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# **Involving Children and Young People in Social Research: Navigating the Balance between Protection and Participation**

A thesis submitted for the Degree of PhD to the National  
University of Ireland, Galway

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## Declaration by Candidate

I hereby declare that this thesis is my own work and effort, and that it has not been submitted elsewhere for an award. Where other sources of information have been used, they have been acknowledged.

Signature.....

Date.....

## Abstract

This thesis is an article-based PhD. Against the backdrop of the almost universal acceptance of the UN Convention on the Rights of the Child and the scholarly works comprising the 'new social studies of childhood', the thesis reflects on a core ethical dilemma facing social scientists today. It explores how researchers can navigate the dichotomy between protecting children and young people from harm and respecting their competence and autonomy as individual beings to participate in research of relevance to their lives. The study is exploratory in nature, utilising primarily reflective strategies of inquiry to: reflect on participation and protection discourses and their influence on children and young people's involvement in research; examine a researcher's ethical duties and rights-based responsibilities; and explore solution focused strategies to support researchers to navigate the balance between protection and participation.

The main body of the thesis comprises three publications. The first publication, referred to as paper one, reflects on a qualitative study with young carers in the Irish population. The paper reflects on the participation and protection discourses at play when seeking to access a representative sample of young carers. The success and limitations of the approaches adopted when obtaining parental consent and imposing limits on confidentiality are evaluated. The second publication, referred to as paper two, provides a more in-depth understanding of a researcher's ethical duty to obtain parental consent. Drawing on the literature and a critical review of ethical frameworks, it explores how researchers can negotiate this ethical standard in the interests of involving young people in research when parental consent is not feasible or appropriate due to the nature of the study or the young participants involved. The third publication, referred to as paper three, argues that central to achieving a balance between participation and protection is the researcher's ethical duty to conduct a rigorous and balanced assessment of harm and benefit. Reflecting on the author's experience of conducting an assessment of harm and benefit, during the course of a baseline study on children and young people's participation in social care services and a youth-led research project on mental health awareness, the paper presents a strategy for conducting such an assessment. The thesis concludes by integrating the learning across the three publications. It distils key messages for ethical oversight bodies and the research and academic community.

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# Chapter 1: Introduction

## 1.1 Introduction

Over the past two decades, there has been a significant growth in the involvement of children and young people in social research. It is now widely acknowledged that children and young people should be key informants and active participants in the production of sociological data relevant to their lives. Although this development is very welcome, it has raised a number of complex challenges. Promoting children and young people's participation in research, in the absence of reflection on the risks involved, can expose them to harm and exploitation. Equally, overly erring on the side of protection can silence their voices and deny the research community the opportunity to generate knowledge informed by their perspectives and lived experiences. Researchers must grapple with this tension by finding the appropriate balance between enabling children and young people's participation in research and protecting them from harm. This is of core importance if their involvement in research is to be ethically compliant and inclusive of the perspectives of all children and young people, including those that are hardest to reach.

With the aim of furthering knowledge on this issue, this thesis focuses on three areas. First, it reflects on participation and protection discourses and their influence on children and young people's involvement in social research. In this context, social research is understood to cover a wide range of social science disciplines, including sociology, psychology, human geography, criminology, politics and social policy (Bryman, 2015). Second, it examines a researcher's ethical responsibilities and rights-based obligations when researching the lives of children and young people. Third, the thesis explores pragmatic and solution focused strategies to support researchers to achieve the appropriate balance between protection and participation. In doing so, it is intended to generate learning for both researchers and ethical oversight bodies.

The study primarily uses the well-established term 'children and young people'. In keeping with the UN Convention on the Rights of the Child (UNCRC), 'children' is defined as all people below the age of 18 years. The term 'young people' commonly refers to those aged 14 to 18. While use of the word children is inclusive of those in the age range 14-18, the author considers it preferential to use the term 'children and young people' to acknowledge and respect the difference in capacity of those at the upper end of the age range. Nevertheless,

the first paper primarily uses the term 'children', while the second paper uses the term 'youth' to meet the publisher's requirements.

The remainder of this chapter is divided into three sections. To set the context, the first section sets out the background to this study, outlining developments in children and young people's research and the author's background. The second section sets out the research aim and the four objectives underpinning the study. The third section details the structure of the thesis and provides an overview of the three publications comprising the main body of this work.

## 1.2 Background to the Study

### Developments in children's research

This study is anchored in recent developments in theorising childhood that gained momentum in the early 1990's, following the adoption of the UNCRC. These developments principally encompass a growing recognition of children as independent rights holders and a shift in the study of childhood towards viewing children as social actors in their own right. This shift in how the research community conceptualises children and young people calls for respect for their views and an acceptance that children and young people's perspectives are pivotal to understanding their lived experiences. This in turn gives rise to an expectation that researchers will involve children and young people in research of relevance to their lives. As a result of these developments, over the past two decades their involvement has evolved from them being objects of research, to subjects of research and, more recently, it is common for children and young people to be collaborators in the research process or to take ownership of the research project.

However, children and young people's participation in research can pose significant methodological and ethical challenges, with the focus of this thesis being on the latter. Alongside the expectation that children and young people will be involved in research, there is an onus on researchers to ensure that meeting this expectation does not take priority over a reflective and ethical approach. Ethical safeguards stem from the vulnerability and incompetence (perceived or otherwise) of children and young people. They also stem from what Morrow and Richards (1996: 98) describe as 'the disparities in power and status between adults and children', thereby requiring stringent measures to be put in place to protect children and young people from harm. Navigating the tension between the ethical duty to protect children and young people from harm, while at the same time respecting the

principles of inclusion and participation, is a significant dilemma confronting researchers today (Daley, 2013; Eriksson and Näsman, 2012; Powell et al., 2011; Carter, 2009). It is this dilemma that the study intends to explore.

### **Author's background**

As a passionate advocate of children's rights and a professional researcher influenced by the 'new social studies of childhood', this thesis topic arises from the author's longstanding commitment to promote respect for the dignity and competence of children and young people and a belief that children and young people have an important role to play in providing adults with a better understanding of their lives. In light of her experience as a former legal and currently a social science researcher, the author is acutely aware of the challenges that can be faced in achieving these objectives in the research context.

The study that initiated the author's line of enquiry was an empirical study on young carers in Ireland. As part of the methodological process, the author supported by the wider research team, sought to recruit a representative sample of children and young people in Ireland whose lives were affected in a significant way by the need to provide care for a family or household member. As detailed in paper one, the recruitment phase was a long and challenging process. It proved difficult to recruit a sufficient sample of young carers and, in particular, a sample that was representative of the spectrum of views within this population group. It is arguable that this was as a result of young carers not being willing to share their very personal experiences with professional researchers, who were relative strangers. But, it was also perceived to be very likely that the researcher's ethical responsibilities increased the obstacles to children and young people becoming involved and decreased the likelihood of participation from the most marginalised young carers. This latter argument is corroborated by existing literature in this area (Skelton, 2008; Williamson et al., 2005). This personal experience prompted reflection on the approaches employed during the study to recruit the sample of young carers. It raised the issue as to whether alternative, more inclusive approaches, could have been adopted while remaining compliant with ethical standards. Ultimately, it led the author to question - when researching children and young people's lives when is their inclusion or exclusion, on the grounds of protecting them from harm, justified?

### 1.3 Research Aim and Objectives

The overarching aim of this study is to explore how social science researchers can navigate the dichotomy between protecting children and young people from harm and respecting their competence and autonomy, as individual beings, to participate in research of relevance to their lives.

The objectives of the study are:

1. To reflect on the participation and protection discourses and their influence on children and young people's involvement in research;
2. To examine a researcher's ethical duties and rights-based responsibilities when involving children and young people in research;
3. To explore solution focused strategies to support researchers to navigate the balance between protection and participation; and
4. To distil key messages for ethical oversight bodies and the research and academic community.

The study is both exploratory and reflective in nature. To address the research aims and objectives it reflects on the author's experience as a professional researcher of involving children and young people in social research. It also draws on contemporary literature and utilises comparative research methods to develop a critical understanding of ethical frameworks. There is a long tradition of reflective strategies of inquiry being viewed as a valid form of knowledge generation. While there are now many models of reflection, as detailed in chapter three, it is Gibbs' (1988) reflective framework which provides the guiding framework for this thesis.

### 1.4 Structure of the Thesis

This thesis is an article-based PhD. In compliance with NUI Galway guidelines, the core of the thesis comprises three papers - one published journal article, one peer reviewed book chapter and a journal article pending publication. The full thesis is divided into seven chapters, as detailed further below.

Following this introductory chapter, chapter two provides a comprehensive review of the literature. This review covers five pertinent areas to this study. First, it outlines the theoretical perspectives underpinning the thesis, namely the conceptualisation of children and young people as vulnerable and in need of care and, comparatively, their conceptualisation as competent, autonomous social actors. It then proceeds to examine

what is understood by children and young people's involvement in social research, setting out the accepted models adopted across the spectrum of children and young people being sources of research data to child and youth-led research. Third, it provides an overview of the literature on developments in the field of ethics and a researcher's ethical duties when involving children and young people in social research. Fourth, it examines children and young people's participation and protection rights relevant to the context of their involvement in social research. Fifth, the chapter examines the literature exploring the interface between protection and participation discourses. The chapter concludes with a summary of the literature reviewed.

Chapter three locates this study within the existing scholarship and describes the study methodology. It elaborates on the rationale for the study and reiterates its overarching aim and four objectives. Having outlined the philosophical considerations, methodological approaches and research methods informing the design of the study, it establishes that a primarily reflective, reflexive and critical inquiry methodology is most suitable for this exploratory study. The following section of this chapter discusses the implementation of the study design with reference to each of the three papers. It outlines how the study was implemented in two phases, with paper one and paper two comprising the 'reflection on action' phase and paper three comprising the 'reflection in action' phase. It details how the reflective process was guided by Gibbs' (1998) model of reflection, with each phase encompassing the full cycle of descriptive, theory and knowledge building, and action-orientated levels of reflection. The final section of chapter three addresses the limitations of the study.

Chapters four, five and six are the core of the thesis, comprising the three publications. The first publication, referred to as paper one, is entitled '*Accessing a hard to reach population: reflections on research with young carers in Ireland*'. It was published in the *Journal of Child and Family Social Work* in 2012 and Dr Allyn Fives and Dr John Canavan are second and third authors respectively. It reflects on the author's experience of a qualitative study with young carers in the Irish population. As referred to above, this qualitative study documented the views of young carers between the ages of 5 and 17 to better understand how their caring role impacts on their lives. The paper describes the methodological approaches adopted and the ethical issues that arose when seeking to access a representative sample of young carers. It critically reflects on self-referral strategies and the use of gatekeepers to identify and recruit a hidden population group. Importantly for the purposes of this thesis, it revisits the

measures taken to comply with the ethical requirements of parental consent and limits on confidentiality. The paper reflects on the success and limitations of the approaches adopted to comply with these ethical requirements and considers whether alternative approaches could have been taken. The challenge of striking the appropriate balance between, what at times seemed to be two competing requirements, protecting children and young people from harm and respecting their autonomy and competence to be involved in research, is discussed.

The second publication, referred to as paper two, is entitled '*Navigating the ethical requirement for parental consent when engaging youth in research*'. It was published as a book chapter in *Youth "At the Margins" Critical Perspectives and Experiences of Engaging Youth in Research Worldwide' in 2014*. The aim of this paper is twofold. First, to provide a more in-depth understanding of a researcher's ethical duty to obtain parental consent. Second, to explore how researchers can take action to negotiate this ethical standard in the interests of involving young people in research when parental consent is not feasible or appropriate due to the nature of the study or the young participants involved. The focus of the chapter is on young people aged between 15-18 years. While there is agreement among the research community on the need for parental/guardian consent in all circumstances when research involves young children, the appropriateness of this ethical requirement in the context of research involving young people is a subject of debate due to its potential exclusionary consequences. To provide a more in-depth understanding, the chapter draws on contemporary literature and uses comparative research techniques to compare ethical frameworks and establish current practice and guidance on the issue. The chapter also provides an overview of the broader legal context this ethical requirement is operating within, outlining examples of how international and national law addresses the issue of capacity to consent. This is followed by a critical review of current ethical frameworks, comparing the stringent to the more flexible approaches adopted across different countries. Drawing from examples documented in the literature, the chapter concludes with an overview of innovative, yet ethically compliant, strategies used by researchers to enable them to satisfy the parental consent requirement and support the inclusion of even the most marginalised young people in research.

The third publication, referred to as paper three, is entitled '*Justifying the involvement of children and young people in social research: assessing harm and benefit*'. It is pending publication in the Irish Journal of Sociology and is co-authored with Professor Pat Dolan. The

paper makes the case that central to achieving a balance between participation and protection is a researcher's ethical duty to conduct a rigorous but balanced assessment of harm and benefit. It describes and analyses the author's experience of being involved in two research projects and documents the authors' reflections on what are the critical considerations when conducting an assessment of harm and benefit. The two research projects are a baseline study on children and young people's participation in social care services and a youth-led research project on mental health. The paper draws on the learning from these projects and other existing literature to suggest that there are three critical considerations when assessing harm and benefit. These are: the purpose and theoretical context of the research; the preferences of the children and young people and their parents; and the available time and resources. Using the above research projects as examples, the paper illustrates this assessment process in practice.

The concluding chapter, chapter seven, draws together and discusses the findings and substantive arguments presented in the three papers. Structured broadly in accordance with the research objectives of this study, it integrates the learning from the three papers and the literature review on the current participation and protection discourses at play and a researcher's ethical duties and rights-based responsibilities; ultimately determining their overall influence on children and young people's participation in research. It concludes by suggesting pragmatic, solution focused strategies to support researchers to navigate the balance between protection and participation and distils a set of key messages for ethical oversight bodies and the research and academic community.

## **1.5 Summary**

The purpose of this introductory chapter is to set the context for the study. It outlines how recent developments in theorising childhood can present a challenge for researchers. These developments create an expectation that researchers will find ways to involve children and young people in research of relevance to their lives, while at the same time rigorously complying with ethical standards to protect children and young people from harm. It explains that as a result of this study it is hoped to bring clarity to how social science researchers can navigate this dichotomy between protecting children and young people from harm and respecting their competence and autonomy as individual beings to participate in research of relevance to their lives. It sets out the four research objectives: to reflect on the participation and protection discourses and their influence on children and young people's involvement in research; to examine a researcher's ethical duties and rights-based responsibilities when

involving children and young people in research; to explore solution focused strategies to support researchers to navigate the balance between protection and participation; and to distil key messages for ethical oversight bodies and the research and academic community. This chapter closes with an overview of the structure of the thesis, including an introduction to the three publications that are at its core.



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## Chapter 2: Literature Review

### 2.1 Introduction

To begin the process of achieving the research aim and addressing the set of objectives outlined in chapter one, this chapter provides a comprehensive review of the relevant literature. It focuses on five core areas and is structured as follows. Section 2.2 outlines some of the main features of the theoretical perspectives central to this thesis. These are conceptualisations on the one hand of children and young people as vulnerable and in need of care and, on the other hand, the idea of children and young people as competent, autonomous actors. Section 2.3 examines what is understood by children and young people's involvement in research. It reviews different models of their involvement, before providing an overview of the literature critiquing the drive to increasingly involve them in social research. Section 2.4 examines the literature on a researcher's ethical duties, while section 2.5 examines a researcher's rights-based responsibilities central to the discourses of participation and protection. This is followed by a review of the literature detailing how researchers have previously addressed the dilemma of balancing participation and protection in section 2.6. It reviews current guidance provided in the literature on how to meet this challenge. The chapter concludes with a summary of the literature reviewed.

### 2.2 Theoretical Perspectives

This thesis is anchored in the new social studies of childhood and the children's rights movement. While the view that children and young people are autonomous and competent social actors is increasingly the dominant theoretical perspective in the study of childhood and described as having global reach (Skelton, 2007), inherent tensions remain between these perspectives and protectionist theories on childhood. The following sections will outline some of the main features of the theoretical perspectives central to this thesis.

#### Children and young people as vulnerable and in need of care

Historically, conceptualisations of children and young people focused on their vulnerability, dependence and need for care (Kjørholt, 2004). The construction of childhood as a period of incompetence and vulnerability requiring protection from the adult world is said to be fuelled by the work of Piaget (Lewis and Lindsay, 1999). Piaget's work (1896-1980) was instrumental in the field of developmental psychology. He identified stages of cognitive growth from infancy through to adolescence. Piaget acknowledged, what is now generally

agreed, that young people during the period of adolescence become more mature in their reasoning and problem-solving abilities. They can apply logical thinking about what 'might' exist not just what 'does' exist and they have the ability to construct logical arguments (DeHart et al., 2004). However, the hierarchical continuum that is implied in Piaget's linear approach to a child's cognitive development is subject to criticism. When the focus is on children 'becoming adults', this generates an assumption of incompetence (Gallagher and Gallagher, 2008). According to Kellet et al. (2009: 31):

If mature, rational adult thought is judged to be the ultimate highly prized goal then the corollary is that child thought can have little intrinsic value, hence notions of childhood as separate and special must necessarily be devalued along with the integrity of the child.

Consequently, children were not considered to merit study in their own right. The lack of data on children and childhood related statistics, prior to the 1990's, is considered illustrative of this (Qvortrup et al., 1994). Children were nearly always described with reference to their parent's circumstances (McCarry, 2012). Piaget's developmental stages, it is said, continues to influence conceptions of childhood, reinforcing perceptions that 'children will be dependent, irrational and vulnerable for a considerable length of time' (Lewis and Lindsay, 1999: 65). Indeed, this perception is considered to still exist among researchers (Kellett, 2011; Lundy et al., 2011) and pose a barrier to children and young people's involvement in research. An international scoping study with 257 researchers globally found that a researcher's perception of children's competence was a key reason why research on children and young people does not include their views (Powell et al., 2011). In particular it has been evidenced as posing a barrier to the involvement of young children (Mayne and Howitt, 2015). The developmental approach to childhood is further criticised for its universal claims and failing to take into account socio-cultural differences and, what sociologists now accept, that children are social actors, active in the construction and determination of their own lives (Graham, 2011; Kellet et al., 2009).

Morrow and Richards (1996) note that the conceptualisation of children and young people as vulnerable is also driven by research being focused on children and young people already damaged from their experiences. Rightly, it is said, these children and young people need to be protected from exploitation and the likelihood of the researcher causing them further distress (*ibid*). But this focus, propels notions of vulnerability. Identities that are stigmatised are also perceived to constitute a vulnerable group in need of protection due to the very nature of the circumstances they find themselves in. The term 'vulnerable' continues to be widely used in social science literature and is inter-changeable with similar terms such as

'marginalised' or 'disadvantaged'. These terms have been used to describe incarcerated youth (Abrams, 2010), children and young people with learning disabilities (Kellett et al., 2010), homeless youth (Gomez and Ryan, 2016) and young lesbians and gay men (Skelton, 2008). Carter (2009: 861) challenges the use of term 'vulnerable', remarking that the notion of vulnerability is all too often inter-changeable with notions of lacking competence. She suggests that these two terms need to be 'unshackled'. Finally, the perspective that the children and young people are vulnerable and in need of care, can be framed within the context of an awareness of the natural power imbalances between adults and children and young people (Morrow and Richards, 1996).

### **Children and young people as competent, autonomous actors**

The adoption of the UNCRC by the UN General Assembly, in 1989, marked a significant milestone in how the world perceives children and young people. It marked a shift in the earlier expression of children's rights as set out in the UN Declaration on the Rights of the Child (1959), which placed an emphasis on protection. The UNCRC recognises children and young people as independent rights holders and demands a respect for their dignity and competence as human beings. It marks a shift from children and young people being viewed as objects to whom rights are applied and instead classifies children and young people as rights-bearing individuals (Cohen, 2006). The Convention codified for the first time in international law the right of the child to have their views heard in all matters affecting them. Article 12(1) of the Convention provides that:

State Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

Those charged with observing adherence to the Convention, the UN Committee on the Rights of the Child, acknowledge that providing children and young people with meaningful opportunities to have their voice heard requires a preparedness to challenge assumptions about children and young people's capacities. The Committee asserts that the UNCRC encourages an environment to enable children and young people to build and demonstrate their capacities (UN Committee on the Rights of the Child, 2009). Article 5 of the Convention calls for a respect for the evolving capacities of the child and thereby is pivotal in this regard (as detailed in section 2.5 below.) In the literature, the UNCRC is described as signalling that children and young people have autonomy and a voice that exists outside family, school and

institutions (Kellet et al., 2009). Hart (1997: 11) observes that it can serve as a 'valuable instrument of persuasion' when seeking to promote the idea of children and young people as independent, competent beings and deserving of a greater degree of participation in research or otherwise. It is long said that legislating for children's rights and positioning the child or young person as 'a social and political actor, a person with opinions, a decision-maker' has infiltrated populist discourse (James et al., 1998: 69).

These developments in international law were part of a wider multi-disciplinary movement to respect children and young people's views and competencies. In social studies, James and Prout (1997) in the seminal text *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood* captured current thinking at the time and presented an alternative view of childhood. Described as a 'rallying point for co-thinkers' (Thomas, 2007: x), an emerging paradigm was presented, the 'new social studies of childhood', which viewed children and young people as social actors; active in shaping their own lives and worthy of study in their own right. Prout and James (1997: 9) identified six key features as being central to the paradigm:

1. Childhood is understood as a social construction. It provides a framework for interpreting the early years of human life.
2. Childhood is a variable of social analysis; it does not comprise a single and universal phenomenon. As there are a variety of childhoods, it cannot be analysed separately from other variables, such as, class gender or ethnicity.
3. Childhood, including children's social relationships and cultures, are worthy of study in their own right, independent of their social construction by adults.
4. Children are and must be seen as active rather than passive in the construction of their own social lives, the lives of those around them and the societies in which they live.
5. Ethnography is a particularly useful methodology for the study of childhood. It allows children a more direct voice and greater participation in the production of sociological data, than may be possible through experimental or survey style approaches to research.
6. To proclaim a new paradigm to understand childhood is to engage in the process of reconstructing childhood in society. As a result, childhood is a phenomenon in which the double hermeneutic of the social sciences is acutely present.

It is said that the development of the new social studies of childhood stems from the approach in developmental psychology to make universal claims about children and families, which disregarded the social context of children and young people's lives (Graham, 2011). The recognition that childhood is socially constructed led to a heightened awareness of the social context within which psychological processes take place (James and Prout, 1997). It also represented a shift in earlier thinking by sociologists, when children and young people were treated as 'objects of socialisation' rather than directly engaging with them as subjects (Hill, 1997: 171). Its development was underpinned by, not only a desire to better understand children and young people's lives, but also by a desire to give a 'voice' to children and young people (Hill et al., 2004; Prout and James, 1997) and to acknowledge their evolving agency (Graham, 2011; Mayall, 2002). The new social studies of childhood forms the theoretical basis to the restructuring of power relations between the adult and child (Mason and Hood, 2011). To conclude this section it is worth noting that the goals of the new social studies of childhood and the propagation of children's rights are very similar. Yet it is observed that there has been little dialogue or collaboration between the two disciplines (Freeman, 2012).

### 2.3 Children and Young People's Involvement in Research

Citing the works of Prout (2004) and James and James (2008), Graham (2011: 1533) surmised:

Under the rubric of 'new social studies of childhood', multidisciplinary approaches have utilised scholarship across the social sciences, building upon the growing acceptance of 'studies' in academic institutions to engage with childhood in a variety of new and interesting approaches.

At the time when the new social studies of childhood was emerging, it was noted that there were few sociological studies capturing the views of children regarding their everyday lives and experiences (Hill, 1997; Morrow and Richards, 1996). In the intervening period, it is observed that an array of participatory approaches to research is gaining prominence across a range of disciplines (Kidd and Kral, 2005). In 2011, an international scoping study, undertaken with 257 researchers from 46 countries across the globe, identified that almost all the participants (92%) thought that children's views were included in research in their country at least 'occasionally' to 'very often' (Powell et al., 2011). There is now an abundance of literature documenting children and young people's involvement in research. The literature tracks an evolving trend from children and young people being subjects, as opposed to objects of research, to their active participation in the research process to more recently examples of child- and youth-led research (Dolan et al., 2016; Bradbury-Jones and

Taylor, 2015; Kellett et al., 2004). The growing trend to involve children and young people in research is widely attributed in the literature to the increasing recognition of children's rights and the emergence of the new social studies of childhood (*see for example*, Mason and Hood, 2011; Sabo Flores, 2008; Hill, 1997).

### What is understood by children and young people's 'involvement' in research

As noted by Fleming and Boeck (2012), the term 'involving children and young people in research' can be interpreted differently, but at its core is an attempt to include children's perspectives in society's understanding of childhood. While the term 'involving children and young people in research' and 'participatory research' can be used interchangeably, the former can be viewed as an all-encompassing term. In contrast, the term participatory research generally signifies children and young people's active involvement in the research process.

### Participatory research

Broadly speaking, the term 'participation' means the involvement of children and young people in decision-making on issues that affect their lives. It is often framed as the sharing of decision-making power with children and young people (Gallagher, 2008b; Kidd and Kral, 2005). The term is used to describe a broad spectrum of children and young people's involvement in decision-making. To capture the threshold for activities to be considered as 'participation', Roger Hart (1992) famously developed a metaphorical ladder of participation. The ladder illustrates that children's participation in projects can range from manipulation, decoration and tokenism, assigned to the bottom rungs of the ladder and described as non-participation, to varying degrees of participation at the upper rungs of the ladder, including informed consultation and child-initiated shared decisions with adults at the top rung.

The use of the term participation in the context of research is similar to its use in the wider context. It is used to describe a wide-ranging spectrum of children and young people's involvement in research. It is generally broadly conceptualised, but at its crux is the idea of the researched being actively involved in the research process (Shaw et al., 2011; Dentith et al., 2009). However, it is observed that there has been limited methodological reflection of what the term 'participatory research' means (Gallagher and Gallagher, 2008). The absence of clarity surrounding the term participatory research is in part due to the lack of agreement on how actively children and young people need to be involved before research can be considered 'participatory'. On this issue there are diverging views. There is a view that all

forms of children and young people's involvement in research are participatory, even if this involvement is limited to them sharing their perspectives (Fernandez, 2007). On the other hand, the increasingly dominant perspective is that the term participatory research should not apply to research where the participants are merely providers of information or the sources of the research data (Dentith et al., 2009; Cahill, 2007; Pain and Francis, 2003; Cornwall and Jewkes, 1995). When children's involvement in research is limited to them generating the research data, they are not involved in decisions regarding the research process.

This mirrors the discussion in the broader literature on children's participation, which makes the distinction between consultation and other forms of participation. Consultation is said to be an adult led process, whereby children's views are sought for the purpose of understanding their experience or perspective but it does not take the next step of sharing the decision-making process with them (Lansdown, 2010: 20). It is considered important to make the distinction between these two terms, consultation and participation, as the former is not characterised by some as a form of participation (Hill et al., 2004; Sinclair, 2004). According to Hill (2004), consultation may only operate in one direction. Children are asked their views and, while these views may be passed on to the decision-makers, there are no assurances that they will be acted upon as appropriate. Unlike participation which signifies the direct involvement of children in decision-making. A similar distinction is made between passive participation and active participation, with passive participation taking on the same meaning as consultation (Sinclair, 2004).

### **Participatory action research**

In contrast, the use of the term 'participatory action research' dispels any ambiguity by clearly signifying the active involvement of children and young people in decision-making around the research process. To constitute participatory action research, children and young people must have more of a role in the research than being the sources of the data; the emphasis is on the process. Hart (1992: 16) identified the main features of participatory action research as follows:

- The research is carried out by or with the people concerned;
- The researcher is committed to the participants and their control of the analysis;
- The participants identify the problem from which the research stems; and
- The research investigates the underlying causes of the problem so the participants can begin addressing the problem.



The collegial nature of participatory action research is also highlighted as a key feature by Cammarota and Fine (2008: 6). Furthermore, they explain that the emphasis on action not only signifies the active involvement of the stakeholders in the research process but that the research findings should also become 'launching pads for ideas, actions, plans and strategies to initiate social change'. The word 'action' signifies a commitment to generate change (Klocker, 2015; Banks et al., 2013).

