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The Impact of Preterm Birth on Adaptive Behaviour and Participation in Childhood Occupation

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TABLE OF CONTENTS

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DECLARATION

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ABSTRACT

Background: Premature infants are at increased risk of developing motor, cognitive and behavioural impairments compared with infants born at term. Outcome studies have tended to focus their assessments predominately on 'components' of skills without relating these deficits to the impact they have on a child's everyday life i.e. 'childhood occupations'.

Objective: To compare the adaptive functioning and participation in everyday life of preterm VLBW infants and their full term, average birth weight peers.

Methods: 44 former premature infants between 6 months – 5 years 6 months, who did not have a physical or intellectual disability, were compared with 51 term born infants, matched for age and sex. Study infants had an average gestation of 29 weeks and birth weight of 1145 grams. Adaptive functioning and participation in everyday life were assessed using established standardised questionnaires: the Adaptive Behavior Assessment Scale-II (ABAS-II) and the Assessment of Preschool Children's Participation (APCP).

Results: Premature infants had significantly lower mean scores in overall adaptive behaviour compared to term control infants, regardless of whether chronological age ($p<0.001$; difference=13.6, 95% CI=[8.2, 19.1]) or corrected age ($p=0.013$; difference=6.6, 95% CI=[1.4, 11.8]) was used. In addition, premature infants had significantly lower mean scores in conceptual, social and practical adaptive skills compared to full term peers when their chronological age was used and in practical and social adaptive skills but not conceptual skills when their age was corrected for prematurity. There was no difference between groups' intensity (Play $p=.773$; Skill Development $p=.661$; Active Physical Recreation $p=.334$; Social $p=.528$) or diversity of participation ($p=0.860$).

Conclusion: Premature infants had significantly lower scores in overall adaptive functioning than their full term peers. These weaknesses appeared to be present despite participation in the same childhood activities. These findings suggest a measurable effect of preterm birth alone on childhood occupations that merits further investigation.

LIST OF ACRONYMS

ABAS-II	Adaptive Behaviour Assessment System, Second Edition
APCP	Assessment of Preschool Children's Participation
APR	Active Physical Recreation
CAPE	Children's Assessment of Participation and Enjoyment
ELBW	Extremely low birth weight
GUH	Galway University Hospitals
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health : Children and Youth
NICU	Neonatal Intensive Care Unit
PREM	Preterm infants, chronological age
PREM-COR	Preterm infants, corrected age
UHG	University Hospital Galway
VLBW	Very low birth weight
VON	Vermont Oxford Network
WHO	World Health Organisation

CHAPTER 1 – INTRODUCTION

1.1 Research Statement

The aim of this study was to compare the ability of children born preterm and children born full term to participate in and carry out adaptive behaviours such as playing, dressing, feeding, and toileting i.e. the ‘occupations’ of a child.

1.2 Brief background and statement of the need for the study

Preterm birth and very low birth weight continue to be major public health concerns (Hobel, Goldstein & Barrett, 2008). With one in eight babies in the US now being born premature (Sullivan et al, 2012) this trend of preterm birth appears to be on the rise (Lumley, 2003; Beck et al, 2010; Tucker & McGuire, 2004; Goldenberg et al, 2008). In the past 20 years medical research in the area of preterm birth has focused successfully on improving the survival and reducing the early morbidity of extremely preterm babies (Horbar et al, 2012). Once the initial anxiety regarding infant survival has past, parents become concerned about how their child will progress developmentally, and what resources will be required to meet their child’s potential, especially in relation to schooling (Johnson et al, 2009). In broad terms a child’s health is defined as ‘the ability to participate fully in developmentally appropriate physical, psychological, and social tasks’ (Hack, 1999, p.321) through which the occupations of the child develop (Case-Smith, 2010a). Although there is no univesally accepted definition, ‘childhood occupations’ are broadly activities that enable the child ‘to learn and develop life skills (e.g. school activities), be creative and/or derive enjoyment (e.g. play), and thrive (e.g. self-care and care for others) as both a means and an end’ (AOTA, 2010). Although engagement in these childhood activities are essential for children’s development and life experience (Bart et al, 2011) they have received little attention in the literature on premature babies.

The ‘International Classification of Functioning, Disability and Health: Children and Youth Version’ (ICF-CY) (WHO, 2007) is a conceptual framework that classifies health and health-related domains in to body, individual and societal perspectives using two lists 1.) body function and structures and 2.) activity and participation. Contemporary frameworks such as this have led to a paradigm shift in rehabilitation services with a greater emphasis on children’s activity and participation. The overarching goal of children’s health services is therefore no longer to ‘fix a deficit’ in the child but to maximise the child’s functional independence and community participation (Morris, 2009; Msall, 2005; Law & Darrah, 2014), once the child is medically stable. This emphasis on the ICF-CY domain level of activity and particpation has not however been reflected in the literature on premature infants. The majority of studies that have looked at outcomes of preterm birth on early childhood have focused their assessments predominately on performance skills such as the child's cognitive, visual-motor or neuromotor development, without relating these deficits back to the impact they have on a child’s ability to function and participate in the activities of daily life.

Studies on neurodevelopmental outcomes following preterm birth have also focused predominately on specific areas of development and demonstrated confliciting results. For example, improvements in survival rates demonstrated in the UK Epicure studies between 1995 and 2006 (http://www.epicure.ac.uk/) were not accompanied by signifincant improvements in neurodevelopmental outcomes in early childhood (Moore et al, 2011). This contrasts however with the results of a prospective population based study over a 20 year period that demonstrated greater percentenges of children born ≤ 30 weeks gestation were presenting without severe neurodevelopmental impairments at 24 months of age (Bode et al, 2009). Despite the ambiguity associated with the trajectory in percentages of preterm infants surving with neurodevelopmental disabilities, the evidence consistently shows that greater numbers of children born preterm demonstrate lower abilities in social, motor and academic skills (Oliveira et al, 2011; Moreira, Magalhães & Alves, 2014) relative to full term peers. These statisitcs are also compounded for males born preterm, with male gender being an important risk factor for poorer neontal outcome, poorer neurological outcome and poorer respiratory outcome (Peakcok et al, 2012) in comparison to their female peers.

There is therefore a consensus that infants born preterm are at greater risk of developing impairments in performance skills such as cognitive and motor development compared with full term peers (Spittle et al, 2009). The extent to which these difficulties however impact on the child's participation and adaptive functioning in everyday life remains unclear. Academic progress has been the childhood activity that has received the most attention in the literature (Van Kessel-Feddema et al., 2007; Rickards et al., 2001, Taylor et al., 2006), and although the initial focus was on performance skills such as intellectual quotients, more recent studies have assesed the childhood occupations of reading and mathematics. Research is beginning to connect the culmative effect of failure of preterm infants to acquire basic skills prior to school entry and the resulting declining motivation that results from this, to the child's poorer school outcomes (Van Kessel-Feddema et al, 2006). Studies like this are clearly a step in the right direction, however the emphasis of these types of studies tend to focus on the impact of preterm birth on educational attainment only, ignoring many of the core occupations of the child's daily life.

A limited number of follow-up studies have expanded the testing of preterm children to include the child's adaptive behaviour. As children with physical and intellectual disability are known to have challenges with adaptive behaviour (Vos et al., 2013) this research focuses on pretern infants without disabilities to establish the impact of 'preterm birth alone' on adaptive functioning. Varying parameters in studies of adaptive functioning such as different ranges of birth weights, gestational ages and follow-periods, and inconsistent classifications of nenonatal morbidities present challenges when attempting to compare and interpret the data (Sullivan et al, 2012). Studies have varied in their focus from very young children (Fernandes et al., 2012; Huang et al., 2012), school age children (Peterson et al., 2006) or adolescents (Sullivan et al., 2012) with little if any attention given to preschool children. In the majority of the studies adaptive behaviour has been assessed as part of a battery of developmental assessments and given little attention in the discussion. For example, in a study by Taylor et al. (2006) a subgroup of extremely low birth weight infants (ELBW) (N=48, 24% of total sample) at a mean age of 8 years, identified as ‘low-risk children’ (free of neurosensory impairments), were found to have significantly lower scores in neuropsychological tests, academic achievement and adaptive functioning in comparison to their full term peers. As with many of these studies, an overall adaptive behaviour score and three domain scores were provided with limited information in relation to the children’s strengths and challenges within the adaptive domains, their profile of skill areas and the possible impact these challenges have on the child’s daily life.

Small sample sizes in these studies have been reduced further by study designs that use numerous categorisations of preterm infants by birthweight and gestational age within the one study. Two recent studies explored the adaptive behaviour of toddlers/preschoolers born preterm and VLBW without neurosensory impairments. Results from both studies demonstrated challenges in adaptive functioning for preterm VLBW infants without physical or intellectual disabilities. In Huang et al.’s (2012) study however only 20 of the 105 Taiwanese infants, 18-36 months of age, were identified as ‘healthy’ preterm VLBW infants. This small sample size reduces the power of these result. Fernandes et al.’s (2012) study of Brazilian children (18-24 months of age) had a larger sample size (N=58) but no control group therefore test results on these South American children were obtained from North American data. Test results must be interpreted with caution as no cultural equivalence testing was performed (Oakland et al., 2013)

Participation in daily activities is a significant indicator of health and well-being, and a major focus of occupational therapy intervention (American Occupational Therapy Association, 2014; Coster et al., 2011). It contributes postively to childhood development, and is one of the greatest goals of rehabilitative and health services for children and young people (Coster et al., 2011). The majority of studies on the participation of children with physical disabilities have focused on cerebral palsy (Law et al., 2006; Anaby et al., 2013). Very few studies have explored the participation patterns of children born preterm and those that have were focused on adolescents (Dahan-Oliel et al., 2014a; Dahan-Oliel et al., 2014b).

Finally, preterm infants that do not present with diagnosed co-morbidities have received little attention in the medical literature, resulting in limited knowledge in relation to their adaptive functioning and participaion in daily life . No studies of this kind have been found on Irish children. The Early Intervention Services in Ireland are in a radical transition stage with no national policy for services and therefore wide variations exist between geographical areas (Carroll, Murphy & Sixsmith, 2013). The focus of services is predominantly on children with complex disability and therefore preterm infants without diagnosed co-morbidities are discharged from services at an early age. In line with the World Health Organisations's recommendations (2001), this project focuses on the impact 'preterm birth alone' may have on a preschool child's adaptive functioning and participation in daily life. It aims to increase the understanding of these issues in relation to the most vulnerable group of preterm infants, those born Very Low Birth Weight (Silverstein et al., 2010), without diagnosed physical or intellectual disabilities.

1.3 Research Questions

1. Is there a significant difference between the adaptive functioning of Irish children, aged between 6 months to 5 years 6 months of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight?

2. Is there a significant difference between Irish children 2 to 5 years of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight in their participation in childhood occupations?

3a. Is there a difference on standardised testing between the adaptive functioning of an Irish control group of full term, average birth weight infants, aged 6 months to 5 years 6 months of age, and normative data available on a North American sample?

3b. Is there a difference on standardised testing between the adaptive functioning of Irish children, aged 6 months to 5 years 6 months of age, born preterm and very low birth weight, and normative data available on a North American sample?

1.4 Definition of Terms

Adaptive Behaviour	‘The collection of conceptual, social and practical skills that have been learned by people in order to function in their everyday lives’ (AAMR, 2002, p.41)
Childhood occupations	There is no universal definition of childhood occupation. For the purpose of this study the following definition will be used. ‘For children and youth, occupations are activities that enable them to learn and develop life skills (e.g. school activities), be creative and/or derive enjoyment (e.g. play), and thrive (e.g. self-care and care for others) as both a means and an end (AOTA, 2010)
Chronological Age	(or “postnatal” age) ‘is the time elapsed after birth’ and can be presented in days, weeks, months or year (Committee on Fetus and Newborn, 2004, p. 1363).
Corrected Age	(or “adjusted age”) described in weeks or months is the chronological age reduced by the number of weeks born before 40 weeks of gestation; the term should be used only for children up to 3 years of age who were born preterm.

	(‘Corrected age is calculated by subtracting the number of weeks born before 40 weeks of gestation from the chronological age’). It is recommended that the term ‘corrected age’ should be used instead of ‘adjusted age’ (Committee on Fetus and Newborn, 2004, p. 1363).
Extremely Low Birth Weight	Infants born weighing 1000 grams or less, or between 22 and 28 weeks gestational age (Vermont Oxford Network, no date)
Low birth weight	Birth weight of 1500 to 2500 grams (Hunter, 2010, p.653)
Normal Birth Weight	‘Infants born above 2500 grams (5.5 pounds) are considered average in size’ (Hunter, 2010, p.653).
Preterm birth	Babies born at less than 37 completed weeks of gestation (Guyer, Minkovitz & Strobino, 2009, p.238)
‘Preterm birth alone’ or ‘healthy preterm’	For the purpose of this study we define ‘preterm birth alone’ as preterm birth free of physical or intellectual disability (Killeen et al., 2014)

Very low birth weight	‘Any infant who is born alive at your hospital and whose birth weight is between 401 and 1500 grams OR whose gestational age is between 22 weeks 0 days and 29 weeks 6 days (inclusive)….’ (Vermont Oxford Network, 2011)
‘VLBW group’	For the purpose of this study, infants in this study born both preterm (less than 37 weeks gestation) and ‘Very Low birth Weight’ as defined by the Vermont Oxford Network (2011a).
Participation	‘The involvement in a life situation’ (World Health Organisation, 2001, p.14)

1.5 Brief Methodology

The initial research design for this study was descriptive, observational. Following review of the pilot study however, a case-control design was deemed more appropriate. The cases were children born preterm and Very Low Birth Weight (VLBW). The Vermont Oxford definition of ‘very low birth weight’ (VLBW) (Vermont Oxford Network, 2011) was used to define the group of premature babies selected. All premature infants born with a birth weight of less than 1500 grams and or less than 30 weeks gestation at University Hospital Galway (UHG), between November 2006 – December 2011, were identified through the UHG neonatal unit database (N=183) using convenience sampling. Inclusion and exclusion criteria were specified, and included the infants being free of physical or intellectual disabilities. 44 parents of preterm VLBW infants who met the study criteria consented to take part in the study. The control group, matched for age and sex, was recruited by convenience sampling in the postnatal unit in UHG. Mothers with a child, born at term, and now between 6 months – 5 years 6 months of age were invited to participate. Parents of three children within the 6 - 9 month age range were recruited from a local crèche to include this age range that had not been accessible through the UHG mothers. The control group consisted of children born full term and of average birth weight.

The primary outcome measure chosen for this study, the Adaptive Behavior Assessment System, Second edition (ABAS-II) (Harrison and Oakland, 2003), was developed on a North American population. Cross-cultural differences were therefore anticipated (Oakland et al., 2013), necessitating the use of an Irish comparison group to strengthen the study design. A secondary outcome measure, the Assessment of Preschool Children's Participation (APCP) (King et al., 2006a) was used to measure the children's participation in childhood activities. Medical information was obtained from hospital databases. A Child and Family Demographic questionnaire was used to control for confounding factors. Potential confounders included parent education and age; occupational classification and health; child's gender, age, and schooling.

Once-off interviews took place between May and September 2012 (Cases) and May and December 2012 (Controls). Standardised face to face questionnaires of 95 parents/families were completed.

A sample size calculation estimated a minimum of 36 participants per group to detect a difference in the ABAS-II of 10 points (assuming a standard deviation of 15) with 80% power. Descriptive and analytic statistics were performed. The level of statistical significance was defined as $p < 0.05$. Effect sizes were calculated along with their 95% confidence intervals. Data was grouped in to three – Controls, VLBW (Chronological age), and VLBW-COR (Corrected age). Adaptive behaviour was divided in to General Adaptive Scores (GAC), conceptual, social and practical domain scores, and the 10 skill area scores. Participation was divided in to Intensity (Skill development, Social, Active Physical Recreation and Play) and Diversity of Participation. Finally, the Irish control group and VLBW group were compared to the data on the North American reference population in which the scale was developed.

1.6 Results

44 preterm VLBW infants were matched by age and sex to 51 full term control infants. A brief summary of the results are summarised below under each research question posed:

1. *Is there a significant difference between the adaptive functioning of Irish children, aged between 6 months to 5 years 6 months of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight?*

   Yes. Regardless of whether chronological age or corrected age for prematurity was used, the VLBW group demonstrated statistically significant lower mean scores in adaptive functioning in comparison to their full term peers. There was a statistically significant difference between the ABAS-II General Adaptive Composite (GAC) Scores ($p<0.001$) of the cases (uncorrected age) and controls (ABAS GAC difference=13.6, 95% CI=[8.2, 19.1]), in favour of the controls. This difference still remained significant ($p<0.05$, ABAS-II GAC difference=6.6, 95% CI=[1.4, 11.8]) when the preterm infants were adjusted for prematurity.

   The 3 domain scores (Conceptual, Practical and Social) of the cases and controls were also compared using independent samples t-tests. There was a significant difference between the cases and controls for conceptual (p<0.001, difference=10.7, 95% CI= [5.1, 16.4]), practical (p<0.0001, difference =12.3, 95% CI= [7.3, 17.3]) and social domains (p<0.001, difference=13.3, 95% CI= [8.0, 18.6). This difference remained statistically significant for practical (difference=6.7, 95% CI= [1.7, 11.7]) and social (difference=8.5, 95% CI= [3.4, 13.6]) domains, when the preterm infants were corrected for prematurity, but not for the conceptual domain (difference =4.1, 95% CI= [-1.5, 9.6]

2. *Is there a significant difference between Irish children 2 to 5 years of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight in their participation in childhood occupations?*

There was no significant difference between the VLBW group and the control group in their intensity of participation in Skill development (p=.661), Social activities (p=.528), Active Physical Recreation (p=.334) and Play (p=.773). There was also no significant difference found between the diversity of participation of both groups (p=.860).

3a. *Is there a difference on standardised testing between the adaptive functioning of an Irish control group of full term, average birth weight infants, aged 6 months to 5 years 6 months of age, and normative data available on a North American sample?*

There was no significant difference found between the ABAS-II GAC scores of the Irish control group and the North American data (p=.962). There were however differences found between the practical and social domain groups, with the Irish control group demonstrating significantly lower mean scores in the practical domain (p=.049)and significantly higher mean scores in the social domain (p=.001) in comparison to the North American normative data. No significant difference was found between the conceptual domain scores.

3b. *Is there a difference on standardised testing between the adaptive functioning of Irish children, aged 6 months to 5 years 6 months of age, born preterm and very low birth weight, and normative data available on a North American sample?*

There was a significant difference between the the ABAS-II General Adaptive Composite score (p<.0001), and Conceptual (p<.0001), Practical (p<.0001) and Social (p<.0001) Composite domain scores of the Irish VLBW infants and the North American normative data, in favour of the North American data.

1.7 Discussion

Regardless of whether or not the VLBW infants' ages were adjusted for prematurity, they demonstrated lower mean scores in overall adaptive behaviour compared to their full term Irish peers. Differences between groups were also observed in the three Domain scores. The Social Composite scores and Practical Composite scores were lower than controls for both chronological and corrected age, while differences in Conceptual Composite mean scores were only significantly lower for chronological age. There was no difference between the two groups in the intensity or diversity of participation. Therefore despite the fact that the VLBW group were exposed to the same variety of childhood activities they still demonstrated weaknesses in adaptive functioning.

This was a questionnaire based study and the data are based on parent report. Although the relatively small number of infants in this study may limit the interpretation of the results, a measurable effect of ‘preterm birth alone’ on adaptive functioning in everyday life was clearly observed, consistent with findings from other recent publications.

1.8 Ethical Considerations

The following ethical issues were identified and the solutions to same are documented below:

- Parents may become concerned when they receive the information pack that there is a risk that their child has/will have developmental difficulties because of their prematurity.
  Solution – The Information in the pack must state clearly that many children born preterm demonstrate no difficulties in developmental skills. This research is only investigating the possibility that some children who were born premature may have some extra needs with everyday activities.

- Parents may think that if they don’t participate in the research that they will not receive a fair healthcare service for their child.
  Solution – It will be made clear that the Principal Investigator is a researcher in the National University of Ireland, Galway i.e. not a HSE employee therefore it will have no impact on their service provision. Also, the information in the pack must state clearly that they have the right to decline participating in this research project and this will in no way influence healthcare services for their child. The information sheet must also state that the parents can, at any time, withdraw from the research without disclosing their reason.

  Also, written informed consent will be obtained from each Parent that wishes to participate in the study. This will be done by either:
    - the parent/caregiver posting back a signed consent form or

- the parent contacting the principal investigator by phone to arrange an interview date. Written consent will then be obtained on the day of the interview prior to interview commencing.

The Interview will not be recorded by audio or video recording.

- Parents who have a child that has significant or multiple disabilities may find some of the questions insensitive as their child will not be performing these task.
  Solution – These children will be omitted from the study, as it is ‘prematurity’ in isolation that we wish to investigate.

- Data obtained from participants are at risk of being disclosed to the public
  Solution – All data obtained will be kept in locked filing cabinets and password protected computers as previously outlined.

In September 2011, ethics was applied for through the Galway University Hospitals *‘Standard Application Form for the Ethical Review of Health-Related Research Studies which are not Clinical Trials of Medicinal Products For Human Use as defined in S.I. 190/2004’.* Approval was granted for the study to proceed on 7th October 2011 by Dr. Shaun O’Keefe, Chairman Clinical Research Ethics Committee, Galway University Hospitals (See Appendix C)

CHAPTER 2 – LITERATURE REVIEW

An infant's premature 'birth marks the beginning of a long trajectory that broadly impacts families, health care, education, and social systems' (Sullivan et al, 2012, p.275). These infants are at increased risk of developing difficulties with many developmental skills including motor, cognitive and behavioural impairments compared with infants born at term (Spittle et al, 2009). Occupational therapists describe these impairments as difficulties with 'performance skills' (American Occupational Therapy Association, 2014, p.612) i.e. deficits in small units of performance that are required for adaptive functioning and participation in life, but are not daily life activities in and of themselves. Although occupational therapists believe that deficits in performance skills can affect or restrict performance and participation in everyday life (World Federation of Occupational Therapists, 2010; American Occupational Therapy Association, 2014), there is little research to confirm this (Law and Darrah, 2014), and the extent to which it is true for premature infants is also unclear. It is now recognised that health is affected by a person's ability to carry out daily activities and participate in daily life, and not only by deficits in underlying body functions and structures (WHO, 2001). Consistent with this, in the past decade, the profession of occupational therapy has shifted its emphasis from focusing on performance skills or 'fixing a deficit' to focusing on a child's ability to function independently and participate in everyday life (Law and Darrah, 2014).

In 2001, the World Health Organisation published the 'International Classification of Functioning, Disability and Health' (ICF). This dynamic and complex classification system of health states (Cramm, Aiken & Stewart, 2012) led to the subsequent publication of a child-specific framework the 'International Classification of Functioning, Disability and Health: Children and Youth' (ICF-CY) (WHO, 2007). The ICF-CY (WHO, 2007) shares the same two-part framework and definitions as the ICF (WHO, 2001); however sub-classifications and descriptors have been adjusted and modified to capture aspects of development (such as delay) that are required to identify children at risk of disability (WHO, 2007).

The ICF-CY marks ‘a global paradigm shift in the conceptualization and classification of childhood disability’ (Cramm, Aiken & Stewart, 2012, p.388), advocating for healthcare professionals to address a child’s functioning and disability at the level of both ‘body functions and structures’ and ‘activities and participation’ and within the context of the child’s environment and personal factors (WHO, 2001). This framework is therefore compatible with other reputable conceptual models that emphasise the child within the context of multiple environments for example, the ecological systems theory (Bronfenbrenner, 1977) that conceptualises the mutual accommodation of the developing person and his/her changing environments and larger social contexts is consistent with this framework. There is also a strong congruence between the ICF-CY and occupational therapy models and practice that recognize the interaction of person, context, and task’ (Cramm, Aiken & Stewart, 2012, p.389). As the ICF-CY classification system also incorporates multiple determinants of health and function, Msall and Park, 2008, have recommended this model as a conceptual framework to understand the outcomes of preterm birth. For these reasons and the positive trends the ICF-CY has demonstrated in facilitating cross-disciplinary communication (Cramm, Aiken & Stewart, 2012, p.389), this study will use this international framework as the foundation to explore the impact that preterm birth has on a child’s adaptive functioning and participation in everyday life.

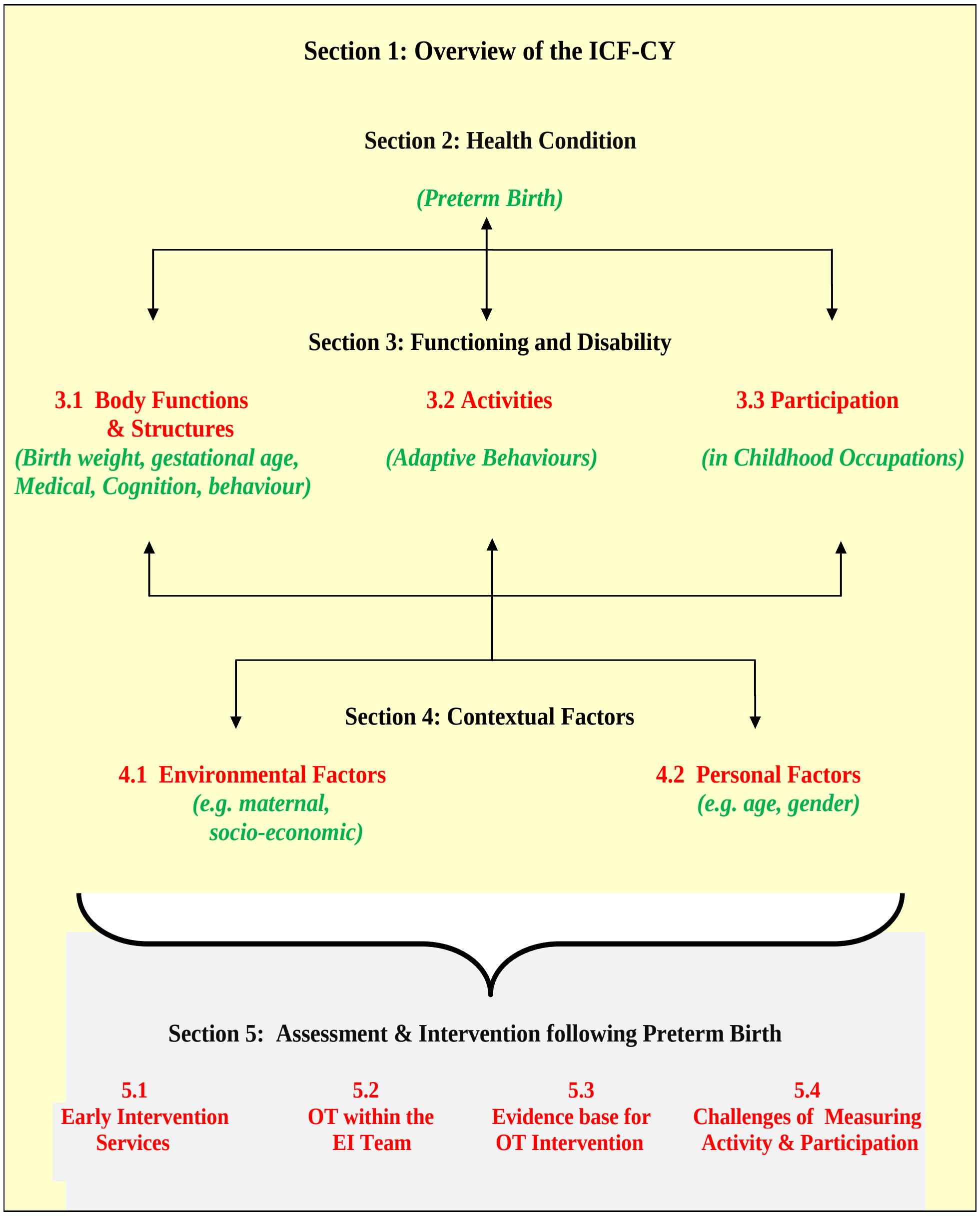
In the past twenty years, a sparse number of studies have focused their attention on the adaptive functioning and participation of this vulnerable population of children (Huang et al, 2012; Fernandes et al, 2012). Of these limited studies, the majority have explored the impact preterm birth has on academic achievement (Aarnoudse-Moens et al, 2009, Taylor et al, 2006). Most of these studies have also included premature infants presenting with major neurological difficulties and this has confounded results (Johnson et al, 2003; Taylor et al, 2006) as children with neurological difficulties are known to present with limitations in adaptive functioning and participation in life (Law et al., 2013; Oakland et al., 2013; Vos et al., 2013). In early intervention services, children with increasing severity of disability are more likely to receive intervention (Roberts et al, 2007). This coupled with the fact that there are limited assessments that measure the everyday tasks of children without physical or intellectual disabilities available, places these children with biological risk factors at a potential greater disadvantage. They may not be identified in routine examinations and therefore not be supported to maximise their potential.

Other than this limited number of studies, the impact that premature birth has on infants' adaptive functioning and participation in activities such as play, handwriting, leisure, dressing and household chores is unknown. Therefore, in keeping with the primary goal of occupational therapy i.e. enabling people to participate in the activities of everyday life (World Federation of Occupational Therapists, 2010), it is imperative that information is obtained about the strengths and challenges that premature infants experience in daily life activities. This information could then contribute to the development of early and focused interventions that maximise the adaptive functioning and participation of these infants in daily life.

A comprehensive search strategy was used to focus the review of the literature. The following relevant electronic databases were searched: **EBSCO** – as a platform for MEDLINE; Academic Search Complete; CINAHL Plus with Full Text; Health Source: Nursing/Academic Edition; SocINDEX with Full Text; **EMBASE;** The **Cochrane Library Trials** - Cochrane Central Register of Controlled Trials (CENTRAL, The Cochrane Library - Cochrane Neonatal Review group; **Pubmed/Medline; PsychINFO; SCOPUS; OT Seeker** (randomised control trials)**; Sciencedirect; National Research Register**

(NNR) – NHS; **Grey Literature** – SIGLE (database for unpublished grey literature), RIAN, ETHos (UK), Proquest Digital Dissertation (Europe & US), Zetoc; Copac. Key word search terms, which were developed in consultation with MeSH term options were used. There was some variation of key words depending on the database searched and Boolean logic (AND, OR) was used to enhance searches as applicable. Additional articles were obtained using the reference lists of all primary articles and hand searches. All articles were subject to inclusion and exclusion criteria and the Critical Appraisal Skills Programme (CASP) (no date) was utilised to appraise individual articles critically. A detailed description of the development of the research question, key concepts and search strategy can be found in Appendix A and B. The ICF-CY framework (WHO, 2007) has been used in this chapter to present the literature reviewed, as presented in Figure 1.

Figure 1 Overview of Chapter Layout - Adapted from Interactions between the components of the ICF (WHO, 2001, p. 18)



Section 1 Overview of the ICF-CY

The World Health Organization's 2001 publication the 'International Classification of Functioning, Disability and Health' (ICF) has been endorsed by all 191 member states as the International standard to describe and measure health and disability. This timely publication demonstrated the international push towards focusing on activity and participation rather than impairments and handicaps (www.who.int/classifications/icf/en/). It describes functioning as a continuum that is applicable to the lives of all individuals to different degrees depending on their life circumstances at any given time; therefore disability is not categorised as something that is only relevant to minority groups (Cerniauskaite et al, 2011). Although this framework was originally intended to be cross-generational, it was acknowledged that nature and intensity of children's and adolescents' functioning, disability and health differs from that of adults and therefore a child-specific framework 'sensitive to changes associated with growth and development' was required (WHO, 2007, p. xiii; Lollar & Simeonsson, 2005).

The World Health Organisation responded to this need by publishing a children's version of the model, the 'International Classification of Functioning, Disability and Health: Children & Youth Version (ICF-CY) (WHO, 2007). The ICF-CY (WHO, 2007) is the first systematic framework and classification system of children's functioning and disability (Cramm, Aiken & Stewart, 2012). Both the ICF-CY and the ICF classify health and health-related domains in to body, individual and societal perspectives by the use of a two-part organizing framework 1.) 'Functioning and disability' which includes the components of 'body function and structures', and 'activity and participation'; and 2) Contextual factors that include the components of 'environmental factors' that are external to the individual and 'personal factors' that are internal to the individual (WHO, 2001). The ICF-CY has also modified the 2nd , 3rd and 4th level classifications to capture the developmental processes, activities and roles unique to children and youth, including providing additional codes for motor coordination, and regulation and organisation of behaviours (Cramm, Aiken & Stewart, 2012; WHO, 2007).

The emphasis on the environment as inherent in the process of human development was conceptualised by a psychologist, Urie Bronfenbrenner (1977) using terminology adapted from Brim (1975) and theories developed by Kurt and Lewin (1935, 1936, 1948, 1951) (as cited in Bronfenbrenner, 1977). This 'ecology of human development' provided the foundation for the theory of mutual accommodation between human beings and their interaction throughout their life span with their changing environments and larger social context. It has also provided the framework for a number of conceptual models developed in healthcare including occupational therapy (Case-Smith et al., 2010c). This attention to the child's environment was acknowledged by Greenspan (1999) who noted a growing appreciation of the importance 'context' plays in the performance of adaptive behaviour, recognising that it can determine the limits of the behaviour. As an example, Greenspan (1999) explained that one may demonstrate relative competency in routine skills but significant incompetence in novel tasks. The ICF-CY (WHO, 2007) has embraced this interaction between the child and their environment with its emphasis on contextual factors.

Research on the ICF-CY also demonstrates a strong congruence with occupational therapy models and practice. Occupational therapy models and practice recognise the interaction between the person, context, and task, and therefore are consistent with the ICF-CY framework (Cramm, Aiken & Stewart, 2012). Therapists can use these models 'with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, (Law et al., 2014) or by modifying the occupation or the environment to better support their occupational engagement' (World Federation of Occupational Therapists, 2010). Consistent with this, the contextual factors of the ICF-CY framework are also used to capture the context of the individual's functioning or disability (WHO, 2007). Thus the philosophy of occupational therapy which encourages healthcare practitioners to address the activity and participation of clients within the context of their environment (World Federation of Occupational Therapists, 2010) sits comfortably within the framework of the ICF-CY (WHO, 2007). Despite this however, 'knowledge of the ICF-CY has been slow to diffuse into clinical occupational therapy practice' (Cramm, Aiken & Stewart, 2012, p.389).

The 'Occupational Therapy Practice Framework: Domain and Process' (OTPF) (AOTA, 2014) is an updated version of a series of documents that have been developed over the 'past several decades to outline the language and constructs that describe the occupational therapy profession's focus' (p.609). On closer examination of the terminology and classifications used by the ICF-CY (WHO, 2007) and the OTPF (AOTA, 2014) there are both similarities and differences between the groupings. As can be seen in table 1, the ICF-CY framework is divided in to two domains: Functioning and disability; and Contextual factors (WHO, 2007). In contrast to this, the OTPF is categorised in to six areas: Performance in areas of occupation, Performance skills, Performance patterns, Context, Activity demands, and Client factors (AOTA, 2014). For the purpose of illustration in table 1, sections of the OTPF (AOTA, 2014) are positioned to align with the ICF-CY framework (WHO, 2007) to demonstrate the similarities and differences between the two models.

As can be seen from the table 1 below, both frameworks define the area of 'body structures' and 'body functions' as discrete groups. For example, OTs use the term client factors to describe 'body functions such as neuromusculoskeletal, sensory-perceptual, visual, mental, cognitive, and pain factors and body structures (such as cardiovascular, digestive, nervous, integumentary, genitourinary systems, and structures related to movement)' (AOTA, 2011, p.4) which is consistent with the definition of 'Body functions' and ‘body structures’ components of Part 1 of the ICF-CY framework (WHO, 2007). The second component in part1 of the ICF-CY, ‘Activity and Participation’, (WHO, 2007) is not separated in to discrete constructs and has been criticised for this. The ICF-CY (WHO, 2007) ‘does not offer any criteria with which to define life situations (Participation) or to distinguish them from tasks (Activity) except for a few statements indicating that life situations represent the interface of the person with the larger society’ (Coster and Khetani, 2008, p.641). This lack of clear distinction between these concepts has led to difficulties discriminating between the areas of ‘Activity’ and ‘Participation’ (WHO, 2007; Cramm, Aiken & Stewart, 2012), leaving these concepts open to wide interpretation and potentially undermining the usefulness of the constructs (Coster and Khetani, 2008)

In contrast to ICF-CY (WHO, 2007), the OT framework clearly differentiates between its corresponding components of ‘Performance in areas of occupation’ and ‘performance skills’. It defines ‘performance in areas of occupation’ as the actual everyday life activities i.e. the ‘occupations’ that the person does, and defines the ‘Performance skills’ as the small units of performance such as bending, choosing and gazing, that are required to complete the task successfully (AOTA, 2014). These concepts will be elaborated on in Section 3.2 below. The AOTA framework will therefore be utilised when necessary to refer to performance skills and performance in areas of childhood occupation (See comparison of terminology in table 1 and table 2). The ICF-CY framework (WHO, 2007) has however been chosen over the OTPF (AOTA, 2014) as the overarching framework for this study as it provides a universal language and therefore a means to achieve shared communication about children’s functioning and disability between all professionals, as opposed to occupational therapists alone (Adolfsson et al, 2010). In view of the criticism that this framework has received for failing to distinguish between the areas of ‘activity and participation’, this study will present these areas separately under the headings of ‘adaptive behaviour’ and ‘participation’.

Table 1 Comparison of terminology in the ICF-CY Framework and the OTPF Framework

ICF-CY Domains	**ICF-CY Components**	**ICF-CY Framework Terminology**	**OTPF Terminology**	**OT Areas**
Part 1: Functioning & Disability	**1.1 Body Functions & Body Structures**	Body Functions	Body Functions	**Client Factors**
		Body Structures	Body Structures	
	1.2 Activity & Participation	Self-care Domestic Life	Activities of daily living Instrumental activities of daily living	**Performance in Areas of Occupation**
		Major life areas (Education, work & employment, economic life)	Education, Work	
		Community, social & civic life	Play, Leisure, Social Participation	
		Mobility	Motor skills	**Performance Skills**
		Learning & applying knowledge General tasks & demands	Process skills	
		Communication Interpersonal interactions & relationships	Communication/Interaction skills	
			Habits	**Performance Patterns**
			Routines	
			Roles	
Part 2: Contextual Factors	**2.1 Environmental Factors**	Products and Technology	Virtual Objects used & their properties* (*Activity demands*)	**Context**
		Natural environment and human made changes to environment	Temporal Physical Space & Social demands* (*Activity demands*)	
		Support & relationships	Social	
		Attitudes	Cultural Spiritual	
		Services, systems and policies	Cultural (includes laws)	
	2.2 Personal Factors		Personal	
			Habits* (*Performance patterns*)	
			Objects used & their properties	**Section 3: Activity Demands**
			Space and Social demands	
			Sequencing & Timing	
			Required Actions, body structures & Functions	

Although the primary aim of the framework is to classify health states (WHO, 2001; WHO, 2007) the ICF-CY also bridges the long opposing medical and social models of disability successfully and integrates them in to the ‘biopsychosocial’ approach (WHO, 2001). Both theoretical and practical reviews also indicate that use of this framework can help clinicians to focus on functional aspects of intervention, promote children’s participation, and encourage coordination of health services including facilitating interaction between stakeholders in intervention and communication within a team (Ibragimova, Granlund & Bjorck-Akesson, 2009). A Swedish, qualitative study of the perceptions and application of the ICF-CY (WHO, 2007) of 113 professionals from 14 interdisciplinary teams found that the framework provided a new perspective on childhood problems and sharpened the professionals’ focus on children’s participation (Adolfsson et al, 2010). Although the data collection was obtained over 3-time points, the sample was obtained by convenience sample from a specific region of Sweden, and only contained one physician.

As the ICF-CY is a framework and classification system, not an assessment tool in and of itself, it can integrate divergent assessment information’ (Cramm, Aiken & Stewart, 2012, p. 390). This is imperative as the functioning of the child, including the child born preterm, ‘cannot be seen in isolation but rather in terms of the child in the context of the family system’ (WHO, 2007, p.xv). The framework therefore facilitates the integration of medical history, child and family demographic information and results of standardised questionnaires of adaptive behaviour and participation to allow for a complex profile of a child born premature. It enables the evolution of childrens’ services from the traditional developmental and diagnostic categorisations which focused on the child's inadequacies to a more functional, context-focused and support driven model of care for young children (Cramm, Aiken & Stewart, 2012; Simeonsson, 2009; Ibragimova, Granlund & Bjorck-Akesson, 2009).

Occupational therapists ‘focus on assisting people to engage in daily life activities that they find meaningful and purposeful’ (AOTA, 2014, p.610). In the context of the ICF-CY framework, this research aims to explore whether there is a significant difference between the adaptive functioning and daily life participation of young Irish children born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight.

Section 2 Health Condition: Preterm birth

Preterm babies are defined as ‘babies born at less than 37 completed weeks of gestation’ (Guyer, Minkovitz & Strobino, 2009, p.238). Although this definition is agreed internationally (Beck et al, 2010), there are discrepancies in the way that gestational age is assessed (Lumley, 2003; Beck et al, 2010) leading to discrepancies in classifications. Internationally, babies are classified at birth using terminology that broadly categorise the infants birth weight and length of gestation. In relation to birth weight, ‘infants born above 2500 grams (5.5 pounds) are considered average in size’, in comparison to a birth weight of 1500 to 2500 grams which is termed ‘Low birth weight’ (LBW) (Hunter, 2010, p.653). ‘Very Low birth Weight’ (VLBW) babies are defined by the Vermont Oxford Network, 2011, as ‘any infant who is born alive at your hospital and whose birth weight is between 401 and 1500 grams OR whose gestational age is between 22 weeks 0 days and 29 weeks 6 days (inclusive)….’. According to Hack, Klein and Taylor, 1995, ‘Very Low Birth Weight’ (VLBW) infants constitute a heterogeneous cohort of infants ‘including children born preterm (at fewer than 37 weeks gestation) i.e. premature, as well as those born at term gestation but subnormal in weight because of various abnormal maternal or fetal conditions’ (p. 177). The Vermont Oxford definition (2011) of VLBW which includes both birth weight and gestational age is therefore more specific and operational than other descriptions of VLBW that define it solely on birth weight (<1500 g) alone (Tucker and McGuire, 2004). Extremely low birth weight (ELBW) infants are defined by the Vermont Oxford Network (no date) as infants born weighing 1000 grams or less, or between 22 and 28 weeks gestational age. This study will focus on children who were born Very Low birth weight (<1500 g) and at preterm gestation (<37 weeks).

Incidence

Preterm birth appears to be on the rise due to a number of factors including greater rates of assisted reproduction, increased numbers of multiple births and more obstetric intervention (Lumley, 2003; Beck et al., 2010; Tucker & McGuire, 2004; Goldenberg et al., 2008). It is the leading cause of mortality and morbidity in infants in developed countries (Goldenberg et al., 2008) and mostly affects infants that are born less than 32 weeks, especially those less than 28 weeks (Tucker & McGuire, 2004). A systematic review by Beck et al., (2010), of the worldwide incidence of preterm birth analysed studies available from 92 countries. 80% of studies from Europe and North America were population-based while all except one study in Africa were facility based. Although the estimate of preterm birth varies between studies, Beck et al. (2010) approximated that the global incidence of preterm birth in 2005 was 9.6%. The review also found significant discrepancies between the rate of preterm birth in various continents with the highest rates of preterm birth occurring in Africa (11.9%) and North America (10.6%), and the lowest level of preterm birth in Europe (6.2%). The review did not however categorise whether the preterm births were very early, early or later preterm, nor did it provide a breakdown of the demographics of the population groups within countries such as the impact of racial differences.

Irish statistics

The Health Service Executive (HSE) (2014) Perinatal Statistics Report 2013 details the statistics of all babies born in Ireland in 2013. The report confirms that Ireland’s birth rate is declining, with an estimated 69,267 babies born in 2013, and 71,986 babies born in 2012. Although the birth rate has reduced to 15.0 per 1000 population (HSE, 2014), Ireland has still the highest birth rate of the 27 European countries which averages at 10.4 per 1,000 population (Economic and Social Research Institute’s (ESRI), 2013). The consistent decline in perinatal mortality in Ireland, with a decline of 31% since 2003, is in keeping with the international change in the profile of preterm birth which shows an increase in survival rate and a decrease in early morbidity (Horbar et al., 2012) 5.4% of Irish babies born in 2012 were low birth weight. Of the VLBW babies born, only 0.6% of singleton live births were less than 1,500 grams compared to 8.3% of multiple births (ESRI, 2013).

Causes

Events linked to preterm birth are still not fully understood. Although the cause of preterm birth appears to be multifactorial, it is unknown if it is a result of several pathways interacting or the effect of a number of independent pathways (Beck et al., 2010). Preterm birth is due to spontaneous labour with intact membrane/idiopathic (45-50%), preterm premature rupture of membranes (PROM) (30%), and labour induction or caesarean delivery for maternal or fetal indications (range from 15-20% to 30-35% depending on the study) (Goldenberg et al., 2008; Beck et al., 2010)

‘Causal factors linked to preterm birth include medical conditions of the mother or fetus, genetic influences, environmental exposure, infertility treatments, behavioural and socioeconomic factors and iatrogenic prematurity’ (Beck et al., 2010, p.2). These factors are explored in the following section: Section 3 – Functioning and Disability; and Section 4 – Contextual Factors.

Major morbidities experience by VLBW infants during initial hospitalisation include ‘bloodstream and central nervous system infections, necrotizing enterocolitis (NEC), chronic lung disease (CLD), intraventricular haemorrhage (IVH), periventricular leukomalacia (PVL), and retinopathy of prematurity (ROP)’ (Horbar et al., 2012, p. 1020).

Co-morbidity

Children born premature are known to be at greater risk of presenting with a number of secondary diagnoses. For example, they are at increased risk of developing a number of motor impairments ranging from Developmental Coordination Disorder (DCD) to Cerebral Palsy (Bracewell & Marlow, 2002). In a population-based study (N=7256) of UK seven and eight year olds, Lingham et al. (2009) found an increased risk of DCD with lower gestation and birth weight (p. 698). This is consistent with results of a systematic review and meta-analysis by Edwards et al. (2011) of 16 cohort and case-control studies that also found DCD highly prevalent in very low birth weight and very preterm populations, and although the relationship is still unclear the authors suggested that the degree of prematurity may influence the prevalence with ELBW infants having the highest rates of DCD.

Significantly higher frequencies of low birth weight and very low birth weight have been observed in study cohorts of children with Autistic Spectrum Disorder (ASD) and attention deficit/hyperactivity disorder, confirming it as a risk factor (Itzchak, Lahat & Zachor, 2011; Mick et al., 2002). For example, a study of Autistic Spectrum Disorder looking at risk factors such as parental age and low birth weight of 529 children with Autistic Spectrum Disorder found significantly higher percentages of low birth weight (<2500 g) and very low birth weight (<1500 g) in this population when compared to their peers on an Israeli newborn national database, there was however no association with the severity of the autism (Itzchak, Lahat & Zachor, 2011)

Section 3 Functioning and Disability

3.1 Impact of Preterm Birth on Body Functions and Structures

According to the ICF-CY (WHO, 2007), ‘body structures are the physiological functions of body systems including psychological functions’, and ‘body structures are anatomical parts of the body such as organs, limbs and their components’ (p.9). These components therefore describe how a child functions at a biological level in relation to sensory, movement functioning and mental functions that are within the systems of the body (Ibragimova, Granlund & Bjorck-Akesson, 2009).

<u>Medical Risk factors for Poor Outcomes</u>

In the late 1990’s researchers suggested that neonatal risk factors have a far greater effect on neuropsychological outcomes relative to the effect of social risk factors. It was suggested that research into preventative therapies or interventions that focus on the neonatal complications of preterm birth, rather than early intervention post discharge, have the greatest potential to impact and improve the future outcomes of this vulnerable population (Hack et al, 2000; Taylor et al, 1998; McCarton et al, 1997). Consistent with this, in the past 20 years, research in the area of preterm birth has focused successfully on improving the survival and reducing the early morbidity of extremely preterm babies. This research however was criticised by the American Academy of Pediatrics reporting the ‘small sample sizes, heterogeneity of cohorts and methodology, diversity of perinatal clinical practice, and the high cost of randomized controlled trials and follow-up care have all contributed to the lack of rigorous data on the sequelae of preterm delivery and the therapies used to improve the long-term outcome of high-risk infants’ (2004, p.1377).

In more recent years a number of large epidemiological studies of preterm infants such as EPICure and EPICure 2 in the United Kingdom (Moore et al., 2012); the EPIPAGE in France (Larroque et al., 2004); the EPIBEL in Belgium (Vanhaesebrouck et al., 2004); the EFTOL in Denmark (Field et al., 2002), the VICS in Victoria, Australia (Doyle & Casalaz, 2001), and the EXPRESS in Sweden (Fellman et al., 2009) have been completed worldwide. These rigorous studies have demonstrated that medical interventions focusing on preventative measures have indeed improved the outcomes for both the mother and preterm baby. These population based research studies have tracked the continuum of care required for preterm infants including obstetrics, neonatal and developmental medicine highlighting medical interventions improving outcomes (antenatal steroids and surfactant) and others that require more evidence (induction and caesarean section) (Marlow, 2015).

Long term outcomes of preterm birth have however received less attention in these studies and the American Academy of Pediatrics have raised concerns that there is a ‘potential disconnect between perinatal outcomes and long-term outcomes such as administration of oxygen and postnatal steroids that may have immediate positive effects but negative long-term effects’ on these children (2004, p.1377). For example, the impact of interventions used to decrease chronic lung disease, parenchymal brain injury (IVH 3/4, and/or cystic periventricular leukomalacia), surgical NEC and threshold ROP require further analysis. The extent that these neonatal interventions impact on neurodevelopmental and functional skill development such as self-care skills, mobility and communication skills, learning and behaviour regulation has received little attention in the literature (Msall, 2006). Some preliminary studies in this area would suggest this concern is warranted. For example, PVL and peri-ventricular haemorrhage (Grade 3 or 4) have been associated with reduced neurodevelopmental scores (Vohr et al, 2000; Silveira &Procianoy, 2011; Taylor et al., 2006).

Using a cohort of 328 very low birth weight infants in 4 subgroups, Vohr et al. (2003) investigated the effects of both Intraventricular haemorrhage (IVH) and indomethacin on the cognitive, language, academic and functional skills of 8 year old school children. The 4 subgroups were indomethacin plus IVH (N=20), indomethacin with no IVH (N=145), saline plus IVH (N=28), and saline with no IVH (N=135). The Vineland Adaptive Behavior Scales Survey Form (Sparrow, Balla & Cicchetti, 1984) was used to assess maternal perceptions' of their children's adaptive functioning in communication, daily living skills, and socialization. A significant negative effect of both IVH (p=.03) and indomethacin (p=.02) was found on daily living skills. As children in the indomethacin and saline groups with IVH were more likely to have cerebral palsy (32%), the negative effect of IVH is consistent with studies that have reported poorer daily living skills with children with physical disabilities (Law et al., 2013; Vos et al., 2013) and children with physical disabilities and VLBW (McCormick et al, 1992). This does not however explain the negative effect of indomethacin on daily living skills as 92% of the indomethacin group who did not have IVH were neurologically normal. Consistent with this study Patra et al. (2006) found extremely low birth weight infants with IVH grade I or II to have poorer neurodevelopmental outcomes at 20 months than their peers with normal cranial ultrasounds while Taylor et al. (2006) found Intraventricular haemorrhage, periventricular leukomalacia and ventricular dilation of grades III/IV predicted especially higher odds for poorer outcomes.

The impact of PIH on the adaptive functioning of former preterm infants has received little attention in the literature and studies that have documented this association have presented conflicting results. A study by Fernandes et al (2012) of 58 preterm VLBW infants with and without PIH found, using a multiple regression controlling for sex, that Periventricular leukomalacia reduced the adaptive behaviour scores of VLBW Brazilian infants (p=0.002). Group comparison of VLBW infants with and without deficits in adaptive behaviour showed a higher frequency of adaptive deficits in those with periventricular leukomalacia. This was not consistent however with Bassan et al. (2007) who assessed 30 former preterm infants with PIH using the Vineland Adaptive Behavior Scales II (Sparrow, Cicchetti, & Balla, 2005) defining an abnormal score as 2 or more standard deviations below the norm. Results demonstrated that the daily living, communication and socialisation skills of over two thirds of the infants were ‘relatively spared’ (p.790) with 10 (33%) infants demonstrating impairments in daily living skills and 6(20%) in socialisation. Both of these studies had small sample sizes and Fernandes et al.’s (2012) study had no control group, using the ABAS-II North American data to document the Brazilian infants’ standardised scores.

Neonatal risk factors have also been associated with fine motor impairments. Bos et al. (2013) reviewed literature on fine motor skills and neonatal of 1 month old to 12 year children born at preterm birth in the past 15 years. Studies explicitly performed with children with cerebral palsy were eliminated in order to focus on the impact of the prematurity alone. From the literature the reviewers identified peri and neonatal risk factors for fine motor impairment to include moderate preterm birth, preterm birth <32 week’s gestation, intra-uterine growth restriction, inflammatory conditions such as late-onset sepsis and necrotizing enterocolitis and dexamethasone therapy for bronchopulmonary dysplasia.

Medical risk factors have also been associated with impairments in adaptive functioning and academic skill development. A study by Taylor et al. (2006) comparing the skills of ELBW infants to a control group at 8 years of age, found, using a linear regression, that children born out of hospital (outborn), ventricular dilation and length of neonatal hospital stay were the neonatal risk factors that were associated with impaired outcomes in adaptive behaviour. This is of concern as the Irish Perinatal Statistics Report 2012 (ESRI, 2013) reported higher mean hospital stays for preterm babies (13.4 days) and low birth weight babies (13.9 days), in comparison to babies born at term (2.6 days) or weighing 2,500 grams or over (2.7 days) therefore potentially predisposing these infants to adaptive challenges. Ultrasound abnormality, intraventricular haemorrhage, periventricular leukomalacia, chronic lung disease, postnatal steroid therapy, necrotizing enterocolitis, meningitis, and a neonatal risk index of more than 3 have also been associated with poorer academic skill development (Taylor et al., 2006) while head circumference has provided an indirect indication of 'intrauterine and postnatal brain growth failure in children born VLBW' (Peterson et al., 2006, p.326).

Gestational Age and Birth Weight

In general, functional disabilities and special health care needs increase as birth weight and gestational age decrease (Hack et al., 2000; Huang et al., 2012; Vohr et al., 2000; Fily et al., 2006). An inverse relationship exists between decrease in birth weight and gestational age and the risk of a disruption in corticogenesis and brain connectivity (Huttenlocher & Dabholkar, 1997). Lower birth weights are associated with a wide range of negative sequelae such as poorer perinatal outcomes, repercussion in later life (Guerra et al., 2014; Hack et al., 2005) childhood disability (Zwicker et al., 2013) and problem behaviours such as conduct problems, hyperactivity and emotional symptoms (Yang, Fombonne & Kramer, 2011). These behavioural problems were also highlighted in a meta-analysis by Aarnoudse-Moens et al. (2009) who found that infants born with lower birth weights and lower gestational ages were more prone to problems with academic achievement, and parent and teacher rated internalizing and externalising behaviours than their heavier, less premature peers. This study is described in more detail below. Studies of children born small for gestational age have also shown that they present with more difficulties with school functioning, motor and language development than their full term peers (Van Kessel-Feddema et al., 2007). With this mounting evidence it is not surprising that the infant's birth weight is therefore widely used as a key indicator of health status and a predicator of later development (ESRI, 2013; Aarnoudse-Moens et al., 2009).

Neurodevelopmental, Cognitive, Behavioural and Motor Impairment

Preterm birth causes increased risk of neurodevelopmental, social, cognitive, behavioural and motor impairment. The evidence that preterm very low birth weight babies are at risk of deficits in motor and cognitive development (Spittle et al, 2009; Oliveira et al, 2011); executive functioning such as impulse control, working memory and cognitive flexibility (Ni et al, 2011) continues to increase.

A systematic review by Moreira, Magalhaes & Alves (2014) synthesized the literature published on the effect of preterm birth on the development of school-aged children (8 – 10 years of age) in the past ten years. Observational and experimental studies in Portuguese, Spanish or English, indexed in a number of international databases, and achieving an article quality of 80% as measured by the 'Strengthening the reporting of observational studies in epidemiology' (STROBE) and the Physiotherapy Evidence Database (PEDro) were included. Of 3,513 articles, 33, all of which were observational studies from developed countries met the inclusion criteria. There was diversity in the gestational ages of the children born preterm. 18 studies (54%) focused on children born at <32 weeks gestation, 5 (9%) focused on children born between 32-36 weeks gestation, 2(6%) covered all children born <37 weeks, and 10 (30%) studied children born <37 weeks but did not specify the gestational age ranges included. Of the outcomes of interest in this review behaviour was most often assessed (20 articles, 61%), then school performance (16 articles, 48%), and finally motor deficits (11 articles, 33%). The review confirmed that preterm infants are vulnerable to long-term motor, behavioural and academic deficits.

Consistent with Moreira, Magalhaes & Alves (2014) review of the literature on motor skills, other literature have acknowledged the impact of preterm birth on the development of children's fine and gross motor skills. According to Bos et al. (2013) a challenge for researchers reviewing the literature on fine motor skills and preterm birth however, is that fine motor skills require other performance skills such as perceptual, visual-motor and motor planning skills that are often not assessed and therefore cannot always be accounted for when interpreting results of fine motor tests. A systematic review by Williams, Lee & Anderson (2010) found the prevalence of fine and gross motor deficits in preterm infants without cerebral palsy to be 40% for mild-moderate and 20% for moderate impairment. Consistent with this, a review by de Kieviet et al. (2009) between 1992 and 2009 on children born very preterm and VLBW without congenital anomalies of 41 articles using standardised testing of 9653 children demonstrated a significant deficit in motor skills for these children that persisted in to childhood.

A quantitative meta-analysis of the neurobehavioural outcomes in very preterm (≤33 weeks) and/or very low birth weight (≤1500g) children was conducted (Aarnoudse-Moens et al., 2009). Previous research published in PubMed, PsychINFO and Web-of-Science between 1998 and 2008 that focused on academic achievement, behavioural functioning and executive functioning were integrated. Reference lists of selected articles were also screened for other relevant publications on these topics and all studies were required to be from peer-reviewed English-language journals. A case-control design was used and only studies that used standardised tests to collect data on these topics were included. To ensure meta-analytic stability however, a minimum of 5 studies that used a particular assessment tool were required, as a cut-off point. As academic achievement was one of the domains being measured all children in the studies were at least 5 years or over (5-22.3 years). As this section of the chapter however focuses specifically on ‘Body Functions and Structures’ only the results for behavioural and executive functioning will be presented here. Effect sizes and 95% confidence intervals in terms of Cohen’s d were calculated for each study and Q-test statistics were used to test the homogeneity among the effect sizes. Aggregated measures of effect sizes for these neurobehavioural outcomes were provided.

