Advancing Inclusive Participation of Children and Young People with Disabilities in Community Leisure and Recreation

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Abstract

Background

Participation on an equal basis with others in all life settings for children and young people with disabilities is enshrined in the United Nations Convention on the Rights of the Child (CRC, United Nations General Assembly, 1989) and in numerous more localised policies. Participation in community leisure and recreation activities is a right of every child and young person with a disability. Inclusion is about all children having the widest choices possible and the opportunity to access those choices in their own way.

Aims

Inclusive participation is the focus of this research; it set out to examine to what extent this is being achieved in community leisure and recreational activities in one community setting in the UK. Although a tautology in academic terms, ‘inclusive participation’ implies a culture that respects rights of access, sharing and choice, which combine to determine the quantity and quality of participation (Valet 2018, p.333). This places the responsibility on organisations to change and provide equality through these rights. This is important to this research because inclusive participation is understood through the level of equality delivered by organisations and experienced by children and young people with disabilities.

Methodology

Parents of children and young people with disabilities and activity providers participated in action research workshops to identify the barriers and facilitating factors to inclusive participation. Through an action research approach, participants were empowered to identify actions and practical solutions that would address the barriers identified or strengthen the facilitating factors, so as to bring about change at a grass-roots level and could be implemented by activity provider participants. The research aimed to contribute to the participation of children and young people with disabilities and their families by involving them in the research and development process, along with the practitioners who facilitate leisure activities in the community. As such, it aimed to construct a collaborative and more inclusive process of research and activity planning, by creating a ‘communicative space’ (Bevan 2013).

Findings

The findings illustrate how a lack of understanding about ‘hidden disabilities’ perpetuate the discrimination that families and children and young people with disabilities experience in their own communities. The findings also show how the challenge of funding detracts from addressing other key issues of inclusive participation. The findings illustrate key mechanisms for inclusive design, which focus on leadership, communication aids, recruitment and training, all requiring inclusion to be part of the design, and collaboration between activity providers and families.

Discussion

The findings focused on three key themes: rights and discrimination; promoting and funding inclusion and inclusion by design. A grassroots approach is required to transform the participation of children and young people with disabilities in inclusive community, leisure and recreation.

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Chapter One: Introduction

1.1 Background

The benefits of involving children and young people with disabilities in leisure and recreation activities are well documented. Participation confers benefits to psychosocial health, physical health, wellbeing, and general quality of life (DePauw and Doll-Tepper 2000) and has therapeutic benefits (Carter and LeConey 2004). Engagement in sports by children and young people with disabilities has been directly linked to improvement in fitness level, muscle strength, as well as general fitness levels (Grenier et al. 2014). One of the emotional benefits of supporting children and young people with disabilities to take part in inclusive leisure and recreational activity is that it enables them to feel more confident about their appearance, a factor that results in positive changes in self-identity (Fitzgerald and Kirk 2009). This highlights the importance of access and opportunity to community leisure and recreation, for the general health and wellbeing of children and young people with disabilities.

Participation in community leisure and recreation activities is a right of every child and young person with a disability. This right is defined in the United Nations Convention on the Rights of the Child, as the right to active participation in the community in conditions that promote dignity and self-reliance (CRC, United Nations General Assembly, 1989, Article 23). It follows that every child and young person is entitled to active, free and meaningful participation in, contribution to, and enjoyment of community leisure and recreation; children and young people with disabilities are equally entitled to the right to participate without discrimination, as all children and young people (Gregor et al. 2018) This is important for this research because it establishes the expectation that children and young people with disabilities will be offered equal opportunities along with other citizens.

However, despite anti-discrimination laws in many countries, for example, the Equality Act 2010 in the UK, fundamental barriers continue to restrict the participation of children and young people with disabilities, including lack of opportunity, negative public attitudes and inadequately skilled staff (Emira and Thompson 2011; Thompson and Emira 2011; Imms et al. 2016). This can manifest in problems such as safety for children and young people with disabilities in non-secure environments, or in activities with a lack of resources for adequate staffing, which make some activities prohibitive (Lyons et al. 2016). Such barriers significantly hinder children and young people with disabilities from participating in leisure and recreation activities (Kanagasabai et al.

2018). This is important for this research because it demonstrates that children and young people continue to experience discrimination and inequality through exclusion.

Thus children and young people with disabilities often find themselves excluded on the grounds of safety, accessibility and support needs (Law et al. 2007). A lack of participation can have psychosocial impacts such as low levels of confidence, self-esteem, self-worth and ambition (Devine and King 2006), as well as impact conditions associated with physical inactivity, including obesity, poor mobility, coordination and motor-skills (Carter and LeConey 2004). Participation' is one of four key issues cited by the World Health Organisation (WHO 2007) and based on the UN Convention on the Rights of Persons with Disabilities (2006), which

> "focuses on participation on an equal basis with others and underlines the importance for children with disabilities to play, participate in sports activities and cultural life" (WHO 2007: xvi).

This fact that participation in play, sport and cultural activities is recognised as a key priority by the World Health Organisation highlights that lack of participation by children and young people with disabilities in community leisure and recreational activities is a major challenge in the developed world.

Participation in community leisure and recreation settings is considered important with respect to a broad range of outcomes for children and young people with disabilities: development of skills and capabilities, formation of friendships and relationships, achievement of mental and physical health and wellbeing, development of self-identity, and becoming empowered to be themselves (Siperstein et al. 2009; Anaby et al. 2015; Law et al. 2015; King et al. 2016; Anaby et al. 2017; Willis et al. 2018b). These outcomes are important because participation empowers children and young people to reach their full potential in life (CRC, United Nations General Assembly, 1989). It is therefore important to understand the factors that foster or hinder participation in community settings.

This chapter includes definitions of key terms including disability, social model understanding of barriers to participation, community leisure and recreation, participation, inclusion and inclusive participation. The policy context and austerity are discussed, followed by the social model of disability. This is followed by a description of providers and services. The chapter concludes with the research aims and questions.

1.2 Definitions of key terms

The key terms in this research are: disability, social model understanding of barriers to participation, community leisure and recreation, participation, inclusion and inclusive participation.

In this research, the term disability is used to refer to physical, mental or intellectual impairments. Terminology can be contentious and Barnes and Mercer (2010) argue that impairment is a medically classified biophysiological condition, whereas disability denotes the social disadvantage experienced by people with an impairment. In this sense, the term ‘disability’ aligns closely to the social model of disability as developed by people with disabilities to identify and take action against the discrimination and barriers created by society (Oliver 2004). However, Barnes and Mercer (2010) avoid the phrase ‘people with disabilities’ because they argue that it blurs the conceptual difference between impairment and disability and implies that impairment defines a person’s disability. In contrast, this research does refer to ‘children and young people with disabilities’, but for a similar reason to Barnes and Mercer (2010); in this research, the phrase ‘disabled children’ is avoided because it introduces the disability first and the child as secondary. Instead, the focus is on the child, and the research positions their disability as secondary; therefore, this research refers to ‘children and young people with disabilities’.

In this research, the social model understanding of barriers to participation is used to refer to the economic, environmental and cultural barriers that limit the access and opportunity of children and young people with disabilities. The social model of disability as defined by Oliver (2004) states that people live with impairments and are rendered disabled by the environment, including a non-inclusive society that is characterised by barriers and negative attitudes:

> “In the broadest sense, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, mental or intellectual.” (Oliver 2004, p.21)

The point made by Oliver (2004) is important because it firmly places the responsibility on society to break down exclusionary barriers and build an inclusive culture. This research focuses on removing the barriers and challenging the assumptions that disadvantage children and young people with disabilities, by offering them the fullest range of choices in order to enable rather than disable them; in this sense then, societal responsibility is taken as a given.

In this research, the term community leisure and recreation refers to activities that children and young people engage in during their free time, that they enjoy, and that are recognised as having social value (Hurd and Anderson 2011). This includes after-school and weekend activities and clubs, including sports and creative arts, but not school-time activities. This distinction is important because the economic, environmental and cultural contexts of community settings are different to educational contexts.

In this research, the term participation is used to refer to a broad continuum of involvement; it is a multi-layered concept involving many different processes (Sinclair 2004). The term participation is generally understood to refer to listening to and engaging with children and young people; however, the term is commonly contested (Lansdown et al. 2014) and there is no single definition. Cornwall (Cornwall 2008) argues that participation is more than simply involvement and denotes a transfer of power so that children and young people's views influence decisions. This is pertinent because in this research, participation refers to both participating in community leisure and recreational activities and participating in the research process itself as well.

In this research, the term inclusion is used to refer to the respect and values of group membership, regardless of ability or special needs. In this research "inclusion" does not simply mean the integration of children and young people with disabilities in mainstream activities, which therefore places the responsibility on the child or young person to change and adapt (Dickins et al. 2003). Edwards (2004) emphasises the importance of community participation and social inclusion in reducing the number of people experiencing exclusion (Edward 2004). This is important because the social model of disability removes the responsibility of the individual to fit in with society and places the responsibility on society to adapt and accommodate different requirements and needs. This concept of inclusion is important for this research because children and young people have the right to be respected and valued for their abilities and differences.

When it comes to inclusion, participation covers the issues related to being active. 'Participation' is homogeneous and generally treats everyone the same, whereas 'inclusive participation' recognises diversity: it is heterogenous in that people are treated as individuals (Browne and Millar 2016). In order to meet the additional needs of children and young people with disabilities in community leisure and recreation, it is vital to recognise the individuality of children and young people. In order to recognise individual needs, activities have to be designed differently; they need to be physically, socially and environmentally accessible.

The term ‘inclusive participation’ is a new and emerging term coming out of developments in disability sport and recreation. Referenced by only a few public bodies in the UK including the NHS, but more commonly used in community practice, internationally the term is defined in policy. The West Australian Department of Local Government, Sport and Cultural Industries, for example, defines inclusive participation as recognising difference, achieved when everyone is engaged, welcomed and provided with practical opportunities to participate. The policy encourages inclusive policies, programs and services across Western Australia (Government of Western Australia 2016).

Inclusive participation is a term that is used more frequently in practice than in the literature and this perhaps points to a gap between academics and practitioners. The term is used by both national and local agencies across the UK, but appears more loosely in titles than in rich description; for example, the NHS England produced a Diverse and Inclusive Participation guide in 2016 but the phrase inclusive participation is not used within the document (NHS 2016). The emergence of this term has not yet been reflected within the peer-reviewed literature where there are many variations of phrases used to discuss the participation of children and young people with disabilities in activities. The literature generally sits in one of two camps, either focusing on participation (Arnell et al. 2018; Willis et al. 2018a) or inclusion and inclusive activities (Jeanes et al. 2018; Smart et al. 2018). Other research discusses integration, which happens when children and young people are taken out of mainstream society, and then re-inserted; they are not seen to be part of the main group but rather, are seen as an addition to the group (Grandisson et al. 2012; Knibbe et al. 2017). They are also often treated ‘the same’ in an attempt to deliver equality, which contradicts the requirements of the Equality Act to ‘make reasonable’ adjustments and treat children and young people with disabilities as individuals. Furthermore, this does not reflect the social model of disability in that the emphasis is on the differences of the child and their ability to adapt to the group, rather than on society adapting to include the child with disabilities.

In this research, the term inclusive participation is therefore used to refer to activities that have been designed to include everyone. If an activity provider is good at working with children, they should be good at working with all children. This challenges the tradition of providing separate activities for able-bodied children, often described as mainstream provision, and activities for disabled children, described as targeted or segregated. The move away from integration toward inclusion over the last two decades is a powerful discursive shift as it places the responsibility on organisations to change and provide equal opportunities (Dickins et al. 2003). Valet (2018) defines inclusive participation through a notion of a culture that respects rights of access, sharing, and choice, which combine to determine the quantity and quality of participation:

> “inclusive participation implies a culture which respects the ‘right of access’ to overcome the exclusion, the ‘right of sharing’ to overcome the segregation and the ‘right of choice’ to overcome the welfarism” (Valet 2018, p.141).

This level of equality denotes a process of change at both macro and micro levels; at institutional (macro) and community (micro) levels there are a number of drivers involved in legislation, policy and practice that enable children of all abilities to participate as fully as possible (Dickins et al. 2003). This is important because the concept of inclusive participation refers to a process of cultural and organisational change driven by equality. It is this concept of inclusive participation, understood through the level of equality delivered by organisations and experienced by children and young people with disabilities, that underpins this research.

1.3 Policy Context

Children and young people have a civil and ethical right to be included fully and meaningfully in all aspects of society (DePauw and Doll-Tepper 2000). In this regard, within the UK, there has been significant improvement from local authorities and institutions, including the modification of legal requirements and adjustments towards a more inclusive society. This has been driven in-part by education reforms and in-part by the global disability movement, both of which experienced rapid cultural change in western society over the last century (Thompson and Emira 2011). Policy and institution changes are important elements in ensuring that children’s rights are upheld and championed. This is important for this research because the rights of children and the obligations of government, local authorities and service providers, lay the foundations for equality through inclusion and inclusive practice.

The Equality Act 2010, which consolidated and updated anti-discrimination law in the UK, emphasises a legal duty on service providers to make reasonable adjustments so that disabled people can participate in education, use services and work (Oliver 2013). Use of services includes engagement in community leisure and recreation activities, which has been identified by both the World Health Organisation and the United Nations as important in contributing to the health and wellbeing of children and young people with disabilities. Communities that enable all citizens to play a full and useful role in the social, economic and cultural life of their community are likely to be healthier than those where children and young people with disabilities face insecurity, exclusion and deprivation (WHO 2007). Article 30 of the UN Convention on Rights of Persons with Disabilities focuses on participation of children and young people with disabilities in community leisure and recreation and addresses both mainstream and disability-specific leisure and recreation activities:

> "Participation in cultural life, recreation, leisure and sport: 1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life [...] to participate on an equal basis with others in recreational, leisure and sporting activities [...], children with disabilities have equal access with other children to participate in play, recreation and leisure, and sporting activities, including those activities in the school system" (Article 30)

The Equality Act 2010 and Article 30 are important because they affirm the right of children and young people with disabilities to participate in leisure and recreation, and place legal responsibility on service providers to deliver equal opportunities. This legislation is relevant for this research because it places responsibility on service providers to break down barriers.

Despite the introduction of the Equality Act 2010, fundamental barriers continue to restrict participation of children and young people with disabilities, including lack of opportunity, negative public attitudes, as well as inadequately skilled staff (Imms et al. 2016; Lyons et al. 2016). This can manifest in problems such as safety for children and young people with disabilities in non-secure environments, or in activities with low staff ratios, which make some activities prohibitive. Such barriers have significantly hindered a number of children and young people with disabilities from participating in leisure and recreational activities, who continue to face challenges to their participation (Kanagasabai et al. 2018). This demonstrates that anti-discrimination legislation alone is not able to break down the barriers. In an alternative approach, this research focuses on community inclusion and participation to break down the barriers to participation for children and young people with disabilities.

Following the introduction of the *Every Child Matters* UK Government initiative in 2003, which was introduced to promote the well-being of children and young people, the level of participation by children and young people with disabilities in mainstream leisure and recreation activities in England increased (Broach et al. 2009). As a result of developments in policy, staff training and the built environment, followed by the introduction of the Equalities Act 2010, children and young people with disabilities were increasingly involved in leisure and recreational activities, including art, sport and cultural activities (Todd 2011). The emergence of disability politics underpinned by the social model of disability, and children's rights in education and equality, provided a context for inclusion and participation. However, Oliver et al. (2011) link the disability movement with social and educational policy and argue that the impact of these developments on meaningful inclusion has been marginal. In community leisure and recreation, the problem of inequality in access and opportunity persists and there is a need to create a more inclusive environment and to reduce the exclusion of children and young people with disabilities.

Austerity

Much of the literature drawn on for this thesis spans the last decade, during which time austerity policy in the UK has impacted children and young people with disabilities. As Porter argues, disabled people are particularly vulnerable during times of recession (Porter 2016). Horridge et al. (2019) analysed the austerity measures of several European countries in response to the financial crisis of 2008 and focused on its impact on children and young people with disabilities and their families:

> "More families that include a disabled person live in poverty, and have inadequate access to mental health services, adequate housing, and transport to enable their participation in society and achieve their hopes and dreams." (Horridge et al. 2019, p.333).

The Equality and Human Rights Commission's 2017 report on disability rights progress across England, Wales and Scotland found that people with disabilities are facing more barriers and falling further behind, leaving people with disabilities more disadvantaged (Equality and Human Rights Commission 2017). This highlights that prior to the global financial crisis of 2007-2008 there was a golden age where there was more funding for progressing disability rights. It is important to consider the changes in the financial context because much of the literature drawn on in this research came from a period where there was more funding available.

As a consequence, the issues faced by children and young people, their families and activity providers were very different a decade ago. For example, prior to the financial crisis, Russell (2003) analysed the UK Government's policies for children and young people with disabilities and their families and found that the issues were more focused on equality, access, and inclusion, early-intervention, and engaging with decision-making (Russell 2003). After a decade of local authority budget cuts, the conversations around the key issues for children and young people with disabilities has changed. Key issues now focus on the rights of children and justice (Porter 2016). Recent studies have focused on rights-based approaches, which measure the quality of life for children and young people with a disability (Davis et al. 2018), and rights-based frameworks for the social inclusion of children and young people with a disability (Browne and Millar 2016). The shift in focus from promotion of inclusion toward promotion of rights suggests that discrimination and inequality are key issues now faced by children and young people with disabilities.

Indeed, disabled people are now fighting for their rights in court. Meers (2017), for example, discusses the British Supreme Court case of 'R. Secretary of State for Work and Pensions' on the issue of the bedroom tax and disability-based discrimination. The article highlights the lack of consideration for the United Nations Convention on the Rights of Persons with disabilities. This is important because it demonstrates that the rights of people with disabilities are being eroded through austerity measures. As such, it is relevant to this research because both local authority and third sector delivery providers of activities for children and young people with disabilities rely on government funding to deliver services, funding which has been subject to severe budget cuts over the last decade.

1.4 Social Model of Disability in this Research

As outlined above, this research is framed by the social model of disability, which is a way of viewing the world developed by disabled people. The social model of disability is a reaction to the way that society treats people who are different or who have disabilities, as a problem. The social model states that people are disabled by the barriers they encounter in society. Society tries to change individuals with impairments, and this creates social attitudes that lead to discrimination. People with disabilities want to be equal and fully participate in and contribute to society. In this research, the social model helps to recognise barriers that make participation harder for children and young people with disabilities, and how changes in society might remove these barriers, thereby creating equality and offering disabled children and young people more independence, choice and control.

Disability was defined in the Disability Discrimination Act (1995) as a ‘physical or mental impairment which has substantial and long-term adverse effect on a person’s ability to carry out normal day-to-day activities. This locates the problem with the individual, and feeds into the impulse to ask ‘what’s wrong’ with someone. This view of disability aligns with the medical model of disability that labels and defines people by their medically defined conditions, for example, ‘David has got Asperger’s’, or ‘Sophie has got Downs syndrome’. The social model of disability presents a different way in which to view the world and understand disability; it is situated in a social context which on the one hand, has seen increased awareness of and improvements to the equality and rights of people with disability, while on the other, has been subject to government funding cuts that limit access and the increased opportunities gained over recent decades. The changes in social attitudes towards inclusion demand more and improved provision, but this has economic consequences and therefore depends on government and economic ideologies.

The changes in social attitude have been driven in part by the social model of disability. The Equality Act 2010, which is based on the principles of the social model of disability, and replaced the Disability Discrimination Act (1995), aimed to define a more progressive view of disability. However, in practice only a few minor changes were made to the wording: ‘a physical or mental impairment that has a substantial and long-term negative effect on your ability to do normal daily activities’. It failed to bring the definition up-to-date and in line with the way many people with disabilities understand their own experience. Whilst people with disabilities accept that they have an impairment, this does not define them; the problems they face come from discrimination in a society that does not accept that it is normal for some people to have impairments. This how the social model of disability defines the disabling attitude and structure of society.

The social model of disability states that if we design our buildings and transport differently, a person with a physical impairment would no longer be disabled by steps and inaccessible vehicles. In other words, if we stop treating people with disabilities as strange or exceptional, and treat them as normal, they will no longer be disabled by our attitudes. This view of disability places the responsibility on society to remove the barriers that inhibit access and opportunity for everyone. For example, safety is a common reason why children and young people with disabilities are excluded from certain activities and therefore, disables their right and ability to participate. The argument from a social model of disability would be that for able-bodied children we find ways for them to have adventure, take risks and challenges, while putting measures in place to ensure their safety. We are passionate about making sure our children have opportunities to participate in the things they enjoy. We should be doing this for all children and young people, not just children and young people that are able-bodied. This is an example of the disabling effect that the medical model of disability can have on the access and opportunity for children and young people to participate in inclusive community leisure and recreation. Negative experiences then reinforce the idea that children with impairments are disabled children.

The social model of disability promotes inclusive principles that confront diversity and differences. This focuses on creating a safe space for everyone to be seen, heard and accepted. Inclusion creates a space for difference to have its voice heard in relationships, family, community, at work, and in the world, treating people not as ‘you’ want to be treated, but as they want to be treated. Exclusion, on the other hand, separates, inhibits, limits, shuts down, sometimes oppresses, even suffocates. Exclusion can create tremendous anxiety, be divisive and lead to conflict. Advocates of the social model argue that exclusion is not just harmful to the person, it is harmful to relationships, families, profit and non-profit organisations and societies (Browne and Millar 2016). Society then loses out on what could be learnt and on what could be accomplished together.

1.5 Providers and Services

There are a variety of places where children and young people with a disability participate in mainstream leisure and recreational activities in England: through children’s and youth services (Collins et al. 2014; Welch et al. 2014), and community centers, sports clubs, and leisure facilities (Thompson and Emira 2011; Grandisson et al. 2012; Lyons et al. 2016). Children’s and youth services, such as Shorts Breaks, which provide respite for families and activities, are statutory services and therefore government funded (Welch et al. 2014), whereas community centers, sports clubs, and leisure centers combine government, third-sector and commercial funding. This is relevant for this research because funding is administered differently across government, third sector and commercial services, and this can determine the level of access and opportunity that children and young people with disabilities experience.

As discussed above, over the last decade, government-funded services have declined as a result of austerity and as a result, there is a reliance on the third sector to deliver provision such as youth clubs, playschemes, and community activities (Horridge et al.

2019). This places a reliance on the third sector to find alternative non-government funding sources or to become self-sustainable. This means that local authorities, the key government bodies responsible for the protection and inclusion of all children and young people in their plan for inclusive mainstream leisure and recreational activities, are largely secluding this group, thus leaving children and young people with disabilities vulnerable to isolation (Grenier et al. 2014). This reduction in services has had a direct negative impact on the access and opportunities available to children and young people with disabilities (Horridge et al. 2019).

1.6 Aims of this research

This research arose from a desire to consider what improvements could be made in providing community leisure and recreation activities to children and young people with disabilities. Organisations using a community centre participated in an action research process to develop inclusive activities. In this sense, the research is impact driven, as it arises from first-hand experience of the barriers that children and young people with disabilities and their families face.

The action-oriented nature of the research aim and the impact stance of the researcher guided the research design and questions. There were two overarching questions, one relating to the evidence base and one looking forward to action:

1. What are the barriers to participation for children and young people with disabilities in inclusive activities?
2. What factors support inclusive participation in community leisure and recreation settings?

This research sought to take a practical approach to improving the lives and experiences of children and young people with disabilities. One of the challenges in involving children and young people with disabilities and their families, in a collaborative research process, was how to most effectively engage participants in the process. In order to encourage participation and develop understanding from the perspectives of the key stakeholders, the researcher's role was to create a communicative space for them. In this endeavour, the researcher drew inspiration from Habermas's theory of communicative space as vital to enable equitable and discursive speech (Habermas 1981, 1987), a space where people can have their voices heard. The research therefore makes both a substantive and methodological contribution. It contributes to understanding the implementation of inclusive participation at the local level and how these implementations are viewed from the perspective of the children and young people with disabilities and their families. Methodologically, action research models an inclusive approach to the research and planning stage of an intervention designed to increase participation of children and young people with disabilities in leisure and recreational activities.