### Models of children and young people's involvement in research

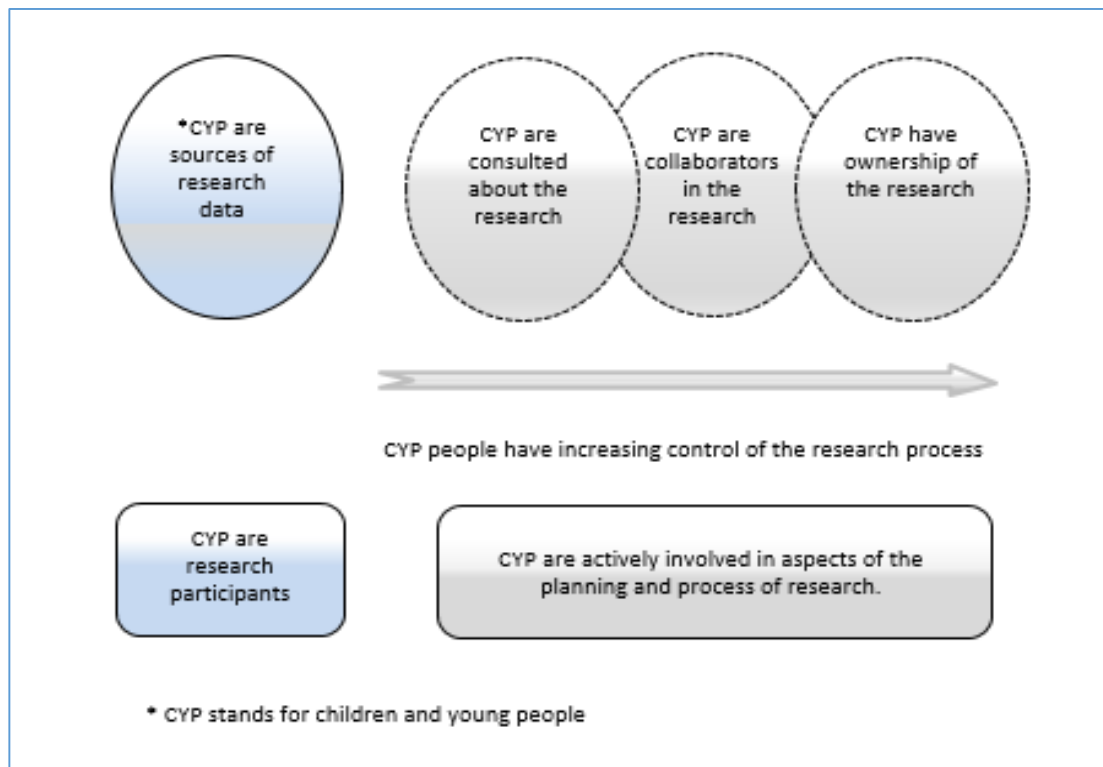
The spectrum of children and young people's involvement in research is illustrated in a range of models. One of the earlier model's of participatory research was Biggs identification of four distinct modes of participatory research: contract (people are contracted to enable the research), consultative (participants are consulted for their views on the topic), collaborative (the research is a partnership between the researcher and the participants) and collegial (the participants have more control over the process) (Biggs, 1989). Specifically in the context of research with children and young people, Christensen and Prout (2002: 480-481) identify four approaches to children and young people's involvement in research. These are:

- The child as an object – their life is investigated from the perspective of adults such as parents, teachers and others;
- The child as a subject – children are involved as informants, but this is conditional on their perceived capacity and maturity;
- The child as a social actor – there is recognition and value placed on children's lived experiences and understandings;
- The child as participant and co-researcher – children are involved, informed, consulted and heard. Research is a co-production with contributions from both the researcher and the informant(s).

Shaw et al. (2011) developed a similar model of children and young people's involvement in research. As illustrated in figure one, they identify four modes of children and young people's involvement in research. First, children and young people are the sources of the research data. Second, children and young people are consulted about the research. Third, they are collaborators in the research. Fourth, children and young people have ownership of the research. This model reflects the evolving trend from children and young people's active participation in the research process to emerging examples of child- and youth-led research. In this way, their continuum goes beyond children and young people being active

participants and co-researchers towards children and young people taking ownership of the research process. Children and young people having ownership of the research has now been defined as ‘when children are facilitated to be “primary investigators” throughout the process from the initial identification of the research topic to the dissemination of the final results’ (Kim, 2015: 230).

**Figure one: Model of Children and Young People’s Involvement in Research (Shaw et al., 2011)**



These levels of involvement in figure one above are represented as overlapping and porous, to illustrate that within a single project the nature of involvement may vary for different children and young people or at different stages of the research process. Shaw et al. (2011: 6) suggest that there is no one form of involvement that is inherently ‘better’ than another. Similarly, in the wider literature on participation per se, hierarchical models of participation have attracted criticism. Hart’s (1992) selection of a ladder as his metaphor of choice has been disregarded by some due to its hierarchical undertones. While Hart himself has noted that it is not necessary for children to engage in the types of participation at the upper rungs of the ladder, others have suggested that the model implies that the optimum levels of participation are those that are child initiated and involve sharing the decision making power with adults. This has subsequently encouraged the development of non-hierarchical models of participation (Shier, 2001; Treseder, 1997).

The degree of involvement by children and young people in research is said to be dependent on a number of factors. Their level of involvement will be determined by the purpose and context of the research (Shaw et al., 2011; Sinclair, 2004; Kirby and Bryson, 2002; Hill, 1997), what is in the best interests of the child (Lundy et al., 2011) and the preferences of the children and young people concerned (Shaw et al., 2011), as well as the available resources and time (McCarry, 2012; Shaw et al., 2011; Kirby and Bryson, 2002). Holland et al. (2010) also suggest that the method of involving children and young people is closely intertwined with their level of involvement. They identify four different methodological approaches. First, children are invited to be participants in a research study, but their involvement may be constrained by the use of traditional methods of data collection, for example the use of interviews and standardised questionnaires. Second, children are enabled to express their views by means of child-friendly communication aids, such as play and drawing. Third, children are encouraged and openings are provided for them to be actively involved in the research process, in terms of research design, analysis and dissemination. Fourth, children are trained in research methods to enable them to carry out the research.

### **Critique of normative assumptions in relation to children and young people's involvement in research**

Caution is expressed against assuming un-critically that children and young people's participation in research is a good thing (Fleming, 2011). It is widely asserted in the literature that the involvement of children and young people as research participants, realises their participation rights (Fleming and Boeck, 2012; Mand, 2012; Tisdall et al., 2008; Dyson and Meagher, 2001). More recently, however, it is acknowledged that there are no certainties in this regard, but that their involvement in the production of knowledge may produce research findings that influence decision-making processes (Kim, 2015). Mortari and Harcourt (2012) suggest that, while statements that children's involvement in research respects their participation rights and their competence to be involved in research may have been necessary at a time when children's voices weren't valued, it is now time to question these routine and overused assertions. Fleming (2011) cautions against overly borrowing from the participation agenda as a justification for involving children and young people in research (*see also*, McCarry, 2012). Fleming argues that its contribution to scientific research must be explored in its own right; otherwise there is the danger that failing to justify its contribution to good research practice will not lend itself to a sustainable approach. Fleming uses the analogy of a bridge, which must span from both the participation and the research side to create a solid foundation for participatory research.

Robust challenges have also been made to the blanket assumption that participatory approaches lead to 'superior' research or 'better' research data (Holland et al., 2010; Francis and Hemson, 2009; Gallagher and Gallagher, 2008; Hill, 1997). In making these challenges, the key argument is that participatory techniques are one methodological approach and cannot and should not be applied to all research focusing on children and young people. Gallagher and Gallagher (2008) argue that good research practice is unpredictable by nature and cannot be constrained by certain techniques. McCarry (2012) queries the assumption that young people's participation in research lends itself to better data on the basis that they are experts on the lives of young people. It is argued by McCarry that young people are only experts on their *own* lives and should not qualify to represent the views of all young people.

## 2.4 Research Ethics

Research ethics are designed to protect research participants, researchers, research institutions, as well as the good name of research. (Alderson and Morrow, 2011). However, the focus of research ethics is not only on protection, it is also concerned with respecting the research participants (*ibid*). According to Mortari and Harcourt (2012: 235) '[e]thics refers to a focus on that which is deemed right and good'.

### Developments in the field of research ethics

Ethical standards were first codified in response to concerns about poor practice in medical research. This approach to the regulation of ethics can be traced back to the Nuremberg Code (1949). This code was developed in response to Nazi research practices that emerged in the Military Tribunals in the aftermath of the Second World War. Other milestones in the codified approach to the regulation of ethics were the Declaration of Helsinki (1964), developed by the World Medical Association, and the Belmont Report (1979) issued by the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research in the United States. UNESCO too has played a leading role in the development of ethical standards. In 2005, it adopted a Universal Declaration on Bioethics and Human Rights, providing an accepted framework of ethical principles to guide UN member states in the field of bioethics. Each of these instruments were developed to regulate standards in bioethics, however, their principles are equally applicable to social research. They are underpinned by core ethical principles, namely beneficence, non-maleficence, justice, self-determination and autonomy. While these are the core underpinning principles their expression in the ethical guidelines varies.

In more recent times, social disciplines have developed their own codes of ethics. The Sociological Association of Ireland, the British Sociological Association and the American Sociological Association have each developed codes of ethics. Other codes are specific to social research involving children and young people. In Ireland, in response to a significant programme of research initiated by Government to improve understanding of children's lives, ethical guidelines were issued by the Department of Children and Youth Affairs to regulate the conduct of social research with children and young people (Department of Children and Youth Affairs, 2012). In 2013, a consortium of researchers established an international project funded by UNICEF's office for research, Innocenti, named Ethical Research Involving Children Project (ERIC). This initiative developed an Ethics Charter designed to provide comprehensive ethical guidance when conducting social research involving children and young people in any geographical, social, cultural or methodological context (Graham et al., 2013).

It is now accepted as standard practice that research involving human subjects is reviewed and approved at the planning stage by ethical bodies. However, there are critics of the codification of ethics approach and the dominant role of ethical oversight bodies. It is said that universal frameworks or a one size fits all approach is not sufficient to ensure good practice in the field (Gorin et al., 2008; Sultana, 2007). A cynical perspective of ethical oversight bodies views them as functioning to protect research institutions from litigation and disrepute (Gallagher, 2008a). Moreover, as Gallagher suggests (2008a), they may reinforce the notion that ethics need only be considered at the research planning and design stage. Some scholars advocate a reflective and ethic of care approach to conducting ethical research (Pittaway et al., 2010; Gorin et al., 2008). Mortari and Harcourt (2012) explain that in contemporary research, there are two approaches to ethics, the ethics of justice and the ethics of care. Adopting an ethics of justice approach means ethical decision-making is informed by universal principles and rules. They explain that the ethics of care approach is focused on a 'singular concrete situation' and the researcher as a moral subject is obliged to exercise reason in response to what is perceived to be good for the individual person (240). In this way the ethics of care approach is a practice rather than a set of rules or principles (Tronto, 1993). However, there are some discernible features of this practice.

A central focus of the ethics of care approach is attending to and meeting the needs of those who we have responsibility for (Mortari and Harcourt, 2012; Held, 2006). It is described as a form of relationship-based ethics, which focuses on responsibilities attached to the

relationship between the researcher and the participant (Banks et al., 2013). Persons are viewed as 'relational and interdependent' (Held, 2006: 13). The ethics of care approach also embraces emotion rather than rejecting its potential influence. Emotions such as sympathy, empathy, sensitivity and responsiveness are valued for their role in dictating reason and determining what morality recommends (Held, 2006). In the research context, an ethics of care approach requires reflexivity (a concept explored in chapter three). It is argued that a researcher must always be cognisant of and guided by the contextual, relational and political environment the researcher is operating within (Sultana, 2007). Mortari and Harcourt (2012) propose that ethical research should embrace a combined ethics of justice and ethics of care approach.

### **Ethics and research with children and young people**

In 2014, a systematic literature review, conducted on the ethical issues arising in qualitative health research involving children and young people found there are three primary ethical issues reported by researchers (Huang et al., 2014). These are evaluating potential risks and benefits, obtaining informed consent/assent and protecting confidentiality and privacy. Elsewhere, these have also been identified as the salient ethical issues in doing social research with children (Davis, 1998; Thomas and O'Kane, 1998). Thomas and O'Kane (1998) note that, while common to research with all age groups, these issues present more sharply when the research participants are children. This is in part due to children's understanding and experience of the world being different to adults, the different ways children communicate, but above all due to the natural power imbalance between adults and children.

While the above mentioned ethical issues can be considered the foremost ethical considerations in research with children and young people, and are discussed in detail in this thesis, there is no one exhaustive list. The range of ethical issues that might arise reflect the nuances of each research project and the individual needs of the research participants. Prior to reviewing the literature on the foremost ethical considerations, it is worth noting that, Daley (2013), for example, remarks that the location of the research, the socio-political context and the competencies of the researcher also shape how ethical a research project is. Moreover, due to children and young people being increasingly active in the research process, the issue of whether to provide incentives or compensation for children and young people's time is increasingly to the fore. Providing incentives or compensation in return for participation in research has until recently been viewed as a contested practice (Daley,

2013), with little consensus about whether this is ethical. However, increasingly it is being viewed as an accepted practice in acknowledgement of the children and young people's time (Daly, 2009; Bouffard and Little, 2002; Moolchan and Mermelstein, 2002). In the systematic literature review conducted by Huang et al. (2014) on ethical issues arising in qualitative health research with children, they found that more than half of the 30 studies included in the review offered an incentive to their research participants, with cash being the common form of incentive.

The following sections provide an overview of the literature on assessing harm and benefit, obtaining informed consent/assent and protecting confidentiality. Not only are these the foremost ethical considerations when involving children and young people in research, but they are also the most relevant ethical considerations in the context of efforts taken to protect children and young people from harm. It is the ethical requirements around parental consent and confidentiality that are said to pose the most significant challenge to a researcher's efforts to involve children and young people in research due to their potentially exclusionary consequences (Morrow and Richards, 1996). The review of the literature presented here is supplemented by the literature reviewed in each of the three papers. Further to the literature outlined below, paper one, provides an account of the literature on the limitations to confidentiality and the requirement to obtain parental consent. The literature on the parental consent requirement is reviewed in detail in paper two and thereby only referred to briefly below. Paper three includes a review of the literature on the ethical requirement to assess harm and benefit. As the core focus of this paper is on presenting a strategy for conducting such an assessment, a more detailed review of the literature in this area is outlined in the following section.

### **Assessing harm and benefit**

An ethical approach to research calls for an equitable assessment of the potential risks and the benefits the research poses to its participants and to society at large. The desired outcome of this assessment process (also known as a risk/benefit analysis) is to ensure the risk of harm does not outweigh the benefits intended. The process of conducting this assessment will enable the researcher to make an informed decision as to whether it is ethically appropriate to proceed with the research and to understand what measures need to be taken to ensure the risk of harm does not exceed the potential benefits. It will also reveal the potential risks and benefits to be communicated to the research participants, to

enable them to make an informed choice about their participation in the research (Alderson and Morrow, 2011).

While the literature reports on the many potential benefits and risks when involving children and young people in research, there is little guidance on conducting this assessment process. However, some of the challenges in adhering to this ethical safeguard are evident from a review of the literature. The following sections set out the risks and benefits, commonly reported in the literature. The risks and benefits reported are for the most part not based on empirical evidence. Regarding risks, they are perceptions based on the belief that children and young people are vulnerable and in need of care and, regarding benefits, they are perceptions grounded in the 'new social studies of childhood' and the children's rights movement. This review of commonly identified risks and benefits is followed by an overview of the literature on the process of conducting such an assessment and the emerging challenges identified.

#### *Perceived risks*

Social science researchers, reflecting on their experience of involving children and young people in research, have highlighted the potential risks of causing harm. Efforts to avoid harm to children and young people have traditionally focused on ensuring the research does not cause undue distress or humiliation (Alderson and Morrow, 2011). A number of the studies included in the systematic literature review, focused on ethical issues arising in qualitative health research with children, reported that researchers were concerned that recalling events when the children experienced pain and fear may result in discomfort and anxiety (Huang et al., 2014). With children and young people being increasingly involved in research, the issue of not over-burdening them is also beginning to emerge as a potential risk. Harcourt and Einarsdottir (2011: 303) starkly drew attention to this issue, noting that, '[u]nder the pretext of child-centred methods and children's rights, children are under the constant surveillance of adults'. Alderson and Morrow (2011: 23) describe the issue of being over-researched as meaning 'too many children being in a study, or too many interventions, too much intrusion or too many repeated studies on the same questions'. However, there is, as of yet, limited reflection from an ethical perspective on this issue in the literature. It is generally discussed in the context of the risk of research fatigue. According to Clark (2008), research fatigue occurs when the research participants become tired of engaging in research and demonstrate reluctance or refuse to engage in further research. It can typically occur during the course of longitudinal studies, which require participation over a long period of



time, or where requests for participation are frequent. Similarly, there is limited literature on the potential harm caused by over-protecting children. It is observed that an overly-protective stance can silence the voice of children and young people by excluding them from research (Alderson and Morrow, 2011). Daley (2013: 122) argues that children and young people's exclusion from research can have implications for their well-being, given that, 'a lack of understanding as to how young people experience their lives may see policy and service provision develop in ways which are counter to their needs' and can limit their opportunities to advocate for change.

Actively involving children and young people in the research process can present its own set of risks. Some researchers have reported negative experiences when directly involving children and young people in the research process. Campbell and Trotter (2007) query the ethical implications of involving young people as co-researchers. They reflected on their experience of an action research project with six young people as co-researchers that explored their invisibility due to them not being in employment, education or training. Despite training and paying the young people for their work they felt their involvement was more exploitive rather than empowering and doubted whether their involvement would be of any benefit to them given that it was an adult initiated piece of research. Schäfer and Yarwood (2008) undertook a participatory research project where the young subjects of the research engaged in peer-to-peer interviewing. Schäfer and Yarwood observed that the constraints of meeting academic requirements may run the risk of participatory research becoming tokenistic and restrict young people from finding their own ways of expressing their views. Children and young people's collaboration in research as peer interviewers is intended to yield ready access to respondents and frank information. Yet Klocker warns that young researchers can be at a loss when faced with traumatic stories during interviews (Klocker, 2015). She found that peer-to-peer interviewing in a research project on child domestic workers placed an undue emotional burden on the young researchers. It also placed the young interviewees at risk of their distress not being dealt with appropriately, when recalling their experiences of being domestic workers. Elsewhere, it is reported that young researchers failed to appreciate the importance of adhering to ethical safeguards and thereby placing their research participants at risk (Francis and Hemson, 2009).

#### *Perceived benefits*

It is said that an examination of the potential benefits of research must reflect on benefits to the research participant as well as societal benefits (Hunter et al., 2012).

**Societal benefits:** From the societal perspective, it is primarily argued that the involvement of children and young people in research is of benefit as it scientifically enhances research. It generates reliable knowledge, informed by their perspectives and lived experiences (Kellett, 2011; Shaw et al., 2011; Schäfer and Yarwood, 2008; Skelton, 2008; Powers and Tiffany, 2006). Holland et al. (2010) emphasise its value in generating rich data, while Jones (2004: 114) argues that 'knowledge about children is incomplete unless it takes into account the knowledge that children have of themselves'. While there are critics and some evidence contradicting the perceived benefits of children and young people's active involvement in the research process (as outlined above), their active involvement is, for the most part, said to offer additional value.

Their involvement in the interpretation of data is considered to improve the quality of the research (Lundy et al., 2011; Powers and Tiffany, 2006) and strengthen its credibility (Fleming, 2012). It can contribute to a more accurate interpretation (Jones, 2004) and it can provide a more nuanced understanding of children's perspectives (Lundy et al., 2011). In turn this can result in the development of services and policies that are more responsive to their needs. When children and young people are involved in the recruitment of their peers it is said to improve access to potential participants (Shaw et al., 2011; Francis and Hemson, 2009) and facilitate the establishment of immediate rapport (Francis and Hemson, 2009). A review of four participatory research projects by Powers and Tiffany (2006) demonstrated promising evidence that youth involvement in the recruitment phase provided improved access to populations, including hard-to-reach youth. Other reasons proffered as to the societal benefit of directly involving children and young people in the research process, are, that it can create more vibrant research agendas (Cahill, 2007) and their involvement can help to ensure that the methods of data collection and the research tools are suitable and relevant for their peers (Shaw et al., 2011). The value of children and young people's active involvement in the research process is succinctly described by Kellet (2010: 105) as follows:

Children observe with different eyes, ask different questions – they sometimes ask questions that adults do not even think of – have different concerns and immediate access to a peer culture where adults are outsiders. The research agenda children prioritize, the research questions they frame and the way in which they collect data are also quintessentially different from adults.

**Benefits for the research participants:** From the children and young people's perspective, there is limited literature in the social science field documenting the personal benefits that their involvement can offer. It is reported that children and young people benefit from being

involved in research for altruistic reasons (Houghton, 2015; Eriksson and Näsman, 2012; Moore et al., 2011). A study of children and young people who had been sexually abused found that the children were committed to sharing their views with the researcher for this reason; they hoped their stories may help others (Roberts and Taylor, 1993). It has also been observed that involving children and young people in research led to self-affirmation (Houghton, 2015) and provides them with the opportunity to have their views heard (Fleming and Boeck, 2012; Mand, 2012; Tisdall et al., 2008). This has been asserted by children and young people themselves (Petrie et al., 2006).

The active involvement of children and young people, as collaborators or partners in the research process, is said to offer a number of additional benefits for children and young people. It is believed to contribute to addressing power imbalances (Shaw et al., 2011; Kellett et al., 2010). Although, caution is expressed that children and young people may negotiate power hierarchies among themselves (Kellett, 2011; Holland et al., 2010; Schäfer and Yarwood, 2008). As discussed in more detail in paper three, children and young people's active involvement in research can be an empowering experience (Kellett, 2011; Jupp, 2007) and positively contribute to their personal development and enhance their skill-set. There are indications that their participation in research can increase their knowledge, confidence and self-esteem (Fleming, 2011; Shaw et al., 2011; Kirby and Bryson, 2002) can build research related skills, including critical thinking, writing and analysis (Powers and Tiffany, 2006) and improve their networks of support (Fleming, 2011; Shaw et al., 2011; Powers and Tiffany, 2006). Schäfer and Yarwood (2008: 126), reporting on their experience of a participatory research project, found that young people were interested and perceived they would benefit from research training for the following reasons: curiosity in a form of activity they weren't familiar with; learning how to use research equipment; interest in the research topic; and vocational preparation.

A review of 15 programmes, which actively involved youth in research and evaluations, revealed five key considerations needed to create the conditions for positive outcomes for youth when involved in social research (Bouffard and Little, 2002). These are:

- Organisational and community readiness – they must be ready for the new way of working and to respect the work of youth;
- Adequate training and support for the youth involved;
- Adequate training and support for adult staff;

- Selecting the right team – cognisant of diversity and levels of experience;
- Sustaining youth involvement.

Elsewhere, the importance of supporting and providing appropriate training is highlighted as essential to achieving positive outcomes for youth (Bradbury-Jones and Taylor, 2015; Powers and Tiffany, 2006). Powers and Tiffany (2006) in their review of four participatory research projects identified additional considerations, which included, establishing realistic timeframes, taking youth voice seriously in terms of acting upon their recommendations and providing different options for preferred methods of participation to be inclusive of all youth.

To conclude this section on perceived risks and benefits, it is worth drawing attention to the work of Newman and Kaloupek (2004). Drawing on their expertise in the field, Newman and Kaloupek identified the range of risks and benefits that might be relevant across studies. While acknowledging that each research project has its particular set of risks and benefits, Table one below identifies typical risks and benefits. While these risks and benefits were identified in the context of clinical research with adults in the field of psychology, many are equally relevant to social research with children and young people.

**Table One: Potential risks and benefits of research (Newman and Kaloupek, 2004)**

Risks	Benefits
<b>Participants</b> Physical Harm <ul style="list-style-type: none"> <li>• Infection</li> <li>• Pain</li> <li>• Health Problems</li> <li>• Disability</li> </ul> Legal Action <ul style="list-style-type: none"> <li>• Mandated reporting of abuse</li> <li>• Deportation/immigration</li> <li>• Criminal/civil proceedings</li> <li>• Research records subpoenaed</li> </ul> Inconvenience <ul style="list-style-type: none"> <li>• Boredom</li> <li>• Frustration</li> <li>• Wasting of participants' time</li> </ul> Economic Risks <ul style="list-style-type: none"> <li>• Loss of wages, employment</li> </ul> Psychological/mental discomfort <ul style="list-style-type: none"> <li>• Worsen condition</li> <li>• Cause painful memories</li> <li>• Evoke strong emotional distress</li> <li>• Evoke shame, anger, fear, other painful emotions</li> <li>• Foster self-destructive behaviour</li> </ul> Social risks <ul style="list-style-type: none"> <li>• Breach of privacy</li> <li>• Rejection by others</li> <li>• Adversely affect others in social network</li> </ul>	Material resources <ul style="list-style-type: none"> <li>• Money</li> <li>• Food</li> </ul> Medical/mental health services Empowerment Learning/insight <ul style="list-style-type: none"> <li>• Reducing stigma/normalising trauma related reactions</li> <li>• Breaking silence/disclosure of information in an accepted setting</li> </ul> Altruism Kinship with others Feeling worthwhile by participating Receiving favourable attention by researcher
<b>Societal</b> <ul style="list-style-type: none"> <li>• Give science a bad name</li> <li>• Create burdens for care delivery service that cannot be met</li> </ul>	<ul style="list-style-type: none"> <li>• Scientific knowledge/outcomes</li> <li>• Greater training to care delivers/augment services</li> </ul>
<b>Researchers, host institutions</b> <ul style="list-style-type: none"> <li>• Bad press</li> <li>• Vicarious traumatization of research staff</li> <li>• Breach of confidentiality</li> <li>• Legal action</li> <li>• Potential political impact of findings</li> </ul>	<ul style="list-style-type: none"> <li>• Foster valuable relationships</li> <li>• Gain resources</li> <li>• Gain recognition</li> </ul>

*Challenges when conducting an assessment of harm or benefit*

It is evident from a review of the literature that an assessment of the likelihood of harm or benefit prevailing is plagued by a number of issues. First, it is reported that there is currently an over-emphasis on the risk of harm, to the detriment of a balanced assessment of harm and benefit. Second, it is evident that there is a shortfall of empirical evidence on the actual benefits and risks of involving children and young people in research, resulting in assessments being based on opinion. These will be considered in turn.

**The current emphasis on the risk of harm:** The ethical requirement that research adds value was formally articulated as far back as the Nuremberg Code of Ethics (1949). The Code required research ‘to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature’. In recent years it is identified that there is less emphasis on this ethical standard. The overall intent behind ethical research has been described as ensuring the participants will suffer no harm (Young and Barrett, 2001; Morrow and Richards, 1996). It is observed that the focus of contemporary ethical oversight bodies seems to be on minimising risk to the exclusion of an

overall assessment of harm and benefit (Mortari and Harcourt, 2012; Daley, 2013; Powell et al., 2011) as well as an openness to flexibility (Banks et al., 2013). Daley (2013) suggests that the intangibility of the benefits of social research can encourage a tendency in researchers to focus on the avoidance of harm. She also suggests that while it is accepted that vulnerable people may be harmed by talking about their experiences, a higher burden of proof is required when arguing that research may be 'therapeutic, validating or empowering' (16). According to Carter (2009), the default position for ethical oversight bodies in many countries is to deem children as vulnerable. She suggests that the use of the word 'vulnerable' in describing children and young people generates a particular dynamic focused on the need to reduce risk.

Indeed looking to ethical guidance for research with children and young people in Ireland and to a leading social research methods textbook, both exclude an assessment of benefit as a key ethical principle (Bryman, 2015; Department of Children and Youth Affairs, 2012). This move away from a balanced assessment of harm and benefit has led Mortari and Harcourt (2012: 236) to argue that, 'it is necessary to move from a regulatory/surveillance interpretation of ethics, which fundamentally aims at avoiding damage and harm, to a promotional conception which invites potential positive experiential possibilities to the participants'. Of note, the emphasis on minimising risk is not unique to research ethics governing children and young people's involvement in research. It is said that social work practice still tends to adopt a paternalistic and deficit view of children's capacities, that leaves little scope for respecting their agency and competence (Graham, 2011).

**The limited empirical evidence:** It is widely recognised in the literature that there is, as of yet, limited empirical evidence of the value of involving children and young people in research (Fleming, 2011; Holland et al., 2010; Powers and Tiffany, 2006). As Holland et al. (2010: 372) comment, due to the weak empirical evidence of children's views on being involved in participatory research, 'the drive for participatory methodologies suddenly doesn't seem very participatory'. While there is the view that participation as a rights-based principle does not need to be justified by evidence that it works (Sinclair, 2004), there is a growing demand in the wider literature on children's participation per se for evidence on the value of participatory practices and its impact (Percy-Smith and Thomas, 2010; Kirby and Bryson, 2002).

The limited empirical evidence presents the dilemma that researchers and research ethics bodies have little information on which to base a decision about the likelihood of research

participants experiencing benefits or harm (Decker et al., 2011b). There are calls for more substantial and robust evidence in order to move beyond normative assumptions on the benefits of children and young people's involvement in research (Kim, 2015). While not specifically focusing on children and young people, Staley (2009) undertook an in-depth review of the literature to explore the impact of public involvement in health and social care research. This report concluded that it was difficult to assess the impact of public involvement in research, from the participants, the researchers or the societal perspective, for the following reasons (89):

- It is too difficult or costly to set up a comparison research project, without public involvement, to assess impact;
- Involvement often comes in the form of personal interactions with the researcher and these are hard to capture and evaluate;
- It can be difficult to assess the impact of any individual on decision-making when decision-making takes place in a group or committee forum;
- Involvement can span several stages of the research process and this can make it difficult to assess impact on any particular aspect of the public's involvement;
- It can take many years for detectable impacts to emerge from a study.

These findings provide some context to the limited empirical evidence available and why arguments as to the benefit or harm that may accrue from children and young people's involvement in research are primarily based on perception.