9 studies on behavioural problems and 12 studies on executive functioning met the inclusion criteria. All 9 studies used the The Achenbach's Child Behavior Checklist and 4 used its Teacher Report Form (Achenbach, 1991) to measure behavioural difficulties. Attention problems were the most pronounced in all 9 studies with both teachers' and parents' ratings for the children who were born very preterm and/or very low birth weight being 0.43 to 0.59SD higher (p<.001) respectively, than their full term peers. Standardised tests used to measure executive functioning included the Controlled Word Association Test (Lezak, Howieson & Loring, 2004), Animal Naming Test (Spreen & Strauss, 1991), Digit Span (Wechsler, 1991; Wechsler, 1998) and the Trail Making Test (Reitan & Wolfson, 1993). Aggregate effect sizes for executive functioning also demonstrated significantly reduced scores (p<.001) for this population in verbal fluency (0.57 SD), working memory (0.36 SD) and cognitive flexibility (0.49 SD), in comparison to controls. Parent and teacher ratings of internalizing behaviour (<0.28) were small while ratings on externalizing behaviour problems (<0.09) were negligible when compared to peers.

Williamson and Jakobson (2014) suggest that social perceptual difficulties may play a significant role in the social and behavioural difficulties these children present with. A study by Williamson and Jakobson (2014) of school aged children compared the social perceptual skills of VLBW children between 8 and 11 years of age to age-matched, full term peers. The VLBW group demonstrated impairments in their ability to perceive nonverbal cues such as interpreting moving faces and bodies, situational cues and correctly identifying the emotions of videotaped characters who were socially interacting. These weaknesses were found in both the VLBW children with and without intellectual or language difficulties. Although Wolfe et al. (2015) did not find a significant difference in the social information processing and parent-reported social adjustment in a small sample (N=20) of 4-6 year old children born VLBW compared to term matched controls of normal birth weight (N=18) they suggested that social difficulties may not emerge until school age.

Despite a myriad of interventions to improve neurodevelopmental outcomes (Spittle et al., 2009), improvement in survival rate of preterm babies demonstrated in the UK Epicure studies between 1995 and 2006 (http://www.epicure.ac.uk/) has not translated in to better neurodevelopmental outcomes in early childhood. That is, between 1995 and 2006 Moore et al. (2011) reported that no significant improvements in neurodevelopmental morbidity in early childhood were found. In contrast, a follow-up study by Bode et al. (2009) reported more promising results demonstrating a significant improvement between two cohorts of infants born ≤30 weeks gestation during the last two decades. Cohort 1 was initially assessed in 1985/1986 and followed-up at 24 months corrected age using the Bayley Scales of Infant Development, first edition (Bayley, 1969) (N=106) while cohort 2 were initially assessed in 2005/2006 and followed-up at 24 months corrected age using the Bayley Scales of Infant and Toddler Development, 3rd Edition (Bayley, 2006) (N=167). There was a significant difference between the groups (p=0.14) with 19% of the infants in cohort 1 and 9% of the infants in cohort 2 demonstrating severe neurodevelopmental impairments. Relative to the Epicure studies this Bode et al.'s (2009) sample is small and the different versions of the Bayley assessment may potentially confound results. Results on neurodevelopmental outcomes may also be confounded by the fact that more babies are surviving at lower gestational ages and decreased birth weights.

3.2 Impact of Preterm Birth on Activity and Participation

Activity and participation are two major components of the ICF-CY framework (WHO, 2007). Both concepts can be measured using the qualifiers of capacity and performance, with capacity describing ‘the individual’s ability to execute a task or an action’ and performance describing what an individual actually does in his or her environment (WHO, 2001, p.15). Within the classification system of the framework ‘Activity and Participation’ have been amalgamated in to one category which has led to difficulties in differentiating between them (Cramm, Aiken & Stewart, 2012). Despite this attempt by the WHO (2001) to combine them, participation has been singled out internationally as the greatest outcome of importance to children and their families (Coster and Khetani, 2008).

Activity and Participation

The ICF and the ICF-CY define activity as ‘the execution of a task or action by an individual’ (WHO, 2001, p.14, WHO, 2007). As discussed in section 1, the ICF-CY (WHO, 2007) has however been criticised for not offering any criteria to distinguish between the construct of ‘activity’ and that of ‘participation’ (Coster and Khetani, 2008). Msall (2006) offers a generic description of activities defining them as the tasks that children do such as learning, communicating, walking, climbing, and self-care skills such as feeding, dressing, toileting, bathing, and grooming’ (Msall, 2006). Coster and Khetani (2008) however are more specific in their working definition of activity stating that ‘activities are the units from which such sequences [life situations] may be constructed’ and gives examples of activities that include ‘both simple functional actions (putting toothpaste on a toothbrush; buttoning a shirt; scooping food on to a spoon) and short sequences of functional actions with a common goal (e.g. brushing one’s teeth; putting on a shirt; eating a sandwich) (p.643). This definition of activity appears to link closely to the definition of adaptive behaviour (AAMR, 2002) that will be described below. It does not however appear to sit neatly into either the AOTA’s (2014) definition of occupation or performance skills. As the AOTA (2014) clarifies, an individual may be involved with activities that are necessary for achieving a goal (such as those described by Coster and Khetani (2008) above) but if the activity does not, in and of itself, hold central importance or meaning for that individual child, it cannot be considered an occupation for them. This terminology is presented in more detail in table 2 below.

In contrast to the definition of activity, participation is defined as ‘involvement in a life situation’ (WHO, 2001, p.14, WHO, 2007). The WHO (2001) do not expand on this definition other than with a small number of statements that suggest that life situations represent the interface between the person and societal situations. Coster and Khetani (2008) argue that the lack of clear definitional criteria for this construct in the ICF (WHO, 2001) allows for a huge variety of interpretation and therefore this useful construct is in danger of being undermined. In an attempt to clarify the construct of participation further, a number of authors have expanded on this definition. Coster and Khetani (2008) proposed that these life situations are characterized by activities that are sequenced and organized in order to fulfil social or personal context-specific goals that are meaningful to the individual. Participation in these situations may also form units of a larger overall goal such as changing clothes in order to participate in physical education class. Other authors have further specified that for children, participation in community life situations include recreational and leisure activities such as playing with peers, skill development, physical, creative and artistic activities; involvement in social family events such as religious services, spending time with relatives, and going shopping; and educational experiences such preschool education (Law et al., 2006; Msall, 2006)

The ICF divides activity and participation in to 9 areas: Learning and applying knowledge; General tasks and demands; Communication; Mobility; Self-care;

Domestic Life; Interpersonal interactions and relationships; Major life areas; and Community, Social and Civic life (World Health Organization, 2001, p.30). In the development of the ICF-CY (WHO, 2007) the area of participation received special attention, acknowledging that as a child develops, the quantity and complexity of life situations the child is exposed to changes from solitary play and relationship with the primary care giver in the younger years to peer relationships, schooling and social play of the older child. Participation in formal and informal activities is the ‘context in which children form friendships, develop skills and competencies, express creativity, achieve mental and physical health, and determine meaning and purpose in life’ (Law & King, 2000, p. 10).

Law (2002) describes the core concept of participation as involvement or sharing, particularly in an activity and suggests that what is important about the definitions of participation is ‘the focus on both the nature and the extent of involvement, with qualitative and quantitative implications’ (p.641). This is also reflected in Coster & Khetani’s (2008) definition of participation which emphasises the extent of involvement in a diverse range of activities that achieve a larger goal such as caring for one’s own hygiene. Contemporary theories of participation have also emphasised this construct as an outcome of dynamic interplays between the individual and their environment (Coster et al., 2011; Lerner, 2002; Bartko & Eccles, 2003). For example Kielhofner’s (2008) definition of participation includes the importance of the environment defining occupational participation as ‘engaging in work, play or activities of daily living that are part of one’s socio-cultural context and that are desired and/or necessary to one’s well-being’ (p.101). Finally, in exploring participation the consideration of the age group of the child is also very important as younger children’s opportunities to participate are most likely determined by their primary caregivers or service providers (WHO, 2007).

Childhood Occupations

The ICF terminology of activity and participation have been embraced by occupational therapists in the literature (Law & Darrah, 2014). Another discpline specific term that occupational therapist refer to regularly in practice and in the literature is that of ‘occupation’. In children’s services, occupational therapists have a unique focus on a child’s occupations (American Occupational Therapy Association, 2014) and although it is conceptually similar to the terms of activity and participation, there are also subtle differences.

Numerous definitions of occupation can be found in the literature. For example, Law et al. (1997) defined occupation as the ‘activities of everyday life, named, organized, and given value and meaning by individuals and a culture’. This includes everything people do to occupy themselves, including looking after themselves …enjoying life … and contributing to the social and economic fabric of their communities ...’ (p.32). The World Federation of Occupational Therapists (WFOT) (2009) define occupation as ‘the everyday activities people do as individuals, in families, as members of groups, and within communities, to bring meaning and purpose to life and to achieve and maintain health’. Although the WFOT did not emphasise the individual’s culture in their definition of occupation the importance of the meaning to the individual is explicit in their definition. This core element of what constitutes occupation is missing from the ICF-CY (WHO, 2007) definitions of activity and participation and therefore appears to be one of the core differences in definition. It could be argued that childhood occupation encompasses a clearer emphasis on cleint-centred practice. Other definitions of participation link more closely to occupation than the WHO’s (2001) broad defintion of participaion as ‘involvement in a life situation’. For example, Kielfhoner’s (2008) defintion of occupational participation with its focus on the individual’s ‘desire’ or neccesity to perform something in a socio-cultural context links more closely to Law et al.’s (1997) defintion of occupation.

As well as discrepancies in the definitions of occupation, authors have argued about what the definitions should focus on. For example, contemporary conceptualizations of occupation have been criticised for having a limited focus on ‘the big three’, ADLs/Self-care, leisure, and work/productivity/education (Jonsson, 2008; Hasselkus, 2006). Jonsson’s (2008) concern is that these categorisations do not emphasize how the occupational form influences human development, health and well-being. He suggests moving towards an experience-based definition of occupation in which it is acknowledged that some occupations are more important than others. Consistent with this, other authors have voiced a preference with a definition of everyday occupation as the phenomenology or lived experiences of daily life (Hasselkus, 2006; Pollio, Henley, & Thompson, 1997). The American Occupational Therapy Association (AOTA) have responded to concerns in relation to this construct. In their most recent framework (already explored in Section 1 of this chapter) they have adopted Law et al.’s (1997) definition of occupation as the operational definition while also expanding the focus from the ‘big three’ to highlight the complexity of occupation. The Occupational therapy practice framework: domain and process’ (AOTA, 2014) therefore encompasses client factors, performance in areas of occupation, performance skills and patterns, contextual components and activity demands.

In contrast to the numerous definitions in the literature describing ‘occupation’, the term ‘childhood occupation’ has received little clarification in the literature. Although many studies refer to the term, few have defined it explicitly. As with adults, the occupations of a child are also often divided in to three main areas i.e. self-care/ADL’s, education/productivity, and play/leisure. As there is no universal definition of childhood occupation the following definition will be used for the purpose of this study. ‘For children and youth, occupations are activities that enable them to learn and develop life skills (e.g. school activities), be creative and/or derive enjoyment (e.g. play), and thrive (e.g. self-care and care for others) as both means and end (AOTA, 2010). For the purpose of this study, ‘learning’ is not considered an occupation as it is more related to competence development rather than an occupation per se i.e. it is what you do to be able to perform an occupation.

Adaptive Behaviour

The construct of ‘adaptive behaviour’ the other major operational term that will be used in this study was first coined by Heber (1959, 1961) and used in the sixth edition of the American Association of Mental Retardation’s (AAMR) broadened definition of mental retardation. Prolific research was then conducted on this concept in 1980’s and 1990’s leading to the emergence of ‘a wide variety of definitions and categories of adaptive behaviour’ (Schalock and Braddock, 1999, p. 1). The factor structure of adaptive behaviour was examined and common elements in definitions were identified, with an emphasis on its reference to intellectual disability. In 1992, the AAMR included 10 adaptive skills in the definition of adaptive behaviour in an effort to operationally define the term. These adaptive skills are: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work.

Despite this operational definition, Schalock and Braddock (1999) argued that there was still ‘no universal agreement on the factor structure of adaptive behaviour, the best method to assess it .... and the relationship between adaptive behaviour and intelligence’ (p. 2). Although this may be true, over the past 50-60 years the concept of adaptive behaviour has evolved into a measureable construct ‘whose factor structure and measurement has been increasingly understood to include conceptual, social, and practical skills that have been learned and are performed in the community by people in their everyday lives’ (Tassé et al, 2012, p.295). The currently accepted definition of Adaptive Behaviour is defined as ‘the collection of conceptual, social and practical skills that have been learned by people in order to function in their everyday lives’ (AAMR, 2002, p.41). Although a concept that was originally emphasized in relation to intellectual disability, the American Academy of Pediatrics (Bernbaum, Campbell & Imaizumi, 2009, p. 869) has recommended that the social-adaptive skills of premature infants are screened from as early as 8 months corrected age.

In comparing the operational definitions of ‘activity and participation’ and that of ‘adaptive behaviour’ (see table 2) it would appear that although the domains are classified in to different groupings, the overall life behaviours described in both constructs are the same. In fact all of the adaptive behaviour skill areas from the ABAS-II can be grouped under the 9 domain areas of ‘activity and participation’ laid out in the ICF (World Health Organisation, 2001, p.14). In relation to the occupational therapy terminology, adaptive behaviours appear to be broader more practical skills than ‘performance skills’ that are defined by AOTA framework (2014) as small units of performance such as bending, choosing and gazing. They do not however constitute ‘occupations’, in and of themselves; rather they appear to be pre-requisite or foundational skills required to successful complete childhood occupations. For example, an adaptive behaviour from the ABAS-II would be for a child to ‘take own clothes from drawers or closet when getting dressed’ and the childhood occupation would be dressing.

For the purpose of this study ‘adaptive behaviour’ will be used instead of ‘activity’ as this construct is more practical with an emphasis on everyday life, is clearly defined and has appropriate sub-categories. Participation will be the other major construct explored in this study as this has been identified as the greatest outcome of importance to children and their families (Coster and Khetani, 2008). Please see Table 2 for comparison of main terminology.

Table 2 Comparison table summarising the main terminology considered for this study

Definitions		
Activity 'is the execution of a task or action by an individual' (World Health Organisation, 2001, p.14) **Participation** is 'the involvement in a life situation' (World Health Organisation, 2001, p.14) 'The central concept in participation is involvement or sharing, particularly in an activity' (Law, 2002, p.641)	**Adaptive behaviour** is defined as 'the collection of conceptual, social and practical skills that have been learned by people in order to function in everyday life' (AAMR, 2002, p.41)	'**Occupation** refers to all everyday activities people do as individuals, in families, as members of groups, and within communities, to bring meaning and purpose to life and to achieve and maintain health' (World Federation of Occupational Therapists, 2009). **Childhood Occupation** 'For children and youth, occupations are activities that enable them to learn and develop life skills (e.g. school activities), be creative and/or derive enjoyment (e.g. play), and thrive (e.g. self-care and care for others) as both means and end (AOTA, 2010)

Comparisons of Operational Definitions			
ICF Domains of Activity and Participation	**Corresponding Domains of Adaptive Behaviour (ABAS-II)**	**Childhood Occupation**	**Commonalities And difference**
• Learning & applying knowledge	Skill area 3: Functional Pre-Academics	Reading, writing, maths*	All pertain to everyday life situations
• General tasks and demands	Skill area 5: Health & Safety		
• Communication	Skill area 1: Communication	Social Communication	
• Mobility	Skill area 10: Motor	Moving around community	
• Self-care	Skill area 7: Self-care Skill area 5: Health & Safety	Self-care	
• Domestic life	Skill area 4: Home Living	Household chores Instrumental activities of daily living	
• Interpersonal interactions & relationships	Skill area 9: Social Skill area 8: Self-direction	Social activities	
• Major life areas (Education, work & employment, economic life)	Skill area 3: Functional Pre-academics	School work, Playground activities and Physical Education.	
• Community, social & civic life	Skill area 2: Community Use; Skill area 6: Leisure	Play, Playground activities, Hobbies, Sports, Plays/Musicals, Crafts, Organized religion, Cycling.	

* For the purpose of this study learning is not seen as a childhood occupation, 'learning' is what you do in order to be able to perform childhood occupations. The list of childhood occupations presented in Table 2 was derived from both occupational therapy literature and discussion with experts in this area.

Studies on the Adaptive Functioning of Children born Preterm

Adaptive behaviour has been assessed in a number of different client groups in both adults and children, most specifically in relation to intellectual disability. In the early 1990's researchers started to include adaptive behaviour in the assessment batteries of children born premature (Saigal et al., 1990). Over the past two decades focused research on specific cohorts of preterm children, based on gestational age or birth weight, have demonstrated in general that as the infants gestational age and birth weight decrease their health and functional challenges increase (Hack et al., 2000; Huang et al., 2012; Vohr et al., 2000; Taylor et al., 2006). A very limited number of these studies have assessed the adaptive behaviour of preterm VLBW infants and these studies have varied greatly in the age range of the children assessed. Participants have generally been researched in specific age ranges such as very young infants/toddlers (Velikos et al. 2015), school age children (Fjørtoft et al., 2012a, 2012b), adolescents (Sullivan, Miller & Msall, 2012) or young adults (Hille et al., 2007) born preterm. Very few studies of adaptive functioning have focused on preschool children. In the majority of studies that have included the adaptive behaviour of preterm infants in their research study, this construct has been assessed in the context of a large battery of developmental assessments and little attention has been given to the reporting of findings in this area. Only recently have studies began to focus on the adaptive functioning of preterm VLBW infants without physical or intellectual disabilities (Huang et al., 2012; Fernandes et al., 2012) and began exploring the long term effects of preterm birth on everyday life skills (Sullivan, Miller & Msall, 2012).

Very few studies on adaptive behaviour have categorised preterm infants into clearly defined groups by neonatal morbidities (Sullivan, Miller & Msall, 2012). Results have therefore been confounded by co-existing morbidities such as neurosensory impairments and physical and intellectual disabilities that have been variably described (Sullivan et al, 2012). This complex interplay obscures the questions as to whether preterm birth alone impacts on these infants' ability to function in day-to-day life. One of the first studies of the adaptive behaviour of preterm infants (Saigal et al, 1990), a follow-up study at the mean age of 5.5 years (N=84), assessed the intellectual and functional status of infants with a birth weight of 501 -1000 grams born in the early 1980's. The main battery of assessments focused on performance components, however, a questionnaire detailing school performance and the Vineland Adaptive Behavior Scale parent questionnaire (Sparrow, Balla & Cicchetti, 1984) were also utilised. Although, in an earlier study of the neurosensory impairments of this cohort of ELBW babies at three years of age (Saigal et al,1984) the children's ages were corrected for prematurity, it was elected to utilise the children's chronological age when scoring the assessments in this study. The authors did, however, allude to some exploration of corrected age for the McCarthy Scales of Children's Abilities (McCarthy, 1972), reporting that correction for prematurity increased both the overall and subscale scores of this intelligence test but these data were not shown.

Further analysis of the data, excluding 18 children with neurosensory impairments, was performed for selected assessments. This did not include the assessment of adaptive behaviour, of which the results of all 84 children were presented together, obscuring the results. In the absence of a control group, the authors reported that the adaptive behaviour of the ELBW children was lower than the expected frequency distribution based on the normative sample, with two-thirds of the children in the adequate range, the majority of the remainder in the moderately low to low range (23%), and 8% scored in the low group (3 times more than the standardised sample). The children's lowest scores were in motor skills, while their best performance was in socialization. No greater classification of these differences was provided. It is challenging to draw any meaningful interpretation from this data in relation to preterm birth alone however, as the results are confounded by the inclusion of 18 children with neurosensory impairments, intellectual disabilities and autism, diagnoses that in isolation are associated with challenges in adaptive behaviour (Vos et al., 2013; Itzchak, Lahat & Zachor, 2011)

Only in recent years is research beginning to suggest that prematurity and VLBW has adverse effects on neurodevelopment, academic attainment and adaptive behaviour 'even among children without clearly deviant head size or neurological complications' (Peterson et al, 2006, p.331). In the few studies published on the adaptive behaviour of young children born preterm and VLBW without physical or intellectual disabilities, greater levels of impairment in adaptive behaviour have been reported relative to their full term peers (Fernandes et al., 2012, Huang et al., 2012). To date there are only two studies that have assessed the adaptive behaviour of healthy preterm VLBW children at a toddler/preschool age using the Bayley Scales of Infant and Toddler Development III (Bayley) (Bayley, 2006). As part of these studies the Bayley III adaptive behaviour parent questionnaire (Bayley, 2006), a questionnaire adopted directly from the ABAS-II parent/primary caregiver form was used.

Of these two studies, Fernandes et al., (2012), utilised a cross-sectional study design to assess the adaptive behaviour of 58 preterm VLBW Brazilian infants at a corrected age of 18 to 24 months. All infants with major neurological impairments were excluded. 22 (37.9%) of these 'healthy' preterm infants presented with impairments in adaptive behaviour. Multiple linear regression was also used to examine associated factors, demonstrating decreased adaptive behaviour scores in infants with periventricular leukomalacia. The adaptive behaviour score of the infants in the 'impaired' range were not elaborated on and their other domain scores (conceptual, practical and social) were not provided. Therefore, other than the acknowledgment that the mean score in adaptive behaviour for the overall group of preterm infants was 90 and the adaptive composite scores of the infants with 'impairments' was less than a standard score of 85, the level of severity of these 'impairments' in adaptive functioning was not clear. The study also lacked a control group and as the normative data for the Bayley III Adaptive Behaviour Scale was developed on a North American population, it is questionable whether these results are a true reflection of South American children. The sample size was also small. The many limitations of this study therefore suggest caution is required when interpreting results.

The other study that focused specifically on ‘healthy’ preterm VLBW children in their toddler/preschool years was by Huang et al. (2012). In this study a cohort of 105 infants in Taiwan, aged 18-36 months, were assessed using a cross-sectional design. The age of infants 2 years and younger were adjusted for prematurity. The cohort was divided in to four groups: full term and normal birth weight infants (N=40), moderate birth weight infants (N=24), very and extremely low birth weight infants (E-VLBW, 12 between 1000-1499g and 8 lower than 1000g) (N=20) and infants at risk of developmental delay (N=21). For the current study the group of most interest is the E-VLBW group (N=20) however the sample size is very small. Huang et al.’s (2012) study is therefore an example of how the inclusion of infants with large ranges of gestational ages and birth weights results in very small sample group sizes in analysis. The Bayley III (Bayley, 2006) was administered as a once-off assessment to all four groups. The parent questionnaires (Social-emotional scale and the Adaptive behaviour scale) were then given to parents to fill in at home.

The E-VLBW group performed significantly worse than their full term peers and infants of moderate low birth weight in social adaptive behaviour and practical adaptive behaviour ($P<0.05$). There was no difference in the groups’ conceptual adaptive functioning scores. Although infants with a history of IVH or PVL were excluded from the study, infants with respiratory distress syndrome (which accounted for 70-75% of E-VLBW infants) were not excluded making unclear if this was a truly ‘healthy’ group of preterm infants. That is, respiratory disorders such as bronchopulmonary dysplasia and chronic lung disease have been suggested to lower neurodevelopmental scores (Van

Marter et al, 2011; Laughon et al, 2009). As the sample size in the specific category of interest for this study was very small and the definition of 'healthy' preterm was different to Fernandes et al.'s (2012) definition it is difficult to make any meaningful comparison between the studies and the results need to be interpreted with caution. The limitations of these two studies support the need for more methodologically robust research on the adaptive behaviour of preterm VLBW pre-schoolers, without physical or intellectual disabilities. A more in depth exploration of this cohort's strengths and challenges in relation to different domains of adaptive behaviour will also support focused service provision for these young children.

A key question to answer in relation to the challenges that preterm VLBW infants present with in relation to their adaptive behaviour is whether these children 'grow' out of these difficulties? To address this question the studies that investigated adaptive behaviour in school aged children were explored.
A case-control study by Peterson et al. (2006) compared the IQ, neuropsychological function, academic achievement, adaptive behaviour, and attention problems of 128 preterm VLBW infants to 58 normal birth weight peers, at a mean age of 6.8 years (range: 5.9 - 9.0 years). Although the VLBW children included children with subnormal head circumference (24%) and those with a diagnosis of neurosensory impairment (12%), a separate comparison excluding these children of 'neurologically intact' VLBW children (N=89) and their full term peers was done. Overall adaptive behaviour, as measured by the Vineland Adaptive Behavior Scales (Sparrow, Balla & Ciccetti, 1984) was significantly lower for the VLBW group (P=.011). There was no more detail on the breakdown of adaptive behaviour domain scores however, and little if any attention was given to this result in the discussion.

Consistent with this, although with former preterm ELBW infants (N=219), Taylor et al. (2006) using a case-control design, compared the adaptive behaviour of ELBW infants, with varying co-morbidities, at a mean age of 8 years with their full term peers (N=173). The Vineland Adaptive Behavior Scales Screener (Sparrow, Carter & Cicchetti, 2000), using parent report, was utilised to assess the adaptive behaviour of the children in the study. Although 96 (48%) of the ELBW group had a high number of neonatal complications as defined by a validated Neonatal Risk Index, a subgroup of the ELBW infants without specific neonatal risk factors i.e. identified as ‘low-risk’ (N=48) were identified. These ‘low-risk’ children were compared to the control group while controlling for background and family factors and demonstrated significantly lower scores in both academic achievement and adaptive functioning than their full term peers. Although a small sample size and a more vulnerable group of infants this result is consistent with the Peterson et al.’s (2006) findings highlighting the weakness in adaptive functioning of these ‘healthy’ preterm infants.

A slightly older group of Norwegian school children (10-11 years of age) were assessed by Fjørtoft et al. (2012a, 2012b) in a hospital follow-up study. 38 Norwegian VLBW children with cerebral palsy (N=10) and without cerebral palsy (N=28), and a term control group (N=31) from four local schools matched for age were assessed using the Vineland Adaptive Behavior Scales II (Sparrow, Cicchetti & Balla, 2005). The VLBW group demonstrated significantly lower scores in overall adaptive behaviour than their full term peers ($p<0.001$). This difference remained when 10 children with cerebral palsy were removed from the VLBW group ($p=0.005$). A strength of this study was that the authors expanded on the VLBW groups’ adaptive behaviour scores reporting that the VLBW group without cerebral palsy demonstrated significantly lower scores in the domains of daily living skills and socialisation but not in communication domain. This allows for some further interpretation of results and is needed to develop a clear profile of these children. As this study has a very small sample size however caution is required in interpreting these results.

The final study of note, although of adolescents, used a prospective, case-control design to investigate the functioning and participation of 180 US 17 year olds, born premature. A strength of Sullivan et al.'s (2012) study design was that it is one of the first studies measuring adaptive functioning that clearly classified preterm infants into distinct groups. The five groups consisted of one full-term group and four preterm groups characterised by neonatal morbidity - Healthy, medical neonatal illness, neurological neonatal illness, and small for gestational age. A limitation of this division however, as reported earlier with Huang et al.s (2012) study, was that as the 180 infants were divided in to five groups, the numbers in some groups were quite low. Interestingly, using Wilk's criterion, with the combined outcome of the four adaptive behaviours of the Scales of Independent Behaviour-Revised (Bruininks et al, 1996), Sullivan et al. (2012) found a significant difference for gender (p=.003), but not for neonatal group (p=.85). Ironically, despite the clarity of the groupings, these results are difficult to compare to the other studies discussed above due to the varying neonatal criteria. Sullivan et al.'s (2012) also found a difference in the adaptive functioning between genders with 17 year old males born premature demonstrating lower scores in social interaction, personal living, community living, and broad independence than their female peers. This male disadvantage has been previously found both in other studies of adaptive behaviour (Fernandes et al., 2012) and in numerous other developmental skills (Johnson et al., 2009) and will be discussed in more detail in Section 4.2.

In summary a very limited number of studies have assessed the adaptive behaviour of 'healthy' preterm VLBW infants. Of these studies their individual classification systems all tend to be somewhat unique and therefore create challenges in comparison. Studies that have included infants with large ranges of gestational ages and birth weights, and then categorized infants' outcomes in relation to these variables have also resulted in very small sample sizes in each category. In the majority of these studies, the reporting of the adaptive behaviour scores is very limited with no expansion on the profile of adaptive strengths and challenges of these children which limits interpretation of results. Although all of these studies have small sample sizes however, the collective findings of the two studies on preschool infants, and the subsequent studies of school aged children born preterm and VLBW without neurosensory impairments, suggest that these children do not grow out of this weakness in adaptive functioning. This limited literature supports the focus of the current study to explore the adaptive strengths and challenges of this cohort of children. Given the move in healthcare towards early identification and prevention of long term difficulties the aim of this project is to explore this very practical area with preschool children.

Childhood Occupations

As described earlier occupational therapists have a unique focus on 'children's occupations' (American Occupational Therapy Association, 2014). Consistent with the lack of research on the strengths and challenges of former preterm VLBW infants in adaptive functioning, few studies have clarified its impact on daily occupations. As alluded to above, the studies that have explored occupations have tended to focus on academic achievement and school performance acknowledging that developmental disturbances resulting from preterm birth impact on normal school functioning (Van Kessel-Feddema et al, 2007). Relative to other occupations, the academic achievement of preterm infants in reading, spelling, and maths has therefore received focused attention (Rickards et al, 2001, Taylor et al, 2006). In the 1960's and 1970's, the initial focus of these academic studies on VLBW children was in relation to the underlying performance skills required for school performance such as intelligent quotients, visual-motor integration, perceptual and language skills (Francis-Williams & Davies, 1974). Many of these earlier studies however, included children with neurosensory impairments, did not have control groups and had disproportionate amounts of VLBW infants from lower socio-economic groups which may have confounded results (Klein et al, 1985). It was only in the 1980’s that studies began to show that VLBW children with normal intelligence and free from neurosensory impairments perform less well academically than their term-peers (Saigal et al., 1990; Klein et al., 1985; Lloyd, Wheldall & Perks, 1988).

A meta-analysis by Aarnoudse-Moens et al in 2009, detailed in the ‘Body functions and Structure’ section of this chapter, aggregated the effect sizes from research studies from 1998 to 2008 in relation to neurobehavioural outcome for very low birth weight (VLBW) and/or preterm infants. The three domains focused on were academic achievement, behavioural functioning and executive functioning. Using a case-control design, 4125 very preterm and/or very low birth weight children were compared to 3197 full term peers. Fourteen studies that used standardised assessments of reading, mathematics and spelling met the inclusion criteria for the study. Aggregated effect sizes demonstrated significantly poorer scores in mathematics (-0.60), reading (-0.48) and spelling (-0.76) for these VLBW and/or preterm infants in comparison to their full term peers. Recent attention has also been given to the neuropsychological antecedents impacting on educational achievement in these areas (Johnson et al., 2011) however relatively little attention has been given to the impact of preterm birth on handwriting (Feder et al., 2005). This weakness of preterm infants in academic performance continues to mount (Taylor et al., 2011) even in children free of neurosensory impairments (Peterson et al., 2006).

The school placements of these children and risk factors associated with learning problems have also been explored. It is now acknowledged that extremely preterm and extremely low birth weight children have greater need for special school placement, have more special educational needs, and receive greater levels of learning support services than their full term classmates (Johnson et al., 2009). Attempts have also been made to establish predictors of learning problems in this group of extremely preterm children such as neonatal risk factors, early childhood neurodevelopmental impairment and socioeconomic status (Taylor et al., 2011). Although this is clearly a step in the right direction these studies tend to focus on the impact of preterm birth on educational and academic attainment alone with the exclusion of the broader picture of the child's successful participation in school and everyday activities related to school.

Few studies have examined the self-care skills of these children. Sullivan and Msall (2007) assessed the functional performance of preterm children (N=155) at four years of age. Children were grouped into one of four priori perinatal groups based on their birth weight and neonatal illness: Infants with a birth weight of <1000g and medical illness (bronchopulmonary dysplasia, necrotizing enterocolitis etc.) (N=41, Group: MPT1); Infants with a birth weight ≥1000g and medical illness (N=39, Group: MPT2); Infants with severe neurological illness (meningitis, hydrocephalus etc.) (N=32, Group: NPT); and healthy full term infants N=43, Group: FT). The Functional Independence Measure for Children (WeeFIM) (Msall et al., 1994) has 18 items and uses a 7-point ordinal scale for each with level 1 and 2 indicating complete dependency compared to level 7 reflecting complete independence. The domains are: self-care, sphincter control, transfer, mobility-locomotion, communication, and social cognition. Standardised motor and visual motor assessments were also used but only scores on the WeeFIM that relate to childhood occupations will be discussed now. Both of the medical preterm groups (MP1 and MP2) scored lower in all four subscales especially in self-care compared to the full term (FT) group but still within 1 SD of the norm. The NPT group scored significantly lower than the other three groups and their scores were 2 SD below the norm in self-care e.g. in bathing and dressing. These low scores in functional performance for the preterm infants with neurological difficulties is consistent with the literature (Msall & Tremont, 2002). There was no significant difference between the scores of the larger birth weight MP1 group and the smaller birth weight MP2 group, although the MP2 group had lower scores in self-care areas such as toileting and eating. Finally, the impact of perinatal morbidity was reflected in the significant differences between the four groups scores.

Rates of functional limitations in self-care skills in preschool children born preterm are reported to range from 5-30% (Msall & Tremont, 2002). A recent cross-sectional study by Lemos et al. (2012) of 98 Brazilian preschoolers born at varying gestational ages and birth weights demonstrated results consistent with this. Although there was no control group, the instrument used to measure self-care, mobility and social function, the Pediatric Evaluation of Disability Inventory (Haley et al., 1992) was reportedly standardized, validated and adapted for a Brazilian population. Data were gathered on these children attending a follow-up service during a once-off parent/caregiver interview. Although children with severe disabilities were excluded from the study, the age range was quite broad (2 years – 7 years) and there were 3 groupings of preterm children included (extremely preterm, very preterm and late preterm) reducing the sample sizes in the respective groups and reducing the power of the study. Overall 25.5% of the sample demonstrated 'abnormal development' in relation to their functional skills in self-care, mobility and social function (individually, 10.2%, 12.2%, 14.3% respectively) and the overall levels of assistance received from caregivers was reflected in delays of independence of 32.7% (self-care-11.2%, mobility-19.4%, social function-15.3%).

Lemos et al. (2012) proposed that the reason that delays in self-care (10.2%) and requirement for assistance in self-care (11.2%) were less than other subscales was due to the mean age of the sample being 4.3 years. The authors suggested that by this age most skills such as food hygiene, clothing and sphincter control had been achieved by the children and testing did not account for if there had been delays in acquisition of these skills. As the scores in self-care and assistance in self-care were similar this suggested that the level of assistance provided by the carer is equivalent to the child's functional repertoire. This weakness in self-care is consistent with a weakness demonstrated in the development of feeding skills in a study by Vohr et al., 2000. In a multi-center cohort study of 1151 extremely low birth weight (401-1000 grams) infants assessed at 18-22 months corrected age, Vohr et al. (2000) found that only 80% demonstrated independence in feeding in compared to 100% of their full term peers who were consistent in independent feeding at 15-18 months. Finally, in Lemos et al.'s (2012) study the children's poor scores in the social function subtest (including communication, language, peer and adult interaction, problem solving, interactive play, household chores and self-protection) is consistent with those found in their adaptive skills. This subtest also includes aspects of participation that will be discussed in detail, in relation to preterm infants, in the next section. Although the small sample size and cross-sectional nature of this Lemos et al.'s (2012) study weakens its strength, the low scores in subtests related to childhood occupations suggest that the impact of preterm birth on everyday life skills requires more rigorous investigation.

In summary, it is now 'well documented that children born prematurely are at risk for adverse developmental outcomes, especially those that relate to school success and academic achievement' (Davis et al, 2010, p.1033). These studies have progressed from measuring cognitive development to measuring actual academic attainment, learning problems and exploring special educational needs. The few studies that have measured self-care skills have found the impact of preterm birth on pre-schoolers to range from 5 – 30% depending on the cohort of preterm infants assessed. Small sample sizes and large variations between the classifications of preterm infants in individual studies obscure direct comparison and limit the generalisability of these results. The next section will move away from studies that measure 'performance' in everyday life to explore the literature available on the preterm infants 'participation' in day-to-day life.

Studies on the Participation of Children born Preterm

Many of the studies on the participation of children with childhood disabilities have focused on children with physical disabilities such as cerebral palsy (Law et al., 2006; Anaby et al., 2013). In contrast few studies have researched the impact of preterm birth on children’s participation (Dahan-Oliel, Mazer, & Majnemera, 2012) and recent studies of former preterm infants have focused on adolescents (Dahan-Oliel et al, 2014a; Dahan-Oliel et al., 2014b) as opposed to young children. This emphasis over the past two decades on participation of school age and older children is reflected in the vast majority of participation measures available being applicable to this age range, as opposed to preschool children. As reported by Law et al. (2012) ‘there has been little research about the participation of preschool children, particularly research focusing on the measurement of sets of activities’ (p.273). The measures of participation will be discussed in more detail in Section 5 of this chapter.

In general, studies of children’s participation have focused on assessing and identifying patterns of participation in vulnerable groups of children and more recently have begun to explore participation as a formal method of intervention (Participation-based therapy) (Palisano et al, 2012). The influence of child and environmental factors on children’s participation have also been explored and demonstrated to have an impact. For example, child factors such as poor motor and cognitive skills are associated with lower levels of participation (Morris et al, 2006; Dahan-Oliel et al, 2014a) while sex and age have been shown to influence participation preferences and intensities (Dahan-Oliel et al, 2014a; Law et al., 2006). Recent studies have also begun to explore the assessment of the children’s participation in the context of the environmental facilitators and barriers influencing them. These studies have focused on school age populations (5-17 years) when comparing the supports and challenges for children with and without disabilities in the school environment (Bedell et al, 2013; Coster et al, 2013), the out-of-school environments (Anaby et al, 2013) and the home environment (Law et al, 2013). Few studies have examined the impact of the environment on preschool children (Khetani, Graham & Alvord, 2013). Of the studies that have explored environmental influences on children's participation the populations focused on most were children with cerebral palsy, followed by physical disabilities, acquired brain injury, autism and Down Syndrome (Anaby et al., 2013) and very recently preterm birth (Dahan-Oliel et al., 2014b). Environmental barriers influencing participation included lower family income, single parenting, lower respondent parent education (Law et al. 2006) and limited access to social support, transportation and respite (Khetani, Graham & Alvord, 2013). Younger children were found to have higher levels of enjoyment in activities (Ullenhag et al., 2014). The most recent publications on the participation of children and adolescents born preterm will now be discussed. For the purpose of this review, social participation will be considered part of leisure participation.

In 2012, Dahan-Oliel, Mazer, & Majnemera synthesised the literature on the leisure participation of former preterm infants throughout their lifespan and the intrinsic and extrinsic factors that may influence this. Inclusion criteria for studies were a gestational age <37 weeks and/or birth weight <1500 g, a control or comparison group and quantitative measurement of leisure participation. As the assessment methods and the presentation of results were reportedly too heterogeneous a formal meta-analysis was not done. Formal quality review of each of the 243 studies with a 3-point likert scale for each criterion and a total score ranging from 0-11 for each paper resulted in 43 studies being selected for abstract, 24 then for full paper review and a final 13 article met the selection criteria for review in the paper. Five of these papers focused on school aged children, four examined adolescents, and four reviewed the leisure participation of young adults born preterm. All studies had a control group and all but one study used a cross-sectional design. The studies of school age children varied in age from 5-7 years to 10-11 years of age, gestational ages varied from under 25 weeks, to 30 weeks and 35 weeks while birth weights were either <1000g or

<1500g. The results of the school age children demonstrated no significant difference between the leisure participation of children born preterm and their full term peers, with the exception of one study that found a difference but examined preterm birth in children who had a diagnosis of developmental coordination disorder. Dahan-Oliel, Mazer, & Majnemera (2012) rated the quality of the school age studies as poor to moderate with less than 40 participants in four of the five studies. These results contrasted with the results of the studies on adolescents and young adults.

Both the studies of adolescents and young adults found a difference between the leisure participation of the former preterm adolescents/young adults compared to full term peers. By self-report or parent proxy report adolescents from 11 to 17 years of age born preterm reported lower scores in social activities, hobbies and sports in comparison to peers with one study's participants attributing this to physical health issues. One study of adolescents born ELBW did not rate their enjoyment of physical activities lower than peers. The quality of these studies on adolescents was rated from poor to high with studies including 50 to 179 participants. Finally, the studies on young adults born <1500g with a mean age of 22-23 years reported less leisure-time physical activity and for shorter durations than their full term peers. These differences were present despite an absence of asthma or bronchopulmonary dysplasia (BPD) in the preterm group, although one study did attribute low participation rates to health conditions in the preterm group. The quality of these studies on young adults were rated as moderate to high with 116 to 163 participants in each study. Finally, only two of the 13 studies reviewed factors that may influence participation. One study of 38 former ELBW school children found no association between child factors such as BPD, birth weight, oxygen at 40 weeks with lung function and physical activity. The other study on young adults found that the low intensity levels in activities for short duration remained despite controlling for numerous child factors including sex, age, and parental education. Dahan-Oliel, Mazer, & Majnemera (2012) suggested a number of reasons for the differences in participation across the life span including the school age studies smaller sample sizes, lower methodological quality and possible discrepancies between self and parent report for this age group. Another suggestion by the authors was that the difference between the school age sample and the older groups may have been the result of a natural reduction of individuals' participation with increasing age, as noted with all children.

Dahan-Oliel et al. (2014a, 2014b) published the results of a Canadian study on the leisure participation of adolescents born preterm in two separate papers. The first paper by Dahan-Oliel et al. (2014a) described how this cross-sectional study used the Children's Assessment of Participation and Enjoyment (CAPE) (King et al., 2004) to assess the participation levels of 128 12-20 year olds born ≤ 29 weeks gestation (mean gestational age of 26.5 weeks), and 22 full term siblings. This is the first study to measure the variety of leisure participation that ELBW adolescents engage in using standardised assessment. The former preterm infants' reported high enjoyment scores in social and active physical activities, and highest enjoyment in skill-based activities. This contrasted with their actual participation as participants highest intensity of participation was in social and recreational activities and lowest in active-physical and skill-based activities. Females demonstrated higher participation levels in social and self-improvement activities ($p<0.05$) than males, while males participated in more active-physical activities ($p=0.01$) and more often than females. Participants with poorer cognitive and motor skills demonstrated lower levels of participation in active physical recreation and social activities. Older adolescents participated in higher levels of social activities ($p=0.01$) and more often ($p=0.002$) than younger adolescents, and overall former preterm infants participated in less activities ($p=0.013$) than their full term siblings. A limitation of this study is that the small sample size includes adolescents with a wide range of disabilities such as physical disabilities (5%), intellectual disability (12%), autism (5%) and psychiatric conditions (22%) that may confound the results of preterm birth. There was also little discussion on the environmental factors associated with the ELBW groups participation levels however this is discussed in detail in the second paper by these authors.

Dahan-Oliel et al.'s (2014b) second paper focused on the child and environmental factors associated with the leisure participation of this same cohort of 128 former preterm adolescents born ≤29 weeks gestation and with a mean birth weight of 898.6g (range: 490-1445g). Child factors included age, sex, gestational age, motor, cognitive and functional status and were measured using a large number of standardised assessments and questionnaires. Measures that were of interest to this study included the Vineland Adaptive Behavior Scales, Second Edition (Sparrow, Cicchetti & Balla, 2005) which was used with parents to record the adolescents' functional status in overall adaptive functioning and three adaptive domains (communication, daily living and socialization). The Preferences for Activities for Children (King et al., 2004) was also used to assess the activities the adolescents most preferred, regardless of their performance in these tasks. Assessors' were blinded to the adolescents' medical history and other test results. Extensive environmental factors were measured using a number of standardised measures. The Family Environment Scale –Fourth Edition (Moos & Moos, 2010) measured the 'family climate' (family social environments in the three dimensions of relationship, personal growth and system maintenance) by parent report. The Social Support Scale for Children and Adolescents (Harter, 1985) was used to assess the perceived support the adolescents received from parents, teachers, friends and classmates by self-report. Finally, the Child and Adolescent Scale of Environment (Bedell, 2004) examined the physical, social and attitudinal barriers of the adolescents by parent report. Maternal education was also documented.

Of the adjusted variance for participation intensity, the contribution of child and environmental factors ranged from between 21% in skill based activities to 52% in active-physical activities. Of the five domains of intensity of participation as measured by the CAPE, Skill based activities were significantly associated with a preference for these types of activities, higher maternal education and a family orientation to leisure participation. Participation intensity in active-physical activities was strongly associated with the child's motor competence, preference for active physical activities, male gender and higher maternal education. Participation intensity in recreational activities was associated with preference for these types of activities but also with lower gestational age. Intensity of participation in social activities was associated with a preference for social activities, increasing age and also perceiving oneself as being socially acceptable. Finally in the fifth area of activity in the CAPE, self-improvement activities, the multivariate regression model demonstrated preference for self-improvement activities to be the only independent variable that reached significance. The authors suggested these differences in associations between environmental and child factors and participation intensity may be a result of the variation in the underlying demands of the five types of leisure activities.

Of interest to this study, correlations between the Vineland II and the CAPE were explored demonstrating a small correlation with participants' overall adaptive behaviour scores and three domain scores with their scores on three of the activity types of the CAPE (active physical, social and self-improvement activities) which reached significance ($p<0.01$). A very small correlation was found between the adaptive scores and the other two CAPE scores (recreational or skill based activities) and this did not reach significance. Environmental barriers (Physical, social and attitudinal barriers), as measured by the CASE were also not significantly associated with any specific activity area of the CAPE. Dahan-Oliel et al. (2014b) acknowledged that variance in certain areas of participation intensity such as active-physical activity were easier to understand in the context of child and environmental factors while skill-based activities had the most unexplained variance. The authors concluded that activities that are individually tailored to the adolescents' skill levels and preferences, including family and friends and encouraging social acceptance, will enhance participation. Finally, the authors acknowledged that although certain environmental and child factors such as age, gender and maternal education cannot be modified they can be used to identify adolescents who may be at risk for low participation. Although a small sample size, this study's results highlight the complexity of understanding the participation of children born preterm in five leisure activity types and therefore the clear need for further studies in this area.

A study by Khetani, Graham & Alvord (2013) although not focused on a preterm population is one of the few studies that reported to explore the participation of preschool children with disabilities. The study examined the community participation patterns of a large subsample of caregivers (N=1509) of children with disabilities drawing from data in the National Early Intervention Longitudinal Study (NEILS; 1997-2007). The study explored the child (4 personal factors and 9 functional abilities), family (N=4) and environmental (N=3) correlates of participation restriction for this group at 46 – 86 months (mean=67.7 months). As with Dahan-Oliel et al.'s (2014b) study the range of abilities and co-morbidities of the sample presents challenges for comparison. The majority of these children had a developmental delay (N=960) or a diagnosis (N=320). The group of most interest to this study would appear to be the 'at risk' group (N=229) however the majority of study results were presented for the group as a whole. 39.3% of the parents surveyed reported restrictions in participation that were strongly related to a number of child and family demographic factors, the child functional abilities and environmental factors. Of the three categories of participation (neighbourhood outings, community-sponsored activities, and recreation and leisure) there were strong and significant concurrences between participation difficulties and neighbourhood outing activities. The three categories contained nine activities in total. The children's functional abilities, rather than their reason for referral to early intervention services, were strongly associated with difficulty participating in seven of the nine activities. Similar to other studies of participation, this study found that families with lower incomes were more likely to express difficulty in participation in seven of the nine activities (Law et al., 2006). Caregivers who reported difficulty managing their child's behaviour were more likely to have difficulties participating in all nine activities. As Khetani, Graham & Alvord (2013) found the three environmental factors (transportation, family/friend support and securing a babysitter) were associated with all nine areas they suggest there may be setting-specific qualities in the environment that influence participation rather than activity-specific influences. This contrasts with Dahan-Oliel et al. (2014b) findings that suggest variations in participation may be a result of underlying demands of the five types of leisure activities they measured.

Finally, a recent scoping review by Anaby et al. (2013) aiming to establish the evidence on the association between the environment and out-of-school participation of children and youth with disabilities, including identifying the key environmental barriers and supports was done. Peer-reviewed articles published between 1990 and 2011 were included if they focused on children between 5 and 21 years of age, out-of-school participation and the influence of any aspect of the environment. Of an initial 1646 articles, duplicates were removed (N=414) and remaining articles were reviewed by two reviewers leaving a remaining 31 articles that met the inclusion criteria. Over half of the articles reviewed children with cerebral palsy (N=17), followed by physical disabilities (N=6), acquired brain injury (N=3), autism (N=3) and Down syndrome (N=2). No articles on children born preterm were reported. This sparsity of information on the child, family and environmental factors associated with the participation of children born preterm, most evident in the preschool population, strengthens the need for the current study.

Section 4 Contextual Factors Impacting on Preterm Birth

4.1 Environmental Conditions

As early as the 1970's Bronfenbrenner (1977, 1998) outlined a structure of the ecological environment using a framework of 4 interdependent systems. The first, a microsystem, is a complex interaction between a developing person and their immediate settings such as their workplace, home and school. A mesosystem, a system of microsystems, is comprised of the interrelations between the major settings in the individual's life at a particular point in time. The extension of the mesosystem is the exosystem. This system is the larger social structure such as government agencies, transport systems and mass media that does not directly contain the person but impinges upon or envelopes the person's direct environments, therefore indirectly influences the person or what goes on in the person's immediate settings. The final overarching system, the macrosystem differs from the previous systems as it does not focus on specific contexts that influence the person, rather it refers to the general prototype or 'blueprint' of the culture that may be explicit in laws and regulations or implicit in the ideology, customs and practice of their daily life. In this context Bronfenbrenner (1979, 1986) reported key influences of child rearing to be parents' informal supports such as extended family and friends, and their formal support systems such as schools, childcare, professional support.

This study of human ecology i.e. human beings and their relationship with their environment has led to the concept of 'person-environment congruence' or 'person-environment fit' (Case-Smith et al., 2010; Law & Dunn, 1993). This congruence or 'fit' is between the person and the physical, social and attitudinal environment in which they live their lives, and, according to the ICF, captures the context of the individual's functioning or disability (WHO, 2001). In childhood, it is widely agreed that environmental factors can facilitate or limit a child's engagement in occupation (Case-Smith et al., 2010). Despites concerns that environmental conditions may aggravate or mitigate the impact of biological risks on a child's development (Oliveira, Magalhães & Salmela, 2011), the association between the environment and vulnerable populations such as preterm infants has received little attention in the literature. Examples of broader environmental facilitators such as 'family leave policies, day care and early education accessibility, and comprehensive health insurance' and environmental barriers including 'negative attitudes of others, lack of legal protections, and discriminatory practices' have been suggested however not specific to preterm infants (Msall, 2006, p.158). Personal factors such as age, gender, interests, and sense of self-efficacy (Msall, 2006) have also been noted as potential facilitator or barriers and therefore Chiarello et al (2011) emphasize that these environmental and personal factors that influence the activity and participation of young children with special needs need to be better understood.

Physical Environment

Numerous studies have documented the impact of the infant's genetic and prenatal environment on their subsequent postnatal development and acknowledge the adverse effect a mother's poor prenatal physical or psychological health impact on the fetus's development (Fraser et al., 2013). For example, even mild to moderate maternal psychological stress can lead to serious adverse effects such as preterm birth and low birth weight (Hobel, Goldstein & Barrett, 2008). A prospective cohort study of finish VLBW infants demonstrated that compromises in maternal or paternal psychological health, if endured in to the infant's early years of life, can lead to increased parent-reports of behavioural, emotional (Huhtala et al., 2012) and cognitive impairments (Huhtala et al., 2011) in VLBW, preterm infants. Substance abuse such as prenatal alcohol abuse and cigarette smoking also have been associated with low birth weight and preterm birth (Bjerg et al., 2011; Goldenberg et al, 2008). A systematic review of the literature on the fetal effects of prenatal binge-drinking

(Henderson, Kesmodel & Gray, 2007) from 1970-2005 focused on adverse outcomes including intrauterine growth restriction, prematurity, birth-weight, small for gestational age at birth, and birth defects. Of the relatively limited literature on this topic, the review found that there was no consistent effect of binge-drinking on the embryo, fetus or developing child across the 14 studies in the final review. The only exception was a possible small effect of binge-drinking on neurodevelopmental outcomes. A study by Crocker et al, (2009) using the Vineland Adaptive Behavior Scales in a case versus matched control group, however suggests that heavy prenatal alcohol exposure has an impact on the adaptive behaviour of children.

Other maternal factors include age and education. Since the 1970's the proportion of first births to mothers in their thirties and forties has risen substantially (Ventura et al, 2000). In North America, the increasing age of women giving birth, which leads to more maternal complications and Caesarean sections, may partially explain the high rates of low birth weight, multiple birth and preterm babies delivered (Beck et al, 2010; Tough et al., 2002) that is also seen in mothers younger than 20 (Ekwo & Moawad, 2000). A systematic review by Newburn-Cook & Onyskiw (2005) investigated the impact of advancing maternal age on the adverse pregnancy outcomes of preterm birth and small for gestational age. Results showed an effect of increased maternal age on both gestational age and birth weight. It was however unclear if age exerts a direct and independent force on birth outcome or it is a risk marker that acts indirectly through its association with age-dependent confounders such as the method the pregnancy was conceived (natural or by assisted reproductive technology), diabetes or prenatal complications that result in early delivery. In relation to child rearing in general maternal chronological age appears to influence different domains of parenting. For example, advanced maternal age has been positively associated with increased parental knowledge and satisfaction, and richer communication with infants and toddlers (Bornstein et al., 2003; Bornstein et al., 2006) but lower levels of stamina to meet caregiving demands compared to younger mothers, given that physical health and fitness generally decline with age (Mirowsky, 2002).

Increasingly women are delaying their age at first birth and first marriage in order to complete their education and pursue their careers (Newburn-Cook & Onyskiw, 2005). This higher maternal education has been associated with decreased morbidities in infants and children (Vohr et al, 2000). For example, Miller et al. (2001) found consistently from both parent and teacher reports that children born ELBW that presented with behavioural problems at 8 years of age were more likely to have mothers who did not complete high school. This finding is consistent with Hille et al. (2007) who researched VLBW infants neurodevelopmental skills and participation and found that the most striking impact on scores was the level of parental education, stating that 'the lower the level, the higher the proportion of problems in any domain or overall' (p. 590). Less well educated parents did not however have more difficulty mobilising extra supports for their children than more educated parents (Kessel-Feddema et al., 2006)

Social Environment

For decades it has been recognised that experimental studies involving socialization should not only stratify samples by social class but also by family structure and/or child care setting, allowing for ecological differentiation between home and day care settings (Bronfenbrenner, 1977). In a population-based study by Jutte et al. (2010) in Canada, social risk factors such as marital status, socioeconomic grouping and maternal age were shown to be stronger risk factors for poor health and educational attainment than biological factors such as prematurity or low birth weight. This has been refuted by other authors (Taylor et al., 1998) while McManus et al.s (2012) suggest a complex interaction of both stating that there is a lot of variation in the cognitive delays observed in preterm children depending on the interaction between the biological risk factors of preterm birth and protective factors such as family support which is also strongly correlated with infant cognitive function. Regardless of the hierarchy, a greater emphasis on the child's social environment has been encouraged in healthcare screenings with the acknowledgement that 'we can never separate the child, the parent, and the child's developmental outcome' (Chandler, 2010, p.78). In fact Silverstein et al. (2010) have been argued that conceptualization of preterm follow-up services should be expanded to include consideration of the entire family's wellbeing. In a study by Taylor et al. (2006) more family resources such as support from spouses, extended family, friends and co-workers were associated with higher global mental processing skills on the Kaufman Assessment Battery for Children (Kaufman & Applegate, 1998) for the normal birth weight group in a case-control trial of children with a mean age of 8 years, but not for the ELBW group. This is not consistent with previous studies that suggest that more advantageous family environments can mitigate some of the adverse developmental effects of VLBW (Taylor et al., 1998; Landry et al., 1998) and therefore suggests that the moderating effects of the environment may be dependent on the outcomes being assessed (Taylor et al., 2006)

Miller et al. (2001) found that children born ELBW that presented with behavioural problems at 8 years of age were more likely than those without difficulties to come from a home that had 3 or more changes to the environment in the past 3 years. Maternal depression is disproportionately common in mothers of preterm infants and, in VLBW infants, has been associated with negative maternal perceptions' of the children's social abilities and preschool participation (Silverstein et al., 2010). The coping strategies of a family of a child with special needs also appear to vary depending on whether or not the child has siblings, and is so the order of the siblings. For example, parents whose first child has special needs do not have the experience to draw on as those with older children (Jaffe, Humphry & Case-Smith, 2010, p.114; Grant & Whittell, 2000)

‘Growing up in impoverished or unsafe conditions is associated with significant threats to long-term physical and mental health, cognitive development, educational achievement, emotional well-being, and social adjustment, and these impacts are particularly potent in early childhood’ (Shonkoff et al., 2012, p.461). Studies show that children of lower socio-economic status have or are more at risk of motor, cognitive and social developmental delays that affect school performance (Golos et al., 2011; Mansour et al., 2003; Marr, Cermak, Cohn, & Henderson, 2003), social functioning (Sullivan et al., 2012), and adaptive behaviour (Taylor et al., 2006). This is compounded by the fact that these infants are more likely to be born VLBW. For example, in 2006, the Institute of Public Health in Ireland produced a report on the analysis of births from 1999-2001 in the Eastern Regional Health Authority, Ireland. In this report, ‘the greatest risk of being born low birth weight was recorded for babies born to parents who were classified in the Unknown and the Unemployed categories’ (McEvoy et al, 2006, no page no.).

A 2012 ERSI report was consistent with this stating the ‘the highest proportions of total births were to mothers whose socio-economic group was classified as either intermediate non-manual workers (20.9 per cent) or home duties (19.2 per cent)’ (ESRI, 2013, p.29). Other international studies of low birth weight babies have found however, a ‘relative lack of effect of social risk on the functional outcomes and special health care needs’, in comparison to effect that neonatal risk factors have demonstrated (Hack et al, 2000, p.559; Taylor et al., 1998; McCormack et al., 1992). Finally, Nuru-Jeter et al. (2010) argue that associations between child health and developmental outcomes and children of lower socioeconomic disadvantage are not static and may vary depending on the SES indicators chosen for measurement and the children's ethnicity or race.

Davison and Lawson (2006) reviewed 33 quantitative studies that assessed the relationship between a child’s physical environment and their level of physical activity. The majority of studies demonstrated that neighbourhoods with available facilities and permanent activity structures in school playgrounds were associated with higher physical activity. Most studies in this review did not however identify an association between the families' home equipment and the children's physical activity. The children's proximity to playgrounds also did not demonstrate consistent results.

4.2 Personal Factors

The second of the two contextual factors, 'personal factors' is used in both the ICF and ICF-CY framework but these factors are not included in the classification system (WHO, 2001; WHO, 2007). In the ICF-CY (WHO, 2007) personal factors are described as non-health related factors such as the person's age, lifestyle, fitness, habits and coping style.

Gender differences

Preterm males have greater mortality (Costeloe et al, 2000) and morbidity than their female peers (Peacock et al, 2012). Using the data from the United Kingdom Oscillation Study, Peacock et al, 2012, reviewed the data of 797 infants (428 males) born at 23-28 weeks. The aim was to determine if the poorer outcomes of preterm male infants was a result of an intrinsic male effect or due to poorer neonatal profiles. Despite controlling for neonatal and maternal factors, and gestational age and birth weight, males remained at significant risk for poor neonatal outcome, including neurological and respiratory outcome. Although a Swedish follow-up study in the early 90's found that low birth weight females, but not males, demonstrated significantly lower Intellectual Quotients and school performance at 10 and 13 years of age in comparison to their female peers of normal birth weight (Lagerstrom et al., 1991) more recent studies have consistently indicated female sex to be a 'protective factor in neurological development' (Fernandes et al., 2012, p. 476; Vohr et al., 2000; Tyson et al., 2008). In a case-control study of extremely preterm children at 11 year of age, males demonstrated significantly lower cognitive scores and reading abilities than females, while both presented with significantly lower scores than their full term classmates (Johnson et al., 2009). Males in this group were also more likely to have serious impairments, have special educational needs and use special education provision than their female counterparts. Taylor et al (2006) found this trend of females having higher scores than males in academic skills evident both in school aged children born full-term and preterm.

