THE CHARACTERISTICS AND COMMUNITY-BASED PARTICIPATION OF CHILDREN WITH DISABILITIES AGED 10-12 YEARS IN THE UNITED KINGDOM

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ABSTRACT

Introduction: Participation is a key therapy and health promotion outcome for children with disabilities. This thesis contributes to childhood disability participation literature by (a) synthesizing evidence on family factors consistently associated with the participation of children with disabilities, (b) providing evidence on characteristics, family circumstances and community-based participation of a nationally representative sample of children with and without disabilities, and (c) identifying factors associated with participation frequency of children with disabilities in community-based social and physical activities.

Methods: A systematic review focusing on family factors consistently associated with participation was completed. This was followed by a quantitative analysis of data from the fifth sweep of the Millennium Cohort Study (MCS5) (2012-2013) which supplied evidence on 1,073 children with disabilities and 11,122 children without disabilities aged 10-12 in the United Kingdom. Chi-squared and logistic regression analyses were used.

Results: Thirty studies included in the review provided evidence on non-modifiable family "status" factors and modifiable family "process" factors. "Status" factors consistently associated with participation were parental ethnicity, parental education, family type and family socio-economic status. Family "process" factors with consistent associations were parental mental and physical health functioning, parental self-efficacy beliefs, parental support, parental time, family preferences, and activity orientation. Quantitative data suggested that children with disabilities were more likely to be boys, have psychosocial and behavioural problems, live in single-parent households and have a parent with a longstanding illness compared to peers without disabilities. They also had greater restriction in community-based participation, especially in social and physical activities. Child psychosocial and behavioural problems, ethnicity, parental education, family income, parental physical activity, parental play of physically active games with a child and parental social support had independent effects on participation frequency of children with disabilities in social and physical activities.

Conclusion: Support services for children with disabilities and their families should be strengthened. Interventions targeting child psychosocial and behavioural functioning and immediate social environment are required to promote children's participation in community-based social and physical activities. Revisions to the "immediate family" component of the WHO's conceptual framework for functioning, disability and health of children and youth are proposed.

Keywords: children, disability, characteristics, participation, family factors, environment, community activities

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LIST OF ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
ASN	Additional Support Needs
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
DDA	Disability Discrimination Act
DWP	Department of Work and Pension
EA	Equality Act
FRS	Family Recourses Survey
GOV.UK	Government of the United Kingdom
GTF	Getting together with friends
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health for Children &Youth
MCS	Millennium Cohort Study
MAR	Missing at random
MCAR	Missing completely at random
MNAR	Missing not at random
OPHA	Organized physical activities
PRISMA	Preferred reporting items for systematic reviews
PROSPERO	Prospective register of systematic reviews
SDG	Sustainable Development Goal
SEN	Special Educational Needs
SDQ	Strengths and Difficulties Questionnaire
UN	United Nations
UNICEF	United Nations Children's Fund
UK	United Kingdom
UPHA	Unstructured physical activities
US	United States
WHO	World Health Organization

LIST OF PUBLICATIONS FROM THIS THESIS

ARAKELYAN, S., MACIVER, D., RUSH, R., O'HARE, A. and FORSYTH, K., 2019. The community-based participation of children with and without disabilities. *Developmental Medicine and Child Neurology.* vol. 62, no. 4, pp. 445-453.

ARAKELYAN, S., MACIVER, D., RUSH, R., O'HARE, A. and FORSYTH, K., 2019. Family factors associated with participation of children with disabilities: a systematic review. *Developmental Medicine and Child Neurology*. vol. 61, no. 5, pp. 514-522.

A NOTE ABOUT LANGUAGE

Throughout this research person-first language (i.e. a noun referring to a person or persons precedes a phrase referring to disability) is used when describing children with disabilities. The Guidelines for Reporting and Writing about People with Disabilities (2014) were consulted at every stage of writing process to ensure children with disabilities are portrayed in a respectful way, and the language used to describe them is accurate, neutral and objective.

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CHAPTER 1 – INTRODUCTION

1.1 Introduction

Childhood disability is a global health priority (Houtrow et al. 2014). Advances in medical technology, health care delivery and public health interventions have sustainably improved survival rates for many paediatric health conditions, including prematurity, acute infectious diseases and complex neurodevelopmental disorders (Allen et al. 2011; United Nations Children's Fund [UNICEF] 2013; Houtrow et al. 2014). The increase in survival rates for many children with complex health needs also results in more comorbidity (Helders et al. 2003; Houtrow et al. 2014). Such comorbidities can cause serious functional limitations which can have long-lasting impact on children's everyday lives (Helders et al. 2003; Houtrow et al. 2014)

Children with disabilities are among the most marginalized groups in society (United Nations [UN] 2018). Although significant progress has been made in recent years to better support children with disabilities, many continue to face social and economic disadvantage (Blackburn et al. 2010; UNICEF 2013; UN 2018) and barriers to participation in their communities (Bedell et al. 2013; UNICEF 2013; Shields and Synnot 2016; Wright et al. 2018; Lynch et al. 2020; Powrie et al. 2020). This threatens the accomplishment of the realization of children's rights to and opportunities for leading fulfilling lives on an equal basis with others (UNICEF 2013; UN 2018).

Chapter 1 provides general introduction to this doctoral research. It introduces the key causes and consequences of disadvantage experienced by children with disabilities and their families, and positions the role of this research in that context. Section 1.2 of the chapter provides a background information on childhood disability, including paradigm shifts in defining disability, prevalence estimates and data sources, and outlines common needs and experiences shared by children and their families. Section 1.3 describes the global and national policy context in relation to children's basic rights to a decent life, equal opportunities and bright future. Section 1.4 provides a problem statement, followed by identifying the rationale for this work in section 1.5. Section 1.6 details the research aims and the research questions. The chapter concludes with a thesis chapter outline.

1.2 Childhood disability

1.2.1 Definition

Response to disability has changed since 1970, prompted largely by paradigm shifts in understanding of disability (UNICEF 2013). Historically, the medical perspective or "medical model" of disability was the standpoint adopted by society (World Health Organization [WHO] 2011; Baglieri and Shapiro 2012; UNICEF 2013). The medical model denotes the influence of a medical etiology in the outcome of various types of disabilities (WHO 2011). In a way, it focuses on pathological sources within the body which restrict individuals to perform activities in a manner or within a range considered as "normal" (Baglieri and Shapiro 2012). Although its dominance has faded with the advent of the social perspective on disability, the Disability Discrimination Act [DDA] 1995 and subsequent the Equality Act [EA] 2010 which reinforce and promote the right of individuals with disabilities are based on the medical model. The DDA (1995) defies disability as "a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities".

The social perspective or "social model" of disability, shaped by activists' and people with disabilities' movements in the 1970s, evolved as a reaction to the medical model (Shakespeare and Watson 1997). The social model defines disability as "a loss or limitation of opportunity to participate brought about by social and physical barriers" (Bickenback et al. 1999, p. 1776). It prioritizes the role of the physical, cultural, and policy environments in enabling individuals with a health condition to fully participate in society (Bickenback et al. 1999).

Adopting the social model of disability allowed socially created barriers and social exclusion to be more observable (Bickenback et al. 1999). It also facilitated the establishment of a so-called workable compromise between the medical and social models of disability – the "biopsychosocial model" of disability (WHO 2001). The biopsychosocial model views disability as neither purely "medical" nor purely "social" phenomenon (WHO 2001). Disability according to this model is an umbrella term for impairments, activity limitations and participation restrictions which arises from the negative interaction between an individual with a health condition and aspects of their context (WHO 2001). Although

increasingly seen as a biopsychosocial phenomenon, disability still tends to be conceptualized according to the DDA (1995) (Cappa et al. 2015).

1.2.2 Prevalence

The rates and trends in childhood disability are changing worldwide (UNICEF 2013; Houtrow et al. 2014), with most recent estimates suggesting that at least 93 million (5.1%) children under the age of 14 have a disability, of whom nearly 13 million (0.7%) experience severe difficulties (UNICEF 2013). Other sources suggest that an estimated 150 million children between 0 and 18 years have a disability worldwide (WHO 2011). Such a notable variation in statistical data is partially explained by a lack of standardization of how disability should be defined and measured (McPherson et al. 2017; WHO 2011). The primary focus of data collection often determines the measurement indicators of disability used in administrative, national censuses and surveys (WHO 2011; UNICEF 2013; Cappa et al. 2015). Collecting reliable data on childhood disability is further complicated by variations in the rates of growth and development in children. It is often hard to accurately distinguish developmental limitations from variations in norm (UNICEF 2013). Therefore, global estimates on disability are likely speculative (UNICEF 2013).

According to the UK Department of Work and Pension (DWP), childhood disability incidence and prevalence have been increasing steadily in the UK (Department of Work and Pension [DWP] 2017). A disability prevalence of 7.3% (952,741 children aged 0-18) was established in 2010 (Blackburn et al. 2010). Approximately 8% of children were reported to have a disability in 2017 (DWP 2017). These estimates are based on the DDA (1995) definition of disability and are supplied by the Family Recourses Survey (2015/2016) (FRS) – a key source of information on childhood disability statistics in the UK (DWP 2017). Other UK surveys provide much higher disability prevalence ranging between 9% and 16% (Read et al. 2010). Studies adopting the definition of disability based on the classification of special educational needs (SEN) or additional support needs (ASN) adopted in the educational sector report that 14.6% of school-age children in England have SEN and 24.9% of school-age children in Scotland have ASN (Carmichael and Riddell 2017).

1.2.3 Data source

Disability data are collected using a range of methods (e.g. national censuses, household surveys, medical records and targeted disability surveys), most common of which are national censuses and household surveys (Bruyere and Houtenville 2006). National censuses yield the least accurate childhood disability prevalence data (Cappa et al. 2015). This is because censuses ask a single generic question about the presence of disability to all members of the population with no specific reference to children. The UN Statistics Commission in its Principles and Recommendations for Population and Housing Censuses, Revision 1 specifically highlighted that:

"The limited number of questions included in the census cannot provide a precise measure of the number of people with disability, especially among children…"

(UN Statistical Commission 1997, p. 94).

National household surveys and targeted disability surveys tend to ask a set of detailed questions on the disability status of each member of the household (Cappa et al. 2015). Childhood disability data provided through these methods of data collection tend to be more accurate. Yet, the terms disability, impairment, long-lasting illness, longstanding health condition, chronic health condition and functional limitation are often used interchangeably in the household surveys depending on cultural context (Cappa et al. 2015). Surveys may also cover different time periods, geographical areas and age groups or children's developmental stages (e.g. early childhood – defined as from birth to year 8, middle childhood – defined as ages 6 to 12) limiting international and intra-national data comparability (Cappa et al. 2015).

There is an acknowledged necessity to improve the collection, sharing and analysis of disability data both nationally and internationally (WHO 2011; Cappa et al. 2015). Producing reliable statistics that are comparable can highlight international and intra-national inequalities between different populations of children with disabilities (Cappa et al. 2015). It will also allow gaining the confidence of local authorities and policy-makers when advocating for allocation of extra funding to better support and promote the rights of children with disabilities (Cappa et al. 2015).

1.2.4 Common needs and experiences

Children with disabilities, like any other children, want to participate in all aspects of life, including growing up with their families in adequate housing conditions, playing with friends, having fun, attending school and learning (UNICEF 2013). Nevertheless, many children with disabilities face various forms of social, material and financial disadvantage (Blackburn et al. 2010; UNICEF 2013; Chatzitheochari et al. 2016) which often prevent them from doing all these things (WHO 2011; UNICEF 2013; UN 2018). Children experiencing social disadvantage, e.g. unsupportive attitudes, bulling, stigma and discrimination from peers and adults in their communities struggle to have a sense of belonging to group membership (UNICEF 2013; Chatzitheochari et al. 2016). As a result, they often prefer to stay at home with a family rather than spend time with peers in the community (Tonkin et al. 2014). This often leads to loneliness and frustration (Langerman and Worrall, 2005; Chatzitheochari et al. 2016). Many children with disabilities are slow in getting assistive technology they need (UNICEF 2013; WHO 2011; Langerman and Worrall 2005). Some children do not get timely access to paediatric care services they are entitled to (UNICEF 2013; WHO 2011; Langerman and Worrall 2005). All these experiences increase children's dependence on their families, especially on parents and other caregivers.

Family is a complex and interactive system where the needs and experiences of each member affect the other (Seligman and Darling 2007). Families are unique (Seligman and Darling 2007). A set of characteristics that shape this uniqueness can affect the manner in which family adapts to a child with a disability and their needs (Seligman and Darling 2007). Having a child with a disability at home can bring family members closer, but it can also have a profound effect on the family by creating many tensions (Langerman and Worrall 2005).

Although families with childhood disability and their experiences vary (WHO 2011), many share commonalities. Direct costs associated with childhood disability are high (Langerman and Worrall 2005; Blackburn et al. 2010; UNICEF 2013). To meet care commitments, some families are unable to participate in employment (Blackburn et al. 2010). Childhood disability often "traps" families in persistent socio-economic disadvantage or poverty (Blackburn et al. 2010; UNICEF 2013). Many families with childhood disability live in poor housing conditions (UNICEF 2013; Blackburn et al. 2010).

Families often do not get enough support and/or brakes from care responsibilities (Langerman and Worrall 2005; UNICEF 2013). Many parents suffer from serious stress (Majnemer et al. 2012) or depression, and experience fatigue and tiredness (Langerman and Worrall 2005). Single-parent households and families where one or both of the parents have a disability are especially prone to experiencing financial, housing and health-related problems (Langerman and Worrall 2005; UNICEF 2013).

Children with disabilities and their families have a variety of needs which are not always met. Unmet needs and disadvantages faced by children and their families can have lasting negative effects, hampering children's and their families' opportunities for decent life and full integration into their communities (WHO 2011; UNICEF 2013). Disadvantages faced can also limit children's participation in social, cultural and economic affairs of their societies and impede their access to gainful employment later in adulthood (UNICEF 2013).

1.3 Historical policy context

The global community is dedicated to decreasing the prevalence of childhood disability and ensuring that children with disabilities enjoy their participatory and other basic rights that flow from good health care, nutrition, adequate housing conditions, inclusive communities and education (UNICEF 2013). These commitments stem from a range of international treaties, including the UN Convention on the Rights of the Child (UN CRC) (UN 1989), the UN Convention on the Rights of Persons with Disabilities (UN CRPD) (UN 2007) and the 2030 Agenda for Sustainable Development (ASD) (UN 2018). Under UN Conventions the signatory governments have taken upon themselves a responsibility to ensure that children with disabilities are able to live a decent life and participate on an equal basis with others in family life, health maintenance, education, public life, and recreational, leisure, and sporting activities. The signatory governments also obliged to collect robust and reliable data on disability to facilitate and monitor the implementation of the key fundamentals of the UN Conventions (UN 1989; UN 2006; UN 2018). Further, in 2015 the UN General Assembly adopted the Agenda for Sustainable Development Goals (SDGs) for the upcoming 15 years based on the principle of "Leaving No One Behind" (UN 2018). Eleven explicit references to persons with disabilities are made in the scope of 17 SDGs

directed towards their empowerment to ensure inclusiveness and equality. The UN Secretary-General made it clear in his last briefing:

"Societies will never achieve the SDGs without the full participation of everyone, including people with disabilities.

(António Guterres, 2018).

In 2019, the UN General Assembly celebrated the 30th anniversary of the UN CRC (1989) – a treaty that sets out the overarching standards for protecting and supporting the rights of children irrespective of their health condition and abilities. As of February 2015, 195 countries had ratified the UN Convention on the Rights of the Child (UN 1989). There are four articles, also known as the "General Principles", in the Convention that are viewed as fundamental in realizing all the rights for all children. Those are (1) non-discrimination (Article 2); (2) best interest of the child (Article 3), (3) right to life, survival and development (Article 6); (4) right to be heard (Article 12). The UN CRC also provides children with a number of individual rights such as (1) right to a name and nationality; (2) right to health; (2) right to play and engagement in age-appropriate recreational activities; (3) right to participate freely in cultural life and the arts; (4) right to an adequate standard of living. Article 23 of the UN CRC sets out the rights of children with disabilities. Paragraph 1 of Article 23 states:

"A mentally and physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community".

(Article 23, paragraph 1, UN 1989).

The UK ratified the UN CRC in 1991, and it came into force in 1992 (HM Treasury 2003). Therefore, realizing all the rights and improving health and social outcomes for children with disabilities to ensure their participation is also a prominent feature of the UK social policy agenda. The Every Child Matters Green Paper (2003) puts forward a set of goals in education, health and social support services to improve the lives of children across all four countries in the UK (HM Treasury 2003). This paper resulted in the establishment of the Children Act (2004), which was consequently updated into the Children's Plan Policy Papers (2007, 2008) (Government of the United Kingdom [GOV.UK] 2007; GOV.UK 2008), the Getting it Right for Every Child (Scotland) Act (2006), the Children and

Families Act (CFA) (2014) and the Children and Young People (Scotland) Act (2014). These national action plans and policy papers set out outcomes, national indicators and targets to ensure that in the UK:

(1) all children are healthy;
(2) all children stay safe;
(3) all children enjoy an active lifestyle;
(4) all children make a positive contribution;
(5) all children achieve economic wellbeing.

The UK Staying Safe: Action Plan (2009) made a commitment to target policies to achieve better outcomes for children with disabilities; outcomes compatible to those outlined for all children of the UK in the Every Child Matters (HM Treasury 2003) and the Getting it Right for Every Child (Scotland) Act (2006) policy papers (HM Government 2008). Therefore, there are increasing expectations that children with disabilities and their families in the UK would enjoy the same rights to opportunities and good livelihood, and participate in all the civic affairs of their communities on an equal basis with others.

1.4 Problem statement

Despite the global and national political commitment to improve outcomes for children (WHO 2011; UNICEF 2013; UN 2018), evidence suggests many children with disabilities continue to face various forms of disadvantage and barriers to their participation in home-, school- and community-based activities (Fauconnier et al. 2009; Ullenhag et al. 2012; Anaby et al. 2013; Bedell et al. 2013; Tonkin et al. 2014; Law et al. 2015; Chatzitheochari et al. 2016; Wright et al. 2018; Izadi-Najafabadi et al. 2019; Lynch et al. 2020; Powrie et al. 2020). Children with disabilities participate in a narrower range of activities, less frequently and are less involved when they do participate (Fauconnier et al. 2009; Ullenhag et al. 2012; Bedell et al. 2013; Tonkin et al. 2014; Izadi-Najafabadi et al. 2019), yet they tend to enjoy similar activities as children without disabilities (Law et al. 2011).

Children with disabilities experience greater participation restriction in out-of-school community-based activities (further referred to as community-based activities) than in home- and school-based activities (Law et al. 2007; Solish et al. 2010; Bedell et al. 2013).

They tend to participate less in outdoor physical activities (Bedell et al. 2013; Tonkin et al. 2014, Shields and Synnot 2016; Wright et al. 2018,) and in social activities, especially friendships (Oates et al. 2011). They have fewer opportunities for developing and sustaining social relationships and often feel social isolation (Frostad and Pijl 2007; Chatzitheochari et al. 2016). Further, a higher proportion of parents of children with disabilities expressed dissatisfaction and desire for change in their children's community-based participation (Bedell et al. 2013; Izadi-Najafabadi et al. 2019). Restricted participation in community-based activities, especially in activities which are social and physical in nature, implies that children with disabilities may lack numerous health benefits linked to participation. This can have a significant negative effect on children's both present and future health, overall well-being and quality of life (Frostad and Pijl 2007; Rosenbaum and Gorter 2012; Bedell et al. 2013).

Importantly, studies have shown international differences in patterns and extent of participation between children with and without disabilities (Fauconnier et al. 2009; Michelsen et al. 2009; King et al. 2010; Ullenhang et al. 2012; Bedell et al. 2013). A study established similar participation rates between age-matched children with and without disabilities living in Denmark (Fauconnier et al. 2009). Another study looking at the group differences in community-based participation among children living in Canada established differences in physical activities and self-improvement activities only (King et al., 2010). Findings of a similar study focusing on children living in the United States and Canada revealed significant group differences in children's community-based participation (Bedell et al. 2013). This implies that children's life circumstances, experiences and community-based participation are influenced by factors that vary across cultural contexts.

Since 1991, the UK Government has been submitting a periodic report to the UN on its implementation of the UN CRC (UNICEF 2016). In the most recent fifth periodic report (submitted 23rd of May 2014), the Committee on the Right of the Child admitted that although sufficient progress has been made by the UK Government to support and promote children's rights, insufficient action had been taken to ensure that the participatory rights of children with disabilities have been fully upheld and called for strengthening the efforts to better support children with disabilities and their families (UNICEF 2016).

1.5 Research rationale

All children irrespective of their disability status have the right to an adequate standard of living, developmental opportunities and full integration into society. All children irrespective of their disability status have a need and right for participation in community-based activities. Participation in community-based activities is a key contributor to a child's health and well-being (WHO 2007; Bedell et al. 2013; UNICEF 2013; Case-Smith and O'Brien 2015). Participation promotes children's social, physical and emotional development and enables experiences of meaning and purpose in life (Law et al. 2006; WHO 2007; UNICEF 2013; Case-Smith and O'Brien 2015). Participation in community-based physical activities is essential for sustaining normal muscle strength, flexibility, and joint structure and function – important aspects of body structure and function that may slowly decline in children because of their underlying health conditions (Durstine et al. 2000). Adequate levels of muscle strength are linked to increased bone mass and greater ability for participation in daily activities (Chad et al. 1999). Participation in social activities is an essential aspect of personhood and central for having a sense of belonging and motivation to achieve social inclusion across environments (Bedell et al. 2009; Solish et al. 2010; Case-Smith and O'Brien 2015).

If resources are to be directed towards better implementation of the UN CRC, the UN CRPD and the UK national policies and strategies, local authorities, policy-makers and paediatric professionals need reliable evidence from nationally representative samples. There is currently a lack of such evidence (Bedell et al. 2013). Much existing research into childhood disability and children's participation is over-shadowed by attention to clinical diagnosis (e.g. cerebral palsy) (Colver et al. 2012; Bedell et al. 2013) and/or include small scale or convenience samples (Bedell et al. 2013; King et al. 2013). Generalization from these studies to a wider population of children with disabilities is limited (Bedell et al. 2013). Expanding study populations beyond physical disabilities and producing more robust evidence has been emphasized as a priority for childhood disability participation research (Anaby et al. 2013). Further, given participation's central role in determining children's health, paediatric health and social care professionals (further referred to as paediatric professionals) are in search of reliable evidence on modifiable predictors of participation to better support children, especially their participation in community-based

social and physical activities (Murphy and Carbone 2008; Rosenbaum and Gorter 2012; Martin Ginis et al. 2016).

According to the ICF-CY, a multidisciplinary conceptual framework of health and health-related components, participation is a complex and multidimensional construct (WHO 2007). The multidimensional nature of participation implies that it can be influenced by multiple factors (WHO 2007; UNICEF 2013). The ICF-CY states that a child's context is a key contributor to participation. It further highlights that child functioning cannot be evaluated in isolation, but within the context of the family system (WHO 2007). Bronfenbrenner's ecological systems theory, which inspired the development of the ICF-CY, distinguishes family as the most proximal element of a child's social environment where dynamic interaction between two is the strongest (Bronfenbrenner 1979). According to this theory, family plays a central role in facilitating children's skills and competence development (Bronfenbrenner 1979) which are important for participation in age-appropriate activities.

Given this theoretical perspective, previous reviews synthesized evidence on child and environmental factors that affect children's participation (Shikako-Thomas et al. 2008; Bult et al. 2011; Shields et al. 2014; Anaby et al. 2013; Tonkin et al. 2014; Bloemen et al. 2015; Li et al. 2016; Martin Ginis et al. 2016). These reviews, however, have described the influence of a range of factors on participation in specific activities (Bloemen et al. 2015; Bult et al. 2011; Li et al. 2016) or settings (Anaby et al. 2013), focused predominantly on children with physical disabilities (Bloemen et al. 2015; Bult et al. 2011; Li et al. 2016; Shikako-Thomas et al. 2008, Martin Cinis et al. 2016), and/or provided a narrative evaluation of the findings only (Anaby et al. 2013; Bult et al. 2011; Shikako-Thomas et al. 2008; Tonkin et al. 2014). No review focused specifically on the family unit and synthesized evidence on family factors consistently associated with childhood disability participation.

During middle childhood (defined as ages 5 to 12), a child's mastery of developmental challenges is strongly influenced by family experiences and dynamics of relationships among family members (Collins et al. 2002; Wise 2003; Case-Smith and O'Brien 2015). Differences in family experiences produce important variations in children's participation, which may affect children's life experiences in and beyond childhood (Case-Smith and

O'Brien 2015; Piškur et al., 2015). Given theoretical and empirical support for importance of family in shaping children's participation and evidence suggesting that children with disabilities spend more time with a family rather than in the community with friends (Imms et al. 2008; Majnemer et al. 2008; Tonkin et al., 2014), it is important to focus on the family unit and identify potentially modifiable family/parental factors consistently associated with children's participation (Anaby et al. 2012; Piškur et al., 2012; Piškur et al. 2015). This will supply paediatric professionals with evidence important for the development and selection of targeted family-centred participation-promoting intervention techniques.

1.6 Aim and scope of the research

This doctoral research seeks to make a unique contribution to knowledge in childhood disability participation research by meeting the following three aims:

Research aims:

(a) To synthesize evidence on family factors consistently associated with the participation of children with disabilities;
(b) To describe and compare the characteristics, family circumstances and community-based participation of a nationally representative sample of children with and without disabilities;
(c) To identify the child, family and community factors independently contributing to participation frequency of a nationally representative sample of children with disabilities in community-based social and physical activities.

Research questions:

(1) What are the family factors associated with the participation of children with disabilities aged 5-12?
(2) What is the relative strength and consistency of these associations in children with disabilities aged 5-12?
(3) Are there any differences in the characteristics and family circumstances of a nationally representative sample of children with and without disabilities?
(4) Are there any differences in community-based participation of a nationally representative sample of children with and without disabilities?

(5) What are the independent effects of the child, family and community factors on participation frequency of a nationally representative sample of children with disabilities in community-based social and physical activities?

To meet the aims of this doctoral research two-stage of evidence inquiry – a systematic review (Study I) and a quantitative (secondary) analysis of existing survey data (Study II) were adopted. Study I followed systematic review methods to synthesize evidence on family factors consistently associated with the participation of children with disabilities and identified a group of modifiable factors as potential primary targets of family-centred participation-promoting intervention techniques. Family factors identified by the review were also used as a guide for the selection of family factors tested alongside the child and community factors in the scope of main Study II. The systematic review is described as a stand-alone chapter nested within the wider literature review.

Study II was a quantitative (secondary) analysis of existing nationally representative survey data. Data for the study were drawn from the fifth sweep of the UK Millennium Cohort Study (MCS5) conducted in 2012-2013 (University of London [UL] 2015). The UK MCS is a nationally representative survey which supplies a wide range of information about 19,000 children (and their families) born in four countries of the UK (Gallop et al. 2013). The sample supplied evidence on 1,073 children with disabilities (DDA-defined) and 11,122 children without disabilities aged 10-12 years.

Participation is complex and contested (Whiteneck and Dijkers 2009; Imms et al. 2016). The WHO's International Classification of Functioning, Disability and Health (ICF) defines participation as "involvement in a life situation" (WHO 2001). This definition has been a subject of ongoing debate (Whiteneck and Dijkers 2009; Maxwell et al. 2012). Many alternative definitions have been proposed, however, limited scholarly consensus exists (Whiteneck and Dijkers 2009; Maxwell et al. 2012; Magasi et al. 2015). Coster and Khetani (2008) describe participation as organized sequences of activities directed towards a personally or socially meaningful goal. Adolfsson et al. (2011) argue that children's involvement in a life situation requires societal involvement. Imms and colleagues (2016) describe participation as consisting of two dimensions: (1) attendance (measured as diversity or/and frequency), and (2) involvement (subjective experience) (Imms et al. 2016;

Imm et al. 2017). These two dimensions seem to describe the essence of the participation construct (Imms et al. 2016).

There is a lack of universally accepted definition of participation (Whiteneck and Dijkers 2009; Maxwell et al. 2012; Magasi et al. 2015). The general consensus (Whiteneck and Dijkers 2009; Dijkers 2010; Imms et al. 2016) is however that research on childhood disability participation should provide upfront:

(a) a working definition of participation,
(b) participation activity domain(s) measured,
(c) participation aspects - and settings (environments) measured.

For the purposes of Study II, participation in community-based activities was defined as a child's attendance at formal and informal everyday activities in the out-of-school community-based environment. The objective aspect of participation or attendance was captured (Imms et al. 2016). Attendance was quantified in terms of (1) "Never Participated" vs "Participated", (2) diversity or range of activities in which the child participated, (3) frequency.

Population-level evidence on children's characteristics, family circumstances and objective aspects of community-based participation can help to identify inequalities between children with and without disabilities, and generate reliable evidence important for advocating for extra funding to better support children with disabilities and their families. Given evidence that children with disabilities entering into adolescence display greater restriction in participation in their communities (Kang et al. 2010; Palisano et al. 2011; Shikako-Thomas et al. 2014), it will supply paediatric professionals, local authorities and policy-makers with a number of important considerations for strengthening of delivery of programmes directed to realizing the rights of children with disabilities. Further, providing population-level evidence on participation frequency associated child, family and community factors will supply paediatric professionals with potentials targets of intervention techniques aiming to increase children's participation in social and physical activities.

What follows is a doctoral thesis outline.

1.7 Chapter Outline

This doctoral research is organized into seven chapters.

Chapter 2 uncovers some of the debates and discussions around the construct of participation and introduces the conceptual framework and empirical research supporting this work. Section 2.2 presents on-going discussions around definitions of participation, introduces the ICF-CY – the conceptual framework guiding this research, flags out debates around its key limitations and provides an overview of measurement tools. Section 2.3 summarizes empirical evidence on factors associated with participation. Section 2.4 provides an overview of participation promoting interventions by placing the client-centred approach at the heart of these discussions. Chapter 2 concludes with a summary and sets the scene for the next chapter.

Chapter 3 describes Study I – a systematic review completed in the scope of this doctoral research to fill the aforementioned research gap in childhood (defined as ages from 5 to 12) disability participation literature. Section 3.2 of the chapter describes mythological considerations for a systematic review. This is followed by the descriptions of methods in section 3.3. Findings of the review including the classification of factors into modifiable family "process" factors (what families experience and do) and non-modifiable or hard to modify "status" factors (who families are) and appraisal of evidence using a multistage "semi-quantitative" approach are presented in section 3.4. Section 3.5 is a discussion of the main findings, which is followed by sequential sections describing the strengths and limitations of the review and considerations for further research. Chapter 3 concludes by providing a summary by highlighting the potential targets of family-centred participation promoting interventions.

Chapter 4 describes the philosophical and methodological context underpinning Study II – the main study of this doctoral research. Section 4.2 presents the philosophical stance and assumptions the investigator espouses to help the reader to understand a set of beliefs that guided the overarching methodology of this work. Section 4.3 describes the research methodology and provides the justification for adopting the quantitative (secondary) analysis of the existing data approach. Section 4.4 describes the methods including the datasets that were considered and the MCS that was selected. Section 4.5 is a description of the fifth sweep of MCS which was used to answer RQs posed by Study II. Section 4.6

refers to ethical research considerations. Section 4.7 describes the preparation of the final data file, including ways adopted to merge several datasets supplied by the UK Data Service. Section 4.8 specifies the main group of measures of interest and the mapping exercise completed. Section 4.9 describes data analysis including statistical programmes, statistical techniques and procedures used before concluding with a summary in section 4.10.

Chapter 5 includes details on the results of the main study (Study II). The chapter begins by providing descriptive statistics on participants' (main-carers) general characteristics in section 5.2 followed by descriptions and comparisons of characteristics of children with and without disabilities in section 5.3. Section 5.4 compares and contrasts community-based participation of children with and without disabilities. From section 5.5 onwards, the chapter describes the logistic regression models fitted to test the independent effects of the child, family and community factors on participation frequency of children with disabilities in physical activities and getting together with friends. The chapter concludes with a summary of the main findings in section 5.8.

Chapter 6 has the purpose of discuss the findings from two studies within the context of current childhood disability participation literature. Section 6.2 of the chapter briefly reflects on findings of Study I (for more details refer to Chapter 3). This is followed by discussion of main findings and strengths and limitations of Study II in section 6.3. Chapter 6 concludes with a summary in section 6.4.

Chapter 7 is the final chapter of this doctoral research. It provides an overview, highlighting unique contributions and conclusions of this work. Recommendations for further research, paediatric practice and policy are considered through sections 7.3-7.5. Chapter 7 concludes by outlining key pathways to research impact in section 7.6.

CHAPTER 2 – LITERATURE REVIEW

2.1 Introduction

This is interdisciplinary doctoral research. Therefore, literature review chapter draws on evidence from allied health, public health and psychology disciplines. The focus of the chapter is on areas which have direct relevance to the daily life of children with disabilities and their families, specifically "participation in daily life" which has received much attention within paediatric research and practice in recent decades as a health outcome and ultimate goal of rehabilitation interventions. Nonetheless, since its first introduction by the WHO (2001), debates and discussions have been ongoing on how participation should be conceptualized, measured and what the primary targets of participation-promoting intervention should be. The literature review uncovers some of these debates and introduces the conceptual framework of participation in section 2.2. Section 2.3 summarizes empirical evidence on factors associated with participation. Section 2.4 provides an overview of participation promoting interventions by placing the client (child) and family-centred approach at the heart of these discussions. Chapter 2 concludes with a summary and sets the scene for the next chapter.

2.2 Participation

2.2.1 Definition

According to a dictionary describing an etymology of words, participation originates from Latin *"particeps"* meaning "sharing, partaking" and *"pars + capere"* meaning "a part, a piece + to take" (Online Etymology Dictionary 2019). The Cambridge English Dictionary defines participation as "to take part in an event or activity" (Cambridge English Dictionary 2018). Participation, therefore, assumes an involvement or taking part in something. However, conceptualizing participation is not as straightforward. Many definitions have been proposed with no consensus reached so far (Whiteneck and Dijkers 2009; Maxwell et al. 2012; Magasi et al. 2015).

The UN CRC (1989) and UN CRID (2007) view participation as a basic human right. Under the UN Conventions, participation is conceptualized as having the right, the means, the spaces, the opportunities and support to participate in and/or engage in activities and influence decisions to contribute to building a better society (UN 2007). The ICF-CY

(WHO 2007) defines participation as "children's involvement in life situations" (WHO 2007). This is the most frequently cited definition of participation in literature and one tightly linked to the concept of inclusion under the UN Conventions. Regardless of its common use, many scholars question its validity and applicability (Whiteneck and Dijkers 2009). They call for further refinements, as "children's involvement in life situations" does not capture the whole complexity, nor does it reduce the inherent ambiguity of the participation construct (Whiteneck and Dijkers 2009; Maxwell et al. 2012; Magasi et al. 2015).

Pioneers in childhood participation research offer their own interpretations and definitions of the participation construct. Law (2002) describes participation as the context facilitating children's acquisition or mastering of skills, performing activities and forming a friendship. Participation, according to Coster and Khetani (2008), involves "sets of organized sequences of activities directed towards a personally or socially meaningful goal." Hoogsteen and Woodgate (2010) describe a list of attributes of what it means to participate, among those are - taking part in something or with someone, feeling included, feeling control over what children are taking part in, and working toward obtaining a meaningful goal or enhancing quality of life (Hoogsteen and Woodgate, 2010). Adolfsson et al. (2011) suggest children's involvement in life situations requires societal involvement. Many scholars use the term "social participation" to explicitly emphasize the importance of involvement in socio-cultural situations (Kielhofner 2009). Yet, it is not clear whether participation and social participation are distinct or overlapping concepts (Piškur et al., 2014).

In the efforts to define participation it is crucial to be clear on what participation is not. Participation is contextual but is not the environment around the child (McConachie 2006). Participation contributes to children's quality of life (QOL) (Law 2002) but it is distinct from the concept of QOL (McConachie 2006; Coster and Khetani 2008). Quality of life is "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHO 1993). It is a person's subjective feelings and perceptions about their life. Participation focuses on everyday functioning, and it is seen as an objective description of what the person actually does (WHO 2001).

2.2.2 Value of participation in community-based activities

All children have a need to participate across a variety of activities and settings, including home, community and school (Law 2002). Children's participation, therefore, is closely tied to these environments (Parkes et al. 2010). Children move between home, community and school settings; each provides a child with a set of meaningful activities linked to their growth and development (Law et al. 2013). The out-of-school community environment provides opportunities for participation in structured organized group activities (e.g. organized sports, classes and clubs) and unstructured spontaneous activities (e.g. outdoor play with peers or siblings, meeting with friends, going to a library) (King et al. 2003). Participation in organized and unstructured community-based activities is important for social, emotional, physical skills acquisition, role competency, experiencing meaning and purpose in life (Law 2002; King et al. 2003; Bult et al. 2011, Peny-Dahlstrand et al. 2013). Participation in community-based activities that are social in nature (e.g. meeting with friends, get together with friends) enables children to form social networks and friendships, to shape their identity and to boost their self-enrichment (WHO 2001, King et al. 2003). Participation in physical activities promotes children's physical and mental health functioning which has positive consequences throughout adolescence and later in adulthood (Lauruschkus et al. 2013). Participation in organized physical activities helps to increase tolerance against stress and anxiety, to enhance cardiovascular and respiratory functions, to improve musculoskeletal function and to raise children's overall fitness (McGarty and Melville 2018).

Active participation in community-based activities, especially in health-promoting social and physical activities, is important for children with disabilities for many reasons. First of all, it allows children to embrace and enjoy their basic rights. Second of all, children with disabilities may experience significant psychosocial and behavioural problems due to either underlying health implements (e.g. physical impairments, sensory and social impairments) or barriers faced in the environments. Psychosocial and behavioural problems can manifest in different ways over children's life course, e.g. issues in mental health functioning and compromised quality of life (Cadma et al. 1987). Active participation in structured community-based activities such as organized physical activities has been linked with reduced psychosocial problems, enhanced quality of life and educational success in children and youth with disabilities (Simeonsson et al. 2001; Law 2002, King et al. 2003). Third of all, it is important for children's optimal growth and development (WHO 2011).

Finally, it is essential for the prevention of health conditions associated with disability, e.g. obesity, depression (Lauruschkus et al. 2013).

2.2.3 The ICF-CY framework

The conceptual framework of this work is guided by the interdisciplinary, biopsychosocial framework of child functioning and disability – the ICF-CY (WHO 2007). The ICF-CY has originated from the ICF the introduction of which by WHO in early 2001 provided researchers and professionals across multiple disciplines with a common framework and terminology to describe human functioning in individuals with and without disabilities (WHO 2001).

The development of the ICF-CY has been based on practical, philosophical, taxonomic and public health considerations (WHO 2007). According to the developers, there was a long-established need for a framework/classification system of childhood disability which (1) can incorporate the specifics on children's growth and development, and (2) could be used across services and disciplines to promote the fundamental rights of children and prevent disability in childhood (WHO 2007).

The ICF-CY does not provide a theory on its own right but a conceptual framework describing the dynamic interactions between the developing child and environment (aspects of the attitudinal, social and physical environment) and resulting functioning in life situations defined as participation (WHO 2007). It is believed that the theory that influenced and inspired the development of the ICF-CY is Bronfenbrenner's ecological systems theory (Bronfenbrenner 1979) which views the environmental systems interacting with a human (child) as a primary mechanism contributing to a human (child) growth and development (an overview of the main elements of the theory is provided in the next subsection).

The ICF-CY emphasizes the importance of focusing on the child in the context of the family system (WHO 2007). The ICF-CY makes it clear that when evaluating a child's functioning in life situations (defined as participation) important consideration should be given to the family influences – a social element of immediate "individual" environment (WHO 2007).

The ICF-CY further notes that family influences on a child's functioning are strongest in early and middle childhood (defined as ages 0 to 12) and less in the adolescence and later adulthood:

"…child and youth environments can be viewed in terms of a series of successive systems surrounding them from the most immediate to the most distant, each differing in its influence as a function of the age or stage of the developing child".

(WHO 2007, p. xvi).

For the last decade, the ICF-CY has been the key overarching framework used to describe the child's functioning and disability which is operationalized as a dynamic interaction between the child's health condition and contextual factors (WHO 2007) (Figure 1). The Health condition construct is described as "impairments that are influential to children's functioning and disability".

Functioning and disability is the first level of the framework and is represented by Body function and Structure, and Activity and Participation. Functioning is an overarching term for body function and structure, activity and participation, whereas disability is as an umbrella term for impairments, activity limitations or participation restrictions (WHO 2007).

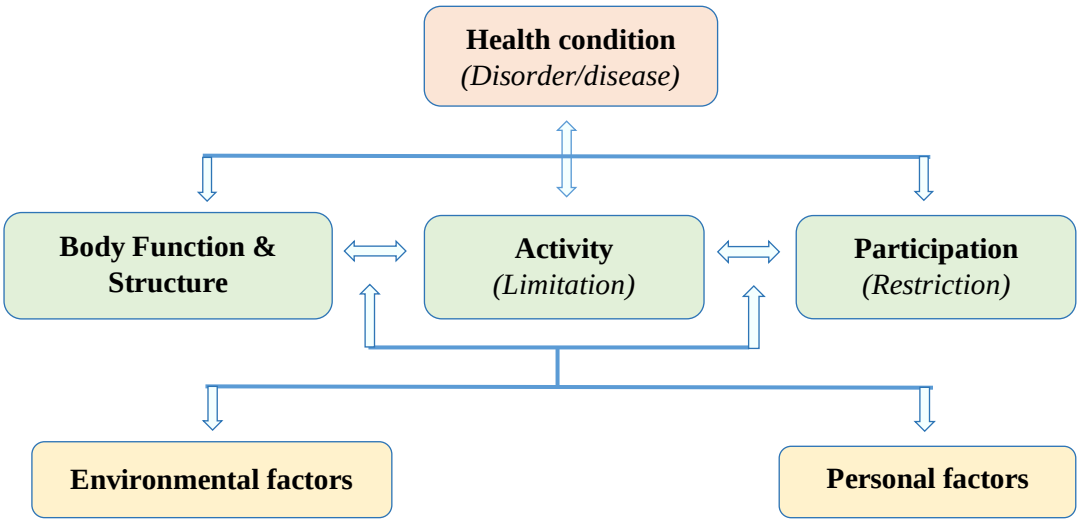


Figure 1. The ICF-CY framework (WHO 2007)

Body structure includes anatomical parts of the body described in 8 Chapters: Chapter 1 – Structures of the nervous system; Chapter 2 – The eye, ear and related structures; Chapter 3 – Structures involved in voice and speech; Chapter 4 – Structures of the cardiovascular, immunological and respiratory systems; Chapter 5 – Structures related to the digestive, metabolic and endocrine systems; Chapter 6 – Structures related to the genitourinary and reproductive systems; Chapter 7 – Structures related to movement; Chapter 8 – Skin and related structures.

Body function is physiological and psychological functions represented in 8 Chapters: Chapter 1 – Mental functions described by two main categories (i) global mental functions (including e.g. b122 - global psychosocial functions, b125 - dispositions and intra-personal functions) and (ii) specific mental functions (including e.g. b140 - attention functions, b147 - psychomotor functions, b152- emotional functions); Chapter 2 – Sensory functions and pain; Chapter 3 – Voice and speech functions; Chapter 4 – Functions of the cardiovascular, haematological, immunological and respiratory systems; Chapter 5 – Functions of the digestive, metabolic and endocrine systems; Chapter 6 – Genitourinary and reproductive functions; Chapter 7 – Neuromusculoskeletal and movement-related functions; Chapter 8 – Functions of the skin and related structures. More detailed descriptions of categories within Body Function and Structure Chapters of the ICF-CY are provided in Appendix A.

The constructs of Activity is defined as "the execution of a task or action by an individual", and Activity limitations – as "difficulties an individual may have in executing activities" (WHO 2007). The construct of Participation is defined as "involvement in a life situation". Participation restrictions, on the other hand, are "problems an individual may experience in involvement in life situations" (WHO 2007).

Although definitions differ, both Activity and Participation cover the same 9 general Chapters/Domains (d) or life areas representing aspects of functioning from an individual (activity) and societal (participation) perspective (Table 1). Those are: Chapter 1 (d1) – Learning and applying knowledge; Chapter 2 (d2) – General tasks and demands; Chapter 3 (d3) – Communication; Chapter 4 (d4) – Mobility; Chapter 5 (d5) – Self-care; Chapter 6 (d6) – Domestic life; Chapter 7(d7) – Interpersonal interactions and relationships; Chapter 8 (d8) – Major life areas; Chapter 9 (d9) – Community, social, and civic life.

Table 1. Activity and Participation chapters and categories of the ICF-CY

Chapters (domains)	Categories
Chapter 1 (d1) - Learning and applying knowledge	d110-d129: Purposeful sensory experience d130-d159: Basic learning d160-d179: Applying knowledge
Chapter 2 (d2) - General tasks and demands	d210: Undertaking a single task d220: Undertaking multiple tasks d230: Carrying out daily routine d240: Handling stress and other psychological demands d250: Managing one's own behaviour
Chapter 3 (d3) - Communication	d310-d329: Communicating-receiving d330-d349: Communicating-producing d350-d369: Conversation and use of communication devices and techniques
Chapter 4 (d4)- Mobility	d410-d429: Changing and maintaining body position d430-d449: Carrying, moving, and handling objects d450-d469: Walking and moving d470-d489: Moving around using transportation
Chapter 5 (d5) - Self-care	d510: Washing self d520: Caring for body parts d530: Toileting d540: Dressing d550: Eating d560: Drinking d570: Looking after one's health
Chapter 6 (d6) - Domestic life	d610-d629: Acquisition of necessities d630-d649: Household tasks d650-d669: Caring for household objects and assisting others
Chapter 7(d7) - Interpersonal interactions and relationships	d710-d729: General interpersonal interactions d730-d779: Particular interpersonal relationships
Chapter 8 (d8) - Major life areas	d810-d839: Education d840-d859: Work and employment d860-d879: Economic life d880: Engagement in play
Chapter 9 (d9) - Community, social, and civic life	d910: Community life d920: Recreation and leisure d930: Religion and spirituality d940: Human rights

The ICF-CY suggests four approaches by which two constructs could be distinguished: (1) dividing the nine domains into either Activity or Participation and allowing no overlap; (2) allowing partial overlap between Activity and Participation; (3) operationalizing Participation as broad domains and Activity as the more detailed domains with either partial or no overlap; and (4) allowing complete overlap in the nine domains (WHO 2007).

Both Activity and Participation concepts consist of two dimensions or qualifiers: Capacity and Performance. Capacity is defined as a child's full ability assessed in "a standardized environment or uniform environment" (WHO 2007) where the impact of environmental factors on a child's ability is neutralized. In other words, it describes what a child "can do in an ideal environment" (WHO 2007) and is commonly presented with the basic ability of

developmental domains in children. Performance, on the other hand, is defined by what a child is "actually does" in their current environment (WHO 2007). Performance can be understood as "involvement in a life situation" or "the lived experience" of children in their context (WHO 2007).

Contextual factors represent the second level of the framework and are described in terms of two broad categories: Environment factors (e) and Personal factors. Personal factors are not classified in the ICF-CY. This is because, according to the ICF's developers, there are huge social and cultural variations in respect to personal factors. However, generally, personal factors are described as features of a child which are not part of a health condition (WHO 2007). These include e.g. demographic characteristics such as age, sex, ethnic origin and lifestyle preferences and habits, education, coping style, motivation and other personality traits. Environmental factors (Table 2) – aspects of the attitudinal, social and physical environments are represented in 5 Chapters. Those are Chapter 1 – Products and Technologies; Chapter 2 – Natural Environment; Chapter 3 – Support and Relationships (including e.g. e310 - immediate family); Chapter 4 – Attitudes (including e.g. e410 - individual attitudes of immediate family members); Chapter 5 – Services, Systems and Policies.

Table 2. Environmental chapters and categories in the ICF-CY

Chapters	Categories
Chapter 1 - Products and technology	e110 Products or substances for personal consumption e115 Products and technology for personal use in daily living e120 Products and technology for personal indoor, outdoor mobility, transportation e125 Products and technology for communication e130 Products and technology for education e135 Products and technology for employment e140 Products and technology for culture, recreation and sport e145 Products and technology for the practice of religion and spirituality e150 Design, construction and building products and technology of buildings for public use e155 Design, construction and building products and technology of buildings for private use e160 Products and technology of land development e165 Assets e198 Products and technology, other specified e199 Products and technology, unspecified
Chapter 2 - Natural environment and human-made changes to environment	e210 Physical geography e215 Population e220 Flora and fauna e225 Climate e230 Natural events e235 Human-caused events e240 Light

Chapters	Categories
	e245 Time-related changes e250 Sound e255 Vibration e260 Air quality e298 Natural environment, human-made changes to environment, other specified e299 Natural environment and human-made changes to environment, unspecified
Chapter 3 - Support and relationships	e310 Immediate family e315 Extended family e320 Friends e325 Acquaintances, peers colleagues, neighbours and community members e330 People in positions of authority e335 People in subordinate positions e340 Personal care providers and personal assistants e345 Strangers e350 Domesticated animals e355 Health professionals e360 Other professionals e398 Support and relationships, other specified e399 Support and relationships, unspecified
Chapter 4 - Attitudes	e410 Individual attitudes of immediate family members e415 Individual attitudes of extended family members e420 Individual attitudes of friends e425 Individual attitudes of acquaintances, peers colleagues, neighbours and community members e430 Individual attitudes of people in positions of authority e435 Individual attitudes of people in subordinate positions e440 Individual attitudes of personal care providers and personal assistants e445 Individual attitudes of strangers e450 Individual attitudes of health professionals e455 Individual attitudes of other professionals e460 Societal attitudes e465 Social norms, practices and ideologies e498 Attitudes, other specified
Chapter 5 - Services, systems and policies	e510 Services, systems and policies for the production of consumer goods e515 Architecture and construction services, systems and policies e520 Open space planning services, systems and policies e525 Housing services, systems and policies e530 Utilities services, systems and policies e535 Communication services, systems and policies e540 Transportation services, systems and policies e545 Civil protection services, systems and policies e550 Legal services, systems and policies e555 Associations and organizational services, systems and policies e560 Media services, systems and policies e565 Economic services, systems and policies e570 Social security services, systems and policies e575 General social support services, systems and policies e580 Health services, systems and policies e585 Education and training services, systems and policies e590 Labour and employment services, systems and policies e595 Political services, systems and policies e598 Services, systems and policies, other specified e599 Services, systems and policies, unspecified

2.2.4 The theory influential to the development of the ICF-CY

The ICF-CY recognizes the prominent role of the context, described as "a series of successive systems" (WHO 2007, p. xvi) determining the child's development and functioning. Even though it appears that the ICF-CY does not conceptually rely on a specified theory, it is believed that the ecological systems theory of human (child) development (Bronfenbrenner 1979) guided and inspired the development of the ICF-CY. Bronfenbrenner's ecological systems theory views a child as a system interdependent from developmental systems – microsystem, mesosystem, exosystem, macrosystem, which he described as a "set of nested structures, each inside the next like a set of Russian dolls" (Bronfenbrenner 1979, p. 3) (Figure 2).

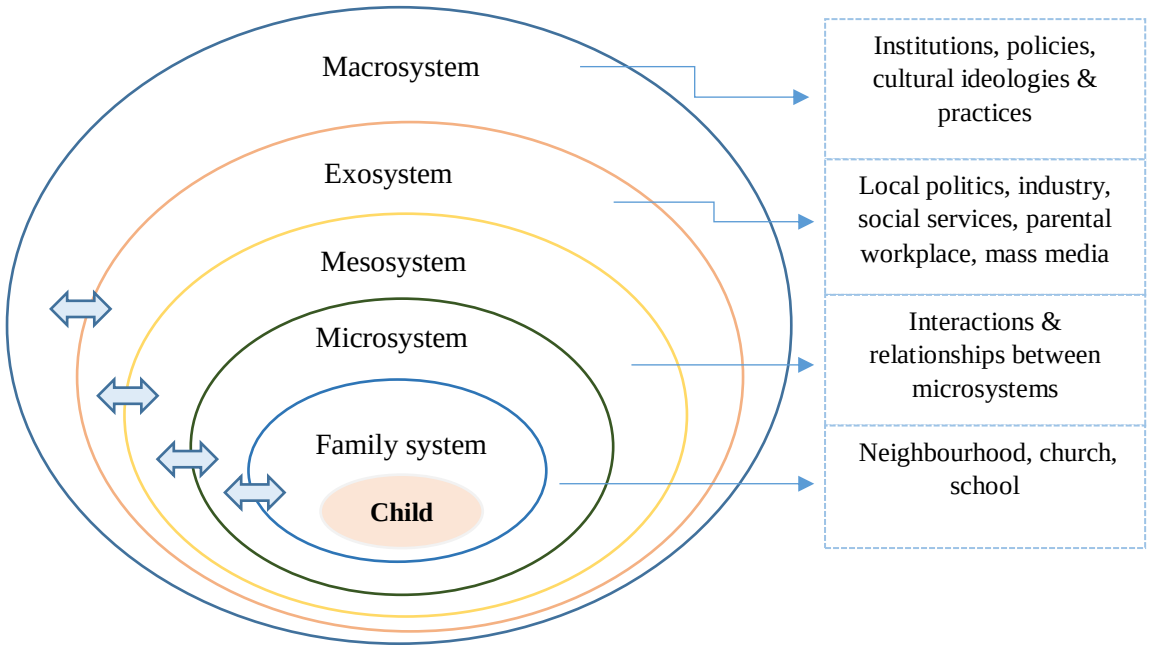


Figure 2. Bronfenbrenner's ecological systems model

The closest (or immediate) of these developmental systems to a child is a microsystem (which comes from Greek "micro" – small). The child has direct, regular and reciprocal (bi-directional) interactions with elements of multiple microsystems, e.g. family at home, peers/friends in the neighbourhood, classmates/teachers at school and professionals in clinical settings. The family system (with its subsystems – parents and siblings), however, is the most proximal microsystem for a child where interactions and influences are the

strongest. The interactions and relationships between multiple microsystems, such as a child's family and community or school setting, is the next layer of the environment in the model – the mesosystem (which comes from Greek "mesos" - middle) (Bronfenbrenner, 1979). The exosystem (which comes from Greek "exo" – outside) contains the formal and informal structures of both microsystems and mesosystems (governmental structures, societal institutions), but not the child. In the exosystem events occur that either affect or are affected by what happens in the microsystem. The macrosystem (which comes from Greek "macros" – large) is the outermost layer of the environment and includes beliefs, culture characteristics, and political ideology.

Bronfenbrenner's ecological systems theory views child development and functioning as a result of a dynamic interaction between elements of a family system nested within micro- and mesosystems and many other environmental systems in which a child even not present (Bronfenbrenner 1979). This theory and its later iterations (Bronfenbrenner 1979; 1986; 1989; Bronfenbrenner and Ceci 1994) are recognized and valued for shaping new ideology that (1) the context is a vitally important aspect of the human development, functioning and resulting behaviour, and (2) genetic, biological characteristics do not produce the final outcomes in the child. Rather, a child's genetic and biological characteristics dynamically interact with contextual experiences to determine a child's functioning and developmental outcomes.

According to Bronfenbrenner ecological systems theory, many characteristics that are attributed to genetics and/or biology of the child can be influenced by context or environmental systems. Therefore, the context surrounding the child could be an entry point for intervention techniques focusing on improving children's functioning, participation and health outcomes. These theoretical principles underpin the biopsychosocial perspective of the child's development, functioning and disability adopted by the ICF-CY (WHO 2007) and this doctoral research.

2.2.5 Limitations of the ICF-CY framework

Although the ICF-CY is firmly secured its place in paediatric research/practice and is used in this study as a guide for conceptualizing key constructs, there are limitations to this framework that needs to be noted and acknowledged. Key limitations, some of which are a

source of ongoing debate and discussion up until now, are concentrated around six main areas:

(1) a lack of theoretical explanations about the relationship between its constructs,
(2) a complexity of the classification system for environmental factors,
(3) a lack of detail in the possibilities to document contextual factors in Chapter 3 – "Support and Relationships" and personal factors,
(4) vague descriptions on how to differentiate activity from participation,
(5) issues with a qualifier capacity as a measure of participation,
(6) a need for inclusion of additional qualifiers to describe frequency (or intensity - an average frequency) of participation and subjective experience.

The ICF-CY positions itself as a theoretical framework for components of health which takes into account the interactions between health condition, components of functioning and contextual factors (WHO 2007). Theoretical frameworks are of key importance as they guide both clinical practice and research (Carter and Lubinsky 2015). However, the ICF-CY does not explicitly describe the theory that underpins it, particularly in relation to the temporal and causal ordering of its constructs (Imrie 2004). There are bidirectional relationships between the ICF-CY's constructs; however, no hierarchy of implied importance is provided (Cerniauskaite et al. 2011; Rosenbaum and Gorter 2012).

The ICF-CY is also a complex classification system (Björck-Åkesson et al. 2010). As a taxonomy derived from the ICF (WHO 2001), the ICF-CY classifies states of functioning and health in codes with a lot of detail and "granularity" (WHO 2007, p. xiii). Nevertheless, scholars argue that the environment, as it is presented in the ICF-CY, is very broad and we cannot begin to measure all aspects of it simultaneously (Whiteneck and Dijkers 2009). There is a need to limit quantifications of the aspects of the human-made, natural, social and cultural environment that potentially have a role in shaping participation (Whiteneck and Dijkers 2009). There is a need for a new theory of how environmental factors affect functioning, however unsophisticated that theory may be, and use this theory (or theories) to develop more targeted measures (Whiteneck and Dijkers 2009).

Factors contributing to participation have been investigated vigorously using ICF's classification-linking procedures and rules (Fekete and Rauch, 2012; Cerniauskaite et al.

2011). In their review, Fekete and Rauch (2012) argue that not all factors contributing to participation could be classified within the ICF-CY. First of all, a classification of personal factors is missing altogether (Fekete and Rauch, 2012; Cerniauskaite et al. 2011; Cieza et al. 2005), although their important contribution is recognized. Second of all, the environmental factors component lacks detail in the possibilities to document aspects of "Support and Relationships" in Chapter 3 (Björck-Åkesson et al. 2010), especially in regards to the family. The ICF-CY takes a social-ecological approach when describing a child's functioning as a dynamic process dependent on continuous interactions with the family (other caregivers) in a close social environment (WHO 2007). The ICF-CY places special emphasis on the central role of the family in children's functioning quoting:

"The functioning of the child cannot be seen in isolation but rather in terms of the child in the context of the family system"

(WHO 2007, p xv.)

Yet, no specific classification system is provided for family factors. Those are broadly presented by e310 - immediate family and e315 - extended family as parts of "Support and Relationships" in Chapter 3, and e410 - individual attitudes of immediate family members and e415 - individual attitudes of extended family members as part of "Attitudes" in Chapter 4 (Table 2).

The ICF-CY provides four possible options to differentiate activity from participation. However, these options vary in the degree of overlap in domains between the two dimensions. Therefore, how to differentiate activity from participation and what should be the key focus of measurement efforts is open to a variety of interpretations. Parkes et al. (2010, p. 305) suggest that "activity reflects the ability to execute a task or series of physical tasks" and "participation is a more complex set of life behaviours that can be achieved using a dynamic variety of tasks". Relatedly, Whiteneck and Dijkers (2010) argue that the first five domains of "Activity and Participation" in the ICF-CY occur at the individual level, and, therefore, should be viewed as covering the activity construct, whereas the other four domains involve role performance at a societal level and, therefore, should be seen as participation. Maxwell et al. (2012) further add that although activity performance does not directly translate into participation, it is necessary for successful participation. Up until now, none of these suggestions have been universally adopted (Coster and Khetani 2008).

It is generally assumed, however, that participation is complex and more contextual, and activity is more distinct and limited by body impairments (Coster and Khetani 2008).

The further debate relates to the ICF-CY's qualifiers of capacity and performance which are objective, observable dimensions of participation. Many authors argue that the capacity qualifier is unsuitable to measure participation because participation is an involvement in a life situation rather than in a standardized or uniform environment. To explain the abilities in life situations, the term "capability" is proposed to conceptualize the measurable dimensions of "independence" or "range of possible functioning" in children (Morris et al. 2006).

Scholars further suggest that participation can be measured with a performance qualifier only. A performance qualifier describes a child's "objective" dimensions of participation. The objective aspect of participation is an essential quantifier of participation and most amenable to measurement (WHO 2001; WHO 2007; Imms et al. 2016). It is important to measure the objective aspect of participation because it provides valuable insights about the availability and accessibility of settings for the child (Maxwell et al. 2012; Imms et al. 2016). In its essence, it is linked to the notion of inclusion and human rights based on equal opportunities and non-discrimination (Maxwell et al. 2012). Coster and Khetani (2008) state that it is necessary to measure the objective dimensions of participation in order to compare the objective circumstances of different subgroups. Maxwell et al. (2012) calls for a need of an additional ICF-CY qualifier that will measure the frequency or intensity of participation, in other words, to measure how often the child participates.

Many scholars, however, equally prioritize a child's own or subjective experience with participation while attending the activity (Coster and Khetani 2008; Imms et al. 2016, Imms et al. 2017). Imms et al. (2016) introduced a family of participation-related constructs (fPRC) within which participation is described as consisting of two dimensions: "attendance" – defined as "being there" and measured as the frequency of attending and/or diversity, and "involvement" – the subjective experience of participation while attending. Imms et al. (2016) further conclude that these two dimensions seem to describe the essence of participation. McConachie et al. (2006) argue that while the subjective experience of participation adds richness and helps to make meaningful interpretations about attendance differences, it will never be a substitute for knowing the attendance of a child in the first

place. Subjective experience or involvement (Imms et al. 2016) however is not a focus of the ICF-CY. Furthermore, in a footnote (WHO 2007, p. 13), the ICF-CY explicitly states that participation should not be equated with the experience or a child's sense of involvement.

2.2.6 The measurement of participation

The last two decades have seen a substantial rise in the development of participation measures (Chien et al. 2014). This makes it difficult for professionals to select the appropriate measures to profile children's participation. The difficulty faced by professionals has been further enhanced by debates regarding conceptualization and differential distinction between Activity and Participation in the ICF-CY. Professionals have little guidance regarding (1) the extent to which existing tools measure children's participation, and (2) the extent to which the item content of existing tools can be classified using the ICF-CY framework (Chien et al. 2014).

Available measurement tools vary in content. Some tools measure participation in a particular environment, e.g. school (the School Functioning Assessment – SFA (Coster et al. 1999)) or home (the Children Helping Out: Responsibilities, Expectations, and Supports – CHORES (Dunn 2004)), and focus on a specific dimension of participation. These tools commonly have a list of detailed activities and/or participation items pertinent to the particular environment along with a scale measuring the frequency of attendance. Other tools measure participation in two or more environments e.g. leisure and recreational activities (the Children's Assessment of Participation and Enjoyment – CAPE (King et al. 2004)), or across all three environments along with a scale describing the frequency of attendance and/or degree of involvement and parental desire for change (The Participation and Environment Measure for Children and Youth – PEM-CY (Coster et al. 2012)).

Chien and colleagues (2014) systematically reviewed the literature to summarize measures of participation applicable for children aged 2-12 by using the existing ICF-CY chapters as a guide (Chien et al. 2014). The authors identified 16 measurement tools, out of which 11 had more than half of their items measuring participation. Participation items identified in the tools captured between 3 and 9 ICF-CY Activity and Participation chapters/domains of the ICF-CY. According to Chien et al. (2014), the Child and Adolescent Scale of

Participation (CASP) and the PEM-CY were the only two instruments that had participation items with coverage of all the 9 ICF-CY chapters/domains (Chien et al. 2014). Both CASP and PEM-CY are developed by Coster and colleagues (Bedell et al. 2009; Coster et al. 2012). The tools consist of fewer items compared to other tools; however, the content density of these tools in relation to the ICF-CY is high (Chien et al. 2014). Each item in the PEM-CY and CASP represents broad life areas consisting of a set of relevant activities in which children might potentially get involved (Chien et al. 2014).

A good example of what Chien et al. (2014) are arguing for could be illustrated in one of the community participation items in the PEM-CY. The item "Organized physical activities" will be considered a good measure of community-based participation because children's participation in organized physical activities incorporates a set of organized sequence of relevant activities (e.g. swimming, gymnastics, and football) directed towards a larger meaningful goal such as improving fitness, and enhancing physical and mental health well-being. This community-based participation item includes several meaningful concepts (i.e. content density) that are linked to 3 ICF-CY Activity and Participation chapters/domains (d5, d7, d9).

How best to define and measure children's participation in meaningful daily activities is complex and contested. However, the consensus is that studies focusing on childhood disability participation should be clear about: (a) a working definition of participation, (b) participation activity domain(s) and (c) participation aspects - and settings (environments) measured (Whiteneck and Dijkers 2009; Dijkers 2010; Imms et al. 2016). Participation in community-based activities in this doctoral research was defined as a child's attendance at formal and informal everyday activities in the out-of-school community-based environment. The objective aspect of participation, or attendance, was captured (Imms et al. 2016). Attendance was quantified in terms of (1) "Never Participated" vs "Participated", (2) diversity, and (3) frequency of participation in each activity.

The sections to follow provide empirical evidence on factors influencing the participation of children with disabilities.

2.3 Factors contributing to children's participation

According to the ICF-CY, participation is a result of dynamic interaction between a child with a health condition and contextual factors (i.e. environmental and personal factors) (WHO 2007). The subsections below synthesize evidence on factors contributing to participation guided by the conceptualization of participation in the ICF-CY.

2.3.1 Body Functions and Structures

Having a longstanding health condition negatively affects participation, but the diagnostic category does not seem to affect participation in various activities (Almqvist and Granlund 2005; Law et al. 2006). Nevertheless, problems in body functioning and the complexity of a child's health condition can have a significant negative effect on participation (Morris et al. 2006; Kerr et al. 2007; Hilton et al. 2008; Fauconnier et al. 2009; Imms et al. 2009; Poulsen et al. 2011; Bult et al. 2011; Jarus et al. 2011; Anaby et al. 2013; Tonkin et al. 2014). The level of gross motor functioning, ability to be independent and manual functioning was shown to be important for participation of children with physical disabilities, specifically cerebral palsy (Morris et al. 2006; Kerr et al. 2007; Fauconnier et al. 2009; Imms et al. 2009; Anaby et al. 2013) and developmental coordination disorder (Poulsen et al. 2011). Levels of cognitive and intellectual functioning were associated with frequency of participation in several studies (Imms et al. 2008; Majnemer et al. 2008; Fauconnier et al. 2009). Literature also established positive associations between levels of communicative functioning and speech and participation (Morris et al. 2006; Majnemer et al. 2008; Fauconnier et al. 2009; Imms et al. 2009).

The complexity of a child's health condition or presence of multiple functional issues and/or comorbidities is another important predictor of participation (Beckung and Hagberg 2002; Morris et al. 2006; Majnemer et al. 2008; Fauconnier et al. 2009; Bult et al. 2011). For instance, studies looking at the participation of children with physical disabilities revealed that those with additional hearing or visual impairments were at risk of reduced participation (Beckung and Hagberg 2002; Morris et al. 2006). Symptoms resulting from the health condition and/or functional limitations, such as chronic pain (Fauconnier et al. 2009; Colver et al. 2012) and chronic fatigue (Lindsay, 2016) have been also identified to influence children's participation.

Psychosocial and behavioural factors

Psychosocial and behavioural factors are a pool of factors involved in cognition, emotion, motivation, behaviour and social connection (Sarafino and Smith 2014). Cognition is a mental function. It involves cognitive functions such as thinking, perceiving, learning, remembering, believing and problem solving (Sarafino and Smith 2014). Emotions are subjective feelings that affect and affected by an individual's physiology, thoughts, behaviour and social connection (Sarafino and Smith 2014). These functions are described in the ICF-CY under "Mental functions" within the body functions component (Appendix A). More specifically, b122 - global psychosocial functions, b125 - dispositions and intra-personal functions within the global mental functions subcategory and b140 - attention functions, b147 - psychomotor functions, b152- emotional functions within the specific mental functions subcategory (Appendix A).

Motivation is the process within the individual (child) described as a driver for involvement in an activity (Sarafino and Smith 2014; Imms et al. 2016; Imms et al. 2017). Motivation, on the other hand, can be mapped to the personal factors component of the ICF-CY. Mapping psychosocial and behavioural factors to a specific component in the ICF-CY is a challenging task; these factors tap into cross-cutting concepts.

