Supporting Participation in Leisure of Children and Young People with Neurodisability:

Developing a Programme Theory for Building Allied Health Interventions.

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Abstract

Participation in leisure is important for children and young people’s social inclusion and physical and mental health. However, children and young people with neurodisability are restricted in leisure participation compared to their non-disabled peers. This research aimed to develop an allied health intervention for supporting participation by: (i) developing a relevant and useful definition of participation in leisure, (ii) identifying modifiable personal and social environmental factors influencing participation, (iii) specifying intervention techniques, and (iv) describing acceptable, feasible ways to deliver the techniques in National Health Service (NHS) settings.

The research drew on behaviour change theory and evidence, the World Health Organization’s International Classification of Functioning, Disability and Health, and the Medical Research Council’s guidance on complex intervention development. The methods were a quantitative systematic review (n=18 papers), a qualitative study (focus groups, semi-structured interviews, go-along interviews, and a workshop, n=32 stakeholders), an online Delphi study (n=68 stakeholders), and two embedded co-production projects. Stakeholders were children and young people, parents, allied health and short breaks professionals, sports coaches, and researchers.

Rather than one definitive intervention as was originally planned, the main output was a comprehensive programme theory of supporting participation in leisure to be used for developing multiple interventions tailored to local contexts. The programme theory defines participation as children and young people attending leisure settings for the first time and exploring activities. It includes four personal factors (e.g. children and young people’s emotions, goals), six social environmental factors (e.g. parents’ goals, beliefs), four features of the local leisure context likely to influence implementation of participation support, and 45 intervention techniques with detailed description of acceptable and feasible delivery.

Future research should translate these results into an accessible intervention manual. Feasibility testing should explore use of the manual in NHS settings, measurement of potential effects, and designs for definitive evaluations of interventions.

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A heartfelt thank you to my family and friends in Yorkshire, Northern Ireland, Leicestershire, and Newcastle. I am pleased to tell you that this is over, we need not discuss it any further, and I am very grateful for all that you have tolerated and delivered.

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1 Chapter 1. The Purpose and Context of the Research Programme

This research programme aimed to develop an allied health intervention for supporting participation in leisure of children and young people with neurodisability. In this opening chapter I will provide an overview of childhood disability in the United Kingdom (UK), describe the health outcome of participation in leisure and the problem of participation restrictions for children and young people with neurodisability, outline the broad policy context within which the research is situated, and set out the practical problem that the research was trying to address.

1.1 Children and Young People with Neurodisability

This research programme focused on children and young people affected by neurodisability, which describes a group of congenital or acquired long-term conditions that are related to impairment of the brain and/or neuromuscular system (1, 2). Common health conditions within neurodisability include cerebral palsy, autism, and learning disability, although many children and young people receive diagnoses of multiple co-occurring health conditions, or no specific diagnosis. The impact of neurodisability may include difficulties with movement, cognition, hearing and vision, communication, emotion, and/or behaviour (2).

Robust population data on the numbers, characteristics, and circumstances of disabled children and young people, including those with neurodisability, have not been readily available to inform evidence-based policy and planning in the UK (3, 4). One key source of information is the Family Resources Survey, an annual government survey that collects information about the incomes and living circumstances of a representative sample of private households. The most recent report indicates that approximately 8% (1.1 million) of UK 0-19 year olds are disabled (5). Neurodisability is one of the largest groups of disabled children and young people; however, the number of individuals with neurodisability is unknown. The Family Resources Survey likely overestimates neurodisability because it uses a broad definition of disability that is compatible with the Equality Act 2010, and therefore includes conditions such as asthma and diabetes. Conversely, the Global Burden of Diseases, Injuries, and Risk Factors Study, whilst comprehensive, likely underestimates neurodisability (6). It reports a prevalence of 4.7% (182,856) of UK children aged under five years, but this does not include cerebral palsy, which is the most common physical neurodisability in childhood and occurs in 2.5 of every 1,000 live births (6, 7).

1.2 Participation in Leisure as a Fundamental Health Outcome

Participation – involvement in life situations – is consistently identified as a priority health outcome for children and young people with neurodisability (8-15). In this research programme I focused specifically on participation in leisure, understood as involvement in discretionary settings or activities outside of education or school hours, self-care, and domestic life. For all children and young people, participation in leisure is a fundamental health outcome, contributing to physical and mental health, subjective well-being, social inclusion, academic achievement, and child and family quality of life (15-31). For those with neurodisability, participation in leisure is also a particularly important way to experience some freedom of choice, fulfilment of potential, and social connectedness (32-35). However, compared to their non-disabled peers, children and young people with neurodisability are restricted in their participation in leisure, often experiencing more limited frequency and diversity of participation, particularly in preferred activities, fewer friendships, poorer quality of friendships, and less meaningful and authentic inclusion in leisure activity settings (1, 27, 34, 36-45). Participation restrictions mean that this population can miss opportunities to gain the developmental benefits associated with leisure activities, which in turn can further disadvantage their wider health and well-being and compound the impact of known health and social inequalities (3, 46-48).

1.3 The Policy Context for Supporting Participation in Leisure

Whilst participation in leisure is conceptualised as a fundamental health outcome, the role of the National Health Service (NHS) in supporting participation is unclear. Participation in leisure has been recommended for inclusion in a common vision of what the NHS is trying to achieve for children and young people with neurodisability, and health professionals have endorsed the importance of leisure for health and well-being (9, 49). However, health professionals do not necessarily regard supporting participation in leisure as a primary concern for the NHS (49). To begin to understand why this may be the case, it is helpful to consider the broader policy context within which supporting participation in leisure is situated.

The imperative to support participation in leisure of children and young people with neurodisability is established first and foremost in international law, specifically the United Nation's Conventions on the Rights of the Child (UNCRC) and the Rights of Persons with Disabilities (UNCRPD). Both ratified by the UK government, the conventions outline individuals' civil, economic, political, social, and cultural rights, provide frameworks to guide legislation, policy, and practice, and specify standards against which progress towards implementation can be measured. Through Articles 23 and 31, the UNCRC requires signatories to recognise and promote children and young people's right to participate in leisure, encourage the provision of appropriate and equal opportunities to participate, and create conditions that ensure active participation. Through Article 30, the UNCRPD emphasises the requirement to ensure that children and young people with neurodisability have equal access with other children to participation in leisure.

This research programme was situated within the more immediate policy context of the UK, and primarily England. The UNCRC and UNCRPD form a key part of the policy landscape for UK legislation within which support for participation in leisure is delivered to children and young people with neurodisability. A comprehensive overview of UK, and specifically English, social policy is beyond the scope of this brief introductory chapter. However, one key feature can be usefully summarised as part of setting the scene for the thesis. Across government legislation, regulations, and programmes, support for participation in leisure of children and young people with neurodisability is largely situated within the 'short breaks' arena. Short breaks encompass, but are not limited to, services commonly known as ‘respite’, and are defined as:

> A range of services which are designed to support parent carers to be better able to continue to care for their children, and to do so more effectively; and services which support disabled children to enjoy different experiences, develop new skills and help them to achieve their ambitions in life. Short breaks services can include day-time or overnight care in the home or elsewhere, educational or leisure activities outside their homes, or services to assist parent carers in the evenings, at weekends and during the school holidays (50 p.5).

Children and young people’s legal entitlement to support for participation in leisure (in the form of short breaks) is enshrined in, amongst others, the Chronically Sick and Disabled Person’s Act 1970, and the Children’s Act 1989. Importantly, the onus in England for implementing these entitlements lies primarily with local authorities as opposed to the NHS. Local authorities are therefore where most of the statutory funding, workforce, and interventions for supporting participation in leisure are located. This paradox of participation in leisure as a health outcome, but support for participation in leisure sitting outside the NHS, may explain, in part, why the role of the NHS in supporting participation in leisure of children and young people with neurodisability is unclear.

1.4 Allied Health Interventions for Supporting Participation in Leisure

Allied health professionals, specifically occupational therapists, physiotherapists, and speech and language therapists, are a key group of practitioners working with children and young people with neurodisability, and are largely employed within the NHS.[1] Through their interventions, these practitioners have an opportunity to enable and increase leisure participation for children and young people with neurodisability. To achieve this, there is a need for interventions that:

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[1] I recognise that some allied health professionals are employed by local authorities, housing associations, schools and education settings, voluntary sector organisations, and private practices. This research is also relevant to them. However, I use the term NHS throughout the thesis both as a shorthand and to reflect that the NHS is where most allied health professionals are employed.

- Are directed towards relevant and useful leisure participation outcomes,
- Target the factors that explain participation in leisure,
- Are specific enough to be evaluated for effectiveness and cost-effectiveness, and replicable enough to be subsequently implemented,
- Can be delivered within the NHS in ways that are acceptable and feasible to key stakeholders.

In terms of actually delivering interventions to support participation in leisure, the allied health workforce faces several problems. To date, there is limited understanding and agreement within allied health regarding what participation in leisure as a health outcome means, what it looks like, and how it should be operationalised and measured. This has made it difficult to establish what exactly allied health interventions should try to achieve with children and young people (11).

There are also few existing allied health interventions that primarily and explicitly target participation in either leisure or other life situations (51-55). Those that are available were developed and piloted in healthcare settings that bear limited resemblance to the NHS, and/or have – at best – preliminary evidence of their potential effectiveness in those settings (52, 56-60). For example, Willis and colleagues described an intervention to support participation in active physical leisure activities in which children, young people, and parents stayed at a rehabilitation centre in Norway for almost three weeks and took part in physical, social, and cultural activities for six days per week (56, 57). In their Australian study, Imms and colleagues described a group-based intervention delivered weekly over eight weeks and involving administration of eleven standardised instruments, none of which are implemented as part of routine allied health practice in the NHS (60). Key stakeholders, including practitioners, parents, children and young people, and funders therefore have limited evidence-based intervention options from which to choose.

In terms of existing allied health interventions that were originally developed for health outcomes beyond participation, there is little evidence that they have any knock-on positive effects related to participation (51, 52, 61). This is likely to be because of the interventions' underlying causal mechanisms. Most current allied health interventions primarily target children and young people's impairments (e.g. problems with muscle strength or coordinated movement), skills (e.g. related to mobility or activities of daily living), or physical environment (e.g. home or classroom accessibility) (54, 62, 63). However, evidence is converging that, in order to change participation outcomes, it is necessary to target causal mechanisms related to children and young people's personal factors (i.e. features of the individual child such as their goals, emotions, or self-efficacy), and social environment (i.e. features of the surrounding people, processes, or social structures, such as the attitudes and actions of others) (15, 17, 34, 42, 64, 65).

Additionally, allied health interventions typically lack clarity on their content. Their 'active ingredients' – the discrete, observable techniques within the interventions that are designed to alter or redirect causal processes – are often poorly specified (66-69). For example, it may not be clear whether an intervention is primarily focused on providing information, or whether it contains additional techniques such as setting goals, providing practical support, or problem solving. Such uncertainty makes interventions difficult to replicate in formal evaluation studies or implement routinely in NHS settings.

Finally, the acceptability and feasibility of delivering allied health interventions for participation in leisure from within the NHS is unknown. Allied health professionals have adopted participation, including in leisure, as a key intended outcome of their interventions, and have claimed a stake in reducing participation restrictions (11, 12, 70). However, as I outlined above, much of the statutory support for leisure is currently located outside the NHS and within local authorities, and health professionals in general have not regarded leisure as an NHS priority. Further systematic investigation is needed to establish whether and how allied health interventions for supporting participation in leisure could be delivered in ways that are acceptable and feasible to the key stakeholders.

There are 111,467 occupational therapists, physiotherapists, and speech and language therapists registered with the UK Health and Care

Professions Council.[2] The number working specifically with children and young people with neurodisability is unknown. However, the Specialist Section for Children, Young People, and Families, and the Association of Paediatric Chartered Physiotherapists are two of the largest professional networks at the Royal College of Occupational Therapists and Chartered Society of Physiotherapy respectively, and the Royal College of Speech and Language Therapists' Clinical Excellence Networks related to neurodisability are well-established nationally. Therefore, it can be assumed that a significant proportion of the allied health workforce are supporting children and young people generally, and those affected by neurodisability specifically. By moving their interventions closer towards evidence-based practice, and potentially working in partnership with the statutory short breaks support provided within local authorities, the allied health workforce is well-placed to optimise participation in leisure of children and young people with neurodisability, and ultimately improve their health outcomes.

1.5 Clarifying Terminology

There are different views on how to describe disability. Two prominent positions are disability-first or identify-first language (i.e. 'disabled children and young people'), and person-first language (i.e. 'children and young people with neurodisability'). Kenny and colleagues provide a useful overview of the history and politics of terminology to describe disability, both in general and particularly in the context of autism (71). In their research on preferred terms for autism amongst members of the UK autism community, they found that there is not one preferred term, and that preferences vary according to people's beliefs about autism and their individual circumstances (71).

Throughout this thesis, I use both disability-first and person-first language. Following the World Health Organization's International Classification of Functioning, Disability, and Health, and Morris and colleagues, when I use the term 'disabled children and young people' I am reflecting the position

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[2] https://www.hcpc-uk.org/resources/data/2018/registrant-snapshot-november-2018/

that ‘disability is created as a consequence of interaction between a person and their environment. Disability cannot be considered as intrinsic to the person’ (2 p.1104, 8). When I use the term ‘children and young people with neurodisability’ I am describing ‘people ‘with’ or who ‘have’ specified characteristics, such as impairments or specific diagnoses,’ in this case a neurodisability, i.e. a congenital or acquired long-term condition that is related to impairment of the brain and/or neuromuscular system (2 p.1104).

2 Chapter 2. Conceptual Framework and Overall Research Design

The purpose of this research programme was to develop an allied health intervention to support participation in leisure of children and young people with neurodisability. In the previous chapter, I described the wider context for the research, including an overview of childhood disability in the UK, relevant social policy, and the key problems with current allied health interventions. In this chapter I will present the conceptual framework for the research, my specific objectives, the overall design and methods, and the structure of the thesis. I will then describe the particular population of children and young people with neurodisability on which the research programme focused.

2.1 Conceptual Framework

In this research programme, the key concepts of interest were the health outcome of participation in leisure, the personal and social environmental factors that influence participation in leisure, and allied health interventions, specifically the 'active ingredients' or discrete, observable techniques within the interventions that are designed to alter or redirect the causal mechanisms of participation (67, 68). To describe and organise these concepts within the research, and think about their interrelationships, my overarching conceptual framework was the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) (8). The ICF integrates biomedical, personal, and environmental perspectives on health, and is commonly used to investigate participation of children and young people, including those with neurodisability. It provides a shared multidisciplinary language for naming and describing health outcomes and related factors. However, with regards to developing interventions, the ICF can be further strengthened by using theory and evidence about behaviour change (72-75).

The ICF defines participation as involvement in life situations (8). However, this definition has been variously interpreted and there is not yet consensus on how participation can best be specified and measured (52, 76-78). In some contexts, participation outcomes have been described as a ‘conceptual maze’ offering little clarity for stakeholders about the intended purpose of interventions (64 p.1). Broadly, participation is agreed to include subjective aspects (e.g. a person’s sense of involvement, engagement, or satisfaction whilst performing activities within life situations), and objective aspects (e.g. how frequently activities are performed in life situations) (32, 78-80). In terms of participation in leisure specifically, the subjective aspects for children and young people with neurodisability are increasingly well-understood. Recent research has highlighted that, as with children and young people generally, for those with neurodisability participation in leisure means opportunities to explore, have friendships, experience a sense of freedom, control, and fulfilment, and – ultimately – have fun and enjoy themselves (32, 35, 42, 81). However, the objective aspects of greatest importance are less clear. It is understood that interventions should support children and young people to attend leisure settings and activities, but there is limited agreement beyond attendance (78). For example, should interventions focus on frequency or intensity of attendance, types, diversity, or average number of leisure activities undertaken, or some other purpose? Conceptualising participation in leisure as a health behaviour and using behaviour change theory and evidence to specify its objective aspects provided a constructive way forward for developing an intervention within this research programme (82-84).

Theory and evidence about behaviour change can also strengthen the ICF by informing how personal factors, social environmental factors, and allied health interventions are conceptualised, and providing specific content for interventions. Specially, I drew on the refined version of the Theoretical Domains Framework (the TDF), an integrative framework of theories of behaviour change developed in the fields of psychology and health services research (85). The TDF has been previously used for similar purposes in allied health intervention research (e.g. 75). According to the ICF, personal factors are internal features of individual child or young people that are not part of their health condition or health state, and that play a role in their experience of disability (8). The ICF does not systematically classify personal factors, placing an added consideration on its use in the context of participation intervention development (86). Evidence-based constructs from the TDF (e.g. goals, emotions, self-efficacy) can be helpfully used to theorise personal factors and specify the role they may play as causal mechanisms of participation in leisure (85). The understanding of the role of social environmental factors classified within the ICF (e.g. support and relationships, social attitudes) can also be enhanced by tying the specific factors to well-established constructs from behaviour change theory that are included in the TDF. For intervention content, I drew on the Behaviour Change Techniques (BCT) Taxonomy v1, an extensive taxonomy of 93 distinct BCTs that can be used as a method to specify interventions (67).

2.2 Research Objectives

My aim in the research programme was to develop an allied health intervention to support participation in leisure of children and young people with neurodisability. With a conceptual framework integrating theory and evidence about health, disability, and behaviour as my starting point, my intention was to work with experienced stakeholders to:

1. Develop a relevant and useful definition of participation in leisure as a health outcome,
2. Identify modifiable personal and social environmental factors that influence participation in leisure,
3. Specify intervention techniques for supporting participation in leisure,
4. Establish the extent of stakeholder consensus about the potential effectiveness of the intervention techniques,
5. Generate descriptions of acceptable, feasible ways for allied health professionals to deliver the intervention techniques in NHS settings.

2.3 Epistemological Standpoint

This research programme was based on a real-world problem: children and young people with neurodisability are more restricted in their participation in leisure than their non-disabled peers and, whilst allied health professionals in the NHS are well-positioned to support participation, they have limited evidence-based intervention options from which to choose. The epistemic aim of this research was to generate knowledge that could usefully inform allied health practice and potentially improve health outcomes for these children and young people. My primary orientation was therefore towards a pragmatic research philosophy, in that I was seeking practical insights and solutions to a concrete problem (87). However, my intention was also to contribute to theorising this problem by doing two things. I wanted to enhance understanding of participation in leisure as a health outcome by going beyond individual children and young people's subjective experiences and meanings of participation and saying something about how participation is commonly and objectively enacted across children and young people as a whole. I also wanted to identify the personal and social environmental factors (i.e. causal mechanisms) that explain variance in participation across diverse populations and leisure contexts.

To ensure the research made a theoretical contribution, I drew on the perspective of realism because it assumes that reality exists independently of individuals' perceptions, that the world is patterned and knowable, and that underpinning causal processes can be studied and explained (87). My research methods borrowed from realist evaluation in that I used realist approaches to qualitative interviewing, generated a programme theory, and was closely attuned to the interplay between context, mechanisms, and outcomes (88-90). However, I did not attempt to go so far as explaining what works, for whom, in what circumstances, and to what extent, and therefore I do not claim that this research constituted a realist evaluation (90, 91).

Both pragmatic and realist inquiry frameworks are conducive to mixed methods approaches. In designing the research programme, I was inclined towards mixed methods because of the fundamental principle that quantitative and qualitative methods are good for different purposes, have strengths that can compensate for each other's weaknesses, and can be successfully integrated to build a more complete picture of a research problem (92-94). For example, I anticipated that the existing quantitative evidence would contribute to knowledge about the relative influence on participation of various personal and social environmental factors, but that relying on a single research method would have disadvantages for causal inference because of the weaknesses of many quantitative study designs (94). Qualitative methods would provide a more in-depth and contextualised understanding of whether and how causal mechanisms of participation play out for various populations of children and young people and in different contexts.

As part of a mixed methods approach, I was conscious that experienced stakeholders – including children and young people with neurodisability – would have considerable epistemic resources to bring to the research programme, in the form of diverse professional and lived expertise, tacit knowledge, and implicit theories about the research problem (95). I believed that wide stakeholder engagement would ensure the research generated knowledge that was congruent with real-world contexts, and produced an acceptable and feasible intervention that could subsequently progress to formal evaluation (66, 96-98). These could be described as the substantive values that I held about how involvement of diverse stakeholders would improve the quality, relevance, and impact of the knowledge created in the research (99). I was also committed to enacting and embedding diverse stakeholder involvement as an ethic throughout the research process (99, 100). My understanding of what this might mean and how it could be achieved was shaped by a number of factors: my prior experience as an NHS allied health professional trying to work collaboratively with children and young people with neurodisability and their parents, my engagement with literature on participatory and inclusive methods of producing knowledge (e.g. 101, 102-104), critical accounts of how public and patient involvement in research may be subverted (e.g. 105, 106-108), and the new stakeholder relationships that I developed throughout the research programme, particularly with young people, parents, and practitioners from non-NHS contexts.

2.4 Broad Methodological Approach

The design for the research programme was based on the UK Medical Research Council's (MRC) guidance for developing and evaluating complex interventions (66). Broadly, complex intervention development is concerned with identifying the evidence base for an intervention, selecting or generating theory to explain how it might work, and modelling its process and outcomes (66). The initial development stage lays the groundwork for subsequent feasibility and pilot testing, evaluation, and implementation, although it is well-established that this overall process is usually cyclical and iterative rather than linear (66, 96, 109, 110). I recognised that an intervention for supporting participation in leisure of children and young people with neurodisability was likely to be complex for several reasons and that these would need to be addressed in the earliest stages of intervention development.

Earlier in this chapter I outlined the notion of participation as a multi-dimensional health outcome, and this was one important dimension of complexity to consider. In terms of research design, it was a priority to define participation in leisure in terms that were relevant and useful for stakeholders, and would enable exploration of outcome measurement in future feasibility and pilot studies (66, 80). A further source of complexity was the number and variability of personal and social environmental factors that may be identified as causal mechanisms of participation in leisure. It was important to clarify and build on what was already known about causal processes, as this would explain how an intervention might work, shape its content, and guide the design of future process evaluations to understand its effectiveness and implementation (66, 111-114). The content of the intervention also introduced complexity in that it was likely to consist of multiple discrete intervention techniques that interact both with causal mechanisms of participation and with each other. The evidence for the potential effectiveness of these techniques needed to be understood, and they needed to be described clearly enough to enable replication for future evaluation and implementation (66-68).

Finally, context contributed to complexity as contextual factors may influence (and be influenced by) whether and how interventions are implemented, towards whom they are directed, and whether their causal mechanisms act as intended (112). As well as shaping interventions and causal mechanisms, contextual factors may also be considered intervention targets in their own right (112). However, intervention development research – including in childhood neurodisability – has tended not to take context into account and instead has emphasised factors at the level of individual and their immediate environment, despite recommendations that interventions may be more effective if they simultaneously target multiple factors at different levels (114-116). This research programme therefore needed to describe contextual factors clearly and outline how they may interact with an intervention for supporting participation in leisure.

2.5 Methods and Structure of the Thesis

This research programme took the form of a sequential mixed methods design, starting with a systematic review (QUANT) followed by a three-stage mixed methods Delphi study (QUAL → QUANT+qual → QUAL):[3]

- The systematic review focused on the quantitative evidence for personal and social environmental factors explaining participation in leisure (research objective 2).
- Within the three-stage mixed methods Delphi study, Stage 1 involved focus groups, semi-structured interviews with adult stakeholders, and ‘go-along’ interviews[4] (117) with children and young people with neurodisability and their parents. The focus was on developing a definition of participation in leisure as a health outcome (objective 1), further exploring personal and social environmental factors (objective 2) and specifying intervention techniques (objective 3).
- Stage 2 involved two rounds of an online survey with parents, multidisciplinary practitioners, and researchers. The focus was on establishing the extent of stakeholder consensus about the

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[3] In this present section I describe the methods as a systematic review and a three-stage mixed methods Delphi. However, in the abstract for this thesis I described the methods as a systematic review, a qualitative study (focus groups, semi-structured interviews, go-along interviews, and a workshop), and an online Delphi study. Later in the thesis, in section 10.7, I explain why I decided to reframed the primary research.

[4] ‘Go-along’ interviews are where the researcher and interviewee go together to a predetermined location relevant to the research objective. This type of interview aligns with participant observation, but differs from observation in that the researcher interacts more with both the participant and the setting (117).

potential effectiveness of the intervention techniques (objective 4), and generating descriptions of acceptable, feasible ways to deliver the techniques (objective 5).

- Stage 3 involved a co-design workshop with multidisciplinary practitioners to further explore how allied health professionals could deliver the intervention techniques in NHS settings (objective 5).
- Young people with neurodisability and their parents helped to prepare the grant application for the research programme and were involved throughout research process. I worked closely with advisors from a parent-led support group, and a group of parent carers who are interested in research and collaborate with a childhood neurodisability research centre. I also conducted two co-production projects that contributed to the data analysis and interpretation and dissemination – one project was with a parent, and one was with a group of young people with neurodisability.

2.6 Study Population

The research programme focused specifically on children and young people with communication and mobility limitations, aged 8-12 years. In chapter 1 I introduced neurodisability as one of the largest groups of disabled children and young people in the UK. Within neurodisability, children and young people who experience marked and co-occurring limitations are at particular risk of restricted participation in leisure (36-38, 118, 119). When considered separately, communication and mobility limitations are both relatively common amongst disabled children and young people. As I highlighted in chapter 1, the Family Resources Survey (FRS) is an annual UK government survey that collects information about the incomes and living circumstances of a representative sample of private households. It is a key source of information about disabled children and young people and the limitations they experience. A secondary analysis of FRS data from 2004-05 estimated that 29% of male children and 22.8% of female children experience communication limitations and 20.7% of male children and 21.1% of female children experience mobility limitations (46). The Annual Report in 2012 of the Chief Medical Officer for England used

FRS figures for 2010-11, which estimated that 22% of disabled children and young people experience communication limitations and 18% experience mobility limitations (1) More recently, the FRS analysis for 2016-17 did not include a discrete category for communication limitations, but estimated that 22% of disabled children and young people experience mobility limitations (5). These three citations describe communication and mobility limitations as being two of the most common limitations experienced by disabled children and young people and they paint a picture of their relatively high prevalence. However, published FRS data does not allow for estimates to be made of co-occurring communication and mobility limitations. Blackburn and colleagues' secondary analysis of FRS data from 2004-05 identified that 35.2% of disabled children and young people experienced two to four limitations and 13.3% experienced limitations in five or more areas (46). A slightly more recent population-based study conducted in Canada found that around half of children and young people with neurodisability experienced limitations in three or more areas (120). These analyses do not allow the number of individuals experiencing both communication and mobility limitations specifically to be quantified. However, they do suggest that it is likely to be a significant proportion of disabled children and young people overall, given the prevalence of communication and mobility limitations separately, and that such a significant proportion of disabled children and young people are thought to experience multiple co-occurring limitations.Additionally, the age range of 8-12 years is a potentially important window for participation support. At this age children and young people in the general population tend to less often spend leisure time with family, and more often spend time talking and doing activities with friends (121, 122). Typically they become more independent in their participation, with parents acting primarily as supporters in terms of transport, finances, and logistics, as opposed to direct facilitators of their children's leisure (123). In this developmental context, the combined impact of communication and mobility limitations plus less direct parental involvement in activities manifests as a widening participation gap between children and young people with neurodisability and their non-disabled peers (123). Therefore, children and young people with both communication and mobility limitations aged 8-12 years are an important group in particular need of participation support and were the focus of the research programme.

I did not focus on particular health conditions such as cerebral palsy or autism, because diagnosis alone does not predict support needs or health outcomes and children and young people with different health conditions share many common experiences of health and disability, including participation and participation restrictions (8).

2.7 Structure of the Thesis

In chapter 3 I will report the methods and results of the systematic review of personal and social environmental factors explaining participation in leisure and consider how the findings compare with wider evidence. In chapter 4 I will set out the methods for the three-stage Delphi study, and discuss the strengths and weaknesses of its design and execution. Chapter 5 presents a definition of participation in leisure as a health outcome. Chapter 6 focuses on personal factors related to participation in leisure, reporting the qualitative results from the Delphi study and bringing them together with the quantitative results from the systematic review. Similarly, chapter 7 brings together the qualitative and quantitative results for social environmental factors. In chapter 8 I will report on intervention techniques for supporting participation in leisure, the consensus amongst stakeholders about their potential effectiveness, and acceptable and feasible ways in which they can delivered. Chapter 9 describes and reflects on the two co-production projects with a parent and young people. Finally, in chapter 10 I will summarise the results, consider the implications for key stakeholder groups, highlight the strengths and weaknesses of the research, and reflect on how I have framed and conducted the overall research programme.

3 Chapter 3. A Systematic Review of Personal and Social Environmental Factors Explaining Participation in Leisure of Children and Young People with Communication and Mobility Limitations

The overall aim of this research programme was to develop an allied health intervention to support participation in leisure of children and young people with communication and mobility limitations, aged 8-12 years. In the previous chapter (chapter 2), I highlighted the importance of identifying an explicit theoretical basis when developing a complex intervention. Clarifying the causal mechanisms hypothesised to underpin participation in leisure would help to shape the content of the intervention and enable a better understanding of whether and how it might work across different contexts and populations (66, 109, 113). In chapter 1, I introduced the rationale for focusing on personal and social environmental factors. These factors potentially explain variance in participation in leisure, but their large number and variability means that a review of the existing evidence would be helpful to clarify what is currently understood about their relative importance.

If a systematic review of relevant evidence is not already available, one is commonly undertaken as part of developing a complex intervention (109, 124). When I embarked on this research programme, I was aware of multiple existing reviews of factors influencing participation of children and young people with neurodisability, either in leisure or in other life situations. However, their usefulness as a theoretical basis for intervention development was limited for three key reasons: (i) they did not include and/or report a quality assessment of included studies, so risks of bias and confounding could not be understood (125-132), (ii) they included only specific populations of children and young people with neurodisability, such as those with cerebral palsy or acquired brain injury (133, 134), and/or (iii) their results were presented as broad, high level factors related to participation, as opposed to more granular factors that could be targeted by an intervention (135).

A further systematic review identified factors that hinder or facilitate physical activity in children and adolescents with physical disabilities.

However, its focus was on habitual physical activity across life situations, as opposed to participation in leisure specifically (136). Additionally, Shields and colleagues investigated the perceived barriers and facilitators to physical activity of disabled children, which included participation in physically active leisure and active play (137). Whilst the authors usefully identified a high volume and wide range of factors, the review did not go so far as ascertaining the relative importance of the factors, making it challenging to use the results as a basis for intervention development.

In the context of the existing evidence, a systematic review was therefore justified to inform this research programme. The review question was: what modifiable personal and social environmental factors either determine or are associated with participation in leisure of children and young people with communication and mobility limitations aged 8-12 years, and what is the quality of the supporting evidence? This reflected research objective 2 (see chapter 2).

3.1 Methods

I conducted a systematic review using established procedures to search for, appraise, and synthesise the research evidence (138, 139). The protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO 2015 CRD42015027769) and the methods are reported in line with established guidelines (140).

3.1.1 Inclusion criteria

I included studies of any language and publication status meeting all the criteria below. No further exclusion criteria were implemented.

- At least some children had communication and mobility limitations and were aged 8-12 years. Communication limitations were understood as problems related to children’s capacity for sending or receiving messages with different types of conversational partners, and/or carrying on or pacing conversations (76, 141). Mobility limitations were understood as problems related to children’s capacity for walking, such that they use a hand-held mobility device in most settings, use a self-propelled or powered wheelchair, or are transported in a manual wheelchair (142).

- At least one of the outcomes reported related to participation in leisure, i.e. children’s involvement in discretionary activities or settings outside of education or school hours, self-care, and domestic life. In accordance with the conceptual framework for the research programme, the focus was on observable frequency, intensity, or diversity of participation, or attending or accessing leisure settings or activities.
- At least one specific personal factor or social environmental factor, hereafter referred to as exposures, had been reported. The focus was on exposures that could be modified through allied health interventions in publicly funded community healthcare settings.
- Relationships between outcomes and exposures had been investigated using randomised controlled trials, non-randomised controlled trials, observational studies (i.e. before-and-after studies, interrupted time series, cohort studies, case-control studies, cross-sectional studies, case series, and case studies), or mixed methods studies. The focus was on quantitative designs that quantified the effects and clarified the relative strength of different exposures.

3.1.2 Search strategy

The search strategy was structured around three core concepts: (i) children with neurodisability, (ii) participation, and (iii) leisure. Key words for each concept were coupled with relevant medical subject heading (MeSH) and thesaurus-controlled standard terms, where available. Search terms within each concept were combined using the Boolean operator ‘OR’, and results within each concept were combined using ‘AND’. The search strategy was developed in MEDLINE and translated to other bibliographic databases (see Appendix A). All key words and terms were truncated as appropriate and variant spellings were used. Sensitivity was prioritised over specificity to ensure inclusiveness. Searches were conducted in November 2015 and results were limited to records published since 2001 when the concept of participation was introduced as a component of health in the World Health Organization’s International

Classification of Functioning, Disability and Health (8). The sources included in the search strategy and specific dates for conducting the searches are summarised in table 3-1.[5]

3.1.3 Screening and selection of studies

All records were imported into a bibliographic referencing software programme (EndNote X7, Thomson Reuters, San Francisco, CA, USA) and de-duplicated. I screened the titles of all records (143), excluded those clearly not meeting the population and/or outcome inclusion criteria, and pooled the remaining records with those retrieved from hand searching. Two reviewers (JM and NK/AC) independently screened a random sample of 20% of titles and abstracts, after which the screening decisions were discussed, decision rules were clarified, and I screened those remaining. Two reviewers (JM, NK) independently screened all full-text records, discussed screening decisions, resolved disagreements, and recorded reasons for exclusion. In particular, reasons for excluding records only narrowly failing to meet the inclusion criteria were documented. Where required, I contacted authors at least once to request copies of abstracts or full texts. Where available, I retrieved published protocols of included full-text records.

3.1.4 Quality assessment

Two reviewers (JM, MS) independently assessed all included studies and agreed final judgements about study quality. We used a published algorithm to classify study designs, enabling us to highlight risks of bias and confounding associated with particular designs (144-146). From conducting scoping searches in August 2015, I anticipated that most of the included study designs would be cross-sectional. Therefore, in the absence of a gold standard quality assessment tool (144, 147-149), I used existing tools to create a checklist of fifteen questions for assessing the risk of bias and confounding (149, 150) and generalisability (47, 151) in observational studies (see table 3-2). The checklist was used as a basis

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[5] Throughout the thesis, all tables and figures are included at the end of their respective chapters in the order in which they appear in the main text.

for critical discussion between reviewers and transparent reporting of judgements about study quality, and did not use numerical rating systems or overall quality scores (138, 144, 147, 150, 152-157). I specified two potential confounders that should be controlled for in the analyses in the included studies: children's movement-related impairments, and socio-economic status (e.g. family income, parent or caregiver education) (17, 28, 41, 119, 158-160).

3.1.5 Data extraction

A Microsoft Excel data extraction spread sheet was agreed amongst the review team and piloted on two included studies. The following data were extracted: publication details (first author, year, type of publication, source of funding), country, setting, study design features (aim, inclusion/exclusion criteria, sampling strategy, sample size calculation, target/actual sample size, rationale for selection of exposure constructs, method of data analysis), and participants' characteristics (age, sex, communication and mobility limitations, intellectual disability). All outcomes and exposures were extracted verbatim, along with their related measures. These were systematically included or excluded in the review according to whether they met the definitions in the inclusion criteria and had been analysed in relation to an exposure or outcome of interest, respectively. Three reviewers (JM, NK, and AC) discussed inclusion/exclusion decisions and resolved disagreements. Point estimates (i.e. uni- and bivariate correlation coefficients, unstandardised and standardised regression coefficients, odds ratios etc.) quantifying the relationship between individual outcomes and exposures were extracted from the final statistical models reported in the studies, along with related confidence intervals (where available), and p-values. Where reported, both total scale scores and subscale scores on the measures of exposures were extracted. For studies including both children with and without disabilities, only data for the former were extracted.

3.1.6 Data synthesis

Meta-analysis was not appropriate due to heterogeneity in definition and measurement of outcomes and exposures, heterogeneity in how point estimates were calculated (i.e. a mixture of unstandardised and standardised regression coefficients, odds ratios, incident rate ratios), and variability in reporting of point estimates and confidence intervals. This variability also meant that it was not possible to compare effect sizes of different individual exposures. Instead, the direction and consistency of associations between outcomes and exposures were evaluated semi-quantitatively (161-163).

First, conceptually similar exposures were grouped into categories and the categories were mapped onto specific, defined constructs from the conceptual framework for the research programme (e.g. emotions, beliefs about capabilities, attitudes) (8, 85). Next, the exposures within each category were coded as positively (+), negatively (-), or not (0) associated with participation in leisure, based on the direction of association and statistical significance reported in the studies (i.e. p≤0.05). Then, for each category, I calculated the percentage of studies supporting an association with participation in leisure and generated a summary code describing the category's overall direction and consistency of association with participation in leisure:

- Where 0-33% of studies supported an association, the summary code was 0 indicating no association,
- Where 34-59% of studies supported an association, the summary code was ? indicating inconsistent association,
- Where 60-100% of studies supported an association, the summary code was + indicating a positive association, or – indicating a negative association,
- Where three or more studies supported no association or an association, the summary codes were 00, ++, or --,
- Where ≥4 studies found inconsistent associations, the summary code was ??.

To strengthen the causal inferences that could be drawn from the body of evidence, I included only results from multivariate analyses, or bivariate analyses that investigated associations between the outcome and at least one of the potential confounders.

3.2 Results

3.2.1 Overview of included studies

Screening and selection are summarised in figure 3-1 (page 40). From the database searches I identified 36,960 potentially relevant records, of which 25,192 remained after duplicates were removed. Screening of titles resulted in exclusion of a further 24,346 records, and the remaining 846 records were pooled with 208 records identified through hand-searching. Therefore, a total of 1,054 records were subjected to title and abstract screening. Of these, I excluded 944 and assessed the remaining 110 records using their full-texts. I excluded 83 of the 110 full-text records because they did not meet the inclusion criteria or could not be retrieved. I excluded a further six of the 110 full-texts because they narrowly failed to meet the inclusion criteria for two reasons: (i) they used a summary measure of the environment, as opposed to investigating specific environmental factors, which limited their application to specifying intervention targets (164-167), or (ii) they included few children with communication and mobility limitations among many children with asthma, diabetes, developmental delay, or autism (168, 169). Eighteen of the 110 full-text records were included in the review, and I retrieved their related protocol or data quality papers for reference purposes (73, 170, 171). The remaining three of the 110 full-text records focused on participation interventions and were not included in the data synthesis but were informally reviewed separately to support intervention development in the wider research programme (172-174).