In the field of psychology there are growing efforts to establish an empirical evidence base to inform an assessment of the risks and benefits of being involved in research. Pioneering research by Newman and colleagues is generating data to enable an assessment on the costs and benefits of participation in trauma related research to be informed by evidence rather than being based on opinion (Newman and Kaloupek, 2009; Newman and Kaloupek, 2004; Kassam-Adams and Newman, 2002). A measure has been developed to assess the risks and benefits of participating in research from the perspective of the research participants. Known as the Response to Research Participation Questionnaire (RRPQ), the children's version of this questionnaire sets out brief statements to assess children's view of being involved in research from a personal perspective and a research integrity perspective (Kassam-Adams and Newman, 2002). This measure is intended to track realised benefits for children and young people and is therefore retrospective in nature. As discussed in more detail in paper three, evidence is emerging from empirical studies, some of which used that RRPQ, that

despite experiencing adversity in their lives participants involved in research generally report a positive experience. Houghton's (2015) research with young people also found that young people felt that distress was an inevitable part of participation, but this was not a reason to refrain from being involved in research. Instead, it should be managed with the right support.

### **Informed Consent**

Consent is, in the words of Alderson and Morrow (2011: 101) 'the central act in ethics'. It provides an opportunity for the research participants to have their say. Securing the provision of informed consent places two primary responsibilities on the researcher. First, the researcher is obligated to inform the research participants about the purpose of the research and its likely consequences (Gallagher, 2008a; Cree et al., 2001). This involves informing the participants about the potential benefits and risks involved in participation and the alternatives to participation (Moolchan and Mermelstein, 2002). In the context of research with children and young people, this information must be presented in a way that is accessible to the cognitive abilities of the young research participants (Marshall et al., 2012). Second there is an onus on the researcher to ensure there is no risk of coercion (Gallagher, 2008a). Reflecting on research in which a community based organisation was involved in the recruitment of the research participants, Anderson (2010) highlights the risk of the participants feeling required to participate to maintain a good relationship with the organisation or the staff member approaching them to participate. In order to reduce the risk of coercion in this context, Marshall et al. (2012) suggest that recruitment should be conducted by staff members who have no invested interest in the research. Marshall et al. (2012) also note there is a risk that large incentives (in their case an all-expenses paid weekend retreat) may unduly influence the consent process. For this reason, they recommend separating the incentive from the research participation itself.

In the context of research involving children and young people, the researchers ethical duty to obtain the informed consent or, in some countries, the assent of the child or young person, is further complicated by the fact that the parents or guardians of young research participants are generally required to also provide informed consent (Thomas and O'Kane, 1998). The literature in this area is detailed in paper one and the central focus of paper two.

### **Protecting confidentiality**

Meeting the ethical requirement of confidentiality is described as 'taking considerable care not to pass on information to those connected in any way with the respondent and disclosing information only in ways which protect the identity of those who provided it' (Masson, 2009:



52). This is generally achieved by anonymising data, while restricting access to the raw data. In the context of research with children and young people, the importance of this ethical standard is heightened as researchers may be confronted with adults expecting to be told about the experiences or thoughts of the children or young people they are responsible for (Thomas and O'Kane, 1998). An additional complication is that children and young people may also disclose information that gives rise to a child protection or welfare concern. Standard child protection procedures require researchers to pass on information disclosed by a child or young person that they are being harmed or ill-treated to the relevant authorities. This limit on confidentiality is said to present a barrier for researchers seeking to involve children and young people in research (Cree et al., 2001). An issue discussed further in paper one. Nevertheless, it is accepted that the same commitments to research confidentiality cannot be given to a child or young person as can be given to an adult.

There is limited discussion in the literature on this ethical requirement, perhaps reflecting that there is little scope for interpretation or negotiation of this ethical standard. However, there are some examples of researchers taking innovative approaches to the practical application of imposing limits on confidentiality. As noted in paper one, Thomas and O'Kane (1998) took the stance that any disclosure of information of concern would not be passed on, but that they would support the child to disclose the information to the relevant authorities. Others have written about their rigorous approach to adhering to this ethical standard, but in a manner that is supportive to the researcher and young research participant, thereby intending to reduce the likelihood of this ethical requirement being a barrier to their involvement. The approach adopted by Gorin et al. (2008) was twofold. First, they were transparent from the outset about the limits to confidentiality, explaining the limitations in child-friendly language. They used the term 'being safe' rather than speaking about abuse or harm. A consultation with children and young people revealed that this was a term that seemed more familiar and acceptable to them. Elsewhere, it is cautioned that the failure to be transparent about the limitations of confidentiality from the outset has implications for children and young people being able to provide fully informed consent (Williamson et al., 2005). Second, Gorin et al. employed two social work practitioners who were child protection experts. This helped the researchers to understand the thresholds for referral, thereby reducing the possibility of their responses being misjudged. Greater confidence in their approach also reduced potential distress for researchers.

## 2.5 Children and Young People's Rights

Powell et al. (2011) observe that the responsibility of a researcher to uphold children's rights sits alongside a researcher's ethical obligations. Both are underpinned by a respect for the dignity of their fellow human beings. The rights discourse is identified as distinguishable from other moral discourses, such as those that emphasise duties and/or benevolence as the emphasis is on the person's 'rightful entitlements' (Freeman, 2011: 61). With the attention on rightful entitlements, an obligation is placed on the duty bearer to respect the rights-holders enjoyment of his/her rights and to provide redress to those whose rights are violated (Donnelly, 2013). Under international human rights law, the state is the primary duty bearer. However, human rights conventions provide a framework not just for binding international law regulating the conduct of state parties, but they also provide a framework for social norms (Pittaway et al., 2010). In this way, researchers who are not agents of the state, are likewise expected to comply with the normative framework articulated in human rights conventions.

The UNCRC is the leading international human rights convention on children and young people's rights, encompassing economic, social and cultural rights. As referred to in section 2.2, the UNCRC marked a shift in earlier expressions of children's rights, which focused exclusively on children's protection rights. Bevan categorised the rights of the child in the UNCRC as either 'protective' or 'self-assertive' (Bevan, 1989: *as cited in* Kilkelly, 2008). Discussing Bevan's work, Kilkelly noted (2008: 8):

Bevan's approach neatly identifies the division of children's rights into those relating to children's innocence, vulnerability and need for protection, on the one hand, and those that promote children's independence, capacity and involvement in decisions that concern them, on the other.

While this division exists, there is a common understanding that human rights are indivisible. All rights have equal status and cannot be ranked in hierarchical order (United Nations, 2003).

### Participation rights

The terms 'independence', 'autonomy' and 'self-determination', when referred to in the context of children and young people's rights, are also described as their 'participation rights' (Kilkelly, 2008: 8). The cornerstone of children and young people's participation rights is their right to have their views heard in all matters affecting them, as enshrined in Article 12 of the UNCRC. However, the right of the child to freedom of expression (Article 13) and the right of

the child to have access to information (article 17) are considered pre-requisites for the realisation of the child's right to be heard (UN Committee on the Rights of the Child, 2009). While it is broadly recognised that children and young people need appropriate information to enable them to form and articulate a view (Lansdown, 2010), in the context of involving them in research it is also said that young research participants are entitled to information about the research in order to enable them to make an informed decision about consent (Alderson and Morrow, 2011).

The UN Committee on the Rights of the Child, the body established to monitor the implementation of UNCRC, issued a General Comment on Article 12 in 2009. This General Comment elaborates on the content of the Article, providing a detailed interpretation of the right of the child to be heard. It reaffirms the right of the child or young person to express their views and have these views taken into consideration as one of the four general principles of the UNCRC. The other three general principles are the right to non-discrimination (Article 2), giving primary consideration to the best interests of the child (Article 3) and the right to life, survival and development (Article 6). Having the status of a general principle requires consideration to be given to it in the interpretation and implementation of all the other rights in the Convention (UN Committee on the Rights of the Child, 2009).

While the term 'participation' is not explicitly referred to in Article 12 of the UNCRC, this Article is attributed to a range of practices that are broadly conceptualised as participation (UN Committee on the Rights of the Child, 2009). It is the act of involving children and young people in decision-making that is commonly referred to as 'participation'. When practices are attributed to a child's *right* to be heard in decisions of relevance to their lives, Article 12(1) is unequivocal in the staged process involved in meeting the requirements of implementing this right. As referred to in paper three, Lundy's (2011: 6) conceptualisation of Article 12 identified four key concepts underpinning its successful implementation. First, 'space' - children must be provided with the opportunity to express a view in a space that is safe and inclusive (*see also* Lansdown, 2010). Second, 'voice' - children must be facilitated to express their view. Third, 'audience' - the view must be listened to. Fourth, 'influence' - the view must be acted upon as appropriate. Under Article 12, children and young people do not have the definitive say in the decision-making process but their views should be given due weight in accordance with their age and maturity. As articulated by Lansdown (1996), adults

retain responsibility for the outcome, while being informed and influenced by the views of the child.

In Article 12, the right of the child to be heard extends to ‘all matters affecting the child’. During the drafting phase of the UNCRC, earlier versions of the Convention provided a specified list of circumstances where a child had a right to express their views, including in matters concerning their education, medical treatment and recreation. However, most UN member states participating in the open-ended working group drafting the Convention felt that the circumstances in which the views of the child should be heard ought not to be subject to the limits of a list. Consequently, the wording ‘all matters affecting the child’ was agreed upon (Detrick et al., 1992). This wording has subsequently been interpreted to extend to children and young people the right to participate in research of relevance to their lives (Lundy et al., 2011; Fernandez, 2007; Petrie et al., 2006; UN Committee on the Rights of the Child, 2006; Taylor, 2000). The threshold set in terms of whether children and young people should be involved in the decision-making process is whether their ‘perspectives can enhance the quality of solutions’ (UN Committee on the Rights of the Child, 2009: 10). While the UN Committee on the Rights of the Child encourages institutions that conduct research on children’s issues for either academic or policy purposes to involve children in the research process, it qualifies this with the wording ‘when appropriate’ (UN Committee on the Rights of the Child, 2006: 6). Nevertheless, research that explicitly adopts a human rights-based or rights informed methodological approach necessitates that children and young people are, not only participants in the research, but are also engaged in the research process, including choices around methods and the analysis and interpretation of findings (Lundy and McEvoy, 2012; Beazley et al., 2011).

### Protection rights

A child or young person’s right to protection is broadly defined as ‘the right to be shielded from harmful acts or practices’ (Hammarberg, 1990: 100). Article 19, described as one of the most ‘comprehensive and unequivocal’ provisions of the UNCRC (Kilkelly, 2008: 243), sets out a state’s responsibilities to protect children and young people from harm, irrespective of whose care they are in. It provides:

States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.

A range of other Articles in the UNCRC also prohibit various other forms of exploitation (Articles 32-36), including economic exploitation (Article 32), exploitation prejudicial to any aspects of the child's welfare (Article 36) and inhumane or degrading treatment (Article 37). Article 16 provides that no child shall be subject to an arbitrary or unlawful interference with his or her privacy. In 2011, the UN Committee on the Rights of the Child issued a General Comment on Article 19. This detailed interpretation of the provision provided that administrative and preventative measures to protect children and young people from harm should include, establishing and implementing professional codes of ethics (UN Committee on the Rights of the Child, 2011). However, it did not go so far as to prescribe what should be included in such codes of ethics. In the literature on children and young people's involvement in research, there is limited discussion on a child's *right* to be protected from harm. As there is a plethora of codes of ethics governing the protection of human subjects in research, the literature generally refers to these codes when discussing children and young people's protection from harm, rather than discussing it from the perspective of children and young people's rights to be protected from harm.

As well as human rights being indivisible, they are also understood to be inter-dependent. This means the realisation of one right often depends, wholly or in part, on the other (United Nations, 2003). Denying certain rights will undermine other rights (Freeman, 2007). In this regard, the UN Committee on the Rights of the Child has explicitly said that 'a child's participation promotes protection and child protection is key to participation' (2011: 24). The Committee goes on to say that inviting children's views and giving them due weight must be a 'mandatory step' at every stage of a child protection process. Article 5 of the UNCRC is described as central to the balance the UNCRC seeks to achieve between recognising children as active agents in their own lives, while being entitled to protection in accordance with their relative immaturity and youth (Morrow and Richards, 1996). Article 5 is pivotal in acknowledging children and young people's competence. It provides that State Parties shall respect the responsibilities, rights and duties of parents and guardians to provide appropriate direction and guidance to their child in the exercise of their rights, but in a manner consistent with the evolving capacities of the child. This provision thereby acknowledges the role of parents and guardians in protecting children and young people by supporting them to exercise their rights, while recognising the capacity of children and young people as they mature to exercise their own rights.

## 2.6 Balancing Participation and Protection

There is limited discussion in the literature on the interface between the protection and participation discourses. Yet the challenge of integrating these discourses is acknowledged as an issue. From the earliest articulations of the new social studies of childhood, the question has been asked 'how can a sociology of childhood be practised in a way which is sensitive to the political and ethical problems it inevitably entails?' (James and Prout, 1997: 30). Similarly, in the aftermath of the adoption of the UNCRC a leading scholar in children's rights asks, '[h]ow could children be granted equal value and at the same time the necessary protection?' (Hammarberg, 1995). Hammarberg situates this statement in the context of the primary philosophy behind the UNCRC being that childhood is not merely a training ground for adult life, but that children and young people are equals and have the same inherent value as grown-ups.

Recently, it is observed that there has been a shift from a predominantly protectionist discourse to an emphasis on children and young people's participation rights (Graham et al., 2013). Although, in the context of children and young people's involvement in research, a disconnect is still said to exist between current ethical responsibilities to protect children and young people from harm and the conceptualisation of children as social actors with participation rights (Skelton, 2008; Morrow and Richards, 1996). Graham et al. (2013) remind us that, while the participation and protectionist discourses may be presented as opposing or contradictory, both are critical to a child or young person's well-being. Likewise, Woodhead (2000: 124, as cited in Kjørholt, 2004) expressed the following caution:

Displacing an image of the needy child with an image of the competent child must not result in the neglect of differences between younger and older human beings. We must not throw out the baby with the developmental bath water. The difference is that a children's rights paradigm alters the status of children as social actors. Respect for their competence as rights bearing citizens does not diminish adult responsibilities.

While the need to balance participation and protection is identified as an issue in the literature, there is very little written or guidance provided on how this might be achieved when involving children and young people in research. Carter (2009) suggests that children and young people should be actively involved in ethical oversight bodies. She contends that they could provide a valuable contribution to ethics bodies by being given the opportunity to offer their opinions on the value and risks of research proposals. This, Carter suggests, is

in keeping with the increasing involvement of children and young people in all stages of the research process. Liebenberg and Ungar (2011: 27) demonstrate that a preparedness to negotiate with ethical oversight bodies can lead to an approval for research designs with marginalised youth that 'fall outside of mainstream models of ethical research'. They found that presenting an argument to a research ethics board based on previous research experience and the views of the individual's participating in the research can facilitate the successful renegotiation of ethical approval and enable the participation of marginalised youth. Reflecting on research with children for the purpose of illuminating the tensions between protection and participation, Daley (2013: 135) developed the following set of questions to guide researchers. She described these questions as instructive in helping researchers to adopt an ethical stance, while maximising the possibility of children and young people's involvement in research.

- 1) Does this research have merit?
- 2) How can I maximise participants' competency?
- 3) Does my design ensure that participants are safe from harm (especially emotional harm)?
- 4) Am I adequately skilled to be making these assessments? If not, who is?
- 5) What are my own moral parameters in relation to disclosure of abuse?
- 6) Do I have a clear ethical framework to guide my reasoning?
- 7) What is my plan for negotiating ethical dilemmas which may arise?

Houghton (2015) observed that, with few exceptions, children and young people's voices are currently missing from the debate regarding the balance between protection and participation. In response, Houghton conducted an exploration with a group of eight young people (aged 15-19) with experience of domestic violence to ascertain their perspectives on participatory ethical principles. A core finding of this study was that there is a need to reposition children as agents in their own (and their family's) protection and to recognise that children and young people are agents of social and political change. This, Houghton suggests, requires current ethical approaches, premised on adult protection of children, to be adapted and expanded to acknowledge children's agency. In conjunction with the young people, Houghton developed a participatory ethics approach. As set out in table two, there are nine domains for consideration when involving children and young people in research. These are what Mullender et al. (2002) describe as the three C's – consent, confidentiality and child protection and the three D's – danger, distress and disclosure. Houghton, in

collaboration with the young people, also identified as a priority the three E's – enjoyment, empowerment and emancipation. These domains are set out in the left hand column with children's perspectives on each of these domains in the right column. In essence the children and young people assert that their agency should be recognised, their competence and experiences validated and they must be key decision-makers in an assessment of risk.

**Table Two: A Participatory Ethics - Three Cs, Ds and Es (Houghton et al., 2015, adapted from Mullender et al., 2002)**

<b>Three Cs, Ds and Es for the participation of young survivors: agency, power and impact</b>	
<b>Consent and information</b>	Young person is the central participant in the process and key decision-maker.
<b>Confidentiality</b>	Young person has control and choice over information sharing. Risks to anonymity require involvement of non-abusing parent.
<b>Child [and adult] protection</b>	Young person is respected as an individual survivor, their own experiences and agency in their family's protection validated.
<b>Danger</b>	Young person's perceptions of risk are vital to assessment and safety planning, alongside others affected.
<b>Distress</b>	Young people are capable of managing and minimising (inevitable distress).
<b>Disclosure</b>	Participation is an act of disclosure for young survivors, thereafter control/choice over personal stories needs maintained.
<b>Enjoyment</b>	Fun while building trust is an essential component of participation and key to feeling able to speak out.
<b>Empowerment</b>	An individual, equal voice (to each other and adults) and recognised status as experts and key decision-makers is crucial.
<b>Emancipation</b>	Real power within the political system that results in an impact on abused children's lives is a condition of involvement.

## 2.7 Summary

This literature review provided an overview of the theoretical developments underpinning the research community's current conceptualisation of children and young people, relevant



to their participation in research. It examines how two opposing discourses on childhood, children and young people as vulnerable and in need of care and children and young people as competent, autonomous actors, have influenced children and young people's involvement in social research. It outlines how the former can propel notions of incompetence and pose a barrier to children and young people's participation in research, while the latter recognises children and young people as rightful informants in the production of sociological data. Typologies are reviewed illustrative of children and young people's varying levels of involvement in research. These typologies depict the growing trend from children and young people being objects of research, to subjects, to collaborators and partners in the research process to more recently child- and youth-led research.

The chapter then proceeds to explore the ethical issues, which require consideration, when involving children and young people in social research. The review of the literature reveals that the following are the foremost ethical considerations in the context of children and young people's involvement in social research:

- Assessing potential risks and benefits;
- Obtaining the informed consent/assent of the child or young person and the informed consent of their parent or guardian; and
- Protecting confidentiality.

Contemporary literature on each of these ethical issues and their potential exclusionary consequences are examined. This is followed by a review of a researcher's rights-based responsibilities when involving children and young people in research. These rights-based responsibilities can be broadly clustered as participation and protection rights. Central to children and young people's participation rights, is the right of the child to have their views heard on all matters affecting them. Equally, children and young people have the right to be protected from all forms of harm and exploitation. The remainder of the chapter examines the literature reporting on the tension between, simultaneously protecting children and young people from harm, while respecting their autonomy as individual beings to participate in research. While clearly acknowledged as an issue, the review of the literature found limited guidance on how to navigate the balance between participation and protection.

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## Chapter 3: Methodology

### 3.1 Introduction

This chapter outlines the methodology employed in the study and is divided into four substantive sections. Following this introduction, section 3.2 elaborates on the rationale for the study and reiterates its overarching aim and four objectives. Section 3.3 describes the development of the research design, including the theoretical considerations and the methodological and research methods informing this process. In section 3.4, the implementation of the study design is detailed with reference to each of the three papers. The chapter concludes by considering the limitations of the research.

### 3.2 Rationale, Aims and Objectives

The rapid growth in children and young people's involvement in research has sometimes come at the cost of a reflective approach to research. On the one hand, Parry-Williams notes (1998: 6) that, '[p]articipation can be preached with too much ideological fervour without enough attention to securing actual tangible benefits', or as observed elsewhere, without enough consideration to the risk of doing more harm than good (Klocker, 2015). On the other hand, a common critique is, as referred to by McCarry (2012), the disjuncture between the move to hear children's voices through social research and the dilemmas of negotiating with gatekeepers, restricted timeframes and ethical considerations. It is of particular concern that as the participatory agenda moves forward harder to reach groups of children and young people will be further marginalised (Kellett et al., 2010).

As set out in the introductory chapter of this thesis, the author personally experienced these realities set out above when conducting an empirical study on young carers in Ireland. In this study the author, supported by the wider research team, sought to recruit a representative sample of young carers to better understand how their caring role impacts on their lives. The recruitment phase of the study raised significant ethical and methodological challenges. The tension between the need to protect young carers from harm and to respect their competence and autonomy to be involved in research, initiated to better understand their lives, was acutely felt. This personal experience and a scoping of the available literature at the time led to a process of reflection, influencing the aim and objectives of this study. Notably, the experience of the author is not unique and is widely corroborated in the literature. Recently, a systematic literature review on ethical issues arising in qualitative health research with children (referred to in chapter 2) brought to the fore the challenges of



recruiting participants, while simultaneously meeting ethical responsibilities to protect children and young people from harm. The authors of this systematic review concluded that how to reach a balance, between protecting children and safeguarding their participation, needs further research (Huang et al., 2014).

The overarching aim of this study is to explore how social science researchers can navigate the dichotomy between protecting children and young people from harm and respecting their competence and autonomy, as individual beings, to participate in research of relevance to their lives.

The objectives of the study are:

1. To reflect on the participation and protection discourses and their influence on children and young people's involvement in research;
2. To examine a researcher's ethical duties and rights-based responsibilities when involving children and young people in research;
3. To explore solution focused strategies to support researchers to navigate the balance between protection and participation; and
4. To distil messages for ethical oversight bodies and the research and academic community.

### 3.3 Designing the Study

Research design is described as a framework for conducting research, involving 'the intersection of philosophy, strategies of inquiry and specific methods' (Creswell, 2009: 5). Guided by the pragmatist philosophy, this thesis is exploratory in nature and utilises primarily reflective strategies of inquiry (otherwise known as methodologies) and research methods to meet its aim and objectives. Exploration is an approach adopted when the subject of study is relatively new (Babbie, 2013). According to Babbie (2013: 90), exploratory studies are typically undertaken for three reasons: to satisfy the researcher's desire for better understanding, to test the feasibility of a more extensive study and to develop the methods to be employed in any subsequent study. The philosophical considerations informing the research design and the theory underpinning reflective methodologies are outlined below. This is followed by an overview of reflective writing as a research method. An overview is also provided of comparative methods in legal research, an approach that influenced the research design in paper two. The chapter concludes by establishing the research design for the overall study.

## Philosophical considerations for the research design

In the social sciences, the term 'paradigm' is referred to as an 'anchor of certainty' (Patton, 2002: 71) and defined as 'the consensual set of beliefs and practices that guide a field' (Morgan, 2007: 49). One form is 'paradigms as worldviews', understood as all-encompassing ways of perceiving and experiencing the world (*ibid*). Creswell (2009: 5) identified four worldviews that influence the practice of research and inform decisions on whether to adopt a quantitative, qualitative or mixed methods approach. As set out in table three below, these worldviews are postpositivism, constructivism, advocacy/participatory and pragmatism. Like positivism, postpositivism derives from an objectivist epistemology, advocating methods from the study of natural sciences for the study of social reality. While positivism seeks to generate hypotheses that can be tested, which can lead to the development of causal laws about social reality, postpositivism marks a shift in earlier thinking by recognising that it is not possible to derive an absolute truth in the study of human behaviour (Bryman, 2015). Constructivism operates on the premise that the study of the social and human world differs from that of the natural world and therefore requires different methods of inquiry (Guba and Lincoln, 1994). Constructivism stems from an ontological position, claiming that truth is 'constructed by humans as they engage with the world they are interpreting' (Crotty, 1998: 43). This worldview holds that historical and social contexts, as well as the researcher's personal experiences, influence knowledge generated. The advocacy and participatory worldview places its focus on the needs of groups or individuals in society who are marginalised. In discussing this worldview, Creswell (2009) notes that its proponents felt that constructivism did not go far enough in advocating an action agenda to help those marginalised. Knowledge is generated in collaboration with those affected and with a goal of reform and change.

Influenced by the works of John Dewy (1859-1952), it is said that at its core, pragmatism offers a consequential action-knowledge framework, where knowledge is derived from reflection (Biesta, 2010; Greene and Hall, 2010; Barbalet, 2009). Collating the views of Cherryholmes (1992), Morgan (2006) and his own, Creswell (2009, 10-11) identifies several assumptions underpinning the pragmatic worldview:

- Pragmatism is not committed to any one philosophy or reality.
- Individual researchers have freedom of choice in terms of the methods they use; they are free to use methods that provide the best understanding of the research problem.

- Truth is what works at the time. It is not based on a duality between reality independent of the mind or within the mind.
- Pragmatists look at the intended consequences of the research - what they want to achieve when determining the ‘what’ and ‘how’ to research.
- Like the other philosophies, pragmatists are cognisant of the social, historical and political contexts the research occurs in.

This led Creswell to conclude that ‘for the mixed methods researcher, pragmatism opens the door to multiple methods, different worldviews, and different assumptions, as well as different forms of data collection and analysis’ (11).

**Table three: Four worldviews and the major elements of each position (Creswell, 2009: 6)**

<b>Postpositivism</b>	<b>Constructivism</b>
<ul style="list-style-type: none"> <li>• Determination</li> <li>• Reductionism</li> <li>• Empirical observation and measurement</li> <li>• Theory verification</li> </ul>	<ul style="list-style-type: none"> <li>• Understanding</li> <li>• Multiple participant meanings</li> <li>• Social and historical construction</li> <li>• Theory generation</li> </ul>
<b>Advocacy/Participatory</b>	<b>Pragmatism</b>
<ul style="list-style-type: none"> <li>• Political</li> <li>• Empowerment issue-orientated</li> <li>• Collaborative</li> <li>• Change-orientated</li> </ul>	<ul style="list-style-type: none"> <li>• Consequence of actions</li> <li>• Problem-centered</li> <li>• Pluralistic</li> <li>• Real-world practice orientated</li> </ul>

In 2007, Morgan observed that much of the discussion in social science research over the past two decades has focused on the distinction between qualitative and quantitative research. However, in more recent years, pragmatism has been understood as offering a guiding paradigm in social science research to support the combination of qualitative and quantitative methods (Creswell, 2009; Greene, 2008; Morgan, 2007). Patton (Patton, 2002: 72) goes a step further to explain that pragmatism promotes ‘methodological appropriateness as the primary criterion for judging methodological quality, recognising that different methods are appropriate for different situations’. However, Biesta (2010: 97) is critical of pragmatism being given the position of a philosophical worldview. She suggests that pragmatism should not be understood as a philosophical position, but rather as a ‘set of

philosophical tools' to address research problems, not least problems created by other philosophical positions.

### Reflective strategies of inquiry

There is extensive literature validating the long tradition of generating knowledge from experiential learning and reflection (*some more recent examples include*, Rolfe et al., 2010; Fook and Gardner, 2007; Dolan et al., 2006; Redmond, 2004). Redmond traces the roots of reflection to predominately the educational and professional discourse espoused by Dewey and later developed by S

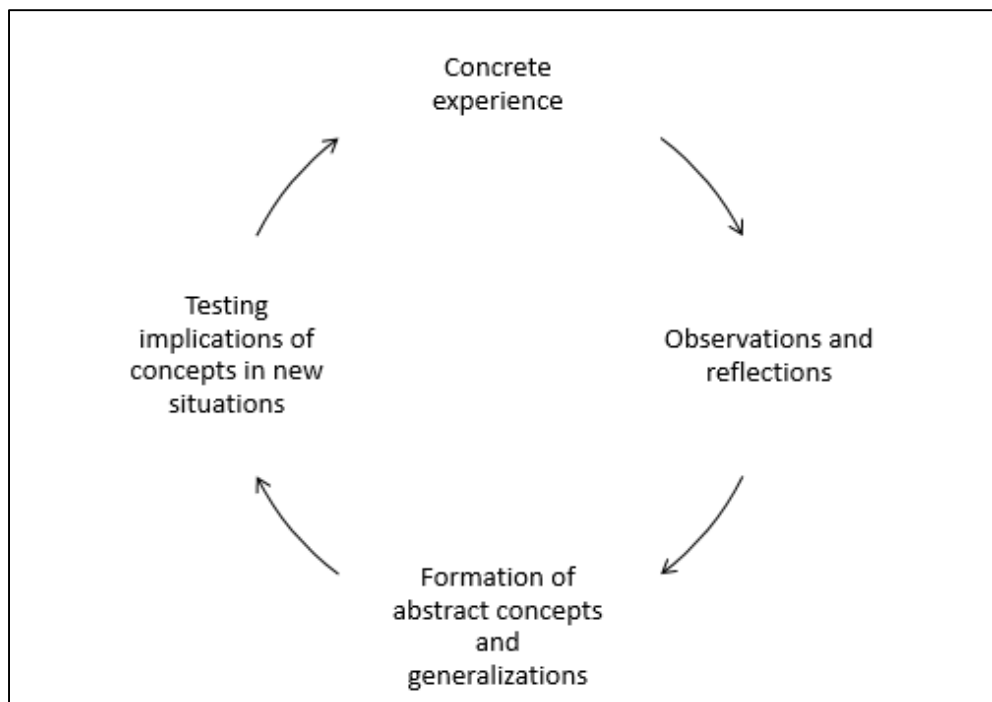
chön (1983), Argyris (1993) and Mezirow (1990). Dewey was a philosopher, psychologist and educationalist, who, as noted by Redmond (2006: 9), 'saw the act of reflection as central to human learning and personal development'. The following model, developed by Dewey (1938), illustrates his approach to reflective learning.