Although important contributors to participation (King et al. 2013; Imms et al. 2016), there is a relative lack of studies which explored the effects of psychosocial and behavioural problems on the participation of children with various disabilities (Taheri et al. 2017). Evidence suggests that psychosocial well-being is positively associated with participation intensity in leisure and recreational activities (King et al. 2013), whereas psychological problems predict restrictive participation and decreased quality of life (Desha and Ziviani 2007; Martin Ginis et al. 2016). Further, King et al. (2010) established that differences in participation profiles of children with physical disabilities in out-of-school activities were associated with children's emotional functioning, peer difficulties and prosocial behaviour rather than motor and communication functional issues.

A need for further research looking at the effect of psychosocial and behavioural problems on childhood disability participation is warranted (Taheri et al. 2017). This is because psychosocial (behavioural) factors affect the child's sense of self, motivation and preferences for participation (Imms et al. 2016; Imms et al. 2017). Those are related to an

individual's previous and present experience with participation and can act as an inner driver or as "intrinsic motivation" for future participation (Imms et al. 2016; Imms et al. 2017).

2.3.2 Contextual factors

Previous research examined the effects of contextual factors, including personal and environmental factors (family and community factors) contributing to the participation of children with disabilities. Most of the research has however focused on environmental factors, given that those are more amenable to intervention techniques than child-specific or personal factors (Law et al. 2007). Personal factors are not specifically identified in the ICF-CY; therefore, it is difficult to explicitly state which child characteristics fall into this component. What is clear, however, is that personal factors are the characteristics of the child which does not relate to their health condition (WHO 2007).

Personal factors

Empirical evidence looking at the effect of personal factors is mainly around child age and sex (Law et al. 2006, Majnemer et al. 2008; Orlin et al. 2010; Oates et al. 2011; King et al. 2013). Children's age and sex have been demonstrated to influence the choice and frequency of attendance in community-based activities. Younger children usually participate in more diverse activities. Older children tend to participate in more informal activities with lower diversity and frequency of attendance (Law et al. 2006; Majnemer et al. 2008; Pratt et al. 2008; Orlin et al. 2010). Age was found not be related to the participation of children with disabilities in physical activities (Orlin et al. 2010) and skill-based activities (Oates et al. 2011).

Sex is predominantly associated with activity preferences (King et al. 2003; Pratt et al. 2008), but overall, levels of participation are higher in girls than in boys (Law et al. 2006; Shikako-Thomas et al. 2008; Engel-Yeger et al. 2009). Girls prefer participation in social, skill-based, and self-improvement activities, as opposed to boys who are more interested to participate in activities that are physical in nature (King et al. 2003; Law et al. 2006; Pratt et al. 2008; Shikako-Thomas et al. 2008; Engel-Yeger et al. 2009).

Family factors

Family is part of a microsystem which constitutes a child's most proximal context (Bronfenbrenner 1979). The family has been described as the most powerful social system one can ever belong to (Seligman and Darling 2007). Children's development and functioning are in dynamic interaction between elements of a family system (Bronfenbrenner 1979; WHO 2007) and many other environmental systems (Bronfenbrenner 1979). Interactions and influences are the strongest at the family system level (Bowen 1970; Bowen 1978; Bronfenbrenner 1979; Seligman and Darling 2007).

Family system theory (Bowen 1978) describes the family as a complex, interactive and interdependent social system (Bowen 1978; Friend and Cook 2002; Seligman and Darling 2007). This implies that the needs and experiences of each member affect the other (Bowen 1970; Bowen 1974; Friend and Cook 2002; Seligman and Darling 2007). Many children with disabilities live with their families where things happening affect everyone (Seligman and Darling 2007), including the way parents care and respond to their children's needs.

Families have a set of characteristics (e.g. family type, family size, ethnicity, attitudes, cultural beliefs, behaviours) that serve to make them unique (Friend and Cook 2002; Seligman and Darling 2007). These unique characteristics play an import role in shaping families' ideological styles, interactional patterns, functional priorities (Seligman and Darling 2007). Family beliefs, attitudes and behaviours, which can be affected by family resources, cultural and ethnic background, can affect the manner in which family adapts to a child with a disability and their daily needs (Seligman and Darling 2007).

Empirical studies established that families (parents) have significant influence on the participation of children with disabilities (King et al. 2006; Rentinck et al. 2009; Oates et al. 2011; Bedell et al. 2013; Law et al. 2013; Kolehmainen et al. 2015; Marquis and Baker 2015; Kamath et al. 2016). Parents carry the primary responsibility for the choice and organization of the child's routines (Rentinck et al. 2009; Kolehmainen et al. 2015). Parents choose activities which they believe are suitable for their child and verbally encourage participation (Kolehmainen et al. 2015). Decisions on a choice of activities can be influenced by a number of factors including parental beliefs, attitudes, behaviour, preferences, availability of family resources, parental health functioning (King et al. 2006;

Law et al. 2006; Bedell et al. 2011; Oates et al. 2011; Palisano et al. 2011; Law et al. 2013; Kamath et al. 2016).

Although much research was published on associations between family factors and participation (King et al. 2006; Law et al. 2006; Majnemer et al. 2008; Rentinck et al. 2009; Oates et al. 2011; Palisano et al. 2011; Bedell et al. 2013; Kolehmainen et al. 2015; Marquis and Baker 2015; Kamath et al. 2016); the evidence is contradictory. In several studies limited resources (money, time and additional support) were identified as barriers for parents to provide children with variety of opportunities and experiences for participation in community-based activities (King et al. 2003; Law et al. 2006; Bedell et al. 2011). This has not been, however, supported in studies simultaneously measuring the effect of a variety of child, family and community factors on the participation of children with physical disabilities in leisure and recreational activities (King et al. 2006; Palisano et al. 2011). Parental mental and physical health functioning was positively associated with children's participation in several studies (Majnemer et al. 2008; Parkes et al. 2010; Oates et al. 2011; Bult et al. 2013). These associations were not established in other studies (King et al. 2009; Marquis and Baker 2015). Parental support has been shown to be positively associated with social participation of children with physical disabilities and friendship formation (Lawlor et al. 2006; King et al. 2007). It was also found to be negatively associated with participation of children with epilepsy in out-of-school leisure activities (Kamath et al. 2016).

Although this evidence is helpful, there is a lack of research synthesis on family factors associated with participation and whether these family factors also have a relation with parental or family needs and desires (Piškur et al. 2014). Evidence at hand provides an insufficient level of detail on potentially modifiable family factors consistently associated with participation - the factors that can be primary targets of family-centred participation promoting intervention techniques. Further studies are needed to fill this gap in the evidence.

Community factors

The UN Committee on the Rights of the Child (2013) puts forward a set of conditions that needs to be assured by the governments if children's rights to participation in community-based activities are fully realized. Key conditions supporting community-based

participation are: (1) spaces secure from social harm, violence and free from pollution, traffic and other hazards; (2) spaces to play outdoors in divers physical environments with access to supportive adults; (3) spaces free from stress, social exclusion, prejudice or discrimination; (4) spaces offering opportunities to experience, interact and play; (5) spaces offering opportunities to participate with other children in games, sports and other recreational activities, supported, where necessary, by adult facilitator; and (6) spaces offering opportunities to explore and understand the cultural and artistic heritage of the communities, participate in, create and shape those (UN 2013).

Previous studies have examined the effects of some of the above-described community factors (or conditions) on children's participation (Fauconnier et al. 2009, Bult et al. 2011; Maxwell and Granlund 2012; Anaby et al. 2013; Tonkin et al. 2014). Most prominent of these studies is a large multicentre European study – the Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE) (Fauconnier et al. 2009; Colver et al. 2012). The SPARCLE has identified that accessibility and availability of spaces and objects in the environment (e.g. adapted toilets, ramps, lifts, aids, parking and public transportation) were key factors shaping participation of children with cerebral palsy across eight European countries (Colver et al. 2012). Emotional and physical supports provided by aspects of social environment (i.e. peers and adults) were also important facilitators for participation (Colver et al. 2012).

Recent reviews and empirical studies echoed and extended the SPARCLE findings (Bult et al. 2011; Maxwell and Granlund 2012; Anaby et al. 2013; Tonkin et al. 2014). A lack of availability and accessibility of spaces (e.g. density, distance, size and layout of places, playgrounds, parks, sport and other recreation facilities,) and objects (e.g. assistive technologies, ramps) were identified as barriers to children's participation in community-based activities forcing them to navigate the environment to overcome barriers (Bult et al. 2011; Maxwell and Granlund 2012; Anaby et al. 2013; Tonkin et al. 2014). Positive attitudes from peers and people in community programmes have been identified as facilitators, and lack of personal assistance and specialist knowledge from staff working in sport and recreation facilities were identified as barriers for participation in community-based physical activities (Martin Ginis et al. 2016). The safety of community spaces was also identified as important for participation (Anaby et al. 2013; Tonkin et al. 2014).

Although environmental factors have been identified as central to shaping children's participation both theoretically (King et al. 2003; WHO 2007) and empirically (Maxwell and Granlund 2012; Anaby et al. 2013; Tonkin et al. 2014; Martin Ginis et al. 2016), a systematic review by Bult et al. (2011) has identified that the effect of environmental factors on childhood disability participation in leisure and recreational activities was not supported by more than half of the reviewed papers. These results are unexpected, however understandable given (1) the multidimensional nature of participation, and (2) a pool of literature suggesting the key role of child-intrinsic factors (e.g. competence, sense-of-self, preferences, motivation) in shaping participation (Majnemer et al. 2008; Fauconnier et al. 2009; Palisano et al. 2011; Imms et al. 2016; Imms et al. 2017).

2.4 Intervention techniques to support children's participation

Participation promoting intervention techniques used in paediatric practice changed throughout history (Rodger and Kennedy-Behr 2017). Since the beginning of the 21st century, there has been more focus on children's development and behaviour within an ever-changing environment as distinct from the traditional approach based on "biomedical thinking" (Case-Smith and O'Brien 2015; Rodger and Kennedy-Behr 2017). The biomedical thinking, which is in line with the medical perspective of disability, includes interventions seeking to address issues in the child's body function and structure through "treatments" to support the development of functional skills (Rodger and Kennedy-Behr 2017). Improved foundational skills assume a reduction in limitations experienced by a child on a day to day basis, and, therefore, improved participation (Imms et al. 2016). More empirical evidence is needed to support the assumption that changes in body structure will directly lead to changes in participation (Janeslätt et al. 2014; Adair et al. 2015; Rodger and Kennedy-Behr 2017). However, some evidence is out there describing the effectiveness of intervention techniques targeting children's activity. Interventions directed towards increasing motor function in children with cerebral palsy (Novak et al., 2013) and other disabilities (Damiano and DeJong 2009) have been shown to have the potential to support children's participation.

As the understanding of disability and predictors of participation have evolved, so have the intervention techniques aiming to promote children's participation. The potential "therapeutic" role of the environment in influencing participation has facilitated the

establishment and implementation of environment-based participation-promoting interventions (Darrah et al. 2011). So-called "context-therapy" approach is focusing on the child in the context and gives a priority to adaptations in the activity and context as well as activity (Darrah et al. 2011). More specifically, "context-therapy" is seeking to promote the child's functional performance, to identify periods of change, to identify and tackle the barriers in the environment, and to provide opportunities for practice (Darrah et al. 2011).

There is no conclusive evidence base on which of these approaches is the best (Rodger and Kennedy-Behr 2017). The best available evidence suggests that individually tailored programmes which involved an establishment of collaborative relationship with parents, setting mutually agreed goals, selecting the most appropriate therapeutic activity for achieving each goal, educating and supporting parents on how to support children in performing these activities and measuring the outcome had a positive effect on children's participation (Adair et al. 2015). These individually tailored interventions which build on close collaboration with parents to achieve desired changes in children's participation are consistent with emerging theories and frameworks on how to achieve better outcomes in children (Graham et al. 2010; Rosenbaum and Gorter 2012; Novak 2014) and an ideology of client-centred approaches (Rodger and Kennedy-Behr 2017).

2.4.1 Client-centred approach

Participation-prompting intervention techniques, irrespective of their primary targets, should be meaningful for a client. In paediatric health and social care services, the client is both the person (child) and the family (Rodger and Kennedy-Behr 2017).

Person (child)-centred approach

Ensuring person (child)-centeredness at all stages of service delivery is one of the priorities within paediatric health and social care practice (Case-Smith and O'Brien 2015; Rodger and Kennedy-Behr 2017), and is believed to be instrumental to achieving positive intervention outcomes for children (Case-Smith and O'Brien 2015). The person-centred approach assumes intervention techniques focusing on activities that are meaningful to the child, matches to the child and family-identified goals and preferences, provides a choice and provokes a child's motivation for participation (Case-Smith and O'Brien 2015). The person-centred approach, therefore, requires the active engagement of both the child and

their families in the process (Case-Smith and O'Brien 2015; Rodger and Kennedy-Behr 2017). This is because children and their family are inextricably linked. Parents of children with disabilities are "experts" on their children's lives (Rodger and Kennedy-Behr 2017). They are well aware of the child's strengths, difficulties, worries and desires – a valuable piece of information for paediatric professionals (Case-Smith and O'Brien 2015). Dunst et al. (1994, p. 9) states that "the greatest impact on child, parent and family functioning is most likely to occur when interventions are based upon the needs, aspirations, and desires a family considers important".

Family-centred approach

Paediatric professionals have always recognized the value of involving families and exploring their issues and realities when working with children (Rosenbaum and Gorter 2012; Case-Smith and O'Brien 2015). A family-centred approach, which gained currency in child health promotion interventions over the last 20 years, provided an opportunity to put those aspirations into practice (Rosenbaum and Gorter 2012). A family-centred approach ensures that services are designed to fit the needs and values of the whole family, not just the person (child) (Case-Smith and O'Brien 2015), and in which family members are recognized as care recipients (Shields 2010). Individualization in a family-centred approach is essential as each family is unique with their own issues, realities, needs. Arrangements are made to ask about and learn how each family defines and describes its routines, values, issues and needs. Then mutually-agreed services are adapted to meet family-specified definitions and descriptions (Case-Smith and O'Brien 2015). Developing trusting relationships and actively collaborating with families to supply them with needed information, resources and targeted supports so that they can make informed choices benefitting both the child and the family is one of the central pillars of the family-centred approach (Rosenbaum and Gorter 2012). Such partnership supports the evolution of both parents and paediatric professionals towards improved competency in their inherent roles (Curley et al. 2013).

Empirical studies have supplied evidence on the effectiveness of a family-centred approach in paediatric practice. When services to children are provided in a family-centred way, parents report better satisfaction, improved physical and mental health functioning, and especially reduction in stress levels (Case-Smith and O'Brien 2015). Parents also display

increased willingness to take more active control and a more central role in the childcare process (Rosenbaum and Gorter 2012).

Family involvement in childcare interventions is not a new process. What is new is the recognition of and a greater focus on family's experiences, needs and wishes when planning, establishing and implementing intervention techniques directed to children's well-being (Rodger and Keen 2010; Rosenbaum and Gorter, 2012; Rodger and Kennedy-Behr 2017). No surprise, a recent development in the childhood disability the "F-words" (Rosenbaum and Gorter 2012) place family among the other five key areas of child development and encourages paediatric professionals to seriously consider family well-being when working with children and their families. The subsections below give a brief description of these "F-words" (Rosenbaum and Gorter 2012) which have been gaining momentum in paediatric health and social care services since their first publication in 2012.

2.4.2 The ICF-embedded "F-words"

Rosenbaum and Gorter (2012) developed a family of "F-words" describing six domains of life based on the ICF, and they encourage professionals, researchers and advocacy campaigners to adopt this way of thinking when working or advocating for children with disabilities and their families. The "F-words" stand for: Function, Family, Fitness, Fun, Friends and Future (Figure 3) (Rosenbaum and Gorter 2012).

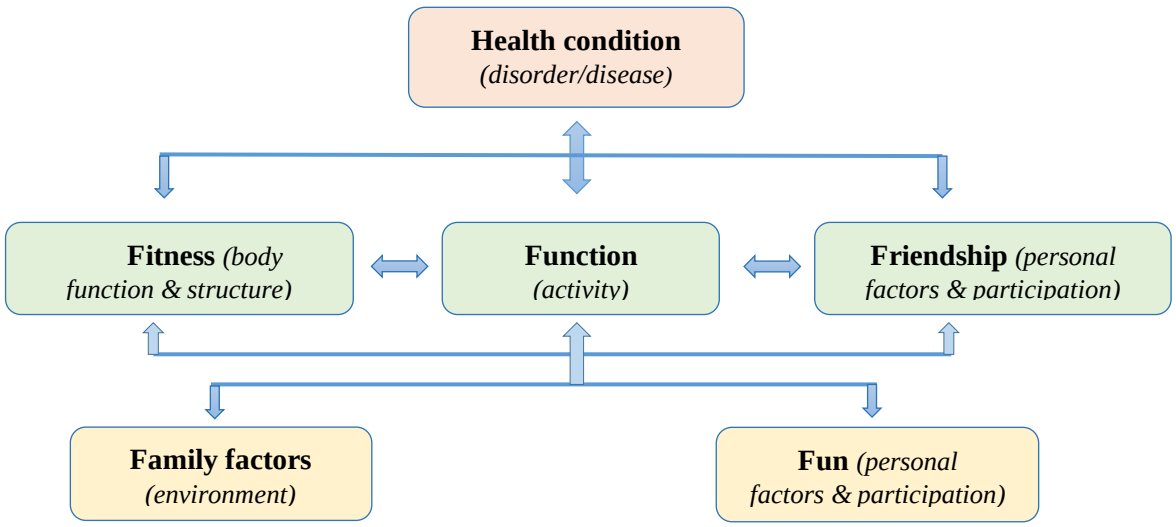


Figure 3. The ICF-embedded "F-words" and interconnections among them

Function is the first word (Figure 4). It represents the activity domain in the ICF-CY. Rosenbaum and Gorter (2012) suggest that performance improves with practice; therefore, paediatric practice should promote activity participation with no focus placed on the concept of "normality". Children should be encouraged to learn activities in their own way rather than the right way. Doing activities in their own unique way might gradually help children to develop specialized skills in those activities.

Family is the second "F-word" and is represented as environmental factors in the ICF-CY (Figure 3-4). Rosenbaum and Gorter (2012) argue that parents are the central "contextual factor" in the children's life. They have concerns, worries and their own needs that should be identified and addressed. Family-centred services, which treat family (parents, siblings, grandparents) as equal partners in the planning, delivery and continuity of childcare, are described as an effective and efficient approach in achieving better therapy outcomes for children (Rosenbaum and Gorter 2012). The authors also highlight the importance of the provision of needed supports and resources to facilitate informed parental decision-making in daily childcare (Rosenbaum and Gorter 2012).

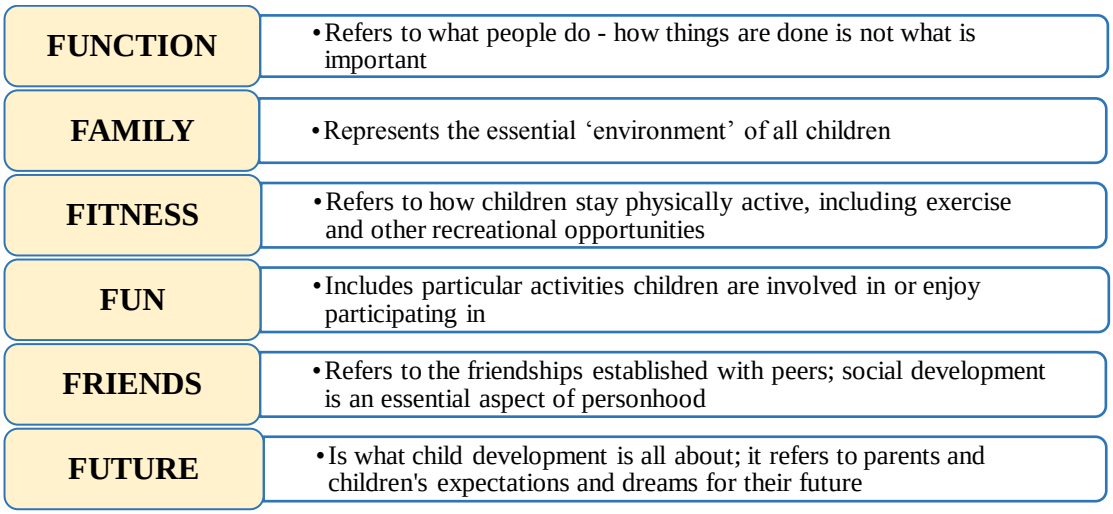


Figure 4. The "F-words" and definitions

Fitness is the third word and represents body function and structure in the ICF-CY (figure 3-4). The authors argue that children's fitness is neglected, yet is one of the important issues in childhood disability. Further research looking at factors contributing to children's

participation in physical activities and identifying ways of promoting participation in those activities is needed. Further, more recreational opportunities should be offered children to encourage greater levels of participation in physical activities (Rosenbaum and Gorter 2012).

Fun is the fourth "F-word" (Figure 4). It is represented as Personal factors and Participation in the ICF-CY (Figure 3). Involvement in meaningful life situations or activities (formal and informal) the child enjoys should be explored. Then adaptations should be made to activities to allow children to pursue the things they want to do in their own way so that they can build confidence, competence, and a sense of achievement and capacity (Rosenbaum and Gorter 2012).

Friends and friendships are the fifth "F-word" and represented in the same ICF-CY "space" as personal factors and participation (Figure 3-4). Social participation is essential for child development and should be actively facilitated. The authors further highlight that the quality of social relationships and friendships rather than quantity should be a primary aim. The professionals should collaborate with parents to identify issues surrounding social participation and find ways to encourage and enhance children's opportunities for socialization and friendship development (Rosenbaum and Gorter 2012).

Future is the sixth "F-word" not specifically represented in the ICF-CY (Figure 4). The professionals and parents need to actively think about children's future. The family and the child should be engaged in a dialog about expectations and wishes for a possible future. However, they should be not be discouraged by drawing attention to aspects of life that would be impossible to achieve (Rosenbaum and Gorter 2012).

2.5 Summary

The ICF-CY is a classification system and an overarching framework that describes the child's development, functioning and disability from a biopsychosocial perspective. The ICF-CY framework recognizes that children's functioning cannot be assessed in isolation but in the context of the family system which is the most immediate of a series of successive systems surrounding a child. It is believed that this perspective stems from the ecological systems theory of human development which makes a clear distinction between the

"layers" of developmental systems surrounding a child. According to this theory, elements of a family system, which is a part of microsystem nested within broader "layers" of the context, are in closer proximity to a child. Child development and functioning are most strongly influenced by bidirectional interactions happening within a family system and less strongly by events (structures) taking place in wider environmental systems.

According to the ICF-CY, the child's disability is a result of a negative interaction between a child's health condition and context within which the child functions. Participation is a natural term in the ICF-CY. It is defined as a societal involvement in everyday activities and real-world life situations. Participation restriction is described as problems the child may experience in involvement in those everyday activities and real-world life situations. According to the ICF-CY, participation can be measured by two qualifiers - Performance and Capacity. Capacity is defined as a child's full ability assessed in "a standardized environment or uniform environment" where the impact of environmental factors on a child's ability is neutralized. Performance is defined by what a child is "actually does" in their current environment.

The ICF-CY has acknowledged limitations. The ICF-CY gives clear descriptions to promote knowledge about the health condition, body structure and functioning of the child and how they are related. Less clear descriptions are provided around activity and participation domains and processes that operationalize these constructs. The ICF-CY definition of participation has been a subject of criticism and ongoing debate. Many alternatives to this definition have been proposed; limited scholarly consensus exists. Many scholars argue that the WHO has to rethink the way participation qualifiers are described in the ICF-CY. Additional qualifiers need to be added including (i) a qualifier measuring the frequency of participation (how often the child attends) and not only where the child attends or not, and (ii) a qualifier for subjective experience (the experience of participation while attending). Further, the contextual component described in the ICF-CY in terms of environmental factors and personal factors has limitations as well. For instance, despite acknowledging a key role of the family in children's functioning (especially during infancy and middle childhood), no specific classification of family factors is provided. Detailed classification of personal factors is missing altogether. These and many other shortcomings limit the capacity of researchers and paediatric professionals to establish effective interventions. Despite these shortcomings, however, the ICF-CY is a multidisciplinary,

public health-oriented conceptual framework of health, child functioning and disability which has strongly secured its central place in research concerned with childhood disability participation.

The conceptual framework of this doctoral research is guided by the ICF-CY framework. The key ideas adopted from the ICF-CY are:

(1) child's functioning cannot be seen in isolation but in the context of the family system – an immediate system of a series of successive systems surrounding the child,
(2) participation is a result of dynamic interaction between a child with a health condition and their contextual factors,
(3) participation can be assessed by the performance qualifier (the objective aspect of participation).

The performance qualifier describes objective aspect of participation or attendance - "being there". In line with scholarly calls, this work places a greater emphasis on the frequency (how often the child attends) aspect of participation.

Literature suggests that children with disabilities are at risk of restricted participation, especially in activities that are based in the community setting. Recent research further indicates greater restriction in participation in physical activities and friendship formation. This is concerning given that participation in community-based activities, especially in social and physical activities, contributes to children's social, emotional and physical development and has multiple mental and physical health benefits. Restricted participation in these activities implies that children with disabilities are at risk of not benefiting from positive health and developmental outcomes linked to participation.

To better support children's participation in their communities, professionals, local authorities and policy-makers need evidence from representative samples across different contexts. Previous research looked at the participation of children with disabilities and identified participation-associated factors to support professionals and other stakeholders in their efforts to improve services for children with disabilities and their families. Much of this research evidence, however, comes from clinical samples, especially children with

physical disabilities or/and small scale or convenience samples. Population-level evidence on children's characteristics, family circumstances, community-based participation profiles and participation frequency associated factors across various cultural contexts is lacking.

Furthermore, research evidence suggests that family has a great deal of influence on the lives of children with disabilities. Differences in family experiences produce important variations in participation which affect children's life experiences in and beyond childhood. Given this evidence and knowledge suggesting that children with disabilities spend more time with a family rather than in the community with friends, it is important to focus on the family unit and synthesize evidence on potentially modifiable family/parental factors consistently associated with childhood disability participation. Previous reviews synthesized evidence on childhood disability participation-associated factors. However, these reviews either focused on children with physical disabilities (especially cerebral palsy), or described an influence of a range of factors in specific settings or activities, or provided narrative evaluations only. No targeted synthesis of family factors consistently associated with the participation of children with disabilities has been completed so far.

The aims of this doctoral research are threefold:

(a) To synthesize evidence on family factors consistently associated with the participation of children with disabilities;
(b) To describe and compare the characteristics, family circumstances and community-based participation of a nationally representative sample of children with and without disabilities;
(c) To identify the child, family and community factors independently contributing to participation frequency of a nationally representative sample of children with disabilities in community-based social and physical activities.

Specific research questions (RQ) sought to be addressed are:

(1) What are the family factors associated with the participation of children with disabilities aged 5-12?
(2) What is the relative strength and consistency of these associations in children with disabilities aged 5-12?

(3) Are there any differences in the characteristics and family circumstances of a nationally representative sample of children with and without disabilities?
(4) Are there any differences in community-based participation of a nationally representative sample of children with and without disabilities?
(5) What are the independent effects of the child, family and community factors on participation frequency of a nationally representative sample of children with disabilities in community-based social and physical activities?

The chapter to follow describes the systematic review (Study I) completed in the scope of this doctoral research to meet the first research aim (RQ1-2). This work has been published in an open access, peer-reviewed journal.

CHAPTER 3 – A SYSTEMATIC REVIEW OF FAMILY FACTORS ASSOCIATED WITH PARTICIPATION OF CHILDREN WITH DISABILITIES

3.1 Introduction

Children do not live in isolation. They are a composite part of a family system (Bowen 1974) which is embedded in broader contexts (environmental systems) of their immediate community and beyond (Bronfenbrenner 1979; Seligman and Darling 2007). According to the ecological perspective of child development, children are in dynamic interaction between elements of a family system and many other environmental systems in which they are even not present (Bronfenbrenner 1979). According to the ICF-CY children's functioning cannot be evaluated separately from the family the child belongs to (Seligman and Darling 2007; WHO 2007). The dynamic interactions within subsystems of the family system are intense (Bronfenbrenner 1979, Case-smith and O'Brien 2015; Seligman and Darling 2007) and have a direct effect on child development and acquisition of skills and competencies necessary for participation (Case-smith and O'Brien 2015).

Each family is unique (Seligman and Darling 2007). A set of family characteristics or factors that define family uniqueness play an important role in shaping families' ideological style, interactional patterns, health beliefs, attitudes, values, functional priorities and behaviour (Seligman and Darling 2007). Family beliefs, attitudes, functional priorities and behaviours, which may be affected by family resources, cultural and ethnic background, religion, and family composition can influence the ways families adapt to the presence of childhood disability at home as well as a child's needs (Seligman and Darling 2007), including a need for participation across various settings.

Recognition of family's important role in shaping children's development, daily functioning and participation has resulted an increased research interest of identifying effects of various family factors on childhood disability participation (King et al., 2006; Law et al., 2006; Bedell et al. 2013; Rentinck et al. 2009; Law et al. 2013; Marquis and Baker 2015; Kamath et al. 2016). Although research on family factors and children's participation is extensive, evidence has been mixed.

Several attempts have been made by previous reviews to aggregate what appears as contested evidence (Shikako-Thomas et al. 2008; Bult et al. 2011; Anaby et al. 2013;

Shields et al. 2014; Tonkin et al. 2014; Bloemen et al. 2015). However, these reviews have described the influence of a wide range of factors on participation in specific activities (Bult et al. 2011; Bloemen et al. 2015; Li et al. 2016) or settings (Anaby et al. 2013), focused predominantly on children with physical disabilities (Shikako-Thomas et al. 2008; Bult et al. 2011; Bloemen et al. 2015; Li et al. 2016) or provided a narrative evaluation of the findings only (Shikako-Thomas et al. 2008; Bult et al. 2011; Anaby et al. 2013; Shields et al. 2014; Tonkin et al. 2014; Bloemen et al. 2015). Although this evidence is helpful, it provides an insufficient level of detail on potentially modifiable family factors consistently associated with participation - factors which can be prioritized as key targets of family-centred participation-promoting interventions.

Chapter 3 describes Study I – a systematic review completed in the scope of this doctoral research to find the answers to two research questions:

Research questions (1-2):

- What are the family factors associated with the participation of children with disabilities aged 5-12?
- What is the relative strength and consistency of these associations in children with disabilities aged 5-12?

Section 3.2 following the introductory section 3.1 describes methodological considerations for a systematic review. This is followed by the descriptions of methods in section 3.3. Findings of the review including the classification of factors into modifiable family "process" factors (what families experience and do) and non-modifiable or hard to modify "status" factors (who families are) and appraisal of evidence using a multistage "semi-quantitative" approach are presented in section 3.4. Section 3.5 is a discussion of the main findings, which is followed by sequential sections describing the strengths and limitations of the review and considerations for further research. Chapter 3 concludes by providing a summary in section 3.8 by highlighting the potential targets of family-centred participation promoting interventions.

3.2 Methodological considerations

Recently the field of structured evidence synthesis has witnessed the emergence of two types of reviews – scoping and systematic reviews. Clear guidance is now exists on when and how to conduct both a scoping (Peters et al. 2015) and a systematic review (Higgins and Green 2011). While there are some similarities between these reviews, there are also key differences (Munn et al. 2018). Research using systemized literature synthesis should make it clear why a systematic review, as opposed to a scoping review, was chosen as a tool of evidence inquiry (Munn et al. 2018).

A scoping review (sometimes also called scoping exercise or scoping studies) is a valid, structured approach to evidence inquiry for determining a scope or coverage of available literature on the topic of research interest (Peters et al. 2015; Munn et al. 2018). As such, a scoping review tends to be used for identifying and mapping emerging evidence, when there is not enough literature to guide the development of targeted questions to be addressed (Peters et al. 2015; Munn et al. 2018;). Key indications (Peters et al. 2015; Munn et al. 2018) for a scoping review are:

(a) to identify the scope of available literature in a given topic/field,
(b) to clarify key concepts and definitions in the literature,
(c) to examine how and what types of research are applied to investigate a given topic,
(d) to identify key contributing factors related to the concept,
(e) to identify and analyse the knowledge gap.

Munn et al. (2018) extended this list by adding that a scoping review is often a precursor for a systematic review – a more targeted synthesis designed to provide a complete, exhaustive summary of current international evidence relevant to a research question (Liberati 2009; Aromataris and Pearson 2014). A systematic review is conceptualized by the Cochrane handbook as a rigorous synthesis of all the empirical evidence from primary studies that meets pre-specified eligibility criteria to answer a specific research question (Higgins and Green 2011). Systematic reviews use structured, systematic and explicit methods to identify, select, critically evaluate review relevant literature, and to extract and analyze (either qualitatively or quantitatively) the retrieved data (Liberati 2009; Higgins and Green 2011; Aromataris and Pearson 2014; Munn et al. 2018). Following these

predefined steps of the review process allows minimizing bias. Thus, systematic reviews provide more reliable results from which conclusions can be drawn and decisions can be made (Higgins and Green 2011; Aromataris and Pearson 2014). These conclusions can inform clinical practice, policy or further research (Higgins and Green 2011). Key indications (Higgins and Green 2011) for a systematic review are:

(a) to uncover the international evidence,
(b) to confirm correct practice/address any variations/ identify new practice,
(c) to identify areas of further research,
(d) to draw a conclusion which can guide decision-making,
(e) to identify and explore conflicting or mixed results.

Given extensive literature on the topic of interest, aim and objectives sought, a systematic review was deemed as an appropriate approach to evidence inquiry for Study I.

3.3 Method

This systematic review followed the standards described in the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guideline (Moher et al. 2010) to ensure transparency and rigour in methodology. A protocol detailing the review aim, objectives, methods, data analysis plan, funding source and dissemination plan was developed *a priori* and registered with the international prospective register of systematic reviews – PROSPERO (registration number: CRD42017078202). The protocol can be accessed following this link: https://www.crd.york.ac.uk/prospero/#searchadvanced

3.3.1 Ethical considerations

In accordance to the QMU Ethical Guideline, systematic reviews are exempt from QMU Research Ethics Panel approval (QMU 2011). This implies that the Panel does not require any investigators undertaking a systematic review of primary literature at QMU to apply for ethical approval.

3.3.2 Inclusion and exclusion criteria

The Cochrane handbook (Higgins and Green 2011) makes it clear that research questions should be specific and clearly defined because they guide the eligibility criteria important for setting boundaries of the review. Given the research questions described in section 3.1, articles of interest for the review were limited to peer-reviewed literature published since 2001 in English aiming to establish a relationship between family factors and participation of children with disabilities aged 5 to 12 (mean age <12y). Key domains/concepts in need of predetermined definitions were: disability, family factors, participation. The presence of disability was identified through diagnosis presented in the article or identification of other health or educational support provisions. Family factors were defined as factors pertinent to the parents or family unit as a whole including any sociodemographic, psychological, behavioural and parental health-related factors. To ensure the inclusion of a wide range of articles, the ICF-CY's definition of participation as a child's "involvement in life situations" was applied (WHO 2007). Articles that considered known participation measures or in which participation items captured any combination of the ICF-CY's 9 activities and participation domains were included. Only observational studies (i.e. prospective and retrospective cohort, case-control, cross-sectional) that reported quantitative evidence on associations of interest were included. Summary of inclusion and exclusion criteria is presented in Table 3.

Table 3. Summary of selection criteria

Domains	Inclusion criteria	Exclusion criteria
Publication period	January 1st, 2001-September 26th, 2017	Prior to December 31st, 2000
Publication language	Articles published in English	Articles published in languages other than English
Publication type	Articles published in full text in peer review journals	Books, editorials, conferences, commentaries, abstracts, theses, dissertations and other "grey literature"
Population	Focus on children with disabilities (age range 5-12y, mean age <12y)	Focus on children with disabilities younger than 5 and older than 12 years old (adolescence); focus on typically developing children (age range 5-12y only).
Predictors	Focus on factors pertinent to parents or family unit as a whole including any sociodemographic, psychological, behavioural and parental health-related factors	Focus on physical factors of the home environment, physical and social factors in the community and school environment
Outcome	Participation, engagement, involvement	Focus on quality of life, behavioural difficulties
Study design	Prospective and retrospective cohort, case-control, cross-sectional	Case reports

3.3.3 Search strategy and screening

A systematic search was performed by the investigator for articles published in English between 2001 and September 2017 in MEDLINE (EBSCO), PsycINFO (EBSCO), CINAHL (EBSCO), Scopus (ProQuest) and ASSIA (ProQuest). Restrictions to the publication date were applied to capture the literature reflective of the WHO's ICF's definition of participation as a health indicator influenced by a dynamic interaction between multiple factors unique to an individual and the environmental factors (WHO 2001). Search terms were determined following the detailed assessment of indexing terms applied to a "known" set of articles meeting inclusion criteria for the review (Higgins and Green 2011) and finalized with an information specialist. A combination of subject headings and free-text terms for disability, age of participants, participation, family factors and study design were applied. Subject headings and keywords used in the MEDLINE database are provided below in Table 4.

Table 4. MeSH terms and keywords used in MEDLINE database

Disability	Age group	Determinant	Outcome	Study design
disabled children disabled persons motor skills disorder developmental disabilities intellectual disability communication disorders "disab*" "special N/1 needs"	child "child*" "girl*" "boy*" "schoolchild*"	family parents parenting social environment family characteristics residence characteristics "family health" "family relations" "interpersonal relations" "social support" "socioeconomic factors" "famil*" "parent*" "home environ*" "family environ*" "family context" "family factor*" "family predictor*" "family N/1 character*" "residence character*" "family health" "parental health" "family N/1 relation*" "interperson* relation*"	social participation community participation activities of daily living leisure activities recreation "participat*" "engage*" "involve*" "life N/2 situations" "human activit*" "leisure activit*	cohort studies longitudinal studies cross-sectional studies case-control studies "cohort stud*" "longitudinal stud*" "prospective stud*" "cross-sectional stud*" "case-control stud*" "model"

Disability	Age group	Determinant	Outcome	Study design
		"socioeconom* factor*" "family income" "finance* vulnerab*"		

Boolean operators (AND, OR) were used to combine the search words. Specially, the "OR" operator was used to combine the subject headings and keywords which describe the same or similar concepts, and the "AND" was used at the final stage combining all the concepts together. A detailed search strategy for the MEDLINE is provided in Appendix B.

Additional studies were identified by reviewing the reference lists of included articles. The contents pages of the following journals published between January 2012 and September 2017 were also manually searched to capture articles which may have been missed in a database search: *Developmental Medicine and Child Neurology, Archives of Physical Medicine and Rehabilitation, Disability and Rehabilitation, Child: Care, Health and Development and Research in Developmental Disabilities.*

The initial electronic search yielded *n*=2547 published articles. After removal of duplicates, 1532 titles and abstracts were screened for relevance by two independent researchers (SA and EC), resulting in 40 full-text articles retrieved for further eligibility assessment. Twenty-five articles corresponding to 21 individual studies met the inclusion criteria. Discrepancies in the agreement were resolved by consensus. A manual search identified an additional nine studies. The Flow chart is presented in Figure 5.

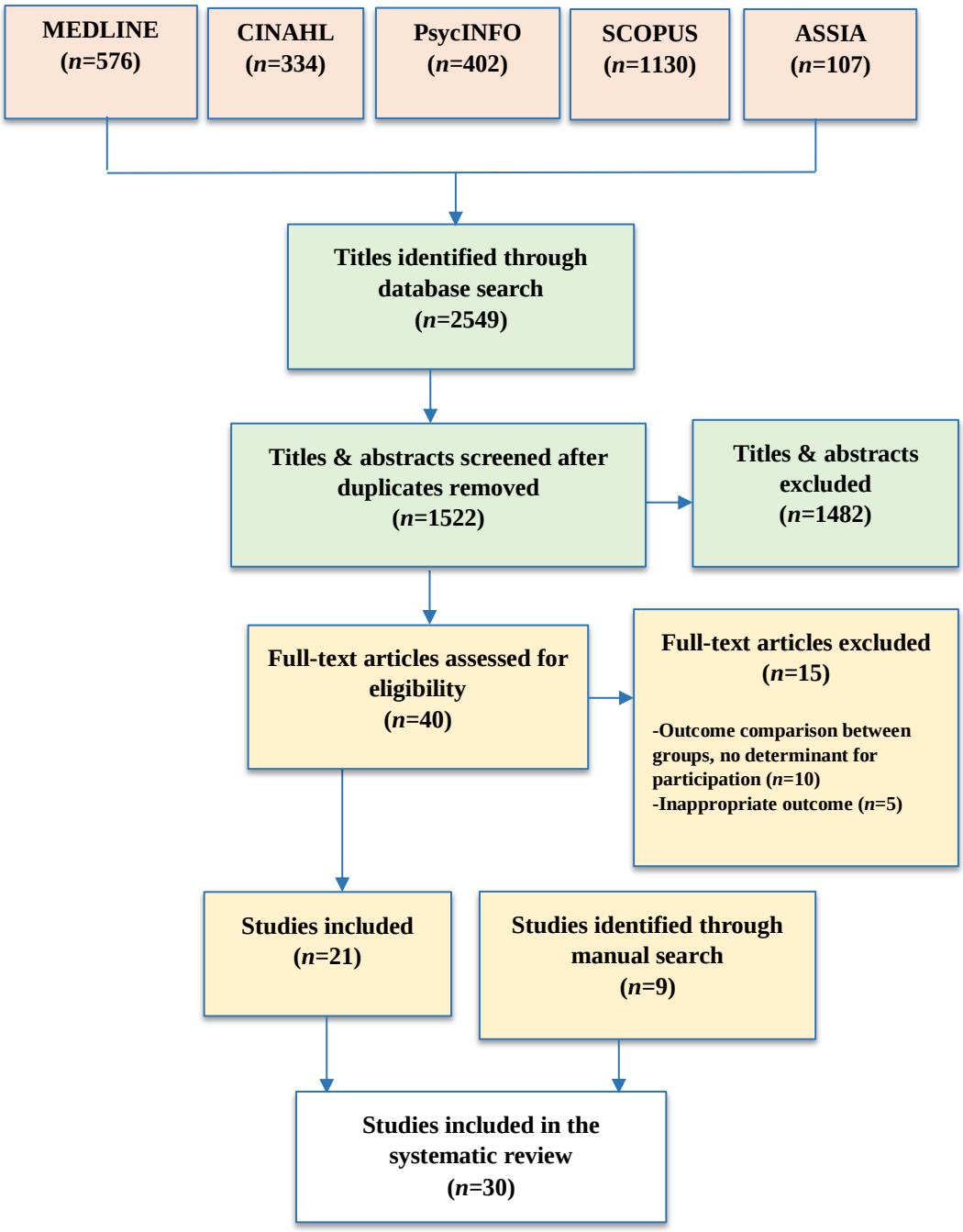


Figure 5. Flow diagram detailing study selection process

3.3.4 Data extraction

Data extraction was performed using a standardized, pre-piloted data extraction form by the investigator with the support of a colleague. The following details were extracted: (a) generic information: study author(s), years of publication, (b) data describing study aims, design and population, (c) details on family factors and participation outcome explored (i.e. activity types, settings, dimensions), (d) study results and information for the assessment of the risk of bias. For studies including both children with and without disabilities of a wider age group, results pertinent to children with disabilities in the targeted age group were extracted if available.

3.3.5 Quality appraisal

The quality assessment of articles reporting observational studies is a challenging but essential task to ensure that reported findings are reliable (Neyarapally et al. 2012). Many tools exist for evaluating the quality of observational studies. Up until now, however, no scholary consensus has been reached about which tool is the best (Neyarapally et al. 2012). Quality appraisal in this review was performed by the investigator and a colleague independently using the adapted version of the Research Triangle Institute Item Bank (RTI-IB) (Viswanathan and Berkman 2012). The RTI-IB as opposed to a more widespread tool - the Newcastle-Ottawa Scale (NOS) (a tool recommended by the Cochrane Collaboration) was used because the former has several advantages over the NOS.

The original RTI 29-item bank (IB) captures all the domains critical for evaluating observational studies: sample definition and selection; descriptions of interventions/exposure/outcomes; specification of treatment groups, blinding procedures; soundness of presented information; descriptions on follow-up; analysis performed - comparability, outcome; soundness of interpretations; evidence presentation and reporting. The ITR-IT is presented as a checklist with summary statements allowing for an informed assessment of the risk of bias for the given study design (Sanderson et al. 2007). Further, the RTI-IB has undergone comprehensive face, content validity and reliability testing (Viswanathan and Berkman 2012). The RTI-IB has good psychometric properties (Viswanathan and Berkman 2012), and most recently, has been used to assess the risk of bias and precision of several observational studies (Galland et al. 2015; Senra et al. 2015).

The NOS, on the other hand, allows quality evaluation of limited domains: sample definition and selection, comparability of study groups, and the ascertainment of exposure (for case-control studies) or outcome of interest (for cohort studies) (Wells et al. 2013). The NOS is presented as a scale where the supposedly best answer is assigned with a star. Evidence suggests that these types of rating systems are prone to misinterpretation of bias unless clear guidance is provided on how the scores are weighted (Sanderson et al. 2007). It further lacks psychometric validity (Hartling et al. 2013) and reliability (Hartling et al., 2013; Lo et al. 2014).

From the descriptions presented it becomes clear that the original RTI 29-IB is complex. However, the tool allows customization from the investigator based on research needs (Viswanathan and Berkman 2012). The investigator adapted the tool to fit the review objectives. The tailored RTI 14-item tool assessed the selection bias, detection bias, attrition bias, selective outcome reporting, confounding and validity of the interpretation of studies (Table 5). Possible response categories to each item were combinations of "yes", "no", "partially", "cannot determine", and "not applicable". For ease of interpretation, the categories "cannot determine" and "partially" were collapsed into "unclear risk of bias" category. Agreement between two researchers was assessed by a joint probability agreement. All the discrepancies in opinion were resolved by consensus.

Table 5. RTI 14-item bank

Domains	Items	Criteria
Sample definition and selection	I_1	Inclusion/exclusion criteria clearly stated
	I_2	Inclusion/exclusion criteria: measures valid and reliable
	I_3	Inclusion/exclusion criteria: applied uniformly
	I_4	Sufficient sample size
Creation of exposure groups	I_5	Selection of the comparison group is appropriate
Soundness of information	I_6	Exposures assessed using valid and reliable measure
	I_7	Outcomes assessed using valid and reliable measures
Follow-up	I_8	Length of follow-up is the same for all groups
	I_9	Attrition from any group exceeds 30% percent
	I_{10}	Attrition differs between the groups by more than 20%
Analysis comparability	I_{11}	Confounding and effect modifying variables are accounted for
Analysis outcome	I_{12}	If high loss to follow-up: the impact assessed
Appropriate analytic method	I_{13}	Any primary outcomes are missing from the results
Interpretation	I_{14}	Results believable taking limitations into account

3.3.6 Data analysis

Initially, it was thought that synthesized evidence can be meta-analysed by directly combining or aggregating the standardized regression beta-coefficients *(βs)* (Borenstain et al. 2009; Cooper et al. 2009). To directly combine standardized β coefficients, the following three assumptions (Cooper et al. 2009) should be met: (1) the outcome and predictor should be measured in a similar way, (2) the covariates included in the models should be the same across studies, (3) the outcome and predictor scores should have similar distribution. Analysis of the final pool of studies included in this review revealed that none of these assumptions could be satisfied.

Literature was searched to identify alternative methods of combining the standardized β coefficients in meta-analysis. The direct conversion of standardized β coefficients to Pearson's zero-order correlational coefficient (r) has been proposed by Peterson and Brown (2005) applying the following formula:

$$r = \beta + 0.05\lambda$$

if β resided in the interval ±0.50. The authors argue that the standardized β coefficients are highly correlated (r=0.84) to r irrespective of the sample size and the number of covariates in a regression equation (Peterson and Brown 2005). Synthesizing and combining regression coefficients following this formula attracted substantial attention in recent years (Backer and Wu 2007). Recent evidence opposes the use of this approach because it generates biased findings (Roth et al. 2018). Further calls have been made for a correlational meta-analysis to use Pearson's zero-order correlational coefficient only (Roth et al. 2017).

Pearson's zero-order correlational coefficient has been reported in only 2 of our 30 studies included in this review (King et al. 2006; Bult et al. 2013). Attempts were made to convert alternative effect size measures into Pearson's zero-order correlation coefficient using the formulas described by Borenstein et al. (2009). Incomplete reporting of findings (e.g. in some cases only significant results were reported) and statistics necessary for the calculation of r or alternative effect sizes (Borenstein et al. 2009; Cooper et al. 2009) precluded this. Further attempts to obtain required statistical information resulted in only a few corresponding authors acknowledging the receipt of data requests. Results were

therefore synthesized and interpreted using a multistage "semi-quantitative" approach (Sallis et al. 2000; Li et al. 2016). If meta-analysis is not possible such an approach is superior to narrative reporting because it provides objective evidence on strength, direction and consistency of associations (Li et al. 2016). Firstly, family factors assessing the same underlying construct but using different terms to describe it were combined into a single identifying factor (Table 6).

Table 6. Factors combined into a single identifying factor

Family factors	
Factors (domain(s) measured)	**Single Identifying Factor**
Household poverty status	Socio-economic status
Socio-economic status	
Socio-economic disadvantage	
Family structure	Family type
Family type	
Single-parent status	
Parental stress (psychological well-being)	Mental health functioning
Parental mental health functioning (psychological/emotional/social well-being)	
Parental self-efficacy beliefs	Self-efficacy beliefs
Mother self-efficacy beliefs	
Parental sense of competence (perception of role/efficacy)	
Attitudes (family/friends)	Attitudes
Attitudes (home/community)	
Social support at home	Supports (for the child)
Parental support	
Parental involvement	
Supports (parent/community)	
Supports (home/community)	
Family structure & relationships (organization/conflict/cohesion)	Family relationships
Family cohesion	
Family intellectual-cultural orientation (preferences for intellectual activities)	Family preferences & activity orientation
Family active-recreational orientation (participation in recreational activities)	
Financial impact	Financial resource
Adequacy of money	
Availability of time	Time resource
Maternal hours worked	
Time impact	
Family support	Supports (for the family)
Familiar assistance	
Family social support	

Secondly, factors were classified into two major groups adapted from previous literature (Christenson et al. 1992; Fan and Chen 2001): family "status" and family "process" factors. Thirdly, for family factors examined by two or more studies two parameters were calculated (Sallis et al. 2000; Li et al. 2016):

(a) the number of studies that attempted to establish relationships between family factors and participation,
(b) the number of studies that established the relationship as significant (p<0.05).

Then, the percentage of studies supporting the established relationship with participation was computed by dividing the number of studies that established a significant relationship by the total number possible. From the obtained percentage value, it was determined whether the family factor and participation outcome had a positive or negative association, inconsistent association, or no association. Family factors association for which was supported by ≥60% (Sallis et al. 2000; Li et al. 2016) of studies were considered as factors associated with participation. The rules of classifying the consistency of evidence were adapted from previous research (Sallis et al. 2000; Li et al. 2016) and are summarised in Table 7.

Table 7. Rules of classifying the strength of evidence

Percent of studies supporting association (%)	Coding	Code meaning
0-33	0	No association
34-59	?	Inconsistent association
60-100	+	Positive association
	-	Negative association

Note. The rules of classifying the strength of evidence are adapted from Sallis et al 2000.
Double summary codes: "++", "--", "00" are applied when ≥ 3 studies support a positive/negative association or no association; "??" is applied when the factor has been studies frequently but findings are inconsistent.

3.4 Results

Thirty studies were included in the review. The detailed description of the characteristics of these studies is supplied in Table 9. Prior to 2010, only six articles (King et al. 2006; Law et al. 2006; Majnemer et al. 2008; Dunn et al. 2009; Imms et al. 2009; King et al. 2009) reporting on four unique samples of children with disabilities met our inclusion criteria (Figure 6). This is reflective of the increased volume of research into children's participation over the last decade.

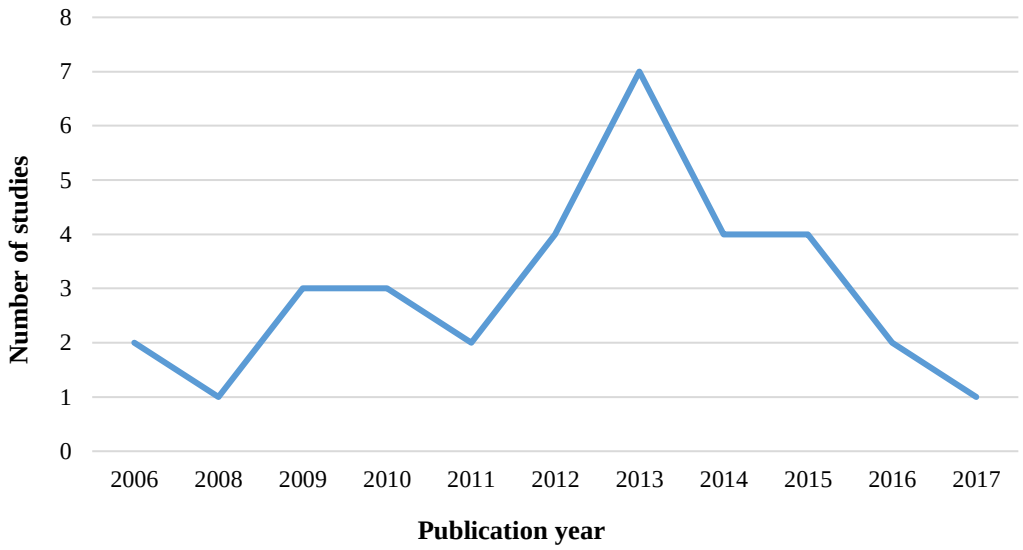


Figure 6. A trend in childhood disability participation research

Six studies shared samples, (Parkes et al. 2010; Colver et al. 2012; Bult et al. 2013; Ullenhag et al. 2012; Ullenhag et al. 2014; Tan et al. 2016) but differed substantially in the methodology and sample sub-groups. These were retained as individual studies. Studies were conducted in Europe (9), Canada (7), United States (5), collaboratively between Canada and United States (2), Australia (4), Israel (3) (Figure 7). Except for four longitudinal studies (King et al. 2009; McCormack et al. 2011; Bult et al. 2013; Tan et al. 2016), all studies used a cross-sectional design (Table 8).

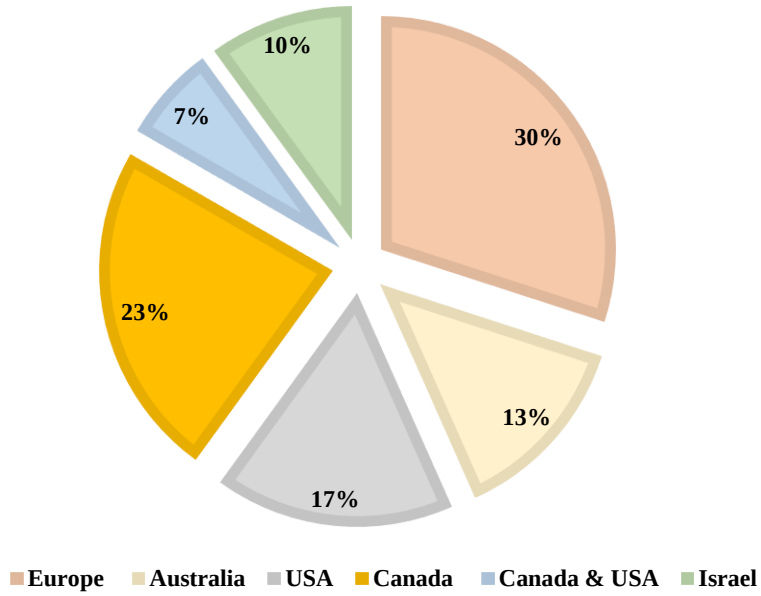


Figure 7. Proportions of research outputs on childhood disability participation by country

Table 8. Characteristics of included studies

First author (year)/ Country	Study Design	Participant details			Exposure(s) of interest	Exposure(s) measure(s)	Outcome(s) of interest	Outcome(s) measure(s)/ Dimensions	Key results
		n (total)	Age range (mean)	Health condition					
Anaby (2014)[a]/ Canada & USA	Cross-sectional	282 (576)	5-17 (11.2)	Mixed disabilities	Family income	Demographic Questionnaire	Home participation School participation Community participation	PEM-CY/ Frequency Involvement	Family income was positively associated with participation frequency (β=0.12, p<0.05) and involvement (β=0.13, p<0.05) at home, and participation frequency (β=0.10, p<0.05) and involvement (β=0.12, p<0.05) at school. Family income was directly associated with participation involvement (β=0.09, p<0.05) in the community and had a significant indirect effect on participation frequency in the community through community barriers.
Axelsson (2013)/ Sweden	Cross-sectional	60 (167)	5-20	Profound intellectual & multiple disabilities	Family income, Parental education	Demographic Questionnaire	Family activities	Child-PFA/ Frequency Engagement With whom Personal assistance Technical aid	Family income was negatively correlated with engagement in shopping for groceries activities (r=-0.435, p<0.01). Parental education was negatively correlated with doing handicraft (r=-0.334, p<0.05) and playing outside with adult (r=-0.348, p<0.05). Maternal education was negatively correlated with doing handicraft (r=-0.561, p<0.01), playing board games (r=-0.340, p<0.05), laying the table (r=-0.353, p<0.05) and doing morning routines (r=-0.303, p<0.05).
Bedell (2013)[a]/ Canada & USA	Cross-sectional	282 (576)	5-17 (11.2)	Mixed disabilities	Adequacy of money, Availability of time	PEM-CY	Community participation	PEM-CY/ Frequency Involvement	A significant group differences were found between parents of children and youth with disabilities versus parents of peers without disability in respect to inadequacy of money (chi-square statistics of association 24% vs 3%, p<0.00) and time (chi-square statistics of association 19% vs 3%, p<0.001) in

First author (year)/ Country	Study Design	Participant details			Exposure(s) of interest	Exposure(s) measure(s)	Outcome(s) of interest	Outcome(s) measure(s)/ Dimensions	Key results
		n (total)	Age range (mean)	Health condition					
									supporting their children's participation in the community.
Bult (2013)/ Netherlands	Cohort	46	5-8	Cerebral palsy	Socio-economic status, Parental stress, Parental coping, Personal participation, Family participation, Family supports, Parental quality of life	Parenting Stress Index, Utrecht Coping List, Questionnaire for measuring supports and quality of life, Postal Coding derived from Statistics Netherlands	Leisure participation	CAPE/ Intensity	The feeling of being restricted in family participation when child was aged 2.5 was negatively associated with participation in formal (R^2=12%, p<0.05) and informal activities (R^2 =25%, p<0.05) when child was 6 years old. Parental stress and parental quantity of life measured when child was 2.5 was associated with informal participation only. Socio-economic status, parental coping, familiar support were not predictors of future participation in leisure activities.
Cavallo (2015)/ Canada	Cross-sectional	4,350[c]	5-14	Arthritis	Family income	PLAS survey	Leisure participation	PLAS survey/ Frequency Diversity	Family income was positively associated with more frequent participation in total leisure activities (β=0.45, 95% CI 0.05,0.86, p<0.05) and informal leisure activities (β=0.47, 95% CI 0.09,0.85, p<0.05). Family income was associated with more frequent participation in physical activities (β=0.75, 95% CI -0.07,1.58), sedentary (β=0.34, 95% CI -0.02,0.70), non-sport skill based (β=0.29, 95% CI -0.36,0.95) and formal activities (β=0.41, 95% CI -0.21,1.03).
Colver (2012)/ Europe	Multi-centre cross-sectional	818	8-12	Cerebral palsy	Social supports at home, Attitudes family & friends	European Child Environment Questionnaire	Participation in everyday activities	LIFE-H/ Difficulty with participation	Social supports at home (β=0.35, 95% CI 0.19,0.5, p<0.001) and attitudes of family and friends (β=0.13, 95% CI 0.06,0.19, p<0.001) were positively related to participation in responsibilities. Attitudes of family and

First author (year)/ Country	Study Design	Participant details			Exposure(s) of interest	Exposure(s) measure(s)	Outcome(s) of interest	Outcome(s) measure(s)/ Dimensions	Key results
		n (total)	Age range (mean)	Health condition					
									friends were positively associated with participation in relationships (β=0.22, 95% CI 0.10,0.33, p<0.001). Supports at home (β=0.35, 95% CI 0.20,0.5, p<0.001) and attitudes of family and friends (β=0.14, 95% CI 0.06,0.23, p=0.001) were related to participation in recreational activities.
Dunn (2009)/ USA	Cross-sectional	22 (44)	9-11	Attention deficit hyperactivity disorder	Family routines, Child's impact on the family, Parental stress, Parental sense of competence, Parental education, Number of siblings, Presence of older sibling, Presence of younger sibling	Conners' Parenting Rating Scale Revised Short Form, Family Time & Routine Scale, Parent Stress Index, Parenting Sense of Competence, Demographic Questionnaire	Participation in household tasks	CHORES/ Performance Assistance	Presence of an older sibling (B=2.27, $SE(B)$=1.13, β=0.29, p=0.04) and higher importance of family routines (B=0.18, $SE(B)$=0.07, β=0.34, p=0.02) were predictors for diversity of participation in household tasks. Parental stress and presence of an older sibling were predictors for amount of assistance the child required in participation. Parents' perspectives on parental competence, child's impact on parents, number of siblings, the presence of a younger sibling and parental educational level were not predictors of participation.
Engel-Yeger (2013)/ Israel	Cross-sectional	45 (70)	6-11	Hearing/ visual impairments	Parental education, Socio-economic status	Demographic Questionnaire	Leisure participation	CAPE/ Intensity Diversity Enjoyment With whom Where	Parental education was positively correlated with participation in self-improved activities with someone (r=0.48, p<0.01) and outside home (r=0.53, p<0.01) among children with hearing, but not with visual impairments. Socio-economic status was correlated with participation in active physical activities at home (r=-0.49, p<0.05) and with higher enjoyment (r=0.48, p<0.05) among

First author (year)/ Country	Study Design	Participant details			Exposure(s) of interest	Exposure(s) measure(s)	Outcome(s) of interest	Outcome(s) measure(s)/ Dimensions	Key results
		n (total)	Age range (mean)	Health condition					
									children with visual, but not hearing impairments.
Furtado (2015)/ Spain	Cross-sectional	102	6-17 (9.98)	Cerebral palsy	Supports from family/community; Attitudes from family/community	Craig Hospital Inventory of Environmental Factors	Participation	SFA/ Level of participation	Supports and attitudes at home and in the community had a very weak effect on school participation.
Houtrow (2012)/ USA	Cross-sectional	15,049 (64,076)	6-17	Health related special educational needs	Parental ethnicity, Household poverty status; Family type	NSCH survey	Participation	NSCH survey /	Being of Hispanic ethnicity was associated with increased odds of not participating in organised activities (*OR*=1.60, 95% CI 1.13,2.28, $p<0.05$). Living in poverty was associated with participation restriction in organised activities (*OR*=5.11, 95% CI 3.53,7.39, $p<0.05$). Living in a single-parent household was related with increased odds of not participating in organised activities (*OR*=1.38, 95% CI 1.07,1.79, $p<0.05$).
Imms (2009)/ Australia	Cross-sectional	108	11.7	Cerebral palsy	Family structure, Socio-economic status	Demographic Questionnaire, Socio-Economic Index derived from Australian Bureau of Statistics	Leisure participation	CAPE &PAC/ Diversity	Socio-economic status was not significantly associated with diversity of participation in informal (*B*=0.94, 95% CI -0.14,2.02, $p=0.09$) and in formal (*B*=0.05, 95% CI -0.38,0.47, $p=0.84$) leisure activities. There was no association between family structure and participation in leisure.
Kamath (2016)/ Canada	Cross-sectional	426	8-14	Epilepsy	Family structure, Parental support, Family income	Social Support Scale, Demographic Questionnaire	Leisure participation	CAPE/ Intensity Diversity	Family structure was positively associated with intensity ($\beta=0.14$, $p<0.01$) and diversity ($\beta=0.12$, $p<0.05$) of participation in leisure activities. Parental social support was negatively associated with diversity of participation in leisure activities ($\beta=-0.09$, $p<0.05$).

First author (year)/ Country	Study Design	Participant details			Exposure(s) of interest	Exposure(s) measure(s)	Outcome(s) of interest	Outcome(s) measure(s)/ Dimensions	Key results
		n (total)	Age range (mean)	Health condition					
Khetani (2014)/ USA & Canada	Cross-sectional	23	5 -17 (11.9)	Developmental delay	Family income	Demographic Questionnaire	Community participation	PEM-CY/ Frequency Involvement	Children from families earning higher income participated in community activities more often (d=0.61, p=0.004).
King (2006)[b]/ Canada	Cross-sectional	427	6–14 (10)	Physical disabilities	Family income, Family intellectual-cultural orientation; Family participation in social & recreational activities, Family cohesion, Supportive relationships for the child, Absence of financial and time impact on family	Demographic Questionnaire, Craig Hospital Inventory of Environmental Factors, IOF Financial Impact Scale, Parent Impact Time Scale, Social Support Scale, Family Environment Scale	Leisure participation	CAPE/ Intensity	Family participation in social and recreational activities was associated with participation intensity in informal activities (β=0.18, p<0.05). Family intellectual-cultural orientation (β =0.16, p<0.05) and participation in social and recreational activities (β =0.18, p<0.05) was associated with participation intensity in formal activities. Family cohesion and supportive relationships had a significant indirect effect on participation intensity in leisure activities.
King (2009)[b]/ Canada	Cohort	427	6–14 (10)	Physical disabilities	Family income, Parental ethnicity, Parental physical and mental functioning, Family cohesion, Family active-recreational orientation, Family intellectual cultural-orientation	Demographic Questionnaire, Short Form Health Survey-36, Craig Hospital Inventory of Environmental Factors, Family Environment Scale	Leisure participation	CAPE/ Intensity	Family income was a significant predictor for participation intensity in social activities for children aged 6-8 (β =0.28, p<0.05). Being of ethnicity other than Caucasian was related to decline in participation intensity in physical activities (β=0.35, $p\leq$0.001) for children with physical disabilities aged 11-15. Parental physical functioning was a significant positive predictor for decline in participation, but mental health was not.
King (2013)[b]/ Canada	Cross-sectional	427 (781)	6-14 (10)	Physical disabilities	Family income	Demographic Questionnaire	Leisure participation	CAPE/ Intensity Enjoyment	Family income was significantly associated with participation intensity in physical activities (β=0.13, p<0.05) and self-improvement activities (β

First author (year)/ Country	Study Design	Participant details			Exposure(s) of interest	Exposure(s) measure(s)	Outcome(s) of interest	Outcome(s) measure(s)/ Dimensions	Key results
		n (total)	Age range (mean)	Health condition					
									=0.12, p<0.05) for children with physical disabilities.
Law (2006)[b]/ Canada	Cross-sectional	427	6–14 (10)	Physical disabilities	Family income, Parental education, Family type	Demographic Questionnaire	Leisure participation	CAPE/ Intensity Diversity	Participation intensity in total leisure (p=0.007) and physical activities (p=0.001) was lower in children living in a single-parent households. Participation diversity in leisure activities was lower in families with lower income (p=0.007), lower parental education level (p=0.01) and in children living in single-parent households (p=0.002).
Majnemer (2008)/ Canada	Cross-sectional	67	(9.7)	Cerebral palsy	Family coping, Parental stress, Family income	Demographic Questionnaire, Parental Stress Index, Impact on Family Scale	Leisure participation	CAPE/ Intensity Diversity Enjoyment	Parental stress was negatively associated with participation intensity in self-improved activities (β=-0.03, p<0.017), and participation diversity in recreational activities (β=-0.05, p<0.035). Children for whom parents reported high level of stress were less likely to enjoy most types of activities. Family coping and income were not identified as determinates of participation.
Marquis (2015)/ USA	Cross-sectional	63 (161)	6-8	Developmental disability	Maternal education, Maternal hours worked, Parenting stress, Negative parenting, Child's impact on the family	Demographic Questionnaire, Family Impact Questionnaire, Parent-Child Interaction rating System	Sports participation	CBC/ Diversity	Maternal hours worked was negatively associated with a number of sport played by children with and without disabilities aged 6 (β=-0.18, p<0.05). Parental education (β=0.20, p<0.05) and parents' perception of their children's positive impact on their family (β=0.23, p<0.05) were positively associated with number of sport played by all children aged 8.