Reference list screening of the 18 included studies yielded no additional relevant records. The included studies were published between 2005 and 2015 and conducted in Canada (n=8), the United Kingdom (n=3), Australia (n=2), the United States (n=2), the Netherlands (n=1), Japan (n=1), and across nine European regions (n=1) (see table 3-3).

3.2.2 Quality of included studies

The quality assessment is summarised in table 3-3. Seventeen (17/18) of the included studies were cross-sectional, which limits the causal inferences that can be drawn from this body of evidence. The remaining study used a prospective cohort design to investigate personal and social environmental factors associated with decline over time in children's participation in leisure (175). Across the studies, the main risks to validity were as follows: (i) selection bias, arising from lack of representativeness of the study populations, and potentially influencing the generalisability of results and estimates of association (176), (ii) confounding, particularly arising from non-adjustment for socio-economic status, and (iii) detection bias, arising from variable reliability and validity of measurement instruments, and subjective reporting of outcomes and exposures. The potential extent of reporting bias could not be clearly determined as only three studies had a published protocol (65, 74, 177). However, all the studies reported results for all the outcomes and exposures included in their analyses.

Variable quality of reporting made it difficult to screen studies and extract and interpret results, all of which significantly prolonged the length of the review. Variable reporting of population characteristics meant that I could not, as I had intended, extract data only for children with communication and mobility limitations. Personal and social environmental factors were usually not defined, which made them difficult to categorise based on their conceptual similarity. Instead, the individual items in their related measurement instruments were reviewed and practical judgements were made about similarities between factors. The validity of exposure measures for the study populations in which they were administered was often unclear. Most studies provided a rationale for selection of exposures, but explicit theoretical frameworks underpinning hypothesised relationships with outcomes were variably articulated. Sample size calculations and statistical results were often not clearly reported. For example, there was very little reporting of confidence intervals, limited reporting of values for point estimates not reaching statistical significance, and in several studies, it was unclear whether regression coefficients were standardised or unstandardised. In addition, multiple publications arising from the same study were often not explicitly cross-referenced, which necessitated considerable detective work to identify related studies and compare them for duplication.

3.2.3 Study samples

The 18 included studies comprised 13 independent samples of children and 3,894 participants in total (see table 3-3). Across the 13 study samples, participant sex could be determined in all but one (74), and 53.23% (n=1,969/3,699) were male. The proportion of participants in specific age groups could be determined in nine study samples (65, 74, 178-184) and 81% (2,041/2,397) were aged 5-13 years. Otherwise, mean ages ranged from 10 years 2 months to 15.4 years (185-188). Communication limitations were variably described and more difficult to identify than mobility limitations, and were not reported for four study populations (182-185). The proportion of children with communication limitations, 63.3% (1,896/2,995), was clear in seven study samples (65, 74, 178, 180, 181, 187, 188). Mobility limitations were reported in 11 studies, with 67.3% (2,136/3,175) of participants described as functioning at GMFCS levels III-V (65, 74, 142, 178, 180-185, 187, 188).

3.2.4 Outcomes

Across the 18 studies there were 33 separate outcomes, measured using five standardised instruments and three study-specific questionnaires (see table 3-4). The relatively high number of outcomes can be attributed to the most common outcome measure, the Children's Assessment of Participation and Enjoyment (CAPE) (189). The CAPE was used in 11 studies to generate and measure 24/33 outcomes. Over half of the outcomes (18/33, 54.5%) were investigated in no more than one study. Nine outcomes (27.3%) were investigated in two studies, two (6.1%) were investigated in three studies, four (12.1%) were investigated in four studies, and one (3%) was investigated in five studies.

3.2.5 Exposures

Across the 18 studies there were 21 separate personal factors and 52 separate social environmental factors (i.e. 73 exposures in total), measured using 23 standardised instruments and five study-specific questionnaires and qualitative interviews. Conceptually similar exposures were grouped into n=16 categories and mapped onto specific constructs from the conceptual framework for the research programme (see table 3-5) (8, 85). The Strengths and Difficulties Questionnaire (SDQ) (190) was the most common exposure measure, used in 7/18 studies, followed by the Family Environment Scale (FES) (191), used in 5/18 studies. Most of the exposures (65/73, 89%) were investigated in no more than one study.

3.2.6 Personal factors

There were four categories of conceptually similar personal factors: child emotions, preferences for activities, beliefs about capabilities, and motivation (see table 3-6). Associations between emotions and participation in leisure were inconsistent across ten studies (seven independent samples) (175, 177, 179-181, 185, 186, 188, 192, 193). The inconsistency may be in part attributable to heterogeneity in study samples, outcomes, the types of factors that were categorised together (e.g. emotional difficulties, trait emotional self-efficacy, and enjoyment), and measurement. However, this is unlikely to be the full explanation as associations remained inconsistent even when only studies using the same measures were considered (i.e. the CAPE for the outcome and the SDQ emotional symptoms subscale for emotions) (175, 179, 193).

Four studies (three independent samples) found a positive association between children’s preferences for particular activities, and their participation in those activities (175, 185, 188, 192). All four studies used the same measures (i.e. the CAPE for participation and the Preferences for Activities of Children, PAC, for preferences (189)). Between them, they investigated preferences in relation to 17 separate outcomes, identifying 13 statistically significant associations, all in a positive direction. No study provided a conceptual or operational definition of the construct of preferences. The PAC manual references the Oxford English Dictionary

(194) to define preferences as, ‘Liking for or estimation of one thing before or above another,’ and states that, ‘PAC scores reflect what children would do under ideal circumstances’ (189 p.2, p.62 respectively).

The category of beliefs about capabilities incorporated several closely related personal factors including perceived competence, self-esteem, and mastery motivation. Four studies (three independent samples) found a positive association with participation in leisure, and particularly with participation in active physical activities (179, 181, 182, 185). One study investigated the association between motivation and participation in leisure, and found no statistically significant relationship (74).

3.2.7 Social environmental factors

There were 11 categories of conceptually similar social environmental factors: parent emotions, beliefs about capabilities, beliefs about consequences, physical functioning, parent/family participation in leisure, demands and impact on the family of caring, family organisation, support and relationships, services, attitudes, and policies (see table 3-7). There were no multivariate results available for the twelfth category of parent goals.

Across four studies (three independent samples) associations were inconsistent between parent emotions and participation in leisure (175, 177, 181, 193). However, two of the studies investigated parenting stress specifically and both found a negative association with participation across two independent study samples (177, 181). In relation to parent beliefs about their capabilities to overcome barriers limiting the child’s participation, and about the consequences of participation, one study found no association reaching statistical significance with participation in physical play/leisure (74).

Two studies (one independent sample) found that better parent physical functioning was negatively associated with participation in leisure (175, 193). On the whole, parent/family participation in leisure was consistently positively associated with child participation in leisure across seven studies (74, 175, 180, 184, 185, 192, 193). The seven studies incorporated four out of the five independent study samples for this category, and in three of those four independent samples the same measures of outcome and exposure were used.

There was limited evidence for a relationship between the demands and impact on the family of caring and participation in leisure (181, 186, 192, 193). Only one out of four studies (three independent samples) found a negative association (i.e. greater demands and impact predicted less intense participation in informal activities) (181). However, this was a particularly heterogeneous category in that the instruments included measured a diverse range of positive and negative demands and impacts of caring, so this result should be interpreted with caution.

Of the two studies (two independent samples) investigating relationships between family organisation and participation in leisure (180, 185), one found a positive indirect association mediated by child adaptive behaviour (180). However, this result should also be interpreted with caution as values for family organisation were combined with those for other exposures not related to the present review, which meant that family organisation could not be considered discreetly.

Nine studies (six independent samples) investigated associations between support and relationships (in the context of the immediate family, extended family, friendships, peers, and teachers) and participation in leisure (65, 74, 175, 178, 179, 183, 185, 192, 193). On the whole, better support and relationships was consistently associated with greater participation, and poorer support and relationships – particularly with peers – with lesser participation particularly in social activities. In the services category, there was some conceptual overlap with support and relationships at the level of the individual items in the instruments used. Services was a particularly heterogeneous category covering exposures related to health, transportation, housing, and general services. This likely explains at least in part the inconsistent findings for services across five studies (four independent samples) (65, 175, 180, 181, 193). In the attitudes category there was also some overlap with support and relationships, and associations were inconsistent across two studies (one independent sample) (175, 193). Similarly, two studies (one independent sample) investigated associations between perceived barriers in the policy environment and participation in leisure, with inconsistent results.

3.3 Discussion

3.3.1 Summary of results

This systematic review attempted to quantitatively evaluate modifiable personal and social environmental factors determining or associated with participation in leisure of children with communication and mobility limitations, aged 8-12 years. Eighteen studies were included, comprising 13 independent samples of children and young people, and covering sixteen categories of conceptually similar modifiable personal and social environmental factors. Child preferences, child beliefs about capabilities, parent/family participation in leisure, and support and relationships were consistently positively associated with participation in leisure. There was some evidence of a negative association with parent emotions, specifically stress, and – counter-intuitively – parent physical functioning. Child motivation, parent beliefs about capabilities, parent beliefs about consequences, and demands and impact on the family of caring, were not associated with participation in leisure. Associations were inconsistent for child emotions, family organisation, services, attitudes, and policies. No multivariate results were available for parent goals.

3.3.2 Strengths and weaknesses of the review

The comprehensive and sensitive search strategy, double-screening of all full-text records, and independent quality assessment by two reviewers enhance the reliability of the results. The explicit mapping of categories of similar personal and social environmental factors onto the conceptual framework for the research programme clarifies and strengthens the review's theoretical basis. However, it is acknowledged that variability in reporting meant that several assumptions were made about the meaning and valid categorisation of many of the factors, and therefore the mapping is open to critique. There were four key limitations of the body of evidence included in the review: the majority of personal and social environmental factors were investigated in only one study, all but one of the included studies were cross-sectional, risks of selection bias and detection bias were identified in most studies, and risk of confounding by socio-economic status was identified in at least a third. The results of the included studies are also subject to the usual limitations associated with multivariate regression analyses (i.e. unknown confounders, unmeasured variables of importance, measurement error), which limit the causal inferences and generalisations that can be made (94). Nevertheless, the results complement existing knowledge in several ways, as described below.

3.3.3 How the results compare with wider literature

The positive association between child beliefs about capabilities and participation is consistent with results from a number of related reviews of participation outcomes published since this present review was conducted (161, 195, 196). Theoretically, beliefs about capabilities include constructs such as self-efficacy, self-confidence, and perceived competence (85). They have a strong wider evidence and theory base for their influential role across health behaviours and are therefore likely to be important in interventions for supporting participation in leisure (197). Importantly, the cross-sectional nature of the body of evidence included in this review highlights the possibility of bi-directional causation between child beliefs about capabilities and participation in leisure. Indeed, a recent intervention positioned child self-confidence as primarily an outcome, as opposed to predictor, of participation in physically active leisure (56).

The results for child preferences are also consistent with some (161, 196) but not all (195) of the more recent related reviews of participation outcomes. The manual for the Preferences for Activities of Children (PAC) that was used to measure preference in the included studies defines it pragmatically as a ‘liking or estimation for one thing before or above another’ (189 p.2). The ‘liking’ would seem to align with an existing, widely established theoretical construct of affective attitude (198), while ‘estimation for one thing before or above another’ would seem to better align with the well-established construct of goals (199). A more recent conceptual analysis defines preferences as ‘the interests or activities that hold meaning or are valued’ (200 p.5), which would also align with the construct of goals. To better understand the potential role of preferences as a causal mechanism of participation in leisure, and target preferences effectively within interventions, it would be helpful to further clarify its theoretical underpinnings and to differentiate it from other closely aligned constructs.

There is fairly consistent support in the wider literature for a positive relationship between parent/family and child participation in leisure (161, 201). In terms of parent emotions, it is well-established that parents and carers of children with disabilities are more likely to report higher levels of stress than parents of typically developing children (202, 203). Parent and carer health problems warrant preventative and therapeutic intervention in their own right, and are receiving attention in current ongoing intervention development research programmes (203). It is plausible that improved mental and physical health outcomes for parents may confer diffuse benefits on child outcomes, including participation in leisure. Support and relationships has been variously conceptualised across reviews of participation outcomes, although in general the evidence appears to consistently support a positive association (195, 196, 204).

3.3.4 Implications for future research

This review raises four key issues for future research. The first concerns the measurement of participation in leisure. The Children's Assessment of Participation and Enjoyment (CAPE) is the most commonly used measure of participation in childhood neurodisability, capturing several dimensions of participation across seven types of leisure activities, and generating multiple discrete outcome constructs, n=24 of which were included in the present review (28, 205-207). By generating so many outcomes, instruments such as the CAPE introduce challenges to cumulatively building and synthesising evidence about causal relationships in childhood neurodisability research. This is particularly the case when combined with the second key issue – a thin evidence base for modifiable determinants of health behaviours. The present review identified a relatively high number of potential determinants of participation in leisure, but the majority of these were investigated in no more than one study.

Additionally, it is clear that related reviews of causal mechanisms of participation outcomes conceptualise and categorise personal and social environmental factors quite differently, with variable and sometimes limited or no mapping of conceptually similar factors onto existing theoretical constructs that have an established evidence base (136, 137, 161, 195, 196, 201). To progress beyond such heterogeneity, the childhood neurodisability field would benefit from significantly more engagement in wider theory and evidence, including but not limited to health behaviour change. This would enable a more cumulative and efficient approach to building evidence about effective interventions for supporting population health, for example by using established theory to inform the selection of explanatory variables in future analyses, interpret the results about their relationships with health outcomes, and build theoretically sound and comparable interventions.

The third issue for future research concerns population sampling and reporting. Only two of the 13 independent study samples included in the review could be determined as representative, to at least a partial extent, of their broader target populations (65, 178). Representative study samples are important for building a more informative and reliable picture of the circumstances of children with neurodisability, but are challenging for researchers to achieve (208). Collaboration with practitioners, policymakers, and families is central to progressing this issue, particularly the possibility of better exploiting routinely collected data. There is also a need to further improve the variable reporting of study sample characteristics, a problem that continues to hamper data synthesis and interpretation in systematic reviews (e.g. 209). This is likely to improve with increasing implementation of validated functional classification systems, which will be particularly useful given that it is functional characteristics that are known to explain variance in outcomes across diagnostic groups (120). Additionally, as many children with neurodisability experience limitations across areas of daily living (e.g. communication and mobility limitations), feasible methods for capturing and reporting individual children’s multiple co-occurring functional limitations are needed to enable more valid description of study samples (46).

Finally, and arguably most importantly, this review raises questions about whether further reviews can be sustained or justified in the near future within the field of childhood neurodisability and participation research. This reflects questions being asked about the efficiency of evidence synthesis in health research worldwide, in light of the rise in popularity of systematic reviews, and evidence of overlapping meta-analyses on the same topics (210). Including this one, there are now multiple broadly related reviews of personal and social environmental factors related to participation outcomes of disabled children and young people, all of which have been cited in the introduction and discussion sections of this present chapter. These reviews overlap to at least some extent in their included primary studies. It is difficult to fully compare their results because they conceptualise and categorise personal and social environmental factors differently and have slightly different scopes in terms of populations and outcomes. However, there is some consistency in their results, which I have discussed earlier in this section and which has been acknowledged by other authors (e.g. 195). Therefore, to translate the knowledge accumulated from these reviews to improvements in participation outcomes for children and young people with neurodisability, there is a need for the field to progress to developing, evaluating, and implementing interventions whose causal mechanisms are based on existing evidence, and taken from shared theoretical frameworks that can be directly compared. Additionally, as the existing reviews are based largely on fairly weak, mostly cross-sectional, heterogeneous, and variably reported evidence that cannot be meta-analysed, there is also a need to improve the quality and scale of future primary observational studies.

3.3.5 Implications for this research programme

When considered in the wider context of current evidence about participation determinants in childhood neurodisability, the results from this review suggest that an intervention for supporting participation in leisure should consider child beliefs about capabilities, child preferences, parent/family participation in leisure, parent emotions, and support and relationships as important causal mechanisms. The next step in the research programme was to further understand how and when these factors should be targeted by an intervention. The nature of the body of evidence included in the review limited the causal inferences that could be made. Therefore, it was also important to continue considering the factors for which inconsistent or no evidence of association with participation in leisure was identified.

In the next chapter I will describe the three-stage Delphi study I undertook to build on the systematic review. In Stage 1, I further explored personal and social environmental factors using focus groups and semi-structured interviews with adult stakeholders and go-along interviews with children and young people with neurodisability and their parents. The systematic review also highlighted the multitude of ways in which participation in leisure has been defined and measured as a health outcome – there was no agreement on definitions across studies. Therefore, in Stage 1 of the Delphi study I worked with stakeholders to develop a shared definition that would be relevant to and useful for an allied health participation intervention.

Table 3-1 Sources included in the search strategy, and dates searches completed

Bibliographic databases – searched 6-8 November 2015:
MEDLINE (Ovid), 1946 – November 2015
PsycINFO (Ovid), 1987 – November 2015
Allied and Complementary Medicine Database (Ovid), 1985 – November 2015
Education Resource Information Centre (EBSCOhost), 1966 – November 2015
The Cochrane Library (Wiley), 1996 – November 2015
Cumulative Index to Nursing and Allied Health Literature (EBSCOhost), 1981 – November 2015
International Bibliography of the Social Sciences (ProQuest), 1951 – November 2015
COS Conference Papers Index (ProQuest), 1982 – November 2015
Dissertations & Theses UK and Ireland (ProQuest), 1716 – November 2015
Web of Science Core Collection: Science Citation Index, Social Science Citation Index
Conference Proceedings Citation Index (Thomson Reuters), 1900 – November 2015
Applied Social Sciences Index and Abstracts (ProQuest), 1987 – November 2015
Journals – searched 20-21 November 2015:
Developmental Medicine and Child Neurology 2001 – 57(12) and Early Online View
Disability and Society, 2001 – 30(10), searched Leisure Studies 2001 – 34(6)
Annals of Leisure Research 2001 – 18(4)
Disability and Rehabilitation 2001 – 38(2)
Disability Studies Quarterly 2001 – 35(3)
Conferences – searched 7 December 2015:
American Academy of Cerebral Palsy and Developmental Medicine, Annual Meetings 2001-15
European Academy of Childhood Disability, Annual Meetings 2001-15
World Occupational Therapy Congress, 2006, 2014 (unable to access 2002, 2010)
Organisational websites – searched 7, 14 December 2015:
Contact a Family (http://www.cafamily.org.uk/)
Scope (http://www.scope.org.uk/)
The Centre for Excellence and Outcomes in Young People's Services (http://www.c4eo.org.uk/)
Council for Disabled Children (https://councilfordisabledchildren.org.uk/)
English Federation of Disability Sports (http://www.efds.co.uk/)
Centre for Disability Studies at University of Leeds (http://disabilitystudies.leeds.ac.uk/)
Social Policy Research Unit at University of York (http://www.york.ac.uk/inst/spru/)
Leisure Studies Association (http://www.leisurestudies.org/)
Reference lists of relevant systematic reviews identified during the search process – searched 3 March 2016
Reference lists of included full-text records/near misses – searched 9 March 2016

Table 3-2 Quality assessment of studies (n=18) included in the systematic review

Signalling questions:	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**
Kolehmainen, 2015	Y	Y	n/a	?n	?n	n/a	N[1]	Y	Y	Y	N	?	n/a	Y	Y
Shikako Thomas, 2015[a]	Y*	?	n/a	?n	?n	n/a	N	Y	Y	Y	N	?	n/a	?**	Y
Shikako Thomas, 2013[a]	Y	?	n/a	?n	?n	n/a	Y	Y	Y	Y	N	Y	n/a	?**	Y
Andrews, 2014	Y	Y	n/a	?	Y*	n/a	N[1]	N	Y*	Y	N	Y*	n/a	?**	Y
King, 2013[b]	Y	Y	n/a	?n	?n	n/a	Y	Y	Y	Y	N	?	n/a	?**	Y
King, 2010[b]	Y	Y	n/a	?n	?n	n/a	Y	Y	Y	Y	N	Y	n/a	?**	Y
King, 2009[b]	Y	Y	n/a	?	?n	n/a	Y	Y*	Y	Y	N	Y	Y	?**	Y
King, 2006[b]	Y	Y	n/a	?n	?n	n/a	Y	Y	Y	Y	N	Y	n/a	?**	Y
Colver, 2012[c]	Y	N	n/a	N[2]	Y*	n/a	?[3]	Y*	Y	Y	N	Y	n/a	?	Y
Parkes, 2010[c]	Y	Y	n/a	Y*	Y*	n/a	?[3]	Y*	Y	Y	N	?	n/a	?	Y
Clarke, 2011	Y	Y	n/a	?n	?n	n/a	Y	Y*	Y	Y	N	Y*	n/a	?**	Y
Palisano, 2011	Y	?	n/a	?n	?n	n/a	Y	Y	Y*	Y	N	Y	n/a	?**	Y
Teramoto, 2011	Y	?	n/a	?n	?n	n/a	N	N	N	Y	Y	?	n/a	?**	Y
Imms, 2009	Y	N	n/a	?n	?n	n/a	Y	Y	Y*	Y	N	Y	n/a	?**	Y
Majnemer, 2008	Y	?	n/a	?n	?n	n/a	Y	Y	Y*	Y	N	?	n/a	?**	Y
Van Eck, 2008	Y	?	n/a	?n	N	n/a	Y	N	Y	Y	N	Y	n/a	?**	Y
Dixon Thomas, 2008	Y	?	n/a	?n	?n	n/a	N[1]	N	N	Y	N	?	n/a	?**	Y
Pan, 2005	Y	?	n/a	?n	?n	n/a	N[1]	Y	Y	Y	N	Y	n/a	?**	Y

[a,b,c] Same sample. All cross-sectional design except King 2009 (prospective cohort). Y=yes, N=no, n/a=not applicable, ?=cannot determine, ?n=probably no, *with caution, **no protocol, [1]only impairment considered, [2]analysis mitigated risk, [3]unclear regarding socio-economic status. Signalling questions:

1. Were the inclusion/exclusion criteria consistently applied across individuals or comparison groups? (Selection bias)
2. Was the strategy for recruiting participants into the study the same across individuals or comparison groups? (Selection bias, confounding)
3. Was the selection of the comparison group appropriate, after taking into account feasibility and ethics? (Selection bias, confounding)
4. Was the response rate satisfactory (≥70%) and were respondents and non-respondents comparable? (Selection bias, generalisability)
5. Was the sample representative of the individual study's target population? (Selection bias, generalisability)
6. Was there any attempt to balance the allocation between the groups or match groups? (Confounding)
7. Were important confounding variables taken into account in the design/analysis (i.e. impairment, socio-economic status)? (Confounding)
8. Were valid AND reliable measures used consistently across all participants to assess outcomes? (Detection bias)
9. Were valid AND/OR reliable measures used consistently across all participants to assess exposures? (Detection bias)
10. Were valid AND/OR reliable measures used consistently across all participants to assess potential confounders? (Detection bias)

11. Was the assessor blinded to the outcome or exposure status of the participants? (Detection bias)
12. Were missing data handled appropriately? (Detection bias, attrition bias)
13. Was the length of follow-up the same across study groups? (Attrition bias)
14. Were variations from the study protocol accounted for? (Performance bias, reporting bias)
15. Were all variables of interest included in the results? (Reporting bias)

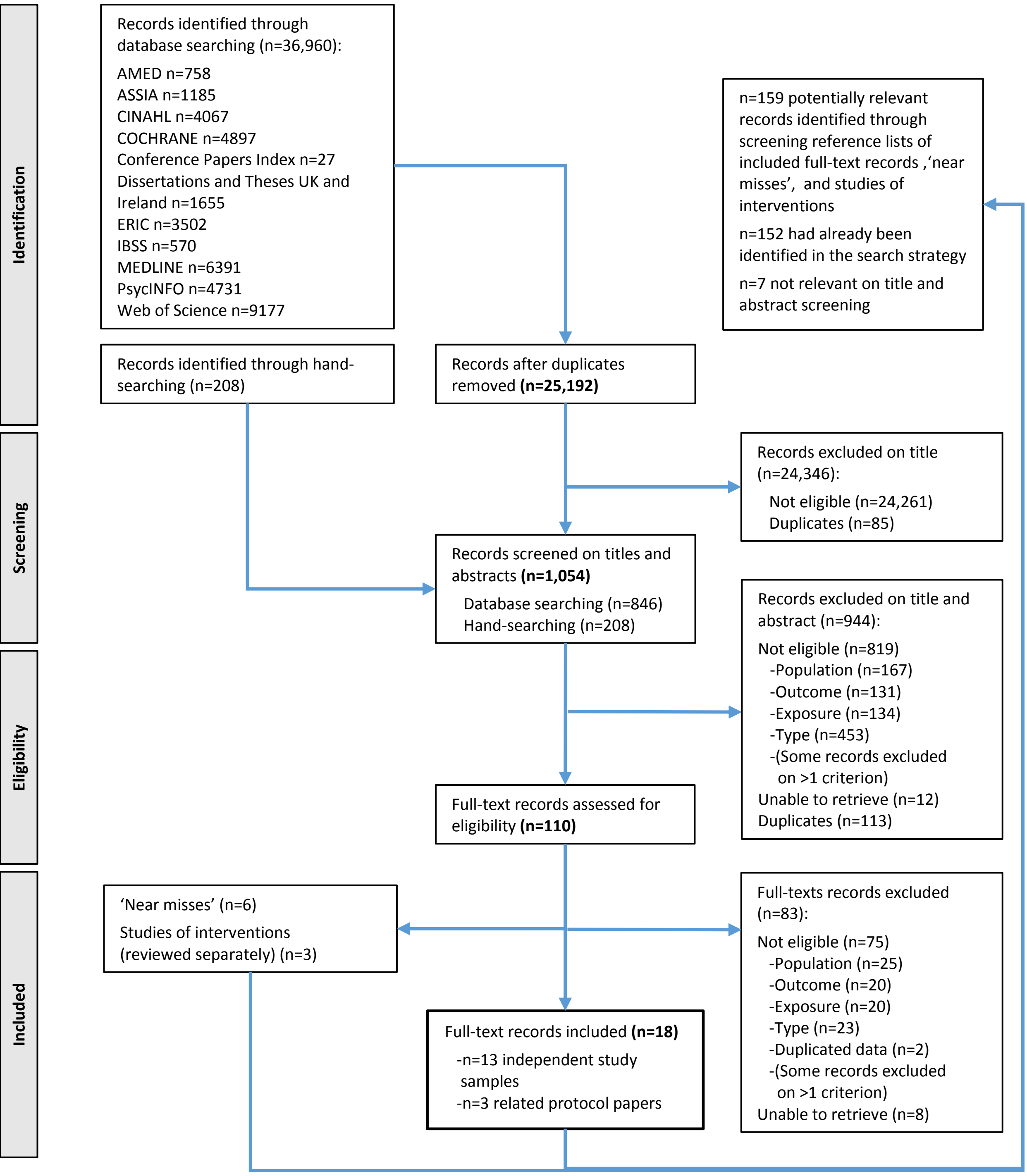

Figure 3-1 PRISMA flowchart summarising the screening and selection of studies

Table 3-3 Overview of independent study populations (n=13) in the primary studies

Lead author, year (study reference)	Country; setting	Sample size (response rate)	Male n (%)	Age	Communication limitations n (%)	Mobility limitations n (%)	Intellectual disability	Health conditions
Kolehmainen, 2015 (74)	England and Scotland (UK); 6 National Health Service Trusts	195 (44%)	n/r	6-8 years	37 (19%)	6 (3.1%)	n/r (73.1, 37.5%, affected by problems in learning)	117 (60%) no medical diagnosis, 17 (8.7%) CP, 14 (7.2%) DCD
Shikako-Thomas, 2015[a] (211)	Canada; specialty clinics in schools, rehabilitation centres, community programs	128 (n/r)	77 (60.2%)	12-19 years; M15.3, SD2.01	47 (36.7%)	36 (28.1%) GMFCS III-V	n/r (41, 32%, attended special school)	CP
Shikako-Thomas, 2013[a] (185)	As per Shikako Thomas (2015)	187 (n/r)	110 (58.8%)	12-20 years; M15.4, SD2.2	n/r	71 (41.5%) GMFCS III-V	n/r (72, 42.1%, attended special school)	CP
Andrews, 2014 (178)	Australia; population-based Rett Syndrome database	214 (82.3%)	0 (0%)	3-34 years (42, 19.6%, aged 8-13 years)	n/r (assumed 100% - see health conditions)	132 (61.7%)	n/r (assumed 100% - see health conditions)	Rett syndrome
King, 2013[b] (179)	Canada; 11 publicly funded	427 (n/r)	229 (53.6%)	6-14 years (146,	n/r	n/r	n/r	Physical disabilities

Lead author, year (study reference)	Country; setting	Sample size (response rate)	Male n (%)	Age	Communication limitations n (%)	Mobility limitations n (%)	Intellectual disability	Health conditions
	regional children's rehabilitation centres, 1 children's hospital			34.2%, aged 9-11 years)				
King, 2010[b] (193)	As per King (2013)	427 (17.3%)	229 (53.6%)	6-14 years (225, 52.7%, aged 6-10 years)	n/r	n/r	n/r	Physical disabilities
King, 2009[b] (175)	As per King (2013)	402 (n/r)	216 (53.7%)	6-15 years (301, 70.5%, aged 6-11 years at T1)	n/r	n/r	n/r	Physical disabilities
King, 2006[b] (192)	As per King (2013)	427 (n/r)	229 (53.6%)	6-14 years	n/r	n/r	n/r	Physical disabilities
Colver, 2012[c] (65)	9 European regions; population-based cerebral palsy registers	818 (63%)	484 (59.2%)	7-13 years	354 (43%)	397 (48.5%) GMFCS III-V	428 (52.6%) had moderate or severe intellectual disability	CP

Lead author, year (study reference)	Country; setting	Sample size (response rate)	Male n (%)	Age	Communication limitations n (%)	Mobility limitations n (%)	Intellectual disability	Health conditions
Parkes, 2010[c] (177)	Northern Ireland (UK); population-based cerebral palsy register	102 (51%)	63 (61.8%)	7-13 years	42 (41.2%)	53 (52%) GMFCS III-V	52 (51%) had moderate or severe intellectual disability	CP
Clarke, 2011 (186)	England (UK); multi-disciplinary assessment services for augmentative and alternative communication	97 (27%)	64 (66%)	M10 years-2 months, SD4 years-8 months	Mean HUI score for speech 0.32 (SD=0.34), where 0=most impaired and 1.00=no impairment	Mean HUI score for ambulation 0.38 (SD=0.45), where 0=most impaired and 1.00=no impairment	Mean HUI score for cognition was 0.71 (SD=0.31), where 0=most impaired and 1.00=no impairment	CP, ASD, Down syndrome, dyspraxia, severe learning disabilities, Worster-Drought syndrome, Dandy-Walker syndrome
Palisano, 2011 (180)	USA; 6 children's hospitals, 1 children's rehabilitation centre	288 (n/r)	166 (57.6%)	6-12.9 years; M9 years-8 months, SD2 years	97 (34.8%)	146 (50.7%) GMFCS III-V	n/r	CP
Teramoto, 2011 (187)	Japan; 117 schools for students who	1,105 (39.1%)	592 (53.6%)	M11 years-7 months, SD3 years-6 months	1105 (100%)	1,105 (100%) GMFCS IV-V	493 (44.6%) had physical and	Severe and multiple disabilities, physical

Lead author, year (study reference)	Country; setting	Sample size (response rate)	Male n (%)	Age	Communication limitations n (%)	Mobility limitations n (%)	Intellectual disability	Health conditions
	are physically challenged						intellectual disabilities	disabilities, intellectual disabilities, other impairments
Imms, 2009 (188)	Australia; Victorian cerebral palsy register	108 (49.3%)	63 (58.3%)	M11.7, SD0.54	53 (49.1%)	43 (39.8%) GMFCS III-V	39 (36.1%) had an intellectual impairment	CP
Majnemer, 2008[a] (181)	Canada; database of children referred to a single neurologist	67 (n/r)	42 (62.7%)	6-12 years 11 months; M9 years-7 months, SD2 years-1 month	35.6 (53.1%)	17.1 (18%) GMFCS III-V	17.4 (25.9%) scored <70 on the Leiter Intelligence Scale	CP
Van Eck, 2008 (182)	Netherlands; rehabilitation centres, hospitals, special schools	72 (n/r)	46 (63.9%)	12-16 years (21, 29.2%, aged 8-12 years)	n/r	16 (22.2%) GMFCS III-V	33 (45.8%) attended a special school	CP
Dixon-Thomas, 2007 (183)	US; routine clinic appointments	60 (n/r)	37 (61.7%)	5-12 years; M8.75, SD1.82	n/r	39.7 (66.1%) GMFCS III-V	n/r	CP
Pan, 2005 (184)	Canada; provincial agencies providing	256 (75%)	136 (53.1%)	6-18 years (123, 48%,	n/r	170 (66.4%)	61.4 (24%) attended fulltime	CP, traumatic head injury, spina bifida,

Lead author, year (study reference)	Country; setting	Sample size (response rate)	Male n (%)	Age	Communication limitations n (%)	Mobility limitations n (%)	Intellectual disability	Health conditions
	services to youth with disabilities			were 6-11 years)			segregated classes	muscular dystrophy

[a,b,c] Papers report separate analyses of data collected from the same study population

n/r not reported, M mean, SD standard deviation, GMFCS Gross Motor Functional Classification System, HUI Health Utilities Index, T1 timepoint 1, UK United Kingdom, USA United States of America, CP cerebral palsy, DCD developmental coordination disorder, ASD autism spectrum disorder

Table 3-4 Participation outcomes and measures in the included studies

Outcome measures (n=8) (no. studies using measure)	Outcomes (n=33) (study references)
Children's Assessment of Participation and Enjoyment (10/18)	Intensity of participation in active physical activities (74, 179, 181, 185, 211*) Intensity of participation in social activities (179, 181, 185, 211*) Intensity of participation in recreational activities (179, 181, 185, 211*) Intensity of participation in skill-based activities (179, 181, 185, 211*) Intensity of participation in self-improvement activities (179, 181, 185, 211*) Intensity of participation in informal activities (181, 186, 192) Intensity of participation in formal activities (181, 192) Intensity of participation in informal/formal activities (180) Change in intensity of participation in active physical activities (175) Change in intensity of participation in social activities (175) Change in intensity of participation in recreational activities (175) Diversity of participation in active physical activities (181, 185) Diversity of participation in social activities (181, 185) Diversity of participation in recreational activities (181, 185) Diversity of participation in skill-based activities (181, 185) Diversity of participation in self-improvement activities (181, 185) Diversity of participation in informal activities (181, 188) Diversity of participation in formal activities (181, 188) Frequency of participation in leisure activities (211*) Estimated physical play/leisure activities per week (74)
Children's Assessment of Participation and Enjoyment & Preferences for Activities of Children (1/18)	'Social participator' profile (characterised by high participation in social activities) (193) 'Broad participator' profile (characterised by high participation in active physical and skill-based activities) (193) 'Recreational participator' profile (characterised by high participation in recreational activities) (193) 'Low participator' profile (characterised by low participation in active physical, recreational, and skill-based activities) (193)
Assessment of Life Habits – Children (2/18)	Participation in recreation (65, 177) Participation in fitness (177) Participation in community (177)
Study questionnaire (1/18)	Overall community participation (178) Frequency of participation in community activities (178)

Friendship Contact Checklist (1/18)	Social functioning (amount of contact with peers) (183)
Canada Fitness Survey (modified) (1/18)	Frequency of participation in family, school, work, and leisure time physical activities (184)
Study questionnaire (1/18)	Intensity of participation in sports and cycling (182)
Study questionnaire (1/18)	Frequency of social participation (187*)

*Studies using only uni- or bivariate analyses, not included in the final synthesis

Table 3-5 Personal and social environmental factors and related measures in the included studies, arranged into categories (n=16) of conceptually similar factors

Measures, n=28 (no. studies using measure)	**Personal and social environmental factors, n=73 (study references)**
Child emotions: a complex reaction pattern involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event (85)	
Strengths and Difficulties Questionnaire (7/18)	Psychological adjustment (185) Emotional functioning/difficulties (175, 179, 192, 193) Behavioural difficulties (181) Psychological health/wellbeing (177)
Child Health Questionnaire – 50 (1/18)	Child emotional function (192)
Children’s Assessment of Participation and Enjoyment (1/18)	Enjoyment of participation (180)
Study questionnaire (1/18)	Temperament (188*)
School-aged Temperament Inventory (modified) (1/18)	Temperament (188)
Trait Emotional Intelligence Questionnaire – 360° (1/18)	Trait emotional self-efficacy (186)
Rett Syndrome Behaviour Questionnaire (1/18)	General mood behaviours (178*) Fear/anxiety behaviours (178*)
Study questionnaire / interviews (1/18)	Emotions (fear, angry anxious, frustration, embarrassed, cries) (74*) Emotions (child to begin to enjoy) (74*)
Child beliefs about capabilities: acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use (85)	
Self-perception Profile for Children and Adolescents (4/18)	Self-concept and self-esteem (179) Perceived competence and self-worth (182, 185*, 193*)
Dimensions of Mastery Questionnaire (2/18)	Mastery motivation (181, 185)
Study questionnaire / interviews (1/18)	Child's beliefs about capabilities (lacks confidence) (74*) Child's beliefs about capabilities (child to become confident) (74*)
Child motivation: commitment and interest to do things or to achieve things, or reluctance to do things (74)	
Study questionnaire / interviews (1/18)	Motivation (strong willed, reluctant, not keen) (74) Motivation (child to become interested) (74*)

