals. While the use of silence can be a beneficial tool for implementation generally, the interaction between

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employment for disabled persons for whom access to open employment is not practicable', (Recommendation 11(b), ILO Vocational Rehabilitation and Employment Recommendation, (No. 168). Standard Rule No 7(7) says that for persons whose needs cannot be met in open employment, small units of sheltered or supported employment may be an alternative. UN General Assembly, Standard rules on the equalization of opportunities for persons with disabilities: resolution/adopted by the General Assembly, (20 December 1993, A/RES/48/96); Theresia Degener, 'Disability in a Human Rights Context', (2016) 5(3) *Laws*, 35–59.

[80] UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 23 (2016) on the right to just and favourable conditions of work, (article 7 of the International Covenant on Economic, Social and Cultural Rights), (7 April 2016, E/C.12/GC/23), para. 47(iii). The Author contributed to this General Comment via a written submission, available at: <https://www.ohchr.org/EN/HRBodies/CESCR/Pages/WrittenSubmissionsGC7.aspx> (accessed 5 April 2019).

[81] The use of silence is not only purposeful but also brings with it a 'creative potential', explains Dhanda, in terms of the interplay between that silence, the explicit text and the tangible opportunities created towards adopting the CRPD's principles. According to Dhanda, there has purposely been a silence regarding specifically sheltered workshops, and it is extremely important to appreciate why. Office of the High Commissioner for Human Rights, 'Sub-Regional Meeting on Disability Legislation: Decent Work for Persons with Disabilities in Asia', (Organised by the ILO and OHCHR funded by the Government of Ireland, 2008), 14.

[82] This approach was also used in Article 12, concerning legal capacity, where the CRPD refrained from any prescriptive reference as to how the right to equal recognition before the law should be designed to give it practical effect.

[83] See, for example: Eva Brems and Saïla Ould-Chaib, *Fragmentation and Integration in Human Rights Law*, (Edward Elgar Publishing, 2018).

what is and what is not said in the CRPD can also have negative side effects. In the absence of a clear position on sheltered workshops, a space is consequentially also created for regressive or other potentially undesirable developments. In the case of sheltered work setting, because the CRPD does not mention these, uncertainty has arisen as to whether the treaty can be interpreted as either in favour of or 'against' their use. As a result of this lacuna, 'the creative potential' of this silence, I would argue, has been exploited and used to justify these practices (a few examples of the myriad interpretations are listed previously). In fact, these interpretations are not arbitrary but, rather, easily made, given how preceding international instruments have been worded to legitimise sheltered workshops, explicitly referring to them as valid alternatives for people with disabilities. Undeniably then, where sheltered work and employment are propagated in the name of the CRPD, this is simply because its purpose and its legal tools are misunderstood.[84]

The silence over sheltered work settings has created a vacuum that has been filled with conflicting interpretations, and, as a result, sheltered work and employment continue to operate largely unchallenged. Indeed, the consequence of this silence has meant that the very topic of sheltered work has been afforded very little discussion. As a result, it has been difficult to find any literature or debates concerning the intersections between the CRPD's principles, the practice of sheltered work, and segregation. Little change, or only a very slow paradigm shift has trickled down into this area of service provision, and people with intellectual disabilities are, once again, the most marginalised at risk of benefitting least from disability reform. The side effect of silence has led to inertia at best, and uncertainty and misinterpretation at worst.

As the aim of this part of the thesis is to consider the impact of the CRPD for the purposes of challenging the segregation resulting from segregated work policies, this chapter will now proceed to examine the discussion during the drafting of the CRPD so as to reveal the drafters true intentions in relation to Article 27 and sheltered work settings.

6.4 DISCUSSION OF SHELTERED WORK DURING THE DRAFTING (TRAVAUX PRÉPARATOIRES)

In instances where the meaning of a treaty is unclear, as is the case in relation to the CRPD's implications for sheltered work, the authoritative Vienna Convention on the Law of the Treaties, (VCLT) provides that recourse may be had to supplementary means

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[84] This is most evident where, as indicated above, the CRPD is argued to provide a legal basis for sheltered work and employment as a form of reasonable accommodation. Not only does this, erroneously, propagate a notion that sheltered work settings are a valid means by which to ensure the right to work on an equal basis with others, but it also comprises a fundamental misunderstanding of the concept of reasonable accommodation. Researchers for the European Parliament claim that because the CPRD affirms the 'human right of people with disabilities to be offered the same employment rights as non-disabled people, (...), this provides a legal basis for sheltered workshops regardless of whether they are economically profitable, as is the case in Austria, Belgium, France, Germany, Greece, Ireland, Italy and Portugal'. European Parliament Directorate General for Internal Policies, n 70.

of interpretation, 'including the preparatory work of the treaty', for confirmation.[85] Specifically, Article 31 VCLT obligations on the rules of interpretation sets out that the treaty text must be interpreted in good faith in light of its objective and purpose, and taking its context into account. Arguably, in this instance, the treaty text is ambiguous and obscure, leading to unfavourable outcomes and resulting in misinterpretations of the CRPD, in discordance with the commanding norms of treaty interpretation established in the VCLT.

Due to the VCLT, it is generally accepted amongst international law scholars that the preparatory work contained in the negotiation archives, (referred to as the 'travaux préparatoires') are meaningful. These comprise a detailed reflection on the various provisions and are valuable sources of information, offering a wealth and breadth of information.[86] The travaux of the CRPD offer a snap shot of the current state of play in regard to disability law and policy generally, and depict the common views held on sheltered work. Furthermore, the travaux indicate that the very issue of whether to include a reference to sheltered work was debated feverishly during the drafting of the CRPD, right up until the final minutes before adoption.[87] Degener and Begg state this was because the shift in the ideology for service provision from segregation to inclusion was uncontroversial, as all could agree on the right of people with disabilities to be included in all spheres of life. With regard to education and employment, however, these debates were drawn out and no consensus could be reached.[88]

Moreover, in line with the findings from Section 1, an examination of the travaux signals that sheltered work settings are not uniquely problematic but a shared phenomenon common to many States Parties.[89] In fact, while many topics were addressed by delegates discussing the draft article on work and employment, almost every contribution noted in the travaux remarked upon the issue of sheltered work settings in some form. Given this frequency with which alternative forms of work were mentioned, it is even more surprising that no reference to these were included in the final text of Article 27. Regardless of this silence, or perhaps because of it, it is

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[85] Article 31, United Nations, Vienna Convention on the Law of Treaties, (23 May 1969, United Nations, Treaty Series, vol. 1155), 331.

[86] Moreover, these provide high-quality content based on the input by disability and international law experts, activists, academics, and government officials who came together on the unique occasion of discussion of a disability human rights treaty in an unprecedented manner and intensity. Alston and Quinn, for example, have signalled the relevance of looking to the Treaty negotiation archives in their discussion of States Parties obligations under the ICESCR. Philipp Alston and Gerard Quinn, 'The Nature and Scope of States Parties' obligations under the International Covenant on Economic, Social and Cultural Rights, (1987) 9(2) *Human Rights Quarterly*, 162.

[87] This highlights the discrepancies in approaches towards disability, ranging from paternalistic to inclusionist which not only reflects the political tightrope the Committee Chair had to walk, but features the exemplary role of silence in the CRPD. As noted above, this was used for political reasons, to avoid an impasse over certain contentious issues that could jeopardize the success of the whole CRPD. Elsewhere, the role of silence is used in Article 17 on personal integrity of the person, which is also a product of the drafting stages, and used to reinforce an implied prohibition against voluntary treatment in the CRPD, according to Weller. Penelope Weller, 'The Convention on the Rights of Persons with Disabilities and the Social Model of Health: New Perspectives', (2011) *Journal of Mental Health Law*, 74-84.

[88] Degener and Begg n 67.

[89] For example, the Committee on Economic, Social and Cultural rights had already addressed the problematic conditions of sheltered work in their legal commentary and jurisprudence, (see specifically their GC No 5 and GC No 23). The soft law instrument of 1993, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, as well as the many influential texts of the International Labour Organization, also reflected similar concerns about sheltered work.

worthwhile addressing the nature of the statements made on the matter in order to uncover precisely what the drafters' intentions were.

6.4.1 Different positions on sheltered work.

An examination of the negotiation archives reveals that the statements made in relation to sheltered work during the discussions can be, broadly, organised into three categories. The first category of statements is those made by delegations that wished to see the continued provision of sheltered work as a useful alternative to proper work. Largely, delegations that supported this idea also expressed the view that based on their lack of, or limited, capacity, some persons with disabilities would never be able to conduct meaningful and productive work and, therefore, sheltered workshops should continue to fulfil an occupational function, serving to protect people with intellectual disabilities. Namibia, for example, wished to see an obligation placed on States Parties to provide resources for alternative forms of employment for those, 'who may not have the capacity to work in the open labour market'.[90] Consequently, Bahrain, India and the Ukraine suggested that Article 27 should encourage the 'creation of workshops for persons with disabilities'.[91] The ILO agreed with this sentiment and spoke of a 'reality' that many people with disabilities are unable to work in the open labour market and thus work in protected workshops, which Article 27 should ensure are adequately resourced.[92] A coalition of National Human Rights Institutions concurred with this view because it considered sheltered work and employment to be amongst the varied measures that serve to ensure the right to work for people with disabilities, and Article 27 should, thus, allow 'space for the continuation of existing approaches that have been successful'.[93]

Aware of the controversial nature of sheltered work, the ILO nevertheless considered that the sheer size, variance and widespread support for the sector proved that this was an accepted practice and should be pursued as a legitimate means to ensure and fulfil the right to work, on behalf of States. Furthermore, the organisation argued that people with disabilities are not a homogenous group, but are individuals with unique differences which impact on their work motivation and job satisfaction. Therefore, the type of employment - whether open, sheltered, or supported - has a different meaning for each person and represents different values. Some might opt for work that best meets their social needs, rather than work that pays more but is less satisfying. Every

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[90] United Nations Enable, 'Proposed Changes to Draft Text - Namibia' (2004) [online], available at:
<http://www.un.org/esa/socdev/enable/rights/ahc3namibia.htm> (accessed on 7 April 2017).
[91] United Nations, 'UN Convention on the Rights of People with Disabilities Ad Hoc Committee Daily Summary: A Service Made Possible by Landmine Survivors Network' (2004) Volume 4, #7; UN Enable, 'Comments on the Draft Text: Draft Article 22: Right to Work' (2004) [online], available at:
<http://www.un.org/esa/socdev/enable/rights/wgdca22.htm> (accessed 17 April 2017).
[92] United Nations Enable, 'Daily summary of discussion at the third session, 3 June 2004', (2004) [online], available at: <https://www.un.org/esa/socdev/enable/rights/ahc3sum3june.htm> (accessed 11 April 2019).
[93] United Nations Enable, 'Daily summary of discussion at the sixth session, UN Convention on the Human Rights of People with Disabilities, Ad Hoc Committee - Daily Summaries, A service brought to you by RI (Rehabilitation International), (August 10, 2005), Volume 7, #8.

person has the right to the free choice of work, which should not be restricted to work 'to earn a living.[94] A singular focus on work on the open labour market thus risked omitting a large population who are, for whatever reason, not in it, explained the ILO.

The second and largest category of comments made by delegations reflected the position that under the CRPD, sheltered work should remain as a viable employment option for people with disabilities, provided these are subject to the full range of laws and regulations that apply on the open labour market.[95] Delegates that argued for this position considered that the realities of informal employment or sheltered work could not be ignored as this would only 'aggravate the precariousness of much of the work engaged in by many persons with disabilities, inhibit or discourage the creation of further such work opportunities, and increase the risk of exploitation'.[96] Those arguing for this position favoured approaches towards normalising and formalising the sheltered work setting by aligning its conditions with that of typical work settings and ensuring that these are governed by relevant legislation. Furthermore, delegates wished to see these developments increase the accountability of the private and non-profit sector since these are often chiefly responsible for such settings.[97]

Opinions differed, however, on the extent of this harmonisation of rules and whether this required a special reference in the final article. Israel considered the topic to be of such importance that it deemed an entire subsection of the article should be devoted to it, mentioning potential derogations from applicable legislation in instances of 'clear proof of reduced output' on behalf of the person with a disability.[98] It argued that it could not be ignored that much of work performed by persons with disabilities was *not* of economic value and was, thus, to be classified as 'only rehabilitative' and falling outside the remit of labour law. The EU disagreed and believed that mentioning alternative employment and any specific conditions or derogations might foster acceptance for lower standards for people with disabilities, with the effect of further solidifying the discriminatory treatment of persons in sheltered employment as compared to those employed in the open labour market.[99]

The International Disability Caucus (IDC) agreed that such an addition would perpetuate sheltered workshops and, 'effectively maintain separate standards'.[100] Instead, as an economic and social right, the right to work must be universally rooted

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[94] International Labour Organisation, 'Draft UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, Chair's Text, 7 October 2005 Provisions on Work and Employment, ILO Technical Advisory Note', (2006).

[95] The European Disability Forum believed that because sheltered work settings 'are a fact, and are helpful in accommodating some people with disabilities that have reduced productivity, thus enabling them to become a part of the labour market', Article 27 must urge States to take an active role in regulating 'non-integrated work settings'. UN Enable, (2004), n 91.

[96] Ibid.

[97] UN Enable, n 91; UN Enable n 92.

[98] UN Enable, 'Contribution by Governments. Israel. Israel Position Paper for the 7th Ad Hoc Committee - First Week', (2006).

[99] UN Enable, n 891; The ILO would later challenge, particularly, this contribution by the EU, arguing that it was contradictory because the EU, itself, pursued provisions that encouraged States to maintain and fund sheltered workshops through State Aid and Public Procurement laws.

[100] UN Enable, n 93.

in the principles of equality, accessibility, and the application of equal standards.[101] Sheltered workers should have the same rights as those who work in the open labour market, without separate standards to end their exploitation.[102] Other DPOs argued specifically for the inclusion of an 'equal pay for equal work provision' to end the economic exploitation rampant in sheltered work, where workers are 'paid token sums for actual productive work'.[103] Exploitation was indeed frequently referred to in the discussions.[104] Delegations, therefore, wished to see the final article take past human rights violations in sheltered workshops into account and suggested that drafters refer to Article 8, ICCPR (slavery and forced or compulsory labour) to counteract this legacy of exploitation associated with sheltered work.[105]

The travaux further reveal that a significant number of delegates wished to see sheltered work and employment mentioned in the CRPD to avoid the persistent confusion around the purpose of work. DPOs, in particular, called for clarity in regard to the otherwise blurred boundaries between rehabilitative, therapeutic and work activities. This is reflective of the concerns previously identified in Section 1 regarding boundaries and status which evidently continue to trouble these settings. It was argued that services that fulfilled hybrid roles required increased regulation because, all too quickly, 'what is called 'rehabilitation' is often 'busy-work' imposed on people in place of real opportunities to build the skills necessary for full social participation'.[106] To this end, the relationship between health care, rehabilitation and employment services needed to be addressed so as to prevent situations where, 'so called treatment programs, (...) actually keep people segregated from society'.[107]

The third category of comments can be grouped by their similarity in sentiment, namely that any form of segregation based on disability is no longer acceptable and that, consequently sheltered work and employment should not be mentioned in the CRPD. According to such views, sheltered work settings epitomise precisely the sorts of practices and rights violations that the CRPD is intended to outlaw. These contributions focused on the contentious history of institutionalisation generally, and how sheltered work denoted meaningless work, exploitative conditions and segregation.[108] Further, delegations that spoke out against segregation viewed sheltered work and employment as measures that limited, rather than protected the rights of

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[101] United Nations Enable, 'Daily Summary of Discussion at the Sixth Session 08 August 2005, UN Convention on the Human Rights of People with Disabilities Ad Hoc Committee - Daily Summaries, A Service Brought to You by RI (Rehabilitation International)' (2005), Volume 7, #5.
[102] UN Enable, n 98.
[103] UN Enable, n 101; UN Enable, 'Daily Summary of Discussions Related to Article 22 Right to Work' (2004) Volume 3, #6.
[104] UN Enable, n 101.
[105] United Nations Enable, 'Comments on the Draft Text: Draft Article 22: Right to Work' (2004) [online], available at: <http://www.un.org/esa/socdev/enable/rights/wgdca22.htm> (accessed 17 April 2017). These contributions are reflected in a dedicated sub-section in the final text of Article 27, (mirrored on Article 8, ICCPR) ensuring that 'people with disabilities are not held in slavery or in servitude and are protected on an equal basis with others, from forced or compulsory labour'. Article 27(2), UNCRPD, n 1.
[106] UN Enable, n 101.
[107] UN Enable, n 9101.
[108] International Disability Caucus, 'Article 22 Right to Work, prepared by the International Disability Caucus', (2004) [online], available at: <http://www.un.org/esa/socdev/enable/rights/documents/ahc6idcda22infosheet_000.doc> (accessed on 17 May 2017).

people with disabilities, wrongfully excluding them and fostering the harmful notion that they cannot be meaningfully employed.[109]

DPO (Disabled Persons Organisations) delegations feared that any mention of sheltered work or employment in the CRPD would legitimise them as a valid means of implementing the right to work of people with disabilities and potentially contribute 'to a permanent warehousing of persons with disabilities'.[110] The IDC would, in later contributions, call for the elimination of all forms of segregation in institutions, especially where these purported to fulfil the right to work.[111] Including sheltered work in the text of the CRPD, even if only to establish safeguards and rights for sheltered workers, would then be inconsistent with the overarching aims of the CRPD.[112] These comments being largely made by international DPOs - as opposed to State delegations – therefore, arguably, represented more accurately the views of people with disabilities on this subject.

As one of the only State delegations that explicitly spoke out against sheltered work practices, New Zealand noted that any support for so-called 'necessary alternatives' for people with disabilities leads to the 'very opposite of inclusion or equality'. The New Zealand delegation considered that the very idea that 'alternatives' need to be found for persons with more serious disabilities would only serve to shift the line of who may be discriminated against.[113] Moreover, it challenged Israel's position that some forms of work conducted by people with disabilities fell outside the remit of general employment laws and regulations, as this was a 'risky assertion' that paved the way for the continued exclusion of people with disabilities in sheltered work settings. Instead, Article 27 should be worded carefully, promote the inclusion of all people with disabilities and acknowledge the different levels and kinds of support needed to achieve this - which, after all, was the original purpose of the CRPD.[114]

Besides repeatedly speaking out against sheltered workshops, New Zealand addressed the on-going segregation of people with disabilities as a broader, persistent problem. The State highlighted the wider, historic segregation of people with disabilities as a detrimental legacy impacting on their rights.[115] Protecting people from segregation was

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[109] It was noted that views such as those expressed by the ILO declaring employment in the open labour market impossible for many people with disabilities represented particularly harmful attitudes which created further disabling barriers to rights and inclusion. Policies premised on such beliefs 'reduced the responsibility of State parties to support people with disabilities into open employment'.
[110] On the other hand, precisely because of this risk some delegates wished to include a clear reference in the Convention explicitly denouncing these so as to avoid any uncertainty regarding its position on them. UN Enable, n 92.
[111] UN Enable, n 98.
[112] Degener and Begg, n 67, 29.
[113] United Nations Enable, 'Daily Summary of Discussion at the Seventh Session 25 January 2006, UN Convention on the Human Rights of People with Disabilities Ad Hoc Committee - Daily Summaries, A Service Brought to You by Rehabilitation International (RI)' (2006), Volume 8, #8.
[114] Ibid.
[115] UN Enable, 'Daily Summary of Discussion at the Fifth Session 3 February 2005, UN Convention on the Human Rights of People with Disabilities Ad Hoc Committee - Daily Summaries A Service Brought to You by RI (Rehabilitation International)', (2005), Volume 6, #9.

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therefore imperative. The CRPD should, thus, be worded in a way that does not present States Parties with a choice between providing inclusive or segregated services.[116]

In summary, this collection and categorisation, of views presents a significant disagreement on whether sheltered employment should be addressed in the CRPD or not. These views diverged on the basis of delegates' support for and against these types of settings. Some delegations were against mentioning them because doing so risked legitimising the segregation and exclusion in them, while others, particularly the ILO and Israel, called for a need to accept the continued need for them and acknowledged the resulting requirement for their regulation.[117] Their contributions focused on the need for the application of employment legislation in an attempt to minimise the exploitation of sheltered workers, while others claimed that the experience of exploitation was interwoven into the very ideology of the practice, which was therefore a discriminatory act. Arguing for the application of employment legislation to sheltered work would further consolidate this type of discrimination and deny its institutional legacy.

Aware of the resulting impasse created by the issue of sheltered work during the negotiations, the Chair of the Ad Hoc Committee tasked with leading the negotiations asked delegations to consult independently to develop language that would address the concerns raised. The Chair defended the decision to finally refrain from including any reference to sheltered work and employment on the basis that no agreement could be reached. The many concerns raised, particularly over the fact that mentioning these could be interpreted as endorsing the segregation and separate standards for people with disabilities, also influenced this decision. Aware of the many different opinions, the Chair remarked that the particular issue of sheltered work required careful attention in the future and should be further reviewed, indicative of the ensuing state of confusion.[118]

6.5   CONCLUSION

With the introduction of the CRPD, people with disabilities are no longer marginalised in human rights law or seen as objects of charity, but as subjects of law. As rights holders, they are entitled to enjoy human rights on an equal basis with others. The CRPD is a holistic document that addresses a wide range of rights covering all aspects of life. It also includes a number of innovative features aimed at promoting positive law reform to protect the rights of people with disabilities. For example, it merges civil,

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[116] UN Enable, 'Daily Summary of Discussion at the Sixth Session 02 August 2005, UN Convention on the Human Rights of People with Disabilities Ad Hoc Committee - Daily Summaries, A Service Brought to You by RI (Rehabilitation International)', (2005), Volume 7, #2. Russia similarly spoke out against the segregation and institutionalization of persons with disabilities, who instead must be viewed as valuable members of society. UN Enable, 'Daily Summary of Discussion at the Fifth Session, UN Convention on the Human Rights of People with Disabilities Ad Hoc Committee - Daily Summaries A Service Brought to You by RI (Rehabilitation International)', (2005) Volume 6, #5.
[117] Degener and Begg, n 67.
[118] UN Enable, n 93.

political and socio-economic rights and imposes negative, as well as positive, obligations to respect, protect and fulfil the rights of people with disabilities, creating a robust legal framework.[119] Some scholars are, however, doubtful of the impact of the CRPD since it relies on conventional principles of international law, rooted in a typical, liberal understanding of people as independent actors before the law. From what has been discussed in Section 2, however, people with intellectual disabilities are typically considered as unable to attain certain standards to become eligible persons under law, thus threatening the CRPD's success in formulating intellectual disability equality. This chapter suggests that one means by which to assess the impact of the CRPD is by considering the extent to which it challenges segregation in sheltered work, given how the practise contradicts the human rights model of disability and represents a major, lingering form of inequality.

This assessment proceeds by exploring Article 27, as it deals with work and employment and sheltered work is typically discussed thereunder. Article 27 obliges States Parties to create an open, inclusive and accessible labour market where people with disabilities enjoy the right to work on an equal basis with others.[120] Precisely where sheltered work and employment fit in with this obligation is left open to interpretation, as neither is mentioned in the text of article, or anywhere else in the CRPD. As a result, different rights and obligations provisioned in the CRPD have been interpreted as either endorsing or rejecting sheltered work. The reason behind the omission of any reference to sheltered employment was, however, purposeful, as no consensus on these could be reached. Indeed, a look at the negotiation archives reveals the extent of the discussions on the subject, based on the diverging attitudes towards disability and institutions. Moreover, a review of the discussions during the drafting of Article 27 reiterates the many problematic aspects linked with the practice of sheltered work, highlighted in Section 1. The examination of the travaux in this chapter ultimately concludes that, even on the occasion of the high level discussions between international experts committed to securing and protecting the rights of people with disabilities, the issue of sheltered work, remained unresolved. As a result, incorrect, and even harmful interpretations of the CRPDs equality provisions relating to sheltered work have surfaced.

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[119] Asbjørn Eide devised a tripartite typology of states obligations. Asbjørn Eide, 'Obstacles and goals to be pursued', in Asbjørn Eide, Catarina Krause and Allan Rosas, (eds.), *Economic, Social and Cultural Rights: A Textbook,* (Martinus Nijhoff, 2001), 553-562.

[120] The Article outlines that the right to work comprises 'the opportunity to gain a living' and does not entail an absolute right to work, a matter discussed at length in other contexts. It is an indivisible, individual right that also has a collective dimension. Nonetheless, it can not be regarded as an absolute and unconditional right to obtain employment. Just like the right to health cannot prevent illness or guarantee good health, the right to work does not guarantee every person employment. Its main force lies in the multifaceted obligations it places on States Parties in terms of the requirements to fulfil the right to work as negotiated, formulated and expanded, overtime in international treaties. See, for example: Virginia Mantouvalou, (ed.), *Right to Work: Legal and Philosophical Perspectives,* (Hart Publishing, 2017).

Chapter 7: The CRPD in Practice: What Future for Sheltered Work?

To further explore the CRPD's impact on sheltered work, this chapter considers CmRPD jurisprudence. Communications from the CmRPD, under the various UN human rights mechanisms, are an important source in discerning the CRPD's tangible impact. Overall, the work of the treaty monitoring body plays a key part in the dialogue between States Parties and in generating international law. By considering the work of this treaty monitoring body, we learn how the CRPD interplays with domestic legislation to secure the rights of people with disabilities. Indeed, as a vital source for learning, the CmRPD's jurisprudence helps achieve traction between international monitoring and implementation to facilitate 'persuasion' and, 'socialisation' in order to harness the CRPD's potential for change.[1] This chapter first considers the Concluding Observations, uncovers some general trends and concerns in the employment of people with disabilities and presents the CmRPD's recommendations for sheltered work. As a result of the findings from the Concluding Observations, the CmRPD issued a General Comment addressing the equality and non-discrimination obligations of States Parties with specific reference to 'segregated work settings'. This chapter discusses a demand contained in this reference of the GC in more detail and evaluates the CRPD's potential to combat segregation as a form of intellectual disability inequality.