First author (year)/ Country	Study Design	Participant details			Exposure(s) of interest	Exposure(s) measure(s)	Outcome(s) of interest	Outcome(s) measure(s)/ Dimensions	Key results
		n (total)	Age range (mean)	Health condition					
Masse (2013)/ Canada	Cross-sectional	77,470[c]	5-14	Neurodevelopmental disorder	Family income, Familiar assistance	PALS survey	Participation in physical activities, educational activities, social/recreational activities	PALS survey/ Frequency Diversity	Children from lower income families had decreased odds for participation frequency in supervised physical activities (*OR*=0.42, 95% CI 0.29,0.62, *p*<0.001), music/art lessons (*OR*=0.53, 95% CI 0.36,0.79, *p*=0.002). Familiar assistance was insignificantly related with increased odds for participation frequency in supervised (*OR*=1.41, *p*=0.24) and unsupervised (*OR*=1.91, *p*=0.053) physical activities.
McCormack (2011)/ Australia	Cohort	1041 (4,329)	7 - 9 (8.25)	Communication impairment	Socio-economic status, Indigenous status	Demographic Questionnaire	Activity and Participation based on conceptualisation of the ICF	ALS, ARSLLS, ARSMTS, SDQ, SATI, PPVT-III, MSDQ-III, STRS/ PST	Socio-economic status and Australian indigenous status were significantly associated with participation of children with communication impairments.
Must (2015)/ USA	Cross-sectional	53 (111)	3 - 11 (6.6)	Autism spectrum disorder	Parental perception of activity demands; Parental beliefs about activity	Questionnaire developed by the research team	Participation in physical activity	A parent-completed questionnaire/ Intensity Diversity	Children of parents who had negative perception of activity demands (e.g. difficult to make necessary arrangements) and negative beliefs about activities (e.g. too overstimulating for my child) participated in fewer physical activities (*p*<0.05) and had higher screen time on weekdays (*p*<0.01) and weekends (*p*<0.05).
Oates (2011)/ Australia	Cross-sectional	208	5-18	Down syndrome	Family income, Parental support, Parental availability of time, Parental physical & mental health functioning	Family Resource Scale, Family Support Scale, Short Form Health Survey-12	Leisure participation	Your Child questionnaire/ Intensity Diversity	Children with better parental mental (*OR*=1.04, 95% CI 1.01,1.07, *p*=0.01) and physical health (*OR*=1.03, 95% CI 1.00,1.07, *p*=0.03 and more family & community support (*OR*=1.04, 95% CI 1.01,1.08, *p*<0.001) had increased odds of having two or more friends. Parental availability of time was associated with

First author (year)/ Country	Study Design	Participant details			Exposure(s) of interest	Exposure(s) measure(s)	Outcome(s) of interest	Outcome(s) measure(s)/ Dimensions	Key results
		n (total)	Age range (mean)	Health condition					
									increased odds of having 2 or more friends (*OR*=1.05, 95% CI 1.01,1.09, *p*=0.01) and having of two or more hobbies (*OR*=1.05, 95% CI 1.01,1.09, *p*=0.01). There were no associations between family income and children's participation in friendships, sport and hobbies.
Palisano (2011)/ USA	Cross-sectional	288	6-12 (9.8)	Cerebral palsy	Family structure & relationships (organization/ cohesion/conflict), Family activity orientation, Parental education, Family income	Demographic Questionnaire, Family Environment Scale	Leisure participation	CAPE/ Intensity	Family activity orientation is positively associated with intensity of participation in leisure activities (β =0.27, p<0.05). Parental education was indirectly associated with intensity of participation through family activity orientation. Family structure and relationships were indirectly related to participation intensity through child adaptive behaviour. Association between income and participation was very weak and non-significant (β=0.07).
Parkes (2010)/ UK	Cross-sectional	102 (928)	8-12	Cerebral palsy	Parental stress	Parent Stress Index	Participation in everyday activities	Life-H & FPQ/ Difficulties with participation Type of assistance required Frequency	Parental stress was associated with decreased odds of children's participation in community activities (*OR*=0.2, 95% CI 0.1,0.7, p<0.05).
Rekkedal (2017)/ Norway	Cross-sectional	167	5-10 grades	Hearing loss	Parental involvement	ICF-CY framework	School participation	ICF-CY/ Attentiveness Involvement	Parental support was moderately correlated with children's social participation and participation in academic activities at school (r=0.25, $p\leq$0.01) and (r=0.40, $p\leq$0.01), respectively.

First author (year)/ Country	Study Design	Participant details			Exposure(s) of interest	Exposure(s) measure(s)	Outcome(s) of interest	Outcome(s) measure(s)/ Dimensions	Key results
		n (total)	Age range (mean)	Health condition					
Rosenberg (2010)/ Israel	Cross-sectional	231 (480)	4-6 (5.16)	Mild to moderate developmental disabilities	Family income	Not reported	Participation in everyday activities	CPQ &VABS/ Intensity Diversity Child Independence Enjoyment Parental satisfaction	Children from families with below-average income participated in fewer activities compared to those from above-average income ($\mu \pm SD$ 35.26±4.30 vs 39.21±2.06, $p<0.05$). Children from below average income had higher participation intensity ($\mu \pm SD$ 4.01±0.36 vs 3.82±0.22, $p<0.001$), were more independent ($\mu \pm SD$ 5.15±0.54 vs 4.85±0.53, $p<0.05$) and enjoyed more ($\mu \pm SD$ 5.47±0.38 vs 5.19±0.39, $p<0.05$) everyday activities compared to peers from families with above average income.
Rosenberg (2013)/ Israel	Cross-sectional	78 (188)	4-6 (5.27)	Mild to moderate developmental disabilities	Family income, Maternal education, Maternal self-efficacy beliefs, Parental self-efficacy beliefs	Environmental Restriction Questionnaire, Parental Self-Efficacy Beliefs Questionnaire, Socio-Economic Questionnaire	Participation in everyday activities	CPQ/ Intensity Diversity Child Independence Enjoyment Parental satisfaction	Family income was positively associated with diversity (β=0.27, $p<0.0001$) and negatively with intensity (β=-0.19, $p<0.05$) of participation for children with and without disabilities. Maternal self-efficacy beliefs (SEB) were positively associated with participation diversity in everyday activities for children with low process skills (B=1.66, SE=0.45, $p<0.001$) and lower independence for children with mild developmental disabilities. Parental SEB were associated with higher enjoyment for all children (β =0.27, $p<0.001$). Maternal education, income, maternal SEB and parental SEB made significant contributions of 13-21% to the overall explained variance in participation.

First author (year)/ Country	Study Design	Participant details			Exposure(s) of interest	Exposure(s) measure(s)	Outcome(s) of interest	Outcome(s) measure(s)/ Dimensions	Key results
		n (total)	Age range (mean)	Health condition					
Shields (2015)/ Australia	Cross-sectional	286	11.5	Mixed disabilities	Socio-economic status	Index of Relative Socio-Economic Disadvantage	Leisure participation	CAPE & PAC/ Diversity	Socioeconomic status was associated with participation diversity of children with disabilities in out-of-school leisure activities (*B*=0.01, 95% CI 0.00,0.02, $p<0.03$).
Soref (2012)/ Canada	Cross-sectional	29 (58)	4.5 -5.9 (5.14)	Mild motor disabilities	Parent self-efficacy beliefs, Parental education, Parental religion, Parental ethnicity, Family structure, Socio-economic status	Parental Self-Efficacy Questionnaire, Socio-Demographic Questionnaire	Participation in everyday activities	CPQ/ Intensity Diversity Child Independence Enjoyment Parental satisfaction	Maternal self-efficacy beliefs (β=0.27, $p<0.05$) and socio-economic status (β =0.30, $p<0.05$) predicted participation diversity in daily activities. Maternal self-efficacy beliefs also predicted participation intensity (β=0.40, $p<0.01$), child independence (β=0.37, $p<0.01$), parental satisfaction (β=0.30, $p<0.05$) and child enjoyment (β=0.27, $p<0.05$) when participating. Parental education was negatively associated with parental satisfaction (β=-0.31, $p<0.05$) and child participation enjoyment (β=-0.44, $p<0.001$). Family religion, family structure and ethnicity did not relate to participation.
Tan (2016)/ Netherlands	Cohort	424	1-24	Cerebral palsy	Parental education	PERRIN programme	Social participation	VABS/ Intensity	Parental education did not contribute to the variability of the development of social participation.
Ullenhag (2012)/ Sweden, Norway, Netherlands	Cross-sectional	278 (877)	6-17	Mixed disabilities	Parental education	Demographic Questionnaire, Statistics Sweden	Leisure participation	CAPE/ Intensity Diversity	Parental education was positively associated with participation diversity in skill-based activities (β=0.15, $p<0.05$) and negatively associated with intensity of participation in skill-based (seldom) (β=-0.15, $p<0.05$) activities.
Ullenhag (2014)/ Sweden	Cross-sectional	55 (392)	6-17	Mixed disabilities	Parental education	Not reported	Leisure participation	CAPE/ Intensity Diversity Enjoyment	Parental education was associated with participation diversity in social activities (β=0.12, $p<0.05$) and physical activities (β=0.19, $p\leq0.01$) for children with and without disabilities. Parental

First author (year)/ Country	Study Design	Participant details			Exposure(s) of interest	Exposure(s) measure(s)	Outcome(s) of interest	Outcome(s) measure(s)/ Dimensions	Key results
		n (total)	Age range (mean)	Health condition					
									education was associated with participation enjoyment in physical activities (β=0.12, p<0.05) for all children.

Note. ADL: Activities of Daily Living, IADL: Instrumental Activities of Daily Living, CAPE: Children's Assessment of Participation & Enjoyment, CBC: Child Behaviour Checklist, Child-PFA: Child Participation in Family Activities , CHORES: Children Helping Out: Responsibilities, Expectations and Support, CPQ: Child Participation Questionnaire, Life-H: The Assessment of Life Habits, PEM-CY: Participation & Environment Measure-Children & Youth, SFA: School Function Assessment, VABS: Vineland Adaptive Behaviour Scale, ARSLLS: Academic Rating Scale Language & Literacy Scale, ARSMTS: Academic Rating Scale Mathematical Thinking Scale, ALS: Approach to Learning Scale, SDQ: Strengths & Difficulties Questionnaire, SATI: School-Age Temperament Inventory, PPVT-III: Peabody Vocabulary Test-III, MSDQ-III: Marsh Self-Description Questionnaire-III, STRS: Student-Teacher Relationship Scale.

[a] *Articles reporting on the same sample of children with disabilities.*

[b] *Articles reporting on the same sample of children with disabilities.*

[c] *Weighed sample.*

3.4.1 Quality appraisal

Most of the studies described the study populations and selection in sufficient detail. One study was at high risk of bias due to study subgroups incomparability by age (Axelsson et al. 2013). Eight studies included a convenience sample and were at unclear risk of selection bias (27%). Study sample size ranged from 23 to 77,470 (weighted). None of the studies with a sample size $n \leq 67$ (Majnemer et al. 2008; Dunn et al. 2009; Soref et al. 2012; Bult et al. 2013; Engel-Yeger and Hamed-Daher 2013; Khetani et al. 2014) provided sufficient justification on the adequacy of proposed sample sizes; hence, they were rated at unclear risk of bias in external validity and precision. Measures used to collect data on family factors varied (Table 8). Two studies, however, did not provide descriptions of how these data were obtained (Rosenberg et al. 2010; Ullenhag et al. 2014; Must et al. 2015).

Participation was assessed using seven measurement tools (Appendix C); with the CAPE (King et al. 2004) being the most frequently used measure. Six studies did not report on validity and reliability of the participation measures used and were rated at unclear risk of bias (Oates et al. 2011; Houtrow et al. 2012; Mâsse et al. 2013; Must et al. 2015; Cavallo et al. 2015; Rekkedal 2017). Out of four studies with longitudinal designs, one study was at high risk of attrition bias (Bult et al. 2013), while the remaining studies provided insufficient information to assess the attrition rate. Six studies provided inadequate adjustment for confounding variables in their analysis and were at unclear risk of bias. Taking into account the individual study's limitations, the findings were considered credible in 24 (80%) and partially credible in six of the included studies (Table 9). Nevertheless, no study was excluded from data synthesis. The agreement in the quality appraisal between the two researchers was high (78%).

Table 9. Quality appraisal based on the customized RTI 14-item bank

First Author(year)	Sample definition & selection				Creation of exposure groups	Soundness of information			Follow-up		Analysis comparability	Analysis outcome	Appropriate analytic method	Interpretation
	I_1	I_2	I_3	I_4	I_5	I_6	I_7	I_8	I_9	I_{10}	I_{11}	I_{12}	I_{13}	I_{14}
Axelsson (2013)	x	x	-	x	-	x	x	*	*	*	?	*	x	?
Bedell (2013)	x	?	x	x	x	x	x	*	*	*	x	*	x	x
Bult (2013)	x	x	*	?	*	x	x	*	-	*	?	-	x	?
Cavallo (2015)	x	x	*	x	*	x	?	*	*	*	?	*	x	x
Colver (2012)	x	x	*	x	*	x	x	*	*	*	x	*	x	x
Dunn (2009)	x	?	x	?	x	x	x	*	*	*	x	*	x	?
Engel-Yeger (2013)	x	?	x	?	?	x	x	*	*	*	?	*	x	?
Furtado (2015)	x	?	*	x	*	x	x	*	*	*	x	*	x	x
Houtrow (2012)	x	x	*	x	*	x	?	*	*	*	x	*	x	x
Imms (2009)	x	x	*	x	*	x	x	*	*	*	x	*	x	x
Kamath (2016)	x	x	*	x	*	x	x	*	*	*	x	*	x	x
Khetani (2014)	x	?	*	?	*	x	x	*	*	*	?	*	x	?
Law (2006)	x	x	*	x	*	x	x	*	*	*	x	*	x	x
King (2013)	x	x	x	x	x	x	x	*	*	*	x	*	x	x
Majnemer (2008)	x	x	*	?	*	x	x	*	*	*	x	*	x	x
Marquis (2015)	x	x	x	x	x	x	?	*	*	*	x	*	x	x
Masse (2013)	x	x	x	x	x	x	?	*		*	x	*	x	x
McCormack (2011)	x	x	x	x	?	x	x	x	?	?	x	?	x	x
Must (2015)	x	x	x	x	x	?	?	*	*	*	?	*	x	x
Oates (2011)	x	x	*	x	*	x	?	*	*	*	x	*	x	x
Palisano (2011)	x	x	*	x	*	x	x	*	*	*	x	*	x	x
Parkes (2010)	x	x	*	x	*	x	x	*	*	*	x	*	x	x
Rekkedal (2017)	x	x	*	x	*	x	?	*	*	*	x	*	x	x
Rosenberg (2010)	x	?	x	x	x	?	x	*	*	*	x	*	x	x
Rosenberg (2013)	x	?	x	x	x	x	x	*	*	*	x	*	x	x
Shields (2015)	x	x	*	x	*	x	x	*	*	*	x	*	x	x
Soref (2012)	x	?	x	?	x	x	x	*	*	*	x	*	x	?
Tan (2016)	x	x	*	x	*	x	?	*	?	*	x	?	x	x
Ullenhag (2012)	x	x	x	x	x	x	x	*	*	*	x	*	x	x
Ullenhag (2014)	x	x	x	x	x	?	x	*	*	*	x	*	x	x

Note. I Item, "x" Low risk of bias, "-" High risk of bias, "?" Unclear risk of bias, "" Not applicable.*

3.4.2 Family factors

This review identified findings in two major groups of family factors: "status" and "process" as illustrated in Figure 8. This taxonomy differentiates modifiable family "process" factors (what families experience and do) from non-modifiable "status" factors (who families are) (Christenson et al. 1992; Fan and Chen 2001). The review distinguished two subgroups of "status" factors: (1) family socio-demographic factors and (2) family structure; and four subgroups of "process" factors: (1) "parental health and well-being", (2) "parental beliefs, perceptions and attitudes", (3) "parental behaviour", and (4) "family resources" (for details on how some factors were collapse into a single identifying factor within each subgroup refer to Table 6). Evidence of the measures of association between each factor and participation dimensions, activity domains and settings is summarised in Table 8. Table 10 shows a summary of evidence on the consistency of associations for family factors examined in at least two studies. The sections below describe the main findings. Associations that were studied most often are discussed first.

Socio-demographic factors

Family income was studied most frequently, but findings showed inconsistent association with participation (Table 10). Parental education was consistently associated with participation, with lower education predicting reduced participation (Law et al., 2006; Ullenhag et al. 2012; Engel-Yeger and Hamed-Daher 2013; Rosenberg et al. 2013; Ullenhag et al. 2014; Marquis and Baker, 2015). However, in two studies (Soref et al. 2012; Axelsson et al. 2013), higher education predicted reduced participation. Lower socio-economic status (McCormack et al. 2011; Houtrow et al. 2012; Soref et al. 2012; Engel-Yeger and Hamed-Daher 2013; Shields et al. 2015) was consistently associated with reduced participation. Hispanic ethnicity increased the risk for non-participation in organized activities (Houtrow et al. 2012), and having ethnicity other than Caucasian was associated with decreased participation in leisure activities (King et al. 2009). Indigenous Australian ethnicity was positively associated with participation in a single study (McCormack et al. 2011). Parental religion was examined in a single study with no association with participation reported (Soref et al. 2012).

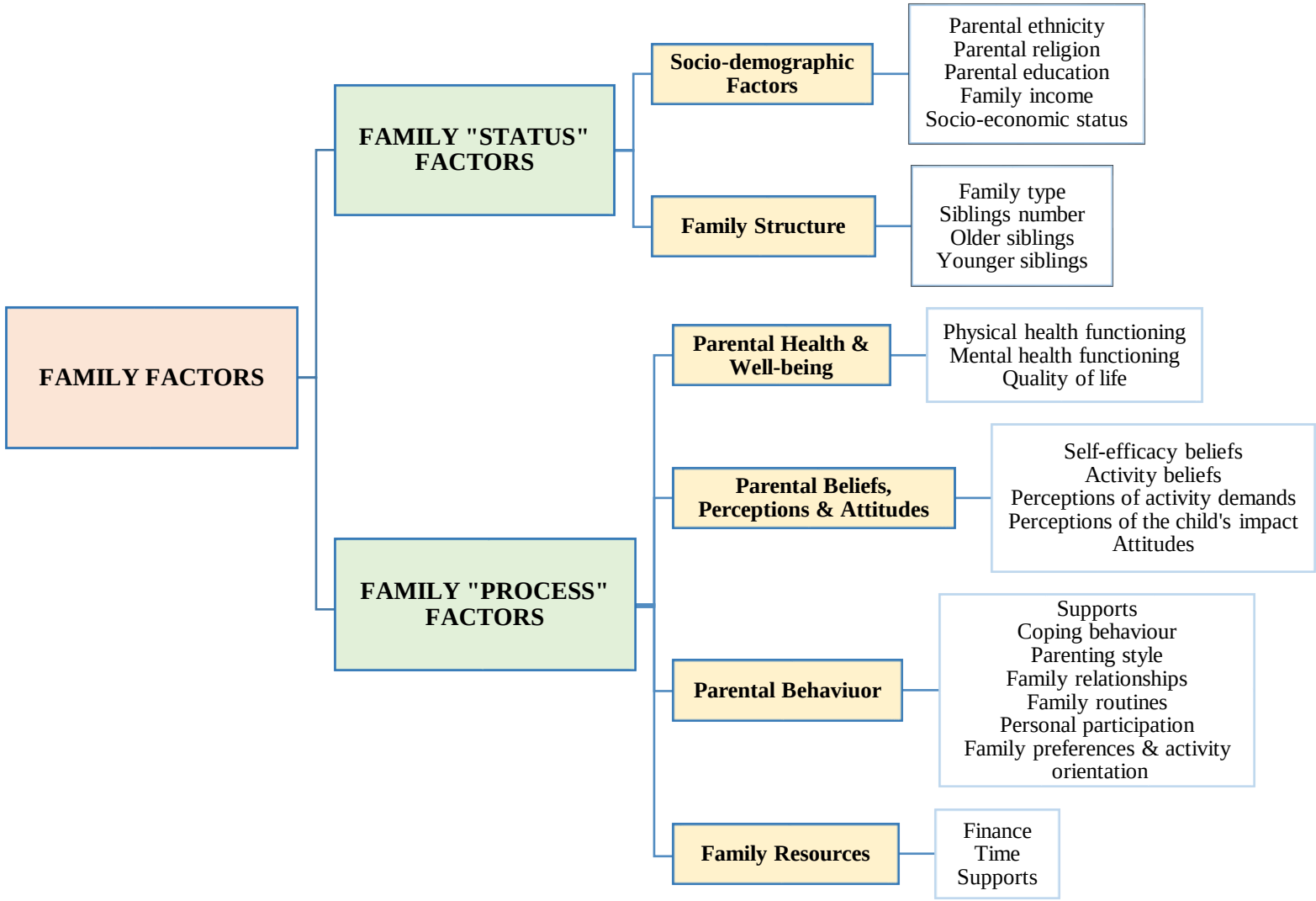


Figure 8. A taxonomy of family factors examined by the included studies

F**amily structure**

Family type was studied most frequently. Living in a single-parent family was consistently associated with decreased participation in leisure activities (Law et al. 2006; Houtrow et al. 2012; Kamath et al. 2016). No study showed a significant association between a number of siblings and participation. The presence of an older or a younger sibling in the household were examined, each in a single study. The relationship was established only between the presence of an older sibling and participation in more household tasks for children with attention deficit hyperactivity disorder (ADHD) (Dunn et al. 2009).

Parental health and well-being

Parental mental health functioning, defined as a state of psychological, social, emotional well-being in which parents can realize their potential and cope with the stresses of life (WHO 2004), was the most frequently studied factor and the one consistently associated with participation. Parental stress was associated with reduced participation of children with cerebral palsy in leisure activities (Majnemer et al. 2008; Parkes et al. 2010; Bult et al. 2013). Higher parental stress was also associated with reduced assistance provided to children with ADHD to support their participation (Dunn et al. 2009). Children of parents with better mental health functioning had better participation in interpersonal relationships (Oates et al. 2011). Parental physical functioning was consistently associated with participation, but the direction of associations varied across disabilities. A positive association was established for the social participation of children with Down syndrome (Oates et al. 2011) and a negative association - for the participation of children with physical disabilities in recreational activities (King et al. 2009). Parental quality of life was examined in a single study with a positive association established for participation in informal leisure activities (Bult et al. 2013).

Parental beliefs, perceptions and attitudes

Parental self-efficacy beliefs were studied most often showing a consistent positive association with participation (Rosenberg et al. 2013; Soref et al. 2012). Attitudes of family/greater community (Colver et al. 2012; Furtado et al. 2015) and parental

perceptions of the child's impact on the family (Dunn et al. 2009; Marquis and Baker 2015) were associated with participation inconsistently (Table 3). Parental beliefs about activity and perceptions of activity demands were examined in a single study (Must et al. 2015). Children of parents who shared negative beliefs about an activity (e.g. physical activity too overstimulating) and perceived it difficult to make required arrangements for their children, participated in fewer physical activities (Must et al. 2015).

Table 10. Family factors potentially associated with children's participation

Family factors	No of studies[a]	Related to participation		Not related to participation	Coding	
		No of studies[b]	Direction of assoc.[c]	No of studies[d]	% of studies supporting assoc.[e]	Assoc.[f]
Family "Status" Factors Socio-demographic Factors						
Family income[*]	12	7	+	5	7/12=58%	??
Parental education	11	8	+	3	8/11=73%	++
Socio-economic status	7	5	+	2	5/7=71%	++
Parental ethnicity	4	3	-	1	3/4=75%	-
Family structure						
Family type (single-parent)	5	3	-	2	3/5=60%	--
Number of siblings	2			2		0
Family "Process" Factors Parental Health & Well-being						
Mental health functioning	7	5	+	2	5/7=71%	++
Physical health functioning	2	2	+/-		2/2=100%	+/-
Parental Beliefs, Perceptions & Attitudes						
Self-efficacy beliefs	3	2	+	1	2/3=67%	+
Attitudes	2	1	+	1	1/2=50%	?
Perception of child's impact	2	1	+	1	1/2=50%	?
Parental Behaviour						
Supports (for the child)	5	3	+	2	3/5=60%	++
Family preferences & activity orientation	2	2	+		2/2=100%	++
Family relationships	2			2		0
Coping behaviour	2			2		0
Family Resources						
Supports (for the family)	3	1	+	2	1/3=33%	0
Time	2	2	+		2/2=100%	+

Note. [a] *The number of studies examined a particular association.*
[b] *The number of studies established an association as being significant ($p<0.05$).*
[c] *The prevailing direction of an association based on the frequency count.*
[d] *The number of studies that established an association as being insignificant.*
[e] *The percentage of studies supporting an association.*
[f] *Double summary codes "++", --" were applied when ≥ 3 studies supported a positive or negative association and "??" when the factor was studies frequently but findings were inconsistent. Code "+/-"was applied when studies differed in respect to the direction of established association.*
[*] *Thirteen studies examined the effect of income on participation, but two studies shared the sample of children with disabilities (i.e. Law et al., 2006 and King et al., 2013), hence, were counted as one study.*

Parental behaviour

Supports for the child from parents/greater community were studied most often (King et al. 2006; Colver et al. 2012; Furtado et al. 2015; Kamath et al. 2016; Rekkedal 2017). The presence of parental support was consistently positively associated with participation (Colver et al. 2012; Rekkedal 2017), except in a single study where the association was negative (Kamath et al. 2016). Family preferences (King et al. 2006; Palisano et al. 2011; Bult et al. 2013) and activity orientation (King et al. 2006; Palisano et al. 2011; Bult et al. 2013) towards social and recreational activities were positively associated with children's participation in leisure activities. Parental coping behaviour (Majnemer et al., 2008; Bult et al., 2013) and family relationships (cohesion/conflict) (King et al. 2006; Palisano et al. 2011) were not related to participation. Parenting style, parents' personal participation, and family routines were examined, each in a single study. A positive relationship was established between parental prioritization of family routines and the participation of children with ADHD in household tasks (Dunn et al. 2009). Negative parenting style (Marquis and Baker 2015) and parents' personal participation (Bult et al. 2013) were not related to participation.

Available Resources

Supports for the family were examined most frequently, but no conclusive evidence was found to support an association with participation. Studies examining the effect of parental time availability on participation revealed a consistent positive association (Oates et al. 2011; Marquis and Baker 2015). Absence of financial and time impact on family (measured as a single construct) was examined in a single study with no association with participation established (King et al. 2006). Another study, however, revealed significant differences between parents of children with disabilities compared to parents of typical peers with respect to finance and time being usually insufficient/inadequate to support their children's participation in the community (Bedell et al. 2013).

3.5 Discussion

This systematic review summarised the evidence for family factors associated with the participation of children with disabilities aged 5-12. Family factors identified in the review were grouped according to a taxonomy which distinguished non-modifiable "status" factors from modifiable "process" factors. "Status" factors consistently associated with participation were parental ethnicity, parental education, family type and socio-economic status. "Process" factors with consistent associations were parental mental and physical health functioning, parental self-efficacy beliefs, parental support, parental time, family preferences and activity orientation. Implications of the key findings are discussed from theoretical, practical and research perspectives.

In line with findings of previous research (Shikako-Thomas et al. 2008; Bult et al. 2011; Tonkin et al. 2014), this review found consistent relationships between family socio-economic disadvantage, parental mental and physical health functioning and children's participation. There is strong theoretical support (Conger et al. 2000) for the role of socio-economic disadvantage in influencing children's outcomes through parental mental health and quality of interpersonal relationships. The family stress model (Conger et al. 2000) suggests that parental psycho-emotional problems (stress, anxiety, depression) triggered or exacerbated by a lack of material resources have a direct negative impact on marital relationships. Accumulated tension from interpersonal problems "splits over" into parent-child interaction and manifests itself in the form of negative or punitive parenting (Conger et al. 2000). Negative parental practices are associated with significant developmental difficulties for children, including behavioural problems, physical health difficulties and problems in interpersonal relationships (Garmezy 1987). These developmental difficulties are linked to reduced participation (King et al. 2003).

Further, parental mental and physical health problems undermine parents' confidence about their ability to successfully raise children, commonly referred to as parental self-efficacy beliefs (Krech and Johnston 1992). Parents with low self-efficacy beliefs are less likely to adopt effective parenting behaviour (Krech and Johnston 1992) and provide safe and positive life situations for their children to participate in (Soref et al.

2012). This, in turn, may reinforce perceptions of low self-efficacy beliefs and increase emotional tension in parents (Krech and Johnston 1992).

It is important to consider that there may be a causal feedback loop. Parental stress and lower self-efficacy beliefs might be caused by having and/or caring for a child with a disability. Evidence suggests that parents, especially mothers of children with disability are at increased risk of poor mental (Lach et al. 2009; Majnemer et al. 2012) and physical health functioning (Lach et al. 2009). This is a result of parental lack of ability to cope effectively with stressors caused by the demands of the child's illness (Cohen 1999).

Given the importance of effective coping strategies in managing daily stressors, developing parental competence and their resilience might be promising targets for family-centred rehabilitation. Further, based on evidence suggesting the effectiveness of direct support strategies in lowering stress levels in families (Allen and Knott 2016), informing parents and referring them to existing counselling services, social parental networks and respite services are important considerations.

Similar to previous reviews (Bult et al. 2011; Li et al. 2016) this review has identified that family preferences and activity orientation are important for children's participation. Families that are better oriented towards intellectual activities and participate more intensely in social-recreational activities create more opportunities for their children's direct involvement in activities (King et al. 2006; Palisano et al. 2011) and competence development for future participation.

Parents play a key role in shaping family routines (Laws and Radford 1998; Rentinck et al. 2009; Law et al. 2013). Some scholars argue that behaviour is informed by knowledge, beliefs and attitudes; therefore, educating parents on importance of development and maintenance of consistent family routines oriented to social-recreational activities should be prioritized (Rentinck et al. 2009; Law et al. 2013). Others, however, consistently report a weak association between positive beliefs and motivation about activity engagement and actual participation (Rhodes and Dickau

2012). Rehabilitation professionals are therefore encouraged to work closely with families (1) to identify and mitigate the effects of environmental barriers to family activity participation, and (2) to provide practical support on how existing family routines should be gradually modified to support child participation in social and recreational activities.

The review found that disadvantaged family circumstances (ethnic minority, material, social and educational deprivation) were associated with reduced participation. These findings were supported by large-scale survey data and are consistent with the results of previous reviews (Shikako-Thomas et al. 2008; Bult et al. 2011). Social disadvantage appears to affect participation irrespective of children's disability types and health support needs. Socio-economically disadvantaged and single-parent families face greater challenges in meeting the child's and family's immediate needs within limited financial and time resources (Corcoran and Adams 1997). Limited resources make it harder for parents to provide children with opportunities and experiences. Persistent lack of resources is also disruptive for parental psychological functioning and family cohesive relationships and can result in a less affectionate and more aggressive family climate (Conger et al. 2000). The latter negatively affects children's well-being (Conger et al. 2000), their beliefs of what they can accomplish and what they can become (Garmezy 1987).

It appears that disadvantaged families encounter stressors associated with their family situations (financial and time tension, inequalities, limited knowledge, and inability to seek needed services) which affect parental attitudes and behaviour and may account for the risk to children's well-being and participation. While such circumstances are hard to modify, rehabilitation professionals may monitor disadvantaged families for factors amenable to change. Additionally, improving parental access to information (e.g. informing them of low-cost or free of charge activities), community support programmes, financial service/schemes and childcare funds might ease the financial and time tension placed on families and support participation.

Review findings supported an association between parental support and participation. However, no association with participation was found for other indicators of family dynamics: family relationships (cohesion/conflict), attitudes and parenting style. These findings appear counterintuitive. However, (1) the effect of these factors was not examined extensively, and (2) an absence of direct association does not imply no association. The effect of these factors might be mediated by the other factors directly affecting participation. Positive family dynamics (emotional bond, helpful and encouraging patterns of interaction between family members) is a distinctive feature of cohesive families. Families that display these characteristics participate more in recreational activities (King et al. 2006) which predicts more intense participation (King et al. 2006). Further, cohesive families exercise effective parenting behaviour which is linked with children's positive development and their social and psycho-emotional functioning (Garmezy 1987) - the predictors of more intense participation in leisure activities (King et al. 2006). Paediatric professionals can inform and educate parents about the importance of cohesive family relationships, positive parenting, provision of supports and opportunities in facilitating children's abilities to support participation in daily activities.

This review did not find a consistent association between family income and participation. This contradicts previous research (Shikako-Thomas et al. 2008; Anaby et al. 2012; Anaby et al. 2013; Tonkin et al. 2014) and earlier findings of this review that socio-economic disadvantage is a barrier to participation. There is, however, evidence suggesting that income in isolation may not be an effective indicator of economic disadvantage. Low income infers economic disadvantage rather than directly measuring it (Pantazis et al. 2006); it reveals little about real-life experiences. High-income families can still experience economic disadvantage through uncontrolled consumption or poor distribution of resources (Treanor 2016). Equally, low-income families may be resource-rich or have measures in place to alleviate disadvantage (e.g. through borrowing). It is difficulties meeting needs on available financial resources that make families economically vulnerable (Chambers 1989).

3.6 Strengths and limitations

This is the first review to systematically examine associations between family factors and participation in children with various disabilities aged 5-12. The review adhered to the PRISMA guidelines to ensure transparency and rigor in methodology. A multistage "semi-quantitative" approach was used to analyse the data, thereby reporting objective evidence on the measures of associations. However, a few limitations should be acknowledged. Participation is a complex construct resulting from a dynamic relationship between a cluster of factors unique to the child, their family and wider environment. This review targeted family/parental factors only and as such did not extract and assess the effect of other factors important to participation. The selection of papers was restricted to those published in peer-reviewed journals in English which might have led to language and publication bias.

3.7 Further research

Systematic review findings were derived from studies having predominantly cross-sectional designs. Prospective studies are needed to confirm the findings. Selective reporting of findings and incomplete reporting of essential statistics were some of the key factors precluding meta-analysis. The strengthening of standard methods of reporting of observational studies (e.g. the STROBE Statement) (Von Elm et al. 2007) is needed as inadequate reporting of research impedes evaluation, study comparisons, and overall, makes research less useful. Research modelling the relationships between socio-economic disadvantage, parental mental and physical functioning, children's developmental outcomes and participation using national longitudinal cohort datasets will help to identify and understand the factors across different international contexts. Findings also highlight the need for research looking at family dynamics and participation. Further, research is needed to test the effect of these factors on the participation of a nationally representative sample of children with disabilities to understand the role of family context factors across different cultural contexts.

3.8 Summary

This review emphasized the role of family factors in shaping the participation of children with disabilities. Family "status" and "process" factors were associated with participation, with varying effects across disabilities and participation activity domains. From the findings of this review, it appears that disadvantaged family circumstances shaped by status factors may predispose families to a variety of stressors. The way parents evaluate and deal with these stressors may adversely affect parental health and well-being, their subjective perceptions and behaviour, which in turn can pose the risk to children's well-being and participation. Family status factors are hard (sometimes impossible) to modify. Paediatric professionals may consider to family process factors as primary targets of person/family-centred participation promoting interventions. Key process factors for interventions are parental mental and physical health functioning, parental self-efficacy beliefs, parental support, parental time and family preferences and activity orientation.

The chapter to follow describes the methodological consideration for and methods used in the main study (Study II) of this doctoral research which aimed to explore characteristics, family circumstances, and community-based participation of a nationally representative sample of children with and without disabilities. Study II also had an aim to identify the child, family and community factors independently contributing to participation frequency of a nationally representative sample of children with disabilities in community-based social and physical activities. Family "status" and "process" factors identified from this review guided the selection of family factors tested in the aforementioned participation-frequency-predicting ordinal models.

CHAPTER 4 – METHODOLOGY

4.1 Introduction

This chapter describes the philosophical and methodological context underpinning Study II. Section 4.2 presents the philosophical stance and assumptions the investigator espouses to help the reader to understand a set of beliefs that guided the overarching methodology of this work. Section 4.3 describes the research methodology and provides the justification for adopting a quantitative (secondary) analysis of existing data approach. Sections 4.4-4.5 describe the method including the datasets that were considered and a description of the fifth sweep of MCS which was used to answer RQs 3-5 posed by Study II. Section 4.6 refers to research ethical considerations. Section 4.7 describes the preparation of the final data file, including ways adopted to merge several datasets supplied by the UK Data Service. Section 4.8 specifies the main group of measures of interest and the mapping exercise completed. Section 4.9 described data analysis including statistical programmes, statistical techniques and procedures used before concluding with a summary in section 4.10.

4.2 Post-positivism research paradigm

Philosophical underpinnings of scientific works remain largely hidden (Robson and McCartan 2016; Creswell and Creswell 2018). Yet, they influence the research methodology and research design, and therefore, need to be identified (Robson and McCartan 2016; Creswell and Creswell 2018). The investigator of this research believes there is an objective reality "out there" in the world. Reality is comprised of an order made up of discrete events and regularities which could be observed and measured (Robson and McCartan 2016). In a way, the investigator's ontological (i.e. the assumption about the form and nature of reality/truth) and epistemological (i.e. the nature of knowledge and ways of knowing, learning about reality/truth) assumptions rest on the positivist research paradigm. However, the investigator also shares the belief that we cannot be absolutely "positive" about our claims of knowledge. While objectivity in observations and measurements ought to be sought, it is often hard to achieve. Further, the theories, hypothesis, background knowledge and values of the investigator can influence observations. The evidence about reality is therefore

imperfect and fallible. It should be open to further investigation and refinement (Robson and McCartan 2016). As such, the investigator's assumptions and beliefs are rooted within the post-positivism research paradigm.

Research embedded in the post-positivism paradigm (sometimes referred to as a quantitative research paradigm) is characterized by objectivity (Robson and McCartan 2016; Creswell and Creswell 2018). Investigators use deductive (i.e. deriving predictions from existing theory to test if those predictions hold in the real world data) approach to test the theory using predetermined design, valid and reliable measures, the effective and feasible sampling approach and procedures (Robson and McCartan, 2016). Observations and measurements are transferred into quantitative (numeric) data and analysed using statistical techniques. Findings either support or refute the theory (Robson and McCartan 2016). Efforts are made to enforce transparency and rigor in methodology. The methods adopted should be able to explain phenomena under consideration with explanatory or predictor variables and outcome variables showing causal or correlational links (Robson and McCartan 2016). Limiting the influence of biases that might interfere with accurate interpretation of data is important (Robson and McCartan, 2016). Typical methodologies nested within the post-positivism research paradigm include fixed research designs that are experimental/quasi-experimental, non-experimental and single-subject experimental (Robson and McCartan 2016).

Non-experimental fixed research design (prospective, cross-sectional, retrospective surveys) is one of the most popular strategies of research inquiry. Central to non-experimental fixed research design is a lack of manipulation of the situation, circumstances or experience of the participants by the investigator with a view to producing a resultant change in the behaviour (Robson and McCartan 2016). Key features of this design are: (a) selection of samples of individuals from a defined population; (b) measurement on a small number of explanatory and outcome variables, (c) hypothesis testing (may not involve if purely an exploratory study) (Robson and McCartan 2016).

Given this short introduction on key features underpinning the post-positivist research paradigm, what follows is the description of the research methodology and rationale behind adopting the quantitative (secondary) analysis of existing data, methods and data analysis considerations.

4.3 Quantitative (secondary) analysis of existing data

This research is a non-experimental (cross-sectional) fixed strategy evidence inquiry based on quantitative (secondary) analysis of existing national cohort survey data. This strategy of evidence inquiry was adopted to meet the second and third aims of this research and find the answers to posed research questions 3-5:

Research aims (2-3):

- To describe and compare the characteristics, family circumstances and community-based participation of a nationally representative sample of children with and without disabilities;
- To identify the child, family and community factors independently contributing to participation frequency of a nationally representative sample of children with disabilities in community-based social and physical activities.

Research questions (3-5):

- Are there any differences in the characteristics and family circumstances of a nationally representative sample of children with and without disabilities?
- Are there any differences in community-based participation of a nationally representative sample of children with and without disabilities?
- What are the independent effects of the child, family and community factors on participation frequency of a nationally representative sample of children with disabilities in community-based social and physical activities?

Reliable population-level data on children with disabilities assume evidence generated from comparable samples (i.e. several hundred or thousands of subjects) of children with and without disabilities (Vartanian 2010). Large, comparable samples should also

be representative of the population from which it is drawn for evidence to be robust and generalizable (Vartanian 2010). This requires a random selection of participants from a targeted population. Primary data collection that would yield large representative samples of children with and without disabilities might not be an achievable task for a single investigator. Lack of personnel and financial resources are the main obstacles (Vartanian 2010).

Quantitative analysis of existing data provides a legitimate form of inquiry and a viable option for investigators who lack resources (Boo and Froelicher 2013). Current advances in digital technology make it possible to access large, high quality survey datasets and analyses of them by investigators who were not involved in primary data collection - defined as secondary data analysis of existing survey data (Boo and Froelicher 2013; Cheng and Phillips 2014). Secondary analysis of the existing survey data is an empirical process that applies the same basic research principles applicable to research based on primary data collection (Boo and Froelicher 2013). Analytical advantages and disadvantages of secondary analysis of the existing survey data should be carefully evaluated before deciding whether to go with it or embark on primary data collection.

4.3.1 Advantages of secondary analysis of existing survey data

The main advantage of secondary analysis of existing national cohort surveys is access to big nationally representative samples. Evidence generated from explorations of national cohort survey studies is possible to generalize to a larger population (Boo and Froelicher 2013; Cheng and Phillips 2014). Generalizations could be made with a good level of confidence, as data are usually of better quality than could be obtained by individual investigators. Data are cleaned by professional staff who also provide detail documentation on data collection and data cleaning procedures (Cheng and Phillips 2014). Besides, teams of statisticians work with data to generate ready-to-use survey weights to facilitate necessary adjustments to estimates in case disproportionate oversampling of certain groups of people has been done (Cheng and Phillips 2014).

National cohort surveys follow the lives of thousands of cohort members of approximately the same age at different time points. This allows performing both cross-sectional and longitudinal explorations on representative samples on the phenomenon of national or global concern. It also offers a possibility for more nuanced evaluations of findings reported by original studies (Cheng and Phillips 2014).

Last but not least, secondary analysis of existing national cohort surveys is cost-effective (Vartanian 2010; Cheng and Phillips 2014). At a time of limited funding it can be an alternative option for conducting good quality research (Boo and Froelicher 2013). Although a fee might be applied to secure access to national cohort datasets, it is substantially lower compared to what it would cost to conduct a primary data collection of a similar scale (Cheng and Phillips 2014). Further, often existing national cohort survey data are available at no cost and could be accessed through arrangements with mediating organizations (Vartanian 2010).

4.3.2 Disadvantages of secondary analysis of existing survey data

National cohort surveys generally supply rich data on various topics some of which might be of no use for a given research (Boo and Froelicher 2013). Screening through the survey datasets and identifying the relevant information and variables might be a time-consuming and laborious exercise (Cheng and Phillips 2014). Additionally, a considerable amount of time should be dedicated to organize and manage a final database (Vartanian 2010; Boo and Froelicher 2013; Cheng and Phillips 2014).

Another issue with national cohort surveys is a lack of control over the framing and wording of survey items (Vartanian 2010; Boo and Froelicher 2013). Questions important for a given research might not be available in the existing dataset. It is not uncommon to find broader or related questions, but not the exact questions of research interest (Vartanian 2010). This requires careful considerations as it might compromise construct validity (i.e. the degree to which a test or variable measures what it claims to measure) (Robson and McCartan 2016).

Investigators involved in data analysis are often not from the original research team involved in primary data collection. The researcher might not be aware of the specifics and nuances of the data collection process which might be important for the interpretation and better understanding of some variables (Cheng and Phillips 2014). Although detailed documentation is generally provided to ease the navigation through the datasets and conduct statistical analysis, the amount of supplied information might appear overwhelming. Investigators might miss key details which potentially can again compromise the research validity (Vartanian 2010; Cheng and Phillips 2014).

4.3.3 Primary data collection - why not?

Primary data collection has many advantages. Primary data is a real-time data collected directly by the investigator for addressing the research questions at hand (Robson and McCartan 2016). Primary data collection assumes the active involvement of the investigator in the data collection process (Robson and McCartan 2016) and is a good learning experience for early career researchers. Nevertheless, it can take a considerable amount of time and financial resources to design, collect, and then organize the data (Vartanian 2010; Robson and McCartan 2016). The investigator of this full-time doctoral research programme had limited time, financial resources and a lack of external assistance required for primary data collection required to meet the research aims. Further, the investigator has experience of designing, piloting and conducting research projects involving primary data collection (in the scope of Masters Programme and research posts held in the past). Nevertheless, assuming a primary data collection for this doctoral research, it would have resulted in:

(a) Having limited time to conduct a systematic review. As a methodology, systematic reviews are complex and require specialized skills. The application of rigorous methods is necessary to ensure the generated results are reliable and make an important contribution to scientific literature.

(b) Having limited time for carrying out a "pilot study" before the primary data collection. A pilot study is a small-scale study where the feasibility of the study design, data collection instruments, sample recruitment strategies and

other research procedures are checked and changes are made if needed (Robson and McCartan 2016). A pilot study is a key stage in research and should be done after ethical approval is granted by the research hosting institution (Robson and McCartan 2016). A pilot study might impose changes in the research protocol and methods. This should be taken back to the research hosting institution for further ethical considerations and approval.

(c) Having data collected from small, convenience or clinical samples. Small samples often make it difficult to apply advanced analysis techniques and limit a scope for comparative research. This would impose major restrictions to the generalizability of findings to a wider population of children with disabilities in the UK.

(d) The recruitment of subjects with a disability or their carers (parents) is an ethically challenging issue. Access to these "vulnerable populations" is generally difficult to achieve (Bracken-Roche et al. 2017). Assuming access is secured, special protection should be ensured, and a subject recruitment process must be fair (Bracken-Roche et al. 2017). Adequate time should be given to the participants to consider whether they wish to participle in the research. Some accounts suggest that participants who cannot provide informed and voluntary consent (which might be a case with some children with disabilities) are susceptible to harm because they are unable to protect themselves and their interests (Hurst 2008). From the ethical viewpoint, "vulnerable populations" should not be overburdened with requests to participate in research, if enough data on the subjects of interest are publically available and accessible (Vartanian 2010).

Because of all the reasons listed above, it was deemed appropriate to use secondary analysis of existing national cohort survey data to meet the aims of this research.

4.4 Method

4.4.1 Datasets considered

It is important to achieve the most appropriate fit between the research questions posed by the study and existing data (Vartanian 2010). Many high-quality national-level cohort surveys are available in the UK. The Centre for Longitudinal Studies (London, England), for instance, is home to four national large-scale cohort studies: the 1958 National Child Development Study (NCDS), the 1970 British Cohort Study (BCS70), 2004 Next Steps (previously known as the Longitudinal Study of Young People in England (LSYPE)) and the 2000 Millennium Cohort Study (MCS). Similar large-scale cohort studies have been carried out in the home nations, for instance, the 2004 Growing-up in Scotland (GUS) (Scotland) and the 2012 WISERDEducation Multi Cohort Study (Wales).

To meet the aims and answer the questions proposed by this research in a time-efficient and effective way, a set of criteria were developed against which the potential datasets were assessed. The criteria were the following:

(1) The dataset should include information gathered from nationally representative samples of children or their families who at the time of the survey reside in Scotland or in the UK;
(2) The dataset should include a set of identifying variables about children or their families – the country of residence, ethnicity, age, sex;
(3) The dataset should have measures of childhood disability;
(4) The dataset should include a rich array of measures on family (including parental health indicators) and neighbourhood/community environment characteristics;
(5) The dataset should include items on the frequency of children's participation in a wide range of (out-of-school) community-based activities.

Several datasets met these criteria, including the MCS, the Avon Longitudinal Study of Parents and Children (ALSPAC), and the Growing Up in Scotland (GUS) survey. The MCS was favoured over the alternative datasets because of following reasons:

(1) The MCS provides information on 19,000 cohort members and their families (Gallop et al. 2013). The GUS dataset, on the other hand, provides data on 5000 children and their families residing in Scotland (ScotCen Social Research 2013), while the ALSPAC - on 14,541 pregnant women, their partners and subsequent children residing in England (Fraser et al. 2012). Big datasets are more preferable options because they allow for: (a) running more complex statistical analysis, (b) producing more accurate estimates, and (c) making more precise predictions (Vartanian 2010).

(2) The MCS includes the most up-to-date data on children and their families.

(3) The MCS supplies data on children and their families who at the time of the survey were residing in the four home-countries of the UK. Cohort members were oversampled from Scotland, Wales, Northern Ireland (NI) and some areas of England to ensure the representativeness of the sample. In contrast, the GUS provides data on children and their families living in Scotland and The ALSPAC – in one geographic area (Avon) in England. Further, the sample in the ALSPAC is not representative of entire Britain. The selection of cohort members was restricted to women residing in Avon who compared to those in the rest of Britain were more likely to live in owner-occupied accommodation and have a car. They also were less likely to live in crowded accommodation (i.e. to have one or more persons per room) and be of an ethnicity other than White.

(4) The MCS oversamples children from disadvantaged backgrounds and ethnic minority families (England only) to allow comparisons in a range of outcomes between different socio-economic and ethnic minority groups as well as partially account for high dropout rates among disadvantaged groups - a common issue in longitudinal cohort studies (Moore et al. 2017).

(5) The MCS data provides access to high quality variables and standardized items of interest, e.g. total difficulties scores in psychosocial and behaviour domains generated from the Strength and Difficulties questionnaire, mental health functioning scale that could be summed to yield Kessler 6 score. Using standardized measures provides a good reference point for future studies

interested in exploring the same measures in similar populations, and therefore improves comparability between studies.

(6) The MCS provides better measures of children's participation in a variety of out-of-school community-based activities which could be cross-referenced to a validated measure of participation such as the PEM-CY.

(7) Access to the MCS and the GUS requires completion of the online proposal form and strict compliance with data security procedures. However, no charges are applied for the MCS and the GUS dataset requests. A charge of £2715 is applied to securing access to the ALSPAC 50 standard variables and £100 for every additional 100 variables requested (University of Bristol 2018).

4.4.2 The Millennium Cohort Study (MCS)

The MCS is one of the UK's most recent national longitudinal birth cohort studies. It is a nationally representative study which supplies data on 19,000 children (and their families) born in millennium (2000-2001) in four countries of the UK (Gallop et al. 2013). The study repeatedly gathers information on children's health, psychosocial and behavioural functioning, schooling, daily activities and behaviour, family, parenting, employment, parental health, income, housing, neighbourhood, social relationships, ethnicity and identity to support research that will help to understand and improve life in Britain and NI (Gallop et al. 2013). The study is funded by the Economic and Research Social Council and a group of governmental departments (i.e. Department of Health, Department for Education, DWP, Welsh Government, Scottish Government, NI Executive, Home Office, Ministry of Justice, Department for Transport) coordinated by the Office for National Statistics (Gallop et al. 2013). Data collection and management is overseen by the Centre for Longitudinal Studies (CLS) at the Institute of Education, University of London and NatCen (Gallop et al. 2013).

4.4.3 Sampling design

The MCS has a complex sampling design. The sampling was done in two stages (Gallop et al. 2013). During the first stage, the electoral wards were identified and clustered into three stratum; during the second stage the selection of families within those wards/clusters was performed (Figure 9) (Gallop et al. 2013). Clustering was a

preferred option for this study as: (1) it is a cost-effective approach (2) it allows potential researchers to evaluate area effects on various outcomes; (3) it allows data merge or matching with other sources based on the electoral wards (Gallop et al. 2013). The two-stage process of sample selection is described in detail below.

Stage 1 of sampling: To take into account specifics of the study design (i.e. sampling births across a 16 month period, including four countries in the UK and oversampling children from disadvantaged/ethnic minority backgrounds), all the electoral wards in the UK were allocated into one of three stratum (1) "Disadvantaged", (2) "Advantaged" and (3) "Ethnic minority" (for England only) (Hansen 2014). "Disadvantaged" stratum composed of children living in the poorest 25% of wards in England, Scotland, Wales and NI which were identified using the Child Poverty Index. "Advantaged" stratum included children living in all the above wards in these countries (Hansen 2014). "Ethnic minority" stratum were defined as wards in England in which 30% or more of the population were "Black" or "Asian". This has been specified according to the 1991 Population Census (Hansen 2014). The population of Scotland, Wales and NI was not stratified according to ethnicity strata due to a low percentage of ethnic minority groups (around 1% of population) residing in these countries (Hansen 2014).

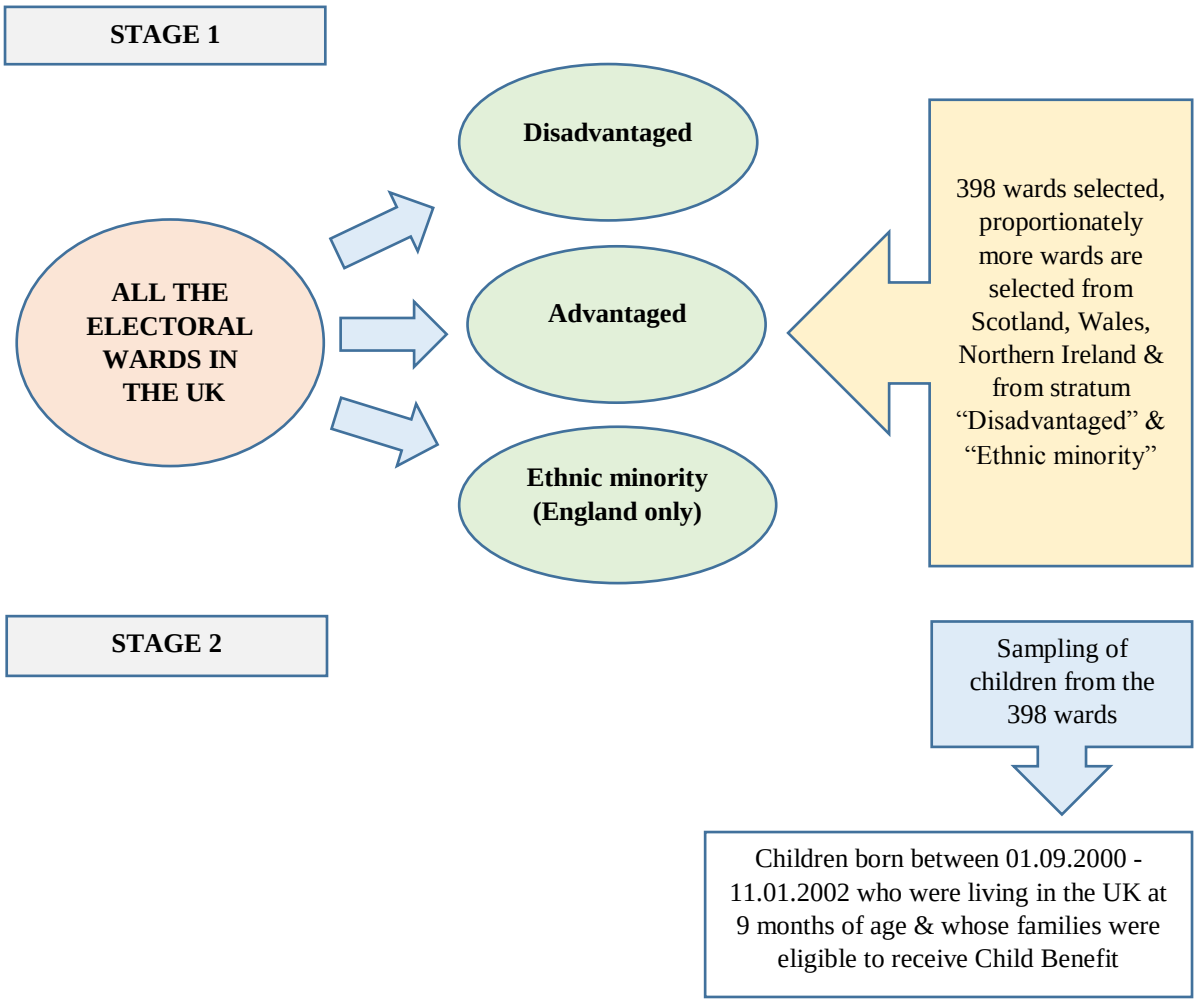


Figure 9. Graphical representation of the complex sampling design strategy

The ethnic minority indicator and the Child Poverty Index used for stratification are area-level measures. These area-level measures are good for identifying both disadvantaged and ethnic minority people living in areas with others sharing similar backgrounds (Hansen 2014). A total of 398 wards were selected. To insure the representativeness of the sample, proportionally more wards were chosen from Scotland, Wales, NI as well as from those wards classified as "Disadvantaged" and "Ethnic minority" (Hansen 2014).

Stage 2 of sampling: The sample of children was selected from a population of children born between 1 September 2000 and 11 January 2002 who were living in the UK in the sampled 398 wards at 9 months of age and whose families were eligible to receive Child Benefits at that age (Hansen 2014). It is worth noting that at the time of sampling, Child Benefits had a universal coverage in the UK (Hansen 2014). In other words, every family with a new born residing in the UK was qualifying for this benefit. The Child Benefit register was supplied by the Department of Social Security (DSS) and subsequently by the DWP (Hansen 2014). Prior to providing the register, the DWP contacted eligible families residing at an address in one of the selected wards asking to opt-out if they did not want to participate in the study. The sensitive cases which were less than 3% of all cases (i.e. children died, children taken into local authority care, investigation into benefit fraud within the family) and families that participated in the Families and Children Survey (*n*=40 cases) were excluded from the issued sample (Hansen 2014). Further, children who might not have been revealed by the Child Benefit Registry (i.e. families moved recently into the sampled wards as the child approached 9 months of age) were identified by the local Health Visitors (*n*=56 families) and asked if they were willing to participate in the study (Hansen 2014).

4.4.4 Available Sweeps

The MCS has been tracking the children through their early lives and plans to follow them into adulthood. Six sweeps have been completed so far and the seventh sweep is underway (Fitzsimons 2017). The first sweep of MCS (MCS1) was carried out in years June 2002 and January 2003 when children (babies) were 9-11 months old (Gallop et al. 2013). Although 20,646 families were issued to the field for MCS1, data were collected on 18,552 families and their 18,818 babies (including twins and triplets) (Gallop et al. 2013). The achieved sample at the first sweep (MCS1) is presented in Table 11. The follow-ups were conducted when children were 3, 5, 7, 11 and 14 years old (Fitzsimons 2017). Details about the dates of data collection, and achieved sample sizes for each sweep are presented in Table 12.

Table 11. MCS1 sample size – clusters, children, families by country

	Number of sample wards	Target sample	Achieved sample*	
			Children	Families
England	200	13,146	11,695	11,533
Scotland	62	2,500	2,370	2,336
Wales	73	3,000	2,798	2,760
Northern Ireland	63	2,000	1,955	1,923
Total UK	398	20,646	18,818	18,552

**Productive contacts*.

Table 12. MCS sweeps – productive sample sizes

Sweeps	MCS1	MCS2	MCS3	MCS4	MCS5	MCS6
Data collection/ fieldwork (years)	2001-2003	2003-2005	2006-2007	2008-2009	2012-2013	2015-2016
Children's age (years)	9-11 months	3	5	7	11	14
Productive sample: Families	18,552	15,590	15,246	13,857	13,287	11,726
Productive sample: Children	18,818	15,808	15,460	14,043	13,469	11,872

4.5 Current sample – the fifth sweep of MCS (MCS5)

This research used data from the fifth sweep of the Millennium Cohort Study (MCS5) (DOI: 10.5255/UKDA-SN-7464-4) carried out when cohort children were 11, age range 10-12 (Gallop et al. 2013). The choice has fallen on the fifth sweep of MCS because:

(1) children aged 10-12 are gaining more independence, but have not yet transitioned into adolescence;
(2) children aged 10-12 are changing physically, biologically and emotionally which makes them sensitive to contextual influences (especially peer influences) and may predispose them to behavioural changes (Centre of Disease and Prevention, 2018);
(3) children with disabilities tend to have more restricted participation in adolescence which might be reinforced given (1) reduced parental opportunities to support their integration into the community environment, and/or (2) a lack of participation-promoting programmes focusing on youth (Shikako-Thomas et al. 2014).

Therefore, assessing characteristics and community-based participation of children with disabilities before they transitioned into adolescence will provide professionals with useful data that can be used in advocating for children's rights and re-allocation of resources to better meet the participatory and other needs of children and their families.

4.5.1 Sampling frame of the MCS5

There were 19,244 families and 19,517 children (253 pairs of twins and 11 sets of triplets) potentially eligible for inclusion in the MCS5. This accounts also for 692 families which were recruited at the age 3 survey – MCS3. These additional families are those that were eligible but were not identified by the Child Benefit System at the time – moved and returned to the UK (Gallop et al. 2013). Nevertheless, 2,851 families were not issued to the field for MCS5 because of multiple reasons: ineligibility (death or emigration) (*n*=545), permanent refusal (*n*=2,215), permanent non-traceability (*n*=86) and sensitive family circumstances (*n*=5). The sample issued to the field therefore was 16,393 families instead of 19,244.

Out of 16,393 families issued in the field, a total of 13,287 was productive (response rate 69% comparable to MCS1, 81.9% comparable to MCS4) (Gallop et al. 2013) (Table 13). The flow chart of contact and response for the MCS5 is supplied in Figure 10.

Table 13. Summary of contact and response for the MCS5

	n
Total issued sample	**16,393**
Total ineligible:	78
Died	2
Emigrated	76
Total eligible sample	**16,315**
Total sample traced and eligible	15,927
Productive	**13,287**
Unproductive:	**2,640**
Refusals	2,026
Non-contact	326
Broken appointment	170
Ill during fieldwork period	17
Away during fieldwork	9
Language difficulties	3
Other reasons	89

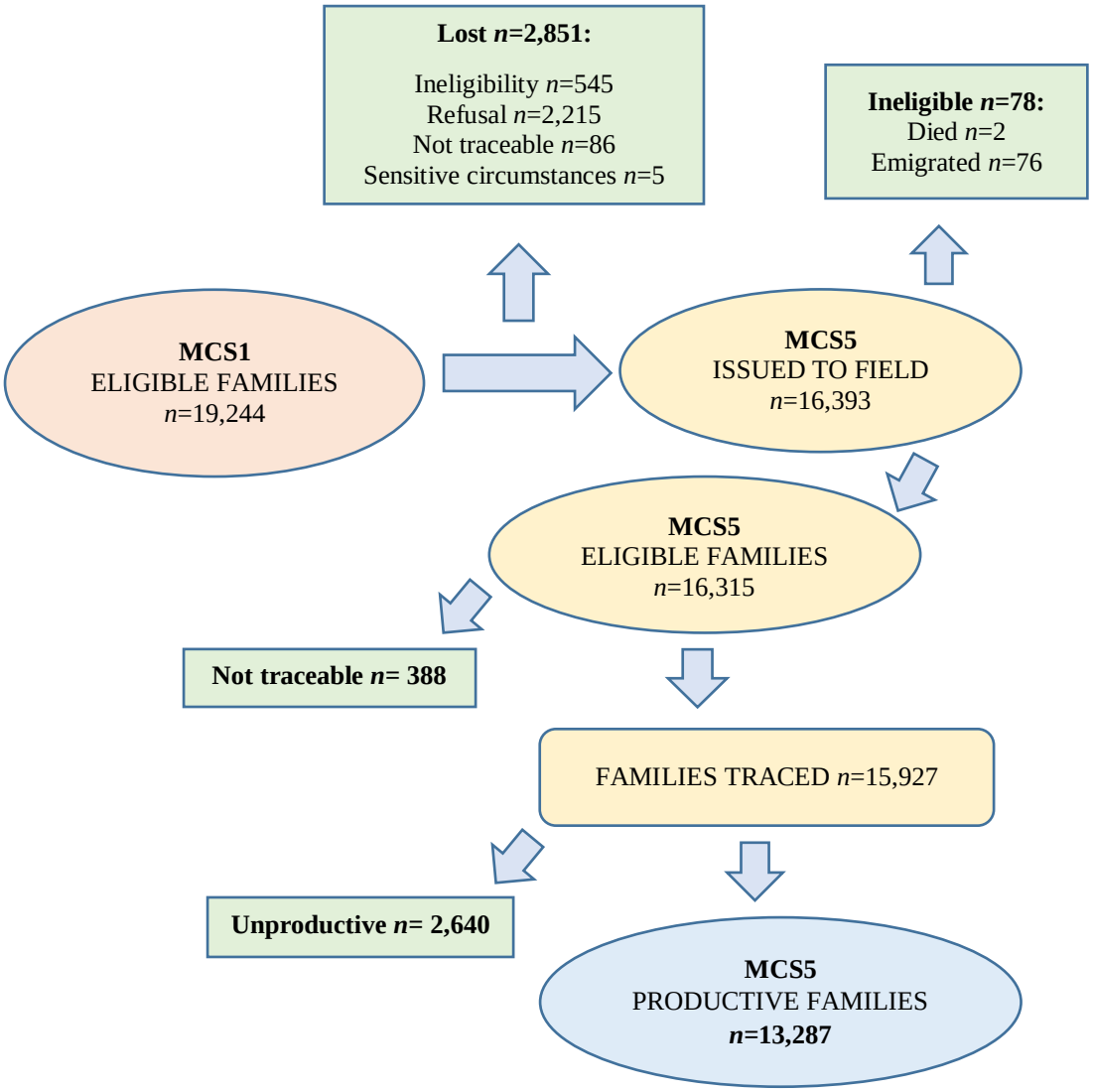


Figure 10. Flow chart of contact and response for the MCS5

4.5.2 Sample size of the MCS5

The fifth sweep supplied information on 13,287 families and 13,469 children aged 10-12 (including twins and triplets) (Gallop et al. 2013). Data were collected from the main carer (98.6 % biological parent), partner (other parent/partner), children and teachers (England and Wales only) through computer assisted personal interviewing (CAPI) and computer assisted self-interview (CASI) (Gallop et al. 2013). The main carer, partner and children were approached at home for completing CAPI and CASI.

Although children participated in three cognitive assessments and completed a self-completion questionnaire about their school, relationships, attitudes and risky behaviours, only data from the main carer was used for the purposes of this research (*n*=13,177). Data collected from children lacked outcome measures of research interest. Further, only reports about singleton births were used as multiple births might have specific problems. Main carer survey elements (Gallop et al. 2013) are presented in Figure 11.

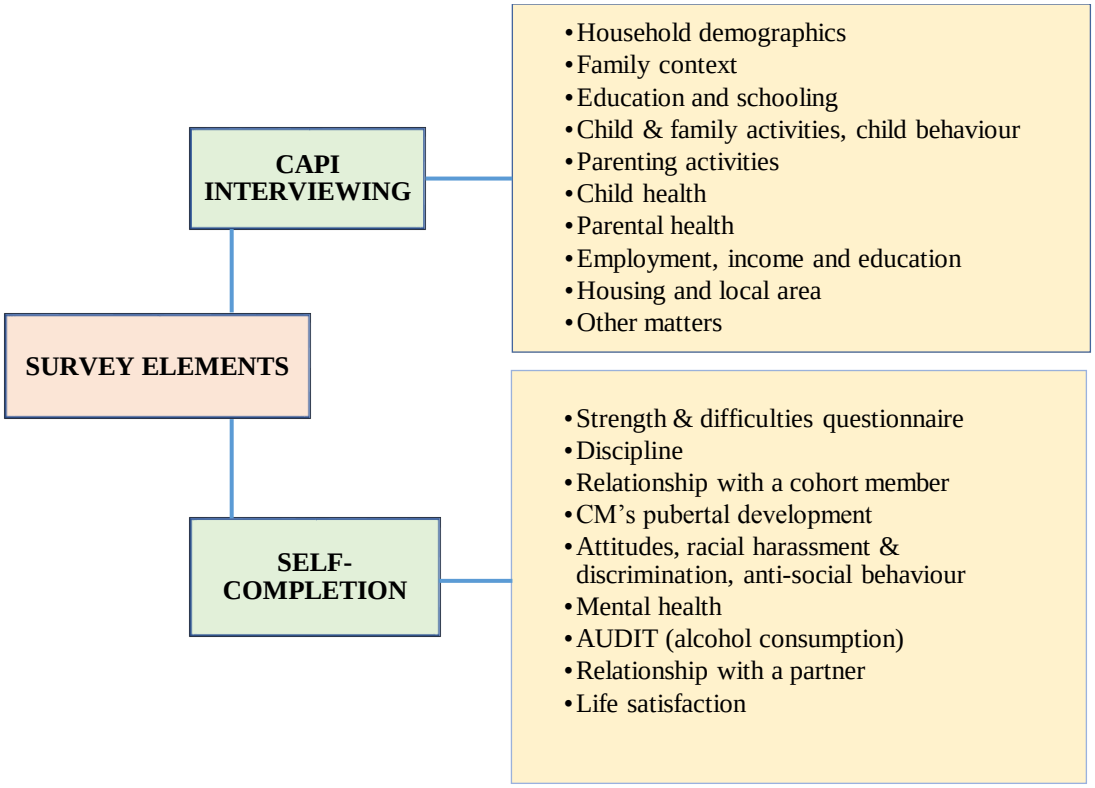


Figure 11. The main carer survey elements

4.6 Ethical considerations

Ethical approval for both the pilot surveys and the main surveys were obtained by the Centre for Longitudinal Studies (CLS). Ethical approval for the MCS5 was granted the NHS Research Ethics Committee - the Yorkshire and Humber REC on 29th July

2011: Ref: 11/YH/0203 (Gallop et al. 2013). Participants provided written informed consent to the survey, contact with teachers and data linkage to their DWP records. Participants also provided consent to the use of survey data and publication of results arising from the data (Gallop et al. 2013).