**Figure two: Dewey's model of reflective learning (reproduced in Rolfe, 2012)**



In essence, it depicts that observation and reflection on one's personal experiences generates knowledge. Likewise, Kolb has advanced a model of reflection grounded in experiential learning. Influenced by the Lewinian experiential learning model, as set out in figure three, Kolb (1984: 38) concluded that 'learning is a process whereby knowledge is created through the transformation of experience'.

**Figure three: The Lewinian Experiential Learning Model (Kolb, 1984)**



The core approaches to reflection are, reflective practice and action research, critical inquiry, and reflexivity. Each of these approaches are discussed below.

### Reflective practice and action research

The work of Schön also made explicit the link between reflection and the development of knowledge. However, the focus of Schön's work was on the generation of knowledge from any form of professional practice. His work challenged a positivist/empiricist approach to professional practice, arguing for a new epistemology of practice that elevates the experience of the practitioner and the process of reflection in action (Schön, 1987). Of note, he did not advocate the scientific approach over a reflective approach, but instead suggested a combined approach to knowledge generation and learning. Schön identified two types of reflection: 'reflection in action' and 'reflection on action' (Schön, 1983: 276-278). Teekman (2000: 1126) defined these concepts as follows:

- Reflection in action - refers to the reflective thinking one is doing while one is doing the action.
- Reflection on action - occurs in contrast to reflection in action, after the experience has taken place.

There are now many definitions and models of reflective practice. Writing in the context of critical reflection in practice, Rolfe et al. (2010: 12) define reflection as:

[A] process of thinking, feeling, imagining and learning by considering what has happened in the past, what might have happened if things had been done differently, what is currently happening, and what could possibly happen in the future.

Dolan et al. (2006) describe the process of reflective practice as comprising description and questioning informed by action for the purpose of leading to change, in both the individual and social context. Both of these definitions place an emphasis on the importance of reflection being, as described by Rolfe, translated into 'positive outcomes in the real world' (2010: 12).

The process of reflective practice has been presented in illustrative frameworks to guide practice. One commonly referred to in the literature is the framework developed by Gibbs (1988). Gibbs' model comprises three core components, description of the experience, evaluating and analysing the experience, and drawing conclusions to inform an action plan.

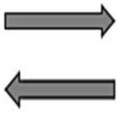
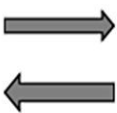

**Figure four: Gibbs' (1988) reflective framework**



Of note, Rolfe et al. (2010) questions the cyclical approach to Gibbs' model, remarking that the process appears to end with the action plan and it is not clear how this phase links back

to the description. Borton (1970) distils the reflective process into three simple questions, 'what?', 'so what?' and 'now what?'. Building on Borton's macro-framework of reflection, Rolfe et al. (2001) sought to provide the micro-structure for this reflection process. As set out in figure five below, they describe the 'what?' as the descriptive level of reflection, the 'so what?' as theory and knowledge building reflection and the 'now what?' as action orientated reflection. These descriptors are accompanied by cue questions for consideration. Rolfe et al. (2010) make explicit that this is a generic framework and the cue questions are intended to be open to change and revisions for different professionals in different situations.

**Figure five: Rolfe et al. (2001) framework for reflective practice**

Descriptive level of reflection	Theory- and knowledge building level of reflection	Action-oriented (reflexive) level of reflection
What ... 	So what ... 	Now what ... 
...is the problem/difficulty/reason for being stuck/reason for feeling bad/reason we don't get on etc.? ...was my role in the situation? ...was I trying to achieve? ...actions did I take? ...was the response of others? ...were the consequences • for the client? • for myself? • for others? ...feelings did it invoke? • in the client? • in myself? • in others? ...was good/bad about the experience?	...does this tell me/teach me/imply/mean about me/my client/others/our relationship/my client's care/the model of care I am using/my attitudes/my client's attitudes/etc.? ...was going through my mind as I acted? ...did I base my actions on? ...other knowledge can bring to the situation? • factual • practical • personal ...could/should I have done to make it better? ...is my new understanding of the situation? ...broader issues arise from the situation?	...do I need to do in order to make things better/stop being stuck/improve my clients care/resolve the situation/feel better/get on better/etc., etc.? ...broader issues need to be considered if this action is to be successful? ...might be the consequences of this action?

Parallels have been drawn between reflective practice and action research (McIntosh, 2010; McMahon, 1999). However, there is little clarity or consensus on how the two approaches differ. The literature reveals three different interpretations. First, it is suggested that reflection as part of action research, must be informed by empirical data. Discussing the work of Elliot (1991), McIntosh (2010: 34) notes:

For Elliot, action research is fundamentally about the transformation of practice. Its role is not purely philosophical, although he recognises that it has philosophical qualities. It is an empirical approach to the importance of data in reflectively improving practice.

Second, some scholars' emphasise the participatory nature of action research, the implication being that reflection is conducted in collaboration with the research participants and/or stakeholders in the issue under consideration. While Bradbury and Reason acknowledge that action research can be an individual affair, through which professionals strive to improve their practice (2008: 7), their often cited definition of action research emphasises its participatory nature. They define action research as, seeking 'to bring together action and reflection, theory and practice, in participation with others, in pursuit of practical solutions to issues of pressing concern to people' (2008: 1). This, it could be said, appears to blur the lines between 'action research' and 'participatory action research'. There is some agreement that individual reflection, with a focus on improving one's own practice, can be one approach as part of a family of approaches to action research (Coghlan and Brannick, 2014; Christ, 2010). Third, McMahon (2010) distinguishes action research on the basis that it requires strategic action to solve a particular problem or set of problems. This, according to McMahon, is not required of the reflective practitioner, as expressed in experiential learning models. It is agreed that core to both reflective practice and action research is the transformation of practice and the production of, what Reason and Bradbury (2008: 4) describe as, 'practical knowledge'.

### Critical Inquiry

The terms 'critical inquiry' and 'critical reflection' are synonymous and often used interchangeably, without, as Redmond (2006) observes, much regard for what defines the critical element of the reflective episode. Following an extensive review of the literature and observing that there is no agreed definition of the term, White (2015) identified three common characteristics of critical reflection. The first characteristic is the role critical reflection plays in questioning deep-seated assumptions. Discussing the work of Mezirow (1990), one of the leading scholars in this field, Redmond (2006) notes that Mezirow believed that the process of transforming an individual's frame of reference begins with critical reflection, which demands that firmly held assumptions are scrutinised. Similarly, Fook et al. (2007: 21) place an emphasis on challenging assumptions in their definition of critical reflection as a process that:

involves the unsettling and examination of fundamental (socially dominant and often hidden) individually held assumptions about the social world, in order to



enable a reworking of these, and associated actions, for changed professional practice.

The second commonly agreed characteristic of critical reflection identified by White, is its focus on questioning and challenging power and power relations within society. Brookfield (1995) argues that reflection becomes critical when it not only questions assumptions and practices, but when it also seeks to understand how power frames and distorts processes and interactions. Taking Foucault's work as the basis for understanding power, that is, that the exercise of power takes place in relationships between people, Fook (2006: 44) suggests that a purpose of the critical reflective process is to 'hunt for' and 'reveal' how power is exercised. Not only, according to Fook, to determine how power is exercised in relationships between people, but also to enable awareness of one's own use of power.

The third commonly agreed characteristic is the emphasis critical reflection places on using the process of reflection to bring about transformation and change. On this issue, Brookfield suggests that 'central to critical thinking is the ability to imagine and to explore alternative ways of thinking and acting' (Redmond, 2006: 21). This transformative perspective, according to Thompson (2008), is often referred to as an emancipatory approach; an approach influenced by the work of Freire (1972) and intended to free people from their restrictive social circumstances by overcoming inequality and disadvantage.

### **Reflexivity**

The terms 'reflective', 'critical reflection' and 'reflexive' are also used interchangeably in the literature, but when the distinction is made it is said that reflexivity is a form of research involving reflection on several levels (Alvesson and Sköldberg, 2009). Similarly, Fook et al. (2007) suggest that reflexivity is one form of being critically reflective. Described as 'a crucial aspect of knowledge construction' (Probst and Berenson, 2013: 3), it is defined as where 'researchers engage in explicit, self-aware analysis of their own role' (Finlay, 2002: 531). Alvesson and Sköldberg (2009: 6) identify two basic characteristics of reflexive research. The first is the 'interpretation of interpretation' in the context of empirical research. That is, critical exploration of one's own interpretations of the data and examining explicit ways in which the data can be qualified. The second is reflection inward towards the researcher, as well as the community, societal, intellectual and cultural research context.

In terms of reflection inwards towards the researcher, the researcher must be aware of her or his own personal biases or worldviews. These can incorporate the non-academic based life experiences of the researcher as well as being personally influenced by constructs within

academia, such as theory, ethics, and research methods (Davis, 1998). According to Patton (2002: 299), the term reflexivity entered the qualitative lexicon to remind the inquirer 'to observe herself or himself so as to be attentive to and conscious of the cultural, political, social, linguistic and ideological origins of her or his own perspectives and voice'. Reflection 'inwards' towards the community, societal, intellectual and cultural research context is, as suggested by Sultana (2007: 376), to be aware of 'what can/cannot be done vis-à-vis the research within the context of institutional, social and political realities'. While some have sought to provide techniques for reflexivity (*see for example*, Patton, 2002), a recent study that gathered information about reflexive activities in qualitative social work research concluded that, it cannot be constrained by a set of techniques, but is an 'attitude' or 'way of being' during the research process (Probst and Berenson, 2013: 8).

### Reflective and comparative research methods

Reflective writing has become established as a research method in its own right and is recognised as central to reflective practice and experiential learning (Jasper, 2005). Rolfe (1997: 448) suggests that every individual carries a 'dismembered' but 'unique body of knowledge' that can only be accessed and pulled into a coherent body of knowledge through the process of writing. Similarly, Jasper (2005) notes that reflective writing is a technique in its own right, which enables the researcher to draw together and express fledgling ideas and connections to contribute to building a body of knowledge. In essence, it involves the application of the techniques of critical analysis, critical thinking and reflection (*ibid*).

In social science, comparative research methods have long been used in cross-cultural studies and in multiple-case studies. The comparative approach 'implies that we can understand social phenomena better when they are compared in relation to two or more meaningful contrasting cases or situations' (Bryman, 2015: 64). Comparative research methods are also common-place in legal research. In this context, it involves critically reflecting on the origin, nature and limits of a law, in two or more jurisdictions, for the purpose of knowledge progression (Paris, 2016). Inspired by the work of De Cruz (1999), Paris (2016: 50-52) proposes a number of steps to the method of comparison. These are:

1. Identifying and naming the issue to be explored.
2. Choosing the comparator or the number of comparators. The choice of comparator(s) can be justified on the grounds of familiarity with the language and proximity in terms of the legal traditions.

3. Determining the strategy to get access to the most relevant, authoritative and up-to-date primary and secondary sources about the foreign jurisdiction(s). This can also be a factor in justifying the scope of the comparison.
4. Conducting the analytical comparison.
5. Producing the research findings. These should be set out in a comparative framework accompanied by a critical commentary, wherever relevant.

The purpose of employing the comparative method in legal research is primarily twofold: to develop a critical perspective on the legal systems compared; and to develop a critical understanding of the area of law and the law in context (Paris, 2016).

### Establishing a research position to address the study objectives

Gallagher (2008a: 26) suggests that ethical practice is ‘an ongoing process of questioning, acting and reflecting’. Similarly, Mortari and Harcourt (2012: 234) advocate that ‘[w]hat is relevant in the field of ethics is the exercise of reason and critical inquiry in order to better give voice to the complexity of ethical questions’. They suggest that it is necessary to take a reflective approach in response to an ethical dilemma. An ethical dilemma is said to occur when a situation gives rise to two opposing solutions. Mortari and Harcourt describe these as the ‘horns’ of the dilemma within which a researcher gets ‘stuck’, thereby requiring deep reflection (236). The author views the dichotomy between protection and participation as fundamentally an ethical dilemma confronting researchers. Guided by the pragmatist worldview and influenced by the wisdom of Gallagher, Mortari and Harcourt, the author concluded that a primarily reflective, reflexive and critical inquiry methodology was most suitable and warranted for this study. Gibbs’ well-established reflective framework (set out in figure four above) was selected to guide the reflection process. It was considered that the outcome of this reflective process would be shaped into a coherent body of knowledge through the method of reflective writing. Comparative research methods were also chosen to critically review existing ethical frameworks.

In sum, reflecting on the author’s experience of involving children and young people in social research, as well as drawing on contemporary literature and utilising comparative research methods to develop a critical understanding of ethical frameworks, this thesis set out to explore how social science researchers can navigate the dichotomy between protecting children and young people from harm and respecting their competence and autonomy as individual beings to participate in research of relevance to their lives. Through the use of primarily reflective strategies of inquiry and research methods, the research seeks to

generate learning on the issue as well as suggest solution focused strategies. It is not the intention to provide definitive solutions to this ethical dilemma as, to seek to do so would be, as Mortari and Harcourt (2012: 234) caution, 'an arduous and endless enterprise'.

### 3.4 Implementing the Study

Having outlined the intent of the research design and the relevant theoretical perspectives underlying the methodology and the research methods, this section focuses on the process of implementing this exploratory study. Implementing the study involved two phases; each phase completing a full cycle of the reflective process advocated by Gibbs (1998). Phase one, documented in paper one and paper two, can be described as what Schön (1987) termed 'reflection on action'. Phase two, written up in paper three, documents the findings during a period of 'reflection in action'.

#### Phase one: Reflection on Action

As set out above, the first phase of this study can be described as 'reflection on action'. It was initiated to generate findings from the experience of recruiting a sample of young carers for a qualitative study in Ireland. Guided by Gibbs' model of reflection, paper one describes the recruitment process, reflects on the author's feelings, evaluates and analyses the experience and draws conclusions as to what else could have been done differently. Implementing these initial stages of Gibbs' reflective framework, laid the foundations for paper two. Paper two explores in further detail a key conclusion in paper one, that is, that the ethical requirement to obtain parental consent had exclusionary consequences. It also generates findings on what could be done if the situation arises again. Combined, these papers complete a full cycle of Gibbs' reflective framework. As explained above, this framework can be broken down into three constituent parts. These are what Rolfe et al. (2001) term, a descriptive level of reflection, theory and knowledge building level of reflection and action-orientated reflection. Each of these stages of reflection, comprising phase one of the study, are set out in further detail below.

#### *Descriptive level of reflection*

A 'descriptive level of reflection' was the first phase of reflection embarked upon. Citing the work of Boud et al. (1985), Atkins and Murphy (1993: 1190) explain that 'description involves the ability to recognise and recollect accurately salient events and key features of an experience and to give a comprehensive account of the situation'. Guided by the initial three steps in Gibbs' model of reflection, paper one sought to pull together and organise the

author's reflections on the recruitment phase of the young carers study into a coherent body of knowledge. It set out to accurately describe the recruitment process, including the researcher's role and what the research team was aiming to achieve. It details the methodological and ethically informed actions taken to recruit a sample of young carers, before analysing the consequences of these actions. As described in detail in paper one, methodologically the research team adopted a two-pronged approach to recruitment. Self-referrals to the study were sought through a nationwide information campaign and gatekeepers were targeted to refer young carers to participate in the research. Ethically, parental consent was sought and adherence to child protection guidelines imposed limits on confidentiality. The paper describes the consequences of these actions for both the research and the research participants. This included difficulties in recruiting young carers to participate in the research and the attainment of a small and potentially unrepresentative sample size. The actions taken were also thought to have excluded the more marginalised young carers from participating in the study. The paper details the feelings that this evoked, analysing the participation and protection discourses at play.

#### *Theory and knowledge building level of reflection*

The next stage in the reflective process is what Rolfe et al. (2001) describe as the 'theory and knowledge building level of reflection'. This encompasses step four and five of Gibbs' model of reflection. These steps involve analysing the situation and drawing conclusions on what could have been done differently. Paper one commences this process by drawing on the learning from the experience of the recruitment process and knowledge generated in similar studies documented in the literature. It analyses the success and limitations of the approaches the research team adopted to enable young carers to participate in the research, while, at the same time, safeguarding them from harm. It revisits the measures taken to comply with the ethical requirement of parental consent and limits on confidentiality. Analysing this experience raised the question as to whether compliance with the parental consent requirement could have been approached differently. One of the conclusions arrived at is that flexibility in the requirement to secure parental consent, in circumstances where a young person has sufficient maturity and capacity to consent to research and is fully aware of the implications of their decisions, could have opened the door to providing some of the most marginalised young carers with the opportunity to have their views heard. This provided the foundation for further exploratory research on this alternative approach proposed. It triggered the final stage in Gibbs' model of reflection by raising the question, if the situation arose again what could be done?

### *Action-orientated level of reflection*

Paper two set out to examine a researcher's ethical and rights-based responsibilities in relation to the issue of parental consent. The research that forms the basis of paper two critically reflects on ethical frameworks governing the parental consent requirement and synthesises contemporary literature to generate its findings. While ethical frameworks are not legally binding, in order to provide clarity on how the issue of parental consent is regulated in different jurisdictions, the comparative method in legal research was considered to be best placed to compare and critically reflect on current ethical frameworks. This involved a number of sequential steps, broadly in keeping with the comparative research method suggested by Paris (2016). After an initial scoping exercise reviewing ethical frameworks that researchers and ethical oversight bodies are operating within, different approaches to the ethical requirement of parental consent were identified. The selection of the ethical frameworks to be included for comparison was both purposive and convenient. The frameworks were strategically chosen on the basis that they were illustrative of these different approaches identified and relatively convenient to source information on.

The strategy for accessing the most relevant, authoritative and up-to-date information on ethical frameworks in different jurisdictions involved sourcing ethical frameworks online and drawing on the literature in the area. The final step involved analysis and critical commentary on the different frameworks included. The second aspect of this study was a review of the literature to identify innovative, yet ethically compliant, strategies employed by researchers to navigate the parental consent requirement, irrespective of the over-arching ethical framework they were operating within. While it was not a systematic review of the literature, every effort was made to uncover a range of examples of innovative and ethically compliant strategies. The searches conducted within relevant social science databases used broad search terms to return all studies in the wider area, as often strategies documented were not the sole or even a key focus of the publication (the literature searches are detailed further in paper two). These studies were reviewed for information on innovative approaches taken to comply with the parental consent requirement. It is envisaged that the findings detailed in paper two could inform an action plan for researchers (including the author) on how to negotiate the parental consent requirement with ethical oversight bodies and gatekeepers, in an ethically compliant and inclusive manner, if the situation arose again where parental consent is not feasible or appropriate due to its exclusionary consequences.

## Phase two: Reflection in Action

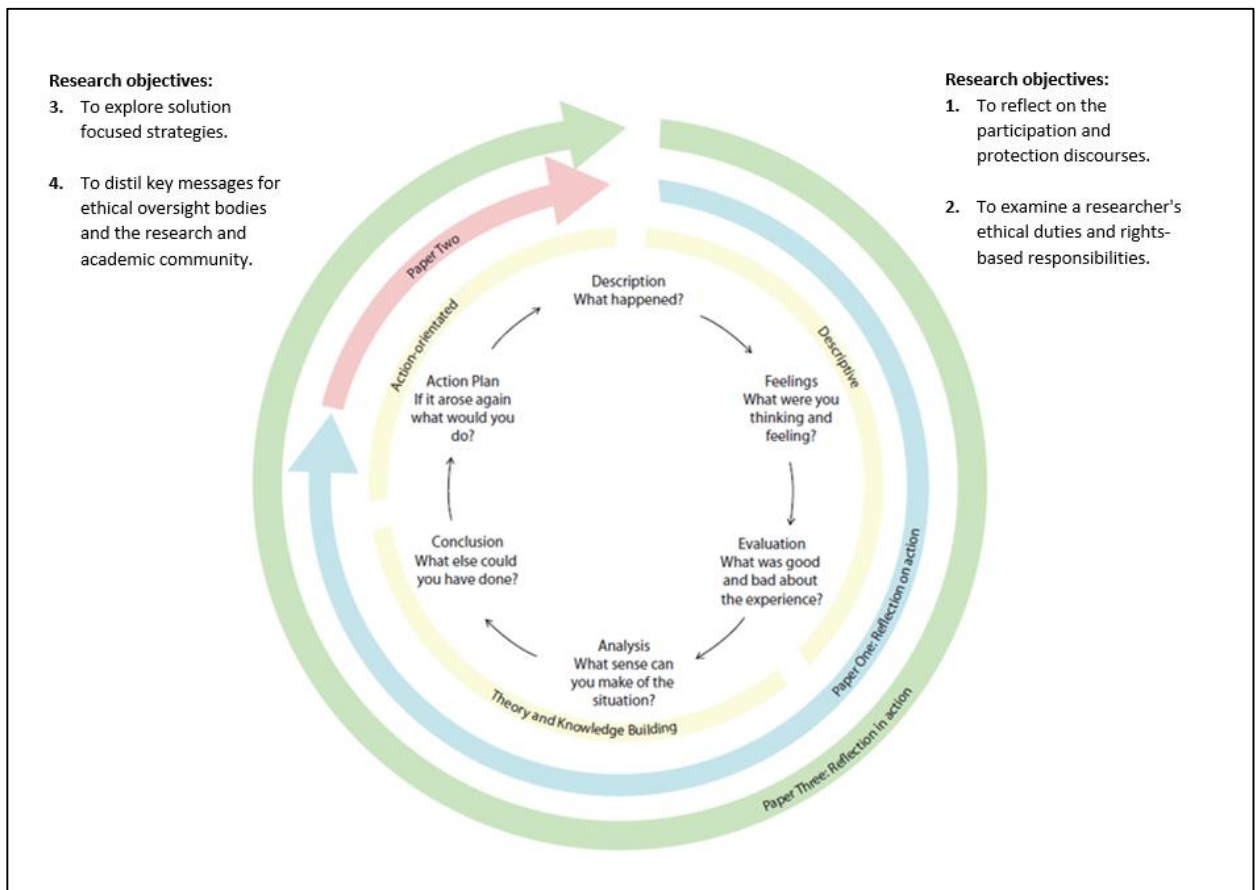
The second phase of implementation can be described as 'reflection in action'. The learning from the literature review conducted for this thesis (chapter two) revealed that the ethical requirement to conduct an assessment of the risk of harm, or the likelihood of benefit prevailing, is central to navigating the dichotomy between participation and protection. Children and young people can be included in or excluded from research on the basis of this assessment process. This led to a heightened awareness, during research projects the author was later involved in, of what are the critical considerations when conducting a rigorous but balanced assessment of harm and benefit. Paper three documents the author's reflections in this regard during the design phase of two research projects.

The first research project was a baseline study examining the extent to which children and young people's right to participate in decision-making is embedded in the structures and culture of Tusla, the Child and Family Agency. The second was a youth-led research project on the topic of youth mental health. Regarding the former, an assessment of harm and benefit was required to assess whether to involve children and young people in the research, at a minimum, as sources of data. Regarding the latter, an assessment was required prior to the author and her supervisor making a decision on whether to facilitate the youth-led research project. These very different projects were selected to form the basis of paper three in an effort to illustrate that the learning generated from the reflection process is relevant to all research projects involving children and young people. The two projects were at opposing ends of the continuum of children and young people's involvement in research, were on very different topics and employed different methodologies.

Guided by Gibbs' reflective framework, paper three describes the two projects and the considerations at play during the assessment of harm and benefit. Describing the author's experiences of conducting an assessment of harm and benefit, it identifies and evaluates three critical considerations that can provide an indication of the likelihood of harm or benefit prevailing. These are, the purpose and the theoretical context of the study, the preferences of the children and young people and their parents, and the time and resources available. It analyses each of these considerations, with reference to the relevant literature in the area. The paper concludes by developing a set of reflective questions to guide future assessments of harm and benefit, thereby completing a full cycle of Gibbs' reflective framework.

Figure six below (reprinted in Appendix one), illustrates how Gibbs’ reflective framework was used to generate learning on navigating the dichotomy between protection and participation. At the centre of figure six is Gibbs’ reflective framework, broken down into the three constituent parts categorised by Rolfe et al. (2001) as, a descriptive level of reflection, theory and knowledge building level of reflection and action-orientated reflection. It illustrates the two cycles of reflection undertaken to generate the study findings. Paper one and paper two comprise one cycle of reflection, while paper three comprises the second. It also depicts how the levels of reflection on the right hand side of Gibbs’ reflective framework address the first and second research objectives, while the levels of reflection on the left hand side of the framework address the third and fourth research objectives.

**Figure Six: Using Gibbs’ (1988) reflective framework to generate learning on navigating the dichotomy between protection and participation**





### Study Limitations

As set out above, this study is exploratory in nature. A known limitation of exploratory studies is that 'they seldom provide satisfactory answers to research questions, though they can hint at answers and suggest which research methods could provide definitive ones' (Babbie, 2013: 91). Indeed, this study does not provide definitive solutions to the ethical dilemma of navigating the dichotomy between participation and protection. Instead, the research generates learning from the author's experiences and proposes solution focused strategies, rather than definitive solutions to this ethical dilemma. As referred to above, to provide definitive solutions would be, as Mortari and Harcourt (2012: 234) caution, an arduous and endless task. It would also fail to take into account the range of ethical issues that can arise and the nuances of each research project.

A second limitation is that the reflective process is not informed by empirical evidence. The learning generated is not produced in collaboration with stakeholders, namely children and young people and other professionals with experience of researching children and young people's lives. However, as established in this chapter, generating knowledge from experiential learning and individual reflection is a valid form of knowledge generation. The focus of this thesis was to reflect on the author's personal experience as a professional researcher of involving children and young people in research and to generate practical knowledge and explore solution focused strategies for other researchers facing similar dilemmas. However, with the conclusion of this exploratory study it would be timely and appropriate to seek the views of other professional researchers and children and young people.

### 3.5 Summary

This chapter set out to describe the methodology developed and implemented to answer the aim and associated objectives of the study. Commencing with a reiteration of the rationale, aim and objectives of the study, the chapter proceeds to examine the three core elements underpinning the study design – the philosophical considerations, the strategies of inquiry and the research methods. The chapter reviews different worldviews and recommended approaches to responding to an ethical dilemma. Guided by the pragmatist philosophy, the author establishes that a primarily reflective and critical inquiry methodology is most suitable and warranted for this study. A range of illustrative frameworks to guide reflective strategies of inquiry are outlined and it is explained that Gibb's well-established reflective framework is selected to guide the reflection process. Next, the implementation

of the study across the three research papers is detailed. Finally, the main limitations experienced by the study were addressed.

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## Chapter 4: Accessing a Hard to Reach Population: Reflections on Research with Young Carers in Ireland

### 4.1 Introduction

An emerging respect for the agency of children has resulted in a notable effort to include children as active participants as opposed to passive subjects of research. This approach involves a commitment to respect the competence of children, both the competence to 'make decisions about whether to participate in research' and also the competence 'to provide valid sociological data' (Morrow and Richards, 1996: 98). Involving children and young people in research respects a child's right to express their views in all matters affecting them as provided in Article 12 of the UNCRC. The general acceptance of children's agency in international law is reflected in developments in social science. The 'new social studies of childhood' conceptualises children as social actors and has equally been identified as a contributing factor to the increasing focus on children's involvement in research (Mason and Hood, 2011).

In keeping with these developments a strong argument can be made that research, which is directly relevant to the lives of children, should seek to capture the views of those children. Not only does this approach respect the right of children to have their views heard in matters affecting them, but also the participation of children can shed light on the reality of their lives and thereby better inform the development of legislation, policies and services. However, to be inclusive in this way is a key challenge for researchers (Masson, 2009: 45). As noted by Masson, researchers cannot only include children who can be 'readily contacted and are articulate' (*ibid*). Efforts must also be made to recruit hard to reach populations. It may understandably be thought that those with the greatest needs or exposed to the greatest risk are the most important group to involve in research, which is to inform policy and service development. However, these groups can often be the most difficult to access.

A recent qualitative study on young carers in Ireland faced such challenges. The study sought to capture the views of young carers in Ireland between the age of 5 and 17 to better understand how their caring role impacts on their lives. The research was intended to provide an opportunity for young carers in Ireland to have their views heard and to inform future policy and service development. Reflecting on the study, this paper aims to explore the ethical and methodological challenges of participatory research with a hard to reach population. Firstly, and consistent with findings from research in Australia (Morrow, 2005)

and the United Kingdom (Thomas et al., 2003), the paper identifies young carers as a hidden population. Secondly, the paper outlines the process of accessing a sample of young carers for the purpose of undertaking empirical work with them. During the recruitment process the research team relied on gatekeepers, sought written informed consent of both parents/guardians and young carers and also informed parents/guardians and participants that guarantees of confidentiality given to participants were limited by the research team's child protection responsibilities. While thereby potentially increasing the obstacles to recruitment and decreasing the likelihood of participation from the most marginalised young carers, this approach was in keeping with current ethical principles for research with children. The discussion section of the paper reflects on these potential obstacles to accessing a hard to reach population, examining if there are alternative approaches, while mindful that the need to protect children from harm may take precedence even in circumstances where it limits the participation of children in research.

