FACTORS AFFECTING THE PARTICIPATION OF PHYSICALLY DISABLED CHILDREN AND YOUNG PEOPLE IN OUT-OF-SCHOOL ACTIVITIES IN CHESHIRE

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ABSTRACT

Physically disabled children and young people (PDC&YP) face many challenges when participating in out-of-school activities. PDC&YP should have the same choices and opportunities as other C&YP; to forge friendships locally and to access out-of-school activities (Knight et al., 2013). However PDC&YP have fewer opportunities than their non-disabled peers due to challenges such as access, support and suitable provision.

This multi-method qualitative study examined the factors affecting participation of PDC&YP in out-of-school activities in Cheshire. The perspectives of PDC&YP, parents and service providers who plan and run mainstream activities were sought using a range of data collection tools. This included interviews, focus groups and creative focus groups with 63 participants across two studies. Study one included the service users: 13 PDC&YP and 19 parents, whilst study two comprised of service providers: 11 activity planners and 20 volunteers. Play-based creative focus groups were specifically designed for PDC&YP aged 7 to 17 years.

Study one demonstrated that PDC&YP enjoy specialist disabled activities to meet others ‘like them’ but want more local opportunities to do this. Some PDC&YP and parents felt they were not disabled enough for ‘disabled’ activities but not able enough for mainstream. PDC&YP requiring personal care were a ‘hidden’ group who are certainly at risk of missing out on experiences that they are entitled to. This group of PDC&YP across the UK need significant attention as the picture in Cheshire gives only a snapshot of the possible limited provision nationwide.

Findings from study two highlighted that service providers had a mix of experiences but most lacked disability awareness but wanted and needed training. Collectively the two studies show that independence, health benefits and role models are facilitators in to out-of-school activities but there are still several challenges to overcome such as access, communication issues and a mismatch of expectations.

The study concludes by presenting the need to improve provision in Cheshire through disability awareness training and a co-ordinated partnership approach to be employed by the local authority to raise the profile of disability and ‘bridge the gap’ between service users and service providers.

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GLOSSARY OF TERMS

Terms
The term **children** is defined according to the United Nations Convention on the Rights of the Child (1989). A child is anyone under the age of 18 years. The UK has ratified this convention. There are a number of different laws within the UK that specify age limits in different circumstances such as people aged 16 or over are entitled to consent to their own treatment (NHS, 2016). **Young people (YP)** are defined by The World Health Organisation as ages 10-19 years. **Physically disabled children and young people (PDC&YP)** in this study range from 7-17 years old. Younger children may have difficulty contributing at the same level as the older children and adolescents and are therefore not included. There is tension in the literature surrounding the terminology used within the field; disabled person versus person with disabilities. This is particularly noticeable across national and international literature. However “the term considered to be best practice from the disabled people’s movement is, in fact, the term `disabled children`” (Kids Playwork Inclusion Project 2011: 2). This was confirmed by gatekeepers of the current study who were consulted about the wording ‘physically disabled C&YP.’ Several gatekeepers were disabled and were happy for me to use this terminology. Any subsequent changes to this will be reflected in subsequent published papers or dissemination. **Gatekeepers** are adults who are there to safeguard the interests of others, for example, potential research participants (Fargas-Malet et al., 2010, Moule and Hek, 2011). The gatekeeper is “someone who has the authority to grant or deny permission to access potential participants and/or the ability to facilitate such access” (King and Horrocks, 2010: 31). This is especially vital in this programme of study to ensure that the research is suitable for PDC&YP at this particular time as the gatekeeper will be aware of anything going on in their lives which may render it inappropriate, for example, family issues or illness. PDC&YP and families are referred to as **service users** as this encompasses the group in terms of users or potential users of out-of-school activities. I am cognisant and respect the discussion from ‘Shaping Our Lives’ (2009), a national service user network, who have questioned the use of the term ‘service user` as it can restrict

identity in terms of being a passive recipient of services. It also fails to capture those who are denied or refuse a service (McLaughin 2010:1-2). However this is the current terminology used in policy documents, any subsequent changes to this will be reflected in subsequent published papers or dissemination.

Disability is defined in The Equality Act (2010:7) as a person who has a "physical or mental impairment which has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities." Within this study the term **physical disability** is only defined as how the participants perceive themselves and if they feel they have a physical disability they volunteer for the study and are therefore included.

An **impairment** relates to the individual's physical, mental or sensory functioning (Scope, 2019). Due to moving away from the medical model and focusing on society's challenges, the term disability will be used.

Out-of-school refers to anything that PDC&YP may or may not do after school or at weekends, for example, sports, social activities, spiritual groups and family activities.

Mainstream activities are referred to as those which are not specifically designed for disabled C&YP. These are activities within the community that any C&YP should be able to access. To echo the point made by Hodge Runswick-Cole (2013) the term mainstream is used with some reluctance and a degree of concern that it continues to "promote the ableist assumption that certain spaces will remain inaccessible to those disabled people who are positioned as not being able to be accommodated within the mainstream" Runswick-Cole (2013:311). With this in mind, the term mainstream is used here simply to reflect policy language and, as a term with which individuals are familiar.

Participation means taking part and is a very broad concept. The International Classification of Functioning Disability and Health (ICF) define participation as involvement in life situations and how attitudinal and environmental factors affect them (World Health Organisation, WHO, 2001). Alderson (2008:106) states that a "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."

In this study **inclusion** is where PDC&YP can join in with activities of their choice and have the right to participate fully in their community (Disabled Children's Partnership, 2017). Beresford and Clarke (2010) promote the need for greater clarity for the meaning of inclusion as they recommended a working definition that is agreed by disabled C&YP, parents, policy-makers and service providers alike.

Facilitators are when factors have a positive influence on an individual's participation with **challenges** being a negative influence (Lawlor et al., 2006).

Within this study **service providers** is the umbrella term used for activity planners and volunteers: they are individuals who plan and/or run out-of-school activities for school-aged C&YP.

Activity Planners are individuals who plan out-of-school activities for school-aged C&YP. For example, head sports coach, group Scout leader, Vicar.

Volunteers are unpaid individuals who run out-of-school activities for school-aged C&YP. They are people who "spend time, unpaid, doing something that aims to benefit the environment or individuals or groups other than (or in addition to) close relatives" (Volunteering England, 2008:2). For example, community coach, youth leader, Sunday school teacher.

In this study, activity planners and volunteers are two separate groups with the activity planners overseeing activities with a more strategic view and the volunteers providing more of the week-to-week running with the C&YP.

Personal Care (can also be referred to as intimate care) which includes: feeding, oral care, washing dressing/undressing, toileting, menstrual care, treatments such as enemas, suppositories, enteral feeds, catheter and stoma care and supervision of a child involved in intimate self-care (Department of Health, 2006). For the purposes of this study, personal care relates to PDC&YP who require support for activities of daily living such as toileting and dressing.

Key Documents: Outline to give context for chapters

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) has been a major development in disability policy internationally. This was ratified by the UK in 2009. This addresses rights of both adults and children with disabilities.

UN Convention on the Rights of the Child (UNCRC, 1989) which covers rights across many elements of children's lives. This came in to force in the UK in 1992 and informs childhood policy and practice.

The principles of the UNCRPD and the UNCRC have informed much of the UK legislation and policy:

Disability Discrimination Act (DDA) (1995) was implemented to protect people with disabilities from discrimination. This only applies now to Northern Ireland and has been amended since The Northern Ireland Act (1998).

England, Scotland and Wales (Great Britain) are covered by the **Equality Act (2010).** The Equality Act (2010) replaced previous anti-discrimination laws with a single Act, which aims to make the law easier to understand and strengthens protection in some situations. It aims to legally protect people from discrimination in the workplace and in wider society. It outlines how it is unlawful to treat someone.

The **National Service Framework (NSF) for Children, Young People and Maternity Services (DH, 2004)** was a ten year strategy produced to take child poverty and inequalities in childhood through to improving the lives of children and families. Section 8 referred to disabled children. This framework was not updated or replaced following Governmental changes. This was closely aligned to **Every Child Matters (DfES, 2003)** which was a strategy produced following an enquiry into the death of Victoria Climbie. This Green paper proposed measures to try and reform children's care. This is now obsolete and the agenda was rebranded '**Help Children Achieve More'** by the Coalition in 2010 though still retaining the five key outcomes including: be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic wellbeing. This has not been updated and local authorities have their own policies and procedures to safeguard children using guidance from the **Working Together to Safeguard Children (DH, 2018).** In response to serious case reviews health, education and social provision have been brought closer together to promote better inter-agency working.

A ten year strategy, **Aiming High for Young People**, was launched with an aim to transform leisure-time opportunities, activities and support services for young people in England. (HM Treasury and Department for Children, Schools and Families, 2007a). This has not been specifically replaced.

Aiming High for Disabled Children: Better Support for Families Report was also published outlining the UK Government priorities, following Every Child Matters, to improve outcomes for disabled children. There was a focus on access, empowerment, timely support and improving quality and capacity (HM Treasury and Department for Children Schools, and Families, 2007b). There has not been a formal evaluation of the transformation plans set out.

Every Disabled Children Matters (EDCM, 2011) came as a response to the policy review `Equality Act 2010: The public sector Equality Duty: Reducing Bureaucracy.` This campaign was for rights and resources for disabled children and their families. It was a campaign run by: Contact a Family, the Council for Disabled Children, Mencap and the Special Educational Consortium. This has now come to an end and has not been replaced.

The Welsh Assembly Government (2007) provided the Local Participation Strategies 0-25 Guidance to support and drive forward C&YP's participation in Wales whilst a wider scoping recommendation **National Institute for Health and Clinical Excellence guideline (NICE 2009)** aims to promote 'Physical Activity for Children and Young People' aimed to increase the uptake of activities in and out-of-school.

The Children Act (2004), supplemental to the primary 1989 Act built in the key outcomes and principles of the Every Child Matters (2004) Green Paper (the latter is now obsolete). Section 17 of the Children Act is important when discussing a team around the child/family for support and additional services. This normally includes health, education and social work professionals where relevant, but this could include community providers where appropriate.

Disabled Children's Partnership (2017) is a major coalition of more than 60 organisations campaigning for improved health and social care for disabled children, young people and their families which was set up in 2017 in England. They have a social media 'Secret Life of Us' campaign which stemmed from the development of a report on the five steps to address the growing crisis in health and social care. The case studies of disabled families were being updated on their website monthly between June 2017 to June 2018. They report that disabled children face inequalities and struggle to access health and social care support. They state that services do not always work together and communicate well with each other.

CHAPTER ONE: INTRODUCTION

1.0 Introduction

This qualitative study adopted a multi-method design to explore the factors affecting participation of physically disabled children and young people (PDC&YP) in out-of-school activities in Cheshire. The programme of research included two studies comparing the perspectives of service users; PDC&YP and parents of PDC&YP and service providers: out-of-school activity planners and volunteers running mainstream out-of-school activities in Cheshire. The focus was on mainstream service providers as it is unknown how many PDC&YP access mainstream provision and even if they wish to do so.

The study was designed following my initial literature review (Knight et al., 2013) and my liaison with gatekeepers working with PDC&YP in the community. The gatekeepers were able to give me an overview of what PDC&YP they supported in the area and established that PDC&YP had specific needs which warranted further investigation as they were not currently being met. This thesis builds on the small body of UK based research evidence (Lawlor et al., 2006; Knight et al., 2009; Hewitt-Taylor, 2008; Sloper et al., 2009; Parkes at al., 2010; Hodge and Runswick-Cole, 2013; Carter et al., 2014; Kolehmainen et al., 2015; Pyer, 2016) and adds context to the wider international picture. It showcases the views of PDC&YP from Cheshire regarding their out-of-school activities. This provides an opportunity to understand more deeply the issues which affect participation in order for service users and policy makers to better appreciate their views. The research included interviews, focus groups and creative focus groups with 63 participants: 13 PDC&YP, 19 parents, 11 activity planners and 20 volunteers.

1.1 Disability in the UK

There are 13.9 million disabled people in the UK, equating to one in five people being disabled, according to estimates from the Family Resource Survey 2016/17 (Department of Work and Pensions, 2018). Children and young people (C&YP) make up approximately eight percent (1.1 million) of this group. This equates to one child in 20 being disabled (Contact for Families with Disabled Children, 2018). Disability is defined as a person who has a “physical or mental impairment which has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities” (The Equality Act, 2010:7).

Definitions of disability tend to be broad and include physical, learning and mental health needs. Disability is politically influenced due to how disability support is funded and policy is developed (see section 2.3). Within the UK, disability has moved away from a medical model, which focused on the impairment or diagnosis as being a challenge (Swain et al., 2003).   An important development in the way disability is viewed was the emergence of the social challenge models of disability, often shortened to the social model in the 1980’s (Goodley, 2011). The social model argues that the main challenges faced by disabled people arise from the way society is organised and not their impairment (Staniland, 2009). This model focuses specifically on the social and physical challenges rather than someone’s disability; for example, if a child who requires a walking frame to walk wants to access a building, they are not disadvantaged because of their disability; it is because the building is not designed to accommodate walking with a frame (Dickens, 2011). While the social model has been adopted within UK disability studies, it has been criticised for being too simplistic and needs to focus on wider individual, cultural and political influences (Jones, 2003; Barnes et al., 2005; Goodley, 2011).

For the purpose of this programme of research, a predominant focus on children and young people with physical disabilities was adopted. Physical disability was specifically chosen due to the lack of research with this particular cohort in the UK which was highlighted by my initial literature review (Knight et al., 2013). The review established that current evidence regarding participation in out-of-school activities weighed heavily towards cognitive and learning disabilities. The current body of work seeks to address this gap in the knowledge base.

1.2 Aim of the Study

The purpose of this multi-method qualitative study was to explore factors affecting PDC&YP’s participation in out-of-school activities from the perspective of both the service users and service providers in Cheshire. The specific research questions guiding the research were:

- What are the current out-of-school activities accessed by PDC&YP within Cheshire?

- What are the preferences of PDC&YP and their parents in relation to out-of-school activities?
- What are the factors that facilitate or create challenges to participation in out-of-school activities for PDC&YP?
- What are the views of the service providers in relation to provision of out-of-school activities for disabled C&YP?

1.3 Rationale for the Study

The idea for this thesis originated from my personal experience of working with school-aged children in a youth setting and seeing only one or two children in 500 during large district youth events who had a physical disability. This made me wonder why there were so few PDC&YP attendees, what was available for them, what they accessed and whether PDC&YP wanted this type of activity. In addition, as a children's nurse I have had the privilege of working with PDC&YP and their families during diagnosis and healthcare provision where I gained a valuable insight into their lives, both in and outside of hospital. Many of the fears parents reported around diagnosis stemmed from an uncertainty about what was available for PDC&YP outside of the healthcare and education settings.

Consequently, I undertook a review of literature to examine the factors affecting PDC&YP (7-17 years) in the UK participating in out-of-school activities (Knight et al., 2013). The review also assessed current provision and identified areas for future research which informed the direction and development of my PhD programme of research. The review demonstrated that there was limited provision for PDC&YP and factors such as accessibility, attitudes, and the need for training affected participation. The review highlighted the absence of service provider's views in the literature and that parental influence and the type of provision available warranted further investigation (see appendix 7.1.1 for published paper). The review of literature highlighted the absence of the both the service user and service provider's views but gave insight on the limited provision and challenges affecting disabled C&YP's participation in out-of-school activities. Some of the disabled C&YP in the reviewed studies were physically disabled amongst a mix of other disabilities. Their specific needs were challenging to separate but gave a clear rationale to establish their specific needs. The body of knowledge in the UK is currently heavily dependent on grey literature predominantly from disability charities and reports (Bennett, 2009; The Bevan Foundation, 2010; Beresford and Clarke, 2010; Disabled Children's

Partnership, 2017). Findings highlighted that C&YP want to mix with peers of their own age but disabled C&YP have found this problematic due to access issues, staff attitudes and worries about what other C&YP might say about their disability (Bennett, 2009, Knight et al., 2009). Disabled C&YP are less likely to be accessing clubs and activities out-of-school due to lack of choice, people's attitudes including peers, accessibility problems and lack of support (Grootenhuis et al., 2007; Fauconnier et al., 2009; Knight et al., 2009; Beresford and Clarke 2010; Bult et al., 2010; Oates et al., 2011). All C&YP can benefit from participating in social activities and a lack of social interaction can have an adverse effect on their quality of life (Grootenhuis et al., 2007; Michielsen et al., 2009; Oates et al., 2011; Disabled Children's Partnership, 2017). This could be mainstream or specialist activity but from the review of literature it is not clear what PDC&YP prefer.

The findings from the review of literature were timely given the national drive to promote physical activity for all C&YP (National Institute for Health and Clinical Excellence, NICE 2009; Public Health England, 2014). For the past decade sport, physical education (PE) in schools and physical activity and health have been prominent issues in the UK policy landscape. This links to physical and mental health improvement and to reducing obesity and related health problems (Dagkas, 2018). There is a worrying debate whether health-related motivations for such activities have decreased the potential for inclusivity (Bailey et al., 2012; Dagkas, 2018) as this may encourage a 'one size fits all' approach to increasing physical activity. There must be a recognition of individual needs and preferences and how these affect participation. Therefore this study looks beyond sport and focusses on the whole out-of-school experience for PDC&YP. For the purpose of this study, out-of-school refers to anything that PDC&YP may or may not do after school or at weekends, for example, sports, social activities, spiritual groups and family activities, to name a few. This definition is based on what can be readily accessed out-of-school (Lawlor et al 2006).

Whilst a range of specialised activity provision is available in terms of 'disabled' groups within communities often run by volunteers or the local council, there appears to be few opportunities, and little evidence of participation, for PDC&YP in mainstream social activities (Lawlor et al., 2006; Knight et al., 2009; Sloper et al., 2009). It is not clear whether mainstream out-of-school activities are what PDC&YP want but given that the UK Government have driven policy to educate disabled children within mainstream education (UNCRC, 1989) it is important to establish what type of provision PDC&YP want for their out-of-school lives for example, mainstream, specialist or something individual. As a researcher, I do not want to make an assumption that mainstream out-of-school provision is what PDC&YP prefer, but this is important to understand in order to establish and to fully understand the factors affecting their participation. It also has implications as to what stakeholders should be planning within their community so provision is more effective and meets key outcomes such as those from the rebranded Every Child Matters (2004) ('Help Children Achieve More') (Beckett et al., 2010). These include being healthy, safe, enjoy and achieve, make a positive contribution and achieve economic wellbeing but currently these are not measured specifically against PDC&YP's needs.

Local policy is driven by national disability policy. Nationally, there is no current driver promoting disability (see glossary p2) and this is a concern due to previous research demonstrating a lack of participation for disabled C&YP (Lawlor et al., 2006; Hewitt-Taylor, 2008; Bennett, 2009; Knight et al., 2009; Sloper et al., 2009; Beresford and Clarke, 2010; Langer et al., 2010; The Bevan Foundation, 2010; Hodge and Runswick, 2013; Carter et al., 2014). The concern about the lack of priority by the Government has more recently been highlighted by a coalition of more than 60 organisations campaigning for improved health and social care for disabled children, young people and their families (Disabled Children's Partnership, 2017). They are campaigning for Government leadership to be accountable and to make positive changes. The focus is on health and social care which they do not specifically define but there are elements from the case studies they present which are pertinent in this research (Disabled Children's Partnership, 2018).

In addition to the paucity of PDC&YP's views on their out-of-school preferences and experiences, an understanding of how the activities run and how they are planned, is unclear. Many activity providers advertise that they are inclusive on their websites, for example, The Scout Association (2019), but the experiences of providers working directly with C&YP need to be established so that they can report whether their activities are/can be inclusive. Many community clubs are run by volunteers and the legal expectation is to ensure they are suitable and welcoming to disabled C&YP (National Institute for Heath and Clinical Excellence (NICE, 2009). However, in reality, it largely depends on the attitude and skills of the providers and their disability awareness (Contact a Family, 2002; The Bevan Foundation, 2010). In order to gain a full understanding of PDC&YP's out-of-school lives, the service provider's perspective is vital to identify gaps between those wanting to use activities and those providing them. There is a dearth of research on the views of staff that plan and run mainstream activities. Beresford and Clarke (2010), The Bevan Foundation (2010) and Brokenbrow et al., (2016) looked at staff disability awareness and highlighted the need to look at factors which may affect participation, such as staff training and attitudes.

During the preparation for the research, I conducted a search to see what mainstream, disabled and specialist activities were on offer via the two local councils in Cheshire. This proved to be difficult because there is no central database where all provision is logged and easily accessible for parents and carers. Some groups were identified whereas some had closed down due to lack of funding. Others were found via word of mouth, posters in leisure centres, and local carers centres. The closest thing to a database that I found was a guide for pre-school children and baby groups but nothing for school-aged C&YP. By conducting this study I was able to compile a list of activities in the area and ascertain what was available for C&YP with various abilities. I was able to disseminate this to gatekeepers and parents if they asked what was available. I continued this review throughout my whole programme of research to stay up-to-date with the provisions available. Improvements have been made in one area of Cheshire where there is a list of activities for disabled people but it is not specific to C&YP so still lacks information for families (see section 6.2.3.3).

1.4 Research Approach

A multi-method qualitative approach was undertaken to gain an understanding of the views and experiences of the participants. Using generic qualitative methodology (Richards and Morse, 2007; Greig et al., 2013) (see section 3.1.2) I included a flexible range of qualitative data collection methods including semi-structured interviews, focus groups and adapted ‘creative’ focus groups (see section 3.2.2). This was the most suitable approach for this study as it explored the participant’s personal views through words and allowed deeper questioning with the flexibility of data collection methods (Drew et al., 2010). Creative focus groups were specifically designed for PDC&YP aged 7 to 17 years as they were play-based and involved developmentally appropriate activities. A range of questions were used which included basic demographics/background, behavioural questions, opinion based questions and feeling and knowledge questions (King and Horrocks, 2010). Service users and service providers were all successfully recruited using purposive and snowball sampling, via a gatekeeper.

1.5 Researcher Position

As a healthcare professional, the biological and social models have a strong influence on my thinking due to my medical and patient-centered training respectively. As well as being a health care provider, I am a youth worker, a parent and a researcher, all of which influence my view of disability. Moreover, families I met and worked with highlighted their individual needs and therefore gave me some insight to their lives.

One of my earliest experiences providing support for PDC&YP was during a local authority play-scheme before I started my nurse training. I was paid as a youth worker to run free activities during the school summer holidays. In a small team we would run activities out of a community centre for the first 30 children who turned up, so many were turned away. One of the clubs I ran, via the local authority, had arranged to bring four children with significant physical disabilities including gastrostomy feeding (giving milk via a tube in their stomach), changing toileting pads and lifting in and out of their wheelchair. I appreciate times have changed, as this experience was over 20 years ago, but this would not be acceptable for a team of young people to be supporting PDC&YP in this way without training. The expectation now is that someone (parent/carer) will attend with PDC&YP which potentially means, there is now no support in community settings for PDC&YP with similar needs unless they go to a very specialised group. I have grown up with a family friend who has significant physical disabilities similar to these young people so had some experience but I appreciate many volunteers in our community have no experience with some having never met a disabled child. Looking back, although we 'included' these young people we were not prepared and lacked skills but had the best intentions of trying to be inclusive, although we felt out of our depth.

To acknowledge my positionality as a researcher I needed to review my views, values and beliefs in relationship to this study, research process and fieldwork (Greenbank, 2003; Cohen et al., 2011; Savin-Baden and Howell-Major, 2013). Family-centred care underpins my professional and volunteer practice and it promotes working in partnerships with the family (Shields et al., 2006; Smith, Swallow and Coyne, 2014) therefore this can have an impact on how I view services. I have examined the impact of my position and presence within the study as a children's nurse, youth leader and a mother and how individuals responded to me. I was able to provide a flexible approach to data collection due to the skills I have from many of my roles but also adapt to other parents to allow to collect data around their needs. Parents talked a lot about their child’s diagnosis as they knew I understood this process as a children’s nurse but this was important for them to outline before answering the study questions. I have provided an insight to the interpersonal dynamics and evaluated this throughout for the benefit of the integrity of the research (Corbin and Strauss, 2008).

1.6 Research Context

This research was conducted in one region in England (Cheshire). Cheshire was used as the site for fieldwork due to my local knowledge of the area which facilitated convenience sampling of the initial gatekeepers. Cheshire is situated in the North West of England and has a total population of 700200 inhabitants (Chester and Cheshire West and Cheshire East Councils, 2016). There are two councils, which divide Cheshire into Cheshire West and Chester and Cheshire East who report together an average of 22.5% of Cheshire’s population being under 20 years old. It is important to note the two councils as they have different budgets, structures and various agendas which caused tension for the residents especially those on a border. This is especially important for PDC&YP and parents who search for suitable activities to understand how any funding and provision works in their local authority.

Figure 1: Maps of Cheshire, the research location, including the breakdown of the different local authorities, Cheshire West and Chester and Cheshire East.

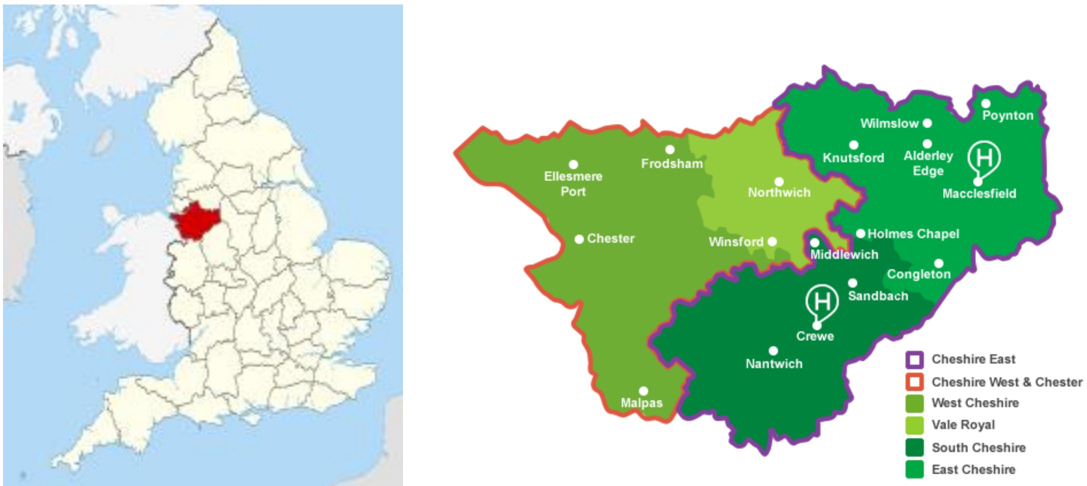


Image – Cheshire Stocktakers (2019)

Disability prevalence in the North West of England is 1.6 million, making it the fourth highest region for reported disability (Department of Work and Pensions, 2018). The overall disability reported in Cheshire is 17.5% but this is not age specific. However, the latest available data (November 2010) from Cheshire West and Chester report a range of 689 to 5306 disabled children. There is no report available specifically from Cheshire East. This wide range appears to be due to the difficulty in defining disability and how it is measured. It does however raise the question of how services can be appropriately planned when the data are so unclear. In 2017, Cheshire West produced a composite of demographics but disability was not included. They do have some information on special education needs in children but this does not include PDC&YP specifically. This is concerning as PDC&YP appear to be hidden amongst general 'disabled' provision therefore any planning does not necessarily include any of their specific needs (Cheshire West and Chester, 2017).

It is impossible to establish the number of PDC&YP in Cheshire, however given that there are 280 primary schools, 47 secondary schools and 14 special schools as well as seven further education colleges, it can be surmised that they will have fairly typical numbers of disabled C&YP within the population group of one in 20 disabled children (Barnes et al., 2005; Contact for Families with Disabled Children, 2018).

Statistics do not specify physical disability numbers therefore there are limitations in the sources of information to gain an accurate breakdown of the split by specific conditions. This is due to the variation in definitions of disability (Goodley, 2011). However, mobility issues are reported highest in children with 22% recognised as having mobility issues (Department of Work and Pensions, 2018). It is difficult to statistically categorise types of disability as many C&YP have a mixture of learning and physical needs and some are yet to be formally diagnosed although have support needs. Gatekeepers also reported to me in my planning that they do not know how many and where PDC&YP are, even in schools, as they are quite 'hidden.'

1.7 Contribution of Research

By examining the provision within Cheshire this allows for a full comparison of the views of service users (PDC&YP and parents) and those planning and running activities (service providers). This outlines the gaps between what service users' want/need and what is offered/available for PDC&YP. This was a vital angle as service providers have an important influence over what PDC&YP participate in. This research is the first to examine, in depth, the views of PDC&YP and their parents living in Cheshire regarding their out-of-school lives. This research makes a significant contribution to the existing literature by providing a synthesis of PDC&YP's needs and service provision in Cheshire. The findings demonstrate that PDC&YP want to participate in mainstream activities but struggle as they need support from service providers who should make necessary reasonable adjustments to include them. PDC&YP enjoy specialist activities to meet others 'like them' but want more local opportunities to do this as many of these opportunities involve a great deal of travel in order to attend. Some PDC&YP felt they were not disabled enough for 'disabled' activities but not able enough for mainstream out-of-school activities, therefore they fell through a service provision gap. These PDC&YP felt like the provision was not suited to their needs as not only are they the only PDC&YP in their school and a mainstream club but they reported often being the only PDC&YP at a 'disabled' club. The clear messages for policy planners and stakeholders are that PDC&YP have individual needs which can differ from what is planned in general for disabled C&YP.

PDC&YP want a mix of mainstream and specialist provision but need service providers to have better disability awareness which could be improved through training. A co-ordinator role has been identified in this research to reduce the gap between service users and service providers and they could be a strong advocate for all disabled C&YP within the community. A co-ordinator, who would need to be employed by the local authority, would be able to get to know the different families and recognise individual needs so they could signpost and link to suitable activities initially whilst helping building a more inclusive capacity in the community.

This research provides new insight into PDC&YP's out-of-school lives and identified new themes which identify facilitators and challenges to participation. The need for PDC&YP to have independence can be facilitated through service providers meeting their needs or more likely through the use of a buddy or personal assistant. Role models are really important to service users as PDC&YP are inspired and motivated by other physically disabled people, therefore disabled adults would make excellent coaches for many PDC&YP. Parents are driven to find activities which help their child with their health and physiotherapy, which is helpful for service providers to understand when advertising and showcasing their activity.

A really concerning finding, which emerged from this research, demonstrated a lack of provision for PDC&YP requiring personal care support. This is a very significant finding showing that these PDC&YP are actually isolated from even the 'inclusive' groups within our community as their personal care needs are not met. PDC&YP

with personal care support requirements are excluded from mainstream and ‘inclusive’ groups and this will not be confined to Cheshire. There is no national driver for disabled children let alone C&YP with specific needs in personal care. This study identified a group who are not visible in our community, or in disability research, so this study has identified this group as a priority. These PDC&YP are not getting their basic needs met and local authorities need to identify and make policy changes in line with what schools offer these C&YP. In addition, more guidance is needed on personal budgeting so parents can more readily access bespoke support in their community. The study has demonstrated that service providers do not know what they are allowed to do, to assist PDC&YP’s personal care, due to safeguarding concerns. Policies on personal/intimate care used in schools need to be shared via local authorities to support out-of-school provision.

In order to ascertain these important views, the study showcased experiences of PDC&YP gathered through the use of flexible and creative data collection methods. Creative focus groups using participatory methods where PDC&YP, as experts in their own lives, were used to actively engage them in the research. They incorporated play and creative activities which were welcomed and positively evaluated by PDC&YP and their gatekeepers. The creative methods were successful with children aged 7-17 years with a range of disabilities and communication needs and could be replicated in multiple settings, for example, education, health and social research. Gatekeepers welcomed further research using this method as PDC&YP are rarely included in research but they were involved in this study in an enjoyable and effective way. So, moving forward these methods could be replicated and evaluated in a range of settings by other researchers to promote and increase PDC&YP’s engagement with and in research.

1.8 Thesis Chapter Overview

Chapter One – Introduction

This chapter gives an overview of the study and identifies the purpose of the research and the research questions guiding this qualitative study on PDC&YP’s out-of-school lives.

Chapter Two – Literature Review

This chapter establishes the background and framework for the study and identifies key UK policy documents as well as exploring theoretical models underpinning disability.

Chapter Three – Methodology

This chapter presents an overview of the methodology including the overarching generic qualitative theoretical perspective, traditional and creative data collection methods, the sampling technique and the procedure used to gather the participants views and experiences. This chapter also includes the ethical considerations of conducting research with disabled children (Ref – 12/HEA/048).

Chapter Four - Results and Discussion of Study 1: Service Users (Physical Disabled Children, Young People and Families)

This chapter presents the findings of the service user study which aimed to identify the current out-of-school activities available to PDC&YP in Cheshire, to establish their preferences and explore the factors affecting PDC&YP's participation in out-of-school activities. The themes which have emerged from the data analysis are outlined and a discussion of the findings is presented.

Chapter Five Results and Discussion of Study 2: Service Providers (Activity Planners and Volunteers)

This chapter presents the findings of data collected from activity planners who plan out-of-school activities and volunteers who run such activities, followed by a discussion of the findings.

Chapter Six - Synthesis of Study 1 and 2: Service Users (PDC&YP and Parents) and Service Providers (Activity Planners and Volunteers) with Recommendations

This chapter presents the commonalities and differences between the service users and service providers and compares study 1 and 2. This chapter draws together the conclusions from the research to provide an overview of the findings and how they respond to the research aims and objectives. It attempts to synthesise concepts surrounding support for PDC&YP and as a method of understanding their out-of-school lives. This chapter outlines a conceptual framework to highlight the conceptual aspects following the synthesis. This chapter draws together recommendations and makes suggestions for future research and practice.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

This chapter sets out the literature reviewed to inform this study and outlines the search strategy and inclusion criteria. Current research is then presented highlighting research and knowledge gaps. Key concepts employed in the study are explored to give the background and context for the programme of research. Due to the limited published work in this area, this review is based on limited national and international literature. The UK sources are predominately around charity documents and a handful of peer-reviewed papers.

2.1 Search Strategy

The initial literature search was conducted between March 2012 and October 2016 and then repeated between October 2016 and January 2019 (See appendix 7.7 for literature tables). The databases searched were Cinahl Plus with full text, Web of Science, Social Care Online, ASSIA, Community Care Inform, Medline, Google Scholar and British Education Index. The search terms used were children, young people, participation, social activities, out-of-school activities and disability. Derivations of these words were also checked including hobbies, leisure, adolescents and teenagers. Boolean operators were applied to the search to narrow and broaden the search where appropriate. In addition, internet searches were conducted using the keywords. A hand search of reference lists of studies included in relevant papers was also done, where each reference list was checked for relevant studies.

The search also included key national UK policy documents, relevant grey literature and government reports. Grey literature (charity and government commissioned reports) has been included (Bennett, 2009; Beresford and Clarke, 2010; Langer et al., 2010; The Bevan Foundation, 2010; Brokenbrow et al., 2016; Disabled Children's Partnership, 2017/8). It was important to include grey literature as this gave a greater insight to views of PDC&YP within the community and highlighted some practical examples. Grey literature also provided a more complete view of available evidence by broadening the scope and having a comprehensive overview. Grey literature can be troublesome to search due to a lack of central sources or databases. It was worth taking the extra time to locate through internet and charity document searches. The grey literature tended to include lengthier documents as they are not constrained to the typical format pre-set by peer reviewed journals (Mahood et al., 2014; Godin et al., 2015). The published and grey literature papers identified (see appendix 7.7) were critically appraised using the Critical Appraisal Skills Programme (CASP, 2019) tool for research. They all met the inclusion criteria and were of satisfactory quality to form part of the review. When reviewing the Disabled Children's Partnership (2018) case studies were read and themes recognised which assisted the health and social care overview. Any limitations within the papers are reflected within the literature tables in appendix 7.7.

When reviewing the evidence base, the international literature in this area was overwhelmingly quantitative providing a limited view of PDC&YP direct views through qualitative means. This search was carried out in the same way (see appendix 7.8). Whereas findings from the UK were limited in both quantitative (n=1), qualitative (n=8) and mixed (n=1), with only ten peer reviewed UK research articles identified (Lawlor et al., 2006; Knight et al., 2009; Hewitt-Taylor, 2008; Sloper et al., 2009; Parkes at al., 2010; Hodge and Runswick-Cole, 2013; Carter et al., 2014; Kolehmainen et al., 2015; Daniels, 2016; Pyer, 2016). There has not been a relevant paper since this time but with the changes in UK Government, disability is not on the political agenda which, in turn, affects the research agenda and funding. It is therefore helpful to include the grey literature to support any contemporary understanding.

2.2 Disability and Disability Models

Disability is an umbrella term to cover impairment, limitations, and restrictions (World Health Organisation (WHO), 2015). Disability is not just defined as a health problem, it is complex and any definition needs to reflect the effect on the whole person and their life. In Great Britain, disability is defined as a person who has a "physical or mental impairment which has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities" (The Equality Act, 2010:7). The whole of the UK is not covered by this definition as Ireland has a similar but separate definition. Definitions vary from country to country globally but they all agree that there are effects on the person's life. An impairment is in relation to the individual's physical, mental or sensory functioning, with disability affected by challenges within society (Scope, 2019).

Disability models are presented first as an introduction as they relate to the literature being reviewed. This will be followed by the discussion of the underpinning model for this programme of research.

By defining disability, national and local governments can plan, implement and evaluate strategies to meet the needs of disabled people. Models of disability are tools for defining disability and these in turn influence how disabled people are supported within society. Models should not be regarded as complete explanations or a ‘one size fits all.’ However, various models of disability needed to be explored to establish how the study was framed. There are many models through which disability can be articulated but the individual needs of PDC&YP must be paramount in all. Models including the medical, social and biopsychosocial have been selected for discussion as they are the dominant influences on the disabled population. They have had the biggest impact on me personally and are, therefore, important to explore for the planning of this study. As a children’s nurse, the medical and social models underpinned much of my training but a more holistic approach is needed to include psychological and political factors.

2.2.1 Medical Model

Traditionally, the medical professions viewed impairment as their primary concern and physical functionality was forefront in treatment plans. This model has, and in many areas, still does dominate, health and social care in both planning, provision and practice for disabled people. Medical professionals have historically focused on identifying deficits, correcting what was ‘wrong’ with the person and seeking to cure. According to this position, disability results from a physical or mental inability or limitation (Davis, 2006; Goering, 2015). For example, a child with cerebral palsy who requires a wheelchair for mobility would be looked at in terms of their physical need rather than their holistic needs such as social, educational and psychological. Research too has historically medicalised disability with non-participation being presumed to be due to the impairments (Lawlor et al., 2006). Illness and impairment are portrayed as being separate entities which neglects the social relationship between the two (Owens, 2015). Despite this, the medical model still retains some utility in providing a label to someone who requires treatment or financial support. There has, however, been a shift in recent years from this biological reductionism to a social models approach (Dickins, 2011).

2.2.2 Social Model

The social model of disability or social challenges approach considers the social and physical challenges that society creates as the disabling factors rather than the C&YP's impairment (Dickins, 2011; Goodley, 2011; Watson, 2012; Owens, 2015). It aims to shift the 'problem' from the individual to society. The social model states that disability is caused by how society is organised rather than by an individual's difference (Goering, 2015). Medical models do not, of course, ignore the environment, and, in fact, the drive in Great Britain to reduce physical challenges often leads to a focus on adaptive equipment such as wheelchairs, lifts and visual aids. But it is the attitudes and understanding within society which have not fully shifted in focus (Hodge and Runswick, 2013). The social model of disability has been a positive move and politically successful for disabled people in society by challenging discrimination and marginalisation (Watson, 2012; Owens, 2015; Scope, 2019). It has been important in the development of the UK disabled people's movement. It is well documented and is still a popular and current model (Dewsbury et al., 2004; Walker, 2006; Goodley, 2011; Watson, 2012; Scope, 2019). However it has also been criticised for being out-of-date as it does not account for how individuals experience disability in different ways, requiring a more personal view (Owens, 2015). Another criticism of the social model is that it can be too simplistic and does not always account for the complexities cutting across the political, social and cultural experiences (Watson, 2012). For example, it does not readily account for the individual's gender, culture or individual demographics and neither does it account for political ideology or changes (Goodley, 2011). It is vital to recognise and account for the complex interactions between individuals, society and health when considering how disability affects individuals and their families.

This study brings in the service providers' view of out-of-school lives synthesised with PDC&YP's views as power is often presumed to be in the hands of the professionals or, in this case, service providers but the disabled C&YP themselves need to have their say in how communities set goals (UNCRPD, 2006; Duffy, 2017).

2.2.3 Biopsychosocial Model

The interaction between impairment and disability is complex and in order to address this, a biopsychosocial model was developed (WHO, 2001). The biopsychosocial approach is an integration of the medical and social models of disability. It considers medical conditions, individual needs and social position (HM Government, 2008). It therefore aims to highlight the complex interaction between real impairments and the disabling society. Perhaps the best known example of the model in practice is the International Classification of Functioning (ICF) conceptual framework (WHO, 2001). This framework, which incorporates multifactorial issues of disability, provides common, multi-disciplinary terminology for coding. It describes components relating to health including “activity, participation, body functions, structures and environmental factors” (WHO, 2001:20). While this framework still has a strong account of the social model it is still too vague for many activists as it misses cultural specifics (Lawlor et al., 2006; Kolehmainen et al., 2011; Aslem et al., 2017).

The biopsychosocial model has not been generally adopted by the disabled people’s movement in the UK with the dominant underpinning still being the social model even with criticism of its simplistic nature. The ICF is readily utilised in UK healthcare, for example, in occupational therapy where there is a move away from standardised assessment to individual needs being assessed and supported (McLaren and Rodger, 2003).

When planning my study it was framed using the biopsychosocial model as it looks beyond the social model and more readily addresses the complex and individual nature of disability to incorporate biological, psychological and social needs. The PDC&YP’s rights are paramount and provision must ensure individual level entitlement to the correct support and access especially where they may be marginalised in society. O’Brien and Lyle’s (1987) normalisation model work highlighted that disabled people can face a critical boundary with potentially nothing much going on in their community lives but it is essential that disabled people fully participate in decisions including political changes (Walmsley, 2001). A shift in thinking is needed moving away from a medical and individual mind-set taking a human rights approach but giving equal attention to attitudes, environments and health (Brokenbrow et al., 2016). There are wider influences on disabled C&YP’s lives including political, cultural, individual and economic circumstances (Anastasiou, 2016). The complex political and economic influences are often overlooked and it has been imperative to explore the political influences as discussed in the introduction which are affected by Government changes to policy and funding. This will now be explored.

2.3 Policy

Under the Equality Act (2010), local authorities and all publicly-funded services in the UK have a duty to promote equality for disabled people. Provision for disabled C&YP is influenced by policy and practice and since the initial conceptualisation of this study the political landscape has changed substantially from the Labour Government to a coalition, with the political influence which is outlined in Table 1. In the UK, there have been national drivers relevant to disability where goals have been set but not specifically renewed with the current Government. Although there is a Minister of State for Disabled People, Health and Work in the UK (Gov.UK, 2019b) this role has such a vast range of priorities but a specific focus on disabled children and families is needed (Scope, 2018b). Therefore, political focus has shifted away from disability and policies have not been renewed to replace out-of-date ones. The implications for disabled people are that there is less of a focus on their needs and groups advocating for the disabled people's movement do not have the same political influence as they may have had previously. These political influences and their impact are important in setting the scene for the programme of study for this thesis as they provide the political backdrop (see glossary p2), with the most current presented first:

Table 1: Political Influences

Strategy	PDC&YP	Impact
Fulfilling Potential: improving the lives of disabled people **Disability Strategy** **(Department for Work and Pensions, 2014)**	The renewal of the cross-government Disability Strategy aimed to break down the challenges to social mobility and to promote equal opportunities faced by disabled people in Britain. This is underpinned by the ratification of the following conventions: **The United Nations Convention on the Rights of Persons with Disabilities (2006)** - Ratified in Britain in 2009, which makes it clear that disabled people should be able to enjoy the same human rights as others. Articles 23 and 31 of the **United Nations Convention on the Rights of the Child (UNCRC, 1989)** - specifically outline the rights of disabled children and the right to relax, play and join in a	There have been no specific published updates or progress reports on the strategy and this is no longer in place therefore this leaves planning and provision for PDC&YP with no specific guidance and it is not a Government priority.

	range of recreational activities. This came into force in the UK in 1992.	
Independent Living Strategy **(HM Government: Office for Disability Issues, 2008a)**	A five year cross-government programme aimed to give disabled people greater access to leisure opportunities and participation in family and community life. This was hoped to have positive potential for PDC&YP to support participation in social elements of their lives.	A review of this strategy showed no evidence of significant progress in disabled people's experiences of choice and control in their lives since 2008. This is reported to be due to ineffective delivery of personal budgets and inadequate restrictions on how personal budgets can be used limiting individual choice and control (Morris, 2014). This impact needs to be explored in the context of C&YP as they are often dependent on providers and families aiding this participation.
Aiming High for Disabled Children: Better Support for Families **(HM Treasury and DfES, 2007)**	Initially there was a commitment to children with complex needs under this English policy to improve “access to mainstream education, inclusive play and leisure opportunities” (HM Treasury and DfES, 2007:31).	Health and social care professionals use this strategy when planning services with evidence of inclusive education being addressed. There is no evaluation outlining the impact on play and leisure for PDC&YP.
Every Disabled Child Matters campaign **(EDCM) (2006)**	The campaign was set up after parliamentary hearings on services of disabled C&YP. The campaign led by professionals and policy makers was proposed to run for three years to protect disabled C&YP’s rights and get them access to the correct services. It actually lasted ten years and has not been replaced.	With no campaign driving disability initiatives for this under-represented group there is not the protection of their rights and access to appropriate services including community provision.
Department of Health **(DH, 2004)** **Ten year National Service**	The framework highlighted the need for disabled C&YP to be supported to participate in family and community activities highlighting that disabled children wish “to do the same things as other C&YP of their age” (DH	Without such a framework focusing on health, which is a major part of disabled children’s lives, there is no priority for children, let alone disabled children. This affects funding streams as child provision

Framework	2004:9). This was a ten year framework and has not been renewed or replaced.	is a small part of the overall national health budgeting so without planning they do not get prioritised.

2.4 Physically Disabled Children and Young People

Historically, children were seen as objects to be studied, being regarded as incompetent, unreliable and incomplete. Historically the focus of research was 'on' children rather than 'with' children (Greene and Hogan, 2005). However, with the promotion of children's rights (United Nations General Assembly, 1989; The Children Act, 1989), children are now viewed by researchers and policy makers as being experts on their own lives (Fargas-Malet et al., 2010). All C&YP including PDC&YP should be involved in decisions and their views and experiences should be taken seriously about matters that affect them (Article 12 UNCRC, 1989).

PDC&YP should be acknowledged as experts of their own lives and should have their rights voiced in health, social and educational research (UNCRPD, 1989; The Children Act, 2004; Drew et al., 2010). They are an under-researched group and lack a voice in the literature (The Council for Disabled Children, 2014). It can be a challenge accessing PDC&YP, as researchers need to rely on gatekeepers, such as social care professionals, to access potential participants. However, it is important to overcome this and to hear disabled children's views. PDC&YP have a much higher degree of adult intervention yet less of a voice, certainly in terms of research (Knight and Oliver, 2007; Dickins, 2011).

PDC&YP are often represented by an adult, such as a parent or carer, as they play a large part in their lives which means they are widely excluded from decision-making (Carpenter and McConkey, 2012). PDC&YP who are not able to utilise verbal language or who have other communication impairments have even more difficulty so it is important not to exclude views of PDC&YP who also have communication difficulties (Knight and Oliver, 2007; Dickins, 2011). Families are powerful advocates but PDC&YP must also be offered opportunities to speak of their experiences (DH, 2007; Elemraid et al., 2013).

A focus on an interpretive paradigm opens opportunities in terms of gathering direct qualitative opinions (Fraser et al., 2004). This is enhanced in this current study by the use of creative participatory methods as it meets the flexible needs and preferences of the PDC&YP. Research with PDC&YP is essential as it advances our understanding of their development and their lives as well as contributing to theory, with an aim to have positive outcomes to help families directly or indirectly (Fraser et al., 2004). Although engagement with service users is becoming increasingly important within research and policy development (McLaughlin, 2010; VIPER, 2012), there needs to be a greater emphasis put on research with and for PDC&YP (DCSF and DH, 2009; Pelchat et al., 2009; VIPER, 2012). There needs to be meaningful participation in decision making across all areas of young people's lives (Brummelaar et al., 2018). Qualitative research is particularly suitable for undertaking research with PDC&YP as it strives for depth of understanding but in a natural setting such as their own home or activity setting (Greene and Hogan, 2005; Greig et al., 2013). PDC&YP are central to the study and are the focus throughout.

Ethical considerations must be highlighted when conducting research especially with PDC&YP which is discussed in full in section 3.6.

2.5 Out-of-School Lives

The focus of this study is on the out-of-school lives of PDC&YP who access either mainstream or specialist schools depending on their individual needs, preferences and availability. The views of PDC&YP, parents and service providers all give an insight into their lives including challenges faced day-to-day.

One element of PDC&YP's out-of-school lives is play. The importance of play is recognised internationally and one of the rights set by the UN Convention on the Rights of the Child is the right to play, leisure and recreation. Play is something that is seen as an integral part of childhood and is natural but disabled C&YP often need adult support in order to do this (Play Wales, 2013). Barnardo's (2005) state that disabled C&YP will play where they can regardless of constraints by adults but play can be enhanced by the encouragement of appropriate physical and social environments. Social environments play a large part and the physical environment can influence participation (Disabled Children's Partnership, 2017; Pouya et al., 2018). In 2008 the Department for Children, Schools and Families (DCSF) set out The Play Strategy which aimed to make a commitment to all children, including disabled C&YP in the plan for improving play opportunities. Play Wales (2013) recognise that play is crucial for development and all children of any ability should be able to play freely, especially in the outdoors. PDC&YP want to play and join in structured activities within the community and also to play with other children in local parks but, due to challenges such as accessibility, travel issues and activities closing down, they feel this is not always possible (Bennett, 2009; Knight et al., 2009; Pyer, 2016). Goodley and Runswick-Cole (2010) agree as they feel that leisure becomes rehabilitation for some disabled C&YP, but Disabled Children's Partnership (2017) state that disabled children find it difficult to access suitable play. The term 'positive activities' is also used by some to describe something disabled C&YP do out-of-school which may be beneficial to them, this can also include volunteering (Adamson et al., 2011).

2.6 Inclusion and Discrimination

Inclusion refers to individuals being involved in different areas of their life, for example, within a group. This study relates to PDC&YP joining in with activities of their choice and having the right to participate in their community, which has an effect on their overall wellbeing (Griffin, 2008; Barnardos, 2012). PDC&YP should have the same choices, opportunities and experiences as other children; to make local friends and to access, play, leisure and recreational facilities as well as having the same aspirations (McConachie et al., 2006). Brokenbrow et al., (2016:7) state that inclusion is "not a static two-dimensional concept, but a multifaceted dynamic and ever changing landscape shaped in constant partnership with disabled people and families."

Inclusion is a dominant issue across the literature and there is consensus that engagement in activities outside school provides all C&YP, including PDC&YP, with opportunities to make friends, increase self-esteem, enhance wellbeing and develop skills (Lawlor et al., 2006; Hewitt-Taylor, 2008; Bennett, 2009; Beresford and Clarke, 2010; Knight et al., 2009; Sloper et al., 2009; Kang et al., 2010; Langer et al., 2010; Mundhenke et al., 2010; Parkes et al., 2010; The Bevan Foundation, 2010; Hodge and Runswick, 2013; Carter et al., 2014; Kolehmainen et al., 2015; Brokenbrow et al., 2016; Pyer, 2016). Promotion of inclusive activities provides disabled C&YP with opportunities to develop friendships and a concept of self (Kang et al., 2010; Mundhenke et al., 2010). The preferences of what PDC&YP want for their out-of-school lives need to be explored (Majnemer et al., 2008; Imms et al., 2008; Kang et al., 2010; King et al., 2010a&b; Palisano et al., 2011).

There are times when disability discrimination is evident as PDC&YP are treated less well or disadvantaged for a reason that relates to their disability in one of the situations covered by the Equality Act (2010). Local authorities have a legal duty to prevent unlawful discrimination and disability discrimination is included (Disabled Children's Partnership, 2017). PDC&YP should not be treated less favourably than others. There is a duty for providers who sit within the local authority to make reasonable adjustments to ensure PDC&YP are not disadvantaged (The Equality Act, 2010). PDC&YP are excluded from social situations due to being made to feel different when trying to access the activity (Bennett, 2009; Knight et al., 2009) which leads to a lack of contact with school friends during out-of-school times, which affected friendship and participation (Johnston and Wildy, 2016).

2.7 Participation

Participation is a very broad concept and essentially means taking part and being involved in life situations, for example, politically, within research and as a community citizen (Kay and Tisdall, 2012; Ghanbari, 2016). My study focuses on how individual PDC&YP participate in out-of-school activities whilst also promoting inclusive research methods to aid participation with the research.

Participation can be classified by the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) using three levels including body function and structure, performance of personal activities and participation in communal life, as they are influenced by personal and environmental factors. This is an instrument to measure participation in disabled adults and children.

Factors influencing participation are complex and multi-factorial. Participation is essential for individual development and PDC&YP's participation in social and leisure activities is linked to their wellbeing and happiness. Limited, and negative, social leisure experiences in childhood can affect development (Imms et al., 2008; Hoogsteen and Woodgate 2010; Mundhenke et al., 2010; Oates et al., 2011; Palisano et al., 2011; Disabled Children's Partnership, 2017). It is important that life situations are socially meaningful for PDC&YP, which is not only important for physical wellbeing but it can also increase positive self-esteem, enjoyment and cognition (Kolehmainen, 2011; Sugden, 2014). All C&YP and their families have rights which need to be protected (UNCRC, 1989) but the right to participate in leisure is less likely to be realised for young people with disabilities (Muir and Goldblatt, 2011). Traditionally, children have been excluded from participating in decisions affecting their everyday lives yet this is even greater for PDC&YP as found in the paucity in views of out-of-school lives (Knight et al., 2013). This is an important area as their out-of-school lives take up a significant proportion of their time and influences friendships, confidence and social networks. All PDC&YP should be able to participate in activities they are interested in (Disabled Children's Partnership, 2018).

Public Health England (2014) raise non-participation in physical activity as a concern when they discuss possible links between disability and obesity in C&YP, however they recognize the multifactorial issues and complex nature of challenges to participation such as family influence, diet, lifestyle and schooling. These issues are often exacerbated for PDC&YP and a lack of physical activity can be linked to non-participation in out-of-school activities which is where other C&YP can access exercise and health advice.

In addition to participating in the out-of-school activities, PDC&YP need to be empowered to understand participation in the wider sense so they can promote change and be heard. Disabled people have been under-represented in research and policy development in the past even though they are able to participate in decision making. Projects such as VIPER (Voice, Participation, Empowerment, Research) promote participation in disabled C&YP (VIPER, 2012). This was a project showing positive practice but has not been updated since. PDC&YP have the same rights as non-disabled C&YP to participate in decisions and issues that affect them (Kay and Tisdall, 2012; VIPER, 2012). PDC&YP's participation is essential in understanding their needs (The Council for Disabled Children, 2014) but they are the "most marginalized in our society" according to Carpenter and McConkey (2012:251). The Disabled Children's Partnership (2018) started to showcase some case studies about their health and social care provision between 2017 and 2018 but at the time of writing this has not been updated. This is a positive campaign which is shared regularly via social media which aims to raise awareness amongst professionals and the public.

2.8 Service Providers

In the context of this research study service providers include activity planners and volunteers who are individuals who plan or run mainstream out-of-school activities for school-aged C&YP. Example areas where service providers work are youth, sports and religious groups. Groups can be run by local authorities. Volunteer groups often pick up services that the public sector no longer provides due to gaps in funding. But voluntary groups equally have funding and resource difficulties (Baker and Hopley, 2011; Kahn and Norman, 2012).

The voluntary sector plays a significant role in promoting opportunities for disabled children, young people and their families and it is often the individuals running such activities who are the first point of contact for PDC&YP and their families. Due to the nature of volunteering there may be a mix of expertise, training and understanding of disabilities. An example of a large voluntary youth organisation is The Scout Association, who provide activities and personal development opportunities for 400,000 young people aged 6-25 years and these activities are all run by volunteers (The Scout Association, 2018).

There are many examples of out-of-school activities such as social and leisure activities, youth clubs, sports clubs, religious activities, individual, group activities and play schemes but there is no evidence of how many of their staff have any disability training. Although all groups should be inclusive and cater for PDC&YP through making necessary reasonable adjustments it is clear that this is not the case across the board.

There is some evidence that some local authorities and the voluntary sector within the UK are taking steps of varying degrees to promote better social inclusion. For example, employing inclusion officers to train mainstream out-of-school activity staff and to make sure the location of the activity is suitable. They were trying to bridge the gap between service users and service providers during school holidays (Knight et al., 2009). This study interviewed 121 staff from across health, education, youth and the voluntary sector about holiday provision for disabled C&YP. They also consulted with service users about any difficulties they faced which helped plan resources. This really positive example was not without problems as they found notable gaps and failures in provision and the report came from middle or senior management rather than individuals who have face-to-face contact with children and families. It is not clear whether this practice continued after Government changes.

Seven UK knowledge workshops conducted for the Centre for Excellence and Outcomes in Children and Young People's Services found a lack of confidence amongst staff demonstrating an urgent need for training and awareness-raising in relation to disability issues (Beresford and Clarke, 2010). It was recommended that volunteers working in activities and local leisure and recreation facilities, as well as the providers should be trained in disability awareness (Beresford and Clarke, 2010).

2.9 Participation in Out-of-School Activities

It is important to understand PDC&YP's out-of-school lives within our communities so that activity provision can be planned accordingly to try to meet their needs. Disabled C&YP need to have the same opportunities for fun and friendship as everyone else (Brokebrow et al., 2016; Disabled Children's Partnership, 2017). At present this is not the case for PDC&YP, nationally and internationally, they have decreased participation in community activities and are at significantly higher risk of being socially isolated (Lawlor et al., 2006; Hewitt-Taylor, 2008; Knight et al., 2009; Sloper et al., 2009; Parkes et al., 2010; Hodge and Runswick, 2013; Carter et al., 2014; Kolehmainen et al., 2015; Ghanbari, 2016; Pyer, 2016; Disabled Children's Partnership, 2017). There is limited evidence of the current picture of PDC&YP's out-of-school lives but it is reported that, in the UK, 73% of families think that the access to play and leisure specifically for disabled children was poor and unsatisfactory (Bennett, 2009). Parkes et al., (2010) highlighted in their Northern Irish study that C&YP with cerebral palsy had reduced levels of participation in social activities and recreation. They used quantitative measures across a large number of parents but it would be helpful to fully understand the reasons through qualitative methods. Disabled C&YP's experiences of play and leisure in Wales were explored by The Bevan Foundation (2010) and 90% of respondents rarely or never attended a youth club such as Scouting or Brownies. Equally, more than half rarely or never attended a disabled children's club because they did not know if there was one in their area. Of those who did attend out-of-school activities, some preferred to be involved in "disabled – only groups" as they felt more comfortable with others like themselves and felt that the adult leaders were very patient. Eight children of the 82 respondents felt there was nothing for them with one young person stating "activities not available locally with people that can cater for my disability" (The Bevan Foundation 2010: 25).

Knight et al's (2009) qualitative UK study found that disabled C&YP wanted to mix with non-disabled C&YP. They found that when exploring social inclusion, many of the experiences were positive. The study highlighted that a major motivator for disabled C&YP to join clubs is being with others and doing activities along with their peers but that they were worried what other C&YP might say about their disability. Brokenbow et al., (2016) in their UK wide qualitative study with ten disabled C&YP found that amongst lots of good practice there was frustration with increased challenges for disabled C&YP being included into mainstream provision. Knight et al., (2009) suggested that disabled C&YP value provision that is designed for all children regardless of their ability with Langer et al. (2010) finding social benefits such as making friends 'like them' within their research on short break provision. Most of these studies report their findings across children with a range of disabilities so it is difficult to ascertain which findings are specific to PDC&YP. However, Carter et al., (2014) identified that the PDC&YP in their North West of England study benefited socially from participation in a wheelchair sports club but they recognised that those with a disability gained more as there were so few other opportunities for them normally. PDC&YP and non-disabled C&YP enjoyed participating in sport together in wheelchairs and gained "insight into each others' worlds" (Carter et al., 2014:938).

The reduced levels of participation in social activities is reflected in the international literature. There are a number of research teams assessing disabled C&YP's (with a mix of disabilities) participation in activities in Canada and America (King et al., 2010; Kang et al., 2010). They echo that disabled C&YP participated in fewer activities and tended to be in less intensive physical and social based activities. They took part in activities closer to home and often with relatives. The pattern of lower participation was clear but PDC&YP's preferences and intensity of participation were not explored (Kang et al., 2010). Three qualitative studies from Australia mirror these findings reporting low participation in hobbies (Imms et al., 2008; Galvin et al., 2010; Oates et al., 2011) but for disabled C&YP with higher general participation in everyday activities, friendships and activities were increased. There were also restrictions found in structured community activities (Galvin et al., 2010; Ghanbari, 2016; Carroll et al., 2018). Ghanbari et al., (2016) presented difficulties faced by blind children in Iran in their recreation time with a major factor being those supporting them needing training.

It is vital that service providers are made aware of the preferences of PDC&YP in their area when they plan their activities (Imms et al., 2008; Majnemer et al., 2008). Sport England (2015) reported a decline in participation in all physical activity and sport especially in under-represented groups which include disabled people. Daniels (2016) recognised this difficulty within Cheshire and targeted girl's disability football and disability gymnastics for the under 16 age group supported by two specialist coaches and equipment. This was to encourage wider participation and create opportunities and evaluate the service. This case study focused on two coaches' views and highlighted the need for targeted input by the likes of sports development teams to improve the disability provision in Cheshire and beyond.

2.10 Facilitators and Challenges to Participation in Out-of-School Activities

Participation can be discussed in terms of factors that facilitate PDC&YP into activities and factors that stop them or create a challenge. When there are challenges this can lead to non-participation and social exclusion (Brokenbrow et al., 2016). Non-participation can have a negative effect on a PDC&YP's development, academic performance, quality of life and can affect their family also (Lawlor et al., 2006; Henderson et al., 2008). The following sections discuss the themes which have emerged from the literature.