In accordance to the QMU Ethical Guideline, secondary analysis of anonymous data which previously received an ethical approval from an authorized body does not require an ethical approval from the QMU Ethics Board (QMU 2011). Instead, in line with procedures, the QMU Application for Ethical Approval form accompanied with the research project proposal for Study II and supplementary documents was handed in to the research department head. Ethical approval for Study II was granted on 2nd of July 2018.

Additionally, authorization to access the fifth sweep of the MCS dataset and use for doctoral research was secured through the UK Data Service (https://www.ukdataservice.ac.uk/) - a depositor body that is licensed to supply a dataset to an applicant after fulfilment of all the conditions specified by the data owners. The copy of the End User License is supplied in Appendix D.

All the data supplied by the UK Data Service are provided in an anonymized form. However, there is still a potential risk of accidental breach of confidentiality and failure to maintain the data security. Therefore, measures were put in place to minimize or prevent the risks of accidental data disclose. Firstly, the electronic datasets were downloaded on a stand-alone laptop by the authorized user (i.e. the investigator). The laptop was kept under the conditions of great security. The access to the laptop was restricted. It was kept in a space locked by a key and only the investigator possessed the key. No additional copies of the datasets were made and transferred to alternative data storages (e.g. other computer, memory stick). Secondly, the access to electronic datasets was protected by personal authentication (i.e. protected by a username and a password) known only to the investigator. The personal authentication information was not disclosed to anybody. Thirdly, the internet network access for the laptop was strongly controlled (e.g. a wifi network was disabled at all times). Finally, the

investigator plans to delete the data from the laptop upon the completion and defence of this doctoral research using a secure erasure programme.

4.7 Preparing the final data file

Electronic SPSS data files containing the information from the MCS5 alongside with the technical manuals providing details about each data file, as well as instructions on how to merge and analyse them were downloaded from the UK Data Service website. To answer the research questions posed by this research, it was necessary to merge separate data files containing main carer report personal and child-relevant data as well as files on derived variables. Derived variables about family, parents as well as a cohort child were developed by the data owners to improve comparability across the sweeps (Gallop et al. 2013). Because the aim of merging the data files was to add additional information about each family (including data on main carer and a cohort child), the ID numbers (identical across all sweeps) were used as a key matching variable. The final data file reported main carer data (*n*=13,177) on children in the UK (further described in the text as children). Only data on singleton births (*n*=12,995) was considered as multiple births might have special problems.

4.8 Measures available in the MCS5

Guided by the ICF-CY theoretical framework, literature review on childhood disability participation and the findings of Study I, six main groups of variables were of interest for Study II:

(1) Measures of childhood disability;
(2) Measures of child psychosocial and behavioural functioning;
(3) Measures of child personal characteristics (sex, gender, country of residence);
(4) Measures of family characteristics tapping into (a) family "status" factors and (b) family "process" factors;
(5) Measures of community characteristics;
(6) Measures of participation in community-based activities including social activities (defined in this research as meeting or gathering with friends,

getting together with friends, friendships) and physical activities (defined in this research as free physical play or unstructured physical activity, organized physical activity or sport play).

4.8.1 Measures of childhood disability

Several measures of childhood disability are available in the MCS5. Respondents were asked about presence of a longstanding health condition/illness and specific functional issues. They were additionally asked whether the child has a teacher-identified special educational needs (SEN) or a statement of special needs. Children with disabilities were identified through the respondents' affirmative responses to two items: (1) whether children have a physical or mental health condition lasting or expected to last 12 or more months, and (2) whether this condition reduces children's ability to carry out day-to-day activities. This definition of disability is used in population surveys since the implementation of the DDA (1995). Measure of disability did not included SEN because special education needs are defined differently across the UK.

The first item assessing the presence of a longstanding health condition was measured on a binary scale ("1=Yes" vs "2=No"), and the second item evaluating the impact of a longstanding health condition on a child's functional abilities on a 3-point Likert type scale corresponding to "1=Yes, a lot", "2=Yes, a little", and "3=No, not at all" (Table 14).

Table 14. Children with a longstanding health condition

Characteristics	**Population estimate *(SE)***	**Per cent (%)**
Presence of longstanding health condition		
Yes	1,843 (82)	14.2%
No	11,122 (430)	85.8%
Total	12,965 (488)	100%
Longstanding health condition limiting daily activities		
Yes, a lot	390 (30)	21.1%
Yes, a little	684(40)	37.1%
No, not at all	770 (82)	41.8%
Total	1,843 (82)	100%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. Sample size n= 12,965.

Of total 12,965 children, 1843 (14.2%) had a physical or mental health condition or illness lasting or expected to last 12 or more months. Out of this 1843 children, 1073 (58.2%) had a physical or mental health longstanding condition or illness that affected children's ability to carry out day-to-day activities – defined in the scope of this research as children with disabilities (Table 15). Children who had a longstanding condition which did not affect their ability to carry out day-to-day activities (*n*=770, 41.8%) were excluded, as they do not meet the DDA (1995) definition of disability adopted by this research. As a result, the final sample composed of 12,195 children with and without disabilities (Table 15).

Table 15. The final sample composition

Groups	Population estimate *(SE)*	Per cent (%)
Children with disabilities	1,073 (56)	8.8%
Children without disabilities	11,122 (430)	91.2%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. Sample size n=12,195.

4.8.2 Measure of child psychosocial and behavioural functioning

Child psychosocial and behavioural functioning was assessed based on the degree of problems (or difficulties) experienced by a child in social, emotional and behavioural functioning. In the MCS5, child psychosocial and behavioural problems (PSB problems) were measured through the parent-report Strengths and Difficulties Questionnaire (SDQ) (Goodman 2001). The SDQ is a standardized screening questionnaire for measuring emotions, behaviours and relationships in children and youth aged 11-17. It consists of 25 items which divide equality into five subscales or dimensions – (1) emotional symptoms, (2) conduct/behavioural difficulties, (3) hyperactivity, (4) peer relationships and (5) prosocial behaviour (Goodman, 2001). Each dimension consisting of five items measured in a three-point Likert scale, ranging from "0=Not true" to "2=Certainly true". The SDQ's first four dimensions - emotional problems, conduct/behavioural problems, hyperactivity and peer problems can be summed to generate the total difficulties scores (Goodman 2001). The items used to generate the total difficulties scores are described in Appendix E. Possible total difficulties scores range from 0-40 where higher scores indicate more problems in social, emotional and behavioural functioning (Goodman 2001).

The SDQ has satisfactory internal consistency (i.e. a degree to which similar items within a scale correlate with each other) (Goodman 2001) and moderate test-retest reliability (i.e. a degree to which the same respondents have the same score after period of time when trait shouldn't have changed) (Yao et al. 2009). Further, the SDQ has been shown to have good concurrent validity (the correlation of the measure with other measures assessing the same concept) (Muris et al. 2003) and good discriminant validity (i.e. a lack of correlation with opposite concepts) (Lundh et al. 2008).

In MCS5, the SDQ total difficulties scores are ready available. The total difficulties scores can be used as either continuous or categorical (ordinal) variables. For the purposes of this research, the continuous scores were categorized into three subgroups "1=Abnormal", "2=Borderline", "3=Normal" based on the standardized cut-offs (YouthInMind 2016). Descriptions of categories are provided in Table 16.

Table 16. PSB problems – new three-band categories

Three-band categories	Score range for categories	Population estimate *(SE)*	Per cent (%)
Abnormal	17-40	1,224 (70)	10.4%
Borderline	14-16	804 (50)	6.8%
Normal	0-13	9,745 (365)	82.8%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Missing data 3.6%.
Sample size n= 11,773.

4.8.3 Measures of family characteristics

Selection of the measures of family characteristics/factors was guided by the findings of Study I. These included factors tapping into family "status" factors including ethnicity, parental education, family type, family (equalized) income, and family "process" factors including parental health indicators, parental time, parental support and family activity orientation. Before describing the family factors selected from the MCS5, it is important to note that for some family factors, and one community factor, the original categories were reverse coded and collapsed into new categories. Reverse coding was applied to ensure that the numerical scoring scale does not run in opposite direction, i.e. the last category is the highest category. Collapsing was applied as in many cases low number of respondents replied in a particular way resulting in

subgroups (or subcategories) with small sample sizes. Running statistical analysis on subgroups with small sample sizes might jeopardize the validity of obtained results (Field 2013). Categories were collapsed in consultation with experts in participation research taking into account frequency distributions for each item, meaningfulness of assessment and contextual relevance.

Ethnicity

Parental ethnicity was provided as a derived variable composed of six ethnic groups measured in a nominal scale, i.e. 1=White, 2=Mixed, 3=Indian, 4=Pakistani/Bangladeshi, 5=Black/Black British, 6=Other Ethnic Groups (Table 18). Due to a small proportion of respondents falling into some of the categories it was necessary to collapse two of the categories which resulted in a four-category nominal scale corresponding to "1=Mixed/Other Ethnic Groups" (2,6), "2=Black/Black British", "3=Indian/Pakistani/ Bangladeshi" (3,4) and "4=White". Descriptive statistics is presented below (Table 17).

Table 17. Ethnicity – an original derived and new variable

Original variable & response values	Population estimate *(SE)*	Per cent (%)	New variable & response values	Population estimate *(SE)*	Per cent (%)
Mixed	426 (39)	3.5%	Mixed/Other Ethnic Gr.	621 (65)	5.1%
Indian	257 (39)	2.1%	Black/Black British	444 (82)	3.6%
Pakist /Banglad	627 (133)	5.1%	Indian/Pakist/ Banglad	883 (138)	7.2%
Black/ British Black	444 (82)	3.6%	White	10,247 (387)	84 %
Other Ethnic Gr.	191 (37)	1.6%			
White	10,247(387)	84 %			

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
No missing data.
Sample size =12,195.
Pakist /Banglad – Pakistani/Bangladeshi.
Other Ethnic Gr.- Other Ethnic Groups.

Parental education

In the MCS, parental education was determined through the highest educational qualification achieved according to the UK's national vocational qualification (NVQ) classification. The variable was measured on a nominal scale ranging from 1= NVQ Level 1 to 5=NVQ Level 5, 95= Overseas qualification only, 96=None of these qualifications. To aid the analytical interpretations, a unified 7-category nominal scale for the item was collapsed into a four-category scale corresponding to "1=no formal

UK qualifications" (95, 96), "2=GCSE or equivalent" (1,2), "3=A levels or equivalent"(3), "4=University degree or equivalent"(4,5) (Table 18). These categories were developed based on the UK Government equivalents for academic qualifications (GOV.UK 2016).

Table 18. Parental education – an original derived and new variable

Original variable & response values	Population estimate *(SE)*	Per cent (%)	New variable & response values	Population estimate *(SE)*	Per cent (%)
NVQ Level 1	1,314 (72)	10.8%	No formal UK qual.	2,396 (148)	19.8%
NVQ Level 2	3,776 (177)	31.2%	GCSE/equival.	5,091 (227)	42.0%
NVQ Level 3	973 (49)	8.0%	A levels/equival.	973 (49)	8.0%
NVQ Level 4	2,925 (134)	24.1%	University degree/equival.	3,660 (174)	30.2%
NVQ Level 5	736 (50)	6.1%			
Overseas qual. only	418 (36)	3.5%			
None of these qual.	1,978 (129)	16.3%			

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Missing data 0.5%.
Sample size n=12,120.
GCSE/euquval. = General certificate of secondary education/equivalent.

Family type

In MCS, respondents were asked to indicate their current legal marital status. They was no other items available in the MCS5 that would describe the type or structure of the family. The respondents' marital status was measured in a 9-category nominal scale ranging from 1=Legally separated to 9=A surviving Civil Partner (Table 19). To be able to measure family type (single vs co-parent family), the original nominal scale was dichotomized into "1=Single parent household" (1, 4-6, 8, 9) and 2=Co-parent household" (2, 3, 7) (Table 19).

Table 19. Family type – an original and new variable

Original variable & response values	Population estimate *(SE)*	Per cent (%)	New variable & response values	Population estimate *(SE)*	Per cent (%)
Legally separated	712 (48)	5.8%	Single-parent house.	4,678 (210)	38.4%
Married	6,442 (260)	52.9%	Co-parent house.	7,509 (297)	61.6%
Remarried	825 (49)	6.8%			
Single	2,509 (130)	20.6%			
Divorced	1,326 (76)	10.9%			
Widowed	113 (14)	0.9%			
Civil Partner	242 (32)	2.0%			
Former Civil Partner	12 (5)	0.1%			
Surviving Civil Partner	7 (4)	0.1%			

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Missing data 0.1%.
Sample size n=12,187.

Family (equalized) income

Various measures of family economic status are available in MCS5. These include family weekly, monthly and annual take home income before and after tax deductions, state benefits, how the family manages financially and amount of debt acquired. As discussed in Study I, a gross or raw amount of family income per week/or month might not be an effective measures of family economic status. Further, items describing how the family manages financially and amount of debt acquired had a high percentage of missing data.

Given this, the measure of family income was determined through the modified Organization for Economic Co-operation and Development (OECD) equivalence scale since it takes into account the size and composition of families (Ketende et al. 2008). To measure family (equalized) income, respondents were asked to select from a range of 17 income bands (ranging from less than £3,999 to £56,000 and more) which best represent family income before tax (including all the benefits and interests). The figures then were equalized by adjusting for the size and composition of the families (Hansen 2014). A value of 0.67 was assigned to the first member of the household (main respondent), 0.33 to each additional adult, 0.3 to each dependent child age between 14 and 18 and 0.2 to each dependent child under 14 (Hansen 2014). The obtained figures then were transferred into quintiles, ranging from "1=Bottom" (the bottom 20% of economically deprived families) to "5=Top" (the top 20% of least economically deprived families). This item was supplied in the MCS5 with other derived variables (Table 20).

Table 20. Family (equalized) income–an original derived variable

Original variable & response values	Population estimate *(SE)*	Per cent (%)
Bottom	2,465 (167)	20.2%
Second	2,436 (115)	20.0%
Third	2,441 (110)	20.0%
Fourth	2,437 (113)	20.0%
Top	2,415 (138)	19.8%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
No missing data.
Sample size n=12,195.

Measures of parental health

Measures of parental health included parental longstanding illness and parental mental health functioning. Presence of parental longstanding illness was established based on a single item asking whether the respondent has any physical or mental health conditions or illnesses lasting or expected to last 12 months or more. Response on the item was measured on a binary scale – "0=Present" vs "1=Absent" (Table 21).

Table 21. Parental longstanding illness –an original derived variable

Original variable & response values	Population estimate *(SE)*	Per cent (%)
Present	2338 (106)	19.2%
Absent	9851 (391)	80.8%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. Missing data 0.09%.
Sample size n=12,189.

Parental mental health functioning was measured using the total scores generated from the Kessler 6 scale (Kessler et al. 2002). Kessler 6 is a six-item psychological screening tool which is broadly used at the population-level to screen for distress (Kessler et al. 2002). Respondents are asked to indicate how often during the past 30 days they felt (1) nervous, (2) hopeless, (3) restless or fidgety, (4) so depressed that nothing could cheer you up, (5) that everything was an effort, (6) worthless. These items are measures in a five-point Likert scale, ranging from "none" to "all of the time". Possible scores range from 0-24, where higher scores are indicative of higher distress levels (Kessler et al. 2002). The scores can be used as either continuous or categorical variables.

For the purposes of this research, the scores were categorized into three subgroups: "1=Serious mental distress"– defined as respondents experiencing clinically significant serious mental distress, "2=Moderate mental distress"– defined as respondents experiencing moderate levels of distress, "3=No distress"– defined as respondents not experiencing any distress. The categories were developed based on population based standardized cut-offs (Prochaska et al. 2012). Descriptions are provided in Table 22. A reliability analysis was undertaken by the investigator to check the internal constancy of the Kessler 6 scale in the MCS5. Cronbach's alpha was 0.89 indicating a high level of internal consistency (Nunnally and Bernstein 1978).

Table 22. Parental mental health functioning – new three-band categories

Three-band categories	Score range for categories	Population estimate *(SE)*	Per cent (%)
Serious mental distress	13-24	720 (49)	6.4%
Moderate mental distress	5-12	3,174 (146)	28.4%
No distress	0-4	7,291(272)	65.2%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Missing data 8.4%.
Sample size n=11,184.

The items to follow were used in ordinal logistic regression models for identifying the child, family and community factors associated with participation frequency of children with disabilities in community-based physical and social activities, therefore, are discussed in respect to children with disabilities only (sample size *n*=1,073).

Measure of parental social support

Parental social support was measured by using parental responses to an item asking the frequency with which respondents talk to their child about things that are important to them. The item was measured in a 6-point Likert scale, ranging from "1=Every day or almost every day" to "6=Not at all". The response categories for this item were reverse coded and collapsed into the following four categories – "1=Never" (6), "2=Seldom" (4,5), "3=Regular"(3) and "4=Often"(1,2) (Table 23).

Table 23. Parental social support - an original and new variable

Original variable & response values	Population estimate *(SE)*	Per cent (%)	New variable & response values	Population estimate *(SE)*	Per cent (%)
Every day/almost every day	698 (37)	65.1%	Never	18 (7)	1.7%
Several times a week	241(25)	22.4%	Seldom	37 (9)	3.5%
Once or twice a week	79 (12)	7.4%	Regular	79 (12)	7.4%
Once or twice a month	26 (7)	2.4%	Often	939 (46)	87.5%
Less often than once a month	10 (4)	1.1%			
Not at all	18 (7)	1.7%			

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
No missing data.
Sample size n=1,073.

Measure of family activity orientation

Family activity orientation was measured using parental responses to three items. Parents were asked to indicate: (1) the frequency with which they play sports and physically active games with their children outdoors and indoors, and (2) the frequency

with which they play indoor games. These two items were measured in a 6-point Likert scale ranging from "1=Every day or almost every day" to "6=Not at all" (Tables 24-25). The response categories were reverse coded and collapsed into four categories corresponding to "1=Never"(6), "2=Seldom"(4, 5), "3=Regular"(3) and "4=Often"(1, 2) (Tables 24-25).

Table 24. Parental play of physically active games with a child - an original and new variable

Original variable & response values	Population estimate *(SE)*	Per cent (%)	New variable & response values	Population estimate *(SE)*	Per cent (%)
Every day/almost every day	44 (9)	4.1%	Never	283 (26)	26.4%
Several times a week	84 (12)	7.9%	Seldom	423 (27)	39.4%
Once or twice a week	238 (18)	22.2%	Regular	238 (18)	22.2%
Once or twice a month	220 (19)	20.5%	Often	128 (15)	12.0%
Less often than once a month	203 (19)	18.9%			
Not at all	283 (26)	26.4%			

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
No missing data.
Sample size n=1,073.

Table 25. Parental play of indoor games with a child - an original and new variable

Variable & response values	Population estimate *(SE)*	Per cent (%)	Variable & new response values	Population estimate *(SE)*	Per cent (%)
Every day or almost every day	75 (12)	7.0%	Never	104 (14)	9.7%
Several times a week	165 (19)	15.4%	Seldom	393 (27)	36.7%
Once or twice a week	335 (24)	31.2%	Regular	335 (24)	31.2%
Once or twice a month	243 (21)	22.6%	Often	241 (23)	22.4%
Less often than once a month	151 (17)	14.0%			
Not at all	104 (14)	9.7%			

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response
No missing data.
Sample size n=1,073.

The third item used was asking the frequency with which respondents were playing sports or doing any physical activity like swimming, running, football, dancing, exercise classes, going to the gym. This item was measured in a 7-pont Liker scale ranging from "1=Every day/almost every day" to "7=Less often than once a year or Never" (Table 26). The response categories were reverse coded and collapsed into four categories corresponding to "1=Never"(7, 6), "2=Seldom"(4, 5), "3=Regular"(3) and "4=Often"(1, 2) (Table 26).

Table 26. Parental physical activity - an original and new variable

Variable & response values	Population estimate *(SE)*	Per cent (%)	Variable & new response values	Population estimate *(SE)*	Per cent (%)
Every day/almost every day	134 (16)	12.5%	Never	402 (30)	37.4%
Several times a week	147 (15)	13.7%	Seldom	170 (19)	15.8%
Once or twice a week	220 (20)	20.5%	Regular	220 (20)	20.5%
Once a month	109 (16)	10.1%	Often	281 (23)	26.2%
Every few months	61 (9)	5.7%			
Once a year	23 (6)	2.1%			
Less often or never	379 (30)	35.3%			

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
No missing data.
Sample size n=1,073.

Parental time

Various items are available in MCS5 to quantify availability of parental time, including continuous variables asking respondents to specify working hours, paid and unpaid overtime working hours and frequency of working during weekends. Respondents were also asked about availability of time to spend with the child. Although detailed accounts on parental working hours can be used as a measure of parental free time, these items were considered as proxy and were not accounted for. It is probable to assume that parents who work longer hours or frequently work over weekends might have less time to spend with their children and provide them with opportunities for community-based participation. Parental long working hours may also be indicative of a higher probability for a child being enrolled into after-school clubs. It is equally plausible however that parents who work longer hours might try to compensate for their frequent absence by providing their children with more frequent opportunities for participation in community-based activities than parents who work less hours or do not work at all. Furthermore, working shorter hours or not working at all do not necessarily imply that parents have plenty of free time for their children. Other family commitments and/or care responsibilities for elderly might consume their time.

Given the absence of any possibilities for the investigator to check the plausibility of any of these assumptions with the data available in the MCS5, it was decided to measure parental time using parental responses to a single item asking how much time they have to spend with their children. Responses to this item were measured on a 5-

point Likert type scale, ranging from "1=Too much time" to "5=Nowhere near enough time". To support analytical interpretations, the response options were reverse coded and collapse into a 3–point Likert type scale corresponding to "1=Not enough time" (5, 4), "2=Just enough time" (3) and "3=Enough time" (1, 2) (Table 27).

Table 27. Parental time – an original and new variable

Variable & response values	Population estimate *(SE)*	Per cent (%)	Variable & new response values	Population estimate *(SE)*	Per cent (%)
Too much time	43 (9)	4.0%	Not enough time	375 (28)	35.2%
More than enough time	296 (23)	27.8%	Just enough time	352 (25)	33.0%
Just enough time	352 (25)	33.0%	Enough time	339 (26)	31.8%
Not quite enough time	301 (25)	28.3%			
Nowhere near enough time	74 (11)	6.9%			

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Missing data 0.8%.
Sample size n= 1,066.

4.8.4 Measures of community characteristics

Two items are available in the MCS5 for assessing community or neighbourhood characteristics. Respondents were asked: (i) whether the area they live in is good for bringing up children, and (ii) about the availability parks/playgrounds or public spaces in the area where the child can play outdoors on his own or supervised. The first item was measured in a 5-point Likert scale, ranging from "1=Excellent" to "5=Very poor". Due to the low number of respondents in the category "Very poor" and because the difference between "1=Excellent" and "2=Good" was difficult to quantify and give meaningful interpretation from a clinical perspective, the original scale was reverse coded and collapsed into three categories - "1=Poor" (4, 5), "2= Average" (3) and "3=Good" (1, 2) (Table 28).

Table 28. Type of area to raise a child - an original and new variable

Variable & response values	Population estimate *(SE)*	Per cent (%)	Variable & new response values	Population estimate *(SE)*	Per cent (%)
Excellent	310 (24)	29.0%	Poor	92 (15)	8.6%
Good	428 (28)	40.0%	Average	238 (24)	22.3%
Average	238 (24)	22.3%	Good	738 (37)	69.1%
Poor	64 (12)	6.0%			
Very poor	28 (7)	2.6%			

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Missing data 0.6%.
Sample size n=1,069.

The second item was measured on a binary scale 1=Yes vs 2=No. The scale for this item was reverse coded so that availability of parks/playgrounds became a reference category – "0=No" vs "1=Yes" (Table 29).

Table 29. Availability of parks/playgrounds for a child to play – an original variable

Variable & response values	Population estimate *(SE)*	Per cent (%)
No	99 (16)	9.2%
Yes	970 (48)	90.8%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Missing data 0.4%.
Sample size n=1,069.

4.8.5 Measures of participation in community-based activities

For the purposes of this research, community-based participation was defined as a child's attendance at formal and informal everyday activities in the out-of-school community environment, including play, sport, entertainment and religious expression. In MCS5, respondents were asked to indicate how often their child had attended a variety of formal and informal activities in the community (Gallop et al. 2013). Most of the items were scored on the 7-point Likert type scale, ranging from daily to never within last month or the past 12 months. Respondents were additionally asked to indicate whether or not their child attended formal cycling proficiency trainings, made trips around the local area on foot, by bike and public transport (Gallop et al. 2013). However, this last set of questions did not include any reference to the frequency with which the children attended these activities.

Community-based participation items were selected based on literature review on participation measurement and completed by matching exercise of available items with the measure demonstrating a contemporary model of participation: the Participation and Environment Measure: Children and Youth (the PEM-CY) (Coster et al. 2012). The PEM-CY is a standardized, valid and reliable parent-report tool that measures the participation of children with and without disabilities aged 5-17 across various settings - home, school and community (Coster et al. 2012). The items for each setting include a wide range of activities that are commonly performed by children in the particular setting. Those were developed in consultations with parents of both children with and without disabilities aged 5-17 (Bedell et al. 2011; Coster et al. 2012).

The aspects of participation measured are frequency (measured in an 8-point Likert type scale which ranges from daily participation to never within last 4 months), involvement and parent's desire for change in their child's participation matters (Coster et al. 2012). The tool has been found to have moderate to good internal consistency (0.59-0.83) and test-retest reliability (0.58-0.84) among children and youth with various forms of disability (Coster et al. 2012).

For the purposes of this research, only the community-based participation section of the PEM-CY was of interest. This section of the tool is presented by 10 community-based participation items. (Table 30). Although the PEM-CY consists of fewer community-based participation items compared to other participation measurement tools, as described in section 2.2.6, the content density of the items in relation to the ICF's participation domains is high (Chien et al. 2014).

Table 30. Community participation items in the PEM-CY

Community participation items I-X	
Item I: Neighbourhood outings	Typically, how often does your child participate in 1 or more activities of this type e.g. shopping at the store/mall, going to a movie, eating out at a restaurant, visiting the local library/bookstore?
Item II: Community events	Typically, how often does your child participate in 1 or more activities of this type e.g. attending a play, concert, sports game, parade?
Item III: Organized physical activities	Typically, how often does your child participate in 1 or more activities of this type e.g. sports teams or classes such as baseball, hockey, martial arts, dance, horseback riding, swimming, gymnastics?
Item IV: Unstructured physical activities	Typically, how often does your child participate in 1 or more activities of this type e.g. nature trail walks, bicycle riding, rollerblading, skateboarding, playing hide-and-seek or chase, playing pick-up games like basketball?
Item V: Classes and lessons (not school sponsored)	Typically, how often does your child participate in 1 or more activities of this type e.g. music, art, languages, computers?
Item VI: Organizations, groups, clubs, and volunteer or leadership activities	Typically, how often does your child participate in 1 or more activities of this type e.g. Boy Scouts, Brownies/Girl Guides, youth groups, public speaking?
Item VII: Religious or spiritual gatherings and activities	Typically, how often does your child participate in 1 or more activities of this type e.g. attending places of worship, religion classes, groups?
Item VIII: Getting together with other children in the community	Typically, how often does your child participate in 1 or more activities of this type e.g. hanging out, informal gatherings outside of the home or school?
Item IX: Working for pay	Typically, how often does your child participate in 1 or more activities of this type, e.g. babysitting, paper route, working in a store, doing chores or running errands for pay?

Community participation items I-X	
Item X: Overnight visits or trips	Typically, how often does your child participate in 1 or more activities of this type? (e.g. sleepovers, vacations, camp)

Based on the matching exercise with the PEM-CY, six items were selected from the MCS5. Those items measured children's participation in community-based activities such as:

(1) Visiting a library (a proxy to the PEM-CY's Item I),
(2) Organized physical activities (a match to the PEM-CY's Item III),
(3) Unstructured physical activities (a match to the PEM-CY's Item IV),
(4) Religious gatherings (a match to the PEM-CY's Item VII),
(5) Getting together with friends (a match to the PEM-CY's Item VIII),
(6) Vacations abroad (a proxy to the PEM-CY's Item X).

The aspect of participation captured was attendance or "being there" (Imms et al. 2016). In line with descriptions supplied by Imms et al. (2016), attendance was quantified in terms of:

(1) "0=Never participated" vs "1=Participated" (binary response)
(2) Diversity- the number of activities undertaken (numerical value calculated based on the binary response "0=Never participated" vs "1=Participated")
(3) Frequency – "1=Low", "2=Regular" and "3=High" (ordinal response)

The binary response - "0=Never participated" vs "1=Participated" was derived by collapsing the original 7-point (or 6-point) Likert type scales for each item into binary categories. Although being a "rough" measure of participation, the binary response allowed to identify the proportions of children with disabilities with the most restricted participation (i.e. those who "Never participated"). It also allowed for describing and comparing patterns of children's participation - the ranking of proportions for participation across six activities within the two groups of children. Diversity was measured by counting the number of activities for which the respondents gave an affirmative response for participation (minimum 1, maximum 6). Mean diversity

scores for both groups were calculated by dividing the number of activities undertaken by the total possible (n=6). Frequency of participation was measured by collapsing the original 7-point (or 6-point) Likert type scales for each item into three new ordinal categories corresponding to "1=Low", "2=Regular" and "3=High" frequency of participation. All the categories were developed in consultation with a group of experts in participation research (Appendix F).

Participation intensity score (an average frequency of participation) described as a quantifier of participation in the PEM-CY, was not measured in this research because of three reasons. First of all, participation intensity score "blues" the actual participation profiles of children. By averaging participation scores across activities it "masks" children's tendency of more frequent participation in some but not other activities. Second of all, the original response provided in the MCS5 for each of the item was categorical, specifically 7-point Likert type scale (in one case 6-point Likert type scale, in another a range from 0 to 10). The differences between response options in the original scales were difficult to quantify. For instance, the difference between "2=Several times a week" and "3=Once or twice a week" may be substantially less than the difference between "3=Once or twice a week" and "4=At least once a month". Finally, although most of the items were measuring participation in the last month, three items assessed participation within in the last 12 months. Therefore, it was deemed inappropriate to calculate the intensity or average frequency of participation from individual item scores which were lacking comparability in a measurement scale.

Individual item descriptions

Item I: Visiting a library

This is a proxy to the PEM-CY's Item I (i.e. Neighbourhood outings) which is looking at children's frequency of attendance to one or more of these activities e.g. shopping at the store/mall, going to a movie, eating out at a restaurant, visiting the local library/bookstore. Item I was derived on the basis of the parental response to an item that asked over the past 12 months, how often the child has been to a library (not a school library) (with response categories ranging from 1= Every day or almost every

day to 7=Less often than once a year or never). Frequency distributions for the original and derived participation frequency categories are presented in Tables 31-32.

Table 31. Visiting a library – an original variable

Original variable & response values	Population estimate *(SE)*	Per cent (%)
Every day/almost every day	53 (9)	0.4%
Several times a week	180 (17)	1.5%
Once or twice a week	901 (55)	7.4%
At least once a month	2,199 (98)	18.0%
Every few months	2,972 (127)	24.4%
At least once a year	1,560 (76)	12.8%
Less often/never	4,326 (197)	35.5%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Missing data 0.02%.
Sample size 12,192.

Table 32. Visiting a library– new variables

New variable & response values (binary response)	Population estimate *(SE)*	Per cent (%)	New variable & response values (ordinal response)	Population estimate *(SE)*	Per cent (%)
Never participated	4,326 (197)	35.5%	Low	8,859 (355)	72.7%
Participated	7,866 (302)	64.5%	Regular	3,100 (136)	25.4%
			High	233 (20)	1.9%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Missing data 0.02%.
Sample size n= 12,192.

Item II: Organized physical activities

This is a direct match to the PEM-CY's Item III (i.e. Organized physical activities) which is focusing on children's frequency of attendance to one or more of these activities: sports teams or classes such as baseball, hockey, martial arts, dance, horseback riding, swimming, gymnastics, or organized physical activities. Item II was derived based on the parental response to an item that asked how many days a week the child usually attended a club or class to do sport or any other physical activity like swimming, gymnastics, football, or dancing (with response categories ranging from 1= Five/more days a week to 7=Not at all). Frequency distributions for the original and derived participation frequency categories are presented in Tables 33-34.

Table 33. Organized physical activities– an original variable

Original variable & response values	Population estimate *(SE)*	Per cent (%)
Five/more days a week	971 (60)	8.0%
Four days a week	972 (50)	8.0%

Original variable & response values	Population estimate *(SE)*	Per cent (%)
Three days a week	1,794 (80)	14.7%
Two days a week	2,441 (97)	20.0%
One day a week	2,653 (132)	21.8%
Less often than once a week	251 (27)	2.1%
Not at all	3,113 (160)	25.5%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. No missing data.
Sample size n= 12,195.

Table 34. Organized physical activities – new variables

New variable & response values (binary response)	Population estimate *(SE)*	Per cent (%)	New variable & response values (ordinal response)	Population estimate *(SE)*	Per cent (%)
Never participated	3,113 (160)	25.5%	Low	3,364 (173)	27.6%
Participated	9,082 (344)	74.5%	Regular	5,094 (209)	41.8%
			High	3,737 (153)	30.6%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. No missing data. Sample size n= 12,195.

Item III: Unstructured physical activities

The second PEM-CY item is looking at children's frequency of attendance in unstructured physical activities, e.g. nature trail walks, bicycle riding, rollerblading, skateboarding, playing hide-and-seek or chase, or playing pick-up games like basketball. Item III was derived based on the parental response to an item that asked, not including clubs or classes, how many days a week the child usually took part in physical activities (e.g. swimming, walking) or physically active play with friends or brothers and sisters, not including walking to school (with response categories ranging from 1= Five/more days a week to 7=Not at all). Frequency distributions for the original and derived participation frequency categories are presented in Tables 35-36.

Table 35. Unstructured physical activities – an original variable

Original variable & response values	Population estimate *(SE)*	Per cent (%)
Five/more days a week	5,757 (230)	47.2%
Four days a week	959 (51)	7.9%
Three days a week	1,428 (76)	11.7%
Two days a week	1,588 (79)	13.0%
One day a week	1,154 (68)	9.5%
Less often than once a week	469 (38)	3.8%
Not at all	838 (66)	6.9%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. Missing data 0.02%.
Sample size n=12,193.

Table 36. Unstructured physical activities – new variables

New variable & response values (binary response)	Population estimate *(SE)*	Per cent (%)	New variable & response values (ordinal response)	Population estimate *(SE)*	Per cent (%)
Never participated	838 (66)	6.9%	Low	1,308 (91)	10.7%
Participated	11,355 (431)	93.1%	Regular	2,742 (131)	22.5%
			High	8,144 (309)	66.8%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Missing data 0.02%.
Sample size n=12,193.

Item IV: Religious gatherings

This is a direct match to the PEM-CY's Item VII (i.e. Religious or spiritual gatherings and activities) which measures children's frequency of attendance to one or more of these activities: places of worship, religion classes or groups. The outcome measure was derived based on the parental response to an item asking over the past 12 months, how often the child had been to a religious service or class (with response categories ranging from 1= Every day or almost every day to 7=Less often than once a year or never). Frequency distributions for the original and derived participation frequency categories are presented in Tables 37-38.

Table 37. Religious gatherings – an original variable

Original variable & response values	Population estimate *(SE)*	Per cent (%)
Every day/almost every day	416 (91)	3.4%
Several times a week	270 (36)	2.2%
Once or twice a week	1,606 (92)	13.2%
At least once a month	829 (54)	6.8%
Every few months	1,248 (62)	10.2%
At least once a year	1,522 (74)	12.5%
Less often/never	6,292 (273)	51.6%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Missing data 0.03%. Sample size n=12,184.

Table 38. Religious gatherings – new variables

New variable & response values (binary response)	Population estimate *(SE)*	Per cent (%)	New variable & response values (ordinal response)	Population estimate *(SE)*	Per cent (%)
Never participated	6,292 (273)	51.6%	1=Low	9,062 (357)	74.4%
Participated	5,892 (261)	48.4%	2=Regular	2,436 (132)	20.0%
			3=High	686 (116)	5.6%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Missing data 0.03%.
Sample size n=12,184.

Item V: Getting together with friends

This is a direct match to the PEM-CY's Item VIII (i.e. Getting together with other children in the community) which assesses children's frequency of attendance to one or more of these activities: hanging out, informal gatherings outside of the home or school places. The outcome measure was derived based on the parental response to an item asking, apart from at school, how often the child spends time with their friends (with response categories ranging from 1=Every day or almost every day to 6= Not at all). Frequency distributions for the original and derived participation frequency categories are presented in Tables 39-40.

Table 39. Getting together with friends – an original variable

Original variable & response values	Population estimate *(SE)*	Per cent (%)
Every day/almost every day	3,138 (152)	25.7%
Several times a week	3,169 (135)	26.0%
Once or twice a week	3,607 (160)	29.6%
Once or twice a month	1,269 (66)	10.4%
Less often than once a month	504 (36)	4.1%
Not at all	509 (49)	4.2%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
No missing data.
Sample size n=12,195.

Table 40. Getting together with friends – new variables

New variable & response values (binary response)	Population estimate *(SE)*	Per cent (%)	New variable & response values (ordinal response)	Population estimate *(SE)*	Per cent (%)
Never participated	509 (49)	4.2%	Low	1,013 (73)	8.3%
Participated	11,686 (439)	95.8%	Regular	4,876 (211)	40.0%
			High	6,306 (255)	51.7%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
No missing data.
Sample size n=12,195.

Item VI: Vacations abroad

This is a proxy to the PEM-CY's Item X (i.e. Overnight visits or trips) which is looking at children's frequency of attendance to activities including sleepovers, vacations and camps. Item VI was derived based on the parental response to an item asking over the past 12 months, how many times, if at all, the child had been on holiday/vacations outside the UK. The original response ranged from 0-10 (Figure 12), with 41% of children having between 1 to 4 vacations abroad (missing data 0.02%). Frequency

distributions for the derived participation frequency categories are presented in Table 41.

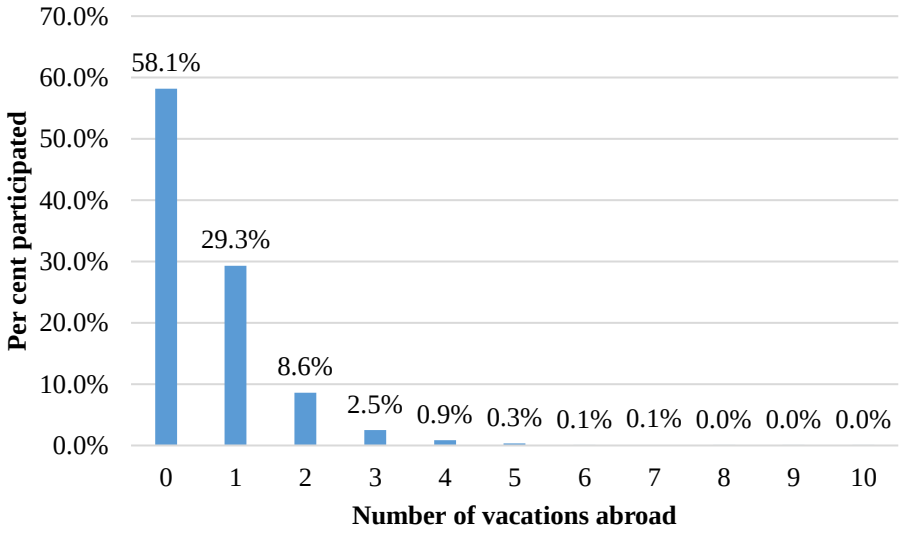


Figure 12. Vacations abroad - an original variable, frequency distributions

Table 41. Vacations abroad – new variables

New variable & response values (binary response)	Population estimate *(SE)*	Per cent (%)	New variable & response values (ordinal response)	Population estimate *(SE)*	Per cent (%)
Never participated	7,088 (301)	58.1%	Low	10,662 (417)	87.4%
Participated	5,104 (222)	41.9%	Regular	1,359 (78)	11.1%
			High	172 (29)	1.4%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Missing data 0.02%.
Sample size n=12,192.

4.9 Data analysis

4.9.1 Complex samples, missing data and weighting

The use of stratified geographical clustering sampling design implies that observations in the MCS are not independent of each other (i.e. observations do not come from a simple random sample) (Jones et al. 2010). A multistage cluster sampling data structure has to account for sampling design as it can affect the accuracy of statistical inferences and generalizability of the results (Jones et al. 2010). As described in subsection 4.4.3, the MCS has a multistage data structure. With this type of data structure weighting is important in any data analysis.

Two type of weights should be considered - variance estimation weights and attrition weights (Kneipp and Yarandi 2002). Variance estimation weights should be used to adjust the data for the complex study design (Kneipp and Yarandi 2002). This is because observations within clusters might have more characteristics in common compared to observations selected randomly from the population, thus affecting the variance (Kneipp and Yarandi 2002). The MCS5 data includes variance estimation weights. The data file with weights can be accessed from the UK Data Service.

Attrition weights should be used if there are attrition and unit non-response issues in data (Kneipp and Yarandi 2002). Attrition occurs when participants in a longitudinal survey are permanently lost to follow-up. Unit non-response, on the other hand, occurs if eligible participants in a longitudinal survey fail or refuse to respond and/or provide incomplete information for the response to be considered informative. Several methods can be used to account for attrition and unit non-response. The selection of a method is typically informed by the type of data "missingness": (1) missing completely at random (MCAR), (2) missing at random (MAR), and (3) missing not at random (MNAR) (Little and Rubin 1987).

Little and Rubin (1987) describe that data are considered MCAR, if the probability of the participant remaining in the longitudinal study is not dependent on exposure, confounders or the outcome. If data are MCAR, no bias is introduced and attrition can be ignored in the data analyses (Little and Rubin 1987). If the probability of the participant remaining in the study is dependent on the exposure or confounders, but not on the outcome, data are considered as missing at random. Regression imputation, weighting and multiple imputation are the most commonly used methods in situations when data are MAR (Little and Rubin 1987; Kneipp and Yarandi 2002). Data are considered as MNAR if probability of the participant being lost to follow-up is dependent on the outcome. Data that is MNAR can yield serious bias and should be adjusted for attrition (Kneipp and Yarandi 2002).

In the MCS, the proportion of productive cases (families) dropped across the sweeps from original 96.4% in the MCS1 to 69% in the MCS5. Response and non-response rates across the sweeps are presented in Table 23. As described in subsection 4.5.1, families in the MCS were deemed ineligible in the event of the cohort child's death or family emigration. Some of the families were also not traceable over time (Table 42, Figure 10).

Table 42. Response rates across MCS sweeps (1-5)

Categories	MCS1		MCS2		MCS3		MCS4		MCS5	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Not issued	692	3.6	0	0.0	0	0.0	2213	11.5	2851	14.8
Productive	18,552	96.4	15,590	81.0	15,246	79.2	13,857	72.0	13,287	69.0
Ineligible	0	0.0	167	0.9	300	1.6	126	0.7	78	0.4
Untraced	0	0.0	687	3.6	547	2.8	706	3.7	388	2.0
Refused	0	0.0	1,739	9.0	2,315	12.0	1,811	9.4	2,196	11.4

Attrition analysis carried out by the data owners showed that families living in material, social and economic disadvantage systematically had lower response rates compared to those living in socio-economically advantaged and affluent conditions (Hansen 2014) (Table 43).

Table 43. Response rates by stratum in the MCS5

Categories	England			Scotland		Wales		Northern Ireland	
	Adv[a]	Dis[b]	Ethn[c]	Adv	Dis	Adv	Dis	Adv	Dis
Unproductive	25.5	31.0	34.2	32.4	40.7	28.3	33.4	30.8	32.7
Productive	74.5	69.0	65.8	67.6	59.3	71.7	66.6	68.2	67.3

[a]*Advantaged wards.*
[d]*Disadvantaged wards.*
[c]*Ethnic minority wards.*

Given that this research is interested in children with disabilities and their participation and the fact that children with disabilities tend to be more prevalent in socio-economically disadvantaged families, data in the MCS5 are deemed to be missing at MNAR and should be adjusted for attrition. The MSC5 data includes attrition weights generated by a team of statisticians at the CLS using socio-demographic characteristics associated with unit non-response. The data file with weights can be accessed from the UK Data Service.

Application of survey design, attrition and unit non-response weights requires the usage of a specific statistical software such as e.g. SPSS, STATA, SUS or R programming language. In SPPS, multistage complex survey data that require application of weights could be analysed through the Complex Samples Module. The SPSS Complex Samples Module, version 23.0 (IBM Corp., Armonk, NY, USA) was used for this research. The file contacting all the weights that potentially might be applicable for data analysis was requested from the UK Data Service. To set up Complex Samples (CS) Plan file containing all the required variables (stratification variable - pttype2, clustering variable - sptn00, finite population correction factor variable - nh2, unique identifier – mcsid) and weight (eovwt2) for data analyses, the *User Guide to Analysing MCS Data Using SPSS* (Jones et al. 2010) was consulted. Analytical outputs produced by the SPSS Complex Samples Module version 23.0 were cross-checked with examples presented in the user guide to ensure the accuracy of procedures.

The SPSS Complex Samples Module runs each analysis on all cases it can use for it while accounting for sample design, attrition and non-response. This implies that cases with missing data at an item or variable level are automatically dropped or excluded from an analysis. Therefore, the investigator should additionally evaluate the "missingness" at a variable level and decide whether special techniques for handling missing data must be applied before running the SPSS Complex Samples Module.

The participants included in the final sample (main carers of children n=12,195) provided relatively complete data on the child, family and community factors of interest. In the majority of cases, the percentage of missing data on variables of interest ranged between 0% and 0.8%. Only two variables had a relatively high percentage of missing data. Those were the child psychosocial and behavioural problems (3.6% missing data) and parental mental health functioning (8.4% missing data). Although there is not a universally established cut-off in the literature regarding an acceptable percentage of missing data at a variable level, the general consensus is that statistical analysis is likely to be biased when more than 10% of data are missing (Bennett 2001; Langkamp et al. 2010). Given that (1) missing data for these two variables did not

exceed a 10% cut-off point, (2) the fact that it was impossible to establish whether data were missing completely at random, at random or not at random, and (3) the relatively big sample size, cases with missing data on these two variables were dropped from the analyses.

4.9.2 Statistical techniques

Frequency distributions and chi-squared (χ^2)

Frequency distributions were used to establish prevalence estimates and proportions. A chi-squared (χ^2) test of independence was used for examining differences in characteristics, family circumstances and participation (measured both as "Never Participated" vs "Participated" and frequency) between children with and without disabilities. A chi-squared test of independence compares the frequencies (or proportions) observed in each of the categories in each variable with frequencies or values that would be expected if there was no association between the two variables assessed (Field 2013). It is based on a cross-tabulation (contingency) table, with observations classified according to the categories in each variable. Although the test is informative in examining the differences between groups and establishing associations, it does not provide a measure of effect size that is the strength of assumption between categorical variables. Odds ratios are more useful measures of effect size for categorical data and can be obtained from 2 by 2 tables or fitting logistic regression models, which was also done in the scope of this research.

Assumptions

Chi-squared (χ^2) is a non-parametric statistical technique, hence, it has less strict set of assumptions to be checked. However, there are still a couple of assumptions requiring verification such as independence of observations and minimum expected cell frequency.

Independence of observations

As has been described in section 4.9, observations in the MCS are not independent of each other – they are not drawn from the population of interest following simple random sampling technique. To account for this as well as for attrition and non-repose,

weighting has been used when analysing data. In the SPSS Complex Samples Module, results of χ^2 are based on the adjusted *F* (F_{adj}) and its degrees of freedom (Jones et al. 2010). The adjusted *F* is a variant of the second-order Rao-Scott adjusted χ^2 statistic (IBM Corp., Armonk, NY, USA). Results are based on the adjusted *F* because of a lack of independence of observations in the MCS5 caused by complex sampling design features of the survey (Jones et al. 2010).

Minimum expected cell frequency

One of the key assumptions of χ^2 is that the lowest expected frequency in any cell should not be less than 5 or at least 80% of cells should have expected frequencies of 5 or more. Frequency distributions were used to assess if this assumption was satisfied. Given the sample size, this assumption was always satisfied.

Logistic regression

Binary Logistic Regression

Binary logistic regression analysis was used: (1) to establish the strength of associations between childhood disability and socio-demographic characteristics; (2) to establish associations between childhood disability and participation frequency in each community-based activity. Binary logistic regression, also known as Logit Regression or Logit Model, is used to predict probability of event occurring or falling into a targeted category (in this case a child has a disability) given one or more explanatory variables measured in continuous or categorical scale (Agresti 2007). Because the outcome of interest is binary (i.e. success or failure), a specific link function called logit is used to change the distribution of the outcome variable so that its relation to explanatory variables is linear (Agresti 2007). An equation for a binary logistic regression model showing what function of the probabilities (Pr) results in a linear combination of explanatory variables can be written as follows:

$$Logit\left[\frac{Pr(category)}{1-\Pr(category)}\right] = \beta_o + \beta_1 X_1 + \beta_2 X_2 \ldots . + \beta_k X_k$$

The left side of the equation is logit and the right side of equation is similar to a simple linear model (i.e $Y = \beta o + \beta X$, where Y-outcome variable, X -explanatory variable, β-slope of the regression line and βo is the Y-intercept), but instead of predicating the value of a variable Y from explanatory variable $X_1 \ldots X_k$, the probability of target category occurring is predicated given known values of $X_1 \ldots X_k$ (Agresti 2007). The beta coefficients in the logistic model show the increase or decrease in the predicted probability of falling into a targeted category due to one unit change or category shift in the explanatory variable (Agresti 2007). Values close to zero indicate low likelihood for an individual with a particular value on an explanatory variable to fall into the targeted category. Higher values or larger coefficients indicate higher likelihood for an individual with a particular value on an explanatory variable to fall into the targeted category (Agresti 2007). To translate logits into probabilities, each side of the equation should be taken as an exponent. Given that the logarithm of the number as an exponent equals the number itself (Agresti 2007), taking the exponential of the equation will give the following formula:

$$\frac{Pr(category)}{1 - Pr(category)} = e^{\beta o + \beta 1 X1 + \beta 2 X2 + \beta k Xk}$$

Solving for Pr will give the formula:

$$\Pr(category) = \frac{e^{\beta o + \beta 1 X1 + \beta 2 X2 + \beta k Xk}}{1 + e^{\beta o + \beta 1 X1 + \beta 2 X2 + \beta k Xk}} = \frac{e^{Logit}}{1 + e^{Logit}} = \frac{1}{1 + e^{-(Logit)}}$$

therefore, the probability of a target category occurring is a ratio of the exponential of the logit to 1 plus the exponential of the logit (Agresti 2007). Given that e^{Logit} produces estimated odds, the formula will correspond to the equation:

$$\Pr(category) = \frac{Odds}{1 + Odds}$$

Probabilities always range between 0 and 1 (Agresti 2007). Based on this formula, the odds of a target category occurring is the ratio of the probability the target category occurs to the probability it does not occur:

$$Odds = \frac{\Pr(category)}{1 - \Pr(category)}$$

If the probability the target category occurs is 0.5 (50%), the odds will be equal to 1 (even odds). When the probability is low, so are the odds for the target category to occur and vice versa (Agresti 2007).

Ordinal Logistic Regression

Ordinal Regression Analysis was used to established associations between the child, family and community factors and participation frequency of children with disabilities in organized physical activities, unstructured physical activities and getting together with friends. Ordinal regression analysis is used to predict the probability of categorical outcome (in this case frequency of participation measured as "1=Low", "2=Regular" and "3=High"); but instead of predicting the probability of an individual event as in binary logistic regression, the probability of an event and all others below it in the ordinal ranking is predicted (Agresti 2007). In other words, cumulative probabilities of the outcome is predicted. In the ordinal regression model, each explanatory variable exerts the same effect at each cumulative split of the ordinal response variable categories or levels of the outcome variable (Agresti 2007). Because of this property, the ordinal model is called a proportional odds model (Agresti 2007). An equation for a proportional odds model for a single explanatory variable can be written as follows (Agresti 2007):

$$Logit\,[P(Y \leq j)] = \alpha j - \beta X, j = 1, J - 1$$

Here the j is a cumulative split for each category or the level of an ordered category with J levels. In the ordinal model, j extends only to J-1 because the probability of being in one category or below in ordinal ranking is predicted (Agresti 2007). A minus

sign before a coefficient for an explanatory variable is there to ensure that the higher predicted value is associated with higher scores (Agresti 2007). In the ordinal model, each logit has its own αj term (i.e. threshold value is playing the same role as intercept in a linear regression model) but the same beta coefficients (Agresti 2007).

Assumptions

As with any other statistical technique, for logistic regression analysis to be valid a set of assumptions must be satisfied:

Multicollinearity

Multicollinearity is a statistical phenomenon in which two or more explanatory variables in a regression model are highly correlated or associated (Agresti 2007; Field 2013). Checking data for multicollinearity is essential for fitting predicative models (Field 2013). This is because the existence of collinearity between explanatory variables makes it difficult to evaluate the predictive power of individual variables (Field 2013); it inflates the standard errors of the estimates and consequently provides incorrect statistical inferences about relationships between explanatory and outcome variables (Field 2013). Multicollinearity, however, does not reduce the predictive power or reliability of the model as a whole; it only affects estimations around individual explanatory variables (Field 2013). Examining the correlation matrix provides a quick way of identifying high inter-correlations among explanatory variables (Field 2013). Although the cut-off point for determining of existence of collinearity is flexible, a general consensus is to avoid inclusion of explanatory variables correlated at $r \geq 0.8$ (Field 2013).

The SPSS Complex Samples Module does not provide an option for measuring correlations between categorical explanatory variables. One option is to generate dummy variables for all the categorical explanatory variables of interest and enter them into a liner regression analysis. This will generate correlation coefficients between levels of response categories for all the explanatory variables. Detailed inspection of correlational matrix derived through this method revealed correlations r = 0.5 or less which is in a range of tolerable inter-correlation (Field 2013). This option however has

a limitation. Reference categories identified for each explanatory variable do not generate any correlational coefficients.

To overcome this limitation, the investigator used the packages “psych” (Revelle 2018) and “survey” (Lumley 2004; Lumley 2019) in R programing language (R Core Team 2017) which allowed generation of single polychoric correlation coefficients between categorical explanatory variables while accounting for complex sample features of the data. Detailed review of the correlational matrix derived yielded identification of correlations $r = 0.6$ or less which is generally considered in a range of tolerable inter-correlation (Field 2013). The correlational matrix retrieved at the initial exploratory stages of this research to check presence of multicollinearity between the child, family and community factors intended for using in predictive models for to answer RQ5 (n=1,073) is presented in Table 44.

Table 44. Correlation matrix

Items	I1	I2	I3	I4	I5	I6	I7	I8	I9	I10	I11	I12	I13	I14
I2	-0.01													
I3	0.23	0.08												
I4	0.07	0.13	0.53											
I5	0.18	-0.08	0.36	0.07										
I6	-0.07	0.10	0.61	0.21	0.12									
I7	0.22	0.23	0.11	-0.06	0.07	0.04								
I8	-0.32	0.07	0.17	0.10	0.36	-0.22	-0.03							
I9	0.33	0.36	0.35	0.22	-0.13	0.10	0.24	0.08						
I10	0.18	0.00	0.02	-0.24	0.50	-0.02	0.53	0.10	-0.05					
I11	0.32	-0.19	0.16	-0.23	0.25	0.03	-0.20	0.14	-0.20	0.46				
I12	0.02	0.14	0.23	0.00	-0.32	0.23	0.53	0.07	0.24	0.20	0.03			
I13	0.05	0.16	0.23	0.29	-0.02	0.30	0.03	-0.04	0.37	-0.04	-0.23	0.01		
I14	0.05	-0.20	0.40	0.23	0.24	0.23	0.06	0.49	0.13	0.00	0.03	0.20	0.14	
I15	0.00	0.23	-0.17	0.08	0.14	-0.23	-0.06	0.02	-0.02	0.25	0.13	-0.32	0.11	0.04

Note. Sample size n=1,073.
I-item, I1 – Child sex, I2 – Parental longstanding illness , I3 – Family (equalized) income, I4 – Family type, I5 – Ethnicity, I6 – Parental education , I7 – Parental play of physical active games with a child , I8 – Availability of parks/playgrounds for a child to play , I9 – Parental mental health functioning, I10 – Parental play of indoor games with a child , I11 – Parental social support, I12 – Parental physical activity , I13 – PSB problems, I14 – Type of area to raise a child , I15 – Parental time.

Sample size

Logistic regression analysis typically requires a large sample size. In case of secondary data analysis of an existing dataset, the sample size is determined. Further, post-hoc sample size calculations in secondary data analysis are not recommended (Boo and Froelicher 2013). Nevertheless, a rough estimation of the sample size required to answer RQ 3-5 based on the formula by Peduzzi et al. (1996):

$$n = 10 \times \frac{k}{p}$$

(*..here p is the smallest probability of observations with a negative or positive outcome and k the number of explanatory variables)* revealed that the sample size of n=12,195 (including n=1,073 children with disabilities and n=11,122 children without disabilities) is adequate to support logistic regression analysis in this research.

Proportional odds assumption for ordinal models

In ordinal logistic regression the beta coefficients of all included explanatory variables are assumed to be parallel, and this assumption of "parallelism" or parallel odds (also know as proportional odds) has to be satisfied for ordinal regression analysis to be valid (Agresti 1996). The assumption of proportional odds can be evaluated through the "test of parallel lines" which compares the ordinal model with single set of coefficients for each cumulative split of the outcome (described as null hypothesis) with a model that has a separate set of coefficients for each cumulative split of the outcome (described as general) (Agresti 1996). If the results of this test shows that general model has a better fit to the data compared to ordinal model (i.e. p<0.05) then the assumption of parallel odds is violated.

If the assumption of parallel odds is not met, a simpler and/or a less restrictive model should be fitted (Agresi 1996). Alternatively, a binary logistic model can be fitted, which will require however dichotomization of the ordinal scale in the outcome variable (Agresi 1996).

4.9.3 Procedures

Research questions 3-4

As described in the section 5.8.2.1, to examine associations between childhood disability and socio-demographic characteristics when other variables were controlled, binary logistic regression models were fitted on an outcome variable – childhood disability. Factors identified as significant (p<0.05) in the univariable analysis were entered into the multivariable binary logistic analysis to explore whether observed differences between children with and without disabilities could be explained by variations in children's socio-demographic characteristics.

Similarly, to explore associations between childhood disability and participation in each community-based activity, binary logistic regression models were fitted on an outcome variable - childhood disability. Firstly, univariable models were fitted without any controls with participation measured on a binary scale ("0=Never Participated" vs "1=Participated"). Secondly, univariable models were fitted without any controls with participation measured as frequency ("1=Low", "2=Regular", "3=High"). This was then followed by fitting a series of multivariable binary logistic regression models to explore associations between participation and childhood disability (outcome variable) when controlling for child sex and socio-economic status (family (equalized) income and parental education) - key covariates associated with children's participation (King et al. 2003; Law et al. 2007, Arakelyan et al. 2019).

Results for binary logistic regression analysis are presented in terms of unstandardized *B* coefficients, standard errors (*SE*), crude odds ratio (*COR*), adjusted odds ratio (*AOR*) and their associated 95% confidence intervals (CI). The *COR* and *AOR* indicate how much the odds of a child with a disability are increased by being in a more disadvantaged group. Differences between groups were considered significant at the 5% level (p<0.05).

Research question 5

As described earlier, ordinal logistic regression models were fitted to test the independent effect of the child, family and community factors on participation

frequency of children with disabilities in organized physical activities, unstructured physical activities and getting together with friends. A conceptual framework reflecting the thinking behind this research question (RQ5) is described in Figure 13. The development of this framework was guided by the ICF-CY framework, literature review, systematic review findings and availability of variables in the MCS5. Although participation is both an outcome and a process (Imms et al. 2017), for the purposes of this research it was conceptualized as an outcome which can be affected by the child, family and community factors.

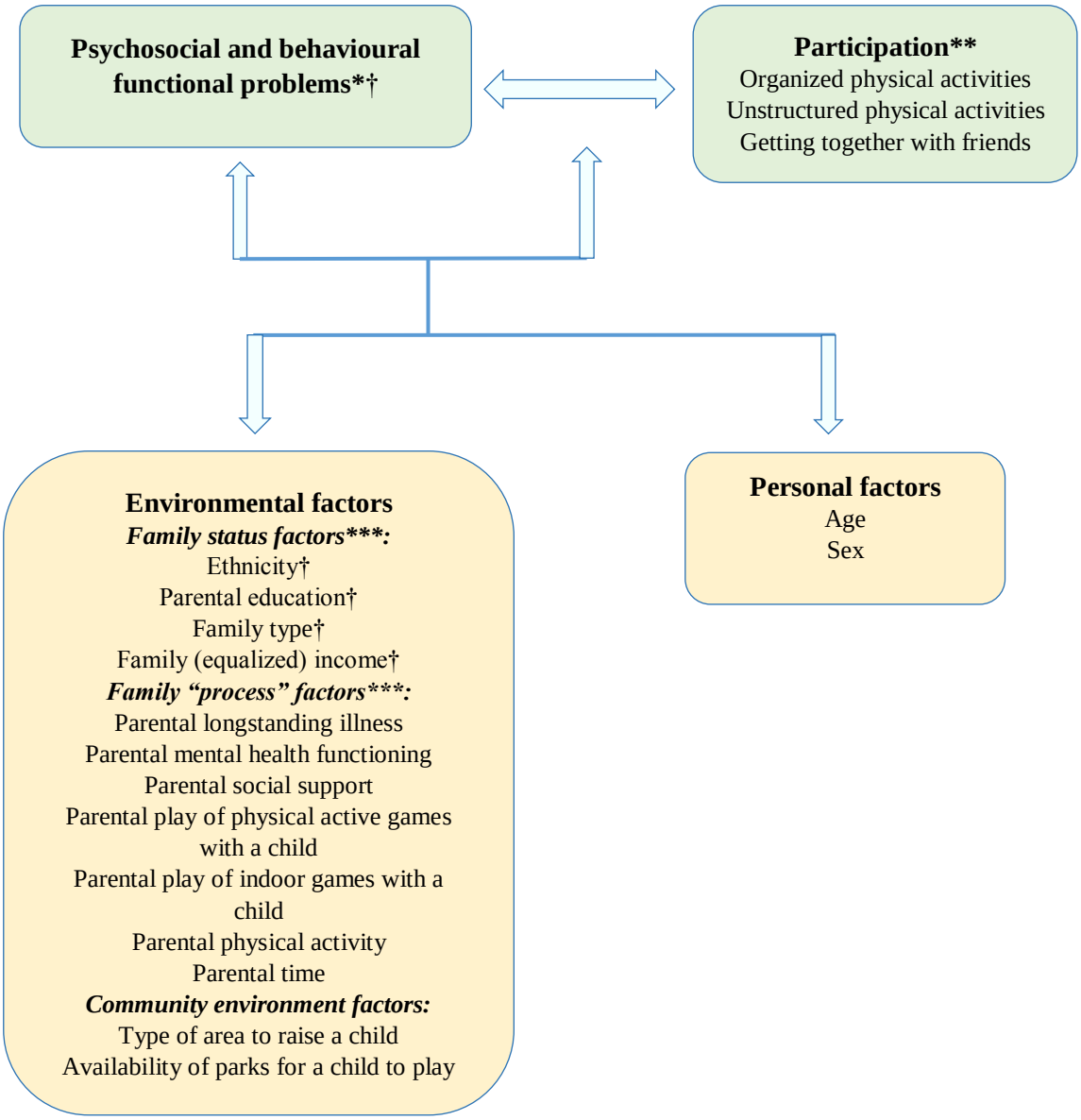


Figure 13. A framework depicting the factors tested in relation to participation

Note. †Factors that can be classified in multiple ICF-CY's components.
** Total difficulties score measured by the SDQ.*
*** Matched to the items in the PEM-CY.*
****Informed by the findings of the systematic review (Study I).*

Before fitting ordinal models for these three outcomes of interest, distributions of categories in each outcome variable were examined and a link function in the models specified. In SPSS Complex Samples Ordinal Regression procedure, five link functions (i.e. Logit, Complementary log-log, Negative log-log, Probit and Cauchit) are available (IBM Corp., Armonk, NY, USA). Logit link function is typically used for predicting an outcome with evenly distributed categories. Complementary log-log link function is used for predicting an outcome for which higher categories are more probable. Negative log-log link function is commonly used for predicting an outcome for which lower categories are more probable. Probit link function is normally used for predicting a normally distributed outcome. Cauchit link is typically used for predicting an outcome which has many extreme values (Agresi 1996; IBM Corp., Armonk, NY, USA).

Because the proportions of children with disabilities at each cumulative split of participation frequency in organized physical activities, unstructured physical activities, and getting together with friends were not evenly distributed (Figure 14), different link functions were used for fitting ordinal models. The negative log-log link function was used to fit the ordinal models predicting frequency of participation of children with disabilities in organized physical activities. The complementary log-log link function was used for fitting the models predicting frequency of participation of children with disabilities in unstructured physical activities and getting together with friends.

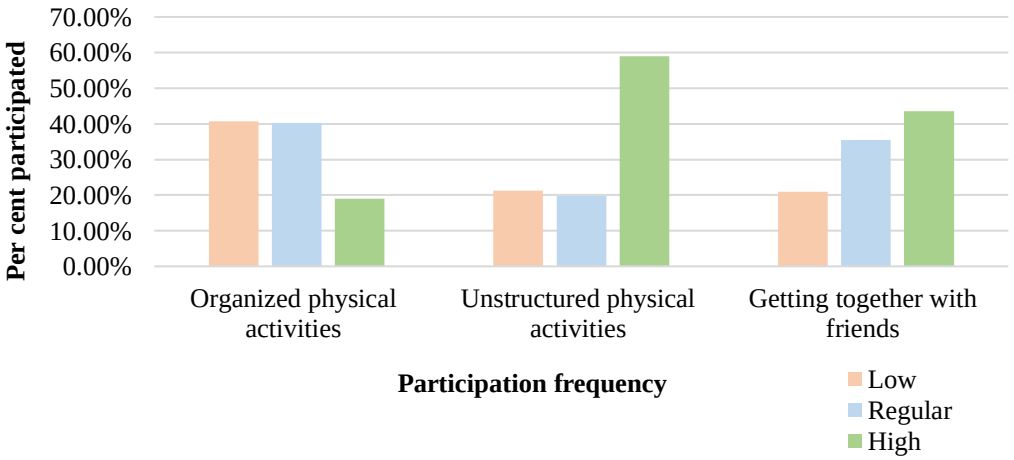


Figure 14. Percentages of children at each level of frequency of participation in three activities

Model building principles

Ordinal models were fitted in a series of steps following the principles of iterative approach also known as "purposeful selection" (Hosmer et al. 2013). The main principal of model building was to select the most parsimonious model (simple model) which would reflect true relationships in the data (Agatsi 1996; Field 2013; Hosmer et al. 2013). First, univariable ordinal models were fitted to explore the unadjusted associations between the explanatory factors and outcome (Hosmer et al. 2013). Explanatory factors identified as significant ($p<0.05$) in the univariable analysis were then entered into the multivariable ordinal regression analysis. Some scholars argue that explanatory factors with a *p* value of smaller than 0.1 can be included for further multivariable analysis (Agatsi 1996). However, because a wide range of variables of known relevance were tested in the univariable analysis, a much stricter *p*-value cut-off point was applied.