## 4.2 Young Carers: An Invisible Population

Children may be considered hard to reach if their situation is sensitive and parents/guardians fear they will be considered 'at risk' if public attention is drawn to it, or alternatively, when there is little awareness of this situation among the family or service providers. For these reasons, it is widely reported that research on young carers must address the 'invisibility' of this population (Thomas et al., 2003). Previous empirical studies have established that much caring can be 'covert' (Banks et al., 2002) or 'hidden' (Gray et al., 2008; O'Connell et al., 2008). The process of researching children and young people who are providing care for a family member can be complicated by a tendency on the part of the carer to avoid telling others about their situation (Banks et al., 2002: 230). Young carers and their families may fear an invasion of privacy and that drawing attention to the family situation could result in a child protection intervention which would lead to the break-up of families (Frank and Slatcher, 2009; O'Connell et al., 2008; Roche and Tucker, 2003; Thomas et al., 2003; Banks et al., 2002). Alternatively, there may be a lack of awareness and understanding among parents as to the implications of caring on their children (Morrow, 2005: 56). Other studies report that young carers fear being bullied at school (Aldridge and Becker, 1999: 80-82) and don't want to be identified as different (Morrow, 2005: 53).

Moreover, young carers may not be identified due to a lack of awareness among service providers (Office for Standards in Education Children's Services and Skills, 2009; O'Connell et al., 2008; Thomas et al., 2003). Morrow reports the anecdotal evidence that some health care

professionals have difficulties distinguishing between a young carer and a child who 'just does things around the house' (2005: 73). Aldridge and Becker note that providing care in the home is something 'most if not all children are encouraged to do' (1999: 312-313); and some degree of caring and household responsibility is generally looked upon as a reciprocal part of family life and a 'beneficial training ground for good citizenship' (Warren, 2007: 136). As caring may be thought of as a 'normal' part of a young person's life within the family, which does not merit the significance associated with the label 'young carer', it is unsurprising if professionals remain unaware of the presence of young carers even where there is direct contact with the families in question.

Although the focus of the study outlined in this paper is on young carers, it is suggested that the methodological and ethical challenges and the lessons learned are applicable to similar research which endeavours to engage other hard to reach populations of children. Previous participatory research with children and young people who had a parent or carer with HIV (Cree et al., 2001) and children and young people who have experienced domestic violence in the home (Hogan and O'Reilly, 2007) encountered similar obstacles.

### **4.3 Access: Methodological and Ethical Issues**

Access is considered to be one of the hardest stages of research with children and young people (Alderson, 2004; Moolchan and Mermelstein, 2002). In the first instance the methodological approaches to be employed to make contact with the target group require careful consideration. Secondly, adherence to ethical guidelines raises the issue of parental consent and the consent of the child participants as well as respect for the limits of confidentiality. These issues and the dilemmas encountered in addressing them will be considered in turn.

#### **Recruitment Methods**

The methods of recruitment employed in the study on young carers are outlined below. What they help illustrate are the challenges the research team faced during the recruitment process and the pragmatic but principled solutions arrived at in the course of the study to address the issues encountered.

From the outset the 'invisibility' of young carers was a predominant concern. Unlike in the United Kingdom and Australia, at the time of the research there was no legislation, policy or targeted services directly focusing on young carers in Ireland. In consequence, families and service providers were unfamiliar with the term 'young carers'. It was therefore considered



important to have a working definition of the target group so as to ensure that the research only engaged participants relevant to the objectives of the study. Building on the work of Frank (2002), Gray et al. (2008) and Thomas et al. (2003), the research team proceeded with the following working definition of young carers:

A young carer is a child or young person under 18 years whose life is affected in a significant way by the need to provide care for a family or household member who has an illness, disability, addiction or other care requirement. This may include a child or young person who provides direct personal care or who takes on a supportive role for the main carer. A young carer may carry out domestic tasks or may provide general, intimate or emotional care. These needs may arise on a regular or on an occasional basis. There is therefore a continuum of caring and as a result the service requirements of young carers will vary. It is important to differentiate between a level of caring that has largely positive consequences and a level of physical or emotional caring that impairs the child's health, development or welfare.

As there were no targeted services for young carers, there was no sampling frame from which to draw a random sample of young carers in the Irish population. In the United Kingdom, Young Carer Projects are well established as providers of support, advice and information to young carers. Researchers have successfully recruited samples of young carers through contact with these Projects (Thomas et al., 2003). However, there is no equivalent to Young Carers Projects in Ireland and, for the most part, young carers are not on the databases of carer professionals in the Health Service Executive (HSE) in Ireland or on the databases of carer organisations in the non-statutory sector.

With no evident access point to approach young carers, the research team initially adopted a two-pronged approach to recruitment. On the one hand self-referrals to the study were sought, while on the other hand gatekeepers were targeted to refer young carers to participate in the research. In relation to the former, child- and youth-friendly posters and flyers were sent to all post-primary schools across Ireland and to a wide range of youth organisations, including youth information centres, youth cafés and family resource centres. The posters and flyers were colourful with images depicting young people in a caring role centred on the wording 'do you care?' They requested young carers interested in taking part in the study, of which details were provided, to contact the research team for further information by email, telephone or text message. Both child as well as parental consent would then be sought. Despite sending posters and flyers to over a thousand venues populated by children and young people nationwide, the information campaign generated only one referral. This referral was as a result of a staff member in a family resource centre seeing a poster and bringing the study to the attention of a family with a young carer

requesting their participation. As there were no self-referrals to the study, the use of gatekeepers to recruit young carers became all the more pertinent.

While the information campaign was under way, the research team began targeting potential gatekeepers, namely agency staff who may have come into contact with young carers through the provision of services. The specific services targeted were dedicated to meeting the needs of adult carers in the Irish population, organisations with youth-specific remits and organisations working with families wherein there are specific needs, such as disability and substance abuse. This purposive sampling approach was chosen to ensure 'that those sampled are relevant to the research questions that are being posed' (Bryman, 2015: 415). Given that it was the first nationwide qualitative study on young carers in the Irish population and a primary purpose of the study was to examine mechanisms through which young carers can be identified, it followed that the initial approaches to service providers were at times exploratory. In the absence of dedicated services for young carers, it was unclear which agencies, divisions or personnel would in fact be best suited to act as 'gatekeepers' for young carers in Ireland.

As was the case with a study in Wales adopting similar methods of recruitment (Thomas et al., 2003), this initial attempt to engage potential gatekeepers proved unsuccessful. It soon emerged that the majority of agencies contacted, while broadly supportive of the aims and objectives of the research, were unable or unwilling to assist with the research and provide referrals. For the most part service providers seemed to have no direct contact with or awareness of young carers. The issue is 'under the radar' for service providers, according to one HSE worker interviewed for the purpose of this study. In total five young carers were accessed through gatekeepers in this phase of recruitment. These were primarily referred to the study by the Carers Association, a non-statutory organisation that provides very limited services to young carers on an ad hoc basis.

A radical review of the sampling and recruitment strategy was embarked upon. The research team decided to expand its contacts with agencies, both statutory and non-statutory, in an effort to generate some of the referrals that were still required. Most of those on the original list of contacts in the purposive sample were returned to again and, in addition, other contacts convenient to the research team were approached. On many occasions, these initial contacts led to other contacts, and the sample snowballed. There is a danger that purposive, convenience and snowball sampling will introduce bias, as the contacts made will be heavily influenced by the initial contacts and the suggestions they generated. To address the

potential for bias the research team consciously looked for balance. In making further contacts, considerations included geographical spread and diversity in the range of agencies contacted. In any case, the research team was aware that this information could not have been generated by any other means, given that this was partly an exploratory study to shed light on mechanisms for the identification of young carers.

In discussions with potential gatekeepers the researchers took the time to explain the concept of young carers, the nature and purpose of the research and its importance to this wider range of service providers. Drawing on the study's working definition, the researchers emphasised that they were interested to speak with young carers aged between 5 and 17 from across the spectrum of caring. Suitable interview schedules for the different age ranges had been prepared. In some instances, frontline staff remained reluctant to raise the issue with the families of young carers. Primarily the reasons provided were either a perceived social stigma or that the parents in question would not accept that their children were young carers. In many cases however, despite initial reluctance caused largely by misunderstandings over what the term referred to, the service provider agreed to act as a gatekeeper and put time and effort into approaching young carers and their families.

This second phase of recruitment was a vast improvement on the first, as a sample size of 26 was reached. The time the research team spent building relationships and raising awareness about young carers as well as highlighting the importance of the research among gatekeepers was the single most influential factor explaining the attainment of referrals. With this greater awareness, service providers became more likely to approach families on behalf of the study.

## Ethical Issues

When carrying out research with human subjects, whether or not they are children, a number of ethical guidelines apply. Participation should be based on *informed consent*; information disclosed during data collection should be treated in a *confidential* manner; participants should not be exposed to unnecessary *risks* by researchers and should be protected from *harm* and *benefits* maximised; and finally the *study design* should be such that it is likely 'to reach reliable conclusions with the smallest number of research participants/volunteers' (Irish Council for Bioethics, 2004: 16).<sup>1</sup> When carrying out research with children, seeking consent from parents/guardians is generally considered a pre-

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<sup>1</sup> Postscript: The publication of this paper predated the Department of Children and Youth Affairs ethical guidance for social science research with children and young people.

requisite of ethically-sound research practice. This in effect creates another layer of gatekeepers, the parents/guardians of the children.

Following an expression of interest to participate in the study, the next stage in the process involved efforts to obtain parental consent and the consent of young carers. To increase the likelihood of agreement from all parties and to facilitate informed consent, time was taken to prepare both adult and child- and youth-friendly information sheets to accompany the consent forms. These information sheets set out the aims of the study, details of the interview process, issues of confidentiality, and the intended use of the data collected. While parental consent was not for the most part an issue with the families referred to the study it raises the question of potential sample bias. It is probable that the service providers acting as gatekeepers only approached families where parents acknowledged the caring role of their child and their parents supported them in this role and thereby were more likely to consent.

The recruitment process was further complicated by limits on confidentiality due to child protection obligations. To build a relationship of trust between researcher and participant and encourage participants' candour, including the candour of child participants, researchers provide assurances that information disclosed during the collection of data will be kept confidential. In this way the researcher shows respect for the agency of the participating children both by treating their information as significant and also by guaranteeing that this information will be kept confidential. However, there is one important exception. In accordance with national child protection policy guidelines, if participants disclose information that raise child protection concerns, the researcher is obliged to report such concerns to the relevant authorities (Department of Health and Children, 1999). In keeping with good practice, this limitation to confidentiality was clearly communicated to the young participants and their parents/guardians during the consent process. In the event there were no child protection concerns requiring such a response. However, it was thought that the researcher's obligations under child protection procedures may have led to the under-representation of the more vulnerable children in this population.

For reasons of both limits on confidentiality and the need for parental consent, it was considered unlikely that the study would receive referrals from those children perceived as the most marginalised or vulnerable. In a study undertaken in the United Kingdom, it was unanimously agreed by the 12 representatives interviewed from Young Carers Projects that young carers with parents who misused substances and/or had mental health issues were

the most difficult to identify (Office for Standards in Education, Children's Services and Skills, 2009). In the present study, this was by and large the case despite the efforts of the research team to engage young carers from across the spectrum of caring circumstances. The research team was of the view that the parents of such children would be unwilling to volunteer information about their home life or encourage outside interest in their family. There were no referrals of young carers with parents who misused substances. However, two siblings caring for a mother suffering from a mental health illness were recruited with the assistance of a social worker to secure the required parental consent. One explanation for this may have been that the children in this case were in foster care already. For that reason parental fears of a child protection intervention as a result of participating in the study were essentially removed. The research team did speak to service providers working with families where the parent(s) had a drug or alcohol addiction and valuable information was gathered in this way about the experiences of children caring in these situations. Nonetheless, it was not assumed that the service providers were acting as proxies for the young carers or that the use of proxies would be good practice. The child should be heard directly where at all possible.

#### 4.4 Discussion

According to Veale, participatory research provides the individuals who are central to the research questions with the opportunity to inform the researcher of the realities of their life experience (2005: 253). As set out above, when the target group is difficult to access, it can be a challenge to recruit the required individuals and to achieve a sample that will sufficiently capture the broad spectrum of views of those relevant to the research question. In the study on young carers, the research team found that the requirements to protect children from harm and to respect children's competence could come into conflict. When this happened the researchers attempted to strike a balance between these two sometimes competing principles. Reflections on the approaches adopted in this study in trying to maintain this balance, as well as an examination of the methods employed in similar research, are outlined below.

##### Gatekeepers

It is not uncommon in social science research for children and young people to be contacted with the help of gatekeepers, usually the provider of a service to the family. Nevertheless, it is argued that reliance on service providers as gatekeepers may further exacerbate power inequalities between service providers and disadvantaged and/or marginalized clients (Curtis, 2004; Freimuth and Mettger, 1990). The use of service providers as gatekeepers

therefore could potentially render the informed consent process meaningless (Curtis at al., 2004). Others have noted the power of gatekeepers to 'censor' children and young people by selecting which children to provide the researcher with access to (Masson, 2004: 46). Gatekeepers may act in this way out of a wish to protect the young participants, even if this means silencing their voice or their actions may reflect assumptions about the competence of the young carers to participate. However, the use of gatekeepers is often necessary for purely pragmatic reasons given the group in question are hard to reach.

This study found that, in a situation where there are no targeted services for the population being recruited and no readily identifiable points of contact to access the participants, directly approaching young carers to invite them to partake in the study was not an option available to the researchers. Efforts were made to indirectly approach young carers by means of the nationwide information campaign. However, no young carers availed of the opportunity to come forward and self-refer. As a result, the researchers had to employ gatekeepers from a range of services to access the required population. It should also be remembered that gatekeepers can have an important role to play in protecting children from harm. Not all research is legitimate or methodologically and ethically sound. As noted by Masson (2004: 46), '[r]esearchers should expect gatekeepers to test their motives for wanting access, and to act as a barrier for poorly thought out or potentially damaging research'. In this study, the researchers had to take the time and effort to engage personally with a broad range of service providers, including frontline staff, to explain the merits of the study and build a relationship of trust.

## Parental Consent

The imperative to balance on the one hand the need to respect children as agents in their own right with on the other hand the duty to protect participants from harm and exploitation is central to the issue of parental consent. For the most part securing parental consent for well thought out research won't be an issue for either parent or child and, as there is good reason for working in partnership with parents/guardians, the requirement of parental consent should be viewed in a positive light. Working in partnership with parents/guardians is an important safeguard to protect children from harm. Furthermore, in accordance with Article 5 of the UN CRC, it respects the right and duty of parents to provide appropriate direction and guidance to the child in the exercise of their rights.

However, recent debate has led some to conclude that Research Ethics Committees are placing unrealistic demands on researchers due to the prevailing perception that children

are 'vulnerable' and need to be protected from unprincipled and opportunistic ('barbarian') researchers (Carter, 2009). It is argued that the ethical demands to protect children from harm should be less onerous and this would create more opportunities for the participation of children in research and in doing so better respect the agency of children (*ibid*; Valentine et al., 2001). It is considered that children are perfectly capable of consenting to their own participation and, if researchers are not required to obtain the consent of parents/guardians, the recruitment of 'vulnerable' participants would be made less difficult (Cocks, 2006; Valentine et al., 2001).

These arguments are particularly pertinent when children reach adolescence and/or when the research subject is of a sensitive nature. The recognition in Article 5 of the UN CRC of the responsibility of parents to provide appropriate direction and guidance to the child in the exercise of their rights is qualified with the wording 'in a manner consistent with the evolving capacities of the child'. There are strong grounds under Article 5 and elsewhere to argue that, as children become more competent, greater weight should be given to the right of children to have their views heard and less importance attached to obtaining parental consent. Masson (2004) suggests that when children are sufficiently competent to understand the impact of participating in research it may be more ethical to act on their consent than to require parental consent. In the research upon which this paper is based, all of the participants were taking on caring responsibilities and in some cases they were the primary carer in the household and/or close to the age of maturity. Yet under current ethical guidelines they were not deemed old enough and/or capable enough to participate in the research in the absence of parental consent. Although the research team were of the view that such young people clearly had the competence needed for participation in research, whether or not they had the capacity to consent to participation without parental consent was a separate issue.

Diminishing parental control as children reach adolescence is reflected in the laws governing other aspects of young people's lives. In Ireland for example, under the Non-Fatal Offences Against the Person Act, 1997 a minor who has reached the age of 16 can consent to any medical treatment; it is not necessary to also obtain parental consent. In the United Kingdom age is not a determining factor. The landmark case in 1985, *Gillick v West Norfolk and Wisbech A.H.A*, held that once children reach a sufficient understanding and intelligence they can consent to medical treatment independently of their parents.

In the context of research, it is not so clear cut. Although the guidance received from the Research Ethics Committee at NUI Galway was that both parental and child consent was required from all participants under the age of 18, it was recently reported that in the absence of clear ethical guidelines and a lack of clarity around the legal requirements in Ireland, many Research Ethics Committees are uncertain about the issue of adolescent consent (Felzmann, 2010). As a result, the study on young carers made no distinction between younger children and older adolescents in the 16-18 age bracket or otherwise. The research team obtained the consent of both the young participants and their parents/guardians prior to conducting the interviews. An additional factor was the study's reliance on gatekeepers who were for the most part providing a service to the family, as opposed to the young carer themselves. Given that access to the young carer in these situations was mediated through the family, parental consent was effectively a pre-requisite to access even prior to consent being secured to participate in the study.

On reflection, the requirement of parental consent in all likelihood excluded the more marginalised young carers from participation in the research. Parental consent is unlikely in a situation where a child has taken on a caring role because of a parent's/guardian's alcohol or drug addiction. As detailed above, only a limited number of young carers in very vulnerable situations participated in the study. Flexibility on the requirement to secure parental consent, in circumstances where a young person has sufficient maturity and the capacity to consent to research and is fully aware of the implications of their decision, could have opened the door to providing some of the most marginalised young carers with the opportunity to have their views heard. In particular, this could have been the case in a situation where it was not necessary to mediate access through the family. As well as maximizing participation, from a research perspective waiving the need for parental consent also minimizes sample bias (Moolchan and Mermelstein, 2002).

While not used in this study, innovative online methods may be an alternative and effective way of maximising participation in research. Email communication and social media forums such as blogs and Facebook are popular mediums of communication among children and young people. Clear ethical guidelines around accessing children by means of online methods could assist researchers to utilise these methods to further facilitate communication with hard to reach populations for the purpose of research. However, as Hill (2006: 79-80) cautions researchers must also be mindful that not all children may have access to computers, be competent in computer-based activity or favour it as a method of consulting



them about their views. In any case, the question of whether or not and in what circumstances parental consent is still necessary for the participation of children in such research is still an issue as the use of innovative technologies does not by itself resolve the tensions and conflicts discussed above.

### Limits to Confidentiality

Issues around confidentiality present a further barrier to participation in research. Fears that researchers will disclose information about the family situation may make children more reticent and the more vulnerable the situation of the child the more likely this will be the case. Placing limits on confidentiality is questioned on methodological and ethical grounds. It is claimed that, if we respect children's autonomy, we should 'allow space' for 'children's own strategies for dealing with difficulties based on their own knowledge and experience' (Thomas and O'Kane, 1998: 340). For that reason, in their study of children looked after by local authorities, Thomas and O'Kane did not regard themselves 'as bound by institutional requirements to pass on any suspicion of abuse to specified people', as such a rule 'would be an inappropriate intrusion into the relationship between researcher and subject' (*ibid.*). The authors did however acknowledge as researchers their 'responsibility to support the child in telling someone who was in a position to do something about it [the disclosure]' (*ibid.*).

In contrast it could be argued that 'the relationship between researcher and subject' involves many ethical responsibilities on the part of the adult researcher and they include the duty to report information which raises child protection concerns. Researchers need to 'recognise their moral obligations as adults to protect children at risk even when this may mean losing access to, or the trust of, the children concerned if they do intervene' (Morrow and Richards, 1996: 98). It is also questionable whether the approach adopted by Thomas and O'Kane in 1998 would be acceptable today given the more recent emphasis on compliance with child protection procedures. Mandatory reporting has now been legislated for in jurisdictions, such as, Australia, Sweden and the United States, whereby researchers are legally bound to report child protection concerns.

While adherence to the limits on confidentiality may on occasion stand in the way of children's participation and/or their candour, the appropriate balance between facilitating children's participation and protecting children from harm must be maintained. Also given that the researchers in this study were reliant on gatekeepers, both service providers and the participant's parents/guardians, it is thought that adherence to the highest ethical

standards was necessary to ensure the continued co-operation of those central to the recruitment process. However, what is crucially important is that the limits on confidentiality must be clearly communicated in child- and youth-friendly language to empower the research participants to make an informed decision about the information they choose to disclose. Failure to do so can lead to a betrayal of the child's trust and jeopardise future involvement in research.

Despite the challenges facing the researchers the recruitment process was for the most part relatively successful. Nevertheless, it remained a time consuming, lengthy and unpredictable process. As well as the ethical and methodological issues facing the researchers, this was the case as the factors which contribute to the hidden nature of caring still remained. There is no one reason why young carers remain hidden. Contributing factors include, perceived social stigma surrounding the caring itself or the illness and disability in question, little or no services being provided to young carers 'as carers', and a lack of awareness among service providers, young carers and their parents. Addressing the challenges that contribute to the hidden nature of caring and thereby facilitating greater access to young carers requires longer term approaches. The study identified awareness raising campaigns and the provision of services, to provide a safe and accessible way for young carers to come forward, as the longer term responses required to address these factors and facilitate future access.

## 4.5 Conclusion

In conclusion, while the move to include children and young people in research and policy initiatives that directly affect them is a positive one, both for the realisation of children's rights and the generation of evidence-based services and policies, it has given rise to additional challenges for researchers. As researchers are often interested in finding out about the service needs of the most marginalised in society and those who are not receiving any services, difficulties with access and recruitment of the targeted population will inevitably arise. When the research participants are children, a distinct set of ethical obligations apply and the research generally requires the negotiation of two stages of gatekeepers: the service providers best placed to identify the target group and the participant's parents/guardians. Yet when the research topic is of a sensitive nature, gatekeepers often have reasons to refuse access due to the intrusion on private family life and in some case the fear of a child protection intervention, particularly in light of the limitations on confidentiality.

This paper has attempted to outline the methodological and ethical approaches employed to work through the dilemmas faced by the researchers in recruiting a sample of young carers from the Irish population. We do not claim to have all the answers to these dilemmas, there were gains and losses in terms of the approaches used. Nevertheless, transferable learning did accrue. Despite the recruitment phase being a lengthy and difficult process, it is an essential one if researchers are to uncover the reality of the lives of hard to reach children and equally respect their right to have their views heard in matters which directly affect them.

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# Chapter 5: Navigating the Ethical Requirement for Parental Consent When Engaging Youth in Research

## 5.1 Introduction

The participation of youth in research is conditional on obtaining their informed consent. When research involves youth below the age of 18 it is a well-established ethical principle to also secure parental consent as part of the research process.<sup>2</sup> While the term ‘youth’ is a fluid concept, the focus in this chapter is on youth aged between 15 to 18 years. There is unanimous agreement among the research community on the need for parental consent when research involves young children. However, whether parental consent should be required for youth is a subject of debate. While considered an important safeguard, the requirement to obtain parental consent can prohibit youth, particularly those on the margins, from participating in research when parental consent is not feasible or preferable due to the nature of the study. Moreover, its focus on protection can fail to respect the competence of youth. It is illustrative of the disconnect that is said to exist between current theoretical perspectives on childhood and ethical requirements (McCarry, 2012; Skelton, 2008). According to Graham and Fitzgerald (2010):

In an era that is increasingly recognizing the agency of children and their capacity to participate in research we are also witnessing an increasingly ‘nervous’ regulatory environment in relation to research ethics committees and children’s involvement in research processes.

Reflecting these debates, ethical guidance on the need for parental consent differs throughout the world. What is considered unethical by some is considered ethical by others and there is the view that different research contexts require different responses (France, 2004). To provide greater clarity on the matter, this chapter draws on the literature and ethical guidelines to review current practice in relation to the application of the parental consent requirement. To provide an overview of the broader legal context the ethical requirement is operating within, the chapter outlines examples of how international and national law addresses the issue of capacity to consent. This is followed by a critique of current ethical guidance on the issue of parental consent. The stringent to the more flexible approaches adopted in different countries are compared.

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<sup>2</sup> The use of the term parental consent in this chapter is intended to encompass the consent of a parent or a legal guardian.

It is observed that uncertainty around ethical requirements can lead to overprotectiveness (Department of Children and Youth Affairs, 2012). Conversely, greater clarity and an understanding of what is considered ethically acceptable practice has the potential to facilitate the participation of even the most marginalised youth in research. To meet this objective, the chapter concludes with an overview of innovative, yet ethically compliant, strategies employed by researchers to enable them to adhere to the parental consent requirement.

## 5.2 Challenges Posed by the Parental Consent Requirement

Working in partnership with parents should in general be viewed in a very positive light. It respects the role of parents to protect their children and to ensure they are not manipulated or harmed (Jones, 2004). When the child or youth is not capable of understanding the consequences of being involved in research, parents can play a particularly important role. If equipped with accessible information on the study, parents can assess, and support their child to assess, the value, authenticity and possible outcomes of the study. Their intimate relationship with the child often means they are best placed to make a decision on whether participation is in their best interests. During the research process parents can take on a supportive role and provide guidance to their child in helping them to formulate their views (Graham et al., 2013). Parents can also be a reassuring presence. As Beazley et al. (2011) remind us, researchers can overlook the fact that they are relative strangers to the research participants. It is said that a further benefit of obtaining parental consent is that it can promote parent-child discussion on sensitive issues and enhance the relationship between the researcher and the community (Moolchan and Mermelstein, 2002).

While there are many potential benefits to obtaining parental consent, a review of the literature brings to light that much is written about the challenges parental involvement can pose. Some of the key challenges outlined in the literature are revisited here. This review of literature involved a search of the academic databases Scopus and Web of Science using key terms and phrases such as 'youth', 'participatory research', 'parental consent' and derivatives of them. The focus was on social science literature. An internet search was also conducted using google to identify relevant reports. Although broadly speaking the literature located by the author emanates from Western countries, a study led by The Childwatch International Research Network<sup>3</sup> underscores that obtaining consent and access to children

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<sup>3</sup> The Childwatch International Research Network is part of Childwatch International, a global, non-profit, non-governmental network of institutions that collaborate in child research for the purpose of promoting child rights and improving children's wellbeing around the world.

and youth for the purpose of research is a challenge experienced by researchers globally (Powell et al., 2011). This study, involving 257 researchers across 46 low, middle and high income countries<sup>4</sup>, found that the ethical issues of most concern to the researchers were overly protective ethical review processes and consent, gatekeeper and access issues. However, while these issues were of concern to researchers across low, middle and high income countries, they were of greatest concern to those from high income countries. Prominent concerns for researchers from low to middle income countries included cultural beliefs about children's place or role in society, fear for the child's safety and concerns that a sensitive topic may cause distress for the child.

It is evident from the literature that gaining access to potential participants by obtaining parental consent can be complex when the research is of a sensitive or private nature. Flynn and Saunders (2015) outline the complexities in securing parental consent when conducting research with children of prisoners. Seeking parental consent has also been identified as a barrier to children and young people's involvement when the research is focused on topics that are in the interests of youth to remain private, such as, studies focused on sexuality (Valentine et al., 2001) or tobacco, drug and alcohol use among adolescents (Moolchan and Mermelstein, 2002). Similarly, it can present a barrier for transient, including homeless youth who have limited contact with their parents (Abrams, 2010) or for youth who are in a situation where there is no parent or legal guardian able to give consent for the child to participate. This is identified as an issue when researchers have sought to involve young carers in studies in sub-Saharan Africa, where the AIDS epidemic has left them in child and youth-headed households (Graham et al., 2013)<sup>5</sup>. Participation may also be precluded when parents, not acting in the interests of their children, are unwilling to provide consent due to their fear of a disclosure and a child protection intervention as a result of their child participating in the study. This can arise in the situation where there is substance misuse on the part of the parent and they may not want to encourage outside interest in their family life or where some form of child abuse and neglect is occurring in the home (Roth et al., 2013; Kennan et al., 2012). Requiring parental consent when operating in these contexts can deny youth the opportunity to participate in research. This is of particular concern when it

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<sup>4</sup> In the study the authors use the terms Majority and Minority world, equating countries with low and middle income economies with Majority world countries and countries with high income economies with Minority world countries. Here the author uses the terms low, middle and high income countries in keeping with the terms used in the book.