7.1 CONCLUDING OBSERVATIONS

The implementation of the CRPD is monitored by the Committee on the Rights of Persons with Disabilities (CmRPD).[2] The primary means by which the CmRPD fulfils this task is by examining the reports that States Parties to the CRPD are required to submit and by publishing Concluding Observations with recommendations to improve treaty compliance.[3]

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[1] Gerard Quinn, 'Resisting the Temptation of Elegance': Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?' in Oddny M. Arnardóttir and Gerard Quinn, (eds.), *The UN Convention on The Rights of Persons with Disabilities: European and Scandinavian Perspectives,* (Martinus Nijhoff, 2009), 220.

[2] A body of 18 independent experts who meet in Geneva twice a year. For more information on the composition and workings of the Committee see here: https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx

[3] States Parties are required to prepare reports outlining measures taken to implement the CRPD, (Article 35). Where States have ratified the Optional Protocol, the CmRPD also has the competence to examine complaints brought by individuals or groups, against their States concerning alleged violations of the CRPD. Guidelines on treaty-specific document to be submitted by States Parties under Article 35 (1), CRPD. Committee on the Rights of Persons with Disabilities, 'Working Methods of the Committee on the Rights of Persons with Disabilities Adopted at its Fifth Session, (11-15 April 2011), (CRPD/C/5/4), 14.

Much debate around the value of this process exists, questioning to what extent States Parties are obliged to consider the output of bodies in place to supervise the human rights treaties they have ratified.[4] Indeed, the precise status of Concluding Observations is difficult to determine and may vary between States. Some scholars believe these Observations carry 'enormous political and moral weight', becoming part of law-making processes, and assume quasi-judicial character.[5] O'Flaherty contend that they serve merely an advisory and recommendatory role with no powers to impose any legal obligations on States Parties, as treaty bodies have no judicial powers. However, in his extensive review of the legal status of Concluding Observations, O'Flaherty concludes that despite having no binding status for States Parties, as outputs of treaty bodies they carry notable authority.[6]

The reporting cycle is not only an international obligation but, also, prompts an internal review process, and encourages States Parties to monitor their own progress on human rights set forth in the CRPD, holding them accountable in an international forum. By issuing Concluding Observations, the CmRPD identifies areas of concern and provides an authoritative overview of the state of human rights in a given country, providing advice on how to systematically improve the state of these rights. Concluding Observations are, thus, a useful tool serving to support national policies and processes of law reform, and comprising a valuable mechanism for governance. The CmRPD has repeatedly used Concluding Observations as an important communication tool to make its position on sheltered work and employment known.

7.1.1 Concluding Observations of the CmRPD on Article 27

7.1.1.1 *General figures, low employment rate*

Concerning Article 27 rights and responsibilities, the CmRPD noted in practically all Concluding Observations, that the unemployment rates for people with disabilities was commonly higher than that of the general population.[7] The CmRPD also often remarked on the low numbers of people with disabilities in formal employment, along with correspondingly higher numbers of people employed outside the open labour

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[4] For a detailed discussion of the legal status, quality, impact and relevance of the treaty reporting process, please see: Michael O'Flaherty, 'The Concluding Observations of United Nations Human Rights Treaty Bodies', (2006) 6(1) *Human Rights Law Review,* 27-52.

[5] Diane Otto, 'Gender Comment': Why Does the UN Committee on Economic, Social and Cultural Rights Need a General Comment on Women? (2002) 14(1) *Canadian Journal of Women and the Law*, 1-53.

[6] This authority is most apparent in situations where the treaty body identifies violations of the treaties and where they otherwise purport to interpret treaty provisions. O'Flaherty explains that their authority is less clear where the treaty bodies provide general advice on strategies for enhanced implementation of a treaty, and when they opine on matters which seem to have little or nothing to do with the actual treaty obligations of the States Party. O'Flaherty, n 4, 36.

[7] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the European Union*', (2015), (CRPD/C/EU/CO/1), para. 64; Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the Czech Republic*', (2015), (CRPD/C/CZE/CO/1), para. 51; Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland*', (2017), (CRPD/C/GBR/CO/1), para. 56 (a).

market or in the informal sector.[8] The CmRPD noted with concern that almost a third of all employed persons with disabilities in the Czech Republic worked 'outside the open labour market'.[9]

The CmRPD also frequently observed that, amongst people with disabilities, it was particular groups that were less likely to be in employment. In their observations for New Zealand, for example, it noted with concern that the employment levels for, especially, Maori and Pacific people with disabilities, were still low.[10] In their comments for the Czech Republic,[11] Italy,[12] and the EU,[13] the CmRPD noticed that women with disabilities were more likely to be unemployed, as compared to the general population. Moreover, the CmRPD also noted that unemployment rates were higher amongst groups of people with intellectual and/or psychosocial disabilities, who were largely absent from the open labour market, (EU, Mexico, Latvia, Nepal).[14] Similar trends were observed in Senegal and Spain.[15]

7.1.1.2 Lack of employment provisions and national strategies

Often, the CmRPD considered that the low employment rate of people with disabilities was because of a lack of employment provisions made by States Parties. It noted considerably few policies or strategies were in place, including a general absence of comprehensive, national disability strategies in Oman,[16] Belgium,[17] and the United Arab Emirates.[18] Where some efforts to promote the inclusion of people with disabilities in the labour market are reported - in Columbia,[19] Mexico,[20] Italy[21] and Chile,[22] for example - the CmRPD lamented, however, that these have had little impact. Elsewhere, in

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[8] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Belgium*', (2014), (CRPD/C/BEL/CO/1), para. 38.

[9] (CRPD/C/CZE/CO/1), n 7, para. 51.

[10] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of New Zealand*', (2014), (CRPD/C/NZL/CO/1).

[11] (CRPD/C/CZE/CO/1), n 7, para. 51.

[12] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Italy*', (2016), (CRPD/C/ITA/CO/1), para. 69.

[13] (CRPD/C/EU/CO/1), n 7 para. 64.

[14] (CRPD/C/EU/CO/1), n 7 para. 64; Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Mexico*', (2014), (CRPD/C/MEX/CO/1), 51; Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Latvia*', (2017), (CRPD/C/LAT/CO/1), para. 47(b); Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Nepal*', (2018), (CRPD/C/NPL/CO/1), para. 39.

[15] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Senegal*', (2019), (CRPD/C/SEN/CO/1), para. 45(c); Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the combined second and third periodic reports of Spain*', (2019), (CRPD/C/ESP/CO/2-3), para. 50(a).

[16] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Oman*', (2018), (CRPD/C/OMN/CO/1), para. 48(a).

[17] (CRPD/C/BEL/CO/1), n 8, para. 5.

[18] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the United Arab Emirates*', (2016), (CRPD/C/ARE/CO/1), para. 49.

[19] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Colombia*', (2016), (CRPD/C/COL/CO/1), para. 44.

[20] (CRPD/C/MEX/CO/1), n 14, para. 51.

[21] (CRPD/C/ITA/CO/1), n 12, para. 69.

[22] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Chile*', (2016), (CRPD/C/CHL/CO/1), para. 57.

Moldova, for example, the criticisms were more structural and the CmRPD deemed the existing national employment strategy and its implementing agencies inadequate in facilitating and promoting the employment of people with disabilities.[23] The CmRPD urged Bulgaria and South Africa to adopt a policy framework and employment strategy to promote the employment of persons with disabilities in the open labour market.[24]

7.1.1.3   *Insufficient equality and non-discrimination legislation*

The two topics which attracted most attention in the State Reports in relation to the implementation of Article 27, are the provision of reasonable accommodation and the functioning of quota systems. In fact, it appears that these are the most widespread mechanisms employed to achieve equality in the context of work and employment. A review of the Concluding Observations reveals, however, that often the legal concept of reasonable accommodation is non-existent, misunderstood, or not regulated.[25] Quota systems along with other affirmative action measures, were often not fully utilised or understood, or were non-existent, along with other measures such as positive action.[26] The CmRPD noted a particular lack of quota systems that target the private sector and that, often, sanctions did not work.[27] It sought to clarify that reasonable accommodation, accessibility, and quotas are all measures that go hand-in-hand and must all be applied to ensure equality and protection against discrimination on the labour market, which the CmRPD found, and which is still rampant in most countries.[28]

7.1.1.4   *Classification of disability, ability and wage assessments*

A further aspect that caught the attention of the CmRPD when observing the implementation of Article 27 was the use of assessments and classifications of disability for the purposes of determining working 'capacity', 'fitness' or 'suitability' of persons

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[23] Committee on the Rights of Persons Disabilities, 'Concluding Observations on the Initial Report of the Republic of Moldova*', (2017), (CRPD/C/MDA/CO/1), para. 48.

[24] (CRPD/C/CHL/CO/1), n 22, para. 57.

[25] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the Dominican Republic*', (2015), (CRPD/C/DOM/CO/1), para. 50. Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the former Republic of Yugoslavia*', (2018), (CRPD/C/MKD/CO/1), para. 45(b); Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Paraguay, Adopted by the Committee at its Ninth Session, 15–19 April 2013', (2013), (CRPD/C/PRY/CO/1), para. 64; Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Haiti*', (2018), (CRPD/C/HTI/CO/1), para. 48(a).

[26] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of China, Adopted by the Committee at its Eighth Session, (17–28 September 2012)' (2012), (CRPD/C/CHN/CO/1), para. 41; Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Croatia*', (2015), (CRPD/C/HRV/CO/1), para. 42; Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Ukraine*', (2015), (CRPD/C/UKR/CO/1), para. 51.

[27] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the Plurinational State of Bolivia*', (2016), (CRPD/C/BOL/CO/1), para. 62.

[28] (CRPD/C/PRY/CO/1), n 25, para. 64; Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the Islamic Republic of Iran*', (2017), (CRPD/C/IRN/CO/1), para. 51(a).

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with disabilities.[29] In certain States, these led to concepts in law such as, 'not suitable for the open labour market',[30] 'unfit for work',[31] 'incapable for work',[32] 'working incapacity',[33] and 'unemployable'.[34] As a result of such labels, people with disabilities were segregated and largely excluded from the open labour market, according to the CmRPD; leaving many 'highly discriminated against as regards access to work'.[35] The CmRPD, thus, urged Sweden to assess the impact of terms like 'people with reduced capacities or limitations', in its legislation, and revise such concepts in accordance with the principles of non-discrimination contained in the CRPD.[36]

Expressing an overall discomfort with ability assessments, the CmRPD noted that Work Capability Assessment in Great Britain emphasised a functional evaluation of skills and capabilities, failing to recognize the interactions between impairments and barriers in society that create a disabling experience.[37] In its Concluding Observations for Serbia, the CmRPD was concerned with methods such as suitability assessments in operation, as these were reminiscent of the medical model approach, and equated disability with 'incapacity'.[38] Similar concerns were raised in the reports for Turkmenistan, Moldova and Malta, where the CmRPD also noted a considerable bias towards medicalised assessments.[39]

The CmRPD clarified that it deemed that the use of such classification as a discriminatory practice itself.[40] It took the view that such assessments often played on the stereotypes of people with disabilities and led to their further perpetuation, thereby preventing inclusion.[41] Classifications of this sort, similarly fostering disability stereotypes, but with a different effect, also caught the CmRPD's attention in China, where certain jobs are made available only to persons with certain disabilities, (i.e.

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[29] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Mauritius*', (2015), (CRPD/C/MUS/CO/1), para. 37; here the Committee noted that a large percentage of persons with disabilities are deemed, 'not suitable' for work.
[30] Ibid.
[31] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Gabon*', (2015), (CRPD/C/GAB/CO/1), para. 59.
[32] Union of Disabled People Organizations (UDPO), 'Implementation of the UN Convention on the Rights of Persons with Disabilities in Azerbaijan Submission to the CRPD Committee for Consideration for the List of Issues on Azerbaijan', (2013), 24.
[33] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Lithuania**', (2016), (CRPD/C/LTU/CO/1*), para. 51; Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Serbia*', (2016), (CRPD/C/SRB/CO/1), para. 55.
[34] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Turkmenistan*', (2015), (CRPD/C/TKM/CO/1), para. 41.
[35] (CRPD/C/MUS/CO/1), n 29, para. 37.
[36] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Sweden*', (2014), (CRPD/C/SWE/CO/1), para. 50.
[37] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland*', (2017), (CRPD/C/GBR/CO/1), para. 56 (c).
[38] (CRPD/C/SRB/CO/1), n 33, para. 53.
[39] Union of Disabled People Organizations, (UDPO), n 32, 24; The Advocates for Human Rights, 'Republic of Moldova's Compliance with the Convention on the Rights of Persons with Disabilities: Women and Girls with Disabilities', (2017), 10; Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Malta*', (2018), (CRPD/C/MLT/CO/1), para. 39(c); (CRPD/C/TKM/CO/1), n 34, para. 41; (CRPD/C/SRB/CO/1), n 33, para. 55.
[40] (CRPD/C/GAB/CO/1), n 31, para. 59.
[41] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Kenya*', (2015), (CRPD/C/KEN/CO/1), para. 47; Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the Philippines*', (2018), (CRPD/C/PHL/CO/1), para. 46(c).

'blind massage'). The CmRPD deemed that this practice of reserved employment, also found in Italy, 'discriminates against persons with disabilities in their vocational and career choices' and that States Parties must ensure that people with disabilities have the 'freedom of choice to pursue vocations according to their preferences'.[42]

In Australia and Korea, the CmRPD noted that working capacity assessments and classifications were used to assess the wages of employees, or to justify the exclusion of some workers from minimum wage legislation.[43] In Korea, the CmRPD was particularly concerned that the use of discriminatory wage payments saw the complete exemption of 'those who clearly lack the capacity to work', from the entitlement to a minimum wage, codified in law.[44] This law affected sheltered workshop employees in particular who, as a result, are compensated very little for their work, keeping them in poverty and segregated from the open labour market. In response to these findings, the CmRPD issued clear, unambiguous guidance. Australia should immediately discontinue the use of its 'Business Services Wage Assessment Tool' and 'productivity' tests,[45] and Korea should introduce a supplementary wage system to compensate those persons excluded from the benefit of the minimum wage law, and work towards eliminating sheltered workshops.[46]

Overall, the CmRPD repeatedly encouraged States Parties to re-evaluate the use of assessments and to eliminate outright the practice of classifying persons as incapable or unemployable. Instead, it urged the promotion and inclusion of people with disabilities in the open labour market, regardless of their disability or abilities.[47] The CmRPD routinely encouraged States Parties to develop and implement efficient strategies, in collaboration with representative organisations, aimed at increasing the employment rate of people with disabilities in the open labour market, and to invest in vocational training and 'appropriately adjusted workplaces, (...)', as opposed to sheltered work environments.[48]

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[42] (CRPD/C/CHN/CO/1), n 26, para. 41; (CRPD/C/ITA/CO/1), n 12, para. 69.

[43] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Australia, Adopted by the Committee at its Tenth Session, (2-13 September 2013)', (2013), (CRPD/C/AUS/CO/1), para. 50; The CmRPD learnt of the practice applied in Australian Disability Enterprises, where employees with disabilities' wages were calculated based on a Business Services Wage Assessment Tool, (BSWAT), developed by the Australian Government.

[44] The CmRPD thus expressed concern over Korea's Minimum Wage Act, not only for its discriminatory and exclusionary potential but also because it, 'fails to set clear standards for conducting assessments and making decisions to define the lack of capacity to work'. Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the Republic of Korea*', (2014), (CRPD/C/KOR/CO/1).

[45] (CRPD/C/AUS/CO/1), n 43, para. 50.

[46] The Committee did not to urge the State to review its Minimum Wage Act, which is surprising considering that this act evidently contains discriminatory provisions contrary to the CRPD; and it is even more surprising if we consider that the CmRPD would later call upon the Czech Republic to ensure the 'same wage for all persons with disabilities, regardless of their disability classification'. (CRPD/C/KOR/CO/1), n 44; (CRPD/C/CZE/CO/1), n 7, para. 51.

[47] (CRPD/C/SRB/CO/1), n 33, para. 55; (CRPD/C/TKM/CO/1), n 34, para. 41.

[48] (CRPD/C/LTU/CO/1*), n 33, para. 52.

7.1.1.5   Sheltered work

In regard to sheltered work, the CmRPD noted the prevalence of sheltered work practices across many States Parties, which contributed to significant 'gaps in the participation of persons with disabilities in the open labour market'.[49] The existence of sheltered workshops was cited as a major barrier to the inclusion of people with disabilities in the regular, open labour market in Cuba.[50] In regard to the report from Turkey, it noted that discriminatory policy on the basis of impairment, promoted sheltered workplaces.[51] The CmRPD also observed that because many people with disabilities are employed outside the regular labour market, their employment is subject to different conditions. In some reports, the CmRPD, therefore, considered that workers in sheltered workshops were at risk of exploitation, and that these environments were not in keeping with the spirit of the CRPD. It also observed that limited efforts to transition people with disabilities onto the open labour market existed, and offered practical advice on how to facilitate transition processes from sheltered models to open employment. Surprisingly, the CmRPD only referred to supported employment as an alternative on a single occasion.[52]

The CmRPD noted in many Concluding Observations that States Parties retained a 'specialized' and segregated employment model' to employ people with disabilities (i.e. Bolivia, Brazil, and Luxembourg).[53] In its observations for Canada,[54] the CmRPD highlighted the intersectional element of segregation, noting that, women and young people with disabilities, particularly, remained in sheltered workshops. The CmRPD explained in its observations for Slovenia[55] that these promoted a charity approach to disability, and particularly preserved the segregation of people with intellectual disabilities in the labour market, labelling them as 'unemployable'. Generally, the CmRPD observed a trend towards an increase in placements in Bosnia Herzegovina, and counted 19,000 people with disabilities employed in sheltered workshops in Austria.[56]

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[49] (CRPD/C/IRN/CO/1), n 28, para. 50.

[50] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Cuba*', (2019), (CRPD/C/CUB/CO/1), para. 45.

[51] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Turkey*', (2019), (CRPD/C/TUR/CO/1), para. 52(a).

[52] (CRPD/C/UKR/CO/1), n 26, para. 51.

[53] (CRPD/C/BOL/CO/1), n 27, para. 61; Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Brazil*', (2015), (CRPD/C/BRA/CO/1), para. 48; Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the Luxembourg*', (2017), (CRPD/C/LUX/CO/1), para. 46.

[54] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Canada*', (2017), (CRPD/C/CAN/CO/1), para. 47.

[55] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Slovenia*', (2018), (CRPD/C/SVN/CO/1), para. 45(a).

[56] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Austria, Adopted by the Committee at Its Tenth Session, (2–13 September 2013)' (2013), (CRPD/C/AUT/CO/1); Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Bosnia and Herzegovina*', (2017), (CRPD/C/BIH/CO/1), para. 47. It is assumed that this observation by the CmRPD was based on the shadow report submitted. International Disability Alliance, 'The Alternative Report on implementation in Bosnia and Herzegovina of The United Nations Convention on the Rights of Persons with Disabilities', (2016) [online], available at: <http://www.internationaldisabilityalliance.org/resources/alternative-report-crpd-implementation-bosnia-and-herzegovina-2016> (accessed on 26 October 2019).

Reporting on the situation in Lithuania, the Committee expressed 'serious' concern at the 'singular focus on segregated work environments', and EU funds being used to maintain and finance these institutions.[57] In Portugal, the CmRPD lamented that often the only employment opportunities for people with disabilities was in an Occupational Activity Centre.[58] The prevalence of sheltered workshops as a means to employ people with disabilities in Slovakia,[59] Serbia,[60] Poland[61] and Moldova[62] also caught the CmRPD's attention, and it noted that in Iran people with disabilities also largely remained secluded in sheltered workshops.[63] The manifestation of a segregated labour market in Germany particularly concerned the CmRPD. These created financial disincentives, it alos noted, that discouraged people with disabilities from leaving the sheltered sector and were thus directly responsible for 'preventing their entry or transition to the open labour market'.[64]

On several occasions where the CmRPD commented on the use of sheltered workshops by States Parties, it provided more details and elaborated on its concerns. For example, it often cited that minimal wages or low forms of payment received by people with disabilities as being problematic. In sheltered workshops operating in Austria, the CmRPD observed that workers received 'very little pay', and it was alarmed about the practices in Portuguese centres, noting in particular the working conditions and the average wage received by workers with disabilities.[65] In its report to Norway, the CmRPD encouraged the State to 'ensure the achievement of full and productive employment and decent work for all, (...) and equal pay for work of equal value'.[66]

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[57] (CRPD/C/LTU/CO/1*), n 33, para. 51. For more information on how EU funds are used to support institutions, see: Neil Crowther et al., 'Opening up communities, closing down institutions: Harnessing the European Structural and Investment Funds', (2017) [online], available at:
<https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/CLE-SFW_Opening-up-Communities-November-2017_FINAL-.pdf> (accessed on 31 July 2019).
[58] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Portugal*', (2016), (CRPD/C/PRT/CO/1), para. 51.
[59] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Slovakia*', (2016), (CRPD/C/SVK/CO/1), 73.
[60] (CRPD/C/SRB/CO/1), n 33, para. 56.
[61] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Poland*', (2018), (CRPD/C/POL/CO/1), para. 47(b).
[62] (CRPD/C/MDA/CO/1), n 23, para. 48.
[63] (CRPD/C/IRN/CO/1), n 28, para. 50.
[64] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Germany*', (2015), (CRPD/C/DEU/CO/1), para. 49.
[65] (2017) (CRPD/C/AUT/CO/1), n 56; (CRPD/C/PRT/CO/1), n 57, para. 51. The CmRPD made these observations on the basis of information from the alternative report submitted by the Austrian National Council of Persons with Disabilities (OEAR). It its report, the OEAR describe that in sheltered workshops, workers activities are 'not considered paid work even though the persons go to work on a regular basis, work on or with machines and produce products or provide services, in some cases also in outsourced groups at companies. Instead of paid work, these activities are perceived as measures of the regions, (...). Persons at day and employment structures are not insured against unemployment and do not receive wages (based on collective agreements) for their work. They only receive a small pocket money that sometimes is less than 10 EUR a month. The legal regulations about employee protection, paid leave and sick leave, employee provision schemes and labour relations (e.g. trade union representation) do not apply'. Austrian National Council of Persons with Disabilities, 'Alternative Report on the implementation of the UN Convention on the Rights of Persons with Disabilities in Austria', (2013) [online], available at: <https://www.behindertenrat.at/wp-content/uploads/2018/07/OEAR-Report_En2013_final_lang.pdf> (accessed 26 October 2019).
[66] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Norway', (2019), (CRPD/C/NOR/CO/1), para. 42.

In the CmRPD's observations for Hong Kong, it considered the use of sheltered workshops by the State in its remarks on the implementation of Article 16 (Freedom from exploitation, violence, and abuse).[67] The CmRPD deemed that the 'daily allowance for persons with disabilities in shelter [*sic*] workshops to be too low and bordering exploitation'.[68] The CmRPD recommended that Hong Kong, 'enact legislation to raise the daily allowance for persons with disabilities in sheltered workshops, so as to prevent their exploitation'.[69] Similarly, in Korea, the CmRPD was concerned that sheltered workers were labelled as 'lacking capacity to work' under the Minimum Wage Act, and they were, therefore, ineligible to qualify for the minimum wage. The CmRPD urged Korea to introduce a supplementary wage system to compensate those excluded from the minimum wage, as this was not in line with the CRPD.[70]

Clearly unhappy with these trends and problems with sheltered work practices, the CmRPD used the occasion of the Danish report to clarify that its preference was for open, formal employment for all people with disabilities. Specifically, it explained that it wished to see the State Party 'take all necessary measures to significantly increase, as soon as possible, the percentage of people with disabilities working in the open labour market.[71] The CmRPD repeatedly encouraged States Parties to promote employment in the open labour market, step up efforts to promote the labour market inclusion of people with intellectual disabilities, and 'do away with segregated working environments' (Portugal and Austria).[72]

Throughout its commentary on sheltered or segregated employment structures, the CmRPD consistently encouraged States Parties to review these practices and related legislation and bring them in line with the CRPD instead. The CmRPD continually clarified that it considered sheltered work practices to be incompatible with the human rights provisions of the CRPD and contrary to its overarching ideology of equality and non-discrimination. Concerning the practice of sheltered work in Hong Kong, for example, the CmRPD carefully noted that it did not 'consider shelter [*sic*] workshops as a good way to implement the Convention, (...)'.[73] In its observations to Serbia, the CmRPD encouraged the State to dismantle its sheltered workshop system and ensure the respect of all rights 'in accordance with the Convention'.[74] Similarly, the CmRPD urged Portugal to review its practices and legislation concerning the operation of its

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[67] Article 16, UNCRPD (2006).
[68] (CRPD/C/CHN/CO/1), n 26, para. 67.
[69] Ibid.
[70] (CRPD/C/KOR/CO/1), 44, para. 50.
[71] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Denmark*', (2014), (CRPD/C/DNK/CO/1).
[72] (CRPD/C/AUT/CO/1), n 56; (CRPD/C/PRT/CO/1), n 57, para. 52; In the reporting process, the State of Portugal had explained that, 'Sheltered employment takes place in specifically created Sheltered Employment Centres called 'Centros de Emprego Protegido' (CEP). It explained that CEPs are production structures, with administrative and financial autonomy- which is probably what cause the CmRPD concern. Committee on the Rights of Persons with Disabilities, 'List of issues in relation to the initial report of Portugal Addendum Replies of Portugal to the list of issues*', (2016), (CRPD/C/PRT/Q/1/Add.1), para. 119.
[73] (CRPD/C/CHN/CO/1), n 26, para. 67.
[74] (CRPD/C/SRB/CO/1), n 33, para. 56.