Explanatory factors which did not contribute to the initial multivariable model were eliminated iteratively resulting in a simpler multivariable model which was the best fitting and the most parsimonious model (Hosmer et al. 2013). Following principles described by Hosmer et al. (2013), in the parsimonious model the unstandardized *B* coefficients for the child, family and community factors were compared to those in the preceding model. If a difference in the unstandardized coefficients between models $(\Delta\beta)$ was more than 20% this was indicative that the deleted variables provided important adjustment of the effect of the remaining variables (Hosmer et al. 2013); therefore, the deleted variables were added back. This iterative approach allowed for an evaluation of the relative importance of each explanatory variable in relation to each outcome separately, and in combination with other variables (Hosmer et al. 2013).

Model evaluation

Goodness-of-fit for ordinal models was evaluated based on the results of the test for the proportional odds assumption (Agatsi 1996). This is the only option for ordinal models evaluation available in the SPSS Complex Sample Module. Since the ordinal model estimates one equation over all levels of outcome variable (described in detail in section 4.9.2), the test for proportional odds assesses whether a one-equation for the

ordinal model is valid (p>0.05) (Agatsi 1996). If the results of the chi-squared score test for the proportional odds assumption were significant at 0.05 level (p<0.05), it was indicative that ordered logit coefficients were not equal across the levels of the outcome, therefore, a simpler model was refitted.

Preliminary explanatory analysis has showed that the proportional odds assumption was not valid for the ordinal models fitted to predict frequency of participation of children with disabilities in getting together with friends. For this outcome only the predictive model was fitted using binary logistic regression analysis. This is because functions that would facilitate application of alternative options (e.g. fitting less restrictive ordinal model) were not present in the SPSS Complex Samples Module.

Chi-squared statistics, classification table, c-statistics and receiver operating characteristic curve (ROC) were used to evaluate the goodness-of-fit for a binary logistic model (Hosmer et al. 2013). The c-statistic or concordance index is a measure of how well the model classifies, and it is derived from the receiver operator curve (ROC). The ROC is a plot of sensitivity by 1-specificity (Hosmer et al. 2013). The general consensus is that if an area under the ROC is 0.5, the model is no better than a chance, whereas if an area under ROC is between 0.8 and 0.9, the model has an excellent fit (Hosmer et al. 2013).

The effect sizes of all the models were assessed based on Pseudo R^2, specifically the parameter estimate for Nagelkerke R^2. This parameter should be treated with caution however. The R^2 in logistic regression is not completely equivalent to the R^2 in a linear regression analysis - a parameter which describes the amount of variance explained in the outcome variable by the fitted model (Hosmer et al. 2013).

Results for predictive models are presented in terms of unstandardized *B* coefficients, standard errors *(SE)*, significance values, exponentiated unstandardized *B* coefficients or odds and their 95% CI. The exponentiated unstandardized *B* coefficients show the odds or likelihood of a child with a disability having a higher frequency of participation

in outcomes of interest by being in a more disadvantaged group. Results were considered significant at the 5% level ($p<0.05$).

4.10 Summary

Research embedded in the post-positivism paradigm aiming to generate population-level data on characteristics, family circumstances and community-based participation of children with disabilities assumes data supplied from large-scale nationally representative samples. Primary data collection by a doctoral investigator that would satisfy this requirement is hardly ever achievable. Quantitative (secondary) analysis of existing nationally representative data presents opportunities for innovative, efficient, and cost-effective research into nationally representative samples of children and their families. Secondary analysis of existing data is an especially valuable approach when researching "vulnerable populations" such as children with disabilities and/or their main carers. This is because recruitment of children with disabilities and/or their carers is a very challenging issue, both ethically and logistically.

Secondary analysis of existing nationally representative survey data presents significant opportunities, but it also poses many challenges. It is important to achieve the best appropriate fit between the research questions posed by the study and existing data. A set of criteria were developed by the investigator to guide this process. Application of these criteria help to identify the dataset used for this research, specifically the fifth sweep of the UK MCS (MCS5). The MCS5 is rich on data pertinent to child health and functional issues, psychosocial and behavioural problems, household demographics, family context, child and family activities, parenting activities, employment, housing, income. Therefore, it presented a unique opportunity to generate reliable evidence on 1,073 (8.8%) children with disabilities (DDA-defined) and 11,122 (91.2%) children without disabilities aged 10-12 and their families.

One of the major challenges when working with existing nationally representative data is lack of control over the framing and wording of survey items. The investigator used the ICF-CY framework, literature evidence and results of the systematic review (Study I completed in the scope of this research) as a frame of reference to guide the selection

of items from the MCS5 relevant to the aims of this research. Matching available variables in the existing survey with standardized and validated measures is often used to aid the selection of outcome variables. Community-based participation items were selected based on the literature review and matching exercise with a validated measure of participation – the PEM-CY.

Given multistage complex sampling design of the MCS and problems with attrition/non-response in the fifth sweep of the MCS, data were analysed using the SPSS Complex Samples Module (through application of required weights). R programming language was also used for a single analysis (to derive correlations between categorical variables). Frequency distributions, chi-squared (χ^2) and logistic regression analysis (binary and ordinal) were used to answer RQ 3-5. Results are reported in accordance with the methodology of complex sampling analysis in the SPSS Complex Samples Module procedure.

The chapter to follow presents the results of the main study (Study II).

CHAPTER 5 – RESULTS

5.1 Introduction

The preceding chapters (1) reviewed evidence on childhood disability and children's participation, (2) provided synthesis on family factors associated with childhood disability participation, and (3) described the methodology and outlined the rationale behind selecting secondary analysis of existing nationally representative survey data to answer RQ 3-5 posed by Study II.

The current chapter includes details on results of Study II. The chapter begins by providing descriptive statistics on participant (main-carers) general characteristics in section 5.2, followed by descriptions and comparisons of characteristics of children with and without disabilities aged 10-12 in section 5.3. Section 5.4 compares and contrasts community-based participation ("Never Participated" vs "Participated", diversity, frequency). From section 5.5 onwards, the chapter descries the logistic regression models fitted to test the independent effect of the child, family and community factors on participation frequency of children with disabilities in physical activities (organized physical activities and unstructured physical activities) and social activities (getting together with friends). The chapter concludes with a summary of main results in section 5.8.

5.2 Participant general characteristics

Participants were main carers of 12,195 children living in the UK. Nearly 99% of participants (n=12,020) identified as natural parents (94.5% natural mothers and 4.1% natural fathers). Sixty two per cent of participants were either married or had a partner (n=7,509). Approximately one third of participants (n= 3,660, 30.2%) had a university or equivalent degree. Two thirds of participants were in employment (n=7,872, 64.6%). Unemployment was higher among participants from a family with childhood disability (48.6% vs 34.3, p<0.001). Descriptive characteristics of participants are presented in Table 45.

Table 45. Participant general characteristics

Characteristic	Population estimate *(SE)*[a]	Per cent (%)
Age group		
16 to 19	2 (2)	0.0%
20 to 29	624 (50)	5.1%
30 to 39	5,310 (238)	43.5%
40 to 49	5,687 (242)	46.6%
50 ≤	572 (33)	4.7%
Relationship to a child		
Natural parent	12,020 (458)	98.6%
Adoptive parent	25 (7)	0.2%
Foster parent	21 (8)	0.2%
Step parent	19 (7)	0.2%
Other relative/non-relative	110 (29)	0.9%
Marital status		
Single/Never married	2,509 (130)	20.6%
Married/Partner	7,509 (297)	61.6%
Divorced/Separated	2,049 (104)	16.8%
Widowed	120 (14)	1.0%
Parental education		
No formal UK qualifications	2,396 (148)	19.8%
GCSE/equivalent	5,091 (227)	42.0%
A levels/equivalent	973 (49)	8.0%
University degree/equivalent	3,660 (174)	30.2%
Parent employment status		
Unemployed	4,323 (207)	35.6%
Employed	7,872 (308)	64.4%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. Because of rounding column percentages may not add exactly to 100 per cent (%).
Sample size n=12,195.
[b]*Population estimate, standard error of the estimate.*

5.3 Children's characteristics

Of total 12,195 children aged 10-12 years (mean age 10y7mo, *SE* 0.07mo), 6,280 (51.5%) were boys and 5,915 (48.5%) were girls. Children were predominantly from White ethnic backgrounds. Eighty three per cent of children were from England, 8.6% from Scotland, 4.9% from Wales and 4% from Northern Ireland. One thousand and seventy three children (8.8%; 95% confidence interval [CI] 8.2, 9.5%) were reported as having a disability. Clinical characteristics of children with disabilities is supplied in Table 46.

Table 46. Clinical characteristics of children with disabilities

Characteristic	Children with disabilities	
	Population estimate *(SE)*[b]	Per cent (%)
Functional issues[a]		
Learning/understanding/concentrating	396 (29)	36.9%
Socialization/behaviour	346 (27)	32.3%
Stamina/breathing	291 (21)	27.1%
Mobility	186 (17)	17.3%
Mental health	159 (20)	14.8%
Memory	133 (16)	12.4%
Dexterity	104 (14)	9.7%
Vision	98(13)	9.2%
Hearing	91(13)	8.5%
PSB problems[d]		
Abnormal	410 (30)	39.2%
Borderline	155 (17)	14.8%
Normal	481 (29)	46.0%
Special education needs		
Yes	517 (31)	48.4%
No	551 (33)	51.6%
Taking medication		
Yes	602 (34)	56.1%
No	471 (32)	43.9%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. Because of rounding column percentages may not add exactly to 100 per cent (%).
[a]*Count represents instances not the actual cases.*
[b]*Population estimate, standard error of the estimate.*
[d]*Psychosocial & behavioural problems.*

The most commonly reported functional and health issues were learning/ understanding/concentrating (36.9%), socialization/behaviour (32.3%), stamina/breathing (27.1%) and mobility (17.3%). Many children with disabilities experienced more than one category of functional issues. Nearly half of the sample (48.4%) had teacher-identified special educational needs and 39.2% had clinically significant (abnormal) psychosocial and behavioural problems. More than half of children with disabilities (56.1%) were taking prescribed medication (excluding "over the counter" medication) on a regular basis (Table 46).

Key clinical characteristics of children with disabilities segregated by child sex are described in Table 47. Based on χ^2 test of independence (as described in section 4.9.2, the results of χ^2 is based on the adjusted F and its degree of freedom) boys were more likely to experience functional and health issues with learning/understanding/

concentrating F_{adj}=16.8, p<0.001; socialization/behaviour F_{adj}=40.7, p<0.001; mental health F_{adj}=7.5, p<0.01; stamina/breathing F_{adj}=5.7, p=0.02, and mobility F_{adj}=6.6, p=0.01. Similarly, a significantly higher proportion of boys had psychosocial and behavioural problems F_{adj}=11.5, p<0.001 and were identified with special education needs F_{adj}= 24.3, p<0.001 (Table 47).

Table 47. Clinical characteristics of children with disabilities by sex

Characteristic	Boys		Girls		
	Population estimate *(SE)*[b]	Per cent (%)	Population estimate *(SE)*[b]	Per cent (%)	χ^2 test[c]
Functional issues[a]					
Learning/understanding/concentrating	285 (24)	42.9%	112 (13)	27.3%	*p*<0.001
Socialization/behaviour	274 (24)	41.3%	72 (10)	17.7%	*p*<0.001
Stamina/breathing	161 (15)	24.2%	131 (14)	31.9%	*p*=0.02
Mobility	97 (12)	14.7%	89 (12)	21.6%	*p*=0.01
Mental health	118 (18)	17.8%	41(8)	9.9%	*p*<0.01
Memory	88 (13)	42.9%	112 (13)	27.3%	*p*=0.39
Dexterity	60 (10)	9%	44 (9)	10.8%	*p*=0.47
Vision	62 (10)	9.4%	36 (8)	8.8%	*p*=0.80
Hearing	52 (10)	7.9%	39 (7)	9.5%	*p*=0.44
PSB problems[d]					
Abnormal	300 (25)	46.3%	110 (14)	27.7%	*p*<0.001
Borderline	89 (12)	13.6%	65 (11)	16.4%	
Normal	258 (19)	39.8%	223(20)	56.0%	
Special education needs					
Yes	367 (26)	55.6%	150 (14)	36.8%	*p*<0.001
No	293 (24)	44.4%	258 (22)	63.2%	

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. Because of rounding column percentages may not add exactly to 100 per cent (%).
[a]*Count represents instances not the actual cases.*
[b]*Population estimate, standard error of the estimate.*
[c]*Significance is based on the adjusted F and its degrees of freedom. The adjusted F is a variant of the second-order Rao-Scott adjusted chi-square statistic and used here because of a lack of independence of data points (or observations) in the MCS5. The adjusted F is calculated in accordance with the methodology of complex sampling analysis in SPSS.*
[d]*Psychosocial & behavioural problems.*

Children with and without disabilities differed in respect to socio-demographic characteristics (Table 48). Differences were established in relation to child sex F_{adj}=31.0, *p*<0.001; psychosocial and behavioural problems F_{adj}=261, *p*<0.001; family type F_{adj}=59.0, *p*<0.001; parental education F_{adj}=6.1, *p*=0.001; family income F_{adj}(4,1506)=18.2, *p*<0.001; parental longstanding illness F_{adj}=159.1, *p*<0.001, and parental mental health functioning F_{adj}=29.1, *p*<0.001 (Table 48).

Table 48. Characteristics of children with and without disabilities

Characteristics	Children with disabilities[a]		Children without disabilities[b]		χ^2 test[c]
	Population estimate *(SE)*[d]	Per cent (%)	Population estimate *(SE)*	Per cent (%)	
Sex					
Boys	663 (40)	61.8%	5,617 (228)	50.5%	p<0.001
Girls	410 (30)	38.2%	5,505 (220)	49.5%	
Country of origin					
England	830 (52)	83.8%	9,007 (409)	82.4%	p=0.39
Scotland	85 (12)	8.5%	936 (51)	8.6%	
Wales	44 (5)	4.5%	538 (47)	4.9%	
Northern Ireland	32 (5)	3.2%	447 (24)	4.1%	
Ethnicity					
Mixed/Other Ethnic group	69 (12)	6.4%	552 (60)	5.0%	p=0.03
Black/Black British	27 (9)	2.5%	417 (77)	3.7%	
Indian/ Pakistani/ Bangladeshi	53 (13)	5.0%	830 (128)	7.5%	
White	924 (51)	86.1%	9,323 (355)	83.8%	
PSB problems[e]					
Abnormal	410 (31)	39.2%	814 (53)	7.6%	p<0.001
Borderline	155 (17)	14.8%	649 (44)	6.0%	
Normal	481 (31)	46.0%	9,264 (348)	86.4%	
Family type					
Single-parent household	569 (39)	53.0%	4,109 (188)	37.0%	p<0.001
Co-parent household	504 (33)	47.0%	7,004 (281)	63.0%	
Parental education					
No formal UK qualifications	262 (27)	24.6%	2,134 (136)	19.3%	p=0.001
GCSE/equivalent	467 (32)	43.7%	4,624 (211)	41.8%	
A levels/equivalent	79 (11)	7.4%	894 (46)	8.1%	
University degree/equivalent	260 (21)	24.3%	3,401(161)	30.8%	
Family income[f]					
Bottom	325 (27)	30.3%	2,140 (153)	19.2%	p<0.001
Second	247 (24)	23.0%	2,190 (106)	19.7%	
Third	212 (17)	19.8%	2,229 (102)	20.0%	
Fourth	152 (16)	14.1%	2,285 (106)	20.5%	
Top	138 (15)	12.9%	2,277 (132)	20.5%	
Parental longstanding illness					
Present	402 (31)	37.5%	1936 (91)	17.4%	p<0.001
Absent	671 (40)	62.5%	9,180 (366)	82.6%	
Parental mental health functioning					
Serious mental distress	130 (20)	13.1%	590 (40)	5.8%	p<0.001
Moderate mental distress	356 (27)	35.8%	2,818 (132)	27.7%	
No distress	509 (35)	51.2%	6,781 (255)	66.6%	

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Because of rounding column percentages may not add exactly to 100 per cent (%).
Missing data are excluded from the analysis.
[a] *Sample size n=1,073.*
[b] *Sample size n=11,122.*
[c] *Significance is based on the adjusted F and its degrees of freedom. The adjusted F is a variant of the second-order Rao-Scott adjusted chi-square statistic and used here because of a lack of independence of data points (or observations) in the MCS5. The adjusted F is calculated in accordance with the methodology of complex sampling analysis in SPSS.*
[d] *Population estimate, standard error of the estimate.*
[e] *Psychosocial & behavioural problems.*
[f] *Based on the OECD equalized quintiles for the entire UK.*

To assess the magnitude of established associations, logistic models were fitted on dependent variable "childhood disability" ("1=Present" vs "0=Absent"). The logistic regression showed that boys had 1.59 times higher odds for having a disability compared to girls (Crude Odds Ratio [*COR*] 1.59; 95% CI 1.35, 1.87) (Table 49). Children with disabilities also had higher odds of having clinically significant (i.e. abnormal) psychosocial and behavioural problems (*COR* 9.70; 95% CI 7.98, 11.8), living in single-parent households (*COR* 1.91; 95% CI 1.61, 2.27), having a parent with no formal UK qualification (*COR* 1.61; 95% CI 1.28, 2.02) or with GCSE/equivalent (*COR* 1.32; 95% CI 1.10, 1.59) and being from the bottom 60% of financially more deprived families (Table 49).

Further, the odds of living with a parent having a longstanding illness was nearly 3 times higher for children with disabilities (*COR* 2.84; 95% CI 2.40, 3.36) compared to peers without disabilities. Children with disabilities also were more likely to be from families with a parent having moderate (*COR* 1.68; 95 % CI 1.41, 2.01) or serious mental distress (*COR* 2.93; 95% CI 2.14, 4.03) (Table 49).

To examine whether observed differences between children with and without disabilities could be explained by variations in socio-demographic and parent health characteristics, a multivariable logistic regression model was fitted (Table 49). Before fitting the multivariable model the explanatory variables were checked for multicollinearity (Appendix G). The highest correlation (r=0.6) was between parental education and family equalized income, which was in the range of tolerable inter-correlation (Field, 2013).

Table 49. Logistic models of childhood disability by child and family characteristics

Characteristics	Univariable			Multivariable[a]		
	B (SE)	*COR*	95% CI	*B (SE)*	*AOR*	95 % CI
Sex						
Boys	0.46 (0.08)***	1.59	[1.35,1.87]	0.32 (0.09)***	1.37	[1.15,1.64]
Girls (ref)	0.00	1.00		0.00	1.00	
Ethnicity						
Mixed/Other Ethnic Gr.	0.23 (0.18)	1.26	[0.90,1.78]	0.19 (0.20)	1.21	[0.82,1.79]
Black/Black British	-0.42 (0.32)	0.66	[0.35,1.22]	-0.16 (0.37)	0.85	[0.41,1.77]
Indian/Pakist/ Banglad.	-0.44 (0.18)*	0.65	[0.46,0.92]	-0.41 (0.19)*	0.66	[0.46,0.96]
White (ref)	0.00	1.00		0.00	1.00	
PSB problems[b]						
Abnormal	2.27 (0.10)***	9.70	[7.98,11.8]	2.18 (0.11)***	8.86	[7.12,11.0]
Borderline	1.52 (0.13)***	4.59	[3.57,5.91]	1.45 (0.13)***	4.27	[3.32,5.50]
Normal (ref)	0.00	1.00		0.00	1.00	
Family type						
Single-parent house.	0.65 (0.09)***	1.91	[1.61,2.27]	0.31 (0.10)**	1.37	[1.11,1.68]
Co-parent house. (ref)	0.00	1.00		0.00	1.00	
Parental education						
No formal UK qual.	0.48 (0.12)***	1.61	[1.28,2.02]	-0.16 (0.15)	0.85	[0.63,1.14]
GCSE/equival.	0.28 (0.09)**	1.32	[1.10,1.59]	-0.11 (0.11)	0.89	[0.72,1.11]
A levels/equival.	0.14 (0.16)	1.15	[0.85,1.56]	-0.04 (0.17)	0.96	0.69,1.33]
Uni. degree/equival.(ref)	0.00	1.00		0.00	1.00	
Family income[c]						
Bottom	0.92 (0.14)***	2.50	[1.92,3.26]	0.21 (0.18)	1.23	[0.87,1.76]
Second	0.62 (0.13)***	1.86	[1.43,2.40]	0.06 (0.16)	1.06	[0.77,1.45]
Third	0.45 (0.13)***	1.57	[1.23,2.01]	0.10 (0.15)	1.11	[0.83,1.49]
Fourth	0.09 (0.14)	1.09	[0.83,1.44]	-0.11 (0.16)	0.90	[0.66,1.22]
Top (ref)	0.00	1.00		0.00	1.00	
Parental longstanding illness						
Present	1.04 (0.09)***	2.84	[2.40,3.36]	0.86 (0.10)***	2.36	[1.94,2.87]
Absent (ref)	0.00	1.00		0.00	1.00	
Parental mental health functioning						
Serious mental distress	1.08 (0.16)***	2.93	[2.14,4.03]	-0.31 (0.19)	0.74	[0.51,1.07]
Moderate mental distress	0.52 (0.09)***	1.68	[1.41,2.01]	-0.14 (0.10)	0.87	[0.71,1.07]
No distress (ref)	0.00	1.00		0.00	1.00	

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
B=beta unstandardized coefficient, SE=Standard error, COR= Crude odds ratio, AOR=Adjusted odds ratio, CI=confidence interval.
[a]*Sample size for the multivariable model n=11,095.*
[b]*Psychosocial & behavioural problems.*
[c]*Based on the OECD equalized quintiles for the entire UK.*
Mixed/Other Ethnic Gr – Mixed or Other Ethnic Groups.
Indian/Pakist/ Banglad – Indian/Pakistani/Bangladeshi.
GCSE/equival – GCES or equivalent.
A levels/equival. – A levels or equivalent.
Uni. degree/equival – University degree or equivalent.
** p<0.05, **p<0.01, ***p<0.001.*

Based on the multivariable adjusted model, other factors fixed child sex, psychosocial and behavioural problems, family type and parental longstanding illness continued to be associated with childhood disability (Table 49). More specifically, boys had significantly higher odds (*AOR* 1.37, 95% CI 1.15, 1.64) for having a disability. Children with borderline psychosocial and behavioural problems were 4 times more

likely to have a disability (*AOR* 4.27; 95% CI 3.32, 5.50), whereas those with abnormal psychosocial and behavioural problems were nearly 9 times more likely to have a disability (*AOR* 8.86; 95% CI 7.12, 11.01). Further, children from single-parent households were 1.4 times likely to have a disability (*AOR* 1.37, 95% CI 1.11, 1.68), whereas those with a parent having a longstanding illness had 2.4 times higher odds for having a disability (*AOR* 2.36; 95% 1.94, 2.87) (Table 49).

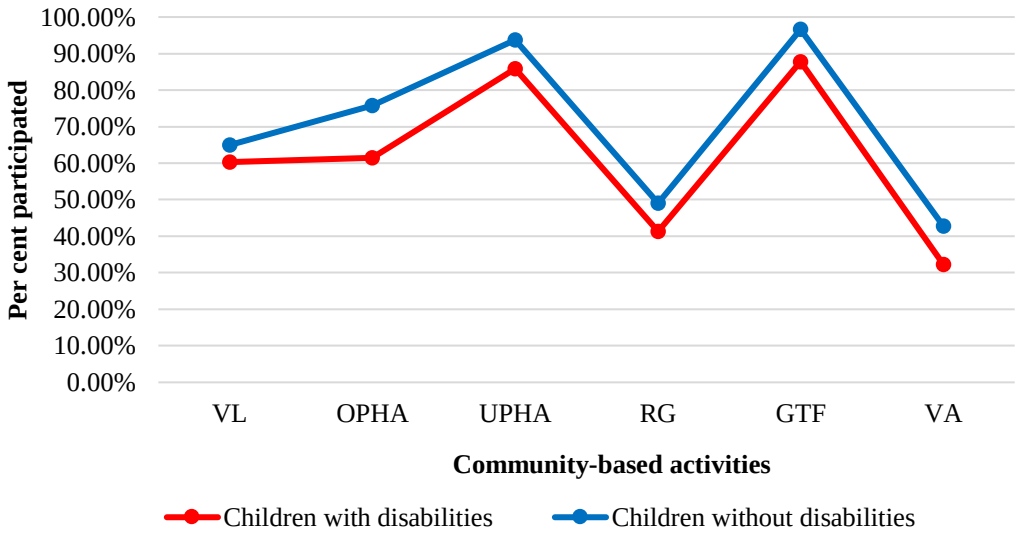
To sum up, in line with preliminary expectations childhood disability was more prevalent in families living in socio-economic disadvantage. Other factors fixed child sex, psychosocial and behavioural problems, family type and parental longstanding illness were factors independently associated with presence of disability in the UK nationally representative sample of children aged 10-12.

The sections to follow describe the results pertinent to RQs 3-5.

5.4 Children's participation in community-based activities

Patterns of participation

In the scope of this research, patterns of participation is understood as the ranking of proportions for participation (based on a binary measure "Never participated" vs "Participated") across six community-based activities within the two groups of children. Participation in community-based activities had similar patterns for children with and without disabilities (Figure 15). Higher proportions of children in both groups participated in community-based activities that were more unstructured in nature. Nearly 88% of children with disabilities and 97% of children without disabilities participated in getting together with friends, and 86% of children with disabilities and 94% of children without disabilities participated in unstructured physical activities (Figure 15, Table 50).



Note. VL - Visiting a library, OPHA - Organized physical activities, UPHA - Unstructured physical activities, RG - Religious gatherings, GTF - Getting together with friends, VA - Vacations abroad.

Figure 15. Percentages of children who participated in each community-based activity

The proportion of children with disabilities who never participated in each community-based activity ranged from 12.2 to 67.7%, whereas among children without disabilities it ranged from 3.4% to 57.2% (Table 50). Similar to children without disabilities, children with disabilities had the highest restriction in participation for vacations abroad. Nearly 68% children with disabilities and 57% of children without disabilities never travelled for vacations abroad in the last 12 months. This was followed by participation in religious gatherings (58.7% and 51% of children with and without disabilities never participated), visiting the library (39.7% and 35.1% of children with and without disabilities never participated). Approximately 39% of children with disabilities and 24.3 % of children without disabilities never participated in organized physical activities (Table 50).

Table 50 describes and compares the proportions of children with and without disabilities who "Never participated" vs "Participated" in each community-based activity. Based on χ^2 test of independent, group differences were established in regards to participation in 5 community-based activities, except for visiting a library (Table 50). Significantly higher proportions of children with disabilities never participated in organized physical activities F_{adj}=53.1, p<0.001, unstructured physical activities

F_{adj}=55.8, p<0.001, religious gatherings F_{adj}=17.6, p<0.001, getting together with friends F_{adj}=100.0, p<0.001 and travelled for vacations abroad F_{adj}=26.0, p<0.001 compared to children without disabilities.

Table 50. Children's participation (never vs ever) across activities

Community-based Activities	Children with disabilities[a]		Children without disabilities[b]		χ^2 test[d]
	Population estimate *(SE)*[c]	Per cent (%)	Population estimate *(SE)*[c]	Per cent (%)	
Visiting a library					
Never participated	426 (34)	39.7%	3,900 (182)	35.1%	p=0.04
Participated	647 (39)	60.3%	7,219 (281)	64.9%	
Organized physical activities					
Never participated	413 (31)	38.5%	2,700 (145)	24.3%	p<0.001
Participated	660 (41)	61.5%	8,422 (324)	75.7%	
Unstructured physical activities					
Never participated	152 (17)	14.2%	686 (58)	6.2%	p<0.001
Participated	921 (51)	85.8%	10,433 (402)	93.8%	
Religious gatherings					
Never participated	630 (40)	58.7%	5,662 (249)	51.0%	p<0.001
Participated	443 (29)	41.3%	5,449 (245)	49.0%	
Getting together with friends					
Never participated	131 (16)	12.2%	378 (43)	3.4%	p<0.001
Participated	942 (51)	87.8%	10,744 (408)	96.6%	
Vacations abroad					
Never participated	727 (43)	67.7%	6,362 (274)	57.2%	p<0.001
Participated	346 (28)	32.3%	4,758 (210)	42.8%	

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. Because of rounding column percentages may not add exactly to 100 per cent (%).
[a] *Sample size n=1,073.*
[b] *Sample size n=11,122.*
[c] *Population estimate, standard error of the estimate.*
[d] *Significance is based on the adjusted F and its degrees of freedom. The adjusted F is a variant of the second-order Rao-Scott adjusted chi-square statistic and used here because of a lack of independence of data points (or observations) in the MCS5. The adjusted F is calculated in accordance with the methodology of complex sampling analysis in SPSS.*

Based on univariable logistic regression results, children with disabilities were less likely to get together with friends (*COR* 3.95, 95% CI 2.96, 5.28) and participate in unstructured physical activities (*COR* 2.51, 95% CI 1.95, 3.22) and organized physical activities (*COR* 1.95, 95% CI 1.63, 2.34) compared to children without disabilities (Table 51). To examine whether observed differences could be explained by variations in child sex (predominantly associated with activity preferences), family income and maternal education, each model was adjusted for these covariates. Based on the adjusted model results, children with disabilities were 3.22 times less likely to get together with friends (*AOR* 3.22; 95% CI 2.38, 4.34) compared to peers. They also were 2.3 times less likely to participate in unstructured physical activities (*AOR* 2.27;

95% CI 1.76, 2.94) and 1.7 less likely to participate in organized physical activities (*AOR* 1.73; 95% CI 1.43, 2.09). Further, in comparison with peers, children with disabilities were 30% less likely to participate in religious services (*AOR* 1.28; 95% CI 1.10, 1.48) and travel for vacations abroad (*AOR* 1.28; 95% CI 1.06, 1.54) (Table 51). The results for vacations abroad should be treated with care as the lower end of confidence interval parameter falls close to 1 (i.e. equal odds).

Table 51. Logistic models of childhood disability by participation (never vs ever) across activities

Community-based Activities	Univariable			Multivariable[a]		
	B (SE)	*COR*	95% CI	*B (SE)*	*AOR*	95 %CI
Visiting a library						
Never participated	0.20 (0.10)*	1.22	[1.01,1.48]	0.12 (0.10)	1.12	[0.93,1.36]
Participated (ref)	0.00	1.00		0.00	1.00	
Organized physical activities						
Never participated	0.67 (0.09)***	1.95	[1.63,2.34]	0.55 (0.10)***	1.73	[1.43,2.09]
Participated (ref)	0.00	1.00		0.00	1.00	
Unstructured physical activities						
Never participated	0.92 (0.13)***	2.51	[1.95,3.22]	0.82 (0.13)***	2.27	[1.76,2.94]
Participated (ref)	0.00	1.00		0.00	1.00	
Religious gatherings						
Never participated	0.31 (0.07)***	1.37	[1.18,1.58]	0.24 (0.08)**	1.28	[1.10,1.48]
Participated (ref)	0.00	1.00		0.00	1.00	
Getting together with friends						
Never participated	1.37 (0.15)***	3.95	[2.96,5.28]	1.17 (0.15)***	3.22	[2.38,4.34]
Participated (ref)	0.00	1.00		0.00	1.00	
Vacations abroad						
Never participated	0.45 (0.09)***	1.57	[1.32,1.87]	0.24 (0.10)*	1.28	[1.06,1.54]
Participated (ref)	0.00	1.00		0.00	1.00	

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
B=beta unstandardized coefficient, SE=Standard error, COR= Crude odds ratio, AOR=Adjusted odds ratio, CI=confidence interval.
[a]*The multivariable models are adjusted for child sex, family income and parental education.*
** p<0.05, **p<0.01, ***p<0.001.*

Diversity

Proportionately more children with disabilities participated in a single activity and fewer in all six activities compared to peers without disability (Figure 16). However, mean diversity scores were very close. Children with disabilities participated on average in 3.69 activities (*SE*=0.06, 95% CI 3.66, 3.81), whereas children without disabilities participated in 4.23 activities (*SE*=0.02, 95% CI 4.18, 4.28) (Figure 16).

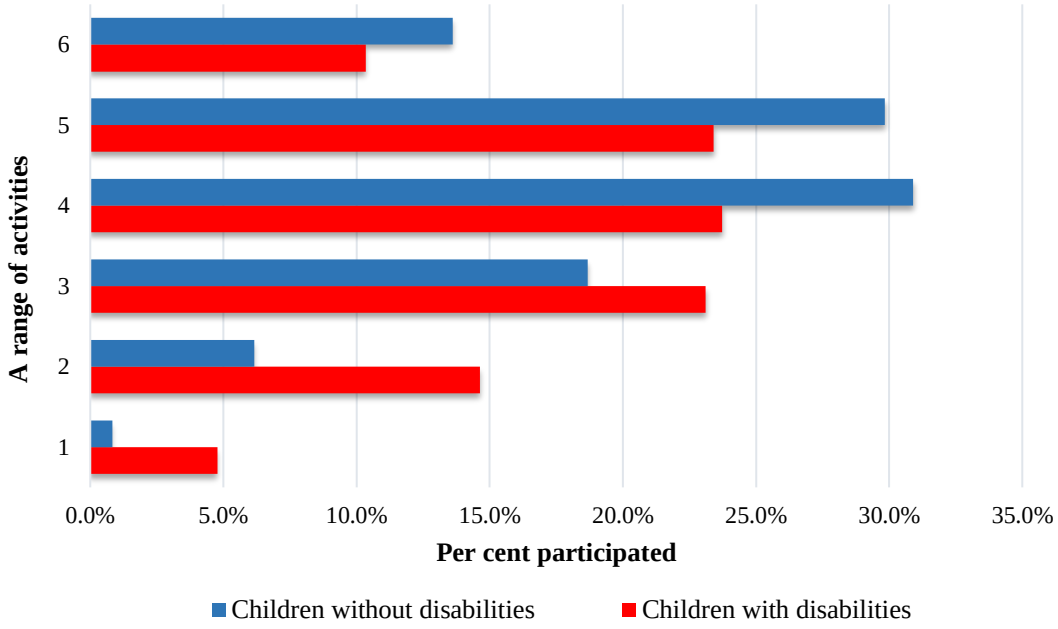


Figure 16. The range of community-based activities children participated

From clinical perspective there is no much difference between these two scores – on average both groups participated in 4 out of six activities. Therefore, it was deemed unnecessary to test if differences in mean diversity scores between children with and without disabilities are statistically significant.

Frequency

The frequency with which children with and without disabilities participated in each community-based activity was significantly different, except for visiting a library (Table 52). Proportionately more children with disabilities participated in activities with low frequency compared to children without disabilities. Of special interest were physical and social activities. About 41% children with disabilities participated in organized physical activities with low frequency, compared to only 26% among children without disabilities. Nevertheless, similar to children without disabilities, 40% of children with disabilities participated in organized physical activities with regular frequency. Twenty one percent of children with disabilities got together with friends with low frequency, compared to only 7% among children without disabilities. Nevertheless, more than one third of children with disabilities got together with friends

either with regular (35.5%) or high frequency (43.5%) (Table 52). These proportions were however higher among children without disabilities.

Table 52. Children's participation frequency across activities

Community-based Activities	Children with disabilities[a]		Children without disabilities[b]		χ^2 test[c]
	Population estimate (*SE*)[d]	Per cent (%)	Population estimate (*SE*)[d]	Per cent (%)	
Visiting a library					
Low	795 (46)	74.1%	8,064 (326)	72.5%	p=0.21
Regular	266 (23)	24.8%	2,834 (127)	25.5%	
High	12 (4)	1.1%	221 (19)	2.0%	
Organized physical activities					
Low	437 (32)	40.7%	2,927 (155)	26.3%	p<0.001
Regular	432 (32)	40.2%	4,662 (194)	41.9%	
High	204 (18)	19.0%	3,533 (147)	31.8%	
Unstructured physical activities					
Low	229 (22)	21.3%	1,078 (77)	9.7%	p<0.001
Regular	211 (21)	19.7%	2,530 (125)	22.8%	
High	633 (39)	59.0%	7,511 (288)	67.5%	
Religious gatherings					
Low	856 (49)	79.8%	8,206 (328)	73.9%	p<0.01
Regular	172 (19)	16.0%	2,264 (123)	20.4%	
High	46 (10)	4.2%	641 (109)	5.8%	
Getting together with friends					
Low	225 (21)	21.0%	788 (62)	7.1%	p<0.001
Regular	381 (27)	35.5%	4,494 (200)	40.4%	
High	466 (32)	43.5%	5,840 (239)	52.5%	
Vacations abroad					
Low	972 (54)	90.6%	9,689 (383)	87.1%	p=0.02
Regular	91 (12)	8.5%	1,268 (75)	11.4%	
High	10 (4)	0.9%	162 (26)	1.5%	

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. Because of rounding column percentages may not add exactly to 100 per cent (%).
[a]Sample size n=1,073.
[b]Sample size n=11,122.
[c]Significance is based on the adjusted F and its degrees of freedom. The adjusted F is a variant of the second-order Rao-Scott adjusted chi-square statistic and used here because of a lack of independence of data points (or observations) in the MCS5. The adjusted F is calculated in accordance with the methodology of complex sampling analysis in SPSS.
[d]Population estimate, standard error of the estimate.

Univariable logistic regression results showed that for children with disabilities the odds for lower frequency of participation in unstructured physical activities (*COR* 2.52; 95% CI 2.07, 3.07), organized physical activities (*COR* 2.58; 95% CI 2.08, 3.20) and getting together with friends (*COR* 3.58; 95% CI 2.84, 4.52) were significantly higher compared to children without disabilities (Table 53). These differences did not change after controlling for child sex, family income and parental education. Based on the adjusted models, children with disabilities were 2 times more likely to have lower

frequency of participation in unstructured physical activities (*AOR* 2.41; 95% CI 1.95, 2.99), organized physical activities (*AOR* 2.29; 95% CI 1.83, 2.86), and religious gatherings (*AOR* 2.08; 95% CI 1.35, 3.20) compared to children without disabilities. They were also 3 times more likely to have lower frequency in getting together with friends (*AOR* 3.31; 95% CI 2.61, 4.20) and 2 times more likely to have lower frequency in participation in religious gatherings (Table 53).

Table 53. Logistic models of childhood disability by participation frequency across activities

Community-based	Univariable			Multivariable[a]		
Activities	*B (SE)*	*COR*	95% CI	*B (SE)*	*AOR*	95 % CI
Organized physical activities						
Low	0.95 (0.11)***	2.58	[2.08,3.20]	0.83 (0.11)***	2.29	[1.83,2.86]
Regular	0.47 (0.10)***	1.60	[1.31,1.96]	0.44 (0.10)***	1.55	[1.26,1.90]
High (ref)	0.00	1.00		0.00	1.00	
Unstructured physical activities						
Low	0.92 (0.10)***	2.52	[2.07,3.07]	0.88 (0.11)***	2.41	[1.95,2.99]
Regular	-0.01 (0.11)	0.99	[0.80-1.22]	0.05 (0.11)	1.05	[0.85,1.29]
High (ref)	0.00	1.00		0.00	1.00	
Religious gatherings						
Low	0.39 (0.20)	1.47	[0.99,2.18]	0.73 (0.22)**	2.08	[1.35,3.20]
Regular	0.07 (0.21)	1.07	[0.70,1.62]	0.44 (0.23)	1.55	[0.99,2.43]
High (ref)	0.00	1.00		0.00	1.00	
Getting together with friends						
Low	1.28 (0.12)***	3.58	[2.84,4.52]	1.20 (0.12)***	3.31	[2.61,4.20]
Regular	0.06 (0.09)	1.06	[0.89,1.26]	0.15 (0.09)	1.16	[0.98,1.38]
High (ref)	0.00	1.00		0.00	1.00	
Vacations abroad						
Low	0.51 (0.34)	1.67	[0.85,3.25]	0.23 (0.35)	1.26	[0.63,2.50]
Regular	0.17 (0.37)	1.19	[0.57,2.48]	0.16 (0.38)	1.18	[0.56,2.48]
High (ref)	0.00	1.00		0.00	1.00	

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
B=beta unstandardized coefficient, SE=Standard error, COR= Crude odds ratio, AOR=Adjusted odds ratio, CI=confidence interval.
[a]Each multivariable model is adjusted for child gender, family income and parental education.
** p<0.05, **p<0.01, ***p<0.001.*

To sum up, although patterns of participation (i.e. the ranking of proportions for participation across six community-based activities within the two groups) and average diversity score were similar between children with and without disabilities, the extent to which children participated differed. Children with disabilities had higher restriction in community-based participation, especially in social activities (described here as getting together with friends) and physical activities.

The following sections describe the results pertinent to RQ5 - the ordinal models fitted to predict participation frequency of children with disabilities in organized physical

activities, unstructured physical activities and getting together with friends based on the child, family and community factors selected from the MCS5.

5.5 Factors associated with participation frequency in organized physical activities

The ordinal models for participation frequency of children with disabilities in organized physical activities (OPHA) in were first fitted with a single explanatory variable – the child, family and community factors using the SPSS Complex Sample Module (PLUM) version 23.0 (IBM Corp., Armonk, NY, USA). Frequency distributions for the child, family and community factors by participation frequency in OPHA are summarized in Appendix H. The explanatory variables associated with frequency of participation in OPHA in univariable analysis (at significance level $p<0.05$) were child psychosocial and behavioural problems, family type, parental education, family income, parental physical activity, parental play of physically active games with a child, parental social support, parental time and type of area to raise a child (Table 54).

Table 54. Univariable ordinal model for participation frequency in OPHA

Characteristics (sig. value for a variable)	**Unadjusted parameters**					
	B	*SE*	*Exp(B)*	95% CI	Sig. value for each category	Test of parallel lines
Sex (*p*=0.35)						
Boys	-0.10	0.10	0.91	[0.74,1.11]	*p*=0.35	*p*=0.68
Girls (ref)	0.00		1.00			
Ethnicity (*p*=0.08)						
Mixed/Other Ethnic Group	-0.54	0.25	0.58	[0.36,0.95]	*p*=0.03	*p*=0.08
Black/Black British	0.28	0.36	1.32	[0.66,2.66]	*p*=0.43	
Indian/ Pakist/Banglad.	-0.19	0.14	0.83	[0.62,1.10]	*p*=0.19	
White (ref)	0.00		1.00			
PSB problems[a] (*p*=0.001)						
Abnormal	-0.43	0.12	0.65	[0.51,0.83]	*p*=0.001	*p*=0.04
Borderline	-0.29	0.15	0.74	[0.55,1.00]	*p*=0.05	
Normal (ref)	0.00		1.00			
Family type (*p*=0.01)						
Single-parent household	-0.24	0.10	0.78	[0.65,0.95]	*p*=0.01	*p*=0.99
Co-parent household (ref)	0.00		1.00			
Parental education (*p*<0.001)						
No formal UK qualifications	-0.83	0.16	0.43	[0.32, 0.59]	*p*<0.001	*p*=0.18
GCSE/equivalent	-0.49	0.12	0.61	[0.49,0.77]	*p*<0.001	
A levels/equivalent	-0.29	0.19	0.75	[0.51,1.10]	*p*=0.14	
Uni. degree/equivalent (ref)	0.00		1.00			

Family income[b]($p<0.001$)						
Bottom	-0.93	0.16	0.40	[0.29,0.54]	$p<0.001$	$p=0.22$
Second	-0.69	0.16	0.50	[0.37,0.68]	$p<0.001$	
Third	-0.56	0.14	0.57	[0.43,0.76]	$p<0.001$	
Fourth	-0.29	0.17	0.75	[0.53,1.05]	$p=0.09$	
Top (ref)	0.00		1.00			
Parental longstanding illness ($p=0.90$)						
Present	0.01	0.1	1.01	[0.84,1.22]	$p=0.90$	$p=0.09$
Absent (ref)	0.00		1.00			
Parental mental health functioning ($p=0.19$)						
Serious mental distress	-0.34	0.20	0.71	[0.48,1.06]	$p=0.10$	p=0.14
Moderate mental distress	-0.14	0.12	0.87	[0.69,1.11]	$p=0.27$	
No distress (ref)	0.00		1.00			
Parental physical activity ($p<0.001$)						
Never	-0.62	0.13	0.54	[0.42,0.70]	$p<0.001$	$p=0.57$
Seldom	-0.14	0.17	0.87	[0.62,1.20]	$p=0.39$	
Regular	-0.05	0.14	0.95	[0.72,1.26]	$p=0.73$	
Often (ref)	0.00		1.00			
Parental play of physically active games with a child ($p=0.01$)						
Never	-0.59	0.18	0.56	[0.39,0.80]	$p=0.001$	$p=0.04$
Seldom	-0.31	0.17	0.74	[0.52,1.04]	$p=0.08$	
Regular	-0.28	0.19	0.76	[0.52,1.09]	$p=0.14$	
Often (ref)	0.00		1.00			
Parental play of indoor games with a child ($p=0.51$)						
Never	-0.07	0.22	0.93	[0.60,1.43]	$p=0.75$	$p=0.96$
Seldom	0.12	0.14	1.13	[0.84,1.48]	$p=0.45$	
Regular	0.18	0.14	1.20	[0.90,1.58]	$p=0.23$	
Often (ref)	0.00		1.00			
Parental social support ($p=0.01$)						
Never	-0.95	0.39	0.39	[0.18,0.84]	$p=0.02$	$p<0.001$
Seldom	-0.43	0.29	0.65	[0.37,1.14]	$p=0.13$	
Regular	0.33	0.19	1.39	[0.96,2.02]	$p=0.08$	
Often (ref)	0.00		1.00			
Parental time ($p=0.04$)						
Not enough time	0.31	0.12	1.36	[1.07, 1.73]	$p=0.01$	$p=0.53$
Just enough time	0.12	0.12	1.13	[0.89, 1.43]	$p=0.32$	
Enough time (ref)	0.00		1.00			
Availability of parks/playgrounds for a child to play ($p=0.09$)						
No	0.26	0.15	1.29	[0.97,1.73]	$p=0.09$	$p=0.39$
Yes (ref)	0.00		1.00			
Type of area to raise a child ($p=0.01$)						
Poor	-0.51	0.23	0.60	[0.38,0.94]	$p=0.02$	$p=0.21$
Average	-0.29	0.11	0.75	[0.60,0.94]	$p=0.01$	
Good (ref)	0.00		1.00			

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Models are fitted using negative log-log link function.
[a]*Psychosocial & behavioural problems.*
[b]*Based on the OECD equalized quintiles for the entire UK.*
Indian/ Pakist/Banglad. – Indian/ Pakistani/Bangladeshi.
Uni.degree/equivalent – University degree or equivalent.

The multivariable initial ordinal model was then fitted (Table 55). Factors associated with frequency of participation in initial multivariable ordinal model were child psychosocial and behavioural problems, parental education, parental physical activity and parental social support. As discussed in section 4.9.2, to check the validity of the ordinal model, the assumption of parallel odds should be tested (Agatsi 1996). The results of the test of proportional odds assumption was significant at 5% level of significance (p<0.001) which was indicative that the initial ordinal model was not fitting data well (Table 55).

Table 55. Multivariable initial ordinal model for participation frequency in OPHA

Characteristics	**Adjusted parameters**				
	B	*SE*	*Exp(B)*	95% CI	Sig.value
PSB problems[a]					
Abnormal	-0.31	0.12	0.74	[0.58,0.93]	*p*=0.01
Borderline	-0.18	0.15	0.83	[0.62,1.12]	*p*=0.23
Normal (ref)	0.00		1.00		
Family type					
Single-parent household	-0.08	0.12	0.92	[0.73,1.16]	*p*=0.48
Co-parent household (ref)	0.00		1.00		
Parental education					
No formal UK qualifications	-0.51	0.20	0.60	[0.41,0.88]	*p*=0.01
GCSE/ equivalent	-0.37	0.12	0.69	[0.54,0.87]	*p*<0.01
A levels/equivalent	-0.18	0.21	0.84	[0.55,1.27]	*p*=0.40
University degree/equivalent (ref)	0.00		1.00		
Family income[b]					
Bottom	-0.30	0.21	0.74	[0.49,1.12]	p=0.15
Second	-0.28	0.19	0.75	[0.52,1.10]	p=0.14
Third	-0.35	0.16	0.71	[0.51,0.97]	p=0.03
Fourth	-0.15	0.18	0.86	[0.61,1.22]	p=0.40
Top (ref)	0.00		1.00		
Parental physical activity					
Never	-0.42	0.14	0.66	[0.50,0.86]	*p*=0.003
Seldom	-0.08	0.18	0.92	[0.65,1.31]	*p*=0.66
Regular	-0.02	0.15	0.98	[0.73,1.30]	*p*=0.87
Often (ref)	0.00		1.00		
Parental play of physically active games with a child					
Never	-0.44	0.19	0.64	[0.44,0.94]	*p*=0.02
Seldom	-0.44	0.18	0.65	[0.46,0.91]	*p*=0.01
Regular	-0.48	0.20	0.62	[0.42,0.91]	*p*=0.02
Often (ref)	0.00		1.00		
Parental social support					
Never	-0.57	0.52	0.56	[0.20, 1.57]	*p*=0.27
Seldom	-0.29	0.32	0.75	[0.40, 1.40]	*p*=0.36
Regular	0.55	0.19	1.73	[1.20, 2.49]	*p*=0.004
Often (ref)	0.00		1.00		
Parental time					
Not enough time	0.23	0.13	1.26	[0.98,1.62]	*p*=0.07
Just enough time	0.10	0.12	1.11	[0.87,1.41]	*p*=0.40

Enough time (ref)	0.00		1.00		
Type of area to raise a child					
Poor	-0.27	0.25	0.77	[0.47,1.25]	*p*=0.29
Average	-0.18	0.12	0.84	[0.66,1.06]	*p*=0.14
Good (ref)	0.00		1.00		
Model fitting information					
Initial Pseudo -2 LL	2182.1				
Model Pseudo -2 LL	2044.0				
Pseudo -2 LL difference	138.1				
Pseudo R^2: Nagelkerke	14.2%				
Test of parallel lines	Wald F 43.04 *df* (23,287) *p*<0.001				

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Models are fitted using negative log-log link function.
Sample size n=1,037.
[a]*Psychosocial & behavioural problems.*
[b]*Based on the OECD equalized quintiles for the entire UK.*

The model was then refitted by removing non-significant variables one by one, adding variables back and checking the fit of the model (Hosmer et al. 2013). Models 1 and 2 were fitting the data considerably better than the constant-only model (Table 56). Based on these models, other factors fixed, child psychosocial and behavioural problems, parental education and parental physical activity were the explanatory variables which independently contributed to participation frequency of children with disabilities in OPHA. Family type and the type of area to raise a child appeared to have an insignificant contribution to the participation frequency in OPHA. Because the difference in unstandardized *B* coefficients *(Δβ)* between Model 1 and 2 was substantially less than 20% (Hosmer et al. 2013) (i.e. family type and the type of area to raise a child did not provided important adjustment of the effect of remaining three variables), Model 2 was chosen as a final predictive model for participation frequency of children with disabilities in OPHA based on the principal of parsimony. Result for Model 2 are presented below (Table 56).

Model 2 goodness of fit and effect size

The assumption of parallel odds was valid for Model 2 - Wald F (8, 302) 1.65, *p*=0.11. This was indicative that the model and data were not poor fit to each other. The effect size for the whole model Pseudo R-squared (R^2): Nagelkerke was 9.6%.

Model 2 parameter estimates

The unstandardized logistic regression coefficients *(B)* for child abnormal psychosocial and behavioural problems, parental lower levels of education and parental physical inactivity were negative (Table 56). Negative logits means that the odds are against children with disabilities with these predictor values to have higher frequency of participation in OPHA. According to Model 2, with other things being fixed, children with disabilities who had clinically significant psychosocial and behavioural problems were 29% less likely to have higher frequency of participation in OPHA (*Exp(B)* 0.71, 95% CI 0.57, 0.90) compared to children with disabilities with no psychosocial and behavioural problems. Similarly, children with disabilities whose parents had no formal UK qualification or GCSE/ equivalent were respectively 49% (*Exp(B)* 0.51, 95% CI 0.37, 0.72) and 36% (*Exp(B)* 0.64, 95% CI 0.50, 0.81) less likely to have higher frequency of participation in OPHA compared to children with parents having university degree/equivalent. Further, children with disabilities whose parents were physically inactive (i.e. engaged in physical activities or sports less often than once in the last 12 months or not at all) had lower odds for (*Exp(B)* 0.64, 95% CI 0.49, 0.83) or 36% less likely to have higher frequency of participation in OPHA compared to children with disabilities whose parents were engaged in physical activities often (Table 56).

Table 56. Multivariable ordinal models for participation frequency in OPHA

Characteristics	Adjusted parameters					
	Model 1	Model 2				
	B	*B*	*SE*	*Exp(B)*	95% CI	Sig. value
PSB problems[a]						
Abnormal	-0.29*	-0.34	0.12	0.71	[0.57,0.90]	*p*<0.01
Borderline	-0.21	-0.24	0.15	0.78	[0.59,1.04]	*p*=0.09
Normal (ref)	0.00	0.00		1.00		
Family type						
Single-parent household	-0.14					
Co-parent household (ref)	0.00					
Parental education						
No formal UK qualifications	-0.60***	-0.66	0.17	0.51	[0.37,0.72]	*p*<0.001
GCSE/equivalent	-0.42***	-0.45	0.12	0.64	[0.50,0.81]	*p*<0.001
A levels/equivalent	-0.20	-0.21	0.19	0.81	[0.55,1.18]	*p*=0.27
Uni. degree/equival. (ref)	0.00	0.00		1.00		
Parental physical activity						
Never	-0.45**	-0.45	0.13	0.64	[0.49,0.83]	*p*=0.001
Seldom	-0.11	-0.14	0.18	0.87	[0.61,1.24]	*p*=0.45
Regular	-0.03	-0.04	0.14	0.96	[0.73,1.27]	*p*=0.82
Often (ref)	0.00	0.00		1.00		
Type of area to raise a child						
Poor	-0.26					
Average	-0.18					
Good (ref)	0.00					
Model fitting information						
Initial Pseudo -2 LL	2188.7	2188.7				
Model Pseudo -2 LL	2086.2	2096.6				
Pseudo -2 LL difference	102.5	92.1				
Pseudo R^2: Nagelkerke	10.5%	9.6%				
Test of parallel lines	Wald F 1.58 *df* (11,299) *p*=0.10	Wald F 1.65 *df* (8,302) *p*=0.11				

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Models are fitted using negative log-log link function.
Sample size n=1,040.
[a]*Psychosocial & behavioural problems.*
Uni. degree/equival – University degree or equivalent.
** p<0.05, **p<0.01, ***p<0.001.*

5.6 Factors associated with participation frequency in unstructured physical activities

The ordinal logistic models for participation frequency of children with disabilities in unstructured physical activities (UPHA) were first fitted with a single explanatory variable – the child, family and community factors using the SPSS Complex Sample Module (PLUM) version 23.0 (IBM Corp., Armonk, NY, USA). Frequency

distributions for the child, family and community factors by participation frequency in UPHA are summarized in Appendix I. The variables associated with frequency of participation of children with disabilities in UPHA in univariable analysis (at significance level $p<0.05$) were child psychosocial and behavioural problems, parental play of physically active games with a child, parental social support and availability of parks/playgrounds for a child to play (Table 57).

Table 57. Univariable ordinal model for participation frequency in UPHA

Characteristics (sig. value for a variable)	Unadjusted parameters					
	B	*SE*	*Exp(B)*	95% CI	Sig. value	Test of parallel lines
Sex (*p*=0.51)						
Boys	0.08	0.13	1.09	[0.85,1.39]	*p*=0.51	*p*=0.96
Girls (ref)	0.00		1.00			
Ethnicity (*p*=0.35)						
Mixed/Other Ethnic	-0.39	0.24	0.67	[0.42,1.08]	*p*=0.10	*p*=0.31
Black/Black British	-0.44	0.48	0.65	[0.25,1.66]	*p*=0.36	
Indian/Pakist/ Banglad.	-0.12	0.32	0.89	[0.47,1.67]	*p*=0.71	
White (ref)	0.00		1.00			
PSB problems[a] (*p*=0.001)						
Abnormal	-0.51	0.13	0.60	[0.46,0.78]	*p*<0.001	*p*=0.38
Borderline	-0.38	0.20	0.68	[0.46,1.02]	*p*=0.06	
Normal (ref)	0.00		1.00			
Family type (*p*=0.59)						
Single-parent household	-0.07	0.13	0.93	[0.72,1.20]	*p*=0.59	*p*=0.24
Co-parent household (ref)	0.00		1.00			
Parental education (*p*=0.68)						
No formal UK qualifications	-0.24	0.20	0.79	[0.53,1.16]	*p*=0.23	*p*=0.37
GCSE/equivalent	-0.14	0.17	0.87	[0.62,1.21]	*p*=0.39	
A levels/equivalent	-0.14	0.23	0.87	[0.55,1.38]	*p*=0.55	
Uni. degree/equivalent (ref)	0.00		1.00			
Family income[b] (*p*=0.49)						
Bottom	-0.08	0.20	0.92	[0.63,1.36]	*p*=0.69	*p*=0.41
Second	0.03	0.22	1.03	[0.66,1.59]	*p*=0.90	
Third	0.20	0.20	1.23	[0.83,1.81]	*p*=0.30	
Fourth	-0.06	0.20	0.94	[0.63,1.40]	*p*=0.75	
Top (ref)	0.00		1.00			
Parental longstanding illness (*p*=0.45)						
Present	0.08	0.12	1.09	[0.87,1.36]	*p*=0.45	*p*=0.16
Absent (ref)	0.00		1.00			
Parental mental health functioning (*p*=0.47)						
Serious mental distress	-0.28	0.23	0.76	[0.48,1.19]	*p*=0.22	*p*=0.34
Moderate mental distress	-0.04	0.15	0.96	[0.71,1.28]	*p*=0.76	
No distress (ref)	0.00		1.00			
Parental physical activity (*p*=0.19)						
Never	-0.37	0.17	0.69	[0.49,0.98]	*p*=0.04	*p*<0.001
Seldom	-0.18	0.23	0.84	[0.54,1.31]	*p*=0.44	
Regular	-0.25	0.19	0.78	[0.53,1.14]	*p*=0.20	
Often (ref)						

Parental play of physically active games with a child (*p*<0.01)						
Never	-0.48	0.24	0.62	[0.38,0.99]	*p*=0.05	*p*=0.24
Seldom	0.01	0.24	1.01	[0.63,1.61]	*p*=0.97	
Regular	-0.23	0.26	0.80	[0.48,1.34]	*p*=0.39	
Often (ref)	0.00		1.00			
Parental play of indoor games with a child (*p*=0.26)						
Never	-0.20	0.24	0.82	[0.51,1.31]	*p*=0.39	*p*<0.001
Seldom	0.20	0.17	1.22	[0.87,1.73]	*p*=0.25	
Regular	0.16	0.17	1.17	[0.84,1.57]	*p*=0.35	
Often (ref)	0.00		1.00			
Parental social support (*p*<0.001)						
Never	-1.32	0.25	0.27	[0.16,0.44]	*p*=0.001	*p*<0.001
Seldom	0.12	0.39	1.13	[0.52,2.45]	*p*=0.76	
Regular	0.26	0.24	1.30	[0.81,2.08]	*p*=0.28	
Often (ref)	0.00		1.00			
Parental time (*p*=0.25)						
Not enough time	0.23	0.14	1.25	[0.94,1.66]	*p*=0.12	*p*=0.14
Just enough time	0.03	0.15	1.03	[0.76,1.40]	*p*=0.84	
Enough time (ref)	0.00		1.00			
Availability of parks/playgrounds for a child to play (*p*=0.02)						
No	-0.45	0.19	0.64	[0.44,0.93]	*p*=0.02	*p*=0.48
Yes (ref)	0.00		1.00			
Type of area to raise a child (*p*=0.19)						
Poor	-0.42	0.23	0.66	[0.42,1.03]	*p*=0.07	*p*<0.01
Average	0.00	0.17	1.00	[0.72,1.39]	*p*=0.98	
Good (ref)	0.00		1.00			

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
Models are fitted using complementary log-log link function.
[a]*Psychosocial & behavioural problems.*
[b]*Based on the OECD equalized quintiles for the entire UK.*
Indian/Pakist/ Banglad. – Indian/Pakistani/Bangladeshi.

The multivariable initial model was then fitted (Table 58). Factors associated with frequency of participation of children with disabilities in UPHA in the initial multivariable model were child psychosocial and behavioural problems, parental play of physically active games with a child and parental social support. The results of the test of proportional odds assumption, however, was significant at 5% level of significance ($p<0.001$) which was indicative that the proportional odds assumption was not satisfied – the model was not fitting data well (Table 58).

Refitting the model by removing non-significant variables, adding variables and checking the model fit (Hosmer et al. 2013) yielded a single model which was retained based on a principle of parsimony (Table 58). Other things being fixed, child psychosocial and behavioural problems and parental play of physically active games with a child were the only explanatory variables associated with frequency of participation of children with disabilities in unstructured physical activities.

Model goodness of fit and effect size

The assumption of parallel odds was met with Wald F (5,305)=1.02, *p*=0.41 which was indicative that the model and data were not poor fit to each other. The effect size for the whole model Pseudo R^2: Nagelkerke was 4.6%. However, as discussed previously, this estimate is not completely equivalent to the R^2 in a linear regression analysis, hence should be assessed with caution (Clark-Carter 2019).

Model parameter estimates

The unstandardized logistic regression coefficients *(B)* for child psychosocial and behavioural problems and parental play of physically active games with a child were -0.49 and -0.52. Negative logits means that the odds are against children with disabilities with these predictor values to have higher frequency of participation in UPHA. According to the model, children with disabilities who had clinically significant (abnormal) psychosocial and behavioural problems were 39% less likely to have higher frequency of participation in UPHA (*Exp(B)* 0.61; 95% CI 0.47-0.80) compared to children with disabilities with no psychosocial and behavioural problems. Similarly, children with disabilities whose parents never played physical active games with them were 41 % less likely to have higher frequency of participation in UPHA (*Exp(B)* 0.59, 95% CI 0.37, 0.94) compared to children whose parents were playing physically active games often (Table 58).

Table 58. Multivariable ordinal model for participation frequency in UPHA

Characteristics	Adjusted parameters					
	Model 1†	Model 2††				
	B	*B*	*SE*	*Exp(B)*	95% CI	Sig. value
PSB problems[a]						
Abnormal	-0.47***	-0.49	0.13	0.61***	[0.47,0.80]	p<0.001
Borderline	-0.32	-0.37	0.20	0.69	[0.47,1.03]	p=0.07
Normal (ref)	0.00	0.00		1.00		
Parental play of physically active games with a child						
Never	-0.55*	-0.52	0.23	0.59*	[0.37,0.94]	p=0.03
Seldom	-0.14	-0.05	0.24	0.99	[0.57,1.52]	p=0.84
Regular	-0.31	-0.25	0.26	0.78	[0.47,1.30]	p=0.34
Often (ref)	0.00	0.00		1.00		
Parental social support						
Never	-1.09**					
Seldom	0.35					
Regular	0.24					
Often (ref)	0.00					
Availability of parks/playgrounds a child to play						
No	-0.31					
Yes (ref)	0.00					
Model fitting information						
Initial Pseudo -2 LL	1990.7	1991.2				
Model Pseudo -2 LL	1929.1	1949.8				
Pseudo -2 LL difference	61.6	41.4				
Pseudo R^2: Nagelkerke	6.7%	4.6%				
Test of parallel lines	Wald F 5.51 *df* (9,301) p<0.001	Wald F=1.02 *df* (5,305) p=0.41				

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. Models are fitted using complementary log-log link function.
†Sample size n=1,045.
†† Sample size n=1,062.
[a]Psychosocial & behavioural problems.
** p<0.05, **p<0.01, ***p<0.001.*

5.7 Factors associated with participation frequency in getting together with friends

The ordinal logistic models for participation frequency of children with disabilities in getting together with friends (GTF) were first fitted with a single explanatory variable – the child, family and community factors using the SPSS Complex Sample Module (PLUM) version 23.0 (IBM Corp., Armonk, NY, USA). Frequency distributions for the child, family and community factors by frequency of GTF are summarized in Appendix J. The variables associated with frequency of participation in getting together with friends in univariable analysis (at significance level p<0.05) were

ethnicity, child psychosocial and behavioural problems, parental longstanding illness, parental playing physical active games with a child and parental social support (Table 59).

Table 59. Univariable ordinal model predicting participation frequency in GTF

Characteristics (sig.value of a variable)	**Unadjusted parameters**					
	B	*SE*	*Exp(B)*	95% CI	Sig. value	Test of parallel lines
Sex (*p*=0.51)						
Boys	0.07	0.11	1.07	[0.87,1.33]	*p*=0.51	*p*=0.90
Girls	0.00		1.00			
Ethnicity (*p*<0.01)						
Mixed/Other Ethnic group	-0.32	0.24	0.73	[0.45,1.17]	*p*=0.19	*p*=0.08
Black/Black British	-0.86	0.24	0.42	[0.26,0.68]	*p*<0.001	
Indian/ Pakistani/ Bangladeshi	-0.20	0.20	0.82	[0.55,1.22]	*p*=0.33	
White (ref)	0.00		1.00			
PSB problems[a] (*p*<0.001)						
Abnormal	-0.57	0.12	0.57	[0.45,0.72]	*p*<0.001	*p*=0.001
Borderline	-0.23	0.19	0.79	[0.55,1.14]	*p*=0.21	
Normal (ref)	0.00		1.00			
Family type (*p*=0.09)						
Single-parent household	0.19	0.11	1.20	[0.97,1.49]	*p*=0.09	*p*=0.03
Co-parent household (ref)	0.00		1.00			
Parental education (*p*=0.22)						
No formal UK qualifications	0.17	0.16	1.18	[0.86,1.62]	*p*=0.31	*p*<0.001
GCSE/equivalent	0.26	0.13	1.29	[1.01,1.66]	*p*=0.04	
A levels/equivalent	0.19	0.17	1.21	[0.86,1.70]	*p*=0.28	
University degree/equivalent (ref)	0.00		1.00			
Family income[b] (*p*=0.13)						
Bottom	0.21	0.17	1.23	0.88,1.72	*p*=0.23	*p*<0.001
Second	0.23	0.17	1.26	0.89,1.77	*p*=0.19	
Third	0.43	0.16	1.53	1.12,2.10	*p*=0.01	
Fourth	0.21	0.17	1.24	0.88,1.74	*p*=0.22	
Top (ref)	0.00		1.00			
Parental longstanding illness (*p*=0.001)						
Present	0.35	0.10	1.42	[1.16,1.73]	*p*=0.001	*p*=0.13
Absent (ref)	0.00		1.00			
Parental mental health functioning (*p*=0.41)						
Serious mental distress	0.22	0.23	1.24	[0.80,1.93]	*p*=0.34	*p*=0.31
Moderate mental distress	-0.08	0.13	0.92	[0.72,1.18]	*p*=0.50	
No distress (ref)	0.00		1.00			
Parental play of indoor games with a child (*p*=0.36)						
Never	-0.21	0.21	0.81	[0.53, 1.23]	*p*=0.32	*p*<0.01
Seldom	0.10	0.16	1.11	[0.81, 1.53]	*p*=0.52	
Regular	-0.02	0.16	0.98	[0.72, 1.34]	*p*=0.89	
Often (ref)	0.00		1.00			
Parental play of physically active games with a child (*p*=0.03)						
Never	0.09	0.21	1.09	[0.72,1.66]	*p*=0.68	*p*=0.01
Seldom	0.08	0.19	1.08	[0.74,1.58]	*p*=0.69	
Regular	-0.26	0.20	0.77	[0.52,1.13]	*p*=0.18	
Often (ref)	0.00		1.00			

Parental social support (*p*=0.04)						
Never	-1.10	0.42	0.33	[0.15,0.77]	*p*=0.01	*p*<0.001
Seldom	0.27	0.31	1.31	[0.71,2.43]	*p*=0.38	
Regular	-0.10	0.20	0.90	[0.62,1.33]	*p*=0.61	
Often (ref)	0.00		1.00			
Parental time (*p*=0.49)						
Not enough time	0.00	0.13	1.00	[0.78,1.28]	*p*=0.98	*p*=0.14
Just enough time	-0.13	0.14	0.88	[0.60,1.14]	*p*=0.33	
Enough time (ref)	0.00		1.00			
Availability of parks/playgrounds for a child to play (*p*=0.85)						
No	-0.04	0.24	0.96	[0.60,1.52]	*p*=0.85	*p*=0.07
Yes (ref)	0.00		1.00			
Type of area to raise a child (*p*=0.40)						
Poor	-0.24	0.21	0.78	[0.51,1.19]	*p*=0.26	*p*<0.01
Average	0.10	0.14	1.10	[0.83,1.45]	*p*=0.50	
Good (ref)	0.00		1.00			

Note.Models are fitted using complementary log-log link function.
[a]*Psychosocial & behavioural problems.*
[b]*Based on the OECD equalized quintiles for the entire UK.*

The multivariable initial model was then fitted for which proportional odds assumption was not satisfied. Refitting the model by removing non-significant variables one by one in an iterative manner did not improve the model fit. The assumption of proportional odds was not met for this outcome of interest in any of the sequential regression models. Therefore, the ordinal regression analysis technique was deemed inappropriate for this outcome of interest.