<sup>5</sup> See Case Study 16: Caregiver consent for child participation in research: Reaching and protecting the most vulnerable. Contributed by Lucie Cluver, Franziska Meinck and Mark Boyes. Young Carers South Africa, University of Oxford. Available at: [http://childethics.com/wp-content/uploads/2013/11/ERIC\\_Compedium\\_Case-Studies\\_Informed-Consent\\_Lucie-Cluver-Franziska-Meinck-and-Mark-Boyes.pdf](http://childethics.com/wp-content/uploads/2013/11/ERIC_Compedium_Case-Studies_Informed-Consent_Lucie-Cluver-Franziska-Meinck-and-Mark-Boyes.pdf) (Accessed on 28<sup>th</sup> September 2016).



silences those already marginalised and most in need of being heard by the very nature of the circumstances they find themselves in.

From a research perspective, requiring parental consent introduces potential consequences for the integrity of the research. The need for parental consent can present difficulties in achieving a representative sample (Shaw et al., 2014). It may bias the sample towards parents who are easier to access and reach, youth who have a good relationship with their parents and have fewer behavioral problems (Moolchan and Mermelstein, 2002). A study in the United States, which synthesised the literature related to the use of parental consent in school-based research on adolescent risk behavior, found that students who secured the consent of their parents were more likely to be female, white, from intact homes with more educated parents and less likely to smoke (Tiggs, 2003).

A further challenge posed by the parental consent requirement is that it can unduly exert adult power and influence over a young person's decision to participate in research. Children and youth may feel constrained to comply with the decision of their parent to provide consent or not (Graham et al., 2013). For this reason, even when parents provide their consent, the importance of emphasising to the young research participant that they can withdraw their consent is highlighted as an important safeguard to ensuring voluntary consent (McCarry, 2012; Shaw et al., 2011).

### 5.3 Capacity to Consent and the Law

The law and ethical guidance are generally closely interlinked. To understand the broader context ethical guidance is operating within it is useful to examine how the issue of capacity to consent is dealt with in law. It is apparent in law that as children mature their competence is recognised and parental control diminishes (Masson, 2009). However, this is a complex area of law and there is no standardised approach across jurisdictions regarding when children are deemed competent to make decisions independent of their parents.

The UN CRC, which enjoys almost universal ratification,<sup>6</sup> established in international law the principle that 'as children acquire enhanced competencies, accordingly, there is a reduced need for direction and a greater capacity to take responsibility for decisions affecting their lives' (Lansdown, 2005). This principle is embodied in Article 5 of the UNCRC, which acknowledges the role of parents in providing direction and guidance to their child in the

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<sup>6</sup> Three UN member states have not ratified the UNCRC. These are the United States of America, South Sudan and Somalia. [Postscript: Somalia has now ratified the UNCRC].

exercise of their rights, while explicitly making provision for the ‘evolving capacities’ of the child. The UNCRC defines a child as a person below the age of 18 years. However, neither the Convention nor the documentation of the UN Committee on the Rights of the Child prescribes an age below 18 when competence can be presumed to be achieved. It recognizes that children are not a homogenous group and their acquisition of competencies will vary according to individual circumstances, social and cultural contexts, levels of support and life experiences (UN Committee on the Rights of the Child, 2009). According to Lansdown (2005), children therefore require varying degrees of protection and opportunities for autonomous decision-making across different contexts.

This established principle in international law is not necessarily reflected in domestic law. An overview of the situation in Ireland and the United Kingdom is illustrative of two differing approaches concerning the law and capacity to consent. For example, in Ireland fixed ages are provided in law regulating competence or capacity to consent. The age of majority in Ireland, or the transition from minority (childhood) to majority (adulthood), is 18 years of age and it is only on obtaining majority that youth are deemed competent to make decisions independently of their parents. Nevertheless, there are many exceptions to this rule. Under Irish law, the age of consent for sexual relations is 17 and at 16 years of age a young person can provide autonomous consent to surgical, medical or dental treatments.<sup>7</sup> In contrast, the United Kingdom provides a good example of domestic law firmly establishing that competence should not be equated to a certain age and an individual assessment of capacity to consent is required. It was the 1985 *Gillick v. West Norfolk and Wisbech Area Health Authority* House of Lords case that had profound implications for the law governing capacity to consent in the United Kingdom. The court found that a child, including those under the age of 16, who has ‘sufficient understanding and intelligence to enable him or her to understand fully what is proposed’, has the capacity to independently consent to medical treatment.

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<sup>7</sup> Irish Criminal Law Amendment Act 1935, Non-Fatal Offences Against the Persons Act, 1997 and the Health Care Act, 1947.

<sup>7</sup> For further information on the ethical guidance governing the situation in Sweden and Poland, as well as other European countries, see the website of the European Union Agency for Fundamental Rights. Available at: <http://fra.europa.eu/en/theme/rights-child?page=child-participation-in-research>. (Accessed on 28<sup>th</sup> September 2016).

Returning to the issue of parental consent in the context of research, there is no law governing the need for parental consent in relation to the participation of youth in social research in either Ireland or the United Kingdom. The Irish courts did come close to pronouncing judgment on the issue. In 2007 the Office for the Ombudsman for Children engaged in an extensive consultation exercise with children from across the country. Children and young people below the age of 18 were asked to vote on the issues they perceived to be most relevant to their lives. Parental consent was not sought for the 74,000 children and young people balloted. An application was made by an individual to the High Court for leave to seek an injunction to stop the consultation on the grounds that the Ombudsman had exceeded her authority in consulting directly with children in the absence of parental involvement. The court held that the Ombudsman had not exceeded her mandate (Irish Ombudsman for Children, 2007). However, it did not directly address or pronounce judgment on the issue of parental consent.

In the United Kingdom, there is a view that the *Gillick* decision applies to all matters, unless otherwise prescribed in law, thereby governing the need for parental consent concerning a child's participation in social research (Masson, 2009). Researchers in the United Kingdom conducting research with young lesbian and gay people, some of whom were between the age of 16-18, relied on the *Gillick* judgment as a justification for not seeking parental consent (Skelton, 2008; Valentine et al., 2001). However, the view that the *Gillick* decision is applicable to social research is not a unanimous view. Others have expressed uncertainty as to whether the case law governing a child's capacity to consent to medical treatment can be translated to the need for parental consent for a child's involvement in social research (Hill, 2005). Furthermore, there is uncertainty around whether it could be relied on as a justification for not obtaining parental consent in other jurisdictions (Felzmann, 2010).

In contrast to the situation in Ireland and the United Kingdom, in South Africa the enactment, in 2012, of section 71 of the National Health Act, No 61, 2003, categorically provides in law that health research can only be conducted with a minor (persons below the age of 18) with the consent of a parent or guardian. Health research is defined broadly in the Act as all research contributing to knowledge of 'the biological, clinical, psychological or social processes in human beings'. It is said that this broad definition of health research could encompass and place the same demands on social science research (Zuch et al., 2012).

Before concluding this section it is worth mentioning the right of a child or youth to privacy. The right to privacy is a fundamental human right of all human beings, including children and

youth and one that is recognized in law. Under international law the right of a child to be protected from arbitrary or unlawful interference with his or her privacy is explicitly protected in Article 16 of the UNCRC. It may be expected that the right to privacy is of relevance to a discussion on parental consent. However, in the literature reviewed, the right of youth to privacy is not an argument raised when debating the validity of the parental consent requirement. The focus is on the capacity of youth under 18 to consent as opposed to a right not to have their parents be aware of or interfere with their decision to partake in research. Similarly, the ruling in the *Gillick* case did not explicitly address the issue of privacy in terms of whether a confidential relationship should exist between a young person and a health professional, although it can be argued that this is implied in the judgment.

## 5.4 Ethical Guidance

While researchers must be aware of and heed the national law of the country they are operating within, when there are no laws governing the issue of parental consent ethical guidelines are the governing authority. Ethical guidance is not binding. However, adherence to ethical standards is generally deemed necessary to give credibility to the research and to satisfy university and funding authorities. When children and youth below the age of 18 are involved in social research, ethically it is the norm that parental consent is actively obtained as part of the research process. This is an almost universal ethical requirement, with very little difference between low, middle and high income countries (Powell et al., 2011). An *International Charter for Ethical Research Involving Children* has been developed by leading academics in the field in collaboration with UNICEF and Childwatch International. It is intended to provide guidance to researchers worldwide irrespective of context and is a useful tool in the absence of national guidance. It states that, in all research involving children, children's informed consent must be obtained alongside parental consent (Graham et al., 2013).

In relation to a child's informed consent, there are some exceptions to the norm that a child's consent must be obtained. Some ethical guidelines require a researcher seeking to involve participants below the age of 18 to obtain their agreement or informed assent as opposed to informed consent. While a detailed discussion of this issue of a child's consent is beyond the scope of this paper it is worth noting that regarding the issue of assent, there is a growing movement away from solely securing a child's informed assent, as opposed to informed consent. Alderson and Morrow (2011) outline the following reasons for rejecting the use of the term assent: it fails to acknowledge that in law minors have been deemed competent to

consent (*for example* the *Gillick* case); assent implies that children do not understand all the issues required for consent and it is questionable whether a partly informed decision can count as a decision at all; and it can mean ‘at least not refusing’, which can mask a child’s wish not to participate. Cocks (2006) reminds us that the process of seeking assent is a valuable method for securing the agreement of children who may not have the competence to consent, but acknowledges that it is not in itself sufficient and should be just one approach available to researchers operating within a ‘framework of ethical reflection’.

The standard procedure for obtaining the informed consent of the young research participant and their parent comprises a number of steps. It requires the researcher to take the time to provide to the research participant and their parent adequate and accessible information on the study, to verify that they have understood the information provided, to ask the participant and their parent to voluntarily document their consent or refusal and to ensure that all parties are aware that consent can be renegotiated or withdrawn at any stage of the research process (Graham et al., 2013; Roth et al., 2013). These steps outline the process of obtaining active consent. While not generally the favored approach from an ethical perspective, as discussed later in this chapter, in some circumstances the parent’s passive as opposed to active consent is deemed sufficient. It is also said that the consent of one parent is generally deemed sufficient, unless the research is of a particularly sensitive nature, exceptionally burdensome or focuses on familial relationships (Shaw et al., 2011).

The question can be asked whose consent should be sought first, the parents or their child’s. Guidelines for research with children and youth recommend obtaining parental consent first to avoid the scenario where a child agrees to participate and subsequently finds out the parent has not provided consent (Shaw et al., 2011). However, there is some evidence that this does not correlate with the views of children. A small scale consultation with children on the matter revealed that some of the young participants were of the view that a child’s consent should precede parental consent (Department of Children and Youth Affairs, 2012). They noted that, in the context of researchers recruiting participants in the school setting, their consent is effectively obtained first as they act as gatekeepers choosing whether to pass on the consent forms to their parents or not.

Some ethical guidelines take into account the difference between young children and mature minors, in terms of competence to consent and the need for parental involvement. In certain circumstances exceptions to the norm of requiring parental consent up to the age of 18 will be permitted. However, on this issue, there is no definitive agreement. Ethical frameworks

can vary greatly on the issue of whether parental consent is required for mature minors and in many countries there is no clear regulation of parental consent. A comparison of current ethical guidance reveals that there are a number of frameworks that ethical oversight bodies can operate within when seeking to maintain ethical standards in research involving minors. These can be broadly distilled as follows:

1. Parental consent is required in all circumstances up to the age of 18;
2. Provision of a fixed age below the age of 18, whereby parental consent is not required once a child reaches the prescribed age;
3. General requirement of parental consent up to the age of 18, but provision is made for a waiver.

Each of these frameworks and illustrative examples of how they operate are set out and critiqued below.

### **Requirement of parental consent in all circumstances up to the age of 18**

This approach embodies the most stringent application of the parental consent requirement. As set out above, it is evident in the legislative framework governing the need for parental consent in health research in South Africa. In terms of ethical guidelines, the situation in Ireland provides a good example of national guidance adopting this approach. In 2012, the Irish Government Department of Children and Youth Affairs published ethical guidance for social science research projects involving children. These guidelines were developed in part to encourage standardisation in the approaches adopted by research ethics committees across Ireland (Department of Children and Youth Affairs, 2012). They state that parental and/or guardian consent is required for a child, defined as all persons below the age of 18, to participate in research. No provision is made for exceptions to this requirement. Of note, these guidelines are also an example of guidance that does not require a researcher to secure a child's consent. However, according to the guidelines good practice requires the child's agreement (informed assent) to participate in the research.

On the one hand this approach is clear-cut. The same ethical rules apply to all research participants below the age of 18 and it relieves ethics committees of undertaking the onerous task of making an individual assessment of whether parental consent is required for the study under review. However, on the other hand, its emphasis on protectionism and its rigidity has the potential to exclude youth under 18 from participating in research. The approach is at odds with the broad recognition of the evolving capacities of youth to make decisions, when appropriate, independently of their parents.

### **Provision of prescribed age limits below the age of 18**

This approach makes the assumption that mature minors of a fixed age have the ability to consent to participate in research independently of their parents. Ethical guidance in New Zealand is illustrative of this approach. According to the national ethical guidelines for health and disability research, the consent of youth aged 16 and over to participate in research must be treated the same as if they were of full age. Their informed consent is sufficient and the consent of parents does not need to be obtained (National Ethics Advisory Committee, 2012). Similarly, in Sweden parental consent is not required for youth who have attained the age of 15 or in Poland for those over the age of 14. The New Zealand framework referred to above also makes provision for children, below the age of 16, to demonstrate their ability to provide informed consent without the need for parental consent. Unlike youth over the age of 16, whose competence is presumed, this requires an individual assessment of the child's 'competence to understand the nature, risks and consequences of the research'.

Providing a fixed age below the age of 18, whereby parental consent is not required once a child reaches the prescribed age, is a more flexible approach to meeting the parental consent safeguard. It ensures consistency in approach to research involving youth of the prescribed age and removes the need for an individual assessment of competence for those within this age bracket. Arguably, not requiring parental consent for those above the prescribed age and below the age of 18 could expose them to the risk of harm. However, it recognises their capacity to make their own assessment, independently of their parents, as to whether participating in research is in their best interests. In any case, it is to be expected that the ethical review process as a whole should act as an important safeguard to minimise the risk of any potential harm. Where the opportunity is provided for those aged under the prescribed age to demonstrate competence, such as in New Zealand, this makes allowance for current thinking that children acquire competence at different ages influenced by their personal experiences (UN Committee on the Rights of the Child, 2009; Hill, 2005; Lansdown, 2005). However, it places an onerous and challenging obligation on researchers to make an individual assessment of competence and to justify their analysis to ethical oversight bodies.

### **Parental consent is required up to the age of 18 but allowance is made for a waiver**

A review of current ethical guidelines brings to light that a more common approach to the parental consent safeguard is to require researchers to obtain the consent of parents when involving children and youth up to the age of 18, while making an allowance for a waiver in certain circumstances. Provision for a waiver is not focused on the competence of children

and youth, but rather the research context. For example, in Denmark, an exemption may be granted to the parental consent requirement when a minor has turned 15 years of age. A decision by a research ethics committee to grant an exemption must take into account the nature of the research and the level of risk (National Ethics Advisory Committee, 2012).

In the United Kingdom and the United States of America, ethical regulations also allow for a waiver of the parental consent requirement. However, the age at which a waiver may be acceptable is not prescribed in the ethical guidance reviewed here and neither is criteria established for when a waiver can be applied. In the United Kingdom, the leading organisation for funding research on economic and social issues, the Economic and Social Research Council (ESRC), has developed a Framework for Research Ethics. It is mandatory for ESRC funded research to comply with the Framework, but it is also intended to establish 'good practice for all social science research' (Economic and Social Research Council, 2012). The Framework allows for a waiver of the parental consent requirement but offers no further guidance than requiring that, where consent is not obtained, this should be justified to the research ethics committee and their approval obtained. Federal regulations governing the protection of human research subjects in the United States provide that, Institutional Review Boards (IRBs) may waive the parental consent requirement if, in light of the research conditions or the subject population, obtaining parental consent is not a reasonable requirement to protect the research participants (US Department of Health and Human Services, 2009).

While these Federal Regulations do not provide any detailed guidance on when a waiver can be applied, a study by American academics has shed some light on the practice of IRBs (Wagener et al., 2004). The study participants comprised 49 IRBs primarily associated with university or academic institutions. Almost half of these IRBs granted waivers of parental consent for non-medical research. Among the research participants who indicated that their IRBs never granted waivers, some had not received such a request, however, the more common response was that parental consent was deemed essential or always required. The most common factors, influencing the non-requirement of parental consent, identified by those who had experience of IRBs granting a waiver, were: the research posed minimal risk; the subject matter; and the inability to carry out the research without parental permission. In the United Kingdom, the National Children's Bureau, offers some guidance on when a waiver to the parental consent requirement may be appropriate. Their *Guidelines for Research with Children and Young People* suggest that parental consent should not be



obtained for 16 and 17 year olds, unless the research is taking place within the family home, the participants are a particularly vulnerable population group or are in the care of the state, in which case consent must be obtained from their social worker. If children are under 16 according to the guidelines, parental consent can be waived if seeking it would breach the child's confidentiality, such as they are using a service without their parents knowledge (Shaw et al., 2011).

This type of ethical framework, whereby there is a general requirement of parental consent up to the age of 18 but provision is made for a waiver, offers an element of flexibility and is cognisant of the challenges the parental consent requirement can pose. Again its implementation can place an onerous task on ethical oversight bodies to assess whether a waiver of the parental consent requirement is justified and is in the interests of the research participants. However, the available guidance on when a waiver may be appropriate can aid the process and is less challenging and resource intensive than making an individual assessment of competence.

## 5.5 Ethically Compliant Practice

When parental consent is required this generally involves obtaining the informed written consent of parents or legal guardians. Some alternative practices have emerged that are also considered ethically compliant. Passive consent is one such strategy that is employed by researchers in meeting their obligation to obtain the consent of parents (Roth et al., 2013; Heptinstall, 2000; Thomas and O'Kane, 1998). Passive consent, or what is also known as the opt-out approach, is where parents receive information about the study and the researcher's intention to ask their child for their consent to participate. If no objections are raised by the parent they are deemed to have given their consent. Ethics committees in general are said to favor active or opt-in consent procedures (Graham and Fitzgerald, 2010). Evidence of this was found in the Wagener et al. (2004) study. Their research, conducted with IRBs in the United States, found that over half of the participating IRBs do not allow for passive consent. However, Shaw et al. (2011: 27) advocate an openness to using this approach and state that whether to adopt an opt-in or opt-out approach to consent should depend on the vulnerability of the young research participants, the nature of the research burden on the participants, the methodology employed and the sensitivity of the subject matter.

There is evidence that the procedures used for parental consent affect a studies participation rates. Tiggs's study in the United States (2003) found that, when passive parental consent is sought in school based research on adolescent risk behavior, parental permission is typically

obtained for 30 percent to 60 percent of those sampled, compared to 93 percent to 100 percent when passive consent is relied on (Tiggs, 2003). Obtaining verbal consent over the phone, as opposed to written consent, is another approach which is considered ethically compliant and one which is effective in encouraging parents to be more responsive (Sime, 2008). It has been found that a key influential factor in the recruitment of hard to reach young people is taking the time to establish a relationship with gatekeepers and raising awareness about the importance of the study on a one to one basis (Kennan et al., 2012). The phone may facilitate one to one contact and initiation of a relationship when it is not possible to meet with the individual parents to secure their written consent.

Other ethically compliant strategies adopted to satisfy the parental consent requirement can be conducive to including even the most marginalised youth in research. It is considered acceptable practice for a social worker's consent to replace that of parental consent, where children and youth are subject to a full care order or parental consent is not possible to obtain (Shaw et al., 2011; Heptinstall, 2000). Where parental consent or the consent of a legal guardian or social worker is not possible to obtain, an alternative approach adopted by researchers is to identify a trusted or responsible adult to give consent for the children to participate. In a study on young carers in sub-Saharan Africa, which was undertaken in the context of the AIDS epidemic leaving children and youth in child and youth-headed households, researchers asked the children to identify another 'trusted adult', such as a teacher, aunt or grandparent to give their consent for the child to participate in the research (Graham et al., 2013). Similarly, a study in the United Kingdom with unaccompanied or separated asylum seeking children meant that parental consent was impossible to obtain. Obtaining the consent of their social worker was also not an option as many of the children did not know who their social worker was. In this case, when the child was under 16, the researcher sought the consent of a 'responsible adult', such as a Children's Unit Manager or other adult working with the children in their place of accommodation (Hopkins, 2008).

It is suggested that the use of online questionnaires may circumvent issues of consent and improve access to potential research participants (Curtis, 2004). However, this is not in keeping with ethical guidance that has provided direction on the issue. It is said that it is critically important for online research to obtain informed consent and to explore ways of ensuring the consent obtained is both genuine and informed (Graham et al., 2013). Shaw et al. (2011) provide two possible options. The first is an opt-in process, whereby the online survey commences by asking the respondent's age and, if the age signifies that parental

consent must be obtained (this will depend on the ethical requirements the study is subject to), the software should be automatically programmed to ask for the parents contact details. The onus is then on the researcher to make contact with the parents and to obtain parental consent. The second is an opt-out procedure, whereby if the participant indicates in an opening question that they are of an age where parental consent is required, they will be asked to consult with their parents and indicate they have done so by, for example, ticking a box. In relation to either process, as there is no way of verifying the information supplied, Shaw et al. note that web-based surveys are generally not recommended for research with children and youth and certainly not for research of a potentially sensitive nature. Finally, educational settings have been identified as important access points for researchers seeking to engage children and youth in research (Sime, 2008; Kirby and Bryson, 2002). However, there is nothing in the literature to suggest that the access school authorities provide to researchers can circumvent the need for parental consent.

## 5.6 Conclusion

In conclusion it is worth re-emphasising that the requirement for parental consent is an important safeguard to protect children and youth from harm and one that should not be renounced lightly. This chapter has examined the dilemmas that can arise as a result of the parental consent requirement. The critical review of the literature and ethical frameworks is intended to go some way towards dispelling the ambiguity surrounding the parental consent requirement. While it is not the intention of the chapter to advocate one approach over another, what the review of the literature has brought to light is the importance of a flexible and tailored approach. Ethical guidelines offer a useful framework for researchers to operate within, but they should not close down any debate on how the appropriate balance between protecting children and youth from harm and enabling their participation in research can be achieved. It may be useful for researchers and ethical oversight bodies to keep in mind the words of Cree, Kay and Tisdall (2001: 48):

[C]odes of ethics and guidelines for research with children offers a helpful starting-point for building an ethical research study...[t]hey offer topics for consideration rather than 'blue-prints' for good practice, and this is important given the uniqueness of individual research projects.

We are often reminded that children and youth are not a homogenous group. As this chapter has outlined, understanding and assessing the local context, that is the immediate context in which the study is operating within, is crucial when determining how to observe the safeguard of parental consent. First and foremost it requires the researcher to be aware of

the law and ethical guidelines in the country they are operating in. It may include factoring in the participant's age, capacity, societal and cultural considerations, the nature of the research study and level of risk posed to the participants. While the local context must be taken into account, learning can also be drawn from the wider global context. Understanding what is considered ethically acceptable practice by looking to the law and ethical guidance offered in different jurisdiction across the world, as well as drawing on the lessons learnt from researchers grappling with the requirement of parental consent, can provide important guidance and learning for ethical oversight bodies, legislators and researchers. With this knowledge also comes the potential to challenge some of the more conservative approaches.

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# Chapter Six: Justifying children and young people's involvement in social research: assessing harm and benefit

## 6.1 Introduction

To better understand the lives of children and young people, social scientists commonly involve them in research as a methodological approach. There has been an evolving trend from children and young people being subjects, as opposed to objects of research, to their active participation in the research process towards child and youth-led research. In the literature reflecting on children and young people's involvement in research two opposing critiques emerge. On the one hand, there is a concern that significant obstacles continue to stand in the way of their involvement. An over-emphasis on minimising risk and protecting children and young people from harm can unjustifiably inhibit their participation in research (Daley, 2013; Dentith et al., 2009; Gorin et al., 2008). A cautious approach can lead to their exclusion and the use of adult proxies; thereby omitting their first hand perspectives (Schelbe et al., 2014). Failure to be inclusive is silencing the voices of children most in need of being heard (Carter, 2009).

On the other hand, there is a concern that as the movement to involve children and young people in research gathers momentum their participation is coming under less scrutiny. Carter (2009) observes that, as a result of developments in the social study of childhood and children's rights, their active participation in research is now considered politically correct and so sacrosanct that it is rarely questioned. While McCarry (2012: 26) notes, 'there has been a paradigmatic shift whereby social scientists no longer need to justify why CYP (children and young people) should be consulted but instead focus on how best to achieve this'. The move to involve them as participants in research in the absence of critical reflection on whether it is the right methodology has begun to trigger alarm bells. Gallagher and Gallagher (2008: 499) describe it as 'methodological immaturity' and there have been calls for greater transparency regarding the decision-making process (Franks, 2011). The risk with such an approach is that their involvement will be tokenistic in nature, a knee jerk exercise in response to what is perceived to be the 'right' thing to do. The ideological drive to promote children and young people's involvement in research can potentially expose the participants to the abuse of being over-researched or to circumstances where they give up their time in return for little or no value.

Dyson and Meagher (2001: 70) caution that the involvement of children and young people in social research should not be the 'product of arbitrary decisions' on the part of the researcher, commissioner or funders. Prior to negotiating access to involve children and young people, there must be a well-reasoned and transparent justification for their involvement. According to Daley (2013: 51), to include or exclude children and young people a researcher must 'think carefully about what constitutes harm and benefit, as well as the likelihood of each prevailing'. Daley suggests that overly erring on the side of protection is only valid if the potential risk of harm outweighs the benefits of children and young people's participation in research. Equally, championing the benefits of participation is only justified if it does not come at the cost of protecting children and young people from exploitation and harm. Navigating the tension between a researcher's ethical duty to protect children and young people from harm and at the same time respecting the principles of inclusion and participation is a dilemma confronting researchers today (Daley, 2013; Eriksson and Näsman, 2012; Powell et al., 2011; Carter, 2009).

This article argues that a rigorous but balanced assessment of harm and benefit goes some way towards responding to this challenge. An analysis of our experience with two research studies discerned three critical considerations when conducting an assessment of harm and benefit. First, reflection on the purpose and the theoretical context underpinning children and young people's involvement in the research can reveal the likelihood of their participation adding value to the research process and yielding a benefit for the research participants. Second, the preferences of the children and young people and their parents<sup>8</sup> to be involved in research are a critical consideration in assessing the likelihood of research posing a greater harm than benefit. Third, giving consideration to the time and resources available to support children and young people's meaningful involvement. It is not our intention to provide an exhaustive set of issues for consideration, rather the paper identifies these as prominent and pragmatic considerations when assessing harm and benefit.

## 6.2 The Studies

The two research projects that generated the learning upon which this paper is based were conducted in Ireland. The first, a Baseline Study on Children and Young People's Participation was conducted by author one (name first author) in 2015-2016. The primary aim of this study was to examine the extent to which children and young people's right to participate in

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<sup>8</sup> The use of the term parents in this article is intended to encompass parents and legal guardians.



decision-making is embedded in the structures and culture of Tusla - the newly formed Government agency for children and family services in Ireland. Tusla is committed to implementing a national programme of action to develop and mainstream participatory practices within the Agency, under the Development and Mainstreaming Programme for Prevention, Partnership and Family Support. Funded by the Atlantic Philanthropies, the aim of this study was to capture baseline data on children and young people's participation within Tusla services. As well as capturing baseline data, it was also intended that the study would be formative in nature and generate learning to inform service delivery and the implementation of the Tusla programme of action to mainstream participatory practices.

The second study, was a Youth-Led Research Project completed in 2015 involving a group of five young people in the west of Ireland. The young people (aged 15-17) were members of a Neighbourhood Youth Project run by Foróige, Ireland's national youth development organisation, and were participants in a Youth Leadership and Community Action Programme (hereinafter the leadership programme). An underlying purpose of the leadership programme is to promote skills building and a commitment to action among its participants (Redmond and Dolan, 2014). It is intended to empower young people to investigate a problem of relevance to their communities and to take steps to address it through a community action initiative. In this case the five young people identified youth mental health as an issue of concern in their locality. They wanted to research what are the triggers of mental health problems in youth and how do mental health problems affect youth in their community. The young people and their youth workers approached the authors for research support. This article does not detail the project findings or outcomes of these two studies. Instead, the focus is on sharing the learning following the assessment of harm and benefit undertaken to inform a decision on whether to involve children and young people in the Baseline Study and whether to support the Youth-Led Research Project.

### **6.3 The purpose and theoretical context of the research**

The purpose of the research is a key factor in determining whether children and young people should be involved in research and to what level (Sinclair, 2004; Hill, 1997). Holland et al. (2010) and Cahill (2007) argue that children and young people's involvement in research must be accompanied by an explanation of where on the theoretical framework the participation sits to clarify its intent. Clarity on the purpose and theoretical context can indicate the likelihood of children and young people's participation adding value to the research process as well as yielding a benefit for the research participants. Therefore, the

first consideration for both projects was the purpose and theoretical basis of the research. The primary purpose of the Baseline Study was to generate safe knowledge on children and young people's experience of participation in decision-making within Tusla. 'Safe' is interpreted as meaning trustworthy (valid, reliable and objective) research (Dyson and Meagher, 2001:71). Children and young people in receipt of Tusla services were seen as key informants in the process of capturing the extent to which participatory practices were embedded in Tusla. In light of the formative component of the Baseline Study and mindful of children and young people's right to have their views heard in all matters affecting them, a core purpose of the study was also to bring the views of children and young people to the attention of the stakeholders developing the Tusla programme of action to mainstream participatory practices.