Sullivan et al. (2012) also found a significant difference for sex (p=.003) when they expanded the developmental domains compared to include broader areas of adaptive functioning, with males born premature at 17 years of age, having lower scores in social interaction, personal living, community living, and broad independence than their female peer. This disadvantage in the acquisition of adaptive behaviour has been

Ethnicity

Black race is a risk factor for preterm birth, and spontaneous preterm birth is more common in white women while premature rupture of the membrane is more common in black women (Goldenberg et al., 2008)

Section 5 Assessment and Intervention following Preterm Birth

5.1 Early Intervention Services

‘Preterm birth not only affects infants and their families – providing care for preterm infants, who may spend several months in hospital, has increasing cost implications for health services’ (Tucker and McGuire, 2004, p.675). The American Academy of Pediatrics suggests ‘Periodic evaluation of the developmental progress of every infant is essential for identifying deviations in neurodevelopmental progress at the earliest possible point, thereby facilitating entry into early intervention programs’ as appropriate (Committee on Fetus and Newborn, 2008, p. 1123). A systematic review of the behavioural, motor and academic skills in school-age children, however, emphasised that the follow up of preterm children to two years of age is inadequate to detect bi-manual, behavioural and visual-motor abnormalities (Moreira, Magalhaes & Alves, 2009). Long term follow-up studies have revealed a high frequency of developmental disturbances in preterm survivors who were formerly considered free of disability (Van Kessel-Feddema et al, 2007), with school entry being a pivotal time for former preterm infants who are requested to perform specific skills that were not previously demanded of them but may be impaired (Moreira, Magalhaes & Alves, 2009).

Frameworks/Models of Practice guiding Early Intervention:

Family-Centred Practice

Occupational therapists working with children typically substitute the term ‘client centred’ with ‘family centred’ to reflect the way the child with special needs is part of a complex family system with reciprocal influence on one another’s ability to participate in life activities (Fingerhut et al., 2013; Jaffe, Humphry & Case-Smith, 2010). ‘Children cannot to be treated as isolated individuals, they are members of families, social units that shape behaviour and life experiences' (Jaffe, Humphry & Case-Smith, 2010, p.108). 'Family-centred practice means that the family is an active participant in early intervention and early childhood programs' i.e. they, most specifically the parents (Fingerhut et al, 2013), 'participate in all aspects of the service provision process as an equal to all providers' (Chandler, 2010, p.80). 'Assessment of family strengths and needs is intertwined with the assessment of the child's needs, with the intervention and with the use of Individual Family Service Plans' (Carroll, Murphy & Sixsmith, 2013, p.23). Even in the Neonatal Intensive Care Units, 'the former approach of "therapist as expert, child as client, parents as students" has evolved to family-centred mutual collaboration' (Hunter, 2010, p.659). In Ireland, the Health Service Executive guidelines 'suggest that to achieve best possible outcomes for children and families, explicit goals and objectives need to be set, responsive to each family's priorities, regular evaluations and feedback from both team members and families, formal and informal evaluation of functional, and clinical and personal outcomes'(Carroll, Murphy & Sixsmith, 2013, p.24).

A systematic review of 42 occupational therapy research articles, of which 18 were chosen for inclusion, Kingsley and Mailloux (2013) concluded that 'family-centred and routine-based intervention was a central theme for many of the studies, and the evidence suggests that embedding intervention within a family's natural routines can lead to positive outcomes, specifically positive parent reports of satisfaction and efficacy' (p.434). In a study by Fingerhut et al, 2013, analysis of interview responses of 28 OTs in the US working in a variety of settings found however that the level of family centred practice varied depending on the setting. Using a classification of seven levels of family centeredness developed by Brown, Humphry, and Taylor (1997), OTs reported a continuum of family centred practice with home-based practice being most family centred, clinic based and private practice being in between, and school-based practice being the least family centred.

Early Intervention in Ireland – Policy and Context

Historically, the progression of early intervention disability services in Ireland has evolved from the initial emergence of the concept of a universal national health strategy in Ireland in the 1940's to the reconfiguration of both public health and disability services in the 1970's (Carroll, Murphy & Sixsmith, 2013). This reform of Irish health care re-structured childrens services from large institutional care to smaller community settings (Quin and Redmond, 2003). Following this reconfiguration, national reports such as the Needs and Abilities report (Government of Ireland, 1990), the National Children's Strategy (Department of Health and Children, 2000), and the Primary Health Care Strategy (Department of Health and Children, 2001) highlighted further gaps in services such as the need for front line personnel to receive training in screening and detection of developmental disabilities, specialist early intervention teams for young children with developmental delays, and a focus on child and family-centred practice within the community. This legislation provided the foundation for The Disability Act (Government of Ireland, 2005), a key element of the National Disability Strategy, which placed 'significant obligations on public bodies to make buildings and services accessible to people with disabilities' (Department of Justice, Equality and Law Reform, 2005).

In 2007, Part 2 of the Act legislated for all children under 5 years to be provided with a statutory assessment of their health and educational needs. This 'Assessment of Need' was time-limited and provided families with a Service Statement including recommendations detailing the services the child required. Despite, however, the implementation of this process and the commencement of the development of a 'National Early Year's Strategy', there is currently "no national policy for the universal or specialist early intervention services in Ireland" (Carroll, Murphy & Sixsmith, 2013, p.20). This has caused wide variation in the referral pathway, length of waiting lists, criteria for access to, model of team-based assessment and provision of early intervention services throughout the country (National Disability Authority, 2011; Carroll, Murphy & Sixsmith, 2013). The National Framework for the Delivery of Early Intervention Disability Services (Health Service Executive, 2010), a collaboration of professionals and families in early interventions services, has produced standards that aim to unify the provision and vision of early intervention services in Ireland.

The Health Service Executive has identified the bio-psychosocial model as the guiding framework for Early Intervention teams in Ireland (Health Service Executive, 2011). There is currently, however, no national early intervention policy, no standardised model for team-based assessment, no unified model of team working, and variations in the professionals who comprise the team in different geographic locations (Carroll, Murphy & Sixsmith, 2013). Thus Early Intervention Services in Ireland are in a significant and radical transition stage.

The challenge of delivering effective Early Intervention Services appears to be international. An Australian study by Roberts et al, 2007, of a cohort of 236 preterm infants (<30 weeks or birth weight <1250g) followed from birth compared the relationship of disability level to early intervention services and social risk factors at 2 years of age. Results showed that almost 50% of children categorised as having moderate to severe disability by parental questionnaire and the Bayley Scales of Infant Development- Second Edition (Bayley, 1993) and 72% of those with mild disability were not receiving services at 2 years of age.

5.2 Occupational Therapy within the Early Intervention Team

'All people need to be able or enabled to engage in the occupations of their need and choice, to grow through what they do, and to experience independence and interdependence, equality, participation, security, health, and well-being' (Wilcock & Townsend, 2008, p. 198). Occupational therapy is a client centred health profession that addresses these aims by 'promoting health and well-being through occupation' and enabling 'people to participate in the activities of everyday life' (World Federation of Occupational Therapists, 2010). OT's believe that participation can be supported or restricted by physical, cognitive, psychosocial, sensory-perceptual or other abilities of the individual , the characteristics of the occupation, or the context and environment (World Federation of Occupational Therapists, 2010; American Occupational Therapy Association, 2011). Within this context, client factors such as body functions and structures are only addressed in order to 'support engagement in everyday life activities that affect physical and mental health, well-being, and quality of life' (American Occupational Therapy Association, 2011)

'A host of developmental conditions continue to be associated with preterm birth including cognitive disability, atypical gross and fine motor patterns, attentional problems, and other behavioural and learning difficulties, all with the potential to disrupt the development of adaptive functioning' (Oakland and Harrison, 2008, p.272). The OT's first possible contact with the preterm infant is in the neonatal intensive care unit. Traditionally, infants identified with specific risk factors such as VLBW or congenital anomalies, or performance indicators such as abnormal tone, poor feeding or developmental delay were referred to OT for rehabilitation and developmental stimulation. In more recent years the OT's role has however expanded to developmentally supportive care that includes both a preventive and protective component that involves protecting the fragile infant from excessive or inappropriate sensory input (Hunter, 2010).

‘The term early intervention connotes different meanings to different professionals’ (Myers, Stephens & Tauber, 2010, p.681) and there is limited research on the overall effectiveness of such programmes (Ziviani, Feeney, Rodger and Watter, 2010). It is agreed however that late intervention is both expensive and inefficient and therefore evidence-based early intervention, when required, maximises the impact of treatment and provides the social and emotional bedrock for the developing child (Allen, 2011).

‘Occupational therapy practitioners work with children, youth, and their families to promote active participation in activities or occupations that are meaningful to them (AOTA, 2010). They ‘develop interventions based on analysis of the child’s behaviours and performance, the occupations in which he or she engages, and the context for those occupations’ (Case-Smith, 2010, p.1). Occupational therapists have many roles on an early intervention team including ‘1) providing family-centred services that honour the family’s priorities; 2) enhancing young children’s play, self-care, and social interaction with implications for benefits across occupational performance; 3) providing services in natural environments and the family’s routine; and 4) emphasizing interventions, including assistive technology when appropriate, that promote the child’s participation in family, school, and community activities’ (Case-Smith, 2013, p.380). According to a systematic review of the occupational therapy literature by Kingsley and Mailloux, 2013, there is no method of service delivery that is clearly identified as superior and most models use a combination of approaches and environments for intervention. Occupational therapy services in early childhood are provided to infants, toddlers, and pre-schoolers who are at risk of or who have a developmental delay or disability (Arbesman, Lieberman & Berlanstein, 2013). This includes the assessment and treatment of children with biological risk factor such as preterm birth. This is very important as the cumulative effect of failing to obtain developmental skills results in decreasing levels of motivation which in turn plays a negative effect on further development (Van Kessel-Feddema et al, 2007)

5.3 Evidence base for Occupational Therapy Intervention

‘Engagement in occupation to support participation in context is the focus and targeted end objective of occupational therapy intervention’ (AOTA, 2014, p.611). OT’s agree that it is useful to use bottom-up approaches to analyse performance skills such as cognitive, motor or sensory components however, emphasise analysis of the direct occupations and argue that ‘at some point it becomes necessary to reframe isolated skills and integrate them into a broader knowledge base that is focused at the level of occupational engagement’ (Parham, 2008, p.26). Bottom-up approaches were developed in the 1960’s and became popular because the skills being treated could be measured however, these deficit oriented approaches have not been found to be effective in improving the occupations of children (O’Brien & Williams, 2010). In contrast to this, the evidence for contemporary task-oriented interventions that became popular in the 1990’s continues to mount. As a result, OT interventions have become more functional and goal focused. Factors that have influenced emerging areas of practice include greater family involvement in the decision making process, changing conceptual and theoretical models such as the introduction of the ICF-CY (WHO, 2007) and enhanced outcome measures (Law & Darrah, 2014). Theories of motor behaviour have shifted from that of traditional hierarchical models to contemporary systems models of motor control and this has influenced occupational therapy practice (Mathiowetz & Bass Haugen, 1994). Therefore as the evidence on bottom-up approaches such as Sensory Integrative Therapy (Ayres, 1972), Neurodevelopmental therapy (Bobath,1971), Perceptual Motor Training (Davidson & Williams, 2000) is inconclusive for children, and the focus of the profession has moved towards occupation or task-oriented interventions, bottom-up interventions will not be discussed in any detail (O’Brien & Williams, 2010).

Many different terms have been used to describe this focus on functional performance such as ‘ecological task analysis, functional therapy, goal-directed functional therapy, activity focused and goal directed, activity-focused, and task-oriented' that emphasise changing the child's ability to complete a task (Law et al., 2011, p.622). These activity-focused interventions include Neuromotor Task training (NNT) for children with developmental coordination disorder (DCD) (Schoemaker et al., 2003; Niemeijer, Smits-Engelsman &Schoemaker, 2007) and the Cognitive Orientation to daily Occupational Performance (CO-OP) approach for children with DCD (Polatajko & Mandich, 2004). Other more recent approaches include Context therapy for children with cerebral palsy (Darrah et al., 2011) and Partnering for Change for children with DCD (Missiuna et al., 2015). These approaches demonstrate the large emphasis of interventions on specific populations of children i.e. those with cerebral palsy and DCD. No studies of activity-focused interventions for children born preterm and VLBW without physical or intellectual disabilities have been found.

Armstrong (2012) reviewed the evidence for specific occupational therapy interventions for children with developmental coordination disorder (DCD). The inclusion criteria for review of articles were that the children in the study had a primary diagnosis of DCD, the study presented actual research in to the effectiveness of the intervention, the intervention was consistent with the philosophy of occupational therapy and they were peer-reviewed journals in the English language. A search of articles from 1984-2011 yielded 61 articles, further analysis reduced this number to 19. Of these articles six types of interventions were identified, four of which were task-oriented (CO-OP approach, NNT, and goal-oriented group intervention). A limitation of this review is that as different outcome measures were used in this study a meta-analysis of the effectiveness of the interventions could not be performed. From the studies presented the author reported that the research on the Cognitive Orientation to daily Occupational Performance (Polatajko & Mandich, 2004) yielded the strongest evidence for improving daily life skills. The CO-OP is 'a client-centred, performance-based, problem solving approach that enables skills acquisition through a process of strategy use and guided discovery' (Polatajko & Mandich, 2004, p.2). The second intervention reported to demonstrate most improvements was the goal-oriented group intervention (Dunford, 2011), an intervention in which the children practised the occupation they wished to improve on in a group setting. The studies on NNT did not reportedly demonstrate a clear focus on the child's specific occupations and it was not possible to ascertain if improvements remained after the sessions or were transferred in to other performance areas. In summary based on this review interventions that focus on children's activities of daily living such as the CO-OP approach are recommended for use with children with DCD.

In recent years a number of studies have performed activity-based interventions to improve the performance of children with cerebral palsy in everyday activities of daily living in their natural environment. This process is supported by the use of collaborative goal setting specific to these activities. A recent systematic review by Carlberg and Löwing (2013) aimed to investigate if goal setting as part of activity based intervention for children with cerebral palsy improved the outcomes. Articles between 2000 and 2012 were reviewed with the following inclusion criteria for article selection: study designs included randomised control trials (RCTs), controlled trials, cohort studies, case-control studies, before-after studies and single-subject experimental designs; activity-focused or task-oriented intervention with therapeutic input combined with goal setting; and children 1-17 years of age with a diagnosis of cerebral palsy. Medline and CINAHL were searched and based on the titles and abstracts 45 articles were selected, of which 12 met the inclusion criteria. A manual search of reference lists retrieved one more appropriate article. These final 13 articles consisted of 6 RCTs, one case-control study, three before-after design and three single-subject experimental designs (each including two or more participants). The age range of participants was between 1-17years of age (mean range 2 years 2 months to 10 years 1 month) and participant numbers ranged from between 3 and 128 participants. In eight of the thirteen studies the Pediatirc

Evaluation of Disability Inventory (Haley et al., 1992) as the standardised measure. 10 of the 13 studies used the Canadian Occupational Performance Measure (COPM) (Law et al., 1990) and/or Goal Attainment Scaling (GAS) (Kiresuk, Smith & Cardillo, 1994) to measure individual outcomes. The other studies used goal setting but not as an outcome measure.

Ten of the thirteen studies demonstrated robust within-group changes based on standardised measures while study designs with between-group comparisons showed less consistent outcomes. Goal setting combined with activity-focused intervention demonstrated better effects on activities of daily living than bottom-up approaches such as neurodevelopmental treatment or activity focused intervention in isolation. In Law et al.'s (2011) RCT comparing activity-focused intervention without goal setting to context-focused intervention with goal setting no significant difference was found between interventions on standardised outcome measures. The other RCTs included focused primarily on upper limb function and included goal setting for all study groups. Of these 5 RCTs only one (Novak, Cusik & Lannin, 2009) demonstrated a difference between groups on standardised measures, in favour of a four or eight week occupational therapy home programme than no intervention at all. When child-specific measures (COPM/GAS) were explored in the RCTs however more differences between the interventions emerged with positive child-specific effects demonstrated. Child-specific positive effects were found for both the four and eight week occupational therapy programmes compared to no treatment (Novak, Cusik & Lannin, 2009), occupational therapy combined with botulinum toxin (BoNT-A) compared to BoNT-A alone (Wallen, O'Flaherty & Waugh, 2007), and hand-arm bimanual intensive training compared with constraint induced movement therapy (Brandao, Gordon & Mancini, 2012). The six studies with before-after design and single-subject experimental designs all demonstrated favourable outcomes reflected in standardised outcome measures including goal setting measures. In all studies that used the GAS scores there was a high attainment (ranging from 60-85%).

Overall, the results of these studies did not provide support for goal setting as a method of improving activity-focused intervention however, the authors cautioned that it was difficult to separate the effect of goal setting from the effect of markedly different interventions that were difficult to compare.

As can be seen from these reviews, occupational therapy interventions that are activity-focused are demonstrating promising effects with children with cerebral palsy and developmental coordination disorder. No OT studies of this nature were found on children born preterm and VLBW without physical or intellectual disability. Therefore despite consensus amongst childhood disability researchers that optimising children's participation in activities of daily life is the overarching goal of health services, once the child is medically stable (Morris, 2009), little knowledge exists in relation to the patterns of adaptive functioning and participation of healthy preterm VLBW children and the best interventions to meet their unique needs.

5.4 Challenges of Measuring Activity and Participation

In an era that emphasises evidence-based therapy, occupational therapists are under increasing pressure to use quantitative measurement tools to justify both the need for service and the value of interventions, in terms of the outcomes achieved (Coster, 2008). Although numerous measures aim to describe, predict and evaluate specific constructs, the specific measures selected have a profound impact on what data is extracted (Coster and Khetani, 2008). It is therefore not just sufficient that the instrument is psychometrically valid and reliable but it most also be the correct tool to answer the research question posed (Eliasson, 2012). That is, a person's behaviour is complex and different patterns may be detected depending on the lens it is viewed through (Coster, 2008).

In an era of unprecedented advances in child development, genetics and neuroscience, the task is not only to prevent disability but also to maximise functional outcomes for children within the context of their family and community (Msall, 2005). The ICF-CY (WHO, 2007) is the international standard for coding childhood function and disability; however there are few measurement tools available that seamlessly match the coding within this framework (Østensjo et al, 2006; Granlund, Eriksson & Yiven, 2004). Coster and Khetani (2008) therefore suggest new measurement tools that are congruent with the domains and definitions of this framework are required to effectively implement its coding and test its proposed relationship with hypothesized pathways to healthcare and disability services across populations. This functional rather than a developmental focus that assesses the everyday life skills that are important to the child in context, rather than providing a comparison of them with other children of the same chronological age is more appropriate (Ibragimova, Granlund & Bjorck-Akesson, 2009). The functional assessments allow for special equipment and assistive devices to be considered in the context of task performance and with the supports required for successful participation in the classroom and community (Msall, 2005).

A recent review of the assessments available to measure activity and participation was performed by Phillips et al. (2013). Twenty instruments that purported to measure this construct were found however, the authors concluded that no single instrument measured activity and participation across all life areas. No single instrument measured the dimensions of the extent of involvement, and the difficulty and satisfaction/enjoyment experienced in all life areas, in line with the ICF-CY framework. These measures will be discussed in more detail in the section on 'Measures of adaptive behaviour' and 'Measures of participation' later in this chapter. Another consideration in relation to measurement tools is their cross-cultural validity when used in a country other than the one they were normed for. In the profession of occupational therapy, the majority of assessments used are developed and validated in the English language, with cross-cultural translations and adaptations that address language and cultural discrepancies becoming increasingly more common (Schulze et al., 2013). Other than the observational section of the Bayley III (Bayley) that has been re-normed for an Irish and UK population of children (Bayley, 2010), the majority of assessments used on young children in Ireland have not been normed in or for Irish children. This issue will be elaborated on in the section on 'Cultural differences in activity and participation'. Finally, the last pertinent issue specific to the use of developmental assessments with preterm infants is that of age adjustment for prematurity and this will be discussed now.

Age Terminology and Age Adjustment of Premature Babies

The American Academy of Pediatrics (AAP) defines chronological age (or postnatal age) as the time elapsed after the infant's birth and it can be presented in days, weeks, months or years. The corrected age (or adjusted age), also described in weeks or months, is the infant's chronological age reduced by the number of weeks the infant is born before 40 weeks of gestation. The AAP states that the infant's corrected age is calculated by subtracting the number of weeks the infant is born before 40 weeks of gestation from their chronological age (Committee on Fetus and Newborn, 2004, p. 1363). As early as the 1930's researchers studying the development of preterm babies adjusted the infant's age for prematurity. Mohr and Bartelme (1930) noted that this eliminated the difference in the development in healthy preterm babies, minimized the differences in development of smaller prematurely born babies and reduced the likelihood of misdiagnoses of mental retardation. Since the 1990's however the parameters for correction for prematurity have been controversial and although correction of age in infancy is more readily accepted, it is argued that there is 'no good evidence to suggest that a similar correction is necessary at an older age' (Saigal et al, 1990). This controversy continues today with research studies in this area continuing to demonstrate considerable variability in their method used to adjust for prematurity, the age at which adjustment for prematurity ceases and the author's provision, if any, of a rationale for adjusting for prematurity (Dodrill et al., 2008; Wood et al., 2003; Amess et al., 2010). This grey area has even led researchers to avoid assessing infants under 24 month to eliminate the dilemma of correction for prematurity (Lemos et al., 2012). Wilson and Cradock (2012) reviewed the literature pertaining to age adjustment of premature babies for the purpose of developmental assessment. The authors concluded that varying methods have been used by assessors from full adjustment of age for prematurity (corrected age) to no adjustment of age for prematurity (chronological age) or some midpoint.

The AAP recommend the term 'corrected age' should be used only for children up to 3 years of age who were born preterm and this term should be used instead of 'adjusted age' (Committee on Fetus and Newborn, 2004, p. 1363). This suggests that it is appropriate to correct the infant's age up to 3 years. This guideline is different however to a more recent publication by the AAP that recommends adjustment for prematurity until 24 months adjusted age when assessing growth, nutrition, development, social interaction, motor and language skills (Bernbaum et al., 2009, p. 868). This message however does not appear to be consistent throughout this textbook with examples of correction of prematurity at older ages within the text. This confusion is further complicated by Wilson and Cradock's (2012) suggestion, albeit it accurate, that there are three options for how to adjust for prematurity when using standardized developmental assessments. 1) The child can be given the set of items according to his corrected age, 2) the clinician can administer the items according the child's chronological age but when correcting the assessment use the normative data corresponding to the child's adjusted age and 3) the items and normative data corresponding to the child's chronological age could be used with clinical consideration given to the level of prematurity (p. 642). In light of these contradictions it appear that this recurrent debate as to whether and for how long preterm infants' chronological age or corrected age should be used for developmental assessment remains somewhat unresolved.

Cultural differences in Activity and Participation

It is now well recognized that measurement tools must be translated and culturally adapted to maintain content validity and ensure effective use of the instrument across different cultures or countries (Stevelink & Brakel, 2013). For this purpose, a number of cultural equivalence frameworks have been designed to guide the effective development of cross-cultural adaptation of measures in different aspects of healthcare such as health related quality of life measures (Herdman et al, 1998; Guillemin, Bombardier & Beaton, 1993) and with specific types of instruments such as self-report measures (Beaton et al, 2000). Beaton et al (2000) proposed specific guidelines for effective development of cross-cultural adaptation of self-report measures. The authors caution that translation and adaptation may affect the psychometric properties of the daily life questionnaires due to the subtle cultural differences that may make specific items more or less difficult than other items.

It is widely assumed that communities and larger cultural environments differ between countries influencing the development and display of adaptive behaviours (Oakland et al., 2013) and other valued developmental skills. Parents or caregivers' expectations of children's skill development also vary culturally. For example, the assumption that play is a major childhood occupation may be a culturally dependent viewpoint (Parham, 2008; Bazyk et al., 2003) and therefore variations in the child's developmental play skills are a result of both their biological abilities and their social, cultural and physical context (Case-Smith, 2010). Studies in recent years on the cross-cultural translation of instruments that measure daily life skills demonstrate that there are cultural differences in the development of these skills in different countries. The Pediatric Evaluation of Disability Inventory (PEDI) (Haley et al., 1992) is an interdisciplinary assessment of activities of daily living developed for children from 6 months to 7 years 6 months of age that has been translated and adapted for use in numerous cultures internationally including Norway (Berg et al., 2008), Germany (Schulze, 2012), Slovenia (Groleger, Vidmar & Zupan, 2005), Holland (Wassenberg-Severijnen, 2005), Puerto Rico (Gannotti & Cruz, 2001), Taiwan (Chen et al., 2010), Turkey (Erkin et al., 2007) and Sweden (Nordmark et al., 1999).

Differences between US and international populations were explicit. For example, Taiwanese children (494 normal developing children and 110 with developmental disabilities) demonstrated lower scores in self-care and in social functioning than the US normative group but were similar in their mobility skills. Although differences may be expected between Asian and western cultures, differences were also found in in other western countries. Norwegian children demonstrated less age-equivalent competency in self-care skills with significantly lower scores in functional values and caregiver assistance than the

US normative data (Berg et al., 2008). Noted differences include that Norwegian children (174 typically developing children) wore diapers for longer duration with 75% of Norwegian children continent during the day at 48 months of age, which was 12-18 months later than the US normative data. These results contrasted with a more robust study using the Assessment of Motor and Process Skills (Fisher, 2003) to compare the activities of daily living of a large group of US and Nordic countries (Peny-Dahlstrand, Gosman-Hedström & Krumlinde-Sundholm, 2012). The Nordic countries included 2374 children without known disabilities from Sweden, Denmark, Norway, Finland and Iceland and were compared to 2239 children without known disabilities from Canada and the United States. No relevant differences were found between the two cultures.

The cross-cultural results of the AMPS are similar to those found in the cross-cultural validation of the ABAS-II in Romania and Taiwan. Oakland et al. (2013) adapted the Parent Form (5-21 years) of the Adaptive Behavior Assessment Scales II (Harrison and Oakland, 2003) using data from children of Romanian (N=801) and Taiwanese (N=660) parents comparing it to standardisation data from the United States (N=1,670). The translation of the ABAS-II from English to Romanian and Taiwanese was performed by a committee of professionals and standardised scores were generated for each group. There were considerable similarities between the psychometric properties of all three groups. Reliability coefficients for all three measures were generally high (in the .90s) and comparable for both overall adaptive composite scores and domain scores for all three groups. Few differences were found between the scores of the older children while some inconsistencies were found with younger children (7.0-7.3 years) which the authors suggested was consistent with patterns of adaptive behaviour that demonstrate reliability estimates to be less stable for younger children. Confirmatory factor analysis demonstrated a similar fit for all three versions of the measure and intercorrelations are moderate. Most measures of adaptive behaviour have been developed in Western cultures with some subsequent efforts made to adapt them cross-culturally. These results are promising, potentially demonstrating some consistency of adaptive functioning across cultures. Oakland et al. (2013) however, suggest cautious clinical judgement is required when interpreting results of adaptive behaviour in countries outside of the country they have been developed for, given the lack of literature available on the cross-cultural adaptation of measures of adaptive behaviour.

Children's participation, as with other concepts such as adaptive behaviour and quality of life, may differ across cultures. Most measures of participation have been developed in Western countries, often in the English language (Stevelink & Brakel, 2013), and more recently, in response to the ICF (Adolfsson et al, 2010). Stevelink & Brakel (2013) systematically reviewed the cross-cultural validation of participation measures using a modified version of the cultural equivalence framework by Herdman et al. (1998). The framework was mainly adapted to assess instruments that measure participation, incorporate quality criteria for measuring psychometric properties as introduced by Terwee et al. (2007), and also item response theory methods such as Rasch analysis. The framework has five categories of equivalence testing: conceptual, item, semantic, measurement and operational equivalence. Each category measured a number of aspects on a 3-point likert scale from minimal/none, 'partial' to extensive therefore the maximum overall score was five 'extensive' ratings. Inclusion criteria for article selection were that it measured participation, was theoretically grounded in the ICF (WHO, 2001) and the cross-validation studies were either instruments developed in a middle to high income country and adapted for a low-income countries or vice versa.

Of 2084 articles in the initial search, 1982 were excluded as they did not focus on instrument development or validation. Of the remaining 102 articles, 73 full text articles were reviewed resulting in 8 cross-validation studies meeting the selection criteria. Five instruments, four of which were developed from high-income countries such as the UK, the Netherlands, Australia and the USA, were detailed in these studies. These measures were the Impact on Participation and Autonomy (IPA) (Cardol et al., 1999), the London Handicap Scale (LHS) (Harwood et al., 1994), the Perceived Impact Problem Profile (PIPP) (Pallant et al., 2006), Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck et al., 1992). The fifth instrument, the Participation Scales (Van Brakel et al., 2006), was developed simultaneously in India, Nepal and Brazil. According to Stevelink & Brakel (2013) the cross-cultural testing of these instruments 'leaves much to be desired' (p. 1262). That is, the formal analysis of three of the five measures with the Herdman et al. (1998) cross-cultural framework received 'partial' or 'none/minimal ratings' in the category of equivalence. The exceptions to this were the Persian version of the IPA which received three extensive ratings, and the Thai version of the PIPP which received two extensive ratings. A limitation of this study was the authors focused only on participation measures that reviewed instruments that were developed in a high or middle income country and adapted for a low income country or vice versa, eliminating both the Children's Assessment of Participation and Enjoyment and Preferences for Activities of Children (CAPE/PAC) (King et al., 2004) and the Assessment of Life Habits (Noreau et al., 2007) from the analysis. The authors cautioned that these ratings may not be completely accurate as instruments may have had extended testing procedures that may not have been published and the study had aimed to assess the process of cross-cultural testing and the cultural equivalence of the measure per se.

The Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children (CAPE/PAC) was tested cross-culturally on 337 typically developing children aged 6-17 years of age in Sweden (Ullenhag et al., 2012a). The instrument was translated, the number and type of activities were adapted based on feedback from interviews with parents and children with and without disabilities, and the adapted instrument was piloted. The final instrument included three new activities while eliminating three of the original activities and for ten of the items new examples were provided. The Swedish children demonstrated mean diversity scores that were significantly higher than with the original CAPE emphasising the importance of not only translating participation instruments but also of validating them for specific cultures. These cultural differences demonstrated between Swedish and North American children were also found between Swedish children and children from neighbouring countries. A further study by Ullenhag et al. (2012b) of 278 children with disabilities and 599 children without disabilities between 6-17 years of age demonstrated that Scandinavian children with disabilities participated in a greater diversity of activities with greater frequency than their Dutch peers. These results demonstrated that the environmental variable of country of residence was the strongest predictor of variance in the intensity and diversity of all activities performed by children with disabilities on a regular basis. This emphasises the importance and the need to cross-culturally test measures of participation to ensure their valid use in countries outside of the one they were normed for.

Measures of Adaptive Behaviour and Participation for Children

Behavioural and developmental assessments of preterm infants in the Neonatal Intensive Care Unit can be educational for parents. They can encourage their confidence in ‘recognising and responding to their infant’s cues of stress or stability, providing therapeutic positioning and developmentally supportive handling, regulating sensory input to avoid over-stimulation, facilitating functional oral feeding, and meeting the infant’s long-term developmental needs’ (Hunter, 2010, p.659). Many assessment tools that are used with paediatric populations however focus on the components of body function and structure and according to Adolfsson et al. (2010) ‘methods and resources are needed to support professionals in focusing on participation-related interventions’ (p.677). Msall and Tremont (2002) illustrated the lack of application of assessments that measure body functions to everyday life by describing the results of the Peabody Developmental Motor Scales-2nd edition (Folio and Fewel, 2000), stating that a child may receive a standardised score on this fine and gross motor test of 'moderately disabled' but this would 'not tell us if Johnny walks, undresses, feeds himself with utensils, communicates by pointing or using words, or follows verbal requests' (p. 261). This example highlights the gap in a child's developmental profile if assessments are not carried out at the level of 'Activity and Participation'. In order for these components of the ICF-CY framework (WHO, 2007) to be used effectively with paediatric populations such as premature babies, proper assessment tools that fit the comprehensive scope of the ICF-CY on functioning and disability will need to be developed (Adolfsson et al, 2010).

A number of researchers have reviewed the instruments that are available to measure the activity and participation of children (Phillips et al., 2013; Morris, Kurinczuk & Fitzpatrick, 2005). Using information generated from these reviews and also a search of the literature a review of all potentially measures was done to establish their suitability for use in this study (See table 3). An initial screening of assessments of adaptive behaviour and participation was done using the following inclusion criteria for selection:

i. Suitable for children within the 0-5 year age range (Measures with age span commencing over the age of 6 will not be considered for review)
ii. Measures adaptive functioning or participation in childhood occupations (Focus on performance in everyday life more than on performance skills such as motor, cognitive and language skills)
iii. Parent/Primary caregiver questionnaire
iv. Standardised measure with acceptable reliability and validity
v. Can be administered by an occupational therapists and does not require any additional formal training e.g. as with the WeeFIM (Msall et al., 1994)
vi. Measure is in the English language

vii. Suitable for children with biological risk factors such as preterm birth

Only measures that received a check for each inclusion criteria were reviewed further.

Table 3 Review of instruments that measure adaptive functioning and participation
(Measures that obtained check marks in all domains are highlighted in red and were selected for further review)

Instrument	Age Appropriate (0-5 years)	Adaptive Functioning or Participation	Parent/Child report Questionnaire Style	Standardised Reliable Valid	Additional training/ Certification not required	English Language	Population appropriate
Adaptive behaviour Assessment System– Second Edition (ABAS-II) (Harrison and Oakland, 2003)	√	√	√	√	√	√	√
Activity Scale for Kids (ASK) Performance (Young et al., 2000)	X	√	√	√	√	√	X
Assessment of Life Habits (LIFE-H) for children (Noreau et al., 2007)	X	√	√	√	√	√	X
Assessment of Motor and Process Skills (AMPS) (Fisher, 2003)	√ (2 years+)	I	X	√	X	√	√
Assessment of Preschool Children's Participation (King et al., 2006a)	√ (2-5 yrs)	√	√	√	√	√	√
Bayley Scales of Infant and Toddler Development III (Bayley, 2006)	√ (0-42 mths)	I	X	√	√	√	√
Child and Adolescent Scale of participation (CASP) (Bedell & Dumas, 2004)	X	√	√	√	√	√	X
Children's Assessment of Participation and Enjoyment (CAPE) and the Preferences for Activities of Children (PAC) (King et al., 2004)	X	√	√	√	√	√	√
Children Helping Out: Responsibilities, Expectations, and Supports (CHORES) (Dunn, 2004)	X	√	√	√	√	√	√
Children Participation Questionnaire (CPQ) (Rosenberg et al. 2010)	X (4-6 yrs)	√	√	√	√	√	√

Instrument	Age Appropriate (0-5 years)	Adaptive Functioning Or Participation	Parent/Child report Questionnaire Style	Standardised Reliable Valid	Additional training/ Certification not required	English Language	Population appropriate
Community Activities Questionnaire (CAQ) (Ehrmann, Aeschleman & Svanum, 1995)	√ (2-5 yrs)	√	√	X*	√	√	√
Functional Independence Measure for Children (Wee-FIM) (Msall et al., 1994)	√	I	√	√	X	√	√
International Classification of Functioning, Disability and Health - Functional Assessment Scale (ICF-FAS) (Mishra & Rangasayee, 2010)	X	√	NR	√	√	√	X
Lifestyle Assessment Questionnaire-Cerebral Palsy (LAQ-CP) (Mackie, Jessen & Jarvis, 1998)	√ (3-10yrs)	√	√	√	√	√	X
Lifestyle Assessment Questionnaire-Generic (LAQ-G) (Jessen et al., 2003)	X	√	√	X*	√	√	√
Miller Function and Participation Scales (Miller, 2006)	√ (2yrs 6 mths-7yrs 11)	√	X	√	√	√	√
National Survey of Schools and Environment (Simeonsson et al., 2001)	X	√	√	X*	√	√	X
PART (Kemps et al., 2011)	√ (2-5 years)	√	√	√	√	X	√
Participation and Environment Measure for Children and Youth (PEM-CY) (Coster et al, 2010)	X	√	√	√	√	√	√
Pediatric Evaluation of Disability (PEDI) (Haley et al., 1992)	√	√	√	√	√	√	X
Preschool Activity Card Sort (Berg & La Vesser, 2006)	√ (3-6 years)	√	√	X*	√	√	√

Instrument	**Age Appropriate (0-5 years)**	**Adaptive Functioning Or Participation**	**Parent/Child report Questionnaire Style**	**Standardised Reliable Valid**	**Additional training/ Certification not required**	**English Language**	**Population appropriate**
The Kid Play Profile (Henry, 2000)	X	√	√	X*	√	√	√
Scales of Independent Behavior-Revised (Bruininks et al., 1996)	√	I	√	√	√	√	√
School Function Assessment (Mancini et al., 2000)	X	√	X	√	√	√	√
Vineland Adaptive Behavior Scales (2nd ed.) (Sparrow, Cicchetti & Balla, 2005)	√	√	√	√	√	√	√

I	Insufficient range of adaptive skills covered (self-care and social only) or emphasis on performance skills (Cognitive, motor and language)
X	No
X*	No. Validity or reliability of measure not reported (Phillips et al., 2013)
NR	Not reported

Measures of Adaptive Behaviour

Since adaptive behaviour formally became part of the definition of mental retardation in 1959, ‘it has been the subject of much research and controversy, and the catalyst for the development of more than 200 scales of adaptive behaviour’ (Schalock and Braddock, 1999, p. 1). Typically, these measures have been developed from representative national samples including people with disabilities, reported for separate age ranges, and considered in the context of the background information gathered by the clinician in relation to the person’s opportunities versus expectations (Oakland et al., 2013). Adaptive behaviour is acquired over the course of a child’s development and can be expected to vary with age (Harrison and Oakland, 2003).

According to Tassé et al. (2012) ‘currently, four comprehensive individualized, standardized, and psychometrically sound adaptive behaviour scales are available that have been normed on a representative U.S. sample of the general population’ (p.293). The four assessments are Adaptive Behavior Scale-School, Second edition (Lambert, Nihira & Leland, 1993), Adaptive behaviour Assessment System–Second Edition (Harrison and Oakland, 2003), Scales of Independent Behavior-Revised (Bruininks et al., 1996) and the Vineland Adaptive Behavior Scales-Second Edition (Sparrow, Cicchetti & Balla, 2005). Assessment of Adaptive Behaviour may assist with the diagnosis and intervention planning of children with a range of developmental disabilities including those with biological risk factors (Harrison & Oakland, 2003). Of the measures reviewed in table 3 the following adaptive behaviour questionnaires were considered suitable for further consideration for this study:

i. ‘Parent/Primary Caregiver Form from the Adaptive Behavior Assessment System, Second Edition (ABAS-II) (Harrison and Oakland, 2003), and

ii. Parent/Caregiver Rating Form - Vineland Adaptive Behavior Scales, Second Edition (Vineland-II), (Sparrow, Cicchetti and Balla, 2005)

Both of these assessments have been shown to be reliable and valid for use with this population of children and have been successfully used in a number of studies of preterm children in the past (Fernandes et al., 2012; Huang et al., 2012; Peterson et al., 2006; Luttikhuizen dos Santos et al., 2013). Each measure will be critiqued in detail below:

i. The Adaptive Behaviour Assessment System, Second Edition (ABAS-II) (Harrison and Oakland, 2003)

The ABAS-II 'is the only instrument that provides standardised scores according to the 10 adaptive skill areas defined by the Diagnostic and Statistical Manual (4th edition – revised text) (American Psychiatric Association, 2000), and the 3 adaptive behaviour domains defined in the 11th edition of the American Association of Intellectual and Developmental Disabilities manual (Schalock et al, 2010; Tassé et al, 2012). The structure of the ABAS-II provides standard scores with a mean of 100 and a standard deviation of 15, for an overall score (General Adaptive Composite or GAC score), 3 domain scores (social, practical and conceptual) and 10 adaptive skill areas (Harrison and Oakland, 2003). The content of this measure will be discussed in more detail in the methodology chapter.

In general the ABAS-II has excellent interrater and test-retest reliability (with coefficients mostly above or near .90 for parent, teacher and adult forms) (Msall & Tremont, 2002) however for the preschool and infant forms reliability coefficients are somewhat lower ranging from .70 to .90 for test-retest reliability and from .50 to .80 for interrater reliability (Harrison and Oakland, 2003). A high degree of internal consistency is demonstrated with the standardisation sample's average GAC scores ranging from .97 to .99 for internal consistency, and the majority of the skill areas internal consistency are .90 or greater (Rust & Wallace, 2004). Correlations of the skill areas are in the moderate range (0.40s to 0.70s) suggesting, in line with the theoretical structure of the ABAS-II, that the skill areas are correlated but remain independent skills (Rust & Wallace, 2004). These correlations therefore also support construct validity of the ABAS-II. Factor analysis is provided in the ABAS-II manual and demonstrates support for a GAC factor and the three-factor model (conceptual, practical and social) as proposed by the American Association of Mental Retardation in 1992 (Rust & Wallace, 2004). Concurrent validity is supported by a number of studies presented in the manual. Correlations with the ABAS-II Teacher/Daycare provider form and the Vineland Adaptive Behavior Scales, Classroom Edition (Sparrow, Balla & Cicchetti, 2005) were high, with a correlation of .75 for the overall composite score and other correlations ranging as high as .84 (Harrison and Oakland, 2003). In contrast, the ABAS-II Parent/Primary caregiver form demonstrated a low correlation with the Early Development Form of the Scales of Independent Behaviour –Revised (Bruininks et al., 1996) with the Broad Independence standard score correlating .18 with the ABAS-II GAC score. The SIB-R Early Development form is however brief with only 40 items in the adaptive domain for young children in comparison to the 241 items in the ABAS-II Parent/Caregiver form for 0-5 year olds. Finally, the standardization of the ABAS-II included sampling from 20 clinical populations including a group of children with biological risk factors, albeit a small sample size. Rust and Wallace, (2004), also report that the manual provides indirect evidence that the items selected are sensitive to growth in adaptive behavior 'by mentioning the success on the items of four forms of the ABAS-II increases throughout childhood' (p.369).

Limitations of this measure include that the original ABAS and the ABAS-II were both criticized for their ‘relatively low ceiling scores (120 for some forms and ages) and the inconsistency for the highest scores available’ (Rust and Wallace, 2004, p.368; Sattler, 2002). The high level of reading ability required for the test has also been criticised and although the forms are reported to be edited to ensure a fifth grade reading level (Harrison & Oakland, 2003), Sattler (2002) declared the reading level to range between 4th and 9th grade reading level.

Finally, the adaptive behaviour questionnaire used in the Bayley Scale of Infant and Toddler Development III (Bayley, 2006) has been adopted directly from the ABAS-II; however, the age range of the normative data provided is limited to 1-42 months. For this reason the original Adaptive Behavior Assessment Scale-II (Harrison and Oakland, 2003) was preferred.

ii. Parent/Caregiver Rating Form - Vineland Adaptive Behavior Scales, Second Edition (Vineland-II), (Sparrow, Cicchetti and Balla, 2005)

The original interview survey the Vineland Adaptive Behaviour Scale (Sparrow, Balla & Cicchetti, 1984) was replaced by the Vineland Adaptive Behavior Scale, Second Edition (VABS-II) (Sparrow, Cicchetti & Balla, 2005). This is one of the most common tools used to measure the adaptive behaviour of premature babies (Saigal et al, 1990). According to Rosenbaum, Saiga &Szatmari, (1995), the VABS compliments other dimension-specific assessments by providing an insight in to the child’s function and allows for much richer characterization of the functional ability of preterm children than would be possible by simply categorizing children as having, for example, a ‘severe disability’ or being ‘moderately impaired’. The VABS-II has four different forms: Parent/Caregiver Rating Form; Survey Interview Form; Teacher Form; and an Expanded Interview Form. The Parent/Caregiver Form and the Survey Interview Form differ only in their method of administration i.e. interview versus rating scale (Sparrow, Cicchetti & Balla, 2005). There are 11 subdomains or less depending on the age being assessed. All of these forms can be used from birth to 90 years with the exception of the Teacher Form that is suitable for 3-18 years. There is one overall adaptive behaviour composite score, four broad domain scores (Communication, Socialization, Daily Living Skills and Motor skills) and an optional domain of Maladaptive Behaviour. Items in developmental sequence are rated using a 3-point scale from zero ‘behavior never performed’ to 2 ‘behavior usually or habitually performed’. Normative data for domain scores are provided in age bands with a mean standard score of 100 and SD of 15. Subdomains have a mean standard score of 10 and a SD of 3.

The VABS-II is reported to have strong psychometric properties including extensive representative normative data (Widaman, 2010 as cited in Tassé et al., 2012). Studies on reliability and validity in the test manual have been established from pooled data obtained from both the parent/caregiver form and the survey/interview form. The VABS-II demonstrates moderate correlations with other measures of adaptive behaviour supporting its concurrent validity. Correlations between the adaptive composite scores of the VABS-II and the Adaptive Behavior Assessment Scales – Second Edition (Harrison & Oakland, 2003) in the three domain composite scores were moderate to high (.60 to .74) while the correlation between the overall adaptive composite score of both tests were high (.78). Its adaptive domains correlated moderately (.38 to .60) with those of the Behaviour Assessment System for Children-Second Edition (Reynolds & Kamphaus, 2004). Estimates of internal consistency reliability ranged from .95 to .97 for the overall adaptive composite, from .89 to .94 for the communication domain, from .88 to .93 for the daily living domain and from .89 to .95 for the socialization domain (Lopata et al., 2013). A comparison of the content of the VABS-II and the ABAS-II can been seen in table 4 below.

Table 4 Comparison of Adaptive Behaviour Assessments – VABS-II vs ABAS-II

	Vineland Adaptive Behaviour Scale, 2nd Edition	**Adaptive Behaviour Assessment System, 2nd Edition**
Area of assessment	Overall Adaptive Behaviour score 5 domains	Overall Adaptive Functioning (General Adaptive Composite) 3 domain scores, 10 adaptive skill areas
Age range	Birth through 90	Birth through 89 years
Domains (0-5 years)	Communication (66) Receptive -20, Expressive - 39, Written – 7	Communication (25)
	Daily Living skills (36) Personal - 24, Domestic - 5, Community – 7	Community use (22)
	Socialization (47) Inter. Rel - 23, Play and Leisure -20, Coping skills – 4	Social (24)
	Motor skills (65) Gross - 40, Fine 25	Motor (27)
		Functional Pre-academics (23)
	Maladaptive Behaviour	
		Home Living (25) Health and Safety(24) Leisure (22)

		Self-care (24) Self-direction (25)
Comment	Large emphasis on communication, gross motor	
No. of items	214	241
Parent Report/ Scales	The survey interview form OR Parent/Caregiver rating form The expanded interview Form The Teacher Rating Form	Adaptive Behaviour Scale (Same) Parent/Primary Caregiver Form (Ages 0-5) Teacher/Daycare Provider Form (Age 2-5yrs) Parent Form (Ages 5-21 yrs) Teacher Form (Ages 5-21 yrs) Adult Form (Ages 16-89 yrs)
Administration Time	20 - 60 minutes	
Hand-scoring	15 - 30 minutes or computer programme 15 - 30 minutes	15 - 30 minutes or computer programme

In summary, both tests are reliable and valid measures of adaptive behavior and have been used successfully in research with former preterm infants in the past. The ABAS-II was however chosen over the Vineland-II due to the preference for its clear layout of the 10 adaptive skill areas defined by the Diagnostic and Statistical Manual (4th edition – revised text) (American Psychiatric Association, 2000), and the 3 adaptive behaviour domains defined in the 11th edition of the American Association of Intellectual and Developmental Disabilities manual (Schalock et al, 2010; Tassé et al, 2012). The ABAS-II also appears to demonstrate a greater focus on practical skills (See table 4). For example, the Vineland-II has a 36 item subsection on daily living skills (Personal - 24, Domestic - 5, Community – 7) in comparison to the ABAS-II which has a 95 item practical domain (Community use (22), Home Living (25), Health and Safety (24), Self-care (24)). This practical intelligence that ‘refers to the ability to maintain and sustain oneself as an independent person in managing the ordinary activities of daily life’ (Luckasson et al, 1992, p.15) is one of the main focuses of this research. The Vineland-II also has a larger number of items that emphasized communication and gross motor skills, areas which have been more routinely assessed in preterm infants (Spittle et al., 2009; Oliveira et al., 2011; Moreira, Magalhaes & Alves, 2014). The Vineland-II interview form also includes all age groups and therefore covers dating, job skills etc. In comparison the ABAS-II that has one specific parent/caregiver form for 0-5 year olds for ease of administration. Finally, it is also recommended that administrators of the Vineland-II are trained psychologists (Sparrow, Cicchetti & Balla, 2005).

Measures of Participation

The construct of participation has been addressed previously in section 3.2.and given the variations in its definition it is not surprising that its measurement has also lacked clarity. Participation for children and youth, a key dimension of the ICF-CY (WHO, 2007), has been acknowledged as an area that has been challenging to measure, especially in relation to children with disabilities, with a paucity of measurement tools available for use (McConachie et al., 2006; Morris, Kurinczuk & Fitzpatrick, 2005, Coster & Khetani, 2008). A review of child and family self-report assessments available to measure the activity and participation of children with cerebral palsy identified seven instruments (Morris, Kurinczuk & Fitzpatrick, 2005). These measures were selected based on the criteria of measuring both activity and participation and were criticised by the authors for their limited content, feasibility and breadth which also reduced their ability to be used with diverse populations or in research contexts (Morris, Kurinczuk & Fitzpatrick, 2005; McConachie et al., 2006).

Coster and Khetani (2008) explored the conceptual issues that challenge the development of useful and valid measures of participation for children and youth. The authors argue that the variations in the way the construct of participation is defined and operationalized may lead to varying measures of participation that embody distinct definitions of this construct. They therefore recommend that developers of new tests of participation should address the following three pertinent issues that impact on the meaning of the data obtained: unclear criteria that differentiate between activity and participation; lack of consensus on whether to measure the objective or subjective aspects of participation or both; and when the focus is on children whose perspective should be measured i.e. who are the most appropriate respondents. For preschool children, for example, Law et al. (2012) report that their participation is more of a reflection of their family's participation choices, their child care needs and the opportunities that are available to them in their immediate environment. Other authors have also argued that all aspects of this multidimensional construct, as defined by the ICF-CY (WHO, 2007), cannot be captured by one single measure (Coster et al., 2011; Morris, Kurinczuk & Fitzpatrick, 2005). Bedell et al. (2011) suggest however that one measurement tool, rather than separate tools, that explicitly links a child's participation to environmental factors in the home, school and community would situate the child's participation in a real-life context.

The assessments that were reviewed in table 3 above measure the following dimensions of children's participation:

- Frequency/Intensity (King et al., 2004; King et al., 2006; Coster et al, 2010)
- Involvement (King et al., 2004; King et al., 2006; Coster et al, 2010)
- Difficulty – level of difficulty when performing a life habit (Noreau et al., 2007)
- Assistance required – Type of assistance (assistive device, adaptation and/or human assistance) (Noreau et al., 2007)
- Satisfaction (Coster et al, 2010)
- Desire for change (Coster et al, 2010)
- Environmental supports and constraints (Coster et al, 2010)

Of the measures of participation (questionnaire style) reviewed in table 3 only six met the criteria of being suitable for administration for children between 0-5 years of age. Of the assessments in this age range four of the five measures did not meet all of the selection criteria. For example, although the Children Participation Questionnaire (CPQ) (Rosenberg et al. 2010) assessed many dimensions of participation including the child's enjoyment of the task, their independence with the task and their parent's satisfaction with their child's performance the age range the measure was developed for was too narrow for this study (4-6 years of age). The Lifestyle Assessment Questionnaire-Cerebral Palsy (LAQ-CP) (Mackie, Jessen & Jarvis, 1998) and the Preschool Activity Card Sort (PACS) (Berg & LaVesser, 2006) were developed for a slightly wider but not adequate age range for this study, both suitable for children from three years of age only. The LAQ-CP was also developed for use with children with cerebral palsy therefore was not appropriate. In addition at the time of this study the psychometric properties of the PACS were poor with its reliability not reported and only minimal evidence of content validity (Phillips et al., 2013; Berg & LaVesser, 2006). The Community Activities Questionnaire (CAQ) (Ehrmann, Aeschleman & Svanum, 1995), the Assessment of Preschool Children's Participation (King et al., 2006a) and the PART (Kemps et al., 2011) were the only three participation measures that assessed children as young as 2 years of age. The PART (Kemps et al., 2011) was developed in the Dutch language and therefore was deemed unsuitable. The psychometric properties of the CAQ were also deemed inadequate as although its reported internal consistency (Cronbach’s alpha) was 0.60 it did not report any studies of validity on its 18 item questionnaire (Phillips et al., 2013). The only assessment that met all necessary criteria, and is critiqued in detail below, is the Assessment of Preschool Children's Participation (APCP) (King et al., 2006a).

The APCP is a newly developed preschool version of the Children’s Assessment of Participation and Enjoyment (King et al, 2004) that focuses on the ICF-CY (WHO, 2007) subset of participation. It has been designed by the Canchild Centre for Childhood Disability Research, McMaster University, Canada, in an effort to capture the participation of children in childhood activities. As one of the very few measures of participation standardised for a preschool population (Table 3) it reflects the focus of research on participation on children with disabilities over the age of 6 years (Law et al., 2012). The assessment captures preschool children's activity patterns in the areas of play, skill development, active physical recreation and social activities (Law et al, 2012, p. 277) and this assessment content will be described in more details in the methodology chapter.

The APCP is a standardised assessment of children's participation in day-to-day activities. Its initial internal consistency and construct validity were established with 120 children between 2 to 5 years 11 months of age with cerebral palsy in Ontario, Canada (Law et al., 2012). The initial 48 items generated were based on developmental literature, age-appropriate items from the CAPE (King et al., 2004), and a pilot study of parents of 57 typically developing children attending local schools in Canada. Internal consistency reliability was performed using Cronbach's alpha coefficient for all four of the domains of the APCP. Scores ranged from good to excellent for diversity of participation (0.73-0.85) and were moderate for intensity of participation (0.52-0.70). The authors suggested that the relatively lower value for Cronbach's alpha for active physical recreation (0.52) may reflect the variation in frequency of physical activity in children with cerebral palsy in the study sample.

The construct validity of the measure was demonstrated by significant differences, with medium to large effect sizes, being found between all activity areas of the APCP and the children classified as levels I-III and those classified as levels of IV-V on the Gross Motor Function Classification System (Palisano et al., 1997). Differences remained significant when age, sex and income were controlled for. Consistent with this, children with more reported health and developmental conditions demonstrated lower levels of diversity and intensity of participation. The APCP was also compared to the PEDI (Haley et al., 1992) with positive moderate to strong correlations found between the diversity and intensity of participation scores of the APCP and the self-care and mobility scores of the PEDI across all activity types ($0.51 < r < 0.78$, $p < .001$). Higher scores in functional independence in self-care and mobility subtests of the PEDI were also associated with higher levels of participation on the APCP. The limitations of this analysis include its relatively small sample size and its focus on children with a diagnosis of cerebral palsy only. As acknowledged by the authors, a larger scale study that includes test-retest reliability and confirmation of the factor structure of the APCP is required to confirm these results.

The psychometric properties of the APCP were examined by Chen et al. (2013) in Taiwan also with a sample of children (N=82) diagnosed with cerebral palsy. The APCP was administered as a baseline assessment and then re-administered at six months follow-up. The Gross Motor Function Measure (GMFM-66) and the Functional Independence Measure for Children (WeeFIM) were also administered at these two time points to establish concurrent and predictive validity. Concurrent validity varied from fair to excellent with the GMFM-66 and the WeeFIM (r =0.39-0.85), as did predictive validity (r = 0.46-0.82). Responsiveness was measured by standardised response mean (SRM) demonstrating the APCP to be responsive to change with the SRM values in intensity and diversity of participation in all four areas between 0.8-1.3. The minimal detectable change (MDC) at the 95% confidence interval ranged from 0.1-0.7 for intensity scores and 4-17% for diversity scores, for all four activity areas and total score. The minimal clinically important difference (MCID) ranged from 0.4-1.2 for intensity and 10-19% for diversity in the same activity areas and total score.

Of the dimensions of participation listed above the APCP assesses the child’s intensity and diversity of participation in 45 childhood activities. A limitation of the APCP is however that it does not measure other dimensions of participation. For example, the APCP does not capture information on the types of environmental supports or barriers the child experiences during participation as measured in participation measures for school age such as the

Assessment of Life Habits (LIFE-H) for children (Noreau et al., 2007) and the Participation and Environment Measure for Children and Youth (PEM-CY) (Coster et al., 2010). For example, in the LIFE-H, a measure developed for 5-13 year olds with disabilities, assistance is grouped in to assistive devices, adaptations and/or human assistance. The PEM-CY combines assessment of children's participation and environment in home, school and community activities (Law et al., 2013; Bedell et al., 2011; Coster et al., 2012). The 25 items in this report tool focus participation in 10 home activities, 5 school activities, and 10 community activities. Accompanying items about the environment for each setting are also included (Law et al., 2013). Therefore this questionnaire combines the measurement of children's participation and environmental factors. Another dimension of participation that is not captured by the APCP but is examined in participation for school aged children such as the PEM-CY (Coster et al., 2010) and the Child and Adolescent Scale of participation (CASP) (Bedell & Dumas, 2004) is the rating of the parents' satisfaction with the child's level of participation in the task.

Conclusion

Over the past 25 years there have been major advances in the survival rate of very preterm babies. However, the prevention of neurodevelopmental morbidities for this vulnerable population continues to be a significant challenge (Msall, 2006). A number of recent, large outcome studies of children born preterm have shown conflicting results possibly due to differences in population risks due to social and demographic factors, and differently defined outcome measures (Marlow, 2006, p.142). The impairments in performance skills identified in many of these studies have not been related back to the impact they have on everyday life. Although occupational therapists 'recognize that health is supported and maintained when individuals are able to engage in occupations and activities that allow desired or needed participation in home, school, workplace, and community life situations' (AOTA, 2014, p.611), little attention has been given to this area of research for children born preterm. That is, little evidence exists on the impact of preterm birth and VLBW on the 'long-term functional abilities, activities of daily living, independence and participation of these children in an environmental context' (Lemos et al., 2012, p.18). According to Marlow and Green (2007), parents have the right to know about the long term problems their unborn or newborn baby may have, including the child's potential risk of disability, what is meant by disability and the long term consequences of their decision making. He recommends that mild to severe disability should be explained, 'along with the potential consequences and the effects on the development of the child' (p. 329).