Given the potential options described in section 4.9.2 and statistical procedures available in the SPSS Complex Sample Module, a binary logistic regression model was fitted. To achieve this, the ordinal scale in the outcome variable GTF ("1=Low", "2=Regular" and "3=High"), was dichotomised into "0=Low" and "1=High". The category "1=High" in the binary variable included respondents from both "Regular" and "High" categories (Table 60).

Table 60. Percentages of children at each level of frequency of participation in GTF

Outcome categories	Population estimate (SE)	Per cent (%)	Cumulative (%)
Low	225 (21)	21%	21%
High	848 (42)	79%	100%

Frequency distributions for the child, family and community factors by frequency of GTF (binary response) are provided in Appendix K. Results of univariable binary logistic regression are presented in Table 61. Ethnicity, child psychosocial and behavioural problems, parental education, family income, parental play of indoor games with a child, parental social support, and type of area to raise a child were factors associated with frequency of participation in GTF in univariable analysis (at significance level $p<0.05$) (Table 61).

Table 61. Univariable logistic model for participation frequency in GTF

Characteristics	**Unadjusted parameters**				
(sig. value for a variable)	*B*	*SE*	*Exp(B)*	95% CI	Sig. value
Sex (*p*=0.77)					
Boys	0.06	0.21	1.06	[0.70,1.60]	*p*=0.77
Girls (ref)	0.00		1.00		
Ethnicity (*p*=0.05)					
Mixed/Other Ethnic group	-0.90	0.35	0.41	[0.20,0.81]	*p*=0.01
Black/Black British	-0.71	0.60	0.49	[0.15,1.62]	*p*=0.24
Indian/ Pakistani/ Bangladeshi	-0.33	0.34	0.72	[0.37,1.39]	*p*=0.32
White (ref)	0.00		1.00		
PSB problems[a] (*p*=0.001)					
Abnormal	-1.56	0.25	0.21	[0.13,0.34]	*p*<0.001
Borderline	-0.91	0.37	0.40	[0.20,0.83]	*p*=0.01
Normal (ref)	0.00		1.00		
Family type (*p*=0.55)					
Single-parent household	-0.13	0.21	0.88	[0.58,1.33]	*p*=0.55
Co-parent household (ref)	0.00		1.00		
Parental education (*p*<0.01)					
No formal UK qualifications	-0.76	0.28	0.47	[0.27,0.81]	*p*=0.01
GCSE/equivalent	-0.03	0.27	0.97	[0.56,1.66]	*p*=0.90
A levels/equivalent	0.45	0.43	1.57	[0.68,3.64]	*p*=0.29
University degree/equivalent (ref)	0.00		1.00		
Family income[b] (*p*<0.001)					
Bottom	-0.64	0.36	0.70	[0.33,1.51]	*p*=0.08
Second	-0.35	0.39	2.23	[0.99,4.99]	*p*=0.37
Third	0.80	0.41	1.08	[0.50,2.33]	*p*=0.05
Fourth	0.07	0.39	1.00		*p*=0.85
Top (ref)	0.00		1.00		
Parental longstanding illness (*p*=0.50)					
Present	0.14	0.20	1.15	[0.77,1.70]	*p*=0.50
Absent (ref)	0.00		1.00		
Parental mental health functioning (*p*=0.43)					
Serious mental distress	-0.08	0.35	0.92	[0.47,1.83]	*p*=0.82
Moderate mental distress	-0.30	0.23	0.74	[0.47,1.17]	*p*=0.20
No distress (ref)	0.00		1.00		

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Parental play of indoor games with a child (p=0.02)					
Never	-0.40	0.35	0.67	[0.34,1.33]	p=0.25
Seldom	0.44	0.27	1.55	[0.91,2.65]	p=0.11
Regular	0.52	0.29	1.68	[0.95,2.99]	p=0.08
Often (ref)	0.00		1.00		
Parental play of physically active games with a child (p=0.21)					
Never	-0.02	0.36	0.98	[0.48,2.00]	p=0.95
Seldom	0.48	0.36	1.62	[0.80,3.25]	p=0.18
Regular	0.17	0.37	1.19	[0.58,2.45]	p=0.64
Often (ref)	0.00		1.00		
Parental social support (p=0.001)					
Never	-1.90	0.48	0.15	[0.06,0.39]	p<0.001
Seldom	-0.53	0.41	0.59	[0.26,1.32]	p=0.20
Regular	0.64	0.46	1.89	[0.77,4.64]	p=0.16
Often (ref)	0.00		1.00		
Parental time (p=0.15)					
Not enough time	0.38	0.26	1.46	[0.88,2.41]	p=0.15
Just enough time	-0.10	0.24	0.91	[0.56,1.47]	p=0.70
Enough time (ref)	0.00		1.00		
Availability of parks/playgrounds for a child to play (p=0.17)					
No	-0.42	0.31	0.66	[0.36,1.20]	p=0.17
Yes (ref)	0.00		1.00		
Type of area to raise a child (p=0.03)					
Poor	-0.83	0.34	0.44	[0.23,0.85]	p=0.01
Average	-0.33	0.22	0.72	[0.46,1.11]	p=0.14
Good (ref)	0.00		1.00		

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
[a]*Psychosocial & behavioural problems.*
[b]*Based on the OECD equalized quintiles for the entire UK*

The multivariable initial model was then fitted (Table 62). Factors associated with frequency of participation in GTF in the initial multivariable model were ethnicity, child psychosocial and behavioural problems and family income. Parental education, parental play of indoor games with a child, parental social support and type of area to raise a child showed little evidence of an effect. Refitting the model by removing and adding non-significant variables in an iterative fashion (Hosmer et al. 2013) (Table 63) yielded the parsimonious Model 3. Based on the results of Model 3, with other factors being fixed, ethnicity, child psychosocial and behavioural problems, family income and parental social support were the factors independently contributing to the frequency of GTF. Although parental play of indoor games had little effect on children's frequency of getting together with friends, it provided important adjustment of the effect of remaining variables (i.e. its removal from Model 3 resulted in substantial changes ($\Delta\beta$ >20%) in B coefficients between original Model 1 and 4) (Table 63).

Table 62. Multivariable logistic initial model for frequency of participation in GTF

	Adjusted parameters				
Characteristics	*B*	*SE*	*Exp(B)*	95% CI	Sig. value
Ethnicity					
Mixed/Other Ethnic group	-0.85	0.39	0.43	[0.20,0.92]	p=0.03
Black/Black British	-0.97	0.61	0.38	[0.11,1.26]	p=0.11
Indian/ Pakistani/ Bangladeshi	-0.63	0.44	0.53	[0.23,1.26]	p=0.15
White (ref)	0.00		1.00		
PSB probmes[a]					
Abnormal	-1.65	0.28	0.19	[0.11,0.33]	p<0.001
Borderline	-0.67	0.40	0.51	[0.23,1.12]	p=0.09
Normal (ref)	0.00		1.00		
Parental education					
No formal UK qualifications	-0.33	0.38	0.72	[0.34,1.51]	p=0.38
GCSE/equivalent	0.18	0.28	1.20	[0.69,2.09]	p=0.53
A levels/equivalent	0.40	0.42	1.49	[0.65,3.43]	p=0.35
Uni. degree/equivalent (ref)	0.00		1.00		
Family income[b]					
Bottom	0.54	0.46	1.72	[0.69,4.25]	p=0.24
Second	0.20	0.43	1.22	[0.52,2.86]	p=0.65
Third	1.24	0.44	3.46	[1.45,8.29]	p=0.01
Fourth	0.31	0.39	1.36	[0.63,2.96]	p=0.43
Top (ref)	0.00		1.00		
Parental play of indoor games with a child					
Never	-0.45	0.42	0.64	[0.28,1.46]	p=0.29
Seldom	0.12	0.32	1.12	[0.60,2.09]	p=0.71
Regular	0.32	0.32	1.38	[0.74,2.56]	p=0.31
Often (ref)	0.00		1.00		
Parental social support					
Never	-1.08	0.66	0.34	[0.09,1.24]	p=0.10
Seldom	-0.26	0.51	0.77	[0.28,2.13]	p=0.62
Regular	0.87	0.48	2.39	[0.93,6.15]	p=0.07
Often (ref)	0.00		1.00		
Type of area to raise a child					
Poor	-0.46	0.37	0.63	[0.30,1.31]	p=0.21
Average	-0.03	0.27	0.97	[0.57,1.66]	p=0.92
Good (ref)	0.00		1.00		
Model fitting information					
Initial Pseudo -2 LL	1035.2				
Model Pseudo -2 LL	898.2				
Pseudo -2 LL difference	137				
Corrected model	Wald F 4.33 df(20,290) p<0.001				
Pseudo R^2: Nagelkerke	19.6%				
% correctly classified	81.5%				

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. Sample size n=1,056.

[a] *Psychosocial & behavioural problems.*

[b] *Based on the OECD equalized quintiles for the entire UK.*

Uni. degree/equivalent – University degree or equivalent.

Table 63. Multivariable logistic models for participation frequency in GTF

Characteristics	Adjusted parameters			
	Model 1 (*n*=1,039)	Model 2 (*n*=1,039)	Model 3 (*n*=1,045)	Model 4 (*n*=1,045)
	B	*B*	*B*	*B*
Ethnicity				
Mixed/Other Ethnic group	-0.85*	-0.83*	-0.84*	-0.86*
Black/Black British	-0.97	-1.05	-1.00	-1.03
Indian/ Pakistani/ Bangladeshi	-0.63	-0.63	-0.65	-0.72
White (ref)	0.00	0.00	0.00	0.00
PSB problems[a]				
Abnormal	-1.65***	-1.67***	-1.66***	-1.66***
Borderline	-0.67	-0.70	-0.73	-0.75
Normal (ref)	0.00	0.00	0.00	0.00
Parental education				
No formal UK qualifications	-0.33	-0.36		
GCSE or equivalent	0.18	0.16		
A levels or equivalent	0.40	0.39		
University degree/equivalent (ref)	0.00	0.00		
Family income[b]				
Bottom	0.54	0.47	0.34	0.19
Second	0.20	0.17	0.10	0.04
Third	1.24**	1.21**	1.24**	1.16*
Fourth	0.31	0.31	0.35	0.27
Top (ref)	0.00	0.00	0.00	0.00
Parental play of indoor games with a child				
Never	-0.45	-0.44	-0.49	
Seldom	0.12	0.14	0.12	
Regular	0.32	0.31	0.31	
Often (ref)	0.00	0.00	0.00	
Parental social support				
Never	-1.08	-1.01	-1.20*	-1.45**
Seldom	-0.26	-0.24	-0.25	-0.35
Regular	0.87	0.90	0.84	0.77
Often (ref)	0.00	0.00	0.00	0.00
Type of area to raise a child				
Poor	-0.46			
Average	-0.03			
Good (ref)	0.00			
Model fitting information				
Initial Pseudo -2 LL	1035.2	1035.2	1047.7	1047.7
Model Pseudo -2 LL	898.2	900.9	911.1	918.7
Pseudo -2 LL difference	137	134.3	136.6	129
Corrected model	Wald F 4.33 *df*(20,290) *p*<0.001	Wald F 4.68 *df*(18,292) *p*<0.001	Wald F 6.44 *df*(15,295) *p*<0.001	Wald F 6.68 *df*(12,298) *p*<0.001
Pseudo R^2: Nagelkerke	19.6%	19.2%	19.4%	18.3%
% correctly classified	81.5%	81.1%	81.2%	81.1%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
[a]*Psychosocial & behavioural problems.*
[b]*Based on the OECD equalized quintiles for the entire UK.*

Model 3 goodness of fit and effect size

Model 3 (*n*=1,045) had an acceptable fit with Wald F (15,295) 6.44 being significant at $p<0.001$ (Table 64). Classification table showed that the sensitivity of the model (true positive -% of children which fell into a given category ("High") and were correctly classified as being in that category) was 98.2% and specificity (true negative-% of children which did not fall into that category and were successfully classified as not being in that category) was 13.1%. Overall, the model accurately predicted 81.2% of children falling into the outcome categories. Result of the c-statistic was indicative that the model had an acceptable fit. The area under the curve *c*=0.73 (*SE* 0.02, 95 % CI 0.69-0.77) and significantly different from 0.5, $p<0.001$. The ROC is presented in Figure 17. The effect size for Model 3, i.e. Pseudo R^2: Nagelkerke, was 19.4%; however, as discussed in section 4.9.3, this is a relative measure of assessing the model in binary logistic regression analysis.

Model 3 parameter estimates

According to Model 3, with other things being fixed, children with disabilities from Mixed/Other Ethnic Groups were 43 % less likely (*Exp(B)* 0.43; 95% CI 0.21, 0.89) to have high frequency of getting together with friends compared to children with disabilities who were White. Further, children with disabilities with clinically significant psychosocial and behavioural problems (*Exp(B)* 0.19; 95% CI 0.11, 0.33) and those whose parents never talked about things important to them (*Exp(B)* 0.30; 95% CI 0.10, 0.88) had significantly lower odds for higher frequency of getting together with friends compared to children who did not have any psychosocial and behavioural problems and those whose parents talked about things important to them often (Table 64). Children with disabilities from the third 20% of equalized family income quintiles had significantly higher odds (*Exp(B*) 3.45, 95% CI 1.44, 8.23) for higher frequency of getting together with friends compared to children with disabilities from the top 20% of equalized family income.

Table 64. Multivariable logistic model (final) for participation frequency in GTF

Characteristics	Adjusted parameters				
	Model 3				
	B	*SE*	*Exp(B)*	95% CI	Sig. value
Ethnicity					
Mixed/Other Ethnic group	-0.84	0.37	0.43	[0.21 0.89]	p=0.02
Black/Black British	-1.00	0.63	0.37	[0.11,1.26]	p=0.11
Indian/ Pakistani/ Bangladeshi	-0.65	0.41	0.52	[0.23,1.17]	p=0.11
White (ref)	0.00		1.00		
PSB problems[a]					
Abnormal	-1.66	0.28	0.19	[0.11,0.33]	p<0.001
Borderline	-0.73	0.41	0.48	[0.22,1.07]	p=0.07
Normal (ref)	0.00		1.00		
Family income[b]					
Bottom	0.34	0.40	1.38	[0.62,3.03]	p=0.43
Second	0.10	0.42	1.11	[0.49,2.52]	p=0.80
Third	1.24	0.44	3.45	[1.44,8.23]	p<0.01
Fourth	0.35	0.40	1.42	[0.64,3.12]	p=0.39
Top (ref)	0.00		1.00		
Parental play of indoor games with a child					
Never	-0.49	0.42	0.61	[0.27,1.39]	p=0.24
Seldom	0.12	0.31	1.13	[0.62,2.07]	p=0.69
Regular	0.31	0.31	1.36	[0.74,2.50]	p=0.32
Often (ref)	0.00		1.00		
Parental social support					
Never	-1.20	0.55	0.30	[0.10,0.88]	p=0.03
Seldom	-0.25	0.51	0.78	[0.29,2.13]	p=0.63
Regular	0.84	0.47	2.31	[0.91,5.85]	p=0.08
Often (ref)	0.00		1.00		
Model fitting information					
Initial Pseudo -2 LL	1047.7				
Model Pseudo -2 LL	911.1				
Pseudo -2 LL difference	136.6				
Corrected model	Wald F 6.44; df(15,295); p<0.001				
Pseudo R^2: Nagelkerke	19.4%				
% correctly classified	81.2%				
% correct positive	98.2%				
% correct negative	13.1%				

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. Sample size n=1,045.

[a] *Psychosocial & behavioural problems.*

[b] *Based on the OECD equalized quintiles for the entire UK.*

Area (*SE*)=0.73 (0.02)
Sig. *p*<0.001
95% CI [0.69, 0.77]

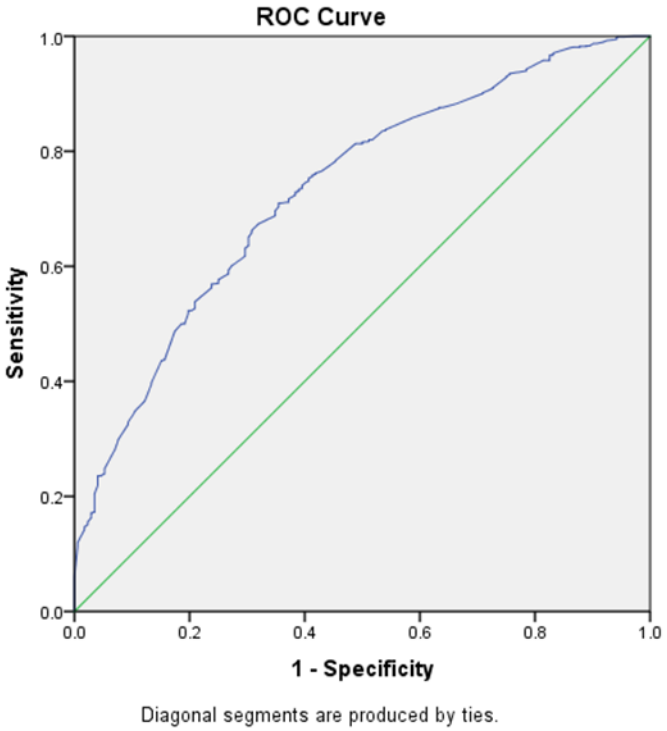

Figure 17. The ROC Curve for Model 3

5.8 Summary

Of total 12,195 children aged 10-12, 1,073 (8.8%, 95% CI 8.2%, 9.5%) were reported as having a disability. The most commonly reported functional issues in children with disabilities were learning/understanding/concentrating (36.9%), socialization/behaviour (32.3%), stamina/breathing (27.1%) and mobility (17.3%), with many children having more than one functional issue.

Children with and without disabilities aged 10-12 differed in respect to personal and family characteristics. Differences were established in relation to child sex (p<0.001), child psychosocial and behavioural problems (p<0.001), family type (p<0.001), parental education (p=0.001), family income (p<0.001) and parental health indicators (p<0.001). Based on multivariable binary logistic regression analysis, children with disabilities were more likely to be boys (*AOR* 1.37, 95% CI 1.15, 1.64, p<0.001), have borderline (*AOR* 4.27; 95% CI 3.32, 5.50, p<0.001) and abnormal psychosocial and

behavioural problems (*AOR* 8.86; 95% CI 7.12, 11.01, $p<0.001$), live in single-parent households (*AOR* 1.37, 95% CI 1.11, 1.68, $p<0.01$) and have a parent with a longstanding illness (*AOR* 2.36; 95% 1.94, 2.87, $p<0.001$).

Participation in community-based activities had similar patterns for children with and without disabilities. Higher proportions of children in both groups participated in community-based activities that were more unstructured in nature. Participation mean diversity scores were also close. Children with and without disabilities participated on average in four out of possible six activities. Nevertheless, group comparisons have shown that children with disabilities were less likely to participate in five out of possible six community-based activities compared to their peers without disabilities. Children with disabilities differ in respect to frequency of participation in five out of six community-based activities. No group differences were established in respect to visiting a library.

Multivariable logistic regression analysis results showed that children with disabilities were 3 times less likely to get together with friends (*AOR* 3.22; 95% CI 2.38, 4.34, $p<0.001$) compared to peers. They also were 2 times less likely to participate in unstructured physical activities (*AOR* 2.27; 95% CI 1.76, 2.94, $p<0.001$) and organized physical activities (*AOR* 1.73; 95% CI 1.43, 2.09, $p<0.001$). Further, in comparison with peers, children with disabilities were 1.3 times less likely to participate in religious services (*AOR* 1.28; 95% CI 1.10, 1.48, $p<0.01$) and travel for vacations abroad (*AOR* 1.28; 95% CI 1.06, 1.54, $p<0.05$).

Multivariable logistic regression analysis further showed that children with disabilities were 2 times more likely to have lower frequency of participation in unstructured physical activities (*AOR* 2.41; 95% CI 1.95, 2.99, $p<0.001$), organized physical activities (*AOR* 2.29; 95% CI 1.83, 2.86, $p<0.001$) and religious gatherings (*AOR* 2.08; 95% CI 1.35, 3.20, $p<0.01$) compared to children without disabilities. They were also 3 times more likely to have lower frequency in getting together with friends (*AOR* 3.31; 95% CI 2.61, 4.20, $p<0.001$).

Explanatory factors that had significant independent contribution to participation frequency of children with disabilities varied across activity types. The factor that had a consistent negative effect on frequency of participation across three community-based activities was child psychosocial and behavioural problems. More specifically, children with disabilities with clinically significant psychosocial and behavioural problems were significantly less likely to have higher frequency of participation in organized physical activities (*Exp(B)* 071; 95% CI 0.57, 0.9, $p<0.01$), unstructured physical activities (*Exp(B)* 0.61; 95% CI 0.47, 0.8, $p<0.001$) and getting together with friends (*Exp(B)* 0.19; 95% CI 0.11, 0.33, $p<0.001$) compared to children with disabilities without any problems in social, emotional and behavioural domains.

Parental education, parental physical activity and parental play of physically active games with a child had an independent effect on frequency of participation of children with disabilities in physical activities. More specifically, lower parental educational attainment i.e. no formal UK qualification (*Exp(B)* 0.51; 95% CI 0.37, 0.72, $p<0.001$) and GCSE/equivalent (*Exp(B)* 0.64; 95% CI 0.50, 0.81, $p<0.001$) was negatively associated with participation frequency of children with disabilities in organized physical activities. Similarly, parental physical inactivity (parents who never engaged in physical activities/sports in the last 12 months or did it only once in the last 12 months) was negatively associated with participation frequency in organized physical activities (*Exp(B)* 0.64; 95% CI 0.49, 0.83, $p=0.001$). Further, parental lack of physical active play with a child (parents who never played sports or physically active games outdoors or indoors with their child) was negatively associated with frequency of participation in unstructured physical activities (*Exp(B)* 0.59; 95% CI 0.37, 0.94, $p=0.03$).

Ethnicity, family income and parental social support had an independent effect on participation frequency of children with disabilities in getting together with friends. As described in section 5.7, the measurement scale for this outcome had to be dichotomised ("Low" vs "High") because parallel odds assumption was not met in any of the multivariable ordinal models fitted. Based on binary logistic regression results

Mixed/ Other ethnic background was negatively associated with frequency of getting together with friends (*Exp(B)* 0.43; 95% CI 0.21, 0.89, p=0.02). Analogous results were obtained in regards to parental social support (*Exp(B)* 0.30; 95% CI 0.10, 0.88, p=0.03). Interestingly, family income was positively associated with frequency of getting together with friends but only for a group of children with disabilities who fall into the middle 20% of equalized family income (*Exp(B)* 3.45; 95% CI 1.44, 8.23, p<0.01). None of the community factors tested had an effect on frequency of participation of children with disabilities across the three outcomes of interest.

The sections to follow are the discussion of main findings from Study I and Study II in the context of current literature.

CHAPTER 6 – DISCUSSION

6.1 Introduction

The present doctoral research used two-stage of evidence inquiry – a systematic literature review (Study I) and secondary analysis of existing survey data (Study II) (a) to synthesize evidence on family factors consistently associated with the participation of children with disabilities; (b) to describe and compare the characteristics, family circumstances and community-based participation of a nationally representative sample of children with and without disabilities; (c) to identify the child, family and community factors independently contributing to participation frequency of a nationally representative sample of children with disabilities in community-based social and physical activities.

Chapter 6 has the purpose to discuss the findings from two studies within the context of current childhood disability participation literature. Section 6.2 of the chapter briefly reflects on findings of Study I (for more details refer to Chapter 3). This is followed by discussion of main findings and strengths and limitations of Study II in section 6.3. Chapter 6 concludes with a summary in section 6.4.

6.2 Brief discussion of Study I findings

Systematic evaluation of the literature resulted in 30 observational studies included in the review. Data extraction on family factors potentially linked to childhood disability participation facilitated the development of a taxonomy differentiating between two major groups and six subgroups of factors. Two major groups are (a) modifiable family "process" factors (what families experience and do), and (b) non-modifiable family "status" factors (who families are). Family process factors further distinguish between (1) "parental health and well-being", (2) "parental beliefs, perceptions and attitudes", (3) "parental behaviour", (4) "family resources" and status factors – (1) family socio-demographic factors and (2) family structure (Figure 8).

Each of these subgroups is a composite of a set of factors tapping into the underlying broader construct the group represents. For instance, family structure subgroup is a composite of four factors – (i) family type (single-parent vs co-parent family), (ii)

siblings number, (iii) older siblings and (iv) younger siblings. This taxonomy supplies a more sophisticated lens for looking at family factors contributing to participation and can be used as a foundation for advancing the ICF-CY's classification system for immediate family factors. This is discussed in more detail in upcoming section 7.2.1.

Using a "semi-quantitative" approach previously applied on other studies (Sallis et al. 2000; Li et al. 2016) (for details refer to Chapter 3), Study I has identified six "process" factors – parental mental and physical health functioning, parental self-efficacy beliefs, parental support, parental time, family preferences and activity orientation, and four "status" factors - parental ethnicity, parental education, family type and socio-economic status consistently associated with childhood disability participation. The direction of the effects of these factors however varied across disabilities and participation activity domains.

Literature has suggested that "status" factors predispose families with childhood disability to a variety of stressors. The manner in which families, more specifically parents interact and respond to these stressors may adversely affect parental health, their subjective perceptions and behaviour, family dynamics and overall family well-being. These processes can pose the risk to children's well-being and hinder their opportunities to participation.

Given that "status" factors are hard to modify, recommendations are made to focus on family "process" factors as primary targets of child/family-centred participation-promoting interventions. Key factors for interventions are parental mental and physical health functioning, parental self-efficacy beliefs, parental support, parental time and family preferences and activity orientation. Nevertheless, paediatric professionals are also encouraged to work closely with socio-economically disadvantaged and single-parent families to identify factors amenable to change. Improving parental access to information (e.g. informing families of low-cost or free of charge activities), community support programmes, financial service/schemes and childcare funds might ease the financial and time tension placed on disadvantaged families and help to support children's participation.

Study I has emphasized the role of family factors in shaping the participation of children with disabilities. It has provided a taxonomy of family factors potentially linked to participation and supplied evidence on "process" and "status" factors consistently associated with participation. The selection of family factors tested in relation to participation frequency of children with disabilities in physical and social activities in Study II was guided by this evidence and discussed within the sections to follow.

6.3 Discussion of Study II findings

6.3.1 Children's characteristics and family circumstances

Childhood disability is complex and contested (WHO 2011; UNICEF 2013). In this study, disability was operationalized in line with the definition provided in the DDA (1995) – a physical or mental health condition lasting or expected to last 12 or more months that reduces children's ability to carry out day-to-day activities. Using this definition, out of total 12,195 children aged 10-12 years included in this study, 1,073 (8.8%) had a disability (Table 14). Other UK-based studies and surveys reported childhood disability prevalence estimates ranging between 4.5% and 16.0% (Blackburn et al. 2010; Read et al. 2010). Therefore, the prevalence estimate provided here falls midrange. This might be partially attributed to definitions and measures of disability used across the studies. For instance, a previous study has found that a use of more inclusive measure of disability resulted in increased prevalence estimates by nearly two percent-age points and 250,000 children above the same data provided for the previous year (Blackburn et al. 2010). Age groups and time points childhood prevalence estimates were measured also might have played a part.

More than one-third of children with disabilities aged 10-12 had functional issues in learning, understanding and concentrating (Table 46). Thirty-two percent of children also had difficulties in socializing and behaviour (Table 46). These statistics parallel data provided by the UK DWP (2017) which suggests that socializing/ behaviour (42%) and learning/understanding (36%) are the most prevalent functional problems reported in children and adolescents with disabilities under the age of 18 (DWP 2017).

The high prevalence of these functional issues in the sample investigated might be indicative that many children with disabilities aged 10-12 had learning disabilities. Globally, learning disabilities are among the most frequently diagnosed developmental disorders in children (Abdullah 2018). According to UK National Health Service (2019) descriptions, a learning disability affects the way an individual learns and understands information and how they communicate with others; but it is distinct from intellectual disability (Abdullah 2018). Specific issues experienced by an individual with a learning disability include problems with concentration, information processing, organizational skills, social perception and social interaction (National Health Service 2019). Given this, it is of no surprise that nearly 50% of children with disabilities aged 10-12 in this sample had teacher-identified special educational needs.

Approximately two-thirds of children with disabilities were boys (Table 48). A significantly higher proportion of boys had issues with learning, understanding, concentrating, socializing and behaviour as well as mental health compared to girls with disabilities. A higher proportion of boys had psychosocial and behavioural problems and were identified with special education needs. An association between child sex and disability was also established in previous research and literature accounts from other cultural contexts (Blackburn et al. 2010, NCLD 2015; Abdullah 2018). A study found that two-thirds of children diagnosed with learning disabilities were boys (Abdullah 2018). Further, the US National Centre for Learning Disabilities (2015) found that a substantially higher number of boys (17%) aged 6-21 received special education services compared to girls (9%).

Many theories have been proposed to explain why more boys than girls are identified with learning and behavioural functional issues and special education needs (Gurian 2010; Quinn and Wagner 2015; Abdullah 2018). Biological vulnerability is one of the proposed explanations to this phenomenon (Gurian 2010; Abdullah 2018). Boys are more often born with or develop a tendency for learning or behaviour disorders early in life. Another theory is the differences in identification due to referral bias (Gurian 2010; Abdullah 2018). Boys are more likely to be referred for special education support when they have learning and behavioural difficulties than girls. Boys who

experience psychosocial problems or struggle with schooling tend to demonstrate greater behavioural challenges (Gurian 2010a; Abdullah 2018). They may present as hyperactive, impulsive, or display disruptive behaviour which makes them stand out (Gurian 2010a; Gurian 2010b; Abdullah 2018). Girls, on the other hand, may tend to show less obvious signs (Abdullah 2018). However, they are more prone to experience anxiety, depression, and low self-esteem (Abdullah 2018). Others argue that it is the absence of accurate, objective measures that contributes to inaccurate identification of functional problems in girls (Galaburda 2010; Gurian 2010b; Quinn and Wagner 2015; Abdullah 2018). Many measures are designed and standardized on samples containing higher proportions of boys (Galaburda 2010; Gurian 2010b; Quinn and Wagner 2015). These measures might not be sensitive to identifying problems specific to girls (Galaburda 2010). On the other hand, a study focusing on children with autism spectrum disorder (ASD) found that delays in the identification of functional issues in girls occur before to referral for specialist assessment through under-recognition (Rutherford et al. 2016). Therefore, under-recognition and under-identification of functional issues in girls by professionals, including teaching staff at schools, might explain why more boys are identified with a disability and/or psychosocial and behavioural problems than girls.

In this research, childhood disability was significantly more prevalent in socio-economically disadvantaged families (Table 48). Similar findings are reported in the literature (Emerson et al. 2006; Blackburn et al. 2010; UNICEF 2013). Several perspectives have been described to explain this association. The family investment model posits that family socio-economic status is tightly associated with child development (Conger and Donnellan 2007). This is because families from higher SES have greater access to financial (e.g. income), social (e.g. occupational status), and human (e.g. education) capital (Conger and Donnellan 2007). The investment of financial, social and human resources by families is linked with the positive development of children and their overall well-being (Conger and Donnellan 2007). For instance, financial capital (income) allows families to purchase goods, experiences and services that directly contribute to child development. A lack of financial capital affects the amount and quality of material investment in children, including the

provision of optimal nutrition and household living conditions (Conger and Donnellan 2007). Growing up in suboptimal household conditions puts children at risk for developmental difficulties (Conger and Conger 2002; Gershoff et al. 2007). Developmental difficulties, on their own turn, might manifest in a range of pervasive behavioural problems (Neppl et al. 2016). Therefore, children living in socio-economically disadvantaged circumstances are at greater risk for developmental delay, or early onset of health conditions and associated disability (WHO 2011, UNICEF 2013).

Others argue that direct costs associated with childhood disability are high and many families have to outlay additional resources (i.e. financial, time, support) to effectively care for and support their children (WHO 2011). To meet care commitments, some parents are unable to participate in employment. Indeed, the annual cost of bringing up a child with a disability is three times higher than that of a child with no disability (Smith 2016). Unemployment, especially among mothers, is significantly higher in families with childhood disability compared to those without childhood disability (DWP 2014). In this research, nearly 50% of the main carers were unemployed. Some evidence suggests much higher proportions (DWP 2014). The strain of living in economic disadvantage, including material deprivation accompanied by the high costs of caring for and supporting children with disabilities, creates conditions of financial hardship for families (WHO 2011; UNICEF 2013).

Although the associations between financial disadvantage and childhood disability are well researched, there is a lack of explicit evidence about what contributes to what. Is it a growing lack of resources (money, time, support, social exclusion, inadequate health-related services) that predispose families with childhood disability to economic and social disadvantage? Or is it a persistent sub-optimal fit between a child's positive developmental needs and a family's disadvantaged circumstances (lack of resources and opportunities, suboptimal nutrition and household living conditions) that contributes to the development of health conditions and associated disability? The answer to this probably lies in both.

In the current study, the odds of living in single-parent households were substantially higher for children with disabilities and this association persisted after adjusting for key confounders (Table 48). Similar results are described elsewhere (Blackburn et al. 2010). Much research looked at the associations between marital status and childhood disability (Fertig 2004; Kulcycki 2007; Urbano and Hoddapp 2007; Blackburn et al. 2010). Much of these research, however, focused on parental relationships when a child is diagnosed with a health condition at or shortly after birth (Fertig 2004; Kulcycki 2007; Urbano and Hoddapp 2007). A US study has found a strong relationship between delivery of a very low birth weight baby and marriage break up (Kulcycki 2007). According to this study, 10% of these marriages broke up within an 18 month post-birth period, compared to 1% of other marriages in the same period (Kulcycki 2007). No differences in the probability of marriage break up were found in the period after 18 months. An earlier study comparing rates of divorce in families with childhood disability between the US and the UK found conflicting results (Fertig 2004). The likelihood of marriage break-up was high in families with children having low birth weight and chronic health conditions in the US (Fertig 2004). However, these findings were not replicated on the UK-based data (Fertig 2004). No differences in divorce rates between families which have a child with Downs's syndrome or birth defect and those with no child health issues were reported elsewhere (Urbano and Hoddapp 2007). There is some evidence to suggest that a higher proportion of single (or lone) parents, particularly mothers, who are separated or divorced live in families with multiple childhood disability (Hoxhallari et al. 2007). Therefore, it might be that apart from a child's health status other factors, e.g. presence of siblings with a disability, low income, and social deprivation may play part in this association (Hoxhallari et al. 2007; Blackburn et al. 2010).

Caring for a child with a disability is difficult (Reichman et al. 2008; Contact a Family 2012). Rearing a child as a single parent is perhaps even more challenging (Langerman and Worrall 2005; Contact a Family 2012; UNICEF 2013). Single-parent households are more likely to experience socio-economic strain than co-parent households, which is mainly down to unemployment (DWP 2014). As many as 36% of single-parent households with dependent children have no adult in employment, compared to 5% in

co-parent households (DWP 2014). Further, evidence suggests that the likelihood of parental poor health and presence of longstanding conditions are much higher in single-parent households compared to co-parent households (Burström et al. 2010). Rearing a child with a disability in the context of health and socio-economic disadvantage can amplify the tensions put on single-parent households and might be a cause of serious parental mental distress. This might be one of the reasons for the observed higher prevalence of mental health functioning problems in families with childhood disability in this study.

As mentioned above, children with disabilities were significantly more likely to be from families with parental mental health problems (Table 48). Previous research has reported higher levels of parental mental distress and negative psychological effects in families with childhood disability (Yirmiya and Shaked 2005; Singer 2006; Contact a Family 2012; Hayes and Watson 2012; Smith and Grzywacz 2014). The complexity of the child's health condition and associated behavioural difficulties, caregiving responsibilities and social isolation are some of the proposed explanations to this (Yirmiya and Shaked 2005; Singer 2006; Contact a Family 2012; Hayes and Watson 2012; Gallagher and Hannigan 2014; Smith and Grzywacz 2014). For instance, evidence collected from the UK families with childhood disability (n=1,148) suggests that nearly 65% survey respondents identified feelings of social isolation which was mainly due to (1) a lack of support from social care and educational services, (2) lack of family resources, especially financial resources, and (3) experience of stigma (Contact a Family 2012).

In this research, children with disabilities were nearly 2.5 times more likely to live in families with the presence of parental longstanding illness (Table 48). This finding is in parallel with results of a recent systematic review which found that parental (maternal) health was poorer in families with childhood disability compared to families with no childhood disability (Miodrag et al. 2015). Literature also suggested that main caregivers of children with disabilities frequently experience poor-health related symptoms including chronic fatigue and sleep deprivation (Murphyet al. 2007),

poorer physical health (Brehaut et al. 2009), and poorer perceived health-related quality of life (Allik et al. 2006; Brehaut et al. 2009).

The results of this research and available literature suggest a link between childhood disability and parental poor mental and physical health functioning. Nevertheless, it is yet to be explored whether parental health problems precede or are triggered or exacerbated by stressors related to having and/or caring for a child with a disability (Blackburn et al. 2010).

6.3.2 Children's participation in community-based activities

Participation is a complex construct (WHO 2007). Definitions and measurements vary; there is no universal acceptance of how participation should be operationalized and assessed (Coster and Khetani 2008; Whiteneck and Dijkers 2010; Dijnerk 2010; Maxwell et al. 2012). Therefore, any study of participation requires a clear conceptualization of the construct, aspects and dimensions measured (Dijnerk 2010; Whiteneck and Dijkers 2010; Maxwell et al. 2012; Imms et al. 2016). Further, clear distinctions should made about the setting and a group of people among whom it is measured (Coster and Khetani 2008; Maxwell et al. 2012).

In this research, children's participation in community-based activities was defined as a child's attendance at formal and informal everyday activities in the out-of-school community environment, including play, sport, entertainment and religious expression. Participation items were selected from the MCS5 based on the literature review and completed by a matching exercise with the PEM-CY (Coster et al. 2012). To have a clear understanding of the profile of participation of children with disabilities aged 10-12, comparisons were made with the participation profile of children without disabilities aged 10-12. This approach is in line with the WHO's descriptions that only by comparing an individual's participation profile to that is expected of an individual without disability in a specific cultural context can one generate reliable evidence on participation restrictions (WHO 2001). The aspect of community-based participation measured was attendance or "being there" (Imms et al

2016) quantified as (1) “Never Participated” vs “Participated”, (2) diversity (the range or number of activities the child participated in), and (3) frequency.

Although measured to gain a more complete understanding of children’s participation, the two quantifiers of attendance – “Never Participated” vs “Participated” and diversity (which is calculated based on the former one) – are “rough measures” of participation. This is because the category “Participated” includes all the children who attended the activity even on a low-frequency level. This is a reason the effect of the child, family and community factors on participation was examined with respect to the frequency quantifier only.

Findings obtained by Study II suggested that the patterns of participation (the ranking of proportions for participation across six community-based activities) in six community-based activities were similar for children with and without disabilities (Figure 15). Children in both groups were more inclined towards participation in activities that were unstructured and spontaneous in nature such as e.g. getting together with friends, unstructured physical activities. These results are echoed in studies comparing community participation of children with and without disabilities in other cultural contexts (Hilton et al. 2008; Bedell et al. 2013; Sheild et al. 2015). Higher prevalence of participation in social activities by children in both groups might be indicative of a desire to develop friendships and gain independence from the family (Berger 2008). It might also suggest a preference for activities that are easy to participate in and do not require following specific structures and routines (Berger 2008). Traveling for vacations abroad had the highest proportion of children who never participated in both groups. However, vacations aboard strongly correlate with the availability of family resources. A lack of financial and time resources might be some of the reasons behind this finding.

The average diversity scores obtained for the two groups were close as well (Figure 16). Children in both groups participated on average in four activities out of possible six. These findings are consistent with the results of a study comparing the diversity of participation of children with intellectual disabilities and ASD with that of children

without disabilities (Solish et al. 2010). These findings, however, contradict the results of a pool of other studies and review findings suggesting that children with disabilities participate in a narrower range of activities, spend more time at home in solitary activities compared to peers with no disability (Hilton et al. 2008; Imms et al. 2008; Orlin et al. 2010; Tonkin et al. 2014). It should be noted, however, that most of the studies which established differences in participation diversity measured the average diversity score in a wider number of activities. It might be that the observed results are down to a number of activities included in this study. Further, average diversity score is a "rough measure" of participation. It tells little about the extent to which children participate in each activity.

When participation in each community-based activity was compared between the two groups, it became clear that children with disabilities had more restricted participation compared to peers (Table 50). The highest restriction in participation was in relation to getting together with friends, which did not change after controlling for child sex and family socio-economic status. These findings should alert paediatric professionals, local authorities and policy-makers. Getting together with friends assumes social interaction – a valuable experience offering numerous benefits for children (Barr and Shields 2011; McGarty et al. 2018). Social interactions support children's social, emotional, and intellectual development and help children to build their self-esteem and confidence (McGarty et al. 2018). Social interactions can facilitate lasting friendship formation and social inclusion (Barr and Shields 2011). Social interactions and connectedness help children to develop social capital – the social, cultural, and material resources that an individual obtains and builds upon to help them in various circumstances and settings throughout their lives (Holland et al. 2007). Social capital is likely to develop from frequent social interaction with friends and peers when pursuing a common goal or activity (Holland et al. 2007).

Social interactions, therefore, should be actively promoted among children with disabilities. Having said that, the importance of quality over quantity should be carefully considered (Rosenbaum and Gorter 2012). A study established that hanging out with friends has been associated with negative outcomes in children, but is

essential for healthy development if oriented towards more meaningful group activities, such as going for a walk together or hiking with friends (Caldwell and Witt 2011).

On the other hand, social interactions with friends have been shown to be a powerful motivator for physical activity (Barr and Shields 2011) and encouraging children to engage in physical activities more regularly (Barr and Shields 2011; McGarty et al. 2018). This is important given the findings of this study that children with disabilities had greater restrictions in participation, including lower frequency of participation in UPHA and OPHA compared to peers with no disabilities. Restriction in physical activity indicates a higher likelihood of sedentary behaviours in children with disabilities. Although the prevalence of obesity in children with disabilities was not measured in this research, the link between sedentary behaviours and obesity has been well-established (Karnik and Kanekar 2012). If children are overweight or have obesity, their obesity and mental health problems in adulthood are likely to be more severe (Bass and Eneli 2015).

Further, findings of this study have shown that children with disabilities were less likely to participate in physical activities with a higher frequency compared to children without disabilities (Table 52). To gain clinically meaningful health benefits from physical activity, children should participate in moderate physical activity for at least 60 minutes every day, and in vigorous physical activity (such as organized sports) 3 days a week (NHS 2018). Only 19% of children with disabilities participated in OPHA with high frequency compared to 32% in children without disabilities. This implies that children with disabilities did not participate in sufficient vigorous activity to gain meaningful health benefits. This is of particular concern given evidence that children with disabilities are inclined to anxiety disorders and reduced cardiorespiratory and muscular function (Oeseburg et al. 2011).

Increasing levels of participation in UPHA and OPHA in children with disabilities should be an important consideration given strong evidence that (1) these activities have numerous physical and mental health benefits (Ahn and Fedewa 2011; Biddle

and Asare 2011; McGarty et al. 2018), and (2) children with disabilities are generally less physically "fit" than other children (van Brussel et al. 2011; McGarty et al. 2018) and less "fit" than they should be (van Brussel et al. 2011). Unstructured physical activities are spontaneous in nature, i.e. they are usually in the form of self-selected free play. Unstructured physical activities assume the active movement of any kind which is central for strengthening children's balance, self-esteem, confidence and coordination. Unstructured physical activities also promote social interaction, hence, they are seen as important for friendship formation. Participation in OPHA positively contributes to a child's gross motor, cardiovascular and respiratory systems development, mental health functioning (Ahn and Fedewa 2011) and overall fitness (McGarty et al. 2018).

6.3.3 Factors contributing to participation frequency in organized physical activities, unstructured physical activities and getting together with friends

As described in section 4.9.3, the selection of child, family and community factors tested in models in relation to participation frequency of children with disabilities aged 10-12 years in OPHA, UPHA, and GTF was guided by the ICF-CY framework, literature review, the findings of Study I and availability of variables in the MCS5 (for details refer to Figure 13). Family factors tested in the models were family "status" factors – ethnicity, parental education, family type and family (equalized) income and family "process" factors – parental longstanding illness, parental mental health functioning, parental social support, parental play of physical active games with a child, parental play of indoor games with a child, parental physical activity and parental time. Based on the logistic regression results, the factors independently contributing to participation frequency of children with disabilities in OPHA, UPHA, and GTF were:

- child psychosocial and behavioural problems,
- ethnicity,
- parental education,
- family (equalized) income,
- parental physical activity,

- parental play of physically active games with a child
- parental social support.

The factor that had a consistent negative effect on frequency of participation across three community-based activities was child psychosocial and behavioural problems. Parental education, parental physical activity and parental play of physically active games with a child had an independent effect on frequency of participation of children with disabilities in organized physical activities and unstructured physical activities. Ethnicity, family income and parental social support had an independent effect on participation frequency of children with disabilities in getting together with friends. Figure 18 graphically presents a link between the findings of Study I and Study II.

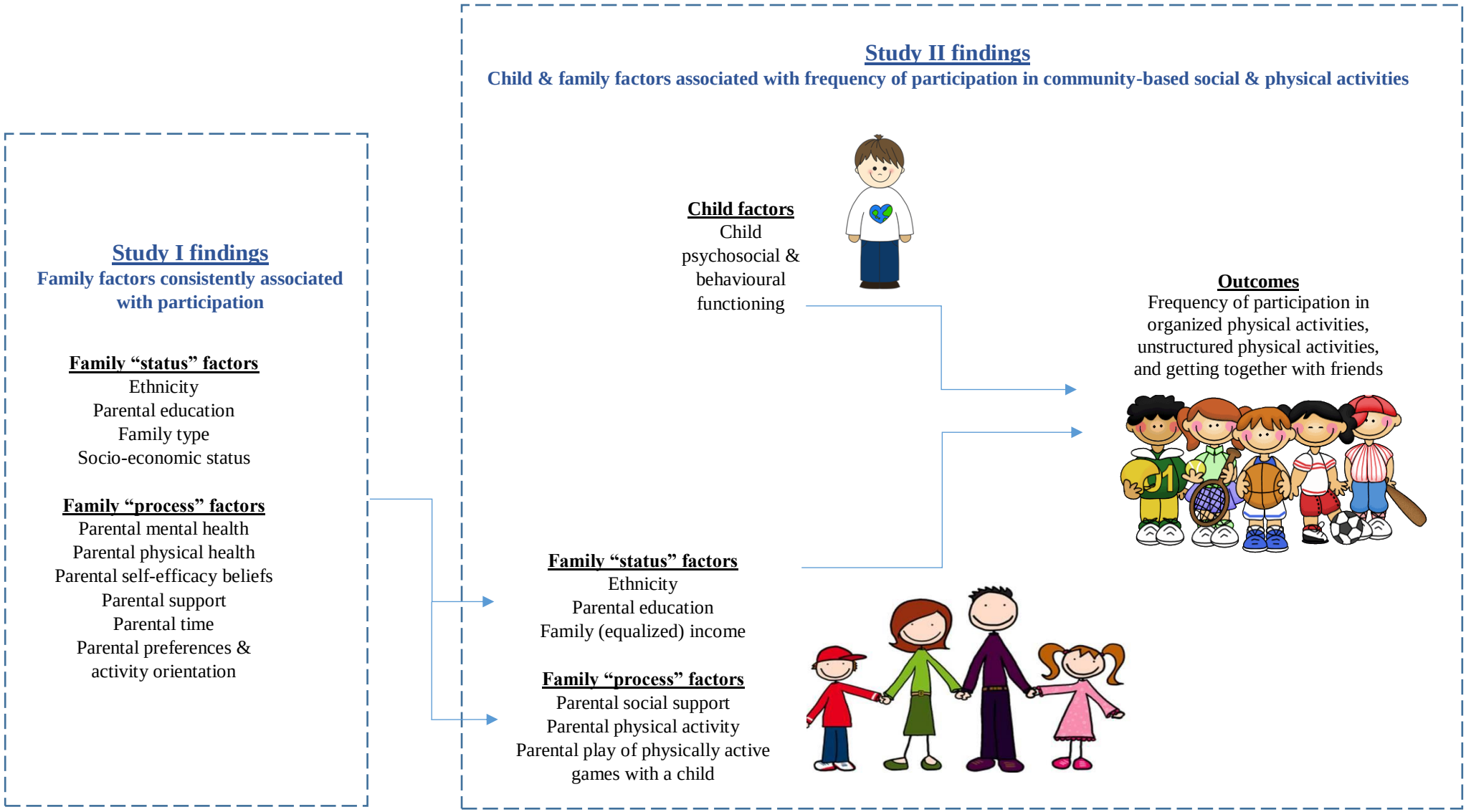

Figure 18. An infographic depicting a link between the findings of Study I and Study II

Child psychosocial and behavioural functioning

In this research, child psychosocial and behavioural problems were assessed based on the degree of difficulties experienced by the child in social, emotional and behavioural functioning using the total difficulties scores generated for a standardized, parent-report Strengths and Difficulties Questionnaire. Child psychosocial and behavioural problems were negatively associated with the participation frequency of children with disabilities in GTF, UPHA and OPHA. The magnitude of the unstandardized B coefficient for abnormal psychosocial and behavioural problems ranged from -1.66 to -0.29. The largest effect was on frequency in GTF, whereby children with abnormal psychosocial and behavioural problems were 81% less likely to have a high frequency of getting together with friends compared to children with disabilities with no psychosocial and behavioural problems. The lowest effect was on frequency of participation in OPHA, whereby children with abnormal psychosocial and behavioural problems were 29% less likely to have a high frequency of participation in OPHA compared to children with disabilities with no psychosocial and behavioural problems.

These findings echo the results of other studies which also found that participation of children and adolescents with and without disabilities in out-of-school activities was associated with child psychological and behavioural functioning (Bartko and Eccles 2003; Sebire et al. 2011; Ramstad et al. 2012). They also parallel the findings of cluster analysis by King and colleagues (2010) who established that differences in participation profile of children with physical disabilities in out-of-school leisure and recreational activities were not associated with a type of health condition or level of physical or communicative functioning but emotional, behavioural and peer difficulties (as measured by the SDQ). More specifically, King et al. (2010) established that children with physical disabilities who displayed the lowest intensity of participation in physical and skilled-based activities had low levels of activity enjoyment, the weakest preferences, the highest level of psychosocial and peer problems (King et al. 2010). They also had the lowest level of self-perceived social acceptance and athletic competence and lowest perceived peer support (King et al. 2010). In contrast, those who participated with the higher intensity, especially in social

activities (clustered as "social participators") were children with low levels of peer problems, the highest self-perceived social acceptance and athletic competence, and the highest perceived peer support (King et al. 2010).

There is evidence to suggest that children with disabilities, especially those who have higher levels of functioning, tend to be more susceptible to negative self-comparisons with peers without disabilities – so-called "internalized stigma" (Hunt 2009), thus experiencing greater negative psychosocial consequences (Crocker and Major 1989). These experiences may contribute to a negative sense of self, higher self-criticism, lower perceived activity competence and lower perceived levels of social support (Bandura 1997; Hunt 2009). These feelings may make children anxious, less interested in participating in activities and result in social withdrawal. Therefore, these feelings contribute to reduced levels of participation in out-of-school activities, especially in socially inclined activities (Hunt 2009, King et al. 2010).

The concepts described above tap into intrapersonal or the intrinsic child-related concepts related to participation - activity competence, sense of self and preferences (Imm et al. 2016). According to Imms et al. (2016), activity competence, sense of self and preferences influence future participation and are influenced by past and present experiences with participation. Activity competence is an ability to perform an activity to an expected standard and involves cognitive, physical and emotional skills and abilities (Imms et al. 2017). A sense of self is linked to one's perception of self – perceived confidence, satisfaction, self-esteem and self-determination (Imms et al. 2016). A sense of self facilitates participation through helping to engage, but it is also formed by one's experience with participation (Csikszentmihalyi and Seligman 2000).

More specifically, sense of self is associated with: (i) the past experience of participation and resulting feelings from failure or success, (ii) the current experience, e.g. feeling of happiness, engagement and flow from participation, and (iii) the future experience, e.g. self-determination, perceived self-efficacy beliefs and independence (Csikszentmihalyi and Seligman 2000; Ryan and Deci 2001, Imms et al. 2016; Imms et al. 2017). Future directed experiences, such as self-efficacy beliefs and autonomy,

have been established as key drivers of participation of children with chronic health conditions (Almqvist and Granlund 2005; Clarke et al. 2011). Those are thought to be stronger predictors of future participation than concepts related to past experience (Gustafsson et al. 2010; Imms et al. 2017). Preferences are interests or activities that have a value for an individual (Imms et al. 2016). They may predict behaviour at both personal and a broader cultural or societal levels (Gustafsson et al. 2010; Imms et al. 2016) Preferences are developed through social interactions, past experiences of failure or success and perceptions associated with participation in a particular setting (Anderson and Fulton 2008). Preferences (e.g. interest, motivation) are thought to be both predictors and outcomes of participation (Bult et al. 2014; Imms et al. 2017).

Imms et al. (2017) further argue that it is "self-regulatory" processes within a child that "glue" intrinsic child-related concepts associated with participation together. In other words, self-regulatory processes mediate the relationships between child's activity competences (e.g. skills), sense of self (e.g. self-efficacy), preferences (e.g. interest, motivation) and participation, therefore should be key targets of participation-supporting interventions (Imms et al. 2017).

Imms et al. (2016, 2017) argumentation only partially overlaps with key postulates of behaviour science literature suggesting that behaviour change interventions focusing on personal factors (e.g. changing beliefs and intentions, increasing motivation) are less likely to be effective than those targeting primarily environmental factors (Greves et al. 2011; Rhodes and Dickau 2012). For instance, a meta-analysis of evidence looking at a link between child motivation and participation in physical activities established a weak relationship which was below meaningful or practical value (Rhodes and Dickau 2012). In a systematic review of reviews of the effectiveness of physical activity promoting interventions, increased effectiveness was associated with a specific cluster of "self-regulatory" behaviour change techniques such as short-term goal-setting and self-monitoring (Greves et al. 2011).

Family "status" factors

Ethnicity

Ethnicity is understood as a common nationality or language shared by a group of individuals (Case-Smith and O'Brien 2015). It tends to be a broad concept and many people may identify themselves as belonging to multiple ethnic groups. In this study, the effect of ethnicity on participation frequency was assessed based on a derived, nominal response variable which distinguished between four groups of children with disabilities corresponding to Mixed/Other ethnic group, Black/Black British, Indian/ Pakistani/Bangladeshi or White. Results of the participation frequency predicative models showed that children with disabilities from Mixed/Other Ethnic Groups were substantially less likely to have a high frequency of GTF compared to children with disabilities who were from a White ethnic background.

There is a wide heterogeneity between families belonging to different ethnic groups (WHO 2011; Case-Smith and O'Brien 2015). Therefore, experiences, needs and circumstances of families and children with disabilities will differ across ethnic groups (WHO 2011). However, only a limited pool of studies has looked at the relationship between ethnicity and childhood disability participation. This might be due to a lack of representative samples from ethnic minority groups in White-dominated populations studied. On the other hand, families might identify themselves as belonging to multiple ethnic groups, making it harder for researchers and paediatric professionals to evaluate the effect of ethnicity in relation to childhood disability participation as well as guide how professionals work with families (Case-Smith and O'Brien 2015).

Available empirical evidence, however, suggests the presence of an association between ethnicity and childhood participation (King et al. 2010; Houtrow et al. 2012). In previous research being Hispanic was linked to reduced participation in organized activities (Houtrow et al. 2012). King et al. (2010) established that children who had a high intensity of participation, especially in organized physical and skilled base activities, were more likely to be Caucasian ethnicity rather than other ethnic groups. They also enjoyed participation and had a higher self-perception of activity competence (King et al. 2010).

There is evidence to indicate that ethnic minority groups living in the UK face substantial disadvantages, material, social deprivation and discrimination (Equality and Human Rights Commission 2016). It is, therefore, possible that due to experience of family disadvantage or recognition of inherent ethnic diversity, children with disabilities from Mixed/Other Ethnic backgrounds feel less confident and/or less able to develop and sustain social relationships. Cultural values, role expectations, habits and language differences might place additional challenges on children and serve as barriers to participation (Anaby et al. 2013). Differences in understanding and definitions of what constitutes "healthy" and what "having a disability" are present among ethnic groups (Case-Smith and O'Brien 2015). Families' and children's vision of what is expected and how children with disabilities are perceived in a broader society might differ as well. Perceived negative attitudes of peers in the community and inadequate competencies in social interactions can lead to a change in a choice of activities for children from Mixed/Other Ethnic backgrounds. Nonetheless, these are only speculations that require further examination. Exploring children's own perspective on social barriers to community-based participation is needed to have more accurate information from and about mixed and minority ethnic communities to better support children's needs.

Parental education

In this research, parental education was measured based on the UK Government equivalents for the highest education qualification archived according to NVQ classification. Results have shown that lower levels of parental educational attainment (i.e. no formal UK qualification, GCSE/equivalent) were significantly associated with lower odds for a higher frequency of participation of children with disabilities in OPHA. The effect of parental education was most prominent at the level of no formal UK qualification, whereby children with disabilities with a parent having no formal UK qualification were nearly 50% less likely to have a higher frequency of participation in OPHA compared to ones with a parent having university degree or equivalent.

These findings echo the results of many studies which establish positive relationship between parental education and children's participation (Law et al. 2006; Ullenhag et al. 2012; Engel-Yeger and Hamed-Daher 2013; Rosenberg et al. 2013; Ullenhag et al. 2014; Marquis and Baker 2015). These results, however, contradict findings of other research which established either negative associations, (Axelsson et al. 2013; Soref et al. 2012) or no significant associations (Dunn et al. 2009; Palisano et al. 2011; Tan et al. 2016) between parental education and childhood disability participation. Nonetheless, studies which evaluated the effect of parental education in respect to participation of children with disabilities in organized physical activities or sports established consistent associations with both intensity of participation and diversity (Ullenhag et al. 2012; Ullenhag et al. 2014; Marquis and Baker 2015).

Children's participation in organized physical activities and sports, therefore, is inevitably linked with the level of parental education. Parents who peruse higher or continued education have better awareness about the importance and value of active physical activities for a child's motor skills development as well as enhancement of physical health and general fitness (Case-Smith and O'Brien 2015). They are more likely to incorporate new ideas about a healthy lifestyle including participation in OPHA into their lifestyle (Case-Smith and O'Brien 2015). Previous empirical research also suggests that parents with higher education have a better awareness of possible opportunities for children's participation and are more competent in using various channels of social media to locate and access community resources (King et al. 2003; Klass et al. 2010).

Studies have shown that differences in the quality of parent-child interactions are associated with the level of parental educational attainment (Bradley et al. 1991; Bornstein and Bradley 2014). Parents with lower or limited education might not be as responsive to children's needs, provide them with fewer learning and developmental opportunities, and have limited engagement in interactive developmental activities (Case-Smith and O'Brien 2015). They may lack the skills and opportunities to gain key knowledge about the role of organized physical activities and sports in promoting children's health and well- being. They may be unaware of how or have no/limited

means and financial resources to pay for sport clubs/classes that offer participation in OPHA. Paediatric professionals need to be mindful of these issues when working with families from disadvantaged social backgrounds. They might need to find a sensible balance between what can be done to help these families through direct service provisions, and what these parents can do themselves to support their children's participation.

Family income

In this study, family income was measured based on a modified OECD equalized scale as it takes into account the size and composition of the family. Results suggested that children with disabilities from the middle quintile of equalized family income were substantially more likely to have a higher frequency in GTF than children with disabilities from the top quintile of equalized family income. This finding contradicts literature which suggests that higher family socio-economic well-being is associated with children's more intense participation in leisure and recreational activities (Imms et al. 2009; McCormack et al. 2011; Anaby et al. 2014; Cavallo et al. 2015). Nevertheless, there is also evidence to suggest that family income is positively associated with diversity (Rosenberg et al. 2013; Shields et al. 2015) but negatively associated with the intensity (average frequency) of children's participation (Rosenberg et al., 2013).

Higher family income assumes better availability of financial resources that could be used to pay fees for various after-school classes/clubs or leisure and recreational activities. Families with childhood disability which are better-off financially might have more structured daily routines that involve organized activities and after-school classes. Families which are financially less secure might find it challenging to pay registration fees for after-school classes and/or drop off their children several times per week for classes. Therefore, children with disabilities from financially less secure families might be inclined to participate more frequently in unstructured activities, such as playing with friends, which do not incur financial consequences. Further research is needed to shed light on this association.

Family "process" factors

Parental physical activity

The frequency of parental engagement in physical activities was associated with children's participation frequency in OPHA. In this research, parental physical activity was measured based on parental response to how often they play sports, swim, run, dance attend exercise classes or go to the gym. Children with disabilities whose parents were not physically active (i.e. did not play sports or do any physical activity within the last 12 months) were 36% less likely to have a higher frequency of participation in OPHA compared to children whose parents were engaged in physical activities often.

Previous research has identified the physical activity levels and beliefs of parents and siblings about the importance of OPHA contribute to the participation of children with disabilities in those activities (King et al. 2003; Barr and Shields 2011, Grandisson et al. 2012). Parents who participate or engage in physical activities themselves tend to promote similar participation for their children with disabilities (King et al. 2003; Living 2006). Descriptive data provided in Appendix G resonates with those descriptions. In this study, more than one-third of children with disabilities whose parents engaged in physical activities often participated in organized physical activities with a high frequency. Meanwhile, nearly 50% of children with disabilities whose parents never engaged in physical activities had a low frequency of participation in organized physical activities themselves. Children's participation in OPHA and sports is therefore linked with parental actions and behaviour (King et al. 2003; Living 2006; Barr and Shields 2011; Grandisson et al. 2012).

The link between parental physical activity engagement and children's participation in OPHA established in this and other studies (King et al. 2003; Living 2006; Barr and Shields 2011) partially overlaps with key postulates of the Social Cognitive Theory (SCT) – a theory widely used in public health promotion interventions (Bandura 2001). According to the SCT, learning of behaviour occurs in a social context with a dynamic and reciprocal interaction between the person, social environment and behaviour (Bandura 2001). A basic premise of the SCT is that people learn not only through their own experiences but also by observing the behaviour of others and the results of those

behaviours (Bandura 2001). Observation of a successful demonstration of healthy behaviour tends to result in a reproduction of observed behaviour (Bandura 2001). By putting this premise in the context of this study, it appears that on one hand, parents who participate in OPHA and sports themselves would be more inclined to initiate and encourage their children's participation in OPHA – "social reinforcement". On the other hand, children who live in a family environment where participation in OPHA is part of the routine would be more included to participate in OPHA themselves through "observational learning" and "modeling" observed healthy behaviours.

Parental play of physically active games with a child

The frequency with which parents play physically active games with a child indoors and outdoors had an independent effect on children's participation frequency in UPHA. Children with disabilities whose parents never played physically active games with them were 41% less likely to have frequent participation in UPHA. This finding supports the earlier description provided in the literature review chapter on the central role of supportive family environments in influencing participation by creating and providing children with opportunities and experiences (King et al. 2006; Law et al. 2006; Palisano et al. 2011).

Families are diverse; the individual parenting practices (i.e. goal-directed activities parents do in raising their children) will differ among families with childhood disability (Case-Smith and O'Braien 2015). Some parents may actively engage with children to support their participation in physical activities. Other parents might commission this responsibility to a school or after school clubs/classes. Some parents might have a desire to engage in shared physical activities with their children, but tensions/stresses might be running high or skills might be lacking. There are no clear-cut rules on parenting practices (Case-Smith and O'Braien 2015). What is clear, however, is that parenting practices that are supportive, responsive and provide structure and learning opportunities are associated with better children developmental outcomes (Case-Smith and O'Braien 2015).

Ensuring family time for unstructured physical activity both through home-based indoor activities and outdoor activities is therefore important. Given that some families might wish to facilitate their children's participation in physical activities but lack skills on how those activities should be conducted (Menear 2007), empowering families and providing practical support on these issues should be an important consideration.

Parental social support

The frequency with which parents talked to their child about things that are important to them was associated with the frequency of GTF. Children whose parents never talked about things that are important to them were 70% less likely to have a higher frequency of participation in GTF compared to children whose parents talked about things important to them often. Relationships between parental social support and participation have been established in previous research (Law 2002; King et al. 2006; King et al. 2007; Colver et al. 2012; Kamath et al. 2016). Parental support positively influences participation in social activities and fosters friendship formation (Law 2002; King et al. 2007). Results of a multicenter European study (Colver et al. 2012) suggested that supports at home and positive attitudes of peers and teachers at school were positively associated with increased participation of children with cerebral palsy in responsibilities and recreational activities. Similarly, greater support from family was associated with the frequency of participation of children with physical disabilities in informal leisure and recreational activities (King et al. 2006).

The ability to socialize is a socio-cognitive skill enabling one to experience thought, intentions, and information (Beauchamp and Anderson 2010). In a way, it determines "the quality of our social relationships" (Beauchamp and Anderson 2010, p.49). Parental social support, on the other hand, is a psychosocial concept (Martikainen et al. 2002) which is associated with both family cohesive relationships (King et al. 2006) and better child psychosocial well-being (Turner 1981). Greater parental social support will be associated with positive family dynamics (Case-Smith and O'Braien 2015) and, therefore, better child psychosocial well-being and better participation in social relationships. This is in line with evidence suggesting that children with disabilities

have a higher frequency of participation when they have more supportive parents and when family members help and support one another (King et al. 2006).

A child develops as a result of complex and ongoing positive interactions between parenting style and practice (Case-Smith and O'Braien 2015). Having this in mind, professionals might try to support and empower parents on the importance of positive family dynamics and family cohesive relationships so that family resources such as time and energy are available for engaging in shared social activities.

6.3.4 Factors not contributing to participation frequency in organized physical activities, unstructured physical activities and getting together with friends

The frequency of participation in physical activities and getting together with friends was not associated with child sex. These findings contradict results of previous research which found that child sex determines patterns of participation for recreational, social and physical activities with boys being more inclined to participate in activities which were physical in nature and girls in non-physical (Law et al. 2006; Ullenhag et al. 2012 King et al. 2013). In studies where child sex was one of the key determinants of frequency of participation in leisure and recreational activities, child preferences and behaviour were important mediating factors (Law et al. 2006; King et al., 2013). Child preferences were not measured in this study, whereas psychosocial and behavioural functioning was. Boys with disabilities had significantly higher odds for clinically significant psychosocial and behavioural problems compared to girls, and clinically psychosocial and behavioural problems had a consistent negative effect on the frequency of participation in physical activities and getting together with friends. Given these interpretations, it seems logical that child sex would have little influence on participation frequency in physical and social activities in the presence of clinically significant (abnormal) psychosocial and behavioural issues.

Opposite to findings of previous research, family type (Law et al. 2006; Hauthrow et al. 2012; Ullenhag et al. 2014; Kamath et al. 2016), parental longstanding illness (King et al. 2009; Oates et al. 2011), parental mental health functioning (Imms et al. 2008; Majnemer et al. 2008; Parkes et al. 2010; Bult et al. 2013;) and parental time (Oates et

al. 2011) did not contribute to participation frequency of children with disabilities in three activities of interest.

Although the systematic review completed in the scope of this research identified that these family factors are consistently associated with childhood (defined as ages 5 to 12) disability participation, it also concluded that the effects of family factors vary as a function of disability type, participation dimensions and settings measured. It might be that these factors are important for determining other aspects of participation in different activities/settings and among children with disabilities of different age groups. Therefore, further population-level studies are needed to shed light on the predictive power of these family factors in the participation of children with disabilities.