Occupational Activity Centres, 'from a human rights perspective to bring them into line with the Convention'.[75]

In addition to remarking on the inconsistencies between the human rights provisions of the CRPD and sheltered work practices, the CmRPD also routinely noted that placing workers in sheltered workshops simply failed to prepare them for, or to promote transitions to, the open labour market'.[76] Unsurprisingly, the CmRPD would go on to repeatedly encourage effective transitions from sheltered work to formal employment, as these were lacking.[77] In its observations for Canada,[78] the CmRPD remarked that alarmingly few strategies to end models of sheltered work existed. It also noted that a large number of people with disabilities remained employed in sheltered workshops in Bulgaria,[79] Slovakia,[80] and Mauritius[81] because of a lack of measures to encourage employment in the open labour market.

The CmRPD repeatedly stressed that States Parties should encourage the immediate and effective transition of all people with disabilities who are currently in sheltered workshops into formal employment and offered advice on how to do this, (Bosnia Herzegovina, Brazil, Mauritius, and Serbia).[82] In Germany, the State should phase out sheltered workshops through 'immediately enforceable exit strategies' and consider its General Comment No. 2 Article 9, (Accessibility) on how to achieve accessible labour markets.[83] Luxembourg should phase out sheltered workshops, with a time-bound schedule, and transfer those currently employed in sheltered workshops onto the open labour market.[84] Transition plans for the Cook Islands should focus on the 'freedom of choice to pursue vocations according to personal will and preferences'.[85] In its observations to Slovakia, the CmRPD also offered practical advice on how to move away from the sheltered workshop model, suggesting an 'action plan, timetable, budget, and training for public and private sector employers.[86] Moreover, the CmRPD also cautioned that any social protection payments currently tied to sheltered work placements should not be retracted or reduced for workers who transition into mainstream employment.[87]

Surprisingly, supported employment as a policy measure and a means to fulfil Article 27 was not mentioned very often. The CmRPD merely recommended this employment

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[75] (CRPD/C/PRT/CO/1), n 58, para. 52.
[76] (CRPD/C/KOR/CO/1), n 44.
[77] (CRPD/C/DEU/CO/1), n 64, para. 49.
[78] (CRPD/C/CAN/CO/1), n 53, para. 47.
[79] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Bulgaria*', (2018), (CRPD/C/BGR/CO/1), para. 57.
[80] (CRPD/C/SVK/CO/1), n 59, para. 73.
[81] (CRPD/C/MUS/CO/1), n 29, para. 37.
[82] (CRPD/C/BIH/CO/1), n 56, para. 48; (CRPD/C/BRA/CO/1), n 52, para. 48; (CRPD/C/SRB/CO/1), n 33, para. 56; (CRPD/C/MUS/CO/1), n 29, para. 37.
[83] (CRPD/C/DEU/CO/1), n 64, para. 49.
[84] (CRPD/C/LUX/CO/1), n 53, para. 46.
[85] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the Cook Islands*', (2015), (CRPD/C/COK/CO/1), para. 50(b).
[86] (CRPD/C/SVK/CO/1), n 59, para. 74.
[87] (CRPD/C/DEU/CO/1), n 64, para. 49.

model as an alternative to sheltered work on one occasion, in its Concluding Observations to the Ukraine, advising that it should 'take measures to provide for supported employment of persons with intellectual and psychosocial disabilities in the open labour market'.[88] This is an indication that such policies are in their infancy and little known, and that, therefore, their implementation is piecemeal.

7.2   GENERAL COMMENTS

As shown in the above review of the CmRPD's extensive reporting archive, the CmRPD has thoroughly used the opportunity of the Concluding Observations to communicate its position in relation to sheltered work and employment. These are, however, not the only instances when the CmRPD has expressed its opinion on this matter. It has used additional formal platforms, such as the publishing of General Comments, to further clarify its view of sheltered work and employment vis-à-vis the CRPD's obligations. Like Concluding Observations, General Comments provide useful analysis and, as Alston describes, 'spell out' the meaning of treaty obligations, making the jurisprudence emerging from the CmRPD more accessible.[89]

As with Concluding Observations, the precise status of General Comments, in terms of their legal significance, is subject to debate in academic circles. Otto, however, believes that these have evolved over time to carry 'enormous political and moral weight', becoming part of the law-making processes involved with ratification, and, thus, possess a 'quasi-judicial' character.[90] Although different views of General Comments as to their purpose and the extent to which they represent a source of law exists, it is clear that their legal status has developed and transformed over time. Their role has thus grown from one of providing technical guidance to that of providing regulation, becoming an authoritative source of interpretation.[91]

Quinlivan and Broderick understand that General Comments are an essential part of the rules of legal interpretation of the duties imposed by human rights treaties contained in the VCLT.[92] The widely accepted norms established by the VCLT, specify interpretative tools that comprise literal, systematic, teleological and historical elements to assist in understanding human rights treaties.[93] Together with a contextual

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[88] (CRPD/C/UKR/CO/1), n 26, para. 51.

[89] Philip Alston, 'The Historical Origins of the Concept of 'General Comments'', in Laurence Boisson de Chazournes and Vera Gowlland-Debbas, (eds.), *The International Legal System in Quest of Equity and Universality: Liber Amicorum Georges Abi-Saab,* (Martinnus Nijhood, 2001), 764; See also: Ann Bayefsky, 'The UN Human Rights Treaty System: Universality at the Crossroads', (2001) [online], available at: <http://www.bayefsky.com/report/finalreport.pdf> (accessed 21 January 2019).

[90] Otto, n 5.

[91] Discussed in particular by: Paula Gerber, Joanna Kyriakakis and Katie O'Byrne, Katie, 'General Comment 16 on State Obligations Regarding the Impact of the Business Sector on Children's Rights: What Is Its Standing, Meaning and Effect?', (2013) 14(1) *Melbourne Journal of International Law*, 93-128.

[92] Andrea Broderick and Shivaun Quinlivan, 'The Right to Education: Article 24 of the CRPD', in Charles O'Mahony and Gerard Quinn, (eds.), *Disability Law and Policy: An Analysis of the UN Convention,* (Clarus Press, 2018).

[93] For a more in-depth discussion of the VLCT see: Ulf Linderfalk, *On the Interpretation of Treaties: The Modern International Law as Expressed in the 1969 Vienna Convention on the Law of Treaties,* (Springer, 2007).

reading of the treaty, subsequent agreements between parties or documents emerging from the application of the treaty can be taken into account. In other words, while not legally binding, *per se*, General Comments and Concluding Observations, become subsidiary, supplementary sources for treaty interpretation.

Indeed, the General Comment today enjoys a status that falls short of positive law but plays a substantive legal role in the elaboration of standards and norms, which States Parties must acknowledge and respect. The General Comment is thus to be regarded as a further cog in the machinery of international human rights law and has even been applied in arguments by litigants and domestic courts, particularly where these have sought a progressive interpretation of the (national) law.[94]

7.2.1 General Comment No. 6 on Article 5, (equality and non-discrimination)

General Comment No. 6 (GC) is one such example of an authoritative interpretation of the CRPD's obligations in relation to Article 5, on equality and non-discrimination.[95] Undeniably, this GC is, above all, a technical descriptor of these obligations and it codifies how the CRPD principles are to be understood and transposed at the national level.

The need for a GC that clarifies States Parties' obligations in relation to non-discrimination and equality arose from the CmRPD's experiences during 70 dialogues with States Parties as part of the reporting process. As is evident from the snippets of the Concluding Observations presented above, the CmRPD repeatedly highlighted significant shortcomings in protecting, promoting and fulfilling the rights of people with disabilities. In particular, the CmRPD frequently found violations of the CRPD's equality principle leading to considerable failings in most regulatory frameworks. As a result, these frameworks remained imperfect, incomplete, or ineffective, and the lack of effective mechanisms of redress rendered certain groups voiceless, unprotected or perpetually excluded, isolated and discriminated against. The CmRPD considered that this shortfall could be traced back to a widespread confusion in regard to the CRPD's vision of equality and misunderstandings of its pivotal Article 5 obligations. The CmRPD subsequently also noted frequent misappropriations of important equality concepts, such as 'reasonable accommodation' and affirmative action.[96]

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[94] Conway Blake, 'Normative Instruments in International Human Rights Law: Locating the General Comment', (Issue 17 of Center for Human Rights and Global Justice working paper), (NYU School of Law, 2008).
[95] The 19 page document clarifies States Parties obligations under Article 5 on equality and non-discrimination, comprising 8 sections, and divided into three main parts. The introductory part gives an overview of the development of international disability equality law, the models of disability and discusses the legal character of non-discrimination and equality. The main part elaborates on the normative content of all four subparagraphs of Article 5, and the obligations of State Parties in regard to these. The final part provides guidelines to implementing Article 5 at the national level. UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 6, (2018), Article 5: Equality and Non-Discrimination, 26 April 2018, (CRPD/C/GC/6).
[96] Ibid, para. 25(a).

The CmRPD decided to take action and adopt a General Comment specifically targeted at re-emphasising the CRPD's original aims and intent. In a way, this GC is perhaps the CmRPD most significant General Comment published to date as it outlines the CRPD's vision of disability rights and how this is to be achieved using principles of international human rights law: equality and non-discrimination. In other words, the GC solidifies these fundamental constructs and their meaning for disability equality, formulating the CRPD's unique approach to equality.[97]

7.2.1.1 Normative content of Article 5

In GC No. 6, the CmRPD clarifies States Parties obligations regarding non-discrimination and equality as enshrined in Article 5 of the CRPD. The CmRPD explain that equality and non-discrimination are not only the cornerstone of human rights law generally, comprising the guiding principles (Article 3) to be used to interpret the CRPD, but also constitute autonomous rights in and of themselves. Promoting equality and tackling discrimination are, therefore, cross-cutting obligations of immediate, rather than progressive, realisation - unlike other rights in the CRPD. This has implications for practices and policies that segregate on the basis of disability, including sheltered work and employment, which will be discussed further below.

The GC addresses the normative content of Article 5(1) and clarifies the concept of being 'equal before and under the law', as well as the distinctions between ensuring 'equal protection' and 'equal benefit' of the law.[98] The GC clarifies that Article 4 obliges States Parties to ensure that public authorities and institutions act in conformity with the CRPD; that existing laws, regulations, customs and practices that constitute discrimination against people with disabilities are modified or abolished; and that the protection and promotion of the rights of people with disabilities is taken into account in all policies and programmes. Article 5 prohibits *de jure* or *de facto* discrimination in any field regulated and protected by public authority. The GC clarifies that Article 5, read in conjunction with Article 4(1), makes this prohibition applicable to the private sector too.[99] Thereunder, this broad application of the non-discrimination duty applies to all work settings, governed by both the public and private sector.

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[97] Ibid, para. 13. The CRPD is based on inclusive equality, a term presented in detail by Degener. Theresia Degener, 'The New General Comment No. 6 of the UNCRPD on Discrimination', (Berkeley Comparative Equality & Anti-Discrimination Law Study Group, 16 May 2018).

[98] These are related but distinct concepts of equality and non-discrimination. The 'equal protection before the law' is well established in treaty law and compels national legislatures to desist from any actions that discriminate against persons with disabilities when enacting laws and policies. Moreover, States must take positive actions to guarantee that persons with disabilities have, 'equal benefit' of the law, meaning that they can enjoy their rights on an equal basis. A combination of systematic accessibility measures; robust reasonable accommodation policies, and the availability of individual supports are required to achieve equal benefit of the law for all persons.

[99] (CRPD/C/GC/6), n 95, para. 13.

Next, the GC proceeds to clarify the normative content of Article 5(2) on the prohibition of discrimination, and equal and effective legal protection.[100] This subparagraph addresses the legal requirements for achieving equality rights for people with disabilities, and spells out the obligations to prohibit all discrimination on the basis of disability. These guarantees and obligations are far-reaching and impose positive duties of protection on States Parties. Specifically, the GC focuses on the various forms of discrimination and the CRPD's definition of disability-based discrimination contained in Article 2 to include any laws, policies or practices that distinguish, exclude or restrict on the basis of disability, with the effect of interfering with the enjoyment of any other human rights and fundamental freedoms.[101]

This definition is based on legal definitions of discrimination in previous international human rights treaties, (Article 1 CERD and Article 1 CEDAW) but goes further by including 'the denial of reasonable accommodation' as a form of discrimination. Moreover, the CRPD definition modifies the basis of equality from being between 'men and women' (as stated in CEDAW) to being, more generally, 'on an equal basis with others'.[102] This latter phrase is sprinkled liberally throughout the CRPD and solidifies the notion that people with disabilities are not granted more or less rights or protections than the general population, but the same, (the limitations of this aspect of equality in the CRPD in relation to intellectual disability equality has been previously addressed, in Chapter 6). Nevertheless, the GC elaborates that the use of this phrase is intended to be merely indicative of the efforts and measures required of States Parties to achieve *de facto* equality for people with disabilities and to ensure a comprehensive enjoyment of all human rights and fundamental freedoms.[103] Further, the GC elaborates that, indeed, some specific measures may go above and beyond what is stated therein to secure rights, and may even be of a permanent nature.[104] This is a novel feature of equality pursued in the CRPD. It is designed to be particularly 'disability sensitive' due to its flexibility and acknowledgement of the extent of measures potentially required to achieve equality.

Next, the GC addresses the third subparagraph of Article 5, with regard to the pivotal concept of reasonable accommodation. The GC considers the full wording of the concept and makes important distinctions between reasonable accommodation and accessibility duties, besides further clarifying the material scope of the duty and

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[100] Ibid, para. 16.

[101] The GC describes States Parties' duty to prohibit all forms of discrimination and explores the concept of multiple and intersectional discrimination. It describes four main forms of discrimination typically identified in international human rights practice: Direct and indirect discrimination, denial of reasonable accommodation and harassment. It also addresses the personal scope of the protection, as well as the terms 'discrimination on the basis of disability' and the 'protection against discrimination on all grounds'. The reasons why the CmRPD goes into such great detail and affords such a wide scope of application of Article 5 rights and protection is to eradicate all forms of discrimination, in any way linked to disability. Ibid, paras. 19-20.

[102] Therein the more limited phrase 'on a basis of equality of men and women' is used. UN General Assembly, Convention on the Elimination of All Forms of Discrimination Against Women, (18 December 1979), United Nations, Treaty Series, vol. 1249, 13, Article 1.

[103] Lisa Waddington and Andrea Broderick, 'Promoting Equality and Non-discrimination for Persons with Disabilities: Contribution to the Council of Europe Strategy on the Rights of Persons with Disabilities', (Council of Europe, 2017), 12.

[104] CRPD/C/GC/6), n 95, para 28.

offering examples of accommodations.[105] The clarification of this legal concept, as an individual, *ex nunc* (to be provided from a specific point onwards, a reactive duty) equality measure is of particular importance as the CmRPD had repeatedly noted in the Concluding Observations that many States Parties did not apply it correctly. Furthermore, on other occasions, as noted above, sheltered work has wrongly been considered as a form of reasonable accommodation and wrongly classified as an *ex ante* measure (to be archived beforehand, a proactive, systematic duty, also described as 'affirmative or positive action'), making this clarification all the more important.

Concerning Article 5(4) on specific measures, the GC explains that any positive or affirmative measures which aim to accelerate or achieve *de facto* equality of persons with disabilities may be based on differential treatment, which shall, however, not be considered discrimination (i.e. positive discrimination).[106] Such measures involve adopting or maintaining certain advantages in favour of an underrepresented or marginalised group, and are usually temporary in nature.[107] In some instances, however, depending on the particular impairment or the structural barrier in question, permanent specific measures are required.[108] The GC emphasise that States Parties must ensure that any measures adopted in accordance with Article 5(4) to promote equality do not result in the perpetuation of isolation, segregation, stereotyping, or stigmatisation, or otherwise discriminate against people with disabilities. Clearly, the CmRPD has formulated this particular warning in reaction to instances where specific measures implemented under the pretence of benefitting certain groups have been at the expense of achieving meaningful equality and inclusion.[109] Examples include the use of segregation policies, such as sheltered work and employment, which, as research

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[105] (CRPD/C/GC/6), n 95, para. 25. Here, the GC explains that accommodations must include the identification and removal of barriers, assessing legal and practical feasibility, suitability and relevance. Additionally, the GC outlines that if such accommodations impose a disproportionate or undue burden, it must be ensured that persons with a disability do not bear the costs; that the burden of proof rests with the duty bearer for claims of disproportionate or undue burden. The GC also clarifies that 'reasonable accommodation' should also not be confused with, 'specific measures' or 'affirmative action measures'. Unlike, these measure to achieve *de facto*, (which involves preferential treatment of groups/persons with disabilities over others to address historic, systematic and systemic exclusion from the benefit of rights), 'reasonable accommodation' is a non-discrimination duty to achieve *de jure* equality. The GC also explains that the 'reasonable accommodation' duty should not be confused with obligations to provide individualised support or procedural accommodations, and determines that if the duty is denied, this must be justified. It also lists essential guidance on how to implement the duty.

[106] Other international human rights treaties, similarly adopt this approach - see Article 4, CEDAW or Article 1(4) CERD. Examples of specific measures comprise 'outreach and support programmes, allocation and/or reallocation of resources, targeted recruitment, hiring and promotion, quota systems, advancement and empowerment measures, as well as respite care and technological aids'. (CRPD/C/GC/6), n 95, para. 28.

[107] The GC explains that States Parties are obliged to identify certain areas and adopt specific measures targeting subgroups of persons with disabilities in order to accelerate or achieve inclusive equality. Article 5(4) requires States to consult closely and actively involve organisations that represent the diversity in society, to tackle multiple and intersectional discrimination, which includes: children, autistic persons, persons with a genetic or neurological condition, persons with rare and chronic diseases, persons with albinism, lesbian, gay, bisexual, transgender or intersex persons, indigenous peoples, rural communities, older persons, women, victims of armed conflicts, and persons with an ethnic minority or migrant background. (CRPD/C/GC/6), n 95, para. 33.

[108] (CRPD/C/GC/6), n 95, para. 28. Bell considers that for persons with intellectual disabilities, permanent specific measures may be a particularly useful equality measure. Mark Bell, 'Workers on the Margins: People with Intellectual Disabilities and Labour Law', (2019), (unpublished) <https://soc.kuleuven.be/ceso/wo/erlm/irec/docs/markbell-leuven-irec-2018-mark-bell.pdf> (accessed 15 March 2019).

[109] As noted above, this is often the case where somewhat arbitrary decisions are taken to forfeit some rights for the benefit of others. In disability services, then, the rights to welfare, food, safety or protection are pursued at the expense of respecting all others. For more on this see: Shunit Reiter, 'Society and Disability: A Model of Support in Special Education and Rehabilitation', (2000) 32(8) *Focus on Exceptional Children*, 1-18.

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presented in Section 1 has demonstrated, overwhelmingly lead to the isolation, segregation and exclusion of people with disabilities and are, therefore, incompatible with Article 5(4).[110]

7.2.1.2   *Sheltered work settings: A problematic, dual track approach*

In GC No 6, the CmRPD also finally addresses the matter of sheltered work, resolving the failure of the treaty text to do so. In interpreting the text of the CRPD, the CmRPD uses the GC as a platform to break the silence, dealing with the ambiguity over interpretations of the CRPD in relation to sheltered work and employment. The CmRPD deploys the GC to clarify that such practices are, indeed, contrary to the aims of the CRPD. Moreover, it addresses the issue by applying numerous Article 5 elements and adopting approaches from both camps of rights, (civil and political, and socio-economic), envisaging a two-pronged approach, as discussed below.

As with the reporting cycle, sheltered work and employment are discussed in the GC in reference to Article 27. Here, the CmRPD clarifies obligations of States Parties to achieve *de facto* equality in the areas of work and employment and to ensure that there is no discrimination on the grounds of disability in relation to them. Thereunder, the CmRPD refers to sheltered work and employment as 'segregated work environments', (cognisant of the diverse range of work measures and multiple definitions thereof), which States Parties must 'facilitate the transition away from', whilst supporting the engagement of people with disabilities in the open labour market. The GC further specifies that in the 'meantime', however, States Parties are simultaneously required to ensure the 'immediate applicability of labour rights to those settings'.[111] Worth noting here is the choice of words the CmRPD employs. By using the term 'segregated work environments', it reflects not only the broad types of settings, but highlights also that segregation is a central component of these, both in terms of their design and the resultant experiences - reminiscent of the working definition used for this thesis, elaborated in Section 1.

The approach to segregated work adopted by the CmRPD in the GC warrants further attention as it comprises a dual-tack approach to achieving equality. States Parties are to transition away from institutions, on the one hand, while ensuring the immediate application of rights in such settings on the other. The binary nature of this demand is exemplary of how the CRPD typically utilises individual, multiple, and group-level, approaches to ensuring equality for people with disabilities. Moreover, it also reflects how the right to work is a subject area that typically spans approaches from both camps of rights to ensure equal opportunities in the work place, as well as the personal rights

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[110] (CRPD/C/GC/6), n 95, para. 35. The GC also clarifies that States Parties have information obligations under Article 5 and must collect and analyse data to identify inequalities, discriminatory practices and patterns of disadvantage, and analyse the effectiveness of existing equality measures. The GC also calls upon States Parties to closely consult and involve representative organisations of persons with disabilities when designing and adopting specific measures.
[111] (CRPD/C/GC/6), n 95, para. 67(a).

of workers at work. The approach taken in respect of sheltered work and employment, then, includes promoting, protecting and fulfilling the rights of persons with disabilities by combining actions that target people with disabilities as a distinct but heterogeneous group. At the same time, the approach includes a requirement for action at the individual level, securing rights of individuals with disabilities at work, in diverse work settings. Indeed, the two-pronged approach to equality and non-discrimination in relation to 'segregated work environments' is also reminiscent of the traditional twin categorisation of rights in international law, as socio-economic and civil and political rights.

The CmRPD's request to transition away from segregated models of work ostensibly equates these with the specific equality measures it identifies that are typically employed to achieve equality, yet, are in fact counterproductive because they contribute to the exclusion and isolation of certain groups. As a result, the CmRPD clarifies, in the GC that such measures are a direct contradiction of the CRPD's equality aims and of Article 5(4), specifically, which sets out that any measures adopted may not perpetuate the isolation, segregation or exclusion of people with disabilities. Under this call to action to end this type of segregation, broad, systematic processes working towards de-institutionalisation and 'transition plans' are to be adopted. This call for a transition away from segregated employment models also featured in many Concluding Observations, as noted above, and it is envisaged that it will be achieved progressively, typically in the context of socio-economic rights.

Reflective of the civil and political tradition of rights in international law, the GC simultaneously sets out how the right to non-discrimination applies to individuals working in segregated work environments. This employment relationship must be subject to all relevant freedoms and entitlements, a matter requiring immediate action by States Parties.[112] Specifically, States Parties are to protect the rights of workers in segregated settings through the, 'immediate applicability of labour rights'.[113] Here, the CmRPD unequivocally establishes that workers with disabilities in segregated work settings must enjoy the same protections and rights as other workers. The sense of urgency in this wording reflects the gravity of the issue and squarely places segregated work in the realm of relevant labour law and subject to the terms and conditions of any other work setting. The application of regular labour rights in the segregated setting is an important means of ensuring the rights of individual sheltered workers - arguably a prerequisite if the principles of equality and non-discrimination are to be applied broadly and include all people with disabilities in their scope.

While the CmRPD's illustration of the obligations the CRPD imposes on States Parties in relation to 'segregated work environments' is a welcome clarification, its guidance is not unproblematic. In fact, one could go so far as to say its suggestions are somewhat

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[112] Edward Zalta, 'Civil Rights', (Stanford Encyclopedia of Philosophy) [online], available at:
<https://plato.stanford.edu/entries/civil-rights/> (accessed 24 April 2019).
[113] CRPD/C/GC/6), n 95, para 67(a).

dichotomous, in that the GC suggests two sets of approaches that contradict and, possibly, even cancel each other out. Calling for a transition away from segregated work settings implies a gradual elimination of such settings. However, the simultaneous call for the immediate applicability of labour rights in segregated work environments arguably, contributes to the manifestation of these and risks being construed as inadvertently envisioning a future role for these settings. In fact, as distilled from a review of the travaux above, this was certainly a concern amongst negotiators, who feared that the treaty could be used to consolidate sheltered work settings by legitimising these practices. Indeed, Quinn agrees that a temporary fix, and often an expensive one, such as that suggested by the CmRPD to grant sheltered workers full rights in the *meantime* is 'highly unlikely to lead to a 'progressive achievement' towards a closure of segregated settings.[114] Instead, it tends to work the other way round; thus, these demands in the GC, as a means to ensure equal treatment and rights for people in sheltered workshops present as a conflict.

Additionally, this commixture of approaches, aiming to both close sheltered work settings and to assimilate the working conditions in sheltered work settings with those on the open labour market, seems conceptually confused. Indeed Quinn and others identify that 'setting one exigency' (ending the exploitation of sheltered workers) 'against another' (achieving inclusion) in this way is illogical.[115] Borrowing from a similar dichotomy applied to maintain residential institutions, they explain that this is because these approaches cannot be viewed as 'two component parts of a natural balance matrix, whereby one naturally yields to the other in the context of resource scarcity'. Rather, framing this approach to sheltered work settings in this way simply runs the risk that 'one will be advanced to the detriment of the other', as one exigency will readily be excused (transition away from sheltered work) on the basis that the other (achieving equal rights for workers) is 'more morally urgent'.[116]

Besides this problematic aspect with such a two-pronged demand, the diverse nature of sheltered work settings, which amalgamate multiple functions, will make it difficult to ascertain precisely which work environments are implicated by the call for the immediate application of labour rights. The operationalisation of rights will be encumbered by the problematic aspects of the setting itself, and may indeed become the very crux of this demand.[117] As previously noted in Section 1, identifying which settings are rehabilitative or serve a training function, as opposed to ones where work is conducted, can be difficult to determine.