Child preferences for activities: a liking for or estimation of one thing before or above another (189)	
Preferences for Activities of Children (5/18)	Preferences for activities (175, 185, 188, 192, 211*)
Parent emotions: a complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant event or matter (85)	
Short Form Health Survey – 36 (2/18)	Parent/caregiver mental functioning (175, 193)
Short Form Health Survey – 12 (1/18)	Parent mental health (178*)
Parenting Stress Index (2/18)	Family functioning (parenting stress) (181)
	Parenting stress (177)
Parent beliefs about capabilities: Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use (85)	
Study questionnaire / interviews (1/18)	Parent beliefs about child's capabilities (has ability to participate in physical play/leisure) (74*)
	Parent beliefs about own capabilities (to overcome barriers limiting child's participation in physical play/leisure) (74)
	Parent beliefs about own capabilities (to persuade child to wear appropriate clothes for participation in physical play/leisure) (74*)
	Parent beliefs about own capabilities (to choose activities that child is able to do) (74*)
Parent beliefs about consequences: Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation (85)	
Study questionnaire / interviews (1/18)	Parent beliefs about consequences (participation in physical play/leisure in neighbourhood puts child at risk of harm) (74)
	Parent beliefs about consequences (participation in physical play/leisure in neighbourhood puts child at risk of injury) (74*)
	Parent beliefs about consequences (participation in physical play/leisure in neighbourhood is bad for child's health) (74*)
	Parent beliefs about consequences (participation in physical play/leisure in neighbourhood has positive impact on child's relationships with other children) (74*)
	Parent beliefs about consequences (participation in physical play/leisure in neighbourhood has positive impact on child's confidence) (74*)
Parent goals: mental representations of outcomes or end states that an individual wants to achieve (85)	
Study questionnaire / interviews (1/18)	Parent goal (important to parent that child participates in physical play/leisure) (74*)
	Parent goal conflict (74*)

Parent physical functioning: general physical health and ability to carry out moderate to vigorous activities of daily living (212, 213)

Short Form Health Survey – 36 (2/18)	Parent/caregiver physical functioning (175, 193)
Short Form Health Survey – 12 (1/18)	Parent physical health (178*)

Parent/family participation in leisure: immediate family leisure behaviours (74)

Study questionnaire / interviews (1/18)	Immediate family behaviours (parent participation in physical play/leisure behaviour without child) (74) Immediate family behaviours (parent participation in physical play/leisure behaviour with child) (74*) All family members' participation in physical play/leisure behaviours (74)
Canada Fitness Survey (modified) (1/18)	Parent physical activity (184)
Family Environment Scale (active-recreational orientation domain) (5/18)	Family participation in social and recreational activities (192) Family active-recreational orientation (175, 185, 193) Family activity orientation (180)
Family Environment Scale (intellectual-cultural orientation domain) (3/18)	Family intellectual-cultural orientation (175, 192, 193)

Demands and impact on the family of caring: the practical requirements related to caring, and associated effects on family members

Family Impact of Childhood Disability (1/18)	Impact of childhood disability on family (186)
Child Health Questionnaire – 50 (Parent Impact – Time Scale) (1/18)	Time impact of caring for a child with a disability (192)
Family Resources Survey (1/18)	Parent availability of time (178*)
Impact on Family Scale (2/18)	Impact on family (193) Family functioning (coping) (181)

Family organisation: clear organisation and structure in planning family activities and responsibilities (191)

Family Environment Scale (organisation domain) (2/18)	Family structure and relationships (180) Family organisation (185)

Support and relationships: people that provide practical physical or emotional support, nurturing, protection, assistance and relationships to other persons, in their home, place of work, school or at play or in other aspects of

their daily activities, and the amount of physical and emotional support the person provides (8)	
European Child Environment Questionnaire (1/18)	Availability of needed environmental items (attitudes - family and friends) (65)
Social Support Scale for Children and Adolescents (2/18)	Supportive relationships for the child (192) Perceived social support (179)
Family Support Scale (1/18)	Community support (178)
Family Environment Scale (Family cohesion subscale) (4/18)	Family cohesion (175, 185, 192, 193)
Craig Hospital Inventory of Environmental Factors (Work/School domain) (2/18)	Perceived barriers in the work/school environment (175, 193)
Study questionnaire / interviews (1/18)	Parent behaviour to encourage participation in physical play/leisure (74*) Child has friends for participation in physical play/leisure (74)
Strengths and Difficulties Questionnaire (7/18)	Peer difficulties/problems (175, 179, 193)
Direct Methods Questionnaire (1/18)	Direct parenting methods (183)
Study questionnaire (1/18)	Number of people who cooperate with the main caregiver for the child's care (187*)
Services: benefits, structured programmes and operations, in various sectors of society, designed to meet the needs of individuals. Included in services are the people who provide them. Services may be public, private or voluntary, and may be established at a local, community, regional, state, provincial, national or international level by individuals, associations, organizations, agencies or governments (8)	
European Child Environment Questionnaire (1/18)	Availability of needed environmental items (social support at home) (65) Availability of needed environmental items (social support in the community) (65)
Measure of Processes of Care – 20 (1/18)	Processes of services (180)
Study questionnaire (1/18)	Extent services meet family needs (180)
Craig Hospital Inventory of Environmental Factors (Services/Assistance domain) (2/18)	Perceived barriers in the services/assistance environment (175, 193)
Study questionnaire (1/18)	Receiving rehabilitation in previous six months (181)
Study questionnaire (1/18)	Use of mobility support services (187*)
Attitudes: observable consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs. These attitudes influence individual	

behaviour and social life at all levels, from interpersonal relationships, community associations to political, economic and legal structures. (8)	
Craig Hospital Inventory of Environmental Factors (Attitudes/Support domain) (2/18)	Perceived barriers in the attitudes/support environment (175, 193)
Policies: rules, regulations, conventions and standards established by governments at the local, regional, national, and international levels, or by other recognized authorities. Policies govern and regulate the systems that organize, control and monitor services, structured programmes and operations in various sectors of society (8)	
Craig Hospital Inventory of Environmental Factors (Policies domain) (2/18)	Perceived barriers in the policies environment (175, 193)
*Signifies results from unadjusted uni- or bivariate analyses, not included in the final synthesis	

Table 3-6 Personal factors and their association with participation in leisure

Personal factor (measure)	Outcome (measure)	Association*
Child emotions – n=10 studies, n=7 independent samples:		
Emotional functioning/difficulties (SDQ emotional symptoms subscale) (193)	Not associated with classification as a ‘Social participator,’ ‘Broad participator,’ or ‘Low participator’. However, ‘Low participators’ had greater difficulties than ‘Broad participators’ (CAPE, PAC)	+
Emotional functioning/difficulties in girls only (SDQ emotional symptoms subscale) (175**)	Greater difficulties associated with a steeper decline over time in intensity of participation in recreational activities (CAPE)	+
Emotional functioning/difficulties (SDQ emotional symptoms subscale) (175**)	Not associated with a change over time in intensity of participation in recreational activities (CAPE)	0
Emotional functioning (SDQ emotional symptoms subscale) (179)	Not associated with intensity of participation in social, active physical, recreational, skill-based, or self-improvement activities (CAPE)	0
Psychological adjustment (SDQ total difficulty score) (185)	Not associated with intensity or diversity of participation in social, active physical, recreational, skill-based, or self-improvement activities (CAPE)	0
Psychological health/wellbeing (SDQ total difficulty score) (177)	Not associated with participation in recreation, fitness, or community (LIFE-H)	0
Emotional function (CHQ 50 role, emotional and behavioural subscale, mental health subscale, self-esteem subscale; and SDQ total difficulty score) (192)	Not associated with intensity of participation in formal or informal activities (CAPE)	0

Behavioural difficulties (SDQ, subscale not reported) (181)	Not associated with intensity or diversity of participation in social, active physical, recreational, skill-based, or self-improvement activities (CAPE)	0
Trait emotional self-efficacy (TEIQ 360° Short Form) (186)	Greater abilities associated with greater intensity of participation in informal activities (CAPE)	+
Temperament (Modified SATI) (188)	Diversity of participation in informal activities (CAPE)	0
Enjoyment of participation in leisure activities (CAPE enjoyment subscale) (180)	Greater enjoyment associated with greater intensity of participation in leisure activities (CAPE)	+
	Proportion of studies supporting an association = 40% (4/10)	
	Summary code = ??	
Child preferences – n=4 studies, n=3 independent samples:		
Preference for formal activities (PAC formal subscale) (192)	Greater preference associated with greater intensity of participation in formal activities (CAPE)	+
Preference for formal activity (PAC formal subscale) (188)	Not associated with diversity of participation in formal activities (CAPE)	0
Preference of children at GMFCS I-IV for formal activity (PAC formal subscale) (188)	Greater preference associated with greater diversity of participation in formal activities (CAPE)	+
Preference for informal activities (PAC informal subscale) (192)	Greater preference associated with greater intensity of participation in informal activities (CAPE)	+
Preference for informal activity (PAC informal subscale) (188)	Greater preference associated with greater diversity of participation in informal activities (CAPE)	+
Preference for active physical activities (PAC active physical subscale) (175**)	Greater preference associated with a less steep decline in intensity of participation in active physical activities (CAPE)	-
Preference for active physical activities (PAC active physical subscale) (185)	Greater preference associated with greater intensity and diversity of participation in active physical activities (CAPE)	+

Preference for social activities (PAC active physical subscale) (175**)	Not associated with a change over time in intensity of participation in social activities (CAPE)	0
Preference for social activities (PAC social subscale) (185)	Greater preference associated with greater intensity and diversity of participation in social activities (CAPE)	+
Preference for recreational activities (PAC recreational subscale) (175**)	Not associated with a change over time in intensity of participation in recreational activities (CAPE)	0
Preference for recreational activities (PAC recreational subscale) (185)	Greater preference associated with greater intensity and diversity of participation in recreational activities (CAPE)	+
Preference for skill-based activities (PAC skill-based subscale) (185)	Not associated with intensity and diversity of participation in skill-based activities (CAPE)	0
Preference for self-improvement activities (PAC self-improvement subscale) (185)	Greater preference associated with greater intensity and diversity of participation in self-improvement activities (CAPE)	+

Proportion of studies supporting an association = 100% (4/4)

Summary code = ++

Child beliefs about capabilities – n=4 studies, n=3 independent samples:

Perceived competence and self-worth in sports (SPPCA athletic competence subscale) (182)	Greater perceived competence associated with greater intensity of participation in sports and cycling (study questionnaire)	+
Self-concept and self-esteem (SPPCA athletic competence subscale) (179)	Greater self-concept and self-esteem associated with greater intensity of participation in active physical activities (CAPE)	+
Mastery motivation (DMQ gross motor persistence subscale) (185)	Greater mastery motivation associated with greater intensity of participation in active physical activities (CAPE)	+
Mastery motivation (DMQ negative reaction to failure subscale) (185)	Not associated with intensity of participation in active physical activities (CAPE)	0
Self-concept and self-esteem (SPPCA athletic competence subscale) (179)	Not associated with intensity of participation in social, recreational, skill-based, or self-improvement activities (CAPE)	0

Self-concept and self-esteem (SPPCA social acceptance subscale) (179)	Not associated with intensity of participation in active physical, social, recreational, skill-based, or self-improvement activities (CAPE)	0
Self-concept and self-esteem (SPPCA scholastic competence subscale) (179)	Not associated with intensity of participation in active physical, social, recreational, skill-based, or self-improvement activities (CAPE)	0
Self-esteem (SPPCA global self-worth subscale) (179)	Not associated with intensity of participation in active physical, social, recreational, skill-based, or self-improvement activities (CAPE)	0
Mastery motivation (DMQ negative reaction to failure, total mastery motivation subscales) (185)	Not associated with intensity or diversity of participation in recreational or skill-based activities (CAPE)	0
Mastery motivation (DMQ total motivation, total persistence subscales) (181)	Not associated with intensity or diversity of participation in formal, informal, active physical, skill-based, or self-improvement activities; or diversity of participation in recreational activities (CAPE)	0
Mastery motivation (DMQ total motivation subscale, particularly mastery pleasure) (181)	Greater mastery motivation associated with greater intensity and diversity of participation in social and recreational activities (CAPE)	+
Mastery motivation (DMQ total persistence subscale) (181)	Not associated with intensity of participation in active physical and recreational activities; or diversity of participation in social activities (CAPE)	0

Proportion of studies supporting an association = 100% (4/4)

Summary code = ++

Child motivation – n=1 study:

Motivation (strong willed, reluctant, not keen) (study questionnaire / interviews) (74)	Not associated with intensity of participation in physical play (CAPE)	0

Percentage of studies supporting an association = 0% (0/1)

Summary code = 0

0 = no association, + = positive association, - = negative association, ? = inconsistent association. Summary codes expressed as ‘00’, or ‘++’, or ‘--‘, indicate where three or more studies have found no association or an association. ‘??’ indicates that the exposure has been investigated in ≥4 studies, with inconsistent findings.

**Evidence from prospective cohort study, all other studies were cross-sectional. SDQ = Strengths and Difficulties Questionnaire, CHQ = Child Health Questionnaire, CAPE = Children’s Assessment of Participation and Enjoyment, PAC = Preferences for Activities of Children, LIFE-H = Assessment of Life Habits for Children, TEIQ = Trait Emotional Intelligence Questionnaire, SATI = School-aged Temperament Inventory, SPPCA = Self-perception Profile for Children and Adolescents, DMQ = Dimensions of Mastery Questionnaire

Table 3-7 Social environmental factors and their association with participation in leisure

Social environmental factor	Outcome	Association*
Parent emotions – n=4 studies, n=3 independent samples:		
Parenting stress (PSI) (181)	Greater stress associated with lesser intensity of participation in self-improvement activities, and diversity of participation in recreational activities (CAPE)	-
Parenting stress (PSI) (181)	Not associated with intensity or diversity of participation in formal, informal, active physical, social, or skill-based activities; intensity of participation in recreational activities; or diversity of participation in self-improvement activities (CAPE)	0
Parenting stress (PSI total score) (177)	Greater stress associated with lower participation in community (LIFE-H)	-
Parenting stress (PSI total score) (177)	Not associated with participation in recreation or fitness (LIFE-H)	0
Parent mental functioning (SF-36 mental functioning subscale) (175**)	Not associated with a change in intensity of participation in active physical, social, or recreational activities (CAPE)	0
Parent mental functioning (SF-36 mental functioning subscale) (193)	Not associated with classification as a ‘Social participator,’ ‘Broad participator,’ or ‘Low participator’ (CAPE, PAC)	0
		Percentage of studies supporting an association = 50% (2/4)
		Summary code = ??
Parent beliefs about capabilities – n=1 study, n=1 independent sample:		

Parent beliefs about own capabilities to overcome barriers limiting child's participation in physical play/leisure (Study questionnaire/interviews) (74)	Not associated with intensity of participation in physical play, or participation in physical play - estimated activities per week (CAPE)	0
	Percentage of studies supporting an association = 0% (0/1)	
	Summary code = 0	
Parent beliefs about consequences – n=1 study, n=1 independent sample:		
Parent beliefs about consequences (participation in physical play/leisure in neighbourhood puts child at risk of harm) (Study questionnaire/interviews) (74)	Not associated with intensity of participation in physical play, or participation in physical play - estimated activities per week (CAPE)	0
	Percentage of studies supporting an association = 0% (0/1)	
	Summary code = 0	
Parent physical functioning – n=2 studies, n=1 independent sample:		
Parent physical functioning (SF-36 physical functioning subscale) (193)	Better functioning associated with lower odds of being classified as a 'Social participator', 'Broad participator', or 'Low participator' (CAPE, PAC)	-
Parent physical functioning (particularly parents of 11-15 year olds) (175**)	Better functioning associated with a steeper decline in intensity of participation in recreational activities (CAPE)	+
Parent physical functioning (SF-36 physical functioning subscale) (175**)	Not associated with a change in intensity of participation in active physical or social activities (CAPE)	0
	Percentage of studies supporting an association = 100% (2/2)	
	Summary code = -	
Parent/family participation in leisure – n=7 studies, n=5 independent samples:		

Family participation in social and recreational activities (FES active recreational orientation subscale) (192)	Greater family participation associated with greater intensity of child’s participation in formal and informal activities (CAPE)	+
Parent physical activity (Canada Fitness Survey, modified) (184)	Not associated with frequency of participation in family, school, work, and leisure time physical activities (Canada Fitness Survey, modified)	0
Immediate family behaviours (parent participation in physical play/leisure behaviour without child) (Study questionnaire / interviews) (74)	Not associated with intensity of participation in physical play, or participation in physical play - estimated activities per week (CAPE)	0
All family members' participation in physical play/leisure behaviours (Study questionnaire / interviews) (74)	Greater family participation associated with greater intensity of child’s participation in physical play, and participation in physical play - estimated activities per week (CAPE)	+
Family activity orientation (FES active recreational orientation, and intellectual cultural orientation subscales) (180)	Greater family activity orientation associated with greater intensity of child’s participation in leisure and recreational activities (CAPE)	+
Family active-recreational orientation (FES active recreational orientation subscale) (175**)	Not associated with a change in intensity of participation in active physical, social, or recreational activities (CAPE)	0
Family active-recreational orientation (FES active recreational orientation subscale) (193)	Not associated with classification as a ‘Social participator,’ ‘Broad participator,’ or ‘Low participator’ (CAPE, PAC)	0
Family activity orientation (FES active recreational orientation, and intellectual cultural orientation subscales) (185)	Greater family activity orientation associated with greater intensity and diversity of child’s participation in self-improvement activities (CAPE)	+
Family activity orientation (FES active recreational orientation, and intellectual cultural orientation subscales) (185)	Not associated with intensity or diversity of participation in active physical, social, recreational, or skill-based activities (CAPE)	0
Family orientation towards intellectual and cultural activities (FES intellectual cultural orientation subscale) (192)	Greater family orientation associated with greater intensity of child’s participation in formal activities (CAPE)	+
Family orientation towards intellectual and cultural activities (FES intellectual cultural orientation subscale) (192)	Not associated with intensity of participation in informal activities (CAPE)	0

Family intellectual-cultural orientation (FES intellectual cultural orientation subscale) (175**)	Not associated with a change in intensity of participation in active physical, social, or recreational activities (CAPE)	0
Family intellectual-cultural orientation (FES intellectual cultural orientation subscale) (193)	Greater family orientation associated with lower odds of being classified as a ‘Social participator’ (CAPE, PAC)	-
Family intellectual-cultural orientation (FES intellectual cultural orientation subscale) (193)	Not associated with odds of being classified as a ‘Social participator,’ or ‘Low participator’ (CAPE, PAC)	0
	Percentage of studies supporting an association = 71.4% (5/7)	
	Summary code = ++	
Demands and impact on the family of caring – n=4 studies, n=3 independent samples:		
Time impact of caring for a child with a disability (CHQ-50 parent impact-time scale) (192)	Not associated with intensity of participation in formal or informal activities (CAPE)	0
Family functioning – coping (i.e. impact of childhood disability on family life) (IOF total score) (181)	Greater impact on family associated with lesser intensity of participation in informal activities (CAPE)	-
Family functioning – coping (i.e. impact of childhood disability on family life) (IOF total score) (181)	Not associated with intensity or diversity of formal, active physical, social, recreational, skill-based, or self-improvement activities; or diversity of participation in informal activities (CAPE)	0
Impact of childhood disability on family life (IOF total score) (193)	Not associated with classification as a ‘Social participator,’ ‘Broad participator,’ or ‘Low participator’ (CAPE, PAC)	0
Impact of childhood disability on family (FICD total score) (186)	Not associated with intensity of children’s participation in everyday informal activities (CAPE)	0
	Percentage of studies supporting an association = 25% (1/4)	
	Summary code = 00	
Family organisation – n=2 studies, n=2 independent samples:		

Family structure and relationships (FES organisation, cohesion, and conflict subscales) (indirect relationship) (180)	Better structure and relationships associated with greater intensity of participation in leisure and recreational activities (CAPE)	+
Family organisation (FES organisation subscale) (185)	Not associated with intensity or diversity of participation in active physical, social, recreational, skill-based, or self-improvement activities (CAPE)	0
	Percentage of studies supporting an association = 50% (1/2)	
	Summary code = ?	
Support and relationships – n=9 studies, n=6 independent samples:		
Direct parenting methods (DMQ number, frequency, and type of direct methods) (183)	Not associated with social functioning (FCC)	0
Supportive relationships for the child (SSSC parent, close friend, and teacher subscales) (192)	Not associated with intensity of participation in formal activities (CAPE)	0
Supportive relationships for the child (SSSC parent, close friend, and teacher subscales) (indirect relationship) (192)	More supportive relationships associated with greater intensity of participation in informal activities (CAPE)	+
Family cohesion (FES family cohesion subscale) (indirect relationship) (192)	Greater cohesion associated with greater intensity of participation in formal and informal activities (CAPE)	+
Family cohesion for girls only (FES family cohesion subscale) (175)	Greater cohesion associated with a steeper decline over time in intensity of participation in recreational activities (CAPE)	+
Family cohesion (FES family cohesion subscale) (175)	Not associated with a change in intensity of participation in active physical or social activities (CAPE)	0
Family cohesion (FES family cohesion subscale) (193)	Not associated with classification as a ‘Social participator,’ ‘Broad participator,’ or ‘Low participator’ (CAPE, PAC)	0
Family cohesion (FES family cohesion subscale) (185)	Not associated with intensity or diversity of participation in active physical, social, recreational, skill-based, or self-improvement activities (CAPE)	0

Availability of needed environmental items (ECEQ items related to attitudes of family and friends) (65)	Availability associated with better participation in recreation (LIFE-H)	+
Community support (FRS) (178)	Greater support associated with higher frequency of participation in community activities (Study questionnaire)	+
Peer difficulties (SDQ peer problems subscale) (179)	Greater difficulties associated with lesser intensity of participation in social activities (CAPE)	-
Peer difficulties (SDQ peer problems subscale) (179)	Not associated with intensity of participation in active physical, recreational, skill-based, or self-improvement activities (CAPE)	0
Peer difficulties (SDQ peer problems subscale) (193)	Greater difficulties associated with lower likelihood of being classified as a ‘Social participator’ (CAPE, PAC)	-
Peer difficulties (SDQ peer problems subscale) (193)	Not associated with classification as a ‘Broad participator,’ or ‘Low participator.’ However, both had greater peer difficulties than ‘Social participators’ (CAPE, PAC)	+
Peer difficulties (SDQ peer problems subscale) (175)	Not associated with a change over time in intensity of participation in active physical, social, or recreational activities (CAPE)	0
Child has friends for participation in physical play/leisure (Study questionnaire / interviews) (74)	Not associated with intensity of participation in physical play, or participation in physical play - estimated activities per week (CAPE)	0
Perceived social support (SSSCA close friends and classmate subscales) (179)	Not associated with intensity of participation in active physical, social, recreational, skill-based, or self-improvement activities (CAPE)	0
Perceived barriers in the work/school environment (CHIEF work/school subscale) (193)	Greater barriers associated with higher likelihood of being classified as a ‘Social participator’ (CAPE, PAC)	+

Perceived barriers in the work/school environment (CHIEF work/school subscale) (193)	Not associated with classification as a ‘Broad participator,’ or ‘Low participator’ (CAPE, PAC)	0
Perceived barriers in the work/school environment (CHIEF work/school subscale) (175)	Not associated with a change over time in intensity of participation in active physical, social, or recreational activities (CAPE)	0
	Proportion of studies supporting an association = 66.67% (6/9)	
	Summary code = ++	
Services – n=5 studies, n=4 independent samples:		
Perceived barriers in the services/assistance environment (CHIEF services/assistance subscale) (175**)	Greater barriers associated with steeper decline over time in intensity of participation in recreational activities (CAPE)	+
Perceived barriers in the services/assistance environment (CHIEF services/assistance subscale) (175**)	Not associated with a change in intensity of participation in active physical or social activities	0
Perceived barriers in the services/assistance environment (CHIEF services/assistance subscale) (193)	Not associated with classification as a ‘Social participator,’ ‘Broad participator,’ or ‘Low participator’ (CAPE, PAC)	0
Availability of needed environmental items (ECEQ items related to social support at home) (65)	Not associated with participation in recreation (LIFE-H)	0
Availability of needed environmental items (ECEQ items related to social support in the community) (65)	Not associated with participation in recreation (LIFE-H)	0
Extent services meet family needs (Study questionnaire) (180)	Not associated with intensity of participation in leisure and recreational activities (CAPE)	0
Processes of services (MPOC) (180)	Not associated with intensity of participation in leisure and recreational activities (CAPE)	0
Receiving rehabilitation services in the previous six months (Study questionnaire) (181)	Receiving services was associated with greater intensity and diversity of participation in skill-based activities (CAPE)	+

Receiving rehabilitation services in the previous six months (Study questionnaire) (181)	Not associated with intensity or diversity of participation in formal, informal, active physical, social, recreational, or self-improvement activities (CAPE)	0
	Proportion of studies supporting an association = 40% (2/5)	
	Summary code = ??	
Attitudes – n=2 studies, n=1 independent sample:		
Perceived barriers in the attitude/support environment (CHIEF attitude/support subscale) (175**)	Not associated with a change in intensity of participation in active physical, social, or recreational activities (CAPE)	0
Perceived barriers in the attitude/support environment (CHIEF attitude/support subscale) (193)	Greater barriers associated with lower odds of being classified as a 'Low participator' (CAPE, PAC)	-
	Proportion of studies supporting an association = 50% (1/2)	
	Summary code = ?	
Policies – n=2 studies, n=1 independent sample:		
Perceived barriers in the policies environment (CHIEF policies subscale) (193)	Not associated with classification as a 'Social participator,' 'Broad participator,' or 'Low participator' (CAPE, PAC)	0
Perceived barriers in the policies environment (as perceived by parents of boys, and younger children aged 6-10 years) (CHIEF policies subscale) (175**)	Greater barriers associated with a less steep decline over time in intensity of participation in active physical activities (CAPE)	-
Perceived barriers in the policies environment (as perceived by parents of girls) (CHIEF policies subscale) (175**)	Greater barriers associated with steeper decline over time in intensity of participation in social and recreational activities (CAPE)	+
	Percentage of studies supporting an association = 50% (0/1)	
	Summary code = ?	

0 = no association, + = positive association, - = negative association, ? = inconsistent association. Summary codes expressed as '00', or '++', or '--', indicate where three or more studies have found no association or an association. '??' indicates that the exposure has been investigated in ≥4 studies, with inconsistent findings.

**Evidence from prospective cohort study, all other studies were cross-sectional. PSI = Parenting Stress Index, SF = Short Form, CAPE = Children’s Assessment of Participation and Enjoyment, PAC = Preferences for Activities of Children, LIFE-H = Assessment of Life Habits for Children, FES = Family Environment Scale, CHQ = Child Health Questionnaire, IOF = Impact on Family Scale, FICD = Family Impact of Childhood Disability, DMQ – Direct Methods Questionnaire, FCC = Friendship Contact Checklist, SSSCA = Social Support Scale for Children and Adolescents, FRS = Family Resources Scale, SDQ = Strengths and Difficulties Questionnaire, CHIEF = Craig Hospital Inventory of Environmental Factors, ECEQ = European Child Environment Questionnaire, MPOC = Measure of Processes of Care.

4 Chapter 4. A Delphi Study to Develop an Allied Health Intervention to Support Participation in Leisure – Overview of Methods

In the previous chapter, I reported the results of a systematic review of modifiable personal and social environmental factors associated with participation in leisure of children and young people with communication and mobility limitations, aged 8-12 years. There was evidence for a positive association with child beliefs about capabilities, child preferences, parent/family participation in leisure, and support and relationships, and a negative association with parent emotions, specifically stress. However, the quality of the body of evidence included in the review limited the causal inferences that could be made, either about these factors or those for which there was inconsistent or no evidence of association with participation in leisure.

The next step in the research programme was to work with diverse stakeholders to build on the results of the systematic review and address the remaining research objectives. I used a Delphi study to achieve this, and the purpose of this chapter is to provide a detailed overview of the methods involved. The results are covered in subsequent chapters, and both the methods and results are reported in line with published recommendations for Delphi studies (214-218). Ethics approval was granted for the study by Newcastle University in October 2016.

4.1 Design

The Delphi method is a flexible way to engage diverse stakeholders in dealing with complex problems. It is well-established in child health research contexts, where it has been successfully used for similar purposes to this research programme including building preliminary theory (219-221), generating intervention content (219-223), and understanding the acceptability and feasibility of interventions (49, 222, 223). Delphi is a systematic approach to building and measuring consensus amongst stakeholders (224-231). Conventionally, a group of stakeholders reaches a pre-determined level of consensus about a particular topic by completing multiple rounds of questionnaires. They generate and rate evidence statements, receive feedback about group ratings, and revise their ratings in the light of the feedback. To encourage independent thought and avoid dominance of particular individuals or subgroups, those taking part are usually anonymous to each other. The overall ratings across the group are then used for decision making. As well as questionnaires, Delphi studies have used interviews, focus groups, and stakeholder meetings (219, 220, 223, 224, 226, 232). These enable open exploration of the research topic and “permit the collection of richer data leading to a deeper understanding of the fundamental research question” (227 p.18).

This Delphi study was conducted over three stages, with each stage contributing to at least one of the objectives for the overall research programme:

- Stage 1 focused on developing a relevant and useful definition of participation in leisure as a health outcome (objective 1), further exploring modifiable personal and social environmental factors (objective 2), and specifying intervention techniques for supporting participation in leisure (objective 3). The methods were go-along interviews with children and young people with neurodisability and their parents, and focus groups and semi-structured interviews with adult stakeholders.
- Stage 2 focused on establishing the extent of stakeholder consensus about the potential effectiveness of the intervention techniques (objective 4) and generating descriptions of feasible, acceptable ways for allied health professionals to deliver the techniques in NHS settings (objective 5). The methods were two rounds of an online survey with parents and multidisciplinary professionals.
- The results of Stages 1 and 2 were brought together with those of the systematic review to form a programme theory of supporting participation in leisure of children and young people with neurodisability (89). The programme theory was generated iteratively throughout the three stages and finalised at Stage 3. Stage 3 focused on exploring how allied health professionals used the programme theory to build prototype interventions for

supporting participation in leisure that would be acceptable and feasible in NHS settings (objective 5). The method was a co-design workshop with multidisciplinary practitioners.

4.1.1 Involving parents and young people

Parent advisors from two networks were involved in developing the protocol for the Delphi study and interpreting the results: Little Hiccups, a parent-led support group for families with disabled children and young people in Leeds;[6] and the Family Faculty, a group of parents and family members who are interested in research, connected to the Peninsula Cerebra Research Unit in Exeter.[7] Their role in the research process is highlighted throughout this chapter.

During the Delphi study, I also began to collaborate on two co-production projects. One was with a parent who took part in Stage 1 along with her daughter. Our collaboration had positive consequences for the research, for me as a researcher, and for the parent herself, and is reported in detail in chapter 9. The other was with young people with first-hand experience of neurodisability or supporting people affected by neurodisability. They were involved in interpreting the results of the Delphi study and influencing my thinking around the programme theory. The young people were members of AniMates, a Leeds-based group that came together to make artwork about the research programme.[8] The nature and impact of our work together is also reported in more detail in chapter 9.

4.1.2 Sampling strategy

I developed an overall sampling frame for the Delphi study from which to purposefully sample participants for each stage (see table 4-1) (87, 233). There is no agreed standard for Delphi sample sizes, and they have varied according to a number of factors including the purpose, scope, and complexity of the study, the degree of uncertainty about the topic, the resources available, and the desired level of stakeholder diversity (225, 228, 230, 234). In this study I determined the sample sizes for each stage

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[6] www.littlehiccups.co.uk

[7] http://www.pencru.org/getinvolved/ourfamilyfaculty/

[8] www.facebook.com/animatesleeds

based on good practice principles for the particular methods used. These are reported in the relevant sections later in this chapter.

Working with parent advisors, I identified seven important stakeholder groups that should be included because of their expertise in supporting participation in leisure of children and young people with neurodisability: (i) children and young people from the study population, (ii) parents of children and young people from the study population, (iii) allied health professionals (occupational, physical, and speech and language therapists), (iv) researchers, (v) short breaks professionals, (vi) teaching assistants, and (vii) sports coaches. The eligibility criteria for each stakeholder group and characteristics desired for a diverse overall sample are outlined in table 4-1.

4.1.3 Recruitment strategy

I populated each of the seven stakeholder groups in the sampling frame with key networks, organisations, and individuals with the necessary expertise to fulfil the eligibility criteria (see table 4-1). In the recruitment strategy for children and young people, the first gatekeepers were teachers (n=3) in the educational support service and special schools. I met with them to clarify the eligibility criteria, and they then posted recruitment packs to parents of eligible children and young people. The second gatekeepers were the parents, who returned the consent form permitting me to visit their child at school or home to discuss the study and potentially gain their agreement to take part (235). Some of the theoretical, ethical, and practical issues I encountered during the recruitment strategy for children and young people are summarised separately in a reflective memo (see Appendix B).

With the exception of researchers, the adult stakeholders were approached indirectly, i.e. recruitment packs were emailed or posted to potential participants by gatekeepers in their respective networks and organisations (see table 4-1). I met with gatekeepers in advance of recruitment to clarify the eligibility criteria and establish ethical ‘ground rules’ around confidentiality and informed consent. The gatekeeper for sports coaches, based in a disability sports network in the North of

England, recommended that this group would be more likely to respond to social media advertisements. The recruitment strategy for teaching assistants was unsuccessful in that only one person responded, so this group was not represented in the study. Researchers were identified through an established international network and existing databases of peer-reviewed participation research,[9] and approached directly by email. All adult stakeholders were asked to return the consent form directly to me.

4.1.4 Changes to the study population

As I set out in chapters 2-3, the planned study population was children and young people with communication and mobility limitations, aged 8-12 years. However, at the time of the Delphi protocol development, parent advisors recommended broadening the inclusion criteria. Their rationale was that the results of the systematic review were relevant to children and young people beyond the planned study population, which was also likely to be the case in the Delphi study; that a more inclusive approach might allow the Delphi study to benefit more children and young people; and that a strict focus on the planned study population would make recruitment more difficult.

I decided not to implement the parent advisors' recommendation because I was concerned about inconsistency between the populations for the systematic review and the Delphi study. However, I subsequently encountered three problems with recruitment: (i) gatekeepers for children and young people identified potential participants who did not meet all the population eligibility criteria, but were clearly relevant for the general study topic and the objectives, (ii) parents and professionals responding to the recruitment strategy did not meet all the population eligibility criteria, but thought they had relevant expertise to contribute, and (iii) during piloting of data collection in the first focus group and interview, stakeholders provided relevant information and examples related to children and young people beyond the planned study population, in particular those with moderate-to-

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[9] The databases were in the form of EndNote Libraries I established during the systematic review (see Chapter 3). I continuously updated these by screening automated alerts from various bibliographic databases.

severe learning disabilities and/or autism. I was unable to implement the planned study population. Instead, I amended the population eligibility criteria to children and young people with communication *and/or* mobility limitations, which could include a broader range of limitations/abilities than those specified in the systematic review, and aged approximately 8-12 years, which allowed for more flexibility and inclusivity.

There is evidence that involving service-users in developing study eligibility criteria adds financial value to research by reducing time spent on recruitment difficulties and associated protocol amendments and changes to ethics approvals, and this was borne out in my Delphi study (236).

4.2 Stage 1. Defining Participation in Leisure, Exploring Personal and Social Environmental Factors, and Specifying Intervention Techniques.

4.2.1 Methods

Go-along interviews with children and young people with neurodisability and their parents, and focus groups and semi-structured interviews with adult stakeholders.

4.2.2 Sample

In total, n=31 stakeholders took part in Stage 1 (n=2 children and young people, n=4 parents, n=14 allied health professionals, n=1 allied health clinical academic, n=6 short breaks professionals, and n=4 sports coaches) (see table 4-2). Twelve children and young people were invited to take part. Parents of three responded, and their children agreed, but one child was subsequently unable to take part due to ill health. The total number of adult stakeholders invited to take part, proportion that responded, reasons for non-response, and characteristics of non-responders compared to responders, are unknown. The sample size was sufficient for capturing much of the desired stakeholder diversity, reflected the breadth, depth and volume of analysis that was feasible, and was broadly in line with conventional practice for focus groups and interviews (237-239).

4.2.3 Data collection

Children and young people took part in go-along interviews with me to a leisure activity of their choosing. I selected go-along interviews for two reasons: (i) they enabled me to be in the situation under exploration, observing and asking about individuals' experiences and responses, accessing their practical knowledge, and seeing the situation through their eyes, and (ii) they are a flexible and inclusive method, enabling children and young people to show rather than describe their participation in leisure; this reduces reliance on modes of communication that may be difficult to access and controlled primarily by researchers (240-247). I selected focus groups for data collection with adult stakeholders because they are well-suited to highlighting diverse perspectives, allow for real-time verification of ideas, can facilitate greater mutual understanding between participants, and tend to be enjoyable (87, 238). Semi-structured interviews were also used where required for logistical reasons.

4.2.4 Materials

Engaging diverse stakeholders in abstract concepts such as health outcomes, causal mechanisms, and intervention techniques is difficult, and careful handling of these concepts is required to ensure relevant data are generated (232, 248, 249). For the focus groups and interviews, the preliminary topic guides were informed by a range of published examples of rehabilitation and public health intervention studies with similar aims to the present study (22, 75, 250-252). It was valuable to explore worked examples of interview questions in realist evaluations, where data collection focuses on gleaning, refining, testing, and consolidating programme theory (88, 248). The questions and prompts included in the preliminary topic guides, and the logic for their use, are presented in table 4-3. These were piloted in the first focus group and interview, and continuously developed and refined as part of an ongoing iterative cycle of simultaneous data collection and analysis.

For the go-along interviews, I used the questions and prompts from the topic guides as sensitising concepts to orient my conversations with parents and family members. I structured my observations and field notes around spaces, objects, acts, activities, events, time, actors, goals, and feelings (253).

4.2.5 Procedures

For the children and young people, the first go-along interview was conducted during a planned family daytrip to a children's museum, with the child, his older sister (aged 8 years), and his mother and father present (duration approximately three hours). The second was conducted at the young person's weekly visit to a disability swimming session at her local swimming pool, with the young person, her mother, her friend, and her friend's mother present (duration approximately one hour).

The nature of a go-along interview introduces the potential for participants to be seen in the company of the researcher. For example, I was aware that we might encounter individuals who know the children and young people, and that those individuals might ask what we are doing. Such encounters could be opportunities to gain further, possibly unanticipated, insights, but they could also compromise confidentiality (242, 247, 254). To manage this, I worked with parents to decide together in advance how we would handle these situations. As recommended in the methodological literature I also used research supervision to reflect on "what constitutes ethical research behaviour" in such situations, and develop a "repertoire of responses…to ethically important moments when they arise" (254 p.165).

During the go-along interviews my focus was on tuning into the children and young people's individual experiences and responses. However, family members played an active and critical role in conveying and interpreting these, particularly in the context of the children and young people's communication limitations and learning disabilities. From the negotiation with parents, the museum go-along was not audio-recorded, and the swimming go-along was audio recorded and transcribed. I recorded extensive field notes immediately afterwards for both, and all data were stored securely, and uploaded to NVivo Pro 11.