Neither the type of the area to raise the child nor the presence of parks/playgrounds for a child to play were factors independently contributing to the frequency of participation in physical activities and getting together with friends. Significant associations, however, were established in univariable analysis. The type of area to raise the child was positively associated with participation frequency in organized physical activities and getting together with friends. In other words, children from more disadvantaged neighbourhoods were less likely to have a higher frequency in organized physical activities and getting together with friends. The presence of parks/playgrounds for a child to play was positively associated with the participation frequency in unstructured physical activities. These associations, however, did not hold true after controlling for other covariates.

Evidence has shown that if community environment is not available, easily accessible or safe children with disabilities might be less inclined to community-based participation (Colver et al. 2012; Anaby et al. 2013; Cavallo et al. 2015). The findings of this study only partially supported this evidence. It should be noted, however, that literature emphasizing the importance of physical aspects of community environments in shaping participation was most pertinent to children with physical disabilities (Colver et al. 2012; Anaby et al. 2013). Meanwhile, a study looking at factors

influencing participation of children with cerebral palsy has shown that type of community did not explain the frequency in participation in the presence of a child's functioning problems and temperament (Imms et al. 2009). Sharing some similarities with findings by Imms et al. (2009), the results of this study have shown that community factors did not explain the frequency of participation of children with disabilities in physical and social activities in the presence of clinically significant psychosocial and behavioural problems and aspects of family context. These results highlight the potential importance of child/family-centred approach in fostering children's participation in community-based physical and social activities.

6.3.5 Study strengths and limitations

Study II is a secondary analysis of existing national survey data. Secondary analysis of data has known limitations (Vartanian 2010). The study, however, used data from a nationally representative sample, a factor which increases confidence in the generalizability of results. Nevertheless, replication of this study in similar cultural contexts is recommended. This will further contribute to the generalizability of the results and facilitate cross-country compositions.

Study II analysed main-carer report data. Although most of the reports were from the biological parents (mothers), information or recall bias might be present. Overall, there is a lack of studies that compared self-reported and parent-reported participation. However, there is evidence suggesting that parents of children with chronic health conditions tend to underestimate the quality of life of their children (Upton et al. 2008). Given similarities between some items of quality of life with items of participation, parents of children with disabilities might have underestimated their child's participation in community-based activities. Some scholars argue, however, that parents have the most privileged knowledge about their own children (Franck and Callery 2004). Parental reports are reliable and a valid source of information, especially in issues concerning their environment and participation profile (McManus et al. 2006).

The MCS5 allowed to produce reliable evidence on DDA-defined childhood disability prevalence rates in the UK. Nonetheless, national survey data on disability such as available in the MCS5 is challenged by definitional, conceptual and practical issues. In the MCS5, parents were asked to identify all the chronic conditions and functional issues applicable to the child. Functional complexity arising from these types of data substantially complicates between-group comparisons based on child health condition and/or functional issues as data is reflective of instances and not actual cases. The presence of category "other functional issues" in the MCS5 with a drop-down box listing a number of disorders further has made it hard to distinguish functional complexity from diagnostic complexity or comorbidity. All these are important aspects of disability which, however, were not clearly presented in the MCS5, therefore, have not been accounted for in statistical analysis.

Six community-based participation items were selected from the MCS5; nevertheless, children's participation in community-based activities is not limited to these activities. Further, the selection of items available in the MCS5 was completed based on a matching exercise with a validated measure of participation - the PEM-CY (Coster et al. 2012). Nevertheless, the validity of these items unknown. Additionally, two of these items, more precisely item I - Visiting a library (proxy to Neighbourhood outings) and item VI - Vacations abroad (proxy to Overnight visits or trips), were less well-targeted to community participations items of the PEM-CY. They captured only specific aspects or activities of the broader PEM-CY items.

Participation was operationalized as "attendance". This is an objective or observable aspect of participation equating to the performance qualifier of participation in the ICF-CY. The literature emphasizes that the objective dimension of participation is essential to measure in research concerned with comparing and contrasting the objective circumstances of different subgroups (Coster and Khetani 2008). Many scholars however equally prioritize subjective experience dimension of participation, described by Imms et al. (2016) as involvement. Although data on the subjective aspect of participation would provide richer and more complete descriptions of children's

community-based participation, items that would allow the investigator to yield these data were not present in the MCS5.

Participation is a complex and multidimensional construct. Not all potential participation-influencing factors were analysed in this study. Although the extensive literature review, the ICF-CY framework and the findings of the systematic review provided a solid frame of reference for variable selection, the child, family and community factors included in this study were still limited to those available in the MCS5. Other unmeasured child and environmental factors can influence participation frequency of children with disabilities in physical activities and getting together with friends.

The ordinal scale for the frequency of getting together with friends had to be dichotomized because none of the ordinal models fitted met the parallel odds assumption important in ordinal logistic regression analysis. Although this was a necessary procedure to be able to answer RQ5, dichotomizing the ordinal scale might have resulted in a loss of potentially valuable information.

The data used for secondary analysis were drawn from the fifth sweep of the MCS. In other words, data used provided evidence on children and their families measured at a single point in time, i.e. a period from 2012-2013. The study is cross-sectional in its nature and, therefore, no conclusions about causality can be drawn from analysis used here. Further, there might be also a causal feedback loop that could not be detected, e.g. a low frequency of getting together with friends might be caused by child psychosocial and behavioural problems or vice versa.

6.4 Summary

This chapter briefly reflected on findings of Study I (for details refer to Chapter 3) and discussed the findings from Study II within the context of existing literature. Study I put forward a taxonomy of family factors contributing to childhood disability participation. It further supplied evidence of non-modifiable "status" and modifiable "process" factors that were consistently associated with participation. From the

findings of Study I, it appeared that disadvantaged family circumstances shaped by family "status" factors may predispose families to a variety of stressors. The way parents evaluate and deal with these stressors may adversely affect parental health and well-being, their subjective perceptions and behaviour, which in turn can pose risk to children's well-being and participation. Family "status" factors are hard (sometimes impossible) to modify. Paediatric professionals therefore may consider to family "process" factors - parental mental and physical health functioning, parental self-efficacy beliefs, parental support, parental time and family preferences and activity orientation as primary targets of family-centred participation promoting interventions.

Study II supplied evidence on characteristics, family circumstances and community-based participation of UK children with and without disabilities aged 10-12. Findings have shown that childhood disability was more prevalent in socio-economically disadvantaged families. A link between socio-economic disadvantage and childhood disability is well-established. Low birth weight, undernourishment and suboptimal living conditions are some of the factors that may predispose children born to socio-economic disadvantage to the onset of health conditions and associated disability. Meanwhile, direct costs associated with childhood disability are high and many families have to outlay additional resources (i.e. financial, time, support) to effectively support children. To meet care commitments, some parents are unable to participate in employment. Due to these reasons, many families with childhood disability may experience socio-economic disadvantage.

Similar to other research, Study II has established that for children with disabilities the odds of living in single-parent households and in families with a parent having a longstanding illness were significantly higher. A high divorce rate and the presence of multiple births and disabilities are some of the proposed explanations to observed high rates of single-parenthood in households with childhood disability. Although associations between childhood disability and parental poor health have been described previously, it is not clear from literature whether health problems precede or are triggered or exacerbated by stressors related to having and/or caring for a child with a disability.

Children living in disadvantaged circumstances are doubly disadvantaged. Disadvantaged families may lack resources and/or knowledge how to seek and gain access to these services they are entitled to. Empowering families with childhood disability and improving their access to support services, counselling, parental networks and financial schemes programmes might help families to improve life chances for children with disabilities.

Children with and without disabilities differ in the extent to which they participate in community-based activities. After adjustment for potential confounders, children with disabilities had higher odds of lower frequency of participation in unstructured physical activities, organized physical activities, religious gatherings and getting together with friends. These results are consistent with studies comparing community participation of children with and without disabilities in other cultural contexts. Participation in unstructured spontaneous activities was proportionately the highest within both groups. Nevertheless, children with disabilities were three times more likely to have a lower frequency in getting together with friends compared to peers. This is concerning given that social participation offers numerous health benefits for children. It also a powerful motivator for physical activity and encouraging children to engage in activities more regularly. This is important given the findings of this study that children with disabilities were twice as likely to have a lower frequency of participation in unstructured and organized physical activities compared to peers.

Given these findings, effective strategies are required to promote the participation of children with disabilities in community-based activities, especially in activities that are social and physical in nature. Factors that had a significant independent contribution to the participation frequency of children with disabilities aged 10-12 in physical activities and getting together with friends were child psychosocial and behavioural problems, ethnicity, parental education, family income, parental physical activity, the parental play of physically active games with a child and parental social support. None of community factors tested had an effect. Therefore, intervention

techniques targeting both child psychosocial and behavioural functioning and immediate social environment as oppose to only child or family are needed.

Chapter 7 to follow is the final chapter of this doctoral research. The purpose of the chapter is to provide an overview of this work and its conclusions. Key recommendations for research, clinical practice, global and local policy are considered and pathways to impact are discussed.

CHAPTER 7 – CONCLUSIONS

7.1 Introduction

The 21st century is witnessing a paradigm shift in the way disability is described and addressed. Following the entry into force of the UN CRC (1989) and the UN CRPD (2007), disability is increasingly understood as a human rights issue (WHO 2011; UNICEF 2013; UN 2018). It is also a development issue with an increasing body of evidence suggesting that globally children with disabilities are at greater risk of material disadvantage, social exclusion, participation restriction and suboptimal health outcomes compared to peers without disabilities (UNICEF 2013; UN 2018). Disadvantages limit children's opportunities to contribute to social, cultural and economic affairs of their societies and impede their access to gainful employment later in adulthood (UNICEF 2013).

Signatory governments to the UN treaties, including the UK Government, and paediatric professionals across disciplines are committed to improving social, economic, developmental and health outcomes for children with disabilities and promoting their participation in life situations (WHO 2011; UNICEF 2013; UN 2018). Although substantial progress has been made in this respect, many children with disabilities continue to face various disadvantages and barriers to participation, especially in community-based activities (Shields and Synnot 2016; Wright et al. 2018; Lynch et al. 2020; Powrie et al. 2020).

Population-level comparative descriptions on characteristics, life circumstances and participation of children with and without disabilities are helpful in exposing inequalities and supporting paediatric professionals, civic societies and families when advocating for extra funding and allocation of services to better support children. There is a dearth of such evidence, however (Colver et al. 2012; Bedell et al. 2013). Furthermore, the ICF-CY states that a child's immediate context – the family – is a key contributor to participation (WHO 2007). Many empirical studies tested the effect of various family factors in relation to childhood disability participation (King et al. 2006; Rentinck et al. 2009; Oates et al. 2011; Bedell et al. 2013; Law et al. 2013; Kolehmainen et al. 2015; Marquis and Baker 2015; Kamath et al. 2016). Evidence

from these studies however is mixed, in places, controversial. Up until now, no review has focused specifically on the family unit and synthesized evidence on family factors consistently associated with childhood disability participation. Knowledge on family factors consistently liked to participation will supply paediatric professionals with evidence important for the development and selection of targeted family-centred participation promoting intervention techniques. It will also facilitate a selection of family factors to be tested alongside the child and community factors to produce context-relevant population-level data on primary targets of child/family-centred interventions techniques. This doctoral research contributes to addressing these gaps in childhood disability participation literature.

7.2 Unique contributions

7.2.1 Theoretical contribution

The ICF-CY is a multidisciplinary classification system for describing and organising information on functioning and disability in children and youth (WHO, 2007). The ICF-CY is also a multidimensional conceptual model. In addition to participation, which is the social dimension of functioning, the ICF-CY includes additional individual dimensions: Body Function and Structure, Activity, and contextual dimensions of Personal factors and Environmental factors (WHO 2007). The ICF-CY views the context surrounding the child as series of successive systems, with the family system being the most immediate of all systems (WHO 2007). The framework recognizes that children's functioning cannot be assessed in isolation but in the context of the family system. Despite its recognized role in shaping children's development and functioning, a classification of family factors within Environmental factors of the ICF-CY framework is lacking.

Study I completed in the scope of this doctoral research provided a taxonomy of family factors potentially linked to childhood disability participation (Figure 8). The taxonomy of family factors distinguishes between two major groups – non-modifiable (or hard to modify) "status" factors and modifiable "process factors". Two subgroups are further differentiated within "status" factors – (1) family socio-demographic factors and (2) family structure; and four subgroups within "process" factors: (1)

"parental health and well-being", (2) "parental beliefs, perceptions and attitudes", (3) "parental behaviour", and (4) "family resources". Each subgroup consists of a set of factors tapping into the underlying broader construct the group represents.

The taxonomy put forward in Study I exposes inadequacies of the classification of family factors in the ICF-CY framework. The developers of the ICF-CY need to adapt a more sophisticated lens regarding classification of family factors contributing to childhood disability participation. The current classification which distinguishes between two main constructs *e310 - Supports and Relationships of Immediate Family*, and *e410 - Individual Attitudes of Immediate Family* is incomplete and needs further revision. The taxonomy developed in the scope of this doctoral research can be used as a foundation for advancing the ICF-CY's classification system for immediate family factors.

7.2.2 Methodological contribution

As described in section 2.2.6, recent years have seen a drastic increase in the development of participation measures making it difficult to select appropriate measures to profile children's participation. A systematic literature review of participation measurement tools identified the CASP and the PEM-CY as measures with items covering all of the 9 participation domains of the ICF-CY (Chein et al. 2014). The PEM-CY, a tool used in this doctoral research in participation items selection exercise, measures an objective aspect of participation – frequency of attendance – by generating a composite participation intensity score. Participation intensity is understood as an average participation frequency across a set of activities.

In Study II community-based participation profiles of children with and without disabilities were compared and contrasted based on stand-alone items measured on an ordinal scale – "Low", "Regular" "High" frequency of participation. This allowed to differentiate between the activities children participated more frequently and those they did not. Assessing participation on stand-alone items measured on ordinal scale also allowed to identify child, family and community factors independently contributing to more frequent participation of children with disabilities in organized

physical activities, unstructured physical activities and getting together with friends. In Study II no attempts were made to calculate participation intensity score from available six community-based participation items, despite this approach to measurement is offered by the PEM-CY.

This doctoral research argues that childhood disability research should revise its approach to participation measurement in respect to participation intensity score. Participation intensity score is a "deceptive" measure. By averaging participation frequency scores across activities, it "masks" children's tendency of more frequent participation in some activities but not in others. Participation intensity score may therefore suggest "misleading" evidence on participation frequency of children with and without disabilities. Measuring children's participation across various activities without averaging frequency scores – on ordinal scales – provides a more objective way of assessing children's participation and should be actively considered in future participation research.

7.2.3 Contribution to knowledge

Study I has supplied a much needed synthesis of evidence on family factors consistently associated with childhood disability participation. By describing four non-modifiable or hard-to-modify family "status" factors and six modifiable family "process" factors consistently linked to childhood disability participation, it provided new information on potentially modifiable targets of family-centred participation-promoting interventions.

Study II has provided reliable evidence on characteristics, family circumstances and community-based participation of UK children with and without disabilities aged 10-12. It has shown that children with disabilities aged 10-12 and their parents face greater personal and material disadvantage than age-matched peers without disabilities. It has highlighted that differences in frequency of participation between children with and without disabilities are most prominent in relation to community-based activities which are social and physical in nature. Study II has also suggested that children's frequency of participation in community-based social and physical activities is a

product of complex interactions between the child psychosocial and behavioural functioning and the influences from family "status" and "process" factors.

Conclusions drawn from Study II suggest that child functioning and the family play a central role in shaping the participation of children with disabilities in social and physical activities. These conclusions converge with key principles of Bronfenbrenner's ecological systems theory and the ICF-CY that a child's participation cannot and should not be evaluated in separation but within the context of their immediate social environment – the family. The family therefore should be a central unit of analysis in childhood disability participation research.

Many resources that enable families with childhood disability to function effectively are present in the community environment. Availability and accessibility of leisure and recreational centres, sports clubs/classes, community support hubs, places of worship are all part of the family's ecology which will shape the ways families spend their time. It is therefore important to take an ecological perspective to explore if children and their families have access to various community resources and provide practical supports on how to make better use of these resources so that families with childhood disability can more effectively fulfil their daily functions.

7.3. Recommendations for further research

Study II has suggested that children with and without disabilities had similar patterns of participation and on average participated in 4 out of 6 community-based activities. Nevertheless, they did differ in the extent to which they attended these activities. This has been established by measuring the frequency with which children attended activities. Maxwell et al. (2012) calls for a need to add an additional qualifier to the ICF-CY that would measure participation frequency. This doctoral research joins these calls and further highlights that future research looking at participation should measure both the number of activities children attend (diversity) and the frequency with which the children attended them.

This research showed discrepancies in participation frequency between children with and without disabilities, and argues for collective action to promote children's participation, especially in community-based social and physical activities. More frequent participation while desirable is not necessarily good for all children with disabilities. Future research should explore children's subjective experiences - enjoyment and satisfaction with participation before piloting participation frequency promoting intervention techniques.

Child psychosocial and behavioural problems were consistently associated with the frequency of participation of children with disabilities in three outcomes of interest. As described earlier, child psychosocial and behavioural problems were evaluated based on the total difficulties scores obtained from summing the scores from the SDQ's four domains/subscales. Further research evaluating the independent contribution of each domain - emotional problems, conduct/behavioural problems, hyperactivity and peer problems on participation of children with disabilities will help to narrow down the targets of child/family-centred participation-promoting intervention techniques.

Further work is needed to better understand a link between family behaviour and participation frequency of children with disabilities in physical activities. Further, in this research, family type, parental health and parental time did not determine the participation frequency of children with disabilities in social and physical activities. This is somewhat surprising given these factors are indicative of the availability of parental resources which are important for supporting children's participation in community-based activities. Further research may wish to check the predictive effects of these factors in representative samples of children with various disabilities and age groups across cultural contexts.

7.4 Recommendations for practice

Paediatric professionals should consider strengthening intervention techniques which promote the participation of children with disabilities in various community-based activities. A systematic literature review of interventions suggests that setting up

family agreed short-term attainable goals for child preferred activities and gradually improving children's activity competence and self-regulatory skills can be effective in promoting participation of children with disabilities in various community-based activities (Adair et al. 2015; Andrew et al. 2015). Inclusion of children without disabilities in these intervention techniques might be helpful as this facilitates social inclusion in the community and friendship formation (Siperstein et al. 2009; Andrew et al. 2015).

Paediatric professionals should consider child psychosocial and behavioural functioning and child immediate social environment – family context – when delivering intervention techniques directed towards increasing participation of children with disabilities in social and physical activities. Paediatric professionals may need:

(1) to formally assess child psychosocial and behavioural functioning using a brief behavioural screening questionnaire and if borderline or abnormal help the child with self-discovery and the identification of perceived environmental barriers for participation;
(2) to help families and children to develop specific, mutually agreed short-term attainable goals and plans for achieving these goals;
(3) to guide parents on strategies that would allow to promote child socio-emotional development and self-regulation, and to discourage undesirable child behaviour;
(4) to provide practical supports to families to eliminate or mitigate the effects of perceived or unexpected environmental barriers for participation in social and physical activities.

Paediatric professionals may need to further expand the scope of applied assessments and formally assess family behaviour. Educating parents on the key role parental behaviour can play in promoting participation should be an important consideration. Education only might not be enough. Not all families will be equipped with the required skills and resources to support their children's participation. Some families

might recognize the importance of shared physical play sessions and engagement in organized physical activities in their children's and their own health but lack the skills on how those activities should be conducted (Menear 2007). Therefore, when working with families especially those from disadvantaged backgrounds professionals might need: (1) to model potentially effective participation-promoting strategies/activities; (2) to provide practical help with accessing local services and/or low-cost recreational alternatives; (3) to help to arrange the logistics for desired activities.

Paediatric professionals may consider putting improving parental health and family well-being at the top of their agenda when working with families with childhood disability. They may need to assist parents experiencing health problems with accessing health and social care support services and counselling programmes. Parents of children with disabilities often feel less stressed and socially isolated when keep in contact with other families sharing similar situations (Contact a Family 2012; Case-Smith and O'Brien 2015). Professionals may consider facilitating the families' access to charitable organizations concerned with protecting the rights of children with disabilities (e.g. Family Fund, KIDS, NewLife, and Disability Grants), parental support groups and networks. This support will help the families to (1) understand their rights and legal entitlements, (2) take more control of family life, and (3) feel stronger and less isolated. After all, if efforts directed towards supporting children with disabilities involve the family's active involvement in the process, parental health and family well-being should be improved and enhanced.

7.5 Recommendations for policy

Under UN Conventions described in Chapter 1 (section 1.5), the signatory governments have taken upon themselves a responsibility to ensure the promotion and protection of the rights of children with disabilities (and their families) to (1) adequate standards of living; (2) participation in civic, social and cultural affairs of their communities; (3) decent lives; (4) good health and well-being (UN 1989; UN 2007; UN 2018). Findings of this research highlight that the full realization of these goals and obligations requires more investment and time from signatory governments. Governments need to strengthen the supports and social protection of families with

childhood disability to ensure that children with disabilities have equal opportunities for participation age-appropriate community-based activities and equal chances for enjoying decent quality of life.

The findings of this doctoral research suggest that at the national level, the existing programmes and interventions are not performing well enough to fully promote and support the rights of children with disabilities and their families. Additional approaches are required to tackle personal and socio-economic inequalities faced by these vulnerable groups of the population. Further, a refreshed set of practical actions should be taken by local authorities and policy-makers to help to tackle potential or perceived barriers to children's participation in community-based activities. Barriers to participation can be addressed by (1) promoting services, sources of support and opportunities for children and their families, (2) creating time and space for children to engage in unstructured or organized physical activities, (3) promoting accessible and low-cost recreational opportunities, (4) commissioning parenting support programmes, and (5) facilitating mentoring and networking between families with childhood disability. Additionally, under Part 3 of the Children and Families Act (2014) the local authorities shall endeavour to extend the rights to a personal budget for supporting children with disabilities or children special needs. The local authorities and policy-makers may consider expanding the benefits system and ensuring local implementation of policy acts they have launched.

7.6 Pathways to impact

An outcome of a doctoral research programme is the ability to articulate how the unique knowledge produced could be put into beneficial use. There are three groups who will benefit from this doctoral research: (1) the academic community and researchers studying childhood disability and participation, (2) paediatric health and social care professionals, (3) children with disabilities and their families.

The beneficiaries will gain knowledge of (1) characteristics, life circumstances and community-based participation of UK children with disabilities aged 10-12, (2) family factors contributing to childhood disability participation, and (3) factors independently

associated with the participation frequency of children with disabilities aged 10-12 in community-based physical activities and getting together with friends. Publication in open access peer-reviewed journals is an essential step to ensure the dissemination of findings to multi-professional groups of beneficiaries of this research. In this regard, the findings of the systematic review on family factors associated with childhood disability participation have been shared in a peer-reviewed publication (Appendix L).

The link to the publication has been disseminated through academic and social media platforms (e.g. Research Gate, Twitter). In a similar vein, the findings of cross-sectional comparative study on community-based participation of children with and without disabilities aged 10-12 has been accepted for publication in a peer-reviewed journal (Appendix M). Priority will now be given to publishing the third paper on factors contributing to participation frequency of children with disabilities aged 10-12 in physical activities in targeted peer-reviewed journals (e.g. *Developmental Medicine and Child Neurology* (impact factor (IF) 3.5, *Archives of Physical Medicine and Rehabilitation* (IF 2.6), PLOS One (IF 2.7), *Disability and Rehabilitation* (IF 1.8), *Research in Developmental Disabilities* (IF 1.8), *Child: Care, Health and Development* (IF 1.2)). Further, conferences will be targeted for sharing the findings with multi-professional groups of beneficiaries, and developing networks and collaborations with academics who have similar research interests to mine.

Improved knowledge of paediatric health and social care professionals will help to promote childhood disability community-based participation, as well as improve overall health outcomes, quality of life and well-being of children with disabilities and their families in the UK via provision of more targeted information, opportunities and practical supports. To contribute to this process, research summary sheets and infographics will be developed (a) to distribute to practice-based clinics and charitable organizations concerned with the welfare of children with disabilities, and (b) to share on social media platforms. This will help to enhance the reach of the findings to children with disabilities and their families both nationally and internationally.

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Appendix A: Descriptions of the Body Functions Component in the ICF-CY

Chapters	Categories
Chapter 1 - Mental functions	Global mental functions b110 Consciousness functions b114 Orientation functions b117 Intellectual functions b122 Global psychosocial functions b125 Dispositions and intra-personal funtions b126 Temperament and personality functions b130 Energy and drive functions b134 Sleep functions b139 Global mental functions, other specified and unspecified Specific mental functions b140 Attention functions b144 Memory functions b147 Psychomotor functions b152 Emotional functions b156 Perceptual functions b160 Thought functions b163 Basic cognitive functions b164 Higher-level cognitive functions b167 Mental functions of language b172 Calculation functions b176 Mental function of sequencing complex movements b180 Experience of self and time functions b189 Specific mental functions, other specified and unspecified b198 Mental functions, other specified b199 Mental functions, unspecified
Chapter 2 - Sensory functions and pain	Seeing and related functions b210 Seeing functions b215 Functions of structures adjoining the eye b220 Sensations associated with the eye and adjoining structures b229 Seeing and related functions, other specified and unspecified Hearing and vestibular functions b230 Hearing functions b235 Vestibular functions b240 Sensations associated with hearing and vestibular function b249 Hearing and vestibular functions, other specified and unspecified Additional sensory functions b250 Taste function b255 Smell function b260 Proprioceptive function b265 Touch function b270 Sensory functions related to temperature and other stimuli b279 Additional sensory functions, other specified and unspecified Pain b280 Sensation of pain b289 Sensation of pain, other specified and unspecified b298 Sensory functions and pain, other specified b299 Sensory functions and pain, unspecified
Chapter 3 - Voice and speech functions	b310 Voice functions b320 Articulation functions b330 Fluency and rhythm of speech functions

Chapters	Categories
	b340 Alternative vocalization functions b398 Voice and speech functions, other specified b399 Voice and speech functions, unspecified
Chapter 4 - Functions of the cardiovascular, haematological, immunological and respiratory systems	Functions of the cardiovascular system b410 Heart functions b415 Blood vessel functions b420 Blood pressure functions b429 Functions of the cardiovascular system, other specified and unspecified Functions of the haematological and immunological systems b430 Haematological system functions b435 Immunological system functions b439 Functions of the haematological and immunological systems, other specified and unspecified Functions of the respiratory system b440 Respiration functions b445 Respiratory muscle functions b449 Functions of the respiratory system, other specified and unspecified Additional functions and sensations of the cardiovascular and respiratory systems b450 Additional respiratory functions b455 Exercise tolerance functions b460 Sensations associated with cardiovascular and respiratory functions b469 Additional functions and sensations of the cardiovascular and respiratory systems, other specified and unspecified b498 Functions of the cardiovascular, haematological, immunological and respiratory systems, other specified
Chapter 5 - Functions of the digestive, metabolic and endocrine systems	Functions related to the digestive system b510 Ingestion functions b515 Digestive functions b520 Assimilation functions b525 Defecation functions b530 Weight maintenance functions b535 Sensations associated with the digestive system b539 Functions related to the digestive system, other specified and unspecified Functions related to metabolism and the endocrine system b540 General metabolic functions b545 Water, mineral and electrolyte balance functions b550 Thermoregulatory functions b555 Endocrine gland functions b560 Growth maintenance functions b569 Functions related to metabolism and the endocrine system, other specified and unspecified b598 Functions of the digestive, metabolic and endocrine systems, other specified b599 Functions of the digestive, metabolic and endocrine systems, unspecified
Chapter 6 - Genitourinary and reproductive functions	Urinary functions (b610-b639) b610 Urinary excretory functions

Chapters	Categories
	b620 Urination functions b630 Sensations associated with urinary functions b639 Urinary functions, other specified and unspecified Genital and reproductive functions (b640-b679) b640 Sexual functions b650 Menstruation functions b660 Procreation functions b670 Sensations associated with genital and reproductive functions b679 Genital and reproductive functions, other specified and unspecified b698 Genitourinary and reproductive functions, other specified
Chapter 7 - Neuromusculoskeletal and movement-related functions	Functions of the joints and bones b710 Mobility of joint functions b715 Stability of joint functions b720 Mobility of bone functions b729 Functions of the joints and bones, other specified and unspecified Muscle functions b730 Muscle power functions b735 Muscle tone functions b740 Muscle endurance functions b749 Muscle functions, other specified and unspecified Movement functions b750 Motor reflex functions b755 Involuntary movement reaction functions b760 Control of voluntary movement functions b765 Involuntary movement functions b770 Gait pattern functions b780 Sensations related to muscles and movement functions b789 Movement functions, other specified and unspecified b798 Neuromusculoskeletal and movement-related functions, other specified b799 Neuromusculoskeletal and movement-related functions, unspecified
Chapter 8 - Functions of the skin and related structures	Functions of the skin b810 Protective functions of the skin b820 Repair functions of the skin b830 Other functions of the skin b840 Sensation related to the skin b849 Functions of the skin, other specified and unspecified Functions of the hair and nails b850 Functions of hair b860 Functions of nails b869 Functions of the hair and nails, other specified and unspecified b898 Functions of the skin and related structures, other specified b899 Functions of the skin and related structures, unspecified

Appendix B: MEDLINE search strategy

S52	**S9 AND S12 AND S32 AND S42 AND S49 (Limiters - Date of Publication: 20010101-20170926 Narrow by Language: English)**
S51	S9 AND S12 AND S32 AND S42 AND S49 (Limiters - Date of Publication: 2001-2017)
S50	S9 AND S12 AND S32 AND S42 AND S49
S49	S47 OR S48
S48	TI “cohort stud*” OR TI “longitudinal stud*” OR TI “prospective stud*” OR TI “cross-sectional stud*” OR TI “case-control stud*” OR TI model* OR AB “cohort stud*” OR AB “longitudinal stud*” OR AB “prospective stud*”OR AB “cross-section stud*” OR AB “case-control stud*” OR AB model*
S47	S43 OR S44 OR S45 OR S46
S46	(MM "Case-Control Studies+")
S45	(MM "Cross-Sectional Studies")
S44	(MM "Longitudinal Studies+")
S43	(MM "Cohort Studies+")
S42	S38 OR S41
S41	S39 OR S40
S40	AB participat* OR AB engage* OR AB involve* OR AB “life N/2 situations” OR AB “human activit*” OR AB “leisure activit*”
S39	TI participat* OR TI engage* OR TI involve* OR TI “life N/2 situations” OR TI “human activit*” OR TI “leisure activit*”
S38	S33 OR S34 OR S35 OR S36 OR S37
S37	(MM "Recreation+")
S36	(MM "Leisure Activities+")
S35	(MM "Activities of Daily Living+")
S34	(MM "Community Participation+")
S33	(MM "Social Participation")
S32	S16 OR S31
S31	S26 OR S30
S30	S27 OR S28 OR S29
S29	TI “socioeconom* factor*” OR TI “family income” OR TI “finance* vulnerab*” OR AB “socioeconom* factor*” OR AB “family income” OR AB “finance* vulnerab*”
S28	AB “home environ*” OR AB “ family environ*” OR AB “family context” OR AB “family factor*” OR AB “family predictor*” OR AB “family N/1 character*” OR AB “residence character*” OR AB “family health” OR AB “parent* health” OR AB “family N/1 relation*” OR AB “interperson* relation*”
S27	TI “home environ*” OR TI “ family environ*” OR TI “family context” OR TI “family factor*” OR TI “family predictor*” OR TI “family N/1 character*” OR TI “residence character*” OR TI “family health” OR TI “parent* health” OR TI “family N/1 relation*” OR TI “interperson* relation*”
S26	S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25
S25	(MH "Socioeconomic Factors+")
S24	(MM "Social Support+")
S23	(MM "Interpersonal Relations+")
S22	(MH "Family Relations+")
S21	(MM "Family Health")
S20	(MH "Residence Characteristics+")
S19	(MH "Family Characteristics+")
S18	(MM "Social Environment+")
S17	(MM "Parenting")
S16	S13 OR S14 OR S15
S15	AB famil* OR AB parent* OR TI famil* OR TI parent*
S14	(MM "Parents+")
S13	(MM "Family+")
S12	S10 OR S11
S11	TI child* OR TI girl* OR TI boy* OR TI schoolchild* OR AB child* OR AB girl* OR AB boy* OR AB schoolchild*
S10	(MM "Child")
S9	S7 OR S8
S8	TI disab* OR TI “special N/1 needs” OR AB disab* OR AB “special N/1 needs”
S7	S1 OR S2 OR S3 OR S4 OR S5 OR S6
S6	(MH "Communication Disorders+")
S5	(MH "Intellectual Disability+")
S4	(MM "Developmental Disabilities")
S3	(MM "Motor Skills Disorders")
S2	(MH "Disabled Persons+")
S1	(MM "Disabled Children")

Appendix C: Descriptions of validated tools used to measure participation

Participation Measure	Population	Age range	Respondent	Participation Focus	Main Domains	Studies
CAPE	Children and youth with & without disabilities	6-21	Child	Leisure & recreation activities	Recreational Physical Social Skills-based Self-improvement	Bult et al., 2013; Engel-Yeger et al., 2013; Imms, 2009; Kamath et al., 2016; King et al., 2006; King et al., 2009; King et al., 2013; Law et al., 2006; Majnemer et al., 2008; Palisano et al., 2011; Shileds et al., 2015; Ullenhag et al., 2012; Ullenhag et al., 2014
CBC	Children and youth with & without disabilities	6-18	Parent	Child competencies & problems	Social Functioning Mood &Anxiety Symptoms Externalizing Symptoms	Marquis and Baker 2015
Child-PFA	Children with & without disabilities			Family activities	Indoor Meal Routine Outdoor Outings Organized activities Vacation & holidays	Axelsson et al., 2013
CHORES	Children with & without disabilities	6-11	Parent	Domestic activities	Self-care Family care	Dunn et al., 2009
CPQ	Children with & without disabilities	4-6	Parent	Everyday activities	ADL IADL Play Leisure Social participation Education	Rosenberg et al., 2010; Rosenberg et al., 2013; Soref et al., 2012
Life-H	Children with disabilities	5-13	Parent	Everyday activities	Daily activities: Health hygiene Personal care Home life Mobility Social roles: Recreation Responsibility Education Relationships	Colver et al., 2012; Parkes et al., 2010
PEM-CY	Children & youth with & without disabilities	5-17	Parent	Home, school & community activities	Home School Community	Bedell et al., 2013; Anaby et al., 2014; Khetani et al., 2014
SFA	Children with & without disabilities	5-12	Teacher/health prof.	School activities	Participation Activity support Activity performance	Furtado et al., 2015
VABS	Children with disabilities	0-18	Parent	Adaptive behaviour	ADL Communication Motor skills	Tan et al., 2016; Rosenberg et al., 2010

Participation Measure	Population	Age range	Respondent	Participation Focus	Main Domains	Studies
					Socialisation	

Note. ADL: Activities of Daily Living, IADL: Instrumental Activities of Daily Living, CAPE: Children's Assessment of Participation & Enjoyment, CBC: Child Behaviour Checklist, Child-PFA: Child Participation in Family Activities , CHORES: Children Helping Out: Responsibilities, Expectations and Support, CPQ: Child Participation Questionnaire, Life-H: The Assessment of Life Habits, PEM-CY: Participation & Environment Measure-Children & Youth, SFA: School Function Assessment, VABS: Vineland Adaptive Behaviour Scale.

Appendix D: End User Licence

UK Data Service

Dear Mrs Stella Arakelyan,

This email has been sent to you because you have registered to access data through the UK Data Service (ukdataservice.ac.uk). This is an automated reminder of the terms and conditions of the End User Licence (EUL) that you agreed to when you registered. A copy of the EUL, including a summary, is available at: ukdataservice.ac.uk/get-data/how-to-access/conditions.

By accepting the End User Licence, you agreed:
- not to use the data for commercial purposes, except with prior permission
- that data supplied under the EUL can only be accessed by registered users
- that data supplied under Special Conditions that are additional to those of the EUL, can only be accessed by registered users who have accepted those Special Conditions
- to preserve the confidentiality of, and not attempt to identify, individuals, households or organisations in the data
- to provide the bibliographic details of any published work based wholly or in part on the data collections accessed via the UK Data Service; information about data and research used by policymakers is particularly welcome. Please email these details send us details, including information regarding the data collections used, using the 'Publications' form available from: ukdataservice.ac.uk/help/get-in-touch/.
- to use the correct form of citation and acknowledgement in publications. Guidance is available in a 'Study information and citation' file, usually supplied with the data and available via the relevant online catalogue record. For more information on citing data, see our citing data page at: ukdataservice.ac.uk/use-data/citing-data
- to offer for deposit any new data collections which have been derived from the materials supplied
- that your personal details are accurate and kept up to date. You can check and update your details by logging into your account via the Login link on the UK Data Service website and following the link to 'Your details'
- to keep your login details and any data stored by you secure.

If your registration period is ending and you are still using data, you should renew your registration. Please note that you must delete any copies of data at the end of the research process. Please ensure that the information in your registered projects is kept up to date, including the number of students for teaching projects. If you are unsure about any of the above, or about any of the clauses of the EUL, please get in touch with the Helpdesk at: ukdataservice.ac.uk/help/get-in-touch

Kind regards

_____
Helpdesk

_____
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UK Data Service

End User Licence

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End User Licence (EUL) Text

This Agreement is made between you and the University of Essex (also referred to as the "registrar") and the service funders in order to provide you (the "End User") with the right to use the collections provided via the UK Data Service and the UK Data Archive, according to the terms below.

In this agreement:

"**Data Team**" means in relation to a particular data collection, the registrar, the relevant data service providers, and (to the extent that the Special Conditions and/or metadata specific to a particular data collection expressly provide) the service funders, data collection funders and/or original data creators or depositors.

"**data service provider**" means the persons or organisations that directly provide you with the data collections (on behalf of the service funder). The data service provider for a particular data collection is identified in the Special Conditions and/or metadata applicable to that data collection;

"**service funder**" means the persons or organisations that fund the data service provider as defined above. The service funder for a particular data collection is identified in the Special Conditions and/or metadata applicable to that data collection;

"**data collection funder**" means the persons or organisations that funded the collection and/or creation of the data collections. The data collection funder for a particular data collection is identified in the Special Conditions and/or metadata applicable to that data collection;

"**original data creator or depositor**" means the persons or organisations that originally collected, created or deposited the materials making up the data collections and/or who own the intellectual property rights in the data collections. The original data creator or depositor for a particular data collection is identified in the Special Conditions and/or metadata applicable to that data collection;

"**registrar**" means the person or organisation responsible for the system that registers End Users and issues them with End User Licences (being the University of Essex);

"**Special Conditions**" means any further conditions applicable to the use of one or more data collections by an End User, as notified to the End User in accordance with paragraph 5 of the End User Licence;

"**metadata**" means any additional or bibliographic information about one or more of the data collections, as notified to the End User from time to time. Metadata may be supplied by electronic means.

I (the "End User") agree to the following conditions of use in consideration of the data collections being made available to me through the various contributions of each member of the Data Team:

1. To use the data collections only in accordance with this End User Licence and to notify promptly the registrar and the data service provider of any breach of its terms in writing or of any infringements of the data collections of which I become aware.
2. To use and to make personal copies of any part of the data collections only for the purposes of not-for-profit research or teaching or personal educational development. To obtain permission prior to using part or all of the data collections for commercial purposes by contacting the registrar and/or relevant data service provider, where relevant, in order to obtain an appropriate licence from the rights holder(s) in question or their permitted licensee

if one is available.

3. That this Licence does not operate to transfer any interest in intellectual property from the data collection funders, service funder(s), the data service providers, the original data creators, producers, depositors, copyright or other right holders (including without limitation the ONS or the Crown) to me. That any rights subsisting in materials derived now or in the future from the data collections which are the intellectual property of the Crown are hereby assigned (by way of assignment of present and future intellectual property) to the Crown by this Licence to the extent not already vested in the Crown. To take all steps necessary to give effect to this Clause (including by executing further written documentation).
4. That the Licence and the data collections are provided by the Data Team on an "as is" basis and without warranty or liability of any kind. Any representations or warranties given by any member of the Data Team relating to this licence, expressed or implied, are excluded to the maximum extent permitted by law.
5. To abide by any further conditions notified to me from time to time by the registrar or the relevant data service provider that may apply to the access to, or use of, specific materials within the data collections or particular data collections. Notice of further conditions under this paragraph may be given to me by electronic means, for example, by way of a pop-up window upon my ordering one or more data collections. My acceptance of the further conditions shall be required before I gain access to the data collections in question. In this Agreement such further conditions are referred to as Special Conditions.
6. To give access to the data collections, in whole or in part, or any material derived from the data collections, only to registered End Users with a registered use who have entered into an End User Licence and accepted the relevant Special Conditions, such as a Commercial Licence, necessary to access and use the data collections (with the exception of data collections or material derived from data collections supplied for the stated purpose of teaching and shared under the terms and conditions of the Access Agreement for Teaching or included in publications made for the purposes set out in paragraph 2).
7. To ensure that the means of access to the data (such as passwords) are kept secure and not disclosed to a third party except by special written permission or licence obtained from the original data service provider.
8. To preserve at all times the confidentiality of information pertaining to individuals and/or households in the data collections where the information is not in the public domain. Not to use the data to attempt to obtain or derive information relating specifically to an identifiable individual or household, nor to claim to have obtained or derived such information. In addition, to preserve the confidentiality of information about, or supplied by, organisations recorded in the data collections. This includes the use or attempt to use the data collections to compromise or otherwise infringe the confidentiality of individuals, households or organisations.
9. To acknowledge, in any publication, whether printed, electronic or broadcast, based wholly or in part on the data collections, the original data creators, depositors or copyright holders, the service funders and the data service provider(s) in the form specified on the data distribution notes or in accompanying metadata received with the dataset or notified to me and without prejudice to paragraph 5 above to comply with any restrictions on my use of the data collections referred to or referenced therein or otherwise notified to me from time to time. To cite, in any publication, whether printed, electronic or broadcast, based wholly or in part on the data collections, the data collections used in the form specified on the data distribution notes or in accompanying metadata received with the dataset or notified to me.
10. To supply the relevant data service provider with the bibliographic details of any published work based wholly or in part on the data collections.
11. That the members of the Data Team may hold and process any personal data submitted by me for validation and statistical purposes, and for the purposes of the management of the service or for any other lawful purpose notified to me and to which I have consented under this Agreement in relation to a particular data collection, and they may also pass the information on to other parties such as: (i) depositors and distributors of material contained in

or accessed via the data service provider; (ii) copyright and other intellectual property rights owners whose material is held by the data service provider; as well as (iii) each member of the Data Team's organisation and (iv) my own institution or organisation, in compliance with the Data Protection Act 1998.

12. To notify the data service provider of any errors discovered in the data collections.
13. That any personal data submitted by me is accurate to the best of my knowledge, and that any changes in that personal data, including my educational or employment status, will be made known to the registrar at the earliest possible opportunity.
14. To meet any charges that may from time to time be levied by any member of the Data Team for the supply of the data collections including, where relevant, annual service fees and royalty fees.
15. At the conclusion of my research (or if earlier at any time at the request of a member of the Data Team), to offer for deposit in the data collection(s) on a suitable medium and at my own expense any new data collections which have been derived from the materials supplied or which have been created by the combination of the data supplied with other data. The deposit of the derived data collection(s) will include sufficient explanatory documentation to enable the new data collection(s) to be accessible to others.
16. I understand that breach of any of the provisions of this Agreement will lead to immediate termination of my access to all services provided by the Data Team either permanently or temporarily, at the discretion of a member of the Data Team, and may result in legal action being taken against me. I understand that where there is no breach of this Licence, it may be terminated, or its terms altered, by a member of the Data Team either after 30 days notice; or, if a service charge has been paid in advance, at the end of the period for which payment has been made, whichever is the longer. The failure to exercise or delay in exercising a right or remedy provided by this Agreement or by law does not constitute a waiver of the right or remedy or a waiver of other rights or remedies.

DISCLAIMERS

To the extent that applicable law permits:

a. The members of the Data Team bear no legal responsibility for the accuracy or comprehensiveness of the data supplied.
b. The members of the Data Team accept no liability for, and I will not be entitled to claim against them in respect of, any direct, indirect, consequential or incidental damages or losses arising from use of the data collections, or from the unavailability of, or break in access to, the service, for whatever reason.
c. Whilst steps have been taken to ensure all licences, authorisation and permissions required for the granting of this Licence have been obtained, this may not have been possible in all cases, and no warranties or assurance are given in this regard. To the extent that additional licences, authorisations and permissions are required to use the data collections in accordance with this Licence, it is the End User's responsibility to obtain them.
d. I agree to indemnify and shall keep indemnified each member of the Data Team against any costs, actions, claims, demands, liabilities, expenses, damages or losses (including without limitation consequential losses and loss of profit, and all interest, penalties and legal and other professional costs and expenses) arising from or in connection with any third party claim made against any member of the Data Team relating to my use of the data collections or any other activities in relation to the data where such use is in breach of this licence.

If the whole or any part of a provision of this Agreement is void, unenforceable or illegal for any reason, that provision will be severed and the remainder of the provisions of this Agreement will continue in full force and effect as if this Agreement had been executed with the invalid provision eliminated.

This Agreement may be enforced separately in relation to each data collection provided to the End User by any member of the Data Team and the End User. No other persons may enforce this Agreement under the Contract (Rights of Third Parties) Act 1999.

This Agreement (which is the entire agreement between the parties and supersedes any previous agreement between them) may be varied in writing by agreement of the relevant service funders, the registrar, and the End User (who may give its consent to such variations by electronic means). No consent from any other party is required to vary or rescind this Agreement.

This Agreement and any documents to be entered into pursuant to it shall be governed by and construed in accordance with the laws of England and Wales and each Party irrevocably submits to the exclusive jurisdiction of the courts of England and Wales over any claim or matter arising under or in connection with this Agreement and the documents entered into pursuant to it.

END USER LICENCE (EUL) SUMMARY TEXT

Sixteen points to help you understand the End User Licence (EUL). These pointers are for general guidance and you must read and understand the full EUL before agreeing to it. By accepting the EUL, you agree:

1. to use the data in accordance with the EUL and to notify the UK Data Service of any breach you are aware of
2. not to use the data for commercial purposes without obtaining permission and, where relevant, an appropriate licence if commercial use of the data is required
3. that the EUL does not transfer any interest in intellectual property to you
4. that the EUL and data collections are provided without warranty or liability of any kind
5. to abide by any further conditions notified to you
6. to give access to the data collections only to registered users with a registered use (who have accepted the terms and conditions, including any relevant further conditions). There are some exceptions regarding the use of data collections for teaching and the use of data collections for Commercial purposes set out in an additional Commercial Licence.
7. to ensure that the means of access to the data (such as passwords) are kept secure and not disclosed to anyone else
8. to preserve the confidentiality of, and not attempt to identify, individuals, households or organisations in the data
9. to use the correct methods of citation and acknowledgement in publications
10. to send the UK Data Service bibliographic details of any published work based on our data collections
11. that personal data about you may be held for validation and statistical purposes and to manage the service, and that these data may be passed on to other parties
12. to notify the UK Data Service of any errors discovered in the data collections
13. that personal data submitted by you are accurate to the best of your knowledge and kept up to date by you
14. to meet any charges that may apply
15. to offer for deposit any new data collections which have been derived from the materials supplied
16. that any breach of the EUL will lead to immediate termination of your access to the services and could result in legal action against you.

Appendix E: Items included in calculations of the SDQ total difficulties score

Subscale/ Domain	Items	Raw scores
Emotional problems	[^Cohort child's name] often complains of headaches, stomach-aches or sickness	0=Not true 1=Somewhat true 2=Certainly true
	[^Cohort child's name] has many worries, often seems worried	0=Not true 1=Somewhat true 2=Certainly true
	[^Cohort child's name] is often unhappy	0=Not true 1=Somewhat true 2=Certainly true
	[^Cohort child's name] is nervous or clingy in new situations, easily loses confidence	0=Not true 1=Somewhat true 2=Certainly true
	[^Cohort child's name] has many fears, easily scared	0=Not true 1=Somewhat true 2=Certainly true
Conduct/behaviour problems	[^Cohort child's name] often has temper tantrums or hot tempers	0=Not true 1=Somewhat true 2=Certainly true
	[^Cohort child's name] is generally obedient, usually does what adults request	2=Not true 1=Somewhat true 0=Certainly true
	[^Cohort child's name] often fights with other children	0=Not true 1=Somewhat true 2=Certainly true
	[^Cohort child's name] often lies or cheats	0=Not true 1=Somewhat true 2=Certainly true
	Cohort child's name] steals from home, school or elsewhere	0=Not true 1=Somewhat true 2=Certainly true
Hyperactivity	[^Cohort child's name] is restless, overactive, cannot stay still for long	0=Not true 1=Somewhat true 2=Certainly true
	[^Cohort child's name] is constantly fidgeting or squirming	Not true=0 Somewhat true=1 Certainly true=2
	[^Cohort child's name] is easily distracted, concentration wanders	0=Not true 1=Somewhat true 2=Certainly true
	[^Cohort child's name] thinks things out before acting	2=Not true 1=Somewhat true 0=Certainly true
	[^Cohort child's name] sees tasks through to the end, good attention span	Not true=2 Somewhat true=1 Certainly true=0
Peer problems	[^Cohort child's name] is rather solitary, tends to play alone	0=Not true 1=Somewhat true 2=Certainly true
	[^Cohort child's name] has at least one good friend	2=Not true 1=Somewhat true 0=Certainly true
	[^Cohort child's name] often fights with other children or bullies them	Not true=2 Somewhat true=1 Certainly true=0

	[^Cohort child's name] is generally liked by other children	0=Not true 1=Somewhat true 2=Certainly true
	[^Cohort child's name] is picked on or bullied by other children	0=Not true 1=Somewhat true 2=Certainly true
	[^Cohort child's name] gets on better with adults than with other children	0=Not true 1=Somewhat true 2=Certainly true

Appendix F: Community-based participation items available in the MCS5

Community-based participation Items	Raw scores	Recoding & Collapsing raw scores	
		Binary response	Ordinal response
Proxy measure: Visiting library			
Over the past 12 months, (that is since [^Date one year ago]), how often has [^Cohort child's name] been to…..a library (not a school library)?	1=Every day/almost every day 2=Several times a week 3=Once or twice a week 4=At least once a month 5=Every few months 6=At least once a year 7=Less often/never	0=Never participated (7) 1=Participated (1-6)	1=Low (5, 6, 7) 2=Regular (3, 4) 3=High (1, 2)
Organized physical activities			
How many days a week does [^Cohort child's name] usually go to a club or class to do sport or any other physical activity like swimming, gymnastics, football, dancing etc?	1=Five/more days a week 2=Four days a week 3=Three days a week 4=Two days a week 5=One day a week 6=Less often than once a week 7=Not at all	0=Never participated (7) 1=Participated (1-6)	1=Low (6, 7) 2=Regular (4, 5) 3=High (1, 2, 3)
Unstructured physical activities			
Not including clubs or classes, how many days a week does [^Cohort child's name] usually take part in physical activities (e.g. swimming, walking) or physically active play with [^his/ her] friends or brothers and sisters? Please don't include walking to school.	1=Five/more days a week 2=Four days a week 3=Three days a week 4=Two days a week 5=One day a week 6=Less often than once a week 7=Not at all	0=Never participated (7) 1=Participated (1-6)	1=Low (6, 7) 2=Regular (4, 5) 3=High (1, 2, 3)
Religious gatherings			
Over the past 12 months, (that is since [^Date one year ago]), how often has [^Cohort child's name] been to...)...a religious service or class?	1=Every day/almost every day 2=Several times a week 3=Once or twice a week 4=At least once a month 5=Every few months 6=At least once a year 7=Less often/never	0=Never participated (7) 1=Participated (1-6)	1=Low (5, 6, 7) 2=Regular (3, 4) 3=High (1, 2)
Getting together with friends			

Apart from at school, how often does [^Cohort child's name] spend time with [^his/her] friends?	1=Every day/almost every day 2=Several times a week 3=Once a week 4=Once or twice a month 5=Less often than once a month 6=Not at all	0=Never participated (6) 1=Participated (1-5)	1=Low (5, 6) 2=Regular (3, 4) 3=High (1, 2)
Proxy measure: Travel for vacations abroad			
Over the past 12 months, that is since [^Date one year ago], how many times, if at all, has [^Cohort child's name] been on holiday outside the UK?	Range from 0-10	0=Never participated (0) 1=Participated (1-10)	1=Low (0, 1) 2=Regular (2, 3) 3=High (≥4)

Appendix G: Correlation matrix

Items	I1	I2	I3	I4	I5	I6	I7
I1							
I2	-0.04						
I3	-0.05	0.19					
I4	0.01	0.24	0.51				
I5	0.06	0.01	0.39	-0.08			
I6	0.00	0.08	0.62	0.21	0.24		
I7	-0.01	0.42	0.37	0.27	0.15	0.26	
I8	0.12	0.24	0.27	0.26	-0.02	0.21	0.55

Note. Sample size n=12,232.
I-item, I1 – Child Sex, I2 – Parental longstanding illness, I3 – Family (equalized) income, I4 – Family type, I5 – Ethnicity, I6 – Parental education, I7 – Parental mental health functioning, I8 – Psychosocial & behavioural problems.

Appendix H: The child, family and community factors by participation frequency in OPHA

Characteristics	Participation frequency in organized physical activities					
	Low		Regular		Often	
	Population estimate *(SE)*	Per cent (%)	Population estimate *(SE)*	Per cent (%)	Population estimate *(SE)*	Per cent (%)
Sex (*n*=1,073)						
Boys	280 (23)	42.2%	260 (24)	39.2%	124 (14)	18.7%
Girls	157 (17)	38.4%	172 (17)	42.0%	80 (9)	19.6%
Ethnicity (*n*=1,073)						
Mixed/Other Ethnic group	40 (9)	58.2%	20 (6)	28.9%	9 (4)	12.9%
Black/Black British	9 (5)	34.8%	7 (3)	24.5%	11 (6)	40.6%
Indian/ Pakistani/ Bangladeshi	24 (6)	44.4%	24 (8)	45.8%	6 (2)	9.8%
White	364 (28)	39.4%	381 (28)	41.2%	179 (16)	19.4%
PSB problems[a] (*n*=1,046)						
Abnormal	193 (20)	47.1%	166 (19)	40.6%	50 (8)	12.3%
Borderline	67 (12)	43.1%	61 (11)	39.5%	21 (6)	17.3%
Normal	161 (16)	33.6%	193 (19)	40.0%	127 (13)	26.4%
Family type (*n*=1,070)						
Single-parent household	253 (24)	44.8%	216(23)	38.1%	97(12)	17.1%
Co-parent household	181 (17)	35.8%	216 (19)	42.9%	107 (12)	21.3%
Parental education (*n*=1,067)						
No formal UK qualifications	143 (17)	54.5%	85 (16)	32.5%	34 (7)	13.0%
GCSE/equivalent	195 (20)	41.8%	201 (18)	43.0%	71 (10)	15.2%
A levels/equivalent	29 (6)	37.0%	28 (6)	35.4%	22 (6)	27.6%
University degree/equivalent	66 (9	25.5%	116 (14)	44.7%	77 (12)	29.7%
Family income[b] (*n*=1,073)						
Bottom	170 (17)	52.3%	116 (18)	35.6%	39 (7)	12.1%
Second	110 (14)	44.8%	92 (14)	37.1%	44 (9)	18.0%
Third	82 (12)	38.8%	94 (11)	44.5%	35 (7)	16.7%
Fourth	48 (9)	31.9%	57 (9)	37.7%	46 (10)	30.4%
Top	26 (6)	18.9%	73 (11)	52.8%	39 (7)	28.3%
Parental longstanding illness (*n*=1,073)						
Present	160 (17)	39.7%	175 (18)	43.6%	67 (9)	16.7%
Absent	278 (23)	41.4%	256 (22)	38.2%	137 (14)	20.4%
Parental mental health functioning (*n*=995)						
Serious mental distress	62 (12)	47.4%	56 (14)	43.5%	12 (4)	9.1%
Moderate mental distress	150 (16)	42.2%	132 (16)	37.1%	73 (11)	20.6%
No distress	189 (19)	37.0%	208 (21)	40.7%	113 (12)	22.2%
Parental physical activity (*n*=1,073)						
Never	215 (21)	53.6%	130 (16)	32.3%	57 (9)	14.1%
Seldom	61 (10)	36.0%	76 (14)	44.9%	32 (9)	19.1%
Regular	71 (10)	32.1%	106 (14)	48.1%	43 (7)	19.7%
Often	90 (13)	32.0%	120 (15)	42.6%	72 (11)	25.5%
Parental play of physically active games with a child (*n*=1,073)						
Never	139 (16)	49.2%	108 (17)	38.0%	36 (6)	12.8%
Seldom	172 (15)	40.6%	155 (16)	36.5%	97 (12)	22.8%
Regular	89 (11)	37.4%	111 (13)	46.6%	38 (6)	16.0%
Often	37 (9)	28.6%	58 (9)	45.5%	33 (7)	25.9%
Parental social support (*n*=1,073)						
Never	13 (5)	69.3%	6 (3)	30.7%	00 (00)	
Seldom	21 (6)	55.6%	12 (4)	32.3%	5 (3)	12.1%
Regular	22 (6)	28.2%	37 (9)	47.2%	19 (7)	24.6%
Often	381 (29)	40.6%	377 (27)	40.2%	180 (16)	19.2%
Parental time (*n*=1,066)						
Not enough time	134 (15)	35.7%	152 (18)	40.6%	89 (12)	23.7%
Just enough time	146 (15)	41.5%	147 (16)	41.6%	60 (9)	16.9%
Enough time	157 (18)	46.2%	127 (16)	37.6%	55 (9)	16.2%

Characteristics	Participation frequency in organized physical activities					
	Low		Regular		Often	
	Population estimate *(SE)*	Per cent (%)	Population estimate *(SE)*	Per cent (%)	Population estimate *(SE)*	Per cent (%)
Availability of parks/playgrounds for a child to play (*n*=1,069)						
No	31 (6)	30.9%	50 (13)	50.1%	19 (6)	19.0%
Yes	406 (30)	41.9%	378 (28)	39.0%	185 (16)	19.1%
Type of area to raise a child (*n*=1,069)						
Poor	52 (10)	55.9%	26 (6)	27.8%	15 (5)	16.3%
Average	111 (13)	46.5%	98 (16)	40.9%	30 (6)	12.6%
Good	274 (22)	37.2%	304 (24)	41.3%	159 (15)	21.6%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
[a]*Psychosocial & behavioural problems*.
[b]*Based on the OECD equalized quintiles for the entire UK*.

Appendix I: The child, family and community factors by participation frequency in UPHA

Characteristics	Participation frequency in unstructured physical activities					
	Low		Regular		Often	
	Population estimate *(SE)*	Per cent (%)	Population estimate *(SE)*	Per cent (%)	Population estimate *(SE)*	Per cent (%)
Sex (*n*=1,073)						
Boys	138 (15)	20.8%	128 (16)	19.2%	398 (27)	60.0%
Girls	91 (16)	22.2%	84 (10)	20.4%	235 (19)	57.4%
Ethnicity (*n*=1,073)						
Mixed/Other Ethnic group	21 (7)	30.1%	15 (5)	22.2%	33 (8)	47.7%
Black/Black British	8 (5)	30.2%	7 (3)	24.0%	12 (5)	45.8%
Indian/ Pakistani/ Bangladeshi	15 (4)	28.5%	7 (3)	13.4%	31 (10)	58.1%
White	185 (20)	20.0%	182 (18)	19.7%	557 (35)	60.3%
PSB problems[a] (*n*=1,046)						
Abnormal	110 (16)	26.9%	85 (15)	20.6%	215 (19)	52.5%
Borderline	34 (9)	22.1%	34 (7)	21.7%	87 (11)	56.3%
Normal	69 (10)	14.4%	88 (10)	18.3%	324 (324)	67.3%
Family type (*n*=1,070)						
Single-parent household	130 (16)	23.0%	105 (16)	18.6%	330 (27)	58.4%
Co-parent household	95 (14)	18.9%	106 (13)	21.1%	302 (22)	60.0%
Parental education (*n*=1,067)						
No formal UK qualifications	72 (13)	27.3%	42 (13)	16.0%	149 (17)	56.7%
GCSE/equivalent	92 (13)	19.7%	102 (12)	21.9%	273 (22)	58.4%
A levels/equivalent	15 (5)	19.0%	18 (5)	22.6%	46 (8)	58.4%
University degree/equivalent	47 (10)	18.0%	49 (8)	19.0%	163 (16)	63.0%
Family income[b] (*n*=1,073)						
Bottom	87 (12)	26.7%	53 (13)	16.4%	185 (19)	57.0%
Second	52 (12)	21.0%	48 (9)	19.6%	147 (17)	59.4%
Third	35 (7)	16.6%	40 (7)	19.0%	137 (13)	64.4%
Fourth	31 (7)	20.6%	35 (6)	23.3%	85 (12)	56.1%
Top	24 (7)	17.6%	34 (7)	24.7%	80 (10)	57.7%
Parental longstanding illness (*n*=1,073)						
Present	73 (11)	18.2%	87 (12)	21.7%	242 (23)	60.1%
Absent	156 (18)	23.2%	124 (16)	18.5%	391 (25)	58.3%
Parental mental health functioning **(*n*=995)**						
Serious mental distress	27 (8)	21.1%	35 (13)	27.0%	67 (12)	51.8%
Moderate mental distress	80 (14)	22.4%	60 (8)	16.8%	217 (19)	60.8%
No distress	97 (13)	19.0%	99 (13)	19.4%	314 (23)	61.6%
Parental physical activity (*n*=1,073)						
Never	118 (15)	29.5%	60 (9)	14.9%	223 (22)	55.6%
Seldom	26 (7)	15.3%	43 (13)	25.5%	101 (13)	59.1%
Regular	31 (6)	14.2%	65 (9)	29.4%	124 (13)	56.4%
Often	53 (12)	19.0%	43 (8)	15.3%	185 (18)	65.7%
Parental play of physically active games with a child (*n*=1,073)						
Never	90 (12)	31.9%	50 (13)	17.8%	142 (15)	50.3%
Seldom	67 (11)	15.8%	85 (12)	20.0%	272 (21)	64.2%
Regular	50 (10)	21.1%	52 (9)	21.7%	137 (14)	57.3%
Often	22 (8)	16.8%	24 (6)	19.1%	82 (13)	64.1%
Parental play of indoor games with a child (*n*=1,073)						
Never	40 (8)	38.9%	9 (3)	8.9%	54 (10)	52.2%
Seldom	78 (12)	19.7%	72 (9)	18.2%	244 (21)	62.1%
Regular	56 (10)	16.7%	78 (11)	23.4%	201 (17)	59.9%
Often	55 (11)	22.8%	52 (13)	21.7%	134 (15)	55.6%
Parental social support (*n*=1,073)						
Never	10 (5)	54.9%	6 (3)	33.6%	2 (1)	11.5%
Seldom	12 (5)	31.3%	1 (1)	3.5%	24 (7)	65.2%

Regular	13 (4)	15.9%	14 (4)	17.6%	53 (10)	66.5%
Often	195 (21)	20.8%	190 (20)	20.2%	554 (32)	59.0%
Parental time (*n*=1,066)						
Not enough time	62 (10)	16.5%	79 (14)	21.0%	235 (19)	62.5%
Just enough time	79 (13)	22.4%	72 (10)	20.6%	201 (19)	57.1%
Enough time	88 (14)	26.0%	59 (9)	17.3%	192 (18)	56.8%
Availability of parks/playgrounds for a child to play (*n*=1,069)						
No	26 (7)	26.1%	29 (12)	29.8%	44 (9)	44.1%
Yes	203 (20)	20.9%	180 (17)	18.6%	587 (35)	60.5%
Type of area to raise a child (*n*=1,069)						
Poor	37 (10)	40.0%	10 (4)	10.6%	46 (9)	49.4%
Average	51 (9)	21.3%	44 (12)	18.6%	143 (18)	60.1%
Good	141 (17)	19.1%	156 (15)	21.1%	441 26()	59.8%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
[a]*Psychosocial & behavioural problems*.
[b]*Based on the OECD equalized quintiles for the entire UK*.