Children born preterm who receive a diagnosis of physical or intellectual disability are followed up and referred on to early intervention services. Although preterm infants without a diagnosis receive initial follow-up in the absence of a co-morbidity they are discharged from services. There is a need for more focused follow-up of these 'at risk' preterm infants. In line with the

World Health Organisation's recommendations, this project will explore the impact of preterm birth on every day participation and activity levels of young children. The research will focus on the children's ability to perform and participate in everyday tasks that are age-appropriate and important for success in home, school and leisure activities. Specifically, the study aims to answer the following questions:

1. Is there a significant difference between the adaptive functioning of Irish children, aged between 6 months to 5 years 6 months of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight?

2. Is there a significant difference between Irish children 2 to 5 years of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight in their participation in childhood occupations?

3a. Is there a difference on standardised testing between the adaptive functioning of an Irish control group of full term, average birth weight infants, aged 6 months to 5 years 6 months of age, and normative data available on a North American sample?

3b. Is there a difference on standardised testing between the adaptive functioning of Irish children, aged 6 months to 5 years 6 months of age, born preterm and very low birth weight, and normative data available on a North American sample?

CHAPTER 3 – METHODOLOGY

3.1 Research Questions

1. Is there a significant difference between the adaptive functioning of Irish children, aged between 6 months to 5 years 6 months of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight?

2. Is there a significant difference between Irish children 2 to 5 years of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight in their participation in childhood occupations?

3a. Is there a difference on standardised testing between the adaptive functioning of an Irish control group of full term, average birth weight infants, aged 6 months to 5 years 6 months of age, and normative data available on a North American sample?

3b. Is there a difference on standardised testing between the adaptive functioning of Irish children, aged 6 months to 5 years 6 months of age, born preterm and very low birth weight, and normative data available on a North American sample?

3.2 Study Design

According to Watt and Van den Berg (2002) research studies can be classified in to three main categories depending on the amount of control the researcher exerts on the conduct of the study. These general categories are experimental, field and observational research. Although interventional approaches, particularly randomised control trials (RCTs) are reported to provide the highest level of data for evidence-based medicine, they are limited in their ability to reflect real-life clinical practice accurately due to rigorous inclusion and exclusion criteria for patient selection and their power of investigator intervention (Yang et al., 2010). Other categories of research such as observational approaches are therefore relied upon heavily in clinical research to describe health, disease and associated outcomes (Luepker, 2005). In this study, the researcher did not manipulate the independent variable or exert any control over the research setting as is characteristic of an experimental design. The focus of this study was on measurement of variables of interest and therefore it is classified as an observational study (Mann, 2003).

The initial design chosen was a descriptive observational design. Review of the pilot study however revealed a number of short comings with this selection. For example, the Adaptive Behavior Assessment Scale, 2nd edition (Harrison and Oakland, 2003), the measurement tool trialed and selected as the primary outcome measure for this study, is standardised on a North American population. As discussed in the previous chapter, numerous studies have demonstrated cross-cultural differences in the emergence of adaptive behavior (Oakland et al., 2013) and other developmental skills. It has been suggested by Marlow (2006) that variation in outcomes of different national studies of preterm children such as the EPICure (UK and Ireland), EPIPAGE (France) (Larroque et al., 2004), and EPIBEL (Belgium)

(Vanhaesebrouck et al., 2004) were partly due to poorly validated and inconsistently defined outcome measures. These inconsistencies may lead to differing cut-off points that may not be representative of local populations.

Concerns such as these have led to the acknowledgement internationally that measurement tools should be translated and culturally adapted prior to use across different cultures or countries (Stevelink & Brakel, 2013). Therefore in this study, it could not be assumed that the normative data available for the ABAS-II was representative of an Irish population of children. A descriptive observational design was therefore deemed insufficiently robust to frame this study. In the context of children’s rehabilitation, various designs were considered. It was decided to strengthen the study by adding a comparison group and changing the design to a case-control study (Law & MacDermid, 2008) allowing for more accurate comparison of Irish cases with Irish controls. The results of both groups could then also be compared to the standardized normative data available for the North American population used to explore whether the cut off points appear to be consistent between cultures.

A case-control study compares two distinct population groups, namely a sample of individuals with a disease or health outcome of interest (in this case preterm birth and very low birth weight infants) and a sample of individuals without the clinical condition under study (full term and normal birth weight infants) (Goldberg, McManus & Allison, 2013). Both samples are most often selected from a dynamic population as for example in this study where individuals were selected from one hospital that has a ‘catchment population’ consisting of inflow and outflow of patients influenced by numerous factors such as referrals from doctors and available resources (Vandenbrouke & Pearce, 2012). An advantage of a case-control study is that when conditions are uncommon (as with this specific cohort of preterm, VLBW infants) this type of study can generate rich data from relatively small numbers (Mann, 2003).

The case-control design contrasts with a prospective or cohort study in that it is retrospective i.e. the research participants are selected after the outcomes have been achieved (Law & MacDermid, 2008), in this instance the outcome being preterm birth. As the prevalence of the outcome is determined by the study design and not by characteristics of the individuals under study, typically it is not possible to calculate the relative risk (Goldberg, McManus & Allison, 2013; Knol et al., 2008) or cause and effect, as can be estimated in cohort studies that measure events in chronological order (Mann, 2012; Mann, 2003) . These were not, however, the aims of this study. This case-control study aimed to generate preliminary findings or hypotheses in relation to the adaptive behavior of a specific under-researched clinical group relative to peers that could then if necessary be studied in more depth using prospective cohort or other studies (Mann, 2012). According to Thabane et al. (2010) ‘it is fair to say that every major clinical trial had to start with some piloting or a small scale investigation to assess the feasibility of conducting a large scale study’ (p. 1).

The research questions are listed above and were used to inform the study design selected. In an investigation of the extent to which research studies in rehabilitation sciences define their research question, 97% (N=83) of case-control studies were found to be incorrectly classified. Mayo, Asano & Barbic (2013) suggested one of the reasons for this was that the authors in a number of these cases had not declared what they wanted to know but instead focused on what data they wished to collect. In this study, the researcher wished to establish if there was a difference between the adaptive behaviour and participation of premature VLBW infants in comparison to a control group of their full term peers. The case-control model allows the researcher to examine both groups to ascertain if there are any factors associated with having or not having these outcomes.

A limitation of the case-control approach, as with all cross-sectional designs, is that parents' perceptions of their preterm children's adaptive behaviour and participation were explored at one point in time, therefore only providing a snapshot of what was happening with the study infants (Mathers, Fox and Hunn, 2009). A longitudinal study may have been more predictive and useful as it could have provided information on issues such as the children's maturation and reorganization in relation to these behaviours over time (Noble and Boyd, 2012). Longitudinal or cohort studies are however, typically expensive and time consuming. They also require the recruitment of a sufficiently large cohort to follow and significant numbers of individuals to develop adverse outcomes in order for the association between risk factors and the development of the disease to be systematically examined (Goldberg, McManus & Allison, 2013).

The main methodological concerns of case-control designs are their susceptibility to confounding and bias (Yang et al., 2010). For example, recall bias is often considered a disadvantage of case-control studies due to its retrospective nature (Goldberg, McManus & Allison, 2013). With the exception of some questions in the demographic questionnaire, this is not a major concern in this study as the standardised parent report measures used mainly focused on the children's present rather than their past abilities. The Assessment of Preschool Children's participation (King et al., 2006) does ask parents retrospective questions in relation to their children's participation however, these questions focus specifically on common everyday activities and recall is limited to the last four months.

Issues in relation to confounding factors occur when an independent variable is associated with the variable of interest and the outcome (Mann, 2003). Although a number of confounding factors can be measured and adjusted for the argument remains that there may be residual or hidden confounding factors that cannot be identified but impact on outcomes (Yang et al., 2010). This issue will be discussed more in relation to sampling methods and matching later in this chapter. Another concern of observational studies in general, relative to randomised control trials, is that they reportedly demonstrate less validity due to their apparent overestimation of treatment effects. A study by Concato, Shah & Horwitz (2000) however refuted this by finding the results of 99 reports on 5 clinical topics to be remarkable similar for both RCTs and case-control studies. The authors argued that a well-designed observational design, whether a case-control or a cohort study, does not overestimate the magnitude of the treatment effect relative to RCTs.

A questionnaire survey/interview was used to compare quantitative data regarding the everyday life skills of children born premature and VLBW with children born full term. These results were also compared to a normative sample obtained from a North American population of children. Surveys are considered cost-effective, flexible, less time consuming and more ethical than other approaches (Mathers, Fox and Hunn, 2009), for these reasons in paediatrics interest is growing in parent questionnaires (Flamant et al., 2011). A self-developed questionnaire would lack validity and reliability and therefore take a substantial amount of time to pilot and standardise, distracting from the original study aims therefore a quantitative standardised questionnaire was preferred to gather data. The disadvantage of this quantitative survey method is that it may not explain the ‘why’ as effectively as qualitative methods, may be influenced by interviewer error or bias, and representativeness is dependent on the sampling frame used (Mathers, Fox and Hunn, 2009).

In paediatrics, for example, responses to parent questionnaires are dependent on a number of factors including the parents’ cultural, social and educational background, their knowledge of normal development, their exposure to other children and early developmental assessments, their child’s previous medical history, and their expectations for their child (Hack, 1999). They can therefore be prone to responder bias with the volunteers not being representative of the whole population (Yang et al., 2010). Despite these potential challenges there are a number of examples of research successfully using standardised questionnaires with parents of preterm infants (Johnson, Wolke & Marlow, 2008; Flamant et al., 2011). This method was therefore deemed a cost-effective method to gather preliminary data in this area (Johnson, Wolke & Marlow, 2008) an appropriate method of gathering data on a sample who were mostly under 5 and therefore children’s self-report may not have been reliable or valid (Varni, Limbers & Burwinkle, 2007).

Finally a number of options were explored in relation to the gathering of the survey data. Phone interviews were not chosen as the complexity of interviews may be limited without visual aids and the duration of time may also be shorter. Postal questionnaires were also ruled out because of their low response rate. Although they are known to be very labour intensive, this study employed face-to-face interviews as they are considered the best method for achieving high quality data. (Mathers, Fox and Hunn, 2009).

3.3 Setting

Details of the study infants were obtained from a hospital-based catchment population. The study site was the Premature Baby Unit (cases) and the Postnatal Unit (controls) of University Hospital Galway.

3.4 Ethical Approval

Initial ethical approval was granted for this study to proceed by Dr. Shaun O'Keefe, Chairman, Clinical Research Ethics Committee, Galway University Hospitals, Galway, Ireland, on 7th October 2011. In February 2012 following the pilot study, an addendum to the original ethics application outlining amendments to the study design, data collection tools and recruitment of participants (see Table 8) was approved by the research ethics committee.

3.5 Participants

Cases

The cases were very low birth weight (VLBW) infants of preterm gestation who had previously attended the Premature Baby/Neonatal Unit in University Hospital Galway (UHG). The Neonatal Unit in UHG, is one of 12 Hospitals in Ireland/Northern Ireland that participates in the Vermont Oxford Network NICORE (Neonatal Intensive Care Outcomes Research and Evaluation) group report annually. Data is gathered on VLBW infants ensuring comparable standards of care in neonatal units internationally and allowing for ongoing research in the area. Former preterm, VLBW infants were therefore chosen for this study for two reasons. Firstly they are one of the most vulnerable of the preterm cohorts (Silverstein et al., 2010). Secondly, information on this category of infants collected by UHG for theVermont Oxford Network

Database is readily accessible to the GUH team and is monitored and compared to outcomes of other similar neonatal units internationally. As performance reports suggest that GUH infants' outcomes, morbidities and mortalities are comparable to international standards the premature infants in this study may be considered to represent a 'typical group' of extremely premature infants. Research findings based on babies born preterm in UHG should not therefore be influenced by a superior or inferior healthcare system.

The Vermont Oxford Network (2011a) defines 'Very Low birth Weight' (VLBW) babies as:

> *'Any infant who is born alive at your hospital and whose birth weight is between 401 and 1500 grams OR whose gestational age is between 22 weeks 0 days and 29 weeks 6 days (inclusive)….'*

This definition implies that VLBW infants may be born at term or preterm gestation, and may also include both Average for Gestational age (AGA) and Small for Gestational Age (SGA) premature infants. It is however estimated that approximately two thirds of all VLBW infants are born preterm (Tucker and McGuire, 2004). As this study is focused on preterm infants, only infants that were born both preterm (less than 37 weeks gestation) and 'Very Low birth Weight' (VLBW) as defined by the Vermont Oxford Network eligibility criteria were eligible for this study. In the context of this study, the term 'healthy preterm' or 'preterm birth alone' will be used to refer to preterm infants free of physical or intellectual disability (Killeen et al., 2014).

Parents of children born preterm and VLBW between November 2006 and December 2011 in UHG were invited to take part in this study. Recruitment, including more detailed inclusion and exclusion criteria will be discussed below.

Please note: All very low birth weight (VLBW) infants in this study were born at preterm gestation. In this thesis these infants will be referred to as the VLBW group.

Controls

The control group consisted predominantly of mothers in the postnatal unit of UHG who had a child born full term and now between 6 months and 5 years 6 months of age. As none of the mothers in the unit had children younger than one year, and additional 3 parents of children born full term were recruited from a local crèche.

3.6 Sampling method

This study used convenience sampling to select the cases (from the neonatal unit) and controls (from the postnatal unit) from University Hospital Galway. Convenience sampling is a non-probability or non-random sampling approach in which the sample of the population are selected for practical reasons such as their geographical proximity, ease of access or willingness to volunteer, reducing the representativeness of the sample and increasing the possible effect of outliers (Farrokhi & Mahmoudi-Hamidabad, 2012). Ideally, to ensure internal validity, a population based sample of both randomly selected cases with carefully matched controls would have been obtained. The resources required to recruit a population based sample were not available for this study but measures were taken to strengthen the rigor of the sampling method and minimising the influence of potential confounders (Goldberg, McManus & Allison, 2013). The controls were selected using matching variables (sex and age) and matching criteria (see inclusion and exclusion criteria for control group). Frequency matching was performed on the control group to the case group, by attempting to match the sex ratio within each 1-year age band, and to maintain the same marginal totals of cases and controls within each age band. Balance was partially successful, and adjustment by sex was performed at the analysis stage.

Although convenience sampling reduces the external validity of the study (Mann, 2003), as discussed earlier the VLBW group selected from UHG form part of the Vermont Oxford Network databases and reports outcomes that are similar to neonatal units internationally suggesting the cases are representative.

In case-control studies sampling bias has also been identified as a common problem (Mann, 2003). In the control group, for example, volunteers are expected to be different from the typical person (Watt & Van den berg, 2002) and may be of specific socio-economic status and age (Mann, 2003). Statistical methods were used to ensure the profile of the cases and controls were similar and no adjustment was required.

3.7 Data Collection Tools

As discussed in the literature review and earlier in this chapter, the assessment of children's everyday life skills may be done utilising direct observation, clinical assessment of the child, or through parent report. A standardised parent questionnaire was deemed an appropriate tool to address this study's research questions. The decision was made to choose standardised questionnaires that demonstrated sound methodological quality, assessed the areas of adaptive behaviour and participation, and were appropriate for this preschool population. Standard scores obtained from the questionnaire would also enable the researcher to speak the same language of multidisciplinary professionals, monitor developmental progress and the impact of intervention if deemed appropriate, compare the child's abilities to a normative sample (Richardson, 2010), and provide objective parent feedback about the child's abilities. Analysis of these data will provide direction and focus to further research in this area i.e. enable the investigator to decide if a more in-depth investigation using an observational assessment battery with individual children born preterm would be warranted.

As detailed in the previous chapter a search was done for assessments that met the following criteria:

i. Suitable for children within the 0-5 year age range (Measures with age span commencing over the age of 6 will not be considered for review)
ii. Measures adaptive functioning or participation in childhood occupations
(Focus on performance in everyday life more than on performance skills such as motor, cognitive and language skills)
iii. Parent/Primary caregiver questionnaire
iv. Standardised measure with acceptable reliability and validity
v. Can be administered by an occupational therapists and does not require any additional formal training e.g. as with the WeeFIM (Msall et al., 1994)
vi. Measure is in the English language
vii. Suitable for children with biological risk factors such as preterm birth

The following assessments were selected for the piloting:

Adaptive Behaviour

i. Parent/Primary Caregiver Form from the Adaptive Behavior Assessment System, Second Edition (ABAS-II) (Harrison and Oakland, 2003)

Participation

ii. Assessment of Preschool Children's Participation (APCP) (King et al., 2006a)

Infants 0-24 months - Questionnaire required to Supplement ABAS-II

The APCP is only suitable for use with children from 2-5 years of age. The researcher therefore considered whether it would be of benefit to supplement the data gathered by the ABAS-II on 0-24 month old children with an additional questionnaire suitable for this age range. It was challenging to source a standardised questionnaire that looked at the functional skills of 0-24 month olds (without a focus on physical disability) and no single questionnaire met the criteria of measuring both adaptive functioning and participation. For each interview of parents with children between 0-24 months of age in the pilot study therefore, the ABAS-II was administered with one of the following two questionnaires that are standardised for the 0-24 month age range used:

iii. 'The Social-emotional Scale' from the third edition of the Bayley Scales of Infant and Toddler Development (Bayley, 2006) or the

iv. Infant/Toddler Sensory Profile (Dunn, 2002).

These four assessments will now be discussed in detail:

i. Parent/Primary Caregiver Form from the Adaptive Behavior Assessment System, Second Edition (ABAS-II) (Harrison and Oakland, 2003)

The ABAS-II is a comprehensive individualised, standardised, and psychometrically sound adaptive behaviour scale that has been normed on a representative U.S. sample of the general population (Tassé et al, 2012) and measures adaptive behaviours that are directly observable (Harrison & Oakland, 2003). Its psychometric properties have already been critiqued in detail in the previous chapter and therefore, the focus in this chapter will be on the content and scoring of the 'Parent/Primary Caregiver Form'. This standardised measure focuses on the functional skills of children from 0-5 years 11months of age. 'The overall adaptive behaviour score (General Adaptive Composite Score or GAC) from the ABAS-II assessment represents a comprehensive and global estimate of an individual's adaptive functioning' (Harrison and Oakland, 2003, p.36).

The primary caregiver form includes 241 items, with 22 to 27 items in each skill area (Harrison and Oakland, 2003). The GAC scores and all other scores are based on age related norms (Rust and Wallace, 2004). The conceptual domain consists of Communication, Functional Pre-Academics and Self-direction skill areas. The practical domain comprises of Community Use, Home Living, Health and Safety, and Self-care skill areas. Finally, the social domain consists of the Leisure and Social Skill areas. The motor skill area is the only skill area that is not included in one of the three domain scores. The overall adaptive behaviour score (General adaptive composite) is therefore the sum of the 241 items from all three domain scores and the motor skill score. The 10 skill areas are:

- Communication (speech, language, listening and non-verbal communication);

- Community use (interest in activities outside home, recognition of diff. facilities);
- Health and Safety (showing caution and keeping out of physical danger);
- Leisure (playing, following rules and engaging in recreation at home);
- Self-care (eating, toileting and bathing);
- Self-direction (self-control, following directions, and making choices);
- Functional Pre-academics (letter recognition, counting, and drawing simple shapes);
- Home Living (helping adults with household tasks, taking care of personal items);
- Social (getting along with others: manners, assisting others, recognising emotions) &
- Motor (locomotion and manipulation of the environment).

For babies 0-11 months the skill areas of Community Use, Functional Pre-academics and Home Living are not assessed and scoring is calculated without these skills (Harrison & Oakland, 2003). All of the adaptive behaviour skill areas from the ABAS-II can be grouped under the 9 domain areas of 'activity and participation' laid out in the ICF (World Health Organisation, 2001, p.14), and thus represent everyday life activity for the young child (See Table 2).

The ABAS-II 'assesses functional performance' (Oakland and Algina, 2011, p.113). The parent reports on their child's performance ability using a 4-point likert scale i.e.

- Is the child able or unable to perform the specific task?
- If the child is able to perform the task how frequently when needed do they do the task ('behaviour frequency') - never, sometimes or always

when needed? There is also a box to tick if the respondent guessed (Oakland and Harrison, 2003). Oakland and Algina (2011) encourage child development teams to use this to decipher whether the child has a skill deficit i.e. does not have the functional skills, or the child has a performance deficit i.e. has the functional skills but cannot use them when required.

There are two methods for categorizing adaptive behaviour 1) using the numerical normative data or 2) using the classification system. Standard scores with a mean of 100 and a standard deviation of 15, are provided for an overall score (GAC), and three domain scores (conceptual, practical and social). Each skill area provides an individual scales score with a mean value of 10 and a standard deviation of 3. The ABAS-II's also has a performance classification system. This system enables the child's performance to be classified using both the domain scores (from very superior to extremely low) and the skill area scores (from superior to extremely low). The child's level of performance refers to 'the rank obtained by an individual on a given test compared to the performance of an appropriate normative sample' (Harrison and Oakland, 2003, p.34).

Using Beaton et al.'s (2000) five possible options for cross cultural adaptation, the ABAS-II can be defined as a self-report measure used in another country with the same language. A limitation of this study is therefore that this measure was not cross-culturally translated before it was used with an Irish population. A pilot test was however undertaken to trial this measure with Irish parents.

Finally, the ABAS-II Scoring Assistant computer programme (Western Psychological Services, 2008) was used to assist with scoring. Raw scores were entered in to the software programme and scaled scores were calculated.

ii. Assessment of Preschool Children's Participation (APCP) (King et al., 2006a)

At the time of data collection only one standardised measure of preschool children's participation was deemed suitable for use in this study (See table 3). This measure, the Assessment of Preschool Children's Participation (APCP) (King et al., 2006a) was developed and designed to capture the participation of young children in childhood activities (Law et al, 2012). A comparison of both the children's participation levels in everyday activities and their strengths and challenges in adaptive behaviour assists in developing a more comprehensive profile of these children at the ICF domain of activity and participation (WHO, 2001). The APCP therefore serves as a secondary outcome measure for this study. As it has been critiqued in the previous chapter the APCP will only be discussed in this chapter in relation to administration and scoring.

The APCP is administered to parents of children from 2 years to 5 years 11 months of age. This standardized questionnaire, although not norm referenced, provides quantitative data on the children's intensity and diversity of participation in everyday activities in a variety of environments including home, preschool and child care arrangements. Intensity scores are measured on a 7-point ordinal scale ranging from '1 time in past 4 months' to '1 time a day or more' if the child does participate. The intensity of participation score, measured over the past four months, represents the average amount of time that a child spends participating in activities across the total number of possible activities (N=45). Participation intensity is analysed by dividing the 45 items of the scale in to the 4 different activity areas (See Table 5) (Law et al, 2012, p. 277). The intensity is then calculated by dividing the sum of frequency (range 1-7 for each item) across all items by the number of possible items in each activity area (See Table 5). The diversity of participation is a count of the total number of a child’s reported activities over the previous four months.

Table 5 Description of the Assessment of Preschool Children's Participation

Assessment of Preschool Children’s Participation (King et al., 2006)		
Activity Areas	**Items**	**Example of Activities**
Play	1-9	Doing pretend or imaginary play; building forts or tents; collecting things; playing with pets; playing with toys; creating a craft project; exploring; watching TV or a video; and playing a musical instrument.
Skill Development	10-24	Helping around the house, building things, painting and drawing, cutting and pasting, taking swimming lessons, doing gymnastics, reading or looking at books.
Active Physical Recreation	25-34	Interacting with nature, dancing, going for walks, riding a bicycle, doing water activities, playing physical games, doing team sports
Social Activities	35-45	Playing dress up, playing board or card games, playing computer games, going to the movies, going to a live event, going on a full or half day outing, having someone over to play, baking and cooking.
Other Activities	46-48	Any additional activities

Infants 0-24 months - Questionnaire required to Supplement ABAS-II

iii. ‘The Social-emotional Scale’ from the third edition of the Bayley Scales of Infant and Toddler Development (Bayley, 2006) or the

‘The Social-emotional Scale’ and the ABAS-II combine to form the ‘Social-Emotional and Adaptive Behaviour Questionnaire’ of the third edition of the Bayley Scales of Infant and Toddler Development (Bayley, 2006). It was therefore decided to trial administering ‘The Social-emotional Scale’ in conjunction with the ABAS-II to establish if it would generate rich information to supplement the data gathered. This scale is standardised for children from 0-42 months and has been taken from ‘The Greenspan Social-Emotional Growth Chart: A Screening Questionnaire for Infants and Young Children’ (Greenspan, 2004). ‘Based on the functional emotional milestones identified by Greenspan, it identifies six stages for children from birth to 42 months of age’ (Bayley, 2006, p.8), and consists of 35 questions. The reliability coefficients suggest strong internal consistency ranging from .83 to .94 (Bayley, 2006). The content validity of the scale is not reported explicitly, instead Bayley (2006) reports that the items in the scale that have been adopted from Greenspan (2004) have undergone over three decades of research.

iv. Infant/Toddler Sensory Profile (Dunn, 2002).

The other additional questionnaire selected for parents of 0-24 month old children in the pilot study was the Infant/Toddler Sensory Profile (Dunn, 2002). This caregiver questionnaire was selected as it aims to evaluate the sensory processing patterns in very young children by measuring their responses to sensory events and providing an understanding of how these patterns affect the child’s participation in activities of daily life. There are 36 items in the profile for infants from birth to 6 months of age, and 48 items for children 7-36 months of age. The questionnaire takes 15-20 minutes to administer and no formal training is required. A review by Eeles et al. (2013) critiquing assessments of sensory processing in infants reported that an expert panel assessed congruence between the Infant/Toddler Sensory profile and the Test of Sensory Function of Infants (De Gangi & Greenspan, 1988) test items and the intended domains measured and found them to have excellent content validity. No construct validity was reported but concurrent validity was demonstrated with 28 items of the Sensory Profile correlating with the Infant/Toddler Symptom Checklist, five of which had correlations over 0.5. Low correlations in items such as sensory seeking were explained by Dunn (2002) as areas that are unique to the Infant/Toddler Sensory Profile.

Reliability was reported by Dunn (2002) to be excellent with sensory section scores (correlation 0.86) and adequate for quadrant scores (correlation 0.74) however Eeles et al. (2013) argue that these results were based on Pearson's correlation which is not a reliability measure. For the 7-36 month age range the authors of the review reported that the value for Cronbach's alpha on the sensory processing section suggested adequate internal consistency for general (0.63), auditory (0.70) and tactile (0.71) sensory processing. Poor internal consistency was found however for the visual (0.55), vestibular (0.42), oral (0.55) sensory processing sections. Three of the four quadrants (Low registration, Sensory Sensitivity, and Sensation Avoiding) demonstrated adequate consistency (0.6997, 0.7165, and 0.6970 respectively) while the fourth quadrant, 'sensation seeking' (0.8580), and the 'Low-threshold' section (0.8307) showed excellent internal consistency. No studies on intrarater or interrater reliability were found.

In summary, a review of the paediatric literature established that there is a limited number of parent questionnaires which focus specifically on functional skills and participation in children under 5 years of age available. Four parent/primary caregiver questionnaires that examine these skills directly and indirectly were selected for the pilot study (Table 6). Prior to the interview, and with the consent of the parents, the VLBW infants' medical data was also retrieved from the Premature Baby Unit database. Each infant's Vermont Oxford Network (2011b) 'Hospital 28 day Form' (focusing on the first 28 days of life) and their 'Discharge Form' (focusing on the infants from day 29 to discharge) was used to obtain background medical information. This data enabled the researcher to explore the neonatal confounding factors associated with poorer outcomes in adaptive behaviour and participation (Vohr et al, 2003, Taylor et al, 2006; Fernandes et al, 2012; Silveira &Procianoy, 2011). Measures of illness on these forms included oxygen at 36 weeks, necrotizing enterocolitis, worst grade of periventricular haemorrhage and retinopathy of prematurity. Any information that required further clarification was discussed with the parents on the day of the interview.

Table 6 Questionnaires selected for the pilot study

Area	**Summary of Assessments Administered in Pilot Study**	**Age Range**
Adaptive Behaviour	The 'Parent/Primary Caregiver Form from the Adaptive Behavior Assessment Scales-II (ABAS-II) (Harrison and Oakland, 2003)	Every child 0-5 years
Participation	The Assessment of Preschool Children's Participation (APCP) (King et al., 2006)	Children 2-5 years
Performance skills	'The Social-emotional Scale' from the 3rd edition of the Bayley Scales of Infant and Toddler Development (Bayley, 2006) **OR** The Infant/Toddler Sensory Profile (Dunn, 2002)	One or other of these questionnaires was administered to parents of infants 0-24 months to supplement the ABAS-II
Medical	**VON Medical Forms from PBU Database, UHG** 28 Day Form Discharge Form (Vermont Oxford Network, 2011a)	All VLBW Infants

The following outlines both the pilot and main study:

3.8 PILOT STUDY

Pilot studies are a fundamental step in the initial stage of the research process (Gardner et al., 2003). The aim of this pilot study was to evaluate the feasibility of i.) Recruitment of the VLBW population, ii.) Appropriateness of fit of the data collection tools and, iii.) the assessment procedures (Leon, Davis & Kraemer, 2011). An observational, descriptive, quantitative design was used and resulted in the identification of modifications required prior to the main study commencing. These amendments, detailed below, were submitted and approved by the GUH ethics committee.

3.8.1 Procedure

The total group of VLBW babies born in UHG between January 2006 and December 2010 were coded by their hospital network number and stratified in to 5 age groups i.e. 0-1 years, 1-2 years, 2-3 years, 3-4 years and 4-5 years. Each child's corrected age was used for categorization. A sample selection of 15 parents/caregivers of VLBW children, now between 0 - 4 years 11 months of age, represented approximately 10% of the population being researched in UHG. This was deemed an adequate sample size to pilot the feasibility issues outlined above (Thabane et al., 2010). 3 children from each of the 5 age categories were selected by computer randomised sampling (http://www.randomizer.org/form.htm).

A detailed medical history from the UHG database, from admission to discharge from the Neonatal Intensive Care Unit (NICU), was available for each of the 15 VLBW infants selected. For each participant, many of the study's inclusion and exclusion criteria (See Appendix D) could therefore be confirmed by screening the child's hospital records. Hospital records also revealed that one child had passed away and thus the family was immediately withdrawn from the study, and another child in this age range was randomly selected. It was not however possible to screen the children's medical charts to ascertain whether or not they had a documented physical or intellectual disability as many of these files were in external storage. This will be discussed further below.

15 Information Packs including a letter of invitation, an information sheet, a consent form and a stamped addressed envelope (Appendix E,F,G) were prepared by the Principal Investigator. To ensure parent confidentiality prior to parental consent being received, these packs were addressed and posted by the medical secretary in UHG on 20th October 2011. Reminder letters were sent out to non-responders (12 families) 3 weeks after initial contact. In total, 4 responses were received from potential participants (27% response rate), with 3 of these families providing written consent (20%) and one family declining consent.

A combination of the parent questionnaires, as outlined in the data collection section, were selected for each participant based on the age band that their child was in at the time of interview. The duration of the once-off face-to-face interview with the principal investigator ranged from 30 – 90 minutes in total and all 3 interviews were completed by 19th December 2011. Each child's corrected age, rather than their chronological age, was used for administration and scoring of standardised parent questionnaires (40 weeks gestation was assumed to be the standard gestation period). Of the three participants, Participant 225 and Participant 280 were parents of children over one year of age therefore their interview encompassed all 10 skills areas of the ABAS-II. As for parents of all babies 0-11 months, Participant 310 (a parent of a VLBW baby 7 months of age) was

interviewed in relation to 7 of their child’s skill areas, with Community Use, Functional Pre-academics and Home Living being omitted.
Finally, each parent that participated in the pilot study was furnished with a written copy of the results of their child’s questionnaire.

3.8.2 Review of Pilot Study

Following feedback from the pilot study, it was confirmed that the main study was feasible the following amendments to the information pack, questionnaires, and interview technique were made:

i. Recruitment of the VLBW population

The response rate of the pilot study was 27%. No parents of children over the age of 3 years engaged with the study and therefore older children were not represented in the pilot. Dilman’s Tailored Design Method was used to customize the survey procedures for this study in the context of resources, the time frame available for the study and the type of people who were being asked to volunteer for the study (Dilman, Smyth & Christian, 2014). For example, the reminder letter in the pilot study furnished one extra response and therefore was deemed to be a potentially useful way of increasing the response rate in the main study. All participants were parents of young children therefore the researcher offered flexibility in the days and times for the interview and participant was encouraged to select a location most convenient for them. Another attempt at increasing the response rate for the main study was to strengthen the cover letter to emphasize the importance of the parents’ responses to the study and the benefits this research would for preterm VLBW children. Parents were also told that they would receive a summary of the overall results and their own child’s results on request. Other methods for increasing recruitment were explored such as sending parents postcards or further reminder letters however this was deemed to be excessive. Increasing respondent trust and commitment by offering a remuneration was also considered but beyond the resources of this project (Dilman, Smyth & Christian, 2014).

The age range of cases in the pilot study was from 0 – 4 years 11 months i.e. Infants and preschoolers. Following the pilot study however some discussion ensued as to whether or not the information obtained in relation to the everyday life skills of Infants less than 12 months was valuable to the study. Growing evidence suggests that the first year in an infant's life is a critical time period of brain development, with myelination occurring most rapidly in this first year of life (Spittle, Doyle and Boyd, 2008). As a result of studies such as Spittle et al, 2008, it was decided not to exclude the first year of life but to commence the age range at 6 months of age. The age range for the main study was 6 months – 5 years 6 months.

ii. Appropriateness of fit of the data collection tools

The *ABAS-II* was confirmed to be an appropriate choice as the primary outcome measure for this study. All of the adaptive behaviour skill areas can be grouped under the 9 domain areas of 'activity and participation' laid out in the International Classification of Functioning, Disability and Health (World Health Organisation, 2001), and thus represent everyday life activity for the young child. As this tool has been standardised on a North American population, it could not be assumed that the normative data were transferrable to an Irish population. As a result, for the main study the design was changed from a descriptive to a case-control design. Other small concerns were noted with the ABAS-II parent caregiver form. For example, in the 'Functional Pre-academics' skill area the ability to count numbers is addressed; however the bands of counting are quite large with parents asked if their child can count from 1-3, 1-10, and 1-20. Some parents commented that their child could, for example, count to 7 or 8, yet they received a zero for this response to this question. In the skill area of Communication the first 10 questions appear quite easy making it hard to differentiate between children of different abilities. The ABAS-II has however been shown to be a reliable and valid tool, as discussed in the previous chapter.

The APCP also provided valuable data in relation to the participation in the pilot study, with the main limitation for this study being that it was developed for 2-5 year old children therefore cannot be used with the younger children in this study. Finally, information gained from the Socio-emotional scale of the Bayley Scales of Infant and Toddler Development (Bayley, 2006), and the Infant/Toddler Sensory Profile (Dunn, 2002) was limited to performance components e.g. emotional development and sensory processing, as opposed to performance areas e.g. self-care, play, and thus were deemed unsuitable tools for the main data collection.

In summary, the two questionnaires that were selected for the main data collection were the 'Parent/Primary Caregiver questionnaire (ages 0-5 years)' from the Adaptive Behaviour Assessment System-II (ABAS-II) and the Assessment of Preschool Children's Participation (King, 2006).

Development of Demographic Questionnaire

The demographic information obtained during the pilot study, as part of the ABAS-II form, was limited to the following: Child Name, Chronological Age, Sex, City; School and School year; Race; Parent's occupation; Number of

Siblings; and Respondent’s relationship to child. This limited information did not appear to capture possible confounding factors, leading to concerns that the effects of VLBW were so mixed up with the effects of other variables that the VLBW effects could not be separated out and analysed (Shott, 1990), a common criticism of case-control studies (Yang et al., 2010). The investigator wished therefore to develop a demographic questionnaire that would control for all major social and health disparities identified in this population. The aim was to eliminate the possibility of creating a cause-effect relationship that does not exist (Bonita, Beaglehole & Kjellstrom, 2006) while also supporting the clinical interpretation of data.

Factors shown to influence adaptive functioning and child development in young children were explored in the previous chapter (Literature Review) and provided the theoretical basis for the questions in this questionnaire. For example, Prenatal alcohol and smoking exposure (Crocker et al, 2009), genetic factors (Fraser et al., 2013), neonatal interventions (Msall, 2006; American Academy of Pediatrics, 2004), gestational age and birth weight (Huang et al, 2012; Fily et al, 2006), parental psychological well-being (Huhtala et al, 2011; Huhtala et al, 2012), maternal age (Newburn-Cook & Onyskiw, 2005), maternal education (Vohr et al, 2000; Miller et al, 2001), socio-economic status (Sullivan et al, 2012, Golos et al, 2011), gender (Fernandes et al, 2012; Tyson et al, 2008) involvement in preschool programmes (Bronfenbrenner, 1986), the child’s physical environment (Davison & Lawson, 2006), support from spouse/extended family (Taylor et al, 2006) and presence of other siblings (Jaffe, Humphry & Case-Smith, 2010, p.114; Grant & Whittell, 2000) have all been shown to impact on a child’s ongoing developmental skills.

Considering these factors the researcher attempted to source a demographic questionnaire that successfully targeted these areas. It was decided to adapt the ‘Child and family Demographic questionnaire’, from Canchild, McMaster University, Canada (Appendix L) as many of the questions were appropriate for this study. The details of the questionnaire are in Table 7.

Table 7 Origins of Child and Family Demographic Questionnaire

Demographic questionnaire for this study	**Source**
Question 2 and 4	Taken directly from Canchild questionnaire, McMaster University - original format.
Questions 1, 3, 12, 13, 16, and 21	Taken from Canchild questionnaire, McMaster University - re-worded to enhance cultural relevance.
Question 11, 14 and 15	Taken directly from Census of Population of Ireland Household Form (Central Statistics Office, 2011). These questions on education, ethnicity and occupation were selected from the Census form as they reflected the Irish ethical groupings and the Irish education system accurately. This also allowed researchers the option of comparing the results of the study sample to the National demographics in Ireland, if deemed necessary.
Questions 13 and 17	Taken from Census - slight adaptations.

This resulted in 25 item demographic questionnaire for this study (Appendix K). The rationale for the questions is presented below:

Question 1-3

The questionnaire commenced with questions in relation to the child's age (Q.1), date of birth (Q.2), and gender (Q.3).

Question 4

This question on 'the type of school setting the child attends' provided seven options to choose from ranging from no schooling, to primary school and special education. Based on the categories selected by parents and for the purpose of data analysis, these categories were reduced to the following five: No school; Preschool; Daycare/Creche; Primary School (regular programme); and other.

Questions 5-10

Basic medical questions with a focus on service provision were only asked as, with parental consent, detailed medical information was obtained from the hospital 28 Day Form and the Discharge Form of the VLBW infants stored on the UHG database.

Question 11

A question in relation to the both parents' education level (Q. 11) was added as 'along with occupation and income, education is a common indicator of socioeconomic status' (Hay, 2006). The question on education provided 11 educational options ranging from no formal education to Doctorate (Ph.D.) or higher. For the purpose of analysis these educational categories of both parents were collapsed in to two groupings: No 3rd level degree; and 3rd level degree.

Question 13-14

In both of the national Irish surveys 'The Census 2006' (Central Statistics Office, 2006) and 'The Census 2011' (Central Statistics Office, 2012,), the socio-economic status or grouping of persons aged 15 years and over was determined by their occupation and employment status. Thus, two occupation focused questions, (Q.13) 'what is your current main activity/employment status' and (Q.14) 'your specific occupation in your main job' were included in the questionnaire. Q.14 was taken directly from the Census of Population of Ireland Household Form (Central Statistics Office, 2011).

The national Irish survey ‘The Census 2011’ has published its results in a number of thematic reports including socio-economic groupings (Central Statistics Office, 2012). These socio-economic population groupings have formed the basis for the socio-economic groupings in this study. The question on main activity allowed participants to select 1 of 12 possible answers, however, for the purpose of analysis these groupings were collapsed to: Looking after home/family; caring for family and working/studying; and working full-time.

In the Profile 3 of Census 2011, 10 specific socio-economic groups were specified, with one additional group for participants who did not supply sufficient information, that is’ ‘all others gainfully occupied and unknown’ (Central Statistics Office, 2012, p.74). Persons with similar social and economic status were brought together based on the educational attainment and skill required for the occupation. The socio-economic grouping was based on the occupation and employment status of the principal reference person in a family. Persons looking after home and family were classified to the socio-economic group of the reference person. In cases where the woman worked and her husband was either unemployed or a student the woman’s socio-economic grouping was used. Where both parents worked, the highest occupational skill level (social class groupings) was chosen to represent the family (Central Statistics Office, 2012, p.74). The 11 categories from the Census 2011 socio-economic groups were originally used to categories the families. As there were limited numbers in each group, for the purpose of analysis the 11 possible socio-economic groupings were reduced to 4 categories: Employers/Higher professionals; lower professionals and non-manual; manual and semi-skilled; and unskilled.

Question 15

The question on ethnicity provided 8 categories from the Census of Population of Ireland Household Form (Central Statistics Office, 2011) i.e. White (Irish, Irish Traveller, Any other white background), Black or black Irish (African, Any other black background), Asian or Asian Irish (Chinese, Any other Asian background) and Other (including mixed race background).

Question 16-22

Environmental factors such as parental marital status (Q.16) and the child's physical environment (Q.17-18) are included, as are the maternal and paternal factors of age (Q.19-20). Q.21 asked parents the 'number of siblings the child had (in the same home)'. This information was analysed in the following groupings: only child; one sibling; two or more siblings. Q.22 asked the child's order in the family.

Question 23-24

A question on the lifestyle (Q.23) and health (Q.24) of the mother before, during and after birth was also included.

Question 25

Finally, Q.25 asks the research participant if they would they be interested in being involved in further research.

In summary, questions focused on the child's schooling, medical and health issues; parent education, occupation, ethnicity and age of parents at time of child's birth; number of parents in household, type of dwelling and amenities; number of siblings and order of this child in relation to siblings; maternal alcohol, drug and non-prescriptive medication consumption;

maternal mental and physical health. Responses varied between tick boxes and free-text sections depending on the question.

Piloting of Demographic Questionnaire

Prior to use of the questionnaire with the sample population, the questionnaire was piloted with 4 mothers who work in the University, one of whom is a single parent. The questionnaire was also reviewed by Ricardo Segurado, Biostatistician in CSTAR in UCD to ensure that the layout of the questions allow for easy coding once the data is obtained. Feedback obtained informed minor adjustments to the questions.

Finally, the Census 2011 form (Central Statistics Office, 2011) did not have a direct question on salary. In the pilot version of the demographic questionnaire, there was a direct question on salary, providing ranges of incomes. Mothers who piloted the questionnaire reported that they did not mind being asked about their salary but they felt that some people might. Based on this feedback and the layout of the Census 2011 form (Central Statistics Office, 2011) which did not have a direct question on salary it was decided that adequate socio-economic information was obtainable with the omission of this question.

The demographic questionnaire was administered as part of the interview process i.e. with the ABAS-II and the APCP. The child specific questions (Page 1 and 2 – See Appendix K) were scheduled to be asked at the beginning of the interview, and the parent questions were asked at the end of the interview when it was anticipated that parents would be more at ease.

iii. Assessment procedures

For these parents, the suggestion that some children born VLBW are at greater risk of difficulties is an emotive topic. The pilot study was used to obtain feedback from parents on the content of the Information Pack they received. The sensitivity of the screening process used to omit children with an existing diagnosis of physical or Intellectual disability was carefully considered by the researcher and discussed with the parents. That is, as mentioned above, due to limited resources it was not feasible to ask hospital administrators to screen large numbers of charts of VLBW babies who were discharged in previous years. These charts were not easily accessible as they were kept in external storage and each individual chart needed to be formally requested. The alternative option chosen was to send out information packs to all families of children who were born VLBW in UHG between 2006 – 2010. The protocol was that once a family made contact with the principal investigator it would then be established whether their child met all the criteria for the study. Parent feedback in relation to this recruitment and the assessment process in general was positive and no suggestions regarding potential changes were offered.

To further support this screening process the researcher decided to amend the invitation letter. It was altered to include the following sentence: *"Following ethical approval from the Galway hospital ethics committee and Dr. O'Donovan and his team this is a generic letter that is being sent out to the families of all children born prematurely between 2006 – 2010 in Galway University Hospital".*

3.8.3 Modifications to Procedure following pilot study

Table 8 below summarizes the changes made to the original Ethics Application and approved by Chairman's approval by Dr.O'Keefe, Chairman Clinical Research Ethics Committee, Galway University Hospitals, following the pilot study.

Table 8 Changes to ethics following the Pilot Study February 2012

	Pilot	**Main Study**
Study Design	• Observational • Descriptive study	• Observational • Descriptive study • Analytical study (Case V's Match control group)
Parent Information Pack	• Letter of invitation • Information sheet • Consent form • Stamped addressed envelope.	Basic changes were made to the Letter of Invitation. Otherwise letters remained the same.
Participants	• Parents of 'Very Low Birth weight babies' born between Jan 2006 – Dec 2010 in University College Hospital Galway.	**Cases:** • Parents of 'Very Low Birth weight babies' born between Jan 2006 - June 2011 in University College Hospital Galway. **Control:** • Parents of children who were born full term and are now between 6 months - 5 years 6 months of age i.e. the 'Normal Population'. These parents would be accessed via the postnatal unit in University College Hospital Galway. * The biostatistician has calculated the minimum sample size for this study as

		36 cases and 36 controls. The aim is to recruit 50 Cases and 50 Controls in total for this study.
Parent Questionnaire	• Parent/Primary Caregiver Form from the Adaptive Behavior Assessment Scales-II (ABAS-II) (Harrison and Oakland, 2003) • Assessment of Preschool Children's Participation (King et al., 2006) • The Infant/Toddler Sensory Profile (Dunn, 2002) • The Social-emotional Scale' from the Bayley Scales of Infant and Toddler Development	• Parent/Primary Caregiver Form from the Adaptive Behavior Assessment Scales-II (ABAS-II) (Harrison and Oakland, 2003) • Assessment of Preschool Children's Participation (Petrenchik et al., 2006)
Demographic Questionnaire	• No demographic questionnaire used for pilot.	• New demographic questionnaire developed for main study - to be administered as part of face-to-face interview.
Recruitment Strategy	• Cases: • Information Pack • Stamped addressed envelope • Follow-up reminder letter 2 weeks after original correspondence.	• Cases: • No changes to recruitment of cases. • Controls: • Recruited in Postnatal unit, University Hospital Galway.

3.9 MAIN STUDY

The main study was carried out between May 2012 and January 2013. The 'Strengthening the reporting of observational studies in epidemiology (STROBE)' guidelines (Vandenbroucke et al, 2007) were used to guide the reporting of the study. As discussed earlier, the original study design was that of an observational, descriptive study however, following the pilot study it was decided to adopt a case-control group design for the main study. The research participants, both the cases and the controls, were obtained through convenience sampling in the UHG. A questionnaire survey/interview was utilised to compare quantitative data regarding the everyday life skills of children born premature and 'Very Low Birth Weight' (VLBW) in the Neonatal Unit in UHG with children born full term. The quantitative results obtained using the ABAS-II were also compared to the normative sample available on a North American population of children.

3.9.1 Procedure

Recruitment of Cases

All premature infants born at UHG are followed up in the Paediatric clinics at the hospital by the admitting physician and a physiotherapist trained in developmental assessment. Where concerns are identified regarding their physical or intellectual development infants are progressed to the local childhood developmental services for further assessment and were not included in the study. Children who continued at the Paediatric clinic were considered free of any physical and/or intellectual disability and these former premature babies formed the cohort of infants that were invited to participate in the study.

An initial list of all parents (N=183) of VLBW babies who were born in University Hospital Galway between November 2006 and December 2011 was prepared by the neonatologist and Co-Investigator. All these children were between 6 months - 5 years 6 months of age. Families (N=15) who had been invited to take part in the pilot study, and one family whose child had a known physical disability, were removed from the list. The medical secretary then screened the hospital records (Medical Records and Outpatient Database) of the remaining infants (N=167) to avoid, as much as was possible, an Information Pack being sent to families whose child had passed away. Infants (N=26) who were identified by the hospital PAS system as having passed away were removed from the list. Current addresses were also cross checked with all available hospital records for possible changes of address. Families who had not been available for follow-up hospital appointments were also removed from the list (1 child living in Germany, 1 child living in England, 1 family who had not attended any follow up out-patient clinic appointments since birth in 2007, and a child in foster care) (N=137). Finally, for statistical purposes, only one child from each family could be involved in the study. Therefore, one child was randomly selected from 12 sets of twins and one set of triplets (N=123). The inclusion and exclusion criteria for cases are outlined in Table 9.

Table 9 Inclusion and exclusion criteria for cases

Inclusion Criteria	**Rationale**
Parents of infants born preterm (<37 weeks gestation) in the Neonatal Unit in Galway University Hospital between November 2006 – December 2011 (Now between the ages of 6 months – 5 years 6 months).	The study aim was to explore the impact of preterm birth on the adaptive functioning and participation of former preterm, VLBW infants who were between 6 months – 5 years 6 months.
Birth weight was between 401 and 1500 grams OR gestational age was between 22 weeks 0 days and 29 weeks 6 days (inclusive) i.e. 'Very Low birth Weight' as defined by the Vermont Oxford Network (2011).	The eligibility criteria for VLBW was used to ensure that the study group selected was comparable to international neonatal units, as was made possible through the Vermont Oxford Neonatal Unit database.
'Healthy preterm' i.e. do not have a documented diagnosis of physical, intellectual or mental health disability.	
May attend healthcare (community or hospital) services but who do not have a formal diagnosis.	
May be a twin	Only one child from a family will be involved in the study as statistically they are not seen as 'independent' participants i.e. their genetics, diet etc. are similar.
Exclusion Criteria	**Rationale**
No longer live in Ireland or are not contactable at last known address.	
Parents who do not give informed consent.	
Parents under 18 years of age.	
Parents who are not fluent in English.	
Parents of children with a known diagnosis of physical or intellectual disability.	Children with diagnoses of physical or intellectual disabilities are known to present with challenges in participation in everyday activities (Chiarello, 2011). Therefore, to assess the impact of VLBW on function, in isolation of other confounding factors, this population of children will not be included in the study.

Data collection

Information Packs, prepared by the principal investigator, were sent by post to parents of VLBW infants by the medical secretary on 18th May 2012 (36 Information packs) and 25th May 2012 (87 Information Packs), at their last known address. To ensure parent confidentiality prior to parental consent being received, the Principal Investigator was not involved in this stage of the process. The packs included a letter of invitation, an information sheet, a consent form and a stamped addressed envelope.

Letters of consent were sent directly to the principal investigator. Two weeks after the initial correspondence the principal investigator furnished the medical secretary with the list of families who had not made contact, a single reminder letter was then sent to these non-responders by the medical secretary.

Once the parent consent form was received by the principal investigator (N=52), the consent form was reviewed. If the family did not give consent these forms were filed and the families name was listed to ensure no further correspondence was made with family. Families who gave written consent to partake in the research study were contacted by phone. This follow-up phone screening of parents who agreed to participate in the study provided an additional vetting process to ensure that the VLBW infants were, as best as we could assess, free of physical and/or intellectual disability.

Phone screening resulted in removal of a further 8 infants. Of the children excluded, five had a diagnosis of Cerebral Palsy, one had a diagnosis of Down Syndrome, one a severe hearing impairment, one had bronchopulmonary disease.

Finally, one of the VLBW infants had a peri-ventricular Haemorrhage Grade 3, and another a Retinopathy of Prematurity Stage 3, however, on further investigation neither of these children have been diagnosed with a disability. Of the two children, the former child is now 4 years of age and discharged from all services, and the latter child has normal vision with glasses and attends community SLT services only.

Studies have differed in their choice to include or exclude infants with a history of peri-intraventricular haemorrhage (PIH). For example, Huang et al. (2012) omitted all children with any level of PVL suggesting its probable ‘effect on psychological development’, while Fernandes et al. (2012) reported that 60% of their study infants had PIH of undisclosed severity. As discussed in the methods section, one child in this study had a PIH of 3, and another a ROP of 3, however, neither of these children were diagnosed with a disability and therefore were included in the study.

Once it was established that each child met the inclusion criteria an appointment was made with the parent/primary caregiver (N=44) to participate in a face-to face interview at the family home or at NUI Galway, whichever was more convenient for the family. The questionnaire/survey was administered and completed by the principal investigator during a single meeting. Parents were aware that they had the right to withdraw from the study at any point without giving any reason why. There were no occasions of withdrawals. Interviews of parents of infants in the VLBW group took place between May – September 2012.

Recruitment of Control Group

It is recommended that for hospital-based case control studies, the control group is recruited from subjects that are admitted to the same hospital and come from the same catchment area (Vandenbrouke & Pearce, 2012). For this reason the control group was recruited from the postnatal unit in UHG. The Nurse Manager in the Post Natal Unit in UHG recommended, in the interest of both staff and parents in the unit, that the interviews be carried out on week days between 12 – 2pm as the main nursing duties were completed by 12pm and visitors had left the Unit. (Visiting times in the Unit are from 10-12pm and from 2- 4pm).

Interviews of parents of the control group took place between May – December 2012. During the study period, the nurse manager on the post-natal unit checked the medical charts of all the mothers in the unit to ascertain if they met the inclusion criteria for the study i.e. they had children at home that were born full term and now between 6 months and 5 years 6 months of age. The number of available/potential participants on any given day varied from 1 – 5 parents. The Nurse Manager gave the researcher a list of the room numbers of potential participants and the researcher approached the parents in the order they were placed on the list until, where possible, two interviews were completed. 48 interviews were completed in the post-natal unit, and frequency-matched to cases for age (one year age bands) and sex (Appendix M).

Of the mothers approached in the Post-Natal Unit in GUH, 48 parents remaining in the Unit consented to being involved in the study. Eight mothers did not consent to take part in the study. Of these mothers, six did not give a reason why they did not wish to partake in the study, one mothers did not consent as she reported to be awaiting discharge, and one mother reported her child was born VLBW therefore was not suitable for the control group. This yielded a response rate of 85%. The inclusion and exclusion criteria for controls are outlined in Table 10 below.

Table 10 Inclusion and exclusion criteria for control group

Inclusion Criteria	**Rationale**
Parents availing of the Postnatal unit in Galway University Hospital, Galway	
Infants born full term (37 weeks gestation or more) between November 2006 – December 2011	Children between 6 months - 5 years 6 months were required to match the cases
Birth weight was within normal limits	
who attend healthcare (community or hospital) services but who do not have a diagnosis	
who have a twin	only one child from a family will be involved in the study as statistically they are not seen as 'independent' participants i.e. their genetics, diet etc. are similar
Exclusion Criteria	**Rationale**
documented diagnosis of physical, intellectual or mental health disability	
who do not give informed consent	
Under 18 years of age.	
Not fluent in English.	

As parents of infants 6-12 months could not be accessed in the Post Natal Unit, an addendum to ethical approval was requested and granted to recruit a total of 4 – 6 children between 6 – 11 months of age from the University Creche and the Oakwood Creche, Newcastle to supplement the age ranges already obtained. The Information Sheet was also adjusted for a crèche environment (Appendix J) and was handed out to parents in the crèche. Parents of three infants between 6-12 months were recruited.

In total 51 interviews were completed with the majority of questionnaires filled in by one respondent i.e. the mother or father. The interview duration varied between 30 – 120 minutes and all interviews were administered by the principal research investigator. Controls were matched with cases for age and sex.

Parent Feedback

The results of the questionnaires were analysed and each parent that had requested feedback from the study received a newsletter reminding families of the aims of the study and highlighting the results of the study. A list of strategies that could be used to enhance the children's adaptive behaviours was also provided. The principal investigator's email address and phone number were also supplied and families were invited to contact the researcher individually if they had any further queries regarding the study (See Appendix W).

During the study two children were identified as having specific health needs. As agreed in the ethics application, parents of these children were provided with relevant information regarding local children's health services.

Data Collected and Entry

All information obtained was stored in accordance with the Data Protection Act 1988 and the Data Protection (Amendment) Act 2003.

Ideally data entry would be conducted by two people to ensure accuracy, however, this was not possible for this study. All data were entered, checked and analysed using the Statistical Package for Social Science software (IBM SPSS Statistics, V. 18). For the ABAS-II assessment, the ages of the children were calculated to the nearest month. When calculating the children's ages in months, the number of days was only rounded up to an extra month if the number of days was 30 or more.

3.10 Statistical Methods

Descriptive and analytic statistics were used to explore the results of this study using both the preterm infants' chronological age and corrected age for prematurity. Comparisons of cases and controls were performed using independent samples t-tests for continuous measures and Pearson chi-square tests for categorical measures. Adjustment for potential confounders such as maternal age, maternal education level, sex of the child was performed using linear regression. For the comparison of children with two, one or no siblings, one-way ANOVA was used. For the comparison of the control group to the expected mean ABAS-II GAC or domain scores, one-sample t-tests were used. All tests were two-tailed and a p-value threshold of <0.05 was used to determine statistical significance. The table below provides the rationale for statistical tests used for each of the study's research questions:

Table 11 Rationale for statistical tests chosen to answer research questions

Research Question 1	Tests used	Rationale
Is there a significant difference between the adaptive functioning of Irish children, aged between 6 months to 5 years 6 months of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight?	Independent samples t-tests	To 'compare the means of two sets of values from one variable' (Griffith, 2010)
Research Question 2		
Is there a significant difference between Irish children 2 to 5 years of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight in their participation in childhood occupations?	Independent samples t-tests	To 'compare the means of two sets of values from one variable' (Griffith, 2010)
Research Question 3a		
Is there a difference on standardised testing between the adaptive functioning of an Irish control group of full term, average birth weight infants, aged 6 months to 5 years 6 months of age, and normative data available on a North American sample?	One-sample t-test	To compare the adaptive behaviour of the Irish VLBW group and the North American normative data of the ABAS-II
Research Question 3b		
Is there a difference on standardised testing between the adaptive functioning of Irish children, aged 6 months to 5 years 6 months of age, born preterm and very low birth weight, and normative data available on a North American sample?	One-sample t-test	To compare the adaptive behaviour of the Irish control group and the North American normative data of the ABAS-II

Controlling for Type I and Type II Errors

The researcher acknowledges the balancing act of reducing Type I and Type II errors, as decreasing the probability of one increases the probability of the other (Mudge et al., 2012)

i. The following measures were taken to reduce the chance of a Type I error, an error that occurs when it is concluded that there is a difference between groups when there is not one (Biau, Jolles & Porcher, 2010) or when 'we reject the null hypothesis when it is true' (Shott, 1990, p.108).

Significance Level:
The level of significance (α) is the probability of making a Type I error. The lower the α value, the lower the risk of making a type I error (Ren, 2009). A statistical significance threshold of 0.05 was applied to all tests on the primary and secondary outcome measures. In the literature, there has been criticism regarding the arbitrariness of chosen significance levels (Mudge et al., 2012) however, in this instance this threshold of 0.05 and a p value of <0.05 were selected for ease of comparison with the results of other recent studies on the adaptive behaviour of preterm infants who used these cut-off points (Huang et al., 2012; Peterson et al., 2006; Fjortoft et al., 2015). A p value less than the α value was used to conclude if findings were statistically significant (Ren, 2009). The p value is 'not the probability of the null hypothesis being true; it is the probability of observing these data, or more extreme data, if the null hypothesis is true' (Biau, Jolles & Porcher, 2010, p. 889) and practically 'represents a single probability across numerous test statistics'. The lower the p value, the more likely there is a difference between study groups (Biau, Jolles & Porcher, 2010, p.888).