The findings in this thesis arose from this research process that brought together the users: young people with disabilities, their carers and families, and the practitioners: the providers of activities in the community centre. The research was carried out within a community setting and consisted of three research cycles. The aim was to include children and young people as participants, but that did not happen because parents chose to participate without their children; instead the first cycle involved the parents and carers of children and young people with disabilities; and the second cycle involved activity providers from host organisations. In these first two cycles, participants analysed, evaluated and reflected on participation in inclusive activities from their perspectives. The third cycle brought together participants to plan and develop actions based on the data generated in the previous cycles. A subsidiary aim, in terms of the researcher's own practice, was to develop a model of research and activity development that is in itself more inclusive, involving the beneficiaries, the practitioners who implement the activities, and the organisations who host the activities.

1.7 Contribution of the research

The majority of peer-reviewed published literature on participation of children and young people with disabilities in inclusive activities, sometimes referred to as inclusive participation, is found within the fields of sport (Shields and Synnot 2016; Valet 2018; Spaaij et al. 2019) and physical education (Kiuppis 2018; Wang 2019). There is a notable dearth of literature on inclusive community leisure and recreational activities outside of school-time. Therefore, this research aims to contribute to this body of research.

Furthermore, studies that evaluate interventions designed to increase participation in inclusive activities, tend to exclude the voices of the children and young people with disabilities and their families, and the interventions themselves seem to be designed with little input from the main stakeholders. This research therefore contributes to the body of evidence about children and young people with disabilities and participation in

these settings, particularly in the context of the Equality Act 2010, from the perspective of both users and providers.
This research also has an action-oriented aim, which is to contribute to the implementation of inclusion of children and young people with disabilities by involving them in the research and development process, along with the practitioners who facilitate leisure activities in the community. As such, it aimed to construct a collaborative and more inclusive process of research and activity planning. This is reflected in the methodological design of this action research, which sought to involve the users and practitioners in the process of research. Despite this aim, the research failed to achieve this in practice, and did not include children or young participants in the research. The reasons for this are discussed in the methodology chapter.

Given that the research aims to contribute to social change, the findings will contribute to academic research, inform the development of theory and practice, and be meaningful and useful to practitioners in the field, activity providers and frontline staff. The findings will not only contribute to the evidence base practitioners can draw on but could also be used to raise awareness and provide tools and concepts that can help with evaluating their provision in terms of accessibility, inclusion and participation.

The thesis comprises four more chapters. In the literature review chapter, key terms are defined, and an overview of relevant research pertaining to participation among children and young people with disabilities in inclusive community leisure and recreation is presented. The methodology chapter details the action research approach that underpins the design and methodology of the research and explains the three cycles. The methodology chapter culminates in a critical discussion of the research methods outlined in the literature review. The discussion chapter brings together the themes that emerged from the three cycles of research activity. The implications of the findings and reflections on the process are discussed in the conclusion chapter.

Chapter Two: Literature Review

2.1 Introduction

This review focuses on studies about the participation of children and young people with disabilities in inclusive community leisure and recreation activities. The chapter begins by describing the approach taken to reviewing this literature. The second section focuses on the implementation of inclusion in community provision and identifies two approaches to improving participation in community leisure and recreational activities: firstly through a child-centred approach, often with Occupational Therapists focused on the individual needs and wants of the child or young person; and secondly, through programme-based approaches that provide inclusive activities. The third section discusses the importance of the social environment in facilitating participation and the misdirection of social inclusion. The fourth section discusses the phenomenon of so-called 'selective' inclusion, and the fifth section illustrates the strengths of the community approach and the reverse-integration model. The sixth section focuses on the role of parents and families of children and young people with disabilities and reviews the common barriers and facilitators that emerge from the studies.

The objectives of the literature review are to identify, analyse, interpret and describe the critical ideas, values, and themes that appear in studies researching participation of children and young people with disabilities in inclusive activities. The aim of the literature review is to understand the way these ideas, values and themes inform and impact participation and inclusion in community, leisure and recreational settings. These themes are further explored and critiqued later in the discussion chapter.

2.2 Search Strategy

This review of qualitative and quantitative research draws on studies conducted from 2008 to 2018. The literature search was confined to a 10-year period because in social science fields change quickly with the acquisition of new knowledge and the need to share it rapidly. The literature search focused on the most recent literature because of the importance of the currency of concepts in the literature review. This 10-year period was considered adequate to cover the most recent research on conditions and qualities of participation in inclusive leisure and recreation activities for children and young people with disabilities. Research papers were sourced in three ways. First, electronic databases were searched, including CINAHL, MEDLINE, PSYCINFO, SOCINDEX, and Web of Science, and subject heading searches were also conducted on these databases. Second, relevant references from primary literature were followed up and included where they met inclusion criteria. Key search concepts were the a) setting: recreational and leisure activities; b) perspective: children and young people with disabilities and their families; and c) intervention: inclusion. Search terms from these key concepts are listed in Table 1.

Table 1: Key search concepts

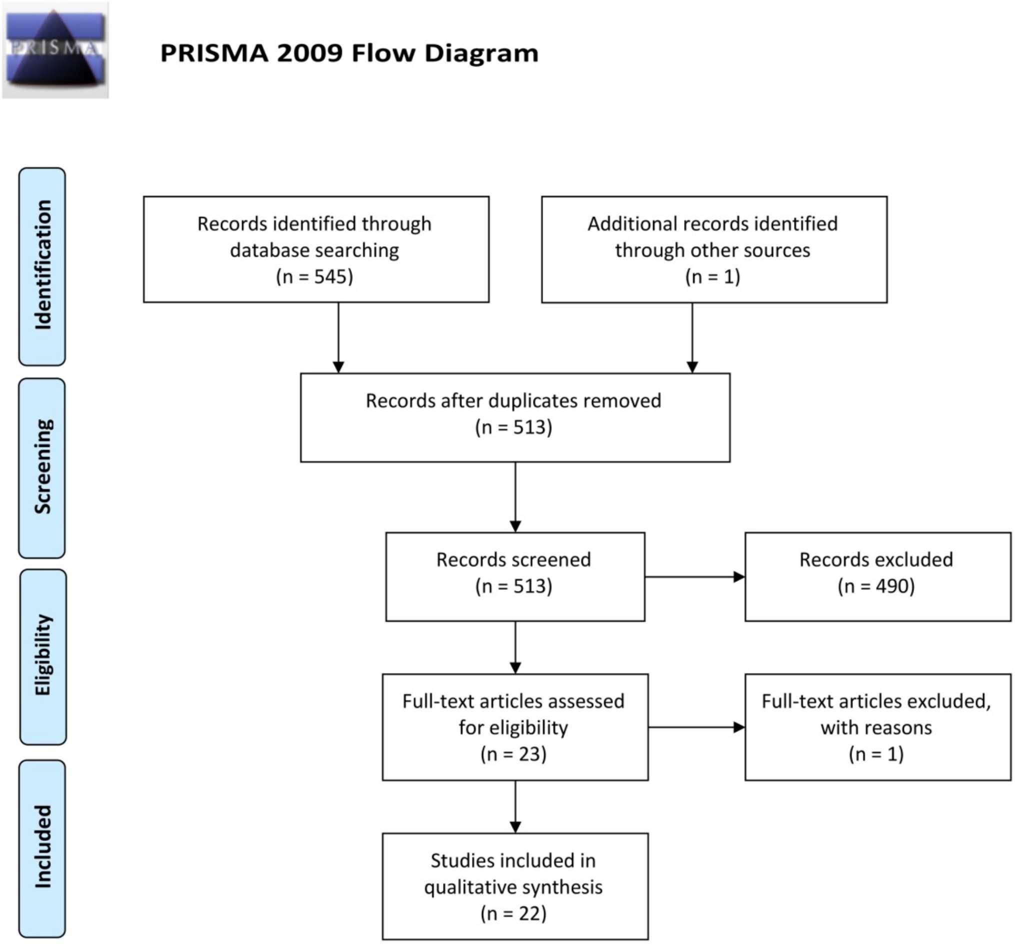
Key concepts	**Setting**	**Perspective**			**Intervention**
	Mainstream recreational and leisure activities	Children and young people with disabilities and their families			Inclusion
Key search words	Recreat* Leisure Activit* Sport* Scout* Cub* Beaver* Guide* Brownie* Rainbow* Youth club* Youth group* Drama Danc* Art* Music* Day camp* Summer camp* Swim* Gymnast* Cycl* Multisport* Judo* Karate* Football* Rugby Tennis	Child* Young Pe* Adolescen* Teen* Preteen* Early Twent* Early 20* Toddler* Youth Kid* Preschool* Young* Juvenile* CYP*	Disab* Impair* Handicap* Limit* Illness* Life Limiting Blind* Deaf* Hearing Impair* Sight Impair* Vision impair* Learning disab* LD Physical disab* PD Learning need* Learning support* Wheelchair user* Downs syndrome Tourette* Autis* Asperger* Cerebral Palsy Attention Deficit Disorder ADD Attention Deficit Hyperactivity Disorder ADHD Dyspraxia Emotion* disorder Behavio* disorder Differently able Cognitive disab* Anxiety Mental* ill* Brain injur* Chronic fatigue syndrome CFS Multiple sclerosis MS Epilepsy	Famil* Parent* Carer* Sibling* Brother* Sister*	Inclus* Participa* Involv* Access* Integrat* Accommo* Guardian*

A total of 513 articles were screened as a result of the search process using the following criteria:

- a) primary focus on children and young people from preschool (age 4) to young adulthood (age 25),
- b) inclusion of at least one child or young person with a disability,
- c) full-text peer-reviewed primary research,
- d) focus on existing inclusive program or activity, or intervention that was examined as part of an experimental design, and/or focus on experiences of engagement with such activities
- e) situated outside of school hours, and
- f) written in English.

Studies were then excluded for the following reasons: studies that focused on school-time activities; studies that did not examine inclusion; studies involving adults older than 25; non-peer reviewed; review and comment articles. In this process, 23 articles were assessed as eligible for full-text analysis and were imported into the EndNote database management system. The Prisma in Figure 1 illustrates the search process. One research paper was excluded during full-text analysis because the research included young adults with disabilities up to the age of 29, which was above the criteria for inclusion up to the age of 25. The maximum age for inclusion of 25 was chosen because the Special Education Needs and Disability (SEND) system, through the Children and Families Act 2014, focuses on ages 0-25, having risen from 18 previously.

Figure 1: PRISMA flow diagram of search process



The six-stage methodological framework developed by Arksey and O’Malley (Arksey and O'Malley 2005) was then used to analyse the remaining 22 studies by a) identifying the research question, b) identifying the relevant studies, c) selecting studies, d) extracting data, e) collating, summarising and reporting the results, and e) consulting references.

The 22 studies were all set in the context of mainstream leisure and recreational activities. Some studies looked at specific inclusive activity provision including day camps, arts-based community programmes and sports clubs, while other studies addressed participation more generally across a range of different inclusive physical activity and leisure provisions. Much of the literature discusses community leisure and recreation activities in terms of ‘provision’ to refer to an organisation providing activities for children and young people with disabilities. This term is less-widely used in mainstream community leisure and recreation, where it is more common to refer to ‘activities’ that an organisation provides. For the purposes of this research, both ‘provision’ and ‘activities’ will be used.

All 22 studies were also included because of their perspective on children and young people with disabilities; a few studies addressed specific disabilities including Autism, Downs Syndrome, Autistic Spectrum Disorder and Attention Deficit Disorder. However, the majority of studies addressed children and young people with disabilities more heterogeneously, to include intellectual disability, developmental disability, physical disability or disability in general. Only four of the 22 studies were conducted in the UK (Emira and Thompson 2011; Thompson and Emira 2011; McConkey et al. 2013; Imms et al. 2016). There is therefore a considerable gap in the literature in terms of the extent to which inclusion is being implemented in community leisure and recreation. Other studies were carried out in Canada (Spencer-Cavaliere and Watkinson 2010; Grandisson et al. 2012; Anaby et al. 2015; Law et al. 2015; Anaby et al. 2017; Knibbe et al. 2017; Taheri et al. 2017; Smart et al. 2018), the USA (Boyd et al. 2008; Miller et al. 2009; Siperstein et al. 2009), Norway (Willis et al. 2018a; Willis et al. 2018b), Australia (Shields and Synnot 2016; Jeanes et al. 2018), Ireland (Lyons et al. 2016) and Sweden (Arnell et al. 2018). Although the policy contexts are different and there are cultural factors that influence the shape of participation in inclusive activities, and the discourse around children and young people with disabilities, this review nonetheless refers to all these studies, as the insights about barriers and challenges, as well as facilitating factors, are likely to be relevant for this research and its research context. Furthermore, it is important for this research to consider a range of different approaches that facilitate participation in inclusive activities.

2.3 Two approaches to increasing inclusive participation: child-centred versus programme-centred

Social inclusion is defined as the process of improving the terms of participation in society, particularly for people who are disadvantaged, through enhancing opportunities, access to resources, voice and respect for rights (Peters, and Besley, 2014). The concept of social inclusion is an abstract term and generates questions, confusion and even some misunderstandings among practitioners; there is a difference between ‘claiming’ social inclusion and ‘doing’ social inclusion. One critique of social inclusion is that the concept is based on an ‘underlying moral meta-narrative’ which assumes that social inclusion is good and advantageous (Hickey & du Toit, 2007: 3). For example, inclusion is seen as valuable in terms of paid employment, however this often excludes people with disabilities. As a result, efforts to improve social inclusion can often be led by implicit normative assumptions about how social life should be organised. This often ignores the ways in which the terms of inclusion can be problematic, disempowering or discriminatory.

Based on the studies reviewed in this chapter, organisations adopt two distinct approaches to implementing inclusion: a) through interventions that work intensively with children and young people with disabilities, their families and activity providers to break down barriers and provide support to individuals; and b) through programmes and clubs that provide inclusive activities for children and young people with disabilities.

Child-centred approaches

In response to the need of families and children and young people with disabilities, interventions have been shown to be effective at sharing the pressures of advocacy, building capacity and promoting a sense of empowerment (Law et al. 2007; Anaby et al. 2015; Imms et al. 2016; Anaby et al. 2017; Willis et al. 2018a; Willis et al. 2018b). Intervention approaches tend to be therapeutic and include home and community-based visits by specialist providers such as Occupational Therapists who may provide weekly sessions or intensive residential breaks. Studies by Anaby (2015; 2017), Imms (2016) Law (2015) and Willis (2018a; 2018b) look at therapeutic interventions that work directly with individual children and young people with disabilities to find ways to improve their community leisure and recreation participation.

Imms et al. (2016) conducted quantitative research with multiple methods into an intervention to improve participation in leisure activities of young people with physical impairments through therapy services in the community. The research measured the outcomes of changing the activity or environment for eight adolescents with a disability aged twelve to 19 who presented with varying function and physical disabilities including intellectual impairment and epilepsy. Data was collected through pre-test and post-test interviews and questionnaires, and outcomes measured using the Goal Attainment Scale and the Canadian Occupation Performance Measure. Imms et al. (2016) found that the effectiveness of the intervention lay in establishing goals for the child or young person and their family, measuring and addressing environmental barriers, and building skills in the chosen activity (Imms et al. 2016). The research highlighted that a multi-strategy approach was important because participation in leisure activities was dependent on complex interactions between several factors: a) the motivation and ability of the child or young person with a disabilities and their family, b) the environment, including accessibility, transportation and availability, and c) the characteristics of the activity. This finding is relevant to this research because it demonstrates that a multi-strategy collaborative approach with families, to address environmental and personal factors influencing leisure participation, can support the achievement of participation goals of children and young people with disabilities.

Anaby et al.'s qualitative research (2015, 2017) focused on a twelve-week intervention that involved weekly home-based sessions to address individual barriers to participation in activities; these methods included modification of activities, managing practical arrangements, facilitating peer interactions and social relationships, and facilitating personal and social development. Twelve Occupational Therapists were involved in delivering the intervention, and twelve parents whose children with physical disabilities aged twelve to 18 had received the intervention, participated in the research. Through semi-structured interviews with Occupational Therapists, Anaby et al. (2015) focused on the environment, resources and problem solving as an approach to implement participation in inclusive activities. Facilitated by individual coaching, this broadened capacity and increased empowerment for children and young people with disabilities as well as activity providers, to advance the participation of children and young people with disabilities (Anaby et al. 2015). Anaby et al. (2017) found that this high level of support, which equipped families and children and young people with disabilities with knowledge, problem-solving and self-advocacy skills, was linked to improvements in physical, emotional and social levels of children and young people with disabilities.

The research findings also indicated that the intervention led to a process of growth for children and young people and their families that extended beyond the activity targeted in the intervention (Anaby et al. 2017). This is important because it demonstrates that with intensive and focused support, children and young people with disabilities are enabled to take more control of their lives and have more of a say over decisions that directly impact them. This finding is relevant to this research because it illustrates how a child-centred strength-based approach to participation can enable children and young people with disabilities to build independence and autonomy.

Law et al. (2015) conducted quantitative research through questionnaires to examine whether an intervention to remove environmental barriers using a coaching approach, improved youth participation in leisure activities. Participants were six young people with physical disabilities aged 13-19, recruited through rehabilitation centres, who took part in a 20-week intervention facilitated by Occupational Therapists. Three individualised participation goals were set by each child and young person and the outcomes were statistically measured against the Canadian Occupation Performance Measure. Although the intervention aimed to modify aspects of the environment that presented barriers to the participation of children and young people, the research showed that the intervention also encouraged behaviour modification in children and young people to break down the barriers, such as participating in activities at less busy times and taking breaks from the activity. Law et al. (2015) failed to consider that this placed the responsibility on the child or young person to adapt to the activity, thereby going against the social model of disability. By contrast, this study begins from the premise that strategies to improve the participation of children and young people with disabilities in community leisure and recreation must be based on the principles of the social model of disability.

Willis et al. (2018a; 2018b) conducted both quantitative and qualitative research focused on a client-centred intervention to improve the participation of children and young people with disabilities in physical activity. Participants of the quantitative pre-test post-test design (Willis et al. 2018a) were 92 children and young people with disabilities aged five to 17 with a range of disabilities, including Cerebral Palsy, intellectual disabilities, and neuro and developmental disorders. The intervention was a 19-day residential program for groups of eight to ten children and their parents, to engage in intensive physical, social and cultural activities, and extensive outdoor activities based on the child's goals. The research evaluated the changes in physical activity in children with disabilities following the intervention. Data collected using the Canadian Occupation Performance Measure and assessed through Goal Attainment Scaling, identified that 32% of children and young people attained their goal after twelve weeks as a result of the intervention. Willis et al. (2018a) found that the process of self-development, which was facilitated through the intervention, promoted the learning of new skills, making choices about activities, and evolving behaviour, all of which optimised participation outcomes for children and young people with disabilities. This is relevant to this research because it illustrates how a child-centred approach, which focuses on self-development, enabling choice and giving a voice to children and young people with disabilities, can optimise their participation.

Willis et al.'s (2018b) qualitative research focused on strategies that facilitated involvement in physical activity for children and young people with disabilities, as a result of the same participation-focused intervention presented in Willis (2018a). Participants of the research (Willis et al. 2018b) were 31 children aged five to 17 and 44 of their parents who took part in interviews and focus groups over a period of 15 weeks following the intervention. The research identified five mechanisms that facilitated meaningful outcomes for children and young people with disabilities and their parents; these were: choice, fun, friends, specialised health professionals and time. Willis et al. (2018b) found that it was the interaction of these five mechanisms that optimised physical activity participation outcomes for children with disabilities. This is relevant to this research because it demonstrates the benefits of the interaction between parents, staff, access, opportunity and enjoyment to facilitate the participation of children and young people with disabilities in inclusive activities.

The research on interventions in advancing the participation of children and young people with disabilities found that various child-centred strength-based approaches that collaborate with families and activity providers to optimise participation in community leisure and recreational activities. The strength of these interventions lies in its concern with developing personalised strategies and the focus on the child or young person. However, the limitations of such individualised interventions s highlighted by Smart et al. (2018), whose research focused on an arts-mediated community garden programme; Smart et al. (2018) argue that direct strategies single out children for special treatment, as opposed to indirect strategies that change the environment. This is an important argument as it highlights the potentially negative attention that child-centred approaches place on the child. This is relevant to this research because it demonstrates the importance of fully considering the strengths and weaknesses of different approaches; multiple and varied approaches can give children and young people with disabilities a variety of opportunities to participate in inclusive community and leisure activities but may have limitations that need to be considered.

Programme-centred approaches

The greatest proportion of studies focussed on participation in inclusive programmes and clubs, in community leisure and recreation, including physical activity and sport participation in general. These approaches are different to individualised interventions which focus on the needs and characteristics of the child, in that programme-centred approaches focus on the needs and characteristics of the community and the capabilities of service providers (Miller et al. 2009). In contrast to child-centred approaches therefore, responsibility is on service providers to deliver activities that are equally accessible with opportunities for everyone, regardless of impairment of disability. These programme-centred studies are relevant for this study because they tend to be local, community-based, and contextual, as well as emphasising the responsibility of providers to engage children and young people with disabilities in inclusive community leisure and recreational activities.

Activity programmes are diverse and providers face specific challenges, depending on their structure (Spencer-Cavaliere and Watkinson 2010). Spencer-Cavaliere et al. (2010) conducted qualitative research into the concept of inclusion in physical activity from the perspective of children and young people with disabilities. Data from interviews with eleven participants aged eight to twelve with a range of physical and developmental disabilities, identified three themes: gaining entry to play, feeling like a legitimate participant, and having friends. Spencer-Cavaliere et al. (2010) highlighted that in child-directed and determined free-play, other children often dictate participation and it is difficult to influence inclusion without interfering with the unstructured nature of the environment. The findings indicated that children and young people with disabilities were less included by their peers in free play settings. This poses a challenge for providers of activities with free-play structures and highlights the importance of activity structure in facilitating an environment that fosters friendship and inclusion.

Grandisson et al. (2012) found that in structured sports programmes, the facilitation of relationships between peers was easier to manage. Grandisson et al.’s (2012) qualitative multiple-method research into the experiences of children and young people with disabilities in physical activity programmes, found that peers without disabilities developed an awareness of children and young people with disabilities by participating in a structured leisure activity. Interviews were conducted with 20 adolescents with mild to moderate intellectual disability aged twelve to 19; 20 of their parents and 39 rehabilitation staff took part in questionnaires and discussion groups (Grandisson et al. 2012). The comprehensive understanding of sports participation gained from a variety of sources was a strength of the research, which found that attitudes, practical support, individuals’ experiences in sports and in integrated settings, as well as behaviour control, emerged as important elements to consider. Grandisson discussed this last element of behaviour control an individual’s capability to manage their own behaviours, as a barrier. This is important because Grandisson et al.’s (2012) research discusses behavioural barriers in terms of *behaviour problems* and *good behaviours*, both of which place the responsibility for this behaviour with the child or parent, and fails to consider how a disability may limit a child’s ability to control their own behaviour. This is relevant for this research because it highlights the challenges of activity structure and peer-relationships in programme-centred approaches among children and young people with challenging behaviour.