On reflection, it is noteworthy that the parents said the go-alongs were a good approach for directly including children and young people who are often excluded from research and gaining a more realistic insight into factors influencing their participation in leisure. Unexpectedly, I felt that the go-alongs created an alliance between myself and the parents, because they explicitly placed value on these families' normal everyday experiences. For example, at the end of the first go-along, all family members thanked me, embraced me, and said it had been an enjoyable experience. Go-along interviews should not be considered a panacea for the limited inclusion of particularly children and young people with learning disabilities in research, and have been discussed in more critical terms in broader disability research (e.g. 100). However, I found that they made an important contribution to this research programme.

For the adult stakeholders, my original intention was to convene heterogeneous focus groups (e.g. parents and allied health professionals together), to stimulate creativity and help avoid inter-personal dynamics between people who already knew each other (87, 227). However, during recruitment this proved not to be feasible, and the number and format of focus groups ended up being determined by stakeholders' geographical locations and schedules, and the preference of established teams to take part together. Focus groups 1 (n=2 stakeholders), 4 (n=4 stakeholders), and 5 (n=5 stakeholders) were conducted using videoconferencing facilities at Newcastle University. Focus groups 2 (n=5 stakeholders), and 3 (n=4 stakeholders) were conducted with teams at their workplaces. The mean duration of focus groups was 1 hour 38 minutes (range = 1 hour 34 minutes to 1 hour 43 minutes). Semi-structured interviews with individuals (n=7) who were unable or preferred not to take part in a focus group were conducted at their workplace, home, or school. The average duration of interviews was 1 hour 13 minutes (range = 58 minutes to 1 hour 23 minutes).

I facilitated all data collection, and created welcoming, informal environments by allowing enough time for introductions and refreshments, and orientation to the research topic and videoconferencing technology (where applicable). I recorded field notes and reflections immediately after each data collection point. All data were audio-recorded, professionally transcribed, anonymised, stored securely, and uploaded to NVivo (QSR International, version 11 for Windows, Pro Edition). The video material from focus groups was converted to audio-recording and the video component was destroyed. Transcripts were not returned to adult stakeholders for comment or correction, and everyone received a summary of the results.

4.2.6 Data analysis

I conducted a framework analysis (255-257) for which the preliminary analytical framework was the overall conceptual framework for the research programme, i.e. the constructs from the Theoretical Domains Framework (TDF) and the World Health Organization's International Classification of Functioning, Disability, and Health, and the behaviour change techniques (BCTs) from the BCT Taxonomy v1 (see chapter 2) (8, 67, 76, 85). To manage the breadth of the analysis and the complexity of the analytical framework, I used additional strategies from grounded theory and the Voice Centred Relational Method (87, 258, 259). The data collection and analysis were carried out in parallel, in that I iteratively collected further data as my understanding and insight developed from the ongoing analysis.

Familiarisation

I read the transcripts and field notes, listened to the audio-recordings, noted the relevant, interesting, repetitive, and dissimilar things the stakeholders said, and sketched out my initial impressions and hunches. I used reflective memos to tune into my pre-existing beliefs and ideas and notice how these influenced my interactions with stakeholders and responses to the data.

Testing the analytical framework

I tested the preliminary analytical framework on two transcripts by:

- Using colour coding to apply the broad categories and specific constructs to the data line by line. For example, I highlighted chunks of data that seemed to relate to participation in leisure as an outcome (i.e. what participation 'looked like'), causal mechanisms of participation in leisure, important contextual factors, or intervention techniques.

- Using open coding to highlight new ideas and patterns in the data that might develop into themes that would extend the analytical framework.
- Physically cutting out and arranging chunks of data according to the categories, constructs, and potential themes I had identified.

These strategies increased my familiarity with the data and the framework, enabling me to practise moving between specific ideas and the wider context of the data. They were also a helpful preparation for manipulating the data electronically in NVivo Pro 11. A portion of the transcript was also openly coded line by line in a group data session with eight researcher peers, and my application of the analytical framework was critically discussed in both the group session and individual supervision meetings.

Indexing

To code stakeholders' full, detailed descriptions onto the analytical framework, I borrowed the idea of a Listening Guide from the Voice Centred Relational Method (259). This is an interpretive, qualitative approach that conceptualises the multiple perspectives and understandings evident within a person's talk as different 'voices'. In my study, the different 'voices' were the broad categories of outcomes, causal mechanisms (i.e. personal and social environmental factors), important contextual factors, and intervention techniques from the analytical framework.

Taking personal factors as an example, first I read each transcript multiple times line by line focusing on the 'voice' of personal factors only. Next, I slowly read through the chunks of data I had highlighted as personal factors, and coded fragments of data onto specific personal factors from the analytical framework, e.g. emotions or goals. I constantly compared newly coded fragments of data to ensure they were consistent with those already coded onto the same personal factor and corresponded closely with the definition of that personal factor. I then repeated this process for the other 'voices' from the analytical framework (i.e. outcomes, social environmental factors, contextual factors, and intervention techniques). I also continued to code for potential new themes that would extend the framework. One researcher not previously involved in the study provided critical feedback on the consistency of my coding and correspondence with definitions. I used detailed analytical memos to track decision making and my evolving thinking about the new themes. My focus zoomed in and out between the finer detail and the bigger picture, to ensure the analysis remained connected to the overarching purpose of the research programme.

To prepare for coding intervention techniques, I undertook the BCT Taxonomy online training.[10] I adopted the following principles when I was coding for specific techniques:

- My focus was on stakeholders' full descriptions of the actions they had taken to support participation in leisure, and not their own informal labels for those actions. For example, if a stakeholder described actions that corresponded with the BCT definition of 'action planning' (67), but happened to informally label those actions as 'problem solving', then my coding was based on the former and the stakeholder's informal label was disregarded. I anticipated that informal labels would be used inconsistently across stakeholders and would have variable correspondence with formal BCT definitions.
- My coding for BCTs was inclusive and sensitive, in that I used a degree of inference when interpreting stakeholders' descriptions of actions and their correspondence with BCT definitions.
- Where stakeholders described actions directed towards outcomes and populations other than those of this research programme, I coded these to BCTs where I judged they corresponded with the BCT definition and could potentially be used by allied health professionals to support participation in leisure in my study population. This contrasts with the more conservative approach recommended for coding BCTs in existing interventions, and the approaches within BCT taxonomy training (260). However, it was useful in the context of an intervention development study where

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[10] The Behaviour Change Technique Taxonomy online training can be accessed at https://www.bct-taxonomy.com/

few published interventions are available, and the objective was to capture all potentially useful intervention content.

Charting

I created one chart of intervention techniques (n=43) related to supporting participation in leisure of children and young people with neurodisability. Each intervention technique was illustrated through direct stakeholder quotes highlighting examples of the techniques' content and context. The chart was reviewed by a public contributor not previously involved in the study and with a professional background as a secondary school teacher. She provided feedback on the correspondence between the technique labels and definitions (taken from the analytical framework) and the direct stakeholder quotes I had selected to illustrate the techniques. She also commented on the accessibility of the chart, and the density of the information included.

Interpreting

To develop a definition of participation in leisure as a health outcome, I engaged in targeted reading of broadly related theoretical and empirical literature (e.g. 261, 262). This informed extensive mind-mapping of the key ideas in the data set, and critical discussions and reflection in meetings with supervisors and parent advisors. I structured a working definition by applying the methodological principle of specifying behavioural health outcomes in terms of their Target, Action, Context, and Time (the 'TACT' principle) (82-84, 263).

The personal and social environmental factors identified in the analysis were presented in the form of explanatory accounts describing how particular factors from the analytical framework played out in relation to participation in leisure. To create the explanatory accounts, I carried out mind-mapping of each personal and social environmental factor, tested out my ideas in informal discussions with two stakeholders (an inclusive sports development advisor and a physiotherapist), and presented rough drafts to parent advisors. I then revised the accounts in light of critical feedback about their relevance and usefulness. These qualitative results about personal and social environmental factors from Stage 1 were brought together with the quantitative results from the systematic review (see chapter 3) through triangulation, which is an appropriate strategy for pragmatic mixed methods studies, including those that draw informally on realist approaches, and involved comparing and contrasting, observing where the results agreed, and actively identifying disagreement (93).

4.2.7 Next steps

The working definition of participation in leisure and the chart of intervention techniques were taken forward to the online survey in Stage 2. The explanatory accounts of personal and social environmental factors brought together with the systematic review results were taken forward to the co-design workshop in Stage 3.

4.3 Stage 2. Establishing the Perceived Effectiveness of Techniques, and Describing Acceptable and Feasible Delivery

4.3.1 Methods

Two rounds of an online survey with parents and multidisciplinary professionals.

4.3.2 Sample

In total, n=75 stakeholders responded to the recruitment strategy for Stage 2, all of whom were invited to take part. Of these, n=68 agreed to participate (90.67%), n=14 parents (20.59%), n=27 allied health professionals (39.7%), n=15 researchers (22.06%), n=12 short breaks professionals and disability and inclusive sports coaches (17.65%) (see table 4-4). The short breaks professionals and sports coaches were pooled for analysis purposes. A sample size of 10-15 individuals per stakeholder group was considered sufficiently diverse, reliable, and efficient, and allowed for some attrition (227, 229, 230, 234, 264, 265). A higher number of allied health professionals was invited to allow wide exploration of their perspectives. Of the n=68 stakeholders, n=26 (38.24%) had also taken part in Stage 1 (see table 4-4). Children and young people were not involved in Stage 2.

4.3.3 Data collection - materials

I designed a questionnaire to elicit stakeholders’ attitudinal evaluations of how effective the intervention techniques from Stage 1 would be for supporting participation in leisure (82). The questionnaire was also an opportunity to gauge stakeholders’ perceptions of the relevance and usefulness of the working definition of participation in leisure from Stage 1 (266, 267).

The questionnaire items used seven-point Likert scales because they enable valid, reliable, and discriminative ratings, are familiar, and are easy to use (218, 268). The scale ranged from 1 to 7 and each point was explicitly labelled (e.g. 1 = very effective, 2 = effective, 3 = fairly effective, 4 = not sure, 5 = fairly ineffective, 6 = ineffective, 7 = very effective). The scales were displayed vertically to fit smartphone screens, and the points were arranged in descending order with the most positive rating at the top.[11] The middle point was consistently labelled as ‘Not sure’, and an additional response option of ‘Unable to rate’ differentiated uncertainty from lack of experience of a particular question’s subject matter, or lack of understanding of the question. Each question included a free text option for additional comments, and no forced response options were included.

Parent advisors made the following recommendations for the questionnaire design, which I implemented:

- A realistic estimation should be provided of how long the questionnaire will take to complete, otherwise stakeholders may feel duped and drop out if it takes longer.
- Stakeholders should be able to save their partially completed questionnaire and return to finish it later.
- A progress bar should be incorporated to indicate how much of the questionnaire had been completed and how much remained.
- Stakeholders might want to respond with ‘it depends’, which should be taken into consideration in the questionnaire design.[12]

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[11] See Toma 2016 for a discussion of potential biases relating to the labelling and layout of Likert scales: http://www.openscienceonline.com/journal/archive2?paperId=3586

[12] Parent advisors also recommended that the questionnaire should use skip logic, which should be thoroughly piloted to ensure smooth, logical transitions between questions. However, this feature was not required in the present study.

I piloted the questionnaire with allied health professionals and public contributors (n=2) known to me but not involved in the study. The final version of the questionnaire distributed to stakeholders is presented in Appendix C.

4.3.4 Data collection - procedures

I had planned a maximum of three rounds of questionnaires but in the end two rounds were implemented. These were sufficient to establish the maximum likely level of stable consensus across stakeholders (91, 225, 234).

In round 1, stakeholders rated the relevance and usefulness of the working definition of participation in leisure, and the effectiveness (rather than feasibility or acceptability) of each intervention technique. To manage responses of ‘it depends on the situation’, stakeholders were instructed to consider the effectiveness of a technique for children and young people with neurodisability in general, assuming the technique was carried out appropriately.[13] The free text comments were used to explore views on the working definition and the feasibility and acceptability of the techniques, and to contextualise and interpret consensus ratings.

In round 2, stakeholders received feedback on the items achieving consensus in round 1. To maximise retention and minimise the burden, they were not asked to re-rate these items. For each remaining item, stakeholders received a brief written description of how it had been rated by each of the separate stakeholder groups in round 1, and a reminder of their own individual rating from round 1. Feedback about the ratings of the separate stakeholder groups was provide because there is some evidence this approach may increase consensus (269, 270). I provided further clarification on the meaning of items where that had been requested, for example where stakeholders had responded with ‘unable to rate’. They were then asked to rate the items for a second time. After round 2 responses had been analysed, stakeholders received a final feedback summary of the overall results.

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[13] As recommended by parent advisors.

I devised and distributed the questionnaire through Qualtrics survey software, which sends a personalised hyperlink to each stakeholder's email address. As recommended by parent advisors, an option to complete the questionnaire by telephone was included in the Participant Information Sheet. All stakeholders (n=68) were invited to both rounds, and in each round the questionnaire was available for approximately one month. I sent personalised email reminders to check junk folders for diverted hyperlinks, which proved useful for encouraging responses. As recommended by parent advisors, parent stakeholders were offered a £75 shopping voucher on completion of the final questionnaire to maximise recruitment and retention. The figure of £75 was based on an estimation of how long each questionnaire would take and cross-referenced with national guidance from NIHR INVOLVE[14] on payments for research involvement. Stakeholders remained anonymous to each other throughout Stage 2, although their identities were known to the research team for analysis purposes. Numeric data were managed in Microsoft Excel and SPSS, and textual data were managed in NVivo Pro 11.

4.3.5 Data analysis

The type of stakeholders completing and dropping out of each round was monitored for systematic bias. Of the n=68 stakeholders, 88.24% (n=60) responded in round 1, and 76.47% (n=52) responded in round 2 (see table 4-4). The response rate between rounds 1 and 2 was relatively consistent for parents and allied health professionals, but reduced significantly in round 2 for researchers, and considerably in round 2 for short breaks professionals and sports coaches (see table 4-4). Overall, the response rates for individual questionnaire items were relatively consistent within rounds, in that most of the stakeholders who responded to the questionnaires submitted ratings for most of the individual items (see table 4-5).

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[14] National Institute for Health Research (NIHR) INVOLVE policy on payment of fees and expenses for members of the public actively involved with INVOLVE. Available from: https://www.invo.org.uk/wp-content/uploads/2016/05/INVOLVE-internal-payment-policy-2016-final-1.pdf

The level of consensus for each questionnaire item was analysed for the overall group ratings and those of the four separate stakeholder groups. There is no agreed standard on measuring and defining consensus in Delphi studies (215, 225, 226, 271). I used the median and interquartile range to measure central tendency and dispersion as they are more robust for ordinal data than means and standard deviations (215, 218, 225, 226, 272). Consensus was defined as an interquartile range of less than or equal to one both across the overall group and within at least three stakeholder groups, indicating that 50% of ratings for that group fell within the median.

Delphi experts have argued that consensus may be meaningless if stability in group ratings has not been achieved across questionnaire rounds, and that, given the tendency in Delphi studies for responses to centralise, a stable lack of consensus may highlight inherent philosophical and practical ambiguities between stakeholder groups (91, 224, 226, 271, 273). I calculated stability for the items that had not achieved consensus at the end of round 2 using the Wilcoxon matched pairs signed ranks test (see chapter 8, table 8-3) (226, 274).[15] Stable lack of consensus was defined as a statistically significant difference in neither the ratings of the overall group nor any of the separate stakeholder groups between rounds 1 and 2. Unstable lack of consensus was defined as a statistically significant difference in ratings of the overall group or at least one of the separate stakeholder group between rounds 1 and 2.

Stakeholders' ratings of the relevance and usefulness of the working definition of participation in leisure and their related free text comments were used to revise the definition. Their free text comments related to intervention techniques were summarised descriptively into key messages for acceptable and feasible delivery and added to the chart of techniques from Stage 1.

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[15] The Wilcoxon matched pairs signed ranks test is based on dependent samples. Therefore, stability of ratings for an individual item was assessed using only data from stakeholders who had submitted ratings for the item in both rounds.

4.3.6 Next steps

The three key outputs of Stages 1-2 were taken forward to the co-design workshop in Stage 3: the revised definition of participation in leisure as a health outcome, the revised chart of intervention techniques with key messages for acceptable and feasible delivery, and the explanatory accounts of personal and social environmental factors brought together in Stage 1 with the systematic review results.

4.4 Stage 3. Using the Research Outputs to Build Prototype Interventions for Supporting Participation in Leisure

4.4.1 Methods

A co-design workshop with multidisciplinary practitioners.

4.4.2 Sample

In total, n=14 stakeholders were invited, of which n=12 agreed to take part and n=9 were able to attend on the day (n=6 allied health professionals, n=2 short breaks professionals, and n=1 sports coach). Eight of the nine stakeholders had taken part in Stages 1 and/or 2 (see table 4-4). The ninth stakeholder was a clinical academic occupational therapist who had not previously taken part in the study. Participants were purposefully sampled to achieve diversity in terms of profession, organisational context, UK geographical region, and expertise in supporting varying groups of children and young people to participate in different types of leisure activities and settings. From my interactions with the majority of stakeholders in Stages 1-2 I was also mindful of individuals' divergent views on the topic, which I anticipated would be of value to the aims of the workshop.

4.4.3 Data collection

The methods were based on published examples of practical and interactive approaches to co-design and usability testing (275, 276).

4.4.4 Materials

The workshop included three activities to engage stakeholders in developing prototype interventions for supporting participation in leisure: orientation, exploration, and prototyping.

Orientation

Once the stakeholders had introduced themselves to each other, I re-oriented them to the overall aims of the research programme, briefed them on the purpose of the workshop, and introduced the outputs from Stages 1-2 of the Delphi study. I had arranged key components of the outputs into a logic model diagram illustrating my initial programme theory of supporting participation in leisure, which was displayed on the walls in large A1 colour print-outs (89).

To enable the stakeholders to be open and critical, the ground rules for the workshop explicitly encouraged exploration and critique. I emphasised that the logic model and initial programme theory should be considered rough sketch as opposed to an almost-finished product. I also ensured the workshop activities were physical and interactive, to relax the stakeholders and support their creativity.

Exploration

Working in small groups of two or three, stakeholders first explored the personal and social environmental factors from the initial programme theory, and thought aloud about their relevance, importance, clarity, and transferability to their own practice contexts. My intention was to establish with stakeholders the idea of personal and social environmental factors as intervention targets, i.e. causal mechanisms of participation in leisure.

To enable exploration, factors were printed on A4 cards with the factor label on one side, and 1-4 brief evidence statements on the other side summarising the related results. The cards were colour-coded (e.g. different colours for factors related to children and young people, parents, and professionals) and arranged label side up across a large conference table. Stakeholders spent time picking the cards up, discussing them, asking for clarification of their meaning, and using sticky notes to attach comments. I encouraged them to move around the room and join different small groups and provided coloured pens for making further notations on the large A1 print-outs on the wall. The activity concluded with a whole group discussion of key thoughts, reflections, ideas, and practical considerations.

I also re-oriented the stakeholders to the intervention techniques they had rated in the online survey in Stage 2,[16] which were displayed separately on the walls in large A1 print-outs.

Prototyping

Working in small groups, I asked the stakeholders to choose 2-3 practice scenarios taken from the research data at Stage 1. The scenarios were in the form of direct stakeholder stories about the problems experienced by individual and populations of children and young people in relation to participation in different leisure settings and activities. I instructed the stakeholders to build two prototype interventions – one for an individual scenario and one for a population scenario. This involved tinkering with the components of the initial programme theory, i.e. the outcome definition, the personal and social environmental factors, and the intervention techniques.

My instructions for this activity were deliberately minimal so as to encourage stakeholders' creativity, and they received only three guidance points: (i) to focus on developing 'wish' interventions that they saw as ideal for responding to the two scenarios, as opposed to what may be acceptable or feasible in their own practice contexts, (ii) to think aloud as they developed the interventions, and encourage each other to articulate their thoughts and impressions, and the obstacles they encountered as they went along, and (iii) to be assured that there were no right or wrong answers.

The paper prototypes were sketched, scribbled, and mapped onto large blank sheets of paper, and then presented back to the wider group. The whole group described how they approached the activity, compared and

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[16] The clinical academic occupational therapist who had not previously taken part in the study was provided in advance with a separate list of the intervention techniques.

contrasted their prototypes, and reflected on the strengths and limitations of the research outputs.

The workshop ended with a brainstorming activity in which stakeholders generated ideas for how to use the logic model and initial programme theory to build acceptable and feasible allied health interventions in their own community practice contexts.

4.4.5 Procedures

The workshop was conducted between 0930 and 1630 in a community centre in central London as this was the most accessible location for stakeholders travelling from various locations in England. I facilitated the workshop with some practical assistance from a clinical academic intern at Newcastle University (a paediatric physiotherapist) and we created a welcoming, informal environment by ensuring sufficient time for introductions, access to refreshments throughout, and an extended lunch break in which stakeholders could connect with each other over areas of common interest. Field notes were recorded immediately afterwards, with three stakeholders further contributing to reflections on the workshop content and process. All data were audio-recorded, professionally transcribed, anonymised, and stored securely. Transcripts were not returned to stakeholders for comment or correction. Everyone received a summary of the overall results for the research programme.

4.4.6 Data analysis

I identified key messages, consistencies, and tensions by reviewing the stakeholders' sticky notes, notations on the A1 print-outs, and paper prototypes, the recorded field notes and reflections, and the activity transcripts. My intention was to organise and summarise the information in relation to what I had already generated about the definition of participation in leisure, personal and social environmental factors, and intervention techniques, as opposed to conducting a deeper, more interpretive analysis (87). Finally, I used the insights gained in the workshop, from Stages 1-2, and from workshops with young people (see chapter 9) to revise the logic model and initial programme theory.

4.5 Strengths and Weaknesses of the Delphi Study Design

The main criticisms of Delphi studies in general are that there is little empirical evidence to guide design choices, little standardisation of how key characteristics should be defined and measured including consensus itself, and reporting has often been poor (215, 231). However, definitions and reporting were some of the key strengths of this Delphi study. I specified a definition of consensus, comprehensively reported the design, and highlighted the reasons for my decision making as recommended by current guidelines (214-218). Data mining and selective reporting of consensus is all too easy because Delphi studies permit so much analytical flexibility, and the set of consensus items may vary depending on the chosen analysis method (277). In this Delphi study I reported the sample, response rates, and outcomes for all questionnaire items at each round (i.e. no selective reporting). However, I could have further strengthened the study by pre-registering complete the analysis plans, as has been recommended (277).

A further strength was sampling. I undertook purposeful sampling of diverse expert stakeholders, particularly at Stage 1 where the main content for Stages 2 and 3 was generated. The stakeholders were geographically spread across primarily England, and the practitioners had experience of a range of organisational contexts. The inclusion of children and young people with relatively complex neurodisability, short breaks professionals, and allied health professionals working specifically in short breaks contexts strengthens the results, as those groups have featured little in research about supporting participation in leisure.

The main weakness of the Delphi relates to generalisability. Delphi studies are not designed to achieve statistical representativeness; however, selection bias is still a risk as the characteristics of those who were not invited or chose not to take part are not known. Within the sample, the failure to recruit teaching assistants and selective drop out of sports coaches was a limitation. For example, it is not known whether stakeholders dropped out because of dissenting views, which may mean that consensus was over-estimated. The results for consensus amongst the short breaks professionals and sports coaches in round 2 should be treated with caution, because there were under 10 stakeholders remaining and this may not be adequately reliable. Multiple reminders by phone call and text message as well as email have been acceptable in other Delphi studies, and could potentially have been used in this study to maximise retention (278). It might also have been helpful to offer an incentive payment to sports coaches as well as parents, as they are often sessional workers who would have been completing the survey in their own time.

Analytically, the topic guides, questionnaire items, and data analysis were informed by established methods and theoretical constructs, and data collection and analysis were iterative with a strong emphasis on reflexivity and awareness of my own subjectivity. Analysis and interpretation were also strengthened by the involvement of other researchers, stakeholders, parent and lay advisors, and young people. However, the validity of the questionnaire for eliciting attitudinal evaluations of 'effectiveness' is unknown. Additionally, triangulation has been criticised as a fundamentally flawed approach for bringing together qualitative and quantitative research results, and other potentially more powerful mixed methods designs have been proposed (94).

4.6 Orientation to the Results Chapters

My aim in this research programme was to develop an allied health intervention to support participation in leisure of children and young people with neurodisability. At the outset of the research I had assumed and anticipated that I would develop one definitive intervention. However, in actual fact the main output is a comprehensive programme theory of supporting participation in leisure to be used for developing multiple interventions tailored to local contexts and diverse populations. Figure 4-1 presents a high-level overview of the programme theory in the form of a logic model. The separate components of the programme theory correspond with the research objectives and comprise a definition of participation in leisure, modifiable personal and social environmental factors, and specified intervention techniques with descriptions of acceptable and feasible delivery and related stakeholder consensus. I will use the next four chapters to present each of these components in turn.

Chapter 5 – the next chapter – focuses on the definition of participation in leisure as a health outcome. Chapter 6 reports the explanatory accounts of personal factors related to participation in leisure, bringing together the results from the Delphi study and the systematic review. Chapter 7 does the same for the explanatory accounts of social environmental factors. I identified key contextual factors that influence and are influenced by the children and young people's participation, towards whom an intervention is directed, and whether, where, how, and by whom it is implemented. These are presented across chapters 6 and 7, in the context of the personal and social environmental factors. Chapter 8 sets out the intervention techniques for supporting participation in leisure, the extent of stakeholder consensus about techniques' potential effectiveness, descriptions of acceptable and feasible ways to deliver the techniques, and key practicalities and recommendations for building prototype interventions using all the components of the programme theory. In chapter 9 I will describe and reflect on the two co-production projects with a parent and young people. Finally, in chapter 10 I will summarise the results, consider the implications for key stakeholder groups, highlight the strengths and weaknesses of the research, and reflect on how I have framed and conducted the overall research programme.

Table 4-1 Overall sampling frame and recruitment strategy for the Delphi study

Stakeholder groups	Eligibility criteria	Desired characteristics for a diverse sample	Recruitment strategy
Children and young people (CYP) with neurodisability	▪ Communication and/or mobility limitations. ▪ Aged approximately 8-12 years. ▪ Willing, and permitted by their parent or carer, to attend a go-along interview in the Leeds or wider West Yorkshire area.	▪ Varying levels of communication and/or mobility functioning, and of different ages and sex. ▪ Diagnosed with different health conditions, particularly epilepsy and sensory impairment, and diagnosed with or understood to have a learning disability. ▪ Attending different types of schools or educational placements.	▪ Educational inclusion support service for students with physical disabilities and/or long-term medical needs attending mainstream or special schools in one local authority in the North of England. ▪ Special schools (n=2) in two cities in the North of England
Parents of children and young people with neurodisability	▪ At least one CYP living at home who has communication and/or mobility limitations. ▪ Living in the United Kingdom (UK).	▪ Male and female parents and carers, whose CYP have varying levels of communication and/or mobility functioning, are of different ages, are diagnosed with different health conditions, and attend different types of schools or educational placements. ▪ Living in rural as well as urban areas.	▪ Parent-led support group for children and families with special needs and disabilities in one city in the North of England. ▪ Special schools (n=3) in three cities in the North of England. ▪ Research involvement network for parents and carers of disabled children in South West England.
Allied health professionals (occupational, physical, and speech and language therapists)	▪ Recent experience of supporting participation in leisure of CYP from the study population. ▪ Providing participation support in the UK.	▪ Supporting participation in CYP with varying levels of communication and/or mobility functioning, of different ages, diagnosed with different health conditions, and attending different types of schools or educational placements. ▪ Working in different geographical regions of the UK.	▪ Royal College of Occupational Therapists – Specialist Section for Children, Young People, and Families. ▪ Chartered Society of Physiotherapy – Association of Paediatric Chartered Physiotherapists.

Stakeholder groups	**Eligibility criteria**	**Desired characteristics for a diverse sample**	**Recruitment strategy**
		- Working in different organisational contexts (e.g. NHS, local authority)	- Royal College of Speech and Language Therapists – Clinical Excellence Networks.
Researchers	- Expertise in developing/evaluating interventions for supporting participation in leisure, or CYP's health behaviours more broadly, demonstrated through recent peer-reviewed publications.	- Working in different geographical regions of the UK, and in different regions internationally.	- Existing databases of participation-related research. - #CountMeIn! international network for advancing research and practice in participation outcomes and interventions.
Short breaks professionals	- Recent experience of supporting participation in leisure of CYP from the study population. - Providing participation support in the UK.	- Supporting participation in CYP with varying levels of communication and/or mobility functioning, of different ages, diagnosed with different health conditions, and attending different types of schools or educational placements. - Supporting participation in different types of leisure settings/activities.	- Short breaks services for CYP with disabilities in one local authority in the North of England.
Teaching assistants	- As above	- As above	- Special schools (n=2) in two cities in the North of England. - Recruitment strategy for teaching assistants was unsuccessful.
Sports coaches	- As above	- As above	- Disability sports network in one local authority in the North of England. - Social media (Twitter, Facebook).

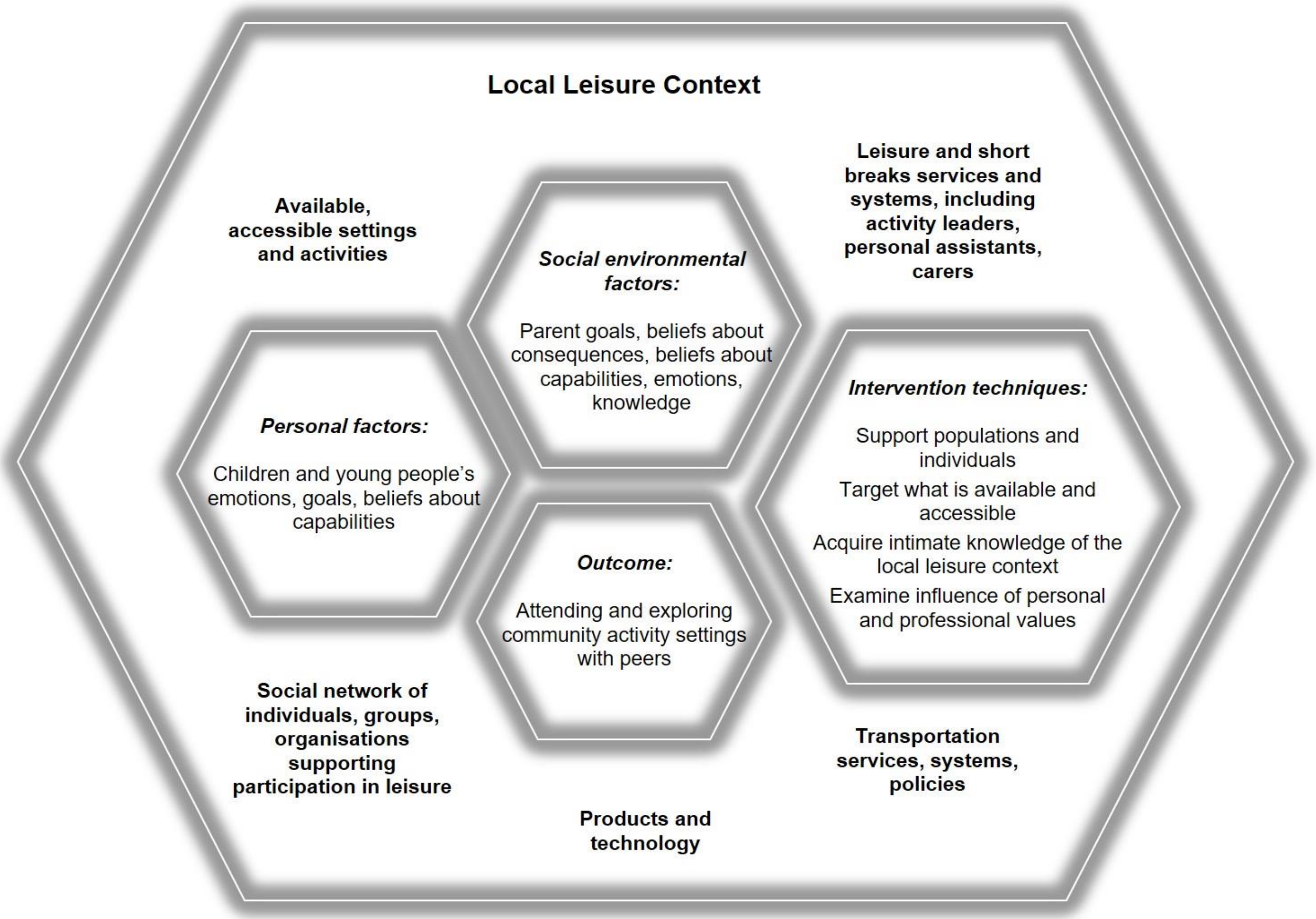

Figure 4-1 Logic model illustrating the programme theory of supporting participation in leisure

Table 4-2 Delphi Stage 1 sample

Stakeholders, n=31 (organisational context)	**Geographical region**	**FG, I, G**
Children and young people (n=2):		
Thomas (aged 7 years)	Yorkshire & Humber	G1
Lucy (aged 15 years)	Yorkshire & Humber	G2
Parents (n=4):		
John, father to Thomas (see above)	Yorkshire & Humber	G1
Liz, mother to Thomas (see above)	Yorkshire & Humber	G1
Diane, mother to Lucy (see above)	Yorkshire & Humber	G2, I6
Michelle, mother to Sienna (aged 10 years)	Yorkshire & Humber	I7
Allied health professionals (n=14):		
Gail, physiotherapist (voluntary sector)	Wales	FG1
Dave, physiotherapist (NHS)	North West England	FG1
Helen, physiotherapist (NHS, LA)[a]	Greater London	FG3
Katie, occupational therapist (NHS, LA)[a]	Greater London	FG3
Gemma, speech and language therapist (NHS, LA)[a]	Greater London	FG3
Niamh, speech and language therapist (NHS, LA)[a]	Greater London	FG3
Simon, physiotherapist (HEI)[b]	Yorkshire & Humber	FG4
Sally, physiotherapist (NHS)[b]	South East England	FG4
Celia, occupational therapist (voluntary sector)[b]	South East England	FG4
Mandy, occupational therapist (private sector)	Greater London	FG5
Connie, occupational therapist (NHS)	North West England	FG5
Abi, physiotherapist (NHS)	Greater London	FG5
Paula, physiotherapist (NHS)	Yorkshire & Humber	FG5
Joanne, physiotherapist (NHS)	Wales	FG5
Researchers (n=1):		
Amanda, clinical academic occupational therapist (NHS)[b]	Yorkshire & Humber	FG4
Short breaks professionals (n=6):		
Adele, short breaks coordinator (LA)[c]	Yorkshire & Humber	FG2
Paul, short breaks coordinator (LA)[c]	Yorkshire & Humber	FG2
Jim, short breaks coordinator (LA)[c]	Yorkshire & Humber	FG2
Halima, short breaks team manager (LA)[c]	Yorkshire & Humber	FG2
Noreen, short breaks development officer (LA)[c]	Yorkshire & Humber	FG2
Justin, accessible activity scheme leader (voluntary sector)	Yorkshire & Humber	I3
Sports coaches (n=4):		
James, disability sports officer (LA)[b]	Yorkshire & Humber	I1
Gerry, disability sports coach (LA)[b]	Yorkshire & Humber	I2
Kate, sports development officer (various)	Greater London	I4
Seb, inclusive sports development advisor (various)	Greater London	I5

All names are pseudonyms.
FG = focus group, I = semi-structured interview, G = go-along interview, NHS = National Health Service, LA = local authority, HEI = higher education institute, a = belonging to one team, b = known to each other, and/or known to the lead researcher, c = belonging to one team.

Table 4-3 Delphi Stage 1 questions and prompts included in the preliminary topic guides, and the logic for their use

Questions and prompts	Logic
Tell me about your work with children and young people with neurodisability (or, tell me about your son or daughter).	Introductory question to get them talking.
What sorts of leisure activities are you supporting children and young people (or your son or daughter) to access?	Introductory question to get them talking. Describing and exploring the outcome of participation in leisure.
What do you do to support participation in leisure of these children (or your son or daughter)? What sorts of techniques, strategies, and approaches do you use? - Talk me through a concrete example of doing *(use stakeholder's words).* - If I followed you through a recent example of doing (…), what would I see you doing, or hear you saying? - How do you go about doing (…)? - When do you do (…)? - Where do you do (…)? - In what other situations do you do (…)?	Identifying intervention techniques. Progressing stakeholder's examples from general descriptions to more detailed, potentially replicable, specifications.
How do you think doing *(use stakeholder's words)* supports participation in leisure? - Why does (…) make a difference? - Why do you do (…) like that? - How does (…) work? - What happens when you do (…)? - What happens when you don't do (…)? - What are the advantages/disadvantages of doing (…)? - What else do you associate with doing (…)?	Eliciting and exploring potential causal mechanisms.
What do you think about *(potential causal mechanism identified in the systematic review, or another focus group or interview)*? - Do you find that *(mechanism)* has an influence on participation in leisure? - How does *(mechanism)* have an influence?	Further exploring potential causal mechanisms.