The primary outcome measure for this study, the ABAS-II, provides confidence intervals (CI) at both 90% and 95%. For this study effect sizes (difference in mean scores, correlation coefficients, etc.) will be calculated with 95% confidence intervals. Secondary measures will be tested to explore and explain the results of the primary tests.

ii. The following measures were taken to reduce the chance of a Type II error, an error that occurs when it is concluded that there is no difference when in fact there is one (Biau, Jolles & Porcher, 2010) or when ‘we fail to reject the null hypothesis when it is false’ (Shott, 1990, p.108).

Study Size

The sample size estimate was calculated by taking in to account the following factors: A sample large enough to detect a clinically significant difference was required; the sample size was not so large that more people than strictly necessary were inconvenienced. As the study is observational, the likelihood of people being inconvenienced is less than that of if the study was treatment focused however, the control group are volunteering time and personal information without any direct personal benefit to them; What is being tested - The primary question is ‘Do children who are born VLBW demonstrate below average adaptive behaviours in the first 5 years of life, in comparison to their full term peers’. The primary measure is testing the Adaptive behaviour of cases and controls; and finally, how big of a difference in the means do we want to be able to detect between the groups?

There are a number of ways of defining and measuring differences in the adaptive behaviour of the two groups of children, so as to incorporate both the statistical significance and the clinical significance of the results. The first is to identify children by how many standard deviations they are from the norm i.e. a difference between the groups in GAC means scores of one, two or three standard deviations would be statistically significant. It would also be clinically significant from a diagnostic perspective. The second option is to use the descriptive classification system that has been developed by the authors of the ABAS-II to describe performance in the General Adaptive Composite, the Conceptual, Social and Practical domains, and the 10 Skill area scaled scores. The descriptive terms that characterize the different levels of performance are 'very superior', 'superior', 'above average', 'average', 'below average', 'borderline' and 'extremely low'. These classifications do not strictly follow the standard deviation i.e. 100 +/- 15. For example a score from 90 – 109 is classified as 'Average' and a score of 80 – 89 is classified as 'below average'.

Using Standard Deviations:

Seven of the ten skill areas apply to children from 0-11 months of age, while all 10 skill areas are applicable to children from 1 year – 5 years 11 months, as a result the sum of the scaled scores for these different age bands are different. For this reason the groups will be presented separately below. See tables 12 and 13 below.

Table 12 ABAS-II General Adaptive Composite (GAC) scaled and standard scores for children 1 year – 5 years 11 months

Range	Sum of Scaled Scores	Composite Score	Percentile Rank
Average	101 - 102	100	50%
1 SD from norm	79 – 80 (21–23 points < the norm)	85	16%
2 SD from norm	64 (37 - 38 points <the norm)	70	2%
3 SD from norm	36 – 37 (64–67 points < the norm)	55	0.1%

Table 13 ABAS-II General Adaptive Composite (GAC) scaled and standard scores for children 0-11 months

Range	Sum of Scaled Scores	Composite Score	Percentile Rank
Average	71	100	50%
1 SD from norm	59 (12 points < the norm)	85	16%
2 SD from norm	44 (27 points < the norm)	70	2%
3 SD from norm	29 (42 points < the norm)	55	0.1%

Variability of Adaptive Behavior Assessment Scale II in the population

If the scale is highly variable from person to person, then the group averages might be different, but the groups will still overlap so much that the statistical test cannot identify differences. As can be seen in table 14 below, the standard deviation for the ABAS GAC score is different for different age groups and depending on whether or not a 90% or a 95% confidence interval is used.

Table 14 Variability in Standard Deviations of the ABAS-II General Adaptive Composite scores

Age range	Standard deviation at 90% CI	Standard deviation at 95% CI
0 – 3 months	9	11
4 – 7 months	6	7
8 – 11 months	6	7
1 yr – 1 yr 3 mths	4	5
1 yr 4 mths – 1 yr 7 mths	3	4
1 yr 8 mths – 1 yr 11 mths	4	5
2 yrs – 2yrs 5 mths	3	4
2 yrs 6 mths – 2 yrs 11mths	4	5
3 yrs – 3yrs 5 mths	3	4
3 yrs 6 mths – 3 yrs 11mths	3	4
4 yrs – 4yrs 5mths	3	4
4 yrs 6 mths – 4 yrs 11mths	4	5
5 yrs – 5 yrs 11 mths	3	4

Primary outcomes for the ABAS-II are the General Adaptive Composite (GAC) score, individual Domain and Scaled scores. The GAC is expected to have a mean value of 100, with a standard deviation of 15. The individual scaled scores have mean values of 10, with a standard deviation of 3. Assuming that independent samples t-tests will be used to compare the mean scores between cases and controls, table 15 gives the minimum necessary sample sizes to detect the specified differences in the GAC or scaled score between cases and controls.

A p-value threshold of 0.05, and a power of 0.8 was specified. Effect sizes were calculated along with their 95% confidence intervals. A sample this size would also permit the detection of a 2 point difference on the ABAS-II subscales (assuming an SD of 3). Required sample sizes are identical for each measure at the specified ranges of differences, thus are represented on one table. As can be seen from Table 15 below a sample size calculation estimated the required sample size as a minimum of 36 per group to detect a difference in the ABAS-II of 10 points (assuming a standard deviation of 15), with 80% power.

Table 15 Sample sizes required to detect ABAS-II GAC score differences between cases and controls

GAC **difference**	Scaled score **difference**	**Sample size** (each group)	To obtain that sample size with a 30% response rate, need to **target**:
10	2	36	120 per group
15 (1 s.d.)	3 (1 s.d.)	17	57 per group
20	4	10	34 per group
25	5	7	24 per group
30 (2 s.d.s)	6 (2 s.d.s)	5	17 per group

Parametric and Non-parametric Testing

In order to select parametric or non-parametric testing for the main data analysis the researcher needed to establish if the data was at an interval/ratio level of measurement and normally distributed (Hicks, 2009), in which case parametric testing would be used. The initial step was to ascertain whether or not the quantitative data obtained using the ABAS-II assessment were normally distributed. Histograms were plotted to visually assess this. Although there are tests for normality e.g. Kolmogorov-Smirnoff, they have low power for small sample sizes (Lilliefors, 1967) therefore were not used.

For nominal data such as infants' sex non-parametric testing was used. For example, a Chi-squared test was used to establish if the proportion of male to females in the Control and VLBW group was equal. ‘If the test result is significant, the fit is said to be poor, meaning that the actual frequencies in your sample do not fit the expected values’ (Batavia, 2001, p. 83), and for the purpose of analysis, adjustment for disproportionate numbers of e.g. males and females would be required.

Data Sources/Measurement/Quantitative variables

This retrospective, analytical, observational study is based on both primary and secondary data. Data gathered as part of this study included the ABAS-II, APCP and the Demographic Questionnaire. Secondary data from the UHG medical records was also used. Data was grouped in to three – Controls, VLBW (Chronological age), and VLBW-COR (Corrected age).

The primary outcome measures used were the ABAS-II GAC score (General Adaptive Composite); and the Conceptual, Social and Practical domain scores (ABAS Composite domains). Adaptive behaviour was divided in to overall score (GAC), 3 domain scores, and the 10 skill area scores (Communication, Community Use, Pre-academics, Home Living, Health and Safety, Leisure, Self-care, Self-direction, Social and Motor skills). The secondary outcome measure was Participation as measured by the APCP. Participation was divided in to Intensity (Skill development, Social, Active Physical Recreation and Play) and Diversity of Participation. Confounding factors were controlled for using the child and family demographic questionnaire, and medical forms from hospital database. Potential Confounders included parent education, gestational age and birth weight, age, occupational classification and health; child’s gender, age, and schooling.

For the purpose of analysis, demographic variables that had excessive numbers of categories for analysis with few if any entries in specific categories/cells were collapsed in to smaller categories to avoid complicating the interpretation of statistical tests done and invalidating tests (e.g. Pearson Chi-square tests). For example, maternal education was reduced from 11 possible educational categories to two categories and coded as an indicator variable (0/1) for having completed a third level degree or not. The Main activity of mothers was reduced from 12 possible categories to four: ‘Looking after home/family’, ‘Working for pay or profit’ and ‘Caring for family and working/studying’. The 11 socio-economic groupings/Parental occupations were also reduced to four categories for the purpose of analysis: ‘Employers/higher professionals’, ‘Lower professionals and non-manual’, ‘Manual and semi-skilled’ and ‘Unskilled’. Details of all these variables and their categorisation have been discussed earlier in this chapter.

Descriptive statistics were calculated for all measures. These included means and standard deviations for normally distributed scores. ABAS-II – adaptive skills, APCP – participation, Child and Family Demographic information, Neonatal 28 day From and Neonatal Discharge Form. All descriptive statistics and testing was done with the VLBW groups using both the VLBW corrected age and the VLBW chronological age.

Relationship between predictors and outcomes were explored using t tests and correlations:

T-tests

Independent samples t-tests were used to establish whether there was a statistically significant difference between the ABAS-II GAC Score of the control group and the VLBW Group (using chronological age), and the 3 Domain scores (Conceptual, Social and Practical Composites) of the Control group, the VLBW Group (using chronological age) and the VLBW-COR Group (corrected age). The t-test uses a statistic that tests whether these two means differ significantly, compared with the null hypothesis of no difference.

Independent samples t-tests were used to establish whether there was a difference in means between the two Independent groups. Although the groups have been broken down in to Control, VLBW and VLBW-COR, there are strictly speaking only two groups i.e. one group (VLBW) has its ABAS-II scores calculated in two different ways, therefore an analysis of variance (ANOVA) to analyse the variance between ‘three’ groups would not be suitable. If an ANOVA was used with the two groups it would produce the exact same p values as the t-tests therefore be of no added advantage.

Independent samples t-tests were also used to ‘compare the means of two sets of values from one variable’ (Griffith, 2010). For example, they were used to analyse subgroups e.g. comparing the adaptive behaviour (mean GAC score) of VLBW babies who received oxygen at 28 weeks v’s those who did not.

One sample t-tests were used to compare the Irish ABAS-II results with the original North American (NA) data. The ABAS-II was designed so that the NA sample, by definition, had mean scores of 100. The comparisons are therefore not between the Irish sample and a NA sample, rather between the Irish sample and a target norm value of 100.

Levene’s test for equality of population variance was used to establish if variances/standard deviations were equal between groups. Levene’s test indicated equal variance could be assumed in all t-test results where $p>0.05$.

The effect size estimates are the differences in the means i.e. mean ABAS-II GAC in the control group minus ASAS-II GAC in VLBW group.

Finally, if scores were not normally distributed, rather than comparing groups with a t-test a non-parametric test such as the Mann-Whitney U test would have been used. Similarly, a non-parametric correlation such as the Spearman correlation coefficient would have been used.

ANOVA

A one-way analysis of variance, an ANOVA, is ‘a statistical technique that allows the simultaneous comparison of three or more sets of data derived from experimental designs’ ……‘which allow the researcher to analyse data from different- , same/matched-subject designs, or a mixture of both’ (Hicks, 2009, p.391). The influence of siblings on the study infants GAC scores was explored. As very few children had 3 or more siblings, the children with 3, 4 and 5 siblings were collapsed in to one new category. A comparison of mean ABAS-II scores between children with two or more, one or no siblings was performed using a one-way ANOVA.

Multiple testing

In epidemiology, strong arguments have been made against the idea of correcting at all for multiple testing (Rothman, 1990) and equally strong arguments have been made opposing that view (Ottenbacher, 1998).

A Bonferroni correction is the most common method for adjusting for multiple tests. This method involves counting the number of statistical tests performed and dividing the p-value threshold for “significant” by that number. This method was deemed far too conservative, particularly due to the expected correlation between the tests (ABAS-II General Adaptive, conceptual, social and practical composite scores, and the 10 skill area scores) (Streiner &

Norman, 2011). No correction for multiple testing was therefore performed. (P values are reported in the tables so readers can interpret them)

Linear Regression

As discussed earlier, confounding occurs when independent variables are associated with both the variable of interest and the outcome being measured (Mann, 2003; Yang et al., 2010). It is important therefore to explore the need for adjustment for potentially confounding factors impacting on the primary outcomes under study through analytic methods (Goldberg, McManus & Allison, 2013). Regression analysis goes beyond suggesting decisions as to whether or not a relationship between two variables exist. It specifies a functional form for the relationship between the variables that allows one to estimate the degree of change in the dependent variable that goes hand in hand with the changes in the independent variable, and make statements about how certain one can be about the predicted change in the dependent variable that is associated with the observed change in the independent variable (Von Eye & Schuster, 1998, p.3)

Simple Linear Regression

As no significant difference between groups does not preclude a confounding effect, a regression analysis (using both chronological and corrected age) was performed on each of the potential confounding variables, individually, and where necessary in a multiple regression. Due to the small sample size, only 5/6 of the most significant or key variables identified on the basis of individual associations with the ABAS-II score, and/or pre-specified theoretical basis for them being potential confounders were explored (VanVoorhis & Morgan, 2007). Adjustment for potential confounders was performed using linear regression of continuous scores on a dummy variable for case-control status and the potential confounders (e.g. maternal age, maternal education level, sex of the child).

Multiple Linear Regression

'Most typically and frequently, researchers predict outcome variables from more than one predictor variable' (Von Eye & Schuster, 1998, p.43). To test the effect of prematurity on the mean ABAS-II GAC score (relative to controls), while controlling for sex, maternal age, and maternal education level, a multiple linear regression was performed. Normality of the residuals, approximate linearity of the relationship between the dependent and independent variables, and homogeneity of the variance were verified by visual inspection of diagnostic plots.

Comparisons between Controls and North American Normative Data

The most robust group comparisons are those with the Irish cases and control group, as there are less confounding factors. Differences found between the control group and North American group may be due to a number of confounding issues.

Correlations

Before testing for correlations a scatter plot was used to inspect the data visually and establish whether non-parametric or parametric testing would be used. As the data appeared normally distributed, Pearson's correlation coefficient was used to assess bivariate (two variable) correlations to determine if there was a correlation between two continuous variables such as adaptive behaviour and birth weight, or adaptive behaviour and gestational age.
Cohen's benchmarks for interpreting effect-size estimates (Dunst and Hamby, 2012) were used. For correlations the effect is the coefficient, r.

Subgroups and Interactions

No subgroup analyses were performed.

Missing Data

There were no missing data on any of the variables of interest. Access to any early medical treatments or morbidities for the control group were not collected, and therefore these could not be compared between groups.

CHAPTER 4 – RESULTS

4.1 Participants

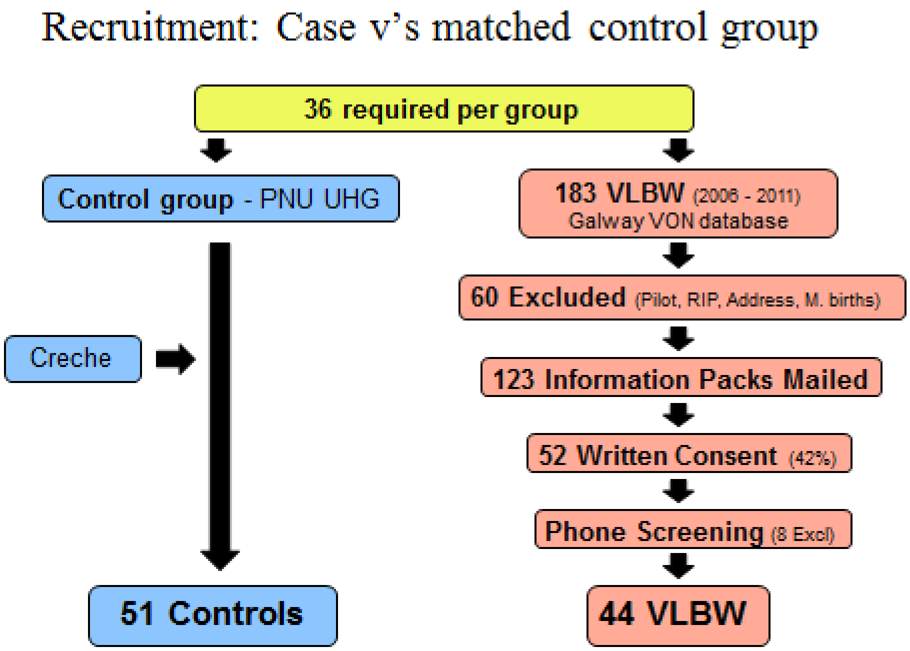
Cases

Parents of 44 infants born premature and very low birth weight in the neonatal unit of Galway University Hospital between November 2006 and December 2011, and now between 6 months and 5 years 6 months of age, were recruited for the study.

Controls

51 controls were recruited. 48 parents of babies born full term and of average birth weight, now between 6 months and 5 years 6 months of age, were recruited by convenience sampling in the Postnatal Unit of Galway University Hospital. 3 control infants between 0-12 months were recruited from a local crèche. Figure 2 below details the numbers in each stage of the recruitment process of both cases and controls.

Figure 2 Breakdown of the number of cases and controls recruited



4.2 Contextual Factors

The contextual factors comprise of the environmental factors influencing the families and infants.

4.2.1 Environmental Factors - Demographic Data of Families

The socio-economic characteristics of the families in both the VLBW and control group are presented in table 16 below.

Table 16 Socio-economic characteristics of families of VLBW & control group

		VLBW Group (N=44)	**Control Group (N=51)**
Siblings: N(%)	Only child:	14 (32%)	24 (47%)
	One sibling:	22 (50%)	16 (31%)
	Two or more:	8 (18%)	11 (22%)
Maternal education*: N(%)	No 3rd level degree:	23 (52%)	22 (43%)
	3rd level degree:	21 (48%)	29 (57%)
Paternal education*: N(%)	No 3rd level degree:	30 (68%	24 (47%)
	3rd level degree:	14 (32%)	27 (53%)
Maternal age at delivery: (Mean; Range)		32 yrs; 21 – 45 yrs	30 yrs; 20 – 38 yrs
Paternal age at delivery: (Mean; Range)		35 yrs; 23 – 49 yrs	32 yrs; 23 – 42 yrs
Maternal ethnicity: N(%)	Irish	35(80%)	44 (86%)
	Irish Traveller	0	3 (6%)
	Any other White background	8 (18%)	4 (8%)
	Any other Asian background	1 (2%)	0
Paternal ethnicity: N(%)	Irish	36 (82%)	45 (88%)
	Irish Traveller	0	3 (6%)
	Any other White background	6 (14%)	3 (6%)
	African	1 (2%)	0
	Chinese	1 (2%)	0
Main maternal activity: N(%)	Looking after home/family:	18 (41%)	16 (31%)
	Caring for family and working/studying:	20 (46%)	17 (33%)
	Working full-time:	6 (14%)	18 (35%)
Family Socioeconomic status: N (%)	Employer / Higher professional	19 (43%)	23 (45%)
	Lower professional / Non-manual	8 (18%)	10 (20%)
	Manual / Semi-skilled	13 (30%)	12 (24%)
	Unskilled	4 (9%)	6 (12%)
Two-parent Household		42 (96%)	50 (98%)
One-parent Household		2 (4%)	1 (2%)

*These variables will be expanded on in the section below

Mothers' Lifestyle

46 (90%) mothers in the control group and 41 (93%) in the VLBW group did not smoke at all during the pregnancy. Of the control group mothers who smoked, 1 (2%) smoked 'a few times' and 4 (8%) smoked 'weekly'. In the VLBW group, 1 (2%) mother smoked 'a few times' and 2 (5%) mothers smoked 'weekly'. 44 (86%) of the mothers in the control group and 37 (84%) in the VLBW group did not consume any alcohol during pregnancy. Of the control group mothers who drank, 4 (8%) drank 'a few times' and 3 (6%) drank 'weekly'. In the VLBW group, 1 (2%) mother drank 'once', 4 (9%) drank 'a few times' and 2 (5%) drank 'weekly'.

Maternal Health Issues before, during or after pregnancy

2 (4%) mothers in the control group and no mothers in the VLBW group reported to take non-prescription medication. Of the control group mothers who took medication, one mother took it 'once' and the other mother 'a few times'. 5 (10%) of the mothers in the control group and 3 (7%) in the VLBW group reported mental health problems before, during or after pregnancy. The 5 mothers in the contol group reported various levels of depression while 1 of the mothers in the VLBW group reported depression and 2 reported anxiety. 9 (18%) of the mothers in the control group reported to have physical problems (mother or baby) during pregnancy. The following physical problems were specified: Liver function concerns, high blood pressure, anemia, trachitis, diabetes, hyperemesis and pre-eclampsia. The majority of mothers/babies in the VLBW group experienced some physical problems associated with pregnancy.

The numbers in the groups were not large enough to use a a chi-squared test to establish whether the proportions in each group were different.

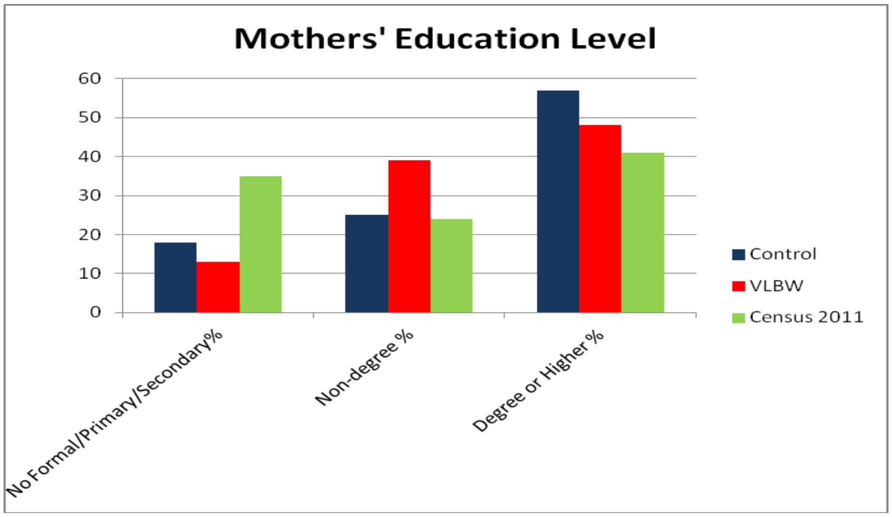
Parental Education

Demographic information on parental education has been expanded on in Table 17 below. All parents of children in the control and VLBW groups had some level of formal education. Their education levels were compared to each other and also to the education levels of the Irish population (Profile 9) as depicted in the National Census 2011 (Central Statistics Office, 2012). Maternal education was also compared seperately between groups in Figure 3 below.

Table 17 Persons aged 20 years and over, classified by age group and highest level of education completed

	No formal/ Primary or Secondary %	Third Level		Total
		Non-degree %	Degree or higher %	
Control				
Males 23-42 yrs	12 (24%)	12 (23%)	27 (53%)	51
Females 23-42 yrs	9 (18%)	13 (25%)	29 (57%)	51
Total 23-42 yrs	21 (21%)	25 (24%)	56 (55%)	102
VLBW				
Males 23- 49 yrs	13 (29%)	17 (39%)	14 (32%)	44
Females 23-49 yrs	6 (13%)	17 (39%)	21 (48%)	44
Total 23- 49 yrs	19 (21%)	34 (39%)	35 (40%)	88
Census 2011				
Males 20-44 yrs	304,463 (44%)	176,515 (26%)	206,855 (30%)	687,833
Females 20-44 yrs	248,510 (35%)	168,835 (24%)	287,437 (41%)	704,782
Total 20-44 yrs	552,973 (39%)	345,350 (25%)	494,292 (36%)	1,392,615

Figure 3 Mothers' education levels - Control group, VLBW group and Irish population



4.2.2 Environmental Factors - Demographic Data of Study Infants

Schooling of Control and VLBW group

Table 18 shows the profile of schooling for both the control and VLBW group. Of the 7 options given (No school; Preschool; Daycare/Creche; Primary School - regular programme; Primary school with Learning Support; Special Education School; Other), no children attended ‘Primary School with Learning support’ or a ‘Special Education School’.

Table 18 Descriptive statistics of school setting of Control and VLBW group

	No School	Preschool	Daycare/ Creche	Primary School (Reg. Programme)	Other	Total
Control	14 (28%)	16 (31%)	16 (31%)	2 (4%)	3 (6%)	51 (100%)
VLBW	13 (30%)	12 (27%)	10 (23%)	4 (9%)	5 (11%)	44 (100%)

4.3 Functioning and Disability

The Functioning and Disability section presents the demographic data of both the VLBW and control group, and the clinical characteristics and major morbidities of the VLBW group at the ICF level of body functions and body structures. Table 19 and 20 presents the clinical characteristics of the groups.

4.3.1 Body Functions and Body Structures - Demographic Data of Study Infants

Table 19 Characteristics of cases and controls

	VLBW Group (N=44)	Control Group (N=51)
Male : Female Ratio: N(%)	23 (52%): 21 (48%)	29 (57%): 22 (43%)
Age at Assessment: Mean (Range)	35 months (8 – 64)	35 months (6 – 66)
Gestation Age: Mean (Range)	29 weeks (25 – 34)	Term
Birth Weight: Mean (Range)	1145g (740 – 1750)	3500g

Table 20 Clinical characteristics and major morbidities in VLBW Group

		VLBW Group (N=44)		
		Yes N(%)	**No** N(%)	**Unknown** N(%)
Antenatal Steroids:		37 (84%)	6 (14%)	1 (2%)
Multiple Birth:		15 (34%)	29 (66%)	-
Conventional Ventilation*:		18 (41%)	25 (57%)	1(2%)
HIFI Vent*:		1 (2%)	42 (96%)	1(2%)
High Flow Nasal Cannula*:		0 (0%)	43 (98%)	1(2%)
Nasal IMV or Nasal SIMV*:		2 (5%)	41 (93%)	1(2%)
Nasal CPAP:		34 (77%)	9 (21%)	1(2%)
Oxygen at Day 28:		11 (25%)	23 (52%)	10 (23%)
Oxygen at 36 Wks Gestation:		9 (20%)	32 (73%)	3 (7%)
Oxygen at discharge:		1 (2%)	42 (96%)	1 (2%)
Patent Ductus Arteriosus:		9 (21%)	34 (77%)	1 (2%)
Necrotizing Enterocolitis:		0 (0%)	43 (98%)	1 (2%)
IVH Cranial Imaging (on/before day 28):		37 (84%)	5 (11%)	2(5%)
Retinopathy of Prematurity Retinal Exam		36 (82%)	7 (16%)	1 (2%)
Worst grade of Intraventricular Haemorrhage (IVH): (0-4) N(%)	No IVH	33 (89%)		
	Grade 1	3 (8%)		
	Grade 3	1 (3%)		
Worst grade of Retinopathy of Prematurity (ROP): (0-5) N(%)	Stage 0	22 (61%)		
	Stage 1	10 (28%)		
	Stage 2	3 (8%)		
	Stage 3	1 (3%)		
Intrauterine growth curve centile: Mean (Range)		45.0 (2 – 99)		
Small for gestational age (<10th centile):		4 (9%)		
5 min Apgar Score (N=43)	4-6	4 (9%)		
	7-8	9 (21%)		
	9	27 (63%)		
	10	3 (7%)		

*After Leaving Delivery Room

4.4 Contextual Factors – Analysis

Parent Education

A Pearson Chi-squared test was used to establish if the education ratios between the control and VLBW groups was the same (Tables 21 and 22). Separate testing was done for paternal and maternal education. The proportions of education in both groups were not different (Paternal education: chi-square test, p=0.104; Maternal education: chi-square test, p=0.385), therefore no adjustment for parent education levels is required in analyses.

Table 21 Chi-Square test comparing proportions of paternal education in VLBW and control group

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	4.533[a]	2	.104
N of Valid Cases	95		

Table 22 Chi-Square test comparing proportions of maternal education in VLBW and control group

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	1.908a	2	.385
N of Valid Cases	95		

Parental Age

An independent sample t-test demonstrated a significant difference in both maternal age (p=0.042) and paternal age (p=0.019), with maternal age in the VLBW group being 2 years older, and paternal age of VLBW children being 2.4 years older than parents in the control group.

Main Maternal Activity

Although the demographic questionnaire allowed particpants to select one main activity from 12 possible categrories, all participants choose from five of the categories i.e. Looking after home/family; Working full-time for pay or profit; Working part-time for pay or profit; Caring for family and working for pay or profit; and Caring for a family and studying. None of the participants in either group selected catergories 7-12 (Unable to work due to permanent sickness/disability; Recovering from illness or disability; Looking for first regular job; Unemployed; Retired from employment; Student or pupil; Other). For the purpose of analysis the five groups chosen were collapsed in to three groups. ‘Working full-time for pay or profit’ and ‘Working part-time for pay or profit’ were collapsed in to one group, as were ‘Caring for family and working for pay or profit’ and ‘Caring for family and studying’.

A Pearson Chi-squared test was used to establish if the proportions of ‘Main activity’ between the mothers in the control and VLBW group was the same (Table 23). No difference was found (chi-square test, p=0.053), therefore no adjustment for ‘Main activity’ levels is required in analyses.

Table 23 Chi-Square test comparing proportions of main activities of mothers in VLBW and control group

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	5.877[a]	2	.053
N of Valid Cases	95		

Socio-economic grouping of Control and VLBW Families

A Pearson Chi-squared test was used to establish if the occupational ratios between the groups was the same (Table 24). The proportions in both groups were not different (chi-square test, p=0.912), therefore no adjustment for socio-economic levels is required in analyses.

Table 24 Chi-Square test comparing proportions of occupational classifications in VLBW and control group

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	.530[a]	3	.912
N of Valid Cases	95		

Maternal and Paternal Employment Rate

In the control group, the reference person of 6 of the 51 families was unemployed. In the VLBW group, the reference person of 1 of the 44 families was unemployed. Due to low numbers in specific categories, formal testing of proportions using a chi-squared test could not be done. Fisher's exact test however demonstrated no significant difference between employment rates of the two groups (p=0.118)

Maternal and Paternal Ethnicity

The ethnicity of the fathers and mothers in the control and VLBW group were divided in to the 8 categories from the Census 2011 i.e. White (Irish, Irish Traveller, Any other white background), Black or black Irish (African, Any other black background), Asian or Asian Irish (Chinese, Any other Asian background) and Other (including mixed race background). Table 25 and 26 give a breakdown of the ethnic or cultural backgrounds of the groups.

Table 25 Descriptive statistics of ethnicity of mothers in VLBW and control and group

	White			**Asian or Asian Irish**	
	Irish	Irish Traveller	Any other White background	Any other Asian background	Total
Control	44 (86%)	3 (6%)	4 (8%)	0	51 (100%)
VLBW	35 (80%)	0	8 (18%)	1 (2%)	44 (100%)

Table 26 Descriptive statistics of ethnicity of fathers in VLBW and control group

	White			**Black or Black Irish**	**Asian or Asian Irish**	
	Irish	Irish Traveller	Any other White background	African	Chinese	Total
Control	45 (88%)	3 (6%)	3 (6%)	0	0	51 (100%)
VLBW	36 (82%)	0	6 (14%)	1 (2%)	1 (2%)	44 (100%)

Study Infants – Male Female Ratio of VLBW and control group

A Pearson Chi-squared test was used to establish if the sex ratios between the control and VLBW groups was the same (Table 27). The numbers of males and females in control groups were 29 (56.9%) and 22 (43.1%) respectively. In the VLBW group the numbers of males and females were 23 (52.3%) and 21 (47.7%) respectively. Appendix M shows the breakdown of male-female ratios. The proportions of males to females in both groups were not different (chi-square test, p=0.654), therefore no adjustment for sex is required in analyses.

Table 27 Chi-Square test comparing proportions of males to females in VLBW and control group

	Value	**df**	**Asymp. Sig. (2-sided)**
Pearson Chi-Square	.201[a]	1	.654
N of Valid Cases	95		

Study Infants – Ages of VLBW and Control group

An Independent Samples t-test was used to establish whether the ages of the Control group and the VLBW group were different (Table 28). Levene's test confirmed that equal variance could be assumed (p<0.05) and visual inspection of histograms did not suggest a skew in data. Test results showed no difference in the mean age between the two groups (p = 0.880). When the age of the cases was corrected (VLBW-COR) results remained the same.

Table 28 Independent Samples t-test comparing mean age of VLBW and control group

Children's Age in Months at time of Interview	T	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
	-.151	93	.880	-.493	3.258	-6.963	5.978

Summary of Potential Confounders

Of the potential confounding factors listed in Table 29 a significant difference was only found between groups in their maternal and paternal age. Both simple and multiple linear regressions are presented with the results of research question 1.

Table 29 Summary of potential confounding factors and their differences between the VLBW and control group

	Control group N=51	VLBW group N=44	Fisher's exact test	Pearson Chi-Square	Independent Sample t-test
Maternal Education				p=0.385	
Paternal Education				p=0.104	
Maternal Age					p=0.042*
Paternal Age					p=0.019*
Main Activity of Mothers				p=0.053	
Occupational Classification				p=0.912	
Unemployment rate	6	1	p=0.118		
Male-female ratios of infants	29:22	23:21		p=0.654	
Ages of infants (months)	6 - 68	8 - 64		p=0.880	
Average Age at time Assessed	35	35			

*Significant p<0.05

4.5 Research Questions – Activity and Participation of Study Infants

Parametric v's Non-Parametric Testing
The General adaptive composite score; the conceptual, social and practical domain composite scores; and 8 of the 10 skill areas for all 3 groups displayed rough bell shaped presentations when plotted on histograms. This confirmed an approximately normal distribution of data and therefore parametric testing was employed throughout the analysis. The 2 skill areas (Communication and pre-Academics) that demonstrated slightly skewed presentations were also analysed with non-parametric tests to confirm their results.

Multiple testing
No correction for multiple testing was performed due to the expected correlation between the tests (ABAS-II General Adaptive, conceptual, social and practical composite scores, and the 10 skill area scores). (P values are reported in the tables so readers can interpret them).

Research Question 1

Is there a significant difference between the adaptive functioning of Irish children, aged between 6 months to 5 years 6 months of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight?

To answer this question:

i. The ABAS-II mean General Adaptive Composite scores (GAC), Conceptual, Practical and Social composite scores, and the 10 skills areas of the VLBW group (using both chronological and corrected age) and control group were explored and are presented descriptively below.

ii. Independent sample t-tests were used to analyse the ABAS-II GAC and domain scores of the VLBW and control group, and the VLBW-COR and the control group. As a secondary measure, Independent sample t-tests were also used to compare the 10 skill areas of the VLBW and control group, and the VLBW-COR and the control group.

iii. Linear regression analysis, both simple and multiple, was used to test the effect of VLBW and prematurity on mean ABAS-II GAC score while controlling for possible confounding factors.

i. ABAS-II Mean Scores for VLBW, VLBW-COR and Control Group

ABAS-II Composite Scores for VLBW, VLBW-COR and Control Group
The ABAS-II results for the VLBW and control group are presented in Table 30 below, with scores for both the VLBW infants chronological age (VLBW group) and their corrected age (VLBW-COR) provided. In all domains the control group demonstrated highest mean scores, followed by the VLBW group adjusted for prematurity (VLBW-COR). When chronological age was used, the VLBW group demonstrated the lowest scores.

Table 30 ABAS-II General Adaptive Composite (GAC), and Conceptual, Social and Practical Composite mean scores for Controls, VLBW, and VLBW-COR

ABAS-II Composite Scores	Group	N	Mean	Std. Deviation	Std. Error Mean
General Adaptive Composite	Control	51	100.08	11.722	1.641
	VLBW	44	86.45	14.930	2.251
	VLBW-COR		93.48	13.807	2.081
Conceptual Composite	Control	51	102.49	11.872	1.662
	VLBW	44	91.75	15.625	2.356
	VLBW-COR		98.43	15.176	2.288
Social Composite	Control	51	105.84	12.207	1.709
	VLBW	44	92.55	13.622	2.054
	VLBW-COR		97.36	12.814	1.932
Practical Composite	Control	51	96.80	11.301	1.583
	VLBW	44	84.50	13.225	1.994
	VLBW-COR		90.09	13.284	2.003

ABAS-II Skill Area Scores for VLBW, VLBW-COR and Control Group
Table 31 below details the mean results of the 10 ABAS-II scaled scores for the VLBW group (using chronological and corrected age) and the control group. The control group demonstrated the highest mean scores in all 10 scaled scores, followed by the VLBW group corrected for prematurity (VLBW-COR). The lowest mean scaled scores were consistently in the VLBW group when chronological age was used.

Table 31 ABAS-II Skill Area mean scores for Control group and VLBW (chronological age) and VLBW-COR (corrected age) group

Scaled Scores	Group	N	Mean	SD	Std. Error M.
Communication	Control	51	11.31	2.035	.285
	VLBW	44	9.55	2.824	.426
	VLBW-COR		10.52	2.921	.440
Community	Control	48	11.10	2.934	.423
	VLBW	41	9.41	2.655	.415
	VLBW-COR	40	10.33	2.536	.401
Pre-Academics	Control	48	9.56	2.192	.316
	VLBW	41	8.07	2.621	.409
	VLBW-COR	40	9.20	2.653	.419
Home Living	Control	48	11.83	2.495	.360
	VLBW	41	8.98	2.979	.465
	VLBW-COR	40	9.70	2.729	.431
Health & Safety	Control	51	9.71	2.042	.286
	VLBW	44	7.91	2.541	.383
	VLBW-COR		8.84	2.614	.394
Leisure	Control	51	11.31	2.429	.340
	VLBW	44	9.05	2.282	.344
	VLBW-COR		9.86	2.398	.361
Self-care	Control	51	6.69	2.054	.288
	VLBW	44	5.34	2.123	.320
	VLBW-COR		6.23	2.321	.350
Self-Direction	Control	51	10.96	3.212	.450
	VLBW	44	9.30	3.261	.492
	VLBW-COR		10.16	3.065	.462
Social	Control	51	11.14	2.367	.331
	VLBW	44	8.91	2.769	.417
	VLBW-COR		9.7	2.539	.383
Motor	Control	51	9.06	3.082	.432
	VLBW	44	7.36	3.119	.470
	VLBW-COR		8.14	3.083	.465

ii. Independent Sample t-tests of control group and VLBW group (chronological and corrected age)

Comparison of ABAS-II Composite Scores - Control group and VLBW
Independent Samples t-tests were used to establish whether there was a statistically significant difference between the ABAS-II GAC scores and three Domain scores (Conceptual, Social and Practical Composites) of the VLBW Group (using chronological age) and the control group (See table 32). A statistically significant difference was found between the ABAS-II GAC scores (t=4.891, p<0.001), the Conceptual Composite scores (t=3.8, p<0.001), the Social Composite scores (t=5.018, p<0.001) and the Practical Composite scores (t=4.89, p<0.001) of both groups. For all these scores, the VLBW group had lower mean scores than the control group. Levene's test for equality of population variance indicated equal variance could be assumed in all t-test results (p>0.05) with the exception of ABAS-II GAC Composite score where P<0.05 required that equal variances were not assumed (See Appendix N).

Table 32 Independent Samples t-tests comparing ABAS-II Composite scores of control group and VLBW group

ABAS-II Composite Scores	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
General Adaptive Composite	4.891	81.156	<0.001	13.624	2.737	8.189	19.059
Conceptual Composite	3.800	93	<0.001	10.740	2.826	5.128	16.352
Social Composite	5.018	93	<0.001	13.298	2.650	8.035	18.561
Practical Composite	4.890	93	<0.001	12.304	2.516	7.307	17.300

Comparison of ABAS-II Composite Scores – Control group and VLBW-COR

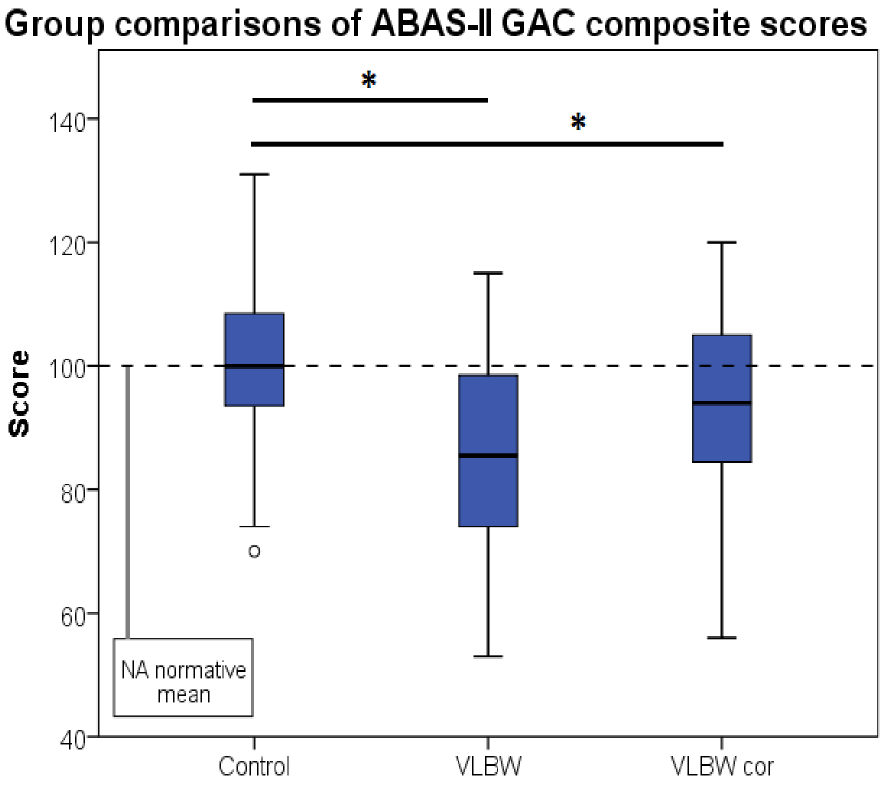
Independent Samples t-tests were used to establish whether there was a statistically significant difference between the ABAS-II GAC Score, and the three Domain scores (Conceptual, Social and Practical) of the Control group and the VLBW-COR Group (corrected age) (See table 33). There was a statistically significant difference in the overall ABAS-II GAC score (p<0.05; CI: 95%), the Social Composite score (p<0.001; CI: 95%), and the Practical Composite scores (p<0.01; CI: 95%). Differences in Conceptual Composite mean scores did not reach statistical significance. As the level of significance on Levene's test for equality of population variance was >0.05, equal variance was assumed in the t-test results (See Appendix O).

Table 33 Independent Samples t-tests comparing ABAS-II Composite scores of control group and VLBW-COR group

ABAS-II Composite Scores	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
General Adaptive Composite	2.521	93	.013	6.601	2.619	1.401	11.802
Conceptual Composite	1.461	93	.147	4.058	2.778	-1.458	9.574
Social Composite	3.299	93	.001	8.480	2.570	3.376	13.583
Practical Composite	2.662	93	.009	6.713	2.522	1.705	11.721

The General Adaptive Composite (GAC) mean scores of controls, VLBW (chronological age), VLBW-COR (corrected age) and normative data (North American) are presented in Figure 4 below. The VLBW and VLBW-COR had lower mean scores on overall adaptive behaviour than controls and normative data for both chronological and corrected age. No significant difference was found between the ABAS-II General Adaptive Composite mean scores of the Irish controls and North American normative data (p>0.05) (This will be discussed in detail with the results of research question 3a).

Figure 4 ABAS-II GAC mean scores of control group, VLBW group (VLBW: Chronological age; VLBW-COR: Corrected age) and normative data (North America)

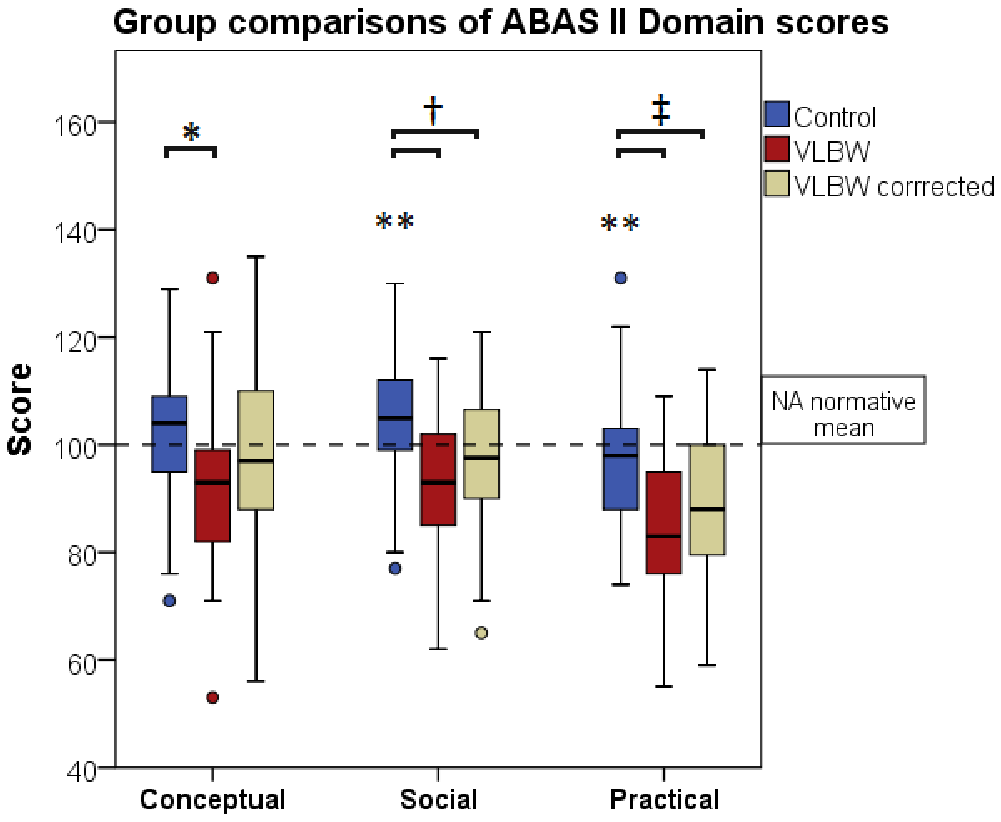


The Mean Conceptual, Social and Practical domain scores of Controls, VLBW (chronological age), VLBW-COR (corrected age) and Normative data (North American) are presented in Figure 5. Differences between groups were observed in the 3 Domain scores**.**

The Social Composite scores (†: VLBW p<0.001, CI: 95%; VLBW-COR p<0.001, CI: 95%) and the Practical Composite scores (‡: VLBW p<0.001, CI: 95%; VLBW-COR p=.009, CI: 95%) were lower than controls and normative data for both chronological and corrected age.

Differences in Conceptual Composite mean scores were only significantly lower for chronological age (*****: VLBW p<0.001; VLBW-COR p=.147). Irish controls had higher Social Domain scores and lower Practical Domain scores than the North American normative data (******: p<0.05).

Figure 5 ABAS-II domain mean scores of control group, VLBW group (Chronological age: VLBW; Corrected age: VLBW-COR) and normative data (North America).



Comparison of ABAS-II Skill Areas - Control and VLBW group

Independent Samples t-tests were used to establish whether there was a statistically significant difference between the 10 ABAS-II skill areas of the Control group and the VLBW Group (See table 34). There was a statistically significant difference in all 10 skills areas (p<0.05; CI: 95%). Levene’s test for equality of population variance indicated equal variance could be assumed in all t-test results (p>0.05) with the exception of the skill area of ‘Communication’ where P<0.05 required that equal variances were not assumed (See Appendix P).

Table 34 Independent Samples t-tests of ABAS-II Skill Areas of control and VLBW group

Skill Areas	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
Communication	3.452	76.879	.001	1.768	.512	.748	2.788
Community	2.828	87	.006	1.690	.597	.502	2.877
Pre-Academics	2.920	87	.004	1.489	.510	.475	2.503
Home Living	4.925	87	.000	2.858	.580	1.704	4.011
Health and Safety	3.819	93	.000	1.797	.470	.863	2.731
Leisure	4.667	93	.000	2.268	.486	1.303	3.233
Self-care	3.134	93	.002	1.345	.429	.493	2.198
Self-Direction	2.502	93	.014	1.665	.666	.344	2.987
Social	4.229	93	.000	2.228	.527	1.182	3.274
Motor	2.659	93	.009	1.695	.638	.429	2.961

Comparison of ABAS-II Skill Areas - Control group and VLBW-COR
Independent Samples t-tests were used to establish whether there was a statistically significant difference between the 10 ABAS-II skill areas of the Control group and the VLBW-COR (VLBW group corrected for prematurity) (See table 35). There was a statistically significant difference in the following skill areas: Home Living, Leisure and Social skills (p<0.05; CI: 95%). Levene's test for equality of population variance indicated equal variance could be assumed in all t-test results (p>0.05) with the exception of the skill areas of 'Communication' and 'Health and Safety' where P<0.05 required that equal variances was not assumed (See Appendix Q).

Table 35 Independent Samples t-tests of ABAS-II Skill Areas of control group and VLBW-COR

Skill Areas	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
Communication	1.508	75.195	.136	.791	.525	-.254	1.836
Community	1.319	86	.191	.779	.591	-.396	1.954
Pre-Academics	.702	86	.485	.363	.516	-.664	1.389
Home Living	3.827	86	.000	2.133	.557	1.025	3.241
Health and Safety	1.776	80.915	.079	.865	.487	-.104	1.834
Leisure	2.919	93	.004	1.450	.497	.464	2.437
Self-care	1.022	93	.309	.459	.449	-.432	1.350
Self-Direction	1.239	93	.218	.802	.647	-.483	2.087
Social	2.845	93	.005	1.433	.504	.433	2.433
Motor	1.025	93	.308	.650	.634	-.610	1.909

Differences between Male and Female ABAS-II Composite Scores

Independent sample t-tests were used to establish whether there was a difference between the adaptive behaviour scores of males and females in each group (controls and VLBW group). No significant difference ($p<0.05$) was found in the General Adaptive Composite (GAC), or the Conceptual, Social or Practical composite scores of males and females in either group. In both the control group and the VLBW group, there was also no significant difference ($p<0.05$) found between males and females in any of the 10 skill areas. The one exception was a statistically significant difference between the Home Living skills of males and females in the control group, in favour of the females.

No significant differences ($p<0.05$) between male and female ABAS-II Composite Scores of the control group (See Table 36). Levene's test for equality of population variance indicated equal variance could be assumed in the conceptual and social domain t-test results ($p>0.05$) but not with the General Adaptive Composite or Practical composite results where $P<0.05$ required that equal variances was not assumed. (See Appendix R).

Table 36 Independent Sample t-tests comparing male (N=29) and female (N=22) ABAS-II composite scores of control group

ABAS-II Composite Scores	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
General Adaptive Composite	-1.757	44.509	.086	-5.298	3.015	-11.373	.777
Conceptual Composite	-1.226	49	.226	-4.094	3.340	-10.805	2.617
Social Composite	-1.173	49	.247	-4.033	3.438	-10.943	2.877
Practical Composite	-1.890	48.611	.065	-5.621	2.974	-11.598	.356

No significant differences (p<0.05) between male and female ABAS-II Skill Areas of the control group (See Table 37). The one exception was a difference between the home living skills of males and females, in favour of the females. Levene’s test for equality of population variance indicated equal variance could be assumed in all skill area t-test results (p>0.05) with the exception of the Health & Safety and Self-care results where P<0.05 required that equal variances was not assumed (See Appendix R).

Table 37 Independent Sample t-tests comparing male and female ABAS-II Skill areas scores of control group

Skill Areas (Scaled scores)	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
Communication	-.013	49	.989	-.008	.581	-1.176	1.160
Community	-1.682	46	.099	-1.402	.834	-3.080	.276
Pre-Academics	-.607	46	.547	-.388	.639	-1.675	.899
Home Living	-2.126	46	.039	-1.483	.697	-2.886	-.079
Health & Safety	-.510	46.426	.612	-.277	.544	-1.371	.816
Leisure	-.357	49	.722	-.248	.693	-1.640	1.145
Self-care	.568	47.458	.573	.328	.576	-.832	1.487
Self-Direction	-1.786	49	.080	-1.588	.889	-3.374	.199
Social	-1.573	49	.122	-1.038	.659	-2.363	.288
Motor	-.889	49	.379	-.776	.873	-2.530	.979

No significant differences (p<0.05) between male and female ABAS-II Composite scores of the VLBW group (Table 38). Levene's test for equality of population variance indicated equal variance could be assumed in all domain t-test results (p>0.05) (See Appendix R).

Table 38 Independent Samples t-tests comparing male (N=23) and female (N=21) ABAS-II Composite scores of VLBW group

ABAS-II Composite Scores	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
General Adaptive Composite	-1.083	42	.285	-4.870	4.497	-13.945	4.206
Conceptual Composite	-1.830	42	.074	-8.404	4.592	-17.671	.864
Social Composite	-.561	42	.577	-2.327	4.145	-10.691	6.037
Practical Composite	-.899	42	.374	-3.598	4.001	-11.672	4.475

There was no significant difference (p<0.05) between male and female ABAS-II Skill Areas of the VLBW group (Table 39). Levene’s test for equality of population variance indicated equal variance could be assumed in all skill area t-test results (p>0.05) with the exception of the Pre-academic results where P<0.05 required that equal variances was not assumed (See Appendix R).

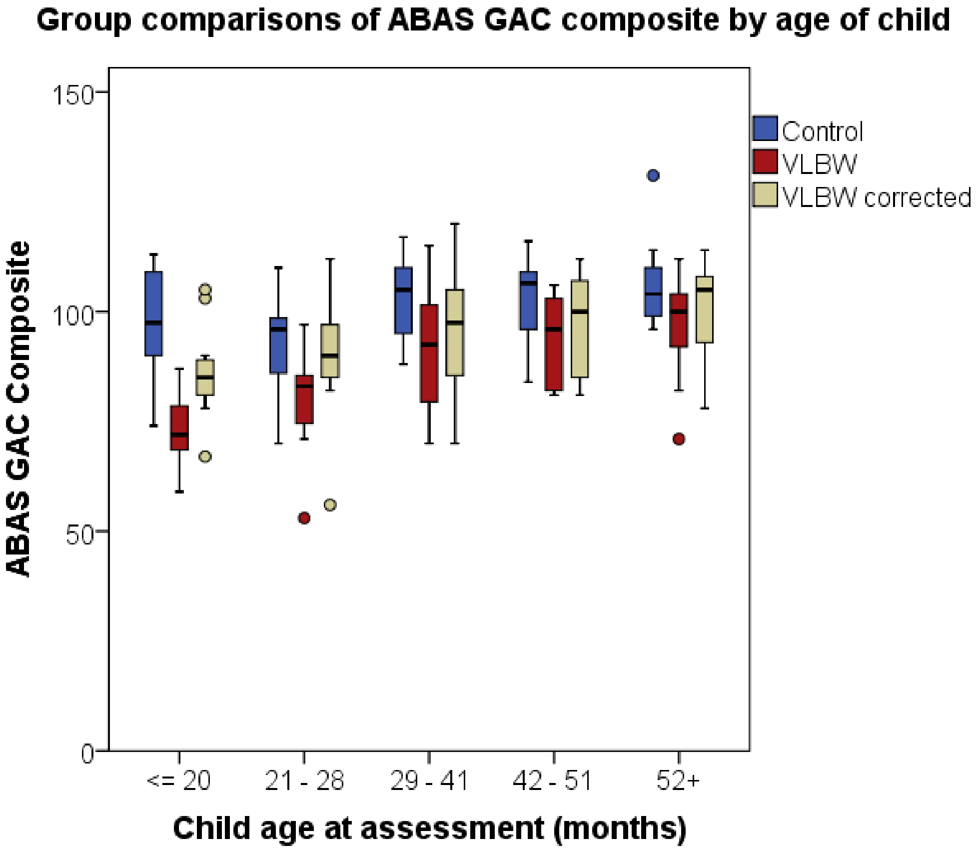
Table 39 Independent Sample t-tests comparing male and female ABAS-II Skill Areas of VLBW group

ABAS-II Skill Area (Scaled Scores)	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
Communication	-1.815	42	.077	-1.507	.830	-3.183	.169
Community	-.618	39	.540	-.517	.836	-2.208	1.174
Pre-Academics	-1.275	29.776	.212	-1.021	.801	-2.658	.615
Home Living	-1.106	39	.276	-1.026	.928	-2.904	.851
Health and Safety	-.224	42	.824	-.174	.776	-1.739	1.391
Leisure	.519	42	.607	.360	.695	-1.042	1.762
Self-care	-.400	42	.691	-.259	.647	-1.565	1.047
Self-Direction	-1.582	42	.121	-1.530	.967	-3.482	.422
Social	-1.424	42	.162	-1.176	.826	-2.843	.491
Motor	.061	42	.952	.058	.952	-1.864	1.980

Effect of Preterm birth Across Age Bands

An effect of being preterm on adaptive behaviour was observed at all ages of assessment. (Figure 6). While the effect was slightly less as the child gets older, testing with an Age by Group interaction term in the linear regression model showed no statistically significant differences (Table 43). Any modification of the group differences by age at assessment is therefore consistent with chance fluctuation. Considerably larger studies would be required to have adequate power to explore such small interaction effects.

Figure 6 Control, VLBW and VLBW-COR comparisons of ABAS-II GAC scores by age of child



Medical considerations

Before testing for correlations, visual inspection of data using scatterplots was done to establish whether a parametric or non-paramettic test would be used. As the data appeared to be normally distributed, Pearsons correlation was used. Table 40 shows the correlations between perinatal/neonatal variables and the ABAS-II General Adaptive Composite scores (ABAS- II GAC scores) for the VLBW-COR group (VLBW group corrected for prematurity). Independent samples t-tests did not find any significant differences (p<0.05) between groups when comparing ABAS-II GAC scores and perinatal/neonatal variables.

Table 40 Comparison between the VLBW-COR ABAS-II Mean GAC score and the perinatal and neonatal variables

		VLBW-COR ABAS-II Mean GAC score	Standard deviation	Pearson's Correlation	p Value
Birth Weight		-	-	.109	.481
Gestational age		-	-	.135	.382
Total Length of Hospital Stay		-	-	-.268	.079
Oxygen at 28 weeks	No	90.91	11.977	-	.987
	Yes	90.82	17.515		
Oxygen at 36 weeks	No	94.06	13.240	-	.574
	Yes	91.00	17.847		
Conventional Ventilation*	No	94.20	13.733	-	.624
	Yes	92.06	14.481		
Patent Ductus Arteriosus	No	94.21	12.348	-	.415
	Yes	89.89	19.284		
Antenatal Steroids	No	85.50	11.709	-	.141
	Yes	94.57	13.973		
Mode of Delivery	Vaginal	92.92	15.201	-	.908
	Caesarean	93.47	13.600		
Multiple Birth	No	93.41	13.809	-	.967
	Yes	93.60	14.287		

*After leaving delivery room

Pearson’s correlation showed a very weak correlation between the ABAS-II GAC score and birth weight (.109) and gesational age (.135). Neither score reached significance. A medium negative correlation (-.268) was found between ABAS-II GAC score (VLBW-COR) and length of hospital stay, though it did not reach significance (p=.079).

Independent samples t-tests were used to establish whether there was a statistically significant difference between ABAS-II GAC score of VLBW infants who received oxygen at 28 and 36 weeks and those who did not. Although the ABAS-II GAC mean scores were higher in the group that did not receive oxygen at 36 weeks (94.06 v’s 91.00), this did not reach significance (p=.574). As the level of significance on Levene’s test for equality of population variance was p>0.05 for oxygen at 36 weeks, equal variance was assumed in the t-test results. This was not the case with Oxygen at 28 weeks where p<0.05 and therefore equal variance could not be assumed.

Independent sample t-tests were used to establish if there was a difference between VLBW infants who received Conventional Ventilation and those who did not. Although there was a difference in means (94.20 v’s 92.06) in favour of those who did not obtain conventional ventilation, this was not significant (p=.624). As the level of significance on Levene’s test for equality of population variance was p>0.05, equal variance was assumed in the t-test results. Finally, Independent sample t-tests were used to establish if there were differences in ABAS-II GAC means scores in VLBW infants who received antenatal steroids, were delivered by different modes of delivery, or were a multiple birth. Significance was not reached with any of these variables.