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[114] Gerard Quinn, Grainne de Burca, Lisa Waddington, Mark Bell, Anna Lawson, Michael Stein, Titti Mattsson, Luke Clements, 'Legal Memo: Segregation and segregated facilities as a *prima facie* form of discrimination. The Impermissibility of using the ESIF to invest in monies in long term care residential institutions for persons with disabilities', (2018), 16, [online], available at: <https://enil.eu/news/segregation-and-segregated-facilities-as-a-prima-facie-form-of-discrimination/> (accessed 16 August 2019).
[115] Ibid.
[116] Ibid.
[117] Elsewhere, this Author has addressed the feasibility of this demand and considered potential solutions. See: Charlotte May-Simera, 'Framing the immediate application of labour standards in segregated employment, a demand by the CRPD Committee: Can the European Court of Justice offer guidance?' (*forthcoming*).

7.2.1.3 Segregation and Exclusion as discrimination

Perhaps the most effective way the CRPD will impact upon sheltered work settings is by framing the continued use of these practices as a form of systematic discrimination. The GC is of further interest in support of this approach. The GC describes how States Parties must modify or abolish practices, in both public and private spheres, that constitute discrimination on the basis of disability, including those that exclude people on the basis of disability. In particular, it identifies actions required to tackle disability-specific discrimination in the form of segregation or institutionalisation which concern residential living, education, employment, and access to goods and services.[118]

In the GC, the CmRPD considers that disability-based segregation is a form of disability-specific discrimination that often goes unrecognised, particularly where such policies and practices are shrouded in blanket policies providing specialist care and reserved only for people with disabilities.[119] Moreover, the CmRPD identifies that often, in such settings, discriminatory actions are, in fact, justified on the basis that they are intended to protect people with disabilities, or are in their 'best interests'.[120] However, it recognises that places of segregation, such as institutions, present a higher risk for experiencing harassment.[121] Particular attention should, therefore, be paid to places of segregation such as residential institutions, special schools or psychiatric hospitals. This is because, due to specific factors inherent to institutions, discrimination, particularly in the form of harassment, is more likely to occur in these places, and is typically invisible, and, thus, likely to go unpunished.[122] Overall, in the GC, the CmRPD identifies that many forms of discrimination go unchallenged, particularly the form experienced in institutions that predominantly affects people with intellectual disabilities.

By incorporating 'exclusion' in the definition of discrimination in Article 2, the CRPD acknowledges the right to the protection from discriminatory acts, such as those that exclude and segregate people on the basis of disability, or those that occur in segregated settings. States Parties have a positive duty towards safeguarding the right to non-discrimination on the basis of disability and must actively combat this form of discrimination where it has the effect of nullifying or impairing the exercise of all other human rights. Elsewhere, the CmRPD clarified this duty when it declared that the definition of discrimination in use in Croatia was unsatisfactory because it did not recognise exclusion and segregation in education, work and residential living as a form of discrimination. The failure to recognize this form of discrimination, it found,

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[118] (CRPD/C/GC/6), n 95, para. 73(c).

[119] Ibid, para. 3.

[120] Ibid.

[121] Ibid, para. 18(d)

[122] Ibid. The CmRPD asserts that 'harassment' is a form of discrimination when unwanted conduct related to disability or other prohibited grounds takes place with the purpose or effect of violating the dignity of a person and of creating an intimidating, hostile, degrading, humiliating or offensive environment. It can happen through actions or words that have the effect of perpetuating the difference and oppression of persons with disabilities.

contradicts the fundamental principles of equality and non-discrimination as set out in Article 5, CRPD.[123]

In the GC, the CmRPD clearly identifies that institutionalisation and segregation are a form of disability-specific discrimination, the protection from which is a right subject to immediate application.[124] Equality scholars have since clarified that 'institutionalisation, [...] can fairly and clearly be characterised as a *prima facie* form of discrimination under Article 5 CRPD'.[125] The CmRPD had already specifically confirmed that the right to non-discrimination includes the right not to be segregated in education and that it considers institutionalisation in residential services a form of 'disability-specific' discrimination.[126] In regard to Article 19, the GC declares that institutions, in fact, represent a failure to create support and services in the community for people with disabilities. As a result of support services only being provided in segregated settings, people with disabilities forfeit their right to participation in the community. The CmRPD is clear that where the only means of receiving public sector services, is via the institutionalisation of people with disabilities, that constitutes differential treatment on the basis of disability and, as such, is discriminatory.[127] While the CmRPD does not go so far as to reiterate as strong a declaration when addressing segregation in work and employment as it has in relation to other policy areas, it nevertheless, attempts to strengthen the protections and rights of segregated workers.

Extending the application of Article 2 to sheltered work settings has the potential to broaden the concept of discrimination to including people with intellectual disabilities. However, this approach will be of narrow application, requiring test cases. These cases will be required to establish the links between exclusion and segregation in terms of their interference with the exercise, enjoyment and recognition of certain rights and freedoms. It is also important to reflect, from a practical perspective, on framing segregation and exclusion as forms of discrimination. The right to non-discrimination is generally an individual right with implications for legal redress, which, if sought in national courts and tribunals, will generate case-specific jurisprudence. Subject to the instances of segregation at hand, being case-specific, these cases will be of little value in terms of challenging wider systems of segregation.

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[123] Croatia was urged to address this by taking 'legislative and policy measures to clarify that disability-based exclusion and segregation in education, employment and other fields of social life is a form of discrimination'. (CRPD/C/HRV/CO/1), n 26, para. 8.

[124] In Article 2, the CRPD establishes that any distinction or exclusion on the basis of disability is included in the definition of 'discrimination on the basis of disability' and is prohibited. In Article 2 it declares that 'discrimination on the basis of disability' means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation'.

[125] Gerard Quinn et al., n. 111.

[126] In its GC No. 4 on the right to inclusive education for example, the CmRPD state at the outset that, '[t]he right to non-discrimination includes the right not to be segregated'. Segregation, it found was incompatible with the CRPD. (CRPD/C/GC/4), para. 13.

[127] (CRPD/C/GC/6), n 95, para. 58.

Indeed, as outlined in Section 2, traditional equality approaches have relied on notions of equal treatment relative to others, i.e. equality is bestowed insofar as individuals can assimilate others, or their situation can be compared. As already discussed, the CRPD builds on this logic by framing rights on an 'equal basis with others' as its rationale for disability equality. This approach, however, fundamentally envisions the concept of equality as one that is underpinned by subliminal references to a collective of 'others'. In other words, as described in Chapter 5, a certain vision of equality is pursued in the CRPD that enforces set, merit-worthy attributes that are built around a normative understanding of worth and intelligence. What this means in practice however, is that only a select group of well functioning individuals stand to benefit from the CRPD, and, specifically, from its new definition of discrimination.

Furthermore, little legal clarity on the definition and the concept of exclusion, itself, exists or how the act of segregation can be quantified or measured to fulfil the required proof of discrimination.[128] Possibly useful guidance on how to assess where segregation constitutes discrimination can be taken from a 2010 judgment by the European Court of Human Rights in *Oršuš and Others v. Croatia,* where the segregation of Roma children in education was considered discrimination. This finding was informed by many reports specifically outlining, the negative consequences of the experience of segregation for the individuals concerned, from material and psychological perspectives.[129] Several UN instruments, and their definition of racial discrimination were cited in this judgement; the CRPD, however, was not. Nevertheless, the CRPD's inflated definition of discrimination comprises an important, if to date untapped, source from which to mount new types of claims.[130] This is a decided step towards broadening the legal scope and applicability of disability equality to include people with intellectual disabilities.

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[128] In regard to cases of direct discrimination, the GC declares that a comparator is no longer required to determine whether discrimination has occurred. In other words, direct discrimination can include any detrimental acts or omissions based on a prohibited ground, even where there is no comparable similar situation. This is an important development in the area of non-discrimination and a decided step towards protecting the rights of persons with intellectual disabilities. This new approach also marks a shift from formal constructs of equality and their inbuilt bias towards dominant groups, as a comparator amongst them had to be found to prove differential treatment (treat like persons alike). Strict comparators were needed. Indeed, the search for a comparator to illustrate the differential treatment of people with intellectual disabilities in sheltered work and employment is nearly impossible, since by their very definition they only employ people with disabilities. In many cases, the impossibility of finding a comparator hindered any claims of discrimination generally by people with intellectual disabilities, and specifically in relation to their placements and treatment in sheltered workshops. The removal of the requirement of a comparator, arguably the CRPD, as clarified in this GC, paves the way for future claims of direct discrimination to be made.

[129] In this judgment, in particular, both the knock-on effects of segregation and the ways in which it impedes the enjoyment of other rights are highlighted: 'Segregation could effectively deny a minority their right to learn the majority language with consequential negative impact on their ability to benefit from education and to effectively participate in, and integrate into, general society'. *Case of Oršuš and Others v. Croatia,* (Application no. 15766/03), (ECHR 16 March 2010), para. 140.

[130] Elsewhere, particularly in the U.S., the case has been made that segregation is indeed a form of discrimination and subject to litigation. For a comprehensive overview of this, see: Mark Bell, 'People with Intellectual Disabilities and Employment Discrimination Law: A US Case Study', (2019) 35 *Comparative Labour Law and Industrial Relations.*

7.2.2 The significance of this GC

While a review of the travaux offers us an insight into the negotiation of the CRPD, and the Concluding Observations offer important information on the human rights issues that States Parties grapple with, the GC provides valuable guidance. In the GC, the CmRPD finally, offers an official position on sheltered workshops, which as the above review of the travaux and the Concluding Observations signals, has been lacking, yet urgently necessary. Moreover, it is an important document for this discussion, for three reasons. Firstly, it specifically addresses segregated work environments, acknowledging both that they remain popular, and that debates as to their legitimacy and future, in light of the CRPD, remain current.

Secondly, the GC is valuable because it elaborates on the definition of discrimination on the basis of disability. The GC clarifies that segregation and institutionalisation of people with disabilities may be considered a form of discrimination, in accordance with the definition of discrimination found in Article 2, CRPD. This is indeed a meaningful development for this discussion as it holds great potential to challenge segregated work practices, with significant implications for many individuals with intellectual disabilities. Moreover, the call for the immediate application of labour rights in segregated settings is a momentous event, with further consequences for not only segregated workers but also the overall design of sheltered workshops and the delivery of employment services generally. If heeded, this call to action constitutes a significant step towards fulfilling the promise of the CRPD to promote, protect and fulfil the rights of all people with disabilities in all life situations, comprising an important component in expanding the concept of intellectual disability equality.

Thirdly, and yet another reason why the GC is valuable is because of how it acts as a stimulus in combating discrimination and exclusion by focusing on promoting inclusion in law, policy and practice. In this way, it approaches the issue of exclusion and segregation on an ideological level, prompting a shift in the philosophical approaches to disability policy that challenge sheltered practices, and institutions in general. This new approach to securing disability rights confronts exclusion in otherwise unchallenged practices and encourages inclusive alternatives (i.e. 'specific measures'). The GC clarifies that the CRPD squarely places 'inclusion' at its centre, both as a fundamental right in itself and as a principle of policy design through which all other rights are achieved. After all, the idea that the CRPD embraces a new vision of equality is confirmed in the GC, wherein it declares from the outset that it is based on an 'inclusive equality' approach to disability rights.[131] Atrey thus claims that the GC

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[131] (CRPD/C/GC/6), n 95, para. 11. Specifically, the GC clarifies that inclusive equality is achieved by adopting a holistic approach to human rights implementation, by focusing on the interrelatedness of economic, social and cultural rights and civil and political rights; recognising the inherent dignity and equal worth of each human being, acknowledging that disability is part of human diversity; accommodating the differences of individuals and groups; and by ensuring participation and giving a voice to people with disabilities. Here, Degener points to the similarities with Fredman's four-dimensional approach to transformative equality, which heavily influenced the 'inclusive equality' model as presented in the GC. The term 'transformative equality' was, however, not chosen for fear that it could be misunderstood by State Parties. Theresia Degener, 'Caroline Gooding Lecture by Theresia Degener, Inclusive Equality - A Human Rights Based Approach to Discrimination', (University of Leeds, 3 October 2018).

marks a pinnacle in the evolution of international law jurisprudence on equality and non-discrimination that will be influential for decades to come.[132]

7.3 CONCLUSION

While the treaty text itself does not explicitly refer to sheltered work and employment, the CmRPD has been anything but silent on the matter. This chapter has considered the CRPD's impact on sheltered work by reviewing two pivotal, interpretive sources of international law; Concluding Observations and General Comments. The review of the Concluding Observations in this chapter focuses on the implementation of Article 27, and provides a global snapshot of work and employment concerns from a disability rights perspective. The CmRPD repeatedly expresses concern about the on-going reliance on sheltered work models witnessed in many countries, and regularly calls upon States Parties to protect the rights of workers in sheltered work, encouraging transition from sheltered to open employment. These recommendations are reflected in the GC published by the CmRPD in 2018 and are also discussed in this chapter.

Based on the many review processes carried out by the CmRPD, GC No 6. tackles the main failings of States Parties in relation to equality and non-discrimination, and clarifies their obligations. In the GC, the CmRPD sets forth how, going forward, States Parties are to understand and implement the CRPD. In particular, its commentary on work and employment explores the expansive rights contained in Article 27, which is reflective of the CRPD's aim to provide a solid legal framework to securing the rights of people with disabilities, spanning approaches rooted in both civil and political and socio-economic legal traditions of international law.

This dualistic approach is also reflected in the arguably ambivalent demand in regard to 'segregated work environments'. In the GC, the CmRPD declares that the rights of sheltered workers shall be protected, on an equal basis with others, with immediate effect, whilst State Parties work towards gradually phasing out sheltered work environments. Besides finally formally addressing the issue of sheltered work and employment, the GC further expands the definition of disability-specific discrimination to include 'exclusion on the basis of disability' where this has the effect of undermining the enjoyment of other rights. In other words, the CmRPD approaches the issue of sheltered work on both an individual and collective level, using approaches from both camps of rights (civil and political rights of immediate realisation and socio-economic rights of progressive realisation). Indeed, these are welcome approaches as they also prompt States Parties to undergo ideological reforms in the area of disability policy. However, the success of these approaches in achieving intellectual disability equality is limited as they are still rooted in a traditional approach to equality, which, as identified

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[132] Shreya Atrey, 'CRPD Committee Adopts New General Comment on Equality and Non-Discrimination', (Oxford Human Rights Hub, 2018); Degener, n 97.

in Section 2, has failed to include people with intellectual disabilities. Despite its focus on human rights and embracing a new vision of inclusive equality, the CRPD's impact on dealing with segregation in sheltered work as a form of discrimination is finite. However, a greater focus on 'inclusion' as a basis for equality is a valuable starting point and, thus, forms the basis for the new approach presented in Chapter 8.

SECTION 3: CONCLUSION

Although 'human rights thinking' on equality has evolved considerably, the 'juridical conception of equality too easily accepts the economic and social exclusion of people with disabilities', argues Quinn.[1] As a result, when it comes to disability, exclusion still tends to predominate in State practice and in the courts and institutionalisation is rationalised in support of segregated education, sheltered workshops and other forms of segregated treatment for people with disabilities. Reviewing the CRPD's ability to disrupt this thinking, and its position on sheltered work is, thus, pivotal.

Overall, this section conducts such a required review by introducing the CRPD and assessing the new approach to equality it envisages, with specific regard to intellectual disability equality. The section then proceeds to discuss the impact of the CRPD and argue that its concrete value for people with intellectual disabilities lies in its ability to challenge structural segregation. This premise is tested by using the example of sheltered work, revealing that such an assessment is far from straightforward. The ensuing discussion of Article 27 and sheltered work shows how the subject area is burdened by starkly divergent opinions as to the purpose and future of these settings. An analysis of the existing commentary by the CmRPD signals that sheltered work settings are generally regarded unfavourably and not in compliance with the rights and freedoms protected by the CRPD, or with its overall ideology of an inclusive society in which each person enjoys equal concern and respect for their inherent dignity. To this end, the CmRPD issues specific recommendations to prohibit further rights violations in sheltered work settings and to suppress their development. Whether this is enough to tackle the widespread, systemic segregation of people with intellectual disabilities is, however, questionable.

Nevertheless, the CRPD's definition of discrimination does, at first glance, look like a promising development towards the achievement of intellectual disability equality. Considering, the theoretical and practical impediments to making the equality claims discussed in Section 2, the use of current equality measures are nonetheless limited by the traditional functioning of legal systems, rooted in a liberal understanding of eligibility for rights. Overall, the CRPD's impact on tackling the widespread segregation of people with intellectual disabilities in sheltered work and employment is, therefore, negligible. Instead, a new approach to equality that emancipates itself from the confines of traditional legalism, along with its idealisation of ability, eligibility and productivity, is required.

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[1] Gerard Quinn, 'Breaking the Link between Poverty and Disability: Re-Purposing Human Rights in the 21st Century', in Martha F. Davis, Morten Kjaerum, and Amanda Lyons, (eds.), *Research Handbook on Poverty and Human Rights*, (Elgar, forthcoming).

Chapter 8: A New Model for Intellectual Disability Equality

Section 3 identifies some limitations in the approach to equality used in the CRPD. Ultimately, its vision of equality is framed within the existing, rigid structures of international law and is dictated by it. As a result, in relation to sheltered work, the CRPD has been interpreted by the CmRPD as warranting two somewhat dichotomous equality responses, making it difficult to categorically counteract segregation in sheltered work. The question remains, then, as to which equality model can best tackle segregation and, thus, achieve intellectual disability equality. On the basis of this investigation, it is evident that achieving equality for people with intellectual disabilities requires more than strictly legal responses, or those already tried and tested as part of established equality theories.

As a response to the findings from Sections 2 and 3, this chapter offers a solution to the identified shortcomings and outlines an approach for a more appropriate and inclusive equality model. Like the CRPD, this model is based on the human rights model of disability and employs human rights principles to tackle inequality in the form of segregation. The Inclusive Model presented here adopts a four-pronged approach to intellectual disability equality. This model consists of the interwoven requirements of recognising, understanding and acknowledging the unique experiences and position of people with intellectual disabilities in society, and, lastly, framing the right to inclusion. Before addressing the four elements in more detail, this chapter, sets out to explain that, at its core, this new model is based on dignity. The following discussion, thus, re-establishes the importance of dignity in human rights law in general, and explains both how people with intellectual disabilities have been denied their inherent dignity and the role that institutions have played in this.

8.1   JUSTIFYING THE NEED FOR A NEW MODEL

The Inclusion Model suggested herein distinguishes itself from other models, previously discussed, as it is informed by an investigation into the ways in which the liberal conventions that underpin our modern rights frameworks have impacted on the experience of intellectual disability specifically. In doing so the model is based on an acknowledgement that the idea of equality is often assumed to have developed to become a universal concept enjoyed by all and applied equally.[1] States are then often

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[1] Hans Reinders, *The Future of the Disabled in Liberal Society: An Ethical Analysis* (University of Notre Dame Press, 2000).

quick to oversimplify what equality is, particularly in the case of intellectual disability, formulating well-intentioned but inadequate disability policies. As a result, the persistent problem of segregation in day services, such as sheltered workshops, remains unrecognised as problematic from an equality perspective, and thus unchallenged. This model is then specifically designed to address this impasse. Further, this model presents a 4-step process formulated to respond particularly to the difference and diversity, in terms of cognitive skills and abilities, presented by the intellectual disability characteristic. Using the human rights promises of the CPRD as an impetus, this model therefore represents a novel departure from existing legal responses that are part of current rights frameworks, to a more relevant approach to intellectual disability equality. Otherwise, as Quinn notes, there is a real danger that the ratification process of the CRPD will remain within the confines of the normativity of traditional human rights law, falling short of fully embracing the CRPD as an opportunity for a new vision of equality.[2]

The CPRD embraces the concept of equality and advances a substantive approach to equality into one termed 'inclusive equality'. This approach extends the concept by elaborating four distinct dimensions that are adopted by the CRPD to achieve equality. These comprise a fair distributive dimension to address socioeconomic disadvantage, a recognition dimension to combat stigma, a participative dimension and an accommodating dimension to make space for difference.[3] The Inclusion Model presented here builds on the foundations of the inclusive equality approach but adds a focus on intellectual disability inequality as a problem to be tackled. The model additionally distinguishes itself from preceding ones in two further ways. First, it concentrates on the aspect of the difference of intellectual disability and the need to respect that difference, as a starting point for any approach to equality. Secondly, it pinpoints the act of including and the status of being included as a prevailing theme of any approach adopted. In this way, the model suggests reinvigorating the concept of inclusion, both in terms of the ideology that it seeks to reinforce and in terms of the tools used. In this way, the Inclusion Model seeks to utilise inclusion by prompting more theorisation and revising the debates as to its meaning.

Inclusion policies have had an impact in disability policy to date, shaping how many services respond to 'diversity' in many countries. However, as Armstrong et al. note, in many cases inclusion has been reduced mainly to a change of language rather than of practice, yet the more the language of inclusion is used in practice, the more evasive it appears to become.[4] The weaknesses of the 'inclusive perspective' is then characterised by the theoretical vacuum in which it is created and actioned. Armstrong et al. lament that much of the underlying idealism of the 'grand project' of inclusion is lost in the watered-down policies that we see and our meaningful engagement with true

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[2] Andreas Dimopoulos, *Issues in the Human Rights Protection of Intellectually Disabled Persons* (Ashgate, 2010).
[3] Marine Uldry and Theresia Degener, 'Towards Inclusive Equality: 10 Years Committee on the Rights of Persons with Disabilities', (2018), 19.
[4] Derrick Armstrong, Ann Cheryl Armstrong and Ilektra Spandagou, 'Inclusion: By Choice or by Chance?' (2011) 15(1) *International Journal of Inclusive Education,* 29-39.

differences are sacrificed. Nevertheless, it is by going back to the 'big picture of inclusion' and reformulating it in the light of knowledge, experiences and learning accumulated by undertaking the 4-steps, as laid out here, that we can find a way forward.[5]

The need for a model that focuses on the distinct aspects of respecting the difference of intellectual disability and on inclusion is perhaps this model's most novel feat. These elements are identified by a review of existing equality models that has shown that, while some reforms reflected in equality legislation benefited some groups, this did not automatically cross over to the benefit of persons with intellectual disabilities. Quinn identifies that this is because many blockages remain, of which perhaps the main blockage is the assertion that persons with intellectual disabilities were (and are) indeed 'different' in that 'their difference of cognitive or communicative capacity meant that civil death [and exclusion] was not only appropriate, but indeed the only way of properly taking care of their interests, generating a sort of hyper-paternalism'.[6] In essence, the model suggested here specifically dismantles unquestioned, cultural narratives that continue to justify the segregation of people with intellectual disabilities by locating an implicit bias in existing equality approaches towards cognitive ability and the demonstration of rational thinking. The main argument for a new, intellectual disability specific model stems from an understanding that the hegemonic discourses of equality have simply overlooked the position of this group. As a result of this, disability policies are designed in a manner that continues to casts many people as fundamentally unworthy of equal treatment or unable to perform according to the standards required under substantive models, and the segregation of people with intellectual disabilities is then simply not of concern. Arstein-Kerslake sums up that, in essence, the subsequent differential treatment of people with intellectual disabilities is a manifestation of the ways in which this group is repeatedly held to a different standard.[7]

In short, the model aims to highlight the need for a respect of difference as means to dispel the idea that difference is unequal. In doing so, this model centrally helps identify that segregation is a problem, using the CRPD as an impetus for this argument. After all, law is both the 'witness and external deposit of our moral life' and has often been used (abused) in the past to cement into place the exclusion of certain groups.[8] 'But just as the law can embed exclusionary ideas (and almost inoculate people against critical self-reflection) it can also be used to unpick the legacy of the past. This performs not just the practical task of removing barriers but also an educative role of conscientising people toward right behaviour'.[9] Attitudes, ideologies and stereotypes all interact to create particularly stubborn barriers for people with intellectual

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[5] Ibid.
[6] Gerard Quinn, 'Reflections on the Value of Intersectionality to the Development of Non-Discrimination Law' (2016) 16(1) *The Equal Rights Review* 63-72.
[7] Anna Arstein-Kerslake, *Restoring Voice to People with Cognitive Disabilities: Realizing the Right to Equal Recognition before the Law,* (Cambridge University Press, 2017), 93.
[8] Oliver Wendell Holmes, cited in Quinn, n 6, 66.
[9] Quinn, n 6, 66.

disabilities. This is where the CRPDs paradigm shift comes in and is best placed to create change, by infectiously challenging attitudes and persuading States into compliant, rights-based action. In a way then my model helps make sense of the CRPD and put its principles into practice, ensuring it will help have a positive impact for all people.

Inclusion does indeed play a central role in the CRPD. Increasingly, discussions are being held about how inclusion as a tool can promote equality and become a human rights principle. On closer examination, the Convention envisages inclusion as a tool to further its equality agenda and utilises the principle of inclusion in numerous Articles. Inclusion is mentioned in the Preamble but also features amongst the general principles outlined in Article 3, whereby the 'full and effective participation and inclusion in society' becomes the leading ideology of the CRPD. Further, notable references to inclusion can be found in Article 19 on the right to life in the community and to live independently, the right to be included in education in Article 24, and in Article 26 on rehabilitation and habilitation, whereby measures shall be implemented to support the full inclusion and participation in all aspects of life on behalf of persons with disabilities. Article 27 then also specifies the right to access a work environment that is 'open', and 'inclusive'.