Table 4-4 Delphi Stage 2 sample and response rates

Stakeholders, n=68 (organisational context)	**UK geographical region / country**	**Round 1**	**Round 2**
Parents (n=15 invited, n=14 agreed):			
Alison, mother[a]	South West England	✓	✓
Tony, father[a]	South West England	✓	✓
Jenny, mother	South West England	✓	✓
Rachel, mother	South West England	✓	✓
Lorraine, mother	South West England	✓	✓
Jayne, mother	South West England	✓	✓
Sheena, mother	South East England	✓	✓
Kathleen, mother	South East England	✓	✓
Michelle, mother	North West England	✓	✓
Alice, mother	Yorkshire & Humber	✓	✓
Ria, mother	Yorkshire & Humber	✓	✗
Elizabeth, mother	Yorkshire & Humber	✓	✓
Nicky, mother	Yorkshire & Humber	✓	✓
Diane mother*	Yorkshire & Humber	✗	✗
	Response rates for parents:	92.86%	85.71%
Allied health professionals (n=27 invited and agreed):			
Abi, physiotherapist (NHS)*+	Greater London	✓	✓
Gemma, speech and language therapist (NHS, LA) [b]*+	Greater London	✓	✓
Niamh, speech and language therapist (NHS, LA) [b]*	Greater London	✗	✗
Helen, physiotherapist (NHS, LA)[b]*	Greater London	✓	✓
Katie, occupational therapist (NHS, LA) [b]*	Greater London	✓	✓
Rosa, clinical psychologist (NHS, LA)[b]+	Greater London	✓	✓
Anna, occupational therapist (NHS, LA)[b]	Greater London	✓	✓
Dan, physiotherapist (NHS)	Greater London	✓	✓
Mandy, occupational therapist (private sector)*	Greater London	✗	✗
Frances, occupational therapist (NHS)	Greater London	✗	✗
Sally, physiotherapist (NHS)*	South East England	✓	✓
Celia, occupational therapist (voluntary sector)*	South East England	✓	✓
Christine, occupational therapist (voluntary sector)+	South East England	✓	✓
Greta, occupational therapist (private sector)	South East England	✓	✓
Anna, speech and language therapist (NHS)	South East England	✗	✗
Connie, occupational therapist (NHS)*+	North West England	✓	✓
Dave, physiotherapist (NHS)	North West England	✓	✓
Helene, physiotherapist (NHS)*	North West England	✓	✓
Pam, physiotherapist (NHS)	North East England	✓	✓
Leanne, physiotherapist (NHS)	East of England	✓	✓
Elaine, speech and language therapist (LA)	West Midlands	✓	✓
Simon, rehabilitation Engineering Specialist (NHS)	West Midlands	✗	✗
Simon, physiotherapist (HEI)*	Yorkshire & Humber	✓	✓
Paula, physiotherapist (NHS)*	Yorkshire & Humber	✓	✓
Jenny, occupational therapist (NHS)	Yorkshire & Humber	✓	✓
Joanne, physiotherapist (NHS)*	Wales	✓	✓

Stakeholders, n=68 (organisational context)	UK geographical region / country	Round 1	Round 2
Gail, physiotherapist (voluntary sector)*	Wales	✓	✓
Response rates for allied health professionals:		81.48%	81.48%
Researchers (n=21 invited, n=15 agreed):			
Amanda, clinical academic occupational therapist (NHS)*	Yorkshire & Humber	✓	✓
Cynthia, associate professor (HEI)	Sweden	✓	✓
Roisin, senior scientist (research institute)	Canada	✓	✓
Judith, assistant professor (HEI)	Canada	✓	✓
Rebecca, research coordinator (HEI)	Canada	✓	✓
Karen, assistant professor (HEI)	Canada	✓	✗
Aislinn, senior researcher (HEI)	Netherlands	✓	✗
Miriam, post-doctoral researcher (HEI)	Netherlands	✓	✓
Grace, professor (HEI)	Australia	✗	✗
Kulwinder, associate professor (HEI)	Australia	✓	✗
Bronagh, associate lecturer (HEI)	Australia	✓	✓
Angie, professor (HEI)	United States	✓	✓
Mona, researcher (paediatric post-acute provider)	United States	✓	✓
Maria, professor (HEI)	United States	✓	✓
Martha, professor (HEI)	Brazil	✓	✓
Response rates for researchers:		93.33%	73.33%
Short breaks professionals, sports coaches (n=12 invited and agreed):			
Adele, short breaks coordinator (LA)[c*+]	Yorkshire & Humber	✓	✓
Paul, short breaks coordinator (LA) [c*+]	Yorkshire & Humber	✓	✓
Jim, short breaks coordinator (LA)[c*]	Yorkshire & Humber	✓	✓
Noreen, short breaks development officer (LA)[c*]	Yorkshire & Humber	✓	✓
Hasan, short breaks coordinator (LA)[c]	Yorkshire & Humber	✓	✓
James, disability sports officer (LA)*	Yorkshire & Humber	✓	✓
Gerry, disability sports coach (LA)*	Yorkshire & Humber	✓	✗
Norman, sports coach (voluntary sector)	Yorkshire & Humber	✓	✗
Justin, accessible activity scheme leader (voluntary sector)*	Yorkshire & Humber	✗	✗
Joe, disability participation officer (NGB)	West/East Midlands	✓	✗
Kate, sports development officer (various)*	Greater London	✓	✗
Seb, inclusive sports development advisor (various)[*+]	Greater London	✓	✓
Response rates for short breaks professionals, sports coaches:		91.67%%	58.33%
Overall response rates:		**88.24%**	**76.47%**

All names are pseudonyms.
NHS = National Health Service, LA = local authority, HEI = higher education institute, NGB = non-governmental body, a = married, b,c = belonging to the same team, *took part in Stage 1, +took part in stage 3

Table 4-5 Delphi Stage 3 response rates for individual questionnaire items

	Round 1 response rates n (%)					Round 2 response rates*				
	P (n=14)	**AHP (n=27)**	**R (n=15)**	**SB/SC (n=12)**	**Overall (n=68)**	**P (n=14)**	**AHP (n=27)**	**R (n=15)**	**SB/SC (n=12)**	**Overall (n=68)**
Definition of participation in leisure:										
Relevant	13 (92.86%)	22 (81.48%)	14 (93.33%)	11 (91.67%)	60 (88.24%)	-	-	-	-	-
Useful	13 (92.86%)	22 (81.48%)	14 (93.33%)	11 (91.67%)	60 (88.24%)	-	-	-	-	-
Intervention techniques:										
1	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
2	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	-	-	-	-	-
3	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
4	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
5	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	-	-	-	-	-
6	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
7	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
8	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
9	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
10	13 (92.86%)	21 (77.78%)	14 (93.33%)	9 (75%)	57 (83.82%)	12 (85.71%)	22 (81.48%)	11 (73.33%)	7 (58.33%)	52 (76.47%)
11	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
12	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	20 (74.07%)	11 (73.33%)	7 (58.33%)	50 (73.53%)
13	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	-	-	-	-	-
14	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
15	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	20 (74.07%)	11 (73.33%)	7 (58.33%)	50 (73.53%)
16	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	-	-	-	-	-

	Round 1 response rates n (%)					Round 2 response rates*				
17	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	22 (81.48%)	11 (73.33%)	7 (58.33%)	52 (76.47%)
18	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	-	-	-	-	-
19	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	-	-	-	-	-
20	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
21	13 (92.86%)	21 (77.78%)	14 (93.33%)	9 (75%)	57 (85.29%)	12 (85.71%)	20 (74.07%)	11 (73.33%)	7 (58.33%)	50 (73.53%)
22	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	22 (81.48%)	11 (73.33%)	7 (58.33%)	52 (76.47%)
23	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
24	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
25	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	-	-	-	-	-
26	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
27	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
28	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
29	13 (92.86%)	21 (81.48%)	14 (93.33%)	9 (75%)	57 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
30	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
31	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	22 (81.48%)	11 (73.33%)	7 (58.33%)	52 (76.47%)
32	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	20 (74.07%)	11 (73.33%)	7 (58.33%)	50 (73.53%)
33	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
34	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
35	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
36	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	6 (50%)	50 (73.53%)
37	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	22 (81.48%)	11 (73.33%)	7 (58.33%)	52 (76.47%)
38	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	22 (81.48%)	11 (73.33%)	7 (58.33%)	52 (76.47%)
39	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	-	-	-	-	-
40	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)

	Round 1 response rates n (%)					Round 2 response rates*				
41	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	-	-	-	-	-
42	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	10 (66.67%)	7 (58.33%)	50 (73.53%)
Bundle 1	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	21 (77.78%)	11 (73.33%)	7 (58.33%)	51 (75%)
Bundle 2	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	22 (81.48%)	11 (73.33%)	7 (58.33%)	52 (76.47%)
Bundle 3	13 (92.86%)	22 (81.48%)	14 (93.33%)	9 (75%)	58 (85.29%)	12 (85.71%)	20 (74.07%)	11 (73.33%)	7 (58.33%)	50 (73.53%)

P = parents, AHP = allied health professionals, R = researchers, SB = short breaks professionals, SC = sports coaches, Overall = overall group.

*Items achieving consensus within at least three stakeholder groups and overall in round 1 were not included in round 2.

Intervention techniques:

1. Set goals with children and young people: identify and agree what leisure activities children and young people are going to do.
2. Explore what leisure activities children and young people might want to, by discussing their current activities and interests, making suggestions, and/or offering options of available activities.
3. Teach / instruct parents or workers which leisure activities to do with children and young people.
4. Set goals with workers: identify and agree what actions workers are going to take, or what they are going to learn about, in order to support children and young people's participation in leisure.
5. Problem solve: analyse the factors influencing whether children and young people participate in a leisure activity and come up with strategies to overcome barriers/increase supports to participation.
6. Action plan: make a detailed plan for doing a leisure activity, including where, when, how, how often, and/or for how long children and young people will attend and explore.
7. Review goals with children and young people: assess whether a previously-set leisure goal has been achieved and consider whether to change the goal and/or the strategy for achieving the goal.
8. Review goals with workers: jointly assess with workers whether a previously-set goal for supporting children and young people's participation in leisure has been achieved and consider whether to change the goal and/or the strategy for achieving the goal.
9. Monitor: observe or record whether workers are providing the agreed support for participation in leisure, with the workers' knowledge.
10. Provide feedback to parents or workers on how they are doing with supporting participation in leisure activities, and/or how children and young people are exploring activities.
11. Self-monitor: establish a method for children and young people to monitor and record their own progress with participating in leisure activities, as part of a strategy for improving or increasing their participation.

	Round 1 response rates n (%)	Round 2 response rates*
12. Provide general support, for example encouragement to participate in leisure activities.		
13. Provide practical support to identify leisure activities that are locally available, accessible, and appropriate for children and young people.		
14. Provide information about local leisure activities and opportunities.		
15. Provide transport for children and young people to attend leisure activities.		
16. Provide practical support (other than transport) for children and young people to get to activity settings.		
17. Provide practical support during leisure activities, to enable children and young people to explore.		
18. Provide practical support to access leisure-related services, entitlements, products, and/or assistive technology and equipment.		
19. Provide information about leisure-related services, entitlements, products, and/or assistive technology and equipment that children and young people may be able to access.		
20. Provide direct payments or personal budgets for children and young people and their parents to use to arrange their own leisure activities.		
21. Provide workers with information about children and young people’s health conditions, strengths, limitations, likes, and/or dislikes.		
22. Provide workers with general information about health conditions, for example cerebral palsy, and neurodisability overall.		
23. Provide emotional support to children, young people, and/or parents, before, during, and/or after children and young people participate in leisure activities.		
24. Teach/instruct children, young people, and/or parents on how to do leisure activities.		
25. Teach/instruct workers in how to support children and young people’s participation in leisure, for example how to adapt activities, restructure the environment, communicate, or move and handle.		
26. Gatecrash: ignore, circumvent, or violate established norms, rules, systems, or expectations, in order to gain access to a leisure setting or activity for children and young people.		
27. Provide information about the health benefits and health risks of doing a leisure activity.		
28. Demonstrate: provide an example of doing or supporting leisure activities, for a child, young person, or adult to aspire to or imitate. Demonstrating may be done either directly in person, or indirectly through pictures or film.		
29. Vicarious experience: Show children and young people examples of others similar to themselves successfully attending and exploring leisure activities, to make them think they could do it too; or show parents examples of others, similar to their sons and daughters, successfully attending and exploring leisure activities, to make them think their sons and daughters could do it too.		
30. During leisure activities, provide children and young people with a prompt or cue to do the activity, or provide a prompt or cue to adults to support children and young people to do activities.		

	Round 1 response rates n (%)	Round 2 response rates*
31. Practise doing or rehearsing, or supporting children and young people to do or rehearse, leisure activities, in a context or at a time when they may not need to do it, order to increase skill and habit.		
32. Prompt repeated participation in leisure activities in the same context so that it becomes a habit.		
33. Generalise a leisure activity from one situation where the children and young people already do it, to another situation.		
34. Grade: make attending settings or exploring activities easier, or gradually more challenging – but achievable – until children and young people successfully attend and explore.		
35. Provide information from a credible source in favour of or against doing leisure activities. A credible source might be other children and young people, another parent, a certain type of professional, or a public figure.		
36. Provide children and young people with material rewards, for example valued objects, for trying to participate in leisure activities, and/or making progress with participating.		
37. Provide children and young people with social rewards, for example praise, for trying to participate in leisure activities, and/or making progress with participating.		
38. Provide a range of leisure activities and opportunities for children and young people.		
39. Provide leisure activities and opportunities in response to children and young people's particular goals and priorities.		
40. Restructure the social environment where leisure activities take place, for example by adapting the usual routines or rules, or organising children and young people into groups who get along well together.		
41. Provide opportunities for individuals to experience direct contact with children and young people with neurodisability, to reduce those individuals' anxiety and increase their empathy.		
42. Add objects to the environment to facilitate participation in leisure, for example adding a racing wheelchair to a training session at an athletics club, or adding equipment into a school playground.		
Bundle 1. Provide activity taster sessions in the form of a brief experience to introduce children and young people to leisure settings and/or activities.		
Bundle 2. Adapt a leisure activity so children and young people can attend and explore, for example by changing when or where it's done, the space in which it's done, the objective of the activity, its duration or timing, the materials or equipment, and/or the rules of the activity.		
Bundle 3. Do a recce: visit leisure activity settings in advance, with or without children and young people, to become familiar with it, and/or help decide if children and young people will be able to attend and explore.		

5 Chapter 5. Developing a Relevant and Useful Definition of Participation in Leisure as a Health Outcome

In the previous chapter I described the methods I used to develop a relevant and useful definition of participation in leisure as a health outcome. I used focus groups and interviews with key stakeholders, targeted reading of theoretical and empirical literature, mind-mapping of key ideas, and critical discussion with supervisors and parent advisors to generate the content for a definition. To structure a working definition, I then applied the methodological principle of specifying behavioural health outcomes in terms of the ‘TACT’ principle: their Target (i.e. who will enact the outcome), Action (what they will do), Context (in what circumstances they will do it), and Time (when they will do it) (82-84, 263).

Stakeholders rated the relevance and usefulness of the working definition and commented on how it could be improved (see table 5-1). There was consensus that it was relevant and useful both across the whole stakeholder group, and within the separate subgroups (i.e. parents, allied health professionals, researchers, and short breaks professionals/sports coaches). I revised the working definition based on stakeholder feedback, and the final definition is as follows:

> For children and young people with communication and/or mobility limitations aged approximately 8-12 years (Target), participation in leisure takes place outside of education or school hours, self-care, and domestic life (Time), in community activity settings with peers (Context). It involves: (i) attending leisure settings and activities, especially for the first time (Action 1), and (ii) exploring activities, which means children and young people getting to the point where they are doing leisure activities in their broadly recognisable and conventional forms, and discovering whether they enjoy them (Action 2).

In this chapter I will set out the Action and Context elements of the definition and illustrate how these are grounded in and were shaped by stakeholders’ lived experience and expertise. I will also discuss the strengths and limitations of the final definition of participation in leisure in relation to the wider literature.

5.1 Action 1: Attending

Attending means being physically present at a community activity setting, and this was understood by stakeholders to be an essential requirement for participation in leisure. However, their descriptions of supporting participation tended to focus especially on attending for the first time. James, a disability sports officer, described getting children and young people – and their parents and carers – to ‘make that first step’ as ‘the biggest area for me…the biggest part of my role.’ Attending for the first time was also a bigger challenge for James than getting people to return to activity settings, because he was confident that local activity leaders would ensure children and young people had fun and enjoyed themselves once they had attended. Other stakeholders commented on the challenge of attending for the first time. For example, during the go-along interview at the swimming pool, the manager commented that ‘one of the hardest things is getting people to come [to the disability swimming session]…once they come they love it.’

Stakeholders framed attending for the first time in two ways. On the one hand, they highlighted how attending for the first time is important primarily because it is a necessary starting point for regular attendance and sustained participation – it is a critical milestone. The activity taster session was one clear example of how this played out in practice. Several of the practitioner stakeholders described how their services organised all-day events to provide children and young people with brief, introductory experiences of novel activities. The idea was to support children and young people to attend a new setting for the first time and try new activities, explicitly with a view to them signing up and attending regularly. Helen, a physiotherapist, described her service’s annual event for children and young people who ‘didn’t have a leisure provision they were regularly going to, or struggling to find an appropriate one.’ Local disability or inclusive activity leaders provided taster opportunities, and the aim was to get children and young people ‘set up with the provision that they could be using regularly.’ Paula, also a physiotherapist, described ‘a young girl on my caseload who I’d been trying to get to play Boccia for months.’ With support from Paula, the girl attended their sports taster day, which was successful because ‘she loved it and then has been going to the club night on a weekly basis ever since.’

Many stakeholders believed it was only worthwhile supporting children and young people to attend things like activity taster sessions for the first time if this could definitely lead to regular attendance and sustained participation:

> There was a charity that did taster sessions about 18 months ago. The taster session didn't lead to anything, which I find, as a sports coach, really frustrating because you might as well not do a taster session because you’ve got these people interested and now you’re like, “Actually, there’s nothing we can provide for you after that.” Don't do a taster session if you’ve not got something to lead to. (Kate, sports development officer)

Kate’s point underlines the way in which stakeholders positioned attending for the first time as a means to an important end – ongoing participation – rather than an end in itself.

On the other hand, attending for the first time *could* also be a worthwhile end in itself, because of the importance of trying out a wide range of activities and having diverse one-off or short-term experiences. This was not necessarily with a view to regular attendance, but was intrinsically valuable as part of any healthy, happy, ‘normal’ childhood. Adele, a short breaks coordinator, described how her own son ‘has done absolutely loads and loads of activities because children as a general rule of thumb are quite fickle.’ She argued that disabled children and young people are similarly inclined to try out lots of new activities: ‘Just because you have a disability doesn’t mean that your attention span or your staying power is any better than a mainstream young person.’ She was making the point that, for all children and young people regardless of disability, childhood is – or ideally should be – characterised by diverse leisure experiences, which may be one-off or short-term, and whose value need not be defined by whether they translate to ongoing participation.

As well as intrinsic value, attending and trying out a wide range of new activities – regardless of whether they translate to sustained participation – was thought to have longer-term benefits. For example, Gail, a physiotherapist, described how, like many children, in their early childhoods her own children had tried out ‘a bit of ballet, then they did a bit of swimming, did a bit of athletics.’ She had hoped that later in childhood, when they were nine or ten, they would have ‘developed a sport that they’re really keen on and perhaps they get involved in a team.’ Her belief was that children and young people establish future leisure-related goals and roles on the back of having had earlier opportunities to attend different settings and activities, either as a one-off or in the short-term.

From the focus groups and interviews at Stage 1 of the Delphi study, attending for the first time was clearly an important action within the outcome of participation in leisure, and one that should be targeted by an intervention. However, during the survey at Stage 2, there was a mixture of support for and uncertainty about this idea. ‘Trying for the first time’ was described as a ‘fundamental indicator of success,’ and ‘turning up’ as an ‘important part of leisure.’ One parent argued that an intervention is effective ‘if it just gets people to have a go’. Conversely, one of the short breaks professionals was concerned that ‘for the first time leads to think that people with a disability have never done a leisure activity,’ and the focus on first time was described as ‘slightly strange/unnecessary.’ A researcher said that ‘I understand the importance of preparing for the first try, but I don’t think it makes sense as part of the definition.’ Some of this uncertainty can be attributed to the limitations of the survey – stakeholders may not have received enough context to understand how and why attending for the first time had been identified in the Stage 1 analysis. However, these comments might also suggest that attending for the first time as a critical milestone and/or intrinsically valuable is understood and accepted by many, but not all, stakeholders. This would have implications for the development and implementation of an intervention for supporting participation in leisure, for example if stakeholders were to overlook the importance of attending for the first time, or if measuring attending for the first time was not acceptable.

5.2 Action 2: Exploring

Exploring means children and young people getting to the point where they are doing leisure activities in their broadly recognisable and conventional forms and discovering whether they enjoy the activity. Most of the leisure settings and activities that stakeholders described were recognisable and conventional in the UK sociocultural context, for example youth clubs, swimming pools, and arts and cultural venues – this is further discussed later in the chapter in the section about context. Exploring, therefore, meant children and young people with neurodisability being in those everyday settings and getting to the point where they are doing those activities in their broadly recognisable and conventional forms – in other words, in broadly the same way as their non-disabled peers. For example, stakeholders often talked about swimming as a particularly common and desirable – but often challenging and inaccessible – leisure activity. It is reasonable to say that, in the UK sociocultural context, recognisable and conventional components of going swimming include paying at the reception desk, changing from clothes into swimwear, getting in the water, being in the water for some time, showering, getting dry, and getting dressed. When children and young people – with or without neurodisability – are exploring swimming, they are getting to the point where they are observably carrying out these components and discovering whether they enjoy it.

A critical nuance here was that doing a leisure activity in its broadly recognisable and conventional form did not mean children and young people with neurodisability having to meet a normative standard of ‘successful’ participation that may actually be inaccessible and irrelevant for them physically, socially, and/or cognitively. Exploring was not about learning to do leisure activities ‘properly’. Instead, the notion needed to be interpreted flexibly. The particular individual ways in which some children and young people with neurodisability do swimming, for example, may look quite different to their non-disabled peers. They may require physical support from another person in the water. They may want to do swimming in a different way that suits their own physicality, e.g. in warm water. The key message here was that children and young people with neurodisability can only explore activities when leisure settings and activities have been adapted to create the conditions within which exploring is possible. If such adaptations are made, then what children and young people with neurodisability are observably doing will reflect – more or less – the recognisable and conventional components of those activities, taking into account the flexibility they may require and/or desire.

A practical example of exploring comes from Lucy, aged 15 years, who took part in the go-along interview at the swimming pool with her mother Diane. Towards the end of the research programme, Lucy coincidentally joined a weekly arts group for children and young people with learning disabilities and/or autism, where I am a volunteer. This was an opportunity for me to consider in real time how I had come to define participation in leisure – particularly the action of exploring. In the UK sociocultural context, the recognisable and conventional components of participating in this, or perhaps any, arts group included, for example, working at a large making table, joining in with warm-up activities, producing artwork on paper, and interacting with peers in ways that are mutually comfortable, accessible, and enjoyable. The goal was for Lucy to get to the point where what she was observably doing more or less reflected these components. She would therefore be doing what everyone else in the group was doing, as opposed to being on the fringe, waiting or watching, or doing something different (42). But importantly, Lucy would only be able to achieve this if the lead artists and volunteers were flexible and adapted the setting and the activities, thus creating the conditions within which exploring would actually be possible.

The action of exploring conveys a sense of process, temporality, and emergence. It may take time for children and young people to get to the point where they are doing a leisure activity in its broadly recognisable and conventional form. Paul, a short breaks coordinator, gave one example that was typical of those described by several stakeholders. He talked about a young person who attended a theatre group on a weekly basis:

> [She] didn’t really want to enter the room on some weeks. The show came and she didn’t want to go into that. The next time the show came round her confidence had massively built. […] whatever level she wants to engage and she is comfortable at […] she can take her time and she can feel comfortable to do that.

Paul illustrates the gradualness of this young person’s exploration of the theatre group, and the flexibility and adaptations required. Whilst this process happens very quickly or even immediately for many children and young people, stakeholders had examples of exploring processes where getting to the point of doing the recognisable and conventional components of leisure activities emerged over up to two years. The important aspect is for children and young people to have had enough time, opportunity, and support to deal with the challenges inherent to many new leisure settings and activities, get to the point where they are actually doing the activity, and discover whether they enjoy it.

Going back to Lucy and the arts group, the lead artists and volunteers needed to deal with the challenge of learning how to successfully communicate and interact with Lucy. Lucy needed to come to understand how the arts group worked and what opportunities and experiences were and were not available. This process of exploring took some weeks. Only then were we at the point where Lucy was actually doing the recognisable and conventional components of the arts group in a way that worked for her and the other members.

I have highlighted how exploring involves children and young people discovering whether they enjoy a leisure activity. It was universally agreed across the stakeholders that enjoyment is the whole point of participation in leisure, i.e. the key consequence of attending and exploring. I did not explicitly work with stakeholders to define what they meant by enjoyment, and I recognise that the construct of enjoyment has a long and complex history within broader leisure studies (279-281). Following Kimiecik and colleagues, I understand enjoyment to be ‘an optimal psychological experience (i.e. flow) that leads to pursuing an activity for its own sake and is associated with positive affective experiences (279 p.260).

Enjoyment was not dependent on children and young people getting to the point where they are doing a leisure activity in its broadly recognisable and conventional form. For example, Lucy enjoyed exploring the arts group immediately, throughout her entire process of exploring, including well before she was doing more or less what everyone else was doing. In that sense, as well as being an outcome of attending and exploring, enjoyment could be said to run in parallel with, and to oscillate with, attending and exploring.

Whilst enjoyment is the whole point of participation in leisure, the stakeholders also highlighted how enjoyment is uncertain, in that it is not guaranteed. It is desirable – but not essential – for participation to have taken place. Children and young people do not necessarily end up enjoying every leisure setting and activity that they attend and explore, but this does not mean they have not participated. Not enjoying an activity does not negate the importance and benefit of having had an opportunity to attend and explore it for long enough, and with adequate flexibility and adaptations, to make that discovery. Enjoyment is also uncertain in that it can be dynamic and unpredictable. Stakeholders and parent advisors described how children and young people's enjoyment of leisure settings and activities may change and fluctuate over time. For children and young people with communication limitations and/or learning disabilities, it might be difficult to tell whether they have enjoyed an activity until sometime later, or they may need to be reminded that they have previously enjoyed an activity, even one they attend regularly.

5.3 Context

I specified the context of participation in leisure as 'community activity settings with peers', reflecting stakeholders' perspectives on the places, activities, and people of particular relevance to the study population (282). Stakeholders highlighted that participation in leisure also takes place in the context of solitary or family activities at home and in school, and in virtual as well as physical settings. However, these contexts did not emerge as the key priorities for intervention development within this research programme.

Stakeholders described a high number and diverse range of leisure settings and activities. The overwhelming majority of these were highly predictable and conventional, in that they probably reflect the leisure participation of most children and young people in the UK and were not somehow particular to those with neurodisability. Activity settings described within the data were largely away from children and young people's homes and outside of school hours, with common examples including youth clubs, swimming pools, sports and leisure centres, local parks, and arts and cultural venues. In this context, the term ‘community’ conveys the practical idea of activity settings within a child or young person’s local area, recognising that ‘local’ will itself be variously defined depending on the situation and people’s individual circumstances (see chapter 7). However, noteworthy exceptions were the activities of hanging out and sleepovers. These activities often (but not always) take place within the home and were identified as very important by the young people involved as advisors in the research programme (see chapter 9).

Stakeholders’ descriptions of participation in leisure almost always involved children and young people with neurodisability doing activities with their peers. This social aspect was consistently framed as the prime feature of participation in leisure, as what children and young people want to do, and as a key mechanism through which they derive fun, enjoyment, and developmental benefits such as new skills and increased confidence. Doing leisure activities with peers was thought to generally be more fun and enjoyable than individual leisure activities, for example because peers introduce the opportunity for competitive games.

Peers were also considered a key source of emotional support and feelings of joint achievement, for example in new and unfamiliar leisure activities and settings. Whilst being with others who also have neurodisability was thought to confer some special benefits related to shared experience and understanding, stakeholders highlighted that children and young people want to participate with non-disabled as well as disabled peers. The young people involved as research advisors endorsed this perspective and added that, ‘it's about getting to choose who you are with, rather than it being set for you’ (Aimee, aged 21 years). Aimee illustrates a higher-level point about the importance of children and young people having a sense of control over with whom they participate in leisure, regardless of the disability ‘status’ of the people involved.

5.4 Discussion

5.4.1 Summary of results

In this chapter I presented a definition of participation in leisure as a health outcome that was relevant and useful to a diverse range of stakeholders, including young people with neurodisability and parents. I have argued that participation in leisure involves two key actions: attending settings, especially for the first time, and exploring activities. Attending for the first time has two possible, and equally important, trajectories: as a pathway to regular attendance and sustained participation, or as a one-off experience that contributes to a happy, healthy, ‘normal’ childhood, and influences future leisure-related goals and roles. I have also argued that, within this research programme, the most important context for participation in leisure was community activity settings with peers, although I have recognised the particular importance to many young people of activities such as hanging out with friends, which may be home-based.

5.4.2 How the results compare with wider literature

The results of this research programme indicate that the action of attending is an essential requirement for participation in leisure, reflecting arguments that are well-established in the wider participation literature (e.g. 52, 283). In their Family of Participation-related Constructs, Imms and colleagues recommend that attending can be measured in terms of frequency of attendance and/or diversity of activities in which an individual takes part (283). This was borne out in the systematic review I conducted within this research programme (see chapter 3). Of the 33 separate outcomes I identified across 18 included studies, 14 related to attending (i.e. frequency and diversity of attending, estimated number of physical play/leisure activities attended per week, and overall participation coded as a binary variable: those who attended, and those who did not). Therefore, support for attending is evident across both the theoretical and empirical literature.

The particular importance of attending for the first time is a novel finding from this research programme. However, there is some evidence that its importance has been overlooked. Some stakeholders expressed uncertainty about whether an emphasis on attending for the first time is warranted, and to my knowledge this idea has received limited if any attention in the wider literature, where attending has been framed as necessary but not sufficient for participation outcomes (283). Whilst attending for the first time in and of itself may not adequately confer the benefits of participation in leisure to children and young people, the results of this research programme suggest that it is a critical step in their overall participation trajectories and would be a relevant and useful target for an intervention.

Regarding the action of exploring, previous research has also defined participation in leisure in terms of doing activities in forms that are recognisable and conventional in particular geographical and sociocultural contexts (8, 42, 284-286). To conceptualise and measure participation in leisure, childhood neurodisability research has also drawn heavily from developmental psychology where leisure as types of recognisable and conventional activities and lists of activity labels is commonplace. For example, the Children’s Assessment of Participation and Enjoyment (CAPE) is the most commonly used participation outcome measure in childhood neurodisability research (see chapter 3) (189). It conceptualises participation in leisure as seven types of activities and a list of 55 activity labels, drawing largely from empirical research within developmental psychology in the 1980s and 1990s (e.g. 287, 288, 289). Equally, there is much agreement in the wider literature that enjoyment is the whole point of participation in leisure (e.g. 32, 81, 281, 290, 291).

This research programme makes a novel contribution to defining participation in leisure by delineating the relative importance of attending, exploring, and enjoyment. I have argued that attending and exploring settings and activities are both necessary for participation to have happened, and that enjoyment of activities is desirable but not essential for participation. In other words, children and young people do not enjoy every leisure setting and activity in which they participate – enjoyment is desirable but not essential for participation. An important distinction with the concept of leisure is that attending and exploring alone may be necessary, but are unlikely to be sufficient, for leisure to have happened.

Recent research in childhood neurodisability suggests that, for leisure to have happened, the activities and settings would need to have been subjectively defined as leisure by those attending and exploring, and enjoyment would need to have been experienced (81). This suggests there may be some important conceptual differences between participation and leisure that may be useful to clarify in future research. Clearly separating these elements would enable investigation of the differential benefits of exploring and enjoying. For example, empirical evidence from within leisure studies indicates that family *participation* in leisure (i.e. frequency or duration) and family *satisfaction* with leisure were both predictive of family quality of life – but that family *satisfaction* had a larger effect size (27). Focusing on both quantity and quality of leisure is therefore important but focusing on quality may be particularly important. It would be useful to know if this also bears out in children and young people with neurodisability.

In relation to my specification of the context of participation in leisure, there is support in the wider literature for an emphasis on children and young people with neurodisability doing activities with peers. Kramer's qualitative meta-synthesis highlighted how disabled children and young people appraised the quality of their participation based on the extent to which they engaged alongside peers and had meaningful roles (42). Young disabled people have defined leisure primarily in terms of who they interacted with, as opposed to the settings or times at which activities were done, or the activities themselves (292, 293). More recently, young people with communication and mobility limitations described being with others, friendship, belonging to a social group, and a sense of social connectedness as part of the essence of leisure, and – whilst their leisure was embedded within activities – these dimensions meant more to them than the activities themselves (32). The role of these social and peer-related aspects as a defining feature of participation in leisure is further reflected in various research across children, young people, and adults (33, 64, 80, 294, 295).

5.4.3 Implications for this research programme

This chapter fulfils objective 1 within the research programme – to define participation in leisure as a health outcome. I have specified participation in leisure in terms of its key actions and context, either of which could potentially be targeted within an allied health intervention. I have not gone so far as to address how this specification of participation in leisure could be measured within an evaluation study, and I will discuss some of the issues around this in chapter 10 (summary and implications of the research programme). In the next chapter, I will present the explanatory accounts of the personal factors related to participation in leisure and bring these together with the quantitative results of the systematic review.

Table 5-1 Delphi Stage 2 stakeholder consensus on the relevance and usefulness of a working definition of participation in leisure

	Round 1 (median, IQR*)				
	P	AHP	R	SB/SC	Overall
Relevant	2 (1)	2 (1)	3 (1)	2 (2)	2 (1)
Useful	2 (2)	1 (1)	2 (1)	1 (0)	2 (1)

*1 = very effective, 7 = very ineffective, 4 = not sure, IQR = interquartile range
IQR ≤1 = consensus).
P = parents, AHP = allied health professionals, R = researchers,
SB = short breaks professionals, SC = sports coaches, Overall = overall group.

6 Chapter 6. Personal Factors Related to Participation in Leisure

In the previous chapter I set out a definition of participation in leisure as a health outcome, focusing particularly on the actions of attending leisure settings and activities, especially for the first time, and exploring activities, which means children and young people getting to the point where they are doing leisure activities in their broadly recognisable and conventional forms, and discovering whether they enjoy them.

The purpose of this chapter is to report the results for personal factors related to participation in leisure, which relates to objective 2 in the overall research programme (see chapter 2). Personal factors were defined as internal features of individual children or young people that are not part of their health condition or health state, and that play a role in their experience of disability (8). They were specified using the Theoretical Domains Framework (85). In both the systematic review (see chapter 3) and the Delphi study (see chapter 4), my emphasis was on modifiable personal factors that could be targeted and potentially changed through allied health interventions in publicly funded community healthcare settings. This chapter focuses specifically on the results from Stage 1 of the Delphi study, which involved focus groups, semi-structured interviews, and go-along interviews with diverse stakeholders (n=31), and discussions with parent advisors (see chapter 4). The results were also informed by two further collaborations with a parent and young people with neurodisability (see chapter 9).

I identified four personal factors of importance – children and young people’s emotions, goals, social role and identity, and beliefs about capabilities. This chapter presents an explanatory account for each personal factor, describing how they played out in relation to participation in leisure. I will illustrate how:

- Emotions and goals can be most usefully conceptualised as determinants of children and young people attending and exploring,
- Social role and identity can be understood as an important part of the context that influences whether and how interventions for

supporting participation in leisure are implemented, for example towards which leisure activities interventions are directed,

- Beliefs about capabilities can be positioned primarily as an outcome of participation in leisure, but also as a key part of the process of exploring, and a determinant of whether children and young people return to leisure settings to further explore activities.

Finally, in the discussion section I will bring together the results of the Delphi study with those of the systematic review and make reference to wider literature that aids further interpretation of the results.

6.1 Emotions

In the conceptual framework for the research programme, emotions were defined as complex reaction patterns, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event (85). Children and young people's emotions related to participation in leisure were central in all but a few focus groups and interviews. I generated two key themes related to emotions:

(i) 'fear of the unknown': describing the worry, nervousness, and anxiety that many children and young people – and their parents – experience about new leisure settings and activities,

(ii) 'intense emotions, high stakes': highlighting the strength of some children and young people's emotional reactions in leisure settings, and the fine line between the associated risk of serious negative consequences versus potential for significant positive consequences of participation in leisure.

6.1.1 Fear of the unknown

Stakeholders described the worry, nerves, and anxiety that many children and young people feel about attending activity settings, or even the prospect of attending, particularly for the first time. This was termed the 'fear of the unknown' by Justin, leader of an inclusive summer activity scheme. The 'fear of the unknown' may result in children and young people not attending or delaying attendance at activity settings for the first time but may also influence whether they return to further explore activities. Gail, a physiotherapist, described one example in the context of cycling:

> [I]f they didn't like [cycling], you know they were crying, not because they were hurt or because it was uncomfortable, it's just something they didn't know. (Gail, physiotherapist)

The child is crying when faced with a new activity, but these emotions are embedded in the novelty of the activity as opposed to its enactment. This is not about the child being physically 'hurt' or 'uncomfortable'. The emphasis here is on the distress tied to the novelty of the broader situation within which the activity is embedded; the novelty of the place, the people, and the material culture, as well as of the specific activity itself.

Michelle, a mother, further highlights the emotional challenge of novel situations and activities:

> I get anxious, taking her to something new. I know what that is, and I can talk my way through it, "It's alright, I know where I'm going," I can understand that, but to Sienna, she's been driven somewhere she doesn't know where she's going, straightaway it's a big, "Where are you taking me?" She's going to do something she's not done before, "What am I doing here?" (Michelle, mother)

Note how even the pragmatics of travelling on an unfamiliar route can potentially introduce a layer of worry and a series of questions and puzzles that need to be solved for the child or young person. Michelle also refers to her own anxiety about taking her daughter to 'something new', illustrating how negative emotions may be distributed across the parent as well as their child or young person. Professionals routinely described worry, nerves, and anxiety embedded in both groups. For example, James, a disability sports officer reported that it can commonly be both 'the parents [who] have been very nervous about signing the child up' as well as the child who has 'been very nervous about attending'. Parents were also described as being, at times, very worried about whether their child would be able to take part in an activity and needing to be reassured that staff in activity settings knew what they were doing. In this way, prior to raising the topic with their child, or introducing the child to a new setting or activity, parents have their own trajectory of the ‘fear of the unknown’.