VLBW ABAS-II GAC score and Retinopathy of Prematurity

Cranial imaging for Retinopathy of Prematurity was performed on 36 (82%) of the VLBW infants. None of the VLBW infants in this study were grade 4. Descriptive statistics are presented in Table 41 below.

Table 41 VLBW ABAS-II mean GAC scores and Retinopathy of Prematurity: Descriptive statistics

	Worst grade of ROP 0-4			
	0	**1**	**2**	**3**
VLBW (Count)	22	10	3	1
Mean ABAS-II GAC Score	88.23	80	89.33	86
SD	14.044	17.994	20.841	-

VLBW ABAS-II GAC score and Peri-intraventricular haemorrhage

Cranial imaging for peri-intraventricular haemorrhage (PIH) was performed on 37 (84%) of the VLBW babies. No VLBW babies were graded as 2 or 4. Descriptive statistics are presented in Table 42 below.

Table 42 Descriptive statistics for VLBW ABAS-II mean GAC scores and Peri-intraventricular haemorrhage

	Worst grade of PIH 0-4		
	0	1	3
VLBW (Count)	33 (89%)	3 (8%)	1 (3%)
Mean ABAS-II GAC Score	86.36	79.33	71
SD	14.5	23.07	-

Regression analysis

Guidance from the literature and visually inspection of the following table suggested the need to look at multiple predictors simultaneously using a linear regression.

Simple Linear Regression

Regression analysis was carried out to estimate the degree of change in the dependent variable (ABAS-II GAC Score) associated with changes in the following independent variables: Paternal education, maternal activity, infant age at assessment, presence of siblings, family socio-economic group. In isolation no single confounding variable tested demonstrated significance (See Table 43).

Table 43 Results of linear regression with dependent variable ABAS-II GAC mean scores and Group, with potential confounders

Predictor:		**Preterm (chronological age)**			**Preterm (corrected age)**		
		Coefficient	*95% CI*	*p-value*	*Coefficient*	*95% CI*	*p-value*
Preterm Group alone		-13.62	-19.06, -8.19	<0.001	-6.60	-11.80, -1.40	0.013
Preterm Group, adjusted for:	*Paternal education*	-13.22	-18.80, -7.64	<0.001	-6.28	-11.62, -0.93	0.022
	Maternal activity	-12.72	-18.26, -7.18	<0.001	-5.85	-11.15, -0.55	0.031
	Infant age at assessment	-13.82	-18.61, -9.04	<0.001	-6.74	-11.64, -1.85	0.007
	Presence of sibling(s)	-14.16	-19.65, -8.67	<0.001	-7.02	-12.29, -1.76	0.009
	Family Socioeconomic Group	-12.73	-18.19, -7.26	<0.001	-5.99	-11.23, -0.75	0.025

Multiple Linear Regression

Multiple regression was carried out to test the effect of VLBW on the mean ABAS GAC score (relative to controls), while controlling for sex, maternal age, and maternal education level, a linear regression was performed (See Table 44). The dependent variable was the ABAS-II GAC Score and the independent variables were Group, Maternal Age, Maternal Education, Child sex. Normality of the residuals, approximate linearity of the relationship between the dependent and independent variables, and homogeneity of the variance were verified by visual inspection of diagnostic plots.

These results indicate that, when controlling for any differences in sex, and maternal age and education between groups, the Very Low Birth Weight cases showed an 11.8 point lower score on the ABAS GAC, on average, a statistically significant difference.

Interestingly, maternal education, age and sex all also showed significant effects on ABAS GAC. Mothers with degrees had children with a 5.99 point higher GAC score, on average. Each additional year of maternal age resulted in a 0.75 point lower GAC score in their child. Female children had a 5.88 point higher GAC score on average, than males.

An exploratory investigation of interactions, in order to determine if the effects of female sex, higher maternal education and younger maternal age on GAC were the same in the Control and VLBW groups, showed no significant results. This indicates that the effects of each predictor are independent of VLBW status.

Table 44 Multiple linear regression with dependent variable (ABAS-II GAC score) and Independent variables

	Chronological-age ABAS			*Corrected-age ABAS*		
Predictor:	*Coefficient*	*95% CI*	*p-value*	*Coefficient*	*95% CI*	*p-value*
Group	-11.8	-17.2, -6.4	<0.001	-2.3	-4.9, 0.29	0.081
Maternal education	5.99	0.48, 11.50	0.034	6.74	1.46, 12.03	0.013
Maternal age	-0.75	-1.36, -0.15	0.015	-0.78	-1.36, -0.20	0.009
Sex	5.88	0.64, 11.12	0.028	3.81	-1.21, 8.83	0.135

Influence of Siblings on children's GAC Scores

An ANOVA was used to compare the mean ABAS-II scores between children with 0, 1, or 2 or more siblings. Sibling category did not have a statistical effect on the ABAS-II GAC Scores (p=0.325).

Correction for Prematurity – Further Exploration

The data were explored from two different clinical perspectives 1) the number of children one or two standard deviations (s.d.) from the norm in both groups and 2) the number of children who scored below average as determined by the ABAS-II descriptive classification system.

Standard deviations from the norm

Both the control and the VLBW groups were divided in to two age groups: children ≤ 24 months, children ≥ 25 months. The results of the VLBW children in the ≤ 24 months group were corrected for prematurity while no adjustment was made to the results of the VLBW children in the ≥ 25 months. Tables 45 and 46 below present the numbers and proportions of children in each of these groups, who lay below 1 standard deviation or 2 standard deviations from the mean score on the four ABAS-II composite scores (< 85 points, <70 points):

Table 45 Groupings of VLBW infants by age and standard deviation below the norm

VLBW	**6 – 24 months; N=18 Corrected Age**		**25-64 months; N=26 Chronological Age**	
Score	<1 s.d.	<2s.d.s	<1 s.d.	<2s.d.s
GAC	4 (22.2%)	2 (11.1%)	7 (26.9%)	0 (0%)
Conceptual	3 (16.7%)	1 (5.5%)	5 (19.2%)	0 (0%)
Social	4 (22.2%)	1 (5.5%)	3 (11.5%)	0 (0%)
Practical	10 (55.5%)	2 (11.1%)	11 (42.3%)	0 (0%)

Table 46 Groupings of Control infants by age and standard deviation below the norm

Controls	**6 – 24 months; N=14**		**25-66 months; N=37**	
Score	<1s.d.	<2s.d.s	<1s.d.	<2s.d.s
GAC	2 (14.3%)	0 (0%)	4 (10.8%)	0 (0%)
Conceptual	2 (14.3%)	0 (0%)	3 (8.1%)	0 (0%)
Social	1 (7.1%)	0 (0%)	3 (8.1%)	0 (0%)
Practical	3 (21.4%)	0 (0%)	7 (18.9%)	0 (0%)

From 25 – 64 months of age, if adjustment for prematurity is no longer made, 7 (26.9%) of the VLBW infants demonstrate overall adaptive behaviour scores of less than one standard deviation below the norm in comparison to only 4 (10.8%) of the control group. On review of the socio-economic profiles of the 7 VLBW children 25 - 64 months who scored <1s.d. the only similarities found were that 6 of 7 of their mothers had an education level of less than degree level (one had a degree), and 5 of the 7 of them were stay at home mothers (one in admin, one in skilled trades).

ABAS-II Descriptive Classification

Splitting the ABAS-II scores (VLBW group) into classes, the division by age ≤ 24 months or ≥25 months showed the following distributions (Table 47 & 48):

Table 47 Numbers and proportions of VLBW group in each descriptive classification of the ABAS-II

	GAC Score by Classification – VLBW Group					Total
	Extremely Low (70 or less)	**Borderline** (71 to 79)	**Below Average** (80 to 89)	**Average** (90 to 109)	**Above Average** (110 to 119)	
Chronological age ≥ 25 mths	1	2	6	15	2	26
	3.8%	7.7%	23.1%	57.7%	7.7%	100%
≤ 24 months corrected	2	1	8	6	1	18
	11.1%	5.6%	44.4%	33.3%	5.6%	100%
Total	3	3	14	21	3	44
	6.8%	6.8%	31.8%	47.7%	6.8%	100%

Table 48 Numbers and proportions of Control group in each descriptive classification of the ABAS-II

	GAC Score by Classification – Control group						Total
	Extremely Low (70 or less)	**Borderline** (71 to 79)	**Below Average** (80 to 89)	**Average** (90 to 109)	**Above Average** (110 to 119)	**Superior** (130 or more)	
Chronological age ≥ 25 mths	1	2	2	24	7	1	37
	2.7%	5.4%	5.4%	64.9%	18.9%	2.7%	100%
≤ 24 months	0	1	1	11	1	0	14
	0.0%	7.1%	7.1%	78.6%	7.1%	0.0%	100%
Total	1	3	3	35	8	1	51
	2.0%	5.9%	5.9%	68.6%	15.6%	2.0%	100%

Research Question 2

Is there a significant difference between Irish children 2 to 5 years of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight in their participation in childhood occupations?

To answer this question:

i. The four areas of intensity of participation (play, skill development, active physcial recreation and social activities) and the diversity of participation, as measured by the Assessment of Preschool Children's participation (APCP) (King et al, 2006), of children 2 to 5 years of age in the VLBW group and control group was explored and is presented descriptively below.

ii. Histograms were plotted. Visual inspection concluded that the intensity and diversity scores were normally distributed, and no significant group differences were seen.

iii. Independent sample t tests were used to compare the mean scores in Intensity and diveristy of participation in the VLBW group and control group, as measured by the APCP. As the level of significance on Levene's test for equality of population variance was >0.05, equal variance was assumed in the t-test results (See Appendix S). The results are presented in both table and graph format below.

iv. Finally, independent sample t tests were used to compare the intensity and diversity of participation in males and females of the overall sample, the control group, and the VLBW group were compared, using the APCP results.

i. Descriptive statistics of Intensity and Diversity of Participation of Control and VLBW Group

The APCP is designed for 2 to 5 year old children and therefore was used with all the children in this age range (66% of VLBW children and 71% of the control group). These results were obtained using the 45 core activities of the APCP. ‘Other activities’ such as farming, shopping, golf and individual athletics were not included. Descriptive statistics are presented in Table 49 below.

Table 49 Descriptive statistics of intensity and diversity of participation of control and VLBW Group

Activity Area	Group	N	Minimum	Maximum	Mean	Std. Deviation
Intensity of Play	Control	36	2.89	6.67	5.0247	1.08220
	VLBW	29	2.89	6.89	4.9502	.96114
Intensity of Skill Development	Control	36	2.20	4.80	3.6130	.64040
	VLBW	29	1.67	4.73	3.5425	.64062
Intensity of Active Physical Recreation	Control	36	2.80	5.10	4.0139	.55144
	VLBW	29	2.30	4.80	4.1483	.55589
Intensity of Social Activities	Control	36	.91	5.36	3.2045	1.01567
	VLBW	29	1.27	4.36	3.0627	.71669
Diversity	Control	36	20.00	40.00	31.9444	5.36094
	VLBW	29	18.00	39.00	32.1724	4.89948

3. Independent sample t tests comparing participation of VLBW and control group

Levene’s test for equality of population variance was >0.05 for all tests therefore equal variance was assumed with t-test results. The only exception was the t-test results for the intensity of play skills for the control group where equal variance could not be assumed (See Appendix T).

Table 50 and Figure 7 presents the intensity of participation of the control and VLBW group. No significant differences were observed between groups.

Table 50 Independent samples t-tests comparing mean APCP intensity scores of VLBW and control group

Intensity of Participation	t	df	Sig. (2-tailed)	Mean Difference	95% Confidence Interval of the Difference	
					Lower	Upper
Intensity of Play	.290	63	.773	.07450	-.43916	.58816
Intensity of Skill Development	.441	63	.661	.07043	-.24893	.38980
Intensity of Active Physical Recreation	-.973	63	.334	-.13439	-.41034	.14156
Intensity of Social Activities	.635	63	.528	.14185	-.30452	.58822

Figure 7 Mean intensity of participation of control and VLBW group

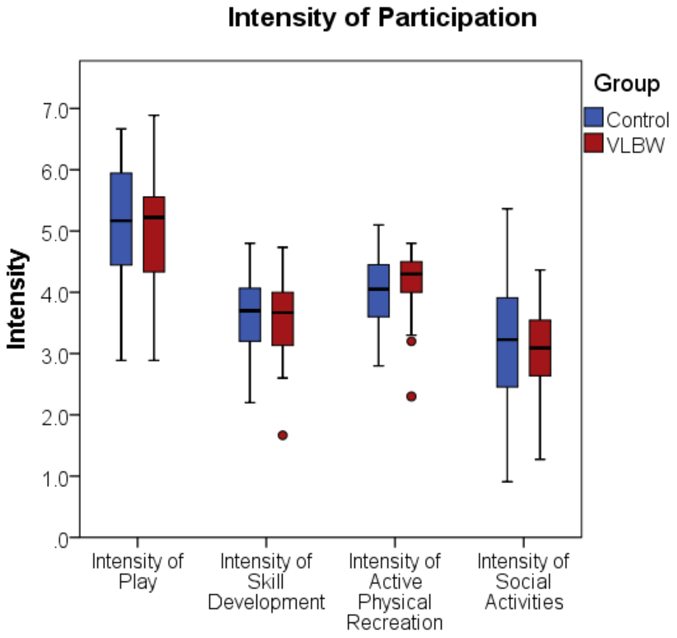


Table 51 presents the results of an independent samples t-test used to establish whether there was a difference between the diversity of participation of the control and VLBW group. No significant difference was found (p=.860).

Table 51 Independent samples t-test comparing diversity of participation of VLBW and control group

Diversity of Participation	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
	-.177	63	.860	-.22797	1.28776	-2.80136	2.34542

iii. Gender differences between male and female scores of Intensity and Diversity of Participation

Independent sample t-tests were used to ascertain if there was a differences between the males (M) and females (F) in intensity and diversity of participation within the overall sample (N=65), the control group (N=36), and within the VLBW group (N=29).

2-5 year old Males and Females in Overall Sample – Intensity of Participation
Tables 52 presents the descriptive statistics and Tables 53 presents the result of the independent sample t-tests between males and females in the overall sample.

Table 52 Descriptive statistics of intensity of participation of all males and females 2- 5 years of age in the study

Intensity of Participation	Sex	N	Mean	Std. Deviation	Std. Error Mean
Intensity of Skill Development	M	30	3.4422	.66101	.12068
	F	35	3.7010	.59834	.10114
Intensity of Social Activities	M	30	2.7061	.80773	.14747
	F	35	3.5143	.79220	.13391
Intensity of Active Physical Recreation	M	30	3.9567	.60211	.10993
	F	35	4.1743	.49429	.08355
Intensity of Play	M	30	4.5815	1.05275	.19221
	F	35	5.3429	.86503	.14622

Independent samples t-tests were used to establish if there was a difference in the intensity of participation of all males and females in the study. In the overall sample (N=65), females demonstrated a significantly greater intensity of social activities and play skills than their males peers. No difference was found between genders in participation in skill development or active physical recreation (Table 53).

Table 53 Independent samples t-tests comparing intensity of participation between overall male (N=30) and female (N=35) scores

Intensity of Participation	t-test for Equality of Means						
	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
Intensity of Skill Development	-1.656	63	.103	-.25873	.15624	-.57095	.05349
Intensity of Social Activities	-4.064	63	.000	-.80823	.19889	-1.20568	-.41077
Intensity of Active Physical Recreation	-1.600	63	.115	-.21762	.13599	-.48937	.05414
Intensity of Play	-3.201	63	.002	-.76138	.23787	-1.23671	-.28604

2-5 year old Males and Females in Control Group - Intensity of Participation
Table 54 presents the descriptive statistics for the intensity of participation of males and females in the control group, while Table 55 presents the difference between male and female controls using independent samples t-tests.

Table 54 Descriptive statistics for intensity of participation of males (N=18) and females (N=18) in control group

Intensity of Participation	Sex	N	Mean	Std. Deviation	Std. Error Mean
Intensity of Skill Development	M	18	3.3815	.63072	.14866
	F	18	3.8444	.57712	.13603
Intensity of Social Activities	M	18	2.5455	.81788	.19278
	F	18	3.8636	.73144	.17240
Intensity of Active Physical Recreation	M	18	3.8778	.57656	.13590
	F	18	4.1500	.50439	.11889
Intensity of Play	M	18	4.4074	1.06506	.25104
	F	18	5.6420	.68552	.16158

Table 55 shows that in the control group (N=36), females have a significantly greater level of social, skill development and play activity than males. No difference was found between the active physical recreation of both genders.

Table 55 Independent samples t-tests comparing the intensity of participation of males and female in the control group

Intensity of Participation	t	df	Sig. (2-tailed	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
Intensity of Skill Development	-2.298	34	.028	-.46296	.20151	-.87247	-.05345
Intensity of Social Activities	-5.097	34	.000	-1.31818	.25862	-1.84377	-.79260
Intensity of Active Physical Recreation	-1.508	34	.141	-.27222	.18056	-.63916	.09472
Intensity of Play	-4.135	29.022	.000	-1.23457	.29854	-1.84513	-.62400

2-5 year old Males and Females in VLBW Group - Intensity of Participation

In the VLBW group (N=29), no significant differences were found between the intensity of participation of males and females. Descriptive statistics are presented for the males and females of the VLBW group in Table 56 and their Independent samples t-test results are presented in Table 57.

Table 56 Descriptive statistics for the intensity of participation of the males (N=12) and females (N=17) in the VLBW group

Intensity of Participation	Sex	N	Mean	Std. Deviation	Std. Error Mean
Intensity of Skill Development	M	12	3.5333	.72251	.20857
	F	17	3.5490	.59932	.14536
Intensity of Social Activities	M	12	2.9470	.76204	.21998
	F	17	3.1444	.69462	.16847
Intensity of Active Physical Recreation	M	12	4.0750	.64544	.18632
	F	17	4.2000	.49749	.12066
Intensity of Play	M	12	4.8426	1.02215	.29507
	F	17	5.0261	.93996	.22797

Table 57 Independent samples t-tests comparing the intensity of participation of males and female in the VLBW group

Intensity of Participation	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
Intensity of Skill Development	-.064	27	.950	-.01569	.24595	-.52033	.48896
Intensity of Social Activities	-.724	27	.475	-.19742	.27254	-.75662	.36179
Intensity of Active Physical Recreation	-.589	27	.560	-.12500	.21208	-.56015	.31015
Intensity of Play	-.500	27	.621	-.18355	.36734	-.93727	.57017

Diversity of Participation of Males and Females

The diversity of participation of all males and females, of males and females of control group, and males and females of VLBW group were compared using independent sample t-tests. A significant difference was found between the diversity of overall males and females (See Table 59), and also between males and females of control group (See Table 61). No difference was found between the diversity of participation of males and females in the VLBW group (See Table 62). The descriptive statistics (Table 58, 60, 62) and independent sample t-tests for each group are presented below.

2-5 year old Males and Females in Overall Sample - Diversity of Participation

Table 58 Descriptive statistics on the diversity of participation of all males and females in sample

Diversity of Participation	Sex	N	Mean	Std. Deviation	Std. Error Mean
	M	30	30.0667	5.57045	1.01702
	F	35	33.7429	4.06088	.68641

Independent samples t-tests were used to compare the diversity of participation of all males (M) and females (F) in the study. Levene's test of equality of variance was assumed (p>.05) (See Appendix U). In the overall sample (N=65), females have a significantly greater diversity of participation than males.

Table 59 Independent samples t-test comparing the diversity of participation of all males and females in sample

Diversity of Participation	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
	-3.069	63	.003	-3.67619	1.19798	-6.07017	-1.28221

2-5 year old Males and Females in Control Group - Diversity of Participation

Males and Females in Control group

Table 60 Descriptive statistics on the diversity of participation of males and females in control group

Diversity of Participation	Sex	N	Mean	Std. Deviation	Std. Error Mean
	M	18	28.6111	5.05428	1.19131
	F	18	35.2778	3.17723	.74888

Independent samples t-tests were used to compare the diversity of participation of males and females in the control group (See Table 61). Levene's test of equality of variance could not be assumed (p>.05) (See Appendix U). In the control group, females have a significantly greater diversity of participation than males.

Table 61 Independent samples t-test comparing the diversity of participation of males and females in the control group

Diversity of Participation	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
	-4.738	28.621	.000	-6.66667	1.40714	-9.54624	-3.78710

2-5 year old Males and Females in VLBW Group - Diversity of Participation

Table 62 Descriptive statistics on the diversity of participation of males and females in the VLBW group

Diversity of Participation	Sex	N	Mean	Std. Deviation	Std. Error Mean
	M	12	32.2500	5.80165	1.67479
	F	17	32.1176	4.34284	1.05329

Independent samples t-test was used to compare the diversity of participation of the males and females in the VLBW group (Table 63). Levene's test for equality of variance was assumed (p>.05). No significant difference was found between genders.

Table 63 Independent samples t-test comparing diversity of participation of males and females in VLBW group

Diversity of Participation	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
	.070	27	.944	.13235	1.88101	-3.72716	3.99187

Comparison of the Social Composite of the ABAS-II and the Social Activity Intensity of the APCP

Pearson's correlation showed a correlation of moderate magnitude (.461) between the Social Composite (ABAS-II) and the Intensity of Social Activities (Assessment of Preschool Children's Participation) that reached significance (p<0.001) (See Table 64 below).

Table 64 Correlation between the ABAS-II Social Composite Scores and the Intensity of Participation in Social Activities (APCP) in overall sample

		Intensity Social Activities Score
Social Composite (ABAS-II)	Pearson Correlation	.461**
	Sig. (2-tailed)	.000
	N	65

In full sample: r=0.461, p<0.001 (N=65)
In the VLBW group only: r=0.436, p=0.018 (N=36)
In the control group only: r=0.498, p=0.002 (N=29)

Research Question 3a

Is there a difference on standardised testing between the adaptive functioning of an Irish control group of full term, average birth weight infants, aged 6 months to 5 years 6 months of age, and normative data available on a North American sample?

To answer this question:

i. A one-sample t-test was used to establish whether there was a significant difference between the ABAS-II GAC Score, the 3 Domain scores (Conceptual, Social and Practical), and the 10 Skill areas of the Irish Control group and the North American normative data. ‘A score of 100 defines the average performance of a given age group’ in the North American data (Harrison and Oakland, 2003, p.32), thus this value was used to compare the data to the Irish controls.

i. Comparison of ABAS-II Composite Scores – Irish Controls and North American Data

No significant difference was found between the ABAS-II General Adaptive Composite of the Irish controls and North American normative data. Of the three domain scores, there was a significant difference in scores in the Social domain, in favour of the Irish controls (p=.001), and the practical domain in favour of the North American sample (p=.049). No difference was found between the groups in the Conceptual Domain (See Table 65 below).

Table 65 One-Sample t-test comparing the ABAS-II GAC, Conceptual, Practical and Social composite mean scores of the Irish control group and North American data

ABAS-II Domain Scores	Test Value = 100					
	t	df	Sig. (2-tailed)	Mean Difference	95% Confidence Interval of the Difference	
					Lower	Upper
General Adaptive Composite	.048	50	.962	.078	-3.22	3.38
Conceptual Composite	1.498	50	.140	2.490	-.85	5.83
Social Composite	3.418	50	.001	5.843	2.41	9.28
Practical Composite	-2.020	50	.049	-3.196	-6.37	-.02

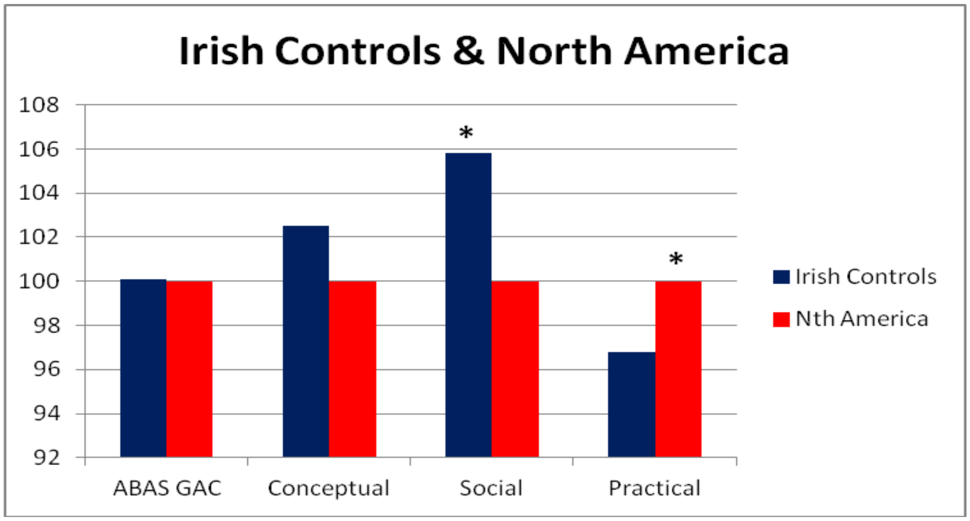
Significant differences were found between 8 of the 10 skill area scores of the Irish control group and the North American data (See Table 66). The Irish control group demonstrated significantly higher mean scores in the Skill Areas of Communication, Community, Home living, Leisure, Self-direction and Social skills and significantly lower mean scores in Self-care and Motor skills relative to the available North American data. Although the Irish control group demonstrated lower mean scores in Pre-academics and Health and Safety, this did not reach significance.

Table 66 One-Sample t-test comparing the ABAS-II skill area mean scores of the Irish control group and North American data

ABAS-II Skill Area Scaled Scores	Test Value = 10					
	t	df	Sig. (2-tailed)	Mean Difference	95% Confidence Interval of the Difference	
					Lower	Upper
Communication	4.611	50	.000	1.314	.74	1.89
Community	2.608	47	.012	1.104	.25	1.96
Pre-Academics	-1.383	47	.173	-.438	-1.07	.20
Home Living	5.090	47	.000	1.833	1.11	2.56
Health & Safety	-1.028	50	.309	-.294	-.87	.28
Leisure	3.863	50	.000	1.314	.63	2.00
Self-care	-11.520	50	.000	-3.314	-3.89	-2.74
Self-Direction	2.136	50	.038	.961	.06	1.86
Social	3.432	50	.001	1.137	.47	1.80
Motor	-2.181	50	.034	-.941	-1.81	-.07

Figure 8 summarises the results of the comparison between the Irish controls and the North American normative data.

Figure 8 Comparison of the GAC, Conceptual, Practical and Social composite mean scores of Irish controls and North American Normative Data



Research Question 3b

Is there a difference on standardised testing between the adaptive functioning of Irish children, aged 6 months to 5 years 6 months of age, born preterm and very low birth weight, and normative data available on a North American sample?

To answer this question:

i. The overall results (General Adaptive Composite - GAC Score), the domain scores, and the 10 skills areas of the ABAS-II of the VLBW group (using both chronological and corrected age) and control group are presented descriptively below, including the descriptive classifications that characterize ranges of performance on this standardised measure (See Table 67).

ii. A one-sample t-test was used to establish whether there was a significant difference between the overall score (ABAS-II GAC Score), the 3 Domain scores (Conceptual, Social and Practical) and the 10 Skill areas of the VLBW group and the North American normative data. As with Research question 3a a score of 100 will define average performance of the North American data.

i. Descriptive Classifications

Table 67 Descriptive statistics of the ABAS-II GAC, conceptual, social and practical composite mean scores for Controls, VLBW, and VLBW-COR (corrected age)

ABAS-II Composite Scores	Group N=44	Mean	Std. Deviation	Std. Error Mean	ABAS-II Classification
General Adaptive Composite	VLBW	86.45	14.930	2.251	Below Average
	VLBW-COR	93.48	13.807	2.081	Average
Conceptual Composite	VLBW	91.75	15.625	2.356	Average
	VLBW-COR	98.43	15.176	2.288	Average
Social Composite	VLBW	92.55	13.622	2.054	Average
	VLBW-COR	97.36	12.814	1.932	Average
Practical Composite	VLBW	84.50	13.225	1.994	Below Average
	VLBW-COR	90.09	13.284	2.003	Average

Of the 10 skills areas, Health and Safety and Self-care were below average on the ABAS-II descriptive classifications regardless of whether chronological or corrected age was used. See Table 68 below.

Table 68 Descriptive statistics of ABAS-II skill area mean scores for controls, VLBW, and VLBW-COR

ABAS-II Skill Area Scaled Scores	Group	N	Mean	Std. Deviation	Std. Error Mean	ABAS-II Classification
Communication	VLBW	44	9.55	2.824	.426	Average
	VLBW-COR		10.52	2.921	.440	Average
Community	VLBW	41	9.41	2.655	.415	Average
	VLBW-COR	40	10.33	2.536	.401	Average
Pre-Academics	VLBW	41	8.07	2.621	.409	Below Average
	VLBW-COR	40	9.20	2.653	.419	Average
Home Living	VLBW	41	8.98	2.979	.465	Below Average
	VLBW-COR	40	9.70	2.729	.431	Average
Health and Safety	VLBW	44	7.91	2.541	.383	Below Average
	VLBW-COR		8.84	2.614	.394	Below Average
Leisure	VLBW	44	9.05	2.282	.344	Average
	VLBW-COR		9.86	2.398	.361	Average
Self-care	VLBW	44	5.34	2.123	.320	Borderline
	VLBW-COR		6.23	2.321	.350	Below Average
Self-Direction	VLBW	44	9.30	3.261	.492	Average
	VLBW-COR		10.16	3.065	.462	Average
Social	VLBW	44	8.91	2.769	.417	Average
	VLBW-COR		9.7	2.539	.383	Average
Motor	VLBW	44	7.36	3.119	.470	Below Average
	VLBW-COR		8.14	3.083	.465	Average

ii. One-sample t-tests comparing the ABAS-II results of the VLBW group and North American data.

In Table 69 results demonstrated that the General Adaptive Composite score, and the Conceptual, Social and Practical Composite mean scores were all significantly lower than the North American normative data from the ABAS-II.

Table 69 One-Sample t-test comparing the ABAS-II GAC, conceptual, practical and social composite scores for VLBW group and North American data

ABAS-II Domain Scores	Test Value = 100					
	t	df	Sig. (2-tailed)	Mean Difference	95% Confidence Interval of the Difference	
					Lower	Upper
General Adaptive Composite	-6.018	43	.000	-13.545	-18.08	-9.01
Conceptual Composite	-3.502	43	.001	-8.250	-13.00	-3.50
Social Composite	-3.630	43	.001	-7.455	-11.60	-3.31
Practical Composite	-7.774	43	.000	-15.500	-19.52	-11.48

There were also significant differences in 7 of the 10 skill area scores in favour of the North American data: Pre-academics, Home Living, Health and Safety, Leisure, Self-care, Social and Motor skills. The VLBW group also demonstrated lower mean scores in Communication, Community and Self-direction but these scores did not reach significance.

Table 70 One-Sample t-test comparing the ABAS-II skill area mean scores for VLBW group and North American data

Skill Areas (Scaled Scores)	Test Value = 10					
	t	df	Sig. (2-tailed)	Mean Difference	95% Confidence Interval of the Difference	
					Lower	Upper
Communication	-1.068	43	.292	-.455	-1.31	.40
Community	-1.412	40	.166	-.585	-1.42	.25
Pre-Academics	-4.707	40	.000	-1.927	-2.75	-1.10
Home Living	-2.202	40	.034	-1.024	-1.96	-.08
Health & Safety	-5.458	43	.000	-2.091	-2.86	-1.32
Leisure	-2.775	43	.008	-.955	-1.65	-.26
Self-care	-14.554	43	.000	-4.659	-5.30	-4.01
Self-Direction	-1.433	43	.159	-.705	-1.70	.29
Social	-2.614	43	.012	-1.091	-1.93	-.25
Motor	-5.608	43	.000	-2.636	-3.58	-1.69

Summary of Results

The results are summarised in table 71 below.

Table 71 Summary of results reported for each research question posed

Research Question	Tests used	Answer
1. Is there a significant difference between the adaptive functioning of Irish children, aged between 6 months to 5 years 6 months of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight?	Independent samples t-tests	Yes. Significant difference found.
2. Is there a significant difference between Irish children 2 to 5 years of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight in their participation in childhood occupations?	Independent samples t-tests	No significant difference found
3a. Is there a difference on standardised testing between the adaptive functioning of an Irish control group of full term, average birth weight infants, aged 6 months to 5 years 6 months of age, and normative data available on a North American sample?	Independent samples t-tests	Yes. Significant difference found.
3b. Is there a difference on standardised testing between the adaptive functioning of Irish children, aged 6 months to 5 years 6 months of age, born preterm and very low birth weight, and normative data available on a North American sample?	Independent samples t-tests	Yes. Significant difference found

CHAPTER 6 – DISCUSSION

This study measured the adaptive behavior and participation of Irish very low birth weight (VLBW) infants who were born at preterm gestation, free of physical and intellectual disability and now between 6 months and 5 years 6 months of age. The children’s strengths and weaknesses were highlighted at the ICF domain of activity and participation, rather than at the domain of body function and structure as has been the dominant focus of research on premature infants to date. The VLBW infants’ results were compared to that of a control group of full term peers with infants matched for age and sex, and regression analysis was used to eliminate possible confounding factors. The results demonstrated that regardless of whether the VLBW infants’ ages were adjusted for prematurity, their overall mean scores in adaptive behavior on the ABAS-II were significantly lower than those of their full term Irish peers. Significant differences between the three ABAS-II adaptive domain scores (conceptual, social and practical) were also found between groups. The VLBW infants demonstrated significantly lower scores than the control group in all three domains when chronological age was used and significantly lower scores in the social and practical domains when the VLBW infants’ scores were adjusted for prematurity. The VLBW group also demonstrated significantly lower mean scores in all 10 skill areas of the ABAS-II when chronological age was used and in three specific skill areas (Home living, Leisure and Social skills) if corrected age was used. To the author’s knowledge, this is the first research study that has identified specific strengths and weakness in adaptive behavior skill areas in preterm VLBW infants.

The results of the Irish control group were also compared to the ABAS-II North American normative data. No differences in scores were found between the overall adaptive behaviour scores of both groups. However, of the three domains, the Irish control group demonstrated significantly higher mean scores in the social domain, and lower mean scores in the practical domain when compared to the North American normative data. There was no difference between the conceptual domains.

A secondary outcome measure, the Assessment of Preschool Children's Participation (King et al., 2006a) demonstrated that despite these differences in adaptive behavior, there was no difference in the intensity or diversity of the Irish VLBW children's participation in play, skill development, active physical recreation and social activities compared to their full term peers. These novel findings on the participation levels of this cohort of preterm infants helps to contextualize the children's results in adaptive behavior and will be discussed in more detail when answering research question two.

The following section will discuss the results of each research question posed and limitations of the study will be integrated throughout. The results will be explored in relation to their possible impact on families of VLBW infants, clinicians who work with these families and policy development in neonatal care in Ireland. They will also be considered in the context of their contribution to current knowledge in this area and to the overall ecology of human development.

Research Question 1

Is there a significant difference between the adaptive functioning of Irish children, aged between 6 months to 5 years 6 months of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight?

The primary outcome measure, the standardised Primary Caregiver Form from the Adaptive Behavior Assessment Scales-II (ABAS-II) (Harrison and Oakland, 2003), was used to obtain a comprehensive and global estimate of the children's adaptive functioning (Harrison and Oakland, 2003). This is both a valid and reliable measure of adaptive behaviour (Msall and Tremont, 2002). The results were interpreted through use of scaled and standard scores obtained from the available North American normative data and also explored in relation to their categorisation on the ABAS-II's performance classification system. In presenting the results, both the infants' chronological and corrected ages were used. This enhanced the transparency of findings, considering the international inconsistencies in the use of terminology (Committee on Fetus and Newborn, 2004) and the variations in methods of correction for prematurity (Wilson & Cradock, 2012). This study showed that regardless of whether the VLBW infants' ages were adjusted for prematurity, they demonstrated significantly lower mean scores in overall adaptive behaviour than their full term peers (VLBW $p<0.001$, VLBW-COR $p=0.013$). This effect of being preterm on adaptive behaviour was observed at all ages of assessment.

Comparison of results with other similar studies

Adaptive Behaviour of VLBW Infants in the Early Years

Impairments in adaptive behaviour found in this study are consistent with results of recent studies in Brazil and Taiwan that also identified challenges for premature VLBW infants without physical and intellectual disabilities, using the same measure of adaptive behaviour (Fernandes et al., 2012; Huang et al., 2012). Both the Brazilian and Taiwanese once-off assessments were only administered to parents of very young children however, 18-24 months and 18-36 months respectively, therefore results could not be compared to the full age range of infants (6-66 months) in this study. Huang et al.'s (2012) sample was also divided in to 4 infant groups of varying birth weights with only 20 of the 105 Taiwanese infants in the 'healthy' low to very low birth weight category, greatly reducing the statistical power of this subgroup. Fernandes et al. (2012) used a larger sample size of 58 Brazilian VLBW infants, more comparable to the VLBW numbers in this study (N=44); however their study had no control group. Their results on adaptive behaviour of young Brazilian infants were therefore derived from North American normative data which may have resulted in an inaccurate representation of these children, given the sociocultural differences between the North and South American populations (Gannotti & Cruz, 2001).

The challenges of comparing the few available studies on the adaptive behaviour of preterm infants, as demonstrated above, are numerous and include inconsistencies in defining the samples. Discrepancies in the categorisation of preterm infants with differing levels of neonatal morbidities such as the inclusion of children with varying ranges of physical and intellectual disabilities (Sullivan et al., 2012), differences in definitions of 'healthy preterm birth', varying cut-off points for birth weight and gestational age categorisations confound results and limit robust comparisons between studies. For example, other than the obvious differences between the cultures and the age ranges assessed, the current study and the studies by Fernandes et al. (2012) and Huang et al. (2012) differ in their basic definition of 'Healthy VLBW infants'. In this study, the Vermont Oxford Network's (2011) definition of VLBW was used and therefore premature infants less than 1500 grams or whose gestational age was less than 30 weeks were included. These criteria allowed birth weights in this study to range as high as 1750 grams, in comparison to a maximum of 1500grams in the other two studies. In defining 'healthy preterm infants' this study also included 4 infants with peri-interventricular haemorrhage (PIH) (3 with grade 1, and 1 with grade 3) while Fernandes et al.'s (2012) reported that 60% of their study infants (N=35) had PIH of undisclosed severity. This contrasted to Huang et al.'s (2012) exclusion of infants with any level of PIH from their study.

Of the few studies that have assessed the adaptive behaviour of former VLBW infants, many have reported the children's overall General Adaptive composite score (GAC) but have failed to present or discuss their conceptual, practical and social composite results relative to peers (Fernandes et al., 2012; Peterson et al., 2006). This has limited the possibility of obtaining a true profile of these infants which could be used to develop targeted interventions. Huang et al.'s (2012) study of a Taiwanese subgroup of healthy VLBW infants (N=20) did find the VLBW infants to have the same pattern on the ABAS-II as the current study i.e. obtaining lower scores in social and practical adaptive domains but not in the conceptual domain. These results do however need to be interpreted with caution due to the very small sample size. Little effort has also been made to highlight possible strengths and weaknesses for this group omitting any discussion in relation to the VLBW infants' 10 skill area scores, and only providing VLBW infants' results corrected for prematurity.

The current study has explored the differences between the social, practical and conceptual domain scores, and the skill areas of the VLBW group relative to peers, using both the VLBW infants chronological and corrected ages. This more in depth analysis has highlighted specific areas of strengths and weaknesses depending on whether or not adjustment for prematurity was made. This will be discussed in more detail below. Finally, neither Fernandes et al. (2012) or Huang et al. (2012) assessed the children's participation levels and therefore it is difficult to judge if deficits identified in adaptive behaviour in these studies are due to a lack of actual skill, differences in cultural expectations or a lack of exposure to everyday activities, as defined by the ABAS-II (Harrison and Oakland, 2003). The adaptive functioning and participation levels of the children in the current study will be compared in addressing research question two below.

Adaptive Behaviour of VLBW Infants at School age

Despite their differences, the results of this study are consistent with Huang et al.'s (2012) and Fernandes et al.'s (2012) overall results of adaptive behaviour, suggesting that weaknesses are present from a very early age and despite some gain in relation to peers, the limitations remain between groups at 5 years 6 months of age, as determined by valid and reliable tests. These persistent limitations in adaptive functioning of former premature babies also appear to continue in to school age. Using the Vineland Adaptive Behavior Scales, Second Edition, (Sparrow, Cicchetti, & Balla, 2005) the adaptive behaviour of school aged children was assessed in two North American studies by Case Western Reserve University with children of mean ages of 6.8 years (Peterson et al., 2006) and 8 years (Taylor et al., 2006) and a Norwegian study of children of 10 years (Fjørtoft et al., 2012a, 2012b). Two of these studies reported to assess former VLBW infants (Fjørtoft et al., 2012a, 2012b; Peterson et al, 2006) while the other focused on former ELBW infants (Taylor et al., 2006) only.

Peterson et al.'s (2006) study investigated the impact of subnormal head circumference and neurological complications on North American children's school performance. 128 former VLBW infants were compared to 58 controls. The ‘healthy’ VLBW infants (N=89), categorised as the ‘neurosensory intact group’, excluded children with cerebral palsy, unilateral or bilateral deafness or blindness. Results demonstrated an adverse effect of prematurity on adaptive behaviour even when neither subnormal head circumference nor neurological complications were present (p=<.01). Fjørtoft et al.’s (2012a, 2012b) hospital follow-up study had a significantly smaller sample size with 38 former VLBW, Norwegian children (including 10 with cerebral palsy) and 31 term control infants, 10-11 years of age. When the 10 children with cerebral palsy were excluded from the analysis, the remaining ‘healthy’ 28 VLBW infants still demonstrated significantly lower mean scores in adaptive behaviour (P=0.001) than their full term peers.

On review of the clinical characteristics of Fjørtoft et al.’s (2012a, 2012b) ‘VLBW’ infants however, information available suggests the infants may have been more appropriately categorised as extremely low birth weight given their mean gestational age of 26.7 weeks (SD: 1.9) and mean birth weight of 876 grams (Hack et al., 2005). Of the original 38 premature infants, 30 had a birth weight <1000g; 6 were between 1000-1100g, and 3 had an undisclosed weight. The authors did not allude to the birth weights of the 10 children with cerebral palsy who were removed from the group, but their removal may have further reduced the small number of infants with birth weights over 1000grams. In comparison therefore to the infants in the current study (Birth weight mean: 1145grams; Gestational age mean: 29 weeks) these infants were a more vulnerable preterm group. Considering that numerous studies have demonstrated that both lower birth weights and lower gestational ages increase limitations in functional outcomes (Hack et al., 2005), these differences in clinical characteristics may confound comparison between these studies.

Of these two studies of school aged VLBW children both presented the results in overall adaptive behaviour relative to the control group; however only Fjørtoft et al. (2012a, 2012b) presented the children's adaptive domain scores. Although the sample size was small Fjørtoft et al. (2012a, 2012b) also found the VLBW group to have significantly lower scores in two of the three subscales of the VABS (Sparrow, Cicchetti & Balla, 2005) i.e. Daily living skills and Socialisation but not Communication. As these three domains of the VABS correlate significantly with those of the ABAS-II (.53-.82) (Harrison and Oakland, 2003) it suggests that these results were also similar to the results found in the current study. However as a limitation of the studies on preschool children above (Fernandes et al., 2012: Huang et al., 2012), neither of these studies on school aged children explored the VLBW children's domain or skill area scores in any depth, therefore providing little insight in to the profile of strengths and challenges of these infants' adaptive functioning relative to peers. In this study, these results will be analysed and explored in more detail below.

Although it can be argued that the sample size of the current study was small, a sample size calculation prior to starting this study estimated that a minimum of 36 infants per group was required to detect a difference in the domain (10 points) or skill areas (2 points) of the ABAS-II with 80% power. The final study population exceeded the estimated sample size by 20% in the preterm group (N=44) and by 40% in the control group (N=51). A larger sample size from multiple sites in Ireland would strengthen the results of this study however as the sample obtained was part of the Vermont Oxford Network this VLBW group's profiles were no different to that expected or reported internationally.

Finally, Taylor et al.'s (2006) study of 204 North American former ELBW (<1000grams) school aged children also found deficits in adaptive behaviour in the premature group in comparison to term matched controls. The study only focused on infants of extremely low birth weights and also neglected to differentiate between children with and without neurosensory disorders. The sample included 31 children with cerebral palsy, one blind and four deaf children. Only 10 of these children were excluded from analysis as they were deemed untestable on standardised developmental assessment due to severity of disability. Results of adaptive behaviour are therefore confounded by the presence of physical disabilities in the ELBW group and therefore cannot be compared accurately to this study.

Despite challenges in comparison, the current study supports the recent body of evidence that suggests young children born preterm and VLBW, without complications of physical or intellectual disability, demonstrate deficits in adaptive behaviour in comparison to their full term peers. Collectively these studies, although limited in sample sizes, also suggest that challenges in adaptive behaviour detected in ‘healthy VLBW infants’ are present in the early years and continue on to school. In school age children, a negative impact of preterm birth on academic achievement (Rickards et al., 2001; Taylor et al., 2006) and handwriting (Taylor et al., 2011; Feder et al., 2005) has been demonstrated. It remains unclear however if deficits in adaptive behaviour disadvantage former VLBW children in school-based activities such as table-top activities and routine daily tasks, relative to peers. Few if any studies have explored this. MacDonald, Lord and Ulrich (2013) did succeed in capturing the association between adaptive behaviour and fine motor skills but this was in relation to young children with autistic spectrum disorder. A few studies of former premature infants have, although not as the main focus of the research, assessed both the adaptive behaviour and motor (Taylor et al., 2006) or perceptual-motor (Peterson et al., 2006) skills of the children as part of an overall battery of standardised measures, finding weaknesses in both areas.

Age adjustment for premature infants

The apparent discrepancy in adaptive behaviour that appears to be present in both the preschool and school aged children, born premature and VLBW, leads to another pertinent question of whether these children ever truly ‘catch up’ with their peers. This concept of premature infants ‘catching up’ has been debated in the literature for generations (Wilson & Cradock, 2012) and evidenced by the numerous allowances or adjustments made for premature infants’ ages during their first few years of life. In fact, this ongoing debate of correcting for prematurity has even led some researchers to strategically choose study infants with a minimum age of 2 years to avoid the need for age adjustments (Lemos et al., 2012). The American Academy of Pediatrics (AAP) recommend clinicians correct for ‘prematurity until 24 months adjusted age when assessing growth, nutrition, development, social interaction, motor and language skills’ (Bernbaum et al., 2009, p. 868), broad areas that can be argued to encompass adaptive behaviour. This correction of age is based on ‘the concept of “catch-up” growth, the idea that premature infants would meet the developmental level of their full-term counterparts within the first years of life, after complete maturation of their central nervous system’ (Wilson and Cradock, 2004). This expectation of premature infants to align with the ability of their peers is evident in the Committee on Fetus and Newborn’s (2004) statement that ‘corrected age’ ‘should be used only for children up to 3 years of age who were born preterm’ (p. 1362). In the context of this study, this statement suggests that time alone would be sufficient to eliminate the discrepancies in adaptive behaviour between premature infants and their peers. The results of the current study and those discussed above however, which demonstrated reduced adaptive behaviour in both preschool and school-aged, former premature, VLBW infants are not consistent with this hypothesis. In fact the cross-sectional nature of the current study demonstrates a reduction in the gap between groups over time but never an elimination of the significant difference between the adaptive behaviour of both groups.

In considering the presentation of the current study results, both the potential advantages and disadvantages of adjusting the infants' ages for prematurity were acknowledged. For example, the VLBW infants ranged from 6 - 64 months of age therefore adjustment for prematurity had different implications depending on the age of the child. For children under 24 months, using their chronological age to generate assessment results may misrepresent the infants by inflating their difficulties in adaptive functioning. In contrast however, for the VLBW infants between 24 - 64 months, adjusting their ages for prematurity may be considered conservative and may in fact minimize any potential deficits in adaptive functioning. This debate was explored further by analyzing the study infants' results in two age categories.

The VLBW group was divided in to 'infants 24 months or less' and 'infants 25 months or more'. The ages of the infants 24 months or less were then corrected for prematurity while the ages of the children 25 months and older were not. In the ≥ 25 months age group, if prematurity was not adjusted for, 26.9% (7) of the VLBW infants demonstrated overall adaptive behaviour scores of less than one standard deviation below the norm in comparison to only 10.8% (4) of the control group. The descriptive classification system of the ABAS-II presented a similar picture with 35% (8) of the VLBW children in the ≥ 25 months age group obtaining scores in the below average, borderline or extremely low classification in comparison to 13% (5) of the control group. These results showed that although the VLBW group as a whole approached normal range after 24 months corrected age, they still had near to double the number of children

25 months and over in the ‘below average, borderline or extremely low’ classifications or one standard deviation from the norm, relative to the control group. The other remaining VLBW infants fell within the average range (Average N=15; Above Average N=2; Superior N=0) however they too demonstrated lower mean adaptive scores than the controls (Average N=24; Above Average N=7; Superior N=1). Although this analysis required further division of the sample size which clearly minimizes the generalizability of findings, these preliminary results do suggest the need to explore this issue of ‘catch up’ with a more robust sample size of VLBW infants.

The extent to which this ‘catch up’ phenomenon occurs with the adaptive behaviour or functional skill development of VLBW infants is poorly researched. It is therefore unknown whether time alone or specific intervention is required to eliminate these adaptive discrepancies between premature VLBW infants and their full term peers. For example, for a small cohort of this study sample between 25 – 64 months of age it would appear that this ‘catch up’ phenomenon has not occurred. On review of the profiles of the mothers of the seven VLBW infants, six of seven of them had an education level of less than a degree and five of seven of them were stay at home mothers. This fuels further questions such as whether there are environmental facilitators that are required for the VLBW infants to ‘catch up’ with peers and whether there is a time period after which the adaptive challenges as demonstrated in young VLBW children in this sample become a long term problem? Finally, to ensure transparency it was decided to present the results of this study using both the infants chronological and corrected ages. With 59% of the VLBW group 25 months or older; however, it could be argued that greater weighting should be given to the uncorrected analysis.

VLBW group's strengths and challenges in adaptive behavior

ABAS-II Adaptive Behaviour Composite Scores

As mentioned earlier, the VLBW group demonstrated significantly lower means in all three domain scores of the ABAS-II (Conceptual, Practical and Social) in comparison to the control group when their chronological age was used. When the VLBW group was corrected for prematurity however, they demonstrated significantly lower mean scores in the social and practical composite scores but not in the conceptual composite scores, in comparison to the controls. This is consistent with Oakland and Harrison's (2003) suggestion that limitations in adaptive skills often co-exist with relative strengths in other adaptive areas. Using the most conservative estimate of the results of the current study therefore, the VLBW infants demonstrated relative strengths in the conceptual domain with their areas of weakness presenting in the practical and social domains.

Acknowledging the VLBW infants' strengths and challenges in conceptual, practical and social adaptive behaviors, although useful, only allows for a certain depth of understanding. To truly comprehend the profile of these VLBW infants, it is necessary to explore the skill areas that each domain comprises of and how they impact on both the infants overall adaptive score (GAC) and domain scores. Each skill area presents behaviours that are relatively independent of each other and can therefore be interpreted independently of one another or in the context of a composite score (Harrison and Oakland, 2003).

As with many standardised tests the authors of the ABAS-II (Harrison and Oakland, 2003) encourage the interpretation of the individual skill areas, suggesting it may be more appropriate and meaningful to obtain a profile of individual children's strengths and weakness instead of the overall adaptive behaviour score, particularly if there is considerable variation between skill area scores. In this study, the VLBW group demonstrated significantly lower mean scores in all 10 skill areas in comparison to the control group when their chronological age was used and significantly lower means in only three of the 10 skills areas when adjustment was made for prematurity. The three skill areas of difference were Home Living, Leisure and Social Skills. Assuming therefore the most conservative estimate of the VLBW group's profile of adaptive behaviour, they demonstrated relative strengths in communication, community use, pre-academics, health and safety, self-care, self-direction and motor skills, and relative weaknesses in home living, leisure and social skills. These challenges in skill areas will now be discussed in the context of the domain score they contribute to.

ABAS-II Home Living and Self-care Skill Areas

The Practical domain comprises of Community Use, Home Living, Health and Safety, and Self-care. Relative to the control group, the VLBW group demonstrated significantly lower scores in all four skill areas if there was no correction for prematurity, but significantly lower scores in Home living only when adjusted for prematurity. Although, the VLBW group's mean score in the Self-care skill area was not significantly lower than the control group once adjustment for prematurity was made, it was the lowest scaled score of all 10 skill areas for the VLBW group.

Fine motor skills have been acknowledged as an area of weakness for preterm infants without cerebral palsy (Bos et al., 2013; Pinheiro, Martinez & Fontaine, 2014; Goyen, Lui & Woods, 1998) with 40% demonstrating mild-moderate and 19% demonstrating moderate fine motor impairment on standardised testing (Williams, Lee & Anderson, 2010; Bos et al., 2013). The VLBW group's weakness in the practical domain may therefore be partially explained by the significant level of fine motor skills required for success in this adaptive area (Bos et al., 2013), especially in Home living and Self-care. Although these two areas are clearly closely linked (Steere, Garrison & Burgener, 2008) once the VLBW group was adjusted for prematurity, Home living was the only skill area in the practical domain that continued to demonstrate a significantly lower mean score, in comparison to the Irish control group. This raises the question as to what skill demands within these two skill areas may have accounted for this discrepancy.

The self-care skill area focuses on routine, personal daily tasks that can be facilitated and performed in a structured way at the same time and in the same location every day, for example washing, feeding, dressing and toileting. In contrast the home living skill area appears to assess more complex functional life skills that are required for daily living such as the ability to care for one's own belongings, maintain one's own immediate environment and complete routine activities (Steere, Garrison & Burgener, 2008). These daily life skills may be more demanding as they are less predictable and less practiced. These home living skills can also be performed in a variety of ways with alternative pieces of equipment and therefore success requires a number of strengths including abilities in self-management and generalization (Steere & Burcoff, 2004) as well as increased motor planning, fine motor and problem solving skills. In comparison to the self-care skills, this skill acquisition is also more reliant on a dynamic interplay with the environment. For example, in the self-care area the child is assessed in relation to skills such as their ability to 'hold and drink from a sipping cup' while the home living area assesses skills such as the child's ability to do 'simple errands when asked, for example, run to get a towel for a spill'. It could therefore be argued that the self-care skills provide the building blocks or foundation required for more complex skills that are necessary for successful home living. These deficits in home living skills but not in self-care skills may suggest that as the complexity of daily living tasks increase, outside of routine, regularly practiced repertoires these preterm infants demonstrate signs of struggle.

In the early years although the initial advancement of these skills is in the home environment, a substantial amount of this continuing skill development occurs in the school environment as the child gets older. Numerous authors have acknowledged the importance of age-appropriate daily skills as well as academic readiness for successful transition and progression through the school system and in to adult life (Sitlington & Clark, 2006; Taylor et al, 2002). It could be argued therefore that this VLBW group's challenges evident in these early years may become more pronounced as task demands become more complex. Of equal concern is that these more complex self-care tasks provide the foundation for higher level skills, or what occupational therapists refer to as 'Instrumental activities of daily living', such as money management, public transport, and contributing to a household. Steere, Garrison & Burgener (2008) weight these areas of development strongly stating that the amount of independence that children obtain with these skills is directly related to the amount and nature of support they will require over their life time and their ability to transition from their family home to independent living. They argue that by addressing these skills early, especially with those with disabilities, clinicians are increasing the likelihood that these people "will have the opportunity for greater choice, independence, and self-determination in their home living situations in later life" (p. 116). Not only therefore is the impact on the VLBW children's ability to transition in to and function in school systems a concern in the short term, but also perhaps their independent living skills in the long term.

ABAS-II Social Skill Area

The Social domain of the ABAS-II comprises of the Leisure skill area and the Social skill area. These two skill areas were identified as two of the three skill areas of weaknesses for the VLBW group, once adjustment for prematurity was made. This significant weakness in the Social domain, relative to peers, is consistent with concerns that children born VLBW are at risk of peer rejection, low self-esteem (Rickards et al., 2001) and screening positively for autism spectrum disorder (Johnson et al., 2010). In the ABAS-II, the social adaptive skill area measures the child's interpersonal and social competence focusing on how independently they can interact socially and get along with others (Park, Loman &Miller, 2008). According to Wolfe et al. (2015) very little research has investigated the impact of VLBW on children's social information processing and social interaction. Of these studies, many have assessed the social skills of VLBW infants at school-age or adolescents (Dahl et al., 2006) demonstrating a negative impact of preterm birth on social skills consistent with the current study's results. For example, a recent study on Canadian 8-11 year old children born VLBW (N=34) found they had difficulties in social perception, relative to a control group (N=36). The VLBW group demonstrated difficulty interpreting emotions due to challenges in identifying non-verbal cues such as facial expressions, body movements and situational cues (Williamson and Jakobson, 2014), cues that the authors suggested may stem from deficits in visually processing 'life motion'. Although a small sample size, these results are consistent with the lower mean scores of the VLBW group in the current study who, as part of the Social skill area, were also asked questions related to social perception such as does your child 'state when others seem happy, sad, scared or angry', 'move out of another person's way without being asked', 'apologize if he/she hurts the feelings of other'.

Wolfe et al.’s (2015) results contrasted with other studies finding no significant difference between the social information processing and social adjustment of 4-6 year VLBW pre-schoolers (N=20), relative to full term controls matched for age, sex and race (N=18). Although a small sample size for sufficient statistical power, this cohort of VLBW infants were very similar to those in the current study as the Vermont Oxford definition (Vermont Oxford Network, 2011) of VLBW was also used to recruit children of a comparable age range, without a physical or intellectual disability. One difference between the studies was that Wolfe et al.’s (2015) control group had all spent time in the Neonatal Intensive Care Unit. The authors also reported that most if not all of the VLBW children in their study had received early intervention services; however the details were left vague, and are therefore difficult to compare. Acknowledging the lack of consistency between their results and other studies, Wolfe et al. (2015) attempted to explain this difference by suggesting that deficits in social functioning may not be apparent at an early age and difficulties therefore only emerge in later childhood and adolescence. The results of the current study are in contrast to this finding.

ABAS-II Leisure Skill Area

The other area of the Social domain, leisure skills, focuses on the child’s ability to choose, plan and initiate age appropriate leisure and fun activities that include cognitive, social and physical performance skills by themselves and with others (Beland, 2008). This significant difference between the leisure skills of the VLBW group in comparison to their full term peers is of concern as leisure is associated with happiness and well-being (Dahan-Oliel, Mazer & Majnemer, 2012) and includes many benefits such as skill development, cardiovascular fitness, lower obesity rates in children (Law, Petrenchik, King & Hurley, 2007), reduced stress and anxiety, and enhanced mood (Harrison and Narayan, 2003). This skill area of the ABAS-II appears to link very closely to the construct of participation as defined by the ICF-CY (WHO, 2007) as ‘involvement in a life situation’ (WHO, 2001, p.14). For example, the skill area includes questions such as ‘plays with a single toy or game for more than 5 minutes’, ‘participates in specific fun activities’, ‘looks at pictures in books or magazines with an adult’. Although the assessment of participation used in the current study, the APCP, also links closely with ICF-CY’s (WHO, 2007) definition of participation, the ABAS-II leisure skill area was not found to link directly to any one of the four specific activity areas measured by the APCP; instead items appeared to be present in all four areas.