8.2   DIGNITY: A FUNDAMENTAL MARKER FOR HUMAN RIGHTS AND EQUALITY

Human rights, as regarded in western, liberal thought, have been developed to protect and promote an evolved ideal of human dignity.[10] The existing international human rights framework establishes that each person has the right to equality and to be treated with dignity and respect.[11] Furthermore, a world consensus, in the form of a 'Declaration of Principles of Equality' clarifies that,

> the right to equality is the right of all human beings to be equal in dignity, to be treated with respect and consideration and to participate on an equal basis with others in any area of economic, social, political, cultural or civil life.[12]

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[10] Andrew Heard, 'Human Rights: Chimeras in Sheep's Clothing?', (1997) [online], available at: <http://www.sfu.ca/~aheard/intro.html> (accessed 21 September 2016); McCann believes that the liberal ideal in human rights theory, which so upholds the idea of individual freedom, is at the same time a paradox of our human rights system. Michael McCann, 'The Unbearable Lightness of Rights: On Socio-legal Inquiry in the Global Era', (2014) 48(2) *Law & Society Review*, 245-272.

[11] The preambles of the two core UN Covenants, on Civil and Political Rights, and on Social, Economic and Cultural Rights, postulate that human rights are comprised of two interlinked aspects: the inherent dignity of human beings, and equal rights. However, the equal protection of neither is self-evident. The rights of specific groups had to be further elaborated in subsequent instruments. Jenny E. Goldschmidt, 'New Perspectives on Equality: Towards Transformative Justice through the Disability Convention?', (2017) 35(1) *Nordic Journal of Human Rights*, 1–14.

[12] The Principles on Equality were agreed by a group of experts and discussed, in stages, and at conferences, such as the conference entitled "Principles on Equality and the Development of Legal Standards on Equality", organised by The Equal Rights Trust on 3 - 5 April 2008 in London. Participants from different backgrounds, including academics, legal practitioners and human rights activists from all regions of the world, took part; Equal Rights Trust, 'Declaration on the Principles of Equality', (2008).

From the above we can glean that dignity, and the respect thereof, are important constructs in determining equality, becoming the 'anchor norm of human rights'.[13] Arendt, a prolific human rights scholar, explained that, more than a right, dignity is the very reason for rights.[14] Undeniably, as a central principle of human rights, dignity is intrinsically interwoven into the fabric of international human rights law, and is also an integral part of the CRPD's new agenda for rights. This commitment is reiterated in its preamble, which consolidates the importance of dignity in the context of disability by specifying that, 'discrimination against any person on the basis of disability is, in fact, a violation of the inherent dignity and worth of the human person'.[15]

As a broad concept the ideal of dignity has had a powerful remit, even in times of controversy. For example, the conceptualisation of dignity as a fundament of human rights was universal enough to unite post-war leaders tasked with the mandate of drafting a document that could unify peoples and ensure peace after decades of war and political dispute. Subsequently, the Universal Declaration of Human Rights (UDHR), which was adopted by the United Nations General Assembly, in 1948, became the founding document of international human rights law.[16] Article 1 of the UDHR states that 'all human beings are born free and equal in dignity and in rights'.[17] As an opening statement, this article signals that human rights flow from the recognition of the equal worth of the human person and the inherent dignity with which we are born.[18] Respecting the equal and inalienable rights and inherent dignity of each and every person was determined by world leaders to be the foundation of freedom, justice and peace in the world.[19] Being included as an addressee within this concept of dignity and

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[13] Although some scholars, such as McCrudden, have argued that dignity beyond a 'basic minimum core does not provide a universalistic of principled basis for judicial decision-making in the human rights context', it is a basis nonetheless. Christopher McCrudden, 'Human Dignity and Judicial Interpretation of Human Rights', (2008) 19(4) *European Journal of International Law*, 655-724; Gerard Quinn and Theresia Degener, 'Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability', (United Nations, 2002).

[14] Natalie Oman, 'Hannah Arendt's 'Right to Have Rights': A Philosophical Context for Human Security', (2010) 9(2) *Journal of Human Rights*, 279–302.

[15] UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, (24 January 2007, A/RES/61/106), Preamble h.

[16] Anna Grear, 'Framing the Project of International Human Rights Law: Reflections on the Dysfunctional "Family" of the Universal Declaration' in Conor Gearty and Costas Douzinas, (eds.), *The Cambridge Companion to Human Rights Law,* (Cambridge University Press, 2012). The UDHR is a declaration that amalgamates all types of rights, without prioritising them, and does not have the legally binding effect of a treaty. The rights contained in the UDHR had to be translated into a treaty in order to make them practicable and enforceable. The question then arose whether there would be one treaty encompassing all the rights held in the UDHR, or whether there would be two different instruments, effectively categorizing the rights. In 1950, the General Assembly reaffirmed that all rights are 'interconnected and interdependent'. However, the political climate that ensued bred the Cold War, which was punctured by the deep dichotomy of the pre-eminence of individual civil and political rights in Western democracies, in contrast with the East's socialist-led focus on social, economic, and cultural rights. This led to the General Assembly ultimately deciding to adopt two separate treaties; the ICCPR and the ICESCR.

[17] Camilla Barker, 'Dignity in International Human Rights Law: Does the Concept of Dignity Have Any Meaning in International Human Rights Law?', (International Write for Human Rights Movement, 2011), 34.

[18] In international human rights law, the right to work is closely connected to the inherent dignity of all persons. The Economic and Social Committee, for example, referred to the right to work as a necessity to live with dignity and also reinstated the importance of inclusion and equality in work and employment. The Committee described how these aspects are interlinked, by stating that 'the right to live a dignified life can never be attained unless all basic necessities of life-work, food, housing, health care, education and culture are adequately and equitably available to everyone'. United Nations Committee on Economic Social and Cultural Rights, 'Fact Sheet No.16 (Rev.1), The Committee on Economic, Social and Cultural Rights', (1993) [online], available at:
<http://www.ohchr.org/Documents/Publications/FactSheet16rev.1en.pdf> (accessed 17 August 2018).

[19] UN General Assembly, Universal Declaration of Human Rights, (10 December 1948, 217 A (III)).

subsequent rights frameworks is a pivotal, universal prerequisite for equality. Based on its universality and central role, 'dignity' is identified herein as an important marker and basis for equality.

Undeniably, the concept of 'dignity' forms the basis of a shared understanding of the purpose of human rights. After all, as Kittay states, the demand for equality - 'whether of rights, resources opportunity, welfare, capabilities - is, at bottom a demand to be accorded the equal dignity due to all' as affirmed, specifically, in the UDHR.[20] There are, however, many ways to conceptualise dignity. Marx, for example, frames dignity within the notion of leading a dignified life that is worthy of human status.[21] Nussbaum considers that at its core, dignity entails that 'each person is treated as an end in themselves'.[22] The positions of both Marx and Nussbaum reflect elements of liberalist thought, as outlined in Chapter 4, in that the idea of dignity is intrinsically linked to the moral status of each human and the recognition of the individual as an autonomous actor, i.e. 'as an end in themselves'. In other words, it would be an indignity if individuals were denied the recognition of their lives as worthy of moral status and of value, and the right to be treated as legitimate actors in society.

The idea that dignity is tied to morality is one that is perhaps most commonly associated with the writings of German philosopher Immanuel Kant. Although Kant never referred to disability specifically in his works, his thoughts have shaped some disability theories. This is because Kant recognised that dignity is a prerequisite for equality, as it establishes the individual's intrinsic worth.[23] Treating people with indignity, by denying their autonomy or undermining their inherent value, is, then, a moral failing, the experience of which amounts to moral abuse. On this basis, Marx outlines that each human life is worthy of human status and, therefore, valuable in itself, and should, on that basis alone, enjoy full citizenship.[24] The recognition of the innate value of each person and that each individual must be treated as an end in themselves, and 'never as a mere means', underpins the concept of dignity that now well established in international human rights law.[25] As a moral obligation, the recognition of equal dignity is universal and underpins the ideal that no differential

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[20] Eva Feder Kittay, 'Equality, Dignity and Disability', (Perspectives on Equality: The Second Seamus Heaney Lectures, 2005).

[21] Karl Marx, *Economic and Political Manuscripts of 1844,* (Progress Publishers, 1959). Indeed, to Locke, often considered the grandfather of liberalist thought, the concept of dignity was imperative.

[22] Martha Nussbaum, 'Capabilities as Fundamental Entitlements: Sen and Social Justice', (2003) 9(3) *Feminist Economics*, 33-59. In this article, Nussbaum explains how she thinks her capabilities approach, rather than existing liberal theories, should be chosen to frame social justice because it offers a more accurate way to discuss human entitlement.

[23] Autonomy, itself, is an important concept, discussed over and over by Socrates and Plato. They asserted that it defines our personhood. Jo Watson explains that the CRPD, as well as the International Bill of Human Rights, affirms the right to lead an autonomous life. People with disabilities have a right to lead an autonomous life. But, more importantly, people have the right to be supported to lead an autonomous life. Autonomy is not an individualised process- it is a collective one. We all make choices with the help of others and on the basis of our preferences. Everyone has the ability to express preferences but some people's preferences are disrespected, ignored, or unrecognised without the required supports; Jo Watson, 'Challenging Assumptions that People with Severe or Profound Cognitive Disability are Unable to Lead Self-Determined Lives', (Ted Inspired Talk given at Financial Counselling Australia Conference, 2016).

[24] Kant would add the following condition: provided they are 'rational persons'. Thomas E. Hill, 'Humanity as an End in Itself', (1980) 91(1) *Ethics*, 84-99.

[25] Melinda Jones, 'Inclusion, Social Inclusion and Participation', in Lee Ann Basser, Marcia H. Rioux and Melinda Jones, (eds.), *Critical Perspectives on Human Rights and Disability Law* (Martin Nijhoff. 2011), 25.

value is placed on any individual based on a particular characteristic, such as intellectual disability.[26] This paves the way for a 'substantively rich reading of human dignity as the fountainhead' of all rights under human rights law, generally.[27]

After all, to Dworkin, who has written extensively on human dignity in the context of dementia, dignity has a 'social side', with specific implications for society, with certain collective duties and requiring collective action.[28] Accordingly, it would be undignified of a society to deny any of its members the recognition of their equal right to dignity. According equal respect of dignity, as identified by Nussbaum, involves regarding each individual as an independent actor, irrespective of their abilities or disabilities. A vital aspect entailed in this respect of dignity involves according a distinct importance to each life by recognising each person as a bearer of critical interests.[29] In essence, dignity has moral implications for the way that people with disabilities are viewed and treated. Applied in this way, dignity becomes a moral code for action, a type of standard below which we 'we must not permit ourselves to fall'.[30]

8.2.1 Segregation as a violation of dignity

Above, I have outlined that equal respect of human dignity is the foundation of human rights law and is instrumental for equality. Briefly, the idea was introduced, that dignity is made up of liberal ideologies that recognise two principles: the value of each individual, and their entitlement to lead a dignified life, based on the recognition that they are bearers of critical interests. Here, it will be argued that segregation interferes with the equal recognition of dignity for people with intellectual disabilities because it frustrates these two principles. As a result, policies and practices that segregate people on the basis of disability should be scrutinised for interfering with an equal respect for the dignity of those they target. Such an analysis would require assessing the impact of the practice, policy or setting with reference to the two principles for dignity, as distilled above. As shown in Section 1, sheltered work as a type of institution operates in a way that confines people with intellectual disabilities, representing a lack of choice and opportunities, and promoting the view of this group as incapable and inferior. In combination, these aspects of the practice, I argue, violate the two fundaments of dignity, underpinning the unequal treatment of this group.

With awareness of its potential to highlight persistent inequalities based on its indisputable and universal nature, the concept of dignity is increasingly used as a fundament in asserting the rights of people with disabilities.[31] Owing to the de-

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[26] Immanuel Kant, 'Foundations of the Metaphysics of Morals' in Rachel James, *The Elements of Moral Philosophy*, (Random House, 1986), 114.
[27] Dimopoulos, n 2, 43.
[28] Ibid.
[29] Ronald Dworkin, *Life's Dominion: An Argument about Abortion and Euthanasia,* (Harper Collins, 1993), 236.
[30] Jack Donnelly, *Universal Human Rights in Theory and Practice* (3rd Edition, Cornell University Press, 2013), 15.
[31] For an excellent discussion on this, see: Niklas Altermark, *Citizenship Inclusion and Intellectual Disability: Biopolitics Post-Institutionalisation*, (Routledge, 2017).

institutionalisation movement, activists' arguments that segregating citizens from society is a denial of basic human dignity and autonomy have gained public recognition.[32] An emerging awareness of the many human rights violations and unwholesome practices in institutions as being detrimental to human dignity is fuelling arguments against these settings.[33] Fundamentally, disability rights activists argue that segregating people on the basis of disability disrespects and 'holds some people to be less equal than others', inhibiting them from participating in their communities.[34] According to this line of thought, institutionalisation constitutes a moral failing and is symptomatic of how many individuals society fails to regard as an 'end in themselves' or acknowledge as the bearers of critical interests.[35] Indeed, this position has been thrashed out in the U.S., where case law involving institutions and institutionalised applicants, ruled that 'unnecessarily' segregating people with disabilities was a violation of their dignity.

In the *Olmstead v. L.C.* ruling, the Supreme Court, for the first time recognised that 'unnecessary' segregation constituted discrimination contrary to the Americans with Disabilities Act, (1990).[36] This landmark case determined that individuals with disabilities have a right, under the law, to receive services in the most integrated settings appropriate. A denial of this right, the Court found, deprives them of the opportunity to participate fully in their communities, and to make their own choices about how to live their lives.[37] *Olmstead* has even been interpreted in subsequent cases as establishing that freedom from segregation is, in fact, a civil right, and that 'individuals [albeit qualified ones] have a right to receive services in a manner consistent with basic human dignity' rather than being shunted aside, hidden, or ignored.[38] As a result, segregated services, particularly residential services, across the U.S., are gradually being challenged for being in violation of an individual's right to dignity.[39]

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[32] For more on this see: Charlotte May-Simera Charlotte May-Simera, 'Reconsidering Sheltered Workshops in Light of the United Nations Convention on the Rights of Persons with Disabilities (2006)', (2018) 7(1) *Laws*.

[33] Eric Rosenthal and Arlene Kanter, 'The Right to Community Integration for People with Disabilities: Under United States and International Law', (International Disability Law and Policy Symposium, 2000); See following reports of institutional abuse and eugenics research: Christopher Kliewer and Stephen Drake, 'Disability, Eugenics and the Current Ideology of Segregation: A Modern Moral Tale', (1998) 13(1) *Disability & Society*, 95–111.

[34] Melinda Jones, 'Inclusion, Social Inclusion and Participation' in Lee Ann Basser, Marcia H. Rioux and Melinda Jones (eds.), *Critical Perspectives on Human Rights and Disability Law* (Martin Nijhoff. 2011), 64; Jerome Bickenbach, 'Disability and Equality', (2003) 2(1) *Journal of Law and Equality*, 7-16.

[35] Many identify that this exclusion is systemic, broad in its scope, and purposeful. Maria Pearce Burgdorf and Robert Burgdorf, 'A History of Unequal Treatment: The Qualifications of Handicapped Persons as a Suspect Class under the Equal Protection Clause', (1974) 15 *Santa Clara Lawyer,* 855-909; Alison Wohl, 'Competitive Integrated Employment as a Civil Right for People with Disabilities', (LEAD Center webinar, 8 November 2016).

[36] Olmstead v. L.C., 527 U.S. 581 (1999); Susan Stefan, 'Beyond Residential Segregation: The Application of Olmstead to Segregated Employment Settings', (2010) 26(3) *Georgia State Law Review*, 875.

[37] Many have called this ruling the *Olmsted* ruling, the '*Brown vs Board of Education*' decision for the disability community. Thomas E. Perez, Department of Labor, U.S. Department of Labor, United States Department of Justice, '*The Promise of Olmstead: 15 Years Later',* (2014).

[38] *Helen L, Beverly D, Florence H, Ilene F, Idell S, and American Disabled for Attendant Programs Today ('ADAPT'), Idell S, Appellant v Albert L Didario, Individually and in his Official Capacity as Superintendent of Norristown State Hospital, and Karen F Snider, in her Capacity as Secretary, Pennsylvania Department of Public Welfare, Karen F Snider, Appellee* [1995] United States Court of Appeals for the Third Circuit 46 F.3d 325, 516 U.S; Sue Jamieson, '*The Promise of Olmstead: 15 Years Later',* (2014).

[39] Sylvia Caley, 'The Olmstead Decision: The Road to Dignity and Freedom', (2012) 26(3) *Georgia State University Law Review* 651-662.

Ongoing institutional practices, such as sheltered work, have also come under fire since *Olmstead*. In a findings Letter issued by the Department of Justice in the case of *Lane v. Brown (formerly Lane v. Kitzhaber)*, the Department claimed that the *Olmsted* argument also applied to segregated day services and employment programmes as they prevent community inclusion and the leading of self-directed lives, which, in turn, frustrated the equal enjoyment of dignity.[40] In accordance with the two principles of dignity listed above, the department stated that such settings failed to recognise each person's innate value and, thus, eligibility for community inclusion and to recognise each person as the bearer of critical interests.

Elsewhere, however, equating segregation with a violation of dignity is not as straightforward - even *Olmstead* placed certain conditions on this argument.[41] Furthermore, a significant group of stakeholders do not consider segregated services as problematic, but rather, that these offer specialised care for people with intellectual disabilities. Indeed, the role of treatment and care facilities must not go unrecognised, and arguing for the complete removal of such settings is not the purpose of this thesis. However, this discussion aims to highlight the fact that people with intellectual disabilities face a disproportionate risk of segregation. This segregation precludes the finding of alternative options to institutional settings and, thus, little progress is made to applying a rights-based approach in disability service provision that might ensure an equal respect of their dignity. As a result, segregated policies are still the main, default policy responses to disability in Western welfare systems. The prevalence of the sheltered work system as identified in Section 1 is evidence of this. The aim of this thesis is, then, to challenge the widespread, blanket exclusion from mainstream participation of people with disabilities. It is suggested here that this is perhaps most effectively broached by scrutinising this type of service provision for its potential to frustrate the equal respect of individuals' dignity.

Undeniably, institutions hamper the lives of people with intellectual disabilities in many ways. So far, this discussion has argued that the segregation of people with intellectual disabilities is only a symptom of the wider problem in law and policy, contributing to intellectual disability inequality, as this group is still largely regarded as fundamentally unequal. Institutions are emblematic of how the same protections that apply to others through the promise of rights frameworks in liberalist societies is denied to people with intellectual disabilities. The root causes of this exclusion originates, as described in Chapter 4, in the notion that people with intellectual disabilities are neither held to be equal people, nor are their lives valued equally, nor

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[40] *Lane v. Brown (formerly Lane v. Kitzhaber)* – 12-CV-00138 – (D. Or. 2012), U.S. Department of Justice, Civil Rights Division, 'DOH Finding Letter', (2012) [online], available at:
<https://www.ada.gov/olmstead/documents/oregon_findings_letter.pdf> (accessed on 19 October 2019).
[41] Individuals protected according to this precedent have to be 'qualified individuals' and their integration only pursued in as far as it is practicable - two very broad qualifications. For a discussion of these see: Michael Perlin, 'Their Promises of Paradise: Will *Olmstead v. L.C.* Resuscitate the Constitutional Least Restrictive Alternative Principle in Mental Disability Law', (2000) 37(4) *Houston Law Review*, 999-1054.

are they regarded equally as bearers of critical interests- all of which are required for an equal respect of their dignity.

This chapter frames dignity as an important ground on which to challenge the unequal status and the segregation of people with intellectual disabilities. Based on the indiscriminate, fundamental value dignity accords to all people, accepting the whole person, including aspects of the person that are 'different' or 'disabled', as a concept, it has been instrumental in many arguments for substantive equality.[42] Having established the universality of dignity, Basser suggests that the internalisation of dignity by institutions is one means of ensuring equality.[43] Indeed, a collective understanding of the Catholic nature of dignity is important, as it becomes the basis for the argument that people with intellectual disabilities have equal rights and freedoms. Essentially, dignity is the virtual threshold that ensures each individual has the right to have rights.[44]

8.3 THE RELATIONSHIP BETWEEN DIGNITY AND INCLUSION: INCLUSION POLICY AS A REMEDY

So far, this chapter has addressed the central role of dignity in human rights and equality considerations and suggested that excluding people is a potential violation of their inherent dignity. Inclusion is then identified as a possible remedy and a particularly valuable concept for people with intellectual disabilities, able to respond to the diversity amongst this heterogeneous group. After all, as Dworkin identifies, within our human rights system, which is based on an ever-developing liberal conception of rights, all claims should be regarded as legitimate that aim to fulfil the fundamental requirements of rights, i.e. the treatment of all people with equal concern and respect.[45] The achievement of these fundamental requirements, however, necessitates more than the mere recognition of the equal worth of all people and the commitment to treating everyone with equal dignity and respect. Rather, to fully operationalize these promises for people with intellectual disabilities, greater consideration and conscious, inclusive action is required, with specific implications for segregated practices.

Given how institutional segregation holds the potential to exclude people with intellectual disabilities and constitutes a violation of dignity, its counterpart, inclusion, is indeed an important remedy. Inclusion plays a pivotal role in the CRPD and underpins its substantive conception of dignity, essential in formulating fundamental rights in the context of disability. This was affirmed and embedded in the narrative of

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[42] Lee Ann Basser, 'Human Dignity' in Marcia H. Rioux, Lee Ann Basser and Melinda Jones, (eds.), *Critical Perspectives on Human Rights and Disability Law,* (Martinus Nijhoff, 2011), 22.
[43] Ibid, 12.
[44] Reminiscent of Arendt's thoughts on the 'right to have rights'. Hannah Arendt. *The Human Condition: Second Edition,* (Rob Shepherd, 2018).
[45] Richard Dworkin, *Taking Rights Seriously,* (Duckworth, 1990).

treaty interpretation by the CmRPD, when it declared that the CRPD relies on a version of equality that is grounded in inclusion, i.e. 'inclusive equality'.[46] However, the term 'inclusion' and its implications for policy require further attention: otherwise, as Cooper explains, without further conceptualising its purpose for disability equality – that much used and abused term - risks becoming a meaningless 'buzz-word'.[47]

In discussing its implications for disability, Goodley maintains that inclusion is a state of nature: the default status.[48] Exclusion, on the other hand, like the very category of disability itself, is something that has been created artificially with the help of abstract constructs such as the social contract, and has served to demarcate certain groups from others. With the advance of the medical professions and, as Foucault would add, the creation of institutions to house society's 'deviants' for treatment, rehabilitation, or incarceration, exclusion has become formalised.[49] It is then through 'entirely unnatural' and arbitrary processes that inclusion has become 'something that has to be asked or fought for'.[50] Recognising the importance of inclusion is, thus, one means by which to, somewhat, 'revert' to or, at least, restore the damage of exclusion caused by segregation, and peel away the artificial barriers created by institutions. In other words, 'inclusion' represents a means of emancipation from the confines of institutions, of reinstatement of certain freedoms that have been immorally denied to people with intellectual disabilities.

As a concept, if employed correctly, inclusion does indeed carry the potential to rectify past transgressions, even violations, and restore dignity.[51] Above, I have outlined how segregation and exclusion frustrate the equal respect of dignity and, therefore, constitute an inequality. As a response to this breach of dignity, it is argued here, that inclusion, offers a remedy. After all, respecting the principle of dignity requires that all human beings are actively 'empowered to enjoy the benefits of society on an equal basis', which precludes their ability to participate and be included in political, social, and cultural pursuits of society.[52] Ensuring the inclusion of people with disabilities is, therefore, a valid method of promoting participation and protecting the individual's dignity. Inclusion becomes, thus, both an operational mechanism and a prerequisite for dignity.