Themes which emerged were identified through the aims and objectives of the study and from major topics identified from the service users and providers comments in the literature.

2.10.1 Facilitators

Factors which help disabled C&YP to join in out-of-school activities are referred to as facilitators. The need to **socialise** and the possible benefits associated with it drive both families and providers to access and plan such activities as this emerged as an important factor in facilitating participation. By socialising, the making and meeting of friends can help boost confidence if they have a positive experience (Beresford and Clarke, 2010; Knight et al., 2009; Sloper et al., 2009; Mundhenke et al., 2010; Parkes et al., 2010; The Bevan Foundation, 2010). This, in turn, could give PDC&YP the confidence to continue to try new clubs (Lawlor et al., 2006; Griffin, 2008; Hewitt-Taylor, 2008). Palisano et al., (2010) echo this in their large American study and state enjoyment facilitated participation in their study of 13 to 21 year old disabled C&YP. They measured this participation through validated quantitative tools which can be further compared to qualitative data below. Where the physical, social and attitudinal environments are positive this can act as a lever to help disabled C&YP join in.

Benefits of participating in out-of-school experiences enables PDC&YP to try new **equipment** as well as learning **new skills** (Bennett, 2009; Kang et al., 2010; Langer et al., 2010;; Barnardos, 2012; Hodge and Runswick, 2013; Brokenbrow et al., 2016; Pyer, 2016). This may include wheelchairs, sports equipment, outdoor equipment or disability aids. For example, a power chair club could provide the adapted wheelchair so a PDC&YP could try it first to see if they liked it. Some PDC&YP use wheelchairs which require a friend or adult to push them but may benefit from a power chair which they could learn to operate themselves, therefore independence is promoted (Lawlor et al., 2006). Examples can be seen through charities such as Whizz-Kidz. (Whizz-Kids, 2019). Lawlor et al. (2006) in their North East of England study with cerebral palsy aged 5-17 years found that these PDC&YP benefited from having an electric wheelchair as it encouraged independence.

A UK-based study which explored the experiences of children, parents, siblings and service providers in a wheelchair sports club highlighted the positive opportunities this gave to everyone involved socially, to boost confidence, to try new equipment and to have fun through thrills and new skills (Carter et al., 2014). The activity evaluated in this study is a model of positive inclusive practice.

A positive factor identified in the review of literature to facilitate PDC&YP participating in social activities is the use of a **buddy** scheme. This is where a disabled C&YP is supported by a volunteer non-disabled buddy who accompanies them to an activity. They could attend rather than a parent needing to be with them. This aims to bridge the gap between service users and providers and particularly promotes participation into mainstream clubs where perhaps support is not as readily available as in a specialist club. Knight et al., (2009) came across a small number of schemes where buddys supported disabled C&YP in mainstream activities, which were good practice examples, but they still noted practice issues and gaps in provision even with this bridging role in place. Disabled children in a qualitative Swedish study expressed the need for support through a personal assistant (Mundhenke et al., 2010) rather than a buddy but with similar intentions. The funding system differs between Sweden and the UK but the idea of one-to-one support is helpful as it can provide support in everyday activities. When conducting an internet search of buddy schemes across the UK for PDC&YP there are many adverts asking for volunteers to fulfil these roles but there is no tried-and-tested model to build such a positive service. Many of them rely on volunteers and they advertise frequently in local Universities and colleges for students. The nature of this means that a buddy would not necessarily be able to provide continuity for a PDC&YP. The nature of volunteering can also lead to a regular shortage or change in workforce (Beresford and Clarke, 2010).

The review of evidence highlighted that when service providers have a **positive attitude**, making the PDC&YP feel welcome this facilitates participation (The Bevan Foundation, 2010). This positive attitude can encourage the PDC&YP and go some way to making them feel safe which is paramount (Beresford and Clarke, 2010). Each child is an individual and this needs to be encouraged by the service providers, who, in turn, need experience and/or disability awareness training (Beresford and Clarke, 2010). Shields and Synott (2016) identified that ‘people make the difference.’ This Australian qualitative study does explore views from disabled children, parents and professionals working in leisure activities which enhances validity but they are all working with disabled people so does not provide the insight needed into mainstream. The message of ‘people making the difference’ is an important one to share to help facilitate participation with PDC&YP in any community activity.

In spite of these facilitators, challenges to participation still exist. It is vital that all staff running community activities, including volunteers, have the skills to support individual PDC&YP (Knight et al., 2009; The Bevan Foundation, 2010; English Federation of Disability Sport, EFDS, 2013).

2.10.2 Challenges

Factors which stop disabled C&YP participating an activity or affected their attendance are referred to as challenges. An appropriate level of support is required for any C&YP accessing any activity to ensure their individual needs are met and this often is even more pertinent for PDC&YP. These support needs must be established with the PDC&YP, family and provider. Support can come in many forms, such as physical, emotional, communication or financial. Challenges can arise from any of these elements in stopping a child being able to participate in an activity, such as an individual’s attitude, providing a bad first impression, leading to the PDC&YP not wanting to attend again. This review of literature highlighted that a range of factors act as challenges to participation in out-of-school social activities for PDC&YP which include difficulties with accessibility, attitudes, communication. These are presented in the areas of support required for the PDC&YP:

Many PDC&YP need physical support in terms of the physical access. **Accessibility** is the ease to which individuals can see, hear and enter a place (Lawlor et al., 2006). A review of the evidence found that accessibility and location of the out-of-school activities were factors affecting participation. This in turn can lead to a lack of contact with school friends out-of-school times, which can affect friendship and participation (Hewitt-Taylor, 2008; Knight et al., 2009). Hewitt-Taylor's (2008) concerns came from 14 parental views and many of them cited transport as an issue. Children who attended special schools away from their local area were found to have reduced social community-based activities (Petrie et al., 2007/Knight et al., 2009; Sloper et al., 2009).

The Equality Act (2010) requires reasonable adjustments be made to remove physical access as a challenge, but the literature suggests in practice this is clearly a key issue affecting participation. Physical challenges can come from the building itself which was highlighted as a major challenge by Lawlor et al., (2006). Their study was based on a small sample of parents and just two children's views but this finding was echoed by The Bevan Foundation (2010) who stated that many of the leisure centres they had visited were good but access was more difficult in clubs, such as community groups. Problems with access were reflected in the large Bennett study (2009) with 615 UK-based families reporting problems finding suitable swimming or local parks with accessible equipment. Bennett (2009) also found that half of the families expressed dissatisfaction with mainstream play and leisure facilities due to lack of accessibility and travel issues. A European-wide quantitative study confirmed the PDC&YP participated less often in the community due to environmental issues such as access than children in the general population (Michielsen et al., 2009). Although this was a large study of 813 parents, it did not take into account any child views. Accessibility remains a challenge despite the introduction of The Equality Act (2010).

Challenges can also come from service provider **attitudes and their ability** to look after a disabled child. There is a lack of confidence in the service providers from parents (The Bevan Foundation, 2010). Their attitudes play a large part in whether the disabled C&YP engage in the activity. Bennett (2009) concluded that there is still a long way to go in changing attitudes towards families with disabled C&YP.

Bennett's (2009) study was based on parents' views alone, but this large, mixed methods, survey provides important insight into the experiences of these UK families.

The Bevan Foundation (2010) compared findings of play workers, some of whom were from the voluntary sector and they acknowledged that, in the past, children may not have felt welcome because staff showed they were afraid about not being able to cope. If parents and C&YP experience these negative attitudes from staff on arrival, this could potentially be a challenge to participation. Carter (2016) reported that there is still a societal uncertainty and reluctance from many people toward getting involved in the lives of disabled people, which can appear unwelcoming and is a reason individuals do not return. To overcome some of these attitudinal issues, as the first point of contact, individuals running the activities need to give a positive first impression and have an openness. Knight et al. (2009) and Brokenbrow et al., (2016) state the importance of exploring the views of those individuals carrying out the activities as their approach to PDC&YP may determine if someone joins or not.

In contrast, service providers may be positive and they want to be inclusive but they do not have the skills. It would be helpful to understand the factors needed to successfully facilitate participation including the skill mix needed within a service provider team. Parents often want children to attend without them but they often end up providing the support for their son/daughter as it is common for parents to be asked to accompany their disabled C&YP to activities (King et al., 2010). Parents play such an influential role in leisure participation for school-aged disabled children and their availability of time was a factor reported in Western Australia with parents of children with Down syndrome (Oates et al., 2011). This would indicate that there is an expectation that parents need to attend with their child in order for them to participate. This is because the needs of disabled C&YP are specific and staff report they cannot or do not wish to provide support. This parental presence may not be what PDC&YP want and may limit their access (Petrie et al., 2007). Hodge and Runswick-Cole (2013) support this point through their qualitative study in the North of England comparing views of disabled C&YP and parents. This study, in design, is helpful to discuss in relation to the current programme of study as it uses some participatory methods, such as art and sought multiple views, but instead of including views from service providers they used views of professionals surrounding the child (teachers and social workers). This resulted in the views of disabled children's advocates rather than identifying the gaps. It did however give a helpful platform in planning my Cheshire study. Likewise, in New Zealand, Carroll et al., (2016) incorporated disabled children, parents and gatekeeper views and although they use mixed qualitative and quantitative methods they do present ‘go-along’ interviews where participants can physically take the researcher and show them the challenges these children face in their community.

In contrast to the service providers requiring parents to stay due to lack of available support, disabled C&YP, in Knight et al’s (2009) study, felt parents prevented them from going out independently and mixing with non-disabled C&YP. They saw parents as over protective. Kolehmainen et al., (2015) in their mixed methods study reported a strong preference for active play by PDC&YP but agreed that adults regulated it. Parents suggest this is a complex issue but relates to being able to trust the service providers (Langer et al., 2010).

To overcome issues of trust Sloper at al., (2009) suggested that **information and communication** are vital in assisting trust both for parents and disabled C&YP (Lambert, 2011). Effective communication and information provision can help form partnerships between the parents and service providers in order to support PDC&YP. Communication was highlighted as a challenge through focus groups with disabled C&YP, parents and sports professionals and better partnerships were recommended to overcome communication difficulties (Shields and Synott, 2016). For example, it is essential that parents are aware of suitable activities as frustrations can arise through activities closing down. This was a factor in Pyer’s (2016) study that used multi-qualitative methods in her UK based study when exploring young wheelchair user’s play and recreation.

Communication in terms of how activity providers verbalise with the disabled C&YP can also be a challenge and this links to the ability and willingness of the adults. Sloper et al., (2009), in their large UK study representing the views of 100 disabled C&YP parents, discussed the importance of all staff in regular contact with the disabled C&YP having the knowledge and skills to understand the child’s means of communication. Sloper et al., (2009) included disabled C&YP with complex needs so the communication issues were a factor so communication techniques must be considered. This was echoed through quantitative research by Majnemer et al., (2008) who factored communication as a challenge when trying to improve participation in leisure activities. Feedback from families often identifies a lack of disability awareness affecting participation into play and leisure activities in the community (Bennett, 2010). Parents were more likely to feel that their child’s needs were being met if they felt the staff member was competent. Everyone in regular contact with the child needs to have appropriate knowledge and skills to understand the child’s means of communication and volunteers need to be trained (Sloper et al., 2009; Beresford and Clarke, 2010).

Further exploration of the attitudes of service provider’s toward PDC&YP is required and, more importantly, ways of ensuring that staff are adequately skilled and resourced to include all children in the activity also needs to be considered. An investigation into the most effective way of communication to establish a positive relationship with PDC&YP is needed to enhance the partnership between service users and providers.

2.11 Training

When reviewing the facilitators and challenges around participation in out-of-school activities a major recommendation from most studies was the need for disability awareness training (Knight et al., 2009; Beresford and Clarke, 2010; Bennett, 2010; Brokenbrow et al., 2016; Shields and Synott, 2016: Ghanbari, 2016). This was not a surprise but no real guidance exists of how to implement the training and what to include. Parents of disabled C&YP cited a lack of training and insufficient staff as possible reasons as to why they did not participate and they recognised that, although staff try, their efforts may be inappropriate (Beresford and Clarke, 2010). The providers, especially the inexperienced ones, require some disability awareness training to enhance inclusive practice within their service (King et al., 2010). Shields and Synott (2016) concur and suggest training to overcome attitude and lack of inclusive practice from their large qualitative study. In line with this, one of the main messages that emerged from Beresford and Clarke’s (2010) consultation looking at the wellbeing of disabled C&YP, through accessing positive and inclusive services, was the need to ensure there is workforce training and development for all play and leisure staff. Training was identified as an urgent need by a high proportion of these service providers as they recognised their lack of skills. One of the main priorities was health care staff and those working in leisure facilities.

It is unclear how many volunteers are trained in the UK as there is no national database, thus there is a need to document any training and to establish areas where training needs to be improved and/or updated. The Bevan Foundation (2010) found in their Welsh study that there were a small number inclusive organisations providing disability awareness training but despite having policies and training in place there was no guarantee of inclusion. Brokenbrow et al., (2016) made a call for evidence on inclusion from service users and providers and, in response to this, have provided some suggestions for more inclusive practice and online training which does offer some assistance for the training gap.

2.12 Limitations

The review was based on a paucity of peer-reviewed papers with a heavy reliance on grey literature. The latter was difficult to search for due to the lack of a central database, so I needed to use open search engines such as ‘Google’ to search for charities and relevant information. This did provide a more complete and balanced view of available evidence by broadening the scope and having a comprehensive overview (Mahood et al., 2014; Godin et al., 2015) rather than relying on peer reviewed papers alone.

When conducting the literature search ‘PDC&YP’ were the focus but, because of the difficulty defining physical disability specifically, many of the papers included a range of disabilities but all focused on C&YP rather than adults. Some of the papers gave a specific sample breakdown so findings could be aligned to PDC&YP where others were more general. This is due to the variation in definitions of disability (Goodley, 2011). When papers discussed ‘disabled’ C&YP this could have been children with learning disabilities and, although this is very important information and assists understanding of disabled children’s needs, they do not necessarily have the same needs and did not specifically meet the inclusion criteria. This study specifically focuses on PDC&YP and, as with any group, some children had a mix of disabilities. The methods worked well across a range of participants.

2.13 Conclusion from the Literature Review

This review of the literature highlights a lack of understanding about the preferences of PDC&YP in relation to their out-of-school activities. The little evidence that is available suggests that disabled C&YP wish to access and participate in out-of-school activities but encounter challenges. Although the literature has given some insights around the facilitators and challenges to participation within community activities much of the research focuses on ‘disabled’ C&YP. This includes a mix of physical and learning disabilities but the preferences of PDC&YP are not specifically available. It is clear through the literature and my youth work that PDC&YP are missing out on mainstream activities and their needs are specific so the research needs to capture what this means in order to plan and provide suitable out-of-school provision. The need for social inclusion is clear but the factors affecting participation need to be explored. Further research is required to investigate the factors affecting PDC&YP's participation in out-of-school activities from the view point of both the service users and service providers. This is vital to establish the gaps between the needs of PDC&YP want and what service providers can and do provide. Without establishing the service provider's needs, plans cannot be established to enhance facilitators and overcome challenges.

CHAPTER THREE: METHODOLOGY

3.0 Introduction

This chapter presents an overview of the study methodology and discusses how the programme of research was conducted, outlining the process from the overall approach through to the detail of fieldwork. The overarching theoretical perspective, data collection methods, the sampling technique and the procedure used to gather the participants' views and experiences will be critically discussed. The ethical considerations of conducting research with disabled C&YP will also be explored.

3.1 Research Design

3.1.1 Qualitative Research Approach

There are many ways of viewing the world and developing a knowledge base. Qualitative research has been chosen for this study as this method explores beliefs and views of the world from people who participate in it, in a systematic and organised way (Flick et al., 2004; Gray, 2014). Qualitative research is characterised by the use of methods that attempt to examine characteristics and these are more interpretive in nature (Grix, 2004). Therefore this study sits within an interpretivist paradigm, which is a belief that individuals continuously make sense of the world around them but different individuals interpret things differently (Bryman, 2004: Parahoo, 2006). This is most appropriate as humans make sense of their reality and apply meaning to it, putting their life into context which this approach can capture. This interpretivist approach aims to explore in-depth opinions from participants and it is the behaviour, attitudes and experiences of the individuals that are important (Creswell, 2013). It explores personal views through words and allows the researcher to use more in-depth questioning during the data collection, (Flick et al., 2004) which is appropriate to explore out-of-school lives of PDC&YP. Kruger (1994) highlights the aim is to gain an insight into individual views and, due to the participants coming from a range of backgrounds and walks of life (service users and providers), this interpretivist view is positive which, in turn, provides rich data (Parahoo, 2006; Polit and Beck, 2009; Gerrish and Lacey, 2010). It allows insight into other people's worlds and in this study the focus is on individual's experiences, perspectives and beliefs, and especially children's experiences (Ross, et al., 2016 and Shields and Synott, 2016). In terms of analysing the data, interpretivists organise or reduce the data to uncover patterns (Alasuutari et al., 2008). This enables individual views to be shared whilst discovering themes and meaning as there is not just one answer or truth for a group of individuals (Berg, 2009; Patel, 2015).

When planning the study it was evident that none of the traditional qualitative designs such as ethnography, case study, grounded theory, or phenomenology were ideally suited to the aim of the study. The research questions did not fit neatly into these methodologies (Bellamy, 2016) and it was clear this study required a flexible approach promoting inclusivity as its ethos (Thomas-Hughes, 2017). This qualitative study explores individual “views, attitudes, beliefs or reflections on their experiences of things in the outer world” (Percy et al., 2015:76-77) and generic qualitative research was adopted.

3.1.2 Generic Qualitative Research

According to Patton (1990) generic qualitative research listens to descriptions of what and how individual’s experience life and simply seeks to understand their perspectives. A generic qualitative method of inquiry is an umbrella term for diverse approaches seeking to understand and explore social phenomena through interactive and flexible methods (Parahoo, 2006; Denzin and Lincoln, 2011; Greig et al., 2013). Generic qualitative research studies resist forming an allegiance to a single established methodology such as phenomenology, grounded theory, and ethnography (Caelli et al., 2003; Richards and Morse, 2007). It seeks to understand and discover the views and perspectives of people’s lives in the world in which they live calling on the positive areas of other traditional methodologies (Caelli et al., 2003; Sandelowski, 2010). Unlike these established qualitative methodologies, generic approaches do not promote a consistent set of theoretical assumptions and established methods can be blended (Crotty, 1998: Caelli et al., 2003). Generic methods allow an opportunity to use the tools that previously established methodologies offer, and to develop research designs that fit the needs of their participants and particular research questions (May, 2011). Kahlke (2014:49) supports this and states that “advocates of generic approaches promote the need for innovation and adaptation in methodologies” to fit the researcher and the discipline. Merriam (2009) and Creswell (2013) agree that generic qualitative studies can promote flexibility whilst utilising strengths of established methodologies and like all qualitative research, a generic approach aims to understand how individuals interpret or give meaning to their experiences.

Generic qualitative research often relies on naturalistic data collection methods such as interviews and discussion with groups of participants (Crotty, 1998). This approach is helpful for studies requiring a multi data collection method as in the case of the current programme of research which utilises focus groups, creative focus groups and semi-structured interviews (Strauss and Corbin, 1990). This allows the flexibility needed to gather such qualitative data but maintains the necessary structure to explore such issues (Holloway and Todres, 2003).

There could be tension between flexibility with methods to suit the individuals participating and the study structure (Holloway and Todres, 2003). There is a valid concern about ensuring congruence in research design (Kahlke, 2014) and this must be addressed. Generic qualitative research is sometimes seen as more simplistic and untidy but it still needs to be planned, implemented and evaluated with the same rigour as other approaches (Greig et al., 2013). To reduce the concerns about trustworthiness the researcher positionality, appropriate data collection methods and strategies to establish rigour need to clear (Caelli et al., 2003; Cooper and Endacott, 2016), and this is evidenced in this study.

There is a paucity of theory and literature of generic approaches with Caelli et al., (2003) stating there is a significant debate regarding validity and credibility. However since this paper was published there is growing guidance for researchers, promoting rigour (Kahlke, 2014). Although guidance is building there is no pre-set theoretical perspective governing generic qualitative research (Bellamy, 2016).

Generic qualitative research is considered the most suitable approach for this study because of the in-depth understanding of all the participants. In line with the whole ethos of the study exploring inclusive practice and positive participation experiences a flexible and adaptive approach through generic qualitative methods promotes this whilst maintaining a high level of rigour. It is vital to hear the views of the individuals at the heart of this study and to explore the facilitators and challenges affecting PDC&YP participating out-of-school activities (Thomas-Hughes, 2017; Bradbury-Jones et al., 2018). It is clearly evident from the qualitative literature review (Knight et al., 2013) that there is a paucity of information surrounding PDC&YP out-of-school lives therefore it is essential to build this evidence base to inform practice within activities and for commissioners within this field.

3.2 Procedure

The study fieldwork took place between October 2012 and August 2014.

The following flow diagram provides an overview of the methods process which will be explored in detail, see Figure 2.

Figure 2: Flow Diagram to demonstrate the Methods Process

	Study 1 **Service Users – PDC&YP and parents**	**Study 2** **Service Providers – Activity planners and volunteers**
↓	**Activity Search** Researcher search of out-of-school activities to locate gatekeepers for service users.	**Activity Search** Researcher search of mainstream out-of-school activities to locate gatekeepers for service providers.
	Gatekeepers contacted Pre-meeting to meet potential gatekeepers, discuss the study and provide information sheets. Inclusion criteria discussed. Purposive sampling used initially and then snowball sampling was effective via gatekeepers and other families.	**Gatekeepers contacted** Pre-meeting to meet potential gatekeepers/activity providers, discuss study and provide information sheets. Inclusion criteria discussed Purposive Sampling.
	Gatekeeper consent and pre-visit Gatekeeper consent for study gained. Gatekeeper contacted families with information and consent forms. Pre-meeting arranged with PDC&YP where appropriate .	**Gatekeeper consent and pre-visit** Gatekeeper consent for study was gained Activity planners interviewed. Gatekeeper contacted volunteers with information and consent forms.
	Joining the study Parents informed the gatekeeper that their child was able to join the study. Arrangements were made on time and location through the gatekeeper. Consent and Assent signed. Parents informed the gatekeeper that they wished to participate directly in the study and arrangements were made via the gatekeeper.	**Joining the study** Activity planners acted as gatekeepers for volunteers Volunteers informed the service provider gatekeeper that they wished to participate in the study and arrangements were made via the gatekeeper.
	Choice of Data Collection PDC&YP - Creative focus groups, paired interviews, individual interviews or family based interviews. Parents - Focus groups, paired interviews, individual interviews or family based interviews. I ensured full understanding of the study and collected written consent/assent.	**Choice of Data Collection** Focus groups, paired interviews, individual interviews I ensured full understanding of the study and collected written consent
	Follow up I was invited back on several occasions to groups to meet with the PDC&YP and gatekeeper	
	Transcription	
	Thematic Analysis	

3.2.1 Pilot Study

It was important to conduct a pilot study to check for the adequacy of the methods and procedures and to identify any potential practical problems or methodological challenges (Polit and Beck, 2009). A small scale pilot study was undertaken, once ethical approval was gained, to ensure the data collection methods and questions were suitable for each individual group of participants (PDC&YP, parents, activity providers and volunteers).

Prior to the pilot, I conducted a full search of activities available in Cheshire to ensure I was aware of available activities to contact (discussed in section 1.3), which enabled me to make contact with the initial gatekeepers. The semi-structured interview/ focus group/ creative focus group questions were previewed by the gatekeepers, before I met any of the participants and were deemed appropriate. They also checked the wording was suitable for the PDC&YP in particular.

The initial gatekeepers introduced me to a number of participants for the pilot study, which included a family (two parents and a young person), a creative focus group with four young people and interviews with four service providers.

All of these participants talked at length and the initial planned questions did not require any additional sub-questioning (appendix 7.5). The methods and questions were successful and the feedback from the participants and gatekeepers about the approach was very positive. No changes were made in light of the pilot study and the findings from the pilot were included in the final study.

As an extra measure, to promote a child-centred approach, two C&YP designed the participation information sheets, advised on the ethics application material and designed the consent forms. These two C&YP, who were not involved in the study, also designed all visual imagery for any dissemination material to ensure it is suitable and appropriate. It may have been more beneficial to have PDC&YP involved in the design but the gatekeepers also checked the use of the wording such as physical disabled rather than children with disabilities. PDC&YP views were forefront in my design and their views are shared verbatim in my findings. This plays an essential role in the quality of the design (Gerrish and Lacey, 2010).

3.2.2 Data Collection Tools

This qualitative study adopted a multi-method approach which is the use of more than one qualitative data collection method rather than relying on only one data source. For this study a range of tools including interviews, focus groups and C&YP-friendly creative focus groups were used. These were chosen as they allowed an indepth discussion to meet the needs of participants and promote participation. I personally collected all the data and it was important to the participants that they met me in person and they also wanted to know the intentions behind the research and my rationale. I gave all the participants the choice of when, where and how they wished to take part in the study using a given set of qualitative tools (semi-structured interviews, focus groups or creative focus groups). This choice was named the `pick-n-mix` as the children who designed my leaflets suggested a sweets theme and wanted it to be child friendly.

The aim of this study was to explore the views of PDC&YP and those supporting them. It was important that the research did not feel an onerous task for any participant. This element of choice fostered individuality and inclusion, the underlying ethos of the study (Thomas-Hughes, 2017). Using a flexible research process promoted a readiness to adapt the methods used in response of the needs of PDC&YP (Carroll, et al., 2018) and the adult participants. The aim was to put them in control of how and when they answered the study questions, for example, if they wanted to sit with a parent, join a group to talk together or be on their own. The participants were able to choose with whom they took part, for example, some young people chose to be with their peers, some children chose to be interviewed with their parent(s). This bottom up approach was instigated by the participants needs (Creswell, 2013: Carroll et al., 2018). The element of choice quickly became popular with the participants and they seemed pleased with the approach. This allowed them to feel comfortable, for example, a child could choose to be with their mother. Many of the participants fed back that they liked being able to choose the location, format and time as it fited around their family, childcare and work needs. Hill (2006) recognised the need for choice and states there is no one-best method from young people’s points of view. A number of gatekeepers commented on the need for flexibility with one gatekeeper saying to me *“My young people have participated in many studies but not one like this and this is just what we need, thank you.”*

However, there can be some drawbacks to using this mix of methods such as concern around analysis of data. With all the qualitative methods chosen, much of the control needed to be with all the participants especially the PDC&YP. I conducted them in a flexible manner in order to encourage free flowing narrative, essentially covering the same broad questions, which kept the process standardised. As an interviewer I was mindful of possible tension between flexibility and standardisation (Parahoo, 2006) and I was able to keep my input to a minimum. In practice, this worked well as the participants verbalised their views with little input from me. Other limitations include the additional time needed as a researcher to flexibly meet the needs of the wide range of participants which can be demanding but worth the effort to gain such valuable insight into their lives.

Multi-qualitative methods have been used in other studies with disabled C&YP where for example, researchers have used questioning techniques using drawings, photographs and other ways of communicating the information. These can be a fun way for PDC&YP to express their own views and experiences (Morgan et al., 2002; Barker and Weller, 2003; Darbyshire et al., 2005; Driessnack, 2005; Leonard, 2007; Noonan et al., 2017). The flexible methods used with PDC&YP enabled children all of varying needs and abilities to join in as also used by Carroll et al., (2018) in their New Zealand study with disabled C&YP. They used a toolbox of methods. Techniques such as drawing or play can enable C&YP to gain more control over the interview/focus group and it allows them time to reflect on their ideas (Miles, 2000). This is explained further in section 3.2.2.3.

When planning activities I also used the experience of the gatekeepers as they had the best knowledge of the PDC&YP. If the PDC&YP chose a group format, they were offered a child friendly format using ‘creative focus groups’ which will be discussed in depth below.

Initial demographics were noted at the start of each interview/focus group. For the PDC&YP this included their age, gender and what type of school they attended. They all discussed their disability as part of the questions so this information was added to the demographic profile immediately afterwards. The questions were on their out-of-school experiences rather than on their ability so it was important not to start with a question about their disability. For the adults, their gender and role were noted e.g. a parent, a youth volunteer or a sports coach (activity provider).

The semi-structured questions were formulated following the literature review on the out-of-school lives of PDC&YP (Knight et al., 2013), and addressed the aims and objectives of the study. The questions for each group of participants can be found in appendix 7.5. Each participant was given the opportunity to offer anything else they wished to add at the end of each interview in order to pick up anything they had thought to add during the process.

Regardless of which data collection tool was chosen, all of the participants were asked the same questions in a semi-structured format helping meet the overall aims of the study. To ensure high quality research the questions were standardised. All of the data gathered from study one and study two was analysed together at the same time and a consistent process applied to all (Burnard et al., 1991, 2008).

3.2.2.1 Semi-Structured Interviews

A research interview is a verbal interaction between the researcher and participant with the aim of collecting valid and reliable data to answer specific research questions (Denscombe, 2014). There are three forms an interview can take; structured, semi-structured and unstructured. In this study, I used semi-structured interviews with some adult participants and some PDC&YP. Semi-structured interviews include a small number of pre-set questions which are devised from the current evidence base (Berg, 2008). There is also scope for participants to discuss and elaborate around the questions. It also allows freedom to explore some of the answers given by the participant, with the order of questions varying to suit the responses (Taylor and Francis, 2013). Semi-structured interviews are effective for researching people's experiences in their own words and for issues that may be considered sensitive (Ellis, 2013). They were effective for both adults and children in this study as some of the topics were sensitive for example, discussing how participants feel about personal care. Semi-structured interviews can be prone to less misinterpretation than other tools, such as questionnaires, as the context can be checked during the discussion. This was important in this study as children and parents talked about activities, which I had not always experienced and which needed clarification. One example of this was the game 'Boccia,' which I was not familiar with and where clarification was needed.

Although questionnaires would reduce bias and promote anonymity (Walsh and Wigens, 2003), I felt these were not suitable to gather such in depth thoughts and feelings. This view was echoed by participants who stated that it was helpful to be able to explain their feelings rather than using an online survey.

Semi-structured interviews can be time consuming, and allow the participants to discuss issues wider than the research study. This could therefore lead to narrative which is not of any use due to the participant discussing a topic outside of the objectives (Ellis, 2013). Although a possible limitation, in this study, some of the parents wished to discuss issues around their child's original diagnosis as this was clearly a distressing time in their lives. Although this did not entirely link to the study objectives this was relevant and important and provided context to the research findings. It was important for me to respect this as it formed part of what I was asking but I was also an active listener for these issues (Walsh and Wigens, 2003; Ellis, 2013). It allowed parents the opportunity to discuss their needs and concerns even if this meant discussing wider issues.

In order for interviews to be successful, the participant must be able to articulate their views and experiences. So this was assessed when PDC&YP in this study chose to be interviewed individually. They were articulate and stated they felt comfortable to do this and in some cases they chose to be interviewed with a family member as this was most comfortable for them. Semi-structured interviews are widely used and there is no clear evidence of any long-term effects from discussing sensitive issues (Watson et al., 2008) but it was crucial to promote trust so they could stop whenever they felt they needed to. Where PDC&YP decided to be interviewed with their family member(s), I took the time at the start to build rapport with the individual child through play and appropriate conversation in order for them to feel comfortable and for me to quickly adapt my communication to meet their needs. This is an area in which I feel comfortable and confident due to my parenting, child nursing and youth work. It is important that there are no adverse effects on the PDC&YP from the research process.

When the interviews were used in a family setting, the questions were communicated appropriately for the PDC&YP to understand rather than questions being aimed at the parent. For example, I used child friendly informal language with appropriate eye contact. Each PDC&YP had the verbal ability to answer the questions themselves but they needed me to adapt my verbal and non-verbal communication skills to ensure they understood what I was asking. This was evaluated by the answer they gave, and whether it was an appropriate response to the question (Greene and Hogan, 2005). This enhanced the credibility of the research. By conducting every interview and I was able to seek clarification from the participants, for example, if any non-verbal and verbal communication conflicted (Parahoo, 2006).

Most of the interviews were conducted face-to-face but due to the demands of home life and childcare, three mothers of PDC&YP requested to be interviewed over the telephone. Limitations such as technical issues and the lack of face-to-face contact were considered as they may not promote the depth of discussion of face-to-face interviews and non-verbal communication cannot be interpreted during the process (Berg, 2008). However, Moules and Goodman (2014) suggested that this approach can encourage participation as it is less intrusive, which is what I found. These interviews were no shorter than others and the parents discussed in great detail the issues being raised. It was important to maintain a flexible approach regarding location and timing to suit the needs of these already busy parents so that the research could be inclusive and not intrusive. All adults stated they felt pleased they had the opportunity to verbalise their issues and it added therapeutic value for them (Moules and Goodman, 2014). I had no technical issues but had a backup recording device, in case.

3.2.2.2 Focus Groups

Focus groups are interviews in small groups that allow for a group discussion and can encourage the more reticent participants to explore their views. The participant views are gathered simultaneously (Vaughn et al., 1996: Bloor et al., 2001; Walsh and Wigens, 2003; Berg, 2008; Gibson, 2007; Taylor and Francis, 2013). This is a dynamic and rapid form of data collection growing in popularity (Gerrish and Lacey, 2010; Stewart and Shamdasani, 2015). In this study, focus groups were used for parents and volunteers as they were naturally gathered into small groups within the activity settings. Focus groups were particularly popular amongst the volunteers in this study. Volunteers are already giving up their precious time running the out-of-school activity so it was easier for them to meet straight after their session together rather than individually.

Focus groups offer a flexible approach and can be used across a range of settings which was required for my participants due to the nature of parenting and volunteering. They also provide a greater degree of spontaneity in the expression of the opinions than alternative methods of data collection and was preferable to some participants (Berg, 2008). This was evident with adult participants who chose this method as the conversation flowed and was detailed.

Some individuals prefer focus groups as they can provide a `safe` environment as they encourage the more reticent participants to explore their views in a flexible way (Kreuger and Casey, 2000; Salkind, 2008; Marshall and Rossman, 2011). They can capture similarities and differences in the opinions expressed, with good facilitation, and conclusions can be drawn from analysing the separate views (Walsh and Wigens, 2003). The analysis was then conducted in line with the semi-structured interview data to ensure consistency and validity (Burnard et al., 1991, 2008).

As discussed above, focus groups have many advantages however researchers need to be mindful of possible limitations such as the data collection can be influenced by the personal characteristics of focus group members. Interpersonal dynamics influenced by demographics, personality and physical characteristics can affect how the information is gathered (Stewart and Shamdasani, 2015). Where topics are very personal a group approach may not be appropriate (Walsh and Wigens, 2003, Parahoo, 2006). The questioning is pre-determined in a semi-structured way which guides conversation but gives flexibility to build on the discussion (Moules and Goodman, 2014). There was a wealth of data collected in this study because the focus groups were made up of natural groupings/teams, which added a natural flow and respectful discussion with minimal input from the researcher. With this in mind, whilst facilitating the focus group, I was aware of more dominant members of the group and encouraged participation from all members by asking each one for their opinion and for feedback on each point and their individual views were recorded and analysed.

Within the focus groups, a broad question was asked at the start (as in the semi-structured interviews) and invited answers from the group members, which in turn generated discussion and some follow-up questions to clarify points (Bloor et al., 2001) (see appendix 7.5). It was possible to observe a large amount of interaction and hear many views in a short space of time which is an economical way of data collection and can promote inter-participant interactions and to discuss views with like-minded peers (Walsh and Wigens, 2003; Fitzgerald et al., 2012; Coates and Vickerman, 2013). Each participant was given the opportunity to offer anything else they wished to add at the end of each focus group. Focus groups were successful with the adult participants but researchers need to be ready to “adapt methods to include all children rather than only engaging those who are able to access the methods already in place” (Coates and Vickerman, 2013: 344). This was ensure it was inclusive as possible for all participants.

3.2.2.3 Creative Focus Groups with C&YP

Focus groups with C&YP are increasingly popular especially in the fields of health, education and psychology (Greene and Hogan, 2005). The traditional focus group method was adapted here to make a `creative` focus group, an age and developmentally appropriate activity and play-based tool for the PDC&YP. Focus groups are especially helpful for children who are not literate as they are easy to understand (Stewart and Shamdasani, 2015) therefore positive for the PDC&YP in this study and the creative element was added to promote inclusion and active engagement.

The participant information sheet explained this approach fully so that the PDC&YP knew that they were not the traditional focus group that they may have seen or been involved in at school. They used the same questioning format as the more traditional focus groups used with the adults in this study, however there were different and important considerations in terms of consent and communication discussed below:

I designed the creative focus groups used in this study following a critique of the evidence base. The evidence is strong for using more creative ways to gather children's thoughts and opinions and involving them in the research and design. This participatory method is being more widely used within health, social care and education with C&YP (Colucci, 2007; Gibson 2007; Fargas-Malet, 2010; Richard, 2012). Participatory methods are where child participants take part in the process of data collection and as the PDC&YP are the experts in their own lives then this actively engages them in the research (Hodge and Runswick-Cole, 2013). PDC&YP are powerful agents in this research relationship and these methods can promote this (Bradbury-Jones et al., 2018). Creative focus groups utilise participatory techniques, which can include drawing, playing, photography and storytelling. The aim with these techniques is to promote an enjoyable environment and activities can promote a friendly environment (Colucci, 2007; Gibson 2007; Hodge and Runswick-Cole, 2013). PDC&YP can draw whilst talking or use the drawing to express themselves. They may use games such as puppets to explain what and where they mean when discussing a topic (Fargas-Malet, 2010; Richard, 2012). It allowed the individuals to leave the conversation for a while, enjoy the activity, and then return once they felt ready and this was important in the study especially for those PDC&YP who had various learning needs. The creativity enabled each PDC&YP time to answer the questions but still in the comfort of play.

Creative focus groups can reduce inhibition and help with group dynamic issues (Gibson, 2007; Marshall and Rossman, 2011). This is important as they are meant to be enjoyable and a successful way of gathering rich data (Fargas-Malet, 2010). This mix of techniques provided PDC&YP with time to think about what they would like to communicate, and not feel pressured to give a rapid answer (Fargas-Malet, 2010). The creative focus groups used child centred collection techniques which resonate with C&YP from their day-to-day activities (Carter and Ford, 2013). Development of the tool was also informed by my own personal experience working with groups of C&YP as a children's nurse and a youth leader.

I ensured the research questions were well framed and the process was well designed and checked with gatekeepers before meeting the PDC&YP. As with all C&YP there will be individuals within a group who have some learning needs and who can have some difficulties communicating (Lewis and Lindsay, 2000). Although the focus of the study is on PDC&YP there were a small number of children who had some level of learning disability as well as a physical need. This is inevitable in any group of children and as long as they deemed themselves to have a physical disability they were included in the study. This has implications for the planning, as it required a larger time investment to accommodate the range of needs of all the PDC&YP. However, this was absolutely vital to ensure all PDC&YP could be and were included, reflecting the ethos of the study. The purpose of the study is to ascertain factors affecting inclusion therefore they needed to be included fully in the study. All the C&YP who participated were able to communicate verbally with some who were very articulate whilst some were more difficult to understand. It was therefore important to allow time, space and creative opportunities for them all to express themselves and their feelings so that their views could be put forward regardless of their communication abilities (Knight and Oliver, 2007). PDC&YP who were unable to communicate verbally due to complex needs were represented by their parents via the interviews. Although the study wanted to focus on the views of PDC&YP themselves it is vital that this group of PDC&YP are represented otherwise they will be completely lost from disability studies.

There were developmental differences and various learning disabilities of participants so I ensured that each PDC&YP had an equal opportunity to share their thoughts in a safe environment. This is vital and, as with any focus group, there are concerns about not everyone in the group having their view (Gerrish and Lacey, 2010) or being swayed by a group norm (Moules and Goodman, 2014). It is important that the facilitator can support individuals to share their thoughts in a safe environment (Parahoo, 2006).

Creative focus groups with PDC&YP are an effective way of gathering views despite sensitive issues being discussed and are thought to promote a greater openness than interviews (Greene and Hogan, 2005). This methodological innovation of adapting to C&YP with a wide range of needs and communication styles made for a unique, enjoyable approach. The `friendly` approach adapting to the situation was positively commented upon by several gatekeepers. Colucci (2007) acknowledged that less traditional ways of facilitating focus groups can make analysis complex but it makes for a more enjoyable experience and a successful gathering of rich data. The data were rich and the questions used were in the same format as used in any other data collection format to ensure rigour and consistency (Burnard et al., 1991, 2008). This ensured that the questions asked were the same but the activity running alongside the questions enhanced their experience. Had I conducted a traditional focus group with PDC&YP the questions and procedure would have been the same but less enjoyable and potentially less data collected as they may not have felt as relaxed, which was pointed out by several gatekeepers.

This illustration is an interpretation of creative focus groups by a young person:

Figure 3: Illustration by Georgina (aged 16 years)

Before meeting with the PDC&YP I worked closely with gatekeepers to gain an understanding of the PDC&YP's needs so that I planned appropriate activities. With some groups I volunteered at the activity club with the gatekeeper first. This was to build up trust and a rapport with the PDC&YP so that I was not a stranger and they could get to know me. If the researcher facilitating is "comfortable and natural, participants will feel relaxed" (Gill, 2008:294). I then pre-planned a number of activities from which PDC&YP could choose what they wanted to do, for example, sports, crafts and games. At the time of the creative focus group I obtained assent from the PDC&YP by asking them what they understood they were going to be doing and checking they were happy to participate (see section 3.6 for further definition and see appendix 7.3). Once granted and I had the parental consent forms I facilitated the creative focus group session. The gatekeepers took the lead in delivering and collecting the consent forms so that both they and I, as the researcher, could check all the permissions were in place (see section 3.6). The gatekeeper was asked to co-facilitate the creative focus groups ensuring the PDC&YP felt comfortable as they were used to working with this person each week during their regular activity. Although by doing this there was potential that the gatekeeper could have influenced what PDC&YP said, but due to the time spent with the gatekeeper prior to the data collection, the level of understanding was high and we had discussed their presence as a possible limitation. They were excellent co-facilitators and knew when they needed to support children and when they let it flow. The questions being asked in the study did not relate to the club which the gatekeeper was from so the PDC&YP talked openly about their likes and dislikes within their general out-of-school lives. The club in which these were held were specialist disabled clubs whilst the focus of the study was on what else was available.

The gatekeeper who knew these young people very well was able to ensure that the meanings of some verbal language was interpreted correctly. An example of this was the term 'activities', some PDC&YP preferred the term 'hobbies'. Richards (2012) supports this approach and looked at workshops as a qualitative research tool recognising that children are natural storytellers. He even goes on to say with some adaptations that they can be used for adults. Although Richard's (2012) study focuses primarily on market research, it does offer some support to the approach used in this research on out-of-school lives.

When I met the PDC&YP, I introduced myself and whilst checking their understanding of the study I found out what they like to do and adapted the activities to them. As an icebreaker, I joined in their activity with their permission e.g. ball games. In order to provide the ‘creative’ element I designed a large bag of activities (see appendix 7.6) using personally tried and tested methods from my youth and health work. I chose sports, ball games, drawing and crafts as the basis of the activities and parachute games, a definite favourite. Greig et al., (2013)’s practical guide was a helpful aid when preparing for these methods. The gatekeepers also deemed the activities suitable, for the PDC&YP. This creative version offered a valuable, fun and developmentally effective method for use with PDC&YP in order to enhance the experience and meet various age, developmental and interests within the group (Hodge and Runswick-Cole, 2013). Creative focus groups fostered a rapport and provided a positive mechanism for asking questions.

The group activity included using the parachute for example, followed by crafts and drawing, whilst we ‘chatted’ through the questions. The groups lasted approximately 30 minutes to one hour and were audio recorded with consent/assent so that I had an accurate record of the full conversation and interaction (see appendix 7.5). This also meant I could concentrate on the interaction and inclusion of the activity. This helped to build a rapport and promote a comfortable and inclusive and flexible environment, for example, when PDC&YP wanted to go to the bathroom, they went and then joined back in afterwards.

I was confident using this approach and could quickly adapt to a different activity where necessary. I believe that adults should not ask C&YP to do something they would not try and therefore I played the games, sports, designed the crafts and did not take myself too seriously. This fun, yet professional approach, worked well. A possible limitation may be that during the fun activities PDC&YP may become distracted. Children can naturally become distracted and need a break and this was important to recognise when working with any child. The flexible approach and ability to adapt as a researcher ensured that all the questions posed were answered in an encouraging and positive way. PDC&YP had small toilet or snack breaks which worked well as some had a short attention ability but with the break were able to continue well. Research should not take place if it becomes a negative experience so this creativity and flexibility worked well. It does need a researcher to have confidence in their own ability and necessary communication skills to facilitate this type of environment and recognise, appreciate and adapt to the PDC&YP’s needs.

I have cared for families from all walks of life with varied communication needs and this proved very valuable in adapting to their needs and preferences, for example, one young boy wanted to join in the activities and chat to me during this but also wanted his Mummy there as he liked to hold her hand. I was able to ask him questions and follow this up by speaking to his mother separately later. Another example of this was during a sports training event, I was able to join in with the activity which allowed interaction straight away and then the young people chose to answer the study questions in small groups at the side of the sports court whilst having drinks and snacks provided by the coach.

The activities/games created a lot of laughter, noise and broke down any initial shyness from the PDC&YP. This is supported by Gibson (2007) who highlight that games, crafts and activities can stimulate conversation for C&YP who are perhaps a little quiet or lack confidence in groups and can assist a situation where they may be reluctant to express their views. This proved successful in this study as all of the PDC&YP fully participated in the study whilst enjoying the activities. They seemed to enjoy this approach together with the gatekeeper's feedback that they had found it an inclusive way of gathering the information. It is a possible limitation, as in traditional focus groups, that the more confident members of the group may dominate discussion not allow others the time to air their views and this may be more evident with PDC&YP with communication difficulties. The activities allowed each PDC&YP time with the researcher so everyone had time to share their views in a supportive way.

Some of the PDC&YP chose to do some drawing during the creative focus groups. Drawing can aid communication, encourage trust and help motivate children (Horstman et al., 2008) which were real positives for this study. In future creative focus groups they could specifically be invited to draw about the subject in hand perhaps their out-of-school experiences. Some of the PDC&YP drew pictures during the creative time but I did not include this in the analysis but future studies could include this with consent / assent. Drawings have been included in child research in education and health for a while such as 'draw and write' where they write down their answers to discussions as well as illustrating their example (MacGregor et al., 1998; Horstman et al., 2008). These studies promote the use of draw and write but report some difficulties analysing the drawings and also researchers need to be careful about the children conferring with each other and ending up with the same drawing. They can be used as an 'icebreaker' and they help C&YP explain their ideas and views (Carter and Ford, 2013). MacGregor et al., (1998) and Horstman et al., (2008) also found that some children in their education and health studies wanted different ways of expressing themselves which the creative focus group choices would allow.

In addition, the writing part of the draw and write, needed to interpret the drawing and is not therefore suitable for illiterate children of which there were many in the study and may create an unnecessary challenge. An alternative may be ‘draw and tell’ where the drawing is explained by the PDC&YP verbally and is recorded to aid analysis. This would be more suitable to meet the needs of the range of PDC&YP. They were all able to verbalise their thoughts but many would have had difficulties with writing views down for ‘draw and write.’ Noonan et al., (2017) reported positive use of ‘draw and tell’ in school-aged children in more of a diary format when discussing physical activity. This could perhaps be added to creative focus groups in the future should PDC&YP choose this as an option.

The PDC&YP who were interviewed in their home with their parent or parents present were given the same option of doing an activity and some of the younger children chose to draw or play with a small object such as a teddy or robot. The older young people chose to be interviewed more formally, again with refreshments provided by their parents.

The PDC&YP were provided with £5 book tokens for their participation. There are mixed views and guidelines about the use of payment for participants. There is no consensus whether time and effort should be rewarded. The RCPCH (2000) clearly states that no financial inducements should be offered to C&YP or parents unless these are expenses and the Medical Research Council (MRC, 2004) agrees due to concerns over coercion. However, National Children’s Bureau (NCB, 2003) and Barnardo’s (2002) say it should be considered a moderate reward such as a gift voucher. Twycross (2009) acknowledges that this is an area where further debate is needed. This payment was agreed through ethics approval.

3.3 Researcher Background and Reflexivity

Qualitative researchers must understand how events are socially constructed and when interpreting data it is important for the researcher to be self-aware, self-analytical and politically sensitive (Sandelowski, 2010; Caelli et al., 2003; Christensen and James, 2008). It is however impossible to achieve complete neutrality and objectivity as one’s own values become an integral part of the research. Therefore, the researcher must be reflexive so they can account for their own position in the setting and situation, as the researcher is the main research tool (Bryman, 2004). Using a reflexive approach, researchers can come up with surprising findings due to the external stance being taken (Bryman, 2004). Reflexivity is the way in which the researcher acts within the study and the study upon the researcher. The researcher stands outside the research process and critically reflects on the process (O'Leary, 2004). The ability for the researcher to maintain self-awareness and be aware of the potential bias is paramount in this process. In this study I was a visitor into the lives of the participants and was aware of the affect my presence could have.

In qualitative research, it is important to account for the researcher's feelings and emotions as well as the participants. There is no doubt that these can be conveyed to participants and in turn, influence the situation, and much of this is on an unconscious level. Researchers need to position themselves in a qualitative study because background, culture and history informs interpretation of the information of the study (Creswell, 2013). It is vital to recognise personal positionality throughout and declare this from the start as outlined below.

I have been sensitive to the ways in which I am part of the research process (Cooper and Endacot, 2007). An example of this was when, at times, some parents swayed on to healthcare issues, as they were aware I am a children's nurse. It was clear from all parents who I met that in order to fully discuss their out-of-school lives they needed to discuss their child's diagnosis. I could relate to this from my experience with parents receiving medical diagnosis for their children in my nursing role. This is a critical part of their lives, which influences many factors of their lives from that point onwards. Therefore, it was important for questions to allow for this to be discussed.

3.3.1 Researcher Positionality

Mays and Pope (2000) highlight that the effects of personal characteristics such as age, sex, social class, and professional status affecting the relationship between the researcher and participant needs exploration and discussion. I am a white female from a middle class background; I was born and live in Cheshire where this study was positioned. My personal and intellectual bias in terms of being a healthcare professional, youth leader, female and a mother has influenced how individuals have responded to me. For example, a mother-to-mother interaction is different to someone who perhaps does not understand the daily needs of young children. Some interviews were conducted over the telephone late at night in order to ensure the mother was free to talk without interruption. I understood this need and adapted to ensure I could include such parents. Even though there is some mutual understanding by being a parent, many of the gatekeepers and parents questioned my motivation for this study, as I was not a mother of a disabled child or, in fact, not personally disabled. This initially acted as a challenge, certainly to many gatekeepers, but once they had asked me what my motivation was for doing such a study there was an obvious change in communication and they opened up quite freely. This was the case with many of the gatekeepers being disabled, many of whom had a physical disability themselves. Interestingly, having made initial contact via email and telephone there was some expectation when we first met that I would be disabled.

I am a children's nurse which study participants were made aware of through the participation information sheets. I have had professional and personal experiences, which have shaped this research, analysis and dissemination. I have over 20 years' experience in paid and ten years in voluntary youth service. I am confident communicating and engaging with C&YP which I felt put the C&YP at ease and it helped me to build a rapport with the gatekeepers which aided recruitment. I used appropriate verbal and non-verbal communication skills such as keeping eye contact, and having open body language (Fargas-Malet, 2010; Dickins, 2011) which allowed for rapid assessment and change in activities responsive to the PDC&YP. I have the communication and facilitation skills from my voluntary work and from clinical nursing practice, however if dynamics in the group changed or had become difficult, I would have sought advice and guidance from the gatekeeper who knew the PDC&YP (King and Horrocks, 2010; Shaw et al., 2011).

My role was also to act as an advocate for the PDC&YP by listening to each individual and to portray their needs by speaking out on their behalf (Nursing and Midwifery Council, 2015), therefore I encouraged PDC&YP to speak up about their needs. This was explained in the participation information sheets (see section 7.3). This may have influenced how the participants viewed me, particularly for parents, as they perhaps leant towards talking a lot more about their child's medical input. When interpreting the data I may also be influenced around the health related behaviours such as personal care but my training and role does prompt me to look at the person from a holistic perspective rather than at their impairment.

Being a resident of Cheshire, I was able to relate to discussions PDC&YP introduced and I did not need to ask them to explain where they were talking about, for example, a leisure centre or a local park.

The participants were aware that I was a youth leader which could have been a potential bias as they may have talked more critically about youth services if they felt

I may have been able to change their experiences directly. This may have led to further discussion in youth. However, the dominant activity they discussed was sport to which I have no link.

The relationship between childhood and adulthood often means that the child's experiences and opinions can be subsumed by well-intentioned researchers. My reflexive approach allowed the PDC&YP views to be kept at the forefront. I have no direct experience of the real life issues faced by these families, however, with the combination of my experience, I was in a good place to understand and was certainly an active listener.

3.4 Population, Participants and Sampling

Multiple sampling strategies were used including purposive and snowball sampling to recruit service users and service providers. (Parahoo, 2006; Berg, 2008; Denscombe, 2014).

3.4.1 Purposive Sampling

Purposive sampling which is a non-probability sampling technique where the participants are selected because they meet the inclusion criteria, was used to recruit all of the gatekeepers and participants in this study. This included PDC&YP aged 7 to 17 years old, parents and service providers. Younger children may have difficulty contributing at the same level as the older children and adolescents and were therefore not included. Purposive sampling is commonly used in qualitative methodology but the researcher must be mindful of any potential bias with it not being a random selection of participants. It is rather based on the assumption that the researcher has knowledge of the population, which can be advantageous in approaching the participants who meet the criteria and therefore not wasting the time of those who do not fit (Polit and Hungler 1997; Berg, 2008; Moule and Hek, 2011). The clear inclusion and exclusion criteria reduce some of the potential bias of a researcher picking their participants. The PDC&YP were approached by gatekeepers as they understood the inclusion criteria and could signpost families to the research. It works on the principle that the best information can be obtained when focusing on specific attributes such as their relevance and knowledge. (Polit and Hungler, 1997; Berg, 2008; Denscombe, 2014). It was important, however, in this study to ensure the participants met the inclusion criteria in order to meet the specific aims of gathering information about PDC&YP out-of-school lives. All the participants essentially volunteer to be in the study, therefore give rise to the possibility that participants who either have had excellent experiences or more frequently those who have poor views to share offer to be interviewed once they read the participation information. This causes a potential bias in that the families with poor experiences may be more likely to volunteer.

3.4.2 Snowball Sampling

Snowball sampling was also employed to recruit service users and service providers. This is another non-probability sampling strategy in which a person who is identified as a valid member of a specified group to be interviewed is asked to provide the names of others who fit the requirements (Corbetta, 2003; Parahoo, 2006; Denscombe, 2014) until the researcher has an adequate sample. It can be helpful to locate participants with certain characteristics (Berg, 2008) and it can be a useful technique in finding a hidden group, which, in this case, was PDC&YP who currently do not engage in any activities. One of the major problems with snowballing is that participants may choose others with the same background and outlook as them (Parahoo, 2006). In this study this would be other families with PDC&YP who access the same activities. The PDC&YP involved accessed a range of activities or none at all. Most of the snowballing came via parents who know other families due to support groups or links with gatekeepers. Payne and Payne (2004) highlighted that the quality of the sample when using snowballing does depend on what the starting point is and what the strength of the network is like. Initial recruitment was very successful through gatekeepers and then snowball sampling was also very effective with parents ringing and emailing gatekeepers requesting to join the study. I was expecting to struggle to reach those who do not do activities but, in fact, parents who struggled with activities were referred to me via carer forums. All of the families were recruited through gatekeepers and five families were recruited through other families.

3.4.3 Service User Recruitment

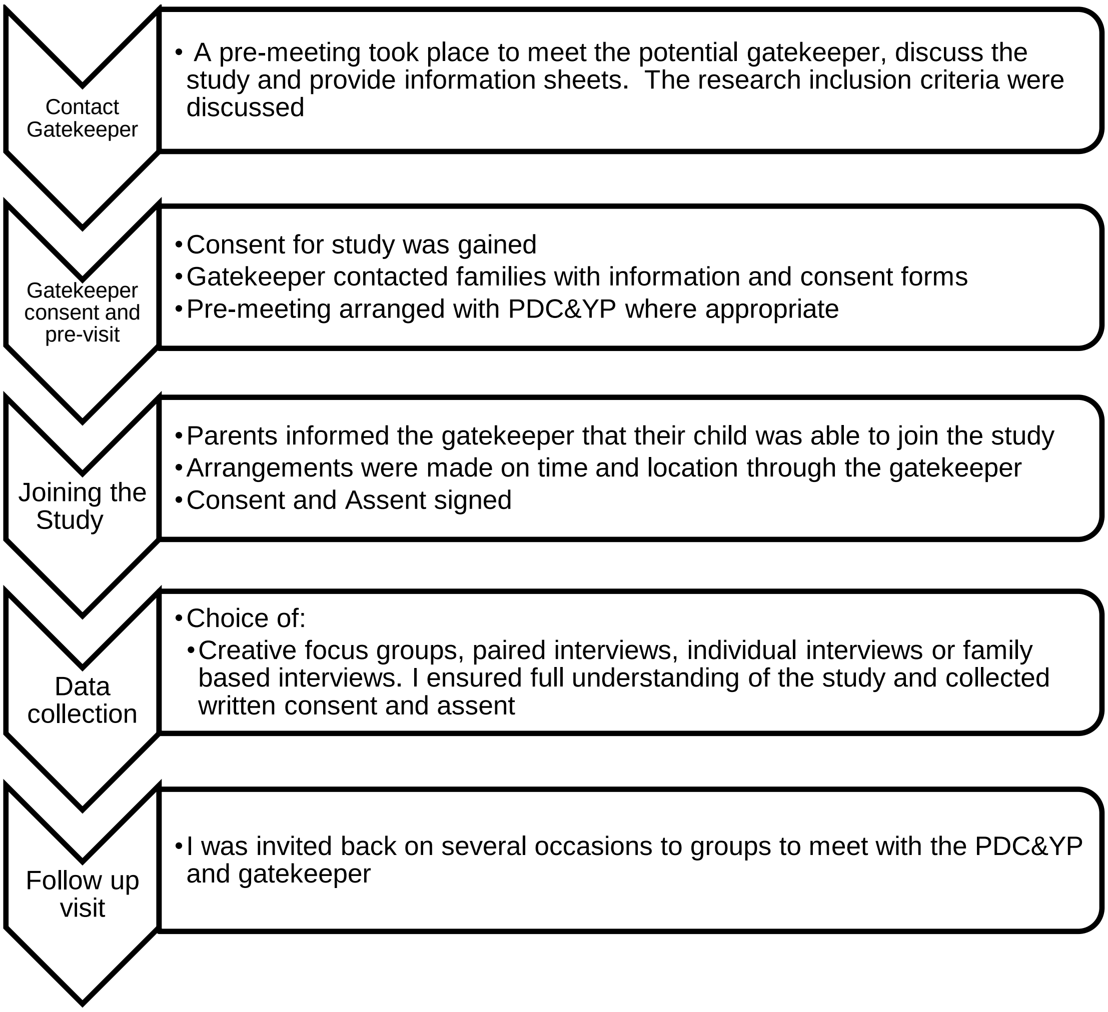
In order to find appropriate groups of service users, before starting the fieldwork in 2012, I searched the `Contact for Families with Disabled Children` website database which holds contact details of groups for disabled C&YP within the UK. The search was narrowed to the North West of England, then specifically Cheshire. I then targeted carer forums, pre-existing youth groups, specialist clubs, respite centres and charity events (see Figure 4 for the processes). I searched for a variety of groups across youth, religious groups and sport, which I felt covered the main activities for C&YP. I ensured a wide range of organisations were involved in the research. I contacted potential gatekeepers of each group via telephone and followed up with a letter, information sheet (option of hard copy or email) and a gatekeeper consent form (see appendix 7.3). The gatekeepers were involved throughout the whole process and that families knew the study had been sanctioned by them. This also ensured I had continuous contact for any safeguarding issues as gatekeepers are there to protect PDC&YP from harm (Fraser et al., 2004). This is supported by Denscombe (2014) who highlights that gatekeepers are not disregarded after the initial approval for their participants to be approached but they maintain a continued influence and support throughout and after the study. It was important for the researcher to fully explain the research process to the gatekeeper, with the aid of the participation information sheet, as they helped recruit appropriate families.

If the gatekeeper was happy to help with recruitment of the PDC&YP and parents, and to help with facilitation of the creative focus group sessions then they were asked to sign the consent form. I met with the gatekeeper to discuss the research in person and collect the consent form. Nine gatekeepers contacted relevant PDC&YP and parents who met the inclusion criteria. The gatekeeper was provided with information packs to hand out to potential participants, which included participation information sheets for the PDC&YP and their parents to read, participation information sheets for the parents for their own participation and expression of interest forms. The parents were asked to complete the expression of interest form and to return it to the gatekeeper. This was to collect demographics and information of suitable times (see appendix 7.3).

The gatekeepers used Facebook and Twitter to recruit and pass on information as well as coffee mornings and word of mouth. Within the groups, all individuals who met the inclusion criteria had equal chance of being invited by the gatekeeper. One example was a young male who was a wheelchair user and required prosthetic limbs to walk unaided. He did not feel ‘disabled’ as he preferred to focus on his abilities. He did however recognise that he had a diagnosis, which labelled him as having a disability which did help him get the medical care and equipment he needed. He volunteered to be interviewed as he recognised he met the criteria but wanted to make it clear that, in his mind, he was able and not disabled.

Figure 4 shows the recruitment process of PDC&YP.