Appendix J: The child, family and community factors by participation frequency in GTF

Characteristics	Frequency of getting together with friends					
	Low		Regular		Often	
	Population estimate *(SE)*	Per cent (%)	Population estimate *(SE)*	Per cent (%)	Population estimate *(SE)*	Per cent (%)
Sex (*n*=1,073)						
Boys	137 (16)	20.6%	231 (20)	34.9%	295 (24)	44.5%
Girls	89 (14)	21.6%	150 (15)	36.6%	171 (16)	41.8%
Ethnicity (*n*=1,073)						
Mixed/Other Ethnic group	26 (7)	37.0%	18 (6)	25.6%	26 (7)	37.3%
Black/Black British	9 (5)	32.6%	15 (6)	55.8%	3 (2)	11.7%
Indian/ Pakistani/ Bangladeshi	13 (4)	25.0%	19 (5)	36.5%	20 (7)	38.5%
White	178 (18)	19.2%	329 (22)	35.6%	417 (29)	45.1%
PSB problems[a] (*n*=1,046)						
Abnormal	134 (16)	32.7%	133 (14)	32.3%	144 (18)	35.0%
Borderline	31 (9)	20.2%	54 (9)	34.7%	70 (11)	45.1%
Normal	45 (8)	9.3%	189 (18)	39.2%	248 (21)	51.5%
Family type (*n*=1,070)						
Single-parent household	123 (16)	21.7%	174 (18)	30.7%	269 (25)	47.5%
Co-parent household	99 (13)	19.7%	207 (16)	41.1%	198 (18)	39.2%
Parental education (*n*=1,067)						
No formal UK qualifications	82 (14)	31.3%	58 (9)	22.1%	122 (18)	46.6%
GCSE or equivalent	85 (13)	18.1%	165 (16)	35.3%	218 (20)	46.6%
A levels or equivalent	9 (3)	12.0%	36 (7)	46.1%	33 (6)	41.9%
University degree/equivalent	46 (9)	17.6%	122 (13)	47.0%	92 (11)	35.4%
Family income[b](*n*=1,073)						
Bottom	96 (14)	29.5%	82 (11)	25.4%	146 (19)	45.1%
Second	59 (11)	24.0%	78 (13)	31.6%	109 (13)	44.4%
Third	19 (5)	9.1%	90 (11)	42.6%	103 (12)	48.3%
Fourth	26 (6)	17.1%	63 (9)	41.3%	63 (9)	41.6%
Top	25 (8)	18.2%	68 (9)	49.2%	45 (8)	32.6%
Parental longstanding illness (*n*=1,073)						
Present	79 (12)	19.6%	114 (13)	28.5%	209 (19)	51.9%
Absent	147 (17)	21.8%	267 (20)	39.8%	258 (22)	38.4%
Parental mental health functioning (*n*=995)						
Serious mental distress	25 (7)	19.2%	38 (8)	28.9%	67 (14)	51.9%
Moderate mental distress	82 (12)	22.9%	129 (14)	36.2%	146 (15)	40.9%
No distress	92 (14)	18.0%	199 (19)	39.0%	219 (19)	43.0%
Parental physical activity (*n*=1,073)						
Never	113 (15)	28.1%	120 (13)	29.8%	169 (18)	42.2%
Seldom	24 (6)	14.2%	52(8)	30.4%	94 (16)	55.4%
Regular	28 (6)	12.8%	101 (13)	45.7%	91 (12)	41.4%
Often	60 (12)	21.5%	109 (13)	38.8%	112 (13)	39.7%
Parental play of physically active games with a child (*n*=1,073)						
Never	71 (11)	25.1%	75 (10)	26.4%	137 (18)	48.5%
Seldom	71 (11)	16.8%	158 (16)	37.3%	194 (16)	45.8%
Regular	51 (10)	21.6%	109 (12)	45.9%	78 (11)	32.5%
Often	32 (8)	24.7%	39 (7)	30.4%	58 (11)	44.9%
Parental play of indoor games with a child (*n*=1,073)						
Never	35 (8)	33.9%	29 (7)	27.8%	40 (8)	38.3%
Seldom	72 (12)	18.2%	139 (14)	35.3%	183 (18)	46.5%
Regular	57 (11)	17.0%	141 (14)	42.2%	137 (14)	40.8%
Often	62 (10)	25.6%	72 (10)	30.0%	107 (17)	44.4%
Parental social support (*n*=1,073)						
Never	11 (5)	63.4%	4 (2)	21.5%	3 (2)	15.1%
Seldom	11 (4)	30.6%	5 (2)	12.4%	21 (6)	57.0%
Regular	10 (4)	12.0%	40 (9)	50.9%	29 (7)	37.1%

Often	193 (20)	20.6%	333 (22)	35.4%	413 (29)	44.0%
Parental time **(*n*=1,066)**						
Not enough time	62 (10)	16.6%	148 (16)	39.4%	165 (18)	44.0%
Just enough time	85 (12)	24.2%	123 (12)	35.0%	144 (14)	40.8%
Enough time	76 (13)	22.5%	107 (13)	31.7%	155 (16)	45.8%
Availability of parks/playgrounds for a child to play (*n*=1,069)						
No	28 (6)	27.9%	28 (6)	28.2%	43 (13)	43.9%
Yes	196 (20)	20.3%	352 (24)	36.3%	421 (28)	43.4%
Type of area to raise a child (*n*=1,069)						
Poor	31 (8)	34.0%	27 (6)	28.7%	34 (9)	37.3%
Average	57 (10)	23.9%	66 (9)	27.9%	115 (18)	48.2%
Good	136 (16)	18.4%	287 (22)	38.9%	315 (22)	42.7%

All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
[a]*Psychosocial & behavioural problems.*
[b]*Based on the OECD equalized quintiles for the entire UK.*

Appendix K: The child, family and community factors by participation frequency in GTF

Characteristics	Frequency of getting together with friends			
	Low		High	
	Population estimate *(SE)*	Per cent (%)	Population estimate *(SE)*	Per cent (%)
Sex (*n*=1,073)				
Boys	137 (16)	20.6%	527 (33)	79.4%
Girls	89 (14)	21.6%	321 (23)	78.4%
Ethnicity (*n*=1,073)				
Mixed/Other Ethnic group	26 (7)	37.0%	44 (9)	63.0%
Black/Black British	9 (5)	32.6%	18 (6)	67.4%
Indian/ Pakistani/ Bangladeshi	13 (4)	25.0%	40 (11)	75.0%
White	178 (18)	19.2%	746 (40)	80.8%
PSB problems[a] (*n*=1,046)				
Abnormal	134 (16)	32.7%	276 (24)	67.3%
Borderline	31 (9)	20.2%	123 (14)	79.8%
Normal	45 (8)	9.3%	437 (28)	90.7%
Family type (*n*=1,070)				
Single-parent household	123 (16)	21.7%	443 (32)	78.3%
Co-parent household	99 (13)	19.7%	405 (26)	80.3%
Parental education (*n*=1,067)				
No formal UK qualifications	82 (14)	31.3%	180 (20)	68.7%
GCSE/equivalent	85 (13)	18.1%	382 (27)	81.9%
A levels/equivalent	9 (3)	12.0%	69 (10)	88.0%
University degree/equivalent	46 (9)	17.6%	214 (18)	82.4%
Family income[b] (*n*=1,073)				
Bottom	96 (14)	29.5%	229 (22)	70.5%
Second	59 (11)	24.0%	187 (19)	76.0%
Third	19 (5)	9.1%	193 (15)	90.9%
Fourth	26 (6)	17.1%	126 (13)	82.9%
Top	25 (8)	18.2%	113 (12)	81.8%
Parental longstanding illness (*n*=1,073)				
Present	79 (12)	19.6%	323 (25)	80.4%
Absent	147 (17)	21.8%	524 (31)	78.2%
Parental mental health functioning (*n*=995)				
Serious mental distress	25 (7)	19.2%	105 (17)	80.8%
Moderate mental distress	82 (12)	22.9%	275 (22)	77.1%
No distress	92 (14)	18.0%	418 (28)	82.0%
Parental physical activity (*n*=1,073)				
Never	113 (15)	28.1%	289 (24)	71.9%
Seldom	24 (6)	14.2%	146 (17)	85.8%
Regular	28 (6)	12.8%	192 (19)	87.2%
Often	60 (12)	21.5%	221 (19)	78.5%
Parental play of physically active games with a child (*n*=1,073)				
Never	71(11)	25.1%	212 (23)	74.9%
Seldom	71 (11)	16.8%	352 (25)	83.2%
Regular	51 (10)	21.6%	187 (16)	78.4%
Often	32 (8)	24.7%	97 (13)	75.3%
Parental play of indoor games with a child (*n*=1,073)				
Never	35 (8)	33.9%	69 (11)	66.1%
Seldom	72 (12)	18.2%	322 (24)	81.8%
Regular	57 (11)	17.0%	278 (21)	83.0%
Often	62 (10)	25.6%	179 (20)	74.4%
Parental social support (*n*=1,073)				
Never	11 (5)	63.4%	7 (3)	36.6%
Seldom	11 (4)	30.6%	26 (7)	69.4%
Regular	10 (4)	12.0%	70 (11)	88.0%
Often	193 (20)	20.6%	745 (39)	79.4%

Parental time (*n*=1,066)				
Not enough time	62 (10)	16.6%	313 (25)	83.4%
Just enough time	85 (12)	24.2%	267 (20)	75.8%
Enough time	76 (13)	22.5%	263 (22)	77.5%
Availability of parks/playgrounds for a child to play (*n*=1,069)				
No	28 (6)	27.9%	71 (15)	72.1%
Yes	196 (20)	20.3%	773 (41)	79.7%
Type of area to raise a child (*n*=1,069)				
Poor	31 (8)	34.0%	61 (11)	66.0%
Average	57 (10)	23.9%	181 (20)	76.1%
Good	136 (16)	18.4%	602 (33)	81.6%

Note. All analyses are adjusted for complex sampling design features of the survey, attrition and non-response.
[a]*Psychosocial & behavioural problems.*
[b]*Based on the OECD equalized quintiles for the entire UK.*

Appendix L: Systematic review – Publication 1

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Authors' contribution:

Stella Arakelyan (corresponding author): identified research questions, defined inclusion and exclusion criteria, conducted systematic searches, selected the final pool of studies based on predefined inclusion criteria, extracted data from included studies, evaluated the risk of bias of included studies, conducted the analysis, interpreted the results, developed and submitted the manuscript.

Dr Donald Maciver: peer debriefing as part of PhD supervision, manuscript review.

Dr Robert Rush: peer debriefing as part of PhD supervision, manuscript review.

Prof. Anna O'Hare: peer debriefing as part of PhD supervision, manuscript review.

Prof. Kirsty Forsyth: peer debriefing as part of PhD supervision, manuscript review.

Family factors associated with participation of children with disabilities: a systematic review

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ABBREVIATION
RTI Research Triangle Institute

AIM The aim of this review was to synthesize empirical evidence of family factors associated with participation of children with disabilities aged 5 to 12 years to inform the development of family-centred participation-fostering interventions.
METHOD A systematic search was performed for articles published in English between 2001 and 2017 in MEDLINE, PsycINFO, CINAHL, Scopus, and ASSIA following the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines. Quality of evidence was appraised using the Research Triangle Institute Item Bank. Family factors associated with participation were identified and assessed using a multistage 'semi-quantitative' approach.
RESULTS Thirty studies were included in the review. Four non-modifiable 'status' factors consistently associated with participation were parental ethnicity, parental education, family type, and family socio-economic status. Six modifiable 'process' factors with consistent associations with participation were parental mental and physical health functioning, parental self-efficacy beliefs, parental support, parental time, family preferences, and activity orientation.
INTERPRETATION Rehabilitation professionals should direct their focus towards modifiable family factors as primary targets for family-centred interventions. Strategies that can improve families' access to information, counselling, and community support services are likely to support children's participation by empowering families and optimizing their health and well-being.

The benefits of participation for physical and psychological health and well-being of children with disabilities are well established.[1,2] Participation, broadly defined as 'involvement in a life situation',[3] is linked to children's growth and development, and enables experiences of meaning and purpose.[1,4,5] Optimizing participation of children with disabilities is an outcome desired by parents[6,7] and a primary goal of rehabilitation services.[5] However, children with disabilities participate less frequently and in a narrower range of activities, and are generally less involved when they do participate compared to their peers without disabilities.[7 10] As a result, children with disabilities may lack the benefits linked to participation.

The need to identify effective interventions to foster children's participation is an urgent priority. Better knowledge about factors contributing to children's participation and interdependencies between them is central for informing participation-fostering interventions. Previous reviews have examined personal and environmental factors that affect participation of children with disabilities.[11 17] The most commonly identified factors were child age, sex, skills and functional abilities, preferences and enjoyment, parental values and preferences, supports and acceptance from others, and accessibility of physical environment.[11 17] However, these reviews have described the influence of a wide range of factors on participation in specific activities[11,15,17] or settings,[14] focused predominantly on children with physical disabilities[11,13,15,17] or provided a narrative evaluation of the findings.[11,13 16]

Skills and competences shape participation, and are shaped by participation in safe and supportive life situations.[4] Family plays a central role in facilitating children's skills and competence development.[4,18 20] During middle childhood (defined as ages 5–12y), a child's mastery of developmental challenges is strongly influenced by family experiences and dynamics of relationships among family members.[21,22] Differences in family experiences produce important variations in children's participation, which affect children's life experiences in and beyond this developmental period.[21,22] It is thus important to focus on the family unit and better understand family/parental factors contributing to children's participation,[23,24] especially in middle childhood. Better knowledge about family factors consistently associated with participation of children with disabilities will support the development of participation-fostering family-centred interventions. The current review

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therefore aimed to: (1) offer an up-to-date, targeted synthesis of empirical evidence of family factors associated with participation; and (2) assess the relative strength and consistency of these associations in children with disabilities aged 5 to 12 years.

METHOD

The Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines[25] was used for this review. A protocol was developed a priori and published in the database of prospectively registered systematic reviews (www.crd.york.ac.uk/PROSPERO; registration number: CRD42017078202).

Search strategy and screening

A systematic search was performed by a single researcher (SA) for articles published in English between January 2001 and September 2017 in MEDLINE (EBSCO), PsycINFO (EBSCO), CINAHL (EBSCO), Scopus (ProQuest), and ASSIA (ProQuest). Restrictions to the publication date were applied to capture the literature reflective of the World Health Organization's International Classification of Functioning, Disability and Health for Children and Youth[3] conceptualization of participation as a health indicator influenced by a dynamic interaction between multiple factors unique to the child and the attitudinal, social, and physical environment. Search terms were determined after the detailed assessment of indexing terms applied to a 'known' set of articles meeting inclusion criteria for the review[26] and finalized with an information specialist. A combination of subject headings and free-text terms for disability, age of participants, participation, family factors, and study design was applied. The detailed search strategy for MEDLINE is supplied (Fig. S1, online supporting information). Additional studies were identified by a manual search of the reference lists of included articles and contents pages of *Developmental Medicine and Child Neurology*; *Archives of Physical Medicine and Rehabilitation*; *Disability and Rehabilitation*; *Child: Care, Health and Development*; and *Research in Developmental Disabilities* published from January 2012 to September 2017.

Initial electronic search yielded 2547 published articles. After removal of duplicates, 1532 titles and abstracts were screened for relevance by two independent researchers (SA and EC), resulting in 40 full-text articles retrieved for further eligibility assessment. Twenty-five articles corresponding to 21 individual studies met the inclusion criteria. Discrepancies in the agreement were resolved by consensus. A manual search identified additional nine studies (Fig. S2, online supporting information).

Articles were limited to peer-reviewed publications in English aiming to establish the relationship between family factors and participation of children with disabilities aged 5 to 12 years (mean age <12y). Presence of disability was identified through diagnosis presented in the article or identification of other health or educational support provisions. To ensure inclusion of a wide range of articles, the International Classification of Functioning, Disability and Health for Children and Youth's conceptualization of participation as the child's 'involvement in child-relevant life situations' was applied. Articles that considered known participation measures or in which participation items captured any combination of the International Classification of Functioning, Disability and Health for Children and Youth's nine Activities and Participation domains[3] were included. Family factors were defined as factors pertinent to the parents or family unit as a whole including any socio-demographic, psychological, behavioural, and parental health related factors. Only observational studies (i.e. prospective and retrospective cohort, case-control, cross-sectional) that reported quantitative evidence on associations of interest were included. Articles were excluded if they focused only on: (1) typically developing children, (2) wider community (e.g. neighbours or peers), (3) children's quality of life, behavioural difficulties, or (4) results were from case studies, conference posters, commentaries, or other grey literature.

What this paper adds

- Non-modifiable 'status' and modifiable 'process' factors are important in participation of children with disabilities.
- Disadvantaged family circumstances shaped by status factors are associated with reduced participation.
- Key process factors for intervention are parental mental and physical health and parental self-efficacy beliefs.
- Other important process factors for intervention are parental support and time, family preferences, and activity orientation.

Data extraction

Data extraction was performed using a standardized, prepiloted data extraction form by two researchers (SA and EC) independently. The following details were extracted: (1) generic information: study author(s), years of publication; (2) data describing study aims, design, and population; (3) details on family factors and participation outcome explored (i.e. activity types, settings, dimensions); and (4) study results and information for the assessment of the risk of bias. For studies including both children with and without disabilities of a wider age group, results pertinent to children with disabilities in the targeted age group were extracted unless no segregation of findings based on disability status and age group was provided.

Quality appraisal

Quality appraisal was performed by two independent researchers (SA and EC) using the adapted version of the Research Triangle Institute (RTI) Item Bank.[27] The RTI Item Bank captures all the domains critical for evaluating observational studies and allows customization from the investigator based on research needs. The RTI Item Bank has high interrater reliability[27] and has been previously used to assess the risk of bias and precision of observational studies.[28,29] The original RTI 29-item tool was adapted to fit the review objectives. The tailored RTI 14-item tool assessed the selection bias, detection bias,

attrition bias, selective outcome reporting, confounding, and validity of interpretation of studies (Table SI, online supporting information). Possible response categories to each item were combinations of 'yes', 'no', 'partially', 'cannot determine', and 'not applicable'. For ease of interpretation, the categories 'cannot determine' and 'partially' were collapsed into the 'unclear risk of bias' category. Agreement between two researchers was assessed by a joint probability agreement. All the discrepancies in opinion were resolved by consensus.

Data analysis

Meta-analysis was not feasible because of significant heterogeneity in study designs, family factors and participation activity types, settings, and dimensions measured. There was also incomplete reporting of findings (e.g. in some cases only significant results were reported) and statistics necessary for calculation of Pearson's zero-order correlation coefficients or alternative effect sizes.[30,31] Attempts to obtain required statistical information resulted in only a few corresponding authors acknowledging the receipt of data requests. Direct combination of standardized regression beta coefficients[30] was not appropriate because of substantial variations in covariates[31] in each multivariate model. Imputation of missing Pearson's zero-order correlations using the existing standardized regression beta coefficients[32] was not considered because this approach results in biased findings.[33]

Results were therefore synthesized and interpreted by a single researcher (SA) using a multistage 'semi-quantitative' approach.[17,34] If meta-analysis is not possible, such an approach is superior to narrative reporting because it provides objective evidence on strength, direction, and consistency of associations.[17] First, family factors assessing the same underlying construct but using different terms to describe it were combined into a single identifying factor (Table SII, online supporting information). Second, factors were classified into two major groups adapted from previous literature:[35,36] family 'status' and family 'process' factors. Third, for family factors examined by two or more studies two parameters were calculated:[17,34] (1) the number of studies that attempted to establish relationships between family factors and participation; and (2) the number of studies that established the relationship as significant ($p<0.05$). Then, the percentage of studies supporting the established relationship with participation was computed by dividing the number of studies that established a significant relationship by the total number possible. From the obtained percentage value, it was determined whether the family factor and participation outcome had a positive or negative association, inconsistent association, or no association. Family factors were considered to be associated with participation if at least 60 per cent of studies supported the established associations with the outcome.[17,34] The rules of classifying the consistency of evidence were adapted from previous research[17,34] and are summarized in Table I.

Table I: Rules of classifying the strength of evidence (adapted from Sallis et al.)[34]

% of studies supporting association	Coding	Code meaning
0 33	0	No association
34 59	?	Inconsistent association
60 100	+	Positive association
		Negative association

Double summary codes '++', ' ', '00' are applied when three or more studies support a positive/negative association or no association, and '??' is applied to show that the factor has been studied frequently but findings are inconsistent.

RESULTS

Thirty studies were included in the review. The detailed description of characteristics of these studies is supplied in Table SIII (online supporting information). Before 2010, only six articles[18,24,37–40] reporting on four unique samples of children with disabilities met our inclusion criteria. Six studies shared samples,[9,41–45] but differed substantially in the methodology and sample subgroups. These were retained as individual studies. Studies were conducted in Europe (n=9), Canada (n=7), United States (n=5), collaboratively between Canada and United States (n=2), Australia (n=4), and Israel (n=3). Except four longitudinal studies,[24,43,44,46] all studies used cross-sectional design.

Quality appraisal

Most of the studies described the study populations and selection in sufficient detail. One study was at high risk of bias because of study subgroups incomparability by age.[47] Eight studies included a convenience sample and were at unclear risk of selection bias. Study sample size ranged from 23 to 77 470 (weighted). None of the studies with a sample size of 67 or lower[37,39,43,48–50] provided sufficient justification on the adequacy of proposed sample sizes, hence, were rated at unclear risk of bias in external validity and precision. Measures used to collect data on family factors varied (Table SIII). Two studies, however, did not provide descriptions on how these data were obtained.[9,52] Participation was assessed using seven measurement tools (Table SIV, online supporting information) with the Children's Assessment of Participation and Enjoyment[53] being the most frequently used measure. Six studies did not report on validity and reliability of the participation measures used and were rated at unclear risk of bias.[51,54–58] Out of four studies with longitudinal designs, one study was at high risk of attrition bias,[43] while the remaining studies provided insufficient information to assess the attrition rate. Six studies provided inadequate adjustment for confounding variables in their analysis and were at unclear risk of bias. Taking into account the individual study's limitations, the findings were considered credible in 24 studies and partially credible in six of the included studies (Table SV, online supporting information). Nevertheless, no study was excluded from data synthesis. The agreement

in the quality appraisal between two researchers was high (78%).

Family factors

This review identified findings in two major groups of family factors: 'status' and 'process' as illustrated in Figure 1. This taxonomy differentiates modifiable family process factors (what families experience and do) from non-modifiable status factors (who families are).[35,36]

The review distinguished two subgroups of status factors: (1) family socio-demographic factors and (2) family structure; and four subgroups of process factors: (1) 'parental health and well-being', (2) 'parental beliefs, perceptions, and attitudes', (3) 'parental behaviour', and (4) 'family resources' (for details on how some factors were collapsed into a single identifying factor within each subgroup refer to Table SII. Evidence of the measures of association between each factor and participation dimensions, activity domains, and settings is summarized in Table SIII. Table II shows a summary of evidence on the consistency of associations for family factors examined in at least two studies (for the assessment rules refer to Table I). The sections below describe the main findings. Associations that were studied most often are discussed first.

Socio-demographic factors

Family income was studied most frequently, but findings showed inconsistent association with participation (Table II). Parental education was consistently associated with participation with lower education predicting reduced participation.[9,40,45,48,59,60] However, in two studies,[47,50] higher education predicted reduced participation. Lower socio-economic status[46,48,50,55,61] was consistently associated with reduced participation. Hispanic ethnicity increased risk for non-participation in organized activities,[55] and having ethnicity other than white was associated with decreased participation in leisure activities.[24] Indigenous Australian ethnicity was positively associated with participation in a single study.[46] Parental religion was examined in a single study with no association with participation reported.[50]

Family structure

Family type was studied most frequently. Living in a single-parent family was consistently associated with decreased participation in leisure activities.[40,55,62] No study showed a significant association between a number of siblings and participation. The presence of an older or a younger sibling in the household was examined, each in a single study. The relationship was established only between

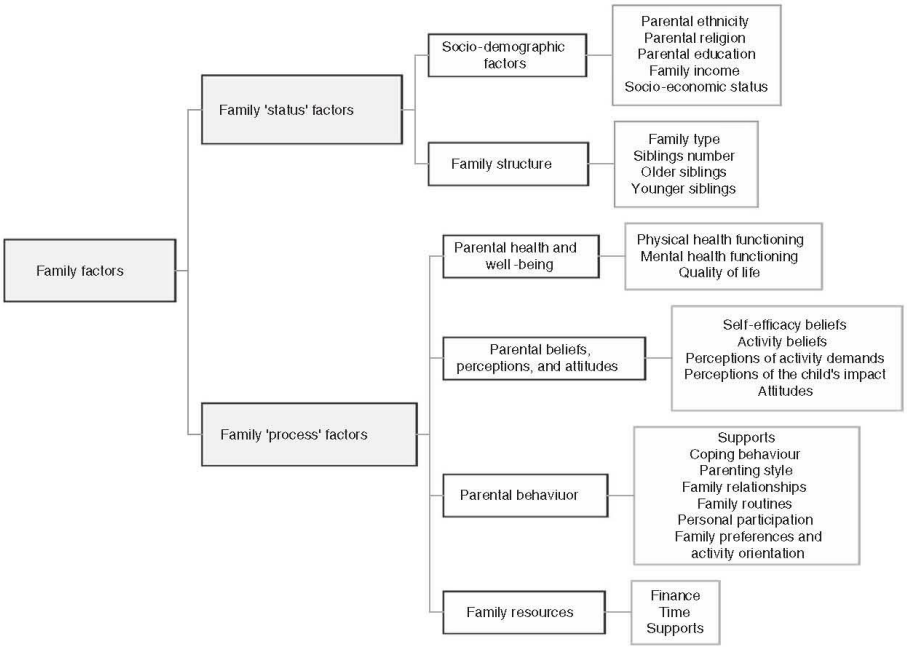

Figure 1: A taxonomy of family factors examined by the included studies

Table II: Summary of family factors potentially associated with participation of children with disabilities

Family factors	Number of studies[a]	Related to participation		Not related to participation	Coding	
		Number of studies[b]	Direction of association[c]	Number of studies[d]	% of studies supporting association[e]	Association[f]
Family status factors						
Family socio-demographic factors						
Family income[g]	12	7[40,47,49,52,54,60,79]	+	5[19,39,56,58,62]	58	??
Parental education	11	8[9,40,45,47,48,50,59,60]	+	3[19,37,44]	73	++
Socio-economic status	7	5[46,48,50,55,61]	+	2[38,43]	71	++
Parental ethnicity	4	3[24,46,55]	–	1[50]	75	–
Family structure						
Family type (single-parent)	5	3[40,55,62]	–	2[38,50]	60	––
Number of siblings	2			2[37,58]		0
Family process factors						
Parental health and well-being						
Mental health functioning	7	5[37,39,42,43,58]	+	2[24,59]	71	++
Physical health functioning	2	2[24,58]	+/–		100	+/–
Parental beliefs, perceptions, and attitudes						
Self-efficacy beliefs	3	2[50,60]	+	1[37]	67	+
Attitudes	2	1[41]	+	1[64]	50	?
Perception of child's impact	2	1[59]	+	1[37]	50	?
Parental behaviour						
Supports (for the child)	5	3[41,57,62]	+	2[18,64]	60	++
Family preferences and activity orientation	2	2[18,19]	+		100	++
Family relationships	2			2[18,19]		0
Coping behaviour	2			2[39,43]		0
Family resources						
Supports (for the family)	3	1[58]	+	2[43,56]	33	0
Time	2	2[58,59]	+		100	+

[a]The number of studies examined a particular association. [b]The number of studies established an association as being significant ($p<0.05$). [c]The prevailing direction of an association based on the frequency count. [d]The number of studies that established an association as being insignificant. [e]The percentage of studies supporting an association. [f]Double summary codes '++', '––' were applied when three or more studies supported a positive or negative association and '??' when the factor was studied frequently but findings were inconsistent. Code '+/–' was applied when studies differed in respect to the direction of established association. [g]Thirteen studies examined the effect of income on participation; but two studies[40,80] shared the sample of children with disabilities and hence were counted as one study.

the presence of an older sibling and participation in more household tasks for children with attention-deficit/hyperactivity disorder.[37]

Parental health and well-being

Parental mental health functioning, defined as a state of psychological, social, emotional well-being in which parents can realize their potential and cope with the stresses of life,[63] was the most frequently studied factor and the one consistently associated with participation. Parental stress was associated with reduced participation of children with cerebral palsy in leisure activities.[39,42,43] Higher parental stress was also associated with reduced assistance provided to children with attention-deficit/hyperactivity disorder to support their participation.[37] Children of parents with better mental health functioning had better participation in interpersonal relationships.[58] Parental physical functioning was consistently associated with participation, but the direction of associations varied across disabilities. A positive association was established for social participation of children with Down syndrome[58] and a negative association for participation of children with physical disabilities in recreational activities.[24] Parental quality of life was examined in a single study with a positive association established for participation in informal leisure activities.[43]

Parental beliefs, perceptions, and attitudes

Parental self-efficacy beliefs were studied most often showing consistent positive association with participation.[50,60] Attitudes of family/greater community[41,64] and parental perceptions of the child's impact on the family[37,59] were associated with participation inconsistently (Table II). Parental beliefs about activity and perceptions of activity demands were examined in a single study.[51] Children of parents who shared negative beliefs about activity (e.g. physical activity too overstimulating) and perceived it to be difficult to make required arrangements for their children participated in fewer physical activities.[51]

Parental behaviour

Supports for the child from parents/greater community was studied most often.[18,41,57,62,64] The presence of parental support was consistently positively associated with participation,[41,57] except in a single study where the association was negative.[62] Family preferences[18,19] and activity orientation[18,19,43] towards social and recreational activities were positively associated with children's

participation in leisure activities. Parental coping behaviour[39,43] and family relationships (cohesion/conflict)[18,19] were not related to participation. Parenting style, parents' personal participation, and family routines were examined, each in a single study. A positive relationship was established between parental prioritization of family routines and participation of children with attention-deficit/hyperactivity disorder in household tasks.[37] Negative parenting style[59] and parents' personal participation[43] were not related to participation.

Available resources

Supports for the family were examined most frequently but no conclusive evidence was found to support an association with participation. Studies examining the effect of parental time availability on participation revealed a consistent positive association.[58,59] Absence of financial and time impact on family (measured as a single construct) was examined in a single study with no association with participation established.[18] Another study, however, revealed significant differences between parents of children with disabilities compared to parents of typically developing peers in respect to finance and time being usually insufficient/inadequate to support their children's participation in the community.[7]

DISCUSSION

This systematic review summarized the evidence for family factors associated with participation of children with disabilities aged 5 to 12 years. Family factors identified in the review were grouped according to a taxonomy which distinguishes non-modifiable status factors from modifiable process factors. Status factors consistently associated with participation were parental ethnicity, parental education, family type, and socio-economic status. Process factors with consistent associations were parental mental and physical health functioning, parental self-efficacy beliefs, parental support, parental time, family preferences, and activity orientation. Implications of the key findings are discussed from theoretical, practical, and research perspectives.

In line with findings of previous research,[11,13,16] this review found consistent relationships between family socio-economic disadvantage, parental mental and physical health functioning, and children's participation. There is strong theoretical support[65] for the role of socio-economic disadvantage in influencing children's outcomes through parental mental health and quality of interpersonal relationships. The family stress model[65] suggests that parental psycho-emotional problems (stress, anxiety, depression), triggered or exacerbated by a lack of material resources, have a direct negative impact on marital relationships. Accumulated tension from interpersonal problems 'splits over' into parent–child interaction and manifests itself in the form of negative or punitive parenting.[65] Negative parental practices are associated with significant developmental difficulties for children, including behavioural problems, physical health difficulties, and problems in interpersonal relationships.[66] These developmental difficulties are linked to reduced participation.[1]

Further, parental mental and physical health problems undermine parents' confidence in their ability to successfully raise children, commonly referred to as parental self-efficacy beliefs.[67] Parents with low self-efficacy beliefs are less likely to adopt effective parenting behaviour[67] and provide safe and positive life situations for their children to participate in.[50] This in turn may reinforce perceptions of low self-efficacy beliefs and increase emotional tension in parents.[67]

It is important to consider that there may be a causal feedback loop. Parental stress and lower self-efficacy beliefs might be caused by having and/or caring for a child with disability. Evidence suggests that parents, especially mothers of children with disability, are at increased risk of poor mental[68,69] and physical health functioning.[69] This is a result of parental lack of ability to cope effectively with stressors caused by the demands of the child's illness.[70]

Given the importance of effective coping strategies in managing daily stressors, developing parental competence and their resilience might be promising targets for family-centred rehabilitation. Further, based on evidence suggesting the effectiveness of direct support strategies in lowering stress levels in families,[71] informing parents and referring them to existing counselling services, social parental networks, and respite services are important considerations.

Similar to previous reviews,[11,17] this review has identified that family preferences and activity orientation are important for children's participation. Families that are better oriented towards intellectual activities and participate more intensely in social-recreational activities create more opportunities for their children's direct involvement in activities[18,19] and competence development for future participation. Given that parents are the planners of family routines,[20,72,73] and behaviour is informed by knowledge, beliefs, and attitudes,[20,72] rehabilitation professionals may consider educating parents on the development of consistent family routines oriented towards active participation in recreational activities.

It was found that disadvantaged family circumstances (ethnic minority status, material, social, and educational deprivation) were associated with reduced participation. These findings were supported by large-scale survey data and are consistent with the results of previous reviews.[11,13] Social disadvantage appears to affect participation irrespective of children's disability type and health support needs. Socio-economically disadvantaged and single-parent families face greater challenges in meeting the child's and family immediate needs within limited financial and time resources.[74] Limited resources make it harder for parents to provide children with opportunities and experiences. Persistent lack of resources is also disruptive for parental psychological functioning and cohesive family relationships, and can result in less affectionate and more aggressive family climates.[65] The latter negatively affects children's well-being,[65] their beliefs of what they can accomplish, and their beliefs in what they can become.[66]

It appears that disadvantaged families encounter stressors associated with their family situations (financial and time tension, inequalities, limited knowledge, inability to seek for needed services) which affect parental attitudes and behaviour and may account for the risk to children's well-being and participation. While such circumstances are hard to modify, rehabilitation professionals may monitor disadvantaged families for factors amenable to change. Additionally, improving parental access to information (e.g. informing them of low-cost or free-of-charge activities), community support programmes, financial service/schemes, and childcare funds might ease the financial and time tension placed on families and support participation. Advocacy efforts directed towards promoting the rights of disadvantaged families with childhood disability can also educate local authorities/policy makers and help to create conditions necessary for positive reforms and reallocation of available resources for social integration and inclusion.

Review findings supported an association between parental support and participation. However, no association with participation was found for other indicators of family dynamics: family relationships (cohesion/conflict), attitudes, and parenting style. These findings appear counterintuitive. However, (1) the effect of these factors was not examined extensively, and (2) an absence of direct association does not imply no association. The effect of these factors might be mediated by the other factors directly affecting participation. Positive family dynamics (emotional bond, helpful and encouraging patterns of interaction between family members) is a distinctive feature of cohesive families. Families that display these characteristics participate more in recreational activities[18] which predicts more intense participation.[18] Further, cohesive families exercise effective parenting behaviour which is linked with children's positive development and their social and psycho-emotional functioning[66] – the predictors of more intense participation in leisure activities.[18] Rehabilitation professionals can inform and educate parents about the importance of family cohesive relationships, positive parenting, provision of supports, and opportunities in facilitating children's abilities to support participation in daily activities.

This review did not find a consistent association between family income and participation. This contradicts previous research[13,14,16,23] and earlier findings of this review that socio-economic disadvantage is a barrier to participation. There is, however, evidence suggesting that income in isolation may not be an effective indicator of economic disadvantage. Low income infers economic disadvantage rather than directly measuring it,[75] and it reveals little about real-life experiences. High-income families can still experience economic disadvantage through uncontrolled consumption or poor distribution of resources.[76] Equally, low-income families may be resource rich or have measures in place to alleviate disadvantage (e.g. through borrowing). It is difficulties meeting needs on available financial resources, gradually accumulating debt and 'money worries' that make families economically vulnerable.[77]

Future research

Results were derived from studies having predominantly cross-sectional designs. Prospective studies are needed to confirm findings. Except in six studies, the remaining studies examined participation in leisure and recreational activities. Research on participation in other settings, particularly school, is required. Research modelling the relationships between socio-economic disadvantage, parental mental and physical functioning, children's developmental outcomes, and participation using national longitudinal cohort data sets will help to identify and understand the factors across different international contexts. Findings also highlight the need for research on family dynamics and participation. Future research should consider measuring family economic vulnerability alongside family income to allow objective evaluations of economic disadvantage.

Strengths and limitations

This is the first review to systematically examine associations between family factors and participation in children with various disabilities aged 5 to 12 years. The review adhered to the PRISMA guidelines to ensure transparency and rigour in methodology. A multistage 'semi-quantitative' approach was used to analyse the data, thereby reporting objective evidence on the measures of associations. However, a few limitations should be acknowledged. Participation is a complex construct resulting from a dynamic relationship between a cluster of factors unique to the child, their family, and wider environment. This review targeted family/parental factors only and as such did not extract and assess the effect of other factors important to participation. The selection of papers was restricted to those published in peer-reviewed journals in English, which might have led to language and publication bias. Substantial heterogeneity in studies, selective reporting of findings, and incomplete reporting of essential statistics precluded correlational meta-analysis. The strengthening of standard methods of reporting of observational studies (e.g. STROBE statement)[78] would improve the ability to compare different studies, and facilitate future meta-analysis.

CONCLUSION

This review emphasized the role of family factors in shaping participation of children with disabilities. Family status and process factors were associated with participation, with varying effects across disabilities and participation activity domains. It appears that disadvantaged family circumstances shaped by status factors may predispose families to a variety of stressors. The way parents evaluate and deal with these stressors may adversely affect parental health and well-being, their subjective perceptions and behaviour, which in turn can pose the risk to children's well-being and participation. Family status factors are hard to modify; hence, rehabilitation professionals should prioritize process factors as primary targets of individually tailored, family-centred interventions. Key process factors for intervention are parental mental and physical health functioning, parental self-

efficacy beliefs, parental support, parental time, and family preferences and activity orientation. Strategies that can improve families' access to information, counselling services, parental support networks, and/or community support programmes are likely to support children's participation by empowering families and optimizing their health and well-being. Additionally, advocacy efforts promoting the rights of families with childhood disability at local and national level can be helpful in reshaping existing policy interventions to meet families' needs more effectively and thereby improve outcomes for children.

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SUPPORTING INFORMATION

The following additional material may be found online:

Figure S1: Search strategy.

Figure S2: Flow diagram detailing study selection process.

Table SI: Research Triangle Institute 14-item tool

Table SII: Factors combined into a single identifying factor

Table SIII: Summary of included studies

Table SIV: Description of validated tools applied to measure participation

Table SV: Quality appraisal based on the customized Research Triangle Institute 14-item tool

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Appendix M: Community participation of children with and without disabilities – Publication 2

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Authors' contribution:

Stella Arakelyan (corresponding author): identified research questions, searched for a suitable dataset based on predefined criteria, applied for an ethical approval, secured access to the fifth sweep of the MCS, identified the variables of interest, conducted the analysis, interpreted the results, developed and submitted the manuscript.

Dr Donald Maciver: peer debriefing as part of PhD supervision, manuscript review.

Dr Robert Rush: peer debriefing as part of PhD supervision, manuscript review.

Prof. Anna O'Hare: peer debriefing as part of PhD supervision, manuscript review.

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Community-based participation of children with and without disabilities

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ABBREVIATION
MCS5 Millennium Cohort Study fifth sweep

AIM To describe and compare the socio-demographic characteristics and community-based participation of children with and without disabilities.
METHOD This cross-sectional study reports data on 1073 children with disabilities (663 males, 410 females) and 11 122 children without disabilities (5617 males, 5505 females) aged 10 to 12 years from the fifth sweep of the Millennium Cohort Study. χ^2 was used to explore differences between the two groups. Logistic regression models were used to assess the relationships between childhood disability (dependent variable) and socio-demographic characteristics. Logistic regression models were also used to examine the associations between childhood disability (dependent variable) and participation in community-based activities.
RESULTS Children with disabilities were more likely to be male, have psychosocial and behavioural problems, live in single-parent households, and have a parent with a longstanding illness. Patterns of community-based participation were similar between children with and without disabilities. However, the extent to which the two groups participated differed. Children with disabilities participated with lower frequency in unstructured physical activities (adjusted odds ratio [OR] 2.41; 95% confidence interval [CI]: 1.95–2.99), organized physical activities (adjusted OR 2.29; 95% CI: 1.83–2.86), religious gatherings (adjusted OR 2.08; 95% CI: 1.35–3.20), and getting together with friends (adjusted OR 3.31; 95% CI: 2.61–4.20).
INTERPRETATION Socio-demographic characteristics differed between children with and without disabilities. Children with disabilities had greater restriction in participation compared to peers without disabilities. Participation promoting interventions are required to support the participation of children with disabilities in social and physical activities.

An estimated 93 million children under 14 years (5.1%) are living with moderate or severe disability worldwide.[1] There is a considerable global commitment to improve the health and social outcomes for children with disabilities and to support their participation in all aspects of life.[1,2] Reliable evidence on characteristics, life circumstances, and the participation of children with disabilities is essential to achieve these internationally agreed goals.[2]

Participation is a key contributor to a child's health and well-being.[3,4] Participation in age-appropriate activities supports social, physical, and emotional development and offers numerous health benefits.[4] Understanding and support for promoting the participation of children with disabilities is improving.[1,2] Nonetheless, recent evidence suggests that children with disabilities participate less frequently and are less involved when participating compared to children without disabilities.[4,5] Children with disabilities also experience greater restriction in community participation compared to participation in home or school settings.[5,6]

To direct the allocation of additional resources towards supporting children with disabilities and promoting their participation, professionals and policy-makers need robust evidence from nationally representative samples. There is currently a lack of such evidence.[5,7] Much existing research into participation in childhood disability is restricted to clinical samples and/or focused on children with physical disabilities.[5,7] Generalization from these samples to a wider population is limited.[5] Further, disability is a biopsychosocial phenomenon;[3] children with the same health conditions can have different experiences and participation in community-based activities depending on the environmental context.[7]

The present study has two objectives: (1) to provide evidence on socio-demographic characteristics of a nationally representative sample of children with and without disabilities aged 10 to 12 years; and (2) to describe and compare community-based participation between children with and without disabilities aged 10 to 12 years. Children between ages 10 to 12 years were of interest because: (1) 10- to 12-

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year-olds are gaining more independence, but have not yet transitioned into adolescence; and (2) 10- to 12-year-olds are changing physically, biologically, and emotionally which makes them sensitive to contextual influences and predisposes them to behavioural inconsistencies.[8] Findings from this study will help to identify inequalities between children with and without disabilities and provide professionals and policy-makers with a number of important considerations for the development of targeted interventions to better support children with disabilities in this age range.

What this paper adds

- Patterns of community-based participation were similar between children with and without disabilities.
- Children with disabilities had lower frequency of participation in physical activities, religious gatherings, and getting together with friends.

METHOD

Data

This is a cross-sectional study based on secondary analysis of an existing national cohort study. Data are from the Millennium Cohort Study fifth sweep (MCS5) carried out in 2012 and 2013.[9] The MCS is a nationally representative study which supplies a wide range of information about 19 000 children (and their families) born in the UK.[10] The first sweep was carried out in 2001 and 2002 when children were 9 to 11 months old and the follow-ups were conducted when children were aged 3, 5, 7, 11, and 14 years old.[10] Detailed descriptions of the complex sampling strategy (i.e. a random two-stage sampling of electoral wards with oversampling of families living in the smaller UK countries, families from deprived backgrounds, and high minority ethnic populations), participant recruitment, response rates, and handling of missing data (multiple imputation) are provided elsewhere.[10]

Ethical approval for the MCS5 was obtained by the Centre for Longitudinal Studies from the National Health Service Research Ethics Committee – the Yorkshire and Humber Research Ethics Committee on 29th July 2011 (Ref: 11/YH/0203).[10] Participants provided written informed consent to the survey and to the publication of results arising from the survey data.[10] Ethical approval for the secondary data analysis was granted by Queen Margaret University on 2nd July 2018. The fifth sweep supplies information on 13 469 children in 13 287 families living in the UK (response rate 69%).[10] This study reports on data collected from the main carer (96% mothers) on singleton births.

Measures

Childhood disability

Children with disabilities were identified through the main carers' affirmative responses to two questions: (1) whether children have a physical or mental health condition lasting or expected to last 12 or more months; and (2) whether this condition reduces children's ability to carry out day-to-day activities.

Psychosocial and behavioural functioning

This construct was measured using the total difficulties score from the parent-report Strengths and Difficulties Questionnaire.[11] The Strengths and Difficulties Questionnaire is a behaviour screening questionnaire for children and young people aged 11 to 17 years.[11] The 25 items in the questionnaire generate five subscales measuring: (1) emotional symptoms; (2) conduct/behavioural problems; (3) hyperactivity; (4) peer relationships problems; and (5) prosocial behaviour.[11] The Strengths and Difficulties Questionnaire total difficulties scores are generated by summing scores from the first four subscales. Based on standardized cut-offs,[12] children can be categorized into three subgroups, corresponding to 'normal', 'borderline', and 'abnormal' psychosocial and behavioural problems.[12]

Socio-demographic characteristics

Measures included child sex, ethnicity, and family characteristics: family type (single vs coparent household), parental education, family income, presence of parental longstanding illness, and parental mental health functioning. The selection of family characteristics was informed by literature showing the important role of these factors in child development and well-being.[1,2]

Parental education was determined through the highest educational qualification achieved according to the UK's national vocational qualification classification. A unified seven-category responses measure was collapsed into four corresponding to 'no formal UK qualifications', 'general certificate of secondary education/equivalent', 'A levels/equivalent', and 'university degree/equivalent'. The categories were developed based on the UK Government equivalents for academic qualifications.[13] The measure of family income was determined through the modified Organization for Economic Co-operation and Development equivalence scale since it takes into account the size and composition of families.[14] Parental mental health functioning was measured using the total scores generated from the Kessler 6 scale.[15] The Kessler 6 scale is a six-item psychological screening tool which is broadly used at the population level to screen for moderate distress (Kessler 6≥5) and severe mental illnesses (Kessler 6≥13).[16] Before calculating the total scores from the Kessler 6 scale, the authors checked the internal constancy of the Kessler 6 items available in the original survey. Reliability analysis for six items produced Cronbach's alpha of 0.89 which is indicative of a high level of internal consistency.[17]

Participation in community-based activities

In this study, participation in community-based activities was defined as a child's attendance in formal and informal everyday activities in the out-of-school community-based environment. In the MCS5, parents were asked to indicate how often their child had attended a variety of formal and

informal activities.[10] Most of the items were scored on a 7-point Likert type scale, ranging from daily to never.

Selection of community-based participation items from the MCS5 was informed by: (1) review of literature on participation measurement, and (2) cross-reference of available items in the MCS5 with a measure demonstrating a contemporary model of participation: the Participation and Environment Measure: Children and Youth[18] (Table S1, online supporting information). Although the Participation and Environment Measure: Children and Youth consists of fewer items compared to other participation measurement tools, evidence suggests its content density is high in relation to the International Classification of Functioning, Disability and Health's participation domains.[19]

Six items related to community-based participation were selected from the MCS5. The aspect of participation captured was attendance or 'being there'.[20] Attendance was measured in terms of: (1) diversity or range of activities in which the child took part;[20] (2) 'never participated' vs 'participated' in each activity; and (3) frequency of participation in each activity.[20] To measure participation diversity, a dichotomized scale was generated by collapsing the 7-point Likert type scale into 'never participated' and 'participated'. Diversity was measured by counting the number of activities for which the parent gave an affirmative response for participation.[20] Participation frequency measure was derived by collapsing the 7-point Likert type scale into three new categories corresponding to 'low', 'regular', and 'high' frequency of participation. These categories were developed in consultation with a group of experts in participation research.

Analysis

The analysis was completed using the SPSS Complex Samples Module, version 23.0 (IBM Corp., Armonk, NY, USA). All analyses were adjusted for complex sampling design features (clustering, stratification) of the survey, attrition, and non-response.[21] χ^2 tests of independence were used to explore the differences between children with and without disabilities on their socio-demographic characteristics and participation in each community-based activity. Results of χ^2 are based on the adjusted F and its degrees of freedom. The adjusted F is a variant of the second-order Rao-Scott adjusted χ^2 statistic and was used here because of a lack of independence of observations in the MCS5 caused by complex sampling design features of the survey.

Univariable logistic regression models were used to assess the relationships between the dependent variable: childhood disability (measured as 'present' vs 'absent') and socio-demographic characteristics. To explore whether differences between children with and without disabilities could be explained by variations in socio-demographic characteristics, a multivariable logistic regression model was fitted accounting for all these characteristics. Univariable logistic regression models were also fitted to explore the associations between childhood disability (dependent variable) and participation in each community-based activity. To explore whether differences in participation between children with and without disabilities could be explained by child sex and variations in socio-economic status (family income, parental education), multivariable logistic regression models were fitted adjusting for these key participation associated covariates.[1,4 6,22]

RESULTS

Children's characteristics and circumstances

The final sample consisted of 12 195 children aged 10 to 12 years (mean age 10y 8mo, standard error [SE] 0.06mo), out of which 6283 (51.5%) were male and 5915 (48.5%) female. One thousand and seventy-three children (8.8%; 95% confidence interval [CI]: 8.2–9.5%) were reported as having a disability and 1406 (11.6%) had teacher-identified special education needs. Clinical characteristics of children with disabilities by sex are presented in Table S2 (online supporting information).

The most commonly reported functional issues experienced by children with disabilities were learning, understanding, and concentrating (36.9%), socializing and behaviour (32.3%), stamina, breathing, and fatigue (27.1%), and mobility (17.3%). Many children with disabilities experienced more than one category of functional issues. Nearly half of the sample (48.4%) had teacher-identified special educational needs and 39.2% had clinically significant (abnormal) psychosocial and behavioural problems. Males were more likely to experience functional issues in learning, understanding, and concentrating ($p<0.001$), socializing and behaviour ($p<0.001$), mental health ($p<0.01$), stamina, breathing, and fatigue ($p=0.02$), and mobility ($p=0.01$) compared to females. Similarly, a higher proportion of males had psychosocial and behavioral problems ($p<0.001$) and were identified with special education needs ($p<0.001$; Table S2).

Children with and without disabilities differed in respect to socio-demographic characteristics (Table 1). Significant associations were established between presence of childhood disability and child sex ($p<0.001$), psychosocial and behavioural problems ($p<0.001$), family type ($p<0.001$), parental education ($p=0.001$), and family income ($p<0.001$). Associations were further established between childhood disability and parental health indicators (Table 1). The odds of having a disability was 1.59 times higher for males compared to females (crude odds ratio [OR] 1.59; 95% CI: 1.35–1.87; Table 2). Children with disabilities also had higher odds of having clinically significant psychosocial and behavioural problems (crude OR 9.70; 95% CI: 7.98–11.8), living in single-parent households (crude OR 1.91; 95% CI: 1.61–2.27), having a parent with no formal UK qualification (crude OR 1.61; 95% CI: 1.28–2.02) or general certificate of secondary education/equivalent (crude OR 1.32; 95% CI: 1.10–1.59), and being from the bottom 60 per cent of financially more deprived families (Table 2).

Further, the odds of living with a parent having long-standing illness was nearly three times higher for children

Table 1: Main carer report characteristics of children with and without disabilities aged 10–12y

Characteristics	Children with disabilities[a]		Children without disabilities[b]		
	Population estimate (SE)	%	Population estimate (SE)	%	χ^2 test[c]
Sex					
Male	663 (40)	61.8	5617 (228)	50.5	$p<0.001$
Female	410 (30)	38.2	5505 (220)	49.5	
Country of origin					
England	830 (52)	83.8	9007 (409)	82.4	$p=0.39$
Scotland	85 (12)	8.5	936 (51)	8.6	
Wales	44 (5)	4.5	538 (47)	4.9	
Northern Ireland	32 (5)	3.2	447 (24)	4.1	
Ethnicity					
Mixed/other	69 (12)	6.4	552 (60)	5.0	$p=0.03$
Black/Black British	27 (9)	2.5	417 (77)	3.7	
Indian/Pakistani/Bangladeshi	53 (13)	5.0	830 (128)	7.5	
White	924 (51)	86.1	9323 (355)	83.8	
PSB problems					
Abnormal	410 (31)	39.2	814 (53)	7.6	$p<0.001$
Borderline	155 (17)	14.8	649 (44)	6.0	
Normal	481 (31)	46.0	9264 (348)	86.4	
Family type					
Single-parent household	569 (39)	53.0	4109 (188)	37.0	$p<0.001$
Coparent household	504 (33)	47.0	7004 (281)	63.0	
Parental education					
No formal UK qualifications	262 (27)	24.6	2134 (136)	19.3	$p=0.001$
GCSE/equivalent	467 (32)	43.7	4624 (211)	41.8	
A levels/equivalent	79 (11)	7.4	894 (46)	8.1	
University degree/equivalent	260 (21)	24.3	3401 (161)	30.8	
Family income[d]					
Bottom	325 (27)	30.3	2140 (153)	19.2	$p<0.001$
Second	247 (24)	23.0	2190 (106)	19.7	
Third	212 (17)	19.8	2229 (102)	20.0	
Fourth	152 (16)	14.1	2285 (106)	20.5	
Top	138 (15)	12.9	2277 (132)	20.5	
Parental longstanding illness					
Present	402 (31)	37.5	1936 (91)	17.4	$p<0.001$
Absent	671 (40)	62.5	9180 (366)	82.6	
Parental mental health functioning					
Serious mental distress	130 (20)	13.1	590 (40)	5.8	$p<0.001$
Moderate mental distress	356 (27)	35.8	2818 (132)	27.7	
No distress	509 (35)	51.2	6781 (255)	66.6	

All analyses are adjusted for complex sampling design features of the survey, attrition, and non-response. Because of rounding column percentages may not add exactly to 100%. [a]n=1073. [b]n=11 122. [c]Significance is based on the adjusted F and its degrees of freedom. [d]Based on the Organization for Economic Co-operation and Development equalized quintiles for the entire UK. SE, standard error; PSB, psychosocial and behavioural; GCSE, general certificate of secondary education.

with disabilities (crude OR 2.84; 95% CI: 2.40–3.36) compared to peers without disabilities. Children with disabilities also were more likely to be from families with a parent having moderate (crude OR 1.68; 95 % CI: 1.41–2.01) or serious mental distress (crude OR 2.93; 95% CI: 2.14–4.03; Table 2).

To examine whether observed differences between groups could be explained by variations in socio-demographic characteristics, a multivariable logistic regression model was fitted. In the multivariable model, child sex, psychosocial and behavioural problems, family type, and parental longstanding illness continued to be associated with childhood disability (Table 2). Based on the adjusted model, males (adjusted OR 1.37, 95% CI: 1.15–1.64), children with borderline (adjusted OR 4.27; 95% CI: 3.32–5.50), and abnormal psychosocial and behavioural problems (adjusted OR 8.86; 95% CI: 7.12–11.01), children from single-parent households (adjusted OR 1.37, 95% CI: 1.11–1.68), and those with a parent having a longstanding illness (adjusted OR 2.36; 95% 1.94–2.87) were more likely to have a disability.

Participation in community-based activities

Patterns of participation (i.e. the ranking of proportions for participation across activities) in community-based activities were similar between children with and without disabilities (Table S3, Fig. S1, online supporting information). Higher proportions of children in both groups participated in community-based activities that were more unstructured in nature, such as getting together with friends (88% and 97% of children with and without disabilities participated) and unstructured physical activities (86% and 94% of children with and without disabilities participated).

The proportion of children with disabilities who never participated in each community-based activity ranged from 12.2 per cent to 67.7 per cent, whereas among children without disabilities this proportion ranged from 3.4 per

Table 2: Logistic regression analysis of childhood disability by socio-demographic characteristics

	Univariable analysis			Multivariable analysis[a]		
Characteristics	*B* (SE)	COR	95% CI	*B* (SE)	AOR	95% CI
Sex						
Male	0.46 (0.08)[b]	1.59	(1.35 1.87)	0.32 (0.09)[b]	1.37	(1.15 1.64)
Female (ref)	0.00	1.00		0.00	1.00	
Ethnicity						
Mixed/other	0.23 (0.18)	1.26	(0.90 1.78)	0.19 (0.20)	1.21	(0.82 1.79)
Black/Black British	0.42 (0.32)	0.66	(0.35 1.22)	0.16 (0.37)	0.85	(0.41 1.77)
Indian/Pakistani/Bangladeshi	0.44 (0.18)[d]	0.65	(0.46 0.92)	0.41 (0.19)[d]	0.66	(0.46 0.96)
White (ref)	0.00	1.00		0.00	1.00	
PSB problems						
Abnormal	2.27 (0.10)[b]	9.70	(7.98 11.8)	2.18 (0.11)[b]	8.86	(7.12 11.0)
Borderline	1.52 (0.13)[b]	4.59	(3.57 5.91)	1.45 (0.13)[b]	4.27	(3.32 5.50)
Normal (ref)	0.00	1.00		0.00	1.00	
Family type						
Single-parent household	0.65 (0.09)[b]	1.91	(1.61 2.27)	0.31 (0.10)[c]	1.37	(1.11 1.68)
Coparent household (ref)	0.00	1.00		0.00	1.00	
Parental education						
No formal UK qualifications	0.48 (0.12)[b]	1.61	(1.28 2.02)	0.16 (0.15)	0.85	(0.63 1.14)
GCSE/equivalent	0.28 (0.09)[c]	1.32	(1.10 1.59)	0.11 (0.11)	0.89	(0.72 1.11)
A levels/equivalent	0.14 (0.16)	1.15	(0.85 1.56)	0.04 (0.17)	0.96	(0.69 1.33)
University degree/equivalent (ref)	0.00	1.00		0.00	1.00	
Family income[e]						
Bottom	0.92 (0.14)[b]	2.50	(1.92 3.26)	0.21 (0.18)	1.23	(0.87 1.76)
Second	0.62 (0.13)[b]	1.86	(1.43 2.40)	0.06 (0.16)	1.06	(0.77 1.45)
Third	0.45 (0.13)[b]	1.57	(1.23 2.01)	0.10 (0.15)	1.11	(0.83 1.49)
Fourth	0.09 (0.14)	1.09	(0.83 1.44)	0.11 (0.16)	0.90	(0.66 1.22)
Top (ref)	0.00	1.00		0.00	1.00	
Parental longstanding illness						
Present	1.04 (0.09)[b]	2.84	(2.40 3.36)	0.86 (0.10)[b]	2.36	(1.94 2.87)
Absent (ref)	0.00	1.00		0.00	1.00	
Parental mental health functioning						
Serious mental distress	1.08 (0.16)[b]	2.93	(2.14 4.03)	0.31 (0.19)	0.74	(0.51 1.07)
Moderate mental distress	0.52 (0.09)[b]	1.68	(1.41 2.01)	0.14 (0.10)	0.87	(0.71 1.07)
No distress (ref)	0.00	1.00		0.00	1.00	

All analyses are adjusted for complex sampling design features of the survey, attrition, and non-response. [a]n=11 095. The multivariable model is fitted on dependent variable: childhood disability adjusting for the socio-demographic variables. [b]$p<0.001$. [c]$p<0.01$. [d]$p<0.05$. [e]Based on the Organization for Economic Co-operation and Development equalized quintiles for the entire UK. *B*, beta coefficient; SE, standard error; COR, crude odds ratio; CI, confidence interval; AOR, adjusted odds ratio; PSB, psychosocial and behavioural; GCSE, general certificate of secondary education.

cent to 57.2 per cent (Table S3, Fig. S2, online supporting information). Similar to children without disabilities, the highest restriction in participation for children with disabilities was for vacations abroad (67.7% never participated), followed by participation in religious gatherings (58.7% never participated), visiting a library (39.7% never participated), and participation in organized physical activities (38.5% never participated).

Participation diversity scores were roughly similar. Children with disabilities participated on average in 3.7 out of 6 activities (SE 0.06, 95% CI: 3.66–3.81), whereas children without disabilities in 4.2 activities (SE 0.02, 95% CI: 4.18–4.28) (Fig. S3, online supporting information). Although sharing similarities in the patterns and average diversity scores of participation, the extent to which children with and without disabilities participated in each community-based activity differed (Table 3).

Based on univariable logistic regression results, children with disabilities had the highest restriction in participation in getting together with friends (crude OR 3.95, 95% CI: 2.96–5.28) followed by participation in unstructured physical activities (crude OR 2.51, 95% CI: 1.95–3.22) and organized physical activities (crude OR 1.95, 95% CI: 1.63–2.34) compared to peers. To examine whether observed differences could be explained by variations in child sex (predominantly associated with activity preferences), family income, and parental education, each univariable model was adjusted for these covariates. Based on the adjusted multivariable model results, children with disabilities were less likely to get together with friends (adjusted OR 3.22; 95% CI: 2.38–4.34), participate in unstructured physical activities (adjusted OR 2.27; 95% CI: 1.76–2.94), organized physical activities (adjusted OR 1.73; 95% CI: 1.43–2.09), or religious gatherings (adjusted OR 1.28; 95% CI: 1.10–1.48), and travel for vacations abroad (adjusted OR 1.28; 95% CI: 1.06–1.54; Table 3).

The frequency with which children with and without disabilities participated in each community-based activity was significantly different, except for visiting a library (Table S4, online supporting information). Proportionately more children with disabilities participated in activities with low frequency compared to children without disabilities. Similarly, a lower proportion of children with disabilities participated in each of these activities with

regular or high frequency (Table S4). Univariable logistic regression results showed that for children with disabilities the odds for lower frequency of participation in unstructured physical activities, organized physical activities, and getting together with friends were significantly higher compared to children without disabilities (Table 4). These differences did not change after adjusting for child sex, family income, and parental education. Based on the adjusted multivariable models, children with disabilities were twice as likely to have lower frequency of participation in unstructured physical activities (adjusted OR 2.41; 95% CI: 1.95–2.99), organized physical activities (adjusted OR 2.29; 95% CI: 1.83–2.86), or religious gatherings (adjusted OR 2.08; 95% CI: 1.35–3.20), and three times more likely to have lower frequency in getting together with friends (adjusted OR 3.31; 95% CI: 2.61–4.20; Table 4).

DISCUSSION

This study provides evidence on socio-demographic characteristics and community-based participation of 12 195 children with and without disabilities aged 10 to 12 years across the UK. One thousand and seventy-three (8.8%)

Table 3: Logistic regression analysis of childhood disability by participation (never vs ever) in each community-based activity

	Univariable analysis			Multivariable analysis[a]		
Community-based activities	*B* (SE)	COR	95% CI	*B* (SE)	AOR	95% CI
Visiting a library						
Never participated	0.20 (0.10)[d]	1.22	(1.01 1.48)	0.12 (0.10)	1.12	(0.93 1.36)
Participated (ref)	0.00	1.00		0.00	1.00	
Organized physical activities						
Never participated	0.67 (0.09)[b]	1.95	(1.63 2.34)	0.55 (0.10)[b]	1.73	(1.43 2.09)
Participated (ref)	0.00	1.00		0.00	1.00	
Unstructured physical activities						
Never participated	0.92 (0.13)[b]	2.51	(1.95 3.22)	0.82 (0.13)[b]	2.27	(1.76 2.94)
Participated (ref)	0.00	1.00		0.00	1.00	
Religious gatherings						
Never participated	0.31 (0.07)[b]	1.37	(1.18 1.58)	0.24 (0.08)[c]	1.28	(1.10 1.48)
Participated (ref)	0.00	1.00		0.00	1.00	
Getting together with friends						
Never participated	1.37 (0.15)[b]	3.95	(2.96 5.28)	1.17 (0.15)[b]	3.22	(2.38 4.34)
Participated (ref)	0.00	1.00		0.00	1.00	
Vacations abroad						
Never participated	0.45 (0.09)[b]	1.57	(1.32 1.87)	0.24 (0.10)[d]	1.28	(1.06 1.54)
Participated (ref)	0.00	1.00		0.00	1.00	

All analyses are adjusted for complex sampling design features of the survey, attrition, and non-response. [a]All multivariable models are adjusted for child sex, family income, and parental education. [b]$p<0.001$. [c]$p<0.01$. [d]$p<0.05$. *B*, beta coefficient; SE, standard error; COR, crude odds ratio; CI, confidence interval; AOR, adjusted odds ratio.

Table 4: Logistic regression analysis of childhood disability by participation frequency in each community-based activity

	Univariable analysis			Multivariable analysis[a]		
Community-based activities	*B* (SE)	COR	95% CI	*B* (SE)	AOR	95% CI
Organized physical activities						
Low	0.95 (0.11)[b]	2.58	(2.08 3.20)	0.83 (0.11)[b]	2.29	(1.83 2.86)
Regular	0.47 (0.10)[b]	1.60	(1.31 1.96)	0.44 (0.10)[b]	1.55	(1.26 1.90)
High (ref)	0.00	1.00		0.00	1.00	
Unstructured physical activities						
Low	0.92 (0.10)[b]	2.52	(2.07 3.07)	0.88 (0.11)[b]	2.41	(1.95 2.99)
Regular	0.01 (0.11)	0.99	(0.80 1.22)	0.05 (0.11)	1.05	(0.85 1.29)
High (ref)	0.00	1.00		0.00	1.00	
Religious gatherings						
Low	0.39 (0.20)	1.47	(0.99 2.18)	0.73 (0.22)[c]	2.08	(1.35 3.20)
Regular	0.07 (0.21)	1.07	(0.70 1.62)	0.44 (0.23)	1.55	(0.99 2.43)
High (ref)	0.00	1.00		0.00	1.00	
Getting together with friends						
Low	1.28 (0.12)[b]	3.58	(2.84 4.52)	1.20 (0.12)[b]	3.31	(2.61 4.20)
Regular	0.06 (0.09)	1.06	(0.89 1.26)	0.15 (0.09)	1.16	(0.98 1.38)
High (ref)	0.00	1.00		0.00	1.00	
Vacations abroad						
Low	0.51 (0.34)	1.67	(0.85 3.25)	0.23 (0.35)	1.26	(0.63 2.50)
Regular	0.17 (0.37)	1.19	(0.57 2.48)	0.16 (0.38)	1.18	(0.56 2.48)
High (ref)	0.00	1.00		0.00	1.00	

All analyses are adjusted for complex sampling design features of the survey, attrition and non-response. [a]All multivariable models are adjusted for child sex, family income, and parental education. [b]$p<0.001$. [c]$p<0.01$. *B*, beta coefficient; SE, standard error; COR, crude odds ratio; CI, confidence interval; AOR, adjusted odds ratio.

out of 12 195 children aged 10 to 12 years were reported to have a disability. Socio-demographic characteristics of children with disabilities differed from those of children without disabilities. Childhood disability was significantly more prevalent in socio-economically disadvantaged families. Children with disabilities were also more likely to be male, have psychosocial and behavioural problems, live in single-parent households, and have a parent with a longstanding illness. These findings are consistent with the results of previous research.[23,24]

A link between socio-economic disadvantage and childhood disability is well established.[1,2] Literature suggests that low birthweight, undernourishment, and suboptimal living conditions are some of the factors that may predispose children born to socio-economic disadvantage to the onset of health conditions and associated disability.[1] On the other hand, direct costs associated with childhood disability are high and many families have to outlay additional resources (i.e. financial, time, support) to effectively support children.[1] To meet care commitments, some parents are unable to participate in employment.[1,2] Because of these reasons many families with childhood disability may experience socio-economic disadvantage.[1,2]

Approximately two-thirds of children with disabilities were male. Moreover, a significantly higher proportion of males had psychosocial and behavioral problems and were identified with special educational needs compared to females. Many theories have been proposed to explain this phenomenon with biological vulnerability, referral bias, and testing bias being the most plausible explanations at hand.[25]

For children with disabilities the odds of living in single-parent households and in families with a parent having a longstanding illness were significantly higher, as found in other studies.[23,24] These associations persisted after adjusting for key cofounders. High divorce rate and a presence of multiple births and disabilities are some of the proposed explanations to observed high rates of single-parenthood in households with childhood disability.[23] Although associations between childhood disability and parental poor health have been described previously,[23] it is not clear from the literature whether health problems precede or are triggered or exacerbated by stressors related to having and/or caring for a child with a disability.

Although patterns of participation were similar, the extent to which children with disabilities participated in each activity differed as compared to children without disabilities. Children with disabilities had more restricted participation in five out of six community-based activities. They also participated in those activities with lower frequency. These results are consistent with studies comparing community participation of children with and without disabilities in other cultural contexts.[5,26] Participation in unstructured spontaneous activities was proportionately the highest within both groups. Nevertheless, children with disabilities were three times more likely to have lower frequency in getting together with friends compared to peers. This is concerning given that social participation offers numerous benefits and is a valuable experience for children.[27] Social participation supports children's social, emotional, and intellectual development and helps children to build their self-esteem and confidence.[27] Social interactions with peers are also powerful motivators for physical activity and encouraging children to engage in activities more regularly.[27] This is important given the findings of this study that children with disabilities were twice as likely to have lower frequency of participation in unstructured and organized physical activities compared to peers even after accounting for child sex, family income, and parental education.

Groups differed in respect to participation in religious gatherings and travelling for vacations abroad. Nevertheless, less than half of children attended religious gatherings in both groups. This is not surprising given that UK church membership has been declining rapidly over the last two decades.[28] More than half of the British public now describe themselves as having 'no religion'.[28] Further, although children with disabilities were less likely to travel for vacations abroad compared to peers, there were no group differences in respect to participation frequency after controlling for potential confounders.

Recommendations for practice and further research

Families of children with disabilities living in disadvantaged circumstances may lack resources to seek support. Empowering families and improving parental access to community support programmes, parental counselling services, and financial schemes may help families to improve life chances of children with disabilities.

Although the average scores for diversity of participation did not differ much, children with disabilities were more likely to have restricted participation and lower frequency of participation in most of the community-based activities assessed compared to children without disabilities. Therefore, to have a more complete understanding about participation differences between groups, it is important to measure both diversity and frequency with which activities are undertaken.

Given observed group differences in participation and evidence suggesting that the gap in participation widens as children move to adolescence,[1] children with disabilities may benefit from strategies directed towards promoting their participation in community-based activities, especially in activities which are social and physical in nature. Previous research[29] identified child functional limitations, high costs, and a lack of nearby facilities or programmes as main reasons contributing to restricted participation in unstructured physical activities and sports. Setting up mutually agreed, short-term attainable goals while taking into account children's functional capabilities, interests, and preferences can help to develop and sustain motivation for activities that are physical in nature. Professionals can also share information on physical activity and sport opportunities in local facilities and educate parents on affordable

alternatives which will enable children with disabilities to be active and which will promote fitness and fun.

This study also established that children with disabilities were more likely to have psychosocial and behavioural problems. Psychosocial and behavioural problems were linked to reduced participation in previous research.[6,26] Further research exploring the independent effect of psychosocial and behavioral problems on the participation of a nationally representative sample of children with disabilities will be helpful. Nevertheless, given the evidence at hand, focusing on children's psychosocial needs and working towards enacting behavioural change strategies may enhance their abilities to effectively socialize with peers, engage with environments, and optimize their participation. More research is needed to explore children's own perspectives on participation to inform the development of more tailored interventions.

Study strengths and limitations

Secondary analysis of data has known limitations. However, this study used data from a nationally representative sample, a factor which increases confidence in the generalizability of results. The study analysed main-carer reports. Although most of the reports were from biological mothers, information or recall bias might be present. Six participation items were selected from the MCS5 and matched to a validated measure of participation. Nevertheless, the validity of these items is unknown. Further, participation in community-based activities is not limited to the activities described in this study. Finally, participation was conceptualized as attendance overlooking at other important aspects of participation such as involvement and enjoyment. Though items measuring subjective aspects of participation were not available in the MCS5.

CONCLUSION

Socio-demographic characteristics differed between children with and without disabilities. Childhood disability was more prevalent in disadvantaged families and families with a presence of parental health problems. Empowering families and improving parental access to support programmes, counselling services, and financial schemes might help disadvantaged families to provide better opportunities for their children and support their participation in community-based activities. Further, given the findings, effective strategies are required to promote the participation of children with disabilities in activities that are social and physical in nature. Development of mutually agreed goal-directed activities which account for children's capabilities, psychosocial and emotional needs, and interests might sustain and increase community-based participation. Further, practical, emotional, and informational support regarding local opportunities and affordable alternatives may enable children with disabilities to be active and promote fitness and fun.

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SUPPORTING INFORMATION

The following additional material may be found online:

Table S1: Cross-reference of available participation items in the MCS5 with the community participation items in the Participation and Environment Measure: Children and Youth

Table S2: Clinical characteristics of children with disabilities aged by sex

Table S3: Children's participation in each community-based activity

Table S4: Children's frequency of participation in each community-based activity

Figure S1: Percentages of children who participated in each community-based activity.

Figure S2: Percentages of children who never participated in each community-based activity.

Figure S3: The range of community-based activities children participated in.

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