On the basis of this interdependency between dignity and inclusion, being included is a precondition for equality of status, treatment and opportunity. Hammarberg for example, points to the relational aspect between dignity and inclusion, which has

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[46] UN Committee on the Rights of Persons with Disabilities (CRPD), General Comment No. 6, (2018), Article 5: Equality and Non-Discrimination, 26 April 2018, (CRPD/C/GC/6), para. 11.
[47] Indeed, the variety of different definitions of this broad concept has caused some debate. Paul Cooper, 'Is "inclusion" Just a Buzz-Word?', (2005) 9(4) *Emotional & Behavioural Difficulties,* 219-222; For an insightful discussion of this term in relation to inclusive education, see: House of Commons Education and Skills Committee, 'Special Educational Needs, Third Report of Session 2005-2006', (2006), 22.
[48] Dan Goodley, *Learning Disability and Inclusion Phobia: Past Present and Future*, (Routledge, 2016), 166.
[49] Felix Driver, 'Bodies in space: Foucault's account of disciplinary power', in Colin Jones and Ray Porter, (eds.), *Reassessing Foucault: Power, Medicine and the Body*, (Routledge, 1994), 113-131.
[50] Goodley, n 48.
[51] Congressional Record, V. 150, Pt. 9, June 2, 2004 to June 16 2004', (United States Government Printing Office, 2004).
[52] Basser, n 42, 12.

become specifically pronounced in law since the introduction of the CRPD. Identifying, also, the reciprocal nature of rights emphasised in the CRPD, he acknowledges this fundamental relationship by declaring that 'a statutory and enforceable individual entitlement to a level of support which is necessary to ensure one's dignity and ability to be included in the community should be determined' in all ratifying States.[53] In this way, Hammarberg clarifies that, for people with intellectual disabilities, to ensure a life of dignity requires increased support and attention geared towards their inclusion. Inclusion takes on greater meaning and importance in defining what a dignified life is for people with disabilities and, undeniably, it also takes centre stage in determining intellectual disability equality. Establishing these links clarifies how legal theorists claim that individuals possess a right to inclusion and demand an explicit expression thereof.[54]

8.4   AN INCLUSION MODEL FOR INTELLECTUAL DISABILITY EQUALITY

With the introduction of the CRPD the concept of inclusion become an overarching goal that spans multiple approaches with a unifying aim to achieve equal rights. In the approach introduced in the following, inclusion will be specifically utilised to ensure equality by tackling exclusion. Bearing in mind the CRPD's vision, inclusion is understood here as a broad concept, encompassing flexible approaches that prompt fundamental and pragmatic shifts in attitudes and thinking. Moreover, as an instrument for policy, it introduces a layer of obligation, pointing to the responsibility of society as a whole in removing inequity of dignity, status and opportunity. Actions, therefore, must focus not only on removing barriers and social structures that impede inclusion, but also on a change in the moral fabric of society. Indeed, a shift in policy and practice towards 'genuine inclusion', as Simpson and Price claim, necessitates a social and democratic transformation of society.[55] Besides reversing oppression and tackling systematic inequality, this requires an active engagement with how we view people who are truly different. Similar to Fredman's transformative equality model, indeed, a shift that is nothing short of transformative is necessary to determine intellectual disability equality. What sets this approach from Fredman's apart, however, is its focus on the leitmotif of inclusion towards, not only a practical and actionable 'shift', but also a narrative and value-based change.

Identifying inclusion as a central concept to achieve intellectual disability equality is a worthy approach. As both a policy tool and an ideology, inclusion is a particularly apposite construct and able to flexibly accommodate the realities of cognitive

[53] Thorsten Hammarberg, Commissioner for Human Rights, 'The Right of People with Disabilities to Live Independently and Be Included in the Community', (2012), (Council of Europe, CommDH/Issue Paper), 3.
[54] Basser, n 42, 12.
[55] Graeme Simpson and Vicky Price, 'From Inclusion to Exclusion: Some Unintended Consequences of Valuing People: Unintended Consequences of Valuing People', (2010) 38(3) *British Journal of Learning Disabilities,* 180-186; Mark Burton and Carolyn Kagan, 'Decoding Valuing People', (2006) 21(4) *Disability & Society,* 299-313.

impairment. After all, the requirements to ensure equal respect of the dignity of individuals will differ based on supports, preferences and circumstances, amongst other factors. It is the very acknowledgment of these differences and the diversity of approaches required to achieve an equal respect of dignity for each person that makes an inclusive approach particularly pertinent. Such an inclusive, approach for example, offers a new dimension in determining what dignity is, and it allows for a wider interpretation of what a dignified life might look like. Arguably, an inclusive approach is fundamentally based on greater understanding of intellectual disability, allowing for increased reflection and personalised responses. This flexibility takes us beyond the limits of traditional activism, and provides a more substantive, tailored and, thus, a more meaningful conception of equality.[56]

Central to this new approach is the idea that inclusion plays an instrumental role in achieving equality, as to be included and able to participate in society is to lead a life of dignity. In other words, 'inclusion' as a process and a status is itself a source of equality. Moreover, this model is based on the belief that access to and the enjoyment of rights, are indisputable and any equality approach must consist of actions towards this recognition. In theory or in practice, this will at times require that the effects of the difference that disability poses are either regarded as irrelevant and ignored or, at other times, recognised and acted upon to manage the consequences or the effects thereof.[57] Increased efforts, beyond such actions are nevertheless required to ensure that people with intellectual disabilities are able to lead dignified lives. This model thus enumerates obligations of wider society, besides legal and policy responses, that formulate a required shift in moral values, using a four-pronged approach.

8.4.1 Recognition of the equal importance of each life as a prerequisite for intellectual disability equality

Similar to the newer models of equality that typically adopt an anti-subordination approach and reject the notion of assimilation expected by older models, this new Inclusion Model for equality suggests a redefinition of status and desired outcomes. Perhaps less structured than Fredman's transformative model, this inclusive approach, nevertheless, argues that the proverbial goal posts of traditional equality theory need to be moved, or even removed. In this way, the pressures of normalcy and normalisation are rejected, and value is sought not in conformity, productivity or intelligence, but on the simple basis of a shared humanity. Indeed, this call for a radical shake-up of ingrained norms is not new in the field of disability equality. In their discussions of how

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[56] It is, however, important to note that other theorists such as Johnson and Walmsley emphasize that the concept of belonging is a better alternative to inclusion, to formulate what is a good life. Kelley Johnson and Jan Walmsley, *Belonging and Social Inclusion for People with Intellectual Disabilities,* (Taylor and Francis, 2019).
[57] Jones, n 25, 64.

to achieve equality for people with intellectual disabilities, Clifford Simplican and Leader similarly call for a non-normative theory of inclusion.[58]

Focusing on our shared humanity is an essential aspect of this inclusive approach, as it tears back the artificial layers of status and eligibility endorsed by the traditional models of equality.[59] Reverting to a simpler grounding of equality emphasises that, first and foremost, every individual is human and, therefore, deserves equal concern and respect based on that immutable fact. Many theorists, such as Sen, have investigated which values can be agreed upon in society to form the basis for distributive justice and equality (as previously noted in Chapter 5, Sen named this search: 'Equality of What?').[60] Dworkin, in a similar search for an equality approach that applies to people with intellectual disabilities, believes that our shared humanity is a good place to ground any theory. This is because our humanity is 'the most basic common denominator which renders members of society equal'.[61] Founding eligibility on this shared feature of individuals necessitates that equality must be afforded, quite simply, to each and every person on an equal basis because they are human.[62]

To make the promise of equal concern and respect for all individuals an inclusive one, it must apply to each human. This entails recognising the importance of each human life so that it is 'successful and not wasted'.[63] Kelley and Walmsley argue that to lead a good life, the concept of 'belonging', rather than inclusion, is a more successful focus for practice.[64] Disability theorists agree that this is best achieved via individualised support to enable people with intellectual disabilities to lead a self-directed and, thus, a dignified life.[65] Indeed, research reveals that a focus on self-determination, dignity and inclusion in disability services facilitates personal development and, ultimately, helps realise the dismantling of institutions.[66] Regardless of how it is achieved, the definition of a 'successful life', according to the liberal tenets as listed by Reinders, is

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[58] Stacy Clifford Simplican and Geraldine Leader, 'Counting Inclusion with Chantal Mouffe: A Radical Democratic Approach to Intellectual Disability Research, (2015) 30(5) Disability and Society, 717-730.
[59] Such as the rigid structures of equality and anti-discrimination frameworks for example. Ronald Dworkin, *Sovereign Virtue: The Theory and Practice of Equality*, (Harvard University Press, 2000), 248.
[60] Morton Deutsch, 'Equity, Equality, and Need: What Determines Which Value Will Be Used as the Basis of Distributive Justice?', (1975) 31(3) *Journal of Social Issues*, 137-149.
[61] Dimopoulos, n 2, 31.
[62] Nussbaum rejects the contractarian theory on which western liberal thought relies on so heavily, whereby rights are only bestowed upon eligible and worthy citizens, and claims that: 'We thus need to adopt a political conception of the person that is more Aristotelian than Kantian, one that sees the person from the start as both capable and needy – in need of a rich plurality of life-activities, (...) Such a conception of the person, which builds growth and decline into the trajectory of human life, will put us on the road to thinking well about what society should design. We don't have to contract for what we need by producing; we have a claim to support in the dignity of our human need itself. Since this is not just an Aristotelian idea, but one that corresponds to human experience, there is good reason to think that it can command a political consensus in a pluralistic society'. Nussbaum, n 22, 54.
[63] A process which contributes to social progress. Dworkin, n 59, 240.
[64] Johnson and Walmsley, n 56.
[65] Wil H. E. Buntinx and Robert L. Schalock, 'Models of Disability, Quality of Life, and Individualised Supports: Implications for Professional Practice in Intellectual Disability', (2010) 7(4) *Journal of Policy and Practice in Intellectual Disabilities*, 283-294.
[66] Michele Di Terlizzi, 'Life History: The Impact of a Changing Service Provision on an Individual with Learning Disabilities', (1994) 9(4) *Disability & Society*, 501-517; Jos Van Loon and Geert Van Hove, 'Emancipation and Self-Determination of People with Learning Disabilities and Down-Sizing Institutional Care', (2001) 16(2) *Disability & Society*, 233-254; John Simon Vorhaus, 'Philosophy and Profound Disability: Learning from Experience', (2014) 29(4) *Disability & Society*, 611-623.

one that is free from external evaluation and influence and, most of all, is regarded as being of equal importance for each human life.[67] Although it is an obvious aim of human rights law in general, the new Inclusion Model presented herein reiterates the recognition of the equal importance of each life, which is fundamental for intellectual disability equality.

There are distinct reasons why the recognition aspect of this new model is mentioned first. As noted above, the liberal tenets are grounded in the liberal ideal that developed to grant individuals certain protections from State interference and external value judgements by third parties. This is evident in the way that the right of expression and free will have been litigated, resulting in numerous protections of individual freedoms, allowing select individuals to lead, somewhat 'free' lives, based on their choices. Ensuring that such protections are granted on an equal basis requires an inclusive stance that not only recognises the equal importance of each life but also understands the alternative ways in which lives can be led. A just and free society, so idealised by liberal frameworks, therefore, requires not only 'the banal individual autonomy of 'negative rights', but the acknowledgement of the many ways people can live their lives'.[68] An increased understanding, then, is pivotal in ensuring that disabled people's lives are acknowledged and included under the promises of liberal protection rather than cast aside as too different. Therefore, this model begins by suggesting that popular conceptions of eligibility for equality must be revised and that equality must be understood as being premised on our shared, common humanity.[69]

8.4.2 Understanding as a prerequisite for intellectual disability equality

Largely, inertia in formulating any formal systematic intellectual disability equality approaches to date is based on a limited understanding of the characteristic.[70] Therefore, the second principle of this four-pronged approach argues that a purely rights-based response is inadequate in tackling inequality. Instead, further actions, beyond the formal framework of rights, are required. Undoubtedly, establishing rights is useful and can provide access to specific services and material needs, yet sustainable change for equality may still be lacking. Actions supporting an understanding of the difference of intellectual disability are necessary. After all, a limited awareness that people with disabilities have rights, a lack of resources needed to enjoy these, coupled with an insufficient awareness of segregated settings, has resulted in a dearth of

[67] Dworkin, n 59, 240.
[68] Damon A. Young and Ruth Quibell, 'Why Rights Are Never Enough: Rights, Intellectual Disability and Understanding', (2000) 15(5) *Disability & Society*, 747-764.
[69] Garland-Thompson highlights this dilemma from a different perspective when she discusses disability equality and the problem with the liberal ideal in western society as one where the 'principle of equality encourages uniformity while the principle of freedom invites distinction. American selfhood is balanced on the tension between the desire for sameness and the longing for uniqueness', Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, (Columbia University Press, 2017), 130.
[70] Rioux declares the concept of disability generally, has been shaped by political conflict more than anything. Marcia Rioux, 'Towards a Concept of Equality of Well-Being: Overcoming the Social and Legal Construction of Inequality'(1994) 7(1) Canadian Journal of Law and Jurisprudence, 127-147, 127.

knowledge and understanding of disabled, institutionalised life. As residents on the margins of society, people with intellectual disabilities, themselves, often know little about their rights and entitlements. A deliberate act of greater understanding is thus required to remedy this knowledge gap, acknowledge the supports required to enjoy rights and, most of all, to fully grasp the inequalities that pervade the lives of many people with intellectual disabilities.[71]

Understanding the experience of intellectual disability and acknowledging that increased efforts beyond rights are required for equality, underpins the 'understanding' aspect of the Inclusion Model. This strand also incorporates an interpersonal element. It identifies that the complex material, legal and social injustices 'can only be redressed by people who understand each other'.[72] This is based on the recognition that the challenges of difference and the precedence of individual autonomy in equality law have overshadowed the requirement of people to afford each other real attention.[73] Some theorists, accordingly, highlight the distinctions between legal equality and social equality, and that the achievement of the former has typically been at the expense of the latter.[74] As reflected in the discussion of traditional equality models in Section 2, most measures have been preoccupied with establishing eligibility and worth; this has, arguably, interfered with the willingness of humans to understand each other, let alone the unique characteristic of intellectual disability.[75]

This new inclusive approach then envisions a greater capacity for understanding as a vital component. Without understanding we cannot comprehend the full spectrum of human existence, or the types of 'different' lives that are led and appreciate alternative forms of behaviours and communication. Furthermore, without this improved understanding, fundamental assumptions and misunderstandings remain unresolved. As a result, people with intellectual disabilities continue to be categorised as problematic rights bearers, if at all, undermining any meaningful efforts to revaluate how to 'treat others who are different'.[76] After all, as Hatton notes, it is because of a lack of understanding in our highly urbanised societies, that people with disabilities are considered as, 'obtrusive', undesirable and incapable of respecting, 'the tightly drawn social mores and routines'.[77]

Due to a failure to truly understand those with an intellectual disability, this group are cast aside and labelled as unworthy and incapable of acting in line with the typical

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[71] Young and Quibell, n 68.
[72] Young and Quibell consider that it might be difficult for an 'able-minded' person to understand a person with an intellectual disability, but that this is largely the case when we begin with the wrong premise, assessing individuals according to their ability or other hegemonic normative frameworks. This is such a pervasive force that dismissing this built-in normative influence must become a deliberate act. Thus, recognising that, in fact, all persons are contributors to society by way of their common humanity is the real challenge.
[73] Young and Quibell, n 68.
[74] Frank Michelman, 'The Meanings of Legal Equality', (1986) 3 Harvard Blackletter Journal, 24-36.
[75] Young and Quibell, n 68.
[76] Ibid.
[77] Chris Hatton, 'Why Be Happy When You Can Be Normal? On Ordinariness and People with Learning Disabilities', (*Chris Hatton's Blog*, January 11, 2014) [online], available at: <https://chrishatton.blogspot.com/2014/01/why-be-happy-when-you-could-be-normal.html> (accessed 9 November 2018).

social contract. Therefore, this Inclusion Model foresees the use of greater understanding as an exercise for society. At the heart of this deeper reflection, based on the requirement of understanding, lies the insight that it is not how people with intellectual disabilities can fit in to an equality model but, rather, how society can include every member in such a way as to ensure equal respect for their dignity.[78] Under this conception of equality, the locus is placed on achieving inclusive communities with certain responsibilities, as opposed to asserting individual rights, so central in liberal theory. Arguably, this reflective process, incorporated in a collective act of understanding, has the potential to minimalize the need to seek remedies for disadvantage or discrimination through rights vindications. After all, a greater emphasis and acknowledgment of the interdependence of society's individuals has the potential to be of benefit to all of its members.

8.4.3 Acknowledging the impact of inequality (exclusion) for intellectual disability equality

The importance of 'understanding' for intellectual disability equality requires a comprehension of specific aspects that determine the experiences of this group. It is then not only our culture of rights that we must begin to unpack but also that of exclusion. An example of this is provided in Chapter 1, where I introduce 'Francesca's story' as a typical example of the pervasiveness of exclusion in everyday life, for people with intellectual disabilities. This vignette is a useful illustration of the need to acknowledge the widespread practice of excluding those deemed 'undesirable' and 'less worthy' by placing them in institutions.[79] A comprehensive equality model, must, therefore, explore the narratives of individuals with intellectual disabilities - an action that, in turn, demands an examination of the broader societal processes of categorising and institutionalising this group.

The 'acknowledgement' element of this Inclusion Model is then informed by characteristics of the critical discipline, in that it prompts an examination of the very processes that underlie society.[80] As with critical theory, the 'acknowledgement' element of this model addresses the relationship between individuals and society, as well as the assumed and invisible rules that govern human interaction. As outlined in Section 2, Foucault believed that polymorphic, liberal society possesses an inbuilt mode of autocritique and an ability to recognise and question its socialised norms and

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[78] Participation and inclusion then become the goal but also a vital benchmark against which to measure this model's success.

[79] In this sense, 'the gap between the 'reality' of the lived experience of disability and the way this is conceptualised is bridged. Young and Quibell, n 68.

[80] Turetzky claimed that the critical approach at the heart consists of the 'dialectic tension between accepting the economic categories of the existing order and condemning them'. The significance of critical theory thus lies in its suspicion of categories and labels such as the 'useful, appropriate, productive, and valuable, and the rules of conduct as understood in the present order, and refuses to take them as extra-scientific presuppositions that it is powerless to change'. Philip Turetzky, 'Outline of Max Horkheimer, "Traditional and Critical Theory"'[online], available at: <https://colostate.academia.edu/PhilipTuretzky> (accessed 10 October 2016).

constraints.[81] Foucault, therefore, undertook his investigation to understand processes of society and, in particular, the institutionalisation of certain groups.[82]

Foucault claimed that most theories fail to properly acknowledge the use of power in society, and its impact on social deviants. As a dynamic of social conformity and control, power is very much present in the social contract process and was applied, particularly, in severe punitive systems and social services created in 18th century Europe.[83] Foucault described how power was used in societies, via these institutions, to legitimize the punishment and confinement of deviants in prisons, schools and mental institutions. He identified that, as a social construct, power is made up of accepted forms of knowledge derived from scientific research and what is agreed to be the truth based on these. More than simply a type of domination of one group over another, power is, more profoundly, employed as a 'regime of truth', which in turn determines the 'natural order of things', in a manner that perpetually induces the effects of that power. According to Foucault, these processes of knowledge govern the rules of society, including the social contract, are internalised in the micro interactions of everyday life and establish people's status in society.[84] These processes, he contested, generated 'normative certainties that seem to sustain the assignment of disability to a devalued and disavowed discourse'.[85] On this basis, Foucault radically deconstructed the institution of law and challenged what are taken to be indisputable truths in respect of the subjugation of individuals (in institutions), paving the way for future anti-subordination theories.

Effectively, Foucault's work prompts us to reconsider the parameters drawn by invisible yet authoritative distinctions between groups of people through modalities of power and the social contract. A critical reflection on the processes of society must be informed by a process of detaching power from socially constructed 'truths' and addressing their influence on social, economic, and cultural forms of hegemony in operation.[86] In a similar vein, Carlson suggests focusing on society as a whole to reveal more about the power relationships exercised and exerted upon 'others'. This exposure

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[81] While not a liberal theorist himself, Foucault was interested in understanding liberalism. He understood liberalism was not merely a doctrine of political or economic theory, but, rather, a theory of governance itself and a method by which to constantly call the art of governance into question. Shelley Tremain, (ed.), *Foucault and the Government of Disability,* (University of Michigan Press, 2005), 12.

[82] Social and sexual deviants, criminals and all those termed 'mad'.

[83] Foucault's writings are still used today to theorise the disproportionate incarceration of minority groups. See, for example: Lorna A. Rhodes, *Total Confinement: Madness and Reason in the Maximum Security Prison,* (University of California Press, 2004), 10.

[84] Referred to as 'epistemes or discursive formations', in Foucault's terminology. Michel Foucault, The Archaeology of Knowledge, (transl. by A. Sheridan, Tavistock, 1972), 191. The Stanford Encyclopaedia of Philosophy therefore explains that, for example, in, *A History of Madness,* Foucault undertook an intellectual excavation of the radically different discursive formations that governed talk and thought about madness from the 17th through to the 19th centuries. Stanford Encyclopaedia of Philosophy and Gary Gutting, 'Michel Foucault', (2013) [online], available at: <http://plato.stanford.edu/entries/foucault/#4.6> (accessed 27 February 2015).; Michel Foucault, The Order of Things, (Random House, 1970).

[85] Margrit Shildrick, *Dangerous Discourses of Disability, Subjectivity and Sexuality,* (Palgrave, 2009), 106; Licia Carlson, 'Docile Bodies, Docile Minds: Foucauldian Reflections on Mental Retardation' in Shelley Tremain, (ed.), *Foucault and the Government of Disability,* (The University of Michigan Press, 2005), 133. Michel Foucault, Discipline and Punish: The Birth of the Prison. (transl. by A. Sheridan, Pantheon, 1977).

[86] Paul Rainbow, (ed.), *The Foucault Reader: An Introduction to Foucault's Thought,* (Penguin, 1991), 75.

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by Carlson and Foucault is a refreshing approach, as it turns the focus away from individuals with disabilities as the subject of scrutiny, towards the non-disabled mass of society that has acted upon 'others'.[87] Such a critical approach, as suggested in the 'acknowledgement' aspect of the Inclusion Model, can help expose the effects of power relationships and facilitate an exploration of how these have culminated in the very classification of 'disability', as well as a justification for institutionalisation.[88]

To some extent, debates about the social model of disability have already instigated processes of critical reflection. These have fuelled challenges to these widely held 'truths' that have resulted in dominant, out-dated perceptions of disability based on over-medicalised approaches. Instigated by this Foucauldian polemic, an acknowledgment of the flaws of past and present institutional polices has taken hold and fuelled a global de-institutionalisation movement. This fire needs to be kept aflame, and further momentum around this awareness of the impact of power on the lives of people with intellectual disabilities is vital to sustain change. Similar to that of the critical doctrine, the model suggested herein prompts a continued identification of how constructs of the truth have created an ideology of segregation, separating 'disabled from non-disabled' people.[89] Fundamentally, this third aspect of the Inclusion Model requires an act of critical reflection and acknowledgement of the ways in which an inferior status is ascribed to, and institutions maintained for, those deemed too different or incapable. Only by acknowledging the impact of power and 'truth', along with reflection on their manifestation in law and policy, can these be challenged, and a meaningful equality approach designed.

8.4.4 Framing inclusion as a right for intellectual disability equality

Rousing an awareness of the sociological determinants of intellectual disability and institutionalisation helps strengthen the underlying argument pursued in this thesis that, at its root, segregation is premised on the unequal status of people with intellectual disabilities, with practices such as sheltered work reproducing archaic inequalities. To address this, the concept of 'inclusion' takes on greater significance in disability policy and is crucial to ensuring more substantive equality for people with intellectual disabilities.[90] Poignantly, in his offensive against segregation, Hatton declares that for people with intellectual disabilities, 'inclusion is freedom'.[91]

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[87] Carlson, n 85, 149.

[88] The role of institutions in the past have indeed, sparked a whole field of sociology and intervention, (see the work of Wolfensberger for example). Foucault is then not the only prolific commentator on the impact of institutions. Goffman also addressed the impact of institutional life on individuals and recognised that an, 'underlife of institutions', existed that creates a, 'moral career of the mental patient'. Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, (Aldine Transaction, 2007).

[89] Carlson, n 85, 149.

[90] Yet actions and practices thereunder have also been criticised. Some theorists point out that not all efforts under the principle of inclusion are beneficial, nor are all forms of segregation to be considered as violations. In fact, according to some researchers, and quite on the contrary, integration and inclusion have had adverse effects. Colker, for example, discusses when the separation of persons with disabilities is, indeed, justified. Ruth Colker, *When is Separate Unequal? A Disability Perspective*, (Cambridge University Press, 2009).

[91] Hatton, n 77.

The Inclusion Model introduced here also identifies inclusion as a suitable response to the segregation and exclusion that has persisted on the basis of intellectual disability. The notion underpinning the fourth element of the Inclusion Model envisions that inclusion itself represents a form of equality and, thus, becomes an overarching, aspirational standard. Further, this element, with awareness of past transgressions resulting from exclusion, is premised on the notion that to be included in society is to be equal. Therefore, any means, falling under formal or substantive equality (utilising positive action, reasonable accommodation, or a range of other measures), employed to achieve this state of inclusion, is permitted where it supports the overarching objective of enabling participation in mainstream settings, in accordance with the dignity principles. The goal of inclusion justifies the means and, thus, equality theorists identify that inclusion itself, must become a form of justice.[92] In this way, inclusion, as both a status and a tool, is formulated not just as a goal, but also as a means by which equality is achieved.

Jones similarly identifies the central role of inclusion as a desired outcome, as well as an instrument for equality. In fact, Jones claims that, over time, international human rights law has evolved to devise a specific right to inclusion.[93] This call for inclusion to become an express right is also echoed in the disability rights movement.[94] As an idea, this argument is perhaps boosted by the CRPD, considering the focus it places on inclusion as a conduit for rights. Indeed, according to Degener, the CRPD fundamentally understands that an equal enjoyment of rights is not possible where people are not included in their communities, in rights frameworks, or in other social spheres.[95] Truly, inclusion, as both an action and a status (i.e. being included) becomes a conduit through which to ensure the enjoyment and access to all other rights and is, thus, arguably a prerequisite for full citizenship. Equating inclusion with equality in this way, and sequentially applying the other elements of this Inclusion Model, helps further illustrate how, by contrast, exclusion is both a product of and a contributing factor in, inequality.

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[92] Alfredo J. Artiles, Nancy Harris-Murri and Dalia Rostenberg, 'Inclusion as Social Justice: Critical Notes on Discourses, Assumptions, and the Road Ahead', (2006) 45(3) *Theory Into Practice,* 260-268.

[93] Precisely to what extent inclusion can be framed as a definitive right is worthy of further discussion. In an American context, at least, the U.S. Supreme Court, in the *Olmstead* ruling, expressly stated that the 'unnecessary segregation' of people with disabilities is a violation of their dignity and constitutes discrimination under the Americans with Disabilities Act (1990). In this example, the Court provides some indication of what an express right to inclusion might look like, by stating that people have the right to receive services in the most integrated settings possible. The terms 'inclusion' and 'integration' cannot be used interchangeably as these do contain some distinct nuances; nonetheless, this ruling does indicate an inclination towards more inclusive ideologies. Absent of any such strong and clear rulings in other jurisdictions, this thesis turns to the CRPD to assess whether we can glean any similarly definitive answers when considering the future legitimacy of sheltered workshops.