Figure 4: Recruitment process of PDC&YP



Contact Gatekeeper

- A pre-meeting took place to meet the potential gatekeeper, discuss the study and provide information sheets. The research inclusion criteria were discussed

Gatekeeper consent and pre-visit

- Consent for study was gained
- Gatekeeper contacted families with information and consent forms
- Pre-meeting arranged with PDC&YP where appropriate

Joining the Study

- Parents informed the gatekeeper that their child was able to join the study
- Arrangements were made on time and location through the gatekeeper
- Consent and Assent signed

Data collection

- Choice of:
  - Creative focus groups, paired interviews, individual interviews or family based interviews. I ensured full understanding of the study and collected written consent and assent

Follow up visit

- I was invited back on several occasions to groups to meet with the PDC&YP and gatekeeper

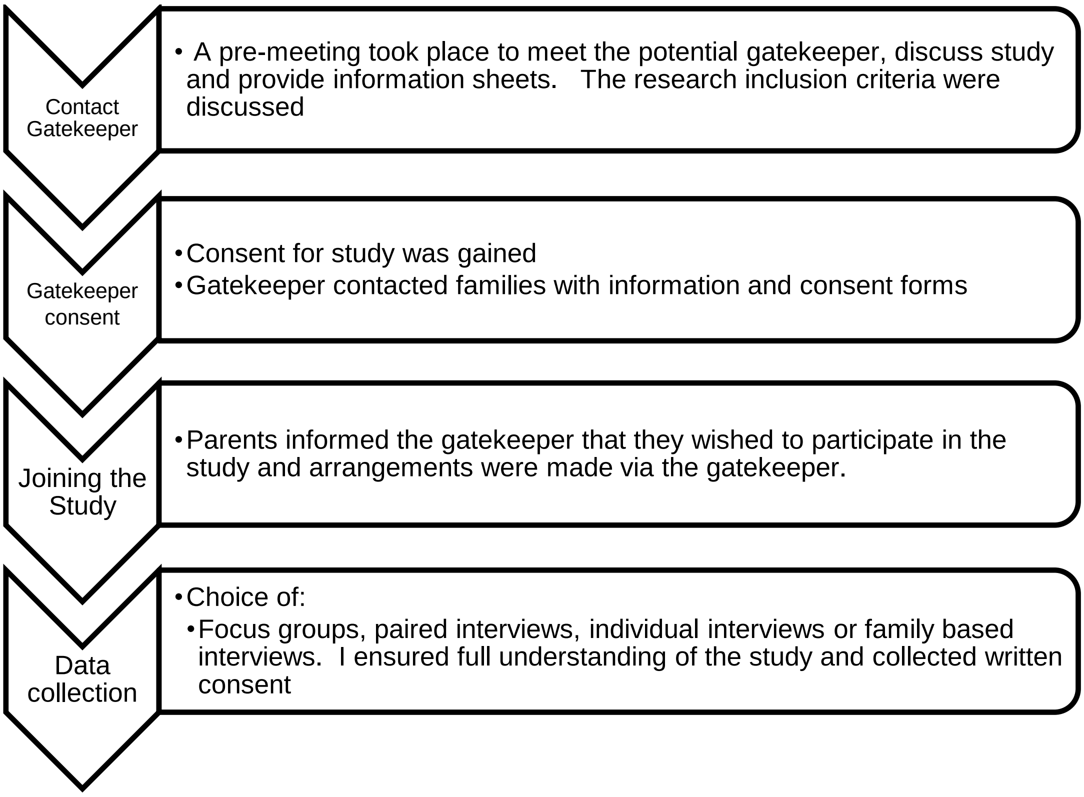
PDC&YP and parents were given participant information in a format suitable for them by gatekeepers and parents (Lambert and Glacken, 2011; Shaw, 2011) (see appendix 7.3). These were designed and edited by two C&YP, independent of the study. This allowed terminology to be checked for understanding and graphics to be age appropriate and appealing to PDC&YP.

The information was also explained by the PDC&YP's parents and this was also checked at the start of data collection by the researcher and gatekeeper to ensure the child fully understood. The physical disabilities included cerebral palsy, amputations, problems with walking or balance and medical conditions, creating mobility problems.

During recruitment for the PDC&YP, the same gatekeepers were asked to identify parents of PDC&YP to participate in interviews. They were recruited at the same time via the gatekeepers (see Figure 5 for the process). If the children wanted to be involved as well as the parents then that was encouraged. Likewise, if only one party wanted to participate for any reason, for example, the child could not verbalise independently, time constraints or choice, then this was also supported. The parents communicated this via the gatekeeper who then made arrangements with me as the researcher. Data collection was conducted separately in most cases unless the child and family chose to be interviewed together. The parents were able to participate without their child being involved and vice versa and they indicated this through the expression of interest forms. The participation information sheets were sent out to the gatekeepers whilst recruiting. The parents were interviewed in the location where the activity normally takes place at a convenient time to them or in a home setting.

Figure 5 shows the recruitment process of parents.

Figure 5: Recruitment process of Parents



- A pre-meeting took place to meet the potential gatekeeper, discuss study and provide information sheets. The research inclusion criteria were discussed

- Consent for study was gained
- Gatekeeper contacted families with information and consent forms

- Parents informed the gatekeeper that they wished to participate in the study and arrangements were made via the gatekeeper.

- Choice of:
  - Focus groups, paired interviews, individual interviews or family based interviews. I ensured full understanding of the study and collected written consent

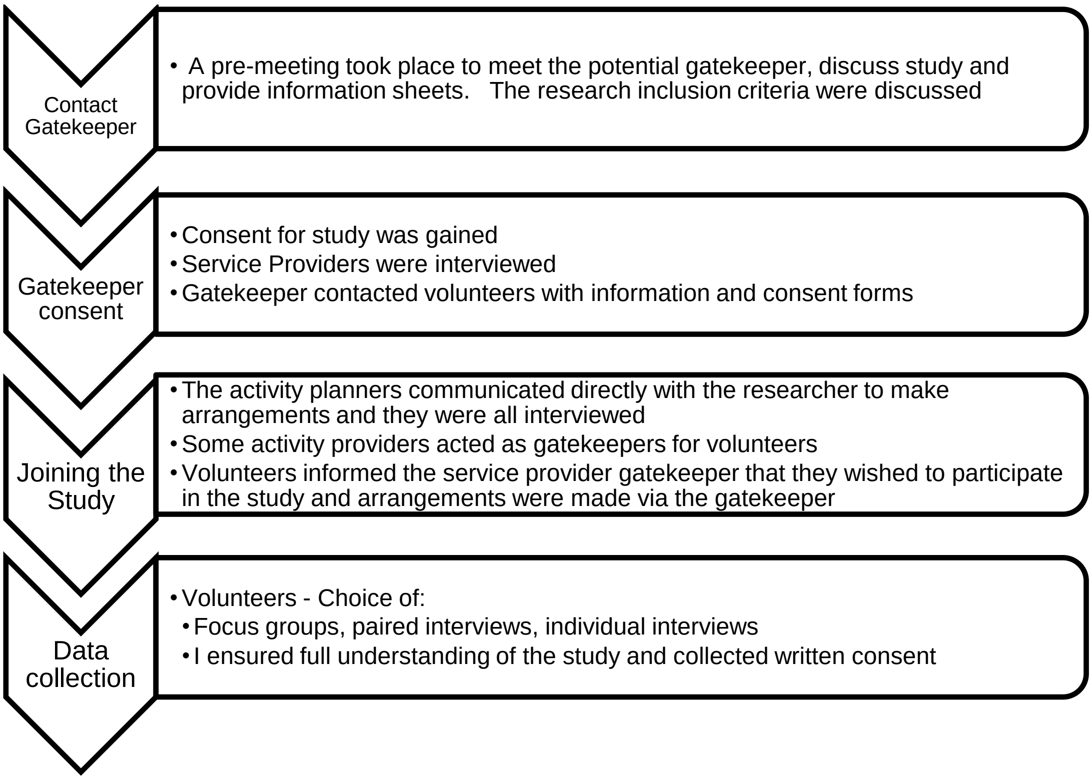
3.4.4 Service Provider Recruitment

The service providers (activity planners and volunteers) were recruited from an array of mainstream out-of-school activities e.g. youth clubs, sports groups and church activities. They were all adults working with school-aged C&YP and interviewed individually or in small groups depending on what they preferred. Volunteers were also recruited through gatekeepers across the same type of activities. A search for mainstream groups was also conducted on the internet, to recruit both well-established groups such as the Scout Association and smaller ad hoc activities within communities. Local newspapers were researched and word of mouth was also utilised once the bigger groups had been approached. From contacting the gatekeepers from each of these areas, word of mouth was the most effective way of snowball sampling and I had no problems accessing groups and individuals. Activity planners and volunteers were invited simultaneously. Participation was not contingent on both provider and the volunteers from the same organisation/activity being involved.

I contacted potential providers directly by telephone, followed up by a written participant information sheet. They then also acted as gatekeepers for volunteers (see Figure 6 for the process). The provider was contacted via telephone to check if their pre-existing club was a suitable place to recruit volunteers running mainstream out-of-school activities. This was then followed up with a letter, information leaflet and a gatekeeper consent form. I met with the gatekeeper and discussed the research in person and collected the consent form (see appendix 7.4). The providers were then interviewed in the location where the activity normally takes place at a convenient time to them which was organised directly with the individual. A consent form was then signed prior to the interview. Each interview lasted no longer than one hour and was voice-recorded.

The volunteers were recruited via gatekeepers (which in some cases were the providers above), for example, the Scouting County Commissioner to speak to District Commissioners, Group Scout Leaders and their volunteers running the Cub Scout packs. Figure 6 shows the recruitment process of service providers.

Figure 6: Recruitment process of Service Providers



- A pre-meeting took place to meet the potential gatekeeper, discuss study and provide information sheets. The research inclusion criteria were discussed

- Consent for study was gained
- Service Providers were interviewed
- Gatekeeper contacted volunteers with information and consent forms

- The activity planners communicated directly with the researcher to make arrangements and they were all interviewed
- Some activity providers acted as gatekeepers for volunteers
- Volunteers informed the service provider gatekeeper that they wished to participate in the study and arrangements were made via the gatekeeper

- Volunteers - Choice of:
  - Focus groups, paired interviews, individual interviews
  - I ensured full understanding of the study and collected written consent

3.4.5 Sample Size

There is no established criteria for sample sizing in qualitative research as it depends on the purpose of the study and trying to define a number can be problematic (Polit and Hungler, 1997; Sim et al., 2018). However, Morse (2000) highlights when gathering in-depth data via semi-structured interviews a small sample of, approximately, six to ten maybe sufficient. Guest et al., (2017) suggest a total of 12 interviews should be enough to reach saturation point but this was a very specific phenomenological study. Parahoo (2006) highlighted that the more varied the population the larger the sample needs to be. The aim was to reach saturation which is described by Corbin and Strauss (2008) as when no new data emerges and enough information is gathered to support the studies (Kvale, 2011, Emmel, 2013; Sim et al., 2018). It was clear during the initial phase of data analysis that data saturation point had been reached as there was repeated information, clear themes and sub-themes.

The initial aim was to recruit five to six PDC&YP per creative focus group, which is deemed an appropriate size by Vaughn et al. (1996) and Kruger and Casey (2000). In reality, due to the natural groupings within the activities, smaller numbers were recruited per group. The PDC&YP requested smaller groups when creative focus groups were being set up with gatekeepers as this made them more comfortable.

The implications of this were positive as it allowed the PDC&YP more time to speak in a calmer environment, which was important for those with a learning disability. Smaller groups of three to four children is considered sufficient according to Coyne et al. (2009) because this may be their natural grouping or they maybe more comfortable to communicate in smaller groups. This size has been used in previous research using focus groups with children (Porcellato et al., 2002).

The focus groups and creative focus groups were all comprised of natural groupings of participants, for example, a group of young people of a similar age who were friends from the youth club. The implications of this were that they may present a group norm and their views similar but alternatively it gave this underrepresented group an opportunity to share the issues they faced. However the findings from one-to-one interviews with PDC&YP highlighted the same issues in participating in out-of-school activities.

Table 2: Breakdown of the Sample and Methods used for Each Group of Participants.

Study		Objectives	Sampling Frame
Service Users	PDC&YP	1, 2, 3, 4	Purposive Snowball
	Parents of PDC&YP	1, 2, 3, 4	
Service Provider	Providers of mainstream out-of-school activities	1, 2, 3, 5	Purposive Snowball
	Volunteers working in mainstream out-of-school activities	1, 2, 3, 5	

3.4.6 Location of Data Collection

All participants were interviewed in a location convenient to them; often this was where the activity normally took place (for example, a sports or youth club) or at the participant’s home. Data collection was arranged at a suitable time for the participants via a gatekeeper.

Parents or carers might wish to be present during the questions with their child, which can influence children’s responses (Scott, 2000). However, in this study parents were present with all of the PDC&YP interviewed when in their home due to safeguarding measures and to comply with ethical approval. I recognise that there may have been some influence by a family member being there but I ensured that each child was given space to talk and I encouraged them to express their views through the creative methods. Hill (2006) highlighted the importance of being aware of the research context, which might affect what C&YP will talk about. In some cases, I also re-visited the home whilst the child was at school to give the parent the opportunity to share their views. This meant that they both had space to talk without influencing the other.

Four families with the PDC&YP present chose to be interviewed in their home. There is some discussion in the literature whether this is a good environment with Scott (2000) highlighting the home is a familiar environment which can promote comfort so they can talk freely but had concerns that it is time-consuming and costly for the researcher. However, Hill's (2006) review highlighted some C&YP felt it was intrusive to be interviewed at home. The four C&YP interviewed at home appeared comfortable, as they were able to play with their own toys and pets whilst talking freely. All four interviews took place in the family kitchen. Although this was time consuming and involved a lot of travel in an evening, for me as the researcher, it was worth the investment to gather such important views and meet the needs of the participants.

All the adult participants (parents and service providers) chose to meet in their activity location or in a neutral convenient setting.

3.5 Data Processing and Analysis

3.5.1 Data Storage

The names, addresses, email addresses and telephone numbers were collected in order to arrange the meetings. These were only accessed and used by me as the researcher and stored securely on LJMU password protected computers and deleted once the fieldwork completed. The anonymised data will be stored for a minimum of five years for reference purposes in accordance with LJMU Ethics Committee recommendations and the Data Protection Act.

3.5.2 Data Processing

In line with the generic qualitative methodology researchers need to stay close to the data when analysing information as the language is drawn directly from the data and then presented using this everyday language (Neergaard et al., 2009; Sandelowski, 2010). All of the interviews, focus groups and creative focus group sessions were digitally voice recorded and transcribed verbatim by the researcher. Recording is utilised to promote trustworthiness (see section 3.7 for further details). When working with PDC&YP I encouraged the children to try the recorder first in a playful way so they could hear their voice back and understood its purpose as many of them had not seen a Dictaphone before. On reflection, this worked well.

The recordings ranged from 20 minutes to 120 minutes. I transcribed each recording personally and this enabled me to hear again what was said and appreciate the pauses for thought and key moments. By conducting my own fieldwork and transcribing by hand, I was able to fully immerse myself in the data, which Marshall and Rossman (2011) recommend. It helped me to organise and reduce data for identifying patterns and meaning giving rise to interpretive data (Corbin and Strauss, 2008; Berg, 2008). This has allowed me to draw conclusions from the data with emerging themes (May, 2002; David and Sutton, 2011; Moules and Goodman, 2014).

A possible limitation with creative focus groups when recording is the noise level as the fun activities meant a lot of laughter. It was vital to have a good recorder with speakers which extended to the different activity areas to ensure all the voices were captured. It would have been difficult to transcribe if I had not carried out each stage myself. I transcribed the day after each creative focus group to ensure I accurately captured all the views. This can put additional pressure on the researcher to ensure the time is built in to do this.

A thematic qualitative analysis based on the stages set out by Burnard et al. (1991, 2008) was adopted for data analysis (Table 3). This is a systematic and manageable way of depicting each participant's views and experience and is commonly used in qualitative research. See Table 3 for a full breakdown of the process followed.

Table 3: Burnard et al's (1991, 2008) stages for analysis and the process taken

No	Stage	Process followed
1	Note taking	I made notes immediately after all of the interviews, focus groups and creative focus groups of any initial feelings or reflective moments. I also made additional notes during my transcription process.
2	Immersion in data	I immersed myself in the data by transcribing all the tapes myself, listening repeatedly to what was discussed. I then re-read my transcriptions and notes for accuracy.

3	Open coding	I imported all the raw data including the audio files and transcriptions into the Nvivo 10, a qualitative data analysis computer software package designed for large sets of large text based data sets (QSR, 2017). The questions used as part of the semi-structured interviews, focus groups and creative focus groups formed the initial categories, which started the theming. Categories were then compared, merging categories to form new key themes. When I read the transcript, I made a list of headings that emerged from the information e.g. personal care. Even though some parents went off track a little particularly when they discussed their child's diagnosis I did not wish to leave this un-coded but I kept it in a separate section. This enabled me to check I had not missed anything.
4-5	Reduction and Refinement	Using Nvivo 10 software, I added the initial codes as above and then went through the transcripts one by one and categorised each line of each transcript. E.g., I enjoy water sports – code into sports, enjoyment, and water. I then condensed any duplication or similar categories into themes e.g. personal hygiene and toileting became personal care. I went through each category and put into more specific categories e.g. temperature of pool, wheelchair access and timing all came under accessibility.
6	Checking	I coded manually using the software but to promote credibility, dependability and validity my supervisor (LP) reviewed the codes and theming. I had regular discussion of themes through supervision and went through a formal process to look at these. Validity can also be enhanced through analytic processes such as employing some triangulation (Morse, 2015: Santiago-Delefosse et al., 2016). Farmer et al's (2006) qualitative triangulation protocol was followed to synthesise the findings from the two individual studies (Chapter Six).
7-8	Re-reading and categorisation	I made a list of new codes that emerged during this phase and then returned to the previous transcripts to check for relevant statements to go into new codes.
9-10	Rearrangement of data	I used Nvivo 10 software to look up each individual category in the way that highlighting and cutting and pasting would work.
11	Informant or	I chose not to send out the data to the participants for informant check as the theming was taken from the

	member checking	direct quotes across all families and service users. Member-checking involves participants being asked to read the transcription of their interviews to check for accuracy which is thought to improve credibility (Cormack, 2000; McDonnell et al., 2000: Bloor, 2001). There are issues with this in establishing rigour verbatim transcription then participants will be able to recognise their words and respond to this (Houghton et al., 2013). This is at the point where member-checking is advised if taking place. Member checking has been previously used to assess the trustworthiness and validate qualitative results (Doyle, 2007; Birt et al., 2016) but contemporary studies argue about the reliability (Brett and McGannon, 2018). This is used prominently with interviews and not as common with focus groups (Klinger, 2005). Ethical questions must be considered to protect participants throughout the research study and this must be built into the ethical framework if used (Fossey et al., 2002). In this study member checking did not take place as this would be a burden to return to the participants particularly the PDC&YP to ask them to review, especially as some were not literate. There can also be questions as anonymity cannot be guaranteed (Thomas, 2017). After this point participants did not contribute to the analysis as, once the study results have been synthesised, in many cases there would be less recognition of their individual points (Morse et al., 2002; Thomas, 2017; Brett and McGannon, 2018).
12-14	Preparing to write, report writing, linking to literature	Writing up the findings ensured a true representation of the meanings within each category. Through the earlier immersion in the data, I can check this regularly. The participant's statements have been kept verbatim under each theme so that these powerful messages can be disseminated through the linked themes.

The core themes are the same for both the service users and service providers but the sub-themes from each differ, reflecting group specific issues. This is explained in the findings (Chapters four and five).

3.6 Ethics

This section highlights the ethical framework underpinning this research. It is important to demonstrate the importance of ethics and how it relates to the participants in this study. Ethics can be defined as moral principles that promote treating participants fairly and responsibly through the process. Alderson and Morrow (2004:11) stated, “Research ethics is concerned with respecting research participants throughout each project, partly by using agreed standards". Ethics approval is sought to ensure that the research conforms to recognised ethical standards and that all participants are protected including respecting their dignity, rights, safety and well-being (Department of Health, 2011). The Royal College of Paediatrics and Child Health Guidelines for the Ethical Conduct of Medical Research Involving Children (RCPCH, 2000) states that all research proposals involving C&YP should be reviewed by an appropriately represented ethics committee.

Ethical approval for this project was sought from Liverpool John Moores University Research Ethics Committee (Reference: 12/HEA/048). Appropriate procedures to ensure good ethical practice were adhered to throughout the duration of the research. I hold a current enhanced police check clearance allowing for work with children and worked within LJMU's Lone Worker Code of Practice.

Barnardo's (2002) statement of ethical research practice highlights how C&YP should be involved in the planning where possible. Although this study did not involve PDC&YP in the design of the study, previous literature was reviewed (Knight et al., 2013). The PDC&YP's forms were designed and edited by two C&YP to ensure they were child friendly and appropriate for the audience. This was commended as good practice by the LJMU Research Ethics Committee.

Each participant was given an information sheet (see appendix 7.3 and 7.4) relating to their section of the study and a consent/assent form. The consent forms (see appendix 7.3 and 7.4) were in the same design as the information sheets and the same colour codes for adults so that they were very clear. Ethical considerations must be highlighted when conducting research especially with PDC&YP.

Prima facie refers to principles that ought to be upheld in any situation which include four moral principles: respect for autonomy, beneficence, non-maleficence and justice (Beaucamp and Childress, 2009). Crookes and Davies (1998) suggested that using this approach can help with decision making when reviewing research. In conjunction with this, I chose to link this with the main ethical guidelines relating to C&YP's research (Medical Research Council Ethics Guide; Medical Research Involving Children, MRC 2004; National Children Bureau's Guidelines for Research, NCB 2003; Barnardo's Statement of Ethical Research Practice, 2002; Royal College of Paediatrics and Child Health, RCPCH 2000). These include respect for autonomy, informed consent, beneficence and justice which will now be outlined.

When addressing respect for autonomy this highlighted the need for participants to have a choice of whether to participate or not. This is in relation to the decision-making capabilities of the participants. Edwards (2009) suggested that if a person is self-governing then they are autonomous. All of the participants were provided with written participation information prior to meeting the researcher so that they could have time to review this and decide whether this is something, they were happy to be involved in. If the participants had any communication and/or learning needs this would allow time for their parents/gatekeeper to go through the information. I also checked whether they had understood and I answered any questions they had. The added feature of the gatekeeper was to ensure that no vulnerable participants were approached. Respect is an important issue and is a basic ethical principle. Alderson and Morrow (2011:120) stated that “listening to children can help adults to discuss and resolve children’s misunderstandings.” If a child becomes upset during the research this must be accepted as valid refusal (MRC, 2004).

Informed consent is vital to safeguard the participants, as they need appropriate information about the research to make a reasonable and informed decision whether or not to participate (Berg, 2008; Fargas-Malet, 2010; Graziano and Raulin, 2010; Greig et al., 2013). Moules and Goodman (2014) highlighted that the preparation of the information is essential for participants to make an informed decision. Written informed consent was sought from all participants prior to the commencement of data collection. Consent was in written format with parents or legal guardians signing consent for the PDC&YP (Gerrish and Lacey, 2010). Kumpunen et al. (2012) suggested that parents are viewed as ultimate authority over C&YP’s participation in social research and some populations are deemed as vulnerable populations when preparing a research study. These include children, individuals with learning disabilities and individuals with mental health problems. This study had potential to have individuals from all of these groups and participants included PDC&YP with mild to moderate learning disabilities. Therefore, the assessment of the individual’s needs and understanding is vital (Crookes and Davies, 1998). The National Research Ethics Service (2007) states that children under the age of 16 can give their consent to take part in a research study if they meet the Gillick competence criteria (1985) which includes that they have been counselled and do not wish to involve their parents and they have sufficient maturity to understand the nature, purpose and likely outcome of the proposed research. Fraser et al, (2004) highlight that including children as participants raises ethical and legal dilemmas about the rights of children and the researcher role. There is a close relationship between law and ethics and not everything that is legal is ethical (Fraser et al., 2004). Within this study anyone under 16 provided written assent as well as their parent signing consent. It was vital that they were happy to take part and understood the process and study as even with parental consent, I did not go ahead without all being in agreement.

All of the PDC&YP in the study were able to assent, which is their agreement to participate, whilst their parents provided parental consent. Gibson and Twycross (2007:16) do however highlight that “there is little to distinguish between assent and consent and the legal position is unclear.” I was constantly vigilant to the PDC&YP’s verbal and non-verbal responses following their assent to ensure that they were `safe` to continue (Cocks, 2006). This aimed to promote a child-parent-researcher partnership as described by Lambert and Glacken (2011). It is important to ensure the children know what is being asked of them and they have the right to say `no` (Dickens, 2011). An open and honest relationship is required (Oulton et al., 2016). I asked the PDC&YP and parents to assent/consent during the same period. The consent and assent was gained in partnership with each other so that the PDC&YP could make an informed decision whether to join the study. Kumpunen et al., (2012) highlighted the responsibility for researchers to keep PDC&YP informed especially during the assent process whilst being careful to think of their uniqueness versus possible power relationships. However, Fargas-Malet et al. (2010:175) highlighted that “some researchers have questioned the assumption of assent and claim that children are fully capable of giving their informed consent.” I believe, in this study, that the older young people would have been able to give their own informed consent and this would have promoted their independent views but I was constrained by the ethical framework so full consent was provided by the parents and assent was given by the PDC&YP.

PDC&YP were reminded that they could leave the study at any time which is in line with the MRC (2004) guidelines that highlight that the research must respect their right to refuse or wish to leave the study. This was via the participant information leaflets and they were also verbally reminded. One seven year-old child got tired during the interview so I stopped the interview and he went off to play with his siblings. I arranged to visit his mother at a later date so she could share her views.

Due to the nature of safeguarding, school systems and families, C&YP are rarely entirely free to decide whether to participate in a research study or not as they are surrounded by gatekeepers (Fraser et al., 2004). These act as controls although may have no legal rights over the C&YP. However, they cannot allow access to the C&YP or dictate the location or timing of research. On the other hand, the positive role of the gatekeeper can be seen in the section 3.2.2. I ensured that a gatekeeper or a parent was present during the interview or the creative focus group. This could have potentially affected what the PDC&YP discussed but was necessary to ensure a safe and ethical practice. I did however use the creative methods to quickly build a rapport to try to reduce this possible limitation. The gatekeepers were able to see my police clearance check and University identification prior to all of the meetings which is in line with the MRC (2004) guidelines.

Whilst the risks of participating in the research were perceived to be negligible, it was acknowledged that some individuals might have found discussing the participation in out-of-school activities slightly distressing. Had the need arisen I would have utilised the gatekeeper, and in the case of the C&YP their parents as support as required, but no C&YP were distressed during the interviews. Some of the parents wanted to discuss their child’s diagnosis, which many found upsetting. I provided space to discuss this and semi-structured interview technique was used to return to discussing activities.

Cocks (2006) highlighted how the issues of privacy and autonomy are so pertinent due to the vulnerability of children in research. Confidentiality was explicitly stressed before all my fieldwork. This is straightforward in individual interviews as I am the only one hearing their response. However, within the focus groups and creative group sessions I explained that I would keep names and details confidential and reminded them that what we discussed would remain within that room and dissuaded them from further discussing this outside. There was no absolute guarantee that they will not discuss anything outside but the measures were in place to reduce risk. In order to promote understanding of confidentiality I explained that, although I will write and talk about what they said, I would never use their names or where I met with them. No data have been reported on an individual basis.

In addition, participants may have inadvertently disclosed information, which could have raised some concerns and suggested their safety might be compromised, for example, a safeguarding concern. In such cases, permission would have been sought from the participants to refer them to the appropriate body such as social services, the police or via the specific activity safeguarding hierarchy. For example, within the Scout Association there is a `Safeguarding Code of Practice` in which the members would contact the District Commissioner who would then liaise with social services or the police. This was outlined as part of the consent process. In all cases, there was a hierarchy and safeguarding policy through the gatekeeper and the activity I had approached. I did not encounter any concerns, however if something was not deemed appropriate, then I would have liaised with my supervision team and have contacted the relevant body.

Balancing the need for beneficence, for the benefit of others and non-maleficence, to do no harm (Beaucamp and Childress, 2009), can initiate a dilemma for researchers. Social research is seen as less risky than medical research but risks such as upsetting or worrying PDC&YP, embarrassing them or by betraying them with false hopes and promises must be taken seriously (Fraser et al., 2004). Therefore, I needed to consider the risks and benefits to the participants. Research questions and agendas are still largely generated and dominated by adults. Christensen and James (2008) highlighted that children’s narratives tend to be edited or reformulated to fit in with the agendas. They also recognised that listening to children is central to recognising and respecting their worth so that they are not simply objects of adult concern. Fraser et al,. (2004) highlight the importance of researching with PDC&YP as it promotes understanding of how they develop and live their lives. This, of course, needs to be done in the best interests of the children.

Justice relates to rights and equality for the participants and a good example is the showcasing of PDC&YP’s rights. This is in line with the United Nations Convention on the Rights of the Child (1989), which clearly states that C&YP should be involved in decisions that affect them. This has been reinforced by the Children Act 1989 (England) and the Children (Scotland) Act 1985. A serious ethical issue is that published works on a specific group may stigmatise or create further problems for that group (Fraser et al., 2004). However they have been forefront in this study and the researcher advocates their views.

3.7 Quality Assurance

Rigour and trustworthiness (credibility, dependability, confirmability, transferability) are essential in qualitative research (Moule and Goodman, 2014) in order to ensure the research process is tight but also to ensure quality of dissemination and to do justice to the stories in which the participants have shared willingly. I have taken clear practical steps showing a transparent process in order to be rigorous in my approach. Lincoln and Guba’s (1985) criteria for establishing rigour and trustworthiness include four components: credibility, dependability, confirmability and transferability, which will now be discussed:

To be considered credible, qualitative research data must represent a `true` picture of what the participant’s views, opinions and experiences were, with readers of this work feeling confidence in the messages portrayed (Shenton, 2004; Moule and Goodman, 2014). The element of choice through the `pick-n-mix` multi-methods enhances credibility as this promotes each participant to be able to discuss freely in a format which is suitable to them, therefore allowing them to express their real life views.

Denscombe (2014) and Moule and Goodman (2014) highlighted that engagement in the field with participants will aid the trust between the researcher, gatekeeper and themselves which in turn enhances credibility. I worked very closely with gatekeepers to build up a rapport and ensure the location, timing and approach was optimised prior to, even, meeting the participants. For the creative focus group approach, I met the PDC&YP beforehand to ensure that they felt as comfortable as possible before discussing the research topic.

There is always a potential power relationship (Fraser et al., 2004; Greene and Hogan, 2005), for example, a teacher interviewing students. This potential was addressed within the ethics approval particularly when exploring the role of the gatekeeper. To try to overcome any potential issues, Moules and Goodman (2014) recommended balancing the relationship in interviews and focus groups by the participants understanding the researcher’s role which, in this study, is all outlined in the participation information sheets (please see appendix 7.3 and 7.4). I prepared for any potential problems by ensuring pre-visits or preparation phone calls to introduce myself and the role prior to the visit (see section 3.2). I wore neutral clothing and whilst I avoided formal attire, I maintained a professional image throughout.

To promote credibility I conducted all of the interviews and ensured that all the pre-set topics were discussed at some point in the interview in order to meet the aims and objectives of the study.

Dependability is the ability of the qualitative data to stand the test of time (Moules and Goodman, 2014). This is difficult in qualitative work but researchers should strive to have the study repeated (Shenton, 2004). The recruitment plan will enable a repeat of this study in a different area of the UK. Lincoln and Guba (1985) suggest an audit trail of the process and this was done by creating a timeline of events, including which gatekeepers supported which individuals to ensure the ability to backtrack if information needed clarification, or a safeguarding issue should arise.

The process was also checked by having a supervision team in order to identify any issues within the process.

Confirmability focuses on the need to produce findings, which are not influenced by the researcher (Denscombe, 2014). Shenton (2004) makes it clear that steps should be taken to ensure that the findings emerge from the data rather than being influenced by the researchers own predispositions. I have followed a planned pathway with regular supervision meetings and by going through a rigorous MPhil to PhD process and been clear throughout about my positionality and how this may influence this study. I have promoted the participants’ individual views throughout.

Researchers are encouraged to demonstrate how the findings of the research can be transferred to another context. This is achieved by providing an in-depth discussion and being transparent with the methods of sampling and data collection (Moules and Goodman, 2014). This chapter includes clear sampling information and data collection methods to provide this transparency.

3.8 Summary

The multi-method qualitative research design was most suited to the participants and generated rich data that provides a comprehensive understanding of the research topic. Given the complex nature of the study in combining the different groups of participants to explore the aims and objectives, a multi-method for a `pick-n-mix` choice was deemed the best approach. The findings from the service providers will be presented in subsequent chapters. This chapter also demonstrated the importance of ethics and how it relates to this study. It outlines the ethical process taken to ensure the safeguarding and appropriate ethical practice for all of the participants.

CHAPTER FOUR: FINDINGS AND DISCUSSION OF STUDY 1: SERVICE USERS (PDC&YP AND PARENTS)

4.0 Introduction

The aim of the service user study was to establish which out-of-school activities PDC&YP's access in Cheshire whilst also ascertaining their preferences. The factors affecting PDC&YP's participation in out-of-school activities were also explored. The themes which have emerged from the data analysis are outlined and a discussion of the findings will then be presented.

4.1 Sample Profile of the Service Users

Profiles of the PDC&YP followed by that of the parents will be presented in Tables 4 and 5.

4.1.1 Service Users – PDC&YP

Thirteen PDC&YP, aged 7 to 17 years old (mean age – 12.8 years), provided their views on their out-of-school lives. The PDC&YP were all white British, seven were male (53.8%) and six female (46.2%). The PDC&YP who participated in the study all self-reported as having a physical disability with five being wheelchair users (38%). Some (29%) also had a mild to moderate learning disability. The PDC&YP attended a mix of mainstream and special schools with one child attending a residential school part of the week.

Six (46%) PDC&YP had personal care needs. The profiles are presented in Table 4:

Table 4: PDC&YP Profiles including data collection methods

Code letter for PD C&YP	Gender	Age	Disability	Wheelchair use	School Attending	Method	Creative Activities (where applicable)	Location
A	Male*	15	Wheelchair user	Manual	Mainstream	Interview with parents		Home
B	Male	10	Cerebral Palsy		Mainstream	Interview with mother	Computer Games Snacks provided by family	Home
C	Male*	7	Cerebral palsy	Electric	Specialist	Interview with mother	Arts, Crafts, Drawing, Computer Games Snacks provided by family Table top ball games	Home
D	Male*	13	Cerebral palsy	Electric	Specialist	Interview with his mother	Computer Games Snacks provided by family Model aeroplanes and cars	Home
E	Male	15	YP with amputations		Mainstream	Interview		Sports Club
F	Male	15	Physical and learning disabilities		Specialist/ Residential	Creative Focus Group	Parachute games Arts, Crafts, Drawing Ball games Snacks provided by the gatekeeper Chatting on the parachute	Youth club
G	Female	14	Physical and mild LD		Mainstream			
H	Female	13	Physical and moderate LD		Specialist			
I	Female	15	Physical and mild LD		Specialist			
J	Male*	9	Child with amputations		Mainstream	Interview with Mother	Basketball, Boccia Ball games These four C&YP were all together at the sports club and the creative methods worked as icebreakers. Then groups separated for questions during their sports break due to the age differences.	Sports Club
K	Female*	17	Physical disability	Manual	Mainstream	Interview		
L	Female	12	Physical disability with a limb problem		Mainstream	Creative Focus group		
M	Female*	12	Cerebral palsy	Manual	Mainstream			

*PDC&YP required help with personal care LD – Learning Disabilities

4.1.2 Service Users – Parents

As outlined in Table 5, 19 parents provided their views on their children’s out-of-school lives. All were white British and in employment. The parents were interviewed either individually, with their child or with other parents. This was decided upon by the individuals themselves. There were 14 mothers (74%) and five fathers (26%). All the parents apart from one set of three friends decided to be individually interviewed or were interviewed in a family unit. All of the parents had one son or daughter with a physical disability aged 7-15 years old. Ten of the parents had children who also participated in the study. Seven parents spoke on behalf of their children, due to their son or daughter having complex needs and therefore being unable to participate directly. These children were not present as they were at school at the time of these interviews. Complex needs refers to C&YP who have multiple health issues who also require a lot of additional support on a daily basis which may include sensory impairments, disability and illness.

Table 5: Parental Profiles including the PDC&YP they are representing

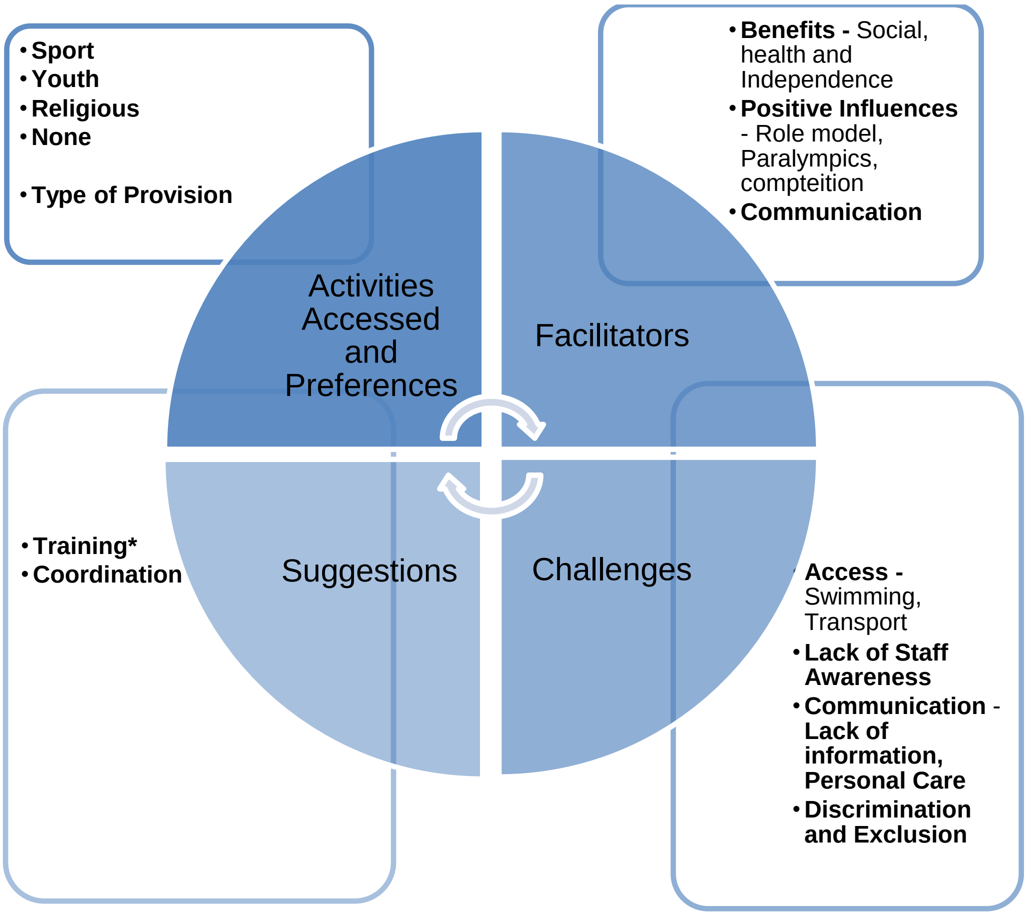
Parent	**Their son or daughter’s details**	**Type of Interview**	**Location**
Mother and Father	A*	Interviewed with A	Home
Mother	B	Interviewed prior to meeting B	Telephone
Mother	C*	Interviewed after meeting C	Home
Mother	D*	Interviewed with D	Home
Mother & Father	E	Interviewed before E	Sports Club
Mother	J	Interviewed with J	Sports Club
Mother	L	Telephone interview after meeting L	Telephone
Mother	12 year-old female with physical disability	Telephone interview after meeting M	Telephone
Mother	8 year-old mixed learning and physical disability *	Interviewed at home whilst child was in school.	At home whilst child was in school
Mother	8 year-old male with complex undiagnosed mix of physical and LD*	Interviewed at home whilst child was in school.	At home whilst child was in school
Mother and Father	15 year-old male with cerebral palsy*	Parent focus group at sports club whilst young people were playing. Their son’s were too tired to participate at the end.	Sports club whilst young people were playing
Mother	15 year-old male newly diagnosed wheelchair user*		

Mother	14 year-old female with cerebral palsy *	Telephone interview	Telephone
Mother	8 year-old male with a physical disability*	Telephone interview	Telephone
Father	8 year-old male with a mixture of physical and LD	Interviewed whilst child in school	Coffee Shop
Father	10 year-old male with a physical disability	Interviewed whilst child in school	Sports Club

4.2 Results

Four main themes emerged from the data across all the PDC&YP and their parents (service users). As illustrated in Figure 7, the main themes were activities that the PDC&YP accessed and preferred, the facilitators and challenges to accessing out-of-school activities and suggestions for improvement. Sub-themes within each theme are also detailed below:

Figure 7: Service Users Emergent Themes



The themes/sub-themes were identified across the PDC&YP and parents. There was much congruence in views between the older children and parents as the older young people understood the bigger picture in terms of how things were organised and funded. The only sub-themes specific to parents' views was the discussion on the provision differences across local authorities and the recognition that staff need more disability awareness training (*). The younger children focused on likes, dislikes and the importance of making friends and having opportunities. (*parents views only)

4.3 Theme One: Mainstream and Specialist Out-of-School Activities Provision and Preferences

Table 6 presents the activities accessed followed by a discussion of the provision and what PDC&YP preferred.

Table 6: Outline of PDC&YP activities:

Activities Accessed	Frequency[1]	Provision	Examples	Travelled outside of Cheshire to access
Leisure	11 (50%)		Going into town, cinema, eating out, bike rides, crazy golf	
Sports	20 (91%)	Mainstream	Football*, Swimming Shooting/archery , Trampolining, Cricket.	Ice skating
		Specialist	Football*, Swimming*, Tennis, Boccia, Racket sport, Table tennis, Horse riding, Running, Athletics, Fencing (*most popular sports cited).	Skiing, Curling, Water sports, Wheelchair basketball
Youth	12 (55%)	Mainstream	Scouts/Brownies Youth club	
		Specialist	Youth club	
Religious	1 (4.5%)	Mainstream	Church group	
None	1 (4.5%)			
Used to go	9 (41%)			

[1]The views of 22 PDC&YP are represented, either directly or via their parents. The numbers included in Table 6 show how many times these views were expressed within each theme.

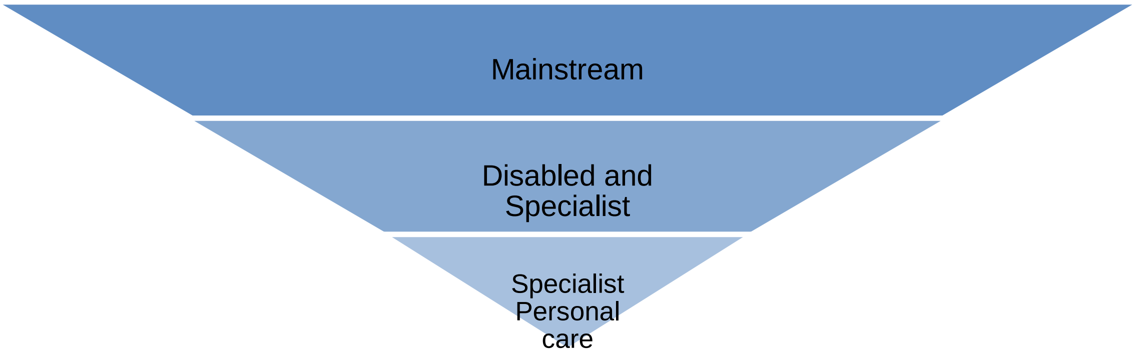
*Parents views only

4.3.1 Type of Provision

Study findings demonstrated that PDC&YP and their families accessed a range of activities within Cheshire (see Table 6). In Cheshire, activities were either: mainstream activities open to all; disabled aimed at disabled children; or specialist activities for specific conditions or sports. The biggest issue with this was that PDC&YP had difficulty accessing both mainstream and disabled, because of challenges such as access and support issues with mainstream groups and the disabled groups catered for children with a range of disabilities. Mainstream activities are those which are open to all children but, in reality, are dominated by non-disabled children who attend mainstream schools. These clubs are evident throughout the community (see Figure 8).

This figure shows how the clubs are made up in the community in terms of numbers

Figure 8: Club Makeup



Specialist activities are those which are designed for disabled children but, in some cases, non-disabled siblings and friends attend. There are a range of specialist disabled groups, for example, disabled youth clubs and wheelchair basketball. There was one specialist activity which specifically catered for disabled children with complex needs and who required assistance with personal care. It is evident that most PDC&YP accessed a mix of mainstream and specialist activities which included sport (91%), half accessed youth clubs, half of the parents representing PDC&YP with complex needs discussed finding music in specialist disabled groups and just one child accessed a spiritual/religious out-of-school activity. Specialist activities dominated their out-of-school lives. There were also times when the PDC&YP stated that they no longer accessed particular activities and the reasons for this will be explored later in the chapter.

The PDC&YP in this study felt disabled groups were not always the right place for them and some of their parents concurred. This was illustrated by one young person and four parents who discussed the type of disabled groups provided within their community. They stated that many groups advertised an activity for `disabled` children but when they attended, it was evident that it was mainly for children with a learning disability. This, therefore, did not meet their expectations as they assumed it would be attended by a range of disabled children so they could meet others with the same condition. They often found that they were the only PDC&YP attending. They wanted the groups to be split by ability or, at least, meet the needs of PDC&YP as well as those with learning disabilities. Similarly, PDC&YP who were wheelchair users accessed `disabled` clubs but stated that the activities were often designed for non-wheelchair users and for C&YP with learning disabilities. PDC&YP expected activities to be suitable for them when it is advertised as a specialist group. This was highlighted by PDC&YP and parents who agreed this was a challenge to participation:

“There was me and another boy and that was it, out of 150 young people” (A – 15 year-old male).

Parents discussed how their son/daughter did not connect as much with the children with learning disabilities. They recognised that disabled C&YP with behavioural issues needed more contact and attention within a group but wanted equal support for their own children’s individual needs. This was an issue for all of these families and whilst they did not want to discriminate against these groups, they felt they were not suitable for their physically disabled child. Parents felt frustrated and raised this very pertinent point as this left PDC&YP in limbo between the disabled groups and the mainstream groups.

“I get frustrated and cross as there is more for those with emotional and behavioural problems rather than a child with just a physical disability who needs that extra bit of help” (Mother of a 14 year-old female).

“There is also the mixing of children with all disabilities … they plump them all together and they can’t” (Mother of D 13 year-old male).

“There does seem to be this umbrella of every disability I took him along and he was the only one there in a wheelchair” (Mother of A 15 year-old male).

4.3.2 Children's Views of Activities

Most PDC&YP in the study opted for mainstream activities and specialist disability provision. They tried a range of activities and then continued with the ones they most enjoyed. Only one child did not attend any activities outside of school. He lived 40 miles away from his school so the after-school activities were not an option due to the timing of his taxi and by the time he got home, he was very tired. He had also tried to access weekend activities but, due to needing a carer at all times, he could not commit to them.

The activities PDC&YP participated in were dependent on several factors including the PDC&YP's ability, for example, if the child was a wheelchair user some chose to attend a wheelchair basketball club. Some of these clubs were able to accommodate siblings so that non-wheelchair users could take part. Choice of out-of-school activity was individualised but was also influenced by where they lived, their previous experience of other activities, and if their friends attended.

Half of the PDC&YP enjoyed socialising in leisure settings and, as expected, these were the older young people who could attend activities more independently for example, going into town or to the cinema. In terms of what PDC&YP wanted more of, sport was a popular suggestion. As well as swimming being popular there were a range of other sports which PDC&YP would like into participate in including: blade running, tennis, fencing, snow and water sports and hydrotherapy at weekends.

"I do lots of different things, painting, I do some drawing… that's it… playing games, ball games" (C -7 year-old male).

"I like water sports as I like getting wet really" (A – Male 15 years old).

"I do basketball and rowing, kayaking in school and went water skiing over a weekend" (A – Male 15 years old).

The majority of PDC&YP in the study expressed a preference for specialist activities where they found others 'like them.' Having friends with similar abilities was a very important part of their out-of-school lives. This had a positive impact on their lives which, the service users stated, boosted their emotional wellbeing and confidence. They highlighted that this worked well as they found the activities were geared up for their ability and they could chat more openly about issues they may have. This was discussed by all of the C&YP as illustrated below:

“I have friends here and friends at (mainstream) school but I spend more time with my wheelchair basketball friends than school friends” (E- 15 year-old male).

“I would like to be with people who have the same disability as me” (E – 15 year-old male).

“It’s the social side as well meeting everyone, meeting new friends and seeing the friends that I have got” (A – 15 year-old male).

“I would kind of like to be with people who have the same disability as me” (A – 15 year-old male).

On many occasions, the PDC&YP travelled to a specialist group designed for those with a particular condition e.g. cerebral palsy. This allowed them to develop wider networks beyond C&YP in their community where perhaps there are no other PDC&YP with similar conditions. A 17 year-old highlighted how she would like additional social opportunities in order to talk to other young people like herself and who she felt would understand. She acknowledged her family support but as non-disabled adults she felt they did not fully understand her specific needs. On the whole, PDC&YP seemed to prefer specialist groups.

“I think somewhere social would be great so activities like cooking or drama or sport. It’s just somewhere to go where you can just be or you can rant about this or whatever. As much as your friends and family can do a good job but they do not totally know what it is like.” (K – 17year-old female).

4.3.3 Parents’ Views of Activities

In line with the PDC&YP’s comments, all of the parents reported that their children had tried different activities and had experienced a mixture of both positive and negative experiences with out-of-school activities. These will be explored later in the chapter when discussing the factors affecting participation activities. Parents echoed findings that the PDCYP were drawn to activities where they could meet others with similar needs to their own.

Several parents made some suggestions to increase provision, having youth clubs and social events with children who share the same ability as their children, therefore favouring specialist activities.

"I would love somewhere local, for kids with her condition, for them to get together so they can talk, can talk face-to-face. This would be fantastic; my ultimate thing" (Mother of 14 year-old female).

"It would be good for him to do more activities in a team as he doesn't have many friends at school" (Mother of J- 9year-old male).

"(The specialist club) has sort of changed our world really, because it has given him and us a social life outside. Prior to this he never really went" (Mother of 15 year old male).

In line with the views of PDC&YP, parents recognised how shared experiences increased confidence and enhanced the social lives of both the PDC&YP and parents. All of the parents encouraged making friends and meeting others. Many parents expressed dissatisfaction with the manner in which provision for out-of-school activity is provided in the county. Within Cheshire, two local authorities (Cheshire West/Chester and Cheshire East) plan and provide out-of-school activities separately using different budgets. This difference in planning and provision created some difficulty and feelings of inequality were voiced by ten parents. For example, a disability cycle club was being planned for one area but not specifically for the others. They wished that the provision was planned across the whole county, as they felt frustrated when one-half provided an activity, which was geographically too far away for them to access.

"Me and my friend live either side of a border in terms of funding, so she can do stuff I can't do and vice versa" (Mother of D – 13year-old male).

4.4. Theme 2: Facilitators to Participation

Factors which help PDC&YP join in out-of-school activities are referred to as facilitators. All PDC&YP and parents (service users) were asked to discuss out-of-school activities and what motivated them or their children to try certain activities. Both PDC&YP and parents recognised that it was beneficial to join in with activities outside of school. All service users felt that the main reason to join was to make and be with friends, which in turn, fosters social support for both the PDC&YP and parents. The parents recognise the need for this social support and this motivated them to find suitable clubs. Table 7 illustrates the key facilitators to participation that emerged from the data. Each will be discussed separately.

Table 7: Facilitators to Participation

Overarching Theme	Themes	Sub-themes
Facilitators to participation	Benefits of Participating Social Benefits and making friends	Independence Health Benefits
	Positive Influences	Positive Role model Paralympics Competitive nature of sport
	Communication	
	Meeting the right people	

4.4.1 Benefits of Participating

In terms of the benefits of participation the older PDC&YP verbalised the specific benefits of making friends, socialising and independence, whereas the younger children (under 10 years) focused on making friends and having friendships in out-of-school activities. The parents focused on the benefits of gaining independence and health benefits to joining more active activities.

Friends were a very important part of PDC&YP's out-of-school lives both making and keeping in touch with them. This was discussed by all of the C&YP as illustrated by the examples below:

"I enjoyed the socialising side of it … it was basically everyone from our school (mainstream)" (A – 15 year-old male).

"I like hanging out with my friends, just being with my friends at weekends which is cool" (K – 17 year-old female).

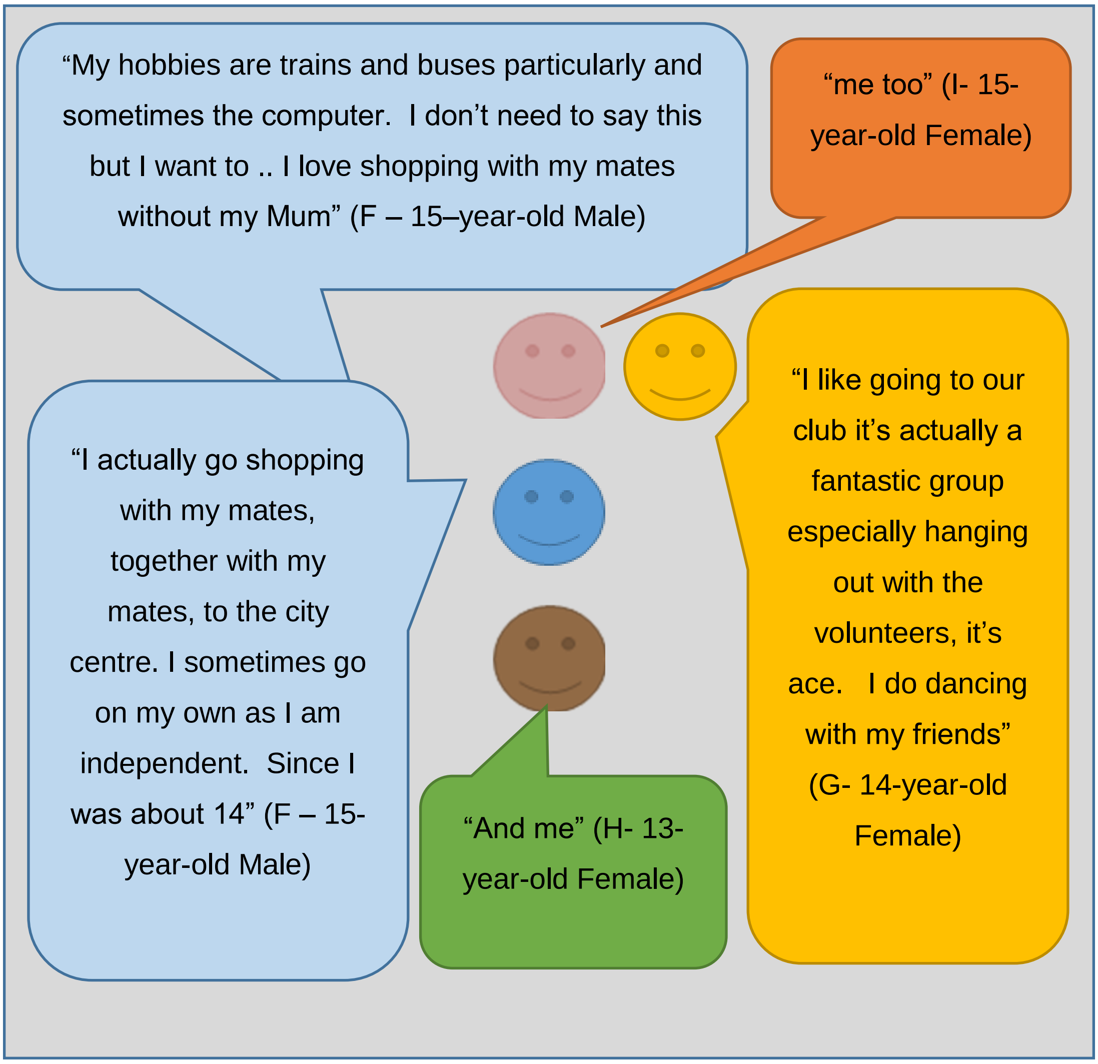
"I like being with my friends" (C-7 year-old male).

4.4.1.1 Independence

In the context of disability, the concept of independence incorporates having choice and control over their lives such as the opportunity to access the physical, social, economic and cultural environment (Scope, 2018a). This includes taking part in leisure activities and being involved in decision making processes (UNCRPD, 2006).

The drive for independence was an important factor which influenced participation in activities and was recognised by five young people (age over 13 years) and four parents. The PDC&YP wanted to be able to socialise more on their own without a parent, see Figure 9.

Figure 9: Creative Focus Group Conversation



"My hobbies are trains and buses particularly and sometimes the computer. I don't need to say this but I want to .. I love shopping with my mates without my Mum" (F – 15–year-old Male)

"me too" (I- 15-year-old Female)

"I actually go shopping with my mates, together with my mates, to the city centre. I sometimes go on my own as I am independent. Since I was about 14" (F – 15-year-old Male)

"I like going to our club it's actually a fantastic group especially hanging out with the volunteers, it's ace. I do dancing with my friends" (G- 14-year-old Female)

"And me" (H- 13-year-old Female)

Personal aides (PA) were sometimes used to facilitate independence. These were employed by parents using independent disability allowance funds. One mother reported that she called them PA's and not carers as she did not want to give the impression of needing care although they did provide help with mobility and toileting. This mother and son discuss his personal aides highlighting their importance in his life:

"They let me do whatever I want (laughing)…It's good fun" (D – 13 year-old male).

"I don't like the name carer but I make it clear that they are there to help him to be independent. Not to do things whilst he sits there and supervises you" (Mother of D).

The right equipment promotes independence and facilitates participation. Some PDC&YP require the assistance of a power wheelchair, which allows them to drive the wheelchair themselves. This also helped parents manage with siblings especially when they are young and in a pram/pushchair. It allowed one mother to go out and do day-to-day activities such as shopping without having grandparents to help. This made a huge impact overall on the family:

"In terms of getting that independence this was great in terms of learning to drive. I had my first experience in the supermarket with him. I was turning around to get some things as he was running off with his wheelchair …. it is how it should be" (Mother of C – 7 year-old male).

4.4.1.2 Health Benefits

Participating in out-of-school activities had perceived positive health benefits for the PDC&YP in this study. Although the PDC&YP themselves did not verbalise these benefits specifically, five parents highlighted the benefit in terms of being physically healthy through exercise, and activities which encouraged physiotherapy for their child's condition. For example, horse riding was helpful for a child with cerebral palsy to strengthen and stretch his legs. One young male started at a wheelchair sports club a few months after getting out of hospital following an acute onset illness. This was driven by his father who was a keen sportsman and knew the benefits of exercise on health. The other families recognised the physiotherapy benefits. Swimming acted like physiotherapy and rowing was good for stamina which helped when pushing their own wheelchair:

"He does the swimming because it's good for his hips" (Mother of J – 9 year-old male).

"He does horse riding, It's riding for disabled…. it's physiotherapy as it helps his legs" (Mother of D – 13 year-old).

4.4.2 Positive Influences

An emergent theme around factors that facilitated participation in out-of-school activities was positive influences. This was discussed by more than half of the PDC&YP and their parents. The positive influences included having good role models, the Paralympics and opportunities to be competitive.

4.4.2.1 Positive Role Models

Having a positive role model was a major facilitator of participation in out-of-school activities, with PDC&YP describing specific role models that had personally influenced them. Examples of role models were disabled adults, famous people and other PDC&YP. Some of the PDC&YP only had elderly relatives who were wheelchair users or had a disability whereas those who had met young people with similar conditions or the same disabilities as them, saw them as positive role models and it gave them courage to try new things. The young males were particularly inspired by army personnel who had been disabled from combat and also sports people they met. They recognised their achievement and felt this helped them to strive towards being better at sport. Some young people found role models who were slightly older than them and were inspired by how they managed certain parts of their life and school:

"There's an older lad, he was a rower before he had his accident so he kind of knew lots of things about rowing as well" (A – 15 year-old male).

"I would also choose them as well if there are people that are disabled they can help you with it. It is easier if the people who are running it are disabled because they know where your challenges are" (A – 15 year-old male).

Parents also spoke positively about the role models their sons and daughters had, and how this had shaped how their child viewed and managed their ability. Parents described how previous experiences of disabled people were often limited to seeing elderly grandparents in a wheelchair after a stroke. Parents therefore wanted positive influences from other PDC&YP. Two parents had struggled to motivate their sons to go and try sports after becoming recently disabled but their lives changed when they met role models who were also wheelchair users and showed their son they could participate in sports:

"*It's nice for him to see the older children like him doing things"* (Mother of an 8 year-old male).

"He did not want to go because he refused to accept he needs a wheelchair. We bumped into the coach somewhere who collared him and said come along, coming here has completely changed his whole outlook" (Mother of 15 year-old male).

"His enthusiasm is just so much more than it ever was at the other one because of the trainer …inspires them" (Father of 15 year-old male).

4.4.2.2 Impact of Paralympics

The data for this study were collected soon after the London Paralympics had finished in 2012 and featured in discussions with both PDC&YP and parents. Paralympians were identified as role models by some PDC&YP. Generally PDC&YP felt that the Paralympics showed ability and how much they can achieve despite their disability. Some wanted to see more disabled sport on television and in their community. Interestingly, although the consensus was that the Paralympics had been a positive experience to watch, one young man did feel that it created a lot of pressure on him personally. He enjoyed trying lots of sports but because he was a keen, and a very able sportsman, he was constantly being asked to sign up to different sports. He felt this pressure was too much and sometimes he just wanted to do a sport to socialise rather than to compete at a high level.

"I think people would like to watch disabled sports" (E- 15 year-old male).

*"They always want me to try and come back and be competitive" (*A – 15 year-old male).

Like the PDC&YP, some parents felt that the Paralympics had been a positive influence and some of their children were motivated by competition:

"He hasn't really done anything until this, so I am really pleased that he has got into basketball. It's since the Paralympics" (Mother of 15 year-old male).

4.4.2.3 Competitive Nature of Sport

Two young males (Child A and E) loved the competitive nature of sport. They competed in many different sports (predominantly specialist sports) and they highlighted how motivating competition is for them. It was acknowledged that those who were motivated by competition tended to be the PDC&YP who preferred sport and had a higher ability in sport. Whilst competition does foster participation for many of the PDC&YP, as they loved to take part in challenges and competitions, for some it brought pressure to perform and excel at a sport which was not what they wanted. Some PDC&YP just wanted to have a go and not worry about being part of a competitive team. One parent highlighted how her son had been put off by competition and would find a sport or activity which did not involve this.

"I love competitive sports, I just love winning" (E – 15 year-old male).

"He did swimming for ten years but he did not want to take that to a competitive level. He likes the competitive nature of sport. Even though he has not been playing (wheelchair basketball) that long, he has won quite a few competitions" (Mother of E – 15 year-old male).