The seminal text *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood* presented an emerging paradigm (the 'new social studies of childhood'), which viewed children and young people as social actors, active in shaping their own lives and worthy of study in their own right (James and Prout, 1997). One of the key features of this paradigm was the acknowledgement that children and young people have a role to play in the production of sociological data. In many cases it is children and young people that are best placed to inform researchers about the reality of their lives and how they perceive and construct their social worlds. There is broad agreement in the literature that children and young people's involvement enhances research as it generates reliable knowledge, informed by their perspectives and lived experience (Morrow, 2012; Harcourt and Einarsdóttir, 2011; Kellett, 2011; Skelton, 2008; Powers and Tiffany, 2006).

While involving children and young people in research can enhance its quality and reliability, children and young people in turn can benefit from research that contributes to an improved understanding of their lives. Studies have found that children and young people have benefited from being involved in social research for altruistic reasons; making other children and young people in similar situations aware of their stories so they realise they are not alone (Eriksson and Näsman, 2012; Moore et al., 2011; Roberts and Taylor, 1993). The value of their involvement may be heightened if they have the sense that the research has the capacity to influence societal change (Decker et al., 2011a). This brings us into the realm of research that is designed to enable voice.

Research that is attributed to what Dyson and Meagher (2001: 71) describe as 'enabling voice' is underpinned by a recognition of children and young people's rights, namely a

respect for the dignity and competence of the individual child to have a voice on issues of relevance to them. Article 12 of the UN Convention on the Rights of the Child (UNCRC) codified for the first time in international law the right of a child to have their views heard in all matters affecting them and for their views to be given due weight in accordance with their age and maturity. Lundy (2011: 6) identifies four key steps required for the realisation of the child's right to have their views heard. First, 'space' - children and young people must be provided with the opportunity to express a view in a space that is safe and inclusive. Second, 'voice' - children and young people must be facilitated to express their view. Third, 'audience' - the view must be listened to. Fourth, 'influence' - the view must be acted upon as appropriate.

As set out above a core purpose of the baseline study was to enable the views of young Tusla service users to be heard on their experience of participation within Tusla services and to generate learning to inform service delivery and the implementation of the Tusla programme of action to embed participatory practices. The authors were of the view that ethical research facilitates children and young people to express their views in a safe and inclusive space. In addition, the documentation and dissemination of their views is a valuable methodological tool for the realisation of their right to be heard. While this is as a worthy goal to strive for, the authors were aware that expectations must be managed. It was imperative to be transparent about the study limitations and aspects beyond their control. While a researcher can make every effort to channel children and young people's views to the relevant decision-makers, the researcher can offer no certainty that these views will be taken seriously and acted upon in the policy and service domain. Having their views listened to and acted upon as appropriate are the final and critical steps in the realisation of a child's right to be heard. As the Baseline Study was being conducted in partnership with Tusla, the researcher was confident that there would be sufficient openings to communicate the research findings on children's experience of participation to the stakeholders responsible for developing and implementing the programme of action to embed participatory practices within the Agency. As a result, the goal to generate safe knowledge and enable the voices of the young Tusla service users to be heard provided a solid rationale for their involvement, at a minimum as research participants, with the likelihood of benefits accruing. These likely benefits being the generation of safe knowledge informed by the perspectives of children and young people with lived experiences of being involved in Tusla decision-making processes. As well as, the opportunity to have their views heard, validated and potentially influence service delivery

within Tusla. Therefore, offering the chance of immediate benefits for the young research participants and gains for future service users.

As referred to above, the Youth-Led Research Project was initiated in the context of a leadership programme that is designed to promote skills building and a commitment to action among its participants. The intended outcomes of the leadership programme, which are to promote positive youth development and to empower the young people to take action for change, provided the theoretical foundation for a youth-led research project. In the literature on children and young people's participation, one of the most commonly cited benefits of participatory practices is its contribution to positive youth development (Thomas and Percy-Smith, 2012; Serido et al., 2011; Checkoway et al., 2003). The positive youth development perspective is a strengths-based approach to conceptualising adolescence (Lerner et al., 2005). The focus is on the potential of youth to be guided towards positive developmental outcomes. These desired outcomes for youth have been classified as the five Cs, which are, competence, confidence, character, connection and caring (or compassion) (Lerner et al., 2000). Establishing positive adult-youth relationships, engaging youth in activities that promote skill-building and giving youth a voice on issues that affect them have all been directly attributed to supporting positive youth development (Serido et al., 2011; Eccles and Gootman, 2002).

The participation of children and young people in research can legitimately be embarked upon for the purpose of positively contributing to young people's personal development (London et al., 2003). The potential for children and young people's collaboration in research to result in positive relationships, an enhanced skill-set and to communicate their voice makes it well placed to support positive youth development. Children and young people's involvement in the research process can increase their knowledge, confidence and self-esteem (Fleming, 2011; Shaw et al., 2011; Kirby and Bryson, 2002), can build research related skills, including critical thinking, writing and analysis (Powers and Tiffany, 2006; London et al., 2003) and improve their networks of support (Fleming, 2011; Powers and Tiffany, 2006; London et al., 2003). These positive outcomes are linked to research where the participants are directly involved in the research process, including design, data collection and dissemination, as opposed to purely being the sources of research data.

Research embarked on to empower young people to take action for change goes beyond a respect for children and young people's rights and a recognition of their capacity to generate expert knowledge on their lives (Kellett, 2011). It places the control in the hands of children

and young people to drive the research agenda and to use the research findings to act on issues of importance to them. Rappaport (1984) defines empowerment as a process whereby people gain control over their lives. In this context 'agency' rather than 'voice' is considered the key concept (Percy-Smith and Thomas, 2010: 359). The literature reveals that, letting children and young people take ownership of the research can provide them with a sense of empowerment and create a more equal power relationship between the adult researcher and the child or young person (Kellett, 2010). Participatory action research in particular is recognised for its capacity to empower research participants (Houghton, 2015). One of its key features is the commitment by the researcher to allow the participants to take control of the research (Hart, 1992). The emphasis on action not only signifies the active involvement of the stakeholders in the research process but also that the research findings are intended to benefit the participants by becoming 'launching pads for ideas, actions, plans and strategies to initiate social change' (Camarota and Fine, 2008: 6).

If the purpose of the research is to promote positive youth development, then a minimum requirement would be that children are collaborators in the research process to provide them with opportunities for personal development. While if the underlying intent of the research is to empower children, it follows that they should have significant control and ownership over the research. The idea for the Youth-Led Research Project was initiated by the young people. It was intended that they would lead on the data collection, analysis and the dissemination of their exploration of triggers of mental health problems in youth and how mental health problems affect their peers. In this context, the authors took the view that the Youth-Led Research Project was well-placed to promote the positive youth development and empowerment of the youth researchers. However, to ensure it achieved these intended benefits would require comprehensive research skills training (a matter returned to below).

#### **6.4 The preferences of the children and young people and their parents**

As set out above, clarity on the underlying purpose and theoretical context of the research can inform an assessment of the likelihood of research being of merit and generating a benefit for its participants. However, in designing the Baseline Study and making a decision on whether to support the Youth-Led Research Project, the authors were of the view that the preference of children and young people and their parents to be involved in the research is a critical consideration in assessing the likelihood of harm or benefit prevailing. In some

instances, an assessment of harm may seem to be very straightforward. If the research will exclude a child or young person from accessing a required service, unduly interfere with the child or young person's education or, if there are clear concerns regarding their safety and protection, the risks may be considered too pronounced to justify the potential benefits.

More often than not, however, and as was the case in the Baseline Study and the Youth-Led Research Project, it is common for the lines between the likelihood of benefit or harm prevailing to be blurred. Unlike medical research, which can immediately and overtly cause physical harm, social research can be seen to be benign, yet can be a significant intrusion into people's lives causing them emotional distress (Alderson and Morrow, 2011). In the Baseline Study, the most prominent risk identified was the potential for the research to be an unwelcome intrusion for young service-users, whose lives may already be under scrutiny by an array of professionals. Although evidence is emerging to the contrary, arguably, sharing their experience of participating in decisions regarding their personal welfare, protection and/or care may also cause distress. Distress may be caused if the child or young person's experience was not a positive one or if the outcome of the decision-making process was counter to their views. Returning to the Youth-Led Research Project, the issues of consent, confidentiality and emotional well-being have been identified as important considerations when protecting young people engaged in youth-led research and their research participants from harm (Bradbury-Jones and Taylor, 2015). These were all relevant considerations and potential risks in the context of this project and the sensitive nature of the research topic.

The literature provides some insight into whether these were valid concerns. Children and young people are often categorised as vulnerable and excluded from research on the grounds of it being 'inherently risky' (Carter, 2009: 585). However, research is beginning to emerge challenging this assumption. In the field of psychology there are growing efforts to establish an empirical evidence base to inform an assessment of the risks and benefits of being involved in research. Pioneering research by Newman and colleagues is generating data to enable an assessment on the costs and benefits of participation in trauma related research to be informed by evidence rather than being based on perception (Newman and Kaloupek, 2009; Newman and Kaloupek, 2004; Kassam-Adams and Newman, 2002). In 2009, Newman and Kaloupek reviewed the evidence on the costs and benefits of participating in research. Of note, this review of the evidence was not limited to research involving children only. They found that contemporary evidence 'indicates a general absence of harm and, in fact, a generally positive experience for most participants' (Newman and Kaloupek, 2009:

601). This includes participants who have been previously exposed to traumatic stress or developed posttraumatic stress disorder. They have found that a minority experience negative emotions and more distress than anticipated, but the majority of these participants do not regret their participation in research (Newman and Kaloupek, 2009; Newman and Kaloupek, 2004). Elsewhere, research finds that children and young people's participation may provide opportunities to validate their traumatic experiences (Eriksson and Näsman, 2012). More recently, a longitudinal study with adolescent girls in the child welfare system who had faced considerable adversity found that from the perspective of the young girls, the positive aspects of participation in a study on a healthy relationship project, outweighed the negative aspects and this finding did not differ over time (Chu and DePrince, 2013).

While the literature provides some indication of the likelihood of risk to emotional well-being, children are not a homogenous group. Therefore, one cannot rely solely on the literature to provide an answer of the likelihood of a research project, with its unique set of participants and circumstances, posing a risk of harm greater than its potential benefits. Moreover, a social scientist or ethical oversight body may not be best placed to make what can be a highly subjective assessment of the likelihood of harm or have the requisite knowledge of the research participant's individual circumstances. For these reasons, the authors took the view that determining the preferences of the child and their parents is critical to the assessment process. Obtaining informed consent is a pre-requisite to determining the child's preference to take part in research and the parent's willingness to permit them to be involved. Obtaining the informed assent or consent of a child or young person and the consent of their parents is a well-established ethical standard.<sup>9</sup> The consent process ensures that children and young people and their parents are informed regarding the purpose of the research and what their involvement entails. It has been described as 'the legal means of transferring responsibility for risk-taking from the researcher to the participant' (Alderson and Morrow, 2011: 23).

Involving children and young people in the assessment of risk, mirrors the emerging approach to child protection in the children's rights sector. In this sector there has been a move away from the traditionally adult-centric approach to assessing a child's protection towards an approach that is inclusive of the views of the child. In 2011, the UN Committee

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<sup>9</sup> In the context of young people between the ages of 15-18, ethical guidance on the requirement of parental consent varies. Some ethical frameworks take into account the competence of young people in this upper age range to consent and provide an exception to the norm. See further, Kennan, D (2015). Understanding the Ethical Requirement for Parental Consent When Engaging Youth in Research. In: Bastien, S and Holmarsdottir, H B (eds), Youth 'At the Margins': Critical Perspectives and Experiences of Engaging Youth in Research Worldwide. Rotterdam: Sense Publishers (pp. 87-103).

on the Rights of the Child stated that inviting children's views and giving them due weight must be a 'mandatory step' at every stage of a child protection process (UN Committee on the Rights of the Child, 2011: 24). More recently, the Committee issued detailed guidance on how to assess and determine the best interests of a child. The Committee states that a child, including a child that is very young or in a vulnerable situation, should be provided with the opportunity to influence an assessment of their own best interests by taking the child's views into account (UN Committee on the Rights of the Child, 2013).

Giving weight to the views of the child or young person and their parent on the likelihood of harm or benefit places an onus on the researcher to have safeguards in place to ensure they are in a position to make an informed assessment and to provide fully informed consent. The standard practice is to provide accessible information on the study, which identifies potential risks and benefits. Having strategies in place to empower the child and their parent to say 'no' are also imperative, as is clarity on what exit strategies there are once consent is provided. Children and young people must be aware that they can withdraw their consent at any point in time without consequence. Anderson (2010) highlights the risk to participants when gatekeepers are used to facilitate the informed consent process. There is the risk of the participants feeling required to participate to maintain a good relationship with the organisation or the staff member approaching them to participate. Marshall et al. (2012) also note there is a risk that large incentives may unduly influence the consent process. These potential pressures place an onus on the researcher to ensure there is no risk of coercion.

There are ambiguities in the research process in that consent is generally only sought after the research is designed and immediately preceding the data collection phase. This gives rise to the concern that making a commitment to involve children and young people during the research design, without gauging the preferences of the child and their parents in advance of recruitment, can open the door to the risk of 'methodological grooming'. Methodological grooming, a phrase coined by Bengry-Howell and Griffin (2012: 405), is described as a form of 'implicit persuasion'; encouraging young people to take part in research despite having demonstrated an initial resistance to engage. According to Bengry-Howell and Griffin (2012), methodological grooming can occur when pressures arise to put research designs into practice or to meet the commitments outlined in research proposals. In the Baseline Study, the implementation of a well-designed research plan, with careful attention to the informed consent process would have established if it was a valid concern that the research would be an unwelcome intrusion into the lives of the young service-users in Tusla. It could also



establish whether the likelihood of the research causing them distress could outweigh the potential benefits. However, the research did not progress to this stage. An overriding factor when assessing harm and benefit and determining whether to initiate empirical research with children and young people was the limited time and resources available. This is discussed in the following section. In the Youth-Led Research Project, by opting in to being a part of the youth leadership programme and initiating the research project, it was clearly the preference of the young people to conduct this research. Their parents provided consent for their children to partake in the leadership programme and all related activities, which they were made aware may include a research project. However, in making the decision to facilitate the research project, the authors were of the view that they still had a responsibility to counter the potential risks in conducting the research. The primary strategy to counter the potential risks was the delivery of a comprehensive research skills training programme and to provide the ongoing support of a professional researcher. A session on research ethics, focusing on the young people's ethical responsibilities to their research participants, as well as the importance of keeping themselves safe from harm, was an essential focus of this training.

## 6.5 The available time and resources

The third consideration when assessing harm and benefit and making a decision on children and young people's involvement in research is whether there is adequate time and resources to support their meaningful involvement. While having the required time and resources are important safeguards to minimise the risk of harm and to ensure the research can deliver on its intended benefits, given that this is an issue that can be underestimated and easily overlooked it is highlighted separately here. It has been established elsewhere, that increasing the likelihood that children and young people's participation in research will achieve its intended purpose is labour intensive (Kellett, 2011). Significant time needs to be invested to support their involvement in research. To access children and young people for the purpose of research, in particular those that are harder to reach, it takes time to build a relationship of trust with the children and young people and their gatekeepers (insert authors own reference). Moreover, it is said that a child's authentic views will only emerge once a positive relationship with the child and the relevant adult has been established and this is unlikely to occur in a single meeting (Archard and Skivenes, 2009). The many methodological challenges to involving children and young people in research have significant resource implications if researchers are serious about children and young people's meaningful involvement.

The time and resources available to the researcher for the Baseline Study was a significant factor in determining whether to directly involve children and young people in the research. During the period of the Baseline Study, the number of children in the care of the state combined with the number of cases open to social work generated a sample size of just over 33,000 children and young people<sup>10</sup>. These numbers exclude other children and young people Tusla provides services to, including aftercare services, education and welfare services and family support services. There was no pre-existing structure within Tusla to access a representative sample of the population group. The project was resourced by one full-time researcher and, as it was intended to capture baseline data, there was a finite amount of time available to collect the data prior to the implementation of the programme of work to mainstream participatory practices. Aware that negotiating access to hard to reach children and young people for the purpose of research can be a time-consuming, lengthy and an unpredictable process (insert authors own reference) and within the constraints of the time available, there was the risk of an insufficient sample size being achieved and /or one that was not sufficiently representative. Yet without including the perspectives of children and young people the validity of the study would be at best questionable.

The researcher was aware that the national Inspectorate for social care in Ireland, the Health and Information Quality Authority (HIQA), monitors Tusla's compliance with children and young people's rights, including children and young people's participation rights. Compliance is monitored against national children's standards, comprising the National Standards for Child Protection and Welfare, Foster Care, Residential Care and Special Care. While these standards vary, they all include standards on children and young people's participation rights. As part of the inspection process, inspectors meet with children, parents/carers, Tusla staff, external professionals,<sup>11</sup> observe practices and review case files and relevant documentation to determine if children and young people's views are listened to and taken seriously. The inspection reports provide a rich source of timely information directly informed by children and young people's views on their experience of participation in decision-making within Tusla. Some of these child informants are in receipt of welfare and

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<sup>10</sup> At year end of December 2015, there were 26,655 cases open to social work and 6,388 children in the care of Tusla. These numbers exclude other children and young people Tusla provides services to, including aftercare services, education and welfare services and family support services. Tusla, Child and Family Agency (2015) Integrated Performance and Activity Report: Quarter 4 2015. Available at: [http://www.tusla.ie/uploads/content/Q4\\_2015\\_Integrated\\_Performance\\_and\\_Activity\\_Report\\_Final.pdf](http://www.tusla.ie/uploads/content/Q4_2015_Integrated_Performance_and_Activity_Report_Final.pdf) (accessed on 24 August 2016).

<sup>11</sup> These may include members of An Garda Síochána, professionals from health services, educators and youth workers.

protection services, while others are in foster care, residential care or special care units. Therefore, they are broadly representative of the range of children and young people in contact with Tusla.

With this knowledge and in light of the time and resources available to the researcher, a decision was taken not to initiate empirical research with children and young people for the baseline study. Instead 53 HIQA inspection reports published in the preceding two years were sampled for secondary analysis of their findings on Tusla's compliance with children and young people's participation rights. Secondary analysis is now widely accepted as a valid form of inquiry, offering the potential of having access to good quality data, while being attentive to good stewardship of resources (Bryman, 2015; Yardley et al., 2014). The reports were imported to QSR NVivo 10 software to aid analyses by extracting and coding the relevant findings documenting children and young people's perspectives on Tusla's compliance with their participation rights. These findings were informed by the views of 371 children and young people. Their perspectives were triangulated with the findings from a questionnaire distributed to Tusla Employees nationally. It was considered that this approach was justified for the Baseline Study as the researcher would not single-handedly have been able to capture the perspectives of such a representative sample within the timeframe and resources available. Indeed, it may have been the more ethical approach, rather than posing an additional burden on young service users and disregarding timely perspectives already documented.

If children and young people are to be actively involved in the research process as collaborators or partners or if they are to take ownership of the research this is also resource intensive from both a human resource and monetary perspective. To engage children as co-researchers, it is said a comprehensive training programme is required (Bradbury-Jones and Taylor, 2015). Additional funds may be needed to offer children and young people the necessary equipment to support their involvement in the research process and to provide remuneration. According to Alderson and Morrow (2011) payments may be made for several reasons: to reimburse expenses (including the expenses of accompanying adults); to compensate for time, inconvenience and/or discomfort; to show a token of appreciation; to pay young people; or to recompense young people who would have otherwise been earning. Finally, children and young people have varying demands on their time including educational, social and sporting commitments, which can leave little time or motivation for involvement in other activities. Consideration needs to be given to whether children and young people

have the time to engage and whether the benefits will outweigh the commitment invested by the child or young person.

The authors were of the view that there was adequate time and resources to support the Youth-Led Research Project. Approximately three months was set aside, during which time the young people provided a commitment to meet at weekends and outside of school hours to progress the research. It was agreed that the financial costs incurred were to be borne by Foróige and the UNESCO Child and Family Research Centre. Having taken all these factors into consideration it was likely that the benefits would outweigh the risks and supporting the Youth-Led Research Project was entirely justified.

A training programme, designed to provide a step-by-step guide on how to conduct a piece of social research, was developed by the authors and delivered to the youth researchers. It included sessions on reviewing current research, formulating a research plan, choosing the appropriate research methods, research ethics, analysis and write-up. The session on ethics was designed to explore how to keep the researchers safe as well as being accountable for their research participants. Having completed the training programme, the young people commenced the research and agreed the appropriate methods. In this case an anonymous questionnaire distributed to their peers was the method of choice. It sought information on what are the triggers of mental health problems in youth and how do mental health problems affect youth in their community. The young people led on the data collection, analysis and the dissemination of their research. Ongoing support and mentoring was provided by their youth worker and the authors as required. To ensure maximum impact, the research was disseminated by producing a short video of their findings with the support of a small film production company and the acclaimed Irish actor, Cillian Murphy, patron of the UNESCO Child and Family Research Centre who provided his time pro bono (*see further*, <http://www.childandfamilyresearch.ie/cfrc/youth-as-researchers>).

## 6.6 Conclusion

Researchers, funders and ethical oversight bodies have a responsibility to not become embroiled in the momentum of actively encouraging children and young people's participation in research in the absence of critical reflection on when it is the right methodology. Equally there is an onus on the research community to not overly err on the side of caution and protecting children and young people from harm at the cost of

unjustifiably excluding them from research. Ethically, researchers have a responsibility to ensure that the outcome of a balanced assessment of harm and benefit underpins all decisions to include or exclude children and young people. Rather than engaging in a loose assessment of harm and benefit, this article provides guidance on some critical considerations for this assessment process. Drawing on the learning from two research projects and supported by the literature, it suggests that the research community's energies are well placed when reflecting on the purpose and theoretical basis of the research to provide an indication of the likelihood of the research yielding a benefit for its participants. To mitigate against the risk of harm, their energies are also well placed in ensuring it is the genuine preference of the child or young person and their parents to be involved in the research, secured through the provision of informed consent. Giving consideration to whether there is the available time and resources increases the likelihood of children and young people's involvement being a positive experience.

The following set of reflective questions can form the basis of a strategy for assessing harm and benefit and inform a decision on whether to involve children and young people in social research, as well as determining the appropriate level of their involvement.

Reflective questions to guide an assessment of harm and benefit

1. What is the purpose and the theoretical context of the research? Are there sufficient safeguards in place to enable the research to achieve its goals?
2. Is it the preference of the children and young people and their parents to be involved in the research? Have provisions been made to enable children, young people and their parents provide fully informed consent?
3. Is there adequate time and resources to support children and young people's meaningful participation?

While not providing an exhaustive set of reflective questions, these are what we consider to be the foremost considerations when engaging in an assessment of harm and benefit. Reflecting on these issues, when determining whether to involve children and young people in social research, lends itself to a more transparent decision-making process.

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# Chapter 7: Concluding Discussion

## 7.1 Introduction

As outlined in chapter one, this thesis is written following a period of significant developments in the study of childhood. The children's rights movement, paralleled with the recognition that children and young people are key informants in the sociological study of childhood, led to a respect for the views of children and young people and generated an expectation that they will be involved in research of relevance to their lives. In the interests of science and its beneficiaries, including children and young people, these are very positive developments and have led to a rapid growth in children and young people's involvement in research. Their involvement now spans the full spectrum of participation, ranging from children and young people being the sources of research data to child- and youth-led research. However, as has been the focus of this thesis, involving children and young people in research presents a challenge for researchers. On the one hand, from an ethical perspective, efforts to protect them from harm can suffocate opportunities for their participation. On the other hand, the ideological drive to promote their involvement in research can come at the expense of protecting them from harm and exploitation. An emphasis on protection and rigorous ethical standards are not the only challenges confronting researchers. From a methodological perspective, children and young people can be perceived as inconvenient and difficult to access and it can be challenging to find the appropriate methods to ascertain their authentic views. However, it is the aforementioned ethical dilemma confronting researchers that is the primary focus of this thesis.

This thesis is premised on the belief that a juncture has been reached where the time has come to reflect and ask, how can social science researchers navigate the dichotomy between protecting children and young people from harm and respecting their competence and autonomy, as individual beings, to participate in research of relevance to their lives. When engaging in research, there is often limited time for reflection. Indeed, it is acknowledged that in any work processes it can be difficult to build in structured time for reflection on action (Canavan, 2006). In the research context, the focus is generally on the interpretation of the data collected rather than reflecting on the research processes and whose perspectives were included or excluded in the generation of knowledge. Reflection on the research process can be seldom mentioned and normally limited to a brief discussion on the limitations of the study, technical matters or in the concluding sections (Alvesson and Sköldbberg, 2009). This thesis has provided the author with the opportunity to reflect on

research projects she was involved in and to generate findings from this reflective process to address the study aim and objective. This thesis contributes to the body of knowledge by bringing together experience and reflection, combined with a critical review of ethical frameworks and contemporary literature in the field to identify practical solutions to navigating the dichotomy between participation and protection.

The purpose of this chapter is to integrate the research findings set out in the three papers comprising the core of this thesis. These findings will be discussed in relation to the aim and objectives of the study. Having reiterated the research aim above, the four research objectives are set out below.

1. To reflect on the participation and protection discourses and their influence on children and young people's involvement in research;
2. To examine a researcher's ethical duties and rights-based responsibilities when involving children and young people in research;
3. To explore solution focused strategies to support researchers to navigate the balance between protection and participation; and
4. To distil key messages for ethical oversight bodies and the research and academic community.

Initially the chapter discusses the research findings in relation to objectives 1-3, before concluding with a set of key messages informed by the findings and in line with objective 4. In particular, in addressing the study's overall aim and objectives, this chapter plays a central role in demonstrating the coherence across the three publications and highlighting the full extent of how the findings generated from this study contribute to the body of knowledge. There follows first an overview of the author's contribution to the authorship and content of the three publications.

### **Contribution to the authorship and content**

Paper one, entitled '*Accessing a hard to reach population: reflections on research with young carers in Ireland*' was published in the Journal of Child and Family Social Work in 2012 and is co-authored with Dr. Allyn Fives and Dr. John Canavan. As presented in chapter four, it reflects on the author's experience of being involved in a qualitative study of young carers in the Irish population. Commissioned by the Department for Children and Youth Affairs, a core objective of this study was to recruit a sample of young carers to better understand the extent to which caring impacts on their lives. The author's role in the study was to recruit the

required sample for the purpose of conducting one-to-one semi-structured interviews. Dr. Allyn Fives, supported by the author, led the overall analysis of the young carer study findings and both authors worked under the supervision of Dr. John Canavan. Having completed the study, the long and challenging recruitment process prompted the author to embark on a journey of reflection, describing and analysing the experience and drawing conclusions on the approaches employed to recruit a sample of young carers. Dr. Allyn Fives and Dr. John Canavan contributed to editing second and third drafts of the manuscript.

Paper two, entitled *'Navigating the ethical requirement for parental consent when engaging youth in research'* was published as a book chapter in *Youth 'At the Margins' Critical Perspectives and Experiences of Engaging Youth in Research Worldwide* in 2014. It is a sole authored publication. Paper three is, *'Justifying the involvement of children and young people in social research: assessing harm and benefit'*. It is pending publication in the Irish Journal of Sociology and is co-authored with Professor Pat Dolan. As detailed in chapter six, it reflects on the process of conducting an assessment of harm and benefit during two research projects the author was involved in. One of the projects was a baseline study on children and young people's participation in social care services. Supported by the wider research team, the author was responsible for the design and implementation of this study and the assessment on whether to involve children and young people in the research. The second was a youth-led research project. In this case the author and Professor Pat Dolan jointly made the decision to support the youth-led project following an assessment of the potential risks and benefits. Having reflected on the considerations informing the assessments, the author collated the experiences and learning from both projects and drafted the manuscript.

## 7.2 Participation and Protection Discourses and their Influences on Research

Objective one of this thesis is to reflect on the participation and protection discourses and their influence on children and young people's involvement in research. The purpose of this section is to integrate the learning addressing this objective. The learning is based on conclusions drawn from both the review of the literature and the analysis of the authors personal experience of being involved in the research projects discussed in paper one (the young carers study) and paper three (the baseline study on children and young people's participation and the youth-led research project). The participatory and protectionist discourses and their influence on research practice will be examined in turn.

## Participatory discourse

Recent developments in the study of childhood are anchored in the new social studies of childhood and children's participation rights in the UNCRC. As a result of these developments, the views of children and young people are increasingly recognised as being central to decision-making processes on matters of relevance to their lives and pivotal to providing adults with a better understanding of their lived experiences. The new social studies of childhood is referred to as a 'new paradigm' (James and Prout, 1997), while the right of the child to have their views heard is designated as one of four general principles underpinning the Convention (UN Committee on the Rights of the Child, 2009). The status afforded to these developments, along with the almost universal ratification of the UNCRC, underscores the international acceptance of the view that children and young people are independent and competent beings.