[94] Yuka Fujimoto, Ruth Rentschler, Huong Le, David Edwards and Charmine E. J. Härtel, 'Lessons Learned from Community Organizations: Inclusion of People with Disabilities and Others', (2014) 25(3) *British Journal of Management*, 518-537.

[95] Theresia Degener, 'Caroline Gooding Lecture by Theresia Degener, Inclusive Equality - A Human Rights Based Approach to Discrimination', (University of Leeds, 3 October 2018).

8.4.5 Measuring intellectual disability equality

The vision of achieving intellectual disability equality through elements of recognition, understanding, acknowledgment and the framing of inclusion as a right is certainly an optimistic aspiration. However, as shown in Chapter 2, with the indicative list of figures of people placed in sheltered work, such segregated services remain popular, suggesting that approaches applied so far, have had limited success. Arguably, this is because such approaches have not been comprehensive, sensitive or even idealistic enough to achieve intellectual disability equality.[96] I am, however, aware that a certain degree of idealism is essential for change. This is even more so the case considering, as this thesis does, how entrenched the unequal status, and how pervasive the exclusion of people with intellectual disabilities is. Any attempt to tackle this form of inequality at its root and to dismantle systems of segregation will undoubtedly necessitate envisaging the 'impossible' - indeed a requirement for any form of innovation. Not least, operationalising the Inclusion Model set forth herein anticipates an act of trust or 'practical naivety', but most of all a readiness to reject the apparent 'immutability of present circumstances' to achieve comprehensive disability rights.[97]

Understandably, the model for equality suggested here may be difficult to comprehend because of its intricate, interwoven elements and how it departs from traditional conceptions of equality. In fact, perhaps the most challenging aspect of this model is its departure from the known measurements of equality. Measurements are indeed essential to assess the methods of equality in use. I am aware, however, that pressures related to the requirement of measurement have the potential to scar the fragile promise of equality, primarily because conventional assessments apply standardised notions of what it should achieve. Amidst the many frameworks and benchmarks that have been developed to measure equality, the subjective nature of equality itself is then quickly overlooked.[98] This Inclusion Model, while aware of the need to appraise the methods implemented, prompts a rethink of the basis of such appraisals. After all, this model locates the very essence of equality in the equal recognition of importance and dignity based on understanding and acknowledging pervasive injustices and, for that reason alone, measurements thereof will differ significantly from previous approaches. After all, the requirement to include participatory elements in any measurements must be respected to ensure compliance with the CRPD's heavy focus on participation in all matters effecting people with disabilities, (Article 4(3) CRPD),

Aware of the multiple equality models, and debates on the matter of which equality model offers a truer measure of what is just, this thesis identifies that overall 'inclusion' is itself, a suitable benchmark. While an equality approach that is succinct and quantifiable, measured perhaps by ensuring equal living standards or equal wealth, is valuable, I argue that it is not paramount in achieving substantively better life

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[96] Ruth Northway, 'Integration and Inclusion: Illusion or Progress in Services for Disabled People?', (1997) 31(2) *Social Policy and Administration* 157-172.

[97] Ibid.

[98] Elizabeth S. Anderson, 'What Is the Point of Equality?', (1999) 109(2) *Ethics*, 287-337.

experiences. Instead, for people with intellectual disabilities, often, the development of social connections and relationships are more important goals than those of a material nature.[99] Research has shown that, for example, in discussions of why people with intellectual disabilities wanted to leave sheltered workshops, this desire was not largely motivated by material ambitions. Instead, being included in the community, along with a sense of acceptance and worth, through finding a job and participating in the mainstream labour market, were far more important than the anticipation of better wages.[100]

Demonstrating a deeper understanding of the experience of intellectual disability, this model suggests a simplified tool to measure equality, one that rejects existing standards in favour of newer, more individualised and unconventional ways to envisage success. Central to the formulation of this new approach to measurement, the proposed methods and outcomes in question should be considered against the primary goal of increasing inclusion, based on the four elements of this model.

First, the equality measure must be assessed against its ability to enforce the principle of **recognising** the equal importance of each human life, stemming from our common humanity. Perhaps this might be measured by the extent to which individuals are supported in living meaningful, self-directed lives and being enabled to flourish.[101] This element ensures all people are included in the scope of equality measures. This aim is further supported by the second requirement, that the equality measure should be assessed on the basis of its approach towards **understanding** the experience of intellectual disability. Actions thereunder involve a collective effort of achieving a greater understanding of impairment and disabled life, as well as greater interpersonal understanding. Third, the equality measure must be assessed against its **acknowledgment** of the impact of exclusion, its pervasive, institutional nature and insidious effect. This acknowledgement aspect also involves a process of critically reflecting on the 'regimes of truth' and the dynamics of power that have evolved from these, using the 'Foucauldian gaze'.[102] This element is premised on the belief that sustainable inclusion can only be achieved if we fully comprehend the experiences of exclusion. And fourth, the equality measure must be measured against its potential to

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[99] It is no surprise that what is taken for granted by others, i.e. being included and having access to the community and being part of a social network, are often designated policy goals for persons with intellectual disabilities. Then why not make inclusion the basis for equality?

[100] Some have even questioned the centrality of paid work in achieving full inclusion and have called for a reconfiguration of the meaning of work for disabled people. Paul Abberly, 'The Limits of Classical Social Theory in the Analysis and Transformation of Disablement', in Len Barton and Mike Oliver, (eds.), *Disability Studies: Past, Present and Future,* (The Disability Press, 1997); But statisticians like Cimera state: 'Put simply, working in the community makes economic sense for people with disability regardless of their diagnoses'. Robert Cimera, 'The Economics of Supported Employment: What New Data tell us', (2012) 37(2) *Journal of Vocational Rehabilitation,* 109-117; Stephen T. Murphy, Patricia M. Rogan, Mary Handley, Charles Kincaid, and Joanna Royce-Davis, 'People's Situations and Perspectives Eight Years After Workshop Conversion', (2002) 40(1) *Mental Retardation,* 30-40.

[101] Discussions about how to define and support 'human flourishing' are taking place and should underpin this element of the Model. See: Laura Davy, 'Philosophical Inclusive Design: Intellectual Disability and the Limits of Individual Autonomy in Moral and Political Theory', (2015) 30(1) *Hypatia,* 132-148; Robin West, *Nussbaum and Law,* (Routledge, 2017).

[102] Janet Heaton, 'The Gaze and Visibility of the Carer: A Foucauldian Analysis of the Discourse of Informal Care', (1999) 21(6) *Sociology of Health & Illness,* 759-777.

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enforce and protect the rights of people with intellectual disabilities and foster **inclusion as a right** in and of itself. It is important to note here that this is merely an indicative list of the ways in which the four principles of the Inclusion Model can be measured. Given how broad these building blocks are, along with the subjective nature of equality and dignity, there are vast possibilities for evaluation. A unique formula to measure the Inclusion Model may be impossible to find.

8.4.6 Putting the Model to work

The model suggested here can be actioned on various levels. It can be utilised at an ideological level to prompt new theorisations of the meaning of equality and inclusion, or an organisational level to restructure and inform service design or assist with decision-making for relevant matters. Moreover, the model can be implemented to fulfil various objectives, including teaching and learning objectives, an assessment of a service or organisation, or to monitor human rights compliance of planned or existing policy.

In terms of its theoretical implications, this model, it is hoped, might prompt a re-evaluation of the concept of equality from the perspective of intellectual disability. Steinhoff argues that our modern notions of equality have become convoluted and ineffective and that we need to wind back our understanding to comprehend the dimensions of basic equality. Accordingly, principles of equal dignity, concern and respect, equal rights, basic equality and equal worth must be re-addressed to 'awaken people from the dogmatic egalitarian slumber of present-day political philosophy'.[103] Steinhoff's reflections resonate with the findings of this research, which identifies that it is precisely because of this convolution, that people with disabilities remain excluded as the boundaries of quality are constantly drawn and re-drawn without them. Similar to Steinhoff's position, it is argued here that the basics of human rights law must be revisited, its purpose remembered with all of its subjects in mind.

The CRPD provides us with new opportunities to start this debate as it injects human rights law with new meaning. This new meaning is, however, only valuable insofar as it is actionable. Equality measures derived from it are only useful insofar as they are practicable. The new model for equality suggested herein introduces a 4-step process to ensure tangible change. It does so by reaffirming the basic principles of equality underpinning human rights law and emphasises that service and policy design must be approached in an inclusive and participatory manner. Generally, it is hoped, that this model would prompt an ideological paradigm shift towards a broader, ethos of inclusion. More theorisation on inclusion is necessary so that, as Sheppard believes, it

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[103] Uwe Steinhoff, (ed.), *Do All Persons Have Equal Moral Worth? On 'Basic Equality' and Equal Respect and Concern* (Oxford University Press, 2015), xii.

is fully embraced as a positive good and used to change the institutional cultures of our everyday lives.[104]

At a structural or organisational level, the Inclusion Model introduced here could be applied in practice to encourage transparency and accountability of services, but also ensure that these are fundamentally grounded on a human rights-based approach to service delivery. To achieve this, the goals of the service or institution could be measured against its capacity to fulfil the requirements of the Inclusion Model. This might include checking that it can objectively rethink the role of dignity, the importance of relationships and understanding, the social context of segregation and the value of inclusion in combatting it. The suggestion to introduce quality checks in service provision is not a new idea, yet the Inclusion Model introduces new elements that would significantly challenge current service delivery models.

Wolfersberger was one of the first academics working in the area of disability to challenge how residential institutions for people with disabilities were run. He introduced the idea of quality tests to assess human services, which at the time seemed radical.[105] Wolfersberger was convinced of the need to introduce quality checks based on a realisation that human services are created and performed within a societal context in which they exist and will inevitably reflect its values and norms inwardly, inclusive of its moral failings. Wolfensberger, therefore, advocated for the need for critical evaluations of services. Assessing the dynamics and systems of human service organisations he believed, would make them more accountable and elucidate their moral foundations.[106] Today, quality frameworks are utilised in most States to assess the provision of services for people with intellectual disabilities. I consider that such quality checks must assess rights compliance and be measured against their focus on achieving equality. The Inclusion Model could provide a basis for such assessments, or even advise departments in charge of regulating the sector. To facilitate this process, the model could be translated into a training package offered to officials, staff, students and other stakeholders via a workshop.

At minimum, it is hoped that the Inclusion Model would be used to assist debates at national level on the occasion of State party reporting as part of the monitoring process to ensure treaty compliance. After all, every country in the world whether rich or poor, developed or developing, is faced with real challenges in implementing the rights set out in the CRPD. It is hoped then, that this model might inform national dialogue processes by centring on the rights of people with intellectual disabilities and highlighting the problematic issue of segregation in sheltered work in particular.

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[104] Colleen Sheppard, *Towards Inclusive Equality: The Relational Dimensions of Systemic Discrimination in Canada*, (McGill University Press, 2010), 146.
[105] Wolf Wolfensberger and Susan Thomas, 'Introductory Social Role Valorization Workshop Training Package', (Syracuse University, Training Institute for Human Service Planning, Leadership and Change Agentry, 2005).
[106] Wolf Wolfensberger and Susan Thomas, PASSING: A tool for analyzing service quality according to Social Role Valorization criteria. Ratings manual (3rd rev. ed.), (Syracuse University Training Institute for Human Service Planning, Leadership & Change Agentry, 2007).
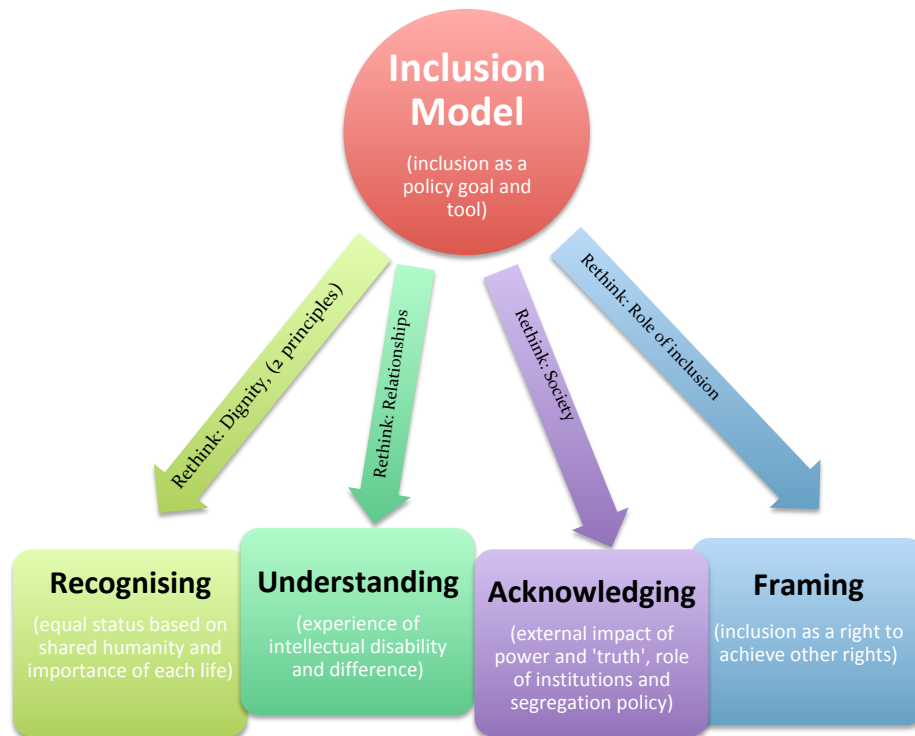
8.5 CONCLUSION

A review of the existing equality models and of equality as pursued in the CRPD, with specific regard to the implications for sheltered work, has highlighted that, despite an evolved approach to equality, the CRPD's ability to effect practical change for people with intellectual disabilities is limited. While previous theories may have advanced rights arguments to tackle the most obvious instances of discrimination and disadvantage, as the previous discussion has revealed, more is required to find an appropriate response to discrimination on the basis of intellectual disability. To remedy the inability of current equality discourses to comprehensively tackle segregation and demonstrate a sensitivity of the intellectual disability characteristic, this chapter introduces its own model to achieve intellectual disability equality that is rooted in dignity and based on inclusion.

The Inclusion Model presented here provides a critical and alternative context within which to examine legal equality (i.e. eligibility for rights) and social equality (i.e. being included) as it prompts a rethink in terms of entitlement, values and goals for equality. Moreover, this model is made up of several elements and suggests multifaceted ways in which the concept of inclusion can be inflated as both an ethos and a right to challenge the exclusion of people with intellectual disabilities.[107] The elements of this new approach interact with and substantially challenge the current hegemony of normalcy that determines 'eligibility' in order to restore the universality principle of human rights. More specifically, the four elements operate to **recognise** people with intellectual disabilities as eligible for equality, to enhance the **understanding** of the experience of intellectual disability, and to challenge existing conceptions thereof by **acknowledging** their exclusion as problematic, and **framing** inclusion as a distinct, justiciable right. The methods employed under this model then require action both on a conceptual and tangible level. Fundamentally, the principles of inclusion that make up this new equality approach build on the equal importance and worth of each human life, restoring the fundamental promises of human rights law with a more inclusive focus.

Below is a graphic representation of the Inclusion Model for intellectual disability equality.

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[107] Aware that the term 'inclusion' is a loaded word, the meaning of which requires further debate, here it is employed as term to confront forced and structural segregation policies and defy the common notion of persons with intellectual disabilities as unequal persons. Inclusion is, then, not solely defined by 'participation', but by being considered as an equal, and by being considered and respected as a bearer of critical interests regardless of what those may be. In this way, real 'choice' might then be a more apt marker of equality as it means that alternatives are offered because other voices have been included in the design of policy and services.

Intellectual Disability Equality

Graphic of Inclusion Model (CMS_2019)

Chapter 9: Conclusion

This concluding chapter summarizes both the findings of this research and the arguments presented in the previous chapters. This chapter will first summarize the findings of each of the 3 sections before providing some broader conclusions that address the overarching research question whether the CRPD can help achieve intellectual disability equality by tackling segregation. Next, this chapter identifies some of the research limitations and suggests further areas of investigative interest identified during the research process. Finally, some policy recommendations are offered before concluding with some words outlining the contribution of this thesis to the field of research.

9.1.   SUMMARY OF FINDINGS:

9.1.1.   Section: 1 Sheltered Work

Having introduced 'Francesca's story' to describe a typical experience and career projection, common to many people with intellectual disabilities, the ensuing discussions in Section 1 listed the common problems associated with sheltered work and employment.

This investigation of the literature and reports of sheltered work, though limited, revealed that sheltered work is an employment model typically used in Western, democratic States with generous welfare systems. In States where an industry of care has developed and become a manifest part of service provision, institutional services have a long history and sheltered work is often the predominant form of employment for people with an intellectual disability. The present study highlighted that although many, multifaceted sheltered work and employment models exist, there are some commonalities and characteristics that create an almost unified experience of the practice across the world. These commonalities and characteristics were distilled from the literature presented in Section 1 and include the experience of segregation and the concomitant sense of exclusion, being stuck in life-long training, low transition rates on to the open labour market, low rates of remuneration, uncertain work status, unfavourable working conditions and a lack of alternative choices, to name just a few. A list of these concerns points to the inevitable finding that, overall, as an element of employment, rehabilitation or training policy, the sheltered workplace, almost by definition, fails to prepare people with disabilities for open employment, or otherwise facilitate the inclusion of people in any meaningful way in their communities.

Despite the controversial legacy of sheltered workshops and the fact that they rarely help people to find real employment, the findings of this research confirm the existence of an unshakeable notion that this type of service is still required and must persist.[1] Indeed, segregated services remain the predominate type of employment service for people with intellectual disabilities. Essentially, they operate as part of a network of 'special' industries created around the label of intellectual disability. One of the most pertinent findings of this section is that overall, as an employment, training or rehabilitation service, sheltered workshops fail to achieve the objective of transitioning and preparing people for work and inclusion. In fact, and this is rarely addressed in the literature or elsewhere, the sheltered work system contains an inbuilt need to maintain itself. Segregated services breed a self-perpetuating cycle of dependency between the service and its clients that we must begin to unpack.

9.1.2. Section 2: Intellectual Disability (In)equality

In an attempt to understand how sheltered work continues as an accepted policy despite its many shortcomings, Section 2 addresses the position of people with intellectual disabilities, using an equality lens. Chapter 4 explores the notion that modern, democratic societies are governed by a social contract that is based on a liberal understanding of equality. Liberal ideals underpinning a collective understanding of equality have shaped most legal orders and served to separate people with intellectual disabilities from other citizens. Indeed, throughout legal history certain groups have been marked and kept apart by deliberate laws and policies on the basis that they did not possess the moral powers required to enter into the social contract and thus be considered as equal. People with intellectual disabilities are still regarded as ineligible for the same balance of rights and, thus, are considered unequal. Disregarded as equal citizens this group remains largely excluded from their communities and mainstream settings, eternally poised as passive objects, rather than subjects of law. Moreover, their subjection to unequal treatment, as exemplified by their segregation in sheltered work and employment, has yet to be recognised as a form of discrimination. This study argues that institutions like sheltered workshops, therefore, play a significant role in perpetuating this form of inequality.

This theoretical discussion exposes how, over time, the exclusion of certain groups has been internalised and legitimised within systems of society. Based on a perceived ineligibility for rights, along with a collective belief as to what is considered 'normal' or merit worthy, the exclusion of people with intellectual disabilities has then been endorsed as the natural, 'normal order of things'. As a result, widespread automatic segregation on the basis of intellectual disability has remained unopposed. The inferior and subordinate treatment of people with intellectual disabilities continues, even as

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[1] Milton Tyree, Michael Kendrick and Sandra Block, 'Strengthening the Role of the Employee: An Analysis of Supported Employment Using Social Role Valorisation Theory', (2011) 35(3) *Journal of Vocational Rehabilitation,* 197-209.

more evolved equality approaches replace out-dated, biased ones. A discussion of these concludes that they are still inadequate and fail to accommodate true 'differences'. The concept of equality as presented in the CRPD is, consequently, explored for its potential to offer a remedy and enable the achievement of intellectual disability equality.

9.1.3.   Section 3: The CRPD

Section 3 examines the CRPD's potential impact on the unequal treatment of people with intellectual disabilities and, specifically, on how it can tackle their segregation. Heralded, through its innovative approach to equality, as the harbinger of change, an exploration of the ability of the CRPD to both challenge current exclusionary practices and dismantle them is overdue. A review of the literature has revealed that an exploration of the CRPD's impact on the practice of sheltered work from an equality perspective is sadly lacking. As a result, and because the CRPD remains silent on the issue, myriad interpretations of its position on these have surfaced, to the effect that exclusionary practices are reconciled with it.[2]

Chapter 6 proceeds to introduce Article 27 and discusses the reason behind its omission of any reference to sheltered work and employment. The ensuing review of the negotiation archives reveals not only how surprising this omission is, given the extent to which sheltered work and employment featured in previous international documents, but finds that this was a purposeful decision made to secure a consensus. Sheltered work and employment were, in fact, discussed intensively during the negotiations, a review of which highlights conflicting positions over the purpose and future of the practice.

Chapter 7 broadens this investigation of the CRPD's impact on sheltered work settings by reviewing jurisprudence from the CmRPD. The CmRPD has used many opportunities to clarify that, in principle, sheltered work does not comply with the equality objectives of the CRPD. The review of the Concluding Observations signals that sheltered work and employment is a popular service and will continue to exist in the future. In response to this, the CmRPD have repeatedly expressed their concern over the continued use of this employment model and of the exploitative conditions in some settings. The CmRPD, therefore, calls repeatedly for the protection of workers in sheltered work and urges States Parties to discontinue this service model. Similar advice also features in its GC No. 6, in which it interprets the CRPD's equality obligations placed on States Parties as these relate to work and employment, and specifically to sheltered work.

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[2] This risks States remaining unconvinced and impervious to the view that these types of institutions are fundamentally problematic.

This review of communication from the CmRPD on sheltered work and employment reveals some conflicting advice. The treaty body has declared that sheltered work is in opposition to the CRPD's ideology of equal rights and inclusion and frustrates the aims under Article 27 wherein, employment on an open, accessible and inclusive labour market is preferred. In line with this position, the CmRPD calls for the immediate enactment of transition plans out of sheltered settings so as to end this form of institutionalisation. The CmRPD simultaneously envisages an approach that secures the rights of workers in segregated work settings, one that promotes their equal status to that of workers on the open labour market. This call for the same conditions and labour standards of work in segregated work settings is, however, a decidedly different recommendation to the aforementioned call to eradicate these settings. In fact, this analysis finds that these two aims are contradictory. Where time and resources are invested in granting sheltered workers equal rights and labour standards, these settings, far from being dismantled, become, instead, legitimate places of work. As a result, people with disabilities, albeit possibly enjoying more labour rights, remain segregated, and the right to inclusion and participation are at risk of being side-lined.

In addition to the above finding, Chapter 7 discusses how the CRPD's equality provisions include a potential for individual claims of discrimination in cases of wrongful exclusion. Article 2 of the CRPD has widened the definition of discrimination on the basis of disability to include any act of distinction, exclusion or restriction on the basis of disability that interferes with the enjoyment, recognition or exercise of any rights on 'an equal basis with others'. While the limitations of ensuring rights on an 'equal basis with others' are highlighted in Chapter 6, this disability-sensitive definition does hold some potential. Arguably, the practice of segregated work could be challenged using the tailored legal concept of discrimination presented in the CRPD. This is a unique and exciting innovation. However, as an interpretive provision, it is one that still relies on traditional systems of redress and requires individual tests for a finding of discrimination. This innovative definition of discrimination in Article 2 is, thus, unlikely to challenge whole policies or dismantle entire systems of segregation and provide immediate results.

9.1.4. Comprehensive Findings

Besides the questionable ethics and ideologies behind segregation, this investigation pinpoints how sheltered work placements may be directly responsible for the multiple disadvantages experienced by people with intellectual disabilities. Apart from presenting a barrier to participation and inclusion, sheltered work interferes with the enjoyment and recognition of many other rights and, thus, is identified herein as a source of inequality. The research then discussed how people with intellectual disabilities, generally, have been regarded as ineligible for equality considerations - a position that is derived from liberal thought and renders this group as fundamentally unequal and subject to unequal treatment. The CRPD was then scrutinised for its

response to this form of unequal treatment and, ultimately, its ability to impact upon the lives of people with intellectual disabilities by challenging their segregation as a form of *prima facie* discrimination.

This thesis thus explored the vision of equality embedded in the CRPD to assess its strength in achieving intellectual disability equality and to challenge sheltered work practices. The CRPD acknowledges the normativity embedded in human rights that must be tackled by devising a disability-sensitive vision of equality. However, tested against the specific practice of sheltered work, identified herein as a significant inequality, its impact is negligible. It does indeed demonstrate an awareness of the multiple experiences of disability discrimination but appears less sensitive to the specific situation of persons with intellectual disabilities. This examination therefore concludes that, although laudable, the liberal ideals that underpin most regulatory frameworks are replicated in the CRPD. As a result, the CRPD is an instrument that is limited to operating within the confines of traditional law and risks further marginalising people with intellectual disabilities. Despite being premised on the principles of inclusion and an equal concern and respect for the dignity of each person, its impact on achieving intellectual disability equality is limited.