"He had a go at table tennis through a charity, the school put him forward, as he was quite good at school, the school put him forward and we went to the next county" (Father of E – 15 year-old male).

"The competition is on personal-best, competing against yourself rather than others. So is not compared to the five foot six lad in his class" (Mother of D- 10 year old male).

4.4.3 Communication

In the context of out-of-hospital activities, communication comes in many forms including verbal and non-verbal communication between individuals, written information provided and the method an activity is advertised. Communication is a two-way process and essential for participation to be successful. As illustrated in Table 8, different strategies of communication were used to engage with PDC&YP in out-of-school activities in Cheshire. These included: advertising activities through websites, social media aimed at older young people (over 13 years due to the 'Facebook' recommendations) and parents. Leaflets were used in schools aimed specially at the pupils. The importance of communication was evidenced when any initial contact with a club was friendly and welcoming. The first impressions made all the difference in how the PDC&YP and parents felt and helped them to feel included therefore facilitating participation from the start. Parents also recognised their role in this initial welcome to communicate their child's needs effectively.

Table 8: Communication that service users encountered when accessing out-of-school activities

	PDC&YP	Parents
How the activity was advertised and any pre-conceived influences	Social media was discussed by PDC&YP as being helpful and necessary to finding out what is going on and to make new friends: *"I find a lot of stuff on Facebook. I'm friends with loads of different basketball clubs and stuff and they are always putting stuff on like there's a new sport coming out"* (A – 15 year-old male). *"If you did not have a computer you wouldn't find much" (*E – 15 year-old male) The PDC&YP themselves appeared to find out a lot via school and this was both in mainstream and special schools. They found this effective. *"This specialist sports club was advertised in school and what's really good it's mainly wheelchair sports and things so it's easy to do." "There are people who come from other schools not just ours"* (L- 12 year-old female).	Social media was discussed many times by parents as an effective method of finding out where current activities are taking place. It was a challenge if they did not use the internet: *"The main thing is through Facebook, which is good and helpful"* (Mother of 8 year-old male with complex needs). Parents of C&YP of any ability need to be able to find activities in their local area so they can read about it before approaching them. This was helpful for this parent: *"We found a sports club through the internet, just rang them up, and explained but said he would like to have a go at this. He's been going 10 weeks this week"* (Mother of an 8 year-old male). A clear benefit to communication is when parents are aware of the out-of-school club's reputation, especially when they have successfully included a disabled child before. This was important to parents: *"I had already checked out this group as I knew they worked with children with disabilities"* (Mother of 12 year-old female). Information via social media was shared by other parents and by parent/carer groups who are advocates for these service users.
First Impressions	First impressions were very important to PDC&YP as they	First impressions were also vital for parents. They counted for a

and Welcome	wanted to have a good experience. They wanted to feel like the people running the activities knew what their needs were: *“To be able to go somewhere where they know there will be people that understand and I mean properly understand. I think that’s really important”* (K – 17 year-old female)	great deal and in this case when it is positive the child stays at the group: *“Talk about inclusive the guy was amazing it did not matter what your disability the guy just picked upon B's personality”* (Mother of B – 10 year-old male). Evidence that the first contact makes all the difference was highlighted by two parents who met proactive activity leaders who made the experience inclusive: *“He was like can’t wait to meet him …. I had not got that from the others. I think with some it is like you are putting challenges in place before you have even met him”* (Mother of C – 7 year-old male).

Discussion of PDC&YP’s needs	Parents felt it was important to give the activity leads some guidance and recognised their part to play. *“To just give them some pre-warning so they can prepare for the session. It's more positive for him because it gives him opportunity to have a go as well”* (Mother of 10 year-old male).

4.4.4 Meeting the Right Person

A key facilitator to out-of-school participation was ‘meeting the right person’ such as a central co-ordinator or a key point of contact. Many of the PDC&YP and parents described needing to meet the right person or being linked with the right clubs where they found out information and opportunities. Young people achieved this through social media but parents highlighted the importance of having a co-ordinator to bridge the gap between families and service providers. Parents found that, when there was a central person families could go to, it was most effective as they could co-ordinate support and signpost the families to provision. There was some evidence of this occurring within Cheshire and it was usually a coach, a sports development officer or a gatekeeper:

> *“What we have found is, it’s who you know, its knowing the right people within the sport who can give you names of people who can guide you in the right direction ”* (Father of E – 15 year-old male).

> *“He has never been able to ride a bike. Then we met a disability sports development worker, he said to us we have a cycle multi-sports session, bring him down `there will be a bike there that he can ride` well he went off and he was laughing and then he was chasing the staff around”* (Mother of 8 year-old male).

4.5 Theme 3: Challenges to Participation

Factors which stopped the PDC&YP accessing an activity or affected their attendance are referred to as challenges. There are five subthemes, which make up the challenges to participation; these are outlined in Table 9.

Table 9: Challenges to Participation Themes

Overarching Theme	Sub-Themes
Challenges to participation	Access Issues • Swimming conditions • Transport
	Lack of Staff Awareness
	Communication - Lack of Information
	Personal Care
	Perceived Discrimination and Exclusion

4.5.1 Access Issues

The Equality Act (2010) requires that reasonable adjustments to be made to remove physical access as a challenge for any activity. This, therefore, should not be a factor affecting participation; however, it is evident from findings that access is a major challenge to out-of-school activities participation for all of the PDCYP in this study. Access means different things to different people but was generally described in this study in terms of physical access, swimming conditions and transport issues.

All five of the wheelchair users discussed physical access to buildings, transport or equipment as an issue. These PDC&YP gave examples of not being able to get into buildings or go on trips with an activity group. Some relied on a parent to lift them in or they could not use the facilities, including the toilet:

> *“It’s not accessible there is still a massive step to get into it, so there was a physical*

challenge to even get into the (youth) hall" (A – 15 year-old male).

"His dad did help him, if I was on my own, I would have really struggled with that, because I can't lift him anymore." (Mother of Male A – 15 year-old male).

This same young male had similar issues when accessing youth activities as he could not take part in any activity, that could not accommodate his wheelchair, for example, hikes or outdoor pursuits:

"If we went on a hike out I wouldn't be able to go as I would not be able to get through the route that they have planned" (A – 15 year-old male).

In order to overcome this he needed to take his father to help. *"When we went to the forest then they asked dad to come with me and he could push me as I couldn't get up all the hills that they went up"* (A – 15 year-old male).

The social benefits of participating in a mainstream activity are thus diminished for this 15 year-old male, as he has to take his father to the youth club where he meets his mainstream school friends. This meant he could not just hang out with his friends without his dad, which created a social challenge. This challenge is an access issue but has an impact on his social and psychological needs, which will be explored later in the chapter.

4.5.1.1 Swimming Conditions

Access challenges specific to swimming were also discussed by the PDC&YP. Some could not use the swimming pools, as they were too cold. Others struggled to physically access the pool and a few reported that access to swimming pools had stopped due to funding cuts:

"I tried the new pool, but it's freezing and it's like doing a North Pole swim" (H - Female 13 years old).

"My mum joined a hotel club… I swim at the pool and it's nice and warm" (I – 15 year-old male).

"The public swimming pool is too cold for him …. we would be there for five minutes and then he would be screaming" (Mother of 8 year old male with complex needs).

Changing facilities, also created access issues, when a child requiring support is a different sex to their carer or does not have hoist facilities. In order to be fully accessible, PDC&YP need suitable changing rooms, a hoist and a pool that is not too cold. Hotels may have warmer water but are not always accessible and cost more to join.

"The problem at swimming is mixed gender disabled changing because he is not always being taken by a male, it's the same problem if you have a couple, husband and wife, so in the whole of our area we have not yet found a pool that has that and a hoist" (Mother of D – 13 year-old).

4.5.1.2 Transport

Transport was discussed predominantly by PDC&YP in relation to taxis home from school and transport to out-of-school activities. Many inclusive out-of-school clubs were many miles from the PDC&YP's home. PDC&YP relied on their parents taking them to attend specific disabled clubs. The young people recognised the need to travel but highlighted that it was at times challenge for them and actually stopped some of their friends accessing clubs.

"You have to travel for disability sports" (A – 15 year-old male).

"We travel to Manchester, Liverpool, Leeds we've been to a few others we tend to make a weekend of it" (B – 10 year-old male).

Two of the PDC&YP relied on taxi transport provided by the local authority to get back and forth to school. They highlighted that the often-long distance to school meant a long taxi or bus ride. This then made them tired when they got home and/or meant they got back too late to join local out-of-school activities. In addition, due to the transport arrangements, they could not stay behind after school for activities as the transport was not flexible and was pre-booked via the local authority. This meant that any after school provision or going to their friends' houses for tea was not possible as the taxi left at specific times and altering the schedule proved another challenge. This is highlighted below by a mother of a 13 year old male who went to school 40 miles away from his home. For those PDC&YP who relied on transport this was a challenge to participation in out-of-school activities and as with a range of other things they relied on a parent/carer to be able to provide this.

"I go on a bus for an hour there and an hour back" (D – 13 year-old male).

"There is no flexibility in it. I have to go through such rigmarole and speak to the council" (Mother of D- 13 year old male).

Transport as an issue was echoed by parents who could not organise anything straight after school which meant they had to either go and collect their child or the child could not attend. Due to their mobility issues or transporting a wheelchair many could not share lifts with other children, which many of their mainstream peers would be able to do.

In addition to accessing activities within Cheshire, all of the parents reported that they often had to travel outside of their area to access activities highlighting that needs were not being met locally. One family reported travelling several hundred miles to attend a water sports session, which was suitable for their son who required physical assistance in the water. Three families regularly travelled over 80 miles every week to a specialist sports activity. This was a club for wheelchair users and was the only one of its kind in the area.

"The transport is only from the end of school" (Mother of 8 year-old male with complex needs).

4.5.2 Lack of Staff Awareness

The PDC&YP felt that service providers under-estimated what PDC&YP could do and focused on their disability and this created a challenge to joining or staying within an activity. PDC&YP wanted service providers to view their ability not their disability. The majority of families, who had previously tried to access mainstream activities, reported negative experiences in terms of poor staff awareness and understanding around disability issues which manifested through poor communication, as demonstrated below:

"As soon as you say disability they think wheelchair" (A – 15 year-old male).

"If they were not doing a match and they were doing skills I couldn't do everything so couldn't fully join in" (M- 12 year-old female).

On the other hand, one young female felt like sometimes she needed to be treated differently in order to have the right support. She wanted to be understood for her needs not just treated like others. Equality aims to promote fairness, but it can only work if everyone starts from the same place and needs the same help (The Equality Act, 2010). PDC&YP need to be supported to give them equity (providing everyone with what they need to be successful) so they can have equality (treating everyone the same).

"I like it when people don't see us as different but now I think it has gone the other way when people see no difference and it's like no, there has got to be some balance of we are different and we may need to do things in a slightly different way" (K – 17 year-old female).

Many parents also felt there was a lack of awareness of disability and a lack of confidence, in relation to supporting their child, felt about the service providers. Parents felt that some service providers view someone who is 'disabled' as someone who is profoundly disabled and lack awareness of the range of disabilities and how able PDC&YP can be. Parents recognised that there are not many PDC&P in their area so activity leaders are likely to have limited exposure to PDC&YP therefore would perhaps be less confident in dealing with them.

Several parents felt that the volunteers lacked knowledge and awareness of disability issues but two parents specifically discussed service providers being afraid which manifested itself in `service provider fear`. This fear actually then stops the service providers communicating with the parents to try to overcome what they think is a big issue:

"They start panicking and they are a bit more afraid than the children I think, they are worried what people think, what people say, how they will coach someone with a disability" (Mother of 15 year-old male).

"They are scared! They don't know how to deal with it and look on all the negative sides, how hard it is going to be for them rather than the positive side" (Mother of C – 7 year old male).

4.5.3 Communication - Lack of Information

Although effective communication was deemed to be a facilitator for participation, the majority of parents interviewed cited poor communication as a significant challenge to PDC&YP participating in out-of-school activities. Poor communication issues revolved around the initial contact a family had with the activity personnel and the attitude of the staff who ran the activities and much of this came from how they discovered the activities. The majority of PDC&YP and parents cited lack of information as an important challenge to participation. As previously discussed, there were many ways that activities were advertised in the community (section 4.4.3) which included; websites, social media, posters up in schools, word of mouth and via specialists groups such as carers groups. Although these advertising strategies were used, as a researcher looking for activities, it took me a great deal of time and effort to find out what was on and when because sometimes details were out-of-date or just not available. This was also the case for families, as they did not always know what was out there for them. Advertising and the way in which information of groups was shared seemed to be either word of mouth, internet or social networking such as `Facebook.' Although parents used the internet to search for activities, the adverts were ad hoc. Parents who were not on social networking sites said they struggled.

"I think one of the biggest issues is not knowing what is out there" (K – 17 year-old female).
"Things need more advertising" (L – 12 year-old female).

"I recently spent two hours on the internet trying to find something on in this area" (Mother of D – 13 year-old male).

"It's about getting to know things. The libraries are very good they have lots of information of what's going on in the local area" (Mother of L – 12 year-old female).

4.5.4 Personal Care

PDC&YP may require support for activities of daily living such as toileting and dressing. The lack of provision and support around personal care was discussed by 12 of the PDC&YP and parents (63% of the service users) as a significant issue which impeded participation in out-of-school activities. This was a novel finding which emerged from this study. All of the young people in the study who required personal care discussed this issue and it was something that caused real stress and upset in their lives. All of the older young people requiring personal care discussed the range of their care needs which included needing support entering a bathroom through to full personal care support. They reported feeling different from other C&YP as they had to use separate changing/toilet areas or there would not be a toilet for them. This could potentially isolate them and could stop them joining in:

"I don't get changed with everybody else, I have got my own little changing room but I have to have someone waiting outside in case I fall out of my chair or something" (Male A – 15 year-old male).

"When we go out on trips and stuff, say when we went on a camping trip and there wouldn't be like disabled toilets" (A – 15 year-old male).

PDC&YP in this study who required personal care were often isolated from both mainstream and specialist disabled groups with many experiencing exclusion from 'inclusive' activities due to the extra care needs they required.

Three of the mothers in this study, who advocated on behalf of their children who needed personal care or assistance, felt that groups did not always cater for their children's needs which meant they did not attend or required someone to accompany them. This impacts on the child's social interaction as they cannot have the same opportunities to explore new relationships and boundaries with other adults if a parent is present. Also other children may not interact with them in the same way if they feel the parent is watching. It also affects any opportunity for parents to have a break for an hour during the activity which could be the only time during their week that this could happen. Activities where a child is supported can act as respite for parents. Respite is where the PDC&YP get support and/or care whilst the regular carer takes a break.

"There are clubs they say `oh we do all inclusive sports` but actually they don't because they don't do personal care or one-to-one; to me it should allow parents a little bit of respite for an hour" (Mother of an 8 year-old male with complex needs).

"The ones who are missing out are the ones who have the toileting issues." (Mother of D – 13 year-old male).

Discussion on personal care raised an issue in terms of safeguarding and how service providers may feel assisting with a child's personal care. For some personal care needs, the local authority can assist families through personal budgeting to pay for assistance but for some PDC&YP their requirements need someone to help them so they do not fall off the toilet or they need supervision. Parents alluded to staff being cautious around taking PDC&YP to the toilet, which created a challenge for four of the PDC&YP. This meant that they either needed their parent/carer to attend with them in case they needed the toilet during the activity or they could not attend. The needs of PDC&YP vary greatly, some children need full assistance whilst others only a bit of help:

"You have got the problem with toileting because in today's climate how do people feel about toileting" (Mother of D – 13 year-old male).

"He needs help with the doing up his buttons on his jeans but can go to the loo fine on his own" (Mother of B – 10 year-old male).

Regardless of how much personal care is needed, without any service provider support, the implications with regard to participation in activities is the same for all the PDC&YP as demonstrated in the discussion and quotes below:

A mother of a seven year-old boy stated that *"the staff at her child's youth activity were not prepared to assist with personal care, which, in this case, was to take him to the toilet "We were met with quite a closed door on that."*
She acknowledged that she felt it was their choice and certainly did not want to force somebody to take her child to the toilet if they feel really uncomfortable about it. Her little boy needed someone to assist him on to the toilet and take his pants down for him and *"make sure that he was pointing down and not up."*
After some discussion they had a plan that if he needed the toilet during the youth club the leaders phoned his mother so she would then drive to where they were and take him. In reality, his mum sat outside in the car waiting for the phone call. Unfortunately, this was the only hour a week she had any form of respite.

4.5.5 Perceived Discrimination and Exclusion

In this study, PDC&YP felt they were socially excluded due to their disability and, in light of current policy which aims to prevent discrimination (The Equality Act 2010), this raised several concerns. The feeling of being socially excluded was evident in some PDC&YP. They alluded to particular issues, such as people not understanding what disability was and why they were different. Examples include where service providers only see the disability or the wheelchair so being placed in a lower ability group with younger children. Also both examples below highlight that they felt as a family they do not see many disabled children so when they go to places people stare which was an issue for all of the family members in this study as illustrated below:

"She always has this thought that everyone is watching her and are going to take the mickey out of her and in fact some people do, so it does impact on what she will do" (Mother of a 14 year old female).

Family Discussion:

(A – 15 year-old male) *"When I was younger, I would stay behind for basketball at school and stuff, now I don't really do it because… Kind of like I will be put with the little men"*

(Father) *"You were sort of ostracised a bit…. His skills weren't appreciated were they?.... A wasn't able to train with the basketball team were you?"*

(A) *"I said 'can I come?' and he said 'I'm not sure about that as you could injure someone else with your chair' so then I sort of just stayed away from that"*

(Father) *"I think it is about their lack of awareness … You do stand out don't you… as a family, wherever you go, you stand out"*

(Mother) *"Everyone is watching*"

(A) *"Like when I get out"*

(Father) *"Coz you are a spectacle, aren't you?"*

Some parents felt that even before they got as far as physically attending an activity, there were challenges in just approaching the group as disability is the first thing they need to discuss. Although this felt challenging, some parents recognised the need to have an open discussion from the start to form a partnership with the leaders of a group. This initial contact also provided an impression of the group and some parents felt like activity providers were not as welcoming as they could have been, citing their child's disability as the challenge. They were made to feel different from other families, which they felt was an 'invisible' challenge:

"They always want you to fill in a form `does your child have any special needs or any disabilities?` as soon as you put something down, it's suddenly like there is no place" (Mother of 8 year-old male).

"It's that stop ….. I'll get back to you … for the other children it is yes bring them along, do you want to start tonight" (Father of A). "*We have always got to ask*

someone superior or have got to think about it before it's a yes isn't there?" (Mother of A).

"I understand people need to ask questions but … straight away thinking of the problems" (Mother of C – 7 year-old male).

Four parents described how they had been excluded from a specialist group as their child did not have the 'right' disability. Some clubs were aimed at C&YP with conditions such as cerebral palsy or Down Syndrome which isolated undiagnosed children or children with other complex needs.

"We went down to try it out but we were basically told he did not meet any of the criteria" (Mother of B – 10 year-old male) talking about trying a disabled tennis club. *"Unfortunately they did not specify the different disabilities they were interested in."*

One mother highlights how service providers can come across as being discriminatory: *"When we said special needs they suddenly came back to us and said `oh we have re-looked at the list and there isn't any places"* (Mother of 8 year-old male).

There was feeling from some that their child's disability was not only stopping them from accessing 'mainstream' groups but some disabled ones too as their child was not 'disabled enough.' They did not meet the disability criteria set by the club. Often this was not clear until the PDC&YP attended the first session. This may be necessary for some sports or activities due to the safety of the individual but this needs to be explicit at the outset. An example where this was very difficult was where a young male could not access mainstream football as he wore prosthetic limbs but he could not access amputee football because he had a double rather than single amputee. This was an important finding as some PDC&YP did not feel welcome in disabled or mainstream activities and were slipping through the net.

"He has got an interest in amputee football …. so we thought that was going to be a route for us but they said you can't do it because he's got two false legs, you have got to play on one leg" (Mother of E – 15 year-old male).

Three parents felt that disability activities were considered to be less important than non-disabled activities and this lack of priority meant access to court or pitch time in sports halls was limited or scheduled at a time that made the activity more difficult time to access. For example, one club ran sessions late on a Sunday evening and the PDC&YP were in school the next morning:

"Everything that says disability, has to take a back seat. Disability sports are at the back of the queue and other sports takes precedent" (Father of 15 year-old male).

"It is like second class people" (Mother of 15 year-old male).

"Disability sports fit in around other sports that take a priority and you kind of like get the court time late at night" (Mother of A – 15 year-old male).

4.6 Theme 4: Suggestions for Improved Participation

During the discussion on facilitators and challenges, a range of suggestions were made by service users with regard to improving participation for PDCYP in out-of-school activities. This included staff training to raise awareness on disability and promote inclusion. For the PDC&YP this involved improved access through a mixture of specialist, condition specific and mainstream activities. For the parents this meant better provision of personal care support, a willingness to give inclusion a try and a co-ordinated information centre.

Table 10: Suggestions for Improved Participation

This table highlights suggestions from service users for improved participation.

Service Users	Suggestions for Improved Participation	Examples
PDC&YP	Improved access through a mixture of specialist, condition specific and mainstream activities.	Disability awareness required. Educating non-disabled people about the needs of disabled people.
Parents	Better provision of personal care support. A willingness to give inclusion a try.	Disability awareness required. Building capacity. Staff training for children with more complex needs or awareness raising for children requiring some personal care.

	A co-ordinated information centre.	Parents could then find out which activities had providers/volunteers who had training and experience with disabled children.

PDC&YP wanted to see improvements both in mainstream and specialist provision to better support them and to become more inclusive. This demonstrates the need for local providers and commissioners to liaise with PDC&YP directly and to get their views and involve them in local decisions. This leads on to the need for PDC&YP and families to know what is available and how to access activities which again could be done in conjunction with PDC&YP themselves:

"Things need more advertising" (L – 12 year old female).

"Just that were more things available as there are not lots of things" (Mother of C – 7 year old male).

"What you need really is more disabled sports arenas that are for the disabled, rather than sports arenas that allow disabled people in" (Mother of 15 year old male).

Disability awareness was at the forefront and increasing awareness would go some way to overcoming some of the challenges highlighted in the study. It is about putting disabled people in charge or in control, for example, including them in youth councils and decision making groups. This was demonstrated by a 17 year-old female who shared her own views on making improvements:

"*I want to educate able bodied people on how we live. So I don't want to exclude anyone as will be open to all but it will just work in a reverse way"* (K – 17 year-old female).

Often the older PDC&YP and parents had similar ideas and made similar suggestions for improvement. The younger children did not have the wider understanding of funding and how things worked but they were very clear that they wanted more opportunities especially around sports:

"I would like to do tennis, athletics and fencing, I did fencing on holiday, it's easy, it's dangerous and it's fun" (B – 10 year old male).

"I want to try diving in the pool" (C – 7 year old male).

"I would like snorkelling. I would like to do ice hockey or hockey" (J – 9 year old male).

Parents wanted better provision of personal care support and a willingness to give inclusion a try, which they felt could be achieved through training and having co-ordinated information. The need for staff to have some training around disability was important to parents. Parents did not know where the activity providers got training but they felt they could use parents as a resource. It was recognised that the lack of awareness was also affected by the turnover of volunteers. So even if training was provided for a particular child this would need to continually refreshed:

"They did not understand the children's needs, it does worry me about the staff they bring in" (Mother of D – 13 year-old male).

*"They did not know what they were doing" (*Mother of D – 13 year-old male).

"There is not going to be a lot of disabled children for the volunteers …there is a turn over …. so if you have you build capacity, understanding and awareness" (Father of Male A talking about a mainstream youth group).

4.7 Discussion

The aim of the service user study was to discover the current out-of-school activities accessed by PDC&YP in Cheshire, to establish their preferences and explore the factors affecting PDC&YP's participation in out-of-school activities.

The findings from this study give a greater insight into PDC&YP's lives and can be used to inform policy and practice when planning and evaluating current out-of-school service provision. The findings also demonstrated the need for local disability training providers to target across all local clubs especially mainstream activities to raise disability awareness at every level. The study idenified a specific need for PDC&YP requiring additional support for personal care needs which requires policy development and guidance for all types of service provider within the community. This needs to enable service providers to have information on what they are able to do to support young people whilst maintaining safeguarding principles of care. For example, having DBS checked adults who can support personal care, not being alone with an individual child, whilst maintaining continued activity for the other children. In order to provide these care practices there needs to be sufficient enough numbers to have a safe adult to child ratio in the rest of the activity. This has implications on staffing levels which also has an impact especially in areas relying on volunteers. One possible solution is a buddy scheme discussed further below.

PDC&YP in the study did not have the same opportunities for out-of-school activities as non-disabled peers due to a lack of inclusive activities suited to their needs with the right support in place. Study findings highlighted that the PDC&YP did not access many activities and when they did, many challenges were encountered. The participants primarily accessed specialist disability activities, as this is where they encountered the least challenges but overall they still faced challenges to participation (Langer et al., 2010). This was especially challenging for PDC&YP in mainstream school who could not always access mainstream out-of-school activities due to the challenges outlined above and provision for PDC&YP with personal care needs was not available. A lack of opportunity for PDC&YP has been found in previous research (The Bevan Foundation (2010); Brokenbrow et al 2016). Equally Carter et al's (2014) North West of England study identified few opportunities for the disabled C&YP in their study. Through appreciative enquiry Carter et al (2014) explored the aspects which were working well for the activity organisation but despite this positive approach still stated a lack of opportunities. This study was similar to current findings in that when PDC&YP found a positive club it really worked but they are limited in availability in Cheshire. Disabled C&YP should have the same choices, opportunities and experiences as other children. They need to be able to make local friends and to access play and leisure facilities. This in turn allows families to meet others with the same needs and promotes stronger peer relationships and a sense of belonging (Ludvigsen et al., 2005; McConachie et al., 2006; Brokenbrow et al., 2016).

One 13 year-old male in this study did not attend any out-of-school activities due to living so far from school and being tired when he got home. He felt he only had some friends in school. He did want to participate and had tried activities in the past but faced challenges such as access issues or not being supported without his parent or paid PA. Having a PA appears a positive way of participating in activities and was certainly advocated in a Swedish study with disabled children (Mundhenke et al., 2010). However this requires funding and a PA to be employed.

A significant finding that emerged from the study was the difficulty around the local governance structures and depending on which area of Cheshire families live means **provision** can vary. In this case Cheshire has two local authorities with differing provision. This led to differences in availability of out-of-school activities. The implications of this was that families had variable access to activities depending on which authority they lived in. This caused frustration between parents as they could see what was on offer in neighbouring areas and yet their child did not have the same opportunities. This frustration needs to be shared with the policy planners and providers who run activities, as there is scope to be more collaborative in order to provide a Cheshire-wide plan. This may not be feasible in local authority run groups but charities such as independent disabled groups have already started sharing resources and advertising across the boundaries so could be explored further. This was more evident in the leisure and specialist activities such as disabled games or social clubs. One good example where these boundaries were not as significant was through a central sports network (adults and children) as they planned for the whole of Cheshire. But they targeted the whole community to raise activity levels therefore in reality have a small focus on disability and an even smaller focus on children's disability. The structuring and re-structuring of public services are well recognised as a challenge to disabled people in terms of budgets and provision (Taylor-Gooby and Stoker, 2011) which was particularly evident in Cheshire due to the two local authorities. Action for Children (2013), a voluntary organisation, found over a three year period that service infrastructures were fragmented due to government spending decisions on the disabled children it works with. The impact on such division needs feeding back to the local authorities to encourage cross working and collaboration.

Study findings illustrated that there was a range of out-of-school activities available to the PDC&YP in Cheshire including leisure activities, youth activities and religious activities. Sport was the most popular out-of-school activity possibly because there are many opportunities to engage in sporting activities in Cheshire and many PDC&YP reported they enjoyed sport. Of all of the sports accessed, swimming was the most popular which concurs with findings from the English Federation of Disability Sport (EFDS. 2013). Swimming was perceived to have both social and therapeutic value. The PDC&YP enjoyed swimming with friends and family, whilst parents felt it was a healthy activity, which helped their child's mobility. Study findings highlighted the importance of having local accessible pools for PDC&YP with the right conditions such as warm water, good access and appropriate changing facilities. Many public pools have good physical accessibility aids into the water but the major challenge that emerged was that public **swimming** pools were often too cold which stopped some of the PDC&YP from engaging in the activity. French and Hainsworth (2001) found that disabled adults do not access swimming due to the cold temperature and acknowledged it was also an issue for young children. Due to the popularity of swimming, provision in Cheshire needs to be re-focused to include more social activities for families to take part and have fun together (English Federation of Disability Sport, 2013). This needs comparing to service provider provision to establish how practical this is to change.

Where there were specialist disabled sporting opportunities within Cheshire, for example, multi-sports clubs, these were positive and PDC&YP could access them. One after-school club offered integrated sports for a mix of abilities including PDC&YP. This has been previously seen in a Northern Irish study by Shapiro and Martin (2010) where disabled C&YP who engage in sport specifically adapted to their needs have greater opportunities. They did acknowledge that there were fewer opportunities for disabled C&YP in sport due to physical differences as well as attitudinal and social challenge. There is an impact on disability sport as PDC&YP are saying they want specialist provision and this needs to be catered for within the area. This has been previously acknowledged by The English Federation of Disability Sport (2013) who stated that whilst it is important to provide joint sporting opportunities for disabled and non-disabled people especially when thinking about talent development but acknowledge that “impairment specific opportunities may be more relevant” (English Federation of Disability Sport, 2013:77). This is a personal preference for each child but there was a definite lack of PDC&YP in mainstream activities in Cheshire therefore indicating they are either opting for specialist provision or are not participating in sport. PDC&YP reported wanting more local specialist provision. PDC&YP who want to participate in mainstream, disabled or specialist groups struggle in all due to needing personal care or one-to-one support. Whether through explicit or implicit segregation the mixture of mainstream or specialist out-of-school activities can teach children that their disabled peers are rightly excluded (Johnston and Wildy, 2016). For example, where non-disabled children see no disabled children in their club this indicates to them it does not cater for their needs and that disabled children go somewhere else. This echoed findings from Carter et al., 2014) recognised a lack of opportunities for disabled C&YP within the North West of England. The disabled C&YP in their study benefited socially from participation in a specialist wheelchair sports club. Policy makers and providers need to ensure there is equal opportunity to take part in activities of the child’s choice which should be facilitated rather than encumbered by challenges to participation (Burns et al., 2013). The other preferences cited by the PDC&YP in this study included leisure and they wanted more art and drama opportunities. The PDC&YP wanted to access leisure opportunities to make new friends. The arts activities available in Cheshire seemed to be geared around the older generation. There has been very little reference to arts and culture engagement previously (Kelly et al., 2016). Some parents reported PDC&YP with complex needs having music in some specialist sessions which they enjoyed.

A finding from this study was that PDC&YP wanted to mix with others ‘like them.’ This important finding really affects how provision needs to be planned for PDC&YP. The overwhelming discussion about finding others who share their experiences was unexpected due to half of the PDC&YP attending mainstream school where the expectation may be to mix with school friends outside of school. However, in reality, PDC&YP identified themselves more closely with other PDC&YP rather than their immediate peer group. They wanted to be able to access specialist activities where they could meet others with the same medical condition or type of disability, for example, cerebral palsy. This has been reported previously by Langer et al. (2010) who found social benefits of this out-of-school provision such as making friends ‘like them` although this data was from only three disabled children accessing short breaks. Humans have a natural drive to find others who share their interests and they find and are drawn to common interests and goals as was the case for PDC&YP as their identity as disabled dominated their need to find others ‘like them.’ Individuals like, and are attracted to, others who are similar to themselves and these shared attitudes and values, bringing people together, can be explained by the similarity and attraction theory (Byrne, 1997). Social and developmental psychology studies outline that there is a tendency for individuals to select friends based on perceived similarities which is described as birds of a feather who flock together (Hamm, 2000). In contrast the desire to socialise with PDC&YP of a similar ability differs from Knight et al’s (2009) qualitative UK holiday study. They found that disabled children wanted to mix with non-disabled young people but were worried what other C&YP might say about their disability. The concern about how they may be received is an issue for some. The contrast in study findings may be due to the fact that many of the PDC&YP in the current study were in mainstream school where they do not mix with other disabled children who share the same experiences as them.

According to UN (1989: Article 23.1 and 23.3) schools should be inclusive and ensure “dignity, promote self-reliance and facilitate the child’s active participation in the community” with extra appropriate support. This aims to achieve “the fullest possible social integration and individual development” (UN, 1989: Article 23.1 and 23.3). These convention rights focus here on education but PDC&YP preferences demonstrate that full integration to them means participation into a group that they want to attend with the right support. To be ‘fully’ integrated is neither desirable nor realistic for some. This is evident in Cheshire as many of the PDC&YP report being the only PDC&YP in their mainstream school but they are opting to socialise within a specialised disabled group out-of-school.

Some schools do not/cannot provide inclusive education due to the access issues of older buildings and this is also the case out-of-school also. This is where PDC&YP have the rights to access but cannot. For the PDC&YP in specialist schooling there can be difficulties when joining in mainstream society as they do not normally learn, interact, play and socialise with non-disabled peers (Johnston and Wildy, 2016; Pearson, 2016; Alderson, 2018).

Factors which helped PDC&YP to join in out-of-school activities were perceived health and social benefits, positive role models and good external and internal communication. Joining in out-of-school activities were perceived to have fostered social wellbeing, the development of independence and had mental, emotional and physical benefits. PDC&YP were motivated to become more independent and find children like themselves through activities. Parents pursued sporting activities for their children to get, and keep, their children active and gain the health benefits. Previous studies recognised the need to socialise, develop new skills and grow in confidence and the benefits of this drives both families and providers to access and plan such activities (Beresford and Clarke, 2010; Knight et al., 2009; Sloper et al., 2009; Langer et al., 2010; Parkes et al., 2010; The Bevan Foundation, 2010; Hodge and Runswick, 2013; Carter et al., 2014).

Study findings demonstrated a drive for independence and engagement with many of the activities; leisure activities in the older young people facilitated this. Some of the parents in the study promoted independence by employing a PA using their personal disability budget so that the young person could access activities without the need for their parent to be with them. The budget is calculated on the PDC&YP’s assessment of care and support needs. The independent living strategy published in 2008 aimed to give disabled people greater access to leisure opportunities and to participation in family and community life (HM Government Office for Disability Issues, 2009, 2011). This current government payment system allowed parents to employ their own PA but this relied on parents being able to work this system and be confident with tax and employment information, whereas some children used their local authorities' assistance with this. The parents who were self managing their own independent living personal budgets relied on PA's rather than on community groups and therefore these PDC&YP were not accessing any mainstream or specialist activities but only activities such as swimming with their PA. This was due to individual needs and preferences as they enjoyed swimming the most and this is what the limited budget would cover. An hour swim may not initially appear too expensive but parents reported that to achieve this they needed to pay their PA time to get the child ready, drive them in the parent's adapted car to the pool, swim and return, would use up approximately three hours. The budget is limited due to their assessed needs so the family needed to prioritise what their children favoured. An evaluation is needed to measure the impact of personal budgets on out-of-school activities.

Some parents opted to rely on the local authority to arrange activity funding. Some children did not have a PA and none of the PDC&YP in the current study used a buddy although one 7 year-old male was waiting to be matched. No other PDC&YP in the study had been in touch with a buddy scheme because many did not know what was available or how it worked. A buddy scheme essentially is set up to have a young adult, in many cases, support a disabled child to a mainstream activity of their choice. Lawlor et al., (2006) suggested using a buddy to promote independence for disabled C&YP, which is where a disabled young person is paired with a non-disabled buddy (Knight et al., 2009). They act as one-to-one support so that the activity setting do not need to provide this. The buddy either goes along with the child or is integrated into the group and can support more discretely if the child does not want others to know. Some areas have small volunteer buddy schemes set up, as in Cheshire, or some private companies run this using personal budgets (Lawlor et al., 2006; Sloper et al., 2009).

Independence can be facilitated by the use of equipment or adaptations in the environment (Lawlor et al., 2006) but this study demonstrated that adult support is vital especially for those requiring some personal care with lifting or one-to-one support. Often this was the parents providing the support therefore not giving the PDC&YP the independence they crave.

Previous research suggests that some PDC&YP felt that parents can be over protective which affects their independence (Knight et al., 2009) but as evidenced in the current study if no one is available to take over this care from their parents this is impossible to overcome. None of the PDC&YP verbalised that parents were overprotective but one young male highlighted how much he loved having a PA and how much freedom this allowed him. This independence was very important and there is a need to enhance this for all C&YP, regardless of ability.

As well as independence and the social benefits of making friends, **health** benefits were also a factor in participation of out-of-school activities. Perceived benefits included promotion of exercise and physiotherapy. This was a particular driver for parents of PDC&YP as they could promote physical and mental strength through physical activity such as swimming, horse riding and wheelchair basketball. Parents discussed how this motivated them to find suitable clubs for their son/daughter. Carter et al., (2014) recognised how disabled C&YP gained both physical and mental strength in their study of a wheelchair basketball club. They noted that although the study was not about medical rehabilitation, the PDC&YP's fitness improved and was highlighted as a health benefit earlier in the sport discussion. Although there is a national drive to promote physical activity for C&YP (Public Health England, 2014; National Institute for Health and Clinical Excellence, NICE 2009) inclusivity must be central to the planning (Downs et al., 2013). These drivers do not have a specific focus on disability which is needed and examples such as wheelchair basketball could be showcased. Wheelchair basketball was an excellent example of inclusive sport in both this study and within a previous North West of England study (Carter et al., 2014). These clubs were found to be very inclusive and PDC&YP travelled to get to them due to their popularity.

There were many positive influences, which promoted participation into out-of-school activities including: positive role models, the Paralympics and the desire to play competitive sport. These positive influences promote independence through social skills and increased self-esteem whilst also enhancing their well-being. No specific literature emerged from the review on the impact of role models but Carter et al., (2014) highlighted the need for PDC&YP to learn from one another. This was clearly evident through the study when they had coaches or other disabled people who were able to inspire them. Some of the coaches had a physical disability and they were able to showcase what they had achieved and also could discuss shared experiences. Role models have long been described as influential in Bandura's social learning theories (1977, 2001) where he described modelling as part of this social learning. PDC&YP were motivated by role models and, in some cases, encouraged them to join an activity for the first time. Having role models can foster new social interactions and enhance personal coping mechanisms. One group of role models they specifically discussed were athletes from the London 2012 Paralympic Games. The PDC&YP felt this was positive for them to show how much disabled people can achieve. The English Federation of Disability Sport (2013) also advocate for young people to have a positive role model. Likewise, Coates and Vickerman (2016) found it was inspirational for PDC&YP in their small study investigating perceptions of the Paralympic games. They found that Paralympians were seen as role models for PDC&YP, it had changed their perceptions of disability, and they were motivated by the games. This helped these young people and their self-perceptions, which was also the case in this study. The PDC&YP did highlight that disabled sport had less coverage than the Olympics and wanted more disability events showcased. While there are indications that the Paralympic Games was initially positive, the legacy for disabled C&YP is unclear (Brittain and Beacom, 2016). However, it certainly influenced some PDC&YP and their families within this study as it either provided the ideas of what they might like to do or they got involved in projects such as Playground to Podium (P2P). P2P was a pathway of targeted interventions to promote disabled C&YP progress from physical education in school or community to performance level sport to compete (Activity Alliance formerly EFDS, 2018). The Paralympic Games also increased public disability awareness.

Leading on from the sports role models a new finding which emerged from this study was the drive for competition as a facilitator for some PDC&YP to participate. Competition, and a desire to win in sport, was a motivating factor which facilitated participation in certain sport. Where PDC&YP had tried mainstream sports, for example, football and basketball they were drawn to specialist disabled sports clubs to play competitively, for example, wheelchair basketball as this put them on more of a level playing field competing with others who had similar abilities. Competitive sport for PDC&YP, such as wheelchair basketball, has been discussed as being exciting, fun and inclusive in the North West of England (Carter et al., 2014). Although a very positive example, it did not specifically explore competition as a driver for PDC&YP to join sports clubs. The Healthy Lives, Brighter Futures document discussed a drive for competitive sport but states that more opportunities are needed for disabled children (Department of Health, Department for Children, School and Families, 2009). This report had an active group of disabled people in their sample which is a possible limitation so it is important to continue to explore the needs of PDC&YP.

Communication is key to all interactions and is a clear factor affecting participation for PDC&YP. Even before the PDC&YP join an out-of-school activity positive communication is required. What were particularly problematic were activity providers who made an issue about the child's disability before they had met them. Service users found it helpful when information was clear regarding who the activity was for and whether their child would be welcome. It is concerning that parents automatically assume they will not be welcome. Study findings illustrated that when positive communication was good it created a welcoming and inclusive experience, for example, when the activity provider worked in partnership with families this supported their child's needs. However, when there were difficulties getting hold of someone to talk to or not being able to plan for support needs it was inadequate and created much frustration amongst PDC&YP and their families.

Service users wanted an up-to-date website, a current phone number for clubs, and a welcome from service providers as well as being able to discuss the PDC&YP needs. The internet was a common method to find new activities and hobbies but this information needed to be up-to-date and welcoming to all C&YP including PDC&YP. Service users who had access to social media and the internet were better able to find out more than those who did not. Specifically 'Facebook' was used by the older PDC&YP and some parents and this was an important part for service providers to improve within advertising and communication. Social media is a very common and often successful method of information gathering for disabled people (English Federation of Disability Sport, 2013). It was important to highlight the needs of the younger children as they could not use social media and therefore wanted information through school such as posters, leaflets and the teachers to know what was available.

This is an area not currently explored in the literature and warrants exploration as PDC&YP in mainstream school did not naturally see specialist groups advertised. There were more links to special schools so specialist groups need to also advertise in all schools. Service providers need to be aware of communication preferences.

Although activities were advertised via social media, local newspapers, schools and word of mouth there was no central database to find this information. Parents stated that they wanted more centralised information to make it easy to find the right out-of-school activity for their child. The closest to a central database available is administered by Contact for Families with Disabled Children (2018) where families can contact regional staff. More recently, KidsGuide (2018) have developed a list of specialist groups within Cheshire. Parents felt it would be helpful if one person could co-ordinate and signpost families. Although this would be the ideal, realistically with no specific funding from the local authority this would be very difficult. It would require policy holders to invest in this specifically but currently there is no specific funding focus on disability activities. There was one sports development worker who had inadvertently taken on some of this role as he had a special interest in disability. He was recommended to signpost families and was an important contact for them. This was the only example of this kind that emerged during the fieldwork. Meeting the right people is vital in improving networking (Knight et al., 2009). Unfortunately, the funding for this post was removed, leaving individual families to navigate accessing activities without support. This sports worker had been a champion for disability and, in the current climate, more liaison between service providers and users is needed at any opportunity. If there was an increased uptake of the free disability awareness training available within Cheshire this could be cascaded through activity providers. Champions could then emerge and would then give more pockets of confidence and knowledge for parents to tap into. The training provided is by an independent charity, which could provide a network of people having trained and ideally would create a network within Cheshire. With these champions advocating for, and working with, families these could inform the service providers about what is required within the community. An example of where this works is through NHS and the social care policy, which requires participation by service users in their development. Individuals should be at the heart of decision-making (Involve, 2018).

As well as communication other challenges which stopped the PDC&YP accessing an activity or affected their attendance were due to access issues, lack of staff disability awareness, poor communication, personal care support issues and at times PDC&YP being discriminated and excluded.

Access was an issue for most of the PDC&YP and parents but it was particularly significant for the wheelchair users who found it difficult across sport and youth activities. Lack of access can lead to a lack of independence so the benefits of participating are diminished. A lack of reasonable adjustment to access is unlawful under The Equality Act (2010) yet is still a challenge to participation due to the lack of physical access in some buildings, suitable hoists or transport issues. Sports clubs had better access than youth clubs and PDC&YP stated that many of the leisure centres they had visited were good but access was more difficult in clubs, such as community groups. This had a social and psychological impact on PDC&YP and their families as they could not just attend any activity which a non-disabled child could attend, it took research, planning, additional support and, at times, major modification to a building in order to access it. Activity providers can take steps toward making their physical space more accessible which would welcome more PDC&YP (Bennett, 2009). Although there is a cost implication for large adaptations small changes, such as having all the children going through the 'alternative' entrance, would enhance inclusion so the PDC&YP do not feel different. PDC&YP are excluded from social situations due to not being able to get in (Bennett, 2009; Knight et al., 2009).

Transport, such as taxis to and from activities after school, or the distance to travel to activities was raised several times by PDC&YP and parents as a major challenge to activity participation, with those requiring taxis being restricted to the travel contract. It is very difficult for PDC&YP to car share due to the extra equipment or space needed, for example, a wheelchair. The issues around transport created social exclusion as PDC&YP had to return home at the pre-booked taxi time so could not attend afterschool activities. To address this, service commissioners who arrange transport and after-school provision need to be mindful of children travelling out of area for schooling and be able to have some flexibility to allow them to join activities. Service providers who have an overview in the area need to invite children and families to discuss their needs across various ages and abilities when planning new activities in the area so they are aware of young people facing these issues. This would need to be arranged and planned through the policy and planning within child services in Cheshire as they pay for this facility, which parents recognise is not realistic. Therefore, there needs to be increased provision in Cheshire in terms of a range of activities suitable for PDC&YP so they do not have to travel a great distance. Previous research has highlighted that children who attended special schools away from their local area were found to have reduced social community-based activities (Knight et al., 2009; Sloper et al., 2009). Lawlor et al. (2006) and Knight et al., (2009) reported a lack of access to public transport, making participation difficult. This problem with access to transport is echoed by Beresford and Clarke (2010) who found a lack of suitable transport as their families reported having to plan journeys far in advance with high costs affecting participation (Kelly et al., 2016). The case studies shared by the Disabled Children's Partnership (2017) demonstrated that disabled children are travelling a great distance to attend activities. Local authorities need this feedback so that, when budgeting for PDC&YP, the full cost of transport needs to be considered and flexibility is written into the contract to go some way to overcome challenges around transport.

PDC&YP had difficulty accessing mainstream out-of-school activities due to the issues raised above but with the added difficulty of finding an activity/club suitable for their needs. The majority of families in this study, who had previously tried to access mainstream activities because they had wanted to be with children their own age initially, reported negative experiences. This was generally due to poor staff awareness and a lack of understanding of the needs of their physically disabled child. Many PDC&YP reported the need to find suitable specialist activities because of negative experiences. PDC&YP need to have a choice of mainstream and specialist activities and access a range within their community if that is what they want to do but this requires them both to be inclusive and meet the child's needs. Some PDC&YP felt disabled groups were not always the right place for them and parents concurred, for example, where there may be only one PDC&YP with no learning needs in a disabled group and the rest of the C&YP had learning disabilities. Therefore, a one-size-fits all approach to disabled children does not work and the type of provision needs to be assessed. All children need to be assessed individually to look at their ability and their access ability in terms of mainstream with some support where required (Knight et al., 2009). Where there is provision but it is not appropriate for PDC&YP, this needs to be adapted to work or a separate provision is required within Cheshire (Carter et al., 2014; Brokenbow et al., 2016). There are examples nationally where condition specific groups plan and operate activities where children travel, to meet others with the same condition, for example, Dwarf Sports Association UK (2018) and Cerebral Palsy Sport (2018). However, these only cater for children with a specific diagnosis and the activities are planned nationally, which require travel and weekends away rather than local provision (Disabled Children's Partnership, 2018). PDC&YP's preferences on provision are clear that they want more local specialist clubs so dissemination of these findings amongst sports providers is helpful and something I have already started in the programme of study (see PhD outputs, p i).

PDC&YP can be isolated from specialist-disabled groups when children do not have a diagnosis or have a different disability to the other children in that group. For PDC&YP without a diagnosis it was difficult to explain and service providers found it hard to understand and appreciate their needs. Bennett (2010) concurred and stated that children are sometimes not considered to be 'disabled enough' to get the extra help they need. Goffman proposed a theory of stigma and identity in 1963, where individuals were given labels or categorised (Zames-Fleischer, 2001). Labels, as seen in the example above, can be very helpful in finding the right support and people understanding their child's needs, for example, most people will know a little about Down Syndrome due to the positive national campaigns raising awareness but for a child with different needs this creates an extra challenge. There has, since, been a debate on how useful labels are for disabled people especially in disability rights and self-advocacy movements (Goodley, 2000). Labelling can be deemed as having narrowing effects by people focusing on a person's disability. However, having a diagnosis can be important to an individual's identity and can help them understand and celebrate their difference (Hatton, 2009). As a healthcare professional I have also seen, first-hand, how gaining a diagnosis can open up focused support and funding to assist the individual in day-to-day life.

In demonstrating staff awareness there were only two examples of a positive experience when participating in mainstream activities and leisure. Two young males accessed a youth and a leisure activity with their mainstream peers and the staff were very positive in their approach, yet with both, they had some access issues. There was evidence from one mother and a family that PDC&YP in the study were actively discriminated against and excluded from mainstream activities due to their physical and personal care needs (section 4.5.5). This is in line with Knight et al's (2009) holiday study, which found that while disabled C&YP wanted to be part of mainstream experiences they felt providers needed a better understanding of their situation, which for those requiring personal care in this study, was far more difficult. A good example of this was of a mother of a seven year-old male who needed to sit outside in the car of a youth club in case her son needed the toilet during the 90 minute session because the leaders were not able/willing to assist. The lack of staff awareness is problematic but training can go some way to address this and raise disability awareness but personal care requires further discussion below. All induction training within youth and sports work with children needs to include disability awareness.

A unique outcome that emerged from the current research concerns the needs of PDC&YP who require assistance and support with personal care for activities of daily living such as toileting and dressing. There is a significant gap in provision for PDC&YP requiring personal care. These PDC&YP were often isolated from mainstream activities as there were no reports of personal care support being provided and as a result the parents needed to accompany them. These PDC&YP were also isolated from specialist disabled provision (see 4.3 for description) as they had difficulty accessing or having support to use the toilet with no one to help them unless their parent accompanied them. When I designed the study, I conducted a search of all of the activities within Cheshire, and found that there was only one specialist group providing personal care integral to their provision and the occasional group using a buddy system where the child brought along a personal assistant to help them. This was a charity group, run mainly by volunteers and, at the time of writing, the group providing the integral personal care had temporarily closed down due to lack of funding and the 70 families registered had to find alternative leisure provision.

This was an area that caused a great deal of upset and isolation for service users. Parents reported a tension between service users and service providers on personal care with service providers raising safeguarding concerns to parents and refusing to assist their child and PDC&YP not being able to join independently. Guidance is needed, for service providers and parents, about the roles of activity leaders in terms of personal care which also would ensure the safeguarding of all children in their care. A discussion about expectations is also needed to identify what a child needs before facing an initial rejection. The parents reported a closed book on this issue with no room for discussion. The service provider’s views will be explored in chapter five. An issue raised by one parent was the gender of whoever was assisting the PDC&YP. It is important to promote self-care here but when a young person does need physical assistance ideally they should have a carer of the same gender which is not always possible. This also links to the discussion on safeguarding both the young person and supporting adult. Safety, privacy and dignity for the PDC&YP is paramount. Large activity providers have their own safeguarding policies and procedures which give leaders guidance but at times are not clear what to do in specific instances, for example, around personal care. This area needs a wider exploration across the UK and more comprehensive guidance.

There have not been specific findings from previous studies on personal care for PDC&YP and the only link to toilets have been around the access issues in disabled toilets and changing facilities lacking hoists (Beresford and Clarke, 2010; The Bevan Foundation, 2010). There was, however, no discussion of direct support needed to either accompany PDC&YP to the toilet or assist them during an activity.

On occasion, parents stated that they felt their child had been discriminated against due to their disability and, those most vulnerable, were those needing personal care. Societal challenges are reported with 80% of people who feel there is prejudice against disabled people (HM Government, 2011; Office for Disability Issues, 2011). PDC&YP were slipping between the cracks of mainstream and specialist activity provision. They had no personal care provision available in mainstream and the specialist groups either catered for different disabilities or did not cater for PDC&YP personal care needs. They were, therefore, isolated from both types of activity without their parent accompanying them. Families can feel like they are an outsider looking in (Bennett, 2009; Knight et al., 2009). There was evidence from parental statements that there was implicit discrimination where providers were not aware of the impact of their actions on participation. For example, providers making assumptions about the child before they know what support they need. The Bevan Foundation (2010) previously reported that there was not enough or the right kind of support for disabled children. With parental partnership and disability awareness training this is something that could potentially improve but it does take a strong parent to persist and organise some of this. On the other hand where there is evidence of the service providers discriminating explicitly; this raises concern about the running of that activity and is unlawful. This included inadequate access to activities and insufficient support to access leisure activities. Parents highlighted that it was vital to explain their child's needs so that the right kind of support can be offered and there is no ambiguity during the activity. The parent, as the advocate for the child, can express their needs through a partnership communication but the advocacy role needs to also be adopted by the service provider (DH, 2007; Carpenter and McConkey, 2012).

Results from the service user study highlighted an urgent need for disability awareness training at the very least through to more specific training in some groups to enhance provision for supporting any PDC&YP with personal care needs. Due to the nature of volunteering the turnover of staff can be high and therefore an ongoing rolling programme of training is essential. Large activity providers such as religious groups, youth groups such as Guiding and Scouting and many sports have training programmes and packages with the aim to support, educate and entertain C&YP within communities. However, there is clear evidence from the parents, when discussing challenges to participation in out-of-school activities, that disability awareness training for service providers could help overcome many of these. Staff disability awareness is required to boost confidence, understanding and increase funding (Knight et al., 2009; Beresford and Clarke, 2010; Bennett, 2010; Brokenbrow et al., 2016). There is a need to build capacity of service providers who are trained to enhance the overall experience for PDC&YP and reduce the challenges affecting participation in out-of-school activities (Bennett, 2009; The Bevan Foundation, 2010). Training can enhance inclusive practice, which promote people with positive, can-do attitudes (Brokenbrow et al., 2016). It is unclear how many volunteers are trained as there is no national database, thus training is an area for improvement and further exploration. A lack of disability training is a national issue and is well-documented (Bennett, 2009: Beresford and Clarke; 2010; The Bevan Foundation, 2010: Brokenbrow et al., 2016) and recognised issue as highlighted by the literature above. Although not a new finding, it is frustrating and disappointing that in Cheshire where there is free training available to any group who wishes to access this. The finding did, however, highlight that there is still this gap so can be clearly disseminated and the training provider has been made aware so can perhaps advertise widely.

4.8 Conclusion

This multi-method qualitative study explored factors affecting participation in out-of-school activities from the perspective of the service users in Cheshire. Thirteen PDC&YP and 19 parents gave their views on their out-of-school lives. The following section outlines the key conclusions drawn from the study:

- PDC&YP and their families accessed a range of activities within Cheshire such as sports, youth and social activities.
- PDC&YP accessed a mix of activities with some being disabled groups, specialist disabled provision such as wheelchair basketball as well as activities attended by non-disabled peers such as youth clubs (mainstream).
- Some PDC&YP found that disabled groups did not have any other PDC&YP and mainly catered for C&YP with learning disabilities.
- PDC&YP preferred specialist disabled groups so that they could mix with others who had the same disability as them.
- PDC&YP who require help with personal care had the most difficulty accessing activities. They were excluded from ‘inclusive’ activities.
- The benefit of taking part was acknowledged by PDC&YP and parents to join in with activities outside of school. The main reason was to make and be with friends.
- The key facilitators were perceived to be social and health benefits, positive

influences motivating the PDC&YP to stay in an activity and communication which influenced inclusion.

- Positive role models promoted participation in out-of-school activities therefore is important to showcase potential role models within the community.
- When communication was effective, up-to-date and in an accessible format, this facilitated participation into out-of-school activities. Poor communication created much frustration amongst C&YP and their families who felt that communication could be easily improved, for example, by having an up-to-date website, having a current phone number, having a welcoming approach when people arrive and being able to discuss the needs of C&YP.
- The PDC&YP access swimming for lessons and for a social activity with friends or family but the temperature and access were clear challenges for them to take part.
- The PDC&YP in this study faced significant challenges which stopped them accessing many mainstream and some specialist out-of-school activities which included: access issues, lack of staff awareness, poor communication and lack of support for personal care.
- There was some evidence of discrimination and exclusion.
- The lack of awareness of service providers played a dominating role when discussing challenges affecting participation in out-of-school activities.
- Parents want a co-ordinated centre where information is held about suitable activities available in Cheshire.
- Specialist activities need to be advertised in both specialist and mainstream schools.
- Disability awareness training is needed for all service providers.

CHAPTER FIVE: FINDINGS AND DISCUSSION OF STUDY 2: SERVICE PROVIDERS (ACTIVITY PLANNERS AND VOLUNTEERS)

5.0 Introduction

This chapter represents the findings of data collected from activity planners who plan out-of-school activities and volunteers who run such activities. This chapter presents the sample profile of the service providers who were consulted and their views ascertained in relation to provision of out-of-school activities for PDC&YP in Cheshire. The themes which have emerged from the data analysis will be outlined. A discussion of the findings will then be presented.

5.1 Sample Profile of the Service Providers

Thirty-one service providers from different sports, youth and religious organisations shared their views on their out-of-school school-aged activity provision in Cheshire. This included 11 activity planners and 20 volunteers (see section 3.4.4 for description). Each interview/focus group discussion lasted between 20 and 60 minutes. The service providers were all drawn from mainstream activity organisations within Cheshire in an attempt to determine what the current provision is for PDC&YP who wish to participate in such activities.

Tables 11 and 12 outline the profiles of the activity planners and the volunteers who participated in the study. These two roles differ as the activity planners have an overview of the activity and are involved in the more strategic elements whereas the volunteers run the after-school or weekend activities with the children. In the larger organisations these roles are quite separate, but with small activities, some individuals would have experience in both roles. Within the data collection their main role dominated the discussion so this was documented but there are times when this may influence their view. The service providers were all white British and predominantly middle class. They were a mixture of paid activity planners such as religious leaders and coaches (eight paid) with the other three providers being voluntary. All the volunteers were unpaid. They all provided mainstream activities with the exception of three coaches who ran specialist activities alongside their mainstream groups.

Table 11: Profile of all Activity Planners

No.	Gender	Activity	Role	Paid/Un-paid	Received disability awareness training	Data Collection Method
1	Male	Youth	Senior Youth Leader	Un-paid	No	Interview
2	Male	Youth	Chairperson	Un-paid	No	Interview
3	Male	Sports	Multi-sports coach (mainstream and specialist)	Paid	Yes	Interview
4	Male	Religious youth	Religious leader	Paid	No	Interview
5	Female	Religious youth	Religious youth worker	Paid	No	Interview
6	Male	Sports	Rugby coach	Paid	No	Interview
7	Male	Youth	Chairperson	Un-paid	No	Interview
8	Male	Sports	Rugby coach	Paid	Yes and provided training	Interview
9	Female	Sports	Basketball coach	Paid	No	Interview
10	Male	Sports	Swimming coach	Paid	No	Telephone Interview
11	Male	Religious youth	Religious leader	Paid	No	Interview

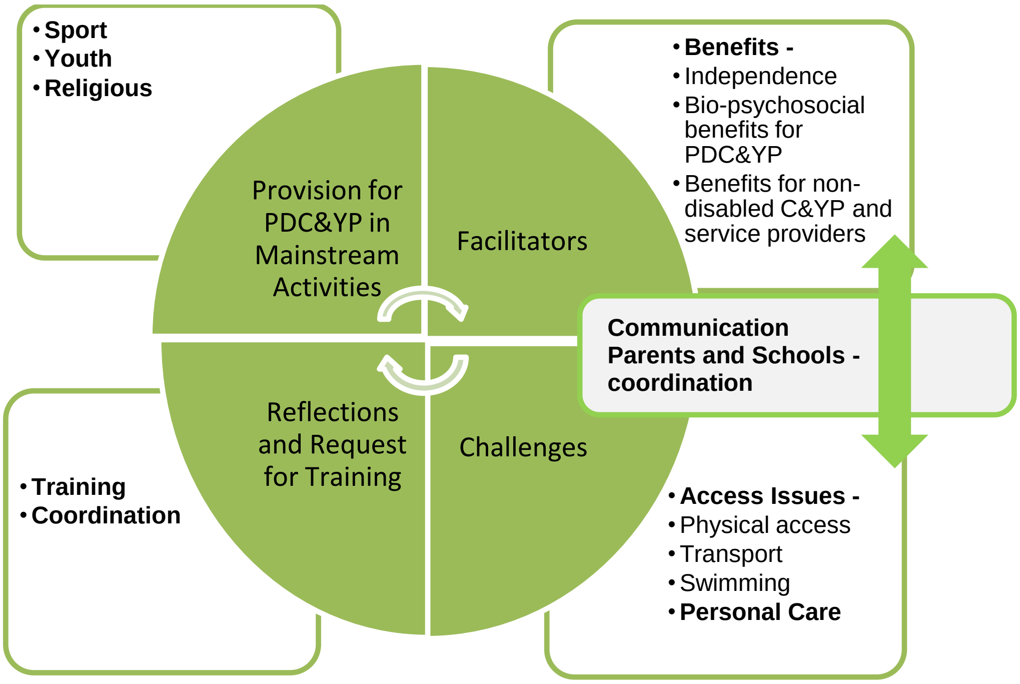
Table 12: Outline of Interviews and Focus Groups of all Volunteers

No	Gender	Activity	Role	Received disability training	Data Collection Method
1	Male	Sports	Squash coach	No	Interview
2	Female	Religious youth	Religious activity helper	No	Interview
3	Male	Sport	Multi-sports coach (mainstream and specialist)	Yes	Interview
4	Male	Sports	Football coach (mainstream and specialist)	Yes	Interview
5	Male	Sports	Football coach	No	Interview
6	Male	Sports	Senior Football coach	No	Interview
7	Male	Youth	Youth Leaders	No	Focus Group
8	Male			No	
9	Female	Religious youth	Religious activity helpers	No	Focus Group
10	Female			No	
11	Female			No	
12	Male	Youth	Youth Leaders	No	Focus Group
13	Female			No	
14	Female			No	
15	Female			No	
16	Female			No	
17	Male	Sports	Rugby Coaches	No	Focus Group
18	Male			No	
19	Male			No	
20	Male	Sports	Cricket Coach	Yes	Interview

5.2 Results

Four main themes were identified from the data and these spanned across all the service providers. As illustrated in the Figure 10, the main themes were the provision for PDC&YP in mainstream activities, the facilitators and challenges to PDC&YP participating in out-of-school activities and suggestions for improvement. Although the main themes align with those of the service users, there were differences found within the sub-themes as detailed below.