Other studies focus on structural barriers more broadly across leisure activities, such as Emira et al. (2011) and Thompson et al. (2011) who conducted qualitative multiple-method research of the perceptions of 44 parents of children aged eight to 17 with Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder in accessing leisure activities. Emira et al. (2011) found that parents had few successful experiences of leisure activities, as a result of structural barriers including staff attitudes, training, availability, flexibility, information, cost, support and distress were a result of the implementation of provision. The research identified that failings in the structure of leisure services resulted in a lack of trust among parents toward leisure providers (Emira and Thompson 2011). Thompson et al. (2011) found that the structural barriers were reinforced by a lack of awareness and understanding among leisure centre staff of hidden disabilities and challenging behaviour; consequently, children with challenging behaviour were viewed as *naughty children* (Thompson and Emira 2011). The research found that assumptions were sometimes made about children based upon unrealistic expectations derived from an assessment of appearance that ignored the hidden nature of the impairment (Thompson and Emira 2011). Subsequently, parents and carers made very strategic decisions, and Thompson et al. (2011) found that parents perceived segregated disability provision to be better than inclusive mainstream provision, an assumption that was not addressed in other studies. This is important because it demonstrates how discrimination impacts access and opportunity for children and young people with disabilities. It highlights the importance of disability awareness and understanding in advancing the inclusion of children and young people with disabilities in community leisure and recreation.

Both child-centred and programme-centred approaches to advancing the participation of children and young people with disabilities in community leisure and recreation have their strengths and weaknesses. The strengths of child-centred approaches are in its use of personalised strategies and the focus on the child or young person. The research into child-centred approaches generally focused on the strengths of the intervention, and research into programme-centred approaches generally focused on the barriers to participation. The weaknesses within programme-centred approaches were identified as structural barriers within the social context that reinforced discrimination. This indicates a lack of inclusion and a need for development of inclusive practice in community leisure and recreation.

2.4 The socially inclusive environment

The social context is central to the implementation of a socially inclusive environment that supports all children and young people to participate together (Knibbe et al. 2017). Knibbe et al. (2017) conducted semi-structured interviews with eleven young people with physical disabilities aged twelve to 18 years, about their experiences of social environments that facilitate physical activity. The research characterised socially supportive environments that helped promote physical activity from the perspective of children and young people with disabilities. Knibbe et al. (2017) revealed that supportive social environments are characterised by equitable participation, a sense of belonging, and opportunities for interdependence and play a critical role in facilitating physical activity among young people with physical disabilities. Through the promotion of diversity and equality in the social environment, the voice of children and young people with disabilities, and cooperative activities, this cooperative approach to the process of social inclusion in community leisure and recreation activities improved the ability and opportunity for children and young people with disabilities (Knibbe et al. 2017). This study argues for the importance of a socially supportive environment where all children and young people with disabilities feel valued, their differences are respected, and their needs are met.

This finding was mirrored by Siperstein et al. (2009) who conducted quantitative research of the social acceptance of children and young people with and without disabilities in an inclusive summer program. The four-week day camp consisted of three daily sports sessions of swimming, basketball and soccer. A unique element of the socially inclusive environment created at the day camp was that all children, regardless of ability or disability participated in all activities, both sport and non-sport. Siperstein et al. (2009) showed how this required children to work together, support one another, to achieve a common goal, all while having fun. The results of this research suggest that promoting and emphasising the individual strengths of all children through cooperatively structured activities can promote the social inclusion of children with mild intellectual disabilities. This is important to this research because it demonstrates how cooperatively structured activities promoting individual strengths support the social inclusion of children and young people with disabilities in inclusive activities.

Another unique programme that promoted social inclusion of children and young people with disabilities is described by Boyd et al. (2008). Boyd et al (2008) conducted quantitative research into the effectiveness of a peer intervention program on children and young people with and without disabilities participating in a day camp activity. Participants were twelve children aged five to ten, half of whom had disabilities. Peers without disabilities were given training based on the STAR programme, which modelled behaviours for including their peers with disabilities: ‘stay’, ‘talk’, ‘assist’ and ‘reward’ (Boyd et al. 2008). During camp activities, participants and their interactions were observed. Boyd et al. (2008) found that after intervention training with peers of children and young people with disabilities, the average percentage of interactions between campers with and without disabilities increased for all participants. The success of this approach, which engaged children and young people to support their peers, illustrates how an intervention programme can increase social inclusion among children and young people with disabilities, and provided a socially inclusive environment. The programme demonstrates the importance of peers of children and young people with disabilities in contributing to a socially supportive environment.

The notion of socially supportive environments and the concept of inclusion are implemented in many different ways across community leisure and recreational activities. McConkey at al. (2013) conducted a qualitative interview research, addressing social inclusion fostered through an inclusive international football and basketball programme. The research combined group and individual interview data of 156 players aged twelve to 25 with intellectual disabilities (called athletes) with 106 of their able-bodied peers of a similar skill level (called partners) for competition, training and social events in the wider community. Data was collected from interviews with both parents, and children and young people with disabilities, who were invited to talk about their extended social activities as a result of opportunities provided by or through the sports programme. McConkey et al. (2013) found that shared activities outside of the programme provided greater social inclusion of athletes with disabilities in wider society. This integrative concept of inclusion off the sports field facilitated participation and broadened the opportunities and experiences of participants in community life, through an increased visibility of disabled people within the community (McConkey et al. 2013). The program provided a vehicle for promoting a socially inclusive environment by building new perceptions; however, this increased visibility of children and young people with disabilities in community activities, placed a reliance on children and young people with disabilities to be the catalyst of change and this directly opposes the social model of disability that places the responsibility upon society to deconstruct negative attitudes and social barriers (Kemmis and McTaggart 2005). This is an example of how misdirected attempts to create a socially inclusive environment can further discriminate children and young people with disabilities.

Nonetheless, the research shows that a socially supportive environment that is crucial to providing an inclusive environment can be achieved through cooperatively structured activities promoting individual strengths, and through peer-relationships. This demonstrates how the strengths of personalisation identified in child-centred approaches can also be applied in programme-centred approaches. However, despite the ambition, not all programmes that are designed to promote social inclusion meet the aims of their inclusive ethos. This may be because the concept of inclusion is not fully understood by community leisure and recreation providers.

2.5 Selective Inclusion

According to Jeanes et al. (2018) the way that community, leisure and recreation providers interpret the requirement to implement inclusion is varied and not necessarily grounded in a social model of disability. In sports and recreation interventions investigated by Jeanes et al. (2018), McConkey et al. (2013) and Miller et al. (2009), attempts to develop inclusion led to selective inclusion which normalised and perpetuated the marginalisation of children and young people with disabilities in their communities. For example, McConkey et al. (2013) highlighted that the competitive nature of the program did not facilitate the participation of children and young people with higher needs, thereby excluding the most vulnerable children and young people with disabilities. This highlights the discrimination faced by children and young people with higher needs who are excluded from certain activities such as sports.

Jeanes et al. (2018) found evidence of segregated training in sports clubs in a semi-structured interview research of how grass roots sports clubs respond to inclusion policy. Participants were 41 club volunteers from 19 sports clubs, including football, cricket, netball, hockey, basketball and lawn bowls clubs, however, only eight volunteers from eight clubs were included in the data set for this research because the remaining eleven clubs presented with low levels of engagement with disability provision. Despite focusing on clubs that provided disability provision, Jeanes et al. (2018) found that disability provision in clubs was separatist, and the response to inclusion policy in clubs was focused on narrow forms of participation and competitive pathways that mirrored mainstream sport. The findings highlighted that sports clubs included in the research positioned disability provision as distinct and separate from their main focus because players were segregated in training. Such activities that provide separate activities position disability as a side-line or inferior and promote ableism, which can lead to physical, social and cultural isolation (Jeanes et al. 2018). This demonstrates the lack of inclusive practice in community sports clubs that engage with children and young people with disabilities.

Another study that raised a concern about selective inclusion across community leisure and recreation is Miller et al. (2009), whose findings revealed that programme staff assessed whether a child or young person with a disability was ‘ready’ for an inclusive program. The interview research with 15 inclusion facilitators and agency administrators from across the US identified programmatic practices in inclusive recreation agencies. Miller et al. (2009) voiced grave concerns about some inclusive practices that assessed children and young people with disabilities based on whether they were capable of participating. Miller et al. (2009) argue that children and young people with disabilities should have the right to choose but found that the decision was often in the hands of the programme staff. Research revealed how this 'gatekeeping' mechanism for access to inclusion was inconsistent with the principles of inclusion (Miller et al. 2009). This is an example of how discriminatory culture is reinforced by excluding children and young people because of capability, as opposed to being excluded because the programme or provider is not capable of providing inclusive activities. This highlights how exclusion and discrimination can be or become systemic in ostensibly inclusive community leisure and recreation organisations.

The findings of Jeanes et al. (2018), McConkey et al. (2013) and Miller et al. (2009) raise a concern about the misdirection of inclusive values among community organisations, grass-roots clubs and sports activities. On multiple levels, selective inclusion excludes, isolates, discriminates and infringes on the rights of children. In contrast, inclusion and inclusion practices give the power and control back to children and young people with disabilities and their families by giving them choice and a voice.

2.6 Community Approaches

King et al. (2016) and Smart et al. (2018) argue that inclusive provision can only be successful when all children and young people feel that they are truly part of the community. Both King et al. (2016) and Smart et al. (2018) conducted qualitative research based on data collected from interviews with 14 past and present service delivery staff. The Spiral Garden, as the project is called, provides an outdoor setting for children and young people with additional needs, and staff foster creative expression in the garden, through facilitating arts-mediated activities. The community approach in this programme is designed to be broadly unstructured in every area. King et al. (2016) identified three themes in the research: the garden as a community, art as the connector, and intentional process-oriented design. The community approach to the implementation of inclusion and participation in the garden was to create an environment where everyone felt valued. The program model, which used storytelling, working with clay, puppetry, gardening, painting, music, ceremony and celebration, was based on a reverse-integration model to bring able-bodied children into the environment of differently abled children (King et al. 2016). Smart et al. (2018) found that this can only happen through open honest discussion about differences and understanding, and respecting people of all abilities; instead of formal disability education for peers, peer interactions initiated and informed conversations about disability (Smart et al. 2018). This is an alternative approach to inclusion in that, unlike other approaches, it is community-driven and unstructured, and focused on values and respect, reverse-integration, and openness about difference.

In addressing the barriers faced by children and young people with disabilities, Smart et al. (2018) found that the service focused on understanding the social context from the perspective of the child's subjective experiences to anticipate barriers that might occur, which enabled activity providers to be proactive about them, and more importantly, enabled children and young people with disabilities to have a voice. Smart et al. (2018) identified three main categories that service providers perceived to be essential to inclusive leisure: engaging children in collective experiences; encouraging peer interactions and friendships; and facilitating collaborative child-directed experiences. Smart et al. (2018) highlighted these strategies in a tree metaphor to engage children in collective experiences. Smart (2018) found that engaging children in collective experiences, encouraging peer interactions and friendships, and facilitating collaborative child-directed experiences, fostered meaningful relationships with peers. A key component in each of the eight strategies analysed in the research was the contribution of meaningful relationships with peers in connecting them with their broader environment (Smart et al. 2018). The approach to inclusion adopted in the Spiral Garden project is both holistic and conceptual; Smart et al. (2018) argue that children and young people with disabilities felt more included when their peers and activity providers showed faith in their abilities without focusing on their inabilities. This study highlights the importance of the relationships between children and young people with disabilities, their families, and activity providers in implementing inclusion, particularly in less-structured activity programmes, such as the Spiral Garden. This demonstrates the importance of people and relationships, through community engagement, in providing a social context that is inclusive.

The importance of community is echoed in research by Taheri et at. (2017) who conducted quantitative research to examine child, family and community variables that impact the activity participation of children and young people with severe developmental disabilities. A strength of this research is its focus on children with severe developmental disabilities, who are a group that are often excluded from activities and research. Participants were 197 parents of children with severe developmental disabilities aged four to 19 years, who completed a survey about their child and the family, and a measure of participation questionnaire, and were recruited through disability agencies across Canada. The data was statically analysed and Taheri et al. (2017) identified that child, family and community factors accounted for 30% of the variance in participation. This demonstrated the importance of supportive relationships, interactions and the community in creating positive outcomes for children and young people with disabilities.

This research shows that community-driven and unstructured approaches, focused on values and respect, and openness about difference, can provide a socially inclusive context that advances the participation of children and young people with disabilities. This research shows a clear link between people and relationships in community approaches to inclusion and participation, and the importance of those people in providing a social context that is truly inclusive.

2.7 The role of parents and families

The role of parents and families, who are arguably the most important people to facilitate inclusion and participation, can be both a critical barrier and/or facilitator for the inclusion and participation of children and young people with disabilities in community leisure and recreation (Shields and Synnot 2016). Six of the 22 studies focused on the role of parents and families, three of which were focused of the perceptions of parents in supporting their children. Lyons et al. (2016) conducted qualitative interview research with seven parents of five children with Down Syndrome aged six to twelve to explore parental views of their children's participation in everyday activities, including physical and social activities. They identified two main themes: participation, which included three subthemes, skill development, enhanced wellbeing and a sense of belonging; and barriers and facilitators, which included four subthemes of child factors, attitudes, environmental modifications and logistical issues. Parent participants in the research focused on their own roles in supporting their children and providing them with opportunities to develop new skills to enable them to participate. Lyons et al. (2016) found that parents predominantly supported their children through motivation but often took responsibility for adapting activities in community. This demonstrates both the importance of parents in facilitating the participation of their children, and the responsibility that they have in facilitating inclusion in community activities. This is important because it demonstrates that when community settings do not provide the adaptions required to meet the needs of children and young people with disabilities, participation of children and young people with disabilities is then determined by parents.

The varying level of proactivity in parents and families is highlighted in a study by Arnell et al. (2017), who conducted qualitative interviews about the perceptions of physical activity among 24 young people with Autism Spectrum Disorder aged twelve to 16. A strength of the research was that the level of participation among participants varied from sedentary to highly active. The main theme identified by content analysis was the concept of conditional participation, and findings revealed that willingness to participate was markedly varied, which showed a heterogeneity within the group not fully captured in previous research. A key finding linked the conditional participation of children and young people with disabilities to the involvement and participation of their parents; children and young people reportedly preferred their parents as activity partners (Arnell et al. 2018). This is important because it demonstrates the vital and proactive role that parents' own participation plays in the facilitation of their children with disabilities in community leisure and recreation.

The pressure on families to be fully engaged with their child's participation is explored by Shields et al. (2016), who conducted qualitative focus groups to explore factors perceived as barriers and facilitators to participation in physical activity by children and young people with disabilities. Participants were 23 children and young people with disabilities aged ten to 18 with a broad spectrum of disabilities, 20 parents of children and young people with disabilities aged six to 18, and 20 sport and recreation staff, recruited through disability, sport and recreational groups, therapy services and special schools. Data from thematic analysis identified four themes: similarities and differences; people make the difference; one size does not fit all; and communication and connections. Shields et al. (2016) identified the pressures experienced by families that influenced the participation of their children, including family attitude toward inclusion, family demographics, and parents' own social participation. The barriers cited by parents in the research included lack of knowledge or means, and doubting their child's safety or ability, both of which excluded children and young people with disabilities, whereas facilitators included parent's proactivity in participating alongside their children. Shields et al. (2016) also found that families often lack the capability, knowledge and resources to fully facilitate the participation of their children in community, leisure and recreational. This is important because it shows how children and young people with disabilities are disadvantaged by family situations that are limited by means or capability and therefore, highlights the support required by families in order to stop children and young people with disabilities from being excluded as a result of their family situation.

In addition, Arnell et al. (2017) and Lyons et al. (2016) reveal that the pressure on families to be fully engaged themselves in the facilitation of their child's participation has not been fully understood. This is concerning when considered alongside research from Shields et al. (2016) which demonstrate that the capability and capacity of families to provide this support is both a barrier and facilitator that includes and excludes children and young people with disabilities from participating in inclusive community leisure and recreation.

2.8 Conclusion

The purpose of this review was to explore the participation of children and young people with disabilities in research within inclusive community leisure and recreation, and to understand the barriers and facilitators. The discourse of inclusion in community provision is developed in both programme-centred and child-centred approaches. Common to both is the notion of 'true' inclusion: the removal of all discrimination, intolerance and barriers (Anaby et al. 2015; Jeanes et al. 2018). Strengths in child-centred approaches were highlighted as being the use of personal strategies that worked with individuals to address the barriers they face. In contrast, barriers were highlighted in programme-centred approaches such as staff attitudes, training, availability, information, cost, support, distress and trust (Emira and Thompson 2011). These structural barriers reinforce discrimination and exclusion of children and young people with disabilities in community leisure and recreation. Although both approaches have strengths and weaknesses, it is clear from the barriers highlighted in programme-centred approaches that that more needs to be done and something needs to change to break down the barriers to participation in inclusive community leisure and recreation activities.

The reviewed literature has demonstrated that socially inclusive environments, which are crucial to the participation of children and young people with disabilities in community leisure and recreation, are not always based on the principles of the social model of disability. Approaches identified as successful in facilitating inclusion and participation were cooperatively structured activities that promoted individual strengths, and through the development of peer relationships, both of which have been shown to have an impact on the social inclusion of children and young people with disabilities in community leisure and recreation activities. However, the research shows that the concept of inclusion within the social structure of some activities is often misunderstood in that there is a reliance on children and young people with disabilities to be the catalyst of change to improve their participation. The social model of disability is clear that children and young people with disabilities are not responsible for their own inclusion or for changing the perceptions of disability among the community. This is a problem because the responsibility to be inclusive, both legally and ethically, lies with government, society, service providers and the community.

The literature reveals other concerns about inclusive values in community organisations, grass-roots clubs and sports activities. The literature demonstrates that some inclusive practices segregate children and young people with disabilities from their non-disabled peers (McConkey et al. 2013; Jeanes et al. 2018), and limit autonomous choice through ‘gatekeeping’ (Miller et al. 2009). Although not intentional, selective inclusion isolates, discriminates and infringes on the rights of children. Selective inclusion, segregation, and social environments that exclude children and young people with disabilities are problematic in the discourse of the social model of disability and lead to a misdirection of inclusive values. This field of inquiry is important because at its centre is a concern about the social norms of society that are discriminatory and impact the socially inclusive environment that is necessary for the inclusion and participation of children and young people with disabilities in community leisure and recreation.

Despite the exclusion faced by some children and young people with disabilities, there is also much literature evidencing good practice and positive outcomes in inclusive community leisure and recreation activities. The literature demonstrates how children and young people can feel more valued and included when they are part of a community. Community approaches embedded in a truly inclusive social context can give a voice to children and young people with disabilities, and equal opportunity for all children and young people to engage and be included in activities as part of the community (King et al. 2016; Taheri et al. 2017). In one community approach, the reverse-integration model, which brought able-bodied children into the environment of differently abled children, a communicative space was provided that enabled open and honest discussion about difference. The literature demonstrated how inclusive community approaches such as this, which are driven by an inclusive social context, are as a result of the people involved in those approaches, and the relationships between those people. The power of community to foster inclusion and participation through peers, parents and families, and activity providers, is clearly linked with the social context. This connection is important because it reveals the mutual dependency of people and place in inclusive practice.

Literature reveals that the group of people who have the biggest impact on the participation of children and young people with disabilities in inclusive community leisure and recreation activities, parents and families, face constant challenges. The demand on parents to advocate, motivate, organise, and participate, puts pressure and responsibility on families. The literature shows that the capability and capacity of families to provide this support can act as both a barrier and facilitator. Participation outcomes were improved for children and young people with disabilities whose families were able to be proactive and make their voices heard. However, this raises concerns regarding the inclusion of children and young people whose families lack the capability or capacity to provide the support required by their children to participate, thus excluding them from community leisure and recreation activities.

A range of methods were used in the studies about activities and programmes designed to change the way children and young people with disabilities participate in inclusive community leisure and recreation. Critical discussion of the research methods outlined in the literature review is explored in the methodology chapter, however no research was found that used Action Research methods to develop practical solutions that impact change. In other words, there is a gap in the research in terms of studies that not only investigate inclusion but are also designed to take action to improve the methods and approaches involved in inclusive participation. Transformative change is needed. The research in the literature demonstrated the importance and value in giving a voice to both the recipients and providers of the activity but also highlights the need for transformative change to break down barriers to participation. Activity providers, who are responsible for delivering inclusion, and families, who play a crucial role in facilitating their children's participation, are key voices in the inclusion literature. To bring these voices together to collaborate makes them stronger and creates a powerful community. This is important because a) it provides a platform to challenge the social norms that discriminate against children and young people with disabilities in community leisure and recreation activities, b) strong communities are reinforced by strong relationships between families and activity providers, which creates a more socially inclusive environment, and c) there can be honest and open discussion about issues of capability and capacity between families and activity providers.

Chapter three: Methodology

3.1 Introduction

This research aimed to increase participation of children and young people with disabilities at a local level through involving children and young people with disabilities, and community leisure and recreation providers in identifying factors that facilitate or undermine inclusion, through collecting and sharing information and then making collective decisions about the development of leisure activities. As identified in the introduction, this research also aimed to inform the development of policy and practice. The focus was inclusive participation, which is concerned with how discrimination and disadvantage is understood, experienced and managed across forms of diversity (Spaaij et al. 2019). By using qualitative action research practitioners and users were involved as participants to identify barriers, facilitating factors, and actions, discrimination and disadvantage; the research was therefore able to address the questions and identify actions from all insider perspectives.

A qualitative action research approach was chosen as most suited to the questions of the research, which were as follows:

1. What are the barriers to participation for children and young people with disabilities in inclusive activities?
2. What factors support inclusive participation in community leisure and recreation settings?

Quantitative methods could have been used to analyse inclusion and participation through statistical analysis, to determine a course of action to improve rates of participation in inclusive activities. However, quantitative research assumes a fixed and measurable reality (Braun and Clarke, 2013), which was considered incompatible with the dynamic and negotiable subjective reality of children and young people with disabilities, who often experience the world in different ways. Multiple perspectives on participation are further explored through critical theory in section 3.5 of this chapter.

Furthermore, in research about participation in inclusive activities, the voice of children and young people with disabilities can tend to be limited. Therefore, seeking a way of working that was itself inclusive, including both the beneficiaries of the change (the children and young people with disabilities and their families) and the facilitators of that change (the practitioners), was central to the research endeavour.

This chapter begins with a critical discussion of the research methods outlined in the literature review chapter before describing recruitment followed by the action research approach. The chapter discusses the theoretical framework to the methodology before describing the research design, data collection, ethical considerations and analysis.

3.2 Methodological approaches used in the field

Given the dearth of studies on children and young people with disabilities and the inherently action-oriented nature of this research about inclusion and participation, it seemed important to look at the literature from a methodological perspective. This section therefore analyses the extent to which the voices of children and young people with disabilities and their carers are heard as participants in the studies. Eleven studies examined therapeutic interventions (Anaby et al. 2015; Law et al. 2015; Anaby et al. 2017; Taheri et al. 2017; Willis et al. 2018a; Willis et al. 2018b), peer intervention (Boyd et al. 2008) and community programmes (Siperstein et al. 2009; McConkey et al. 2013; King et al. 2016; Smart et al. 2018) from an outsider's perspective looking in, observing the interventions as they happened. These studies try and make sense of what works and what does not for the inclusion of children and young people with disabilities. The findings from these studies have contributed to the continued development of the research itself, to the wider academic understanding of participation, and provide findings that are applicable to similar research.

Seven studies were disability specific exploring Autism (Arnell et al. 2018), Attention Deficit Disorder and Attention Deficit Hyperactivity Disorder (Emira and Thompson 2011), intellectual disabilities (Grandisson et al. 2012), physical disabilities (Imms et al. 2016; Anaby et al. 2017; Knibbe et al. 2017) and Down Syndrome (Lyons et al. 2016), while other studies discuss disability more heterogeneously. Parental perceptions of participation are represented in a research by Lyon et al. (2007) of children with Downs Syndrome; the advantages of focusing on a specific disability were illustrated in the findings of this research that addressed specific challenges for children and young people with Downs Syndrome, such as speech and language, which may be different to the challenges faced more generally by children and young people with disabilities. The remaining 15 studies were broader in their participant populations, exploring disabilities in general. For example, Spencer-Cavaliere's (2010) research aims to understand inclusion from the perspectives of children with disability, purposely recruiting children and young people with a diverse range of disabilities to capture differences and identify patterns in shared experiences. This enabled the findings to be applicable to all children and young people with disabilities, providing a platform for the voice of disabled children as a community. Given the importance of this research to making the research process itself inclusive and applicable to all children and young people with disabilities, and in order to understand the different challenges faced, it was considered be important to recruit participants from across the spectrum of disability experiences.