It is evident throughout the thesis, that these developments have had a major influence on children and young people's involvement in research. The literature review revealed that it is now well-established in the literature that children and young people should be approached as social actors, with a valid role to play in the production of sociological data. Indeed, this assumption underpinned the design of the three research projects discussed as part of the thesis. The young carers study, for example, was commissioned by the Department of Children and Youth Affairs in Ireland in the context of a national policy commitment to generate empirical data informed by the perspectives of children and young people.<sup>12</sup> Accordingly, it was a requirement of the Commissioner that the author and her colleagues accessed a representative sample of young carers to generate findings informed by their views. In the design of the baseline study, children and young people in receipt of Tusla services were viewed as key informants in the process of capturing the extent to which participatory practices were embedded in the Agency.

Participatory discourses have also influenced children and young people's more active involvement in the planning and process of research. This has led to the development of models capturing the evolving trend from children and young people being subjects, as opposed to objects of research, to their active participation in the research process towards child and youth-led research. As set out in the literature review, one of the more recent models, developed by Shaw et al. (2011), reflects the emergence of child-and youth-led

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<sup>12</sup> See Department of Health and Children, *National Children's Strategy: Our Children – Their Lives*. Dublin: Government Publications.

research. Shaw et al.'s continuum ranges from children and young people being consulted about the research, to being collaborators, to children and young people taking control and ownership of the planning and research process. The youth-led research project discussed in paper three, is illustrative of how participatory discourses have now influenced children and young people's involvement in research spanning all levels of participation, including the upper levels, whereby research is facilitated by adults but initiated and implemented by children and young people.

### **Protectionist discourse**

Protectionist discourses place the emphasis on children and young people's vulnerabilities and need of care. Proponents of the protectionist discourse can construct childhood as a period of incompetence and vulnerability requiring protection from the adult world. Ethical frameworks are situated within this discourse. They are primarily designed to protect research participants, researchers, research institutions, as well as the good name of research (Alderson and Morrow, 2011). The literature reveals that the default position for ethical oversight bodies is to deem children as vulnerable (Carter, 2009) and that the emphasis behind ethical research with children and young people is often on minimising risk (Daley, 2013; Powell et al., 2011; Young and Barrett, 2001; Morrow and Richards, 1996). An emphasis on protection propels notions of incompetence and vulnerability and, as set out in the literature review, it is believed that perceptions of incompetence remain a key reason why children and young people's views are not included in research of relevance to their lives (Kellett, 2011; Lundy et al., 2011; Powell et al., 2011).

The influence of the protectionist discourse can lead to the exclusion of children and young people, even when there is a desire by the researcher to be inclusive. Paper one is illustrative of how the desire may be there to be inclusive, but pragmatically this is difficult to apply in light of a researcher's ethical commitments and, given that a researcher's access to children and young people is mediated through either their parents or gatekeepers and in many cases both. Paper one adds to the growing body of knowledge that compliance with ethical requirements can have exclusionary consequences. It found that the limits on confidentiality and the ethical requirement of obtaining parental consent most likely excluded the most marginalised young carers from participating in the study, including those from families where the parent or parents had a drug or alcohol addiction. It was considered that the parents of such children would be unwilling to volunteer information about their home life or encourage outside interest in their family. As the study did not succeed in recruiting the

more marginalised young carers, it relied solely on information provided by service providers working with these families. In this way, these children and young people whose lived experiences were excluded remained the objects of research being denied the opportunity to be involved as informants. This was potentially the case even in circumstances where the young person was the primary carer in the household and/or close to the age of maturity. These realities are evident of the gap that still exists between the theory that children and young people are competent social actors, whose perspectives should rightfully be included in research of relevance to their lives, and practice.

To be clear, this thesis does not suggest that protectionist theories are unwittingly disregarded in the interests of enabling children and young people's participation in research. As referred to throughout the thesis, there is the risk and some evidence of participation being viewed as unquestionably good to the detriment of children and young people's protection from harm (Klocker, 2015; Campbell and Trotter, 2007). Alongside new approaches to studying childhood, there are many elements of the old conceptualisations of children and young people that remain valid. As Graham et al. (2013) advocate, both participation and protection discourse are critical to child well-being.

### **7.3 Ethical Duties and Rights-Based Responsibilities**

Objective two of this thesis is to examine a researcher's ethical duties and rights-based responsibilities when involving children and young people in research. The learning to address this objective is informed by the literature and the critical review of current ethical frameworks in paper two. As observed by Powell et al. (2011), the responsibility of a researcher to uphold children's rights sits alongside a researcher's ethical obligations. However, this thesis brings to the fore a fundamental difference. The emphasis in research ethics is on protectionism, while children's rights frameworks equally promote protectionism and a respect for children and young people's autonomy and self-determination. When involving children and young people in research, traditionally the focus has been on a researcher's ethical responsibilities. More recently a researcher's responsibilities to respect children's rights is in focus, influenced by the UNCRC and championed by scholars, such as, Lundy (2012; 2011) and Beazley et al. (2011).

#### **Ethical duties**

The broad ethical issues that arise in the context of social research with children and young people are similar to those that present in all forms of research with human subjects,

however, there are unique aspects. As outlined in the literature review, this is primarily due to children and young people being viewed as less able to protect themselves from harm than other population groups and the inevitable power imbalance between adult researchers and the young research participants (Thomas and O'Kane, 1998; Morrow and Richards, 1996). This influences a paternalistic approach to ethics, placing the emphasis on an adult's responsibility to protect children and young people from harm. With few exceptions, there are three universal ethical considerations that researchers are duty bound to adhere to in order to protect children and young people from harm. These are a researcher's ethical duties:

- To conduct an assessment of harm and benefit and the likelihood of either prevailing;
- To protect the confidentiality of the young research participant(s), except when the child or young person discloses information that gives rise to a child protection concern; and
- To obtain the informed assent or consent of the child or young person and the consent of their parent or guardian.

There are other ethical considerations, as alluded to in the literature review, but an in-depth consideration of these issues is outside the scope of this thesis. The focus of this study is on the core ethical considerations designed to safeguard children and young people from harm.

In relation to the first ethical consideration, set out above, it can be said that ethical research is first and foremost premised on an assessment of harm and benefit. If research is not of merit or poses too great a risk it should not proceed. A range of possible perceived risks and benefits are identifiable in the literature, but do date limited guidance has been provided on how to conduct an assessment on the likelihood of harm or benefit prevailing (an issue returned to in section 7.4). In relation to a researcher's duty to impose limits on confidentiality to safeguard children and young people who disclose information of concern, both the literature and the analysis of the author's experience in the young carer's study establish that it is broadly agreed that researchers have a non-negotiable ethical duty to report to the relevant authorities information disclosed that raises a child protection concern. Moreover, as set out in paper one, in some countries this duty has moved beyond an ethical requirement to a legal obligation. Since publishing paper one, mandatory reporting is now legislated for in Ireland under the Children's First Act, 2015. While the Act does not

explicitly name researchers as ‘mandated persons’, it adds more weight to the importance of compliance with this ethical standard.

While developmental psychology and the law take into account that as young people mature they develop increased competencies during the period of adolescence, this study found limited evidence of ethical frameworks acknowledging the evolving capacities of children and young people. For the most part, ethical frameworks categorise all persons 0-18 as children in need of protection in equal measure, without making allowances for their range of competencies. In the context of the parental consent requirement, paper two found that there is unanimous agreement among the research community on the need for parental consent when research involves young children. However, whether parental consent should be required for young people aged 15-18 is a subject of debate. Some ethical guidelines make provision for the differences between very young children and those in this age range. The comparative review of current ethical frameworks revealed that there are three approaches to the parental consent requirement internationally. As set out in chapter five these three approaches are as follows. First, parental consent is required in all circumstances up to the age of 18. This is the approach adopted in Ireland. Second, in some countries there is a provision for a fixed age, below the age of 18, whereby parental consent is not required once the child reaches the prescribed age. Third, in certain countries parental consent is required up to the age of 18 but allowance is made for a waiver. However, with the exception of New Zealand, there is evidence to suggest that provision for a waiver is generally not focused on the competence of the young person, but rather on the research context, the level of risk posed and the researcher’s inability to carry out the research without parental permission (National Advisory Committee, 2012; Wagener et al., 2004).

### **Rights-based responsibilities**

As set out in chapter two, a researcher’s rights-based responsibilities are framed within a discourse of rightful entitlements. Children and young people have rights that researchers are obligated to respect. Under the UNCRC the state is the primary duty bearer, but it is said that children’s rights provide a framework for social norms (Pittaway et al., 2010) that all researchers can be expected to operate within. This places a responsibility on researchers in two respects. First, Article 12 of the UNCRC has been interpreted to extend to children and young people a substantive right to participate in research of relevance to their lives (Lundy et al., 2011; Fernandez, 2007; Petrie et al., 2006; UN Committee on the Rights of the Child, 2006; Taylor, 2000). Second, as discussed in paper three, from a methodological perspective,



research can be a valuable tool to realise the participation rights of children and young people. Research can provide them with a safe and inclusive space to have their views documented for the purpose of being brought to the attention of decision-makers. In this way, it can be said that researchers have a rights-based responsibility to include the views of children and young people in research initiated to inform decision-makers about their lived experiences.

It is arguable that the original intent of Article 12 would not, in all circumstances, extend to a right of the child to be involved in decision-making around the research process. As set out previously, the threshold laid down in terms of whether children and young people should be involved in the research planning and process is whether their ‘perspectives can enhance the quality of solutions’ (UN Committee on the Rights of the Child, 2009: 10). The UN Committee on the Rights of the Child has gone so far as to encourage institutions that conduct research on children’s issues, for either academic or policy purposes, to involve children in the research process. However, it stopped short of recognising this as a right of the child or young person, qualifying this call for action with the wording ‘when appropriate’ (UN Committee on the Rights of the Child, 2006: 6). Researchers also have a rights-based responsibility to protect children and young people from physical and emotional harm or maltreatment and all forms of exploitation. As set out in the literature review, Article 19 of the UNCRC is the relevant provision in this regard, accompanied by a range of other provisions prohibiting all forms of exploitation. However, as outlined, given there is a plethora of codes of ethics governing the protection of human subjects in research, the focus is usually on a researcher’s ethical duty to protect children and young people from harm as opposed to a child’s right to protection.

#### **7.4 Navigating the Balance between Participation and Protection**

Objective three of this thesis is to explore solution focused strategies to support researchers to navigate the balance between protection and participation. As set out previously, it is not the intention to provide definitive solutions to this ethical dilemma. There is no one ‘right’ approach. Instead this section suggests a number of possible strategies to guide social science researchers. The findings addressing this objective are informed by the literature, paper two and the findings in paper three. Three approaches are suggested to support researchers to navigate the balance between participation and protection. First, the importance of conducting an overall assessment of harm and benefit is discussed. It reiterates the strategy proposed in paper three for conducting such an assessment,

elaborating on the discussion in this paper and identifying key considerations going forward. Second, it proposes an approach that acknowledges the interdependence of participation and protection. It suggests an approach whereby the views of children and young people are central to decisions taken regarding their protection and safeguards are put in place to ensure their meaningful participation. Third, it reiterates what has previously been said, that researchers should approach ethical frameworks as a guiding tool. There should be a preparedness and openness to flexible and innovative approaches. Each of these proposed strategies are discussed in turn.

### **Assessing harm and benefit**

There is very little discussion in the literature on the interface between participation and protection and a researcher's ethical duties and rights-based responsibilities. However, an observation by Daley (2013) brings an insightful perspective into the fold. As suggested by Daley (2013), it is only valid for a researcher to overly err on the side of protection if the potential risk of harm outweighs the benefits of children and young people's participation in research. While, championing the benefits of participation is only justified if it does not come at the cost of protecting children and young people from exploitation and harm. Accordingly, at the heart of achieving an equitable balance between participation and protection is an assessment of harm and benefit.

As set out in paper three, analysis of the author's experience of designing a baseline study, to capture the extent to which children and young people's participation is embedded in the structures and culture of Tusla, and her experience of assessing whether or not to provide professional support to a youth-led research project found that there are three critical considerations when conducting an assessment of harm and benefit. First, reflecting on the purpose and the theoretical context underpinning children and young people's involvement in the research can reveal the likelihood of their participation adding value to the research process and yielding a benefit for the research participants. Second, the preferences of the children and young people and their parents to be involved in research are a critical consideration in assessing the likelihood of research posing a greater harm than benefit. Third, consideration must be given to whether there is the time and resources available to support children and young people's meaningful involvement. The outcome of this assessment process can provide a solid footing for researchers to negotiate the inclusion or exclusion of children and young people in an ethically compliant and inclusive manner.

While these considerations underpinning an assessment of harm and benefit are discussed at length in paper three, there is one issue worth discussing further here. Paper three brought to the fore that there are many assumptions underpinning children and young people's involvement in research that have over time become normative. The theory underpinning why children and young people should be involved in the study of childhood is not grounded in empirical evidence. There is limited empirical research to support the assumption that their involvement in research generates safe knowledge, enables voice, and contributes to their positive youth development and empowerment. The literature provides some indications of why this may be. Sinclair (2004) suggests that participation as a rights-based principle does not need to be justified by evidence that it works, while others remark that the new participatory approaches to childhood research are now so sacrosanct that there is a belief that they do not need to be grounded in evidence (McCarry, 2012; Carter, 2009). Staley's (2009) review of the literature on the impact of the public's involvement in health and social care research sheds further light on the possible reasons behind the lack of evidence. As outlined in chapter two, this review established that assessing the impact of research is difficult for a number of reasons, including that it can be costly to set up a comparison research project without the public's involvement and it may take years for detectable impacts to emerge from the study. Close to 30 years post the adoption of the UNCRC and 20 years since James and Prout (1997) presented a new paradigm for the sociological study of childhood, it would seem timely to empirically test the hypothesis that research is an important medium to enable voice and to yield tangible benefits for children and young people as well as for the wider society. This echoes previous calls made for a closer examination of children and young people's experience of participating in research (Decker et al., 2011b; Holland et al., 2010).

Similarly, there is very limited empirical research on the harms caused to children and young people as a result of their involvement in research. As discussed in paper three, evidence generated in the field of psychology is beginning to emerge challenging normative assumptions that participation in research is 'risky' and may harm children and young people's emotional well-being when they have experienced a period of adversity. Adopting an evidence informed approach to assessing harm and benefits could ensure researchers don't overly err on the side of protection or excessively champion the benefits of participation.

## Embracing the interdependence of participation and protection

Embracing the interdependence of participation and protection suggests it is time to move beyond the perception that balancing the two presents a natural dichotomy. Both have merits in their own right. In this regard there is learning from the approach advocated in the human rights field. As set out in chapter two, all human rights are viewed as inter-dependent, with the realisation of one right often depending wholly or in part on the other (United Nations, 2003). Writing in the context of the interdependence of children and young people's participation and protection rights, the UN Committee on the Rights of the Child issued guidance that hearing the views of children and young people promotes protection and protecting the child from harm and exploitation is key to participation (UN Committee on the Rights of the Child, 2011).

Much can be learned from this approach when navigating the balance between participation and protection from a research ethics perspective. The approach advocated in paper three to assessing harm and benefit is mindful of the interdependence of participation and protection. Paper three on the one hand makes the case that children and young people's participation in research will only be meaningful and yield the intended benefits if safeguards are in place to protect them from harm and exploitation. Having the requisite safeguards in place when involving children and young people in research is essential for their protection. One such safeguard emphasised in paper three is the importance of there being sufficient time and resources to support their meaningful participation. On the other hand, determining the views or preferences of the child and their parents, through the consent process, is critical to their protection. The provision of or refusal to provide informed consent provides an indication of the views of the child or young person and their parents on the potential risks involved. As discussed in paper three, safeguards must be in place to ensure the child and their parents are in a position to provide fully informed consent.

While the interdependence of participation and protection is an approach advocated by the children's rights sector, it is also an approach suggested by children and young people themselves. Houghton's (2015) research exploring the perspectives of young people on research ethics, found that the young people believe that they need to be repositioned as agents in their own protection. They recommended that young people's perceptions of risk are vital to an assessment of their safety. In terms of how this can be achieved in practice, paper three suggests that the informed consent process has a crucial role to play in this regard. It is also worth recalling Carter's (2009) suggestion that children and young people

should be actively involved in ethical oversight bodies as key informants in any assessment of the risk or value of research.

To conclude this section, the interdependence of participation and protection is evident in the set of reflective questions developed in paper three to guide an assessment of harm and benefit. These are:

1. What is the purpose and the theoretical context of the research? Are there sufficient safeguards in place to enable the research to achieve its goals?
2. Is it the preference of the children and young people and their parents to be involved in the research? Have provisions been made to enable children and young people and their parents provide fully informed consent?
3. Is there adequate time and resources to support children and young people's meaningful participation?

### **Openness to flexible and innovative approaches**

Paper two concludes that ethical guidelines offer an important framework for researchers to operate within to safeguard children and young people. But as non-binding instruments, they should not close down any debate on how the appropriate balance between protecting children and young people from harm and enabling their participation in research can be achieved. The review of the literature and ethical frameworks brought to the fore the importance of a flexible and tailored approach. Children and young people, like all population groups are not homogenous. Therefore, while guided in their decision-making by ethical frameworks, researchers must be responsive and accommodating of children and young people's individual circumstances and competencies. Paper two suggests a two-step strategy when determining the approach to take to the issue of parental consent. These suggested steps are equally applicable to a researcher's approach to all ethical issues.

First, it suggests that researchers should look to the local context that they are operating within. They must be aware of the approach of the law and ethical guidelines in the country that the research is taking place. They then need to factor in the participant's age, capacities, societal and cultural considerations, the nature of the research and the level of risk posed. In this way, the researcher is informed by the principles and rules regulating ethical research, but is cognisant of their moral responsibility to do right by the individual research participant. It can be described as adopting the combined ethics of justice and ethics of care approach

advocated by Mortari and Harcourt (2012). It also opens to the door to taking an approach that factors in the evolving capacities of the child.

Second, researchers should look to the wider global context. As set out in paper two, understanding what is considered ethically accepted practice by looking to the law and ethical guidance in different countries across the world, as well as, drawing on approaches adopted by other researchers can provide important guidance and learning. For example, approaches taken internationally to the issue of parental consent can provide learning for researchers on how to factor in children and young people's evolving capacities when complying with this ethical issue or others. Three approaches to acknowledging children and young people's evolving capacities were identified from the review of ethical frameworks in paper two. First, an age is prescribed below the age of 18, whereby all young people of that age and older are presumed to have the capacity to consent. Different countries, prescribed different ages ranging from 14-17. Second, in New Zealand, all young people who have reached the prescribed age of 16 are presumed to have the capacity to consent, but children and young people below the age of 16 can demonstrate their competence to provide informed consent without the need for parental consent. This places an onus on the researcher to assess and demonstrate the child's competence to understand the nature, risks and consequences of the research. Third, all children and young people up the age of 18 are treated as having the same competencies, but provision is made for a waiver, with no prescribed age attached to the conditions of a waiver. However, as set out above, with the exception of New Zealand, the decision to grant a waiver is generally not focused on the competence of the young person, but rather on the research context.

As well as providing learning on how the evolving capacities can be factored into ethical decision-making, paper two also brought to the fore learning from the literature on innovative approaches adopted by researchers to comply with the parental consent requirement. As set out in paper two, uncertainty around ethical requirements can lead to overprotectiveness, while greater clarity and an understanding of what is considered ethically acceptable practice has the potential to facilitate researchers to be inclusive of even the most marginalised children and young people in research. It can support researchers to have the confidence to enter uncharted waters when navigating the balance between participation and protection and challenge the normative approach. Paper two, reviewed innovative and effective approaches to the parental consent requirement that are considered to be ethically compliant. These include approaches as simple as obtaining

parental consent over the phone, as opposed to the standard and more onerous written consent. Proceeding on the basis of passive consent from the parents, alternatively known as the 'opt-out' approach and identifying a suitable proxy to provide consent for the child or young person when parental consent is not possible to obtain. In the absence of an openness to flexible and innovative approaches, it leaves the door open to compliance with ethical standards being a tick-box standardised exercise to safeguard against litigation, rather than doing right by the research participants.

## 7.5 Key Messages

Objective four of this study is to distil key messages for ethical oversight bodies and the research and academic community. As set out below, it is possible to identify a core set of messages from the findings of this study. It is hoped that these core messages will influence the practice of researchers and ethical oversight bodies; encouraging them to simultaneously protect children and young people from harm, while promoting their participation in research of relevance to their lives. The growth of children and young people's involvement in research has seen a rise in publications on ethical approaches to working with children and young people (*for example*, Daley, 2013; Gallagher, 2008a; Gorin et al., 2008; Morrow and Richards, 1996). This thesis has contributed to this body of knowledge, specifically by exploring how social science researchers can navigate the dichotomy between protecting children and young people from harm and respecting their competence and autonomy, as individual beings, to participate in research of relevance to their lives. As suggested by Daley (2013), it is the responsibility of researcher's to publish their reflections and experiences of negotiating ethical dilemmas to inform both their peers and researchers who are not governed by ethical oversight committees and practitioners. As Daley notes, researchers linked to programmes and smaller organisations will not have access to formal ethical review and can learn from the experience of others. It is also arguable that influencing the practice of researchers and ethical oversight bodies has the potential to filter down to the next cohort of adult decision-makers (parents, teachers, social workers etc.) who likewise play a gatekeeping role in determining children and young people's involvement in research. The following are the key messages distilled from the findings of this study.

**Message one: Current approaches to research ethics that are heavily focused on minimising risk can have potentially unjustified exclusionary consequences.** Categorising all children and young people as vulnerable and all persons 0-18 as children, without making allowances for their range of competencies, is problematic. It can perpetuate unjustified

erring on the side of caution and exclude children and young people from research. Yet it is wise to heed the caution expressed by Woodhead (2000) to not throw out the baby with the developmental bathwater. The difference in competencies between older children and young children ought not to be neglected and, as adult researchers, we cannot diminish our child protection responsibilities in the interests of meeting our targets to involve appropriate numbers and a sufficiently representative sample of children and young people in research. However, research ethics should move away from a deficit-based approach to children and young people towards an acknowledgement of their evolving capacities.

**Message two: A rigorous assessment of harm and benefit is critical to achieving the balance between protecting children and young people from harm and respecting their competence and autonomy, as individual beings, to participate in research of relevance to their lives.** An overall assessment of benefit as well as harm may go some ways towards moving beyond the current emphasis on minimising risk. There are three critical considerations when conducting an assessment of harm and benefit. First, reflection on the purpose and the theoretical context underpinning children and young people's involvement in the research can reveal the likelihood of their participation adding value to the research process and yielding a benefit for the research participants. Second, the preferences of the children and young people and their parents to be involved in research are a critical consideration in an assessment of risk and the likelihood of research posing a greater harm than benefit. Third, the time and resources available to support children and young people will indicate the likelihood of their meaningful involvement.

**Message three: It is time to move beyond normative assumptions underpinning children and young people's involvement in research.** Empirical evidence informed by the views of children and young people is required to provide researchers and ethical oversight bodies with a better understanding of how children and young people can benefit from being involved in research and what are their perceptions of the realities of the risks involved. This can support researchers and ethical oversight bodies to make an informed assessment of the likelihood of harm or benefit prevailing. To support researchers in this regard, realised benefits and harms experienced at the time of participation should be routinely reported in the literature. This information can be obtained by a simple or standardised questionnaires with children and young people immediately post their involvement in research. The evidence based approach pioneered by Newman and colleagues is instrumental in this regard.



**Message four: Embracing the interdependence of participation and protection can support researchers and ethical oversight bodies to navigate the balance between participation and protection.** On the one hand, children and young people's views must be central to an assessment of risk and an understanding of how to protect young participants from harm. On the other, to meaningfully participate in research appropriate safeguards must be put in place to protect children and young people from harm.

**Message five: Ethical research requires an openness to a flexible and tailored approach.** Children and young people like all population groups are not homogenous. They possess a range of competencies and come to research with unique circumstances. While guided in their decision-making by ethical frameworks, researchers must be responsive and accommodating of the individual circumstances of children and young people including their age and capacities, the societal and cultural considerations, the nature of the research and the level of risk posed. Researchers should also look to the wider global context to understand what is considered ethically accepted practice.

## 7.6 Concluding Remarks

This article-based PhD has contributed to the growing body of knowledge on ethical and rights-based practice when involving children and young people in social research. It adds to the body of knowledge by publishing reflections and learning from the author's experience of navigating ethical dilemmas. The knowledge generated evidences the influence of the participation and protection discourses on children and young people's involvement in research. It clarifies a researcher's ethical duties and rights-based responsibilities and identifies both ethical and rights-based strategies to support social science researchers to navigate the balance between protecting children and young people from harm and respecting their competence and autonomy, as individual beings, to participate in research of relevance to their lives. The strategies identified are inclusive of supporting even the most marginalised children and young people to be involved in research.

The knowledge generated is published in three papers comprising the core of this thesis. The first publication '*Accessing a hard to reach population: reflections on research with young carers in Ireland*' is published in the Journal of Child and Family Social Work. The second publication, '*Navigating the ethical requirement for parental consent when engaging youth in research*' is published as a book chapter in *Youth 'At the Margins' Critical Perspectives and Experiences of Engaging Youth in Research Worldwide*. The third publication is '*Justifying the involvement of children and young people in social research: assessing harm and benefit*', is

pending publication in the Irish Journal of Sociology. These publications were designed to meet each of the following study objectives:

1. To reflect on the participation and protection discourses and their influence on children and young people's involvement in research;
2. To examine a researcher's ethical duties and rights-based responsibilities when involving children and young people in research;
3. To explore solution focused strategies to support researchers to navigate the balance between protection and participation; and
4. To distil key messages for ethical oversight bodies and the research and academic community.

Achieving the appropriate balance between children and young people's participation and protection may seem utopian in nature. However, by bringing together the author's reflections on her personal experiences of involving children and young people in research, along with the critical review of ethical frameworks and contemporary literature in the field, practical solutions have been explored to balance participation and protection. The thesis concludes by suggesting that when conducting research to better understand the lives of children and young people, researchers have a responsibility to conduct a rigorous assessment of harm and benefit to justify their inclusion or exclusion. Researchers must also be prepared to embrace the interdependence of participation and protection and be open to flexible and innovative approaches to research ethics that are cognisant of the evolving capacities of children and young people and their individual circumstances. With the conclusion of this exploratory study, it would now be timely and appropriate to ascertain the views of other professional researchers and the views of children and young people on the outcome of the author's reflection process and to examine the implementation of these proposed strategies in conjunction with both children and young people and the research and academic community.

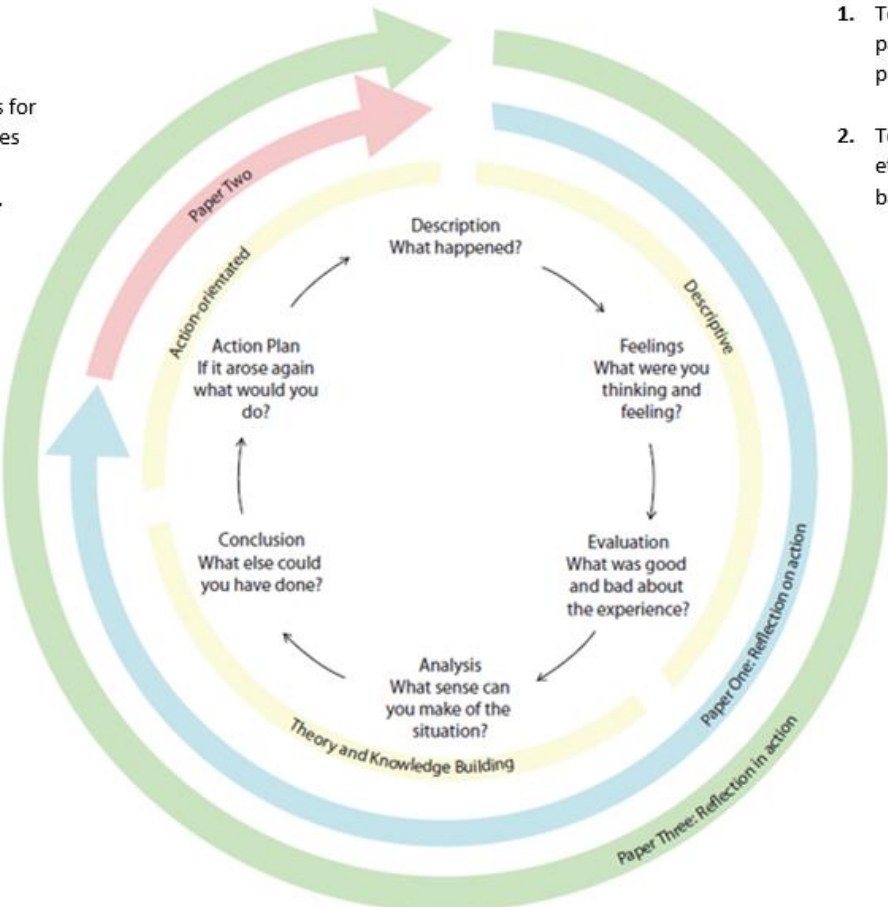
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Appendix One: Using Gibb's (1988) reflective framework to generate learning on navigating the dichotomy between protection and participation

- Research objectives:**
- 3. To explore solution focused strategies.
  - 4. To distil key messages for ethical oversight bodies and the research and academic community.



- Research objectives:**
- 1. To reflect on the participation and protection discourses.
  - 2. To examine a researcher's ethical duties and rights-based responsibilities.

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