Figure 10: Service Providers Emergent Themes



5.3 Theme One: Provision for PDC&YP

All of the service providers were asked to describe their out-of-school provision for PDC&YP. The service providers were all from one of three backgrounds: sport, youth and religious provision (see Table 13). Sports provision had the most PDC&YP participating whereas the youth and religious service providers reported no PDC&YP in their groups currently apart from one church which had a separate group for disabled people to attend.

Table 13: Overview of Service Provider Participants split by Activity Type

Service Providers Total (n=31) which include activity planners and volunteers from three backgrounds: • Sports (n=14) • Youth (n= 10) • Religious Activity (n=7)	**Activity Planners** (n=11) • Sports (n=5) • Youth (n=3) • Religious Activity (n=3)
	Volunteers (n=20) • Sports (n=9) • Youth (n=7) • Religious Activity (n=4)

5.3.1 Sports

The 14 sports service providers (activity planners n=5 and volunteers n=9) came from a range of sporting backgrounds such as football, rugby, cricket, swimming and multi-sports, which included basketball and boccia. Almost all of the 14 sports providers and volunteers discussed at least one PDC&YP participating in their group (n=11). Most sports clubs had small numbers of PDC&YP unless they actively worked with a special needs school and only one sports provider had never worked with a child with a physical disability. Sports clubs were the only service providers to report having had any disability awareness training and had the strongest links with schools, which could help with the participation should PDC&YP approach them. It may also be due to sports being the most popular reported activity for PDC&YP.

"I have always had disabled children in my classes and apart from a few cases those children have always participated in a mainstream class" (Activity Planner of sports activities – Swimming).

"Out of 50, I think we had one may be two" (Volunteer in sports activities - Junior

football coach).

“We have had many special needs kids and their needs are often physical needs” (Volunteer in sports activities – Squash).

A number of coaches had run mainstream groups for their sports but had then gone on to have specialist groups for disabled C&YP. It therefore initially appeared to be a mainstream group but actually had separate disability provision. For example, multi-sports and one football club in the area, which both run specialist provision however the football is mainly for children with learning disabilities rather than PDC&YP.

5.3.2 Youth Activities

There were ten service providers from a youth activity setting of which none of them currently had PDC&YP in their group (Activity planners n=3 and volunteers n=7). They had a small number of C&YP (n=3) with learning disabilities. There are many C&YP with learning disabilities within the community and there are many special schools within a concentrated area in Cheshire which clubs and religious groups have links with.

“I am not aware of anyone who was disabled enough that is obvious that we take” (Activity Planner of a youth activity).

“We haven’t had anyone who has had what I would class as a stereotypical disability and you don’t tend to see many around in our youth movement” (Volunteer of youth activities).

5.3.3 Religious Activities

The study included seven service providers offering religious activities including two activity planners and four volunteers. Similar to those in the youth setting, they had no PDC&YP in their mainstream groups in the whole time they had run the activities, although one church was supporting a ‘disabled only’ group which parents/carers had set up for young adults. This church provider had little information about it as it was separate to their youth engagement programme.

"I don't know that we ever have had which is sad isn't it" (Activity Planner of youth religious activities).

"We have the summer group and that's really busy, but we don't get any disabled children" (Volunteer in religious activities).

5.4 Theme Two and Three – Facilitators and Challenges to Participation

Activity planners and volunteers were asked to reflect on why they did not have PDC&YP in their activities. There were several themes which were both facilitators and barriers, therefore themes 2 and 3 are presented together. Table 14 shows sub-themes which cross both facilitators and challenges:

Table 14: Facilitators and Challenges to Participation

	Overarching Theme		
	Facilitators to Participation	Both Facilitator and Challenge	Challenges to Participation
Sub-Themes	Benefits of Participating • Independence • Biopsychosocial benefits for PDC&YP • Benefits for non-disabled C&YP and service providers		
	←	Communication	→
	←	Parents and Schools	→
			Access Issues
			Personal Care

5.4.1 Facilitator - Benefits of Participating

All of the service providers highlighted joining in activities as being beneficial to all children but some recognised that their activity was perhaps not suitable for some PDC&YP. The volunteers gave some very specific examples below which is not surprising as they work directly with the C&YP during the activities, whereas some of the activity planners may be removed from the week-to-week running. The main factors that positively influenced PDC&YP to join in out-of-school activities was the promotion of independence and biopsychosocial benefits. It was also clear that there were benefits for the volunteers and other C&YP in their group by promoting inclusion. These will now be presented.

The drive for **independence** was discussed specifically, particularly by youth volunteers, as an important facilitator to encourage all C&YP to join any activity. They felt this would be a driver for PDC&YP to potentially join them and to socialise without a parent. This was a motivating factor for youth workers to enhance the activity to promote this, as illustrated below:

"Especially at the age they are now, they want to be out on their own a bit more and show off in front of their mates" (Volunteer in youth activities).

"It is an outlet from home and coming to do something on their own, where parents are not supervising them" (Volunteer in youth activities).

Service providers reported benefits for all C&YP joining in their activities including: physical health benefits (biological), psychological aspects of well-being and making friends (social) (See link to biopsychosocial benefits section 2.2.3). There were **health benefits** to physical activity recognised which, unsurprisingly, was reported by sports volunteers as they recognised the cardiovascular and physiotherapy benefits to joining a sporting activity. They were keen to state that it helps with C&YP's fitness but also their personal development as they learn new skills.

"Healthcare professionals are very keen to get all children and disabled children into some sort of physical activity … it's a great delight" (Volunteer in sports activities – Squash).

"It can help with their development" (Volunteer in sports activities – Rugby).

"They can get a lot of therapeutic well-being and progress in their lives through physical activity" (Volunteer in sports activities – Squash).

Many of the volunteers recognised the **social** benefits for the C&YP and this was promoted through their activities. They recognised that to be with friends was forefront in their out-of-school activity for any C&YP. The volunteers designed their activities so members got to know different people in the group perhaps from outside their normal school friendship group. One volunteer did, however, recognise the social benefit for the parents also, which was really important to report, as they were keen to entertain the C&YP to give parents a chance to sit and have coffee and talk to other parents. They felt this helped if they had not got friends themselves or needed a new social network.

"It helps with friends" (Volunteer in sports activities – rugby).

"Football is the medium to deliver the social contact, friendship, learning those skills" (Volunteer in sports activities – football).

"Half the point of coming is so the mums can talk" (Volunteer in religious activities).

There were **wider benefits** of having an inclusive group which benefitted the service providers and non-disabled peers and, in some cases, motivated the volunteers to continue in the role. Two volunteers encouraged PDC&YP into their groups as they felt it taught children and adults to be compassionate, to communicate effectively and to be more inclusive in nature. This, however, was not the view of all service providers especially three activity planners who felt that their activity may not be the right place for PDC&YP. These service providers need to consider ways to be inclusive. They would benefit from working with other groups who do make positive adaptations and learn from others.

"It teaches the others to be compassionate, it educates them and enables them to not be afraid of someone's ability" (Volunteer of youth activities).

"It's definitely a passion for me and I get a great deal out of seeing what they can do and what we can achieve" (Volunteer in sports activities – squash).

"Generally speaking groups will try to accommodate people with disabilities but there are caveats" (Activity Provider – youth).

5.4.2 Facilitator and Challenge - Communication

Half of the service providers (n=16) (activity planners and volunteers) discussed communication strategies that would encourage PDC&YP. There was mixed discussion on communication strategies and what worked (facilitators) and what did not (challenges). Communication was a positive tool when providers recognised that every C&YP needs individual assessment and when there was an initial discussion with parents to form a partnership. This was evident through the sports service provider discussion who appeared to be more inclusive in their approach. When effective communication was not utilised it created a challenge to PDC&YP participating in out-of-school activities. If a service provider is proactive and ensures their planning and communication strategies are inclusive to all before a disabled child asks to join then this facilitates a more positive start for both the child and the provider. But the experience the PDC&YP received was very dependent on the individual service provider's communication and approach. If they had an open and inclusive attitude and a welcoming approach this made for a positive experience. But if service providers focused on the disability first this was an issue. The examples below were all from activity planners due to them having an overarching viewpoint:

"There is nothing preventing us making the same effort should it come along" (Activity Planner in youth activities).

"It would depend mainly on the attitude of the youth leader, also the provider, the aim of this youth group is that we would try and accommodate somebody" (Activity Planner of youth activities).

"It's really about understanding the needs of the individual" (Activity Planner of sports activities – swimming).

The next section is presented in table form (see Table 15) to demonstrate the different stages of communication that service providers discussed when planning and running out-of-school activities. The facilitators and challenges will be presented as a comparison. Most activities were advertised via social media, word of mouth or leaflets. Social media was helpful although it can be an issue if a club gets a poor reputation to try and overcome this. Word of mouth was considered very powerful in all groups. One service provider had links with a local hospital who handed out leaflets for this club and this worked well for him. Service providers recognised the need to make a good first impression and some identified strategies like welcome packs and a positive attitude. Some volunteers were not in control of their advertising as they were part of a national volunteer group and sometimes they felt this did not give the most inclusive impression.

The findings are presented from both the views of activity planners and volunteers.

Table 15: Views of Activity Planners and Volunteers

	Facilitators	Challenges
	Activity Planners	
How the activity was advertised and any pre-conceived influences Social Media Word of Mouth Leaflets/ tasters	*“Social media, I think that’s the way it works here”* (Activity Planner of religious activities). *“Most people look at the website I guess or come and talk to us”* (Activity Planner of religious activities) *“One of my parents said to me that her friend had gone on ‘Facebook’ and said does anyone know of a good swimming school and she said my name came up about 10 times”* (Activity Planner of sports activities – swimming). *“Parents seem to know each other”* (Activity Planner of religious activities) *“Most come via word of mouth and have for the last 12 years”* (Activity Planner of sports activities – swimming).	The internet, either through websites or social media, was discussed by five activity planners (religious and sports activities). *“Social media, it also works negatively too as they can say I had a bad experience here so they say don’t go”* (Activity Planner of religious activities). *“I have put a couple of adverts in a local kids magazine … quite expensive … it goes directly into children’s bags to go home.. response was very very small”* (Activity Planner of sports activities – swimming). Aside from the internet and word of mouth at schools there were other forms of recruitment and information through telephone calls or referrals from healthcare. However one Activity Planner was very clear that he felt this was an area for improvement: *“Parents don’t know what’s out there. There is no network which says this is what we do and this is where we are doing it … please attend.”* (Activity Planner of Sports – multi-sports).
	Volunteers	
	“We have a website and there are posters up round the town” (Volunteer in sports activities – Football). *“We tend to get a lot of people interested through our website”* (Volunteer in sports activities - cricket coach). Word of mouth was cited to be popular across the activities (n=6): *“Word of mouth, and the numbers are sustained”* (Volunteer in sports activities – football coach).	Social media was discussed *“If a parent read about our activity should we saying we are accessible, but I don’t know. Perhaps we should say on our website, I don’t know”* (Volunteer in religious activities).

	“We are so well known they find us” (Volunteer in youth activities). *“Leaflets through schools”* (Volunteer in sports activities – Football) *“There is leafleting in the local schools and we have a big push at holiday club where it is very busy”* (Volunteer in religious activities) *“We do have some coaches that go to school and do taster sessions, with leaflets to encourage them to come”* (Volunteer in sports activities – Rugby).	

	Activity Planners	
First Impressions and Welcome	*“It is all about teaching the individual and that really is our ethos”* (Activity Planner of sports activities – swimming).	*“We have a parents information pack to go to all children but actually there is probably nothing on disability. We ask for additional needs etc but we don’t make much of saying we would welcome anyone”* (Activity Planners of youth religious activities).
	Volunteers	
	“I think I would say, yes no problem, yes he would be welcome” (Volunteer in youth activities).	Youth volunteers felt concerned about how their activity was perceived which were things out of their direct control as are set from a more central place or are a historical societal view: *“I think it’s the perception of what we are about”* (Volunteer in youth activities). *“The YouTube advert of scouting portrays a very physical side”* (Volunteer in youth activities).

There are clearly defined challenges to information, advertising and networking and the specific issues between the service users and service providers need to be explored in the next chapter. There are key elements that should be disseminated to stakeholders and service providers to promote improvement in this area.

5.4.3 Facilitator and Challenge - Parent Partnerships and School Links

A major theme which emerged from the service provider data is that all of the service providers wanted and needed a good relationship with the parents. When the relationship is positive, and service providers see parents as supportive and helpful, then they act as a facilitator for participation.

Twelve service providers (including both activity planners and volunteers) highlighted the importance of the parent partnership saying they rely on them for information, help and feedback. They would use them as information providers, teachers, helpers and health providers. This could be a positive or negative relationship, for example, a service provider who welcomes a discussion about every child's needs or ability works well versus someone who assumes the parents of PDC&YP have to stay to look after their child.

"I think part of it is working closely with the parents as, at times, we can be out of our depth" (Volunteer in youth activities).

"We are trying to work in partnership with parents" (Activity Planner of youth religious activities).

"You always need the parents with them, … what we don't do is to actually disadvantage the learning to everybody else" (Activity Planner of youth activities).

"Parents need to be present at all times because otherwise our leaders are not specifically trained to meet all sorts of different disability conditions" (Activity Planner of youth activities).

Many of the service providers expected a PDC&YP's parent to stay to provide the support for their child as they were best placed to do so. Some providers felt C&YP did not attend mainstream out-of-school activities due to parents being worried that their child would not cope with it or may get hurt. Five people stated that they felt the reasons why some C&YP did not participate was down to the parents. Some providers recognised their role in breaking down this challenge and building trusting relationships and they state clearly that a partnership is key.

"It's breaking down the trust challenge in a way so the parents are not scared of them getting hurt" (Activity Planner of sports activities - rugby).

"I think a lot of it is parents not having an open mind to it as well. Can you accommodate my child, well yes of course we can but we have to change things" (Volunteer in youth activities).

"I think it's the parents probably, they look at us as a physical activity and perhaps as our group we should be promoting something to bring them in" (Volunteer in youth activities).

Whilst links with schools were deemed as important as well, providers felt that the relationship could be strengthened in this area. The activity clubs which had the strongest relationships with local mainstream and special schools had the most PDC&YP attending their clubs. There are PDC&YP in mainstream schools who do not get to play in their school team as they are not good enough but they love the sport/activity. Service providers do not know where these children are and cannot ask schools specifically to target them but they are missing out because they are hidden. With the right support they could play this sport/activity in a community team.

"These kids will never ever get to play for their school team as they may just not be good enough ….. but they love to play but we don't know where they are" (Activity Planner of sports activities – rugby).

Support for service providers particular came from special schools. The sports clubs had a closer relationship with special schools in Cheshire due to previous networking led by the schools. But were less able to identify PDC&YP in mainstream school and they felt these children were hidden and hard for them to reach. Youth and religious groups had better relationships with mainstream schools and religious groups regularly accessed all the mainstream schools in the area. From the discussion about schools, it was highlighted that a co-ordinator was essential.

Activity planners recognised the role of a special educational needs co-ordinator (SENCO) within schools and how they may be able to refer children to activities. One planner expressed concerns about being able to communicate effectively with the SENCO network and they felt this was a challenge that needed to be addressed to move forward in order to support PDC&YP. Not linking with a SENCO network is a wasted opportunity but their already large remit within schools has to be acknowledged. As well as having a co-ordinator, schools can positively promote out-of-school activities to all of their pupils to ensure all local children find out what is available. Some providers discussed their past reliance on co-ordinators from the local authority or sports development which had broken down due to these posts being lost, therefore leaving groups without anyone to go to recruit children.

"The key person is the sports co-ordinator at this special school without her this wouldn't happen" (Volunteer in sports activity – squash).

"The sports co-ordinator in the area puts you in touch with the special schools and now that post has gone with the new government changes" (Volunteer in sports activities – squash).

"We struggle to communicate with the SENCO network" (Activity Planner of sports activities – rugby).

5.4.4 Challenge - Access Issues

All of the service providers discussed accessibility as a challenge with physical access, timing and finance as examples.

Service providers planning and running activities in newer buildings will be able to provide good physical access as they have been recently built under the newer legislation (The Equality Act, 2010). One rugby club and all of the church groups had accessible buildings and they reported that they had no physical access issues. However, those in older buildings (youth clubs) reported issues as they require adaptations. Youth clubs in Cheshire were all run by charities and therefore did not have funds for new buildings. Some had lottery money for some adaptations but certainly not to the same extent as some of the sport and church groups.

"We don't have wheelchair access going from the front... I was going to say we have it from round the side but I think even that's up a step... But you are being deemed to be different because you have to go round the back so that doesn't help either" (Activity Planners of youth activities).

"It's not as accessible as it should be" (Volunteer in youth activities).

Two activity planners recognised that transport was an issue as they had experience of some PDC&YP not being able to access activities due to not being able to get there. They reported having children who wanted to attend their afterschool sports event but the PDC&YP had to get their pre-arranged taxi straight after school and this could not be changed one night a week for the club.

"Another reason disabled kids can't access after-school club was because of transport, the taxis just won't do it. They are booked to do that one specific job so they miss out because of stuff like that" (Activity Planner of sports activities – multi-sports).

There was an access challenge specific to swimming conditions, where a swimming teacher discussed the issue around water temperature and how this could be an access challenge for many PDC&YP. This swimming activity planner who ran paid lessons recognised the difficulties with the pool temperature. This is due to conflict between the needs of PDC&YP and very young children/babies who do not like the cold water versus the needs of the competitive swimmers in swim clubs who cannot have the water too warm. There is not an obvious solution and when I have discussed this with swimming service providers at a sport conference they suggested having separate pools as water temperature cannot be frequently changed between classes/events, for example, have a leisure pool and a race pool. There may be some opportunity in some areas, for example, within the cities, but this is not practical or financially viable for smaller towns.

"Temperature of the pool is a big problem for example, for people with cerebral palsy. Warm is great for younger children and it's great for children with special needs. But it is too warm when children are physically working out" (Activity Planner of sports activities – swimming).

5.4.5 Challenge - Personal Care

Personal care was discussed in relation to toileting and changing needs when at an out-of-school activity. No service providers had experience of directly providing personal care but half of the service providers (n=16) did discuss this hypothetically. A number of volunteers (male and female) were willing to support personal care needs but they raised a number of concerns which included staffing levels, toilet accessibility and safeguarding issues. Service providers felt that they would need extra staff/help to take children to the toilet so that they maintained a safe ratio of adults to children for the activity. They stated that they would need to rely on the PDC&YP's parent to do this. There was one activity planner who was very positive and proactive towards personal care but, interestingly, he had worked in a special school previously so had professional experience. Therefore this could not be generalised to the other service providers:

"I don't mind taking on the personal care role as long as they can participate in the sport" (Activity Planner of sports activities – multi-sports).

"We would ask the parent to stay, around toilet issues. We honestly need to stay with the children who are playing so it affects the ratio if one of us needed to go to the bathroom" (Volunteer in sports activities – cricket).

The physical access to the **toilets** was an issue for some activity planners as the toilets were not next to where children did the activity. The implications of this are that children cannot be supported without a parent or PA as the staff need to stay with the other children in the group. In practice many send children in pairs or they would need an adult or buddy to assist them. In addition the youth providers stated they had no accessible/disabled toilets available which has an impact on personal care.

"The toilets are up on the first floor. It lengthens the toilet trip for them and that's the only downside of my venue at the moment" (Activity Planner of sports activities – multi-sports).

"The kids take themselves to the toilet as the indoor pitch is right next to it so you can see" (Volunteer in sports activities – football).

Most of the service providers who discussed personal care verbalised concerns about appropriateness and safeguarding issues. They stated concerns around taking a child to the toilet and being worried about possible allegations. Gender was an additional issue specifically discussed by male service providers and was seen a challenge when supporting female C&YP. Some parents were happy for the males to carry out personal care but the service providers themselves did not feel comfortable. They stated that they wanted to bring in other help and have female leaders around.

"It is a big deal to ask a man to go and wipe their daughter's bottom. Mum was happy but that would be my career on the line if an accusation was made" (Activity Planner of religious activities).

"We are a community of amateurs, it is not like a hospital or a school where everyone is highly trained" (Activity Planner of religious activities).

"You have a lot of people who are scared of the safeguarding side of it and we need to break down that challenge …. it's because of the fear factor" (Activity Planner of sports activities – multi-sports).

5.5 Theme Four – Reflection and Request for Training

Service providers reflected on their experiences and overwhelmingly requested disability awareness training. The service providers all appeared to lack disability awareness and many stated that this was the case. Three of the volunteers and two activity planners had had specific disability training (See tables in section 5.1). They were from a sports background and their coaching course included some basic disability awareness. Across the rest of the service providers none of them had sought disability awareness training but stated that following the interviews they were going to look into this. All youth and religious volunteers stated that they would need to go to activity planners for guidance but the latter reported a lack of training and confidence. Many wanted to discuss possible provision and had a willingness to increase their awareness.

"Disability can mean … oooh in my old work definition … my definition is people who are diabetic, I have forgotten" (Activity Planner of youth activities).

"If you've never worked with children and disabilities before then you might be unsure what to do. They might find it quite intimidating and quite scary" (Volunteer in sports activities – cricket).

“I have never really known a disabled person and never had that interaction with someone to really experience anything like that so it would all be new to me” (Volunteer in youth activities).

There was concern with some service providers that if they advertised that they had attended disability training that it may open the flood gates and their groups be full of disabled children. This demonstrated a lack of insight into what disability included, children in their community and expectations of any group:

“A lot of mainstream clubs are run by volunteers and a lot of them can still think that disability means wheelchairs” (Activity Planner of sports activities - rugby).

“People think that if they become an inclusive club they will suddenly get 10 kids in wheelchairs, 9 blind kids, and 6 kids with learning needs all in the same club and that’s not the case” (Activity Planner of sports activities - rugby).

Many of the activity planners accessed training around their role but disability was not included, which they were surprised about. Any activity planners who had accessed disability awareness training had done so through alternative means, for example, working in a special school. One of the providers offered disability training for clubs as part of his paid activities. Some activity planners recognised that there may be training available but they felt that they would find it if and when it was needed. In terms of youth and religious groups there was no evidence of disability training and they felt they would need to go to the activity planners to find out what may be needed to support a PDC&YP:

“The FA are quite strict on coaching and even mainstream youth clubs … then you do the one day disability” (Volunteer in sports activities – football).

“It does include training cards. We have illustrations about children in wheelchairs and things like that to conduct our session” (Volunteer in sports activities – cricket).

“No, we do some child protection but not disability” (Activity Planner of religious activities).

“If I look at the fantastically wide training available, I don’t think there is a single bit in there that covers this sort of field” (Activity Planner of youth activities).

Following this lack of training, it was clear that many of the volunteers wanted to increase their knowledge and confidence of the needs of disabled children. Many of the service providers (activity planners and volunteers) asked for information about disability training:

> *"I would want training on specific disabilities as I wouldn't know what to do and how they react. I think there are additional courses?"* (Volunteer in sports activities – football).

5.6 Discussion

The aim of the service provider study was to explore the current provision of mainstream out-of-school activities available to PDC&YP within Cheshire as it is not clear whether mainstream provision attracts, or is suitable for, PDC&YP. All the service providers recognised the benefits of children being able to make friends and join in. Being included in out-of-school activities was essential for the development of independence and had mental, emotional and physical benefits and they recognised this would be the case for PDC&YP as well.

Sports provision in this study shows a greater uptake of PDC&YP than youth or religious activities in the service providers view point but this needs to be compared to the service user findings within Cheshire. There was a lack of disability training across both groups especially in youth and religious groups. This is important to understand for service providers and policy planners to plan and evaluate activities in their area and to enhance training in the areas lacking inclusive practice. It has been previously stated that service providers felt that inclusive practice is more likely in after-school clubs/play schemes than activities provided by leisure and sports centres (Beresford and Clarke, 2010) however this was not the case in the current study. This may be due to sports providers having had more disability training and PDC&YP wanting more sports activities. There is a paucity of literature around religious activity provision and PDC&YP's out-of-school lives with only Langer (2010) reporting disabled short breaks provided by the church whereas training needs have been previously identified for youth activities (Beresford and Clarke, 2010 and Brokenbow et al, 2016). The training available in Cheshire needs to focus on youth and religious groups as a matter of urgency. This has been fed back to the disability training providers in Cheshire so that they can advertise across all youth and religious settings. Most of the service providers were aware of their responsibility of needing to make reasonable adjustments to their activity for an inclusive experience and had a willingness to welcome PDC&YP if approached but they were not proactive in promoting whether their activity is inclusive.

Independence was an important factor which influenced participation in activities. It was recognised particularly by youth volunteers who wanted to encourage independence in young people. They promoted the need for PDC&YP to socialise without a parent, which enhanced their independence. This was previously found by Carter et al. (2014) who looked at experiences of a UK wheelchair sports club. One of their stakeholders interviewed raised the point that the activity promoted skills to work together in a team as the child was not the only one in a wheelchair and it gave them an opportunity to make friends. Implications from this are to encourage activities to facilitate and support PDC&YP to attend with either a buddy or to train members of their own team to allow PDC&YP to come without their parents and be more independent. Encouraging independence is essential when promoting activities as this is such a key driver for the young people themselves (The Bevan Foundation, 2010).

Communication was a theme that crossed over facilitators and challenges to participate in out-of-school activities. Depending how effective communication was really determined how successful the participation was. Communication is key to all interaction especially through the marketing of out-of-school activities (Knight et al., 2009; Brokenbrow et al., 2016). Communication mainly focused on the need to advertise clubs effectively. Service provider felt that social media, leafleting in schools and word of mouth was the most effective method of encouraging C&YP to their activity. Although they recognised that some of their marketing material may not encourage someone with physical difficulties (Knight et al.,2009; Sloper at al., 2009), for example, a non-disabled person abseiling on the website. The methods of communication need to align to service users communication styles. Some word of mouth is done through schools to promote activities and C&YP may hear from their peers about activities within the community. Word of mouth is not without limitations as the families who are not able to meet with others regularly, and the C&YP who go to school out of area may not benefit from this.

The initial verbal and non-verbal communication used between a parent and service provider on first contact with a group plays a key part in establishing that relationship and has the potential to promote an open and inclusive organisation. Without a positive start PDC&YP will not return (Speraw, 2006; Jacober, 2010; Carter et al., 2016). Service providers need to appreciate and plan for differences and abilities, which need to feature in their communication (Beresford and Clarke, 2010; The Bevan Foundation, 2010). Service providers who used positive communication acted as a facilitator to making an activity inclusive, as they liaised with PDC&YP and parents to assess what was needed and made necessary adjustments, for example, a cricket coach who discussed with a family what would help a child be able to play and he brought in some equipment to help a young player. This planning promoted inclusion.

Many service providers wanted parents to help guide them to know what children's needs were and often wanted parents to stay. Notably issues of resources and staffing levels did not dominate the discussion as it has done in previous research (Beresford and Clarke, 2010). Beresford and Clarke (2010) were the only study to specifically question service providers about the lack of support but they cited a lack of sufficient staff. However the service providers (particularly activity planners) in this study defaulted to want parents to attend to accompany their child rather than wanting extra staff even though they also stated they like to promote independence. This 'default' position was particularly clear for PDC&YP who needed personal care support. This stance was most evident in youth and religious activities and access to mainstream leisure opportunities was very much dependent on a parent attending (Knight et al., 2009). This highlighted a mismatch with service provision as they wanted to give opportunities for C&YP to be independent but this did not extend in practice for all PDC&YP as there was a natural assumption that parents would stay to provide any one-to-one support. There was one provider who did act like a 'bridge' between families and services and this was well received by families. Having this 'bridge' or co-ordinator is a very positive facilitator into activities (Knight et al., 2009). This helped build a network around the PDC&YP. Parental influence has been previously cited (Knight et al., 2009; Sloper et al., 2009; Langer et al., 2010; The Bevan Foundation, 2010; Kolehmainen et al., 2015). The family can be the positive influence by being an advocate and promoting independence (Lawlor et al., 2006).

The relationship between service providers and schools directly influenced the number of PDC&YP in their activity, for example, a number of sports clubs had built relationships with local special schools meaning children from those schools attending the club such as football and squash. Youth and religious groups had better relationships with mainstream schools and religious groups regularly accessed all the mainstream schools in the area. However, there was no relationship between the local youth and religious activities with local special schools in the area. This is not to say that this is reflected wider than the study as it was very much driven by the individuals and connections they had. Religious group volunteers and providers, however, wanted better relationships with the local special schools. When these relationships were good then participation in mainstream activities was optimum. In terms of youth groups many had waiting lists so they did not need to canvas or be proactive. It is unknown whether PDC&YP were on any waiting lists as they usually just comprise of an age and date of birth.

There was evidence of a couple of sports staff, with an interest in disability, who aided the take up of PDC&YP in Cheshire. Disability sport officers had a critical role in helping to set up groups and ensured they ran effectively as well as helping mainstream groups to be fully inclusive (The Bevan Foundation, 2010). During the time of the study there were very few sports officers and I was able to identify only one disability sports office within Cheshire working with the families. As an alternative the service providers in The Bevan Foundation’s (2010) fair play study in Wales stated that the key providers of information were physiotherapists. Health care professionals such as physiotherapists and occupational therapists can bridge the gap for some information and provide the link to health but a co-ordination between health, social activities and education needs to be explored further.

Many service providers have historically discussed access as a challenge and disappointingly this is still an issue (Lawlor et ., 2006; Petrie et al., 2007/Knight et al., 2009; Sloper et al., 2009; Bennett, 2010; The Bevan Foundation, 2010). Youth leaders had the greatest concern in the area as they had the oldest facilities and their buildings were supported by charity money or local people taking care of them therefore not adapted in many cases. There was not a quick or easy fix with this; however some leaders did discuss having all the children use the ‘alternative’ entrance so that one child did not feel singled out. Service providers from sports environments raised transport as an issue as they were frustrated by this as they saw PDC&YP not able to attend due to having to catch their taxi straight after school. Similarly, Bennett (2009) had previously found that half of the families expressed dissatisfaction with mainstream play and leisure facilities due to lack of accessibility and travel issues

There were no service providers that carried out any personal care support within their activities, either because a parent was present to provide this or they had no

C&YP requiring this specific support. There is no specific literature about PDC&YP's personal care support in community activities. The only similar findings were in relation to manual handling rather than specific personal care (Hodge and Runswick-Cole, 2013; Disabled Children's Partnership, 2018). This researcher highlighted a concern by a youth volunteer in their North of England qualitative study where a young woman who needed 'lifting' to assist her to go to use the toilet. The solution has been, and remains to be, that parents are expected to stay to care for their child and take them to the toilet themselves which does not promote independence for the young person and is unlikely to be what they want. Service providers need to have adequate training or the activity group needs to get in touch with a local independent living centre to explore if there is any support. Service planners, policy makers and providers need to be aware of these issues and develop robust policies such as supporting personal care, lone worker policies and disability support. This is to ensure support for the young person as well as safeguarding the providers and the volunteers providing care. This would aim to reduce the challenge of the safeguarding concerns and, with the local training providers being able to train staff, this could be improved for both service users and providers. There also needs to be an understanding of exactly what a child may need before there is an immediate closed door on the matter.

Most of the service providers expressed the need for disability awareness training, such as getting to know different disabilities and support needs. They wanted to know what the expectations are, what they should be providing as well as tips to make their club more inclusive and accessible. The need for training was evident but not unexpected. There was a lack of evidence of training amongst both the activity providers and volunteers with only 16% accessing overall. Those who were accessing training had greater numbers of PDC&YP in their activity.

Within Cheshire there is some free disability awareness training sessions available but many clubs were not aware of this. It is, therefore, unclear if this alone would be successful in enhancing provision and due to a potential high turnover of volunteers an ongoing training programme is essential but onerous for the training provider. The volunteers relied on activity planners for guidance or training, but in reality, the planners did not have experience or training in disability either. Training therefore would be required at every level and would need to be built into core mandatory training which adults working with C&YP need to complete such as 'safeguarding' in order to ensure staff compliance as it is would be difficult to add more hours to a volunteer beyond their current commitments. There are multiple on-line safeguarding training packages available and used in many local authorities and charities, something similar developed for disability awareness could work as a baseline tool.

As well as the general disability awareness training discussed above, when a child is participating, then the providers need specific training on the support that the individual PDC&YP needs. As well as having a good partnership approach with parents there is an opportunity to link with healthcare professionals and perhaps the school where appropriate. For example, a child who has diabetes type one requiring require regular blood testing, food monitoring and insulin injections/infusion and would require links to a local community nursing team to have training for the volunteers running the activities. This ensures the child can attend without a parent and promotes independence but also ensures a safe environment for the child. Any provider doing a risk assessment for any activity should build this in as part of the risk assessment. Reducing the risk by not including PDC&YP is not an acceptable solution.

Many children with disabilities or health issues will have a professional team around the family which includes schooling and healthcare (Section 17 of the Children Act, 2004: Department of Health, 2018). This team should be there to provide support, and at times a point of access, to assist the family to co-ordinate professional services. The social needs of PDC&YP needs to be incorporated under this umbrella within their remit.

Having policies and training in place is no guarantee of inclusion and although activities may state they are inclusive, unless the infrastructure supports this fully then inclusivity will not be evident (Knight et al.,2009; Sloper et al.,2009; Beresford and Clarke, 2010; The Bevan Foundation, 2010). Bennett (2009) stated that everyone in a public facing role in the UK should have disability equality training, with a priority of health care staff and those working in leisure facilities. It is unclear how many volunteers are currently trained, as there is no national database, but is a significant area of concern from my research, thus training is an essential area for improvement. The service providers interviewed by Beresford and Clarke (2010) identified an urgent need for training to raise disability awareness but they recognised a lack of suitable funding. This could potentially be overcome in Cheshire as the training provided is free to service providers, paid for by a disability charity. Inclusion needs to be monitored in order to make improvements and measure the impact of training (The Bevan Foundation, 2010).

5.7 Conclusion

The purpose of this multi-method qualitative study was to explore factors affecting participating in out-of-school activities from the perspective of both the service user and service provider in Cheshire.

- Sports provision had the most PDC&YP participating in mainstream out-of-school activities.
- Youth and religious service providers reported no PDC&YP in their direct groups apart from one specialist disabled group for young adults at a church.
- Facilitators in this study are factors which help PDC&YP join in out-of-school activities, which included health benefits, communication and positive networks with schools and parents.
- The main factors that positively influenced C&YP to join in out-of-school activities were the promotion of independence and biopsychosocial benefits. It was also clear that there were benefits for the service providers and other C&YP in their group from promoting inclusion.
- Service providers felt positive relationships with parents and schools facilitated participation into mainstream out-of-school activities. When providers, schools and parents worked together and communicated well this made for a positive environment to support a PDC&YP.
- Challenges to participation are factors which stopped the PDC&YP accessing an activity or affected their attendance, which included mainstream service providers lacking disability awareness, access issues and a lack of personal care support.
- Both activity planners and volunteers recognised inclusive practice and had the intention of making changes to their practice should a PDC&YP approach their group but the volunteers stated they would need to go to the planners to do this on most occasions.
- There was a clear need for training identified from both activity planners and volunteers, many of whom suggested it themselves. They felt that they would welcome training but often did not know where and how to access any suitable disability awareness training. Many of the service providers asked about training and reflected on their practice as wanting to make changes.
- The training available in Cheshire needs to focus on youth and religious groups as a matter of urgency and this has been communicated to training providers so that they can advertise across all youth and religious settings.

CHAPTER SIX: SYNTHESIS OF STUDY 1 SERVICE USERS AND STUDY 2: SERVICE PROVIDERS

6.0 Introduction

The aim of this study was to explore the factors affecting participation of PDC&YP in out-of-school activities from the viewpoints of PDC&YP, parents and service providers who plan and run mainstream out-of-school activities. The previous two chapters have provided the findings from these four viewpoints in two separate studies. I will outline the process of synthesising the two studies during the analysis. Similarities and differences will be discussed in relation to the literature and existing theories in order to set the findings in a wider context. I will summarise the findings based on the study objectives. Based on these findings, suggestions for policy, practice, and future research will be presented. The lessons learnt along with limitations, recommendations, ideas for future research and reflections on the study as a whole will also be discussed.

6.1 Synthesis of the Two Studies

Thematic qualitative analysis based on the stages set out by Burnard et al. (1991, 2008) was adopted for both studies. Both studies were analysed immediately after the completion of the fieldwork (section 3.5).

To promote credibility and trustworthiness of the analysis triangulation was employed to enhance validity during the synthesis stage of data analysis (Morse, 2015: Santiago-Delefosse et al., 2016). Triangulation uses “multiple methods, sources, theories, and/or investigators” (Farmer et al, 2006:377). I employed two types of triangulation; methodological triangulation where results were gathered from multiple qualitative data collection techniques and also data triangulation involving multiple participant groups including service users versus service providers (Farmer et al., 2006; Twinning et al., 2016). Although there is a difference between these units of analysis, the decision to employ multiple triangulation techniques complemented the generic qualitative approach by using the flexible qualitative multi-method (Meijer, Verloop, and Beijaard, 2002). It was also successful in exploring all the perspectives of PDC&YP’s out-of-school lives.

To synthesise the findings from the two individual studies, Farmer et al's (2006) qualitative triangulation protocol was followed. Farmer et al., (2006) developed this protocol with qualitative child cases and is therefore, directly applicable to this study. Using this process promotes methodological integrity by recognising the underpinnings of method triangulation, for example, convergence (Lambert and Loiselle, 2008). All five steps of the original protocol were employed to promote a robust approach to merging the two studies. This process is outlined in Table 16:

Table 16: The Triangulation Process (Farmer et al., 2006:383) with the Action and Themes from this study

Step	Action
Sorting	The findings from study one and study two were reviewed to ascertain any overlap between service users and service providers to address the research questions to include: • Provision • Preferences • Facilitators • Challenges • Suggestions
Convergence Coding	The findings of both studies were compared to determine the dominant themes and to discover the similarities and differences between service users and service providers. This included coding in relation to Farmer et al's (2006) convergence codes: <u>Agreement / partial agreement</u>: This outlines the overlap of themes and how much agreement there was between the service users and service providers. <u>Silence</u>: This code identified themes only pertinent to one set of participants. <u>Dissonance</u>: This code identified any disagreement between the sets of results. Table 17 portrays the level of convergence across the two studies

	using these codes.
Convergence Assessment	A global view and overall description of the themes to establish agreement and practical application was devised and is presented in the data triangulation matrix (see Figure 11).
Completeness Assessment	All the findings were compared and unique topic areas were highlighted which emerged as the sub-findings. This revealed areas for future research (section 6.7).
Researcher Comparison	The themes were discussed with my supervisor LP to reduce bias and promote researcher triangulation.
Feedback	Key findings were fed back to stakeholders and gatekeepers to share more widely. This was important to ensure dissemination was provided to those making decisions and planning out-of-school activities. Informant/member checking was not carried out as participants did not contribute to the analysis once the study results had been synthesised (Thomas, 2017; Brett and McGannon, 2018) (See Table 3).

Table 17: Data Triangulation Matrix

This table presents the main themes which emerged referencing the level of convergence across the two studies.

Main Themes	Presence in Studies		**Themes which have emerged and Findings**	**Convergence Coding**
	*1	*2		
Preferences	*		Feeling Different. PDC&YP and parents want some mainstream activities but need disability support. PDC&YP want 'specialist' activities to meet others 'like them' not just 'disabled' groups. Sport is the preferred activity for PDC&YP.	**Silence** Only discussed in Study one due to the nature of the research question.
Provision	*	*	Mainstream activities lack inclusion. Sports has most PDC&YP involved with highest number of disability trained staff. No PDC&YP accessing religious out-of-school activities.	**Partial Agreement**
Facilitators	*	*	Benefits - Drive for Independence and Health Benefits.	**Partial Agreement**
	*		Showcasing Disability – Positive Influences.	**Silence**
	*	*	Communication	**Agreement**
		*	Networks.	**Silence**
Challenges	*	*	Mainstream service providers lack disability awareness	**Agreement**
	*	*	Communication	**Agreement**
	*	*	Physical Access	**Agreement**
	*	*	Personal Care.	**Dissonance.** Although both studies discussed, no PDC&YP had personal care support and no service providers provided this.
Suggestions	*	*	Training	**Agreement**
	*	*	Advocate/Co-ordinator	**Agreement**

*1 – Study 1 – Service Users (PDC&YP and parents). *2 – Study 2 – Service Providers (Activity Providers and Volunteers). Presence in Study.

6.2 Synthesised Results

Through the triangulation convergence assessment, 11 emergent themes were identified. Communication was both a facilitator and challenge.

Figure 11: An Overview of Convergence Assessment identifying the Themes which emerged

Themes Emerging from the Synthesis	
Agreement	• Co-ordinator • Communication • Mainstream service providers lack disability awareness • Physical Access • Training
Partial Agreement	• Provision • Benefits - Drive for Independence and Health Benefits
Silence	• Preferences (Study 1) • Showcasing Disability – Positive Influences (Study 1) • Networks (Study 2)
Dissonance	• Personal Care

The majority of the themes which emerged showed agreement or partial agreement indicating these were pertinent in relation to PDC&YP's out-of-school lives from the perspective of both service users and service providers. Four sub-themes showed agreement across service users and service providers demonstrating important implications for practice and provision. With both groups agreeing on the need for a co-ordination role this, in turn, could have a positive influence in identifying areas requiring disability awareness. Joining activity planners and volunteers up with training providers promotes collaborative working with an aim to growing inclusive provision within the community. Physical access continues to be a problem despite legislation. Methods of communication differ between participants but communication is key to making participation in out-of-school activities successful no matter what the needs of the child are. Three themes had partial agreement and this prompted debate around the mixed provision available. Three themes were only evident in one of the studies. With equal importance there were themes affecting only one of the studies and of course the novel finding identified on the overall lack of provision of personal care for PDC&YP.

In the following sections the interpretation of the five main themes (provision, preferences, facilitators, challenges and suggestions) are discussed in relation to relevant literature:

6.2.1 Provision

Provision refers to the out-of-school activities available to school-aged PDC&YP in Cheshire. Findings from the two combined studies showed a partial convergence agreement between service users and providers. The studies illustrated PDC&YP accessed a range of activities and in Cheshire, activities provided were either mainstream activity 'open to all, ` disabled groups or specialist activities, for example, condition specific or wheelchair sports. PDC&YP wanted to attend local mainstream clubs especially youth and sports activities to be with peers from school. They needed support to do this as many of these clubs were not set up to easily accommodate PDC&YP. There was evidence of mainstream activities lacking inclusion but with pockets of good practice particularly in the sports arena. PDC&YP sometimes stopped participating in some mainstream activities due to a lack of support, lack of service provider awareness and difficulty with physical access, which was echoed by service providers. Provision that is not appropriate for PDC&YP needs to be adapted by working with PDC&YP and gatekeepers to find out how it can be made more inclusive (Knight et al., 2009; Carter et al., 2014; Brokenbow et al., 2016).

In addition, many PDC&YP attended 'specialist' disabled provision with others 'like them' but this was often provided outside of Cheshire meaning additional travel. Langer et al. (2010) highlighted that disabled C&YP wanted to find friends 'like them' and although this was on short break provision, it demonstrated that specialist provision with the right people in place to support, does work. The Bevan Foundation (2010) agreed as disabled C&YP felt more comfortable with others like themselves and felt that the adult leaders were very patient. Both of these scenarios required large input and commitment from parents to drive to it or to provide the support in mainstream. Without this parental support participation was difficult. Many parents accompany their child as they want to give them the opportunity to reach their full potential (Bennett, 2009).
To reduce the need to travel to specialist provision outside of Cheshire more of these out-of-school clubs are required locally (Knight et al., 2009; Carter et al., 2014; Brokenbow et al., 2016). There appears to be small numbers of PDC&YP accessing these so it would be difficult to convince local stakeholders to put on new specialist provision. There is clear evidence of PDC&YP in Cheshire not being able to currently attend these specialist opportunities as their parents cannot take them, the time they run is not accessible for some and some PDC&YP do not know they exist.

If there was similar local provision that was well advertised the uptake may be greater. Alternatively if there was an opportunity to rotate the clubs around areas this may assist participation. Practically, however this may be difficult for some activities due to the local governance structures within Cheshire. Provision in the county varied due to having two local authorities leading to differences in availability of out-of-school activities. However in the case of many specialist groups they are driven by the sports association they are connected with and have fewer boundaries when trying to meet the needs of their participants. The issue they have is locating the PDC&YP, as many gatekeepers reported.

Most of the service providers in the study understood their responsibility to legally make reasonable adjustments for inclusivity but many felt that they were not outwardly proactive. Although PDC&YP and their families accessed a range of activities across sports and youth activities within Cheshire very few mainstream service providers had any PDC&YP within their groups with even less in religious groups. Beresford and Clarke (2010) reported in their UK study researching positive and inclusive activities that inclusive practice is more likely in after-school clubs than sports centres which differed from the findings in my study. It is not clear whether this is due to sport providers increasing their disability awareness or just differences in research sample.

PDC&YP and parents reported limited opportunities within art and drama with none of them reporting accessing any specific groups. During the study the only art clubs advertised were for adults during the day when PDC&YP would be at school. Similarly there were no service providers from an art or drama activity represented due to none being located when the research was being conducted. Since the study fieldwork, several mainstream dance and drama groups have populated the area but there is no information on their websites or social media about meeting the needs of disabled C&YP. They run with a high weekly cost which is a potential challenge for all children but the inclusivity and accessibility is an issue for PDC&YP specifically (see section 6.2.4).

6.2.2 Preferences

The preferences on what PDC&YP wanted to participate in out-of-school were ascertained from the PDC&YP and parents in study one. During synthesis this has a convergence code of silence as the service providers were not able or required to answer this research question. This theme was characterised by the idea that every PDC&YP had different needs and the type of activities that they wanted to participate in were different. This is discussed in full in section 4.7.

Many PDC&YP felt ‘too disabled’ for mainstream but the ‘wrong’ type of disabled for disabled groups. PDC&YP reported feeling different in the ‘disabled’ groups and felt they did not fit in as there were no other PDC&YP as the groups mainly catered for C&YP with learning disabilities and parents concurred. This was in addition to feeling like they did not fit into mainstream clubs as they could not take part easily without a parent or facing access issues. As PDC&YP want a mix of well supported mainstream activities this provision needs to be more inclusive to make the local meeting of friends easier. But in addition the specialist provision meets the needs to meet others ‘like them.’

PDC&YP who required help with personal care had the most difficulty accessing activities and were excluded from ‘inclusive’ activities. This is a novel finding as this has not been previously reported and is important because this group is both ‘hidden’ in their community but they are ‘hidden’ in disabled and children’s research. The key messages were that specialist clubs such as wheelchair basketball were the most preferred as it met their needs as well as providing opportunities to meet others, however they often had to travel a great distance to these.

Sport was the most popular activity with PDC&YP and parents with sports providers reported having the highest number of PDC&YP in their groups (11 of the 14 sports service providers). Although there was a good range of sports being offered PDC&YP wanted more specific disability sports in Cheshire such as competitive wheelchair basketball in Cheshire at suitable/sociable times rather than travelling out of area late on a Sunday evening. All of these preferences need to be fed back to the service providers so that they can, where necessary, try to make changes and this may help reduce some of the current gaps in provision.

6.2.3 Overview of themes which emerged which facilitated out-of-school participation

PDC&YP wanted to have some independence and meet/make friends. Service providers wanted this too but there was a mismatch of expectations as they assumed parents would attend to support their child but this did not promote independence. Parents wanted their children to do activities, especially sports, to be healthy and to help their disability, for example, promote physiotherapy. Sports providers wanted to encourage C&YP into their sport for the health benefits as well; this is why they were involved. Effective communication was key to including PDC&YP and this could be enhanced through good partnerships between parents, schools and service providers. Many of these findings reinforced messages from the literature review but novel findings such as positively influencing role models and being inspired by disability events assist understanding of what can enhance facilitate and promote positive out-of-school lives for this under-presented group.

6.2.3.1 Benefits

There was partial agreement between the two studies that potential benefits of PDC&YP participating in out-of-school activities encouraged service users to find activities. The literature is clear that benefits include the need for PDC&YP to socialise, develop new skills and grow in confidence (Beresford and Clarke, 2010; Knight et al., 2009; Sloper et al., 2009; Langer et al., 2010; Parkes et al., 2010; The Bevan Foundation, 2010; Hodge and Runswick, 2013; Carter et al., 2014). Whilst this study demonstrated that PDC&YP wanted to be independent the parents were also motivated by health benefits of participation.

PDC&YP wanted to attend activities independently without their parents but recognised that they needed some support. When PDC&YP attended mainstream activities, many service providers wanted parents to stay, which many PDC&YP accepted but felt this inhibited their independence. Lawlor (2006) echoed the concern that much of a disabled C&YP's participation needed the commitment and support of adults, especially parents. Although the literature review did highlight the need for independence (The Bevan Foundation, 2010) much of this was concerning equipment such as electric wheelchairs enhancing this (Lawlor et al.,2006; Whizz-Kids, 2019) and a parental drive for independence (Oates et al., 2011; King et al., 2010). A positive factor identified in the literature (Knight et al., 2009) to facilitate PDC&YP participating in social activities is the use of a buddy scheme. There was little evidence of this being utilised in Cheshire but I saw evidence through social media of local independent-living disability charities advertising for buddy volunteers with only one young child waiting to be paired who had been waiting a long time (Friends for Leisure, 2019). Therefore, although this appears potentially very positive, in reality the uptake seems limited. Many families in the study had not heard of such a scheme. If there was a confident disability trained buddy in place they could in time train the local service providers how to support the individual. If this was successful the buddy would be able to go on to support another child whilst the service provider continues the support for the PDC&YP.

The service providers wanted parents to stay due to their lack of confidence and lack of disability awareness. They had concerns about what PDC&YP may need and some felt they could not provide support. Unfortunately as many service providers focused on the disability and did not explore the child's abilities demonstrating a deficit rather than asset-based approach. Parents had had previous negative experiences so often expected the next service providers to not understand. This did not help the initial relationship building. Parents and service providers did agree that a partnership approach was needed and that they should both have an open conversation about the needs of any child. This was especially important for a PDC&YP where service providers must include any reasonable adjustments so they are not discriminating (The Equality Act, 2010; Department of Health, 2018). This will be explored further in section 6.2.4.

Parents were driven to find activities for their children as they recognised health benefits such as physiotherapy, building strength and stamina. Sports service providers recognised the benefits in terms of general weight, obesity management and skill development (NICE, 2009). This motivated sports coaches to work with PDC&YP. This has not been reported in the studies included within the literature review but physiotherapy and occupational therapists have witnessed this motivation with some sports coaches to work with children (Beckers et al., 2017). The PDC&YP did not specifically mention these health benefits; they were more interested in sports for competition and making friends. It is important for service providers to advertise and showcase the health and physiotherapy benefits via communication streams that parents tend to prefer, for example, carer forums, websites and word of mouth.

6.2.3.2 Positive Influences

Findings from study one highlighted that PDC&YP benefit from having positive role models and seeing motivating disability sports. This was not recognised by the service providers but could certainly be used by providers to encourage participation through advertising and mentoring opportunities. PDC&YP stated that their role models were other PDC&YP who were perhaps a little older. In addition the most positive role models reported by the PDC&YP were disabled coaches as they were very encouraging and promoted opportunities for them. Parents also wanted their child to be influenced by another child with similar needs who was just a little older than them, to show them what they could achieve or how they cope with certain everyday activities. In light of these findings, there is a need to capacity build disabled athletes to become coaches for PDC&YP. This direct role modelling could increase participation in more general terms as well as out-of-school activities. This is supported when reviewing O'Brien and Lyle's (1987) normalisation model work as although they highlighted that disabled people can face a critical boundary, with potentially nothing much going on in their community lives, through modelling positive interactions with others this can change. In addition, Carter et al., (2014) highlighted the positive impact of learning from one another.

The PDC&YP in this current study were clear that they needed role models to not only learn from but also to inspire them. Some found they could talk to their role models about things they could not talk to their family about which is such a powerful influence. Role models have been evidenced through short break evaluations (Welch et al., 2014) but not specifically in out-of-school activities. These do not directly relate to this study but could be helpful if/when used in other areas of disabled children's lives.

To encourage the use of role models, a recommendation would be to have a mentoring scheme where older PDC&YP could support and welcome younger/newer members of a club. Mentoring can be a positive support as they can advise and provide new opportunities (Welch et al., 2014). Study findings highlighted a small case study as an area of good practice which is presented below as it promoted many of these facilitating elements above:

A specialist wheelchair basketball club, which many of the PDC&YP travelled to, has reported as having positive role models. Their members were young children through to adults and encouraged parents to attend to socialise rather than to provide one-to-one support. It was a specialist club with volunteers who could provide sports coaching but also supervision.

They encouraged social activities to meet friends and the PDC&YP stated that they talked to their friends at this club about things they could not talk to family or school friends about, related to their disability.

This case study has parallels with a successful wheelchair basketball club promoted in Carter et al's (2014) study. Their stakeholders showed how positive it was to have a new network of friends and to not be the only one in a wheelchair.

Mentoring schemes can be rolled out into mainstream activities. Older PDC&YP will be role models for younger PDC&YP therefore could make excellent mentors within mainstream activities as well as disabled groups. If a PDC&YP is the first to attend a mainstream club then an older non-disabled child can buddy them to introduce them to the activities and help them make friends. There is a risk if the PDC&YP's parent is attending that they miss out on having a mentor as parents may be seen to fulfil this role. Specialist groups need to make more of the opportunities of the role models that they have within their group to inspire others through their adverts and social media communication (section 6.2.3).

Disability advocates such as The English Federation of Disability Sport (2013) focus on disabled adults and C&YP and want them to have positive role models but this needs to be rolled out beyond sport. Some PDC&YP did not enjoy sport and although many were inspired by the achievements of disabled athletes in the Paralympics, not everyone will relate to them.

The Paralympics encouraged some PDC&YP to join sports activities as they saw the success of role models (Brittain and Beacom, 2016: Brown et al., 2018). Coates and Vickerman (2016) also found it was inspirational for PDC&YP in their small study investigating perceptions of the Paralympic games. There is, however, criticism about the lack of a legacy from the Olympics (Coates and Vickerman, 2016). There may have been a positive influence at the time but once every four years does not help keep momentum. So, although the Paralympics appeared to be a facilitator to participation in out-of-school lives particularly for PDC&YP and parents there needs to be stronger 'showcasing of disability' through other methods such as the Invictus Games (Brittain, 2016). Having the influence of Prince Harry in these games has demonstrated an initial positive impact on how businesses hire disabled people which then could be used more to influence PDC&YP (Parnell, 2014). Large events are helpful to 'showcase disability' but, for sports coaches, the influence needs to be continued through opportunities within the local community rather than PDC&YP needing to travel to large events.

Service providers did not discuss the Paralympics as a facilitator but the implications for this group across all out-of-school provision is to use the Paralympics positively for all children. Most service providers will look for themes and world events to give them ideas for their curriculum and programme development. The Olympics features in schools, community and activity planning but to raise disability awareness service providers also need to focus on the Paralympics also. This is not only inspiring for PDC&YP but for all children.

6.2.3.3 Communication

All four groups stated the need for positive communication (agreement convergence). Communication is a complex two-way interpersonal interaction and includes verbal and non-verbal communication between individuals, written information and the method an activity is advertised (Stacks and Salwen, 2009). Lambert (2011) offered up the Child Transitional Communication Model (CTC) and referred to a temporary and ever-changing positioning for children within the communication process. Although this model has a healthcare focus it does suggest that staff should be flexible in their interactions and meet individual needs of disabled children. Verbal and non-verbal communication requires continuous assessment and service users and service providers need to reflect on how the interaction works (Lambert, 2011). When communication is not effective it becomes a challenge for PDC&YP to participate in out-of-school activities as it can negatively affect the building of trust both for parents and PDC&YP (Sloper at al., 2009). Some service providers accepted responsibility within the partnership but also indicated some responsibility should lie with parents. Due to the mismatch in expectations between parents and service providers, partnership building is essential. The service providers need to promote positive communication with a welcoming attitude, whilst parents need to be able to outline their child’s needs. Although this partnership approach is required to make any of this work (Shields, 2006; Aslem et al., 2017) the service providers need to be proactive and plan for differences and abilities (Beresford and Clarke, 2010; The Bevan Foundation, 2010).

A positive method of communication for young people and service providers but less so for parents, was the use of social media. Service providers who used social media were aiming communications at young people but unless they were old enough to use ‘Facebook’ they relied on their parents to find out what’s on in their area. This created a challenge in finding out about clubs. This delays effective communication until teenage years and young children need to be able to engage. Parents need to be encouraged to engage in social media but equally service providers need to recognise not all parents want to and need to find alternative methods of communication such as parent/carer forums and word of mouth. Rather than just relying on parents, it is imperative that PDC&YP are involved in choosing activities and they can only do this when they know what is available. They need to be active participants in any communication (Lambert, 2011).

Since the fieldwork was conducted there has been a positive development of a web page in Cheshire East for physically disabled people to find ‘what’s on’ (Cheshire East, 2019). This includes two activities designed for disabled C&YP both of which do not stipulate what types of disabilities but one does specifically state they are unable to provide personal care. This could be a positive improvement as long as parents are clear whether these groups actually cater for the physical disability and they are the ‘right’ disability as it is not clear from the adverts. It still indicates exclusion for PDC&YP who need personal care support.

As highlighted in section 6.2.3.1 parents are drawn to activities to find health benefits and promote independence so if service providers understand this they can use these to promote PDC&YP. I would imagine this would be most helpful for specialist service providers initially until disability awareness is raised in mainstream provision. Role models can also help in advertising for example, when clubs only use non-disabled C&YP on their ‘Facebook’ websites or posters and this does not encourage PDC&YP (see section 6.2.3.1). Improving the amount of information available to families about services was highlighted by Beresford and Clarke (2010) but it has to be done in the most effective way by understanding the preferences of the different members involved.

Finding activities via word of mouth was very effective for parents of PDC&YP as they formed small support networks with each other through carer forums and healthcare appointments. Parents tended to seek out other disabled families in their area which promoted a sense of belonging and engagement (Yamamoto, 2011; McConnell et al., 2015). Word of mouth was mainly positive although could be problematic for service providers to overcome if one family had had a negative experience (Knight et al., 2009; Brokenbrow et al., 2016).

This reinforces the need to have someone as a co-ordinator to be able to assist service providers and work with families to fill this gap and showcase good practice. They could also use a range of communication to meet the varied needs and preferences. This would allow providers to advertise their activities and locate children and what they wanted but also would allow service users to find the right club for them. There should also be a record of which providers had experience and/or training with disability.

6.2.3.4 Networks

Networks refer to partnerships between service users and key stakeholders from the service providers, education and government sectors. Having a positive network is key in facilitating PDC&YP into out-of-school activities (Shields, 2006; Aslem et al., 2017). Although this was a finding which predominately emerged from study two parents did allude to needing such partnership working through positive two-way dynamic communication between them and service and providers. Partnerships were also raised as important by Brokenbrow et al., (2016).

PDC&YP want more specialist activities so stakeholders and local authorities need to liaise with national specialist provision to promote more local networks and events. PDC&YP also want mainstream activities with support to be able to participate, whether that is accessing a building, having a buddy or personal care support. Since the fieldwork there has been another development within one area in Cheshire where PDC&YP and parents can contact a disabled charity to ask for a buddy to attend specifically 'mainstream' activities. They do highlight this can take a while to organise as they need to find the right volunteer to do this. This is very positive and the impact needs to be measured to see how far reaching this is and how successful this is as a child in my study had approached a similar charity but had been waiting a long time which was disappointing (Friends for Leisure, 2019). This charity provides friendship support for disabled C&YP who live in Cheshire East only and links back to the difficulties of having two local authorities in Cheshire. There is a contact number at Cheshire West and Chester to enquire about getting a 'bridging worker' but the details are limited.

Planning for individual needs is vital so stakeholders need to encourage specialist local and mainstream service providers to be prepared to more actively support PDC&YP. However, they can only do this if they are aware of disability and what to do to make reasonable adjustments to proactively be more inclusive. Service providers and service users need to be supported in working together in planning and providing suitable out-of-school provision so that the expectations are more closely aligned and that they can overcome some of the challenges identified. This could be through promoting local youth forum groups enhancing participation in decision making as seen in VIPER (2012), as discussed in section 2.7.

A positive outcome, which emerged from the study was the recognition from both activity planners and volunteers as to how they could promote more inclusive practice. They had the intention of making changes to their practice should a PDC&YP approach their group but the volunteers stated they would need to go to the planners to do this on most occasions. Study findings concur with Brokenbrow et al., (2016) who included a large sample of service providers (professionals) who made a call for more inclusive practice and by getting service providers to reflect on their own attitudes they felt changes can be made.

Positive relationships with schools also facilitated participation into mainstream out-of-school activities. When providers, schools and parents worked together and communicated well this made a healthy environment to support a PDC&YP. The activity clubs which had the strongest relationships with local mainstream and special schools had the most PDC&YP attending their clubs and the SENCO network was a great asset to clubs if they could make an initial connection. There is no specific literature looking at how education, health and social support work together to overcome issues and the SENCO network would be best placed to start.

Each PDC&YP and family has contact with schools, social workers, school nurses, healthcare support and provides a professional team around the family. In many cases this will require someone to co-ordinate support or have regular input (Section 17 of the Children Act, 1989; Department of Health, 2018). Professionals supporting the PDC&YP and family can support and promote skills in self advocacy or parents advocating for the child, which, in turn, may help overcome some of the challenges faced by PDC&YP in the community. By empowering service users to attend community forums or liaise directly with service providers they can potentially influence service provision impacting them (Fumagalli at al., 2015). This is difficult for parents who have faced challenge after challenge in getting their children into activities over years and it was clear from the parents' findings that many had given up trying. Many of these parents attend carer forums so this is the point where advocacy needs to be developed (section 6.2.5.2).

6.2.4 Overview of themes which emerged which were challenges for out-of-school participation

A lack of service provider disability awareness, accessibility and no support for PDC&YP with personal care needs created difficulty for participation. PDC&YP had experience of accessing some out-of-school provision but experienced challenges such as access, lack of communication and a lack of support for their needs.