Of the methods described in the 22 studies, 17 studies used interviews, five studies used focus groups, five studies used surveys and questionnaires, two used observation, one research used field notes, one used historical research, and one research used qualitative enquiry. Six studies were quantitative, concerned with discovering facts about the inclusion of children and young people with disabilities, collecting measurements, analysis through numerical comparison, and statistical analysis (Boyd et al. 2008; Siperstein et al. 2009; Law et al. 2015; Imms et al. 2016; Taheri et al. 2017; Willis et al. 2018a). All but one of these six studies collected data from children and young people with disabilities as participants, giving children and young people with disabilities a voice on the issue of their own participation. However, none of the quantitative studies involved staff as participants. By contrast, this research considers the voice of activity providers to be crucial in the action research design as key to the implementation of the action research plan.

All but one of the 16 qualitative studies used interviews in their data collection. The method in Arnell et al. (2017) used pilot interviews to revise the interview questions to make them more directed and context specific. The advantage to conducting the pilot interviews gave insight into the social interaction and communication needs of the participants, and enabled researchers to refine their approach. However, the interview questions were refined to elicit specific information from participants, rather than allowing the participants to lead the direction of research. In this approach, therefore, research focuses on the questions that the researcher wants answered, rather than the issues that are important for the participant. As a result of this researcher bias, one to one structured interviews were considered not appropriate in this research.

The context of the data collection can be important in creating a communicative space (Bevan 2013) and only a few studies referred to above critically discussed the context within which the data was collected and how this might affect the research findings. The interviews with children and young people with disabilities conducted as part of a research by McConkey et al. (2013), for example, promoting social inclusion through an international integrated sports program, took place on the day of a competition tournament. Data collection with participants took place as participants became available while they were waiting for their next game. The potential distraction of the participants excitedly waiting for their next game and reflecting over the previous game, was likely to have had an impact on the findings, which may have been different, had the interviews taken place on a non-competition day. As a result of the potential impact on participants during data collection, this research was designed to create a communicative space for participants with few distractions, scheduled away from activity programs.

One method used to enable participants to take more of a lead in the direction of the research was focus groups. Shields et al. (2016), one of five studies to use focus groups (Emira and Thompson 2011; Thompson and Emira 2011; Grandisson et al. 2012; Shields and Synnot 2016; Willis et al. 2018b), explored the experience of participation in physical activity by children with a disability through focus groups with children, parents, and sports and recreation industry personnel. The researchers chose this method to take advantage of group interaction and encourage discussion between the participants in comparing and contrasting their experiences and views. This also presented the opportunity to observe group interaction. Shields et al.'s (2016) research was the only one of the five focus group studies to use a single method of data collection. An advantage used by the other four studies was the use of multiple data collection methods to ensure validity and generate a deeper and broader understanding of inclusion and participation. This research adopted the premise that a combination of methods would generate richer findings.

Nine studies used multiple methods of data collection. Emira et al.'s study (2011) used three methods of data-collection to triangulate data to understand the perceptions of parents on accessing leisure services for disabled children; telephone surveys, focus groups and individual interviews were transcribed by the researcher and coded into themes. A comparison of data from the three methods provided robust findings and added reliability and credibility to the research. Another piece of research with strength in the use of multiple methods by King et al. (2016), examined an inclusive arts-mediated community programme. The triangulation of historical documents with interviews with staff spanning 26 years of the programme's activities, substantiated the research themes. These studies demonstrate how the triangulation of data from multiple methods of data collection can increase the validity of the findings; this research also used multiple methods and triangulation (discussed in 3.6).

Another strength of the research by King et al. (2016) was the operational perspective of inclusion in community recreation; with most studies focused on the experiences of children and young people with disabilities, fewer studies focus on the experience of staff, and even fewer, on the operational aspects of inclusion. This highlights a gap in the research for addressing the operational barriers to inclusion and participation. By contrast, as the aim of this research was to understand inclusion and participation from the perspective of activity providers, and indirectly, of organisational responsibility, staff members were included in the research design from the beginning; in this sense, this research fills a significant gap in the literature.

Seven studies with children and young people with disabilities as participants used multiple sources of data and included parents, non-disabled peers and/or staff in the data collection (Boyd et al. 2008; Siperstein et al. 2009; Grandisson et al. 2012; McConkey et al. 2013; Shields and Synnot 2016; Willis et al. 2018b). Research by Grandisson et al. (2012) into enabling integration in sports for adolescents with disabilities used multiple sources of data from adolescents with intellectual disability, their families, and rehabilitation staff. Participants were divided into two groups, children and young people with disabilities and their parents took part in an interview and questionnaire, and staff took part in a discussion group and questionnaire. This approach provided a comprehensive understanding of the outcomes of sports participation by cross-referencing and analysing data from all sources together. Giving children and young people with disabilities a voice in the research and combining their voices with those of the parents and staff, provided a range of views, which added a level of richness to the findings. There have only been four studies that combined two or more participant groups; however, data from the participant groups was collected separately. To develop multiple source data research, this research combined the three participant groups during the data collection process to provide a deeper level of understanding in the findings.

The methodological approaches from these studies informed the design of this research with regards to the importance given to voice, to fully understand the challenges for all children, the importance of activity providers to the implementation of the action research plan and achieving this through participant-led research. These studies also contributed to the idea of creating a communicative space for participants with few distractions, scheduled away from activity programs. These studies contributed to the approach in this research to triangulate data from multiple methods to add validity to findings, and to combine participant groups to provide a deeper level of understanding in the findings.

Within these methodological approaches there was qualitative research and there was quantitative research, but no action research. As will be argued in this chapter, action research was considered to be appropriate in the case of this research aims and questions because of its potential for transformation. Indeed, it has been used in disability related studies. For example, it had a transforming effect on students with disabilities to be their own advocates (Agarwal et al. 2015), has been used to enhance disability awareness of young people through action research workshops (Hale et al. 2013), and has guided collaborative action research steps to analyse experiences of students with disabilities (Nevin et al. 2002). This research set out to offer more than focus groups and more than interviews, however; through the lens of community development, through action research, this research aimed to identify actions that could be implemented by activity provider participants that would address the barriers identified or strengthen the facilitating factors, thereby bringing about practical solutions and change at a grass-roots level.

3.3 Action Research Approach

Choosing the most appropriate methods for this research was largely determined by the research questions and aims focused on understanding the barriers to inclusion and participation and the factors that might compound or reduce these barriers. Action research was chosen as the most fruitful methodology for this research because it provided a platform for qualitative research based on similarities with critical theory about the understanding of society and culture. In a rapidly shifting world of inclusion, action research is a method that empowers change at a grass-roots level; action research is led by the people who are involved in the research creating a bottom-up grassroots approach (Greenwood and Levin 2006). Indeed, Kurt Lewin developed the idea of action research as a democratic method of improving people's lives as well as professional practice, by doing field research to solve a problem or answer a question in a professional capacity (Edwards and Willis 2014).

Lewin's conception of action research was an approach that applied the methodology of social science to challenge actual, practical, and major problems in real-life environments; he demonstrated that complex social phenomenon could be explored scientifically, through a subjective understanding of human behaviour (Edwards and Willis 2014). This research draws on action research methodology in focusing on social change and the inclusive values that underpin the research aims. Action research was most appropriate for this research because the research questions focus on the barriers and supporting factors to participation and the research aims seek to address the issue of inclusion in a real-life context.

The research questions aim to address participation of children and young people with disabilities in both practice and in research. Action research requires action in both these fields; it aims to change what is being researched within the context of practice (Kemmis et al. 2014). The research design draws on action research methodology in approaching the dual aims of the research: identifying issues, planning and implementing solutions. The four-step action research process to plan, act, observe, and reflect, developed by Kemmis and McTaggart (1988), provided a method to transform inclusive practice at a local level and inform research on inclusive practice in community leisure and recreation.

In other words, the research aimed to improve inclusive practice in community leisure and recreation through the research process itself. When principles of inclusive practice are embedded within an organisation, inclusion becomes institutional within that organisation as well as the wider-community (Jeanes et al. 2018) and therefore it is important to consider the drivers for better practice. Reason and Bradbury (2008) describe how improving practice enhances the quality of the process, and this is important to this research because the research focused around the professional practice of activity providers. Action research has been used effectively in research on professional practice in different contexts and for social transformation, and was therefore considered ideal in achieving the aims of this research.

This research was also participatory and focused on turning participants into researchers, co-learning to identify the problem, followed by a process of analysing, reflecting and planning action. This was important because increased community and stakeholder participation has been shown to enhance empowerment, education, knowledge, development of programme infrastructure, and sustainability (Justin et al. 2012). This research was designed to recognise the value of group dynamics, under the theory that people learn best and more willingly apply what they have learned when they do it themselves (Park 2003). The involvement of participants who are also stakeholders was central to the research design, because in keeping with critical theory, stakeholders are seen as best positioned through experience as parents, as activity providers, and as participants themselves, to understand the barriers and supporting factors to participation in activities.

The research was community-based, and the research aims focused on transformation at a community level that would have a real impact on the lives of local children and young people with disabilities. Action research promotes local solutions to local problems identified by stakeholder participants through collaboration (Cassell and Johnson 2006). In this sense, action research provided a method of contextual examination, considering benefits and limitations of context, which contributed to understanding how to solve the problem. This was important for this research because the contextual limitations experienced across communities are varied and will be dependent on a variety of community-dependent factors.

The research methodology therefore flowed from the research question and aims that focused on the barriers and supporting factors of participation in inclusive community leisure and recreation. Participatory and community-based action research was considered most suitable in meeting the aims and addressing the questions; furthermore, due to it being the approach was designed to reduce power in-balances in the research process, and to affect structural inequalities more widely, which matches well the social model of disability discussed in the previous chapter.

3.4 Critical Theory

Critical theory reveals and questions traditional power assumptions about communities, relationships, societies, groups and organisations to promote social change (Carr and Kemmis 1986). Through critical theory, people identify societal problems and bring about change that enables them to develop solutions in a local context (Edwards and Willis 2014). The theorist Horkheimer determined that critical theory explains the problem with the current social reality, identifies actors to change it, and achieves practical goals for social transformation (Horkheimer 1993). The principles of critical theory were important for this research because the research not only aimed to explain the problem of exclusion in community leisure and recreation, but set out to find ways, with the key actors, to achieve the practical goals of social transformation, specifically that of increasing inclusivity and improving access and opportunity for children and young people with disabilities.

A quantitative paradigm was rejected for this research because quantitative research often aims to reduce diversity and seeks norms in general patterns (Braun and Clarke 2013). This contrasted with the aims of this research to value and understand diversity. Of the qualitative paradigms, critical theory is focused toward critiquing and changing society, going beyond traditional theory which only seeks to understand or explain society (Scotland 2012). In the context of this research, this reflects the decision to engage activity provider participants with children and young people with disabilities and their families who have multiple perspectives on participation. Participants' combined experiences provided richer data that addresses the experiences of all stakeholders involved in inclusion.

In this research, it was important to understand philosophical paradigms because the research questions themselves already reflect ontological, epistemological and political positions. According to Guba (Guba 1990), paradigms can be characterised through their ontology (what is reality?), epistemology (how do you know something?), and methodology (how to go about finding out?). These characteristics create a philosophical view of how we perceive knowledge, how we see ourselves in relation to this knowledge and the methodological strategies we use to discover it. Critical theories aim to explore social life and reveal the assumptions that limit our understanding of how the world works (Howell 2016). As knowledge is socially constructed by people active in the research process, researchers attempt to understand the complex world of lived experience from the point of view of those who live it (Burr 2015). In the context of inclusion and participation, knowledge is a social reality; therefore, gathering the experiences and stories of those affected was key to building knowledge. Drawing on critical theory, the questions and aims of this research were predicated on assumptions that children and young people have a right to access community leisure and recreation and that inclusion is something which is good, is wanted, and should be researched and evidenced.

Much of our knowledge appears to us through our senses, through the complex process of perception; the way that we experience the world may be determined in part by the world, but it is also determined in part by us (Greenwood and Levin 2006). The information that we receive through our senses contributes just as much to our experiences as do the objects that they are experiences of (Armstrong 1963). For children and young people with wide-ranging and often complex sensory needs, and the inequalities placed on children and young people with disabilities by society, their experience of the world, and specifically, in the context of this research, their experience of inclusion and participation, can be very different. How we understand the process of perception, and how this influences our understanding of the world is consequently critical for epistemology; how we construct the realities of the world generates the knowledge needed to answer the research questions. In order to interpret participation in inclusive activities, a range of experiences are required to consider the ‘how’, ‘why’ and ‘what’ around participation and look at what can be done to provide better opportunities for more children and young people with disabilities. Each experience is part of an individual’s reality, and as experiences are different, so too will realities be different (Howell 2016); the reality for one family is likely to be very different to the reality for another family. This important insight guided the understanding that participants’ interpretations of reality are based on their experience of inclusion, which may be through personal or professional experience, or both.

A qualitative paradigm was also important because it provided depth and a diverse understanding of societal issues; in this research it was the inclusion and exclusion of children and young people with disabilities in community leisure and recreation. Critical theory was useful in that it allowed the focus on recognising and questioning the norms of disability and identifying the assumptions that lead to the exclusion of children and young people with disabilities. Lived experience is important because at a grass-roots level of real and lived experiences, constructed knowledge through subjective data collection of children and young people with disabilities and their families, and activity providers, is influenced by the context and other factors.

3.5 Action Research Design

The design of the research was guided by the methodological aim of the research, which was to create action research that included and facilitated the participation of children and young people with disabilities and their families. Therefore, there was a need to attend to both the physical and the conceptual space to ensure inclusive access and equal opportunity to all potential participants.

The physical space for the research was welcoming, accessible and comfortable. The venue was known to the majority of the participants and this was important because participants were familiar with the space and had confidence that the venue provided the facilities required to meet their needs (ground level access, changing places facility, hoist etc.). The workshops were promoted as creative and appropriate for all ages and abilities, and this was particularly important in order to provide the opportunity and choice for families to attend with or without their children, noting that this would inevitably impact group dynamics. The room was laid out with a flip chart board with chairs around it, and several tables with chairs around the space with pens, paper, stickers, glue, tape, and other creative stationary. This layout invited participants to move freely between the group and individual creative spaces. The research was located at a familiar venue, with accessible facilities, designed with creative and appropriate research activities, and offering choice to participate as a family or individually.

The conceptual space for the research facilitated open and honest discussion about disability and difference. Conceptually, communicative spaces provide a discursive arena in which people's voices can be heard (Bevan 2013). Bevan (2013) discusses Shutz's (Schutz 1958) interpersonal theory and describes three stages that groups progress through to develop and function effectively: 'inclusion', 'control' and 'intimacy'. In the first phase, the inclusion phase, participants find their place, the purpose and expectations of the group. In the second phase, the control phase, participants gain confidence to challenge and discuss important issues. In the final phase, the intimacy phase, the group dynamics become more supportive, sympathetic and dependant. Bevan (2013) emphasises the need to understand how the conceptual communicative space will develop as the research progresses to truly engage and empower people in a process of change. This aspect impacted the research design: an ice-breaker activity was planned to introduce participants, followed by an open discussion about the meaning of inclusion. Creative activities followed, and finally group reflection, to enable participants to gain confidence to challenge and discuss the often-sensitive issues of inclusion and provide an opportunity for participants to tell their stories, have their voices heard and engage in working towards a common goal with each other.

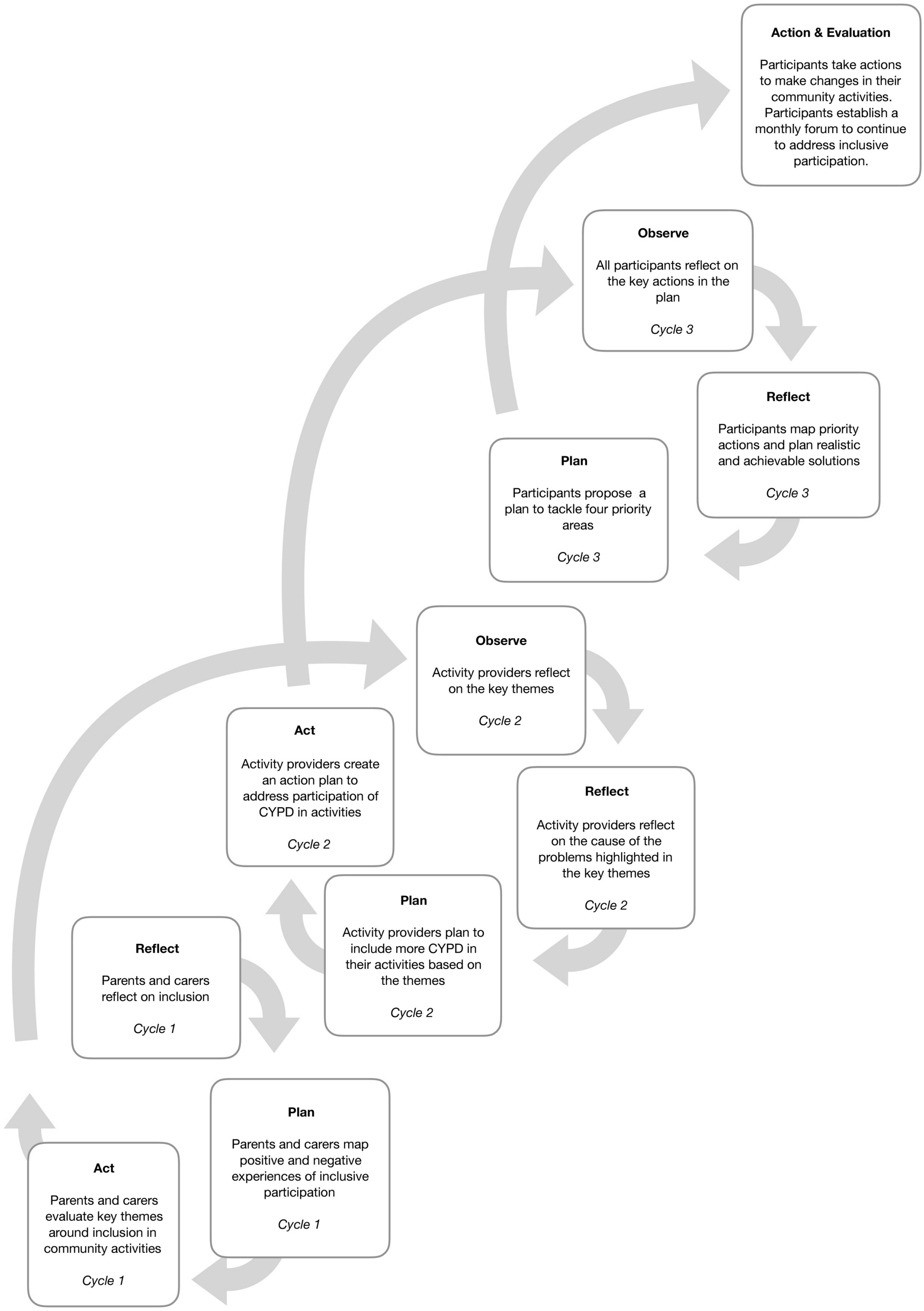
Several key considerations were identified for participant engagement, the first of which was to be clear about what participation in the research design would involve. Participant satisfaction, and the quality of the project and its findings, will depend on clarity about respective roles, building honest relationships and clear agreements about what each party expects from the research process. The researcher acted as facilitator and was ethically responsibility to ensure that the participants were supported as a result of participating in the research. The process was to be balanced in order to create an environment that was welcoming, friendly, safe, open, confidential and non-judgemental (Bevan 2013).

Another key consideration was the clarity of objectives, approach and planned outcomes; it was essential that these were communicated clearly to all participants, including timeframes and key milestones. This was achieved through Participant Information Leaflets (appendices' 1-4), informal discussions ahead of the research, and reiterated by the researcher during the research with participants. The researcher was realistic with participants about what could be achieved, and what they could expect to get out of their involvement, which aimed to manage their expectations by acknowledging the limitations of the impact that could be achieved during the research. It was anticipated that some of the changes to advance participation in inclusive activities could take a long time to happen and would need further resourcing.

Recognising the cost of research was the final key consideration; research that seeks to involve participants and have an impact on policy and practice has a cost. It takes time and resources to develop and deliver actions. In some of the actions identified as a result of the research, findings could only be implemented if additional resources could be found.

This research followed Lewin's Action Research framework for developing and testing practical solutions, through development and implementation of a proposal for change, followed by a study of the results to observe and analyse any change. Lewin describes a 'spiral of steps' (Lewin 1946) that involves seven recurring actions: 1. identify an idea, 2. conduct reconnaissance, 3. plan, 4. implement, 5. evaluate, 6. revise, and 7. begin cycle again (Lewin 1946). The cycles in this research are based on the four-step plan, reflect, and act cycle developed by Kemmis and McTaggart (1988). Figure 2 demonstrates how the phases progressed through cycles in this research. This research aimed to find practical solutions to exclusion through the development and implementation of inclusive practice, followed by a study of the results to observe and analyse any change in inclusive practice.

Figure 2: Phases of cycles in this research based on Kemmis and McTaggart (1988)



The methodological speciality of action research is the spiral of cycles, although these are not predetermined, and change with each cycle. An important aspect of action research is the repetition or spirals of re-working, and re-delivery; analysis takes place alongside data collection, and evaluation infers to the next spiral and further data collection (Reason and Bradbury 2008). This research closely followed this process through three cycles of research, each cycle re-working the plan to advance inclusion. This was a three-phase study and within each phase there was a cycle; this was the process for revisiting the data with participants in subsequent cycles.

Action research cycles, distinctively different to other research methods, enable a continuous process of learning, development and growth (Cassell and Johnson 2006). This research is guided by the action research cycles of learning, development and growth in the design of participant involvement; families participated in the first cycle and their data and evaluation informed the second cycle with activity providers, which informed the third cycle, which brought both groups of participants together. This separation and coming together was important for the research because it provided a communicative space for different perspectives and contexts to be considered.

The ‘co-ness’ of design was a prominent feature as the research moved through the spirals of development; the co-researchers’ input into the research by providing insight, validity and feedback, relating to the three sub-questions that aimed to understand: why some activities are more inclusive than others; why some children are more included than others; what are critical success factors in the implementation of inclusion of children and young people with disabilities in community leisure and recreation; and how activity providers can be successful in implementing inclusion. Importantly, co-researchers had an impact on the development of the research, and this made the data more resilient and more specific to the local context.

The ‘co-ness’ of design situated in the cycle of activity resulted in changes to the design during the developmental process; the co-researchers worked through the cycle of spirals a few times to be confident that the design was refined, or the co-researchers could have been in position to start the research process again if it was not working; the end result of the intervention had the potential to be completely different to initial intentions.

3.6 Recruitment

The research was designed to involve children and young people with disabilities and their parents or carers, siblings and other family members. Participant flyers and information were sent to local children’s centres, specialist and mainstream schools, and community groups and activity providers. However, each of the families who agreed to take part in the research elected not to include their children in the research.