Stakeholders were well-versed in the ‘fear of the unknown’ – both for children and young people, and parents. They anticipated negative emotions in advance of attendance at activity settings and considered them as something commonly experienced by children and young people in general. There was the idea that ‘all children are the same’, in that ‘you introduce a new leisure activity, unless it’s something they desperately want to do… [it’s] always a little bit frightening’ (Michelle, mother). Stakeholders were aware, in part through thinking about their own personal experiences, that as ‘a kid’ going ‘somewhere new’ meant that ‘you worry about it’ (Noreen, short breaks coordinator). And negative emotions were thought by some to be just as relevant to adults as they were to children and young people:

> But most children don’t want to do something because they’re scared, just like as adults we’re scared of doing something we’ve never done before, because we might fall, we might hurt ourselves, we might make ourselves feel foolish or look foolish. (Gail, physiotherapist)

In this way, negative emotions were positioned, in part, as a routine and therefore understandable aspect of navigating the social world. However, whilst common and well-understood, negative emotions were not described universally. For example, during the go-along interview at the children’s museum, I observed – and parents confirmed – that Thomas (aged seven years) was ‘good at going to new places, very easy-going, doesn’t need lots of preparation’ (field notes). And Lisa, a parent advisor, noted that her own ‘profoundly disabled’ son is, ‘…so chilled and laid back that he just goes with it…some children do just go with the flow.’ Whereas, in her role as leader of a parent support group, she understood that some children and young people find it ‘traumatic’ to learn to tolerate new environments, they ‘fall at that first hurdle’, and ‘then don’t come back’. ‘Fear of the unknown’ is therefore a potential determinant of whether and how some, but not necessarily all, children and young people participate in leisure.

Dave, a physiotherapist, further described how the ‘fear of the unknown’ might influence whether children and young people return to further explore activities. In an example of three separate young people who had wanted to go to the gym, he recounted how, within his particular NHS service context, he had not been able to offer enough support to ‘get them over the bumps of going to the gym’, and how after one visit the young people had ‘probably said, “Oh no, I don’t like it” and then the parents haven’t taken them.’ In Dave’s example, ‘the bumps’ represent the worry, nerves, and anxiety that the three young people experienced at the prospect of the new leisure setting and activity. Their expression of these negative emotions, in the form of ‘I don’t like it’, contributed to the discontinuation of participation. Importantly, Dave believed that the young people did in fact want to participate; that they had not simply tried it out, discovered they did not enjoy it, and moved on to something else, and that ‘if they’d have had more support, they’d have all kept going.’ This reflects stakeholders’ wider descriptions of negative emotions as a factor that is highly amenable to intervention.

Stakeholders described their considerable practical experience of routinely and successfully ‘taking away the fear of the unknown’ (Justin, leader of an inclusive summer activity scheme). Dealing with negative emotions was also, on the whole, considered by stakeholders to be a key function of interventions for supporting participation:

> We’ll try it again in three months’ time, when perhaps he’s gotten over this fear. And it’s also about coaxing children into doing what we know they will enjoy, but might be a little bit unfamiliar with them. And that’s what we do with our own children; we don’t…If we think they’d love cycling, we’re not going to give up because they didn’t want to go on, or because they’re crying…We’re not going to let that hinder them. (Gail, physiotherapist)

Here, Gail frames the ‘fear of the unknown’ as something that is commonly experienced by children (as discussed above), something that simply needs to be – and usually is – ‘gotten over’ with support (i.e. amenable to intervention, as discussed above), and – similarly to Stuart’s example – something that should not necessarily be interpreted as children not wanting to participate. Instead, the imperative is to support children and young people to persist through negative emotions towards participation in the activities that ‘we know they will enjoy’, and ‘we think they’d love’.

6.1.2 Intense emotions, high stakes

Stakeholders described some children and young people whose emotional reactions in leisure settings were particularly intense. This generally related to children and young people with moderate-to-severe learning disabilities and/or autism. Their emotions could be stronger than those of other children and young people, whether disabled or in the wider population, they could last longer, and continue well into adolescence. Intense emotions manifested in part as a more extreme ‘fear of the unknown’ in new leisure activity settings, or as a response to changes in the physical or social environments of more familiar settings, or as a result of exploring the setting and the activity. In other words, intense emotions could be both a potential determinant and consequence of these children and young people’s participation in leisure. Their feelings in and about leisure settings could also change quickly – and sometimes apparently unpredictably – from intensely positive to intensely negative. Stakeholders were particularly concerned about the risks and consequences of extreme negative emotions like anxiety and distress.

Lucy’s experiences serve as one detailed illustrative example of the nature and impact of intense emotions related to participation in leisure. Lucy is aged 15 years and has learning disabilities. Along with her mother Diane, she took part in a go-along interview at the disability swimming session she attends most weeks in her local swimming pool. In a separate individual interview, Diane recounted one of the first times she had taken Lucy to the session:

> Reception areas in leisure centres were a nightmare. So many people to touch, hug, and engage with. When we finally got into the changing room, she was self-harming, screaming, and hitting out. The swimming pool was another level of sensory overload. She was overwhelmed. […] She was overexcited and overstimulated to get her in when she hadn’t been swimming very much. […] So she goes in the water. […] she won’t come out. […] I can’t get her out of the pool; I can’t get her to the changing room. I can’t get dressed, because she’s very inappropriate and becomes very anxious and angry and is wanting to get out of the changing room. […] It’s

> traumatic […] and this is the first time I'd taken her locally to a special-needs disabled swim […] lots of noise, lots of unknowns, lots of courage on my part, adjustments to, "Is it risky?" or whatever. […] Then she wouldn't come out of the swimming pool. I totally get it: "Why would I want to come out? This is fantastic, this is unbelievable. It's hitting all my senses. There's no way I want to finish this." (Diane, mother)

Diane highlights the strength of Lucy's emotional reactions, which ranged from very positive to very negative, and were sustained in their intensity throughout the swimming session. Whether Lucy was, in part, experiencing an extreme 'fear of the unknown' is open to interpretation. However, it is conceivable that her subjective experience may have in fact been of three relatively unfamiliar settings – the reception area, the changing room, and the swimming pool itself, all in the context of a relatively new leisure activity – going swimming with her mother, as opposed to with her class from school.

Although Lucy continued to explore swimming, as I will further describe later in this section, intense emotional reactions could lead to discontinuation of participation or lack of initiation of new activities. Two examples illustrate how this might come about. Sam, a mother who took part in a parent involvement workshop, described her son's reaction to swimming, recalling that he was 'grabbing my neck, grabbing hold of my ears, scared stiff' and 'screaming his head off.' Sam 'then left it for a year…because I myself couldn't cope with it all the time.' Gemma, a speech and language therapist, described a mother who 'hadn't really used a short break for a while', because 'she didn't feel comfortable and confident taking [her son] out anymore. He's a teenager now and he was quite unpredictable.' Her reference to 'unpredictable' encompassed the behaviours thought to result, at least in part, from this young person's emotional reactions particularly in unfamiliar situations. These examples highlight how the impact of intense emotional reactions on parents, who largely mediate children and young people's participation in leisure, may be one pathway explaining participation restrictions.

Intense emotional reactions went hand in hand with high stakes, in other words the simultaneous risk of serious negative consequences, and potential for significant positive consequences of participation in leisure.

Continuing with Diane's detailed account of Lucy's swimming, there were two particular points at which she described serious negative consequences. The first was an incident occurring during one of Lucy's first disability swimming sessions. She would not come out of the swimming pool and Diane described how the pool manager, without warning, physically removed her:

> He put his arms in […] got hold of her hands […] and he just lifted her up bodily […] and he turned around and he put her down […] [Lucy] went absolutely ballistic […] She had a meltdown and she was thumping me, she was biting me […] She was biting herself because she self-harms. The outcome is we were both injured, she and I. I was very distressed and hurt, and she was. (Diane, mother)

Diane highlights the severe negative consequences of this particular incident, including physical injury and emotional distress for both Lucy and herself. The second point related to changes in the physical environment that occurred when Lucy had been attending the disability swimming sessions for some months and was familiar with the setting. Without notice, a padded bed in the changing room was replaced with two commode chairs and two baby changing mats. Lucy was 'confused and distressed' in response to these changes, because 'it means that the routine is done completely differently…she was quite thrown…she had hit Diane a few times. Diane's now having to dress and dry Lucy while she's stood up, which is awkward' (field notes). Again, the negative emotional consequences for both Lucy and Diane are highlighted, as well as the 'awkward' physical and practical consequences for Diane.

Conversely, Diane also described key significant positive consequences of Lucy's participation in swimming. At the time of the go-along interview, Lucy had been attending the disability swimming session for over one year and had learned how to be in the setting and how to swim independently. Diane spoke with great personal pride about their achievement, and described working for 'nine months, week in, week out, to get Lucy to come out of the swimming pool when asked, and we never gave up, and it got hostile and it got difficult.' She also described considerable physical and emotional benefits for Lucy, including 'socially, physically because of her medical needs, emotionally, confidence building, an ability to listen and to take somebody's instructions.'

The high stakes associated with some children and young people's intense emotional reactions meant that, for parents, participation in leisure involved a 'fine line' between letting their children 'do something to see if they'll enjoy it', and 'traumatising somebody' (Sam, mother who took part in a parent involvement workshop). Diane described this tension in terms of 'risk assessments versus pleasure.' Parents had to weigh up whether the nature and likelihood of the potential gains were worth the risk of the potential losses – as well as the considerable practical effort involved, a factor that I will further discuss in chapter 7. In fact, across both emotional themes ('fear of the unknown' and 'intense emotions, high stakes'), several stakeholder groups – both parents and professionals – were navigating 'fine lines' and related dilemmas about how much to push children and young people towards, and how much to protect them from, participation in leisure.

Importantly, the young people with neurodisability involved in the co-production project shared insights into these 'fine lines.' Holly (aged 17 years) recognised that 'when children aren't comfortable with an activity it takes time to get used to it, to get involved', which relates closely to the idea I have presented about persisting through the 'fear of the unknown', and conveys the notion of pushing children and young people towards participation in leisure. Conversely, Aimee (aged 21 years) was concerned that young people should not be 'made to do a leisure activity…pushed too hard', and Sol (aged 16 years) added that it was acceptable to 'try a bit of coaxing but don't go too far', which is more aligned to the idea of protecting children and young people from the risk of serious negative consequences.

6.2 Goals

The term 'goal' was used liberally but almost exclusively by the allied health professionals in the sample (n=105 uses by allied health professionals, compared to n=5 uses by all other participants). However, the concept of goals, meaning mental representations of outcomes that an individual wants to achieve or end states than an individual finds desirable, was implicit in stakeholders' discussions of 'what children and young people want to do' (85, 199). Such discussions were central in almost all the focus groups and interviews.

All stakeholders recognised the influence on participation in leisure of 'what children and young people want to do', and this relationship was sacrosanct for the short breaks professionals in particular:

> In the city it is not about going to visit a young person and going, "So you want to go somewhere, what is your postcode?" "[postcode]" "Right in your area tomorrow night there is a club that starts, you can go there." It doesn't mean anything to that young person, the young person isn't going to engage and want to go or get anything out of doing something they feel they have to go to because we told them to go to it and because they can get there themselves. It has to be something that they want to do. (Adele, short breaks coordinator)

Adele highlights two important dimensions of children and young people's goals. First is the notion that children and young people doing what they want to do, as opposed to what happens to be available or accessible, or what they have been told to do, is how they derive meaning from and 'get anything out of' leisure activities. Second, and of more direct relevance to my research programme, is the role of children and young people's goals as a determinant of their participation in leisure. In other words, for children and young people to 'engage' in a leisure activity (i.e. to attend and explore) it 'has to be 'something that they want to do.'

Establishing goals for participation in leisure directed much of the adult stakeholders' interactions with children and young people. Across their interactions, I identified three distinct scenarios highlighting the different ways in which children and young people's goals materialised:

- 'pre-formed goals' – where children and young people already know and can state what they want to do,
- 'co-constructed goals' – where goals are established on the basis of children and young people's general interests and professionals' intimate knowledge of local leisure activities,

- ‘relational goals’ – where parents and professionals make informed judgements about what children and young people would probably want to do now and in the future.

The diversity across the scenarios indicates that much flexibility and nuance is required in how the construct of goals is operationalised with children and young people. The scenarios focus as much on setting goals, an intervention technique, as they do on children and young people’s goals as a causal mechanism of participation in leisure. However, it was almost invariably by describing their interactions around goal-setting that stakeholders made visible the nature and importance of the relationship between goals and participation. The central idea shared across the scenarios is that children and young people’s goals for participation in leisure influence their actual participation by directing the support provided by adults.

6.2.1 Pre-formed goals

This was the most commonly described of the three scenarios and was characterised by a straightforward type of interaction directly between children and young people and adults. Children and young people knew what they wanted to do, and could make that clear:

> Yes, we have been up to Newcastle. Paul got some funding, they are into wrestling and football, so we managed to take them up to Newcastle to see WWE wrestling and we have been to Leeds to see them as well. […] We have done cinema trips once a month and trips into town to a classic car show because they are into their cars. We even visited a local car showroom in the city that’s like sport Lamborghinis and Porches, they are really into their cars and we even managed to get a visit arranged there. Basically they decided what they wanted to do and we made it happen. (Jim, short breaks coordinator)

Jim’s example highlights how minimal interactional work was required to establish an understanding of these young people’s goals, and how the goals directed the participation support provided. The ‘pre-formed goals’ scenario relied on an underlying conceptualisation of goals as things that have already been formed in children and young people’s minds prior to their interactions with adults, meaning that adults need only ask: what do you want to do? This assumption held across numerous examples from stakeholders interacting in diverse contexts, typically with individuals, but there were also examples related to groups and populations. For example, in one local authority covering a large city in the North of England, the short breaks coordinators described how they are ‘always doing consultations with children to get more information about what the next thing they want to do is’ (Paul, short breaks coordinator). The team described how they asked young people and families in the city about what they wanted out of a short break. One of the biggest things they identified was residentials, which led to them ‘organising a residential summer camp for children to come with us’ (Adele, short breaks coordinator). Again, Adele’s example highlights how some children and young people have pre-formed goals and are able to articulate them, and how professional support directed by these goals mediates the relationship between the goals and participation in leisure.

6.2.2 Co-constructed goals

In the second goal scenario, children and young people had only a general idea of, or did not know, what they wanted to do. Therefore, adults – in this dataset, often professionals – needed to do more interactional work to establish goals that would direct participation support. This work took the form of probing into children and young people’s interests, listing options, and recommending activities, effectively proposing candidate or provisional goals to be finalised or rejected after children and young people had experienced the particular activity first-hand. Abi, a physiotherapist, provided an example of a 13 year old girl who ‘absolutely loves sport’:

> I kind of got the impression that “If you love sport so much, what are you doing outside of school?” and she’s not doing anything. […] This list of activities that I was running through, I pulled it up on the computer and I said, “Right, you’re really sporty, you’re so determined. You’re going to choose one of these activities.” I was reading through them; she’s like, “No, no. No, that’s a Saturday; no, I want a lie in.” I said, “Well, no, I’m not taking no for an answer,” so we went through and she then picked out sailing so went away and gave her the information on sailing. She said “Yes, that would be really, really good,” and then she said her brother would quite like to go with her. It’s kind of something that if I hadn’t have had that like

> push, push, push, would she have done it? Potentially not. The hope is when I see her again I'll obviously follow up on it and see if she has attended […] If not, why not? (Abi, physiotherapist)

In this example, the conceptualisation of goals as things pre-formed in children and young people's minds, as per the first scenario, would have had limited practical use. The young person is interested in sport generally, and Abi works to establish more specifically what she wants to do by listing options. This active co-construction of a goal can be conceptualised as a joint decision-making process distributed between the two of them. Critically, the success of Abi's interactional efforts to establish a goal depend upon her having intimate knowledge of available local leisure activities; she mentions her 'list of activities', which is comprehensive information about 15 accessible leisure activities in her borough that she described spending days putting together. It is noteworthy that, in other examples, professionals also had intimate knowledge of the nature of local leisure activities, for example how and by whom they were facilitated, and whether they were perceived by children, young people, and parents to be of good quality. As well as enabling those professionals to list options, as Abi did, intimate knowledge of the nature of activities enabled them to go further and more pro-actively recommend activities that were both available and likely to be a successful experience for the child or young person. Intimate knowledge is further discussed in chapter 8.

6.2.3 Relational goals

The third goal scenario related to children and young people who were unable or found it difficult to clearly express what they wanted to do, or for whom parents and professionals found it difficult to know what they wanted to do. These were typically children and young people with communication limitations, often related to moderate-to-severe learning disabilities. Asking these children and young people what they wanted to do (as per the first scenario), or listing options and making recommendations (as per the second), would have had very limited relevance and accessibility. Instead, parents and professionals acted as proxies, making decisions on their behalf. For example, Sandra, a parent advisor, noted how her son would ‘never’ really be able to say what he wanted to do, and therefore she had to be ‘a bit of his investigator.’ In this way, decisions about participation in leisure were highly relational as they were based on adults’ experience of what they felt children and young people had enjoyed doing in the past. Experience enabled them to make informed judgements about what children and young people would probably want to do now and in the future. Michelle, a mother, described an example of how this was necessary but challenging:

> Yes, and that’s the trouble, because she’s not verbal, because obviously she can’t see something out there and go, “I want to do that, and I want to do that,” so you’re always looking and trying to spot stuff she can do and can get involved with. So it’s a case of sometimes saying, you want to give her the choice, “Do you want to do it?” Sometimes she doesn’t understand what that choice is, so it is a case sometimes of just going and taking her, and saying- You know, because she didn’t want to go to the bikes, the race running, and when we got there, and luckily the other little boy is a friend of hers from mainstream school who’s got cerebral palsy. When we actually got there, she saw Liam, she was happy, “Oh right, great, Liam is here,” and then when we got on the track and she saw them and she realised they were like virtually what she had [at school], she couldn’t wait to get on it. But if I’d have just said, “Sienna, do you want to go race running?” and shown her a picture, she’d have just gone, “No.” (Michelle, mother)

Similarly to the previous example of Sandra and her son, Michelle highlights how her daughter Sienna is unable to reliably say ‘I want to do that’, and so Michelle needs to decide on her behalf based on her experience that Sienna wants to do a similar activity in a different setting (i.e. school). Her picture of what Sienna wants to do is therefore situational and emergent as well as relational, built up over time and with experience across different contexts.

Importantly, Michelle identifies a key challenge in these relational goal scenarios. She wants to give Sienna choices but risks further restricting Sienna’s participation if she acts in accordance with those choices, which in any case she takes to be unreliable. But separately in the interview she gives examples of taking Sienna to activities, ‘and you think she’s going to love it, and then when you actually get to it, she doesn’t want to do it at all […] And she does make that decision, she will quite clearly tell you if there’s something she doesn’t want to do.’ Relational goals therefore involve a degree of trial and error and the ability to differentiate between unreliable and definitive choices on the part of children and young people.

Of the three goal scenarios, this third one entailed the greatest risk of goals for participation in leisure not actually materialising, which in turn meant that adult support was not directed towards participation in leisure. Gemma, a speech and language therapist working within a short breaks service, described a mother who no longer felt comfortable and confident taking her teenage son to leisure settings because of his unpredictable behaviour:

> That has turned into a much broader piece of work saying, this is impacting – it's not just his leisure. She doesn't take him out of the house to go anywhere anymore, like just walking. Mum didn't drive, so that turned into, we need maybe a referral to CAMHS, we need to loop social services in. That turned into a much broader scope, didn't it? We weren't really able to set a goal because we don't know what is realistic then. (Gemma, speech and language therapist)

Gemma is describing a young person with moderate-to-severe learning disabilities and autism for whom a relational approach to establishing what he wants to do is required. However, neither his mother nor the professionals involved in his care appear to make decisions about participation in leisure on his behalf, based on their experience of what he has previously enjoyed. The reasons for this cannot be known from the information available in Gemma's account. However, it is clear that, in the absence of an established goal, professional support is quickly directed away from participation in leisure (which is the purpose of Gemma's involvement) and towards a 'much broader scope' including referrals to other services and agencies. Note Gemma's conclusion that establishing a leisure goal had not been possible in this situation, and her uncertainty about what leisure may be realistic for this young person. So, not only is professional support intended for participation in leisure directed elsewhere, and goals as a causal mechanism of participation in leisure thought not to apply, but the feasibility of participation in leisure itself is questioned for this young person. Gemma's example serves as an illustration of one way in which children and young people who are unable or find it difficult to clearly express what they want to do may become particularly vulnerable to participation restrictions.

6.3 Social Role and Identity

Social role and identity was understood as a coherent set of behaviours and displayed personal qualities of an individual in social settings, and forms an important part of the wider context within which interventions for supporting participation in leisure are developed and delivered (85, 296). Stakeholders described participation in leisure as a major part of 'being a young person' (Adele, short breaks coordinator) and closely connected participation to discovery and affirmation of children and young people's identity:

> It's their identity; it's them as an individual. They are a United fan, they are a reader, they are a sports person or they're a Minecraft geek you know. It gives them an identity and it gives them… You're acknowledging who they are. (Connie, occupational therapist)

Connie describes the inextricable links between what children and young people do in relation to leisure activities and who they are as individuals. Her examples focus on social role and identity in the present, but stakeholders recounted varied stories of children and young people whose trajectory of participation in leisure over time had been instrumental in the formation of new roles and identities. This was commonly, but not exclusively, described within structured sports programmes such as adapted cycling, where children would start out as participants, progress to volunteer roles, and end up in positions of paid employment. There were examples of similar trajectories in diverse contexts such as a water park project, a learning disability theatre company, and an accessible summer activity scheme.

The key idea that underpinned the connections between participation in leisure and social role and identity was that of equivalence between children and young people with and without neurodisability. What those affected by neurodisability want to do, and what stakeholders thought they should be doing, were the same as their non-disabled peers. In particular, there were shared understandings across the stakeholders of particular ages and developmental stages at which most children and young people do certain types of leisure activities. These norms were described as applying equally to all children and young people, albeit with those affected by neurodisability requiring more support to participate. Examples included getting a tricycle for your third birthday, cycling independently around age seven or eight years, and staying away from home on a school residential around age ten years. Activities such as swimming, Brownies, dancing, and learning to play a musical instrument were described as being equally relevant to all primary school-aged children, and becoming more independent and hanging out with your mates described as a key feature of life for all teenagers.

As well as what they want to do and should be doing, this principle of equivalence between children and young people with and without neurodisability was also expressed explicitly in terms of identity, i.e. their common experience of being a child or young person. Kate, a sports development officer, commented that, ‘At the end of the day, they’re still kids that have got the same needs as mainstream kids.’ Although an obvious-seeming idea, Kate’s statement resonated in particular with three mothers taking part in a parent involvement workshop:

> Sam: At the end of the day, they’re still kids. Okay, they’ve got different needs, but they’re still kids, they still will enjoy what any other kid will enjoy. Why shouldn’t they?
>
> Sandra: I suppose the concept that they’re still kids, is like, we think they should be enjoying their childhood. What does childhood mean? It’s being the same and doing all kinds of different stuff. So, yes, they are still kids […]
>
> Lisa: And it’s about removing the disability there, because once you remove the fact that there is a disability there, they are still a child. And they still deserve to be a child.

Sam and Lisa highlight the fundamental sameness of children and young people with and without neurodisability (‘they’re still kids’, ‘they are still a child’) and Sam clearly separates this fundamental sameness of identity from the practical reality of disabled children and young people having ‘different needs’ (i.e. participation support needs). Sandra further highlights how this sameness is expressed through disabled children and young people doing the same wide variety of leisure activities as other children and young people (‘all kinds of different stuff’).

6.4 Beliefs About Capabilities

Beliefs about capabilities were defined as acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use, and included constructs such as self-confidence, perceived competence, self-efficacy, and self-esteem (85). Stakeholders positioned beliefs about capabilities primarily as an outcome of participation in leisure, i.e. something produced during and subsequent to participating. For Gerry, a disability sports coach, positive beliefs about capabilities were the whole point of participation in leisure; he explained that ‘what we’re trying to do is build the confidence.’ And Adele, a short breaks coordinator, described how ‘things like their self-esteem and their confidence and all of those underlying things are raised through accessing a short break […] If they didn’t go to that club their confidence, their self-esteem […] all of that goes. How would you fill that gap?’

A key dimension of how participation in leisure generated positive beliefs about capabilities was through children and young people experiencing mastery within the context of leisure activities. In other words, their experiences of doing and persevering with challenging leisure activities until they are successful. This was particularly pertinent in relation to sports, where ‘actually sometimes they need to make mistakes within coaching and develop themselves’ (Kate, sports development officer), and ‘making sure that young person is challenged’ was thought to be a central element (James, disability sports officer). In a similar way to how Gail (physiotherapist) framed the ‘fear of the unknown’ as something that many children and young people simply need to get over, Dave, also a physiotherapist, framed persevering through challenge as a common feature of sports and physical activities that ‘all of us’ need to deal with, i.e. something that is not specific to children and young people with neurodisability:

> Because it’s, in a way, so easy for them to fail at something if they’ve only done it once, I think I would look at my role as trying to

> encourage them to keep trying something. You know, at least giving something a reasonable go to see whether they can get it. And I think it’s only when you start to get a little bit better at something, that you actually you start enjoying it. And that goes for all of us. (Dave, physiotherapist)

Note how Dave highlights that doing something once is unlikely to be adequate for experiencing success, and that mastering an activity – in this case getting ‘a little bit better’ at it – is linked to enjoyment. Importantly, mastery experiences and the notion of perseverance were not exclusive to participation in sports. Paul, a short breaks coordinator, recounted an example of a young person he had supported to attend weekly rehearsals with a theatre group. He described how she ‘didn’t really want to enter the [rehearsal] room on some weeks. The show came and she didn’t want to go into that. The next time the show came round her confidence had massively built.’ Again, his example illustrates that some young people will require considerable time and support to persist with attending and exploring leisure activities until they are successful, which for this young person meant feeling ‘safe’ and ‘comfortable’ (Paul, short breaks coordinator).

6.5 Discussion

*6.5.1 Summary of result*s

One of the key objectives in this research programme was to identify modifiable personal and social environmental factors that influence participation in leisure (objective 2). I systematically reviewed the existing evidence on personal and social environmental factors (see chapter 3) and further explored this topic with diverse stakeholders in Stage 1 of the Delphi study (see chapter 4). This present chapter has reported the results of Stage 1 of the Delphi study, where I identified four personal factors of particular importance: children and young people’s emotions, goals, social role and identity, and beliefs about capabilities.

6.5.2 How the results compare with the systematic review and wider literature

Stakeholders identified children and young people’s emotions as an important determinant (and consequence) of attending and exploring leisure settings and activities. However, the systematic review identified inconsistent quantitative evidence supporting this relationship (see chapter 3). The discrepancy in these results can be explained at least in part by two important distinctions between the studies. First, in the Delphi study emotions were conceptualised as children and young people’s complex reaction patterns specifically within the context of participation in leisure. Some aspects of emotions (e.g. the ‘fear of the unknown’) were framed as being commonly experienced by children and young people, and therefore largely developmentally appropriate. Conversely, in the review, emotions were primarily measured using the Strengths and Difficulties Questionnaire which conceptualises emotions as symptoms of mental health or behavioural disorders that children and young people experience across life contexts, for example generalised worry or anxiety (190). It is possible that such different conceptualisations, and the different methods used in their elicitation and measurement, would generate different results. Second, the Delphi study related to children and young people with neurodisability who experience communication and/or mobility limitations, with the results including a particular focus on those with moderate-to-severe learning disabilities and/or autism. However, the review only included papers about children and young people with communication and mobility limitations. Broader population inclusion criteria in the review may well have generated different results.

In the context of the discrepancy in the results between the two studies, it is noteworthy that three previous reviews found significant associations between emotions and physical activity of children, young people, and adults with physical disabilities, including but not limited to leisure-time physical activity (136, 161, 195). Overall, the results on emotions from the Delphi study offer a specific, contextually valid, and definitive change mechanism to include in an intervention for supporting participation in leisure of children and young people with neurodisability and have at least some broad support in the wider literature. They also draw attention to the inextricable links between children and young people’s emotions and those of parents.

Children and young people’s goals for participation in leisure were identified by stakeholders as a key determinant of their actual participation (i.e. of attending and exploring). However, goals did not feature as an independent variable in any of the studies included in the systematic review (see chapter 3). The review did find a consistently positive association between children and young people’s preferences for particular leisure activities and their participation in those activities. In chapter 3 I discussed that, whilst further clarification of the theoretical underpinning of preferences is required, it would seem to align with the construct of goals. Specifically, the instrument used to measure preferences in the systematic review papers, the Preferences for Activities of Children (PAC), presents the child or young person with a series of activity cards and asks, ‘If you could do anything in the whole world, would you like to be (doing the activity on the card)?’ The response options are, ‘I would not like to do at all,’ ‘I would sort of like to do,’ and ‘I would really like to do’ (189). This would appear to closely relate to the Delphi stakeholders’ implicit conceptualisations of goals as ‘what children and young people want to do’. Indeed, the PAC manual recommends that preference ratings ‘are used to identify activities that the child would like to pursue, which is particularly helpful in setting goals’ (189 p.53). Recent research lends further support to the equivalence of goals and preferences. A conceptual analysis of participation defined preferences as ‘the interests or activities that hold meaning or are valued’ (283 p.5) and empirical studies of participation interventions have either used the constructs virtually interchangeably (60, 297) or focused exclusively on goals (59, 298). Therefore, I elected to include children and young people’s goals as a key mechanism in an intervention for supporting their participation in leisure.

Social role and identity did not feature as an independent variable in any of the studies included in the review (see chapter 3) but was identified in the Delphi study as an important part of the wider context within which interventions for supporting participation in leisure are developed and delivered. Participation in leisure is well-recognised as being related to the formation and expression of social role and identity in children, young people, and adults with and without disabilities (286, 295, 299-302). Wider evidence also supports the results in my research programme that highlight how, when it comes to participation in leisure, children and young people with and without neurodisability generally want to do the same sorts of things (42, 246, 284). Therefore, when developing interventions for supporting participation in leisure, one starting point should be an understanding of what children and young people want to do and are doing in that particular intervention context (e.g. city, town, neighbourhood, community). Such understandings will likely inform the goals that are established for participation in leisure of children and young people with neurodisability.

The results for children and young people's beliefs about capabilities were consistent across the Delphi study and the systematic review (see chapter 3). Stakeholders considered beliefs about capabilities to be closely related to participation in leisure and highlighted the importance of mastery experiences, i.e. experiences of persevering with challenging activities until successful, particularly but not exclusively in sports and physical activity contexts. The review also found a positive association between beliefs about capabilities and participation in active physical activities in particular, a result which is consistent with previous reviews and has a strong wider evidence and theory base, as highlighted in chapter 3. For their well-established influential role across participation in leisure and wider health behaviours, I included beliefs about capabilities as a key factor within my intervention development.

However, I encountered some complexity regarding where beliefs should be positioned in relation to participation. The evidence from the systematic review within this research programme is based on four cross-sectional studies, and so does not fulfil the temporality criterion for establishing causal relationships and cannot clarify whether beliefs about capabilities predicts participation or vice versa. The stakeholders positioned beliefs primarily as an outcome of participation in leisure, whereas a recent evaluation described the role of 'self-confidence' in both the processes and outcomes of an intervention for supporting participation in physical leisure (56). Theoretically, the main way to change beliefs about capabilities is by actually doing the behaviour under consideration. Therefore, I have positioned beliefs about capabilities primarily as an important part of the process of exploring and a consequence of exploring leisure activities, but also as a potentially important determinant of whether children and young people attend leisure activities subsequently, either to further explore the same activity or to try a new activity.

6.5.3 Implications for this research programme

This chapter fulfils one aspect of objective 2 within the research programme – to identify modifiable personal factors that influence participation in leisure. I have identified: (i) children and young people's emotions and goals as key factors influencing whether children and young people participate, (ii) their beliefs about capabilities as an important part of the process and a consequence of participating, and (iii) their social role and identity as an important part of the wider context within which interventions for supporting participation in leisure are developed and delivered. In the next chapter, I will present the explanatory accounts of the social environmental factors related to participation in leisure and bring these together with the quantitative results of the systematic review.

7 Chapter 7. Social Environmental Factors Related to Participation in Leisure

In the previous chapter I set out the results for personal factors related to participation in leisure of children and young people with neurodisability. This chapter uses a similar structure to report the results for social environmental factors, which also relates to objective 2 in the overall research programme (see chapter 2). Social environmental factors were defined as features of the people, processes, or social structures surrounding children and young people, such as the attitudes and actions of others. They were specified at Stage 1 of the Delphi study using the Theoretical Domains Framework and the World Health Organization's International Classification of Functioning, Disability, and Health (8, 85). As with the personal factors, my emphasis was on modifiable social environmental factors that could be targeted and potentially changed through allied health interventions in publicly funded community healthcare settings. The results were also informed by two co-production projects with a parent and young people with neurodisability (see chapter 9).

I identified six parent-related social environmental factors of importance. This chapter presents an explanatory account for each them, describing how they played out in relation to participation in leisure:

1. Parent **goals** – what they wanted their children to do, and what they wanted their families to do together – were central. They were a fundamentally important determinant of children and young people's participation, in that they focused parents' attention, efforts, and actions towards participation. However, this could only be the case if: (i) participation in leisure featured prominently in parents' broader and values and priorities, and (ii) the goals were congruent with the immediate practicalities and logistics of their everyday lives, because these influenced whether and to what extent their attention, efforts, and actions could be realistically focused towards participation.
2. Parent goals were also shaped by their outcome expectancies (i.e. **beliefs about consequences**). They weighed up of whether the benefits they expected their children and young people to get out of

particular activities were worth the practical work they would have to put in to support participation. They judged whether the expected outcomes were worth the effort.

3. Goals were also shaped by parent **beliefs about their own capabilities** to support their child's participation in leisure.
4. Parent **beliefs about their child's capabilities** to participate further shaped the goals.
5. These factors were permeated by parent **emotions**.
6. Finally, parents' detailed **knowledge** of specific settings and activities was important because it influenced their outcome expectancies, and their beliefs that their children were capable of participating.

I will also present four important features of the local leisure context that may influence and be influenced by the health outcome of interest (i.e. participation in leisure), towards whom an intervention is directed, and whether, where, how, and by whom it is implemented:

1. The availability and accessibility of leisure settings and activities,
2. Leisure and short breaks services and systems, particularly factors related to 'workers' (i.e. activity leaders, personal assistants, and carers),
3. The social network of people and organisations supporting participation in leisure,
4. Transportation services, systems, and policies.

Finally, in the discussion section I will bring together the results of the Delphi study with those of the systematic review and make reference to wider literature that aids further interpretation of the results.

7.1 Parent Goals

In the conceptual framework for the research programme, goals were understood as mental representations of outcomes that an individual wants to achieve or end states that an individual finds desirable (85, 199). In relation to participation in leisure, parents' goals encompassed what they wanted their children to do, and what they wanted their families to do together. The goals influenced participation by focusing parents' attention, efforts, and actions towards particular, often challenging, activities. For example, Connie, an occupational therapist, described two parents who organised birthday sleepovers for their sons with Duchenne muscular dystrophy. Sleepovers were challenging because of the assistive technology required by both young people, but the parents 'wanted to invest the time in it […] they really, really put that in.' The pathway between parents' goals, their efforts and actions, and their children's participation was apparent for groups of parents as well as individuals. Seb, an inclusive sports development advisor, described the example of frame football, an adapted sport for children and young people who use walking equipment. The game was invented and developed by 'a group of families that had kids that were using frames that wanted them to play football […] it's coming out of people wanting to play.' Parents' efforts flowed from their desire and their children's desire to do the activity.

Another key component of the trajectory from parents' goals to children and young people's participation was enjoyment:

> Are the parents enjoying it? And then they would go to an activity, just like you or I would take our children to an activity; we don't take them either if they don't enjoy it. (Gail, physiotherapist)

Gail explains how the enjoyment of both the children and the parents serves to maintain parents' goals and sustain their efforts and actions towards particular activities – in this case taking the children to adapted cycling. She also frames this feedback loop between enjoyment, goals, and efforts as universally relevant, and not specific to parents whose children and young people are affected by neurodisability.

Centrally, parents' goals were embedded in a broader hierarchy of what they valued and held important both in relation to participation in leisure, and to their parental role and identity. Michelle, mother of Sienna (aged 10 years) highlighted participation in physically active leisure as an important principle guiding her priorities for both her children:

> She was a very active child. We were always active with our son, so she did swimming, she did dancing, running, you know, athletics, anything we could get her involved in that she would have a go at, we got involved. (Michelle, mother)

Her children’s participation in physically active leisure was a direct expression of Michelle’s desired identity as a physically active parent. When she described the considerable practical challenges involved in supporting Sienna’s participation, Michelle described a ‘fear of apathy […] that suddenly I’ll go “I can’t be bothered” […] I don’t want that to be me as a mum.’ Her desired identity influenced the sorts of activities Michelle wanted Sienna to do, her subsequent efforts and actions towards those activities, and in turn Sienna’s participation. Conversely, Paula, a physiotherapist, described a young wheelchair user who lives with his family above the shop that they run. The parents ‘are very much tied to being at that shop, because they don’t employ staff’ and they ‘don’t do a massive amount themselves’ in terms of participation in physically active leisure. Paula is unaware of what these parents may hold particularly important. However, it is plausible that their values – and therefore their related goals, efforts, and actions – are focused on areas other than participation in physically active leisure, for example work or education. Parents’ goals may therefore be a powerful mechanism that could be targeted by an intervention to support participation in leisure, but this is likely to depend on whether and how participation in leisure features within their broader values and priorities.

7.2 Parent Everyday Practicalities and Logistics

As well as their broader values and priorities, parents’ goals for their children’s participation in leisure were also embedded within the practicalities and logistics of their everyday lives. Within the conceptual framework for the research programme, these were understood as parents’ environmental context and resources, in other words any circumstance of their situation or environment that encourages adaptive behaviour, in this case participation in leisure (85). The practicalities and logistics within which parents’ goals for children’s participation were embedded included a number of factors: mothers’ hours of employment, where families lived in relation to activities, when families had free time in their weekly routines, the timing and duration of activities, availability of transportation, availability of practical support, and the need to balance employment, children, and managing the household.

The degree of congruence between parents' goals and everyday practicalities influenced whether and to what extent their attention, efforts, and actions were focused towards participation in particular desired activities. Where desired activities were in harmony with the practicalities that were most important to particular individual or groups of parents, these were goals that the parents could support and pursue. For example, Diane, mother of Lucy (aged 15 years), described how she wanted an activity for 'family time altogether' specifically on Sunday afternoons, and tried out an autism-friendly trampoline session because 'this just ticked the box' in terms of the timing of that activity – her most important practical consideration. Adele, a short breaks coordinator, described a consultation exercise with children, young people, and parents across one local authority covering a large city in the north of England. Parents wanted the local authority to provide more day trips as opposed to more activity clubs, which Adele thought was because 'a trip tends to last six hours and includes transport.' Trips were therefore more feasible for many parents to support in the context of their daily and weekly routines.