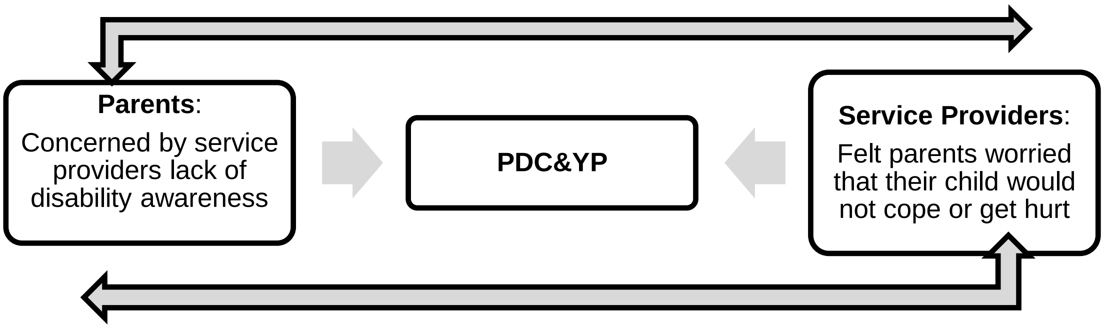
6.2.4.1 Mainstream Service Providers' Disability Awareness and Expectation Mismatch

There were concerns raised about a lack of disability awareness across the study in mainstream out-of-school activities. There was agreement across both studies that disability awareness needed to be improved and this echoed previous literature (Knight et al., 2009; Beresford and Clarke, 2010; Bennett, 2010; Brokenbrow et al., 2016; Shields and Synott, 2016: Ghanbari, 2016). This study demonstrated a real tension between service user needs and service provider's expectations.

Parents and service providers often had misconceptions about each other's 'role' without ever having had a partnership discussion, and this resulted in a mismatch of expectations. One example, where some providers had concerns that it was the parents not bringing the PDC&YP in case they would not cope or may get hurt. On the other hand some parents stated that service providers have a lack of disability awareness so could not support their child. Some PDC&YP felt that service providers under-estimated what they could do and focused on their disability. All of these views and perceptions created a barrier to joining or staying within an activity. PDC&YP potentially end up in the middle with some who reported not being allowed to join some mainstream sports due to service providers worrying about them getting hurt, for example, falling out of their wheelchair.

This is an important finding that other studies have not revealed and whilst this mismatch exists many challenges cannot be overcome. This is yet further support and evidence that some co-ordination is needed as they would be able to overcome and challenge misconceptions and reduce the mismatch. Figure 12 depicts the PDC&YP being stuck in the middle of a mismatch of expectations which is often the result of ineffective or non existent communication.

Figure 12: The relationship between PDC&YP, parents and service providers.



Some service providers echoed this concern and recognised themselves that they lacked disability awareness and confidence in working with PDC&YP. This differed from previous reports where PDC&YP felt their parents were over protective which sometimes stopped them joining in (Knight et al., 2009) but in this current study the PDC&YP did not voice these concerns. Parental influence on participation has been previously cited (Knight et al., 2009; Sloper et al., 2009; Langer et al., 2010; The Bevan Foundation, 2010; Kolehmainen et al., 2015). Disabled children were clear in the study on play in Wales that over protective relatives stopped them doing some activities (The Bevan Foundation, 2010). Kolehmainen et al., (2015) in their UK quantitative study looked at multiple factors of PDC&YP's lives and suggested that parents behaviour influences physical play, although there was not a great deal of context around this finding. Sloper et al., (2009) expanded by stating that parents were needed for support but this study focused on the support being given by parents rather than what support parents need. So parents do influence participation as without them being present many PDC&YP could not attend as parents were their support. There was concern from some parents about service provider's ability to cater for their child's needs which matches Langer et al., (2010) who highlighted parents can feel vulnerable leaving their PDC&YP. If they can overcome this it can allow them time with siblings (Langer et al., 2010). Apart from training there was no other obvious solution for these parents without paying for a PA.

When reviewing the bigger picture, if there was someone coordinating and advocating activities in Cheshire, parents would have someone to go to seek advice before joining a group with training being promoted within the groups. This would promote understanding of reasonable adjustments to ensure PDC&YP are not disadvantaged or discriminated (The Equality Act, 2010; Department of Health, 2018). PDC&YP know what they want to do and what they can do, what they need is for someone to ask them. By doing so co-ordinators could target those specific activities to increase initial inclusive opportunities.

6.2.4.2 Communication

Whilst communication can be an effective facilitator to participation, it can also be a real challenge especially when PDC&YP and parents have to fight to be included. PDC&YP want to be asked what they like and do not like and more importantly what they can do rather than focusing on their disability. The initial welcome to an activity was so important to PDC&YP and parents and service providers need to reflect on their own practice when any child joins. Bennett (2009) also reported that some disabled C&YP encountered activities where they are not initially welcomed or included. PDC&YP can feel isolated because they do not know anyone else in the same situation or who to turn to for support (Bennett, 2009). To overcome this initial worry and possible difficulties during the 'induction' period, a buddy they bring along or a mentor from within the group could alleviate some of these difficulties (section 2.10.1). This does still require the service providers to recognise the need for this and encourage such practices (Knight et al., 2009).

Some parents in this study reported avoiding activities after having a negative experience during initial contacts with clubs previously and therefore feel they cannot collaborate effectively. Service providers need to develop community opportunities and bring the key people together to do this, in this case children, parents and volunteers.

6.2.4.3 Physical Access

All four groups (PDC&YP, parents, activity planners and volunteers) reported challenges in terms of physical access to buildings and changing facilities (convergence agreement). This was also a dominant theme found in the literature review (Bennett, 2009; Knight et al., 2009; Sloper et al., 2009; Beresford and Clarke, 2010; The Bevan Foundation, 2010). The service providers reported that church buildings were less problematic as they had much newer facilities but they had no PDC&YP accessing their activities. Therefore, the lack of PDC&YP would potentially be linked to factors such as lack of disability awareness, communication or possibly due to service providers not wishing to access this particular religious setting. The study sample was limited due to the availability of providers being form church groups so this needs to be explored in other religious settings. Youth services reported the worst access conditions again with very few PDC&YP attending. Sport facilities were on the whole more accessible with swimming and water sports being reported as more difficult in Cheshire due to some changing facilities and water temperature. PDC&YP wanted warmer water but due to swimming club competition requirements there was a total mismatch of provision with no obvious solutions. Previous studies found the best access in sports and leisure clubs but had problems with community group/settings (Bennett, 2009; Bevan Foundation, 2010) and therefore an ongoing problem is seen in youth settings. Bennett (2009) previously demonstrated dissatisfaction with mainstream play and leisure opportunities particularly around lack of accessibility and having to travel to find suitable activities. Due to a lack of steady funding this is very difficult to overcome and unless there is a mandatory update of older buildings in line with The Equality Act (2010), this is not achievable.

Service users and previous literature (Lawlor et al., 2006; Knight et al., 2009; Sloper et al., 2009; Beresford and Clarke, 2010; Kelly et al., 2016) reported issues with transport and especially about the lack of flexibility with taxis and this stopping PDC&YP accessing after-school activities. Service providers running clubs have no control over this and this can only be influenced by local authority which needs addressing.

6.2.4.4 Personal Care

A significant challenge cited by all four groups was difficulties with supporting personal care (see section 4.5.4). Although discussed in both studies there was significant disagreement (dissonance) between what PDC&YP need and what service providers can and want to provide. This was a novel finding with no specific literature previously focusing on the needs of PDC&YP requiring personal care support and the impact on participation. PDC&YP requiring personal care support reported exclusion from even the ‘inclusive’ groups due to no one being able to help them go to the toilet which matched the service provider’s report of no experience of providing personal care. All members believed that this role fell to the parents although some service providers were willing to try and support but did not know what they were allowed to do. The concerns were predominately about staffing levels, toilet accessibility and safeguarding issues. Expectations between service users and providers did not match up with all four groups’ finding it difficult to make suggestions to overcome the many challenges of personal care.

The concerns raised by service providers around safeguarding, staffing numbers and being unsure what they could and could not do clearly indicated a knowledge gap and training issue. An understanding of what service providers can provide in their ‘job’ or volunteer role is needed to reduce any misconceptions and a potential mismatch of expectations between service users and providers. Linking back to my researcher positionality (section 1.5), I outlined my early experience of supporting PDC&YP with minimal experience, where I had a naïve and inexperienced approach. Parents sending their children to those activities may have assumed that we were trained but, on reflection, I recognise now that we were not providing suitable provision. As a researcher, assumptions cannot be made about what service providers should provide but these PDC&YP have the right to opportunities and provision (UNCRC, 1989; The Equality Act, 2010) like any other child so some understanding is needed to improve this support.

Training packages for service providers need to be established in order to specifically support PDC&YP with personal care issues and the exact needs of the child needs to be known to properly support them. In section 2.10.1 buddy schemes were discussed which could facilitate PDC&YP into activities however to be effective the buddy needs to have the necessary skills and/or training. It is clear, however, that due to the lack of evidence of volunteer buddy’s in Cheshire this will remain a challenge and potentially an even greater one when being asked to support personal care. In terms of where to seek advice and support about training the most obvious choice would be with community healthcare professionals. An example would be through children’s community nursing teams in Cheshire but with their already large remit it would not be realistic to be able to take on this additional role. If there was further government investment in this role the out-of-school provision could be supported by up-skilling service providers with their support. This, in turn, would promote respite opportunities for parents whilst the PDC&YP being better supported within their community. The alternative is for PDC&YP to use personal disability budgets to pay for PA’s to support personal care that would be locally trained by the child’s parents. As the study showed not all the parents chose to manage their own budget due to the concerns about tax and employment (section 4.7) so without close guidance for parents on this, this will remain a challenge. The political influence of personal budgeting has a huge impact on this group. Opportunities for PDC&YP cannot rely on the employment of a PA, there needs to confidence in what can be provided locally through local authorities. For PDC&YP with significant or complex personal care needs a PA is best positioned to provide this. On the other hand

PDC&YP who need help pulling their zip up or a little supervision, local arrangements need to be supported with clear policies to protect both the child and the service providers. For example, in a younger childcare setting there are procedures in place for younger children needing help with toilet training so this could be rolled out for older children with additional needs. The only documented evidence of personal care for PDC&YP is with paid teaching assistants in schools and parents are advised on the Government website (Gov.UK, 2019a) to apply for this through their personal budget to help with assistance for community groups.

There is a mismatch of information between what is available, what providers can do and what parents expect to support the individual PDC&YP. Therefore implementation of clear policies and personal care protocols by local authorities within community activity settings would go some way to reduce such ambiguity. These protocols are already in place in schools that sit under the local authority so policies can be shared from in school to out-of-school provision. In addition guidance for personal care budgets and the personal care support provided is needed within local authorities. Another proposed solution to move this debate forward is to use the education and health approach. Each school in the UK has a children's individual intimate care policy/guidelines adapted from the Department of Health (2006). The local authority could use this as a basis to have their own policy to disseminate across their local community groups. Alternatively large voluntary organisations could cascade their policy across their groups. As they do relate to safeguarding this fits more with the social model of disability as the population is ensuring reasonable adjustments are made to safeguard an individual (Department of Health, 2018).

Supporting personal care did not feature in any local induction training for activity planners or volunteers. This area needs full exploration, initially at a local level, in order to have the infrastructure and support in place for service providers to provide personal care. There needs to be a wave of change in safeguarding policies, training and attitudes. When exploring personal care it was clear that the medical model of disability dominated as the focus was on 'what was wrong' with the child to help them go to the toilet (WHO, 2001). Regardless of the type or severity of a disabled child's impairment, they are not a homogeneous group that can be accommodated easily without accounting for their individual or collective needs (Oliver, 1998). In relation to PDC&YP with personal care needs the social needs cannot be met as their biological requirements are not supported. This links to Maslow (1943) who described physiological needs as fundamental basic human needs, which includes being able to go to the toilet. Without this need being met this affects self esteem and a feeling of belonging. In addition this has an effect on their wellbeing as they may not fully participate in out-of-school activities like other children their age. All of these factors need to be addressed in order to meet the needs of PDC&YP

It is currently impossible for families to know which providers could and would provide personal care for their child so it potentially takes many attempts with different groups to find a suitable club. This inevitably creates a feeling of rejection if clubs are not able or willing to help. On the other hand, there are providers who are able and want to support children, but do not have children within their club perhaps due to other challenges or families not being aware of what they can provide. This is yet more strong evidence to promote the need to have a central co-ordinator within Cheshire to be able to connect families and providers together (section 6.2.5.2). if service users know what provision is available and service providers understand the needs of PDC&YP this can reduce some of the challenges reported.

PDC&YP can regularly frequent healthcare where family-centered care is promoted. Care is planned around the whole family's needs in order to support the child fully (Shields, 2006; Smith, Swallow and Coyne, 2014). A challenge to family-centered care is the uniqueness of families (Shevell et al., 2019). Going back to the principles that underpin this philosophy, the family is usually a constant in the child's life, so cultural, economic and individual differences need to be respected whilst family-to-family support and networking should be encouraged (Shelton and Stepanel, 1995). This also links with an earlier partnership philosophy (Casey, 1995) which is explored within this study.

Family-centered care and partnership working are helpful to utilise in planning and promoting personal care needs for a PDC&YP in the community. These models would promote the child, family and the service provider to work together to enable the child to be fully included (Shields, 2006; Aslem et al., 2017). This would encourage a move from a paternalistic approach to one based on partnership where parents are able and encouraged to share valuable knowledge and skills with staff and this is vital within voluntary organisations who support PDC&YP (Itzhaky and Schwartz et al., 2001).

6.2.5 Suggestions

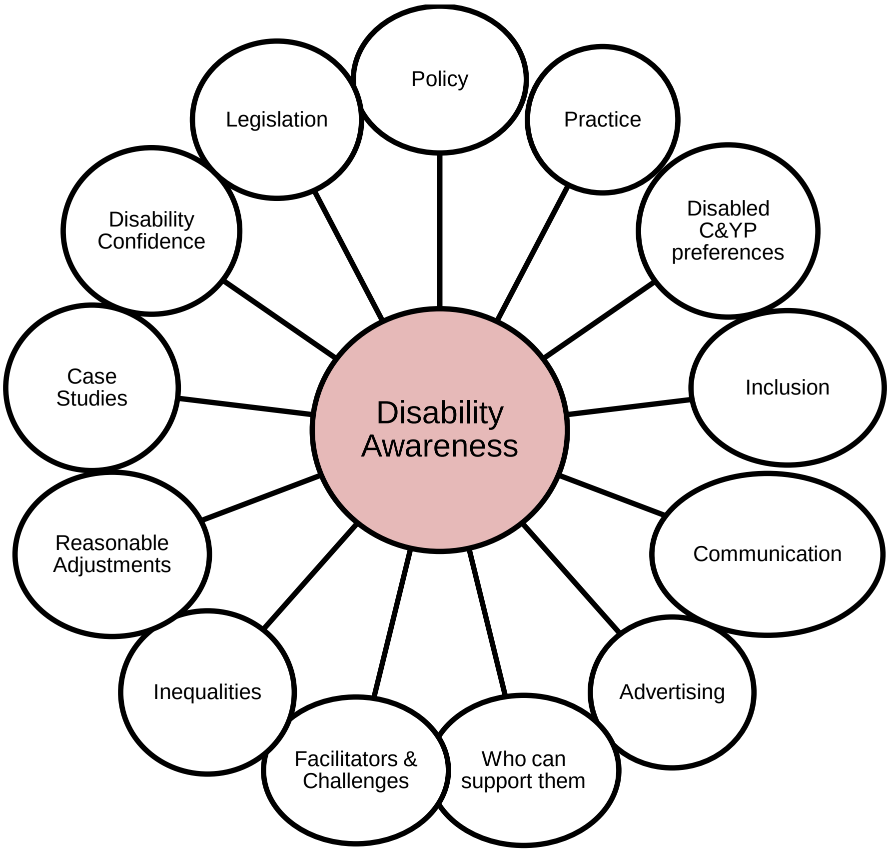
Two key suggestions which came from both studies and the literature review. Firstly the need for disability awareness training and secondly to have a disability co-ordinator who can bridge the gap between service users and service providers as well as to advocate the needs of PDC&YP to stakeholders.

6.2.5.1 Training

There was a clear need for training identified from both activity planners and volunteers showing convergence agreement. Service providers frequently asked for details of disability awareness training at the end of their interviews/focus groups often after they were asked to reflect on their practice. They reported that they would welcome disability awareness training but did not know where and how to access any. This was frustrating given the free training offered in Cheshire by a local independent living centre, who due to the limited resources did not advertise widely. They targeted activity clubs where disabled children known to them had tried to access provision without success.

The training available in Cheshire needs to focus on youth and religious groups as a matter of urgency and this has been fed back to training providers so that they can advertise across all youth and religious settings. Previous recommendations suggested that everyone working in a public facing role in the UK should have such training (Bennett, 2009; Beresford and Clarke, 2010) but they suggested health care professionals and staff working in leisure facilities should be priorities. This programme of study would suggest that priority should also be with volunteers working in community activities where PDC&YP are currently struggling to access provision. I do however agree that disability awareness should be taught in early years and schools throughout the UK, as recommended by Bennett (2010).
Recommendations from both studies and previous literature strongly suggest the need for disability awareness training, funded and organised through charities, local authority provision or by the activity planner, such as sports groups. My study has been able to highlight some areas throughout which need to be included in training. They have been summarised in figure 13:

Figure 13: Suggested Disability Awareness Training Content



6.2.5.2 Co-ordination Role

A key facilitator to participating in out-of-school activities was ‘meeting the right person’ such as a central co-ordinator or a key point of contact to bridge the gap between families and service providers. Some families found elements of this through specialist disabled sports coaches but they felt this was just lucky that they had fallen upon these helpful well networked people. Many parents suggested having an advocate who knows families and providers and can co-ordinate and aid communication. Service providers also suggested having someone they could go to for information, signposting and support.

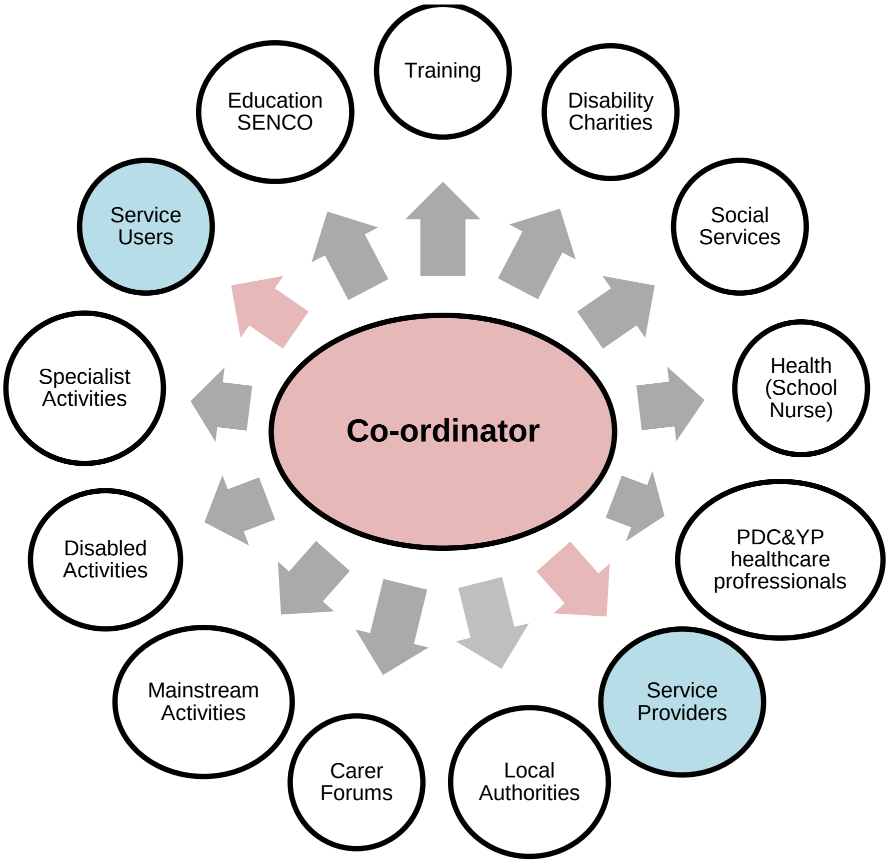
There is anecdotal evidence of pockets of this being provided within the UK as seen through forums such as `Mums Net` and disability chat groups However, it was a clear solution put forward by families and some volunteers. They would be able to know families through carers events, hospital referrals, networking events and social media which this co-ordinator could then liaise with all types of groups within the area to know what is provided. This has previously been recommend by Petrie et al., (2007:5) who described this role as ‘bridging’ staff, where the “local authority facilitates the inclusion process in mainstream settings, including youth, leisure, play and childcare services" and Knight et al., (2009) who suggested a 'bridge' or co-ordinator as it could be a very positive facilitator into activities. This role is not however currently in place in Cheshire and nationally there is no funding for such roles.

Brokenbrow et al., (2016) stated that cuts in funding have meant the removal or reduction in support services which, in this case, has been staff who had previously bridged between parents and providers. The example that a couple of parents gave was the sports development officer role. They reported that there were very few left who had an interest in disability. Parents and sports service providers shared their concern that this role was no longer being funded by local government. Introducing and maintaining a role like this across activities, and not just sport, would be a positive move to support PDC&YP and their families. Sport, youth and wider activities could work more collaboratively if there was someone amalgamating them. Stakeholder and child provision planners within the local authority in Cheshire must stay abreast of PDC&YP experiences, identifying gaps in provision. The impact of losing roles such as disability co-ordinators and sports development officers must be evaluated in local authorities to provide evidence of the resulting impact of such a change. A targeted approach is needed to start improving opportunities and widening participation for PDC&YP and then ongoing support (Daniels, 2016).

All children have a health visitor or school nurse, dependent on their age, who can act as an advocate for health needs. The social needs of children require the same focus and attention to aid their wellbeing and to enhance out-of-school lives. This advocate role could be replicated in relation to their out-of-school and non-health teams by having someone who knows the PDC&YP and can signpost them in the most effective way.

Recommendations from both studies strongly suggest the need for a co-ordinator, funded and organised through a local authority. Figure 14 highlights the possible roles a co-ordinator could have and who they would act as a link between. This has been devised from the service users and providers suggestions throughout the study.

Figure 14: Suggested Co-ordinator Role

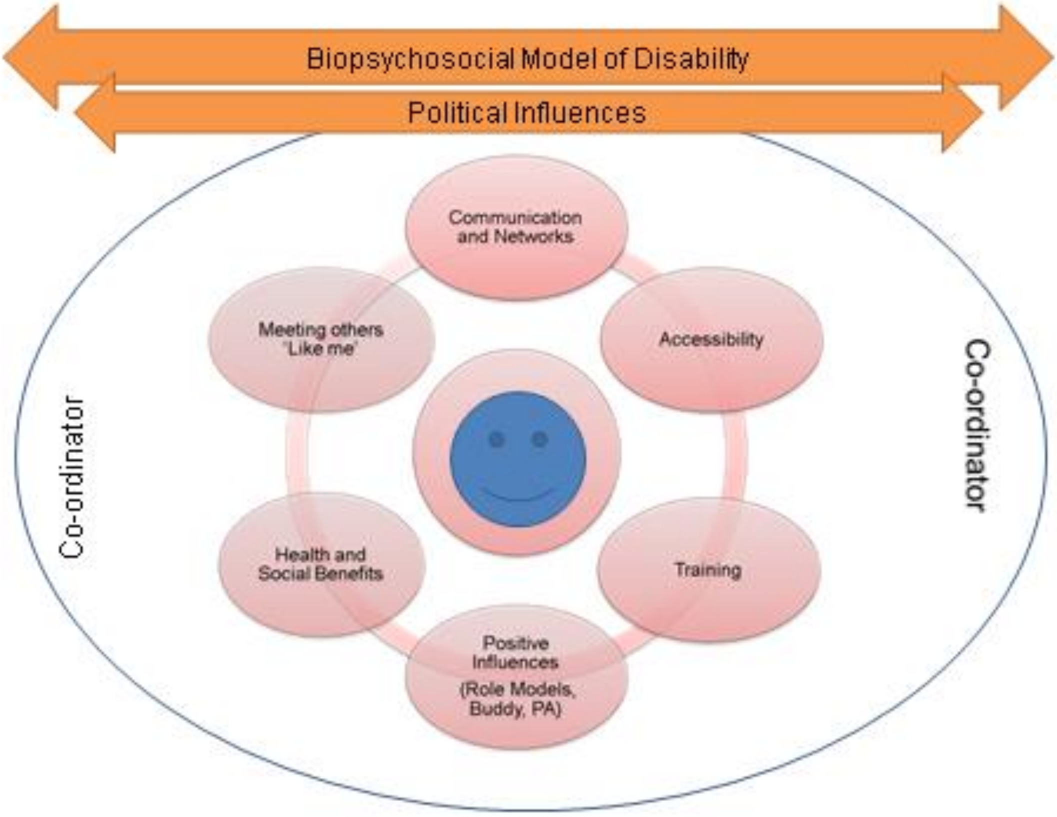


It is not clear whether this role exists elsewhere, therefore it is difficult to establish how effective this would be, although one service provider who ran mainstream and specialist activities attempted to bridge the gap between disabled C&YP and activities which was a positive step. But, with the challenges to participation highlighted in the findings of this study, local authorities need to firstly understand the needs of PDC&YP in order to meet the training and support needs of the local service providers. Any implementation must be evaluated and compared against these findings in order to establish any improvement in provision.

6.3 Conclusions

This study asked both service users and service providers about the facilitators and challenges within the community. There is a clear gap between service users and service providers and the themes which emerged were essential to understand PDC&YP out of school lives. The conceptual diagram has been created since the synthesis of the findings (Figure 15) to demonstrate the emergence of factors affecting participation in out-of-school activities.

Figure 15: Conceptual diagram to reflect the conceptual aspects of the study



The biopsychosocial elements of disability were clearly evident throughout but with the additional complexity of political influences. In terms of the biological influences, there was evidence of the more traditional medical focus (section 2.2.1) as service providers and parents focused on the diagnosis and label 'what was wrong' with the PDC&YP. But in contrast, by having a 'health' focus, parents focused on health benefits, which was a driver for many sports coaches, for example, natural physiotherapy. Interestingly, unlike previous research by Knight et al., (2009) where disabled children wanted to mingle together with others, PDC&YP were clear they wanted more activities to meet others 'like them.' This favours a condition or disability specific focus, which links more to the biological/medical approaches to disability, for example, cerebral palsy sports. As well as choice, this was partly due to the lack of provision in the community to access mainstream activities with their peers. There was however, the psychological focus on individual needs, with a drive for independence, although the mismatch of expectations between service providers and parents was a challenge. The social influence was clearly evident throughout the study as all of the participants had a drive to socialise and encourage C&YP to do so, whilst recognising that PDC&YP were still not included due to the communication and ability of those planning and running some of the activities. In addition to these biopsychosocial influences the political influence was strong and whilst the complex political and economic influences have often been overlooked it was imperative to explore the political influences affected by Government changes to policy and funding. As highlighted in section 2.3, national drivers relevant to disability in the UK are not a priority for the current Government. With this political shift away from disability, and policies not being renewed, there are negative implications for disabled people and consequently less focus on their needs. The groups advocating for disabled C&YP do not have the same level of political influence as they may have had previously (Disabled Children’s Partnership, 2017). This reflects the need for personalisation of support services and to promote citizenship to give power to PDC&YP’s views and a voice of how communities set goals (UNCRPD, 2006: Duffy, 2017). Citizenship can promote inclusive communities. Although the models are derived from work with adults with learning disabilities the key features on segregation, non-inclusive and critical boundaries are helpful but more understanding is needed, specifically for PDC&YP. VIPER (2012) have some evidence of including young people in decision making and this needs to be implemented effectively across the local authorities which can then feed into the Department of Health and Department for Children, School and Families. Local authorities need to ensure that disabled people fully participate in decisions (Walmsley, 2001), and PDC&YP need to be invited to share their voices in youth forums which could feed directly into services.

Some of the expected factors affecting participation in out-of-school activities included communication and access which reflected the initial literature findings. The new results which emerged included the lack of inclusive activities for the PDC&YP requiring personal care which shows a ‘hidden’ group who are certainly at risk of missing out on out-of-school experiences that they are entitled to. This group of PDC&YP across the UK need significant attention as the provision in Cheshire gives a snapshot of the provision nationwide.

Findings show additional influences which can facilitate PDC&YP’s participation in out-of-school activities, including the drive for independence, health benefits and positive influences. With this in mind, specialist service providers can utilise these when promoting their activities and they can form part of the disability awareness training for mainstream providers.

In order to make overarching changes there has to be a focus on the needs of PDC&YP and how communities can enhance provision. Within Cheshire, PDC&YP should to be able to promote their needs through local council and be part of the planning, along with the issues raised by the service providers, currently this is not in place. This could be done through parent carer forums being invited to stakeholder events which would open the gateway for PDC&YP. An example where this has been done in Cheshire was through a local sports provider wanting to improve disability provision, but for adults. They focused on day time activities which would not be relevant for PDC&YP as they would be in school. This was a positive step but PDC&YP need to be included. I was able to disseminate some of the findings from the study to this sports provider but when asked if disabled C&YP would be involved they stated they did not have the resources or expertise to carry this out. In order to manage these differences it is essential to understand the needs of the people at the centre of it (McKibben, 2017) which includes PDC&YP.

The purpose of this multi-method qualitative study was to explore factors affecting PDC&YP's participation in out-of-school activities from the perspective of both the service users and service providers in Cheshire. The specific research questions guiding the research were:

What are the current out-of-school activities accessed by PDC&YP within Cheshire?

The results show that PDC&YP accessed a range of activities in Cheshire, either mainstream activities, disabled groups or specialist activities across mainly sports and youth. There was evidence of mainstream activities lacking inclusion but with pockets of good practice particularly in the sports arena. Provision that is not appropriate for PDC&YP must be adapted by working with PDC&YP and gatekeepers to find out how it can be made more inclusive. There is no provision for PDC&YP needing personal care support unless parents employ a PA.

What are the preferences of PDC&YP and their parents (service users) in relation to out-of-school activities?

PDC&YP wanted to attend local mainstream clubs especially youth and sports activities to be with peers from school. They needed support to do this as many of these clubs were not set up to easily accommodate PDC&YP and often this came via parental support. They also wanted to find more local specialist activities to find other PDC&YP 'like them.'

What are the factors that facilitate or create challenges to participation in out-of-school activities for PDC&YP?

Factors that facilitate PDC&YP participation in out-of-school activities include; motivation to gain the benefits of independence and health, role models and other positive showcasing of disability, support such as a buddy or mentor, positive communication.

Factors that create challenges for PDC&YP to participate in out-of-school activities include: accessibility, communication, service provider ability through lack of disability awareness and a lack of personal care support.

What are the views of the service providers in relation to provision of out-of-school activities for disabled C&YP?

Service providers shared many of the same concerns but highlighted a need for positive partnership relations between parents and schools. There is a need for disability awareness training and a co-ordinator to bridge the gap between service users and service providers.

With the new findings which have emerged, especially identifying ‘hidden’ and ‘at risk’ groups coordination between health, social and education is required as outlined in 6.2.5.2. In essence a biopsychosocial model of disability with political links (local government) and education partnership is in essence what the coordinator would be.

6.4 Recommendations

The following section outlines recommendations from the study:

Stakeholders and Local Authority Actions:

- Local authorities and stakeholders need to think strategically about how to engage PDC&YP in consultation as feedback is crucial to successful participation and to planning and budgeting. Similarly they also need to engage parents of C&YP with very complex needs who cannot share their own views verbally.
- Where disabled people in Cheshire are asked about disabled sports provision, disabled C&YP must be included, for example, youth forums.
- To bridge the gap between service users and service providers, local authorities need to introduce a central co-ordinator to advocate for PDC&YP and act as a conduit into community services.
- Local authorities need to provide more information on how personal budgets can assist PDC&YP specifically in their out-of-school lives.
- Local authorities need to fully explore the role of buddies or mentors and implement a robust structure to promote continuity for PDC&YP. If this is a volunteer role then local authorities need to provide training to young people who are looking to volunteer into the role. They also need to form and enhance relationships with local schools, colleges and Universities to build up a pool of volunteers.
- The ‘professional’ team around the child (schools, social workers, school nurses) need to promote partnerships between parents and activity providers.

Service Providers Actions:

- Activity planners need to promote inclusive practice within the staff and volunteers and encourage them to reflect on their own practice.
- Effective out-of-school provision helps with respite for families so service providers need to be trained to be able to support children in order that their parents do not have to always attend with them.
- Service providers need to engage in disability awareness training.
- Activity planners need to facilitate and encourage volunteers to access disability awareness training. There may be skills within the activities team to be able to adapt and support PDC&YP but the skill mix needs to be explored.

- Mandatory training for service providers is required to improve assistance in line with safeguarding and safety training, which community providers have to complete. Training is currently free to service providers and available in Cheshire through a local disability charity. This charity need to be encouraged to advertise across specialist and mainstream out-of-school activities.
- Specialist groups need to advertise in both mainstream and special schools to reach PDC&YP who may be ‘hidden.’

Service Users Action:

- Where PDC&YP have ideas about improving participation, which many demonstrated they did, they need to be empowered to approach individuals who should be natural advocates in their lives (such as parents, teachers, healthcare professionals, social workers, service providers) to gain support and to speak to the right people who will listen and implement these changes.

Future Researchers Actions:

- Researchers need to develop a baseline online disability awareness training module and then evaluate the impact of this on PDC&YP’s out-of-school lives.
- Before applying through research ethics, researchers undertaking research involving any children should volunteer with C&YP, especially with the same age group and ability of those children in their study, to ensure a suitable child-centred approach.
- Researchers could adopt creative focus groups to engage with C&YP of all abilities as it is a positive and inclusive method of collecting their views (see appendix 7.6 for practical application ideas, to address and plan appropriately).

6.5 Implications for Practice

- Each school in the UK has a children’s individual intimate care policy and guidelines which are adapted from Department of Health (2006). As schools sit within local authorities the personal care policies can be disseminated beyond schools and adapted for out-of-school provision.
- The overwhelming message which came from both service providers and parents was that there needs to be a co-ordinator acting as a conduit between service users and service providers. This would allow providers to

advertise their activities and find out how to reach PDC&YP and find out what they wanted but also would allow service users to find the right club for them. At a local level, local authorities could host such a service and run this to ensure it remains up to date. In turn, this could allow a national picture to emerge by assimilating information from local authorities.

- A consultation on community swimming provision is required to re-focus the opportunities to meet the needs of the competitive structure and provide more social activities for families to take part and have fun together. This requires attention from the UK Swimming Academy.
- Positive role models promote participation in specialist and disabled out-of-school activities and, therefore, it is important to showcase potential role models within general media as well as in the local communities.
- A number of families in the study opted to use personal payments, which they managed themselves, to promote participation into out-of-school activities, whereas some children used their local authorities assistance with this. The families who were self managing their own independent living personal budgets, relied on PA’s rather than on community groups. Therefore, these PDC&YP were not accessing any mainstream or specialist activities, only those such as swimming where their one-to-one adult personal assistant took them. It was not clear whether this was due to choice or due to the funding strategy but this certainly required further exploration.
- Specific needs of PDC&YP with personal care requirements must be shared with service planners and providers to promote an increase in opportunities for these children. PDC&YP should be at the heart of decision making through community youth forums feeding into local authority decisions (Involve, 2018).

6.5.1 Key Messages

Key Messages

- **Participation in out-of-school activities can help PDC&YP make and meet friends.**
- **PDC&YP like a mixture of mainstream and specialist activities but want more opportunities to meet children ‘like them.’ They need support within mainstream activities to overcome challenges such as access, lack of disability awareness and communication differences.**
- **Communication is vital for advertising, for the initial welcome and to facilitate the ongoing partnership between service providers and PDC&YP and their parents.**
- **Service providers want parents to stay to support the PDC&YP but the PDC&YP and parents want independence and to attend activities with support from service providers, mentors or a buddy.**
- **A partnership is required between service users and providers which often needs an initial introduction so an advocate for families as a co-ordinator would enable this.**
- **Service users and service providers also need to understand each others expectations so that assumptions are not made before an initial meeting.**
- **All participants welcomed the need for disability awareness training and some gatekeepers within Cheshire provide this free of charge.**
- **PDC&YP requiring personal care are isolated from even the ‘inclusive’ groups within our community. Apart from one very specialist club found in Cheshire, both mainstream and ‘disabled’ groups do not provide personal care support. This needs to be addressed by stakeholders and through policy development for the community. The policy could potentially reflect education and healthcare guidance (Department of Health, 2006).**

6.6 Study Strengths and Limitations

This research had limitations that have been acknowledged within each chapter but this section provides a holistic overview of what worked well and what could be done differently.

A real strength of the this research was that PDC&YP and parents shared their views as have not had a large say in the previous body of research, (Knight et al., 2013). In addition the service providers who are an under-researched group provided a helpful comparison, where the two studies allowed for facilitators and challenges to be established from the various view points affecting PDC&YP's out-of-school lives.

The creative focus groups were a real strength and could be repeated because PDC&YP are the experts in their own lives and this participatory method actively engaged them in the research (Hodge and Runswick-Cole, 2013; Bradbury-Jones et al., 2018). PDC&YP stated the creative focus groups were enjoyable and friendly, which is vital when engaging with this participant group. The creative focus groups met the communication needs of participants, especially for those with various learning difficulties. Gatekeepers reported that the creative focus groups reduced inhibition and that the PDC&YP appeared comfortable which helped build a trusting relationship with the researcher (Gibson, 2007; Marshall and Rossman, 2011; Carter and Ford, 2013). As part of the creative focus groups PDC&YP had the option of arts and crafts during the time with me. Some of them used this but, in future, this could be built into the data analysis by using the 'draw and write' or 'draw and tell' method depending on their preference and ability (Knowles et al., 2013). This would enhance the information gathered and give the child a different way of expressing themselves (Noonan et al., 2017) I would suggest this as purely optional as part of the creative methods as some PDC&YP may not be able, or want to draw. The drawbacks are discussed in full in section 3.2.2.3 but there is scope to trial them as part of the creative focus groups.

Sloper et al., (2009) stated that the involvement of children can be both a strength and a limitation due to challenges in obtaining the data. In my study the development of the creative tool was successful in gaining a rich set of data with positive feedback. However it is very much dependent on the child and researcher relationship promoting researcher validity. The design was informed by my own personal experience working with groups of C&YP as a children's nurse and a youth leader but this could be a limitation if this communication and experience was outside of a researcher's competence and confidence. All C&YP need to be able to respond to the researcher and feel comfortable and safe. I was confident in this approach and could quickly adapt to a different activity where necessary. I played the games, sports, designed the crafts whilst maintaining my professional role.

In addition, to the flexibility used for the PDC&YP, the multi-method `pick-n-mix` choice was not only successful in meeting the aims and objectives, incorporated innovative participatory methods (section 3.2.2.3) but also met the needs of the adult participants. This element of choice was welcomed by the gatekeepers, service users and service providers. There was a wealth of information that came from the all the data collection methods. As well as the PDC&YP, all adult participants had the choice of where, when, how and with whom they wished to take part in the study using a given set of qualitative tools (focus group or interview) which was welcomed by all and was a strength of the study. The flexibility of location, style, pace and method of data collection was welcomed and the creative methods I used have been adopted by several researchers after I have disseminated the information at conferences (see section on output from PhD page i). This flexibility was key to including participants that may not have joined in conventional methods because of the timing and communication methods. Some of the PDC&YP would not have been able to sit in a conventional focus group for any more than a couple of minutes due to their needs but they were able to participate fully using the creative methods. The parents interviewed by telephone could not have met me face-to-face due to childcare needs therefore I could conduct these at a time that suited them. This choice fostered individuality and inclusion, the underlying ethos of the study. Many of the participants and gatekeepers liked my flexible approach in terms of choosing the location, format and time as it suited their family, childcare and work needs (section 3.2.2). This put them in control. Although flexible, the questions were standardised and all of the data gathered was analysed together and were consistent across all participants ensuring a rigorous process. As predicted in my planning, this method promoted a bottom-up approach, instigated by the participants needs and this flexibility allowed individual needs to be met (Creswell, 2013).

The qualitative multi-method study enabled the participants to be in control of their data collection method, especially the PDC&YP. There is a debate about a possible tension between flexibility and standardisation especially for data analysis (Parahoo, 2006) but by using the same semi-structured questioning format for each method this provided sufficient structure to analyse the findings and ensure consistency and validity (Burnard et al., 1991, 2008; Merriam, 2009; Neergaard et al., 2009; Creswell, 2013; Kahlke, 2014 and Percy et al., 2015). Using semi-structured questioning produced a wealth of rich data but a limitation is that participants can deviate from the aims and objectives of the study (Ellis, 2013). This did occur with parents of PDC&YP and many of the parents discussed issues around their child's original diagnosis. It was a distressing time in their lives and was the start of their experience of physical disability. This discussion did not directly meet the aims of the study but it provided context to the research analysis and helped develop rapport (Walsh and Wigens, 2003).

I invested a great deal of time and effort into the pre-planning and ground work conducted before each creative focus group as I volunteered in many of the groups via the gatekeepers before starting the fieldwork. This was a real strength of the study as the PDC&YP could meet me, ask me questions about myself and the research before they started. This allowed me to build a rapport with them which made them able to talk through their ideas, views and issues at ease. A limitation to this was the additional time required on top of the creative focus groups but it was worth the input to ensure the research time was optimised. Working with C&YP before also meant that I was able to communicate effectively and iron out any practice issues before hand. This approach and method can be applied to other research to ascertain views and options of any C&YP regardless of ability or needs but it does, however, require the researcher to be prepared and have the necessary communication skills. The communication with the PDC&YP was essential but the professional positive partnership with gatekeepers helped facilitate this. The gatekeepers (section 3.2.2) played a key role in assisting facilitation of the creative focus groups but, with this, came a potential that the gatekeeper could have influenced the views of the PDC&YP. In reality, they were very effective facilitators within the creative focus group as they knew when they needed to support children and when they let it flow (Moule and Hek, 2011).

If the research was being conducted in an area the researcher was not familiar with, it may be helpful for the PDC&YP to take the researcher and show them what they describe. Carroll (2018) and Hayball and Pawlowskic (2018) both used 'go along' interviews when exploring outdoor spaces which allowed researchers to go with disabled C&YP to see what they are talking about. This would be very positive to potentially include as an option when future research was exploring a very specific activity. But, in terms of creative focus groups or family interview, it would be difficult to facilitate due to the logistics of taking a group of C&YP, the timing often being in an evening, and getting consent. It could however, be adapted where PDC&YP took photographs to provide examples which fit in with draw and talk methods.

As all the participants volunteered to be in the study, this raised the possibility that participants, who either have had excellent experiences, or, more frequently those who have poor views to share, offer to be interviewed once they read the participation information. There was a potential bias in encouraging a self-selected sample (Denscombe, 2014). It is unclear whether this sample had greater challenges than the wider population but as multiple facilitators as well as challenges emerged so a rounded viewpoint.

Participants in this programme of research were all white British and, therefore, not fully representative of the total range of PDC&YP across the UK. Whilst Cheshire was the focus of the research, which has 98% of its population as white (Cheshire West and Chester, Cheshire East) a more diverse population would be beneficial to portray an equally diverse community. Disabled C&YP are not a homogeneous group, and this study focuses on PDC&YP as their specific needs are unknown and the support from service providers is unclear. This means that the results of the research do not necessarily apply to other groups who were not part of the project. Research with a larger more diverse sample is required to include different cultures, ethnic background and more diverse backgrounds to explore different religious activities beyond church settings and to establish any cultural differences in out-of-school lives.

Although the sample was representative of the area, the findings reflect the wider national context in terms of the pressures, challenges and political agenda and, therefore, findings potentially have wider relevance as the challenges faced by these PDC&YP are not unique to just this group. For example, there is no obvious provision for PDC&YP with personal care needs within the UK, with only pockets of specialist practice, such as PA provision; therefore the issues faced in Cheshire are highly likely to be replicated in other areas.

In relation to the research questions only the service users were asked about PDC&YP's preferences of out-of-school activities but this is a possible limitation as it might have been useful to ask providers what they think PDC&YP preferences are and see if they concur. If this study was repeated this could be included.

6.7 Future Research

Research questions have been devised from the outcomes of this study as these areas require further exploration:

Research need identified	Proposed future research
All participants recognised a need for a co-ordinator between service users and providers. They promote positive communication and bridge the gap between services and users. There were reports from parents and service providers who had helped co-ordinate in the past but their roles had been lost due to the role no longer being funded.	**What is the impact of having sports development officers with a priority for disability on PDC&YP through regional case studies?** To establish the need for the role and determine whether they act as an advocate and could fill this gap for sports and other activities.
The study demonstrated that no mainstream service providers were currently providing any personal care. It would be beneficial to find specialist services nationally who provide personal care in the community in an activity setting to compare practice with the procedures within health and education.	**What are the views of care, education or volunteers providing personal or intimate care for PDC&YP?** To provide a platform and standards of care to build guidance for large voluntary groups.
Swimming was very popular amongst PDC&YP yet almost all found the cold water temperature a challenge. Currently competitive swimming clubs determine the temperature of the public swimming pool water due to their specific training needs.	**Who gets the nice warm water? What are the needs of the swimming provider versus users of the service?** To establish whether there could be cost effective provision for PDC&YP wanting to swim regularly or socially.
There were a couple of families identified in the study who used personal budgets to pay for personal aids to promote independence (both needing personal care support). It is not clear whether this was the reason	**What is the impact of personal budgeting on out-of-school activity provision?** This fairly contemporary Government initiative needs further exploration as to

PA's were used but these C&YP did not access any mainstream activities.	the impact on PDC&YP out-of-school lives.
A clear lack of disability awareness was identified in the study and although there is free disability awareness training in Cheshire, it is not widely used and known about.	**What needs to be included in national disability awareness training?** Training needs to be cascaded across school and community groups in a cost effective and efficient way.
PDC&YP want to participate in out-of-school activities independent of their parents but need support particularly in mainstream activities. There is limited information on buddy schemes (Knight et al., 2009) but the idea seems sensible. Challenges around getting suitable volunteers needs to be assessed.	**Do buddies or mentors influence participation into out-of-school activities for PDC&YP?** New local charity provision (Friends for Leisure, 2019) needs to be assessed to determine whether this assists participation for PDC&YP specifically.
Free disability awareness training is available in Cheshire and currently being used when clubs request it or when parents of disabled C&YP report problems.	**Evaluation of disability awareness training in Cheshire.** If any training is implemented the impact needs to be measured.

6.7 Reflection

As a children's nurse and a nurse teacher, reflective practice is integral to my role and has an impact on how I live my life and behave as a professional. This practice was extremely helpful as a researcher working with PDC&YP and the adults in this study. I maintained good self-awareness throughout.

Gaining an understanding of the provision, preferences, facilitators, challenges and suggestions reported by PDC&YP has been extremely valuable as I was able to share my findings with gatekeepers, service planners and service providers immediately after the fieldwork. Dissemination of my findings at conferences and with local service providers and stakeholders has included feedback directly to those organising such out-of-school activities. One notable example where this has been successful was a specialist sports club funded within Cheshire who invited me to be part of their working group in setting up this club. I could give specific examples of what the PDC&YP in this area wanted and this was taken into account for this club, which is now up and running and growing in success. Within this scoping group they did not have the confidence or expertise to take this forward and, therefore, they used the research findings from this study to inform some of their practice group.

Whilst maintaining full confidentiality, I was able to act, in some way, to aid communication, for example, when parents asked if I knew of any groups that did a particular activity I was able to signpost them. When providers asked if there was any training I was able to pass details about the free training available. This created a novel opportunity to enhance communication and provide some information where appropriate. This role I had inadvertently assumed highlighted the importance of the need for someone to work with and advocate for these C&YP and families. A central co-ordinator would build up these types of networks.

As a researcher known to be working in the area of PDC&YP's out-of-school lives, by local gatekeepers, I was invited to a sports strategy group looking at disabled sports provision for adults and, therefore, was able to raise the issues highlighted to me by the PDC&YP. I strongly advocated the input of the PDC&YP themselves as they do not get opportunities to discuss their needs. Many PDC&YP reported to me that they had done surveys before to evaluate their wheelchairs and equipment but they had never been able to verbalise their needs and feelings which they were pleased to do. The PDC&YP may be the only physically disabled child in their school so, to take part in research in that sort of setting immediately identifies them, whereas being part of a wider disability study they remain anonymous and they can discuss their disability openly. I am, and will always be, an advocate for C&YP and I was privileged to be able to listen and share such important views from PDC&YP who are often not heard and marginalised in our society. After I had completed the fieldwork some of the gatekeepers invited me back to some of the groups where I had met some of the PDC&YP as they wanted me to see how they were showcasing their skills during a celebration evening. I was of course thrilled to be invited but this also demonstrated the important relationship and connection to gatekeepers. They must be confident in the researcher to conduct the research to ensure the wellbeing of the PDC&YP but also to be able to share their needs in the right way.

I continue to volunteer in mainstream youth work and, with only one young disabled child in the group, I am conscious of my practice and that of my group. I use every opportunity to influence the way we advertise and welcome all C&YP as well and am trying to overcome accessibility issues with the group executive team. I conduct disability awareness training with the C&YP as well as raising awareness with fellow leaders. It is evident that this does need someone driving inclusion forward and keeping disability on everybody’s agenda.

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CHAPTER SEVEN: APPENDIX

7.1 Published Articles Arising from the Study

- 7.1.1 Literature Review Article
- 7.1.2 Poster Published

7.2 Ethical Approval

7.3 Ethical Approval; Letters, Consent forms and Participation Information for Study 1 (Service Users)

- 7.3.1 Gatekeeper Letter to recruit PDC&YP
- 7.3.2 Gatekeeper Consent Form
- 7.3.3 Service User Expression of Interest Form
- 7.3.4 Parents Participation Information Sheet
- 7.3.5 PDC&YP Participation Information Leaflet
- 7.3.6 Parent Consent Form – own participation
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- 7.3.8 PDC&YP Assent Form

7.4 Ethical Approval; Letters, Consent forms and Participation Information for Study 2 (Service Provider)

- 7.4.1 Gatekeeper Letter
- 7.4.2 Gatekeeper Consent Form
- 7.4.3 Service User Expression of Interest Form
- 7.4.4 Activity Planner Participation Information Sheet
- 7.4.5 Volunteer Participation Information Sheet
- 7.4.6 Activity Planner Consent Form
- 7.4.7 Volunteer Consent Form

7.5 Participant Questions

7.6 Creative Focus Group Activities

7.7 Literature Tables

- 7.7.1 UK Literature Table (Published Peer-reviewed)
- 7.7.2 UK Literature Table (Grey literature)
- 7.7.3 International Literature Table

7.8 International Literature Flow Diagram to complement to UK literature as presented in 7.1.1

7.1 Published Articles Arising from the Study

The following papers arising from the current study have been published in peer-reviewed journals.

7.1.1 Literature Review Article

Knight, K. Porcellato, L. and Tume, L. (2013) Out-of-school lives of Physically Disabled Children and Young People in the UK: A Qualitative Literature Review. Journal of Child Health Care 18 (3) 275-285. Available at: http://chc.sagepub.com/content/early/2013/07/01/1367493513490446

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Out-of-school lives of physically disabled children and young people in the United Kingdom: A qualitative literature review

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Abstract

Currently there appears to be few opportunities and little evidence of physically disabled children and young people (C&YP) participating in mainstream social activities. A qualitative review was undertaken to examine the factors affecting physically disabled C&YP (8–15 years) in the United Kingdom participating in out-of-school activities. Views and experiences were explored from the perspective of the service users and providers to assess current provision and to determine the need for future research into factors that may affect participation. Searches were conducted across eight databases, the references of the included studies were checked and the websites were searched. Studies that used a qualitative design that examined the views relating to out-of-school activities were included. Nine papers were identified, which included three peer-reviewed papers and six pieces of grey literature and pertinent government documents to include views and experiences of out-of-school activity provision. The main themes emerging from the review were the need for social inclusion, out-of-school activities run by volunteers and accessibility, with threads throughout, which require further research including parental influence, provision, training and attitudes. This review highlights the absence of the service user's voice and sheds light on the limited provision and barriers affecting participation in out-of-school activities.

Keywords

Children, young people, physical disability, disabled, participation, social activities and out-of-school activities

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Introduction

Disability issues are high on the current political agenda, with the launch of the new cross-government Disability Strategy in September 2012 (Department of Work and Pensions, 2012), which aims to break down the barriers to social mobility and equal opportunities faced by disabled people in Britain (Department of Health (DOH), 2011). Disability is defined by The Equality Act (2010: 7) as a person who has a 'physical or mental impairment which has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities'. There are over 10 million disabled people in Great Britain today. According to the estimates from the Family Resource Survey (HM Government: Office for Disability, 2011), disability prevalence in the North West of England is 1.5 million, higher than any other region in the United Kingdom (UK). Every Disabled Child Matters (2011) highlights that there are around 770,000 disabled children aged 0–16 years in the UK. This equates to one child in 20 being disabled. Terminology changes from time to time but 'the term considered to be best practice from the disabled people's movement is in fact the term "disabled children"' (Kids Playwork Inclusion Project, 2011: 2).

In the UK, a 10-year National Service Framework highlighting the need for disabled C&YP to be supported to participate in family and community activities has been set (DOH, 2004). Whilst a range of specialised activity provision is available, there appears to be few opportunities and little evidence of participation in mainstream social activities. Given the known benefits of participating in social activities and the adverse effect the lack of social interaction can have on quality of life, understanding why disabled C&YP are excluded from or less likely to access clubs and activities out-of-school is warranted (Bennett, 2009; Beresford and Clarke, 2010). To elicit greater understanding of the reasons for the lack of engagement, it is vital to hear from the service users or potential service users of social out-of-school activities themselves. Service user research is increasingly becoming important within research and policy development (McLaughlin, 2010). It is only by listening to service user and provider views about factors that influence participation and inclusion in out-of-school activities that improvement can be promoted (Pelchat et al., 2009).

The purpose of the review is twofold: to explore factors that may affect physically disabled C&YP accessing out-of-school activities and to define future areas for research in this field. A qualitative methodology was chosen, as it is the voices of the C&YP, their families and those involved in activities that are most important. The paucity of research is highlighted by Carpenter and McConkey (2012) and Stalker et al. (2012) who state the need to hear disabled children's voices about their lives but highlight that there is very little in general. Kay and Tisdall (2012) demonstrate the importance of hearing children's voices, but research needs to look beyond the direct quotes and focus on the various means of communication through non-verbal, play and observation, which unfortunately are lacking in UK studies.

Search strategy

The literature search was carried out by K.H.K. with clarification from a Research and Learner Support Officer to ensure all relevant databases were covered and to check search strategies. The results and themes were discussed with L.P. and L.T. The literature search was conducted between March and July 2012 to answer the following question: What are the factors affecting physically disabled C&YP (8–15 years) participating in out-of-school activities in the UK? The databases searched were Cinahl Plus with full text 2006–2012, Web of Science, Social Care Online, ASSIA, Community Care Inform, Medline, Google Scholar and British Education Index. The search terms used were children, young people, participation, social activities, out-of-school activities and disability. In addition, Internet searches were conducted using the keywords 'Boolean logic' and 'snowball techniques'. This process was checked by RC for quality assurance. A hand search of reference lists of studies included in relevant papers was also done. Key national policy documents were checked for relevance. The search included published studies, relevant grey literature and government reports. As the focus was on UK provision of services, the review excluded non-UK papers that could potentially reflect a different cultural view of disability. Grey literature was sought using Google scholar, reference lists from the published literature and relevant websites relating to C&YP and disability. The grey literature is defined here as any information that has not been published in a peer-reviewed journal. This has been included as it provides relevant qualitative information that can add to the understanding of the needs of C&YP and their families and those providing out-of-school activities.

UK studies were only included if they meet the following inclusion criteria:

- Included views of services users: physically disabled C&YP aged 8–15 years and their families. The age range corresponds with much of the out-of-school provision of social activities.
- Included views of service providers running out-of-school activities.
- Included issues relating to participation, out-of-school, social leisure or community activities.
- Papers published after 2006, to critique the recent literature within the last 6 years due to the paucity of published literature and to include changes in policy and government drives.

This literature review is based on nine papers including both published and grey literature (summarised in Tables 1 and 2). Published studies that met all of the inclusion criteria were limited to three papers (Knight et al., 2009; Lawlor et al., 2006; Sloper et al., 2009). A further five reports (Bennett, 2009; Beresford and Clarke, 2010; Langer et al., 2010; Petrie et al., 2007; The Bevan Foundation, 2010) and one briefing paper (Kids Playwork Inclusion Project, 2011) were identified through relevant websites. Knight et al. (2009) and Petrie et al. (2007) present research results pertaining to the same study, which will be discussed together. All peer-reviewed papers that have met the inclusion criteria have been critiqued using the Critical Appraisal Skills Programme (CASP, 2012) tool for qualitative research by the lead author (K.H.K.). Eight were key government and charity documents, which were relevant to this literature search. Of these, four were key documents from the UK (DOH, 2004; Welsh Assembly, 2007; National Institute for Health and Clinical Excellence (NICE), 2009; HM Government: Office for Disability, 2011). These key documents were pertinent to this topic, and although the DOH National Service Framework was published in 2004, it is a 10-year plan so warranted review (a flowchart relating to the search is in Figure 1).

Results

Three main themes emerged from the review: the need for social inclusion, out-of-school activities run by volunteers and accessibility. Themes were identified through the aims of the study and from major overriding topics identified from the service user and service provider's comments found within the literature review, but there are points identified, which are threads across the themes that require further investigation, such as parental influence, provision, training and attitudes.

Table 1. Characteristics of the included published peer-reviewed literature.

Study	Aims	Location	Sampling		Data collection	Findings
			Sample	Details		
Knight et al. (2009)	To understand how provision for holidays and other out-of-school times may contribute to the social inclusion of families with a disabled child	Six local authorities in the UK	86 children and young people (C&YP)	7–19 years old; 38 girls/48 boys; represented; mixture of disabilities – included 17 physically disabled C&YP	Semi-structured interviews; case study approach	High levels of social isolation and exclusion during out-of-school periods and during school holidays in particular. The topic areas included rather than themes presented: • Experiences/perspectives of disabled young people of the school holidays • Holiday clubs/other leisure opportunities • Promoting social inclusion for disabled young people • Gaps in provision • Meeting disabled children's rights
			90 parents	Higher number of White British represented		
			121 staff	Mostly middle/senior management – local authority social services, education, early years, special and mainstream schools, health services, play, youth services and voluntary organisations		
Lawlor et al. (2006)	To ascertain from families of children with cerebral palsy the features of physical, social and attitudinal environments that facilitate or restrict participation	North East of England	Families of C&YP with cerebral palsy aged 5–17 years	Five mothers, three fathers, one grandmother, three both parents; only two children gave views; cerebral palsy with a variety of mobility (six walking and six non-walking)	In-depth interviews using a topic guide	The main themes presented were: • Importance of mobility • Transport • Support by and to parents • Attitudes of individuals and institutions towards children.
Sloper et al. (2009)	To explore how disabled children and their parents defined their desired outcomes for their own/their child's life	Three local authorities in the UK	Families of C&YP aged 1–18 years; 95 families took part representing 100 children; 90 mothers; 18 fathers; included seven bereaved parents of children with degenerative conditions; 27 'other informants' (person child choose to accompany); 29 C&YP participated directly	55 boys/45 girls; 27 minority ethnic group families; four groups of disabled children: • Autistic spectrum disorders • Complex health needs • Degenerative conditions • Children who do not use speech to communicate for physical or neurological reasons.	Semi-structured interviews	The themes presented were: Fundamental outcomes • Physical well-being • Communication • Staying Safe Higher level outcomes • Enjoying and achieving • Socialising and having friends and relationships • Activities and experiences • Education and learning • Self-care skills • Life skills Making a positive contribution; economic well-being

C&YP: children and young people.

Table 2. Characteristics of the included grey literature reports.

Study	Aims	Location	Sampling		Data collection	Findings
			Sample	Details		
Bennett (2009)	To ask families about their social emotional and practical experiences of raising a child with a disability	UK	615 families caring for a disabled child/young person aged 0–19 years	22% have child 0–5 years; 52% have child 6–12 years 26% have a child 13–19 years; range of disabilities and health conditions	Online survey with open/closed questions	Three clear themes were presented: Lack of services, attitudes towards disability, lack of support from professionals; 73% of respondents said their child's access to play/leisure specifically for disabled children is poor or unsatisfactory; Families want more play/leisure and choice
Beresford and Clarke (2010)	To describe what works in improving access to positive and inclusive activities for disabled C&YP (excludes literature where mental health problems were the disabled child's primary diagnosis)	UK	16 disabled C&YP	10 C&YP Six young people (aged 14–25 years)	Two focus groups Interviews and questionnaires	Key messages presented included: • Positive activities associated with positive outcomes in terms of health, experiences, enjoyment and community participation. • Existing services need to examine whether the services they believe to be inclusive are truly inclusive
			19 parents of disabled C&YP	15 mothers; 4 fathers; range of disabilities	Interviews or email views	
			170 service providers	Across seven regional workshops; including mainly local authority children's services	Knowledge workshops	
Kids Playwork Inclusion Project (2011)	Briefing paper looking at myths based on inclusion of disabled children in play setting and services					
Langer et al. (2010)	To assess the impact of short break provision on the lives and well-being of disabled C&YP	North of England (mainly North West)	17 parents/carers; three disabled C&YP three siblings of disabled C&YP		Semi-structured individual interviews using topic guides	Some of the related major findings reported: • There was a wide range of short break provisions, parents use and value short breaks for different reasons. • Have positive impacts on children's lives, e.g. developing and maintaining social relationships and being able to enjoy fun activities. • Leaving the child could make parents feel vulnerable
			Four interviews with eight parent/carers		Group interviews	
			Nine parent/carer responses		Narrative tools (e.g. story space')	
Petrie et al. (2007)	Report of 'On holiday!' study, which is published by Knight et al.'s (2009) study					
The Bevan Foundation (2010)	To explore views of disabled C&YP's experiences of play and leisure; to ascertain experiences of providers of leisure/play activities for C&YP	Wales	82 disabled C&YP	Aged 11–17 years	Short-questionnaire survey – open and closed questions; observation of activities with discussions with young people	• The majority of disabled C&YP in the study participate in a limited number & range of activities and some feel there is 'nothing for them'. • They face barriers from lack of provision, lack of support, poor access to buildings and negative attitudes.
			25 providers; 22 from voluntary/community organisations; three from local authorities		Survey and interviews	18 of 25 provided integrated provision; 1 of 25 did not involve any disabled C&YP 9 of 25 provided activities exclusively for disabled C&YP three provided both • Of the inclusive organisations, eight knew whether they had policies on inclusion of disabled C&YP • 10 provided disability awareness staff training

C&YP: children and young people.