This decision was challenged by the researcher who discussed with parents the inclusive nature of the research, as well as the creative and inclusive mapping tools designed to capture data from children and young people who may use different communication methods, or may not want to voice their opinions in a workshop setting, and the importance of the voice of children and young people with disabilities. The feedback from parents was that they felt they (the parents) would not be able to fully engage in the research themselves if their children were part of the process as their focus would be on their children's participation in the process rather than engaging in the process as a parent. Some parents also discussed how their children had taken part in previous research that had not lived up to their children's expectations, which had caused disappointment and frustration. Although some parents expressed an interest in their children participating, they were unavailable at the time of the research.

As a result, no children and young people with disabilities participated in this research. This prevented the collection of data from the perspective of children and young people. Children's views sometimes contradict those of adults, and without the voice of children and young people, we may not fully understand their views and experiences so that efforts to address their needs can be appropriately targeted. On the other hand, the absence of children and young people alongside their parents and carers facilitated a communicative space where parents were freer to talk about their experiences.

The position of the researcher was that participation is a choice, and therefore if families and children and young people made the decision not to participate, or decided to only participate as parents, that decision should be respected. The lack of children and young people with disabilities in the research challenged the inclusive intentions of the research to give children a voice. Ensuring that their voice was heard through their families and activity providers was important, and the research was designed to encourage storytelling, which facilitated their voices through the sharing of their experiences, albeit through the perspective of a parent of staff member.

This changed the research approach and design; it meant that the data would be limited to triangulation between just two groups, rather than three; parents and activity providers. Despite this major change to the methodology, the methods remained broadly the same because the research was designed to be participant-led and accessible by all ages and abilities. The absence of children and young people with disabilities as participants did not impact the ability to answer the research questions; however, it did change how the research questions were answered. The lack of children participants also shifted the central focus of the research away from children and young people and onto activity providers. This affected the outcome of the research by limiting the context of the findings to the parent and activity provider perspectives.

After electing not to include their children, the first group consisted of parents of children and young people with disabilities (n=7). The second group of activity providers (n=14) consisted of coaches, volunteers, programme managers, and play workers from across five different local organisations. There were 21 participants in the research. Participants were seven parents and carers of five children and young people with disabilities aged seven to 15 years with Autism, Asperger's and Learning Difficulties; and 14 activity providers, from across five organisations one of which was a provider that delivered activities targeted at children and young people with disabilities, one of which was a provider of activities designed for children and young people with disabilities but open and inclusive to all children and young people, and three of which were at different stages of transitioning from mainstream to inclusion by making their activities more accessible for children and young people with disabilities. Table 3 lists parent and carer participant information, and Table 4 lists activity provider participant information. Working with a range of participants helped to inform and review the research design, frame the research findings within a local engagement strategy, and helped to strengthen relationships and build trust with participants.

Table 3: parent and carer participant information

Gender	***Age***	***Ethnicity***	***Group***	***CYPD (n=)***	***Age and gender of child***	***Disability***
Female	40-49 years	White British	Parents / Carers	1	11 (M)	Autism / Complex Needs
Male	40-49 years	White British	Parents / Carers	1 (duplicate)	11 (M)	Autism / Complex Needs
Female	40-49 years	White British	Parents / Carers	1	12 (M)	Autism / LD
Male	40-49 years	White British	Parents / Carers	1 (duplicate)	12 (M)	Autism / LD
Female	40-49 years	White British	Parents / Carers	2	11 (M) 15 (M)	Autism
Female	40-49 years	White British	Parents / Carers	1	7 (F)	PMLD
Female	40-49 years	White British	Parents / Carers	2	10 (M) 14 (M)	Asperger's

Table 4: activity provider participant information

Gender	*Age*	*Ethnicity*	*Group*	*Role in organisation*	*Type of organisation*
Female	16-18 years	White British	Activity Providers	Volunteer	Targeted activity provider
Female	40-49 years	White British	Activity Providers	Volunteer	Targeted activity provider
Female	18-25 years	White British	Activity Providers	Volunteer	Targeted activity provider
Female	26-39 years	White British	Activity Providers	Play worker	Targeted activity provider
Female	26-39 years	White British	Activity Providers	Play worker	Targeted activity provider
Female	26-39 years	White British	Activity Providers	Play worker	Targeted activity provider
Female	40-49 years	White British	Activity Providers	Program Manager	Targeted activity provider
Male	18-25 years	Black British-Ghanaian	Activity Providers	Coach	Transitioning activity provider
Female	26-39 years	White British	Activity Providers	Play Worker	Open Access provider
Female	26-39 years	White British	Activity Providers	Program Manager	Transitioning activity provider
Male	18-25 years	White British	Activity Providers	Coach	Transitioning activity provider
Female	18-25 years	White British	Activity Providers	Play Worker	Targeted activity provider
Female	26-39 years	Black British	Activity Providers	Program Manager	Transitioning activity provider
Male	26-39 years	White British	Activity Providers	Volunteer	Open Access provider

3.7 Data Collection

To identify how inclusion was taking place and to explore the improvements that were needed to increase participation, data was collected through a cycle of three phases. The action research cycle of plan, act, observe, reflect was followed through each cycle. The action research cycles were designed for participants to identify specific actions that they might want to take, or actions needed more widely, to address some of the challenges and opportunities of participation in inclusive activities. The plan, act, observe, reflect framework was easy to understand and based on questions that participants could relate to. This framework followed a logical progression, which meant that each research activity built on the previous one. The key research findings from each previous cycle were presented to participants. The presentations were followed by a planning discussion and further group activities, which invited participants to reflect, react and develop the most important and relevant ideas. Throughout the research process, participants were reminded that the direction and quantity of cycles was participant-led, flexible, and driven by the evolution of the process, considering the aims and objectives of the research. The discussion part of the sessions was audio recorded and data transcribed for analysis. The workshops were observed by the researcher and these observations recorded in writing.

For this research into inclusion and participation, concept mapping was developed as a visual tool for analysis and a practical tool for the action and development process. Thinking creatively about research tools was a key consideration in providing inclusive access to the research process for a range of participants, as well as providing rich data. The use of a concept mapping research tool offered a creative way to help people define what they saw as appropriate actions, rather than telling them the right thing to do. This was important because it provided opportunities for participant practitioners to consider the implications of inclusion and participation and to identify the information relevant to their own inclusive practice.

The use of concept mapping as a visual tool for engaging participants during research and as a tool for the analysis of qualitative data (Burgess-Allen and Owen-Smith 2010), provided a way to fulfil the action research objectives to impact both research and practice. Although the use of concept mapping approaches in action research is not unusual, it is rarely significant in the analysis of the data. Concept maps in this research were created on large pieces of paper using pens and sticky notes, and these were photographed and digitised for data analysis (appendix 1). The data collected from the concept mapping was triangulated with data from the workshops to add to the validity and depth of findings.

The notion of concept mapping was further developed for this research using tree metaphors to organise concepts. Smart et al. (2018) was the only research in the literature reviewed that used concept mapping as a tool for research through the use of a metaphorical tree to highlight strategies and represent collective moments:

> "Taking this metaphor further, we suggest that the leaves, buds, and life located between the tree's branches represent the collective moments created by the first category of strategies on engaging children in collective experiences" (Smart et al. 2018, p.202).

This research combined Smart's metaphorical tree with Burgess-Allen's method of concept mapping to stimulate rapid and focused action and development within the action research process, described by the researcher as 'inclusion mapping' for this research. Burgess-Allen and Owen-Smith (2010) admit that concept mapping is limited by the analytical depth and opportunity for interpretation of the data, which makes it more difficult to go beyond the what and understand the why. This limitation was mitigated in this research, by combining inclusion mapping and workshop discussion, which enabled a broader analysis of action (what) and understanding (why).

The use of the tree metaphor in this research provided a strategy that was clear, easy to understand, and helped to create an underlying notion that inclusion can be grown through and developed through, the tree of life. Concept mapping was adopted and conducted with a tree metaphor using ‘seeds’ as the metaphor for what inclusion is, ‘flowers’ growing from the seeds, as the metaphor for where inclusion is happening, the ‘roots’ of the tree being the cause of the problem, the ‘birds’ being the resources required, the ‘branches’ being the assets of the organisation, and the ‘sky’ being the vision that participants were aiming for.

Concept mapping was an effective research tool because it allowed the group to tell their stories in their own voices, stories that helped the group understand who they were and how they got there and explained how they experienced the world and each other. In addition, given that this research explored a practical problem and sought multiple perspectives as a basis for action, the concept-mapping tool used to generate and collect data, facilitated collaboration between participants that was applied and practical.

Concept mapping is an important tool with implications for both practice and research; in this research, concept mapping provided opportunities for activity provider participants to consider inclusion and participation in their own inclusive practice, and also triangulated the data collected from workshop discussions to add validity and depth of findings. This concept-mapping tool, along with the tree metaphor, was a practical and useful element of the research process in creating action for change.

The first cycle of data collection with parents and carers of children and young people with disabilities, reflected on the meaning of inclusion from the perspective of families, identified inclusive and exclusionary practices, collected information about each other’s experiences, analysed the barriers and facilitators, and evaluated these into five key themes: opportunity, communication, barriers, education and environment. The second phase with activity providers reflected on the themes evaluated at the end of the first cycle and organised them to identify the structural causes of the barriers to participation. Participants mapped actions to address the barriers, and analysed these, sharing actions for development, followed by a group evaluation of the action plan. The third cycle brought families together with activity providers to reflect on the action plan in the context of the organisations represented by the participants. Collaboratively, participants organised the implementation of the action plan and concluded with an agreement to deliver the action plan and establish a local forum to continue to develop inclusive practice in the community.

Each cycle was set up as a discussion structured around concept mapping as a clear, visual and systematic model for gathering and categorising relevant data, identifying participant problems, and developing goals, interventions and outcomes (Schuster 2016). The concept mapping allowed participants in this research to visualise relationships between barriers to participation and inclusion strategies. The concept-mapping element of the cycles was designed to engage a broad participant group, to create richer data, and to provide a clear process for action.

3.8 Ethical Considerations

Ethical considerations in researching with and for children and young people with disabilities are fundamental. After the introduction of the UN Convention of the Rights of the Child in 1989, upholding the rights of children to high standards of research about their lives (article 3), research 'with' rather than research 'on' children became the dominant discourse (Kellett 2011). This ethical position was consistently considered throughout the research given that the design included the participation of children and young people with disabilities. Doing research with children and young people must balance the aims of the research with the safety and wellbeing of the children and young people (Skånfors 2009). By taking the time to consider the ethics of involving children in the research, children feel respected and can take part safely. In particular, the ethical considerations for this research included how to obtain informed consent, how to manage the risk of harm to participants, and what to do with the information gathered during the research.

In the UK, the Economic and Social Research Council lists research with vulnerable individuals (this includes children and those with cognitive impairments) as 'high risk' with criteria for a full ethical review (Farrimond 2012). For this research, robust standardised ethical procedures including a risk assessment and reduction, and Data Barring Service checks served to address the relevant ethical considerations (Farrimond 2012). Ethical approval was granted by Bournemouth University and additional external governance approval was granted by the Board of Trustees of the charity involved in supporting the research. Ethical implications were discussed with the participants involved as a matter of course and the charity's Safeguarding Children and Child Protection policy also guided this.

Informed Consent

A central tenet of informed consent is that participation must be voluntary and free from coercion. The issue of informed consent with regard to children and young people with disabilities as participants is complex; competency issues are particularly acute for younger children and those with disabilities:

> “The principle of assent recognises that explicit, prior consent may not be appropriate for all participants, and that the researcher should attend to children’s behaviour in the process of research so as to judge whether their continued involvement is appropriate.” (Kellett 2011, p.13).

In this research, every effort was made to acquire assent from vulnerable children and young people with disabilities whose consent is provided on their behalf. The comfort and wellbeing of all participants was considered with, special consideration given to the ongoing consent of children and young people with disabilities, to ensure they understood they could withdraw their consent to participate at any time.

Participant information leaflets (appendices’ 1-4) were provided to all participants explaining the purpose and nature of the research, methods and timing, possible benefits, harms and outcomes. Two minors Participant Information Leaflets (appendices’ 3-4) were created to make it easy for children and young people to understand the research and their involvement. Consent was given through a Participant Agreement form (appendices’ 5-6). Had participants under 18 taken part, they would have required consent from a parent or carer in addition to their own informed consent, and an easy to understand Minors Participant Information Leaflet (appendix 4) was created to explain the research. One of the challenges when working with children and young people with a limited capacity for understanding is ensuring that each child or young person fully understands their participation and is not coerced into participating. Parents are the key to helping find methods that help children and young people understand this concept. There was clarification from the start of the project that a child, young person or parent could choose to refuse or withdraw their participation from the research at any point. It was recognised that consent is not a one-off process, and the researcher (or the parent if present) must be aware of signs that a child may no longer want to participate. They may show this through non-response, pulling away or ignoring (Skånfors 2009). There is a risk that children and young people may feel implicitly coerced into participating, and therefore it is the responsibility of the researcher to recognise the signs that a child may not want to participate and act upon it.

Safety and avoiding harm

Ethical considerations are integral to the research; the topic of the research itself may give rise to ethical sensitivities, if for example, participants have had negative experiences of inclusion, this might cause distress or anxiety when exploring this topic. Equally, it is important that these issues are explored so that we increase our knowledge and understanding, and hopefully improve inclusion for children and young people with disabilities. An assessment of the harms and benefits demonstrates how risks can be reduced and benefits promoted (appendix 7). Most important was the consideration of the impact on children and young people participating in the research. One of the key considerations for children and young people was to ensure that they would be supported by the researcher, and by their parents and carers.

There was also the risk that children or young people taking part would feel pressured or anxious (Skånfors 2009). The researcher prepared to observe the behaviour of children and young people during workshops and discuss any concerns with children, young people and families, with regular reminders that if they felt uncomfortable or unhappy about anything, they could talk to the researcher, or their parents. Potential participants were informed that their personal information and identity would remain confidential. The emphasis for all the children involved was focused on encouraging and supporting each other to have fun in inclusive and disability friendly ways. Children and young people would have been supported with skills and strategies to make sure that they felt empowered, confident and comfortable (Klavina and Block 2008), and know what to do if they needed additional help or support.

Beneficence

The benefits of participation can be an important factor in participant engagement; these include the opportunity to meet others, share perspectives and test ideas together (Grieg et al. 2013). In action research all participants have a vested interest in the conduct and outcome of the research because they want to see and contribute to transformation; they stand to gain from their participation. Other potential benefits were gaining skills in confidence, communication, inclusion awareness, and enjoying the experience of participating. Refreshments were provided at the workshops, and a voucher to access a free session at a local inclusive community activity was also offered.

Power dynamics

This research aimed to reduce power differences between the researchers and participants, as well as among the participants themselves; promotion of equal participation in the research process was key. Therefore, one of the ethical considerations for this research was the relationship of researcher to the participants; outside of the research, the researcher was positioned as line-manager to two of the participants, and service provider to host organisations whose staff were participants. In the work environment the professional relationship with two of the participants generated a level of authority that the researcher sought to redistribute in the research environment. The two participants voluntarily provided their time outside of working hours, without incentive, and were two of seven colleagues who were eligible to take part. In the researcher's professional role as service provider to some of the host organisations involved in the research, there was also no incentive to participate, although similar questions should be addressed around the potential perceived advantages to taking part; the participants' motivations are likely to have been either driven by career progression, personal experience, or the desire to make a difference (or a combination). Each of these motivations in a participatory setting places the power with the participant; however, this raises questions about how these motivations might interfere with the relationship between them and the development of the research. Existing relationships with participants enabled the researcher to build a rapport to facilitate genuine and honest data collection, as opposed to participants saying what they think the researcher wants to hear, and not pressured to hide or share something they otherwise wouldn't. The researcher's existing relationships with participants served to support ethical responsibilities towards the participants in trusting and feeling comfortable around the researcher.

Respect for confidentiality and privacy

Maintaining confidentiality is a key measure to ensure the protection of private information. Although the researcher knows the identity of the participants, steps have been taken to protect that identity from being discovered by others. Information was recorded by code in a way that does not link subject responses with identifiable information. All the information collected during the course of the research was kept strictly confidential, both password-protected and in a locked environment. No individual was identifiable in any findings, reports or publications. Each participant was assigned a pseudonym. When the results are published, participants in the project will be able to request a copy of the results from the researcher. Some data was recorded in hard copies, catalogued and stored in a secure locked cabinet in a secure locked office. Only the researcher had access to the secure cabinet. Back-ups of all the hard copies were made by photographing documents and recording them electronically. All data was stored electronically, catalogued on a laptop computer, with a back-up copy on a portable hard drive. Both the laptop and portable hard drive were accessible only by the researcher and by password. Personal information such as date of birth, gender, disability (if applicable), job title (if applicable), and similar information was sought to enable the project to understand the background of participants. Activity providers also provided information about their organisation and the activities that they deliver. This information was relevant when evaluating how the background of the participants might have had an effect on the outcomes of the research.

3.9 Data Analysis

As discussed at the beginning of this chapter, this research is underpinned by critical theory, where reality is subjective, and knowledge is socially constructed (Howell 2016). From this relativist position, instead of seeing inclusion and participation as scientific variables, they can be understood as becoming meaningful as we interact with others and the world. This can only be understood, captured and analysed through language and discourse (Burr 2002). Qualitative analysis typically revolves around the impressions and interpretations of the researcher after the research has been collected; however, as discussed in the previous section, through concept mapping, participants in this research took an active role in identifying key themes in the data. This was achieved through a visual organisation of knowledge that linked ideas and concepts in the form of key words.

The reason for using Braun and Clark's (2013) six stage thematic analysis was to bring in different perspectives, the first level being emic in that it stays close to the experiences of the participants and the second level bringing in a more etic perspective that connects with theoretical perspectives on inclusion and participation. The analysis of both the workshop discussion and the concept maps aided the analytic process; in this sense, concept mapping was both a tool for generating data and analysing the data. At the end of the three cycles, the Braun and Clarke (2013) six stage thematic analysis was applied to the transcripts and concept maps were digitised, generating insights that shed light on the inclusion of children and young people with disabilities in community leisure and recreation activities. The analysis of the workshop transcripts, and the digitised concept maps provided the basis for interpretation. By using different methods of collecting and coding data, there was also a degree of triangulation in looking at the overlaps between the perspectives. The dual methods of workshop discussions and concept mapping provided different benefits: the language used in conversation in the workshops was more personal and emotive, and the text used in the concept-mapping was more direct and contextual. This enabled a comparison of the findings to explore the similarities, differences and contrary findings. Finally, the thematic analysis made links to previous research regarding participation of children and young people with disabilities in inclusive community leisure and recreation.

Coding

Concept mapping was useful as a tool for coding the data. Qualitative data analysis in public participation processes have been analysed by Burgess-Allen and Owen-Smith (2010), who have argued that mind mapping can help stimulate discussion, focus the topic, and enhance transparency and group ownership of the data analysis process. The transcripts from the three cycles were coded following Braun and Clark's six stage thematic analysis (Braun and Clarke 2013), which started by identifying meaning in passages of data and coding them with appropriate keywords or phrases. At this stage, the focus was more on the context, consistency and contradictions of views, frequency and intensity of comments, as well as emerging themes, which added validity to the themes identified in the concept mapping analysis. The process of thematic analysis, which can be time-consuming, and usually tends to be researcher-led, is a process that can be achieved faster when led by co-researchers: 'as the concept map develops, the researcher is in essence generating coded categories' (Burgess-Allen and Owen-Smith 2010, p.13). The coding was therefore both deductive and inductive, involving data-derived and researcher-derived codes (Braun and Clarke 2013). Burgess-Allen and Owen-Smith (2010) found that mind mapping was considerably faster than traditional methods for the analysis of group research methods, while resulting in similar broad themes. This research tested this theory by deriving codes from both the concept map data and workshop discussion transcript data.

The concept mapping exercise therefore provided the initial coding framework for the data. New codes were added as the analysis progressed through the transcripts, continually developing the coding framework. Once the data was coded, themes were abstracted from the codes. Underlying patterns and structures, including differences between types of respondents, were analysed together, and codes were grouped together to represent common and significant themes.

The coded data was collated, and table 2 provides an example of collated coded data for two codes.

Table 2: Two examples of coded data

Families avoid opportunities as a result of prejudice	**There is prejudice toward 'hidden' disabilities**
Rose: You just you don't go to certain places, because you know you're gonna get looked at or judged, so you stop going to places and the child misses out on that activity or opportunity. John: But a lot of people, I think they avoid going places. Phil: So we just didn't go any longer because it was a very difficult situation, weren't it? You're supposed to feel good at the end of it.	John: The universally known sign for disability is a wheelchair and unfortunately if you don't fit into that category people just do not understand, you know. John: People do not understand -when you explain to the person at the gate they say 'come on in no problem at all', the looks on everyone one else, because once again it's that universal sign you're not in a wheelchair 'that's all I understand as a disability'. Rachel: They think your child's normal. Phil: But it's some of the parents do look at you 'well you look normal, why are you going in there?'. Rachel: But I've got really bad because when I was stood in that queue, and I look at people I think look normal, I tell them to go back to the other entrance if they want to queue for the ride. John: And there was about 8 Americans with this one person that was in a wheelchair, so we walked in and the mother said no you're in the wrong place…so you're not with us.

Following coding, a search was made for patterns in the data, links formed, and relationships found between the codes. Following Braun and Clarke's six stage thematic analysis, patterns were identified in the data that grouped codes together. Some codes were grouped together because of their similarities, and because they had something in common, although sometimes the commonality consisted of differences. Codes were grouped together and given headings based on their theme.

By grouping codes together, themes were identified through the patterns in the data. The themes explored barriers and facilitators of participation, and from these themes, three overarching dimensions emerged: values, rights and discrimination, real life and collaboration. The patterns, themes and dimensions derived from the codes were born out of the coding and analysis of data and represent an organisation of the coding that aligns with the research aims to advance the participation of children and young people with disabilities in inclusive community leisure and recreation. Thus, the qualitative analysis used in this research drew on thematic analysis; the data analysis reflected the aims and objectives of the participants in a way that was thematical, in that it approached the framework from an exploratory perspective, and allowed for new impressions to shape interpretation in different and unexpected directions.

3.10 Conclusion

This chapter started with a description of the research approach, recruitment, and justification of the research method, followed by a discussion of the theoretical framework, description of the data collection, ethical considerations and analysis processes. The next chapter will discuss the data, how it was analysed and what findings were generated.

Chapter Four: Findings

4.1 Introduction

The main purpose of this research was to increase the evidence base regarding the barriers and facilitating factors to inclusive practice in community leisure and recreation activities for children and young peoples with disabilities. The research also aimed to be in itself more inclusive, involving not only children and young people with disabilities and their families but the practitioners who can then implement the activities and the organisations who host these activities. There were two overarching questions, one relating to the evidence base and one looking forward to action:

1. What are the barriers to participation for children and young people with disabilities in inclusive activities?
2. What factors support inclusive participation in community leisure and recreation settings?

This chapter presents the three phases of data collection and describes the findings that emerged from the concept mapping, reflecting the iterative nature of the data collection and analysis through group discussion and concept mapping. The last section presents the findings that emerged from the six-stage thematic analysis of the data. A discussion of the key themes and the impact they have on the participation of children and young people follows in chapter five.