Leisure skills area can be negatively affected by impairments in motor coordination, cognition or behaviour, all of which very and extremely preterm infants are at risk of (Dahan-Oliel, Mazer & Majnemer, 2012). In relation to broader child and environmental factors however, the research on specific factors associated with leisure participation in preterm infants is very limited, and appears to depend on the type of leisure activity being explored (Dahan-Oliel et al., 2014b). For example, child factors such as cardiorespiratory limitations have been shown to impact on endurance in physical activities despite the preterm children’s and adult’s lung function being within the expected range (Kriemler et al., 2005; Vrijlandt et al., 2006). The leisure area will be discussed further when answering the research question (Question 2) which focuses on the children’s participation. Finally, the parental expectations of the groups may have varied with the reports of parents’ of VLBW infants being influenced by their infants’ challenging start in life (Wightman et al., 2007).

In summary, the VLBW infants in this study demonstrated lower mean scores in three specific skill areas in comparison to full term peers when their ages were adjusted for prematurity. These challenges in home living skills present in the VLBW group may be signs of initial weakness in developing more complex skills required for school and independent living. Weaknesses in both social and leisure skills are concerning as these are the skills that allow children engage successfully in activities that increase their quality of life by providing them with a social network, enjoyment and constructive use of non-school hours (Vroman, 2010). These challenges must however also be seen in the context of relative strengths in the conceptual domain that encompass the skill areas of communication, functional pre-academics and self-direction.

Environmental & personal factors impacting on adaptive behaviour

Multiple contextual factors may influence the adaptive behaviour of the VLBW infants and it is not possible to disentangle all of them in this study. Some of the pertinent influencing factors are however discussed now.

Gender Differences

An association between gender and adaptive behaviour has been demonstrated in the literature. Male gender has been shown to be disadvantageous in the acquisition of many developmental skills including adaptive behaviour relative to their female peers. This finding however, is inconsistent (Taylor et al., 2006; Sullivan et al., 2012; Cho et al., 2010; Brand et al., 1994). Researchers have therefore emphasised the importance of recruiting an equal mix of males and females for developmental studies (Brand et al., 1994). In the current study, proportionate numbers of males and females were recruited and although in isolation no difference was found between the male and female adaptive behaviour scores of each group, once the effect of maternal age and education were controlled for VLBW females demonstrated significantly higher mean scores than the VLBW males. This is consistent with a number of recent studies that demonstrates a trend of former preterm females having higher scores than males (Taylor et al., 2006; Sullivan et al., 2012). For example, in a long term follow up study of premature babies, using Wilk's criterion, with the combined outcome of the four adaptive behaviours of the Scales of Independent Behaviour-Revised (Bruininks et al., 1996), Sullivan et al. (2012) found a significant difference for gender (p=.003). Formerly premature males at 17 years of age demonstrated lower scores in social interaction, personal living, community living, and broad independence than their female peers. This discrepancy in favour of females, although found in another North American longitudinal study in relation to motor and cognitive development, was not found in relation to adaptive behaviour (Cho, Holditch-Davis & Miles, 2010).

Neonatal Risk Factors

As well as gender differences a number of other factors could have contributed to the significant differences in adaptive behaviour demonstrated between the VLBW group and control group in this study. Impairments in the domain of body function and structure as defined by the ICF-CY (WHO, 2007) such as neonatal risk factors may also have impacted on the VLBW group's results. In fact it has been argued that relative to the risk of social factors, neonatal risk factors have a far greater impact on functional skill development (Hack et al, 2000; McCormack et al, 1992; Taylor et al, 1998). This debate is ongoing and regardless of the hierarchy of risk, it has been suggested that confounding factors at both the level of body function and structure such as neonatal risk factors and environmental influences such as socio-demographic grouping influence the activity and participation trajectories of all premature babies to a greater or lesser extent (Hack et al., 2000; Taylor et al., 1998; Msall, 2006). For example, Taylor et al. (2006) found that neonatal risk factors may impact and predict the functional and adaptive development of preterm infants, with greater culminations of risk factors leading to progressively poorer outcomes. In their study of ELBW infants at a mean age of eight, neonatal risk factors associated with worse outcomes in adaptive behaviour were outborn, length of hospital stay and ventricular dilation (Taylor et al, 2006).

Cooke (2004) argues that most follow-up studies of this nature suffer from bias i.e. they are hospital based cohorts that are usually selected by birth weight rather than gestational age which increases the proportion of growth restricted infants included. In the current study although the cohort was selected from one hospital, the Vermont Oxford definition (Vermont Oxford Network, 2011) of VLBW was used, which includes both gestational age and birth weight, and therefore only 4 of the 44 VLBW infants were small for gestational age. Clinical characteristics and major morbidities in the VLBW group were also explored in relation to their adaptive functioning with no distinct subgroups identified. This was consistent with the results of Fjørtoft et al. (2012a, 2012b) who researched a similar cohort of VLBW children as in this study. As the sample sizes of both groups were relatively small however, it could be argued that this may have influenced the results.

Intelligence Quotient of VLBW group

Intelligence Quotient (IQ) is another major client factor that influences functional development. In fact by definition, children with intellectual disabilities demonstrate deficits in adaptive behaviour (American Psychiatric Association, 2013). Although this study did not explicitly rule out intellectual disability by standardised IQ testing, parent report, exclusion of children with a diagnosis of a physical and/or intellectual disability, and routine follow-up hospital screenings that ruled out need for referral to psychology suggested there were no clinical indicators for significant intellectual disability in this cohort of infants. Also, as part of test development, the ABAS-II was correlated with measures of intelligence and achievement. As the authors had expected, the Full scale IQ scores of the Wechsler Intelligence Scale of Children – Third Edition correlated most highly with the Conceptual Adaptive Domain (.50) and the Functional Academics Skill Area (.61) of the ABAS-II (Harrison and Oakland, 2003). The VLBW group in this study demonstrated relative strengths in the Conceptual domain or Functional pre-academics, obtaining similar results as the control group. This further suggests that the preterm cohort were functioning within the average range of intelligence.

Age range of Study Infants

Although the sample may be considered heterogeneous with respect to the age range, the rationale for this age band was to capture the adaptive behaviour of premature babies from infancy to school entry as recommended by the American Academy of Pediatrics (McInerny et al., 2009), using standardized questionnaires specifically designed for these age ranges. A systematic review of the literature on preterm infants also concluded that follow-up to two years of age is insufficient to detect deficits in fine motor, behavioural and visual motor skills (Moreira et al., 2014). In the current study therefore, this broader age range was explored to ascertain if there is a consistent trajectory of clinical indicators signalling weaknesses in adaptive behaviour from a very early age or whether these limitations emerge at a specific age when environmental demands increase. Studies of the adaptive behaviour of these VLBW infants appear to focus on a very young infants or a school age with little focus on preschool children transitioning in to formal schooling. In this study, a significant impact of being preterm on adaptive behaviour was observed at all ages of assessment. While the effect was slightly less as the child gets older, the difference between groups was still significant.

Parental Over-protection of VLBW Infants

Another possible reason for the lower mean scores of the VLBW group could be that they are being over-protected by their caregivers, relative to their peers. Thus, they may not be given the same opportunities to develop the age appropriate home living, leisure and social skills that are assessed in the

ABAS-II. Little research has been done on preterm infants and parental protection (Wightman et al., 2007). A population based study of 892 parents by Thomasgard et al. (1995) reported increased parent protection scores to be associated with unmarried maternal status, lower education, lower socio-economic group and younger age of mother and child. In the current study, both groups had similar proportions of two parent households and socioeconomic groupings. They were also more educated than the Irish National population (Census 2011) with 55% of the parents in the control group and 40% of the VLBW group having a degree or higher, compared to 36% of the national population, arguably typical of a volunteer sample (Watt & Van den Berg, 2002). This trend was also present in maternal education, a factor that is associated with lower levels of morbidity in infants (Vohr et al., 2000; Hille et al., 2007) and the group of VLBW children excluded children with physical and intellectual disabilities reducing the likelihood of these infants being overprotected (Wightman et al., 2007).

It could be argued however that although it did not reach statistical significance (p=0.053), there was a trend for more mothers in the control group to work for pay (35%) compared to mothers of VLBW infants (14%), who tended to look after family and at most work part-time. This is consistent with the literature that shows that mothers of children with health problems work less (Porterfield, 2002) and could suggest that the mothers of the VLBW group spent more time with their young child, potentially influencing their child's environment. The nature of this influence is however unknown and as the overall proportions of mothers in both groups that cared for their family, worked for pay or profit, or did both did not differ statistically this suggestion must be treated with caution. Overall the demographic profile of this study sample do not match the factors associated with parental over protection, as described by Thomasgard et al. (1995). Finally, the results of question two, which compare the participation levels of both groups using the Assessment of Preschool Children's Participation (King et al., 2006a) refutes this argument further, with no difference found in the participation levels of both groups in play, skill development, active physical recreation and social activities. Over-protection of these VLBW infants is therefore unlikely to be the primary cause of their weaknesses in adaptive behaviour. Instead, as mentioned above, the lower mean scores in home living, leisure and social skills may suggest that these children are not actually over-protected but are demonstrating the early stages of weaknesses that are challenged by more complex activities of daily living.

Statistical testing of Contextual Factors

The environmental and personal factors are the context that create the facilitators and barriers to health and well-being for the child (WHO, 2001) and therefore were also examined further statistically. Simple linear regressions exploring the impact of parental education, main activity of mothers, unemployment rate, ages of infants, child's age in months at time of assessment, gestational age, and presence of siblings on the VLBW children's adaptive behaviours did not demonstrate significant results. Further investigation using a multiple linear regression controlling for any differences in sex of infant, maternal age and maternal education between groups was also performed with significant results not found. This suggests that the environments of both groups were relatively similar. As both groups appear to be surrounded by similar environmental opportunities and resources is it possible that the VLBW group may not be able to take advantage of these environmental benefits as suggested by Taylor et al (2006). This will be discussed further when answering research question two in the context of the children's results in both adaptive behaviour and participation.

Clinical Importance of Results

Finally, the results need to be considered not only in relation to statistical significance but also in relation to their clinical importance. As this study aimed to measure the adaptive behaviour and participation of VLBW infants it is important to establish whether this discrepancy in standardised scores translates in to a clinical difference that is meaningful. For example, the VLBW lower mean scores in home Living, social and leisure skills in comparison to their peers leads to the pragmatic question of what is it that this group cannot do in daily life and, perhaps more importantly, what would improvements in these areas allow them to do? In the Focus on Function study (Law et al., 2011) of children with cerebral palsy a number of outcome measures including the Pediatric Evaluation of Disability Inventory (PEDI) (Haley et al., 1992) and the APCP were used. The authors attempted to translate statistical differences obtained in the PEDI in to its clinical relevance in everyday life. For example, a difference of 4 points on the Functional Skills Scales self-care subscale translated in to an improvement in a child's performance across 7 activities.

In this study, there was a statistical difference of 1-2 scaled scores between the ABAS-II Home Living, Leisure and Social skill areas of the control and VLBW group, depending on whether chronological or corrected age was used. These statistical differences translated to the children in the control group being able to perform tasks that the VLBW group were not capable of. For example in clinical terms this weakness in home living skills may present as, a two year old child (24-26 months) from the VLBW group not being able to refrain from throwing food and paper on the floor; assist adults with preparing simple snacks or meals; or place dirty clothes in the proper place, for example, a hamper or clothes basket. In the leisure skills area they may not be able to invite others to join them in playing games or other fun activities or participate in a specific fun activity on a routine basis, for example, listening to a certain type of music or playing a favourite computer game. In the social skill area these two year olds may not respond appropriately when introduced to others, for example, say “Hello”, or move out of another person’s way without being asked.

For older children these clinical differences remained. For example, in the home living area in comparison to the control group, 4 year old VLBW children may not put things in to their proper places when finished using them; keep toys, games and other belonging neat and clean; or wipe wet and dirty shoes before entering a house or building. In the leisure skill area the children may not play simple board games or may not have started to follow the rules in games. Finally, in the social skill area the VLBW group may not apologize if they hurt the feelings of others; or may not able to place reasonable demands on friends, for example, may become upset when a friend plays with another friend.

These differences and their impact on the children’s development within the context of their everyday life in their environment, including their families, will be discussed further in question two.

In summary, to answer this research question, the ABAS-II was used to compare the adaptive behaviour of the VLBW group to an Irish control group, using both the premature infants chronological and corrected ages. Although the relatively small number of infants in this study may limit the interpretation of the results, a measurable effect of prematurity on adaptive behaviour was clearly observed, relative to peers and consistent with observations from other recent studies. Considering the most conservative estimate, the VLBW group demonstrated relative weaknesses in General Adaptive Behaviour, Practical

Adaptive Behaviour and Social Adaptive Behaviour, and a relative strength in Conceptual Adaptive Behaviour. Of the ABAS-II 10 skill areas the VLBW group demonstrated relative strengths in Communication, Community use, Functional pre-academics, Health & Safety, Self-care, Self-direction and Motor skills, and relative weaknesses in Home Living, Leisure and Social skill areas. This depth of analysis of the adaptive behavior of former premature, VLBW infants has not been presented in the other studies of adaptive behavior. The next research question will address whether these VLBW children participated in the same childhood activities as their peers and will therefore provide an insight in to whether these deficits in adaptive behaviour were present despite equal environmental opportunities.

Research Question 2

Is there a significant difference between Irish children 2 to 5 years of age, born at preterm gestation and very low birth weight, and those born at full term gestation and of average birth weight in their participation in childhood occupations?

The Assessment of Preschool Children's Participation (APCP) (King et al., 2006a), the only standardised measure of preschool participation that met the selection criteria for use in this study at the time of this research, was used to answer this question. The APCP measures the child's intensity and diversity of participation in 45 identified childhood occupations. No difference was found between the VLBW and full term groups' intensity of participation in play (p=.773), skill development (p=.661), active physical recreation (p=.334) or social activities (p=.528); or in their diversity of participation (p=.860).

The APCP results therefore bring an additional perspective to the study. In contrast to the ABAS-II's measurement of the children's performance in daily tasks and their ability to perform these tasks on demand, the APCP focuses on whether these children are actually participating in these age-appropriate childhood activities and, if so, how often in the past four months. These differences between the two measures used will be discussed below further. It will also be highlighted how this novel information on the intensity and diversity of participation of preschool children born preterm and VLBW contributes to a more holistic understanding of this population, relative to their Irish peers.

Comparison of results with other similar studies

To the author's knowledge no previous studies have been done on the participation of preschool children born preterm and VLBW. Therefore the results of this study cannot be compared directly to age-equivalent peers but will be placed in the context of studies that have measured participation of preterm children at school age and older.

A review of the literature on preterm birth and leisure participation by Dahan-Oliel, Mazer & Majnemer (2012) found the impact of preterm birth on leisure participation to be different depending on the age group assessed. There were no studies found on preschool children. Of the five studies on school aged children, four found no significant difference between the preterm infants and the term born controls in their unstructured and structured physical activity levels. The fifth study was of former preterm, school-aged children with Developmental Coordination Disorder, therefore was not comparable to this study's population. Keller et al.'s (2000) Canadian study of 5 -7 year old children born ≤1500 grams (N=34) compared to 24 term controls was the most comparable with the current study, in terms of age range and birth weight. The results of this study were consistent with those in the current study showing no significant difference between the activity levels of both groups. The quality rating of this study was however classified as 'poor' in Dahan-Oliel, Mazer & Majnemer's (2012) review who described the studies of school-aged children as having smaller sample sizes and poorer methodological rigour than the studies an adolescents and adults. The review included four studies of adolescents and four of young adults' participation. All of these studies demonstrated significantly lower scores for the preterm group in comparison to their full term peers. For example, the former preterm adolescents, with mean ages ranging between 11 – 17 years, demonstrated significantly lower scores in leisure participation including social activities, hobbies and sports. The young adults, with mean ages between 22 - 23 years, and born <1500 grams reported less leisure-time physical activity, of shorter duration, than their full term peers.

More recently, Dahan-Oliel et al. (2014a) researched 12-20 year old Canadian adolescents (N=128) born ≤ 29 weeks gestation using the Children's Assessment of Participation and Enjoyment (King et al., 2004). This assessment measured both the adolescents' participation in activities and also their enjoyment of these activities. Adolescents were found to have high enjoyment scores in social and active-physical types of activities, and highest enjoyment scores in specific skill-based activities. These enjoyment scores did not however match with the adolescents' intensity of participation scores. Instead the adolescents demonstrated high intensity of participation in social activities but less intensity of participation in active-physical and skill based activities, areas they enjoyed most. This sample differed from the current study however in that it included adolescents with physical, intellectual and psychiatric disabilities and did not have a control group.

In summary, the results of the current study were similar to those found in the studies of school-aged children born preterm, demonstrating no significant difference between the preterm VLBW group and the controls. In contrast however, an adverse long term impact of preterm birth on participation appears to be consistently present in the studies of adolescents and young adults. A number of factors may influence this change in participation of the children born preterm. For example, participation in everyday activities may evolve and become more complex with age. The small numbers in the studies of school-aged children may also not have had sufficient statistical power to detect differences, and differences across developmental stages may be due to the natural decline in leisure participation evident in all children and youth (Dahan-Oliel et al., 2012).

Gender Differences

Gender differences have also been explored in relation to the participation of preterm infants at school age and adolescence but not at preschool. As a group, when all children in this study were compared, greater intensities of social and play activities were reported for females. This trend for females to participate in more social activities has been demonstrated in numerous studies (Law et al., 2006; Dahan-Oliel et al., 2014b). Results of Sullivan et al.'s (2012) five-group design study of 180 US 17 year olds who were born premature was also consistent with this trend. In this study the Youth Self-Report of the Achenbach System of Empirically Based Assessment (Achenbach, 1991) was used to interview these students in relation to their involvement with friends, groups and recreation finding a significant difference for gender (p=.05), with boys reporting lower social competence than girls. Sullivan et al.'s (2012) study of the participation of 17 year old US adolescents however categorised the participants in to five clearly defined groups including a full term, and four preterm groups characterised by neonatal morbidity as 'healthy', 'medical neonatal illness', 'neurological neonatal illness' or 'small for gestational age'. Infants less than 37 weeks were included in all four preterm groups and infants with and without medical problems were included in the small for gestational age group. These differences in groupings in birth weight, gestational age and neonatal morbidities reduce any meaningful comparison between these and the current study results.

In the current study, this greater intensity of participation for females was inconsistent when explored in individual groups. Females in the control group demonstrated greater intensities of play, social and skill development than their male peers but no gender differences were found in the VLBW group. Diversity of participation was similar with females demonstrating greater diversity in activities than their male peers, as an overall sample and in the control group, but no gender difference was again found in the VLBW group. No studies that measured preschool children's participation could be found therefore the results of the current study could not be compared to studies of similar age groups.

Measuring participation of preschool children

Measuring the participation of young children in a standardised way is challenging given the lack of valid and reliable tools available to measure this construct and its various aspects (King et al., 2006b). The APCP was the first standardised assessment of preschool children's intensity and diversity of participation and the only measure of its kind available when this research was done. This study has shown that it can be used successfully with parents of former preterm infants. There is however also a need for other specific aspects of preschool children's participation to be measured such as the additional dimensions of participation that are being captured in more recent school-aged measures (Coster et al, 2010; Noreau et al, 2007). For young children for example, adult assistance, most likely from the children's parents, caregivers or service providers is considered normal and has a large influence over children's overall participation and play structure in their early years. These adults define the opportunities the children are exposed to and the social context in which this occurs (WHO, 2007), in a more controlled manner relative to older children.

At different ages and stages of these early years however there is an expectation, depending on the specific tasks, and frequency of exposure to such tasks, that children require lesser degrees of human assistance (Noreau et al., 2007). Support required due to functional limitations that would exceed this level of assistance would be described as additional human assistance (Noreau et al., 2007). The APCP does not capture this dimension of the children's participation which limits interpretation of results. Lemos et al. (2012) who assessed the self-care, mobility and social functioning of late preterm, very preterm and extremely preterm children without physical disabilities, using the PEDI (Haley et al., 1992) attempted to capture this concept. A difference was found between group scores in 'caregiver assistance in self-care' in which children, 2 to 7 years of age, of lower gestation and lower birth weight scored more poorly. This study did not however measure the participation levels of the children so it was unclear whether the preterm group had received the same exposure to childhood activities as their full term peers. As the authors suggested that the caregivers of premature infants may have offered their children more help than was necessary, it is possible that they also sheltered them more from age appropriate developmental experiences (Wightman et al., 2007). This suspected additional assistance also confounds results making it unclear whether these children were given more help than they required or were provided with extra support because they actually needed it.

In the current study it could have been argued that the VLBW group's lower mean scores in adaptive behaviour may be considered as a result of lack of exposure to age appropriate childhood experiences that provide the foundation for developmental skills. This rationale is supported by studies that suggest these children are over-protected (Wightman et al, 2007) from well-intentioned parents. The APCP enables this valuable consideration to be explored in more depth by establishing the VLBW children's level of participation relative to their full term peers. The results demonstrated that despite these VLBW infants participating in the same intensity and diversity of everyday activities as their full term peers, there was a significant difference in the two groups' adaptive functioning as determined by the ABAS-II. This discrepancy between the participation levels and adaptive behaviour of the VLBW group warrants further exploration. Ecological, observational assessments of the children participating and performing functional skills, rather than sole reliance on parent report that may be influenced by their expectations, would validate these study results further and provide possible insights in to the nature and cause of these differences.

As the APCP does not measure the level of support the child requires for participation, it is unclear whether the VLBW children required greater levels of assistance either from adults, adaptive equipment or environmental adaptations, outside of a range that would be considered typical for this age group. This may, in part, explain the discrepancy between the APCP and ABAS-II results as the ABAS-II captures the child's independence in behaviours as they are needed in daily life using a 4-point likert rating scale, recording a score of '0' if the child 'is not able' to perform the task to a score of '3' if the child 'displays the behaviour most or all of the time without being reminded'. It could therefore be argued that parents of VLBW children in the current study may be scaffolding their children's participation at this age but that this was not captured through the APCP assessment. This may be an over simplistic hypothesis however and is unlikely to be the only reason for the difference between the VLBW group's scores on the two measures.

An alternative hypothesis is that these VLBW pre-schoolers are in fact participating at the same level of their peers. Their profile of age appropriate participation levels are consistent with the results found in the studies of former preterm infants at school age (Dahan-Oliel et al., 2012). Their profile is also clearly unlike that of children with physical disabilities (King et al, 2006; Law et al, 2006). If additional support was all that was required for successful and optimal participation of the children there would be little reported difference between the children with physical disabilities and that of the current VLBW group. That is, children with physical disabilities demonstrate lower levels of participation regardless of the level of adult support provided. In fact, the VLBW group's participation results also validate this study's exclusion of premature infants with physical disabilities in order to obtain a true picture of the consequences of prematurity in isolation of further confounding factors.

Comparison of the APCP and ABAS-II results

Although the APCP and the ABAS-II for the most part measure different skills some exploration of similar areas was possible. For example, the VLBW group demonstrated similar levels of participation in social activities as their full term peers, as determined by the APCP. As mentioned when discussing question one above, this result contrasted with the weakness demonstrated by the VLBW group in the social skill area of the ABAS-II, relative to their full term peers. Further explanation of these differences may be that the Social skills area of the ABAS-II tends to measure a child's ability at the ICF-CY (WHO, 2007) level of 'activity' while the APCP measures a child's ability at the ICF-CY (WHO, 2007) level of 'participation'. For example, the social skill area of the ABAS-II measures the child's performance in discrete skills that are desirable for age-appropriate interaction in a social context e.g. 'runs to meet special family members', 'shares toys willingly', 'seek friendships with others in her age group', and 'shows sympathy for others'. These items focus on the child's ability to perform quality social behaviours independently but do not measure social participation in and of itself.

In contrast to the ABAS-II, the APCP does not measure the child's performance in tasks; rather it measures the child's participation in childhood activities. The variety of activities the child participates in and how often the child engages in these activities in a four month period is assessed but the quality of the interaction during this participation is not. As the VLBW group's social participation was comparable to their full term peers despite demonstrating deficits in the social skills area of the ABAS-II, it could be argued that although the 24 items in the social skill area of the ABAS-II are desirable in supporting childhood participation, they may not all be necessary for successful social participation. In fact if the VLBW group are actively engaging in social activities similar to peers it could be argued that intervention is not required.

As the literature discussed earlier has highlighted significant deficits in the participation of adolescents and young adults, it is important to explore if these deficits may be prevented by early intervention. For example, weaknesses in social skills, as demonstrated in the ABAS-II, may be masked in social participation initially by additional parental assistance, altered expectations or by the demands of early participation being less complex and therefore may not restrict pre-schoolers' initial engagement with their world. These skills in social adaptive behaviours intended to be learnt at an early age may provide the foundation for successful participation in adolescence and young adulthood. Of concern is, that as these VLBW children are not demonstrating difficulties in childhood participation in their early years, they are less likely to be picked up by services which may identify underlying weaknesses. These factors may in part explain the differences in results between the tests and also highlight how the APCP and ABAS-II complement each other in providing a holistic view of these young children.

As discussed in question one, leisure skills, another area of the ABAS-II that the VLBW group had deficits in relative to peers, links with the participation domain of the ICF-CY (WHO, 2007), as does the APCP. The 22 items in the leisure skill area do not appear to link specifically with any one of the four activity areas of the APCP but appear to be dispersed throughout the four areas of Play, Skill development, Active Physical Recreation and Social Activities. For example, item two of the ABAS-II leisure skill area 'plays alone with toys, games, or other fun activities' is similar to item five of the APCP Play Area 'plays with toys'. Item eight of the ABAS-II leisure skill area 'plays on playground equipment with an adult' is similar to 'playing on playground equipment' in the APCP Active Physical Recreation Area. Item 20 of the ABAS-II leisure skill area 'plays simple board games' matches with 'playing board or card games' in the APCP Social Activities Area. Finally, item 22 of the ABAS-II leisure skill area 'participates in an organised programme for sport or hobby, for example takes a music class' links to 'taking music lessons' in the APCP Skill development Area. The leisure skill area therefore has a number of items that link closely with participation items in the APCP albeit not in one specific Activity Area as defined by the APCP.

A limited number, if any, paediatric assessment tools are standardised to measure all aspects of everyday life (Msall and Tremont, 2002). The ABAS-II and APCP enabled information on the adaptive behaviour and participation of former premature VLBW infants to be gathered by parent report and compared to age matched peers. As the research shows, responses to parent questionnaires are dependent on a number of factors (Hack, 1999). For example, it could be argued that there may have been volunteer bias in this study. With parents acutely aware of their child's difficult start in life there is a risk of positive bias as parents who are concerned about the development of their VLBW children may have been more invested in participating in the study. The participation rate of approximately 36% of the infants that were sent information packs could raise concerns regarding selection bias with more motivated parents or parents of infants who were concerned about their child's development more likely to participate. When administering the interviews, the researcher was also not blinded to whether the parent was a parent of a full term or VLBW baby. This may have caused interview bias, as the researcher was aware that the cases were born very premature she may have unconsciously prompted the parents more during questioning. However the ABAS-II is a standardised, valid and reliable tool and thus any bias effect should be minimal. According to the Harrison and Oakland, 2003, ‘the user can have a greater level of confidence in the data when two or more sources of information are available and provide generally similar ratings’. This also allows for inter-rater or cross-form reliability (p. 36). Supplementary data for this study were obtained from demographic forms, in-patient medical forms and assessment of preschool children’s participation, which ‘may serve as a substitute for not having multiple respondents’ (Harrison and Oakland, 2003). The addition of a teacher questionnaire could also have been used in order to understand and obtain a profile of older children's development across multiple environmental settings.

The VLBW child within their environment

The interdependence between the child and their environment has been acknowledged for decades (Brown et al, 1997; Bronfenbrenner, 1977). In the 1970’s and 1980’s psychologists such as Bronfenbrenner (1977) and Gibson (1988) developed theories and models that focused on the relationship between humans and their environment. Bronfenbrenner’s (1977) conceptual model the ‘Ecology of human development’ deconstructed the environment into interdependent systems within which the social and cultural environmental demands opposed on, and afforded to, the child could be explored. These theories have also influenced the profession of occupational therapy, providing the foundation for conceptual models of practice that emphasised the environment (Case-Smith et al., 2010c). Consistent with these early theoretical frameworks, a much more recently developed conceptual model, the ICF-CY (WHO, 2007) views participation as the result of the interaction between the child and their social and physical environment (WHO, 2007). This expansive view of the child interacting dynamically within an every changing environment assists the therapist to both assess and provide intervention strategies that include the child's family and community (Case-Smith et al., 2010c).

The child and environmental factors that influence the participation of children have been explored by a number of authors. Law et al. (2006) examined the influence of these factors on the recreational and leisure participation of children 6-14 years of age, finding direct and indirect predictors of participation. Although these children had physical disabilities, some results were similar to those found by Dahan-Oliel et al. (2014b) in relation to adolescents (12-20 years) born ≤29 weeks gestation. For example, both studies found that children were more likely to participate in greater numbers of recreation and social activities and lower numbers of active physical recreation and skill-based activities. Law et al (2006) found that the children with physical disabilities' participation intensity was greater in informal activities than with formal activities. This emphasis on unstructured activities was also noted by Dahan-Oliel et al. (2014b) in relation to preterm infants. Although Law et al. (2006) suggested this gravitation of the children towards informal activities may be due to the adverse effect of the physical and institutional environmental barriers present for formal activities this may be specific to children with physical disabilities. In relation to former preterm infants, Dahan-Oliel et al. (2014b) found that physical, social and attitudinal barriers as measured by the Child and Adolescent Scale of Environment (Bedell, 2004) were not significantly associated with the intensity of the adolescents' participation.

Dahan-Oliel et al. (2014b) found child factors such as sex, motor competence and mastery motivation, cognitive ability, functional status and perceiving oneself as socially acceptable to correlate moderately with the adolescents' intensity of participation in specific areas of activity. The authors suggested that the former preterm infants' intensity of participation was linked to the underlying demands of the specific activities rather than the larger environment. This is consistent with the concern of the current study that as the underlying demands of the tasks become more complex these preschool children may demonstrate more challenges in participation, as is evident in the studies of school aged children and adolescents born preterm. Law et al. (2006) found the children's participation was also lower in families with reported lower incomes, single-parent families and lower parent education. Dahan-Oliel et al. (2014b) found a similar trend with maternal education correlating with intensity of participation in active-physical recreation moderately, while lower socio-economic status was correlated with less engagement in skill-based activities. Finally, Dahan-Oliel et al. (2014b) found environmental factors such as family support and friend support were correlated modestly with the participation of intensity of the former preterm adolescents in active-physical, social, skilled-based and self-improvement activities while classmate support was correlated moderately with intensity of participation in social activities.

In this study the researcher also gathered information on former preterm VLBW infants within the context of their environment. The VLBW group's personal factors such as their age and gender and environmental factors such as their schooling, parental education, main activity of mothers, socio-economic status of families, and parents' ethnicity were all examined and found to be comparable to the control group. The only exception was that of the parental ages of the children in the VLBW group. In comparison to the control group, the VLBW parents' ages were significantly higher which would be expected for this group (Newburn-Cook & Onyskiw, 2005) and is consistent with other studies of this population (Fernandes et al, 2012). Overall the VLBW group therefore appeared to be afforded the same environmental supports as their full term peers and were reported to participate in the same real-world environmental opportunities (King et al, 2005), as evidenced by the results of the APCP. These environmental influences or this person-environment fit (Law & Dunn, 1993) did not however appear to be effective in closing the gap in adaptive skills between the VLBW group and their term matched peers.

Unlike the studies on school age children (Dahan-Oliel et al., 2014b), at this preschool stage, the VLBW children's participation levels suggest they are functioning at close enough to average to be able to avail of typical childhood opportunities. These environmental supports do not however appear to afford the VLBW children the quality of experience necessary to adapt successfully to their environment at an age-appropriate developmental level (Gibson, 1988; Case-Smith et al., 2010c) and therefore maximise their adaptive functioning. This lack of person-environment fit (Law & Dunn, 1993) that appears to be demonstrated in this study has been alluded to in previous studies in relation to specific outcomes for preterm infants. For example, Taylor et al. (2006) suggested that children with higher neonatal risk are less able to benefit from environmental advantages than their full term peers. These authors argue that the moderating effect of advantaged families, demonstrated in previous studies in relation to developmental skills of preterm infants (Landry et al., 1998; Taylor et al., 1998), may suggest that the preterm infants capacity to benefit from an enhanced environment may depend on the outcome being assessed (Taylor et al, 2006). In the current study, this group of VLBW infants do not appear to face overt barriers in their social and physical environments; rather they may lack the subtle environmental supports necessary to truly nurture areas of adaptive weaknesses. This suggests that some form of additional environmental support may be required to optimise their potential. Intervention strategies will be discussed in more detail below.

It is acknowledged that the APCP does not consider the role of the environment explicitly in its assessment of children's participation. The only tool available at the time of this study that assesses both the child's participation and the influence of environmental factors is standardized on school aged children (5-17 years of age). In the Participation and Environment Measure for Children and Youth (PEM-CY) (Coster, Law & Bedell, 2010) the parent is asked 'how involved the child is with the activity?', whether the parent would like their child's activity to change and if so how would they like their child's activity to change. The PEM-CY also obtains both the parents' and children's views on participation. Since data collection for this study was completed a preschool version of the PEM-CY, the Young Children's Participation and Environment Measure (YC-PEM) (Khetani et al., 2013) has been developed for children 0-5 years 11 months with and without disabilities.

Although Irish and UK legislation clearly advocates for the involvement of children in decision making (Kirby et al., 2003; The National Children's Office) and research has demonstrated the positive benefits of encouraging children's unique perspectives (Freeman & Mathison, 2009), as a group, the children in this sample were too young to take on this role. Different adult's views of the same behaviours could have been explored using the ABAS-II in multiple environments with different caregivers to establish if the children were exposed to differing environmental demands depending on the setting (Wallace and Shubert, 2008).Considering the age range of the children, the fact that both groups had mostly two parent families living in the same household, and that very few children were in formal schooling, it may not however have generated significantly more information. Alternatively, more ecologically sound assessment could be done through direct observation of the children participating in tasks within the natural environments that they occur.

Implication of results for clinical practice

It is crucial to identifying the specific type and extent of challenges preterm VLBW infants without physical or intellectual disabilities demonstrate in everyday life skills compared to their peers as it has implications for resource services. The model of early intervention services in Ireland is focused on infants and young children with physical, intellectual and mental health diagnoses (Carroll, Murphy & Sixsmith, 2013). With limited resources, this biopsychosocial model does not focus on preventative measures which would be most beneficial for this group of vulnerable children. These children's weaknesses may require focused assessment to reveal impairments and therefore may not be picked up with routine follow-up services (Fjørtoft et al, 2012a, 2012b). Ironically, even when tested with targeted assessments, the likelihood is that these children will not fall in to the 'disability' range i.e. two standard deviations from the norm at this young age, despite the fact that they are clearly at a disadvantage to their peers. In the present financial climate in Ireland this will mean that these children are discharged from health services. This 'wait to fail' approach (Hale, 2008) suggests that these functional weaknesses that appear to be present at this very early stage in development are ignored providing a poor foundation for future skills. Few studies are available on the long term consequences for this cohort of children but preliminary evidence suggests that they demonstrate reduced social functioning and increased unemployment rates in later years (Hille et al, 2007).

One of the main goals of educational, health and rehabilitation services for children is to improve their participation in activities of daily life (Law, 2002). For decades, occupational therapists have been researching and providing interventions for children with challenges in this area (Shepherd, 2010; Law et al., 2011). The results of this study highlight the complex profile of adaptive strengths and weaknesses these preterm VLBW children demonstrate in activities of daily life. The varying range of standardised scores in adaptive functioning both pre and post 24 months of age, suggests that a ‘one size fits all’ approach to intervention may not work for these children. Instead, a multi-tiered approach that provides a range of services for the families of these VLBW infants along a continuum from preventative information, education for parents to actual one to one intervention, depending on the individual needs of the child, may be required. This will ensure focused care for children with more complex issues (Missiuna et al., 2015) and therefore may attenuate long term sequelae. ‘Partnering for Change’ (P4C) (Missiuna et al., 2015), both a service delivery model and research project evaluating its implementation, has been developed by the Centre for Childhood Disability Research Centre, McMaster University. This multi-layered model based on the ‘response-to-intervention’ approach was originally developed by and for occupational therapy services. Missiuna et al. (2015) report however that the fundamental principles and features of the model are relevant for all healthcare professionals and educators. This progressive and clinically relevant approach to early intervention for these children will be discussed further in the implications for practice section of this chapter.

Impact on family

There is a positive message in the results of this study for parents. Despite these children’s turbulent start in life and weakness in adaptive skills, their parents are encouraging them to participate in the same variety and intensity of activities as their full term peers. These parents must therefore be commended for their positive parenting and for providing the children with multiple opportunities to participate in regular childhood activities. Parents could therefore collaborate with therapists and educators to explore leveraging these opportunities by combining them with intervention strategies to enhance the children's participation in order to impact positively on their adaptive skills (Palisano et al., 2012)

Knowledge is also power for these families. Parents who are aware of their children's relative strengths and weaknesses can nurture their strengths and coach them in challenging daily life skills such as home living, leisure and social skills. With professional support they can learn to adapt their child's environment and use strategies that maximise their child's adaptive functioning in their home. For some families, interventions to enhance adaptive functioning skills may be as simple as attending informal parent education sessions, clarifying developmental expectations for their children in different age ranges, and/or learning about simple strategies for use with their children (Wallace and Shubert, 2008).

Cultural equivalence

Cross cultural equivalence testing is required to ensure participation measures developed in specific countries are valid for new cultures or countries (Stevelink & Brakel, 2013). For example, the importance of participation in childhood activities such as play holds different values depending on the individual culture (Parham, 2008). The APCP was developed on a North American population of pre-schoolers in the English language and has not been cross-culturally adapted for an Irish population of children. This is a limitation of this study. As the test is not norm referenced it reduces the possible cross-cultural concerns and the VLBW group's results were also compared to a matched control group of Irish peers.

The APCP looks at how frequently a child has participated in 45 activities over the past 4 months. In Ireland, many activities are weather dependent and therefore the activities that a child is involved in from November to February may be very different than those they may participate in from June to September, relatively drier, warmer months when the children have a long period off school. In the summer months, participation may comprise of more outdoor, physical activities and therefore motor differences may be more pronounced. In this study, as a case-control approach was used the children in both groups were assessed during the same time period therefore this would not have affected relative results.

In summary, the APCP was used to measure the preterm VLBW group's participation in childhood activities relative to a matched control group. The information gathered assisted in placing the results of the primary outcome measure in context as the ABAS-II focused on the children's performance in daily life while the APCP measured the children's participation in childhood activities. The results of the APCP demonstrated that the children in the VLBW group and the control group did not differ in their intensity of participation in play, skill development, social activities, or active physical recreation, or in their diversity of participation. Gender differences, in favour of females, were found in the overall sample and in the control group who demonstrated greater intensity and diversity of participation. This difference was not observed in the VLBW group. As the participation levels of children born preterm and VLBW, without physical and intellectual disabilities, has not been previously documented for this preschool age range, there is little if any literature to compare these results to. Results of school aged children and young adults born preterm and VLBW have however consistently demonstrated difficulties in participation in comparison to peers. This is a cause of concern and this knowledge combined with the challenges that these preschool children presented with in adaptive functioning suggests that they may be presenting with the early signs of struggle that may become more apparent as tasks and their environmental interactions become more complex.

Limitations of the APCP were acknowledged and other areas of participation that could have enhanced the researchers understanding of these children's participation were discussed such as the level of human assistance they received, the children's activity preferences, where they do the activities (home or community), who they do these activities with, and whether they enjoy them (King et al., 2006b). These important aspects of participation would also assist with designing targeted interventions for this cohort of children. A new tool of preschool children's participation, the YC-PEM (Khetani et al., 2013), that also includes measurement of the child's environment was noted to have been published since this study was done.

Research Question 3a

Is there a difference on standardised testing between the adaptive functioning of an Irish control group of full term, average birth weight infants, aged 6 months to 5 years 6 months of age, and normative data available on a North American sample?

On standardised testing using the ABAS-II, no significant difference was found between the mean General Adaptive Composite score of the Irish control group and the North American normative data. The Irish control group demonstrated a different profile of strengths and weaknesses in Conceptual, Practical and Social adaptive composite scores than was present in the North American normative data. Results demonstrated significant differences between the Practical and Social composite mean scores of both groups. The Irish control group demonstrated significantly higher mean scores in the Social domain while the North American normative data suggested the North American children demonstrated significantly greater ability in the Practical domain. There was no significant difference between the mean conceptual domain scores.

In the ABAS-II skill areas, the Irish control group demonstrated significantly higher mean scores in the areas of Communication, Community Use, Home living, Leisure, Self-direction and Social skills. With the exception of the Home living skills area, these skill areas contributed to the higher mean composite score in the Social domain and, although not significant, the trend of a higher mean composite score in the conceptual domain. In contrast, the Irish control group demonstrated significantly lower mean scores in Self-care (a skill area of the practical domain) and Motor skills relative to the available North American data. Although the Irish control group also demonstrated lower mean scores in Pre-academics and Health and Safety, these scores did not reach significance. Of these lower mean scores obtained by the control group in the skill areas, their mean score in the self-care skill area was the most significantly low, in comparison to the North American data, described by the ABAS-II classification system as ‘below average’.

These results highlight possible important cross-cultural differences between the overall practical and social adaptive functioning and the specific adaptive skill areas of Irish and North American children without disabilities. That is, the age that these adaptive skills are developed and the parents’ expectations of when children are expected to be independent with them appear to differ between these two countries. Although the ABAS-II was developed with a western culture and in the English language, it requires cross-cultural testing using a framework for cultural equivalence if results between an Irish and North American culture are to be compared validly (Stevelink & Brakel, 2013).

Clinicians can be very clear in acknowledging the differences between western and eastern cultures but may minimise the differences between different western cultures. For example, in practice, measures of adaptive behaviour developed in North America are used in other western countries such as Australia, Canada, New Zealand and the United Kingdom, with the unproven assumption that similar behaviours are characteristics or prevalent in all five of these cultures (Oakland et al., 2013). This is not consistent with the American Association of Intellectual and Developmental Disabilities (AAIDD) (2010) recommendation that adaptive behaviour is assessed within the context of ‘typical’, age appropriate, community and cultural environments, relative to peers. Subtle cultural differences may make specific items more or less difficult than other items, affecting the psychometric properties (Beaton et al, 2000). In acknowledging the scarcity of knowledge on the cross-cultural adaptation of measures of adaptive behaviour, Oakland et al. (2013) caution clinicians and researchers when reviewing results in countries outside of the country the measure was developed. As the ABAS-II, or other available measures of adaptive behaviour, have not yet been culturally validated for an Irish population of children this study employed a case-control design to ensure the VLBW children were compared to culturally appropriate norms.

This is timely research as, as part of the National Clinical Programme for Paediatrics and Neonatology, a model of care for neonatal services in Ireland is currently being developed. This best practice model, although still in draft format, recommends that all former preterm infants are assessed with the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley, 2006) at 2 years of age. This North American developmental assessment is comprised of 5 subscales. Three of the subscales are observational tests of the child's language, cognitive and motor skills and have been re-normed for an Irish and UK population of children. The other two subscales however, the Adaptive Behaviour Parent Questionnaire (adopted directly from the Parent/Primary Caregiver form of the ABAS-II) and Socio-Emotional Parent Questionnaires have not been cross-culturally tested for use with an Irish or UK population of children. This study demonstrates that use of this adaptive behavior parent questionnaire without accurate normative data on an Irish population of children may misrepresent these preterm infants' adaptive functioning relative to their full term Irish peers.

In summary, despite high degrees of cultural similarities, it cannot be assumed that measures of adaptive behaviour developed in specific western cultures can be used validly in other western cultures. This study, although of small sample size, demonstrates a significant difference between the practical and social adaptive functioning and the specific skill areas of Irish controls and North

American normative data, as measured by the ABAS-II. It is recommended therefore that the ABAS-II is cross-culturally tested at a population-based level to establish its transportability to an Irish population and to confirm it can be used validly as part of the new model of care for neonatal services in Ireland.

Research Question 3b

Is there a difference on standardised testing between the adaptive functioning of Irish children, aged 6 months to 5 years 6 months of age, born preterm and very low birth weight, and normative data available on a North American sample?

Cross-cultural differences may exist for both children with and without disabilities. As discussed in question 3a, the main data collection tool for this study, the ABAS-II, was developed on a North American population of children, therefore the researcher aimed to explore whether these data were suitable for use with an Irish population of children with and without biological risk factors. The results of question 3a demonstrated that the Irish control groups mean scores were significantly different to the ABAS-II North American data suggesting that cultural differences may exist between the Irish and North American children. Evidence from the literature, demonstrating differences in age related norms of activities of daily living of US (Haley et al., 1992), Norwegian (Berg et al., 2008), Puerto Rican (Gannotti & Cruz, 2001) and German ((Schulze, 2012) children 6 months to 7 years 6 months of age using the Pediatric Evaluation of Disability Inventory (Haley et al., 1992) supports this. Given the cultural differences between Irish and North American children, it may therefore be less meaningful to try to establish whether or not these VLBW children scores are within average range, or one, two or more standard deviations below the mean as defined by ABAS-II North American normative data. This sub-question therefore will overlook cultural differences briefly to present the VLBW children's' scores relative to the North American data.

As with the Irish control group, the North American normative data was compared to the VLBW group's results, assuming a standard score of 100 was average for the North American data. The VLBW group demonstrated significantly lower mean scores in the ABAS-II General Adaptive Composite score, and the Conceptual, Social and Practical composite mean scores compared to the North American normative data. The VLBW group also scored significantly lower scores in seven of the 10 skill area scores: Pre-academics, Home Living, Health and Safety, Leisure, Self-care, Social and Motor skills. In the other three skill areas, the VLBW group also demonstrated lower mean scores (Communication, Community Use and Self-direction) but these scores did not reach significance.

Does this difference translate in to an impairment or merely demonstrate a lower adaptive mean score within the average range, as defined by the ABAS-II? Of the 6-24 month range (N=18) VLBW infants, corrected for prematurity, four obtained GAC scores of less than one standard deviation (<1SD) below the norm, while three did in the conceptual domain, four in the Social domain, and a notable 10 in the Practical domain. Only two infants obtained a GAC score of <2SD below the norm, while one did in Conceptual domain, one in Social domain and two in the Practical domain. In the older age range 25-64 months (N=26), seven children had a GAC score of <1SD below the norm, while five did in the Conceptual domain, three in the Social and again a notable 11 in the practical domain. No children presented in the <2SD below the norm in this age range. This suggests that most of the VLBW group with difficulties were <1SD below the norm. In order to advocate for these children successfully their scores need to be presented relative to normative data, as allocation of resources and intervention are linked to disability as is predominantly determined by standardised testing (Government of Ireland, 2005). As these scores are not in the ‘impaired’ range this may have negative implications for resources. Due to the cross-cultural concerns of this assessment measure these results need to be interpreted with caution.

Finally, in relation to the ABAS-II classification system, when the VLBW group were not corrected for prematurity they were classified as ‘below average’ in their General Adaptive Composite mean score and their Practical Adaptive Composite score, while their Conceptual and Social Composite mean scores were in the ‘average range’. Once adjusted for prematurity, all of the VLBW groups composite scores were classified as in the ‘average range’. In relation to the skill areas, when the VLBW was not corrected for prematurity their scores were classified as below average in pre-academics, home living, health and safety, self-care (borderline) and motor skills. Using VLBW group’s scores, adjusted for prematurity, the groups’ scores remained in the ‘below average’ range in the Health and Safety and Self-care skill areas. Again these scores need to be interpreted with caution given possible cultural differences.

In summary, this sub-question has overlooked cultural differences to explore whether these VLBW children’s’ ABAS-II mean scores were comparable to North American normative data. The VLBW group demonstrated significantly lower means scores in the General, Conceptual, Practical and Social Adaptive Composite scores, and seven of the 10 skills areas. The majority of VLBW children who demonstrated difficulties also tended to be in the ‘<1SD below the norm’ range, with few <2SD below the norm. This ‘mild’ range of difficulty has implications for resources and services for this population. Finally, results need to be interpreted with caution given the possible cross-cultural differences demonstrated between the Irish control group and the North American normative data on the ABAS-II.

Conclusion

The ABAS-II is a standardised parent questionnaire that provides valid and reliable scores for adaptive behaviour for children 0-5 years of age. The results of this assessment demonstrated that despite challenges in comparison, the current study supports the recent body of evidence that suggests young Irish children born preterm and VLBW, without complications of physical or intellectual disability, demonstrate deficits in adaptive behaviour in comparison to their full term peers. In contrast to these results, there was no difference between the groups (2-5 years of age) in their intensity or diversity of participation in childhood activities, as measured by the Assessment of Preschool Children’s Participation (APCP). This suggests that these children present with challenges in adaptive functioning despite exposure to the same activities as their full term peers. Although the sample size is small, the results also suggest that this weakness in adaptive behaviour is present from a very early age and despite some gain in relation to peers, the limitation remains between groups from 6months - 5 years 6 months of age.

The results of both the Irish control group and the VLBW group were also compared to the ABAS-II North American normative data. Although a significant difference was not found between the General Adaptive Composite mean scores of the control group and North American normative data, differences were found between the Social Composite mean scores (in favour of the Irish control group) and the Practical Composite mean scores (in favour of the North American data). Differences were also found between the groups’ strengths and challenges in the 10 ABAS-II Skill areas. The VLBW group also demonstrated lower mean adaptive scores than the North American normative data and those that presented with difficulty tended to be in the <1SD below the mean range. This mild level of impairment has implications for both services and resources available to these children and perhaps may be the reason this specific cohort of preterm infants has no formal pathway of care in Ireland. That is, they may receive a limited therapeutic out-patient service from the hospital team but without complications of physical or intellectual disability are discharged from hospital services and remain in the community without support, in a ‘wait to fail’ approach. Cross-cultural testing is required before the ABAS-II can be used validly with Irish preterm infants as a tool to advocate for the unique needs of these children, and therefore these standardised scores must be interpreted with caution. As this parent questionnaire however, (as part of the Bayley III (Bayley, 2006)) has been recommended as the screening tool for all two year old former preterm infants in the draft model of care for neonatal services in Ireland, this research is timely.

Limitations of the study, as discussed throughout this chapter, include its small sample size and the relatively large age range of the former preterm infants. The ABAS-II and the APCP questionnaires have however been specifically validated for use with these age ranges and the sample size is larger than what was deemed necessary for statistical power. The findings from this study are also consistent with other studies published in this area and demonstrate a measurable effect of preterm VLBW birth on overall adaptive behavior. This weakness in adaptive function is present regardless of whether the infants’ chronological or corrected gestational age is used for assessment, and in the absence of physical or intellectual disabilities. These preschool weaknesses are of concern as the cumulative effect of failing to obtain developmental skills results in decreasing levels of motivation which in turn plays a negative effect on further development (Van Kessel-Feddema et al, 2007). To avoid these negative long term implications, a focused model of service delivery that emphasises a continuum of possible interventions is required for these former preterm children. This will be discussed in the implications for practice section below.

Implications for Practice

As long term follow-up studies have revealed a high frequency of developmental difficulties in preterm survivors who were formerly considered free of disability (Van Kessel-Feddema et al, 2007), the American Academy of Pediatrics therefore suggests ‘periodic evaluation of the developmental progress of every infant is essential for identifying deviations in neurodevelopmental progress at the earliest possible point, thereby facilitating entry into early intervention programs’ as appropriate (Committee on Fetus and Newborn, 2008, p. 1123).

Although these preterm VLBW children, as a group, appear to have a specific profile of strengths and challenges in adaptive functioning, the extent of this difficulty for individual children appears to vary suggesting a continuum of service options would be most appropriate. A possible model of the services will therefore be presented using the Partnership for Change (P4C) (Missiuna et al., 2015) framework. Although this framework has been developed for school-based services (Missiuna et al., 2013), the core concepts embrace a dynamic, ‘response to intervention’ approach that appears applicable to this population’s range of preschool needs. This tiered approach may be the most progressive and clinically relevant approach to address these early signs of functional limitations and therefore support the foundations for the development of more complex skills required for daily life. As is core to the

P4C model, this collaboration will use coaching in context for capacity building. The following is a brief example of how this framework might be applied to these preterm VLBW pre-schoolers:

Layer 1

This first layer of the P4C aims to 'wrap the services around the child'. It emphasises the importance of the partnership between the occupational therapist in the community, the parents and, in this case, the crèche or preschool teacher in changing the life and daily environment of the preterm infant.

Layer 2

In this layer, two core activities are used 'Relationship building' and 'Knowledge Translation'. In the relationship building stage the occupational therapist (OT) needs to be available in the community and seeking opportunities to connect with the parents, crèche and/or preschool teacher. Therapy services need to be responsive to the parent and schools concerns and the child must be provided with the appropriate services in the correct environment in a timely way.

Knowledge Translation requires the OT to provide evidenced-based information about how the child can be supported to maximise their adaptive functioning and overall participation in childhood activities at home and in preschool, in a way that all parents and teachers can understand. The aim is to build the capacity of parents, caregivers, support staff and teachers who interact with the preterm child by problem-solving and exploring what, how and why strategies work to improve the child's participation, and integrating these strategies in to the child's daily activities.

Layer 3

In the third layer, the P4C model uses the Response to Intervention pyramid to provide services to the former preterm children. This includes three tiers.

The first tier 'Universal Design for Learning' (UDL) could use strategies that are applicable to all children in the crèche, preschool or home environment to improve adaptive skill development with the models ethos of these strategies being 'good for all and essential for some' (Missiuna et al., 2015, p.7). Preterm infants who were within average range in the ABAS-II may be suitable for this tier. The OT could help the parents and preschool teachers clarify developmental expectations for the child's adaptive functioning and participation at different ages and stages of the preschool years. They could also collaborate with the parents and teachers to maximise the child's opportunities to enhance their adaptive functioning by altering the environment.

In the second tier of service 'Differentiated Instruction', the OT, parents and teachers start to identify smaller groups of children who may not be demonstrating age-appropriate adaptive skills relative to peers in the home and preschool, despite using the strategies as identified in the first tier (UDL). This tier may be appropriate for the preterm infants identified with adaptive behaviour scores of <1SD below the norm on the ABAS-II. Functional checklists that provide broad age equivalents could be used with parents and teachers to ascertain the child’s strengths and challenges in daily activities, relative to peers. These challenges could also be explored to ascertain if they are due to lack of exposure or are genuine weaknesses. Extra instruction or additional strategies may be trialled.

The third and final tier is 'Accommodation'. It focuses on the preterm children who demonstrate more complex needs. This tier may be appropriate for the preterm infants identified with adaptive behaviour scores of <2SD below the mean, as defined by the ABAS-II. Over the past two decades rehabilitation has become more functional, child-focused and goal directed. Mounting evidence suggests this approach provides superior results than the traditional approach of focusing on isolated performance skills (Law & Darrah, 2014). These children could therefore be assessed using an observational measure of functional skills and intervention could use a 'Dynamic Performance Analysis' (DPA) of functional activities. Missiuna et al. (2015) describe DPA as a method in which the therapist tries implementing specific strategies that focus on making changes to the task or the environment. The child is observed using these strategies, outcomes are evaluated. Based on the results changes may be made or new strategies trialled and less effective strategies omitted. For children in this tier, environmental support and assistive technology in the home and preschool and/or referral to an early intervention team may be required. Importantly, these strategies that are used with daily activities and the rationale for them, is then shared with both the parents and teachers.

Layer 4

The final layer of P4C emphasises that as the intensity of intervention required increases the number of students needing this level of support reduces. The aim of the model is that each child's service is needs-based and reaches all children.

Finally, occupational therapists are skilled in the assessment and intervention of children's daily life skills. Research shows that functional challenges left unmonitored often do not self-correct but instead may provide a poor foundation for the child. As the complexity of tasks increase and environmental demands become more challenging in later life these weaknesses may also be compounded impacting on all areas of the child's life (Van Kessel-Feddema et al, 2007). A model such as P4C that focuses on the unique needs of each child at an early stage of development would ensure all children receive the level of service they need. The proactive identification of clear strengths and challenges at a preschool stage will also allow the OT, parents and teacher to assist these children make a smooth transition in to primary school, and therefore mitigate the wide range of difficulties that have been identified in these children in numerous studies once they enter the formal school setting.

Future Research

According to Marlow and Green (2007), parents have the right to know about the long term problems their unborn or newborn baby may have, including the child's potential risk of disability, what is meant by disability and the long term consequences of their decision making. He recommends that mild to severe disability should be explained, 'along with the potential consequences and the effects on the development of the child' (p. 329). This is an insurmountable task if health care professionals do not actually know what the everyday effect that being born preterm and VLBW have on a developing child.

Future research is needed to confirm the results of the parent interviews by observational assessment of these preterm VLBW children. This study examined a parent's perception of their child's ability at one time-point only. A longitudinal assessment would be more predictive and useful than this type of once off assessments, 'as they provide information on maturation, recovery from injury, and reorganization' (Noble and Boyd, 2012, p.129). In order to establish if the challenges of these preterm VLBW children increase over time a prospective longitudinal study, as opposed to a retrospective longitudinal study, would be preferable. Standardised observational assessment should be used to measure the functional skills and participation levels of these children at different age ranges, over a number of time periods to improve the generalisability of results. A preschool teacher questionnaire focusing on functional skills could also be administered to provide a comprehensive profile of the children. At present, in Ireland the Early Intervention Teams developed as a consequence of the Disability Act 2005, focus resources on children with a confirmed diagnosis therefore this cohort of preterm VLBW children are discharged from services with a ‘wait to fail’ approach. The establishment of normative data for the ABAS-II for on Irish population of children will allow clinicians to present a realistic profile of these children’s adaptive strengths and challenges relative to Irish peers. If the results of observational assessment of these children concur with the findings obtained by parent reported standardized questionnaires, these children will need to be provided with a formal pathway of care, as alluded to above. A multicentre randomised control trial could then be performed with all Irish VLBW infants in this age range randomly allocated to either an intervention group (Partnering for Change Programme) or a control group to establish the effectiveness of this emerging approach to intervention for the preterm VLBW infants of the future.

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LIST OF TABLES

LIST OF FIGURES

APPENDICES

APPENDIX A: Development of Research Question

Research Question - What is the Impact of Preterm Birth on Participation in Childhood Occupations?