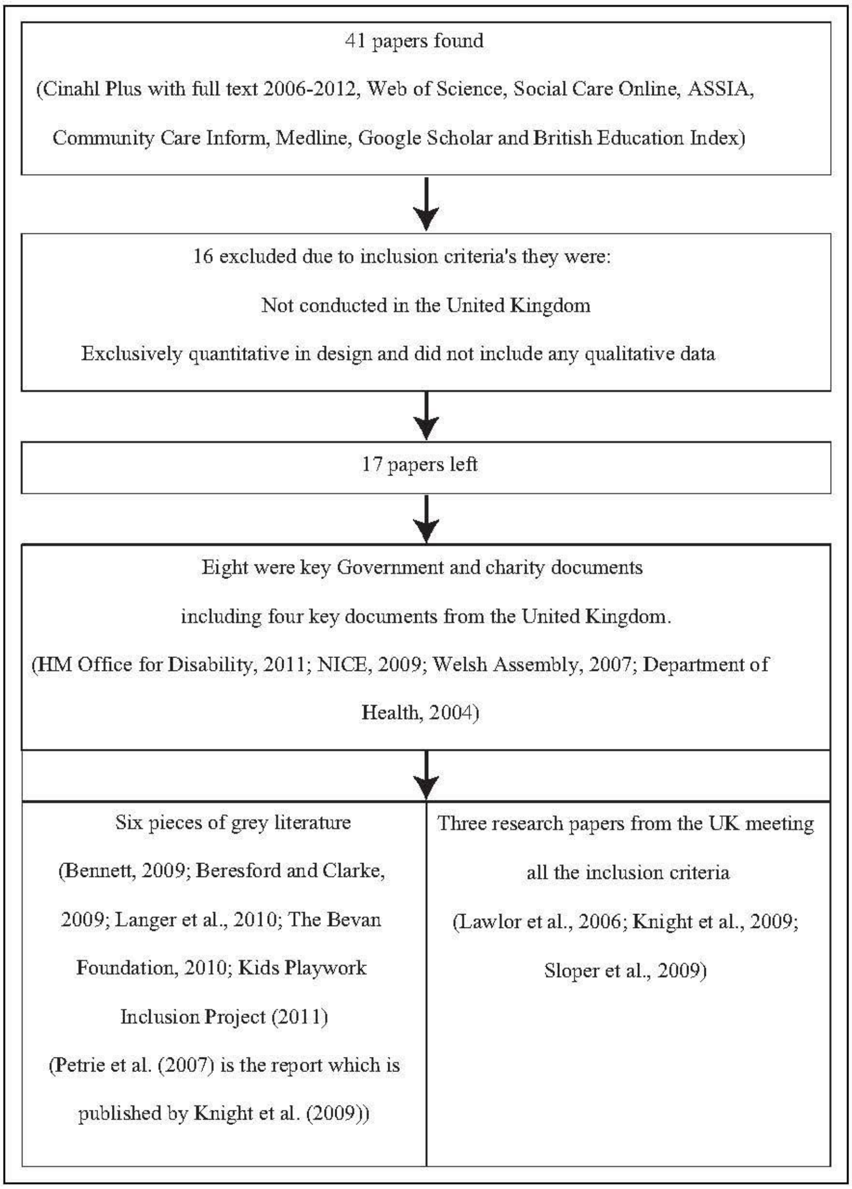

Figure 1. Flowchart of the literature search.

The need for social inclusion

All of the literature discussed the issue of social inclusion. Social inclusion refers to C&YP joining in with activities of their choice and having the right to participate fully in their community (Barnardos, 2012). Barnardos (2012) believe that disabled C&YP must have the same choices, opportunities and experiences as other children, to make local friends and to access, play, leisure and recreational facilities. According to DOH (2004: 9), disabled children wish to 'have friends of the same age or who share similar experiences and to do the same things as other C&YP of their age'. This suggests a desire for inclusion in mainstream activities. This is confirmed in The Bevan Foundation's (2010) cross-sectional mixed method study exploring disabled C&YP's experiences of play and leisure in Wales. A total of 82 disabled C&YP completed the questionnaire that included open questions (aged 8 years to young adults). The response rate was not stated. They found a number of activities were rarely undertaken, with 90% replying rarely or never attending a youth club such as Scouting or Brownies. More than half of the respondents rarely or never attended a disabled children's club because they did not know whether there was one in their area. Of those who did attend out-of-school activities, some preferred to be involved in 'disabled – only groups' as they felt more comfortable with others like themselves and felt that the adult leaders were very patient. Eight of the 82 children felt there was nothing for them, with one young person stating 'activities not available locally with people that can cater for my disability' The Bevan Foundation (2010: 25). This is an interesting starting point, but this study gave a limited voice to the disabled C&YP, as it did not provide them with the opportunity to elaborate on responses. The sample included C&YP aged 11–17 years; therefore, the findings need to be interpreted with caution as some of the issues raised may relate to adult provision or the transition into adult services, so the findings may not be representative of the child population.

The need for social inclusion also featured in Knight et al.'s (2009) qualitative holiday study with 86 disabled 7–19 year C&YP across the UK. Within this sample, only 17 C&YP were reported as having physical disabilities; so it is difficult to gain their views from the overall findings, which showed that disabled children wanted to mix with non-disabled young people but the experience was problematic. Often these children were worried what other C&YP might say about their disability. They found that when exploring social inclusion, most of the experiences were positive. There was some boredom reported, however, this issue would need to be compared to findings with their mainstream peers. They also highlighted that a major motivator for disabled children to join clubs is being with other young people and doing activities along with their peers. In this study, it was suggested that disabled C&YP value provision that is designed for all children regardless of their ability (Knight et al., 2009). Although useful to ascertain C&YP voices, including children who only used non-verbal communication, the study did not report piloting the interview questions. A further limitation is that the age group was broad (reported as 7–19 years), and it is unclear how many children were in each age group. If the average age in this sample was high, this may bias the findings due to issues around transition between child and adult services. In support of the need for social inclusion, Langer et al. (2010), through interviews and focus groups, explore short break provision with a total of 34 parents/carers and three disabled C&YP. They -portrayed the social benefits of this out-of-school provision, but only reported the type of activity the C&YP engaged in and the contact with friends rather than how the short breaks affect them individually. In order to evaluate out-of-school lives like in the previous two papers, the UK disabled children's charity, 'Contact a Family', commissioned an online survey, including open-ended questions, in which families were asked to describe their experiences (Bennett, 2009). The 615 families taking part in their survey had children with a range of disabilities. The C&YP represented were aged 0–19 years, which again makes it difficult to elicit findings specifically to those aged 8–15 years. However, 78% of their sample was over 6 years of age, information is of value to ascertain factors affecting the access to out-of-school activities. Seventy-three percent of the families said that the access to play and leisure specifically for disabled children was poor and unsatisfactory. A parent of a severely physically disabled child stated that her child 'has a very active social life which is due to the support networks I have fostered' with another describing how their daughter 'gets fed up being around her family and enjoys the company of others' (Bennett, 2009: 10–11). It is helpful to have the parent's views, where the C&YP were unable to communicate verbally due to their disability, but it is important to listen to C&YP also. This section gives a strong message that social inclusion is vital for all C&YP, the preferences of the service users and factors affecting access needs now be explored.

Out-of-school activities run by volunteers

The National Institute for Health and Clinical Excellence (NICE, 2009) promotes accessible physical activity for all C&YP and the voluntary sector plays a significant role in promoting opportunities for disabled C&YP and their families. When approaching an activity group, first impressions can be vital, and it is the individuals running them who are the first point of contact. Due to the nature of volunteering, there may be a mix of expertise, training and understanding of disabilities. There is a dearth of research on the views of staff that plan and run mainstream activities for all C&YP regardless of whether this is inclusive mainstream or specialist provision. Knight et al. (2009) claims it is important to explore the attitudes of those individuals carrying out the activities as this may determine if someone joins or not. In Knight et al.'s study, 121 staff from across health, education, youth and the voluntary sector were interviewed about holiday provision for disabled C&YP. Most were middle or senior management rather than individuals who have face-to-face contact with children and families. Study findings highlighted areas that the C&YP and families felt were inadequate even though the staff highlighted the steps to promote greater social inclusion. It is vital that all staff running community activities, including volunteers, have the skills to support individual C&YP. They also need to have a positive attitude, making the C&YP feel welcome and encourage each child as an individual (The Bevan Foundation, 2010). When 16 disabled C&YP were interviewed, they felt afraid of being bullied and made to feel different, with an example from a young person who stated 'just because you talk funny, people think you are thick' (Beresford and Clarke, 2010: 15). Therefore, an environment where C&YP feel safe is paramount (Beresford and Clarke, 2010). In order to explore how this could be reduced both Beresford and Clarke (2010) and the Bevan Foundation (2010) looked at staff disability awareness in terms of confidence, funding and understanding. The Bevan Foundation (2010) highlighted that the relationship between the volunteers and the parents can affect the participation. However, this study did not obtain the parents views in order to compare. Although this work does indicate the need to look at factors that may affect participation, such as staff training and attitudes, neither of these studies have been published in peer-reviewed journals. Bennett (2009) found that half of the families expressed dissatisfaction with mainstream play and leisure facilities due to the lack of accessibility, travel and lack of disability training amongst staff. Therefore, there appears to be a generalised dissatisfaction in these areas so any best practice found when this is researched needs to be shared. This is supported by The Bevan Foundation's work on providers of out-of-school activities, which found that the attitudes of staff can affect the participation experiences of C&YP and their families. They compared this to the findings from interviews and observations of play workers, some of whom were from the voluntary sector, where the staff acknowledged that in the past, children may have not felt welcome because of staff attitude as they were afraid about not being able to cope. On arrival, parents and C&YP experience these negative attitudes from staff, and this will naturally cause a barrier to participation. Such a premise needs further exploration as service providers could identify negative attitudes within their teams and more importantly consider ways of ensuring that staff are adequately skilled and resourced to include all children in the activity. This study was conducted in Wales (mid and south Wales); so this needs to be extended across the UK as there may be regional funding or training differences. It is recommended that volunteers working in activities, local leisure and recreation facilities as well as the providers should be trained in disability awareness (Beresford and Clarke, 2010). It is unclear how many volunteers are trained as there is no national database, thus training is an area for improvement. In the study by Sloper et al. (2009), the need for staff to be trained was important for all the 95 families with disabled children (100 children represented), which were identified through semi-structured interviews. Of the children, 29 directly participated. This large sample included C&YP with a range of disabilities and many with complex health needs. The findings showed the importance of everyone in regular contact with the child to have appropriate knowledge and skills to understand the child's means of communication. They highlighted the importance of socialising, having friends and relationships, for example, 'when she is not at school, she wants to go places where other young people go' (Sloper et al., 2009: 271). Whilst some conclusions might be drawn from this study, it needs to be with caution. There may be some additional difficulties in this group of children related to their communication needs that may not reflect the needs of all physically disabled children. This study included families with children aged 0–18 years, therefore, like previous studies discussed, this limits the information specifically in school children aged 8–15 years. This theme highlights the need to understand the provision, training and attitudes within the out-of-school activities in order to have an understanding of a gap between service providers and service users.

Accessibility

Knight et al. (2009) found that the accessibility and location of the out-of-school activities were factors affecting participation. This can lead to a lack of contact with school friends' out-of-school times, which can affect friendship and participation. Children who attended special schools away from their local area were found to have reduced social community-based activities (Knight et al., 2009; Petrie et al., 2007; Sloper et al., 2009). The Equality Act (2010) requires reasonable adjustments to be made to remove physical access as a barrier and, therefore, should not be a factor affecting participation. However, children interviewed by the Bevan Foundation (2010) stated that many of the leisure centres they had visited were good but access was more difficult in clubs, such as community groups. This was also found in Knight et al.'s study (2009), where a 12-year-old girl could not access a youth club due to physical access barriers. This limits their choice, which links back to the importance of the C&YP having a preference to any activity. Petrie et al. (2007) also found that the requirement in some cases was for parents to accompany the disabled child/young person to holiday activities, which may not be what they want. In addition, Lawlor et al. (2006) reported problems in accessing social and leisure provision in their study in the North East of England. Twelve parents/grandparents of 5- to 17-year-old children with cerebral palsy outlined lack of access to public transport and to buildings, making participation difficult. This study did not solely focus on the leisure activities but addressed it as one area of difficulty within their aim looking at activities of daily living. It does, however, give good insight into the factors affecting participation in out-of-school activities. It would have been beneficial to hear from more of the C&YP themselves in this study as only two children gave their views. This problem with access is echoed by another parent in the study by Bennett (2009: 10), who states that 'there is no suitable swimming or parks nearby with accessible equipment'.

Multiple issues within this overarching theme such as activity timing, location and physical access need to be specifically compared from a service user and service provider view in order to fully understand the challenges faced by disabled C&YP.

Limitations of the review

Due to the limited published work in this area, this review is based predominately on the grey literature, which is not peer reviewed and can potentially introduce bias into the results. To overcome this, all work was critically appraised. The weak evidence base demonstrates the lack of robust evidence about the out-of-school lives of disabled C&YP and their families in the UK.

Conclusion

This review of the qualitative literature highlights the absence of the service user's voice in relation to out-of-school activities in the UK. The evidence suggests that disabled C&YP wish to access and participate in out-of-school activities but encounter barriers. The need for social inclusion is clear, but the mitigating factors include the need for training and addressing accessibility issues. There are threads throughout, which require further research such as parental influence, provision, training and attitudes within the out-of-school activities. Further research is required to investigate the factors affecting physically disabled C&YP's participation of out-of-school activities from the viewpoint of both the service users and service providers.

Acknowledgement

We would like to acknowledge Rob Caley, Research and Learner Support Officer, for his assistance in choosing appropriate databases and checking search strategies.

Funding

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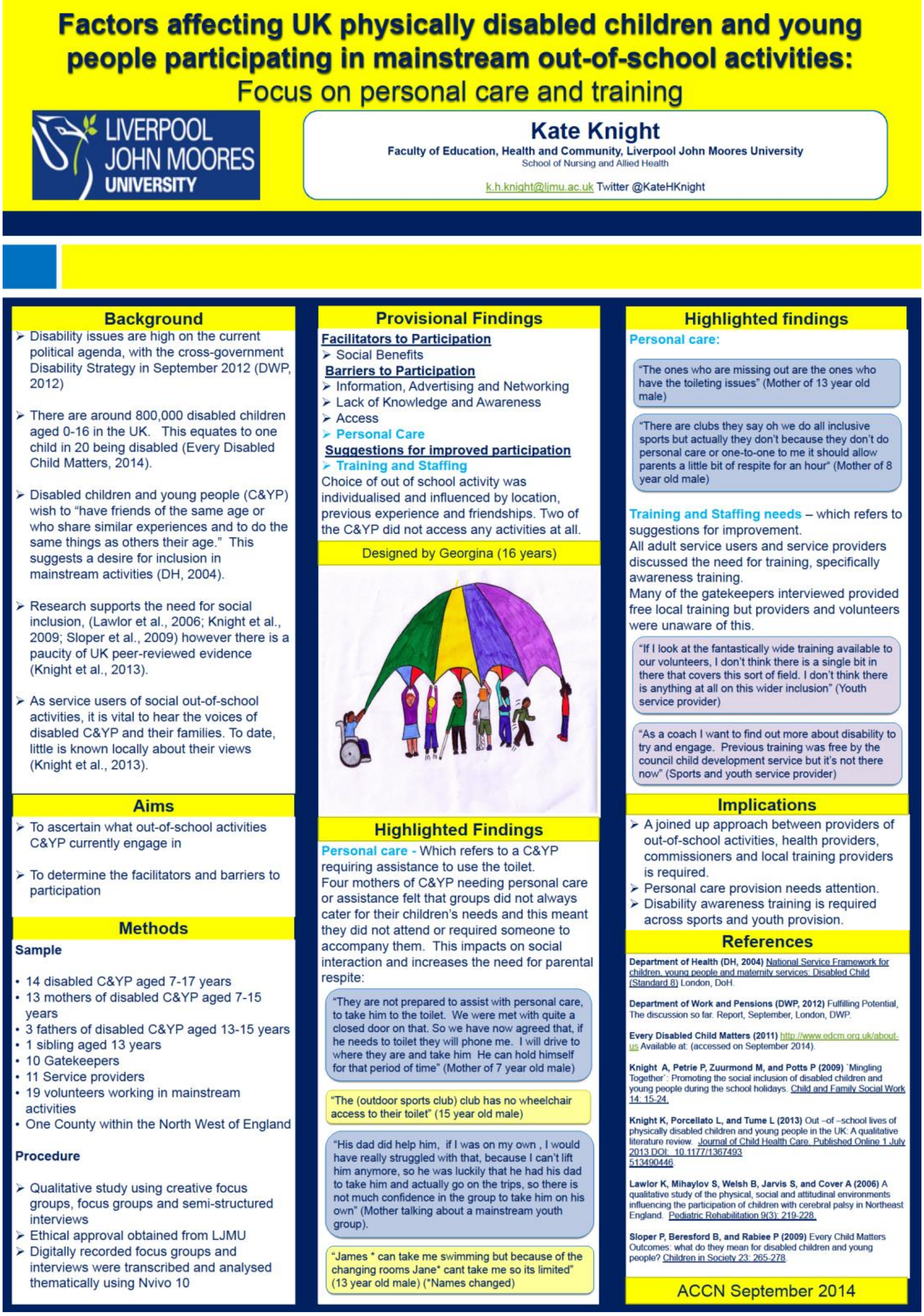
7.1.2 Poster Published

Knight, K. Porcellato, L. Vickerman, P. Greenop, D. (2014) Factors affecting UK Physically Disabled Children and Young People Participating in Mainstream Out-of-School Activities: Focus on Personal Care and Training. Working Papers in the Health Sciences (2014). Autumn edition. Available at: http://www.southampton.ac.uk/assets/centresresearch/documents/wphs/POSTER%20KATE%20KNIGHT%20June%202014.pdf



Factors affecting UK physically disabled children and young people participating in mainstream out-of-school activities:

Focus on personal care and training

LIVERPOOL JOHN MOORES UNIVERSITY

Kate Knight

Faculty of Education, Health and Community, Liverpool John Moores University

School of Nursing and Allied Health

k.h.knight@ljmu.ac.uk Twitter @KateHKnight

Background

- Disability issues are high on the current political agenda, with the cross-government Disability Strategy in September 2012 (DWP, 2012)
- There are around 800,000 disabled children aged 0-16 in the UK. This equates to one child in 20 being disabled (Every Disabled Child Matters, 2014).
- Disabled children and young people (C&YP) wish to "have friends of the same age or who share similar experiences and to do the same things as others their age." This suggests a desire for inclusion in mainstream activities (DH, 2004).
- Research supports the need for social inclusion, (Lawlor et al., 2006; Knight et al., 2009; Sloper et al., 2009) however there is a paucity of UK peer-reviewed evidence (Knight et al., 2013).
- As service users of social out-of-school activities, it is vital to hear the voices of disabled C&YP and their families. To date, little is known locally about their views (Knight et al., 2013).

Aims

- To ascertain what out-of-school activities C&YP currently engage in
- To determine the facilitators and barriers to participation

Methods

Sample

- 14 disabled C&YP aged 7-17 years
- 13 mothers of disabled C&YP aged 7-15 years
- 3 fathers of disabled C&YP aged 13-15 years
- 1 sibling aged 13 years
- 10 Gatekeepers
- 11 Service providers
- 19 volunteers working in mainstream activities
- One County within the North West of England

Procedure

- Qualitative study using creative focus groups, focus groups and semi-structured interviews
- Ethical approval obtained from LJMU
- Digitally recorded focus groups and interviews were transcribed and analysed thematically using Nvivo 10

Provisional Findings

Facilitators to Participation

- Social Benefits

Barriers to Participation

- Information, Advertising and Networking
- Lack of Knowledge and Awareness
- Access
- **Personal Care**

Suggestions for improved participation

- **Training and Staffing**

Choice of out of school activity was individualised and influenced by location, previous experience and friendships. Two of the C&YP did not access any activities at all.

Designed by Georgina (16 years)

Highlighted Findings

Personal care - Which refers to a C&YP requiring assistance to use the toilet.
Four mothers of C&YP needing personal care or assistance felt that groups did not always cater for their children's needs and this meant they did not attend or required someone to accompany them. This impacts on social interaction and increases the need for parental respite:

> "They are not prepared to assist with personal care, to take him to the toilet. We were met with quite a closed door on that. So we have now agreed that, if he needs to toilet they will phone me. I will drive to where they are and take him He can hold himself for that period of time" (Mother of 7 year old male)

> "The (outdoor sports club) club has no wheelchair access to their toilet" (15 year old male)

> "His dad did help him, if I was on my own , I would have really struggled with that, because I can't lift him anymore, so he was luckily that he had his dad to take him and actually go on the trips, so there is not much confidence in the group to take him on his own" (Mother talking about a mainstream youth group).

> "James * can take me swimming but because of the changing rooms Jane* cant take me so its limited" (13 year old male) (*Names changed)

Highlighted findings

Personal care:

> "The ones who are missing out are the ones who have the toileting issues" (Mother of 13 year old male)

> "There are clubs they say oh we do all inclusive sports but actually they don't because they don't do personal care or one-to-one to me it should allow parents a little bit of respite for an hour" (Mother of 8 year old male)

Training and Staffing needs – which refers to suggestions for improvement.
All adult service users and service providers discussed the need for training, specifically awareness training.
Many of the gatekeepers interviewed provided free local training but providers and volunteers were unaware of this.

> "If I look at the fantastically wide training available to our volunteers, I don't think there is a single bit in there that covers this sort of field. I don't think there is anything at all on this wider inclusion" (Youth service provider)

> "As a coach I want to find out more about disability to try and engage. Previous training was free by the council child development service but it's not there now" (Sports and youth service provider)

Implications

- A joined up approach between providers of out-of-school activities, health providers, commissioners and local training providers is required.
- Personal care provision needs attention.
- Disability awareness training is required across sports and youth provision.

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ACCN September 2014

7.2 Ethical Approval

12/HEA/048 Liverpool John Moores University Research Ethics Committee (REC)

Dear Kate,

With reference to your application for Ethical approval.

12/HEA/048, Kate Knight, PGR, Factors affecting UK physically disabled children and young people participating in mainstream out-of-school activities (Lorna Porcellato)

Liverpool John Moores University Research Ethics Committee (REC) has reviewed the above application at the last meeting. I am pleased to inform you that ethical approval has been granted and the study can now commence.

Approval is given on the understanding that:

- any adverse reactions/events which take place during the course of the project are reported to the Committee immediately;
- any unforeseen ethical issues arising during the course of the project will be reported to the Committee immediately;
- the LJMU logo is used for all documentation relating to participant recruitment and participation eg poster, information sheets, consent forms, questionnaires. The LJMU logo can be accessed at http://www.ljmu.ac.uk/corporatecommunications/60486.htm

Where any substantive amendments are proposed to the protocol or study procedures further ethical approval must be sought.

Applicants should note that where relevant appropriate gatekeeper / management permission must be obtained prior to the study commencing at the study site concerned.

For details on how to report adverse events or request ethical approval of major amendments please refer to the information provided at
http://www.ljmu.ac.uk/RGSO/RGSO_Docs/EC8Adverse.pdf

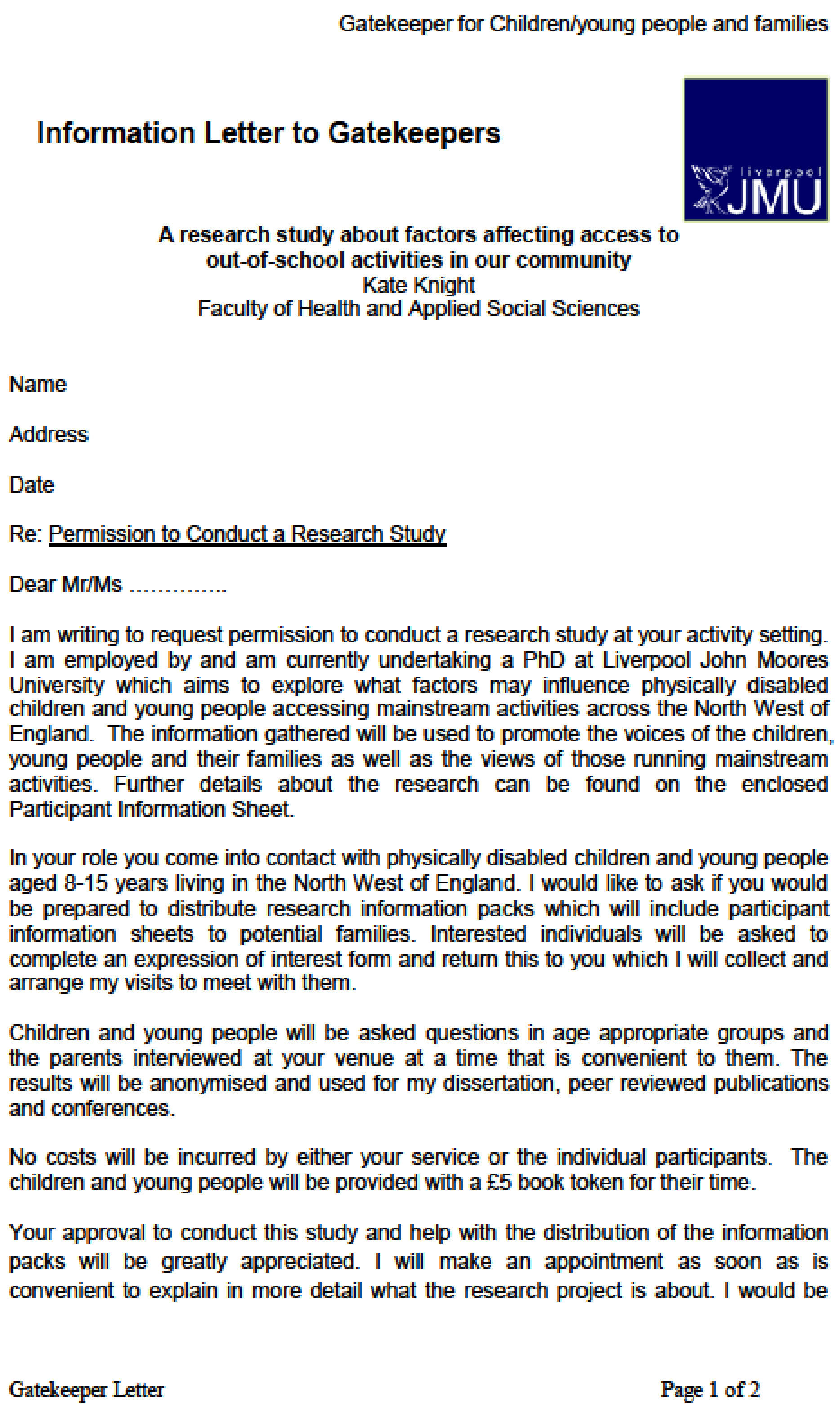
Please note that ethical approval is given for a period of five years from the date granted and therefore the expiry date for this project will be September 2017. An application for extension of approval must be submitted if the project continues after this date.

Mandy Williams
Research Support Officer
Research Support Office
4th Floor, Kingsway House
Hatton Garden
Liverpool L3 2AJ
t: 0151 904 6467
f: 0151 904 6462
e: a.f.williams@ljmu.ac.uk

7.3 Ethical Approval; Letters, Consent forms and Participation Information Sheets for Study 1 (Service Users)

The following documents were utilised to ensure the research followed educational research ethical guidelines from Liverpool John Moores (LJMU) Research Committee and Ethical guidelines.

7.3.1 Gatekeeper Letter to recruit PDC&YP



Gatekeeper for Children/young people and families

Information Letter to Gatekeepers

A research study about factors affecting access to
out-of-school activities in our community
Kate Knight
Faculty of Health and Applied Social Sciences

Name

Address

Date

Re: Permission to Conduct a Research Study

Dear Mr/Ms ....

I am writing to request permission to conduct a research study at your activity setting. I am employed by and am currently undertaking a PhD at Liverpool John Moores University which aims to explore what factors may influence physically disabled children and young people accessing mainstream activities across the North West of England. The information gathered will be used to promote the voices of the children, young people and their families as well as the views of those running mainstream activities. Further details about the research can be found on the enclosed Participant Information Sheet.

In your role you come into contact with physically disabled children and young people aged 8-15 years living in the North West of England. I would like to ask if you would be prepared to distribute research information packs which will include participant information sheets to potential families. Interested individuals will be asked to complete an expression of interest form and return this to you which I will collect and arrange my visits to meet with them.

Children and young people will be asked questions in age appropriate groups and the parents interviewed at your venue at a time that is convenient to them. The results will be anonymised and used for my dissertation, peer reviewed publications and conferences.

No costs will be incurred by either your service or the individual participants. The children and young people will be provided with a £5 book token for their time.

Your approval to conduct this study and help with the distribution of the information packs will be greatly appreciated. I will make an appointment as soon as is convenient to explain in more detail what the research project is about. I would be happy to answer any questions or concerns that you may have. You may contact me at my email address: k.h.knight@ljmu.ac.uk

With many thanks in advance

Kate Knight

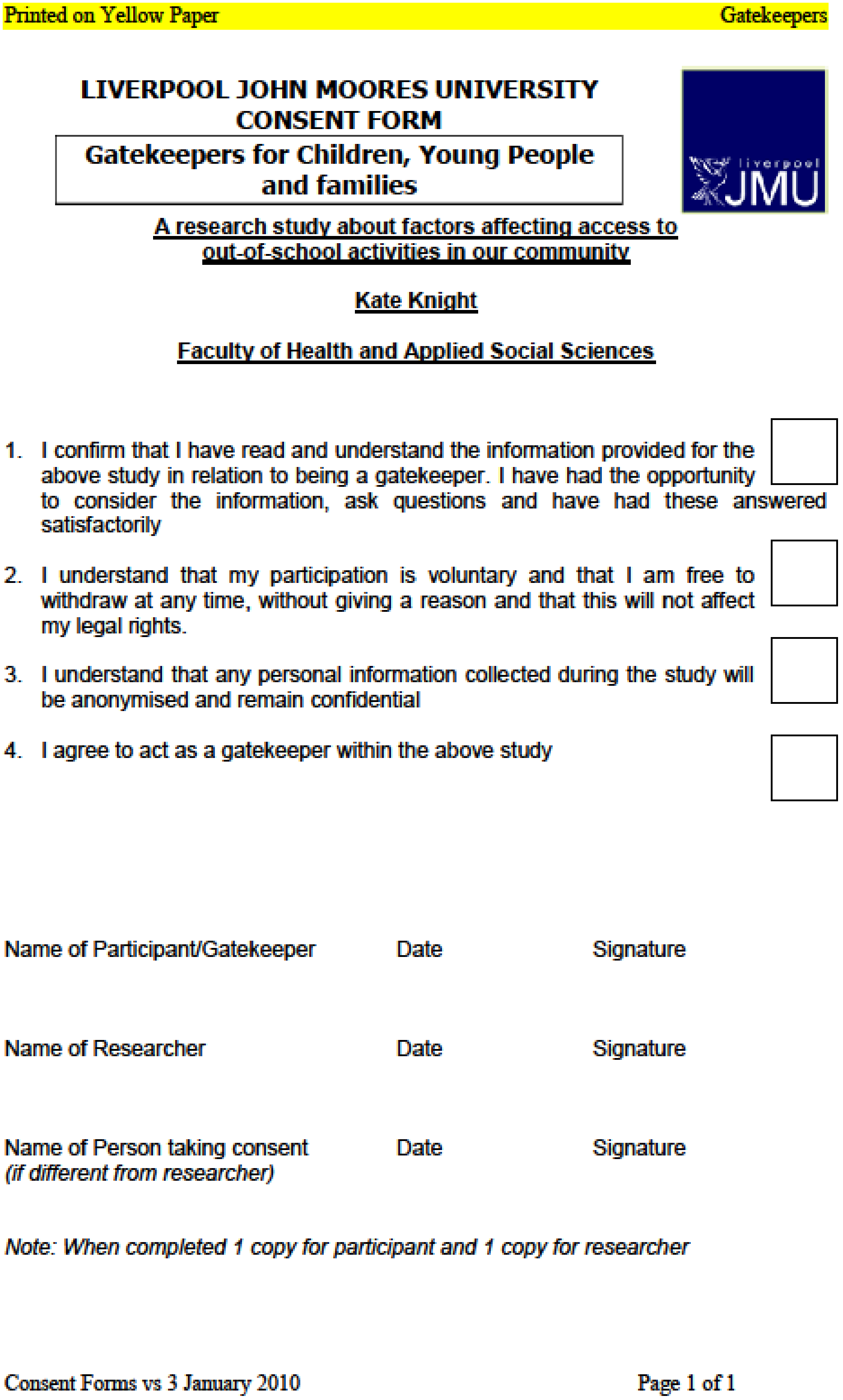
liverpool JMU

Faculty of
Health and Applied Social Sciences

Kate Knight *RNC BA(Hons) M.Res PG cert HE*
Senior Lecturer Child Nursing
Faculty of Health and Applied Social Sciences

Room 3.33 Henry Cotton Campus , 15-21 Webster Street,
Liverpool , L3 2ET
t: 01512314503 e: K.H.Knight@ljmu.ac.uk
w: www.ljmu.ac.uk

7.3.2 Gatekeeper Consent Form



Printed on Yellow Paper Gatekeepers

LIVERPOOL JOHN MOORES UNIVERSITY
CONSENT FORM

Gatekeepers for Children, Young People and families

A research study about factors affecting access to out-of-school activities in our community

Kate Knight

Faculty of Health and Applied Social Sciences

1. I confirm that I have read and understand the information provided for the above study in relation to being a gatekeeper. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and that this will not affect my legal rights. ☐
3. I understand that any personal information collected during the study will be anonymised and remain confidential ☐
4. I agree to act as a gatekeeper within the above study ☐

Name of Participant/Gatekeeper Date Signature

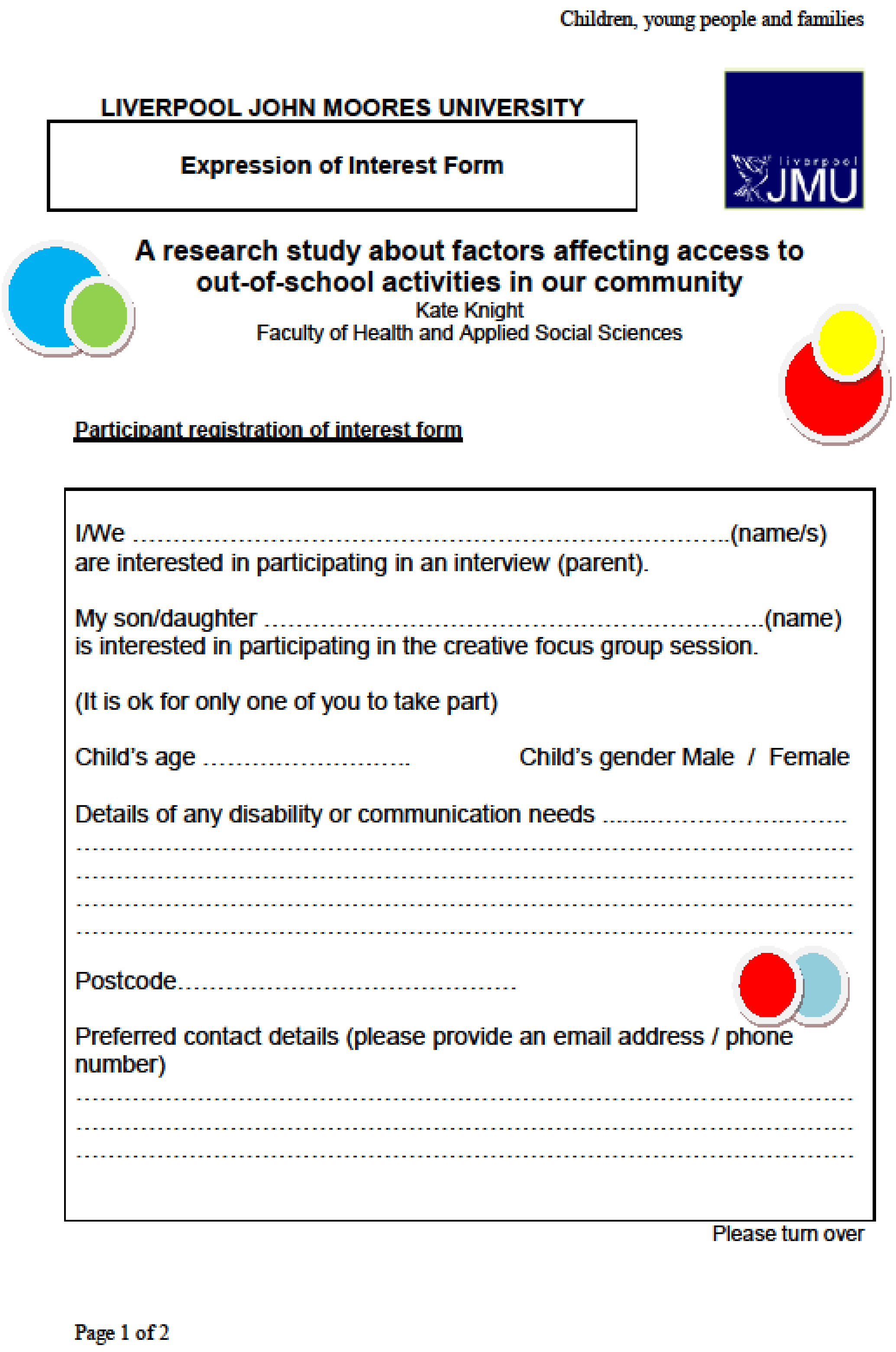
Name of Researcher Date Signature

Name of Person taking consent Date Signature
(if different from researcher)

Note: When completed 1 copy for participant and 1 copy for researcher

Consent Forms vs 3 January 2010 Page 1 of 1

7.3.3 Service User Expression of Interest Form



Children, young people and families

LIVERPOOL JOHN MOORES UNIVERSITY

Expression of Interest Form

A research study about factors affecting access to out-of-school activities in our community

Kate Knight

Faculty of Health and Applied Social Sciences

Participant registration of interest form

I/We ....(name/s)
are interested in participating in an interview (parent).

My son/daughter ....(name)
is interested in participating in the creative focus group session.

(It is ok for only one of you to take part)

Child's age ....   Child's gender Male / Female

Details of any disability or communication needs ....
....
....
....
....

Postcode...

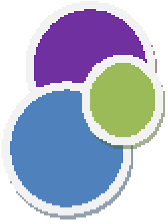
Preferred contact details (please provide an email address / phone number)
....
....
....

Please turn over

Page 1 of 2

Parent availability

What would be the best day and time for you to attend an interview?
(Please circle all that apply)



- Monday
- Tuesday
- Wednesday
- Thursday
- Friday
- Saturday
- Sunday

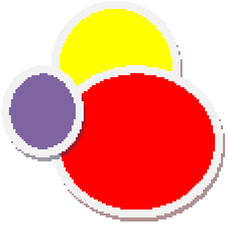
- Morning
- Afternoon
- Evening

Details ………………………………………………………………………………………

Child/young person availability

What would be the best day and time for your son/daughter to attend a group session?
(Please circle all that apply)

- Monday
- Tuesday
- Wednesday
- Thursday
- Friday
- Saturday
- Sunday

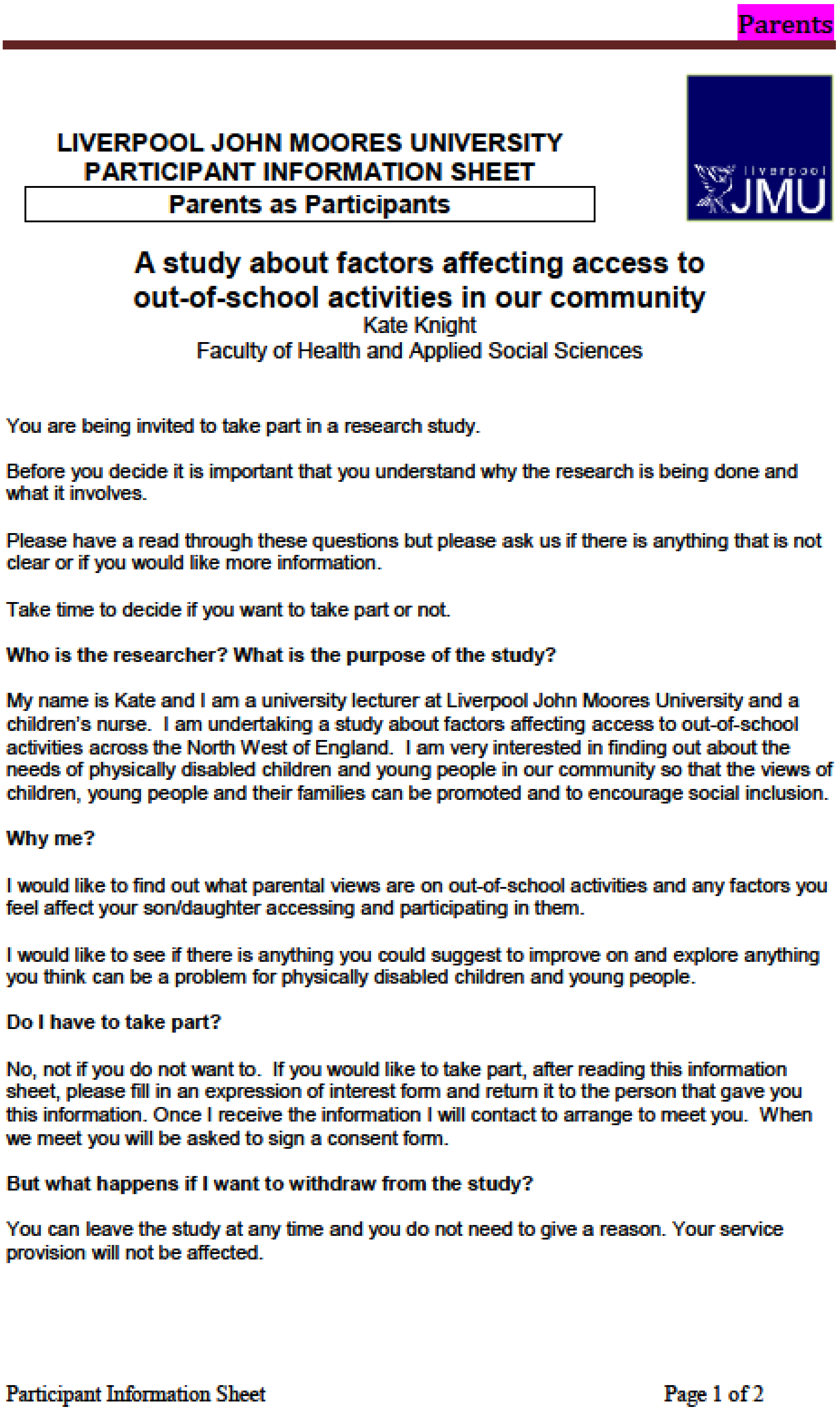


- Morning
- Afternoon
- Evening

Details ………………………………………………………………………………………

Please return this completed form to the person who gave you the information about this study. You will shortly be contacted by researcher Kate Knight .

7.3.4 Parents Participation Information Sheet



Parents

LIVERPOOL JOHN MOORES UNIVERSITY
PARTICIPANT INFORMATION SHEET
Parents as Participants

A study about factors affecting access to out-of-school activities in our community

Kate Knight
Faculty of Health and Applied Social Sciences

You are being invited to take part in a research study.

Before you decide it is important that you understand why the research is being done and what it involves.

Please have a read through these questions but please ask us if there is anything that is not clear or if you would like more information.

Take time to decide if you want to take part or not.

Who is the researcher? What is the purpose of the study?

My name is Kate and I am a university lecturer at Liverpool John Moores University and a children's nurse. I am undertaking a study about factors affecting access to out-of-school activities across the North West of England. I am very interested in finding out about the needs of physically disabled children and young people in our community so that the views of children, young people and their families can be promoted and to encourage social inclusion.

Why me?

I would like to find out what parental views are on out-of-school activities and any factors you feel affect your son/daughter accessing and participating in them.

I would like to see if there is anything you could suggest to improve on and explore anything you think can be a problem for physically disabled children and young people.

Do I have to take part?

No, not if you do not want to. If you would like to take part, after reading this information sheet, please fill in an expression of interest form and return it to the person that gave you this information. Once I receive the information I will contact to arrange to meet you. When we meet you will be asked to sign a consent form.

But what happens if I want to withdraw from the study?

You can leave the study at any time and you do not need to give a reason. Your service provision will not be affected.

Participant Information Sheet Page 1 of 2

What does the research involve?

This will involve a one-to-one interview with me to discuss your views. It will take approximately one hour at a convenient time for you. It will take place at the venue where you heard about this study.

With your consent, I will record the interview using a digital voice recorder. This will then be typed up so that the information can be analysed but the recording will be destroyed at the end of the research study.

What are the risks/benefits?

I am sure there are no risks from doing this but if you have any concerns or worries about anything we talk about then please let me know and we can stop at any time.

I hope by listening to the views of children, young people and their families we can share these views to others involved in planning and running activities so services can improve.

Who has checked if this study can go ahead?

All research projects have to be reviewed for ethical approval to make sure that they are worthwhile, well organised and safe for the people taking part. The decision is made by a committee of experts who are not connected to the project in any way.

Will it be kept confidential?

Any information we discuss will be kept confidential. Some sections of what we discuss will be used to portray your views but we will never put your name with this. If you want to look at any of the anonymised findings you can do that by contacting me directly.

The only time I will have to break confidentiality is if I feel someone is not safe.

What happens after the study?

All the information collected will form the basis of my PhD which I will publish in some peer reviewed journals. I am also planning to promote this during conferences which will involve large groups of people with the aim to promote the needs of physically disabled children and young people.

Who can I talk to about the study?

I can be contacted on 0151 231 4503 or k.h.knight@ljmu.ac.uk. I am based at Liverpool John Moores University.

7.3.5 PDC&YP Participation Information Leaflet

Is everything we talk about private?

Yes, I will not tell anybody your name or that it was you in the study. I may publish some sections of our discussion but I will never use your real name. If you want to look at any of the findings or what may go in a published article you can do and you can do that by contacting me. Whoever looks after you will know you are in the study.

However if I feel someone is not safe I have to tell somebody.

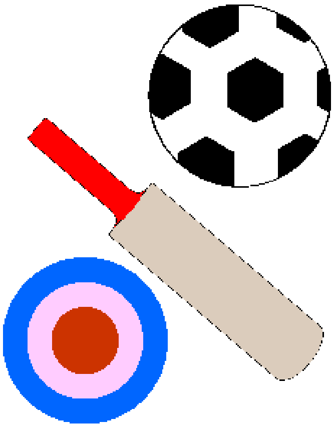
What happens after the study?

I am going to collect all the information and put it together in a big project that I will share. I am planning to go and talk to groups of people about the findings so that the needs of disabled children and young people can be promoted.

Who can I talk to about the study?

You can talk to your family, your activity leader or me about the research.

I can be contacted on 0151 231 4503 or k.h.knight@ljmu.ac.uk. I am based at Liverpool John Moores University.



Designer/Editor—Georgina, age 16
Editor—Lucas, age 10

A study to determine factors affecting access to out-of-school activities in our community

Kate Knight
Faculty of Health and Applied Social Sciences

Who is the researcher?

My name is Kate and I am a children's nurse and a university lecturer.

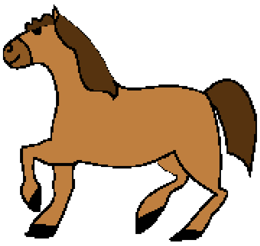
In my spare time I am also a volunteer as a cub scout leader in my local area

Why me?

I would like to invite you to help me find out about out-of-school activities in your area.

I am asking disabled children and young people aged 8-15 years old.

Before you decide it is important that you understand why the research is being done and what it involves. Please have a read through this leaflet but please ask me if there is anything that you are unsure about. Please take time to decide if you want to take part or not.



Do I have to take part?

No, not if you do not want to.
If you would like to take part after reading this leaflet, you will be asked to sign a form to say you would like to join in. The person/people who look after you will be asked to sign a consent form also.

But what happens if I want to drop out of the study?

If you feel you don't want to carry on, please just tell me or the person you came with, and you don't even need to give a reason.

What happens if I take part?

You, me and some other children/ young people will meet and chat about the out-of-school activities, but we will do this whilst doing some fun activities.
If it is ok with you I will record this using a digital voice recorder as I can not remember what everybody says. Once the study has finished the recording will be destroyed.

The whole thing should only last about an hour. We can have regular breaks.

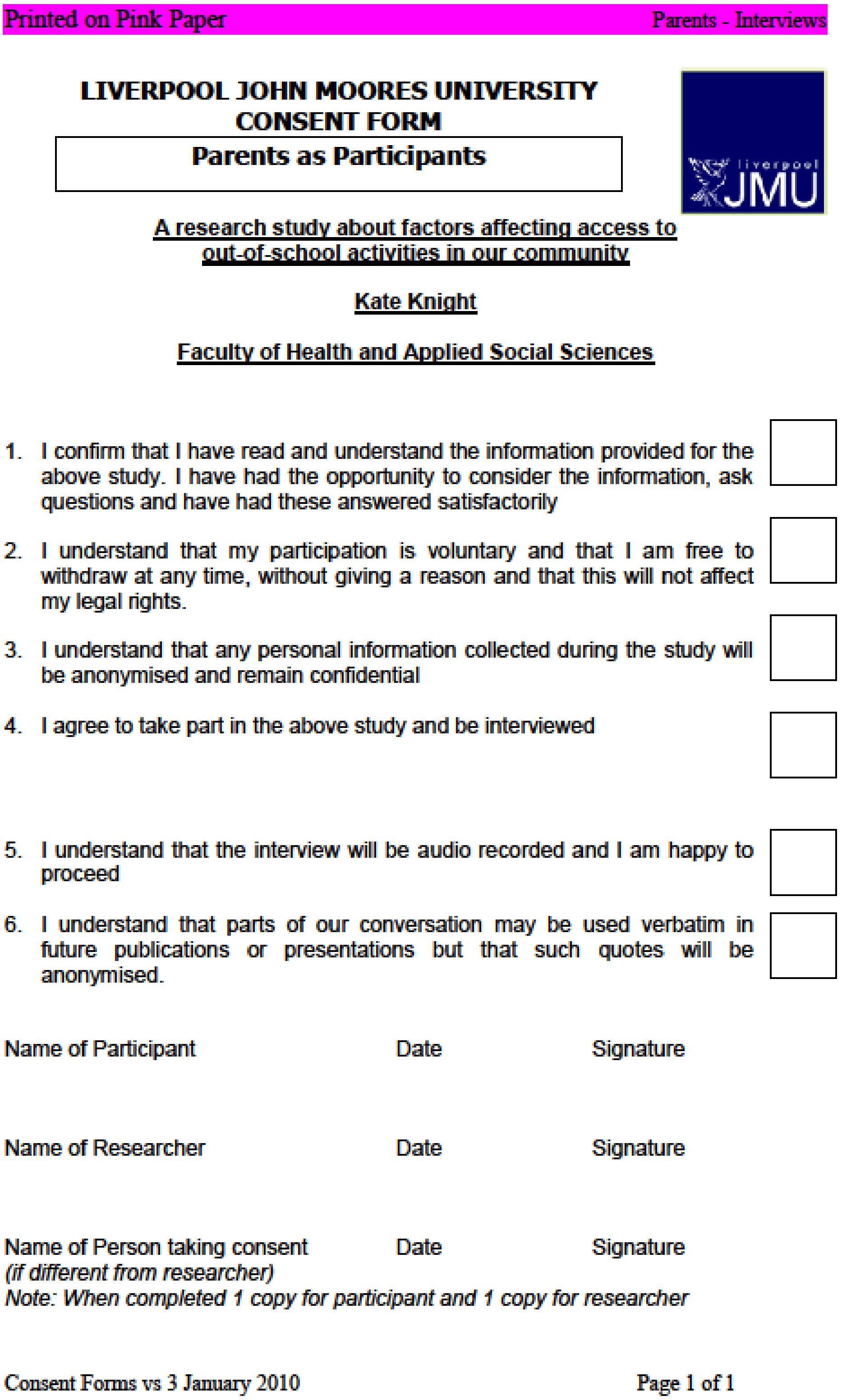
Will anything bad happen to me?

No, but if you have any concerns or worries about anything we talk about then please let me know and we can stop at any time.

Can anything good happen to me?

I hope that my work will help people understand improvements that can be made to accessing out-of-school activities.
You will get a £5 book voucher.

7.3.6 Parent Consent Form – Own Participation



Printed on Pink Paper Parents - Interviews

LIVERPOOL JOHN MOORES UNIVERSITY
CONSENT FORM

Parents as Participants

A research study about factors affecting access to out-of-school activities in our community

Kate Knight

Faculty of Health and Applied Social Sciences

1. I confirm that I have read and understand the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and that this will not affect my legal rights. ☐
3. I understand that any personal information collected during the study will be anonymised and remain confidential ☐
4. I agree to take part in the above study and be interviewed ☐
5. I understand that the interview will be audio recorded and I am happy to proceed ☐
6. I understand that parts of our conversation may be used verbatim in future publications or presentations but that such quotes will be anonymised. ☐

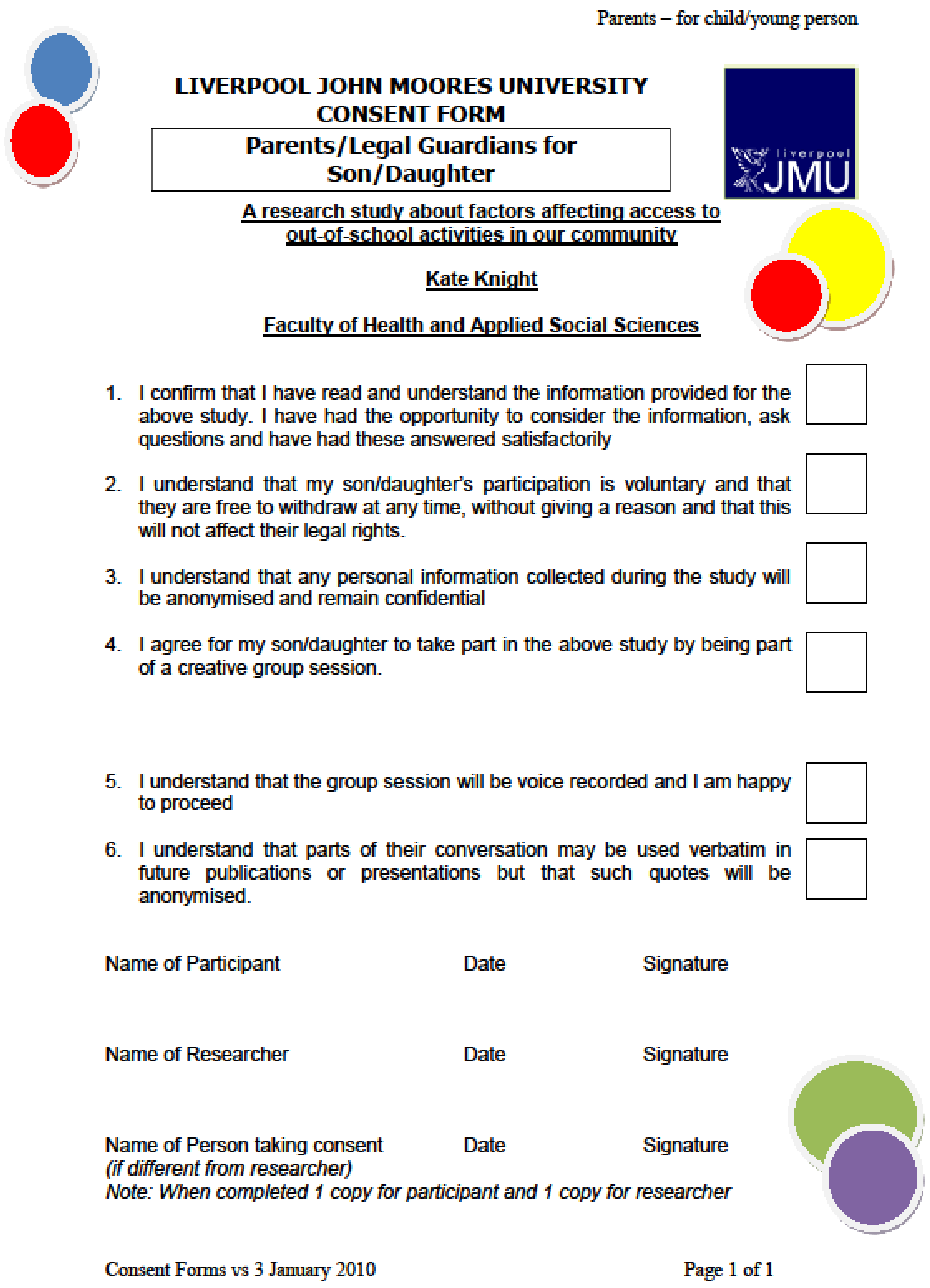
Name of Participant Date Signature

Name of Researcher Date Signature

Name of Person taking consent Date Signature
(if different from researcher)
Note: When completed 1 copy for participant and 1 copy for researcher

Consent Forms vs 3 January 2010 Page 1 of 1

7.3.7 Consent Form – Parent for PDC&YP



Parents – for child/young person

LIVERPOOL JOHN MOORES UNIVERSITY
CONSENT FORM

Parents/Legal Guardians for
Son/Daughter

A research study about factors affecting access to out-of-school activities in our community

Kate Knight

Faculty of Health and Applied Social Sciences

1. I confirm that I have read and understand the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐
2. I understand that my son/daughter's participation is voluntary and that they are free to withdraw at any time, without giving a reason and that this will not affect their legal rights. ☐
3. I understand that any personal information collected during the study will be anonymised and remain confidential ☐
4. I agree for my son/daughter to take part in the above study by being part of a creative group session. ☐
5. I understand that the group session will be voice recorded and I am happy to proceed ☐
6. I understand that parts of their conversation may be used verbatim in future publications or presentations but that such quotes will be anonymised. ☐

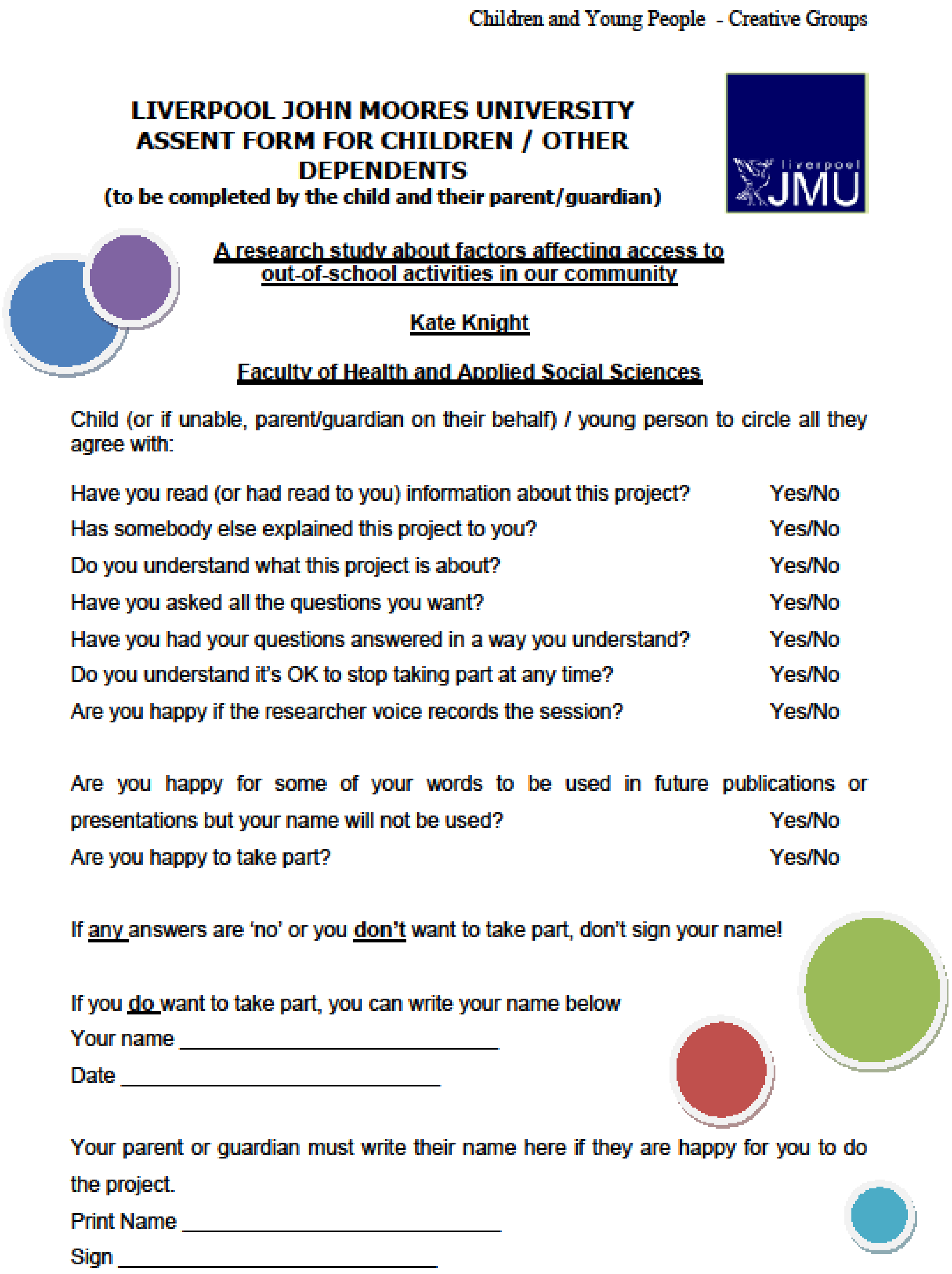
Name of Participant Date Signature

Name of Researcher Date Signature

Name of Person taking consent Date Signature
(if different from researcher)
Note: When completed 1 copy for participant and 1 copy for researcher

Consent Forms vs 3 January 2010 Page 1 of 1

7.3.8 PDC&YP Assent Form



Children and Young People - Creative Groups

LIVERPOOL JOHN MOORES UNIVERSITY
ASSENT FORM FOR CHILDREN / OTHER DEPENDENTS
(to be completed by the child and their parent/guardian)

A research study about factors affecting access to out-of-school activities in our community

Kate Knight

Faculty of Health and Applied Social Sciences

Child (or if unable, parent/guardian on their behalf) / young person to circle all they agree with:

Have you read (or had read to you) information about this project?	Yes/No
Has somebody else explained this project to you?	Yes/No
Do you understand what this project is about?	Yes/No
Have you asked all the questions you want?	Yes/No
Have you had your questions answered in a way you understand?	Yes/No
Do you understand it's OK to stop taking part at any time?	Yes/No
Are you happy if the researcher voice records the session?	Yes/No
Are you happy for some of your words to be used in future publications or presentations but your name will not be used?	Yes/No
Are you happy to take part?	Yes/No

If any answers are 'no' or you **don't** want to take part, don't sign your name!