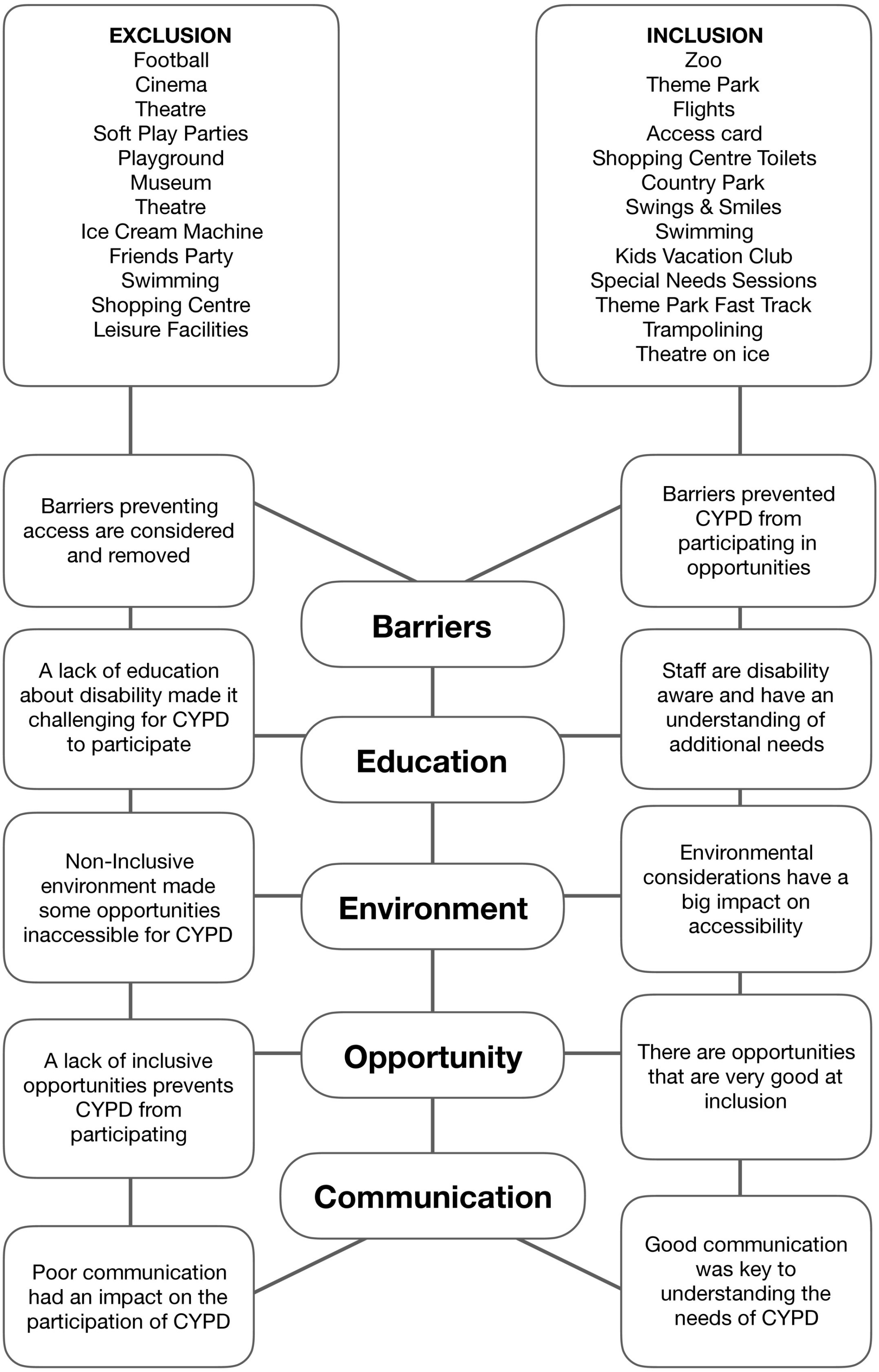
4.1 Phase One

The first workshop participants were four parents and carers of children and young people with disabilities. Data was collected in the form of participant-created concept maps of their experiences of inclusion and exclusion. During the workshop activity, participants and the researcher analysed those experiences and organised them into themes. In this first phase, parents and carers of children and young people with disabilities reflected on the problems of inclusion, and participants mapped out their experiences to identify the barriers and facilitators of participation in mainstream activities. The workshop explored methods to improve the inclusion of children and young people with disabilities in community activities to make them inclusive.

Parents and carers considered the problems of inclusion through a combination of concept mapping and workshop discussion. This allowed the researcher to develop and strengthen relationships and to introduce the project to a wide range of people in an informal way. After an introduction and icebreaker, in small groups, participants used concept mapping to reflect on their own experiences of inclusion in activities that their children and family had participated: ‘Seeding Sessions’ were used to identify inclusion. These were interactive, dynamic and fun, and less intimidating for some than text-based techniques. The ‘Seeding Sessions’ started with a short discussion about people’s understandings of what inclusion is and is not (e.g. seeds are the metaphor for inclusion). This helped to break down the barrier between the ‘expert’ researcher and the ‘subject’ of the research. In small groups, participants were asked to draw flowers (e.g. growing from the seeds metaphor) on a large blank piece of paper, using a variety of materials, and to populate the leaves with the activities where inclusion occurs. Participants were also asked to draw fallen leaves and populate these with the activities where there are barriers to inclusion. This invited dialogue - the discussions during and after the actual mapping were often very rich.

This research tool allowed the participants to direct the process and to identify their own priorities rather than those of the researcher. This provided valuable data for the subsequent stages of the research. Figure 4 illustrates the concept mapping data collected in phase one. The left side of the diagram lists the experiences of exclusion as identified by the participants such as ‘football’ and ‘soft play parties’; and the right side lists the experiences of inclusion such as ‘zoo’ and ‘gateway card’. The experiences of inclusion and exclusion range from specific activities at specific locations to general activities such as ‘swimming’. The middle left and middle right columns describe the patterns identified, such as ‘barriers prevented children and young people from participating in opportunities’, and these link to the five resulting theme that are central in the data map: Opportunity, Communication, Barriers, Education and Environment. This data map is an amalgamation of the concept maps created by participants during phase one. All of the entries in Figure 3 are text provided by the participants themselves with identifying names removed for anonymity.

Figure 3: Phase one data



Participants shared experiences of inclusion, and the mapping process provided rich data that the researcher analysed looking for similarities, themes and differences. During the workshop activities, the researcher guided thematic analysis of the data, and themes were identified. The five themes around inclusion that were identified as important to families were: Opportunity, Communication, Barriers, Education and Environment. Participants decided on the five themes after mapping their experiences of inclusion and used the map as a guide to share and discuss their experiences with other participants. The theme of barriers was the first theme discussed, highlighting the salience of barriers in the stakeholder experience. The nature of each theme was complex and personal, as highlighted in this comment from Phil (all participants were attributed pseudonyms) about the theme of 'barriers' and understanding that barriers impact each child differently:

> "Removing the barriers that prevent taking part and understanding what those barriers are. I think that with Autism, Luke has Autism, every child is different so a different set of barriers."

Themes emerged for the participants during discussions about their experiences; 'education' for example, emerged as a complex and personal theme. Participants' frustrations with a lack of education among others, and a sense of personal responsibility to educate those people, was highlighted in this conversation between Phil, John and Rose:

> Phil: "but it's educational for people that don't understand"
> John: "very much so"
> Rose: "it hits the point which you think as well. I haven't got enough time to educate the world"

The discussions around the complexity of each theme illustrate the role participants had in this research as having expert knowledge with regards to the research questions; frequent references to personal and first-hand experiences added validity to the data.

Analysis of the data demonstrated a commonality around the five themes. Data for the theme of environment for example, demonstrated that non-inclusive environments made some activities inaccessible for children and young people with disabilities, and that inclusive environmental considerations had an impact on accessibility. Whilst these are from two different perspectives of inclusion and exclusion, combined they show the importance of the environment with regards to accessibility. The same tautological commonality appears throughout the other four themes; negative experiences involved barriers that excluded children and young people with disabilities from participating in activities.

The data collected and analysed in cycle one was made up of three components: a) the two lists of experiences of inclusion and exclusion b) the patterns identified in these experiences and c) the themes identified. The patterns identified in the data are collated in Table 9.

Experiences of exclusion	Experiences of inclusion
Barriers prevented CYPD from participating in opportunities	Barriers preventing access are considered and removed
A lack of education about disability made it challenging for CYPD to participate	Staff are disability aware and have an understanding of additional needs
Non-Inclusive environment made some opportunities inaccessible for CYPD	Environmental considerations have a big impact on accessibility
A lack of inclusive opportunities prevents CYPD from participating	There are opportunities that are very good at inclusion
Poor communication had an impact on the participation of CYPD	Good communication was key to understanding the needs of CYPD

Table 9: Patterns identified in phase one data

The patterns identified showed that participants experienced both barriers and facilitators in similar environments. An example of a facilitator cited by participants was access to a fast-pass system to enable children and young people with disabilities and their families to avoid queuing for activities. Conversely, the lack of access to a fast-pass was also a barrier and an example of exclusion cited by parents.

The patterns identified experiences of inclusion as a result of good communication; the ‘Access Card’, for example, provides families with an information database of activities for children and young people with disabilities. This demonstrated the importance of communication with families and sharing information about access and opportunities.

The patterns identified showed that poor disability education made it challenging for children and young people with disabilities to participate, and that participants experienced a lack of inclusive opportunities; examples cited by participants were ‘soft-play parties’, ‘football’ and the ‘cinema’. In positive experiences, examples of inclusive opportunities, and staff awareness and understanding of additional needs were cited by participants as examples of inclusion at the ‘Kids Vacation Club’ and ‘Special Needs Sessions’. As with these examples, the patterns identified environments that were inclusive and environments where participants experienced exclusion. Examples of inclusive environments were generally specific activities and providers, including ‘swimming’ and ‘Trampolining’.

The data generated in phase one provided the framework for phase two, with which to consider the barriers and facilitators to participation in inclusive activities; the five themes of barriers, communication, education, environment, opportunity initiated the development of an action plan to develop inclusive practice in community leisure and recreation activities.

4.2 Phase Two

The second workshop participants consisted of 14 providers of community leisure and recreation activities. Data was collected in the form of participant-created concept maps of the five themes highlighted in the first workshop, within their own organisations. In this cycle, participants identified specific actions that they could take forward to develop their own practice and generated recommendations to inform wider general practice.

In phase two, activity providers and organisation representatives discussed the key findings from phase one. ‘Growing Sessions’ were used to explore research findings from the phase one activity mapping workshops on inclusion. The ‘Growing Sessions’ started with a discussion to observe and reflect on the data captured in the phase one sessions. This provided participants with the opportunity to meet others, share perspectives and test ideas together. In small groups, participants were given a large paper tree on which to explore in more depth a particular challenge or opportunity they wanted to work on based on the phase one findings. ‘Growing Sessions’ provided a creative and informal way of thinking about solutions to issues. This metaphorical approach is linked to an approach in the literature that highlighted inclusive strategies through a tree metaphor (Smart et al. 2018). The creative approach is linked to an approach in the literature that used images to facilitate the participation of young people with intellectual disabilities (Grandisson et al. 2012). These creative and metaphorical approaches to gain data were developed by the researcher based on the idea that inclusion is an evolving process, as nature evolves, so action research evolves.

Participants mapped the structural causes of the barriers identified by the parents within each of the five themes: Opportunity, Communication, Barriers, Education and

Environment. Through concept mapping, participants were asked to examine the deep causes of the issue (e.g. the ‘roots’ in the tree metaphor), identify the resources or assets already available (e.g. the ‘branches’ and ‘birds’) and explore the vision (e.g. the ‘sky’) that they are ultimately aiming for. This gave people a greater sense of ownership of the actions identified. Once they identified specific actions to address the challenge or opportunity they had chosen and written on green sticky leaves, participants were asked to identify their top three priority actions on three golden leaves. Participants discussed the challenges and opportunities these presented for their own activities. At the end of the exercise, each group presented their golden leaves back to the full workshop and these were all grouped together on one large tree mural. This provided valuable data for the following stages of the research.

Tables 5 to 9 show the collated data from the concept mapping exercise within each of the five themes. Participants addressed the following questions in each theme: the causes, resources needed, vision, and specific and realistic actions. The questions were designed by the researcher to provide a framework for participants that aligned with the research questions to address the barriers and facilitators to inclusion and participation. All of the entries in Tables 5 to 9 are the participants’ own words.

Participants evaluated the five themes and planned actions to address each of the five themes; transforming knowledge into action. Table 5 shows the data collected from the concept mapping exercise on the theme of barriers. Within this theme, the data showed that participants felt fundraising was a key tool to overcome barriers to participation, and this was mirrored in the theme of education. Although costs and affordability were highlighted as barriers to families in the literature (Anaby et al. 2017), fundraising was not discussed in the studies reviewed, as a barrier or facilitator.

The data demonstrated that participants felt advertisement was a key barrier, and this was also prioritised in the theme of opportunity. This resonates with Shields et al. (2016) who found that parents found it difficult to locate opportunities for their child. Shields et al. (2016), whose participants also included children and young people and activity providers, found that activity providers had similar concerns about poor promotion in their difficulty to connect with children and families.

The data also showed that participants felt that venue accessibility was a key barrier. Thompson and Emira (2011) make the point that legislation for physical access is far more advanced than legislation for disability awareness training (Thompson and Emira 2011).

Table 5: Data from ‘barriers’ concept mapping exercise

	Roots *deep causes of the issue (why might this be a problem for CYP?)*	**Branches** *Identify the resources or assets required (what is needed to overcome the issue?)*	**Clouds/Sky** *Explore the vision that you are ultimately aiming for (what is the perfect scenario?)*	**Leaves** *Specific and realistic actions to address the issue*
B **A** **R** **R** **I** **E** **R** **S**	Stigma Finance Psychological Physical Capabilities Transport-Geographical Lack of Resources Specific Care Availability	Anti-bullying policies, awareness Grant funding, loyalty bonuses Reassurance, motivation Specialised transport, local clubs, social stories Venue, specialised equipment Training, DBS More staff, more sessions available	Everyone Active Accessible Resources Affordable Safe Local Available Beneficial Positive Experience	Positive advertisement Available in different location Training Good setting Fun Fundraising Government Grants Wheelchair Access Staffing – volunteering Transport available Accessible venue Safeguarding
	PRIORITY ACTIONS 1. Fundraising 2. Advertisement 3. Accessible venue			

Table 6 shows the data collected from the concept mapping exercise on the theme of communication. Within the theme of communication, participants prioritised the right to have access to basic communication aids such as the Picture Exchange Communication System (PECS) and Makaton. Although the literature highlighted the importance of removing the barriers to communication with children and young people with disabilities and their families (Anaby et al. 2015), there was no discussion on how a lack of communication resources excludes children and young people with disabilities.

The data also demonstrated that participants felt recruitment of appropriate staff was important: employing the ‘right people’ with the ‘right personality’ and knowledge of the job. Although the literature highlights the lack of training and the requirement for further training of staff (Emira and Thompson 2011), there was no discussion in the literature about recruitment in organisations.

The data showed that participants felt it was important to obtain accurate and thorough information from parents and carers, before a child attends an activity. This resonates with Grandisson et al.'s (2012) research with activity providers that regarded intervention plans as an essential process in the design of inclusion for children and young people with disabilities.

The data also demonstrated that participants prioritised training and resources to support medical needs, personal care and communication. The discussion on personal care resonates with Miller et al. (2009) who established that half of recreation providers provided personal care, and the other half supported the presence of carers, leaving the responsibility of personal care to participants.

Table 6: Data from the 'communication' concept mapping exercise

	Roots	**Branches**	**Clouds/Sky**	**Leaves**
C O M M U N I C A T I O N	Brain damage – diagnosis, how does that effect person and what is required to support Understanding issues – parents, carers, bystanders, behavior of child as a result, frustration Language Problems Medication – how does this impact on communication, slower faster, does it impact on speech?	Not being afraid to ask Patience and personal skills, perseverance Visual support Being educated on how to deal with diagnosis (professional or otherwise) Having the right tool (tangible or concrete) PECS, Makaton etc. Reviewing and learn from mistakes Observation and learning Empathy Reduce anxieties, calm environment to enable comms to start	Achieve what they would want for themselves Ultimately for them to be happy and secure For them now to fit a stereotype	Access to communication aids: PECS, Symbols, Makaton, Training (share cost with other providers) Talking to parents and carers, making sure needs are known (awareness), Activity provider to have a good system in place for collecting info and storing (safely) Sharing good practice at the end of the session – all staff Allow a small budget for basic equipment Forum for activity providers, what works well, what didn't? Sharing resources??
	PRIORITY ACTIONS: 4. Have access to basic communication aids i.e. PECS Makaton 5. Right people with right personality and knowledge of the job 6. Getting the correct and most thorough information from parents/carers before child attends 7. Correct training and resources: medication, personal care, communication			

Table 7 shows the data collected from the concept mapping exercise on the theme of education. Within the theme of education, the data showed that participants felt it was important to share their experiences and knowledge with each other.

The data showed that participants prioritised the organisation of fundraising events to get communities together. This resonates with the findings of Smart et al. (2018) and King et al. (2016) whose research based on perceptions of staff and service users of an art-mediated community garden, showed how inclusion developed in the community as a result of opportunities to get the community to engage together.

The data also showed that participants felt it was important to work with colleges, schools, and companies to recruit volunteers. The importance of volunteers in providing inclusive opportunities resonates with Jeanes et al. (2018) who examined how diversity is understood and managed within community sports clubs and was the only study to collect data from club volunteers. Jeanes et al. found that the role of volunteers within community recreation was pivotal to their success.

Table 7: Data from ‘education’ concept mapping exercise

	Roots	**Branches**	**Clouds/Sky**	**Leaves**
EDUCATION	Money Equipment Staff Lack of education Area Transport – trips Accessibility e.g. ramps Training Knowledge all round	Not being afraid to ask Patience and personal skills, perseverance Visual support Being educated on how to deal with diagnosis (professional or otherwise) Having the right tool (tangible or concrete) PECS, Makaton etc. Reviewing and learn from mistakes Observation and learning Empathy Reduce anxieties, calm environment to enable comms to start	All buildings fully accessible Local activities to home All staff, understand, are trained and have experience – part of their daily routine as a teacher Always money available Free sessions due to funding from Government All schools have all equipment needed	Plan weekly transport rota Share experiences with each other Speak with schools, colleges, companies for volunteer hours: incentives e.g. courses/vouchers Organise fundraising events and get the community involved Doing our own research and watching/listening to the individuals Give out time at every opportunity Open days check everything is there e.g. ramps
	PRIORITY ACTIONS: 8. Share our experiences and knowledge with each other 9. Organise fundraising events getting communities together 10. Work with colleges/schools/companies to gain volunteers			

Table 8 shows the data collected from the concept mapping exercise on the theme of the environment. Within this theme, the data showed that participants prioritised adapting the environment to eliminate sensory stressors such as lighting, sounds and smells. The data shows that participants perceived the sensory element of the physical environment to be one of the major contributing factors to participation in inclusive activities. The physical environment in terms of architectural barriers and physical access was, however, only briefly highlighted in both the data and the literature. Miller at al. (2009) and Thompson and Emira (2011) briefly discussed architectural barriers and physical access with activity staff and parent participants, although these topics were not analysed in any depth.

The data showed that participants also prioritised the needs of families in terms of support and advice that is respectful, understanding and meets their needs. This resonates with Anaby et al. (2015) and Willis et al. (2018) who both illustrated how the role of the family was intertwined in the process of supporting the participation of children and young people with disabilities.

The data also demonstrated that participants felt that training was a priority within the theme of environment. This resonates with Miller et al. (2009) who found that comprehensive training of all staff within recreation programmes was a necessary component of inclusive practice in design.

Table 8: Data from ‘environment’ concept mapping exercise

	Roots	**Branches**	**Clouds/Sky**	**Leaves**
ENVIRONMENT	Parking Being judged Unpredictable surroundings – cancellation – routines Discrimination/lack of understanding Enjoyable and fun Access i.e. wheelchairs being able to take part Sensory overload, sound/noise, lighting/smells, overcrowded, heat/too cold Lack of provision – no disabled toilet/changing areas/special equipment Safety CCTV Trust in person or organisation if unknown Cost, entry fee, petrol/travel New people/anxiety Comfort	Accessible parking and facilities and specialised equipment Understanding Check beforehand for any distinct light/sound and smells possibly in a chill out area Funding/discounts, money off vouchers Effective use of colour/light, green emits a calm feeling in a waiting room for example Go with someone you trust Reassurance/taster session to alleviate anxiety Have a backup plan in event of cancellation or venue change Photographs/resources i.e. social stones CCTV where possible, monitoring of area/spaces used (risk assessment) Training of all staff members/users where pre-booked	Appropriate for age group Child-friendly spaces that can be adapted if needed Accepting change/ understanding choices Comfortable in environment including being around/interacting with others Clear communication – being able to communicate thoughts – (Makaton, PECS) Being respected and understood Independence Choice Full access to facilities alongside others – peers/family Accessible facilities – hoist/changing facilities Being listened to/being able to share thoughts about what is liked/disliked in environments	Good first impressions Sharing expertise and teamwork Supporting/developing needs – targets Communication – Makaton training – on-the-job and more formal Clear rules shared and developed with children Taster days/experience for kids and parents Promote healthy life choices Child initiated – adapted where needed Activities reflect children’s needs Reassurance/approachable More child choice Whole family support and advice Adapting environment eliminate stressors Individual profiles about condition for staff including info from parents (medical info/likes/dislikes) Staff checks DBS Travel arrangements for families Risk assessment Involve siblings Health and safety policies Safeguarding procedures training
	PRIORITY ACTIONS: 11. Adapting environment to eliminate stressors i.e. lighting/sound/smells, risk assessment, turning off hand dryers for example 12. Whole family support and advice – be age appropriate and respectful, - respect and understand their needs and wants, - reassurance 13. Training			

Table 9 shows the data collected from the concept mapping exercise on the theme of opportunity. Within the theme of opportunity, the data showed that participants felt that media was important in creating awareness among families about opportunities. This resonates with Anaby et al. (2017) who found that parents of children and young people with disabilities highlighted how a lack of information about opportunities was a barrier in the promotion of inclusive activities.

The data showed that parents felt the age range for inclusive activities was too narrow. This lack of inclusion by design resonates with Emira (2011) who found that parents experienced other structural exclusions in the availability, flexibility and information of leisure services for children and young people with disabilities

The data also demonstrated that participants felt it was important to keep records of achievements to support fundraising efforts. The importance to be able to provide a demonstration of success was not discussed in the literature, although the research itself forms part of the evidence of success for some of the interventions and programmes (Boyd et al. 2008; Siperstein et al. 2009).

Table 9: Data from ‘opportunity’ concept mapping exercise

	Roots	**Branches**	**Clouds/Sky**	**Leaves**
OPPORTUNITY	Barriers Transport Lack of information Social interaction Lack of understanding Diagnosis – waiting – referral Lack of support Funding Not independent Lack of motivation – don’t want to Fear Parents struggle to find time Lack of availability – different activities – support groups – schemes Lack of resources – personal care not offered – not available Lack of correct training Accessibility – age restricted – not under the right catchment	Funding – try and offer cheaper of free opportunities where possible Chase-up diagnosis Breaking down social systems Provide where possible emotional support Provide a range of age appropriate activities for different age groups Correct training – personal care – medication – communication – age appropriate Make info readily available, up to date, correct and available to all Strong social links between groups, parents and carers Ensure everyone has basic understanding of SEN and the individual	Funding for all The right support to equality No barriers – age – funding Awareness Happiness Community Fairness Communication Inclusion Independence Friendships – social inclusion Needed respite At least 1 activity available for everyone	Inclusion for older people 12+ Keep record of achievement for funding Updated social media Advertise who we are and what we do Correct training and resources Keep strong social links between groups
	PRIORITY ACTIONS: 14. Updated media: advertise who we are and what we do 15. Inclusion for all: wider age range 16. Keep record of achievements for fundraising!			