Where desired activities did not fit in with practicalities and logistics, parents adapted their goals accordingly:

> Yes, I would like to get her back into the swimming, because she does love it. She loves being in the pool, but (…) we've got a son who's nearly 17, so it's balancing work, him, her, household. You know, it's hard, really, so the swimming sort of took a back seat because it is more labour intensive. I mean, we do have family that support us, but again, they work, and you don't want to take up somebody's weekend when they've worked all week, so it's quite hard, really. (Michelle, mother)

Michelle illustrates how her main goal of swimming was not congruent with a number of practical and logistical considerations in her everyday life, and later in the interview she went on to describe how she changed her focus to the activity of RaceRunning, which was a better fit and more feasible to pursue. For some parents there was a risk that the practicalities of daily life, including caring for children and young people with neurodisability, were so demanding that pursuing their children's participation in any desired leisure activity could not be a priority.

Practicalities also featured strongly in parents' weighing up of whether the benefits they expected their children and young people to get out of particular activities were worth the practical work the parents would have to put in to support participation. Such practical work encompassed trying to find accessible activities that were suitable for children and young people, which the short breaks coordinators described as a complex, confusing, and time-consuming task:

> I had to actively search for [activities]. I had contacts in certain places that was easier for me to get that information. For a parent it is impossible. Some parents just haven't got the time, haven't got the resources and haven't the way to find them. (Paul, short breaks coordinator)

As well as the considerable logistical demands of identifying activities that Paul is describing, practical work also involved contacting activity settings to find out about accessibility, visiting settings in advance, navigating traffic and parking, and carrying out informal risk assessments to decide whether to allow children to attend.

Practicalities sometimes had a further, more emotional dimension. Michelle, a mother, recounted how 'you get guilt about not being able to find anything, or doing stuff that's not really suitable.' Diane, a mother, also highlighted the risk of disappointment and let-down for everyone involved when practical efforts do not translate to successful participation. Parents weighed up the practical work they would have to do against the likelihood of whether, on attending the activity setting, their children would end up actually exploring and enjoying the activity, which in turn related to their perceptions of whether the activity could and would be successfully adapted.

Parents also considered the potential biopsychosocial benefits of participation particularly in, but not limited to, physically active leisure. I have interpreted these theoretically as parents' outcome expectancies (85). They judged whether the outcome – that is the extent and quality of their child's participation – was 'worth all that effort' (Michelle, mother) and whether they could ‘guarantee the success of the outcome’ (Diane, mother). Gerry, a disability sports coach, explained that a parent ‘wouldn’t want to travel half an hour, three quarters of an hour, to go to a class or a group, and then it not to work.’ The allied health professionals working in a short breaks service described one example of parents of autistic children and young people attending a particular specialist school. For these parents, the practical effort of supporting their children’s participation in a specific community activity setting was not worth either the potential benefits for their children, or the opportunity for a short break for the parents. If the participation was unsuccessful, parents had to ‘deal with the aftermath’ (Helen, physiotherapist), which was ‘more exhausting than just having them calm and happy for the whole day (at home)’ (Gemma, speech and language therapist). This meant that ‘it wasn’t respite for the parents, because they had to manage that situation’ (Katie, occupational therapist). This example draws further attention to how, as well as the practical effort involved, parents whose children may have intense emotional reactions are also weighing up the risk of severe negative consequences of participation against the potential for positive benefits (see chapter 6).

Based on the conceptual framework for the research programme, the considerations around parents’ environmental context and resources can be interpreted theoretically as follows: the practical and logistical demands within parents’ everyday lives, and the practical work involved in finding and accessing leisure activities, both influenced parents’ beliefs about whether they were able to support their children and young people’s participation in leisure, i.e. parents’ beliefs about capabilities. In turn, parents’ beliefs about their own capabilities, their outcome expectancies of particular leisure activities, and their broader values and priorities, all shaped parents’ goals for their children’s participation in leisure, and their related efforts and actions.

In terms of an intervention, then, it may be important to explore which aspects of participation in leisure are valued by parents, and to identify leisure activities that are not only desirable but also practically feasible in the context of parents’ most important practical and logistical considerations. Reducing the effort required to find and access activities may increase parents' confidence that they can actually support their children's participation, and simultaneously targeting parents' positive outcome expectancies of activities could tip their weighing up further towards the 'worth it' side. As reported in chapter 6, emotional support will also be important for some children, young people, and parents.

7.3 Parent Beliefs About Their Own Capabilities

Beliefs about capabilities were defined as acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use (85). During the go-along interviews, I noted the importance of parents' beliefs about their own capabilities to support their children's participation in leisure, specifically their confidence to try new activities, break down barriers, and solve problems related to participation. For example, at the children's museum, Thomas's father John helped him to explore the under 5s play area, even though Thomas is seven years old. John explained to me that the activities in this area were relevant because of Thomas's 'mental age', and because they were lower down so he could get to them by crawling on the floor. John seemed confident to experiment with breaking the under 5s rule, which was key to enabling Thomas's successful participation, and required him to withstand 'funny looks' from the other parents.

After the go-along interview at the swimming pool, I also noted how Diane, Lucy's mother, was confident to solve problems, to 'analyse the situation, come up with options, and try them out' (field notes), and was doing this in an activity setting (the swimming pool) that both Diane and Lucy (aged 15 years) found highly challenging and unpredictable. In her own interview, Diane provided further examples of confident problem solving across diverse activity settings ranging from trying out the climbing wall and the trampoline park, to regularly attending the youth club. Taken collectively, the examples across the parent stakeholders illustrate some of the ways in which parents' beliefs about their own capabilities to support participation play an influential role both before children and young people attend activity settings for the first time, and whilst they are exploring leisure activities over time. Parents' confidence to try new activities, break down barriers, and solve problems related to participation may therefore be a relevant and useful intervention target.

7.4 Parent Beliefs About Children and Young People's Capabilities

There were a wide range of parental beliefs about what their children and young people were able to do and enjoy. Some parents were described as holding strong positive beliefs that those with neurodisability can participate in leisure in the same way and to the same degree as non-disabled children and young people, particularly their siblings. Beliefs did not necessarily involve comparing the participation of disabled and non-disabled children and young people. For example, Diane talked about her 'dream' that her daughter Lucy (aged 15 years) is 'going to be the best she can be, because maybe she can be better.' This highlights, in broad terms, how she holds ambitions and goals for Lucy, which she believes Lucy to be capable of achieving. There were also descriptions of more tentative beliefs about capabilities, where parents consciously restrained their expectations and waited to see how their children's capabilities emerged over time, partly to protect themselves and their children from failure and disappointment. Some parents were thought to not realise what their children were able to do, unable to 'see that potential' (Abi, physiotherapist), and there were some examples of parents holding low expectations of their children and automatically assuming they would be unable to take part in particular activities.

Parents' beliefs were often informed by their awareness of whether and how leisure activities could be adapted and made accessible for individuals with similar impairments and limitations to those of their own children. Gerry, a disability sports coach, described the example of canoeing and sailing. In his experience, if parents had limited exposure to accessible water sports facilities, skilled, workers, assistive products and technology, and exemplars of children similar to their own taking part in such activities, they tended to believe their own children would be unable to participate, and were less likely to bring them along. Whereas, actually seeing what their own children and other similar children and young people can do with the necessary supports in place highlighted the potential of what may be possible. Exposure to such examples may therefore be an important target for an intervention.

Parents’ beliefs were sometimes permeated by negative emotions that could pose an additional barrier to attending, some of which I reported in chapter 6. Examples included worry about children being unable to participate, being scared to bring children to the activity setting in case they are unable take part and enjoy, and frustration when children struggled to explore activities. This again highlights the potential importance of emotional support for some parents. It also draws attention to commonality of experience across parents regardless of neurodisability, because such emotions are something that many parents can relate to.

7.5 Parent Knowledge About Local Leisure Activities

In the conceptual framework for the research programme, knowledge was understood as an awareness of the existence of something (85). Stakeholders explicitly linked parents’ knowledge of leisure activities to children and young people’s participation. Parents were described as the ‘feeders’ and ‘gatekeepers’ of information about leisure activities, on whom children and young people depend to know and make choices about leisure activities. Several stakeholders explained that, if parents know about local leisure activities, they – as the decision makers for their children – will bring them along to attend. However, parents’ knowledge went beyond awareness of what activities exist locally. It encompassed their more detailed and setting-specific understanding of whether activities could be adapted and made accessible for their individual children.

If parents knew that activities were accessible, this knowledge informed two pathways that I have reported earlier in the present chapter: (i) their outcome expectancies, i.e. their beliefs that their children would end up actually exploring and enjoying the activity, which would help tip parents’ weighing up further towards the ‘worth it’ side, and (ii) their beliefs that their children were capable of participating in the activity, which would make them more likely to bring them along. An intervention to support participation in leisure should therefore target parents’ knowledge and beliefs collectively, as they appear to be interdependent and may have more explanatory potential in combination than separately.

7.6 Local Leisure Context

The local leisure context refers to the complex socio-ecological system within which children and young people participate in leisure, and interventions are delivered to support their participation (303). ‘Local’ could be understood in at least two ways. One way was in relation to the defined geographical and administrative boundaries of the local authority area within which you live. The second was the idea of ‘close to where you live’, which wasn’t necessarily the same thing as your local authority area, but rather was personally defined depending on the circumstances of individual families. Close to where you live might mean your immediate neighbourhood or postcode within your local authority area. Or it might encompass a considerably larger geographical area beyond the boundaries of your local authority that you still consider to be close – or close enough – because you have a means of transport.

I identified four factors[17] within the local leisure context that were particularly important in relation to interventions for supporting participation in leisure:

- Available, accessible settings and activities,
- Leisure and short breaks services and systems,
- Social network of people and organisations supporting participation in leisure,
- Transportation services, systems, and policies.

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[17] Stakeholders also identified products and technology that, depending on their design and availability within the local leisure context, constrained and enabled children and young people’s participation in leisure. Products and technology were not my main focus in the research programme, so I have not included those results in the main body of this thesis. However, I have recognised their importance to stakeholders by including products and technology in the logic model illustrating the programme theory (figure 4-1). The three most commonly mentioned items related to products and technology were: (i) design, construction, and building products and technology for gaining access to facilities inside buildings for public use (particularly accessible toilets such as Changing Places), (ii) assistive products and technology for culture, recreation and sport (particularly sport), and (iii) assistive products and technology for personal indoor and outdoor mobility and transportation (including walking frames, hoists, and wheelchairs).

These factors may influence and be influenced by the health outcome of interest (i.e. participation in leisure), towards whom an intervention is directed, and whether, where, how, and by whom it is implemented.

7.6.1 Available, accessible settings and activities

The leisure settings and activities that were both available and accessible in local leisure contexts were important because they determined opportunity for all children and young people, including those with neurodisability. Opportunity was in turn said to influence what children, young people, and parents wanted to do (i.e. their goals) and what they actually did. This relationship was multi-directional, in that the established activities of children and young people without neurodisability also drove the creation of similar accessible opportunities for those with neurodisability. One example came from the short breaks professionals who described setting up a new opportunity for children and young people with neurodisability to pursue the Duke of Edinburgh's youth achievement award, because children and young people without neurodisability across their local leisure context were already doing this activity. I previously discussed this result in relation to children and young people's social role and identity in chapter 6.

Stakeholders described how the availability of accessible settings and activities was variable and dynamic both within and between particular local leisure contexts. Availability varied by a myriad of factors including where you live, whether it is an urban or rural area, children and young people's ethnic/cultural requirements and age, structural factors such as funding streams and service eligibility criteria, and the impact of national events such as the Paralympics. Availability also varied according to demand, although this was not a straightforward relationship. Sometimes increased demand for particular activities drove increased capacity, whereas sometimes there was more capacity than demand and practitioner stakeholders tried to increase attendance in an effort to sustain settings and prevent them from closing down.

Availability of accessible settings and activities also varied across local leisure contexts according to the nature of children and young people's limitations and health conditions. However, there was not an archetypal restricted population towards whom interventions should be directed. Rather, stakeholders’ examples of children and young people who experienced restrictions to their participation in leisure ranged from those with relatively simple to relatively complex communication and/or mobility limitations. The more pertinent factors supporting or restricting participation were the features of the local leisure context, in terms of what happened to have been made available for children and young people with different limitations and health conditions. These included, for example, availability of transport (discussed below), availability of confident and skilled workers (discussed below), policies on self-care (particularly toileting and personal hygiene), costs for activities, and availability of assistive technology. Selecting which of these contextual factors to target within an intervention is therefore likely to be interlinked with selecting the population towards whom the intervention is directed.

7.6.2 Leisure and short breaks services and systems

In the conceptual framework for the research programme, services and systems were understood according to their definitions in the International Classification of Functioning, Disability and Health (8). Services are designed to provide benefits, involve structured programmes and operations, and include the people who provide them; systems are the administrative mechanisms that control, organise, and monitor services (8).

Almost all the stakeholders identified ‘workers’ as a critically important factor within the local leisure context. Workers refers to the leisure activity leaders, personal assistants, and carers whose primary role is to directly support children and young people’s participation in leisure. They are often funded by the local authority as part of their administration of short breaks services and policies, and may be employed directly by the local authority, or by a voluntary sector organisation commissioned by the local authority to provide short breaks, or by parents within short breaks personal budget arrangements. Workers may also be volunteers. At Stage 1 of the Delphi study I identified nine further factors specifically related to workers:

- Worker goals, e.g. whether activity leaders want children and young people with neurodisability to attend their settings, what personal assistants and carers want to learn about so that they can better support children and young people to explore activities.
- Worker emotions, i.e. how workers may feel about supporting participation in leisure of children and young people with neurodisability (e.g. ‘scared’, ‘apprehensive’, ‘overwhelmed’, ‘panic’, ‘comfortable’).
- Worker professional role and identity, e.g. whether workers believe it is their role to support children and young people’s personal care or gastrostomy feeds,[18] whether workers see themselves as a ‘champion’ of supporting participation in leisure.
- Worker beliefs about their own capabilities to support participation in leisure (e.g. their confidence or uncertainty about supporting particular activities) and their beliefs about children and young people’s capabilities to participate (e.g. their beliefs about what children and young people are physically capable of, and whether and how activities can be adapted and made accessible).
- Worker skills, defined as their ability or proficiency acquired through having practiced supporting children and young people in the following domains: communication and interaction, handling health conditions and medical needs, moving and handling, personal care, assisting with eating and drinking, involving children and young people in leisure activities/adapting activities, preventing and supporting challenging behaviour, using products and technology, and treating all children and young people equally (85).
- Worker beliefs about the consequences of participation in leisure, including holding beliefs about positive consequences (e.g. benefits of sport and being active, wellbeing for children, young people, parents, and siblings, leisure supports self-esteem, confidence, communication, life skills, friendships, educational attainment), and holding beliefs that participation in leisure is inconsequential (e.g. ‘low priority’, ‘it’s just a club’, ‘what does it really do? What are they

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[18] A gastrostomy is the creation of an artificial external opening into the stomach for nutritional support.

getting from this? They’re not doing owt. They’re just coming and sitting down, they’re just playing on the PlayStation.’).

- Worker knowledge e.g. about health conditions and disability, available and accessible settings and activities in the local leisure context, how to support participation in leisure/adapt activities.
- Worker enjoyment of supporting participation in leisure, e.g. having fun, loving the job, getting a buzz out of it, a sense of getting something back from the children and young people, or a sense of giving something back to the community.
- Worker attitudes to inclusion, i.e. whether activity leaders are open and willing to including children and young people with neurodisability in their settings.

Worker-related factors had considerable influence on the implementation of interventions for supporting participation in leisure. For example, the practitioner stakeholders described spending much of their time identifying workers, training them in how to support participation in leisure, and monitoring the quality and impact of their support. The systems for recruitment, management, retention, and turnover of workers was a major challenge in some local leisure contexts. Parent beliefs about the capabilities of workers were also critically important for whether they would allow and trust workers to take care of their children and young people and support their participation in leisure.

7.6.3 Social network

Social network refers to the web of individuals, groups, and organisations in the local leisure context that are connected by various sorts and sets of social relationships. It includes people in formal (e.g. practitioners, service managers) and informal (e.g. parents, volunteers) roles, operating individually or in small groups on the ground, or at different levels of organisations (e.g. NHS, local authorities, schools, parent support groups, charities, non-governmental organisations, funders).

Those in the social network bring different resources for supporting participation in leisure to the table. They may bring material resources such as funding, leisure venues, or equipment, human resources such as staff or volunteers, skills in particular leisure activities such as sports or arts, or symbolic capital such as professional endorsement or brand sponsorship. They may bring resources in the form of access to certain populations, for example an NHS physiotherapy service within a local leisure context would bring access to a critical mass of children and young people with mobility limitations and their parents. Or they may bring complementary attributes and qualities, for example Gail (a physiotherapist) described how sports coaches and physiotherapists have different attitudes to risk – sports coaches are more prepared to let children and young people fall, because ‘that’s just part of athletics.’ Whereas for physiotherapists, ‘it’s quite scary, it’s much safer to have children that aren’t moving, because they don’t fall.’ Conversely, physiotherapists ‘know the children, know that they can’t save themselves’ by extending their arms, ‘whereas the coaches are used to children who can save themselves.’

The extent to which the NHS in general, and allied health professionals in particular, were part of the social network was highly variable. The allied health stakeholders in the Delphi study expressed a consistent view that supporting participation in leisure needs to be implemented primarily in the community, as opposed to the clinic or health centre. However, they described various experiences of the extent to which implementing support for leisure in the community would be expected, prioritised, or even permitted within their professional roles. Equally, other non-allied health stakeholders expressed different views about whether the NHS and allied health professionals were even relevant to the social network and had various understandings of what they would actually bring.

The connectedness of those in the social network varied between local leisure contexts, and there were examples of loose and dense ties between individuals, groups, and organisations. Connections could be formal or informal, relational or structural, transient or longstanding, and fragile or durable. On the whole, stakeholders in the Delphi study were operating within complex and dynamic social networks characterised by fickle, fragile, and ever-changing relationships. This may be in part because they were based largely in urban leisure contexts, and there was some suggestion that other contexts may have ‘less going on’. The social networks were messy and imperfect, in that there were examples of people, groups, and organisations operating in silos, duplicating effort, and missing opportunities to implement joint strategies, and the functioning of the networks sometimes relied on serendipity and luck.

The social network was characterised by interdependence. In terms of supporting participation in leisure of children and young people with neurodisability, stakeholders described how making participation happen – implementing and sustaining effective support – required the cooperation of more than one individual, group, and/or organisation. Those within the network learned together, problem solved together, and established feedback mechanisms about what was and was not working. Resources (e.g. venues, access to populations) needed to be shared and actively linked together, and this linking was a key part of the work involved in supporting participation. Stakeholders recognised that it was through the ties and relationships within the social network that accessible activities were made available, for example by collective understanding of gaps and demands; and that children and young people became connected with activities, for example by informal word of mouth communication and recommendations between parents.

The vital importance of the social network was illustrated in part through how much effort stakeholders put in to being a part of it, and working within it to create, maintain, and make use of connections and relationships. For allied health professionals, this point was well illustrated by Gemma (speech and language therapist) and Katie (occupational therapist), both of whom had been working specifically within a short breaks service for under one year:

> Gemma: I think what I’ve found challenging was understanding the more logistical side of it, all the stuff I’d never thought about before […] Getting my head around all the jargon and all the different people that you make contacts with and who can help with what and the processes and procedures of things. That is what I wasn’t prepared for. We just both, I guess, spent quite a lot of time researching that, and just getting used to it, meeting people, talking to people, attending events and meetings hosted by short breaks and getting to know some of the providers and, yes, I think that side of it definitely doesn’t feel like therapy to me. I don’t know about you

> guys, but that side of it feels very alien, unlike anything we would normally do.
>
> Katie: You have to pick that up over time, it’s not something you can just turn up and know. You have to meet these people and you have to get the email…yeah, it’s the kind of networking that we don’t have to do in therapy that you have to do in this job.

Gemma and Katie highlight the necessity of being in the social network – it is not optional – and how it takes time to be part of it and understand its key players, complex relationships, and formal and informal processes. James, a disability sports officer, described the complexity and demands of maintaining these multiple relationships as a ‘minefield’. Gemma and Katie also draw a stark contrast between their necessary work within the social network and more conventional forms of allied health practice. Similar views were reflected more widely across the allied health stakeholders, signalling potential acceptability and feasibility issues that can be anticipated for allied health professionals who may be implementing the intervention developed within this research programme.

7.6.4 Transportation services, systems, and policies

Several stakeholders identified a lack of transportation services or family transport as an important factor restricting participation in leisure, although this varied widely between individual and populations of children and young people, geographical locations, leisure settings, and leisure activities. Key practical problems included local policies that did not permit short breaks direct payments to be used for transport to leisure settings, inflexibility in local school transport systems that prevented attendance at after-school activities, limited capacity on wheelchair-accessible buses, and excessive bureaucracy and inequity when practitioners attempted to arrange transport services for individuals.

More generally, the topic of providing transport was a site of some tension between stakeholders. On the one hand, transportation was talked about as being no longer feasible for public services to provide in the context of United Kingdom government austerity policies. The knock-on effect of such policies on parents was that ‘the more they’ve cut services the more parents have to take responsibility for stuff like [transport]’ (Paul, short breaks coordinator). However, there was a belief that this was appropriate because individuals ‘need to get out of that culture that everything is free,’ and ‘should use [disability living allowance] for what it should be used for – transporting your young person’ (Adele, short breaks coordinator). On the other hand, the counter argument was that transport should be provided or subsidised as much as possible because it would ‘clearly help’ with attending leisure activity settings, and ’having a child with disability is ultimately more expensive than having a child without disability’ (Ava, occupational therapist).

7.7 Discussion

7.7.1 Summary of results

In this chapter I have presented six parent-related factors that influence participation in leisure children and young people with neurodisability: parent goals, outcome expectancies (i.e. beliefs about consequences), beliefs about their own capabilities to support participation, beliefs about their child’s capabilities to participate, emotions, and detailed knowledge. Critically, I have described how these factors are situated within and contingent upon parents’ broader values and the practicalities and logistics of their everyday lives. I have also highlighted the complex interactions and feedback loops that connect the factors together.

I have also set out four key features of the local leisure context that may influence and be influenced by the health outcome of interest (i.e. participation in leisure), towards whom an intervention may be directed, and whether, where, how, and by whom it is implemented: the availability and accessibility of leisure settings and activities, leisure and short breaks services and systems (especially factors related to workers), the social network of individuals, groups, and organisations supporting participation, and transportation services, systems, and policies.

7.7.2 How the results compare with the systematic review and wider literature – parent-related factors

Parent goals for participation in leisure, encompassing what they wanted their children to do and what they wanted their families to do together, featured in neither the synthesis of multivariate results for the systematic review within this research programme (see chapter 3), nor in another recent review of family factors associated with participation (201). However, there is a plausible link between the Delphi results for parent goals and the review results for parent/family participation in leisure. The Delphi found that parent goals were embedded in a broader hierarchy of what they valued and held important both in relation to participation in leisure, and to their parental role and identity. If participation in leisure is valued by parents, this will influence their goals, which in turn will influence their actual participation. The review found that parent/family participation was consistently positively associated with children and young people's participation. Therefore, I argue that a positive relationship between parent goals and child participation may be mediated by parent/family participation in leisure.

The Delphi study found that the practicalities and logistics of parents' everyday lives influenced whether they pursued, adapted, or abandoned their goals for participation in leisure. Two of the eleven categories of conceptually similar social environmental factors in the systematic review are worth considering here: demands and impact on the family of caring, and support and relationships. There was limited evidence for a relationship between demands and impact of caring and children and young people's participation in leisure. However, this was a particularly heterogeneous category and should be interpreted with caution (see chapter 3).

Of the nine studies within the support and relationships category, three (three independent samples) warrant further attention. Colver and colleagues considered 'availability of needed environmental items – attitudes of family and friends', operationalised in terms of emotional support and physical help from family and friends, and having family and friends to look after the child for a few hours (65). Andrews and colleagues considered community support, operationalised in terms of the amount of support parents receive from family, spouse, friends, and professionals (178). King and colleagues considered family cohesion, defined as the degree of commitment, help, and support that family members provide to one another (192). All three studies found a positive association with participation in leisure. Notwithstanding the limitations of these studies, as discussed in chapter 3, when taken alongside the Delphi results they do suggest an important relationship between the practicalities and logistics of parents' everyday lives – the demands of which are likely to interact strongly with the support they receive from family and friends – and children and young people's participation in leisure. I argue that this relationship is mediated by parent goals. There is some support for my argument in the wider literature. For example, a recent study has highlighted how caring responsibilities and obligations shaped the leisure participation choices of mothers of children and young people with autism (304).

Parent goals were also shaped by their outcome expectancies (i.e. beliefs about consequences) in that parents weighed up whether the benefits they expected their children and young people to get out of particular activities were worth the practical work they would have to put in to support participation. The systematic review included one study that examined parent beliefs about consequences, specifically beliefs about whether participation in physical play/leisure in the neighbourhood puts children at risk of harm (74). Although there was no statistically significant association with participation in that particular study, there is some wider supporting evidence for the influence of parents' outcome expectancies and risk perceptions on children and young people's participation in sports (204). There is also support for my findings that supporting participation is labour intensive for parents (305). In particular, locating accessible settings and activities is 'immensely effortful', and one aspect of the 'everyday hidden labour' parents experience (306 p.342). A novel contribution of this research programme is that it highlights parents' weighing up of *both* the potential benefits and risks *and* the work involved, thereby situating these aspects in context, and indicating practical ways forward in terms of intervention targets.

The systematic review included no evidence supporting a relationship between parent beliefs about capabilities and children and young people's participation. The wider evidence is mixed, in that a recent systematic review supported the influence of parental self-efficacy beliefs on a range of participation outcomes (201) but a recent literature review found that the influence of parental self-efficacy on sports participation has received limited attention (204). As with parent beliefs about consequences, this research programme has presented nuanced qualitative evidence that contextualises parent beliefs about capabilities, and illustrates how these beliefs interact with parent goals, and are influenced by the everyday practicalities and logistics that parents experience in their parental and caring roles.

The Delphi study found that parent knowledge about inclusive activities was linked to participation in leisure because it influenced parent outcome expectancies and beliefs that children and young would be capable of participating, both of which would make parents more likely to bring their children along. Parent knowledge was not considered in the systematic review. However, a recent study highlighted the importance of providing parents with information about physical activity opportunities in ways that target not only their knowledge of what is available, but also their self-regulation (e.g. how they plan to support their children's physical activity, and how they monitor that support) (307). This study supports the notion that knowledge may be an important causal mechanism of participation insofar as it interacts with other key pathways related to parent beliefs and implementation planning.

In terms of parent emotions, I have described in this and the previous chapter how these permeated several personal and social environmental factors that were related to participation in leisure. The systematic review found a negative association between parenting stress specifically and participation in leisure (see chapter 3). This result has been further supported more recently in a partially over-lapping systematic review (201). There seems to be consistent support, therefore, for providing emotional support to parents as part of an intervention targeting participation in leisure.

7.7.3 How the results compare with the systematic review and wider literature – local leisure context

In the systematic review within this research programme, three of the eleven categories of conceptually similar social environmental factors related broadly to the local leisure context: services, attitudes, and policies (see chapter 3). These categories comprised five studies in total (four independent samples) and identified limited evidence for relationships between factors and participation in leisure of children and young people with neurodisability. I have therefore looked towards wider literature to interpret and situate the results of the Delphi study.

It is well-established that participation in leisure of children and young people with neurodisability varies substantially according to country and district of residence, and that some of the variance is explained by availability of accessible settings and activities (36, 38, 168, 195, 308-310). From the Delphi study, it is particularly noteworthy that the opportunities available in a local leisure context influenced the goals for participation and actual participation of children, young people, and parents. Qualitative research with young people with learning disabilities has also highlighted how, in their local areas, not all sports clubs or associations were equally accessible, and the young people had to ‘settle for what was available’ (309 p.299). Conventional allied health interventions target individual children and young people and start off by identifying individual goals. However, if availability of activities drives goals, and goals drive actual participation, an alternative approach would be interventions that target and open up what is available in local areas for particular populations of children and young people.

The results on the critical importance of workers – i.e. activity leaders, personal assistants, and carers – align with recent research both within participation in leisure and more broadly within special educational needs and disability (81, 311). Workers play a fundamental role in supporting participation, and studies have begun to unpick some of the challenges, and optimise the potential, of implementing assistance from workers in different community contexts (311-313). Worker-related factors was clearly a major topic that warranted further research in its own right. However, further exploration was not feasible within the resources of this research programme. In particular, just as stakeholders described the considerable resources they invest in training workers, the need for training programmes that produce skilled and confident workers has been consistently highlighted in wider research (195, 314). Further studies to establish the most useful theory and evidence base for developing and implementing such training, and assure parents of workers' competence, may optimise the impact of training on health outcomes. The data from this research programme could potentially be used for secondary analysis to inform the development of such a training intervention for workers.

The essential role of the social network in supporting participation in leisure has been recognised in terms of co-operating to address barriers to participation, sustain community-based activities, and accelerate the development and implementation of environmental policy (195, 315, 316). A recent qualitative case study illustrated in detail how one such network functioned, and the value it contributed in the context of delivering services for children with speech, language, and communication needs across one local authority area in England (317). It is clear that allied health services seeking to support participation in leisure would benefit from understanding the nature of the social network in their local leisure context, gauging their current and potential place within it, and considering the resources they may be able to contribute.

Finally, regarding transportation services, systems, and policies, the Delphi results reflect wider evidence supporting a relationship between participation in leisure and, for example, accessible buses, trains, and taxis, and grants for vehicles and vehicle adaptations (65, 195, 318).

7.7.4 Implications for this research programme

This chapter further fulfils objective 2 within the research programme – to identify modifiable social environmental factors that influence participation in leisure of children and young people with neurodisability. I have identified six parent-related factors that influence participation in leisure children and young people with neurodisability: parent goals, outcome expectancies (i.e. beliefs about consequences), beliefs about their own capabilities to support participation, beliefs about their child's capabilities to participate, emotions, and detailed knowledge. I have described how these factors are situated within and contingent upon parents' broader values and everyday practicalities and logistics, and highlighted the complex interactions and feedback loops that connect the factors together. This potentially enables development of a more targeted, contextualised, and efficient intervention for supporting participation in leisure.

I have also set out four key features of the local leisure context that may influence and be influenced by participation in leisure of the study population, towards whom an intervention is directed, and whether, where, how, and by whom it is implemented: the availability and accessibility of leisure settings and activities, leisure and short breaks services and systems (especially factors related to workers), the social network of individuals, groups, and organisations supporting participation, and transportation services, systems, and policies. This provides valuable insight to inform intervention development, future process evaluation, and implementation.

In the next chapter, I will present intervention techniques for supporting participation in leisure and report the extent of stakeholder consensus on their potential effectiveness. I will also describe key messages for acceptable and feasible delivery of each technique, and cross-cutting principles for delivery that build directly on the key features of the local leisure context that I presented in this present chapter, particularly the availability and accessibility of leisure settings and activities, and the social network. Finally, I will summarise key practicalities and recommendations for building prototype interventions using all the components of the programme theory that I have set out in chapters 5-8.

8 Chapter 8. Intervention Techniques for Supporting Participation in Leisure

In the results chapters so far, I have presented a relevant and useful definition of participation in leisure as a health outcome and brought together the qualitative and quantitative results for modifiable personal and social environmental factors related to participation in leisure. I have also identified a number of key contextual factors that influence whether, where, how, by whom interventions for supporting participation in leisure are implemented, and towards which populations of children and young people, and which leisure settings and activities, they are directed.

In this chapter, I will present intervention techniques for supporting participation in leisure and report the extent of stakeholder consensus on their potential effectiveness. I will also describe key messages for acceptable and feasible delivery of each technique, and cross-cutting principles for delivery that build directly on the results for local leisure context in the previous chapter, particularly the availability and accessibility of leisure settings and activities, and the social network. Finally, I will summarise key practicalities and recommendations for building prototype interventions using all the components of the programme theory.

8.1 Specifying Intervention Techniques

In the conceptual framework for the research programme, intervention techniques were defined as the discrete, observable ‘active ingredients’ within interventions that are designed to alter or redirect causal processes (67, 68). Through focus groups, semi-structured interviews, and go-along interviews with diverse stakeholders, I identified and specified n=43 intervention techniques related to supporting participation in leisure of children and young people with neurodisability (objective 3 in the research programme). The techniques are presented in table 8-1 alongside their corresponding behaviour change technique (BCT) from the Behaviour Change Technique Taxonomy (v1) (67). Note that they are arranged in the same order as the BCTs in the taxonomy, meaning that techniques with similarities in terms of their content or possible mechanisms of change are grouped together. Each intervention technique is illustrated through direct stakeholder quotes highlighting examples of the techniques' content and context.

The correspondence between the intervention techniques and BCTs lends further support to the proposition that allied health interventions can be usefully informed by behaviour change theory and evidence (73). However, it is noteworthy that I was able to correspond all n=43 of the techniques with a BCT. As I described in chapter 4, the data analysis at Stage 1 of the Delphi study was strengthened by one researcher not previously involved in the study providing critical feedback on the consistency of my coding and correspondence with definitions of specific BCTs. However, my coding onto BCTs remains open to further scrutiny as it is entirely possible I have been overly focused on making techniques 'fit' with BCTs.

Overall, the n=43 intervention techniques corresponded with 26/93 (28%) BCTs in the taxonomy. This was because there were several cases of multiple techniques corresponding with a single BCT. The most marked example was that of techniques 13-22 (n=10), all of which corresponded with the BCT '3.2 social support (practical)' (see table 8-1). These ten techniques represent qualitatively different ways of providing practical support towards participation in leisure, including providing information, assistance, transport, and direct payments. However, there is probably conceptual overlap between at least some of them, and they may represent different modes of delivering one central technique as opposed to distinct techniques. The advantage of presenting them separately is that they each contain description that is tailored to specific aspects of the context of supporting participation in leisure. This should better enable replication, evaluation, and implementation of the techniques than would be possible if all ten had been collapsed into the single BCT of 'social support (practical)'.

No intervention techniques were identified to correspond with the remaining 67/93 BCTs in the taxonomy. This is likely to be for three key reasons: (i) the known limitations of self-report which mean that people do not always fully or accurately describe what they do, (ii) some of the remaining BCTs may be beyond stakeholders' direct experience or scope of professional practice, and (iii) some may not be relevant to the population or outcome of interest. However, the remaining n=67 BCTs may represent opportunities to extend the type of interventions delivered to support participation in leisure, and this could be explored further with stakeholders.

In addition to the n=43 intervention techniques, I also identified n=3 bundles of techniques that were commonly delivered as standalone interventions across the stakeholders' different contexts (see table 8-2).

8.2 Acceptable and Feasible Delivery of Intervention Techniques

Table 8-1 also presents stakeholders' key messages for acceptable and feasible delivery of the intervention techniques (objective 5 in the research programme), summarised from free text comments in the online survey at Stage 2 of the Delphi study. A recent theoretical framework of acceptability from Sekhon and colleagues provides a helpful structure for collectively interpreting some of the key messages (319):

Perceived effectiveness

This is the extent to which techniques are perceived as likely to achieve their purpose (319). Several techniques were perceived by stakeholders only to be effective, or to be more effective, when they are delivered along with other techniques. For example, providing information about leisure activities was perceived to be more effective when delivered in combination with practical support to identify, attend, and explore activities (techniques 13-17). Such perceptions of effectiveness could guide decisions about how to evaluate techniques. For example, it would be useful to compare individual techniques that may be commonly delivered in usual care with combinations of techniques that are perceived to have greater potential for effectiveness than usual care.

Ethicality

This is the extent to which techniques have a good fit with individuals' value systems (319). Some techniques did not seem to fit well with some stakeholders. For example, parents rarely referred to 'setting goals', and parent advisors in the public involvement workshops rejected the word ‘goal’ as too technical, not family-friendly, business-like, and emotionally charged, with connotations of measurement, success criteria, and failure. However, it was also very clear that the parent advisors did have goals for their children and young people, and that these were important to them. So, they were not rejecting the concept of goals, but how the concept is used or talked about in interactions with health professionals. These are useful insights that could guide how interventions are presented to parents, in the context of both usual care and evaluation research.

Intervention coherence

This refers to individuals’ understanding of techniques and how they work (319). The term ‘goal’ was used almost exclusively by the allied health professionals in the sample. However, their descriptions of goals suggested a limited overlap with theoretical understandings of how the technique of setting goals is hypothesised to actually work. They primarily framed setting goals as a mechanism for holding services to account and demonstrating the value of services, as opposed to a mechanism for directing attention, efforts, and actions towards particular desired outcomes (199). This reflects similar findings in other studies of allied health professional practice (320-322). Insights into practitioners’ understanding of intervention techniques may help to identify future problems with replicating the techniques, for example whether there is a risk of adaptations to techniques that undermines their theoretical basis.

Affective attitude

This refers to how individuals feel about techniques (319). One technique in particular – ‘gate-crash’ – illustrated the potential range of different feelings that stakeholders may hold about interventions. In the survey, gate-crash received a high number of ‘unable to rate’ and ‘not sure’ responses, considerably more than any other technique, and mostly from allied health professionals and researchers. Positive free text comments from parents about gate-crash included: ‘Yes, we need to do this!’ and ‘I like the idea of this!’ Whereas, more cautious or possibly uneasy comments from allied health professionals included: ‘I think some children will be uncomfortable violating norms, and some rules are there for sound reasons.’ These sorts of responses were not universal within those respective stakeholder subgroups and are not particularly surprising given the different contexts within which parents’ and allied health professionals are supporting participation in leisure (i.e. the ‘real world’ versus NHS service delivery). However, gate-crash serves as an example of intervention techniques that may prompt strong and potentially different reactions from stakeholders, which could in turn influence whether and how they are delivered in evaluation and implementation contexts. For example, in the context of disability studies, gate-crash could be conceptualised through the lens of resistance theory and political activism (323, 324), which might evoke negative reactions from stakeholders for whom the political is less palatable. On the other hand, it may simply be that the manner in which I presented gate-crash to stakeholders in the survey prompted more emotive reactions than had I, for example, chosen a different label.

As well as these key messages for acceptable and feasible delivery of individual intervention techniques, I identified three cross-cutting principles of particular relevance to public service delivery contexts, including allied health professional practice. First, intervention techniques may be grounded in and directed towards participation in leisure settings and activities that are already available and accessible in the local leisure context. A particularly clear example was that of providing activity taster sessions, one of the bundles of intervention techniques presented in table 8-2. Stakeholders consistently highlighted the importance of ensuring that brief activity tasters could lead on to regular opportunities to take part that actually existed in children and young people’s local area.