If you **do** want to take part, you can write your name below

Your name ______________________________

Date ______________________________

Your parent or guardian must write their name here if they are happy for you to do the project.

Print Name ______________________________

Sign ______________________________

Date ____________________________

The researcher who explained this project to you needs to sign too.

Print Name ____________________________

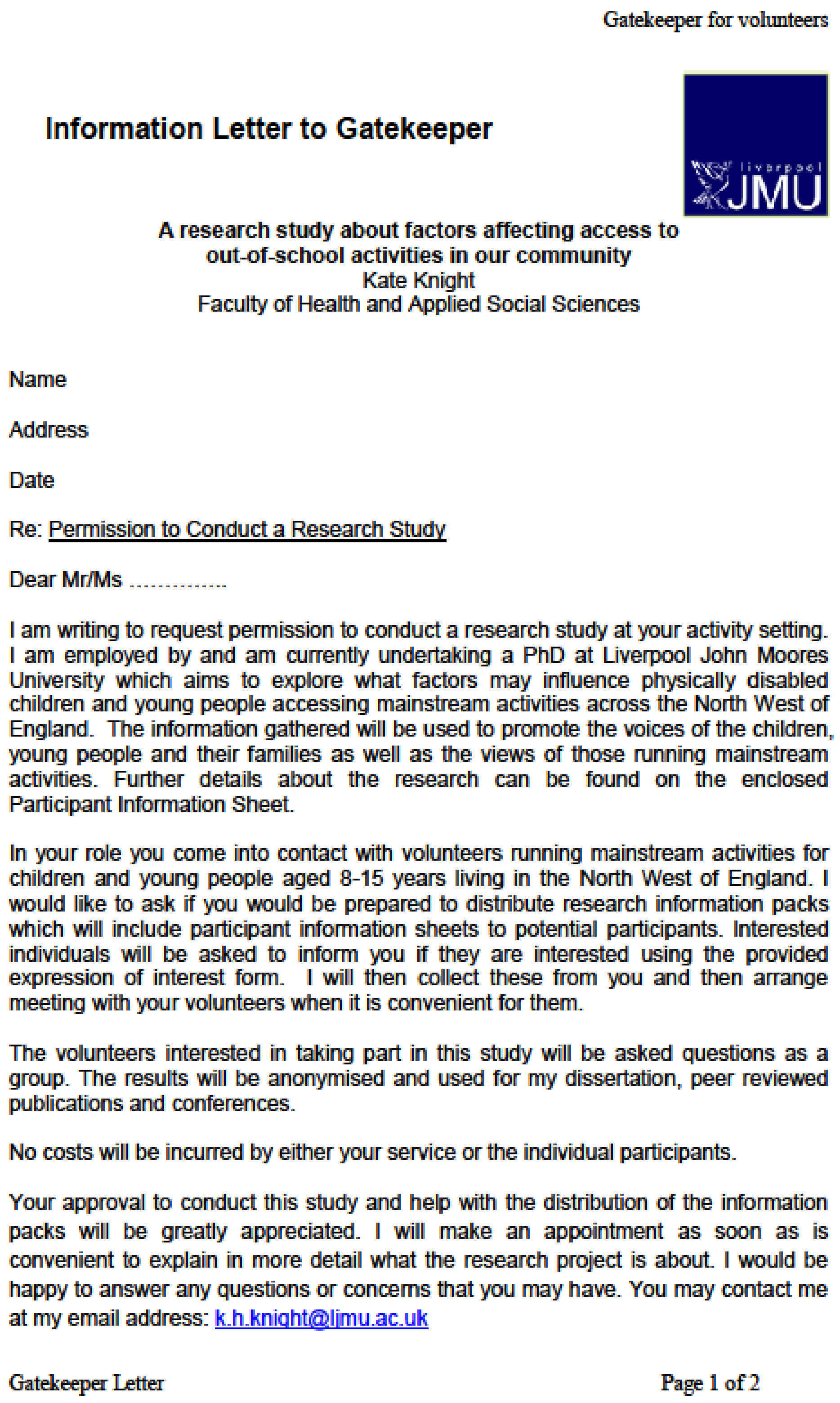
Sign ____________________________

Date ____________________________

7.4 Ethical Approval; Letters, Consent forms and Participation Information Sheets for Study 2 (Service Providers)

The following documents were utilised to ensure the research followed educational research ethical guidelines from Liverpool John Moores (LJMU) Research Committee and Ethical guidelines.

7.4.1 Gatekeeper Letter



Information Letter to Gatekeeper

A research study about factors affecting access to
out-of-school activities in our community
Kate Knight
Faculty of Health and Applied Social Sciences

Name

Address

Date

Re: Permission to Conduct a Research Study

Dear Mr/Ms ....

I am writing to request permission to conduct a research study at your activity setting. I am employed by and am currently undertaking a PhD at Liverpool John Moores University which aims to explore what factors may influence physically disabled children and young people accessing mainstream activities across the North West of England. The information gathered will be used to promote the voices of the children, young people and their families as well as the views of those running mainstream activities. Further details about the research can be found on the enclosed Participant Information Sheet.

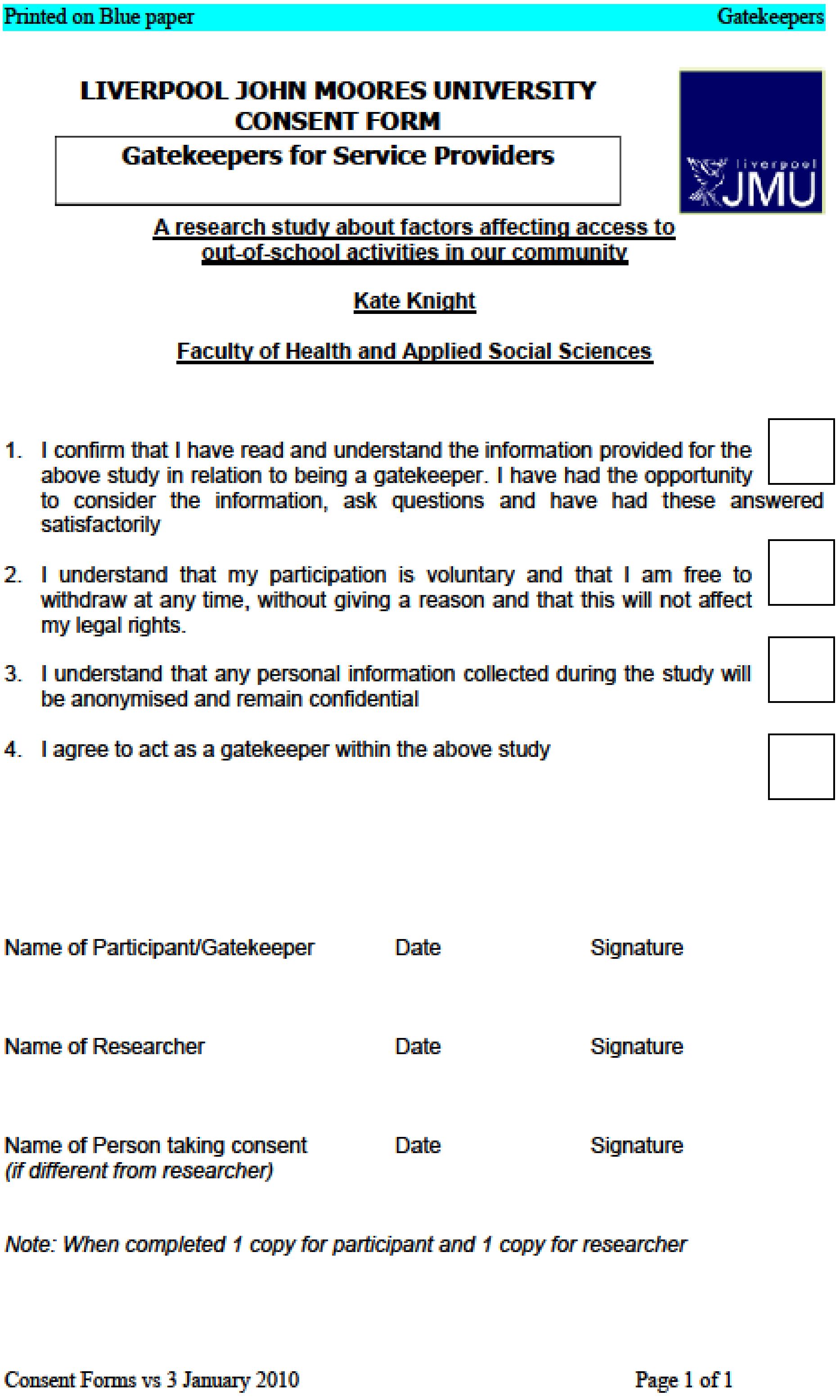
In your role you come into contact with volunteers running mainstream activities for children and young people aged 8-15 years living in the North West of England. I would like to ask if you would be prepared to distribute research information packs which will include participant information sheets to potential participants. Interested individuals will be asked to inform you if they are interested using the provided expression of interest form. I will then collect these from you and then arrange meeting with your volunteers when it is convenient for them.

The volunteers interested in taking part in this study will be asked questions as a group. The results will be anonymised and used for my dissertation, peer reviewed publications and conferences.

No costs will be incurred by either your service or the individual participants.

Your approval to conduct this study and help with the distribution of the information packs will be greatly appreciated. I will make an appointment as soon as is convenient to explain in more detail what the research project is about. I would be happy to answer any questions or concerns that you may have. You may contact me at my email address: k.h.knight@ljmu.ac.uk

7.4.2 Gatekeeper Consent Form



Printed on Blue paper Gatekeepers

LIVERPOOL JOHN MOORES UNIVERSITY
CONSENT FORM
Gatekeepers for Service Providers

A research study about factors affecting access to out-of-school activities in our community

Kate Knight

Faculty of Health and Applied Social Sciences

1. I confirm that I have read and understand the information provided for the above study in relation to being a gatekeeper. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and that this will not affect my legal rights. ☐
3. I understand that any personal information collected during the study will be anonymised and remain confidential ☐
4. I agree to act as a gatekeeper within the above study ☐

Name of Participant/Gatekeeper Date Signature

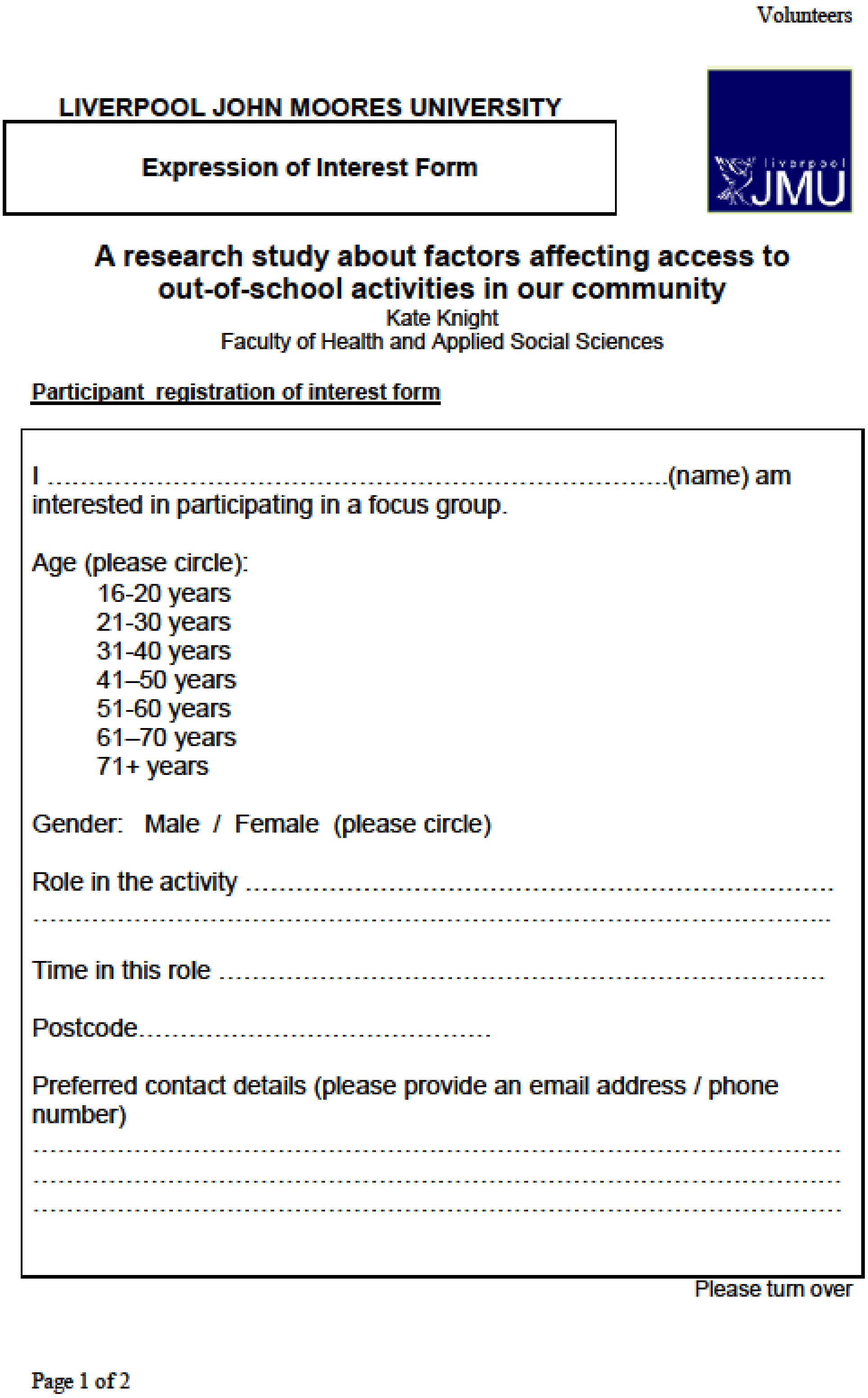
Name of Researcher Date Signature

Name of Person taking consent Date Signature
(if different from researcher)

Note: When completed 1 copy for participant and 1 copy for researcher

Consent Forms vs 3 January 2010 Page 1 of 1

7.4.3 Service User Expression of Interest Form



Volunteers

LIVERPOOL JOHN MOORES UNIVERSITY

Expression of Interest Form

A research study about factors affecting access to out-of-school activities in our community

Kate Knight

Faculty of Health and Applied Social Sciences

Participant registration of interest form

I ....(name) am interested in participating in a focus group.

Age (please circle):

- 16-20 years
- 21-30 years
- 31-40 years
- 41–50 years
- 51-60 years
- 61–70 years
- 71+ years

Gender: Male / Female (please circle)

Role in the activity ....
....

Time in this role ....

Postcode..

Preferred contact details (please provide an email address / phone number)

....
....
....

Please turn over

Page 1 of 2

Volunteer availability

What would be the best day and time for you to attend a focus group? (Please circle all that apply)

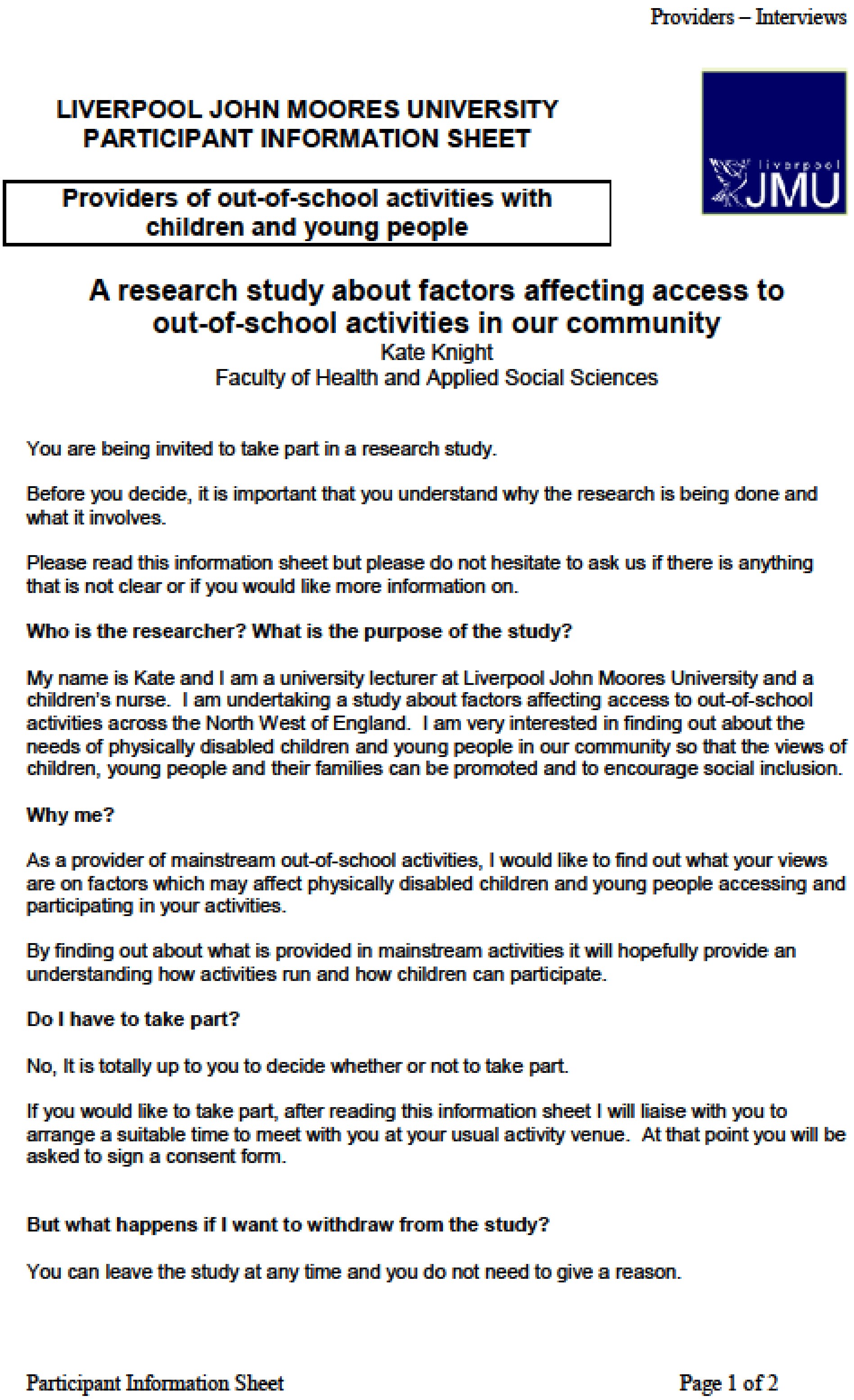
- Monday
- Tuesday
- Wednesday
- Thursday
- Friday
- Saturday
- Sunday

- Morning
- Afternoon
- Evening

Details ....
....

Please return this completed form to the person who gave you the information about this study.
You will shortly be contacted by researcher Kate Knight .

7.4.4 Activity Planner Participation Information Sheet



Providers – Interviews

LIVERPOOL JOHN MOORES UNIVERSITY
PARTICIPANT INFORMATION SHEET

Providers of out-of-school activities with children and young people

A research study about factors affecting access to out-of-school activities in our community

Kate Knight
Faculty of Health and Applied Social Sciences

You are being invited to take part in a research study.

Before you decide, it is important that you understand why the research is being done and what it involves.

Please read this information sheet but please do not hesitate to ask us if there is anything that is not clear or if you would like more information on.

Who is the researcher? What is the purpose of the study?

My name is Kate and I am a university lecturer at Liverpool John Moores University and a children's nurse. I am undertaking a study about factors affecting access to out-of-school activities across the North West of England. I am very interested in finding out about the needs of physically disabled children and young people in our community so that the views of children, young people and their families can be promoted and to encourage social inclusion.

Why me?

As a provider of mainstream out-of-school activities, I would like to find out what your views are on factors which may affect physically disabled children and young people accessing and participating in your activities.

By finding out about what is provided in mainstream activities it will hopefully provide an understanding how activities run and how children can participate.

Do I have to take part?

No, It is totally up to you to decide whether or not to take part.

If you would like to take part, after reading this information sheet I will liaise with you to arrange a suitable time to meet with you at your usual activity venue. At that point you will be asked to sign a consent form.

But what happens if I want to withdraw from the study?

You can leave the study at any time and you do not need to give a reason.

Participant Information Sheet Page 1 of 2

What does the research involve?

It would involve a face-to-face interview with me to discuss your views. It will take approximately one hour at a convenient time for you.

With your consent, it will be recorded using a digital voice recorder. This will then be typed up so that the information can be analysed but the recording will be destroyed at the end of the research study.

Are there any risks/benefits?

I am sure there are no risks from doing this but if you have any concerns about anything we talk about then please let me know and we can stop at any time.

I hope by listening to the views of the providers we can better understand the needs of those managing out-of-school activities and how this can affect the overall provision of services for physically disabled children and young people.

Who has checked if this study can go ahead?

All research projects have to be reviewed for ethical approval to make sure that they are worthwhile, well organised and safe for the people taking part. The decision is made by a committee of experts who are not connected to the project in any way. I have a PhD supervision team who already have their PhD and they are bound by the same rules as I am regarding confidentiality. I hold a clear enhanced CRB (police check).

Will it be kept confidential?

Any information we discuss will be kept confidential. Some sections of what we discuss will be used to portray your views but I will never put your name with this. If you want to look at any of the anonymised findings you can do that by contacting me directly.

The only time I have to break confidentially is if I feel someone if not safe.

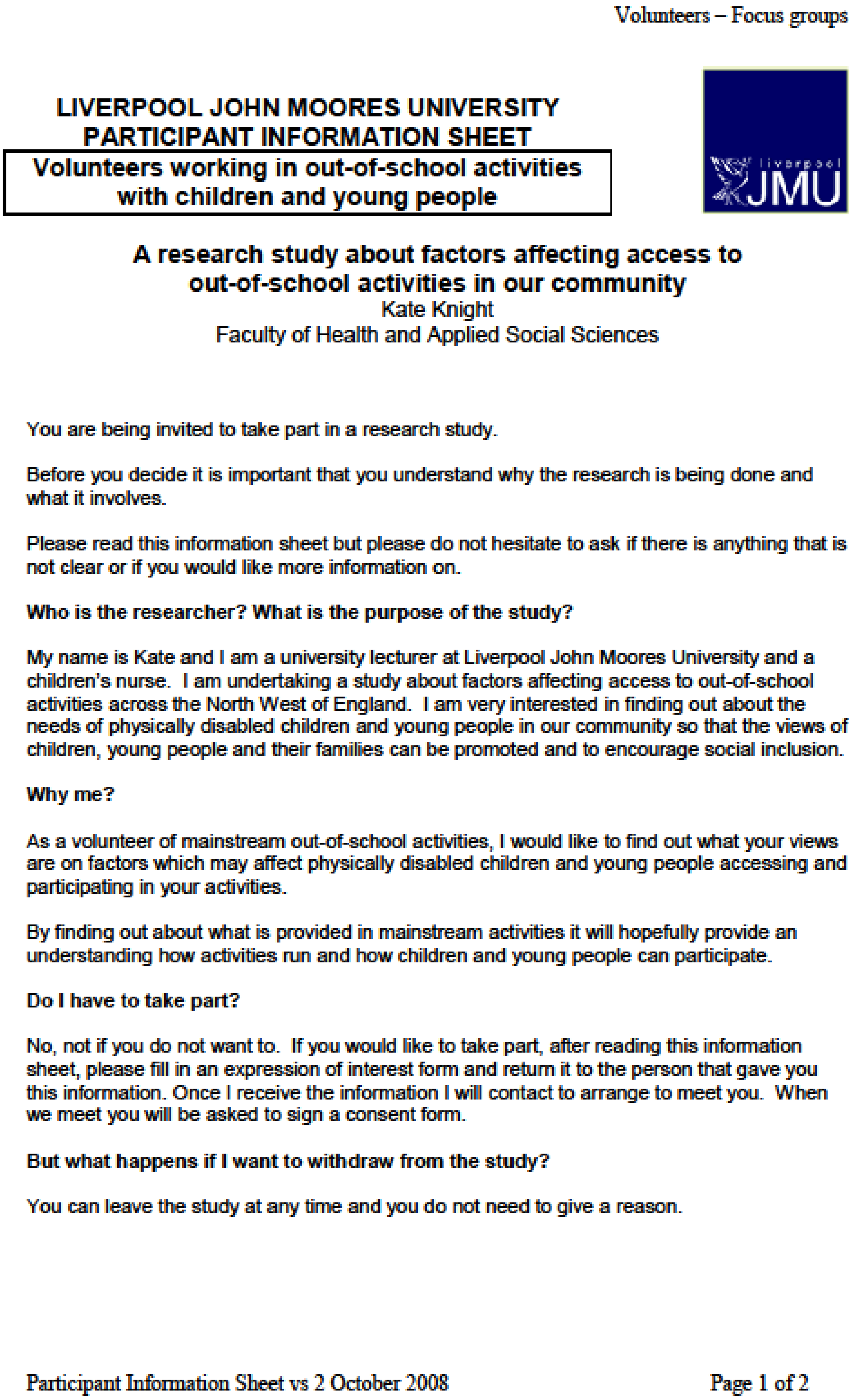
What happens after the study?

All the information collected will form the basis of my PhD which I will publish in some peer reviewed journals.
I am also planning to promote this during conferences which will involve large groups of people with the aim to promote the needs of physically disabled children and young people.

Who can I talk to about the study?

I can be contacted on 0151 231 4503 or k.h.knight@ljmu.ac.uk. I am based at Liverpool John Moores University.

7.4.5 Volunteer Participation Information Sheet



Volunteers – Focus groups

LIVERPOOL JOHN MOORES UNIVERSITY
PARTICIPANT INFORMATION SHEET

Volunteers working in out-of-school activities with children and young people

A research study about factors affecting access to out-of-school activities in our community

Kate Knight
Faculty of Health and Applied Social Sciences

You are being invited to take part in a research study.

Before you decide it is important that you understand why the research is being done and what it involves.

Please read this information sheet but please do not hesitate to ask if there is anything that is not clear or if you would like more information on.

Who is the researcher? What is the purpose of the study?

My name is Kate and I am a university lecturer at Liverpool John Moores University and a children's nurse. I am undertaking a study about factors affecting access to out-of-school activities across the North West of England. I am very interested in finding out about the needs of physically disabled children and young people in our community so that the views of children, young people and their families can be promoted and to encourage social inclusion.

Why me?

As a volunteer of mainstream out-of-school activities, I would like to find out what your views are on factors which may affect physically disabled children and young people accessing and participating in your activities.

By finding out about what is provided in mainstream activities it will hopefully provide an understanding how activities run and how children and young people can participate.

Do I have to take part?

No, not if you do not want to. If you would like to take part, after reading this information sheet, please fill in an expression of interest form and return it to the person that gave you this information. Once I receive the information I will contact to arrange to meet you. When we meet you will be asked to sign a consent form.

But what happens if I want to withdraw from the study?

You can leave the study at any time and you do not need to give a reason.

Participant Information Sheet vs 2 October 2008 Page 1 of 2

What does the research involve?

I would like to meet in a focus group which will be a small meeting with other volunteers from your group to discuss your thoughts. It will take approximately one hour of your time when it is convenient for you.

With your consent, this will be recorded using a digital voice recorder in order to record all the views. This will then be typed up so that the information can be analysed but the recording will be destroyed at the end of the research study.

Are there any risks/benefits?

I am sure there are no risks from doing this but if you have any concerns about anything we talk about then please let me know and we can stop at any time.

I hope by listening to the views of volunteers we can better understand the needs of those running out-of-school activities and how this can affect the overall provision of services for physically disabled children and young people.

Who has checked if this study can go ahead?

All research projects have to be reviewed for ethical approval to make sure that they are worthwhile, well organised and safe for the people taking part. The decision is made by a committee of experts who are not connected to the project in any way. I have a PhD supervision team who already have their PhD and they are bound by the same rules as I am regarding confidentiality. I hold a clear enhanced CRB (police check).

Will it be kept confidential?

Any information we discuss will be kept confidential. Some sections of what we discuss will be used to portray your views but I will never put your name with this. If you want to look at any of the anonymised findings or what may go in a published article you can do and you can do that by contacting me directly.

The only time I have to break confidentially is if I feel someone is not safe.

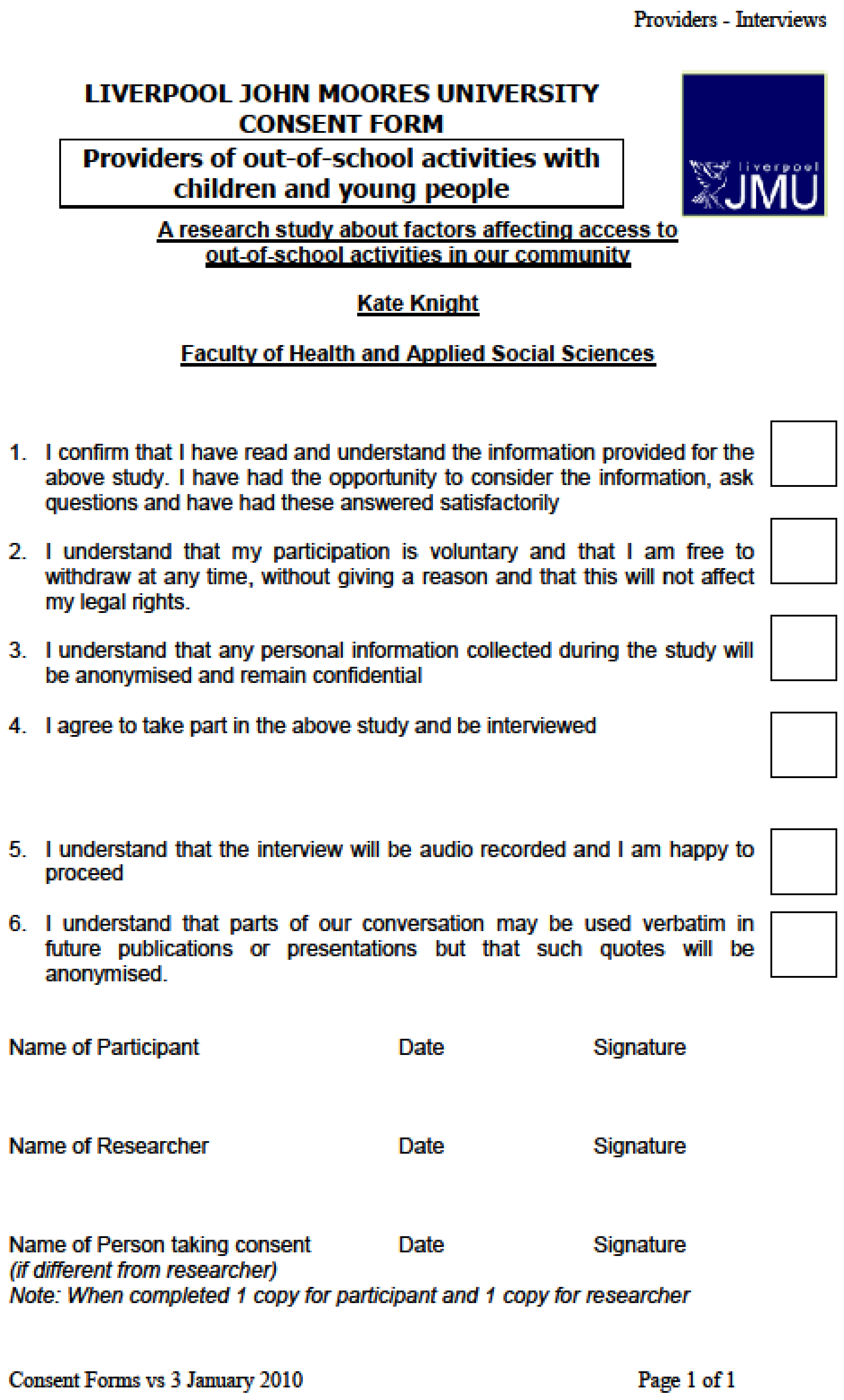
What happens after the study?

All the information collected will form the basis of my PhD which I will publish in some peer reviewed journals.
I am also planning to promote this during conferences which will involve large groups of people with the aim to promote the needs of physically disabled children and young people.

Who can I talk to about the study?

I can be contacted on 0151 231 4503 or k.h.knight@ljmu.ac.uk. I am based at Liverpool John Moores University.

7.4.6 Activity Planner Consent Form



Providers - Interviews

LIVERPOOL JOHN MOORES UNIVERSITY
CONSENT FORM

Providers of out-of-school activities with children and young people

A research study about factors affecting access to out-of-school activities in our community

Kate Knight

Faculty of Health and Applied Social Sciences

1. I confirm that I have read and understand the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and that this will not affect my legal rights. ☐
3. I understand that any personal information collected during the study will be anonymised and remain confidential ☐
4. I agree to take part in the above study and be interviewed ☐
5. I understand that the interview will be audio recorded and I am happy to proceed ☐
6. I understand that parts of our conversation may be used verbatim in future publications or presentations but that such quotes will be anonymised. ☐

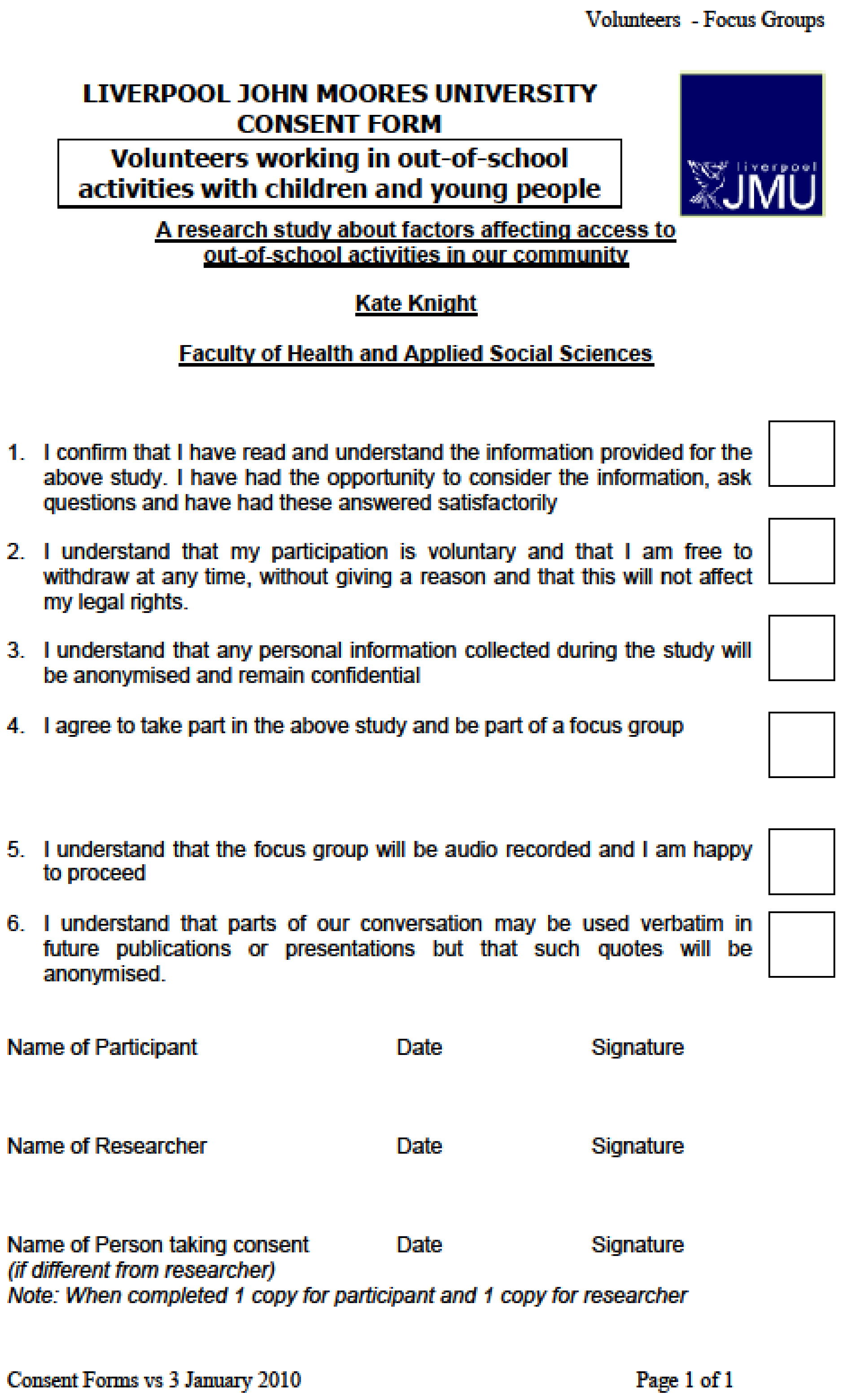
Name of Participant Date Signature

Name of Researcher Date Signature

Name of Person taking consent Date Signature
(if different from researcher)
Note: When completed 1 copy for participant and 1 copy for researcher

Consent Forms vs 3 January 2010 Page 1 of 1

7.4.7 Volunteer Consent Form



Volunteers - Focus Groups

LIVERPOOL JOHN MOORES UNIVERSITY
CONSENT FORM

Volunteers working in out-of-school activities with children and young people

A research study about factors affecting access to out-of-school activities in our community

Kate Knight

Faculty of Health and Applied Social Sciences

1. I confirm that I have read and understand the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and that this will not affect my legal rights. ☐
3. I understand that any personal information collected during the study will be anonymised and remain confidential ☐
4. I agree to take part in the above study and be part of a focus group ☐
5. I understand that the focus group will be audio recorded and I am happy to proceed ☐
6. I understand that parts of our conversation may be used verbatim in future publications or presentations but that such quotes will be anonymised. ☐

Name of Participant Date Signature

Name of Researcher Date Signature

Name of Person taking consent Date Signature
(if different from researcher)
Note: When completed 1 copy for participant and 1 copy for researcher

Consent Forms vs 3 January 2010 Page 1 of 1

7.5 Participant Questions

The following questions formed the semi-structured interviews, focus groups and creative focus groups

Questions with Children and Young People

Study 1 –
Creative focus group sessions with physically disabled children and young people aged 8-15 years old.
Can you tell me a bit about yourself (demographics, activities, participation level)

Tell me about the different out-of-school activities you access? (Discuss specific services or mainstream)

Why do you enjoy…?

Why do you go to ….?

What is it about that type of activity?

Would there be any activities you would like to see provided or would like to join?

What do you think about what activities are on in your area? (Discuss of specific services or mainstream)

What affects you joining in ………..?

Anything else you would like to add?

Questions with Parents

Study 1 –
Semi-structured interviews with parents / families of physically disabled children and young people

Can you please tell me about your son/daughter?

Which out-of-school activities do they access? (Discuss specific services or mainstream?)

Can you tell me about the activities they enjoy? Participate in?

Can you tell me about what they may not be able to join for whatever reason? (Explore demographics, activities, participation level as appropriate).

Can you tell me about the provision of mainstream out-of-school activities in your area?

What else would you like to see provided?

What are the factors affecting access/participation in your opinion?

Anything else you would like to add?

Questions with Providers

Study 2 –
Semi-structured interviews with providers of mainstream children's out-of-school social and leisure activities.

Can you tell me about your organisation? (History, provision)

Can you please tell me about what activities you provide?

Do you have any physically disabled children/young people who access your activities?

Yes – could you tell me about what you provide and are there any factors which make this participation successful or if you feel you would like to improve on?
No – what are the factors you think affect this? What provision do you have for physically disabled children and young people?

Who runs the activities? What training are they given?

Can you tell me anything about the policies you have on disability?

Anything else you would like to add?

Questions with Volunteers

Study 2 –
Focus groups with volunteers within mainstream children's out-of-school social and leisure activities.

Can you please tell me about what activities you provide?

Do you have any physically disabled children/young people who access your activities?

Yes – could you tell me about what you provide and are there any factors which make this participation successful or if you feel you would like to

improve on?
No – what are the factors you think affect this? What provision do you have for physically disabled children and young people?

Can you tell me a bit about the people running the activities? What training are you given?

Can you tell me anything about the policies you have on disability?

Anything else you would like to add?

7.6 Creative Focus Group Activities

Creative focus groups include a range of activities with PDC&YP and is prepared by the researcher in conjunction with the gatekeepers each time. This is an example of one set used. It is imperative that all researchers analyse the practice aspects of conducting creative focus groups to be fully prepared before starting. This was used as a basis of a presentation for PhD students and researchers looking to conduct research with C&YP.

Knight, K. Porcellato, L. Vickerman, P. Greenop, D. (2018) Qualitative Research with Disabled Children and Young people – Practical Aspects. Public Health PhD Symposium on Improving and Understanding Health. Wednesday 4th July 2018 Liverpool John Moores University. Oral Presentation.

7.7 Literature Tables

- 7.7.1 UK Literature Table (Published Peer-reviewed)
- 7.7.2 UK Literature Table (Grey literature)
- 7.7.3 International Literature Table

7.7.1 UK Literature Table (Published Peer-reviewed)

Characteristics of the included published peer reviewed literature – UK

- 9 Peer reviewed papers UK
- 7 grey literature UK
- 4 Government related documents

Study	Aims	Location	Sampling		Data collection	Findings
			Sample	Details		
Lawlor et al., (2006)	To ascertain from families of children with cerebral palsy the features of physical, social and attitudinal environments which facilitate or restrict participation.	North East of England	Families of C&YP with cerebral palsy aged 5-17 years	5 mothers, 3 fathers, 1 grandmother, 3 both parents Only two children gave views Cerebral palsy with a variety of mobility (6 walking, 6 non-walking)	Qualitative In-depth interviews using a topic guide	The main themes presented as both facilitators and challenges were: • Importance of mobility • Transport • Support by and to parents • Attitudes of individuals and institutions towards children.
Knight et al., (2009)	To understand how provision for holidays and other out-of-school times may contribute to the social inclusion of families with a disabled child.	6 local authorities in the UK.	86 children and young people (C&YP)	7-19 years old 38 girls/48 boys Higher number of white British represented Mixture of disabilities - Included 17 physically disabled C&YP	Qualitative Semi-structured interviews Case study approach	High levels of social isolation and exclusion during out-of-school periods and during school holidays in particular. The topic areas included rather than themes presented: • Experiences/perspectives of disabled young people of the school holidays • Promoting social inclusion for disabled young people • Gaps in provision • Meeting disabled children's rights
			90 parents	Higher number of white British represented		

			121 staff	Mostly middle/senior management - local authority social services, education, early years, special and mainstream schools, health services, play, youth services & voluntary organisations		Facilitators: • Buddy Challenges: • Opportunities • Awareness
Hewitt-Taylor (2008)	To gain an understanding of parents views regarding the social inclusion of their children who have complex and continuing health needs.	Southern England	14 parents Two male and 12 female	Parents of C&YP aged 18 months to 18 years.	Qualitative Semi-structured Interviews	• Everyday facilities • Leisure activities • Social Opportunities • Education Challenges: • Play – lack of facilities • Access Transport • Attitudes • Communication
Sloper et al., (2009)	To explore how disabled children and their parents defined their desired outcomes for their own/their child's life.	Three local authorities in the UK	Families of C&YP aged 1-18 years 95 families took part representing 100 children. 90 mothers 18 fathers Included 7 bereaved parents of children with degenerative conditions 27 \`other informants\`(person child choose to accompany)	55 boys/45 girls 27 minority ethnic group families Four groups of disabled children: • Autistic spectrum disorders • Complex health needs Degenerative conditions Children who do not use speech to communicate for physical or neurological	Qualitative Semi-structured Interviews	The themes presented were: Fundamental outcomes • Physical well-being • Communication • Staying Safe Higher level outcomes • Enjoying and achieving • Socialising & having friends and relationships • Activities and experiences • Education and learning • Self-care skills • Life skills

			29 C&YP participated directly	reasons.		<u>Making a positive contribution</u> <u>Economic well-being</u> Challenges: opportunities
Parkes at al (2010)	To describe participation of children with cerebral palsy in everyday life situations.	Northern Ireland	A total of 102 parents opted in (51% response rate).	Children with cerebral palsy born between 31⁄8⁄1991 and 1⁄4⁄1997 were identified from a case register of people with the condition.	Quantitative Cross-sectional survey: Life Habits Questionnaire (Life-H) Frequency of Participation Questionnaire (FPQ), to measure frequency of participation with comparative data for children without disability.	Overall, children with cerebral palsy participated less often than their non-disabled peers across a number of lifestyle and cultural pursuits. <u>Facilitators:</u> Participation in ‘relationships’ was the least disrupted area of everyday life <u>Challenges:</u> Higher parenting stress was significantly related to lower child participation in ‘community activities’. Communication .
Hodge and Runswick-Cole (2013)	To explore participation of disabled C&YP and families in leisure activities.	UK The study was based in the North of England and ran from September 2008 to April 2011.	11 children 23 parents Professionals who work with them e.g. teachers, health workers, social workers.	4-16 years Inc physical disability	Qualitative Interviews and use of photographs and art	Disabled families and children occupy a mix of ‘mainstream’, ‘segregated’ and ‘separate’ leisure spaces. Many accessed segregated leisure opportunities- because access to the activities is dependent on having a diagnosis or label. ‘Like me’
Carter et al.,	This appreciative,	A wheelchair sports club,	Sixty-three people	37 children,	Qualitative	Children who use wheelchairs have few opportunities to play sport with

(2014)	qualitative study explored the experiences of children, families and stakeholders at a wheelchair sports club. The aims of the study were to explore, from the children's, parents'/carers', siblings' and stakeholders' perspectives, their experiences and perceptions of 'The Cheetahs' Benefits (if any) occur as a result of bringing children with disabilities and children without disability together.	based in the North West of England, for children with disabilities and able-bodied children and their families, was the chosen site for the study.	participated	14 stakeholders, 10 parents, Two older siblings	Participant observation, research activities, focus groups and interviews were used. Participant observation, photographs and conversational interviews.	their able-bodied peers and siblings. Thematic analysis identified one unifying theme (realising potential) and four main themes: Invisibility of disability; ambivalence and attraction of the chair; fun and fellowship; and thrills and skills. Points of interest: • Children with disabilities tend to engage in more play on their own or with adults than in play with friends, they play closer to home and they engage in fewer informal and formal activities. • The children with disabilities gained confidence and were able to share their wheelchair expertise. Facilitator: • Sport is a social opportunity for child and family • Stakeholders discuss 'energy' and breaking down barriers.
Kolehmainen et al., (2015)	To identify, in children with motor impairments, body function and structure, activity, environmental, and personal	6 regions in the United Kingdom	195 children Quant 17 children Qual 152 Parents	Aged 6–8 years old With motor impairments, mobilizing independently with or without equipment and seen by physical therapists or occupational therapists	Mixed-methods, intervention development stud. Self-reported PPP (participation in physical play/leisure) was assessed with the	Mainly 'recreational' (eg, pretend play, playing with pets) rather than 'active physical' (eg, riding a bike/scooter). Therapists reported 23 unique Impairments (eg, muscle tone), 16 activity limitations (eg, walking), and 3 personal factors (eg, child's PPP confidence).

	factors.				CAPE. Therapists' observations Parental questionnaires Child-friendly interviews	Children interviewed reported a strong preference for active play but indicated that adults regulated it. Themes: Environmental factors: • Places, activities, people • Rules, norms, routines Personal Factors: • Play, imagination, fantasy • Scary and too hard.
Pyer (2016)	Exploring young wheelchair users' play and recreation		69 young people (Structured interviews) 13 Young people (photograph exercise/associated interview) 9 young people (participant led video tours)	Aged 13-17 years Recruited through special schools in the midlands, East and South East of England. Young people who could verbalise.	Qualitative Multi-method approach	Themes: • Family Geographies and Leisure: Barrier, Cause and Response • "Closing Down" Leisure: Environments, Decision Making and Anxieties. • "Opening Up" Leisure: Strategies, Aspirations and Negotiations.
Daniels (2016)	To explore the experiences of a disability sports programme and identify the mechanisms and context influencing its sustainability	Cheshire	Two coaches		Qualitative Case study	Targeted girl's disability football and disability gymnastics for the under 16 age group supported by two specialist coaches and equipment. The coaches observed improvements in social and physical aspects of health and the development of physical skills in the programme participants – targeted.

7.7.2 UK Literature Table (Grey Literature)

Characteristics of the included grey literature reports - UK

Study	Aims	Location	Sampling		Data collection	Findings
			Sample	Details		
Petrie et al., (2007)	Report of `On Holiday!` study which is published by Knight et al., (2009) study.					
Bennett (2009)	To ask families about their social emotional and practical experiences of raising a child with a disability.	United Kingdom (UK)	615 families caring for a disabled child/young person aged 0-19 years.	22 percent have child 0-5 years 52 percent have child 6-12 years 26 per cent have a child 13-19 years Range of disabilities and health conditions	Online survey with open/closed questions	Three clear themes were presented: Lack of services Attitudes towards disability Lack of support from professionals 73 % of respondents said their child's access to play/leisure specifically for disabled children is poor or unsatisfactory Families want more play/leisure and choice.
Beresford and Clarke (2010)	To describe what works in improving access to positive and inclusive activities for disabled C&YP.	UK	16 disabled C&YP	10 C&YP	2 focus groups	Key messages presented included: • Positive activities associated with positive outcomes in terms of health, experiences, enjoyment and community participation. • Existing services need to
				6 young people (aged 14-25 years)	Interviews and questionnaires	
	(Excludes literature where mental health problems were the		19 parents of disabled C&YP	15 mothers 4 fathers Range of disabilities	Interviews or email views	

	disabled child's primary diagnosis).		170 Service providers	Across seven regional workshops Including mainly Local authority children's services.	Knowledge workshops	examine whether the services they believe to be inclusive are truly inclusive
Langer et al., (2010) Report for Department for Children, schools and families	To assess the impact of short break provision on the lives and well-being of disabled C&YP	North of England (mainly North West)	17 parents/carers 3 disabled C&YP 3 siblings of disabled C&YP		Semi-structured Individual interviews using topic guides	Some of the related major findings reported: • There was a wide range of short break provision, parents use and value short breaks for different reasons. • Have positive impacts on children's lives, e.g. developing and maintaining social relationships and being able to enjoy fun activities. • Leaving the child could make parents feel vulnerable
			4 interviews with 8 parent/carers		Group interviews	
			9 parent/carer responses		Narrative tools (e.g. story space')	
The Bevan Foundation (2010)	To explore views of disabled C&YP's experiences of play and Leisure To ascertain experiences of providers of leisure/play	Wales	82 disabled C&YP	Aged 11-17 years	Short-questionnaire survey – open and closed questions Observation of activities with discussions with young people	• The majority of disabled C&YP in the study participate in a limited number & range of activities and some feel there is `nothing for them.` • They face challenges from lack of provision, lack of support, poor access to buildings and negative attitudes.

	activities for C&YP		25 providers 22 from voluntary/ community organisations 3 from local authorities		Survey and interviews	18/25 provided integrated provision 1/25 did not involve any disabled C&YP 9/25 provided activities exclusively for disabled C&YP 3 provided both • Of the inclusive organisations 8 knew whether they had policies on inclusion of disabled C&YP • 10 provided disability awareness staff training
Brokenbrow et al., (2016) Disability Matters in partnership with the Royal College of Paediatrics and Child Health (RCPCH)	Disability Matters launched a Call for Evidence on Inclusion in February 2016. Disabled young people and their parent carers experiences of inclusion, and how easy they had found it to access education, leisure and social activities, health providers, community services, and further training or work during 2015. Social model of disability.	UK	10 disabled young people 123 parents 128 professionals and volunteers (Includes 96 from health sector so 33 from other sectors)	Appears aged 17-24 years Age 0-26 years represented mix of disabilities and mental health problems. From education, activities, healthcare and community	Online survey leading to qualitative findings Includes case studies	Facilitators: • People with positive, can-do attitudes • Physical accessibility • A quiet place • High-quality services • Risk assessments (includes personal care) • Information and support Challenges: • Poor attitudes • Inexperienced staff • Inaccessible buildings • Lack of awareness • Hard to find opportunities • Communication • Cuts in funding meaning the removal or reduction in support services.

Disabled Children's Partnership: 5 Steps (2017) Disabled Children's Partnership: Case Studies (2018)	Major coalition of more than 60 organisations campaigning for improved health and social care for disabled children, young people and their families set up in 2017.	England	Secret Life of Us campaign - case studies of disabled families being updated on their website monthly between June 2017 to June 2018.	Disabled C&YP and families	Case Studies	Disabled children face four big challenges. • There are not enough health and social care services • Many of those that exist are not good enough. • Families cannot access them easily • Services do not always work together and communicate well with each other. From reading their case studies themes emerging highlight; • Travel and transport • Manual handling • Disability awareness • No political driver

7.7.3 International Literature Table

Characteristics of the included published peer reviewed literature – International

Study	Aims	Location	Sampling		Data collection	Findings
			Sample	Details		
Majnemer et al., (2008)	Characterize participation in leisure activities in children with cerebral palsy (CP) and identify determinants of greater involvement.	Canada	67 children	School-aged 42 males, 25 females Most had mild motor dysfunction	Quantitative CAPE Biomedical, child, family and environmental predictor variables were considered in the analysis.	Children were actively involved in a wide range of leisure activities and experienced a high level of enjoyment. Involvement was lower in skill-based and active physical activities as well as community-based activities. Challenges: • Cognitive and behavioural difficulties • Activity limitations • Parental stress
Imms et al., (2008)	To investigate the participation of children with CP in activities outside school	Victoria, Australia	114 Children with CP born in in 1994 and 1995.	65 males, 49 females Ages - 10 years 9 months and 12 years 9 months Comparison study	Quantitative A population-based survey Participation was measured using the CAPE	Intensity of participation was low. More children with CP participated in organized sports compared with other children, although with lower frequency.
Michielsen et al., (2009)	How frequency of participation varied between children with CP and the general	9 regions of 7 European countries	Parents of 813 children with cerebral palsy and 2939 children from the general populations completed the	8–12year-old children	Quantitative A multi-centre, population-based study in children with and without cerebral palsy.	Children with CP participated less often in community groups, sports and outdoor games than children in the general population. Attending a special school or class was not associated with further reduction in participation

	population		questionnaire.		A questionnaire developed with the Life-H instrument, to capture frequency of participation.	in most areas of everyday life. Environmental factors - Access Severity of impairment predicts frequency of participation
Galvin et al., (2010)	To describe participation at home, school and in the community of Australian children who had sustained an acquired brain injury (ABI).	Australia	20 parents of children who had sustained an acquired brain injury (ABI) who had GCS between 3-12 on admission, stroke or encephalitis.	Between Sept 2006-Sept 2007	Quantitative. Cross Sectional with convenience sampling. Parent survey ratings regarding the impact of cognitive, motor and behavioural impairments . Child and Family Follow up survey (CFFS).	The children were reported to have the greatest participation restrictions for structured events in the community, and social, play or leisure activities with peers either at school or in the community. Children were least restricted moving about in and around their own homes.
Kang et al., (2010)	To identify youth, family, and service determinants of the participation of youths with CP in leisure activities with friends and others who are not family members.	Recruited from 7 children's hospitals in 6 different states. Canada and USA	209 youths	13 to 21 years old (52% male), had CP, and were classified in Gross Motor Function Classification System (GMFCS) levels I to V as well as their parents.	Quantitative. Cross-sectional analysis. CAPE in structured interviews. Parents completed the Coping Inventory, Pediatric Outcomes Data Collection	<u>Challenges:</u> Sports and physical function Communication or speech problems Limitations. The youths' activity preferences and intensity of participation were not examined.

					Instrument, Family Environment Scale, Measure of Processes of Care, and demographic and service questionnaires.	
King et al., (2010a) A developmental comparison of the out-of-school	Similarities and differences examined in the out-of-school recreation and leisure participation	Canada	422 children 352 children	With physical disabilities Without disabilities (Ages – 6-14 years) Matched	Quantitative CAPE	Dimensions and types of activity participation are differentially influenced by age, gender and disability.
King et al., (2010b) Draw and write	To determine out-of-school activity participation profiles of school-aged children with physical disabilities.	Canada	Parents of 427 school-aged children (229 boys, 198 girls), ages 6–14 years, with physical disabilities	Activity participation profiles were determined by cluster analysing responses on multiple dimensions of participation (intensity, location, companionship, enjoyment, preference) in five activity types (recreational, active physical, social, skill-based, self-improvement). Socio-demographic, child, parent, family and environmental	Quantitative the Family Environment Scale, the Impact on Family Scale, the Strengths and Difficulties Questionnaire Craig Hospital Inventory of Environmental Factors (CHIEF; and the MOS 36-Item Short-Form Health Survey CAPE; and the Activities Scale for	Facilitators: Person–environment approach in understanding the complexity of children's out-of-school activity participation.

				predictors of group membership were determined, along with child functioning, socio-demographic, self-concept and social support variables significantly associated with group membership.	Kids (ASK).	
Mundhenke et al., (2010)	To describe the experiences of everyday activities and social support in daily life in children with disabilities.	Sweden	33 Children	Inc: 14 girls and 19 boys Ages 7-13 years. With physical and learning disabilities and Mental health.	Qualitative Interviews	Described themselves as being like any other child or adolescent. Themes: • Living with a disability – own reflections and social integration • Possibilities and hindrances – Daily routines/chores, school activities (liking or disliking), leisure time and friends, Ideas about the future. • Social support in everyday activities – social support from close friends/relatives, need for a personal assistant, assistive devices and adaptation, social support in school activities.
Palisano et al., (2011)	To test a model of determinants of intensity of participation in leisure and recreational activities by youth with cerebral palsy	Children's hospitals USA	205 children with CP Parents	Ages 13 – 21 Years 166 males 122 females	Quantitative Prospective cohort study Children completed CAPE via an interview Parents completed the Pediatric Outcomes Data	Results indicate that higher physical ability, higher enjoyment, younger age, female sex, and higher family activity orientation are associated with higher intensity of participation. Intensity of participation in leisure/recreation activities by children with CP was influenced by multiple child and family characteristics.

	(CP).				Collection Instrument, Family Environment Scale, Coping Inventory, Measure of Processes of Care, a demographic questionnaire, and a services questionnaire.	
Oates et al., (2011)	To describe leisure participation for school-aged children with Down syndrome To investigate how factors, classified by the WHO's ICF influence their leisure participation.	Western Australia	208 families were surveyed	With a child aged 5–18 years with Down syndrome	Quantitative In a population-based study in 2004.	One-third of parents reported that their child with Down syndrome had no friends although half reported two or more friends. Factors: Child's functional ability, behavioural issues and parent's availability of time. All children participated in predominantly solitary and sedentary leisure activities. Parental influence.
Ghanbari, (2016)	To compare the participation in life habits of children with blindness with their normal peers	Iran	20 children	Eleven children with blindness and nine without. Seven boys and two girls along with three boys and eight girls participated in groups of normal and	Quantitative, cross-sectional, and comparative Life-habit questionnaire, analyzed by SPSS-21 software with the Mann-Whitney statistical	Differences between these two groups in overall participation, nutrition, communication, participation at home, mobility, responsibility, interpersonal relationships, education, and recreation. Blind children had lower participation in most

				blind children, respectively. Convenience sampling	test.	areas of life habits compared to their peers. The differences from the necessary education and training, differences in the social contexts of both groups.
Shields and Synott (2016)	To explore factors perceived as barriers and facilitators to participation in physical activity by children with disability.	Australia	63 participants including: 23 children with mixed disabilities 20 parents of children with disability 20 sport and recreation staff	Child ages 10-18 years with a disability (congenital or acquired) Parents of a child with disability aged between 6–18 years. Professional working in the sports and recreation sector with people with disability	Qualitative Focus groups	Four themes were identified: • Similarities and differences • People make the difference • One size does not fit all • Communication and connections. Key facilitators Need for inclusive pathways Better partnerships between key stakeholders from the disability, sport, education and government sectors. Lack of instructor skills and unwillingness to be inclusive Negative societal attitudes towards disability, and a lack of local opportunities.
Carroll et al., (2018)	To and promote pathways for environmental change to increase opportunities for their effective community participation and full Citizenship.	New Zealand	35 young people Parents 13 gatekeepers	Aged 12–25 years with mobility, vision or hearing impairments	Mixed-methods CAPE and semi-structured interviews ‘Go-along interviews’	Looks beyond barriers in the physical environment to the interplay of personal, social and physical factors that enable or constrain the community participation of disabled young people. Focused more on flexible methodology than child views in this paper.

7.8 International Literature Flow Diagram to complement to UK literature as presented in 7.1.1

37 papers Found

(Cinahl Plus with full text 2006-2012, Web of Science, Social Care Online, ASSIA, Community Care Inform, Medline, Google Scholar and British Education Index)

8 were key Government and charity documents

including 4 key documents from the UK.

(HM Office for Disability, 2011; NICE, 2009; Welsh Assembly, 2007; Department of Health, 2004)

6 pieces of grey literature

(Bennett, 2009; Beresford and Clarke, 2009; Langer et al., 2010; The Bevan Foundation, 2010; Brokenbrow et al., 2016)

(Petrie et al., (2007) is the report which is published by Knight et al., (2009))

10 research papers from the UK meeting all the inclusion criteria

(Lawlor et al., 2006; Hewitt-Taylor, 2008; Knight et al., 2009; Sloper et al., 2009; Parkes et al., 2010; Hodge and Runswick-Cole, 2013; Carter et al., 2014; Kolehmainen et al., 2015; Pyer, 2016; Daniels, 2016).

13 international research papers meeting all the inclusion criteria

(Majnemer et al., 2008; Imms et al., 2008; Michielsen et al., 2009; Galvin et al., 2010; Kang et al., 2010; King et al., 2010a; King et al., 2010b; Mundhenke et al., 2010; Palisano et al., 2011;Oates et al., 2011; Ghanbari et al., 2016; Shields and Synott, 2016; Carroll et al., 2018).