As a process and an abstract concept, equality demands constant re-negotiation to operationalize its meaning and impact in law. This discussion highlights how people with intellectual disabilities remain excluded as the boundaries of equality are constantly drawn and re-drawn. Even the latest iteration of equality, as presented by the CRPD, yields disappointing results in terms of its impact on instigating real change for people with intellectual disabilities. All is not lost, however. While the CRPD does contribute little towards ruling out segregation in segregated work settings *per se*, it does provide us with some direction. The human rights model of disability that it envisages serves to provide a basis for further discourse. In an attempt to take up where the CRPD's 'equality buck' stops, this thesis develops an alternative approach to securing intellectual disability equality. The new model for equality is designed to specifically tackle exclusion and segregation by focusing on inclusion.

The new model, also founded on the human rights model of disability, reaffirms the basic principles of equality underpinning human rights law, whose purpose is to ensure an equal concern and respect for the inherent dignity of each person. The Inclusion Model presented here is a layered approach, comprising a 4- step process outlining sequential 'principles of inclusion' that must accompany all rights and equality actions. These steps comprise, 1) **recognising** the equal importance of each life, 2) facilitating a greater **understanding** of disabled lives, 3) **acknowledging** harmful traditional practices of exclusion and segregation, and 4) **framing** inclusion as a human right and, by contrast, exclusion as violation thereof.

9.2. LIMITATIONS

This study has faced some limitations, which are identified and reflected upon in the following discussion. These limitations arise from the subject matter itself, but are also influenced by the researcher's own views on the practice of sheltered work.

During the research conducted for the thesis, the researcher noted that little material exists that addresses the CRPD's impact on sheltered work. Indeed, this was one of the fundamental gaps in the current knowledge that this thesis aimed to plug. Moreover, during the course of the investigation into both the literature and the reports used for Section 1, it became evident that only limited and dated research existed addressing the impact of sheltered work on those attending such services. Overall, there was a significant scarcity of any reports listing any negative consequences upon the enjoyment of rights arising out of sheltered work settings. This investigation reveals that the practice as a whole has, to date, not been challenged from a rights-based, legal perspective in any comprehensive manner. Consequently, sheltered work and employment models have never before been analysed in terms of their impact on intellectual disability inequality. Addressing the inequality of segregation in sheltered work has, therefore, been a novel feat, with little and limited literature to inform this journey.

Undeniably, the reasons for this dearth of available literature lies in the fact that intellectual disability rights research is only emerging as a field of study currently. The persistent and on-going marginalisation and disenfranchisement of this group, coupled with their resulting voicelessness, is, indeed, both the reason for, and the consequence of this lacuna. Even when intellectual disability rights are addressed in reports and publications, these are rarely legal texts, and the issues addressed are often limited by a preoccupation with the fight for rights to basic services, such as care, rehabilitation or education. Rights entitlements in terms of work and employment for people with intellectual disabilities have, thus, simply not been addressed in academic scholarship. The experiences of people with intellectual disabilities have largely remained under-researched using an equality lens, which brings us to a further limitation of this study in terms of study design.

Aware of the precarious position of people with intellectual disabilities in policy and law, this research could have rectified this and included their voices. Certainly, participatory research that involves researched groups at all stages of the research design is expanding across some disciplines. However, the decision here was, instead to refrain from including a selection of individual voices, and present a single example in the vignette in Chapter 1. Strategically placed at the beginning of this study, the vignette serves to depict the social exclusion experienced by most people with intellectual disabilities. As a very typical story, 'Francesca's story' is, thus, symbolic enough to illustrate the problem being researched. This study also refrained from any participatory elements as the aim was not to explore individual experiences but, rather, to address the structures of in/equality more broadly. Conducting interviews, or

otherwise collecting raw data from this population, which is already subjected to much medical and psychological research probing, was deemed superfluous.

My own experiences and personal involvement in the disability rights movement could be perceived as another research limitation, contributing to a pre-existing bias against sheltered work services. Indeed, it must be acknowledged that many stakeholders, and often even sheltered workers themselves, vehemently oppose the closure of such institutions. A further limitation of this study is, perhaps, the lack of attention afforded to such stances. However, as previously noted, the aim has not been to fight for the indiscriminate termination of all forms of existing institutional service provision. Rather, the aim has been to highlight how sheltered work is still the predominant service for most people with intellectual disabilities, and the reason for their continued exclusion. As a result, the argument that these placements potentially constitute a violation of their rights must be explored.

A last limitation I would like to address concerns the topic of sheltered work itself. This investigation has unearthed just how divisive the topic of sheltered work is, making generalisations difficult. Indeed, there are, perhaps, no 'right' or 'wrong' forms of sheltered work, and arguing that there are was not the purpose of this study. In fact, one of the main challenges in researching the subject lies in the overwhelming diversity of such programmes, structures and systems across the globe, which can even differ internally, at domestic level. The extent of this diversity makes comparisons difficult and dilutes the effectiveness and impact of broader discussions, representing a significant limitation of this thesis. Articulating a global response is impossible; nevertheless, as an employment model, sheltered work does exist in some format in most industrialised countries and shares some common characteristics. So while there are considerable differences in practices across the globe, there are sufficient, inherent commonalities that warrant being addressed in a single study.

9.3.   FUTURE RESEARCH AGENDA

In accordance with the research focus of each section discussed previously, this research was conducted with a narrow scope, spanning the topics of sheltered work, intellectual disability and equality, and assessing the impact of the CRPD thereupon. Other important issues, outside of the scope of this study, were identified throughout the course of this research and ought to be addressed in the future. It is worth mentioning those areas of research that require further attention so as to generate a comprehensive understanding of sheltered work, its legal ramifications and its impact on the lives of persons with intellectual disabilities. After all, identifying gaps in the research is the first step towards generating holistic solutions with appropriate responses to on-going inequalities. The following addresses areas of further research, with some suggestions.

With the introduction of the CRPD, a new ideology of disability is in circulation and this has translated into more rights-based policies for people with disabilities. Without doubt, the CRPD has spurred wider discussions on fundamental rights issues, particularly legal capacity and the Article 12 obligations on equal recognition before the law. Yet, other fundamental issues concerning the rights of people with intellectual disabilities remain largely ignored or unexplored. In particular, the topic of segregated service provision is limited in academic debate. Often, this is reduced to the issue of residential institutions and discussions on Article 19 rights with regard to independent and community living. Segregated educational services for children are also often addressed in scholarship on Article 24, on the right to inclusive education.[3] However, other forms of segregated services, especially those for adults with intellectual disabilities, are largely unexplored in rights research. Further research is needed to identify more forms of segregation and investigate services in a critical light, using the CRPD as a framework for discussions.

One of the main findings of this research is the fact that sheltered work and employment is not explicitly addressed in the CRPD, leading to problematic interpretations as a result. Considerably more work is needed to determine and clarify how States Parties should regulate and (re)define existing sheltered services. This throws up further questions as to how these facilities and services should be organised and run by authorities and viewed ideologically, by society. Herein, I have exposed how, under its definition of discrimination, and despite some unfavourable interpretations, the CRPD carries the potential to be used as a tool to challenge the segregation of people with intellectual disabilities in sheltered work. Provided that the practice of sheltered work can be objectively shown to lead to exclusion and isolation, it could potentially be tested as a form of discrimination in legal arenas. A test case that addresses specifically this issue would be particularly welcome and could further clarify States' obligations on the matter.[4]

Specifically, in the US, interesting developments in this area are taking place, thanks to the Supreme Court ruling in *Olmstead*, in which it ruled that segregation could be considered a form of discrimination. Since then, legal challenges of various forms of segregation have taken place, including actions challenging sheltered workshops. A review of these cases, particularly those bought by the Department of Justice against the States of Oregon and Rhode Island, would be of compelling interest. The U.S. has not ratified the CRPD, in accordance with its general policy of non-observance of UN human rights treaties. However, its Americans with Disabilities Act of 1990 has secured rights in many areas through litigation; its application in *Olmstead* was hailed as a landmark achievement in recognising the rights and dignity of people with intellectual disabilities. Further research that focuses on these developments and compares them

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[3] For a holistic handling of the topic, see the authoritative work of: Gauthier de Beco, Shivaun Quinlivan and Janet E. Lord, (eds.), *The Right to Inclusive Education in International Human Rights Law,* (Cambridge University Press, 2019).
[4] I have discussed potential guidance for CRPD implementation by using EU case law on sheltered work. Charlotte May-Simera, 'Framing the immediate application of labour standards in segregated employment, a demand by the CRPD Committee: Can the European Court of Justice offer guidance?' (*forthcoming*).

with similar litigation attempts elsewhere, along with the rights framework laid out in Article 27, CRPD, would be a worthwhile endeavour and would promote further learning on the future of sheltered work.[5]

As noted above, this research did not include any direct consultation with persons with intellectual disabilities, which is certainly one of its limitations. People with disabilities, as a group, have largely been treated as objects of research rather than active participants. It is important to acknowledge that their voices have remained silent for too long. Endeavours to include people with intellectual disabilities in research that concerns them must be a priority. Further qualitative and quantitative research that is cognisant of the participative dimension of the CRPD (Articles 3, 31) is required. Ideally, this type of research would draw on the advocacy efforts of international, national and regional DPOs directly representing the interests of people with intellectual disabilities. Specifically, a wider, systematic research project with the aim of investigating the desired alternatives to sheltered work, as expressed through these organisations, is urgently required.

A further topic for future research identified herein, could explore how States can re-direct its resources and attention away from an old agenda (incentivising sheltered workshops though state aids, public procurement exemptions, capital grants, wage subsidies) to supporting supported employment. This would examine what inclusion in the open labour market might look like. Human rights, to be useful, must have something positive to say about the shaping of the private market – and not just about its desired results. Additionally, this research identified that the very concept of sheltered work contains an inherent flaw, i.e. that its purpose of training and rehabilitation while aiming to sustain itself, represent a dichotomy, (see Chapter 3.5). As a result of this important finding, I suggest that the link between private interests and public policy as a complicating factor in the process of change (i.e. corruption) could be further examined.

Lastly, this research would greatly benefit from a follow-up investigation to explore the implications of its revised equality approach. Indeed, an investigation of the practical application of the Inclusion Model, developed in Chapter 8, would be a valuable endeavour. The model could be tested by analysing a planned policy, in the initial stages of design, aimed to increase the inclusion of people with intellectual disabilities in the context of employment.

9.4.   POLICY RECOMMENDATIONS

Evidence from this study suggests that it cannot be assumed that human rights law as prescribed in the CRPD will be automatically adapted by ratifying States and translated

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[5] See the paper by Prof. Mark Bell addressing: 'People with Intellectual Disabilities and Employment Discrimination Law: A US Case Study', (2019) 35 *Comparative Labour Law and Industrial Relations*.

into tangible rights for people with intellectual disabilities. Rather, the CRPD should be viewed as a powerful tool for social change, provided it is employed strategically and is meaningfully utilised by agents of change. While the Inclusion Model suggested herein may play an important role in advancing disability rights and inclusion, this alone will not suffice in harnessing the CRPD's potential for change. Further actions and learning are required. In support of this, the findings generated by this study are presented as a set of 4 general recommendations that can be used to develop more rights-based disability policy:

1) Implement policies that prevent segregation from early on:

Despite an increasing awareness of the problems associated with sheltered work and employment, this research indicates that it is unlikely that segregated systems will be eradicated overnight. Not only have figures attending sheltered work risen, but disagreements exist as to their role and, subsequently, also with regard to their future. What is evident in this research, and is portrayed in 'Francesca's story', is that one segregated service seamlessly feeds into another, creating 'wraparound' models of service provision. This research has also exposed the self-serving characteristics of the sheltered work setting. To curtail the need for sheltered work settings, it is important to implement policies that prevent the segregation and exclusion of workers with disabilities from the outset, starting with education. With a realisation of the complementary nature of education and work, measures to tackle segregated services should be geared to those services designed for young people, thus ensuring that they do not begin on a path that eventually, automatically places in a workshop.[6] To this effect, more investment into developing supports in education and employment is required. While it has not been the focus of this research, there exists a wealth of research that illustrates how early intervention with individuals with intellectual disabilities positively impacts on their finding employment on the open labour market.[7]

2) Hold sheltered work services accountable:

This research has discussed how large organisations that often function as institutions still hold great power over the lives of persons with disabilities.[8] This body of work maps how disability services operate in a way that exacerbates the dependency of their

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[6] Michael Weber and Britta Wagner, 'Inklusion, Integration und Lebensqualitatet in Werkstaetten fuer behinderte Menschen', ('Inclusion, Integration and Quality of Life in Workshops for Disabled People'), (2015) 66(3) *Zeitschrift for Heilpaedagogik (Journal of Rehabilitative Education)*, 128.

[7] See, for example: Domingo Garcia-Villamisar, Paul Wehman and Maria Diaz Navarro, 'Changes in the Quality of Autistic People's Life That Work in Supported and Sheltered Employment. A 5-Year Follow-up Study', (2002) 17(4) *Journal of Vocational Rehabilitation*, 309-312; Gary Bond, 'Supported Employment: Evidenced for an Evidence-Based Practice', (2004) 27(4) *Psychiatric Rehabilitation Journal,* 345-359; Kim Mueser, Deborah R. Becker and Rosemarie Wolfe, 'Supported Employment, Job Preferences, Job Tenure and Satisfaction', (2001) 10(4) *Journal of Mental Health*, 411-417.

[8] For more discussions on this topic, see: Jeanne Hayes and Elizabeth Hannold, 'The Road To Empowerment: A Historical Perspective on the Medicalization of Disability', (2007) 30(3) *Journal of Health and Human Services Administration*, 352-377; or: Kelley Johnson and Rannveig Traustadóttir, (eds.), *Deinstitutionalization and People with Intellectual Disabilities: In and out of Institutions,* (Jessica Kingsley Publishers, 2005).

subjects and disempowers them. Ultimately, the institution, whether residential, educational or work-related, undermines the autonomy of its participants, represents a lack of choice, and interferes with their ability to govern their own lives.[9] Finkelstein speaks of a, 'social death' that occurs in institutions and, more generally, through segregation.[10] Furthermore, the criticisms of sheltered work, listed in Section 1 of this study, show that the commercial interests of these settings may often be incompatible with the interests and goals of individuals therein. On the basis of these concerns, social policy researchers have suggested operationalising a 'Model Coherency Analysis', first introduced by Wolfensberger and Thomas, to assess the quality of services. According to this method of program analysis, services are scrutinised for their objectives and priorities, and whether these are working to benefit the intended addressee.[11] This research study confirms the continued need for independent review, assessment and accountability of sheltered work services.

3) Fully commit to the idea of 'inclusion' (identify action):

Because the experience of segregation is so pervasive amongst people with intellectual disabilities, this thesis has introduced a 4-step approach to facilitate a process of 'rights-repatriation.' With the aim of formulating intellectual disability equality, the suggested model places inclusion at the centre of this process. As a concept, a right and a policy, 'inclusion' has, however, been subject to much debate regarding its concrete meaning and its tangible implications.[12] As a tool for intellectual disability equality, inclusion has to mean change and choice, not simply a confirmation of a right to be included geographically or permitted to participate on paper. Rather, a process of critical reflection and 'enablement', based on a true understanding and acknowledgment of intellectual disability inequality is essential, and must accompany any future efforts. Inclusion must become internalised in law and policy as a systematic approach, an attitude, an ethos, a belief.[13] Just as segregation does not simply refer to a place but is the manifestation of a set archaic practices and a lack of choice, a philosophy of inclusion also necessitates being incorporated into laws, systems and minds.

As part of this process, the assumption that the material difference of intellectual disability, often argued to justify or even necessitate their continued segregation in institutions such as sheltered workshops, must be challenged. Quinn et al. suggest, that,

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[9] Paul Wehman, Grant Revell and Valerie Brooke, 'Competitive Employment: Has It Become the "First Choice Yet"?', (2003) 14(3) *Journal of Disability Policy Studies*, 163-173.

[10] Vic Finkelstein, 'Disability: An Administrative Challenge?' in Mike Oliver, (ed.), *Social Work – Disabling People and Disabling Environments,* (Jessica Kingsley Publishers, 1991).

[11] An updated version of this method can be found at: Wolf Wolfensberger and Susan Thomas, *PASSING: A tool for analyzing service quality according to Social Role Valorization criteria. Ratings manual (3rd rev. ed.),* (Syracuse University Training Institute for Human Service Planning, Leadership & Change Agentry, 2007).

[12] See, for example: Deborah Metzel and Pamela Walker, 'The Illusion of Inclusion: Geographies of the Lives of People with Developmental Disabilities in the United States', (2001) 21(4) *Disability Studies Quarterly*, 114-128.

[13] National Council on Disability, '(IDEA Series), The Segregation of Students with Disabilities', (National Council on Disability (NCD) 2018).

[i]nstead, the actual wishes of the person counts and must be ascertained in circumstances that allow for realistic alternatives. The separate treatment, if it is allowed, must always be pegged to a larger dynamic of inclusion, which foresees measureable investments in alternatives. And in any event, a totalizing option (like a long term care residential institution) that effectively constricts a person's life-chances could hardly be warranted.[14]

4) A call on the CmRPD to clarify its position on Sheltered Work:

In GC No. 6, the CmRPD outline their interpretation of Article 5 CRPD on equality and non-discrimination in reference to Article 27 CRPD on work and employment, with conflicting advice. Similar to its recommendations to States Parties in the Concluding Observations, the CmRPD propose both moving away from sheltered workshops, as well as ensuring worker's rights therein. As outlined in more detail in Chapter 7, this dualism is somewhat contradictory and has the potential to cause confusion, or even further justify the provision of sheltered work services. As a result of this finding, I recommend that the CmRPD provide clarification of its position with a conclusive, authoritative interpretation of the CRPD with regard to sheltered work. In other policy areas, the CmRPD has already definitely established segregation in institutions as a *prima facie* form of discrimination (for example, in regard to segregation in residential institutions and in education).[15] A similar clarification, addressing the exclusion and segregation in sheltered workshops, is required so that an unwavering process of transition and replacement can begin.

9.5.   RESEARCH CONTRIBUTION

This research positions itself amidst a growing catalogue of disability rights research, spurred in particular by the adoption of the CRPD. More specifically, this research offers a significant contribution to a wider movement that sees a gradual focus on the hitherto unchallenged, widespread segregation of people with intellectual disabilities in institutions and similarly structured services. The research tackles, particularly, sheltered work and employment therein, as one such type of institutionalised form of service provision. Ultimately, this thesis calls into question the logic behind such practices and highlights their harmful philosophies, providing evidence that these repeatedly fail to transition people onto the open labour market or other settings in the community.

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[14] Gerard Quinn, Grainne de Burca, Lisa Waddington, Mark Bell, Anna Lawson, Michael Stein, Titti Mattsson, Luke Clements, 'Legal Memo: Segregation and segregated facilities as a *prima facie* form of discrimination. The Impermissibility of using the ESIF to invest in monies in long term care residential institutions for persons with disabilities', (2018), 8, [online], available at: <https://enil.eu/news/segregation-and-segregated-facilities-as-a-prima-facie-form-of-discrimination/> (accessed 16 August 2019).
[15] In fact, the CmRPD identify the problem of segregation and exclusion in Institutions in each of its General Comments published to date. Segregation and exclusion is perhaps most holistically addressed in the CmRPD's GC No. 4 on the right to inclusive education. Therein, the CmRPD elaborates from the outset that, '[t]he right to non-discrimination includes the right not to be segregated'. (CRPD/C/GC/4), para. 13.

Using evidence from social research, this study discusses the dimensions and effects of an identified social problem and exposes its legal roots. With help from a discursion into the liberal underpinnings of equality, this investigation unpacks how some members of society have been discounted and, as a result, excluded both from rights and dignity deliberations, and from participating in society on an equal basis with others. This research identifies how, on the basis of being, fundamentally, held as unequal members of society for too long, the unequal treatment of people with intellectual disabilities has come to be perceived as an inevitable consequence of their differences. In a society in which the entitlement to rights is ascribed on the basis of merit-worthy attributes that favour ability and productivity, this exploration has prompted the reader to question this perception of the 'natural order of things'. As a result of such widely held 'truths', the inequalities experienced by people with intellectual disabilities are simply not identified as such.

It is hoped that the exercise of highlighting the practice of sheltered work and its problems will prompt a wider re-thinking of the kind of society of which we want to be a part and, finally, see a re-positioning of people with intellectual disabilities in law and policy. Quinn discusses the practice of excluding people with disabilities and describes the need for a deep reflection on who we are as a collective, and what sort of a society we want. He contemplates that, 'all societies are defined as much by whom they exclude as by whom they include. This applies literally at our borders'.[16] Looking inwards then, this constant act of defining and redefining of who is 'in' and who is 'out' sees an organisation of society, whether economically or socially, in 'concentric circles of exclusion'.[17] In an attempt to combat this social process of exclusion, this research looks to the potential impact of a new human rights framework, with a somewhat naïve belief in legalism, to prompt a cure for the social ills of society.

While highlighting the persistent disregard of a particular group in society, this study shines a light on the potential the CRPD has to instigating changes in policy and law. This study is steadfast in the belief that with the CRPD we have at our hands a predefined vision of the kind of society we should aspire to and work towards creating, along with a directory of laws and policies required to achieve this vision. To ensure a homogenous application of the CRPD, this thesis has unpacked its intention and its text to consider its utilisation in combating segregation in sheltered work. Investigations of this nature are indeed necessary. As Quinn explains, the CRPD, in effect, creates space for a new politics of disability, and it is up to us to fill that space by giving it further meaning and maximising its potential.[18]

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[16] Gerard Quinn, 'Reflections on the Value of Intersectionality to the Development of Non-Discrimination Law, (2016) 16 *The Equal Rights Review*, 63-72.

[17] Gerard Quinn, 'The Human Rights of People with Disabilities', in Philip Alston, (ed.), The EU and Human Rights, (Oxford University Press, 1999), 281.

[18] Gerard Quinn, 'Bringing Rights Home, Civil Society Impacting Change- Making the Most of the New Politics of Disability Created by the UNCRPD', (8th International Summer School on Disability Law, Centre for Disability Law and Policy, National University of Ireland, Galway, 2016).

It is the intention of this thesis to contribute to filling this space, not only by examining the cross-sections of sheltered work, equality and the impact of the CRPD, but by adding its own 4-step Inclusion Model to fully achieve the aims of inclusion and equality set out in the CRPD. In spite of its limitations, the study certainly adds to our understanding of the experiences of persons with intellectual disabilities, and offers valuable insights into thinking that justifies their segregation. This thesis aims to prompt fresh thinking and encourage policy reform for intellectual disability equality so as to address the current blind spots in law and policy. The true value of this endeavour can only be measured via the practical application of this new ethos of inclusion. The formulation of the 4-step model is designed to be an approach that helps identify and rectify the wrongs that many face in their everyday lives. Overall, this model offers a more appropriate basis for the making of policy and law, one that is sensitive to the specific difference of the intellectual disability characteristic. By suggesting a process that creates a more applicable equality approach, this Inclusion Model complements the changes instigated by the CRPD, ensuring that it is a meaningful document for people with intellectual disabilities, and creating sustainable change.

Appendices

APPENDIX A: CONSENT FORM TO USE 'FRANCESCA'S STORY' AS A VIGNETTE

<u>**MY PhD, Your Story**</u>

March 2019

Research Info Sheet

Dear Francesca,

I, Charlotte May-Simera, hereby seek your consent to use your name, story and photograph in my research.

My PhD research is on people working in sheltered workshops and on the rights of people with intellectual disabilities.

As part of this work I would like to include a section called 'Francesca's story' to highlight a typical situation of how people with intellectual disabilities are often placed in sheltered workshops. By including you in this research I am showing the reader how people with intellectual disabilities spend most of their lives in segregated facilities, kept apart from the mainstream community and in the sheltered economy.

Aims

My research aims to challenge the unchallenged and unnecessary segregation of people with intellectual disabilities.

Using a rights-based framework in the form of the UN Convention on the Rights of People with Disabilities, I suggest that this automatic placement of people with intellectual disabilities in sheltered workshops is potentially a form of discrimination on the basis of disability.

I hope that my research will provide a set of legal arguments with which to challenge the on-going segregation of people with intellectual disabilities.

Method

My research is desk-based using documents such as journal articles, books, reports, case files and jurisprudence by the CRPD

1

Committee.

Format

My research will be presented as a manuscript (book format) submitted as part of the requirements for the degree of Doctor of Philosophy at NUI, Galway.

My research has also been published in two journals (_Laws_ and _Journal of Policy and Practice in Intellectual Disability_). However, your name or story was not included in these.

I also plan to publish some of my work on a blog called IDEA Network Ireland (Intellectual Disability Exploration & Approaches).

For this I would like to include the following picture of you (your name will not be included):

Dissemination

Part of the manuscript may be published in the future in academic journals. I will remove your name from these future publications.

Your name does not appear in any of the existing publications, nor is your story used.

Journal articles are typically available and accessed by an academic audience.

I plan to use your picture in a blog, reporting on segregated services in Ireland.

2

You can choose whether you would like me to use your name or not.

You will be provided with a copy of the finished manuscript and with a link to the blog post.

Your involvement

Having grown up as twin sisters our lives are intertwined. The experience of being your sister has shaped me as a person, as well as my political interests, my career and also this research.

You are at the heart of this investigation and what prompted it. I therefore seek your consent to include your story as part of my thesis.

I also seek your consent to use the above photograph for a blog post I intend to use.

I will share all information published with you at any time.

Consent

I, Francesca May-Simera hereby confirm that I have been informed of the research and it has been explained in a way that I understand. I consent to my name and story being used for the thesis and for my photograph to be used for the report on the IDEA Blog.

I have also been informed that I can ask for more information or withdraw consent at any time.

Signed: _Francesca May-Simera_ Place/Date: _Lüdenscheid_
_23.3.2019_

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