Patient or Participant	Very Low Birth Weight Babies (The Vermont Oxford Network eligibility criteria, 2011) • whose birth weight was between 401 and 1500 grams OR whose gestational age was between 22 weeks 0 days and 29 weeks 6 days (inclusive) • born preterm in the Neonatal Unit in Galway University Hospital between 2006 – 2010, • who are now between the ages of 0 – 4 years 11 months. • All reasons for prematurity included. • No formal diagnosis of physical, intellectual or mental health disability.
Intervention	N/A
Comparison	N/A - This study does not have a comparison group (In the future? - Children that match the criteria and/or receive a service from EIS **V's** children that do not match criteria or receive a service for EIS. Services for children with a diagnosis **V's** services for children without a diagnosis)
Outcome	• Earlier access to appropriate Early Intervention Services e.g. OT, SLT, PT, Psychology • Preventative service provision e.g. referral to community services to monitor high risk factors, educate parents on the promotion of their child's developmental skills. • Advocate for extra support (special needs assistant/resource teaching) in preschool/school environments, as necessary. • Predict the impact of preterm birth on the child's every day skills and need for resources. • Early diagnosis (Other - Reduce community waiting lists by decreasing inappropriate referrals. Identify a pathway for premature babies)
Study Design	• Questionnaire survey will be used to gather quantitative data. Description of patterns in play, self-care, and preschool activity (Childhood Occupation)

APPENDIX B - Key Concepts and Search Strategy

Analysing the Research Question

	Concept 1 **Preterm birth**	**Concept 2** **Childhood**	**Concept 3** **Occupation**	**Concept 4** **Prognosis**
Search terms (connectors)				
SYNONYMS	24 – 28 weeks	0 -4 years	Play	Disability
	Low Birth weight	Infant	Dressing	handicap
	Preterm babies	Toddler	Feeding	Developmental disorder
	Premature birth	Child/children	Toileting	Developmental disabilities
	Preterm Infants		Sleep	Neurological
	Gestational Age		Washing	Congenital malformation
	Extreme/Extremely preterm Infants		Leisure	Long term care
	Prematurity		Pre-writing	Cerebral Palsy
	Premature labor		Pre-scissors	Chronic lung disease
BROADER TERMS	New born	Paediatrics	Occupational Therapy	
			Pre-academics	
			Preschool activities	
			Participation	
			Engagement	
			Performance areas	
			Social skills	
NARROWER TERMS			Fine motor skills	
			Gross motor skills	
			Perception	
			Hand function	
			Development	
			Performance components	
			Attention	
			Motor Planning	

			Problem solving	
RELATED TERMS	Corrected for gestational age		Attachment	Hospital discharge
	Neonatal Intensive care units		Neuromotor disability	Newborn intensive care
	Mild preterm (32-36 weeks)		Environment	
	Very preterm (28-31 weeks)			
	Morbidity			
	Mortality			
	Medically indicated (iatrogenic) preterm birth			
	Preterm premature rupture of membranes (PPROM)			
	Spontaneous (idiopathic) preterm birth			
	Multiple pregnancies			
	Intrauterine infection			
	Risk Factors			
	Premature rupture			
	Pregnancy complication			
ALTERNATIVE SPELLINGS				

Key Word Search Strategy – Phase 1

Key Word Search Strategy – Phase 1

“24-28 weeks” OR “Very Low birth weight” OR “Preterm babies” OR “Premature birth” OR “Preterm Infants” OR “Gestational age” OR “Extrem* preterm infants” OR Prematurity OR “Premature labour” OR “new born” OR “corrected for gestational age” OR “neonatal intensive care units” OR “mild preterm” OR “very preterm” OR Morbidity OR Mortality OR “medically indicated preterm birth” OR iatrogenic OR “preterm premature rupture of membranes” OR “spontaneous preterm birth” OR idiopathic OR “multiple pregnancies” OR “intrauterine infection” OR “risk factors” OR “Premature rupture” OR “Pregnancy complication” OR VLBW

AND

0-4 years OR Infant* OR toddler OR child* OR Paediatrics OR bab*

AND

Play OR Dressing OR Feeding OR Toileting OR Sleep OR Washing OR Leisure OR Pre-writing OR Pre-scissors OR “Occupational Therapy” OR Pre-academics OR “Preschool activities” OR Participation OR Engagement OR “Performance areas” OR “Social skills” OR “Fine motor skills” OR “gross motor skills” OR Perception OR “Hand function” OR Development OR “Performance components” OR Attention OR “Motor Planning” OR “Problem solving” OR Attachment OR “Neuromotor disability” OR Environment.

AND

Disabilit* OR handicap OR “developmental disorder” OR neurological OR “congenital malformation” OR “long term care” OR “Cerebral Palsy” OR “chronic lung disease” OR “hospital discharge” OR “newborn intensive care”

Inclusion & Exclusion Criteria for Literature Search

SELECTION CRITERIA

	Inclusion criteria	Exclusion Criteria
Types of studies	All studies	
Articles	Peer-reviewed journals Other scholarly articles i.e. commissioned reports, working reports, conference reports. Grey Literature – PhD and Masters theses, conference proceedings/posters/ abstracts	Magazines Newsletters
Profile of Participants	Preterm infants Very Low Birth Weight Babies (VLBW) 401 - 1500 grams And/or 22 weeks 0 days and 29 weeks 6 days Children between 0 - 4 years 11 months of age.	
Diagnosis	All reasons for prematurity	
Types of interventions	Occupational Therapy, Speech and Language Therapy, Physiotherapy, Psychology, Paediatrician, Neonatologist	
Types of outcome measures	Occupation or activity based, performance components	
Languages	All	
Population	Humans	Animals
Publication dates	1956 - 2011	

Refinement of Key Word Search Strategy – Phase 2

It was decided that the Key word search terms could be further refined. Using **EBSCO** as a platform for MEDLINE; Academic Search Complete; CINAHL Plus with Full Text; Health Source: Nursing/Academic Edition; SocINDEX with Full Text, the concepts were further explored and refined:

Concept 1

- *Preterm* and premature** were used to pick up all variations of *Preterm babies, Premature birth, Preterm Infants Extrem* preterm infants, Prematurity, Premature labour, mild preterm, very preterm, medically indicated preterm birth, preterm premature rupture of membranes, and spontaneous preterm birth*.
- *(*When the term preterm was searched using an asterisk it picked up 29 extra articles, thus the asterisk has now been added i.e. preterm*).

Concept 3

- *"Occupational therapy"* was removed from concept 3 (occupation) and added to concept 4 (interventions/disabilities).
- *Skill** was used to pick up all variations of *fine motor skills, social skills, gross motor skills*.
- Using the term s *"childhood occupation", "childhood activity", "performance component*"* and *"pre-academics"* did not influence results at all (EBSCO – May 13 2011), thus they were not used.
- 'Activit*' was added.
- The word *'preschool'* exploded the search but it was seen as important.
- '*Participat**' (participation) also yielded a large number of articles but was thought to be too vague/generic a term. The term *Environment* was removed for the same reason.
- The following terms were written with an asterisk to ensure all derivatives of the terms were picked up - *writ*, dress*, toilet*, sleep*, feed*, play*, wash.* It was decided that it was important to comprehensively search these 'childhood occupations'. (These terms added approx. 500 extra articles to the literature search).
- Bath* was also added.

Concept 4

- Other disciplines were added to this concept and some disability terms were removed. "Newborn intensive care" was omitted as it was thought that the term prematur* or preterm would be sufficient to pick up these children. The term ‘Long term care’ was also removed.

- It was thought that where abbreviations such as ‘OT ‘or ‘SLT ‘ were used in the literature the author would have initially used the traditional title such as ‘occupational therapy, thus the article would have been picked up already. However, when the abbreviations were omitted from the search 10 less articles were found, suggesting in some cases that the abbreviations were being used in isolation, thus the abbreviations were added to the key word search strategy.

Key Word Search Strategy – Phase 2

"low birth weight" OR preterm* OR prematur*

AND

Infant* OR toddler* OR child* OR paediatrics OR pediatrics

AND

Play* OR dress* OR feed* OR toilet* OR sleep* OR wash* OR bath* OR writ* OR leisure OR pre-scissors OR activit* OR skill OR Preschool OR Perception OR Hand function OR Development OR Performance components OR Attention OR Motor Planning OR Problem solving OR Attachment

AND

"occupational therapy" OR "speech and language therapy" OR physiotherapy OR psychology OR OT OR SLT OR nursing OR paediatric* OR pediatric* OR neonatolog* OR disabilit* OR handicap* ORdevelopmental OR "cerebral palsy" OR "chronic lung disease" OR neurological OR congenital malformation

Final Key Word Search Strategy – Phase 3

Concept 1- Changed the term from Low birth weight to ‘Very low birth weight’ as that is the group of children that the project will be focusing on.

Concept 2 – Added bab* - baby, babies

Concept 3 – Participat* - Was re-introduced in to search terms as the Assessment of Preschool Children’s Participation will be used for data collection. All performance components i.e. words that are not skills but components of skills were eliminated i.e. Perception OR “Hand function” OR Development OR “Performance components” OR Attention OR “Motor Planning” OR “Problem solving” OR Attachment. The term “Childhood Occupation” was added as it is the study title.

Concept 4 – The following terms were removed as this study is based on children without a diagnosed physical, intellectual or mental health disability - OR disabilit* OR handicap* OR developmental OR "cerebral palsy" OR "chronic lung disease" OR neurological OR congenital malformation

"very low birth weight" OR preterm* OR prematur*

AND

Infant* OR toddler* OR child* OR paediatrics OR pediatrics OR bab*

AND

Play* OR dress* OR feed* OR toilet* OR sleep* OR wash* OR bath* OR writ* OR leisure OR pre-scissors OR activit* OR skill OR Preschool OR Participat* OR “childhood occupation”

AND

"occupational therapy" OR "speech and language therapy" OR physiotherapy OR psychology OR OT OR SLT OR nursing OR paediatric* OR pediatric* OR neonatolog*

Additional Search Strategy – Phase 3

It was decided that the first 3 concepts would also be used with key words
e.g. "adaptive behav*"
development and follow*

"very low birth weight" OR preterm* OR prematur*

AND

Infant* OR toddler* OR child* OR paediatrics OR pediatrics OR bab*

AND

Play* OR dress* OR feed* OR toilet* OR sleep* OR wash* OR bath* OR writ* OR leisure OR pre-scissors OR activit* OR skill OR Preschool OR Participat* OR "childhood occupation"

AND

KEY WORD

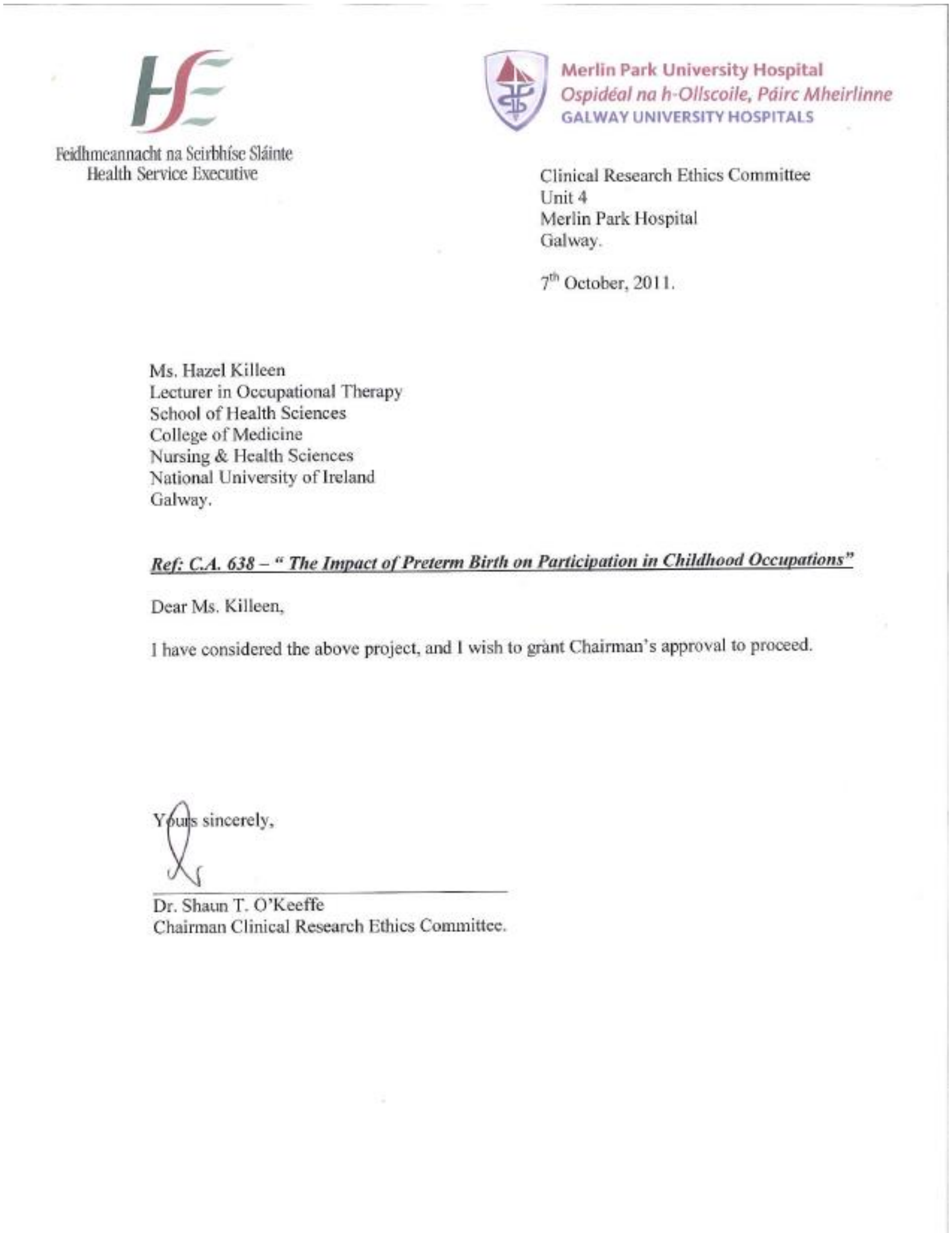
Databases Searched

The following databases were searched using:

- Key word search terms (May 2011)
- Inclusion and exclusion criteria.
- Boolean logic – AND, OR

- **EBSCO** – as a platform for MEDLINE; Academic Search Complete; CINAHL Plus with Full Text; Health Source: Nursing/Academic Edition; SocINDEX with Full Text
- **EMBASE**
- The **Cochrane Library Trials** - Cochrane Central Register of Controlled Trials (CENTRAL, The Cochrane Library - Cochrane Neonatal Review group),
- **Pubmed/Medline**
- **Grey Literature** – SIGLE (database for unpublished grey literature); RIAN; ETHos (UK);
  Proquest Digital Dissertation (Europe & US); Zetoc; Copac.
- **PsychINFO,**
- **SCOPUS**
- **OT Seeker** (randomised control trials)
- **Sciencedirect**
- **National Research Register** (NNR) - NHS
- Proquest Science Journals New Platform (Journal – Neonatology)

APPENDIX C: Letter of Ethical Approval



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Merlin Park University Hospital
Ospidéal na h-Ollscoile, Páirc Mheirlinne
GALWAY UNIVERSITY HOSPITALS

Clinical Research Ethics Committee
Unit 4
Merlin Park Hospital
Galway.

7th October, 2011.

Ms. Hazel Killeen
Lecturer in Occupational Therapy
School of Health Sciences
College of Medicine
Nursing & Health Sciences
National University of Ireland
Galway.

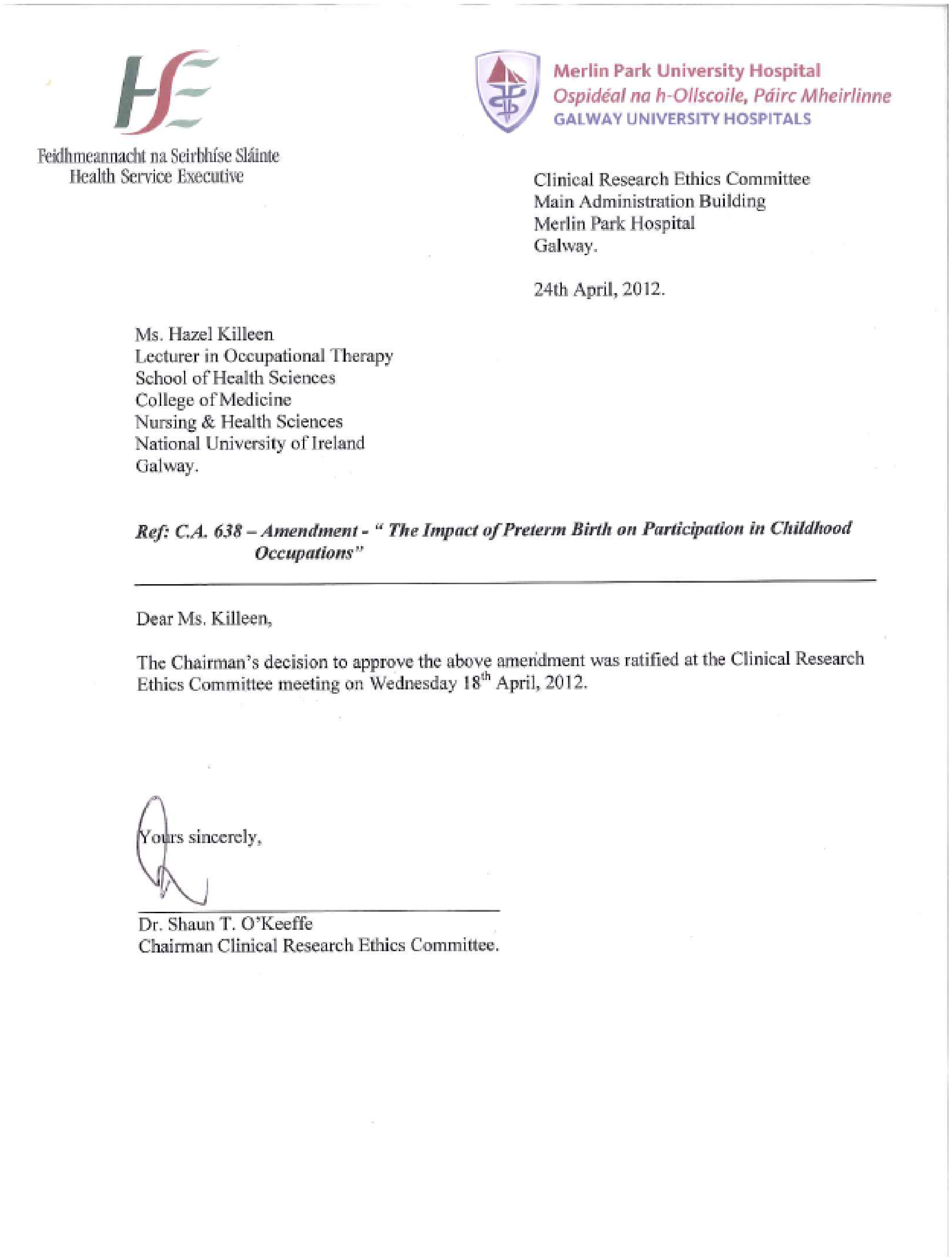
<u>Ref: C.A. 638 – " The Impact of Preterm Birth on Participation in Childhood Occupations"</u>

Dear Ms. Killeen,

I have considered the above project, and I wish to grant Chairman's approval to proceed.

Yours sincerely,

Dr. Shaun T. O'Keeffe
Chairman Clinical Research Ethics Committee.



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Merlin Park University Hospital
Ospidéal na h-Ollscoile, Páirc Mheirlinne
GALWAY UNIVERSITY HOSPITALS

Clinical Research Ethics Committee
Main Administration Building
Merlin Park Hospital
Galway.

24th April, 2012.

Ms. Hazel Killeen
Lecturer in Occupational Therapy
School of Health Sciences
College of Medicine
Nursing & Health Sciences
National University of Ireland
Galway.

Ref: C.A. 638 – Amendment - " The Impact of Preterm Birth on Participation in Childhood Occupations"

Dear Ms. Killeen,

The Chairman's decision to approve the above amendment was ratified at the Clinical Research Ethics Committee meeting on Wednesday 18th April, 2012.

Yours sincerely,

Dr. Shaun T. O'Keeffe
Chairman Clinical Research Ethics Committee.

APPENDIX D: Inclusion/Exclusion Criteria for Pilot Study Infants

Inclusion and Exclusion Criteria for Preterm Study Infants in Pilot Study

Inclusion criteria	Rationale
Parents of children born preterm (less than 37 weeks gestation) in the Neonatal Unit in Galway University Hospital between January 2006 – December 2010	The study aim was to explore the impact of preterm birth on participation in childhood occupation.
Birth weight between 401 and 1500 grams OR gestational age between 22 weeks 0 days and 29 weeks 6 days (inclusive) i.e. 'Very Low birth Weight' as defined by the Vermont Oxford Network (2011a).	The eligibility criteria for VLBW was used to ensure that the study group selected was comparable to international neonatal units, as was made possible through the VON Unit database.
who are now between the ages of Birth – 5 years 0 months	
'Healthy preterm' i.e. who do not have a documented diagnosis of physical, intellectual or mental health disability	
May attend healthcare (community or hospital) services but who do not have a diagnosis	
May be a twin	Only one child from a family can participate in study as statistically they are not seen as 'independent' participants i.e. their genetics, diet etc are similar
Exclusion criteria	**Rationale**
Family no longer live in Ireland or are not contactable at last known address	
Parents that are under 18 years of age.	
Parents who are not fluent in English.	
Parents who do not give informed consent	
Parents of children with a known diagnosis of physical or intellectual disability.	Children with diagnoses of physical or intellectual disabilities are known to present with challenges in participation in everyday activities (Chiarello, 2011). Therefore, to assess the impact of VLBW on function, in isolation of other confounding factors, this population of children will not be included.

* Text in red colour denotes differences between inclusion and exclusion criteria between pilot and main study

APPENDIX E: Consent Letter for Parents

APPENDIX F: Information Sheet for Parents of VLBW Infants

APPENDIX G: Letter of Invitation for Parents of VLBW Infants

LETTER OF INVITATION

RESEARCH STUDY ON THE ACTIVITY PATTERNS OF CHILDREN BORN PRETERM

Dear Parent,

Following ethical approval from the Galway hospital ethics committee and Dr. O'Donovan and his team, this is a generic letter that is being sent out to the families of all children born prematurely in Galway University Hospital between 2006 and 2011.

We are commencing an important research project to explore the effect, if any, that preterm birth has on young children's abilities to participate in and carry-out everyday activities such as dressing, feeding, toileting, play and handwriting. Please see the 'Information Sheet for Parents' enclosed for more details.

Our aim is to talk to parents whose child/children were born preterm. The questions that will be asked are related to your child's development and the activities your child does each day. For example, you will be asked about your child's ability to dress, feed, play, and write. We will use standardised questionnaires specific to your child's age so we can compare your child's results with other children of the same age. We will also provide you with a copy of your child's results if you so wish. The overall results of these questionnaires will help to guide the delivery of services for preterm children in Galway.

If you would like to participate in this important research project please fill in and sign the enclosed Consent form and return it to *Ms. Hazel Killeen, National University of Ireland, Galway,* in the enclosed stamped addressed envelope at your nearest convenience. We will then arrange a date to meet with you. The interview will take approximately 1 hour and can be done in the University or at your home, whichever you prefer. The questionnaires will be coded so you and your child's information will be totally confidential, as will your participation in the research. Finally, please be aware that even if you agree to take part in this important study you can change your mind and withdraw from the study at any time without explaining why.

Please do not hesitate to contact Ms. Hazel Killeen at 091-495767 or hazel.killeen@nuigalway.ie if you have any further queries regarding the research.

Thank you in advance for your time,
Sincerely,

___________________________________	___________________________________
Ms. Hazel Killeen	Dr. Donough O'Donovan
Lecturer in Occupational Therapy,	Consultant Neonatologist / Paediatrician,
College of Medicine, Nursing & Health Sciences,	University Hospital Galway (UHG),
National University of Ireland, Galway.	Galway.

APPENDIX H: Reminder Letter for Parents of VLBW Infants

REMINDER LETTER

RESEARCH STUDY ON THE ACTIVITY PATTERNS OF CHILDREN BORN PRETERM

Dear Parent,

Further to our previous correspondence, we are now commencing the research project to explore the effect, if any, that preterm birth has on young children's abilities to participate in and carry-out everyday activities such as dressing, feeding, toileting, play and handwriting.

If you have not already sent back your written consent letter and wish to partake in this research please do so as soon as possible. If you have already sent back your written consent form, we thank you.

Please don't hesitate to contact Ms. Hazel Killeen at 091-495767 or hazel.killeen@nuigalway.ie if you have any further queries regarding the research.

Thank you in advance for your time,
Sincerely,

Ms. Hazel Killeen Lecturer in Occupational Therapy, College of Medicine, Nursing and Health Sciences, National University of Ireland, Galway. 091-495767	Dr. Donough O'Donavan Consultant Neonatologist / Paediatrician University Hospital Galway.

APPENDIX I: Information Sheet for Parents of Control Infants in Postnatal Unit, UHG

APPENDIX J: Information Sheet for Parents of Control Infants in Crèche

APPENDIX K: Child and Family Demographic Questionnaire for Main Study

Child and Family Demographic Questionnaire

We would like to ask you to complete the following background questions. The questions are about your child and your family. This information will be used only to describe the group of families participating in this study. Your individual responses will not be identified in any way.

Research Participant ID: ______________________ Date: _________________

Relationship to child: ______________________ Location: ______________

---

1. How old is your child? _________________
2. What is your child's date of birth? _____/______/______
   Day Month Year
3. What is your child's gender? ○ Male ○ Female
4. What type of school setting does your child attend? **Tick all that apply**
   - ○ No school
   - ○ Preschool
   - ○ Day Care/Creche
   - ○ Other, please specify: ____
   - ○ Primary school, regular program
   - ○ Primary school, learning support
   - ○ Special Education School

MEDICAL

5. Does your child have any specific medical or health issues? ○ Yes ○ No
6. If yes, please elaborate

   ____
   ____
   ____

7. Did your child attend any health care or hospital services in the past? ○ Yes ○ No
8. If yes, please list the services and how often they were attended

   ____
   ____
   ____
   ____

Preterm Birth Research Project 2012
Ref: Hazel Killeen, National University of Ireland, Galway; Dr. Donough O'Donovan, Consultant Neonatologist, UHG.

9. Is your child currently attending any health care or hospital services? ○ Yes ○ No

10. If yes, please list the services and how often they are attended

____
____
____
____

EDUCATION

11. What is the highest level of education that you (and your child's biological father) completed? **Tick <u>one</u> level for each parent**. Answer only for yourself if you are a single parent.

	Yourself	**Your spouse/partner**
a. No formal education/training………………………………...	○	○
b. Primary education …………………………....................... NFQ Levels 1 or 2; FETAC Level 1 or 2 Cert. Or equivalent	○	○
c. Lower Secondary ………………………………...................... NFQ Level 3; Junior/Inter/Group Cert., FETAC Level 3 Cert., FAS Introductory Skills, NCVA Foundation Cert or equivalent	○	○
d. Upper Secondary …….. NFQ Levels 4 or 5; Leaving Cert (including Applied or vocational programmes) or equivalent.	○	○
e. Technical or vocational ………... NFQ Levels 4 or 5; FETAC Level 4/5 Cert.; NCVA Level1/2; FAS Specific Skills; Teagasc Cert. In Agriculture; CERT Craft Cert. or equivalent.	○	○
f. Advanced Certificate/Completed Apprenticeship ………….. NFQ Level 6; FETAC Advanced Cert; NCVA Level3; FAS National Craft Cert.; Teagasc Farming Cert.; Cert Professional Cookery Cert. or equivalent	○	○
g. Higher Certificate ………………………………...................... NFQ Level 6; NCEA/HETAC National Cert. or equivalent	○	○
h. Ordinary Bachelor Degree or National Diploma ………..... National Diploma NFQ Level 7	○	○
i. Honours Bachelor Degree ………………………………......... Professional qualification or both; NFQ Level 8	○	○
j. Postgraduate diploma or degree.. NFQ Level 9; Postgraduate Diploma, Masters Degree or equivalent	○	○
k. Doctorate (Ph.D) or higher.. NFQ Level 10	○	○

12. What language is spoken most often at home? **Tick <u>one</u> only**.

○ English
○ Other, please specify: ____________________________

OCCUPATION

13. What do you consider to be your current main activity? **Tick <u>one</u> only**.

○ Looking after home/family
○ Working full-time for pay or profit
○ Working part-time for pay or profit
○ Caring for family and working for pay or profit
○ Caring for a family and studying
○ Unable to work due to permanent sickness/disability
○ Other, please specify: ____
○ Recovering from illness or disability
○ Looking for first regular job
○ Unemployed
○ Retired from employment
○ Student or pupil

14. What is (was) your occupation in your main job?

Your occupation ________________ Occupation of Child's father _______________

ETHNICITY

15. What is your ethnic or cultural background? **Tick <u>one</u> only.**

	Yourself	Your spouse
<u>White</u>		
Irish	☐	☐
Irish Traveller	☐	☐
Any other white background	☐	☐
<u>Black or Black Irish</u>		
African	☐	☐
Any other Black background	☐	☐
<u>Asian or Asian Irish</u>		
Chinese	☐	☐
Any other Asian background	☐	☐

<u>Other, including mixed background</u>

Other, write in description: ____

SOCIAL

16. Is your family a one or two parent household (two parents are living in the same house)?

○ Single-parent household ○ Two-parent household

17. Please tick which of the following applies to your home:

○ Flat/Apartment ○ House ○ Caravan or other mobile or temporary structure

18. Please tick which of the following are within walking distance of your house?

○ Friend's back yard ○ Park ○ Playground ○ Green area in front of house

19. What age was the mother at time of birth? __________ years ○ Don't know

20. What age was the father at time of birth? __________ years ○ Don't know

21. How many siblings does your child have (living in same home)? _______________

22. Where does this child come in the order of your children? ________________

23. Please tick, if you engaged in any of the following during pregnancy?

Smoking cigarettes	○ Yes ○ No	If yes,	Once	a few times	____	(per week)
Drinking alcohol	○ Yes ○ No	If yes,	Once	a few times	____	(per week)
Non-prescription medication	○ Yes ○ No	If yes,	Once	a few times	____	(per week)

24. Did you experience any health issues, at any stage, before, during or after pregnancy?

Mental health (e.g. depression) ○ Yes ○ No
If yes, please specify: ____

Physical health (e.g. diabetes) ○ Yes ○ No
If yes, please specify: ____

Other: __________________ ○ Yes ○ No
If yes, please specify: ____

25. Are you interested in participating in further research? ○ Yes ○ No

Please note: This questionnaire includes a number of questions from the Census Form 2011, Ireland, and from Canchild's 'Child and family Demographic questionnaire, McMaster University, Canada.

APPENDIX L: Copy of CANCHILD'S 'Child and Family Demographics' Form

(Used with permission of Professor Mary Law, Co-founder, Canchild, McMaster University, Canada)

Child and Family Demographics

We would like to ask you to complete the following background questions. The questions are about your child with a health or development condition and about your family. This information will be used only to describe the group of families participating in this study. Your individual responses will not be identified in any way.

Please fill out what time you started this questionnaire:

1. How old is your child with a health or development condition?
____ years

2. What is your child's sex?
○ Male ○ Female

3. What is your child's date of birth?

_____/______/______
Day Month Year

4. What is your child's <u>current</u> **primary** health or development condition? **Check <u>one</u> only**.

○ Acquired brain injury
○ Autism/Pervasive Developmental Disorder
○ Cerebral palsy
○ Communication disorder
○ Developmental Coordination Disorder
○ Developmental Delay
○ Muscle Disease
○ Spina Bifida/Hydrocephalus
○ Syndrome, please specify:

○ Other, please specify:

5. Overall, how would you rank the severity of your child's condition or problem? Please mark an X on the line below

1= Mild; 10= Severe

2 3 4 5 6 7 8 9

1 10

6. How old was your child when the health or development condition was first diagnosed?
Check <u>one</u> only.
○ Before birth
○ 24 to 35 months old (2 yrs. old)

○ Immediately at birth
○ Before 12 months
○ 12 to 23 months (1 yr. old)
○ 3 - 4 years old
○ 5 - 6 years or older

7. In what type of community do you live? **Check <u>one</u> only.**
   ○ Large metropolitan (population over 1,000,000)
   ○ Medium metropolitan (population 250,000 – 999,999)
   ○ Small metropolitan (population 50,000 – 249,999)
   ○ Non-metro, small city or town (population 20,000 – 49,999)
   ○ Non-metro, small town (population 2,500 – 19,999)
   ○ Rural area (population less than 2,500)

8. What is your postal code?__ __ __ __ __ __

9. What language is spoken most often at home? **Check <u>one</u> only**.
   ○ English
   ○ French
   ○ Other, please specify: ____________________________

10. How many children are in your family? ______

11. How many children do you have with a health or development condition? _______

12. How many children in your family are currently living at home (including your child with a health or development condition)? ______

13. Please indicate if you are a two parent (parents living together in the same house) or a single parent family. **Check <u>one</u> only.**
   ○ Two parent family
   ○ Single parent family

14. What is <u>your</u> relationship to the child with a health or development problem? **Check <u>one</u> only.**

○	Natural mother	○	Adoptive mother
○	Natural father	○	Adoptive father
○	Stepmother	○	Other guardian, please specify:
○	Stepfather		

15. Please check the category that includes your age.
- ○ Under 20 years
- ○ 20 - 34 years
- ○ 35 - 49 years
- ○ 50 - 64 years
- ○ 65 or over

16. What is the highest level of education that you (and your spouse) completed? **Check <u>one</u> level for each parent**. Answer only for yourself if you are a single parent.

EDUCATION	**Yourself**	**Your spouse/partner**
a. No schooling…………………………………………………...	○	○
b. Elementary school (grades 1-8)……………………………....	○	○
c. Some high school (grades 9-11)…………………………….	○	○
d. Completed high school (grade 12 or 13)……………………	○	○
e. Some college or technical training (at least 1 year)………..	○	○
f. Completed college or technical training……………………...	○	○
g. Some university (at least 1 year)…………………………….	○	○
h. Completed university degree…………………………………	○	○

17. What do you consider to be your current main activity? **Check <u>one</u> only**.
- ○ Caring for family
- ○ Working full-time for pay or profit
- ○ Working part-time for pay or profit
- ○ Caring for family and working for pay or profit
- ○ Recovering from illness or disability
- ○ Looking for work
- ○ Going to school
- ○ Retired
- ○ Other, please specify: ____________________________

and from Canchild's 'Child and family Demographic questionnaire, McMaster University, Canada.

18. What is this child's ethnic background? This information will tell us whether all the ethnic backgrounds of families currently living in Ontario are represented in this study. Your responses to this question will not be discussed individually but will be reported as a summary for the entire group. We appreciate your sharing this with us. **You may mark more than one if applicable.**

ETHNICITY	**Yourself**	**Your spouse/ partner**
White	☐	☐
Chinese	☐	☐
South Asian (e.g., East Indian, Pakistani, Punjabi, Sri Lankan)	☐	☐
Black (e.g. African, Jamaican, Somali)	☐	☐
Arab/West Asian (e.g., Armenian, Egyptian, Iranian, Lebanese, Moroccan)	☐	☐
Filipino	☐	☐
South East Asian (e.g., Cambodian, Indonesian, Laotian, Vietnamese)	☐	☐
Latin-American	☐	☐
Japanese	☐	☐
Korean	☐	☐
North American Indian	☐	☐
Métis	☐	☐
Inuit (Eskimo)	☐	☐
Other, please specify: ___________________________	☐	☐

This question has been adapted from the Statistics Canada 1996 Census survey.

19. Which category listed below represents your total family income before taxes? Please include income from sources such as wages, salaries, commissions, pensions, family allowance, rental income, and so forth. **Check <u>one</u> only.**

○ Less than $15,000
○ $15,000 to $29,999
○ $30,000 to $44,999
○ $45,000 to $59,999
○ $60,000 to $74,999
○ $75,000 to $89,000
○ More than $90,000

20. What type of school setting does your child attend? **Check <u>all</u> that apply**

○ No school
○ Preschool
○ Day Care
○ Regular school, regular program
○ Reg. school, special education program
○ Special Education School
○ Other, please specify:
____

and from Canchild's 'Child and family Demographic questionnaire, McMaster University, Canada.

21. Overall, how challenging do you find traveling to and from your child's treatment centre? Please mark an X on the line below

1= Not challenging 10 = Very Challenging

2 3 4 5 6 7 8 9

1 10

and from Canchild's 'Child and family Demographic questionnaire, McMaster University, Canada.

APPENDIX M: Ratio of Males to Females in Age Categories

Table 72 Ratio of males to females in age categories

AGE RANGE	CONTROL GROUP (Male : Female)	VLBW Group (Male : Female)
6 -12 months	3:0	3:0
1 year	7:4	8:4
2 years	7:4	3:4
3 years	6:7	4:5
4 years	5:6	3:7
5 years – 5 years 8 months	1:1	2:1
Total Male : Female	29:22	23:21

APPENDIX N: Levene’s Test for Equality of Population Variances for Control & VLBW group – ABAS-II Composite Scores

Independent Samples t-tests and Levene's Test for Equality of Variances for Control and VLBW group – ABAS-II Composite Scores

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
ABAS-II GAC Composite	Equal variances assumed	4.610	.034	4.978	93	.000	13.624	2.737	8.189	19.059
	Equal variances not assumed			4.891	81.156	.000	13.624	2.786	8.081	19.166
Conceptual Composite	Equal variances assumed	3.572	.062	3.800	93	.000	10.740	2.826	5.128	16.352
	Equal variances not assumed			3.725	79.531	.000	10.740	2.883	5.002	16.478
Social Composite	Equal variances assumed	.468	.496	5.018	93	.000	13.298	2.650	8.035	18.561
	Equal variances not assumed			4.977	87.219	.000	13.298	2.672	7.987	18.608
Practical Composite	Equal variances assumed	1.121	.292	4.890	93	.000	12.304	2.516	7.307	17.300
	Equal variances not assumed			4.834	85.174	.000	12.304	2.545	7.243	17.365

APPENDIX O: Levene's Test for Equality of Population Variances for Control & VLBW-COR group – ABAS-II Composite Scores

Independent Samples t-tests and Levene's Test for Equality of Variances for Control and VLBW-COR Group – Composite Scores

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
ABAS-II GAC Composite	Equal variances assumed	2.525	.115	2.521	93	.013	6.601	2.619	1.401	11.802
	Equal variances not assumed			2.490	84.878	.015	6.601	2.651	1.331	11.872
Conceptual Composite	Equal variances assumed	3.172	.078	1.461	93	.147	4.058	2.778	-1.458	9.574
	Equal variances not assumed			1.435	80.979	.155	4.058	2.828	-1.568	9.685
Social Composite	Equal variances assumed	.290	.592	3.299	93	.001	8.480	2.570	3.376	13.583
	Equal variances not assumed			3.287	89.508	.001	8.480	2.579	3.355	13.604
Practical Composite	Equal variances assumed	2.038	.157	2.662	93	.009	6.713	2.522	1.705	11.721
	Equal variances not assumed			2.630	84.975	.010	6.713	2.552	1.638	11.788

APPENDIX P: Levene's Test for Equality of Population Variances for Control & VLBW group - ABAS-II Skill Area Scores

Independent Samples t-tests and Levene's Test for Equality of Variances of Control group and VLBW group – Skill Areas

ABAS-II Skill Areas Scaled Scores		Levene's Test for Equal. of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% CI of the Difference	
									Lower	Upper
Communication	Equal variances assumed	5.012	.028	3.534	93	.001	1.768	.500	.775	2.762
	Equal variances not assumed			3.452	76.879	.001	1.768	.512	.748	2.788
Community Use	Equal variances assumed	.516	.474	2.828	87	.006	1.690	.597	.502	2.877
	Equal variances not assumed			2.851	86.691	.005	1.690	.593	.512	2.868
Pre-Academics	Equal variances assumed	.449	.505	2.920	87	.004	1.489	.510	.475	2.503
	Equal variances not assumed			2.879	78.289	.005	1.489	.517	.459	2.519
Home Living	Equal variances assumed	1.170	.282	4.925	87	.000	2.858	.580	1.704	4.011
	Equal variances not assumed			4.857	78.360	.000	2.858	.588	1.686	4.029
Health & Safety	Equal variances assumed	2.336	.130	3.819	93	.000	1.797	.470	.863	2.731
	Equal variances not assumed			3.759	82.306	.000	1.797	.478	.846	2.748
Leisure	Equal variances assumed	.267	.607	4.667	93	.000	2.268	.486	1.303	3.233
	Equal variances not assumed			4.689	92.303	.000	2.268	.484	1.308	3.229
Self-care	Equal variances assumed	.070	.791	3.134	93	.002	1.345	.429	.493	2.198
	Equal variances not assumed			3.126	90.007	.002	1.345	.430	.490	2.200
Self-Direction	Equal variances assumed	.285	.594	2.502	93	.014	1.665	.666	.344	2.987
	Equal variances not assumed			2.499	90.556	.014	1.665	.666	.342	2.989
Social	Equal variances assumed	1.458	.230	4.229	93	.000	2.228	.527	1.182	3.274
	Equal variances not assumed			4.181	85.186	.000	2.228	.533	1.169	3.288
Motor	Equal variances assumed	.000	.987	2.659	93	.009	1.695	.638	.429	2.961
	Equal variances not assumed			2.656	90.644	.009	1.695	.638	.428	2.963

APPENDIX Q: Levene's Test for Equality of Population Variances for Control & VLBW-COR group– ABAS-II Skill Area Scores

Independent Samples t-tests and Levene's Test for Equality of Variances for Control and VLBW-COR Group – Skill Areas

ABAS-II Skill Areas Scaled Scores		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% CI of the Difference	
									Lower	Upper
Communication	Equal variances assumed	5.921	.017	1.547	93	.125	.791	.511	-.224	1.806
	Equal variances not assumed			1.508	75.195	.136	.791	.525	-.254	1.836
Community Use	Equal variances assumed	1.295	.258	1.319	86	.191	.779	.591	-.396	1.954
	Equal variances not assumed			1.336	85.872	.185	.779	.583	-.380	1.938
Pre-Academics	Equal variances assumed	.622	.432	.702	86	.485	.363	.516	-.664	1.389
	Equal variances not assumed			.690	75.680	.492	.363	.525	-.684	1.409
Home Living	Equal variances assumed	.015	.901	3.827	86	.000	2.133	.557	1.025	3.241
	Equal variances not assumed			3.796	80.042	.000	2.133	.562	1.015	3.252
Health & Safety	Equal variances assumed	4.338	.040	1.809	93	.074	.865	.478	-.085	1.815
	Equal variances not assumed			1.776	80.915	.079	.865	.487	-.104	1.834
Leisure	Equal variances assumed	.016	.898	2.919	93	.004	1.450	.497	.464	2.437
	Equal variances not assumed			2.922	91.301	.004	1.450	.496	.464	2.436
Self-care	Equal variances assumed	.773	.382	1.022	93	.309	.459	.449	-.432	1.350
	Equal variances not assumed			1.013	86.695	.314	.459	.453	-.441	1.359
Self-Direction	Equal variances assumed	.003	.958	1.239	93	.218	.802	.647	-.483	2.087
	Equal variances not assumed			1.243	92.035	.217	.802	.645	-.479	2.082
Social	Equal variances assumed	.424	.517	2.845	93	.005	1.433	.504	.433	2.433
	Equal variances not assumed			2.830	88.745	.006	1.433	.506	.427	2.439
Motor	Equal variances assumed	.001	.973	1.025	93	.308	.650	.634	-.610	1.909
	Equal variances not assumed			1.025	90.961	.308	.650	.634	-.610	1.909

APPENDIX R: Levene's Test for Equality of Population Variances for Males & Females in Control group - ABAS-II Composite & Skill Area Scores

Independent Samples t-tests and Levene’s Test of Equality of Variances for Male & Females in Control group - ABAS-II Composite Scores

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
ABAS-II GAC Composite	Equal variances assumed	6.449	.014	-1.625	49	.111	-5.298	3.261	-11.851	1.255
	Equal variances not assumed			-1.757	44.509	.086	-5.298	3.015	-11.373	.777
Conceptual Composite	Equal variances assumed	3.239	.078	-1.226	49	.226	-4.094	3.340	-10.805	2.617
	Equal variances not assumed			-1.301	47.738	.200	-4.094	3.147	-10.423	2.235
Social Composite	Equal variances assumed	3.431	.070	-1.173	49	.247	-4.033	3.438	-10.943	2.877
	Equal variances not assumed			-1.233	48.591	.223	-4.033	3.270	-10.605	2.539
Practical Composite	Equal variances assumed	5.105	.028	-1.798	49	.078	-5.621	3.126	-11.903	.662
	Equal variances not assumed			-1.890	48.611	.065	-5.621	2.974	-11.598	.356

Independent Samples t-tests and Levene's Test of Equality of Variances of Males and Females in Control group – ABAS-II Skill Areas

ABAS-II Skill Area Scaled Scores		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% CI of the Difference	
									Lower	Upper
Communication	Equal variances assumed	.328	.570	-.013	49	.989	-.008	.581	-1.176	1.160
	Equal variances not assumed			-.014	47.410	.989	-.008	.573	-1.160	1.145
Community	Equal variances assumed	.238	.628	-1.682	46	.099	-1.402	.834	-3.080	.276
	Equal variances not assumed			-1.687	45.214	.098	-1.402	.831	-3.076	.271
Pre-Academics	Equal variances assumed	1.425	.239	-.607	46	.547	-.388	.639	-1.675	.899
	Equal variances not assumed			-.615	45.982	.542	-.388	.631	-1.659	.882
Home Living	Equal variances assumed	2.961	.092	-2.126	46	.039	-1.483	.697	-2.886	-.079
	Equal variances not assumed			-2.172	45.668	.035	-1.483	.682	-2.856	-.109
Health & Safety	Equal variances assumed	4.242	.045	-.477	49	.636	-.277	.582	-1.447	.892
	Equal variances not assumed			-.510	46.426	.612	-.277	.544	-1.371	.816
Leisure	Equal variances assumed	2.835	.099	-.357	49	.722	-.248	.693	-1.640	1.145
	Equal variances not assumed			-.375	48.762	.709	-.248	.661	-1.575	1.080
Self-care	Equal variances assumed	.029	.866	.560	49	.578	.328	.585	-.848	1.503
	Equal variances not assumed			.568	47.458	.573	.328	.576	-.832	1.487
Self-Direction	Equal variances assumed	3.300	.075	-1.786	49	.080	-1.588	.889	-3.374	.199
	Equal variances not assumed			-1.888	48.154	.065	-1.588	.841	-3.278	.103
Social	Equal variances assumed	.579	.450	-1.573	49	.122	-1.038	.659	-2.363	.288
	Equal variances not assumed			-1.608	48.242	.114	-1.038	.645	-2.335	.260
Motor	Equal variances assumed	.059	.809	-.889	49	.379	-.776	.873	-2.530	.979
	Equal variances not assumed			-.877	43.025	.385	-.776	.884	-2.559	1.008

APPENDIX S: Levene’s Test for Equality of Population Variances for Males & Females in VLBW group - ABAS-II Composite & Skill Area Scores

Independent Samples t-tests and Levene's Test for Equality of Variance for Males and Females in VLBW group – ABAS-II Composite Scores

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
ABAS-II GAC Composite	Equal variances assumed	2.227	.143	-1.083	42	.285	-4.870	4.497	-13.945	4.206
	Equal variances not assumed			-1.075	39.672	.289	-4.870	4.529	-14.025	4.286
Conceptual Composite	Equal variances assumed	1.760	.192	-1.830	42	.074	-8.404	4.592	-17.671	.864
	Equal variances not assumed			-1.809	37.773	.078	-8.404	4.645	-17.808	1.001
Social Composite	Equal variances assumed	.698	.408	-.561	42	.577	-2.327	4.145	-10.691	6.037
	Equal variances not assumed			-.559	40.461	.579	-2.327	4.164	-10.741	6.086
Practical Composite	Equal variances assumed	.006	.938	-.899	42	.374	-3.598	4.001	-11.672	4.475
	Equal variances not assumed			-.900	41.708	.373	-3.598	3.999	-11.670	4.473

Independent Samples t-tests and Levene’s Test for Equality of Variance for Males and Females in VLBW group – ABAS-II Skill Areas

ABAS-II Skill Areas Scaled Scores		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Communication	Equal variances assumed	.056	.813	-1.815	42	.077	-1.507	.830	-3.183	.169
	Equal variances not assumed			-1.821	41.974	.076	-1.507	.828	-3.178	.163
Community Use	Equal variances assumed	1.433	.239	-.618	39	.540	-.517	.836	-2.208	1.174
	Equal variances not assumed			-.621	38.155	.538	-.517	.832	-2.200	1.167
Pre-Academics	Equal variances assumed	9.263	.004	-1.256	39	.216	-1.021	.813	-2.666	.623
	Equal variances not assumed			-1.275	29.776	.212	-1.021	.801	-2.658	.615
Home Living	Equal variances assumed	1.019	.319	-1.106	39	.276	-1.026	.928	-2.904	.851
	Equal variances not assumed			-1.100	36.849	.278	-1.026	.933	-2.916	.864
Health & Safety	Equal variances assumed	.592	.446	-.224	42	.824	-.174	.776	-1.739	1.391
	Equal variances not assumed			-.224	41.072	.824	-.174	.778	-1.744	1.396
Leisure	Equal variances assumed	.560	.459	.519	42	.607	.360	.695	-1.042	1.762
	Equal variances not assumed			.515	40.006	.609	.360	.699	-1.052	1.773
Self-care	Equal variances assumed	.010	.922	-.400	42	.691	-.259	.647	-1.565	1.047
	Equal variances not assumed			-.397	39.908	.693	-.259	.651	-1.575	1.058
Self-Direction	Equal variances assumed	.043	.836	-1.582	42	.121	-1.530	.967	-3.482	.422
	Equal variances not assumed			-1.584	41.813	.121	-1.530	.966	-3.480	.420
Social	Equal variances assumed	.107	.746	-1.424	42	.162	-1.176	.826	-2.843	.491
	Equal variances not assumed			-1.421	41.184	.163	-1.176	.828	-2.847	.495
Motor	Equal variances assumed	.123	.728	.061	42	.952	.058	.952	-1.864	1.980
	Equal variances not assumed			.061	40.001	.952	.058	.958	-1.879	1.995

APPENDIX T: Levene's Test for Equality of Population Variances for Control and VLBW group – APCP Intensity of Participation Scores

Independent Samples t-tests and Levene’s Test for Equality of Variance for Control and VLBW group – APCP Intensity Scores

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Intensity of Skill Development	Equal variances assumed	.330	.568	.290	63	.773	.07450	.25704	-.43916	.58816
	Equal variances not assumed			.294	62.361	.770	.07450	.25375	-.43267	.58167
Intensity of Social Activities	Equal variances assumed	.092	.762	-.973	63	.334	-.13439	.13809	-.41034	.14156
	Equal variances not assumed			-.972	59.883	.335	-.13439	.13821	-.41086	.14209
Intensity of Active Physical Recreation	Equal variances assumed	2.482	.120	.635	63	.528	.14185	.22337	-.30452	.58822
	Equal variances not assumed			.659	62.020	.512	.14185	.21533	-.28858	.57228
Intensity of Play	Equal variances assumed	.105	.747	.441	63	.661	.07043	.15982	-.24893	.38980
	Equal variances not assumed			.441	60.079	.661	.07043	.15982	-.24925	.39012

APPENDIX U: Levene's Test for Equality of Population Variances for Males and Females in Overall Sample, Control & VLBW group – APCP Intensity of Participation Scores

Independent Samples t-tests and Levene's test for Equality of Variance for Overall Males (N=30) and Females (N=35) in APCP Intensity of Participation Scores

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Intensity of Skill Development	Equal variances assumed	.381	.539	-1.656	63	.103	-.25873	.15624	-.57095	.05349
	Equal variances not assumed			-1.643	59.152	.106	-.25873	.15746	-.57379	.05633
Intensity of Social Activities	Equal variances assumed	.102	.751	-4.064	63	.000	-.80823	.19889	-1.20568	-.41077
	Equal variances not assumed			-4.057	61.105	.000	-.80823	.19919	-1.20653	-.40992
Intensity of Active Physical Recreation	Equal variances assumed	.698	.406	-1.600	63	.115	-.21762	.13599	-.48937	.05414
	Equal variances not assumed			-1.576	56.188	.121	-.21762	.13808	-.49420	.05896
Intensity of Play	Equal variances assumed	2.180	.145	-3.201	63	.002	-.76138	.23787	-1.23671	-.28604
	Equal variances not assumed			-3.153	56.218	.003	-.76138	.24150	-1.24512	-.27764

Independent Samples t-tests and Levene's test for Equality of Variance for Males (N=18) and Females (N=18) in control group - APCP Intensity of Participation Scores

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Intensity of Skill Development	Equal variances assumed	.207	.652	-2.298	34	.028	-.46296	.20151	-.87247	-.05345
	Equal variances not assumed			-2.298	33.735	.028	-.46296	.20151	-.87259	-.05334
Intensity of Social Activities	Equal variances assumed	.038	.847	-5.097	34	.000	-1.31818	.25862	-1.84377	-.79260
	Equal variances not assumed			-5.097	33.584	.000	-1.31818	.25862	-1.84401	-.79236
Intensity of Active Physical Recreation	Equal variances assumed	.443	.510	-1.508	34	.141	-.27222	.18056	-.63916	.09472
	Equal variances not assumed			-1.508	33.410	.141	-.27222	.18056	-.63940	.09496
Intensity of Play	Equal variances assumed	5.545	.024	-4.135	34	.000	-1.23457	.29854	-1.84128	-.62786
	Equal variances not assumed			-4.135	29.022	.000	-1.23457	.29854	-1.84513	-.62400

Independent Samples t-tests and Levene’s test for Equality of Variance for Males and Females in VLBW group - APCP Intensity of Participation Scores

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Intensity of Skill Development	Equal variances assumed	.005	.946	-.064	27	.950	-.01569	.24595	-.52033	.48896
	Equal variances not assumed			-.062	20.892	.951	-.01569	.25422	-.54454	.51317
Intensity of Social Activities	Equal variances assumed	.006	.937	-.724	27	.475	-.19742	.27254	-.75662	.36179
	Equal variances not assumed			-.712	22.392	.484	-.19742	.27708	-.77147	.37663
Intensity of Active Physical Recreation	Equal variances assumed	.175	.679	-.589	27	.560	-.12500	.21208	-.56015	.31015
	Equal variances not assumed			-.563	19.770	.580	-.12500	.22198	-.58839	.33839
Intensity of Play	Equal variances assumed	.202	.657	-.500	27	.621	-.18355	.36734	-.93727	.57017
	Equal variances not assumed			-.492	22.532	.627	-.18355	.37288	-.95580	.58870

APPENDIX V: Levene's Test for Equality of Population Variances for Overall Sample, Control and VLBW group – APCP Diversity of Participation Scores

Independent Sample t-tests and Levene’s Test for Equality of Variance for All Males and Females in Study – APCP Diversity of Participation Scores

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
APCP Diversity of Participation	Equal variances assumed	3.254	.076	-3.069	63	.003	-3.67619	1.19798	-6.07017	-1.28221
	Equal variances not assumed			-2.996	52.199	.004	-3.67619	1.22699	-6.13809	-1.21429

Independent Sample t-tests and Levene's Test for Equality of Variance for Males and Females in Control group – APCP Diversit of Participation Scores

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	T	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
APCP Diversity of Participation	Equal variances assumed	5.446	.026	-4.738	34	.000	-6.66667	1.40714	-9.52631	-3.80702
	Equal variances not assumed			-4.738	28.621	.000	-6.66667	1.40714	-9.54624	-3.78710

Independent Sample t-tests and Levene’s Test for Equality of Variance for Males and Females in VLBW group – APCP Diversity of Participation Scores

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	T	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
APCP Diversity of Participation	Equal variances assumed	.279	.602	.070	27	.944	.13235	1.88101	-3.72716	3.99187
	Equal variances not assumed			.067	19.342	.947	.13235	1.97847	-4.00368	4.26839

APPENDIX W: STROBE Statement (Vandenbroucke et al, 2007)

Available at: http://www.strobe-statement.org/?id=available-checklists

APPENDIX W: Research Newsletter for Parents of VLBW Infants who participated in the Study

RESEARCH NEWSLETTER

The Activity Patterns of Children Born Preterm - September 2014

THANK YOU

We would like to thank all the families who participated in the research study on the everyday life skills of children born preterm.

The purpose of this newsletter is to update you on our research findings, as we had promised.

NEED FOR THIS STUDY

As you may know, most babies are born at full term or at '40 weeks gestation'. When a baby is born before they reach 37 weeks gestation they are described as being born 'preterm'. To date, only a very small number of research studies have looked at the impact that preterm birth has on a child's ability to become Independent in everyday activities such as feeding, dressing, toileting and play.

PROJECT AIMS

This study 'The Activity Patterns of Children Born Preterm' involved 44 children who were born preterm (< 30 weeks or <1500 grams in weight) at Galway University Hospital, and are now between 6 months – 5 years 6 months of age. Their ability to participate in and carry out age-appropriate, everyday activities such as playing, dressing, and toileting was compared to 51 children the same age and sex who were born full term.

REMEMBER!

AS THE TOTAL NUMBER OF CHILDREN INVOLVED IN THE STUDY WAS 95, THE RESULTS MUST BE INTERPRETED WITH CAUTION. THE QUESTIONNAIRE USED IN THIS STUDY WAS ALSO DEVELOPED FOR NORTH AMERICAN CHILDREN THEREFORE MAY BE LESS ACCURATE FOR IRISH CHILDREN.

MAIN RESEARCH FINDINGS OF THIS STUDY

Children in this study, born preterm appear to be involved in the same level of activities as the children that were born full term. The amount of time and the types of play, skill development, physical recreation and social activities that the preterm and full term children participate in is the same.

Although there were a range of scores, as a group, children born preterm appeared to experience some more challenges with everyday tasks (Adaptive Behaviours) compared to children born at full term. Their best scores from the parent questionnaire were in relation to communication, understanding their community and self-direction. They scored lower in Home living (helping in the home, putting away toys etc.), plays skills and interacting with others.

When compared to North American children, the Irish children (both preterm and full term) were reported to have better social skills while the North American children appeared to have better Independence skills in feeding, dressing, and toileting.

The Activity Patterns of Children Born Preterm *September 2014*

TOP TIPS FOR PARENTS – HELPING YOUR CHILD TO BE MORE INDEPENDENT

Be a Detective

- Watch how much your child helps with his/her own dressing, washing and feeding. Does he/she help at meal times e.g. by setting the table, clearing off plates or preparing simple snacks with adults? Or help make and pack his/her lunch for crèche/preschool? Or tidy up his/her toys or put wasted paper in the bin?

  Then ask yourself ………. Could I encourage my child to get more actively involved at home?

Practice and Routine

- Which daily tasks will you focus on? Skills are learned in developmental stages so break down the task into small steps, starting with easier tasks and building on these. For example, with dressing it is easier for a child to learn to take off most parts of clothing before learning to put them on. The best way to learn any new movement based task is PRACTICE, PRACTICE, PRACTICE! Therefore try to build the new tasks into your child's daily routine.

Keeping Motivated

- Setting goals can be a great motivation. Make a 'Chore' or daily routine chart. Place a star on the chart each time the child follows the routine/succeeds. 5 stars may deserve a little treat. Here is a website that has charts you can download: http://www.kidpointz.com/printable-charts/sticker-charts/

  Motivations tips: http://www.nasponline.org/resources/home_school/earlychildmotiv_ho.aspx

- Be fair to yourself and your child. Add tasks to the daily routine in small parts and leave learning of harder skills to the weekend or days when you know you will have more time. Slow and steady is the best plan! Backward chaining is a great strategy for teaching your child new skills. With this method you ask your child to do the last step of the task. For example, if you are teaching your child to button, you may start by fastening the first four buttons yourself and asking your child to close the last one, giving him/her a sense of achievement. You can find a whole workbook on Backward chaining for dressing at http://www.canchild.ca/en/canchildresources/resources/chaining.pdf

Remember

The Independence skills your child learns at home will also help strengthen his/her hands for handwriting, teach them attention and organisational skills necessary for doing homework, and teach them about the teamwork that is required for friendships.

Again, thank you for your time.

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