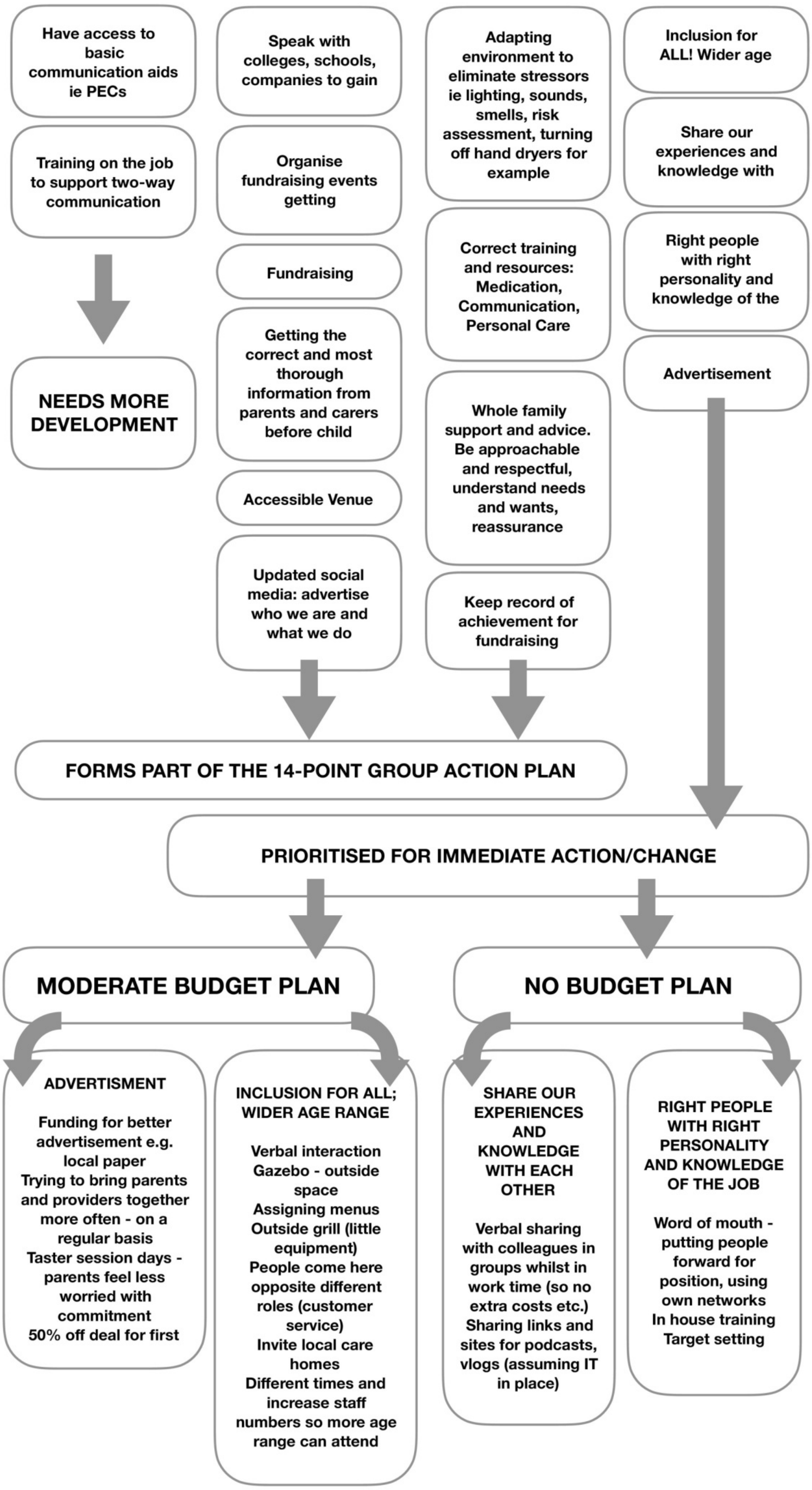
The data influenced phase three, providing the framework with which to consider actions to address the barriers and facilitators to participation in inclusive activities; the culmination of sixteen priority actions initiated the development of the next phase to develop inclusive practice in participants’ own practice and settings.

4.4 Phase Three

Participants from both groups elected to take part in a third phase workshop to analyse the relevant, specific and important issues and solutions that would most benefit children and young people with disabilities and be realistic for activity providers to implement. The third workshop brought parents and carers together with activity providers to reflect on the priority actions, among the organisations represented by the participants. The group reflected on the data from phase two and focused on how these sixteen priorities could be actioned in their own organisations and settings. The participants discussed barriers and facilitators in terms of their organisations' capability to address the priority actions. In groups, participants planned exactly how they would make actions possible, with solutions. Together, participants used concept mapping to address the underlying issue of funding and costs across the sixteen priority actions. The group voted to include 14 of the 16 actions in an action plan and decided that two of the solutions required further development.

In the phase three cycle, participants also took the opportunity to think about the implications of the research data and explored in small groups the challenges and opportunities that the findings presented for inclusion, the work of activity providers, and the wider sphere. Figure 4 illustrates the process of research in phase three.

Figure 4: Phase three data



The challenge of funding the cost of inclusion was an underlying theme in the second phase and as a result, during the third phase, participants planned solutions in the context of a range of financial budgets. Participants considered actions that were realistic and achievable, and this resulted in the final action plan consisting of four actions for immediate development in the organisations that either they work for, or their children participate in. Two of these four priority actions were considered under with the expectation of no budget and were ‘right people with right personality and knowledge of the job’, and ‘share our experiences and knowledge with each other’, and two were considered under the expectation of a moderate budget: ‘advertisement’ and ‘inclusion for all – wider age range’. The action plans created by the participants demonstrated very specific and individual approaches to specific issues in their own organisations; for example, the action plan for ‘Inclusion for All: wider age range’ specifically addressed the issues of expanding an accessible catering project at the charity where the participant worked. Table 10 shows the four priority actions and accompanying action plans.

Table 10: Priority actions and action plans

NO BUDGET	**Share our experiences and knowledge with each other**	Verbal sharing with colleagues in groups whilst in work time (so no extra costs etc) Sharing links and sites for podcasts, vlogs (assuming IT in place)
	Right people with right personality and knowledge of the job	Word of mouth – putting people forward for position, using own networks In house training Target setting
MODERATE BUDGET	**Advertisement**	Funding for better advertisement e.g. local paper Trying to bring parents and providers together more often – on a regular basis Taster session days – parents feel less worried with commitment 50% off deal for first taster sessions
	Inclusion for All: wider age range	Verbal interaction Gazebo – outside space Assigning menus Outside grill (little equipment) People come here opposite different roles (customer service) Invite local care homes Different times and increase staff numbers so more age range can attend

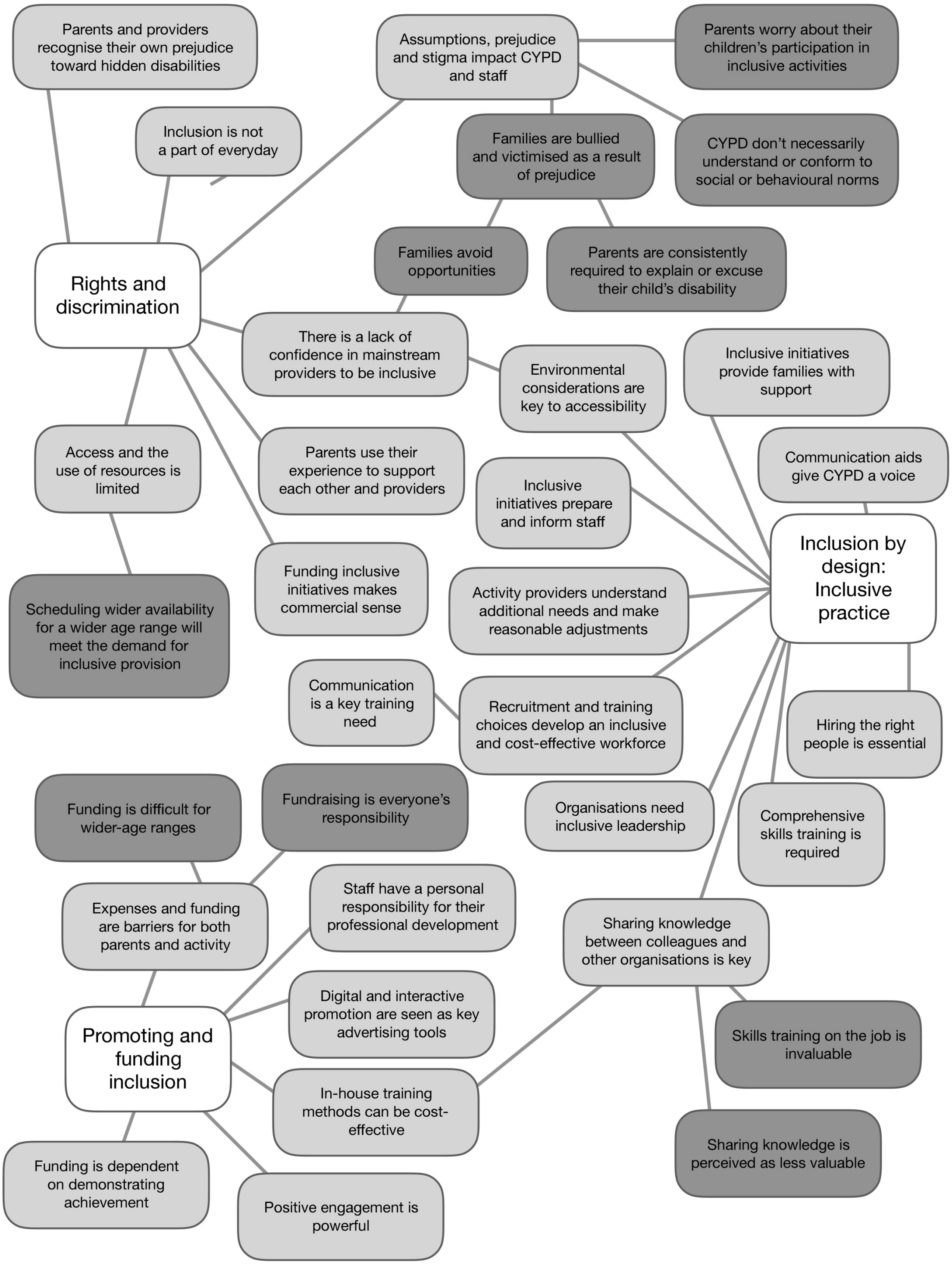
In phase three, participants focused on four priority actions and created actions plans for immediate change in their organisations. The data showed that participants perceived that sharing experiences and knowledge, and recruiting the right person with the rights skills for the job, were organisational priorities in the effort to increase the participation of children and young people with disabilities. The data also showed that participants viewed advertisement as a priority for promoting and funding inclusive community leisure and recreation activities. The data collected for the fourth action plan ‘Inclusion for All – wider age range’ does not relate to the action and therefore the data was not analysed.

4.5 Themes

Following the three phases of cycles, data from the workshop discussions was thematically analysed using Braun and Clarks six-stage thematic analysis (2013). The first stage was transcription of the audio recordings. The second stage was familiarisation with the data to reveal items of particular interest, and the third stage was complete coding across the entire dataset. The fourth stage was searching for themes. The fifth stage was reviewing themes by producing a thematic map of the themes, subthemes and relationships between them. The sixth stage was the analysis of the themes.

Thematic analysis derived from patterns in the codes revealed three themes: rights and discrimination, promoting and funding inclusion, and inclusion by design. Figure 5 shows the thematic map of themes, subthemes and relationships. The rest of this chapter provides a discussion on the analysis of the themes that resulted from the thematic analysis.

Figure 5: Thematic Map of themes, subthemes and relationships



Chapter Five: Discussion

5.1 Introduction

The main purpose of this chapter is to discuss, interpret and describe the significance of the findings in light of what is already know about participation among children and young people with disabilities in inclusive community leisure and recreational activities. Three themes emerged from the findings and are discussed in this chapter: rights and discrimination, promoting and funding inclusion, and inclusion by design.

The aim of this research was two-fold: to understand what the barriers and facilitators were to the participation of children and young people with disabilities in inclusive activities in community leisure and recreation settings; and to facilitate, with parents and activity providers, the planning and development of solutions for implementation. Two levels of analysis were conducted to reveal connections, differences and contrary findings; the key difference between the findings that emerged from the three research phases and the analysis of the transcripts is that during the cycles, data was analysed continuously and influenced subsequent cycles. Participants analysed their own experiences through concept mapping, providing a micro-level analysis that stays close to the experiences and words of the research participants. The thematic analysis of the transcripts represents a meso-analysis, using a theoretical framework. This conclusion brings together the two levels of analysis, identifying points of corroboration but also points of divergence.

It was clear that the experiences that participants chose to relate to and talk about were very relevant to the issues and discussions currently happening in their families, and their organisations. It was also clear that the participants were all at different stages of understanding and awareness of inclusion and participation, both professionally and personally. This influenced the way they spoke about their experiences, the language they used, the references they made, and the suggestions and ideas that presented. There was a notable difference in the responses from the activity providers who work with children and young people with disabilities on a more regular basis and have enhanced knowledge and experience. There was value in combining the experience and knowledge of families with activity providers. Both parents and activity providers felt judged over the issue of inclusion, but parents especially found therapeutic benefit in sharing their experiences.

Table 11 provides an overview of what happened in the research for each participant.

Table 11: Participant overview

Pseudonym	**Parent or Provider**	**Participant overview**

Rachel	Parent	lack of confidence in providers, self-awareness of internal prejudices
John	Parent	experience of discrimination, concerned about social barriers
Rose	Parent	experience of discrimination, helpful comments about societal norms
Phil	Parent	experience of discrimination
Jane	Parent / Provider	focused on communication aids, helpful comments on giving children a voice
Candice	Parent / Provider	focused on communication aids, helpful comments on recruitment
Sheila	Parent / Provider	experience of parent support networks, helpful comments about inequality
Toni	Provider	helpful comments about family support
Harriet	Provider	helpful comments on training and knowledge sharing
Julia	Provider	helpful comments on organisational development
Peta	Provider	lack of personal confidence
Trina	Provider	helpful comments on funding training and sharing knowledge
Laura	Provider	lack of confidence in mainstream providers
Talia	Provider	experience of organisational management
Blake	Provider	experience of volunteering
Annie	Provider	helpful comments about resources and funding
Sheila	Provider	experience of discrimination, helpful comments on promotion
Jake	Provider	helpful comments on fundraising and community responsibility
Maz	Provider	no coded transcript data
Melody	Provider	lack of inclusive experience
Louis	Provider	no coded transcript data

5.2 Rights and Discrimination

The theme of ‘Rights and Discrimination’ brings together the experiences of systematic prejudice that families shared in attempting to access inclusive activities. Views of the participants show that judgement and a lack of understanding about disabilities perpetuated the discrimination that families and children and young people with disabilities experience in their own communities**.** Although inclusion does happen and children and young people with disabilities are not excluded all of the time, participants felt that inclusion was not a part of everyday life, as demonstrated in this story from Phil about his son being stopped from diving at a public swimming pool:

> “They have a diving pool you know so you it’s 15 feet deep, but Jack is very proficient in the water - not a problem at all - and he can dive off of the one of the springboards into the water no problem. [We] spoke to the attendant and said that’s absolutely fine so Jack straight in, dived in, and then he swims to the side as other children had done. And then a manager came around and

> stopped him from doing it and yet while we're talking there these other children are doing it."

Phil and his son's experience of discrimination in the swimming pool was one of many that led him to believe that inclusion is not a part of everyday life. This resonates with Lyons et al. (2016) who highlighted the value of the social model of disability in the complexity of the attitudinal environment. The social model frames disability as a phenomenon that occurs because of society and environmental barriers driven by non-impaired values (Wang 2019). Analysis of the data found that families avoided opportunities as a result of prejudice, unfair treatment, judgement, victimisation and bullying from staff, other parents and other children. All of the parent participants in this study experienced discrimination in community leisure and recreation through societal and environmental barriers. This finding indicates that more needs to be done to uphold the rights of children and young people with disabilities and to limit the discrimination they face through social and environmental barriers.

Discrimination was experienced most often by participants in mainstream settings. The perception of mainstream providers was generally very poor among participants because of a lack of trust based on negative experiences. The lack of trust among parents towards providers is also highlighted in the literature through failings in the structure of services, and reinforced by a lack of awareness and understanding among staff (Thompson and Emira 2011). The data was full of comparison with mainstream activities to reiterate the inequalities in inclusive provision. The main focus for participants was on mainstream activity providers scheduling wider availability of inclusive activities, as captured in this comment from Sheila:

> "the play scheme that a lot of us have worked at only actually runs four weeks throughout the year but sort of more mainstream playschemes, I went to one at the [leisure centre], and I saw that they have a holiday club on and that would be happening throughout all of the holidays."

This and other participants' experience of a lack of inclusive opportunities were indicative of their frustrations with inclusion in wider society. Parents frequently described a lack of opportunity for children and young people with disabilities in community leisure and recreation and contrasted this with concerns about their children's participation. A lack of 'opportunity' was found to be more of a priority for parents than a lack of 'access' in the findings of the participant data collection cycles. This implied an internal struggle for parents who wanted their children to be included but had concerns about their ability to fit into an inclusive environment; as captured in the following comment from Rachel, a parent:

> "You don't want to put your child in, you want them to learn, you want them to make friends, but also you don't want them to be completely alienated, and looked at differently, so as parent's it's, it's quite difficult."

This concern is reinforced by the negative experiences of families and children and young people with disabilities, leading to the lack of confidence in mainstream activity providers. Such findings indicate that a lack of confidence in providers is linked to experiences of discrimination that stem from a lack of disability awareness.

Disability awareness is also linked in the data to removing the assumptions, prejudice and stigma experienced by participants. This was also explored in the literature which highlights the challenge of attitudes among staff and peers in community sport settings in particular (Grandisson et al. 2012). These attitudes manifest in segregated disability provision and selective inclusion, promoting ableism and cultural isolation (Miller et al. 2009; Jeanes et al. 2018). Participants in the research described the experience of prejudice from staff as a lack of understanding from individuals, which was set-up to imply that employers and organisations were not responsible for the non-inclusive actions of their staff. These distinctions between individual and organisational responsibility for inclusion are related to the judgement of staff, which is more personal than a lack of training, as captured in the following comment from Rose, a parent:

> "It's the judgement isn't it, it's not about people being educated, but it's the judgement you get, so you can understand people and if you don't understand something ask…you don't need to understand a disability to actually speak to the parents say 'how can I help you?' and to speak to the child as well because they may not be verbal but the child can still understand you sometimes."

This experience of prejudice reflects societal norms that some people view people with disabilities as lesser than themselves in some way. The principle of the social model of disability that focuses on attitudinal change is important because the attitude of some people towards hidden disabilities is based in fear or ignorance of what they cannot know or understand or see. In many instances where children and young people with hidden disabilities did not understand or conform to social or behavioural norms, parents were repeatedly required to explain or excuse their child's hidden disability, as captured in the following comment from Rose:

> "because he's non-verbal the way he communicates is with his hands, so he touches the children. And I've had occasions where I've had sort of negative conversations with the parents because they're like "tell him to get off my child" and you say "well he's trying to communicate with your child"… even when I said he was Autistic, "no tell him to get off my daughter that's not an excuse" she said."

This shows that children who don’t confirm to social norms are not accepted and often feared by society. This resonates with Thompson and Emira (2011) in relation to their research on parental perceptions of access to leisure, which found that prejudice around hidden disabilities led some parents to choose segregated disability provision over inclusive provision (Thompson and Emira 2011). The data shows that this was linked to the widespread lack of understanding of disability, and specifically, ‘hidden disabilities’. These findings suggest that more needs to be done to address attitudes toward disability, and the assumptions, prejudice and stigma that impact children and young people with disabilities.

Shields et al. (2016) found that the attitudes of peers, staff and parents were more influential than other barriers. Participants' experiences reflected not only the judgement and lack of understanding of parents of peers, but also the reactions of other parents of children and young people with disabilities, as highlighted by John and Rachel as they talked about queuing in a fast-pass disability line:

> “and there was about eight Americans with this one person that was in a wheelchair, so we walked in and the mother said “no you’re in the wrong place, this is for people with disabilities, so you’re not with us”, and you’re kidding can you believe it? They were expecting Peter to start doing something and kick off in the queue. Once again you can’t put a sign on your child - they should just understand there’s a reason why you’re there, it’s crazy isn’t it?”

Judgement and a lack of understanding about ‘hidden disabilities’ perpetuated the discrimination that families and children and young people with disabilities experienced in their own communities. Inherent in their own communities, participants also recognised their own prejudice towards others with hidden disabilities, as Rachel went on to comment:

> “but some of the parents do look at you: “well you look normal, why are you going in there?”, but I’ve got really bad because when I was stood in that queue, and I look at people I think look normal, I tell them to go back to the other entrance if they want to queue for the ride.”

As well as highlighting their own prejudice, this demonstrated a notion of self-segregation among parents of children and young people with disabilities where hierarchies of disability entitle special treatment that segregates children and young people from the non-disabled community. Added to this was the use of non-inclusive language by participants such as ‘normal’ and ‘regular kids’.

> “ they might not accept sort of harder children, air quotes around harder, they may just not have the sort of abilities to be able to work with them because some of them do need the one to one thing… I think that the play scheme that we worked for does enough it’s just it’s a shame that there’s not more of them because there are for mainstream children and yet they’re the (air quotes) sort of easier children to deal with.”

What this comment also shows is the language used around children that are ‘harder’ or ‘easier’ demonstrates that even within the disability sector, the notion of disabled children as being ‘harder’ to deal with is endemic; it comes with negative connotations of bad behaviour, and this is not conducive to the inclusive ethos of the social model of disability. The participants use of the word and actions for ‘air quotes’ suggests that they acknowledged their incorrect use but could find no better word or phrase to use in that situation. When children and young people with disabilities are undervalued, their self-esteem suffers, and they are excluded and experience further discrimination. This finding suggests that discrimination of children and young people with hidden disabilities is a major problem for advancing participation of children and young people with disabilities in inclusive activities.

The findings of this theme ‘rights and discrimination’ show that judgement and a lack of understanding about ‘hidden disabilities’ perpetuate the discrimination that families and children and young people with disabilities experience in their own communities. Participants viewed discrimination as systemic in our culture, and this suggests that this is damaging the progression of inclusion. The findings also show a level of internal prejudice through self-segregation and non-inclusive language among those from within the disability community. These findings suggest that discrimination is deep-rooted in the disability community as well as widespread in society.

5.3 Promoting and Funding Inclusion

The theme of ‘Promoting and Funding Inclusion’ explores the challenges of funding inclusive activities, the reliance of powerful promotion on continued funding, and the universal responsibility of fundraising. Although there was a dearth in the literature on promotion and funding inclusion, the issue was so prominent in the data collection and was instrumental in the action research, that it was important to dedicate a section to this theme. Funding inclusion was woven into almost all of the participant discussions around inclusion; expenses and funding were key concerns for both parents and activity providers.

Analysis of the data shows that funding was both a barrier and a facilitator. The data from phase two demonstrated that among the realistic actions, participants focused on how they could implement inclusive provision at a reduced cost, or ways that they could generate an increase in funding. Each of the sixteen priority actions developed by participants during cycle two involved some level of funding, and the frequency of financial concerns apparent in the data demonstrated a high level of financial anxiety among participants. This may have been different in another population group. The data demonstrated that there was a focus on funding among activity providers; it also demonstrates a lack of focus on other areas highlighted in the literature such as self-development of children and young people with disabilities (Willis et al. 2018a), or the pressure on families (Shields and Synnot 2016). This suggests that the financial pressure on activity providers detracts from other key issues addressed in the literature.

Costs, funding and finance were not so widely discussed in the literature, despite the obvious expense of the home-based and residential programmes, and multi-agency approaches (Anaby et al. 2015; Anaby et al. 2017; Willis et al. 2018a; Willis et al. 2018b). The only research in the literature review to research ‘community’ clubs was focused on sports clubs in Australia (Jeanes et al. 2018), although many of these clubs had wider-support from governing bodies in terms of management, finance, development and inclusivity. In contrast, the community clubs in this research were all small and independent clubs, and either run as not-for-profit, or start-up family businesses. Funding inclusion in these smaller clubs relied on local government funding, charitable grants and fundraising. In larger organisations, there is a high level of management dealing with finances so activity providers can focus on the activities without the concerns of finance. By contrast, in smaller organisations, funding is often the responsibility of those also providing hands-on in delivery of the provision. The finding that there was more pressure on community clubs to both fund and deliver participation in inclusive activities is a major concern, impeded further by austerity measures, reduced budgets and the reduction in grants. The literature on austerity demonstrates that austerity has led to a reduction in the quality of services and opportunities for children and young people with disabilities to participate in inclusive community leisure and recreation activities (Horridge et al. 2019). This poses a major threat to the development of the social model principles that can unite society through equality.

The data revealed that the reduction in quality of services has further damaged the level of mistrust of mainstream activity providers among parents of children and young people with disabilities. Research on austerity by Horridge et al. (2019) found that most families reported services to be worse than three years prior, and some families reported that the needs of their children were less well met than ten years ago. The data in this research found that participants held the view that major providers were driven by profit over inclusivity, and that parent participants perceived inclusive initiatives to be profitable for mainstream providers, with the potential to fill a large gap in the market. Parent participants firmly believed that funding inclusive initiatives made commercial sense, and although they were aware of the impact of austerity, this did not seem to translate in their views about profit over inclusivity. In contrast, the experiences of activity provider participants demonstrated a desire to make change happen despite financial constraints, with a huge sense of personal responsibility for fundraising and professional development, as captured in this comment from Annie:

> “if there’s any specialist kit or anything that we can use to help develop children and adults then you know rather than trying to struggle to get the money if we get everyone involved and actually organised some fundraising ourselves we can sort of generate it that way.”

The data implies a level of personal responsibility among those who work in the sector to support funding for inclusive leisure provision for all children. In contrast to the negative perceptions from parent participants, evidence from activity provider participants demonstrated that organisations wanted to provide more support to children and young people with disabilities.

In the current financial climate, continued funding is incredibly important to activity providers. Data from participants links the reliance of continued funding on the demonstration of achievements with positive advertising, success stories and community engagement to reduce stigma. In discussion about fundraising and promotion, Annie considered how engaging communities through fundraising events helped generate both awareness and funds:

> “And then we’ve also got organised fundraising events, getting community involved, spreading awareness, but also if there’s any specialist kit or anything that we can use to help develop children and adults, then you know rather than trying to struggle to get the money. If we get everyone involved and actually organised some fundraising ourselves we can sort of generate it that way.”

The data shows that both parents and activity providers felt that the responsibility for funding inclusion and promoting awareness of inclusion was a community responsibility. Although this misaligns with the social model of disability that places the reliance on the state to make change happen (Oliver 2013), the current situation of a lack of available funding means that this is the reality.

Participants also felt that staff should fundraise for their own training development, which raised a question about the lack of essential resources, the provision of which is essential for the social model of disability. Lack of training is also highlighted as a structural barrier in the literature (Emira and Thompson 2011). The cost of training as an issue was prominent throughout the data and focused on the alternative lower cost methods of training, which included on the job training, peer-training, and sharing experience and knowledge with colleagues and organisations; these are explored in more depth in the next section.

One challenge for the research considering the focus that developed around funding, was that the level of knowledge about the costs of providing activities and all the associated overheads among activity staff and volunteers was varied and led to some debate among the participants during the research. Data from participants demonstrates that social media and other online promotion and marketing tools were viewed as having no cost, and there was a lack of understanding about the overhead costs involved for organisations, as captured in this conversation between Melody and Talia:

> Melody: “Even where you put regular website updates, I think that would come into the no budget anyway, but I understand what you’re saying about the time.”
>
> Talia: “Yeah it’s the time and sometimes you have to generate people to go on the website haven’t you, you’ve got to push the people to go on it, so you kind of think well actually is that the way to go anyway - should you just be putting information on social media so it’s free?”

The theme of funding and promoting inclusion, strongly highlights how the issue of funding inclusion is prominent, immediate, and concerning. Funding was at the forefront of participant data across the participant-derived themes: the cost of overcoming barriers, the cost of communication aids, the cost of education, the cost of activities, and the lack of funding. Austerity has shifted the responsibility for funding inclusion away from government and onto activity providers and communities. The finding that such a focus on funding could have the potential to detract from the key focus of enhancing inclusion, is also worrying. The findings suggest that the lack of investment into inclusive provision at a local grass-roots level is perceived by stakeholders as a major barrier.

5.4 Inclusion by Design

The theme of inclusion by design explores the inclusive practice and organisational development necessary to advance participation in inclusive community leisure and recreation. The findings of the data within this theme demonstrate that the person-environment interaction implicit in the paradigm-shift from a medical to a broader social model of disability in inclusive practice, requires special attention be given to the design of inclusion. This section focuses on the inclusive design elements that were prominent in the data, including leadership, communication aids, recruitment and training choices, skills training, and knowledge sharing.

The data revealed a wealth of examples of inclusive practice among community leisure and recreation providers; inclusive initiatives that provided families with support, respite, sibling engagement, advice, empathy and reassurance. The data showed examples of best practice where activity providers understood additional needs and made adjustments. The analysis of the data suggests that the key mechanisms for inclusive practice lie within leadership, communication, recruitment and training and environmental considerations, all of which require inclusion to be part of the design, with collaboration between host organisations, activity providers, and families. This resonates with King et al. (2016) and Smart et al. (2018) who found that a multi-agency collaborative approach with local activity providers developed inclusive practice in a community approach where inclusion was built into the design of the space and social environment (King et al. 2016; Smart et al. 2018).

Participant data shows that inclusion was more successful through inclusive initiatives that prepare and inform staff through team planning meetings, knowledge about individual children's needs, and briefing and debriefing sessions for all staff. The data demonstrates that participants perceived organisations with inclusive leaders to support staff, provide training and promote knowledge sharing, all of which were viewed as important for inclusive practice. The notion of inclusive leadership was captured in this comment from Talia who managed a targeted service provision:

> "From the perspective of wanting to do things differently, and making sure that the guys are always supported, and the team supported in the organisation, I just wanted to make sure that we always share what we should be sharing about the children in a professional manner, and making sure that we are as trained as possible."

This demonstrates that inclusive leadership fostered collaboration within Talia's organisation. The data further revealed that partnership work, parent provider forums and engagement of clients in planning activities, further developed the collaborative platform created through inclusive leadership. Similar collaborative multi-strategy approaches are also highlighted in the literature as crucial to the effectiveness of advancing inclusion (Anaby et al. 2015; Law et al. 2015; Imms et al. 2016). These findings suggest that the success of multi-agency interventions heavily relies on the support of the community and services to provide intensive family and one to one support.

The findings show that inclusive design is achieved through inclusive leadership, fostering collaboration between host organisations, activity providers, and parents, to make choices in the best interests of all stakeholders. This aligns with cycle two findings that collaborative actions rooted in culture and social values enable communities to work together and share knowledge and skills, and cycle three findings that a multi-agency collaborative approach with local activity providers, develops inclusive practice. The importance of collaboration is also reinforced by cycle one findings that a multi-agency intervention, which heavily relies on the support of the community and services to provide intensive family and one to one support, is required.

A key design element revealed in the data was the importance of communication aids. Resources such as the Picture Exchange Communication System and Makaton, were perceived by participants as cost-effective and easy to use. What made communication aids so important to the outcomes for participation of children and young people was the ability of communication aids to give the child a voice and facilitate engagement, as captured in this comment from Jane:

> “because we do want our children or young adults or whoever to have a voice, and I think you know it needs to be accessible and I don’t think it is.”

The data also shows that awareness of communication aids was mixed among participants, with contributions on this topic concentrated on participants with the most knowledge and understanding of inclusion in the group. Studies that focused on the potential of communication aids to give children and young people with disabilities a voice (King et al. 2016; Knibbe et al. 2017) demonstrated how the broader socially inclusive and cooperative environment was responsible for giving children and young people with disabilities a voice (King et al. 2016; Knibbe et al. 2017). This takes us back to the lack of essential resources, which is a key social support of the social model of disability. This suggests that despite their vital role in giving children a voice, communication aids are not commonly known resources and need to feature more prominently in inclusive design.

Another design element of inclusion revealed in the data was the importance of recruitment and training choices; the data links human resource management to knowledge transfer for organisational development and the findings suggest that recruitment and training play an important role in sharing skills and knowledge as a method to develop an organisation's capacity for inclusion. The data shows that participants perceived that hiring the right people with the ability to develop an inclusive and cost-effective workforce through safer recruitment and recruiting staff with the right personality and ethic, was essential. There is a link here with research by Miller et al. (2009) who revealed that inclusion in community recreation was often founded on key individuals to promote inclusive change in community and grass-roots settings (Miller et al. 2009).

The findings also suggest that participants felt that hiring the right person for the job was more important than existing experience and training, because experience can be gained, and skills learnt on the job. However, the participants suggested that the right personality for working with children and young people with disabilities is something you either have or don't have, as captured in this comment from Sheila:

> "obviously having the right personality, I'm not sure if this means like the right person with the right personality of child, or the right people and them themselves have the right personality, but I do think it's important that the child and the carer…have a bond because you need both people to feel comfortable."

This focus on employing the right people suggests that participants have experienced previous poor recruitment choices or colleagues who were not right for the job. The findings show that participants perceived the recruitment and training process as important in finding people with the right qualities for the role. One of those qualities is the ability to share information with colleagues and other organisations. The literature shows how important this collaborative quality is to the success of building capacity in participation (Anaby et al. 2015; Anaby et al. 2017). The participant-derived no budget action plans in cycle three both involved more collaboration than the moderate budget plans, for example sharing knowledge with colleagues, in-house training, and collaboration with other organisations. A large element of skills training is done through sharing knowledge; however, this method of training was perceived as less valuable against skills training, which was perceived as invaluable. This presents a dichotomy in the findings: sharing knowledge isn't perceived as official training because it is non-accredited; however, skills training on the job generates value in terms of being thrown in at the deep end, combining learning on the job with knowledge.

As previous findings have demonstrated, the importance of training is balanced against the cost of training. Activity providers engaged in alternative lower cost methods of training included on the job training, peer-training, and sharing experience and knowledge with colleagues and organisations. Harriet described how the cost of training was prohibitive, but alternatives such as in-house training and sharing knowledge could facilitate staff development:

> "We found quite a lot of the time that it's hard to get training because of funds and the cost of everything, and then hiring in somebody to train everyone. So some of our training we do in house, if somebody has or already learned stuff. We not so much training in sort of formal terms, but we sort of pass on knowledge to each other you know."

The data suggests that exploiting networks and contacts provided cost-effective knowledge sharing tools. The findings demonstrate that small practical actions that are cost-effective are more achievable and realistic for local grass-roots activity providers than intensive approaches.

The theme of Inclusion by Design has explored the findings of the data and key factors of best practice in inclusion among community leisure and recreation providers. The findings pinpoint leadership, communication aids, recruitment and training, and sharing knowledge as key mechanisms of inclusive design.

5.5 Conclusion

The broad range in terms of the depth of understanding about inclusion across the participants resonates with the literature that demonstrates that there is a broad understanding of the concept of inclusion in practice (Miller et al. 2009; Jeanes et al. 2018). The literature review findings identified aspects of misdirection in the values of inclusion in some community settings, and although this was not a finding of this research, some of the participants in this research demonstrated a disconnect with the concept of inclusion. For example, the action plan for a wider age range was about expanding a café, rather than designing activities for a wider age range of children, and this demonstrates a lack of focus and understanding. Moreover, several action plan points were somewhat irrelevant, such as 'inviting care homes', and some demonstrated a very basic level knowledge of inclusion, such as 'verbal interaction'. The findings in this research were a reflection on the time and place of the participants in their own inclusive journeys, whether that was professional, personal or both. They were also a reflection on their own journeys of inclusion, with some participants demonstrating a greater level of understanding about participation in inclusive activities.

The research findings show that discrimination emanating from a lack of understanding about children and young people with disabilities, negatively impacts access to inclusive activities and leads to inequalities in accessing community leisure and recreational activities. The research findings also identified internalised stigma and lack of understanding from participants themselves, and from within their own communities, resulting in self-segregation, thus further limiting the progression of inclusion. Internalised stigma is self-judgement which is perpetuated by shame or blame from others (Peterson et al. 2008). The findings illustrate how a lack of understanding about 'hidden disabilities' perpetuates the discrimination that families and children and young people with disabilities experience in their own communities.

The findings show that the challenges and responsibilities of funding and costs, focus attention away from inclusion and this further negatively impacts access.
Financial pressures resulting from the rising demand for inclusive activities, and budget cuts as a result of austerity, limit the capability of local providers to deliver activities that are inclusive. And yet the financial pressures faced by activity providers are not discussed in the existing literature, so this perspective fills a gap in the understanding of the contextual factors that create barriers to participation and how they interact with one another. The research has also highlighted funding as a barrier that both children and young people with disabilities and providers are keenly aware of. Funding issues were particularly prominent in the cycle three workshop, not surprisingly, since the aim of this cycle was to move towards actions that would improve provision. The findings also show how the challenge of funding detracts from addressing other key issues of inclusion.

While other studies focus on one or more of facilitating factors, this research shows that action research has the ability to address many aspects, recognising how they are interwoven. The findings illustrate key mechanisms for inclusive design that focus on leadership, communication aids, recruitment and training, all requiring inclusion to be part of the design, and collaboration between activity providers, and families.

Chapter Six: Conclusion

6.1 Introduction

Article 23 of the UN Convention on the Rights of the Child (1989) and Articles 23-30 on the UN Convention on the Rights of Persons with Disabilities (2006) state that children with disabilities should have the opportunity to participate on an equal basis with others in all life settings, and have access to services. Yet this research has shown that despite the benefits of involving children and young people with disabilities in mainstream leisure and recreation, and anti-discrimination laws, barriers continue to restrict the participation of children and young people with disabilities. This research has sought to capture the complex contextual factors and multiple layers that create, contribute to and exacerbate these barriers. At the same time, it sought to identify facilitating factors and the key mechanisms for participation in inclusive activities.

This research set out to not only find out about but also address the needs of children and young people with disabilities and their families in community leisure and recreation activities and to facilitate community change at a local level by looking at the barriers and facilitating factors to participation in community leisure and recreation. It involved families of children and young people with disabilities in a research process that was accessible to them and provided the opportunity for local community organisations to engage in a process that would have a direct impact on their practice. It did this by creating a communicative space in which families could be heard and where participants were invited not only to share their experience with regards to the issues impacting participation, but to contribute to change.

In this concluding chapter, there is a synthesis of the substantive findings, the methodological contribution is discussed, and recommendations made for increasing participation. The chapter ends with some concluding remarks about the limitations of the research and proposals for further research.

6.2 Synthesis of substantive findings: contribution to knowledge

Inclusion is about all children having the widest choices possible and the opportunity to access those choices in their own way. The findings show that this comes from sharing a welcome attitude of respect and responsiveness that entails participation and belonging. Children and young people with disabilities need to feel not just included but need to know they belong; they are individual and important.

The UK government focuses on inclusion in education, but outside of the school environment, little has been done to develop inclusive practice for children and young people with disabilities. There are things that can be done to begin to make recreational activities more accessible to children and young people with disabilities.

The current policy and practice is not working for many children and young people, and unless there is a willingness to think differently about inclusion, the situation with regards to inclusion is likely to deteriorate. In law, equal value is placed on all children and young people; in practice, current approaches will need to change for the advancement of an inclusive society.

Children and young people with disabilities have traditionally been excluded from the public view by segregating them in hidden communities. The inevitable consequence of this has been the disengagement of people with disabilities among people without disabilities, which has created a ‘them’ and ‘us’ and built barriers, ignorance and prejudice. Changing attitudes and views is challenging and will not happen overnight; however, we can’t change societal attitudes without changing policy.

There is a tension between providing meaningful choice, and the reality that activity providers have limited resources to accommodate such choices. Despite the gains made by the social model of disability movement, despite the legal status of disabled people and changes to policy and legislation, and despite the Equalities Act 2010, there has been minimal response in terms of implementation at grassroots level. This perhaps indicates the need for an alternative approach. The momentum for change may come from the discrimination experienced by children and young people and their families and from local people investing in promoting equality, access and opportunity for their communities: parents of children and young people with disabilities, activity providers from organisational management through to volunteers, and children and young people themselves.

For activity providers, as this study has shown, there can be a feeling of helplessness and inadequacy when they are unable to help a child due to the organisational and societal constraints discussed in this research. Solving the issues requires a change from the very core of society all the way out to the edges. To achieve true, meaningful inclusion there is a need for new policies, new procedures, fresh minds to work on it and new funding to build it. This research demonstrates a need for new research, new ways of thinking and new methods of training. This requires an investment that reflects the true value of society caring well for its most vulnerable; an investment that politicians seem unwilling to make.

This research demonstrates that the alternative is a grassroots-up approach that works bottom up rather than top down. It is reliant on being led by the people experiencing it. There are parallels with grassroots health-promotion literature underpinned by the respect for diverse yet complimentary perspectives and skills from the grassroots up

(Estacio et al. 2017). Inclusion is not something that can be achieved by adding ramps and rails and special needs clubs and saying we are trying our best. Real inclusion requires a complete change of approach that aims not just to add the needs of children and young people with disabilities as an extra at the end of planning but incorporating them from the beginning.

6.3 Methodological contribution

Methodologically, in conducting action research, by bringing host organisations and activity providers together with families of children and young people with disabilities, this collaborative action research provides findings that give a broader and more comprehensive, situated perspective of inclusion. Engaging at the local grass-roots level with providers of a range of activities and clubs has generated new data to demonstrate how collaboration is interwoven through inclusive practice, with a focus on inclusive design. This collaborative approach toward research reflects the different agendas and ideas between children and young people with disabilities and their families, and activity providers; by sharing those with each other through action research, participants developed a greater understanding of the challenges they each faced, and this helped improve outcomes.

Building the concept of communicative space (Bevan 2013) into the design of the research through ice-breakers, creative activities, and group reflection, was an important part of giving participants an arena in which their voices could be heard. This design provided participants with opportunities to tell their stories, have their voices heard, engage in common goals, and build confidence to challenge and discuss the often-sensitive issues of inclusion. The concept of communicative space was developed as the research progressed, to truly engage and empower participants in the process of change. Participants in the research evolved through the three phases of ‘inclusion’, ‘control’ and ‘intimacy’ described by Bevan (2013) in each cycle, rather than evolving across the research as a whole. This likely happened because the cohort of participants changed in each cycle, from parents in the first cycle, to activity providers in the second cycle, to a mix of both in the third cycle. Almost as soon as participants arrived for each cycle, in the arrival conversations between participants, they were finding their place within the group.

Concept mapping was useful as a tool for action research, because of its capacity to map out the territory, both conceptual and concrete. In this instance, it built a picture of the extent to which inclusive participation was being implemented in community leisure and recreation. This research, which combined Smart's metaphorical tree with Burgess-Allen's method of concept mapping, coined by the researcher as 'inclusion mapping' was new in this area of research. The concept mapping exercises in each cycle provided participants with the confidence to challenge and discuss the barriers and facilitators of inclusive participation. Moreover, the participants did not have to speak to have their voices heard, and this provided the opportunity for different methods of communication. Finally, in each cycle there was opportunity for discussion and reflection of the ideas presented through concept mapping, and this is where group dynamics became more supportive, sympathetic and dependant. The metaphorical lifecycle of a tree was a metaphor for the underlying notion that inclusion can be grown and developed. Combining concept mapping and the metaphorical tree in the research process, coined as 'inclusion mapping' was unique to this research.

6.4 Limitations

One limitation of the research was the lack of the voice of the child. Although the research was promoted as creative, and age and ability appropriate for children and young people, parents chose to participate without their children. This inevitably impacted group dynamics and resulted in a powerful voice from parents within the research. The separation of the voice of the child and the voice of the parent is arguably more difficult in research with disabled children because of their reliance on their parents and families to support their participation. In future research, individual children and young people with disabilities could be supported by staff members rather than parents, in being research participants.

There was a lack of clear ground rules given to the focus group participants, and it is likely that this placed limitations on the participants and the data. Each participant must be engaged in the conversation by providing his or her honest feedback on the questions asked. The lack of ground rules was an intentional decision by the researcher to facilitate among participants who already knew each other, however this meant that there was nothing to reinforce that participants are free to express their opinion without consequence and may have limited honesty in the participant responses. In future focus groups, the facilitator should be charged with guiding the participants to start each session by creating a set of mutual ground rules including the right to challenge or criticise, the right to respectfully disagree, and the responsibility to respect and build on the strength that diversity provides.

Another limitation of the research was that it was only able to record a snapshot of inclusive provision. A longitudinal design would have complex methodological and practical implications. Perhaps it is for this reason that evaluations of programme and interventions in the literature also tend to be conducted over short periods of time. Generally speaking, more longitudinal designs that can chart, evaluate and monitor inclusive development over time would make a huge contribution to sustainable and on-going efforts to improve participation in the domain of inclusive community leisure activities.

The missed opportunity to include a third research question in line with the third part of the action research process was a limitation. At this point in the research participants took autonomy of the process and the actions agreed to make changes in their community activities. No further data was collected, however a further analysis of the action taken by participants at this point would have provided richer data. Future research could explore how the actions taken by the participants have impacted the participation of children and young people in the community.

6.5 Recommendations for increasing inclusive participation

In this section, recommendations are made in relation to the key findings. The misdirection of practices, discrimination and lack of understanding is contributing to the widespread level of inequality and prejudice experienced by children and young people with disabilities and their families. Both the UK Government, local councils and service providers need to do more to meet the standards for access and opportunity as already set out in The Equality Act 2010. The possible consequences of not addressing the advancement of inclusive participation is that poor practices continue, children and young people with disabilities become further excluded from community leisure and recreation, and this reinforces the normalisation of discrimination and equality in society.

There needs to be more funding in local and grass-roots inclusion. The social model of Disability, which places the responsibility on the state to provide equal opportunity and access, has been passed on to local and grass-roots providers as a result of austerity. The potential consequences of failing to invest in local and grass-roots inclusion, is a reduction in community leisure and recreation opportunities for children and young people with disabilities because activity providers are unable to afford to deliver activities.

Beyond the funding needs, but impacted by the costs, more training support in terms of education and best practice needs to be provided to local and grass-roots community leisure and recreation providers. The potential consequences of failing to address the gap in training and expertise, is the continued misdirection of inclusive values in the way that inclusive activities are delivered.

Finally, there is a lack of research that focuses on inclusive participation of children and young people with disabilities in community leisure and activities in the UK. In order to address many of the issues raised by this research with regards to access and opportunities for the inclusion of children and young people with disabilities, it is necessary for further studies to concentrate on community leisure and recreation in UK settings.

6.6 Concluding remarks

This research has argued that participation for children and young people with disabilities in inclusive activities can only be successful when individuals feel that they are truly a part of the community (Willis et al. 2018b) and this comes through choice, autonomy, and support. The way in which individuals measure how included they feel is not aligned with the way society measures inclusion through statistical levels of inclusion and exclusion. This requires open and honest discussion about difference, and a foundation of equality without discrimination (Oliver and Barnes 2010). In inclusive activities, this ethos fosters an environment where children and young people, and their families are valued for who they are. As such, effective models of inclusion not only benefit children and young people with disabilities, but also create an environment in which every child and young person has equality, access and opportunity to participate in community, leisure and recreation.

Although there was no formal follow-up on the implementation of strategies identified in the research process, following the research, a group of participants established a ‘parent and provider forum’ with the aim of meeting regularly to support the advancement of inclusive participation of children and young people with disabilities locally. Informal feedback from participants suggests that being involved in the research process has been a catalyst that has inspired participants to be more proactive about advancing inclusive practice within their community and their practice, and has prompted more collaboration with parents and carers to enhance the experiences of children and young people with disabilities in community leisure and recreation.

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