A parallel approach would be to direct intervention techniques towards opening up what is not yet available and accessible locally for particular populations of children and young people. As I set out in chapter 7, available and accessible settings and activities determines opportunity for all children and young people, including those with neurodisability. Opportunity in turn influences what children, young people, and parents want to do (i.e. their goals) and what they actually do. Some scenarios appeared to lend themselves particularly well to interventions that targeted opportunities for populations rather than individuals. One example was swimming. In England, swimming is one of the most common sports – half of 5-10 year olds go swimming outside school, and a third of 11-15 year olds (325). Internationally, it is one of the top five leisure-time physical activities of children and young people (326). However, swimming pools were identified several times across the stakeholders as a particularly inaccessible setting for many children and young people with neurodisability. Some stakeholders were targeting opportunities for swimming by attempting to join forces with other individuals, groups, and organisations in their local leisure contexts. Whilst these types of population health approaches are much less established in allied health professional practice, they have shown promise when delivered in tandem with more conventional and familiar individual approaches (313).

Second, practitioners delivering intervention techniques should have an intimate knowledge of the leisure settings and activities with which they are connecting children and young people, and they can gain this knowledge by embedding themselves within the social network in their local leisure context. Intimate knowledge includes up to date information on practicalities and logistics, for example when and where activities take place, accessibility of venues, and costs. But crucially, it also includes inside information about the quality of activities, how confident and skilled the workers are, whether settings are as inclusive as they claim to be for different groups of children and young people, and what sorts of experiences other parents have reported. In chapter 7 I described the importance of the social network; the web of individuals, groups, and organisations in the local leisure context that are connected by various sorts and sets of relationships. I argued that the resources needed to support participation in leisure are distributed across the social network and are unlikely to reside in one individual or group – and these resources would include intimate knowledge of leisure settings and activities. As Katie (occupational therapist) described, you have to be an active member of the social network to ‘pick that up over time, it’s not something you can just turn up and know. You have to meet these people and you have to get the email…yeah, it’s the kind of networking that we don’t have to do in therapy that you have to do in this job.' My results on intimate knowledge are supported by wider evidence within allied health and physical activity research (195, 307, 315, 327).

Intimate knowledge was particularly useful when providing information to parents about local leisure activities and opportunities (technique 14). Providing information could be construed as a minimum standard within usual care, and a relatively mundane aspect of supporting participation in leisure. However, in the absence of intimate knowledge, there was a significant risk that the information provided would be inadequate for parents' decision-making needs. Inaccurate or irrelevant information would frustrate and alienate parents, lead to wasted time exploring promising opportunities that prove unavailable or inaccessible. In practice, this could undermine the credibility of practitioners' future suggestions and recommendations.

Third, practitioners should explicitly reflect on their implicit personal and professional value systems related to participation in leisure, as these are likely to drive which leisure settings and activities they deem it acceptable and feasible to support. Reflecting the wider literature within participation research and leisure studies, leisure settings and activities in this research programme were generally conceptualised as either formal (i.e. structured, planned, usually facilitated by adults, for example organised clubs and outings), or informal (i.e. less structured, spontaneous, largely unsupervised by adults, for example sleepovers and hanging out with friends). For many of the practitioner stakeholders, it was more important and worthwhile to support participation in formal settings and activities. The informal were often cast as less worthwhile, more difficult to justify to decision makers, more practically and logistically challenging to support, and somebody else's responsibility, particularly parents. Similar issues have been highlighted in wider research and expert opinion (262, 280, 328, 329) Conversely, informal settings and activities – particularly friendships and being with friends – are of critical value and importance to children and young people with neurodisability, and are often where they experience restrictions to their participation (see chapter 9) (39, 44, 45, 81, 249, 330). Practitioners will need to consciously consider the limitations they are placing on the participation support they are prepared to deliver, the rationale for these limitations, and whether the rationale is justifiable.

8.3 Stakeholder Consensus on the Potential Effectiveness of the Techniques

Stage 2 of the Delphi study used two rounds of an online survey with diverse stakeholders (n=68) to establish consensus about the potential effectiveness of the intervention techniques for supporting participation in leisure (objective 4 in the research programme). The survey included 42/43 intervention techniques. Technique 43 ‘punish’ was not included as general behaviour management was considered beyond the scope of the present research programme. However, the three bundles of intervention techniques (see table 8-2) were also included. There were therefore n=45 questionnaire items in total, hereafter referred to collectively as techniques. The results are presented in table 8-3, where the techniques are labelled with the same identification number as in table 8-1 and arranged according to the whole stakeholder group’s consensus on their potential effectiveness. For each technique, table 8-3 also presents the consensus on potential effectiveness from within the separate stakeholder subgroups.

All but 13 (28.9%) of the techniques achieved whole group consensus by the end of the second round in the survey. Of these, 26.7% (n=12) were rated as ‘very effective’, 33.3% (n=15) as ‘effective’, and 11.1% (n=5) as ‘fairly effective’. Between the stakeholder subgroups, I identified no patterns suggesting particularly important systematic differences in ratings, other than for technique 26 ‘gate-crash’, which I have discussed above. There was a tendency for the researchers to rate techniques as slightly less effective, which I attributed to the aspects of their academic training that promote reservation and scepticism about the potential effectiveness of any intervention.

It was noteworthy that the ‘very effective’ and ‘effective’ categories included six of the ten techniques that corresponded with the BCT ‘3.2 social support (practical)’, five of the eight techniques that corresponded with BCT ‘1.1 goal setting (behaviour)’, and two of the three bundles of techniques that were made up of multiple individual techniques (provide activity taster sessions, and adapt a leisure activity). This may suggest that interventions containing practical social support and goal setting could be particularly useful in leisure participation contexts. However, as I highlighted in Chapter 4, all these results should be interpreted with some caution because they are derived solely from stakeholder opinion. The validity of the survey question for eliciting stakeholders' attitudinal evaluations of 'effectiveness' is unknown. It is plausible that stakeholders approached the concept of effectiveness in quite different ways. On reflection, it may have been useful to ask stakeholders to further differentiate the techniques by ranking them, since almost two thirds were rated as either very effective or effective.

Within the remaining 13/45 techniques that did not reach consensus by the end of the second round, this was largely a stable lack of consensus suggesting differences of opinion that a third round would probably not have resolved. The tendency for most of the 13 remaining techniques was towards a consensus of at least fairly effective, and again I identified nothing of particular note between ratings of the stakeholder groups or in the free text comments, other than for technique 26 'gate-crash', which I have discussed above.

8.4 Building Prototype Interventions for Supporting Participation in Leisure

Stage 3 of the Delphi study used a co-design workshop with multidisciplinary practitioner stakeholders (n=9) to build prototype interventions for supporting participation in leisure. I oriented stakeholders to the initial programme theory, which they then used to build individual- and population- level interventions. We also brainstormed ideas for acceptable and feasible interventions in allied health community practice contexts. Through the discussions, thinking aloud, and prototyping, a number of key practicalities and recommendations were identified:

- Services seeking to support participation in leisure, and practitioners embedded within such services, should be familiar with the nature of their local leisure context (see chapter 7). They should recognise and analyse their own current and potential place in the social network of individuals, groups, and organisations supporting participation, and consider what resources they can bring to the table.

- There was not a single, definitive intervention for supporting participation in leisure of children and young people with neurodisability. Stakeholders engaged with the initial programme theory in different ways and came up with multiple approaches to building prototype interventions for various scenarios. In particular, there were different 'starting points' for interventions. The obvious starting point was an individual or group of children and young people who want to attend and explore a particular setting or activity. However, other places to start included: (i) focusing on a specific technique that was acceptable and feasible for a practitioner or overall service to deliver (e.g. technique 14, provide information about local leisure activities and opportunities), and considering how it could be optimally delivered across a service for maximum benefit, (ii) prioritising and targeting an aspect of the local leisure context, e.g. the accessibility of a district's swimming pool for a particular population, or the confidence and skills of workers across a borough to support certain children and young people's participation in specific settings and activities, or (iii) prioritising and targeting a personal or social environmental factor of importance within a given population, and in relation to a certain setting or activity, e.g. parent beliefs in the capabilities of children and young people with mobility limitations to explore a climbing wall.
- Notwithstanding the value of multiple potential starting points, stakeholders agreed that it was helpful at the outset of building interventions to be specific about which children and young people were supposed to benefit (individuals or populations) and which settings or activities were to be targeted. In the case of the latter, the exception was when the intervention was to actually identify the setting or activity that would be attended and explored.
- The intervention techniques were specified at a helpful level of granularity and provided stakeholders with a means to describe and

differentiate the content of their interventions for supporting participation in leisure. The relatively high number of techniques, and lack of guidance on how to select them when building their prototype interventions, meant that stakeholders were led by their perceptions of techniques' acceptability (319). They selected techniques based on their fit with professional and personal value systems, how they felt about them, and their beliefs about potential effectiveness (319).

- Stakeholders readily drew on personal and social environmental factors when analysing causal mechanisms of participation in leisure. However, they required more guidance on the relationship between factors and techniques. Mapping techniques onto the factors that they are best placed to target for change was beyond the scope of this research programme, although theory and evidence in health behaviour change could provide a basis for such mapping (113, 331, 332).

These insights can be used to produce detailed practical guidance for stakeholders on the process of using the programme theory to develop interventions for supporting participation in leisure. I plan to produce a guidance document in a knowledge translation follow-up study.

Table 8-1 Delphi Stage 1 intervention techniques for supporting participation in leisure

Intervention techniques ***Corresponding behaviour change techniques (67)***	**Direct stakeholder quotes illustrating the intervention techniques**	**Key messages for acceptable and feasible delivery of the intervention techniques**
1. Set goals with children and young people: identify and agree what leisure activities children and young people are going to do. *1.1 Goal setting (behaviour)*	Dave: But I think if I was looking at encouraging participation, it would be what's available; it's not just what the child's choice is. What is practically available. Gail: Definitely. Dave: And I think that would, to a large extent, you know, guide things. I would probably be saying, "Look, we can either do, we can either try A, B or C; we're not going to have A to Z". And so then I would go with, you know, once we'd you know we'd decided on say three possibilities; which do you want to try first? You know, and then I'd go for whatever the child wanted to try first.' (Dave & Gail, physiotherapists)	- Challenging goals might be more acceptable to some children and young people, as long as the goals are also feasible. - To be acceptable and feasible for parents, setting goals should take account of the everyday practical and logistical demands that parents are managing (see Chapter 8). - For some children, young people, and parents, the notion of 'goal' might not be acceptable in relation to leisure if it evokes ideas of targets, measurement, and testing. Consider talking about 'what children and young people want to do' instead (see Chapters 7 and 8). - Important to also review the goal once children and young people have attended and explored (technique 7) to check if they enjoyed themselves; - For children and young people who are not sure what they want to do, it might be better to explore activities (technique 2). (See also Chapter 7)

		- As well as setting goals with individuals, it is also acceptable and feasible to provide a range of leisure activities for children and young people to attend and explore (technique 38) to help inform what they want to do. Setting individual goals might not be acceptable in the context of group activities, if it takes away from the 'natural feel' of the group.
2. Explore what leisure activities children and young people might want to, by discussing their current activities and interests, making suggestions, and/or offering options of available activities. *1.1 Goal setting (behaviour)*	Sitting down and going through all the things that are available and saying, "Well come on, there must be one thing in all of our area that looks good." Maybe if they've tried one thing and they didn't like that, we'd just sit down again and say, "Why don't you have a go at climbing? Why don't you have a go at skiing?" and just see if you could find something else that they'd be willing to go along and have a go at. (Joanne, physiotherapist)	- A menu or picture cards of locally available and accessible activities could enable some children and young people to explore activities they might want to do. - Making suggestions and actively offering options is likely to be more acceptable than prescribing activities (which was unacceptable to stakeholders) or listing available activities. - Active and balanced involvement of children, young people, and parents is likely to make exploring more acceptable to all involved.
3. Teach / instruct parents or workers which leisure activities to do with children and young people. *1.1 Goal setting (behaviour)*	For example, at the moment we're working with a family who Mum feels that the carers could do with some support to help have a range of activities that they might want to do with the child. We're going in and we're going to provide some information about sensory stories or different things they can be doing with the child. (Helen, physiotherapist)	- Active involvement of parents and workers – and, where possible, children and young people – is likely to increase acceptability. - At least on face value, instructing in particular might be incompatible with some stakeholders' concept of participation in leisure, for example 'sounds very directive and prescriptive', and 'don't think this can be classed as leisure'.

		- Exploring (technique 2) might be more acceptable to parents and workers, particularly in terms of avoiding prescribing activities, and ensuring activities are based on what children and young people are known to enjoy. - To be acceptable and feasible for parents and workers, this technique should take account of the everyday practical and logistical demands within their caring roles (see Chapter 8). - Important to also review the activities once children and young people have attended and explored (technique 7) to check if they enjoyed themselves; and give/receive feedback (technique 10).
4. Set goals with workers: identify and agree what actions workers are going to take, or what they are going to learn about, in order to support children and young people's participation in leisure. *1.1 Goal setting (behaviour)*	Helen: With our training, we ask people that attend our training for a goal and we follow that up (…) Gemma: It's got to be something they want to achieve, so if it's something we've trained on and we've done a bit of training on intensive interaction, a lot of them will say, "I'm going to try intensive interaction." Katie: Yes, I'm going to use it to work out what's going on." (Helen physiotherapist, Gemma speech and language therapist & Katie occupational therapist)	- Important also to review the goals (technique 8) but stakeholders reported that both setting and reviewing goals with workers was often not feasible in practice. - Involvement of workers in participation should be managed carefully – essential and unobtrusive support for children and young people needs to be balanced with unsupervised or minimally supervised time with peers.
5. Problem solve: analyse the factors influencing whether children and young people participate in a	It's talking to staff and saying, "I don't like this because I've got to go down a very steep hill and I can't see what I'm doing." Or, "There's no rail where you've got to go up the two steps for the boys toilets." So we've put a handrail up	- Active involvement of children and young people where possible, parents, and workers, is likely to increase acceptability and feasibility.

leisure activity and come up with strategies to overcome barriers/increase supports to participation. *1.2 Problem solving*	there. And it's getting that feedback from people with disabilities or learning needs that helps us. It's sitting down, sometimes, and talking to them and the parents to find out what they think about it and can we make it any better? It's easy because if we can make it better for them it's a better experience for the staff as well because they're enjoying it. (Justin, accessible activity scheme leader)	- Likely to be more feasible and relevant when done in relation to a specific setting and activity. - Might be perceived as unacceptable / not feasible by allied health professionals, particularly in relation to overcoming environmental barriers and time required to do problem solving.
6. Action plan: make a detailed plan for doing a leisure activity, including where, when, how, how often, and/or for how long children and young people will attend and explore. *1.3 Action planning*	I found out about her mobility and her transfers and her communication and her likes and dislikes (…) I went away and found out some options of things that I would think would be beneficial for her and would be something that she'd be interested in. Then I came back and did planning with her. This is by email with her carer, to then plan some sessions where we were going to go and try these things out. Then we went and did those. Then together we decided a plan for them to carry on with it afterwards, and I stepped back.' (Katie, occupational therapist)	- Action planning might be particularly acceptable and feasible for: complex activities that require much planning; anxious or autistic children and young people who might appreciate routines and predictability; and families with a weekly timetable into which they would like to schedule children and young people's participation. - Active involvement of children, young people, and parents might increase acceptability and avoid action planning feeling prescriptive or dictatorial. - Flexibility is likely to increase acceptability to parents, by accommodating unexpected interruptions to the plan, and avoid parents feeling guilty and under pressure. - Also consider: problem solving (technique 5) to identify required support to implement the action plan, and review goals (technique 7) and

		feedback (technique 10) to assess whether the plan was implemented and was successful.
7. Review goals with children and young people: assess whether a previously-set leisure goal has been achieved and consider whether to change the goal and/or the strategy for achieving the goal. *1.4 Review behaviour goal(s)*	Needs do change all of the time and it is about being adaptive to when a young person stops attending something and questioning why. (…)A young person might start to do something and just think, "Yes, I have done it now. It was crap, I don't want to do it anymore." Rather than them not getting a service anymore it's kind of like, "Right, well what else do you want?" (Adele, short breaks coordinator)	- For some children, young people, and parents, talking about a 'goal' might not be acceptable in relation to leisure if it evokes ideas of targets, therapy, measurement, and testing. Consider talking about 'what children and young people want to do' instead (see Chapters 7 and 8).
8. Review goals with workers: jointly assess with workers whether a previously-set goal for supporting children and young people's participation in leisure has been achieved and consider whether to change the goal and/or the strategy for achieving the goal. *1.4 Review behaviour (goals)*	Katie: You go to training, you sit there, you listen and it's great, but then you go away and you leave. So the idea is they think about something they've learned today, think about someone they are going to apply it to. Then we offer to contact them in whatever time they set and then get back in touch with us, but our response rate has been quite low to be honest. I think we worked out today we had- Helen: 16 out of 75 or something- Katie: -have replied, so it's really low. So we're now thinking instead about setting a follow-up visit that's booked in when they book in the initial training. (…) Actually do a follow-up visit to actually check are they putting it into practice and then and there, do you have any problems? It's easier for them to maybe go then, "Actually, I've really thought about what you said in terms of this, I've tried this and this, this	- Active involvement of children and young people where possible, parents, and workers is likely to increase acceptability. - Stakeholders reported that both setting and reviewing goals with workers was often not feasible in practice, for example due to staff changes and competing commitments (see Chapter 8). - Involvement of workers in participation should be managed carefully – essential and unobtrusive support for children and young people needs to be balanced with unsupervised or minimally supervised time with peers. - Likely to be more acceptable if delivered along with feedback for workers on how they are

	might not be working as well," and then on the spot we can give some advice and recommendations… (Katie, occupational therapist & Helen, physiotherapist)	doing with supporting participation (technique 10).
9. Monitor: observe or record whether workers are providing the agreed support for participation in leisure, with the workers' knowledge. *2.1 Monitoring of behaviour by others without feedback*	I think it is harder to put a young person in somewhere if you don't know exactly what they do or how they run. You get an idea of the ethics and the structure of the service. That is why we are going out on Sunday to go and view one. (…) You get an idea of how they run and you get an idea of the team. (…) So you get an idea of that sort of, how things work there. That is why a lot of time we will view places, we will go down. It is hard to promote a service you haven't seen or you haven't got an understanding of how it works. (Paul, short breaks coordinator)	- Likely to be more acceptable and feasible if the possible outcomes of monitoring are known, understood, and acceptable. - Likely to be more acceptable if delivered along with feedback for workers on how they are doing with supporting participation (technique 10).
10. Provide feedback to parents or workers on how they are doing with supporting participation in leisure activities, and/or how children and young people are exploring activities. *2.2 Feedback on behaviour* *2.7 Feedback on outcomes of behaviour(s)*	We have some monitoring systems in place in our clubs and camps so we can get direct feedback from children and young people about their thoughts and activities, what they like to do, what they've enjoyed, and we you know we that's quite a key source of information from a young person's point of view. (James, disability sports officer)	- Likely to not be feasible for sports coaches leading weekly group activities. - Acceptability may vary depending on who is providing the feedback, for example feedback from children and young people might be more acceptable to workers. - Acceptability may vary depending on the nature of the feedback, for example supportive feedback might be more acceptable than evaluative feedback.
11. Self-monitor: establish a method for children and	In the past we have done groups of gym. We call it Young People's Exercise Group, or something. And they used to	- Simple, visual, and interesting self-monitoring systems might increase acceptability and

young people to monitor and record their own progress with participating in leisure activities, as part of a strategy for improving or increasing their participation. *2.3 Self-monitoring of behaviour*	love that. And it was just a way of getting them used to the three or four different machines, and they did it against themselves. So they timed themselves, and they had their own little thing to write up what they'd done. (Gail, physiotherapist)	feasibility, for example paper charts, rating systems, or smartphone apps such as Fitbit. - Acceptability might vary depending on what aspect of participation is monitored, for example enjoying might be more acceptable than attending and exploring. - Active involvement of children and young people is likely to increase acceptability by ensuring self-monitoring does not feel or appear imposed. - At least on face value, self-monitoring might be incompatible with some stakeholders' concept of participation in leisure, for example 'leisure should be relaxed'.
12. Provide general support, for example encouragement to participate in leisure activities. *3.1 Social support (unspecified)*	I think it is that constantly pushing, and prompting, and saying, "Go and have a go, go and have a go," because you have to say it a lot of times to just get the couple that then do really catch onto that. (Joanne, physiotherapist)	- Likely to be more relevant to parents to provide specific information and practical support (for example techniques 13, 14, 18, 19).
13. Provide practical support to identify leisure activities that are locally available, accessible, and appropriate for children and young people.	So that's why we always go in and say there is a lot more in the city than people realise. (…) We get good feedback from [parents] not knowing and then we go in and go, "We will do the finding. We will do the searching. Just give us a little bit of direction then we will roll with that and then we can take	- May be necessary but not sufficient on its own for many children and young people. Additional practical support to attend settings for the first time, and explore activities, may be necessary and acceptable to parents in particular (for example techniques 15-17).

3.2 Social support (practical)	that off you.” It is just that finding stuff a lot of the time for young people. (Paul, short breaks coordinator)	
14. Provide information about local leisure activities and opportunities. *3.2 Social support (practical)*	The biggest part of my role is to promote what’s out there... (…) we have Facebook, we have Twitter we’ve got a website. All three of those elements are key because some people will access one and not the other. Some people will prefer a static website to reference back to. (…) you’ve got the Disability Sport Programme where you can download it or we recognise that a lot of people don’t have access to the internet or the ability to use it, so we still need to print out hard copies of information (…) I have a monthly mailing list that that has about a thousand contacts on, yeah well we’re told that that’s been really valuable cos its gone are the days whereby someone will be bombarded with lots of flyers and information (…) So that’s really important to get that information out there. (James, disability sports officer) It’s so time-consuming. (…) It’s probably taken about over a day in putting it together of a comprehensive list of about 15 kind of leisure activities that would be suitable for our children. That’s just getting up-to-date times, speaking to the right contacts, making sure they’re appropriate for our children with or without mobility aids, and financially, waiting lists, things like that… (Abi, physiotherapist)	- Likely to be necessary but not sufficient on its own. Additional support for children and young people to attend settings for the first time, and explore activities, is likely to be necessary and acceptable to parents in particular (for example techniques 15-17). - Providing information in multiple formats and through multiple channels is likely to increase acceptability to a wider range of people. - Taking account of socio-cultural and health literacy requirements is likely to increase acceptability to a more diverse range of people. - Detailed, reliable, and welcoming information is likely to be more acceptable to parents, who will want to know whether the right support is in place to enable their child’s participation. - Exciting and fun information might be more acceptable to children and young people.

15. Provide transport for children and young people to attend leisure activities. *3.2 Social support (practical)*	Transport is a huge one as well. I think for one child my colleague was trying to arrange transport, and that just took up much time. It's kind of like this is part of our responsibility for that child, but we couldn't do that for every child, because we just wouldn't have the capacity and the time to do that. So I think for individual cases where you can really see that potential, it's great and we can offer that extra additional time, but for every child that we see we couldn't do that. (Abi, physiotherapist)	- There was wide variation in the acceptability to different stakeholders of providing transport. - Providing appropriately trained and familiar escorts/carers is likely to increase acceptability and feasibility for parents. - Providing accessible parking or drop-off spaces may increase acceptability and feasibility for parents or be as good as/better than providing transport. - Acceptability to professionals might be increased if providing transport can be sustained financially and enables young people to attend settings independently.
16. Provide practical support (other than transport) for children and young people to get to activity settings. *3.2 Social support (practical)*	She used to go, she had a little friend, tap, ballet, and street dance on a Saturday morning. I think it was only an hour. (…) I used to take this [other] little girl as well, because her mum was a hairdresser and she worked Saturdays obviously, so I used to take her. (Michelle, mother)	- Acceptable and feasible options might include hands-on carer support or help with time management for young people wishing to get to settings independently.
17. Provide practical support during leisure activities, to enable children and young people to explore.	The problem sometimes is that people overcomplicate it in short breaks. You are looking at a young person and saying he needs one-to-one constantly, well no he doesn't there are just elements of that time that he needs one-to-one. The rest of the time, come back, let him find his own feet. Let him find out what he wants to do and where he wants to be	- Might be particularly acceptable to target support towards developing positive relationships and friendships with peers, especially if this involves young people spending time away from parents. - Involvement of workers providing practical support should be managed carefully –

3.2 Social support (practical)	at. Because a child, a young person is never going to develop those skills if there is somebody sat beside them. (Adele, short breaks coordinator)	essential and unobtrusive support needs to be balanced with unsupervised or minimally supervised time with peers, and (where appropriate) opportunities for children and young people to overcome barriers themselves, learn new skills, and feel a sense of achievement. - Acceptability of practical support to activity leaders might vary across different activity settings, for example how open activity leaders are to support 'from outside'.
18. Provide practical support to access leisure-related services, entitlements, products, and/or assistive technology and equipment. *3.2 Social support (practical)*	I think also about helping families to find the right kind of equipment to help that child to be able to participate, so it may be about finding a trike that is right for them or a more stable scooter, for instance, or just something really that enables that child to be able to join in the way that they want to join in. I think families often are very pleased to have that kind of support to be able to find out what kind of equipment the child could use. (Sally, physiotherapist)	- Working with advocates and interpreters might increase acceptability and feasibility.
19. Provide information about leisure-related services, entitlements, products, and/or assistive technology and equipment that children and young people may be able to access.	In [town], there is a group called [parent forum] (…) it's like a group of parents that got together to answer questions that people had about all sorts, benefits, health, schools. And they try to sort of funnel stuff through, so if they hear of something they'll put that on their website or on their Facebook page. So a lot of it is through social media. A lot of it is through word of mouth; somebody will say, "Oh, I was	- Providing information in multiple formats and through multiple channels is likely to increase acceptability to a wider range of people. - Information that is specific to a particular leisure activity setting might be more acceptable.

3.2 Social support (practical)	in such a place the other day, and I saw such a thing going on…” (Michelle, mother)	- Taking account of socio-cultural, language, and health literacy requirements is likely to increase acceptability to a more diverse range of people. - Acceptability and feasibility might be increased by providing in tandem with practical support to actually access services and entitlements (technique 18), for example help to fill out and chase up applications.
20. Provide direct payments or personal budgets for children and young people and their parents to use to arrange their own leisure activities. *3.2 Social support (practical)*	And he and his mum both said the same thing all he ever wanted to do was to go swimming. (…) And because there wasn’t any service available they gave him a teatime visit at a residential respite unit with some young people who were quite complex in their disability and he is quite able. So what we were able to do is offer him direct payments for him to pay a paid worker at school who now picks him up on a Wednesday, takes him swimming and drops him off at home. (…) Whereas before he used to get on the school transport, be taken to our residential respite unit, and then sent home. And he just wasn’t happy to go because that is not what he wanted to do. (Adele, short breaks coordinator)	- Likely to be more acceptable and feasible for parents if accessible activities are also provided locally (techniques 38, 39) and support is also available to identify, identify, and explore the activities (for example techniques 13-19). - Involvement of workers funded through direct payments should be managed carefully; for example, in the absence of local accessible activities with peers, children and young people might end up staying at home with the worker or only spending time the worker. - Likely to be less acceptable and feasible for parents if highly bureaucratic to administer. - Acceptability and feasibility are likely to vary by parent characteristics, for example according to parents’ capacity and inclination to administer direct payments, whether children,

		young people, and parents know what they want to do etc.
21. Provide workers with information about children and young people’s health conditions, strengths, limitations, likes, and/or dislikes. *3.2 Social support (practical)*	If they have eating or drinking guidelines or if they have particular transfer guidelines or manual handling risks. We can take that information into the leisure centre setting to make that child be able to safely access that leisure setting if that makes sense, and provide information about their likes, their dislikes. We are doing sort of a bit of a project on leisure passports at the moment. (…) So just anyone that’s working with them has that core information so that they know how to communicate with them, what they might learn by, what equipment needs they have, what support needs they need and what they like and they dislike. (Helen, physiotherapist)	- Likely to be more acceptable if information about health conditions is: pertinent to the specific setting/activity under discussion; credible; and challenges stereotypes about the capabilities of children and young people with particular health conditions, and what sorts of activities they are likely to enjoy. - A balance of parent and children and young people’s involvement in creating and providing the information might increase acceptability. - Strengths, limitations, likes, and dislikes are likely to change over time, including in response to participation in leisure. Therefore, regularly reviewing and updating information might increase acceptability.
22. Provide workers with general information about health conditions, for example cerebral palsy, and neurodisability overall. *3.2 Social support (practical)*	I’d like to think it’s getting better and the only way it can get better is the national governing bodies of sport have specific disability-awareness training courses that their coaches there can access so that they’re aware of it, and it really is it’s just a general awareness of what people’s needs will be. It might be generic disability awareness, it might be specific to that sport. (James, disability sports officer)	- Likely to be more acceptable if general information does not focus overly or exclusively on health conditions. - Basic, high priority information about health conditions – as relevant to specific settings/activities – is probably desirable. However, the overall emphasis should be on discovering children and young people’s strengths, and teaching/instructing workers how

		to support participation in leisure (technique 25).
23. Provide emotional support to children, young people, and/or parents, before, during, and/or after children and young people participate in leisure activities. *3.3 Social support (emotional)*	I know if I was going somewhere new as a kid… When anybody goes anywhere new you worry about it. If there is a nice friendly face there that is going to support you into that, help you make friends, chat to people or do whatever you want to do that is a bit of a safety blanket to be able to try a few bits. (Noreen, short breaks development officer)	- Likely to be particularly acceptable in the form of offering to attend a new leisure activity setting with the child, young person, and/or parent for the first time, or first few times.
24. Teach/instruct children, young people, and/or parents on how to do leisure activities. *4.1 Instruction on how to perform the behaviour*	We worked very well together because sometimes it wasn't appropriate for me to direct Lucy. I was wanting her to get used to having an authoritative person that has got more clout, in a setting such as a swimming pool, for her, the little girl, to share her experiences: "I don't only have to listen to Mum sometimes; I have to listen to directives from an appropriate adult that is always in this setting." That's a win-win for me. I have to be able to transfer that responsibility to another adult – if I think they're appropriate, and this lady was. And it took us nine months, week in, week in, to get our child to come out when asked. And we never gave up, and it got hostile and it got difficult. (Diane, mother)	- Acceptability and feasibility is likely to be increased by ensuring teaching/instruction is tailored and accessible, and takes place within the activity setting. - Might be more acceptable and feasible in a sports context, when delivered by suitably qualified and experienced workers, for example sports coaches. - Might be more acceptable and feasible when delivered in tandem with demonstration (technique 28), practical support to explore the activity (technique 17), and grading (technique 34). - Likely to be more acceptable to children and young people if pacing is carefully timed in line with their readiness for the setting/activity.

25. Teach/instruct workers in how to support children and young people's participation in leisure, for example how to adapt activities, restructure the environment, communicate, or move and handle. *4.1 Instruction on how to perform the behaviour*	I went to the first two sessions to support her and the coach, who was a little bit apprehensive about having someone with visual impairment in the group. But then, boom, no problem. Coach got a bit of confidence, because actually all I said to him, "Well, all you've got to do is make sure she's facing forward. If she turns her head, she can't see the ball." "Oh, okay." "And just have a bit of patience. If you ask her to pick up the ball, it's because she can't, stuff like that, she can't see within her range of vision. You might see some balls that need picking up, but she can't see them. So just have a little bit of patience," and then, yes, it kind of twigs. (Seb, inclusive sports development advisor)	- Might be particularly acceptable and feasible for workers with no/minimal prior experience of supporting participation in leisure of children and young people with neurodisability. - Active involvement, where possible, of children and young people might increase acceptability and feasibility. - Should include a focus on increasing the workers' understanding that essential and unobtrusive support needs to be balanced with unsupervised or minimally supervised time with peers.
26. Gate-crash: ignore, circumvent, or violate established norms, rules, systems, or expectations, in order to gain access to a leisure setting or activity for children and young people. *4.4 Behavioural experiment*	Social events we have always gate-crashed them. Because of the abilities of our young people we get a lot of restrictions, but we just turn up and they have to adapt to us when we are there. (Jim, short breaks coordinator)	- Likely to be less acceptable to allied health professionals, compared to parents and short breaks professionals. - Emphasis should be on ensuring children, young people and parents feel comfortable, involved, prepared, and supported. - Consider providing advance notice to activity settings, to prepare them for children and young people's requirements, and ensure a warm welcome. - Consider visiting activity settings in advance of children and young people, for example to problem solve (technique 5) and reduce risks. - Consider also supporting gate-crashed activity settings to improve participation e.g. problem

		solving (technique 5) or teaching/instructing workers in how to support participation (technique 25).
27. Provide information about the health benefits and health risks of doing a leisure activity. *5.1 Information about health consequences*	I would say it's about convincing people that this matters, that it improves lives and that it actually does promote health. (…) A lot of them will actually promote their physical health, their mental health, it will encourage them to develop some of their self-care skills because they want to go and do this thing, it's very motivating. So I think it's explaining to people why this is good and it's not just about leisure, the broader impacts that it will have on people's lives by engaging in leisure activities that they want to do. (Celia, occupational therapist)	- Emphasising benefits including enjoyment and fun is likely to be more acceptable to children, young people, and parents than emphasising risks. For example, discussion of risks may lead to overthinking and worry for some children and young people. - However, it might also be acceptable and desirable for professionals to be informed and open about risks with parents, as this may assure parents that specific activity settings pro-actively assess and mitigate risks.
28. Demonstrate: provide an example of doing or supporting leisure activities, for a child, young person, or adult to aspire to or imitate. Demonstrating may be done either directly in person, or indirectly through pictures or film. *6.1 Demonstration of the behaviour*	The canoeing up at the sailing, you get people, we get them all in. Everybody helps. You go to the leisure centres, you can go to swimming. There's a hydrotherapy pool up here, there's an arm that takes you in and everything. I think the parent would probably think, "Oh, I bet we won't be able to do it." But, I think they're always worth coming to have a look, and see just what they could do, and what they can't do. (Gerry, disability sports coach) So they had a bit of a [RaceRunning] taster last year, which we missed, (…) I didn't think Sienna would be able to do it. I don't know why, really, but you know when you think, "Oh, it's not for us." Then I saw a picture of it in the paper and I thought, "To be fair, they look just like her walker here, but	- Likely to be more acceptable if the demonstration is conducted by someone similar to the children and young people receiving the demonstration (see vicarious experience, technique 29).

	with bigger wheels.” They’re amazing little machines, they’re fab. (Michelle, mother)	
29. Vicarious experience: Show children and young people examples of others similar to themselves successfully attending and exploring leisure activities, to make them think they could do it too; or show parents examples of others, similar to their sons and daughters, successfully attending and exploring leisure activities, to make them think their sons and daughters could do it too. *6.1 Demonstration of the behaviour*	So we have leaders that are in wheelchairs or power wheelchairs and they’ll be leading students similar to them, say in Boccia, and reffing Boccia. It’s quite a powerful tool that’s quite hard to measure. For me, it’s more that they can aspire to, “Look, wow, they’re running this Boccia. If they can do aspire to that, I can do that as well.” So there’s like a... Not an end goal but there’s something to lead to. You can’t just run sessions and then not have someone of that same user group involved in it. I just think it’s a bit weird. It’s like doing women’s football and having always male coaches. (Kate, sports development officer)	- Likely to be more acceptable if the examples are closely relevant to the children and young people to whom they are delivered, and/or feature peer or adult role models. - Likely to be more acceptable and feasible if the examples: are embedded within locally available and accessible activities; give parents in particular a clear sense of what the activity setting is like; and inform parents of what practical support is available in that particular setting to enable children and young people to attend and explore. - Likely to be less acceptable and feasible for children and young people who do not identify with or understand examples of others with similar health conditions, impairments, or limitations.
30. During leisure activities, provide children and young people with a prompt or cue to do the activity, or provide a prompt or cue to adults to support children and young people to do activities.	A lot of times I’ve got to reinforce with the teachers and parents, “Can you just step away? Let them do it,” and then I’ll be doing a little bit of coaching with them actually, and they’re like, “Wow. Hold on a minute, she’s just done something, she couldn’t do it at school…” (Kate, sports development officer)	- Likely to be more acceptable in situations where there is evidence children and young people are actively exploring or enjoying the activity, as opposed to prompting children and young people who appear disinterested or to dislike the activity.

7.1 Prompts/cues		- Might be particularly acceptable and feasible for children and young people with more severe and/or profound impairments and limitations, or those with impairments related to memory or sequencing. - Might be particularly unacceptable for children and young people who are dealing with emotional and/or sensory factors related to participation. For example, prompting may need to be avoided in favour of giving time and space for these children and young people to feel safe and comfortable. - At least on face value, prompting might be incompatible with some stakeholders' concept of participation in leisure, for example 'leisure as freely-chosen and fun probably does not require prompting', and 'not sure how this relates to leisure, as opposed to therapy or schooling'.
31. Practise doing or rehearsing, or supporting children and young people to do or rehearse, leisure activities, in a context or at a time when they may not need to do it, order to increase skill and habit.	A lot of stuff I've done around is eating out and things like that, so it's been around self-feeding and things like that. Families have wanted to go out to eat, so we've looked at cutlery, self-feeding, quiet restaurants for children who have communication social problems, using ear defenders in restaurants so that children aren't bothered by noise. Exploring if that's a goal that the family wanted to do, is go out and eat, then we can look at using cutlery in a therapy session and then them taking it out.	- Might be more acceptable and feasible in the context of having set a goal for participation in leisure (technique 1, 2). - At least on face value, practice might be incompatible with some stakeholders' concept of participation in leisure, for example 'leisure is not a habit'.

8.1 Behavioural practice/rehearsal	(Connie, occupational therapist)	
32. Prompt repeated participation in leisure activities in the same context so that it becomes a habit. *8.3 Habit formation*	Nudging. Reminding them. Sending them an email. Texting them saying, “Session’s this Sunday. Hope to see you along.” Giving them the information at the beginning of the session saying, “This is when the next sessions are.” (…) Reinforce it so they think about it and it becomes the norm. “Every Sunday I’m going to a session.” (…) It’s like it becomes the norm. “They need to go to the session on Sunday.” (Kate, sports development officer)	- Might be particularly acceptable and feasible where children and young people require time and routine opportunities to attend, in order to they feel comfortable with exploring an activity, and potentially to enjoy it (as opposed to one-off opportunities). - Might be useful for parents, as they may have busy schedules and are usually relied upon to transport and/or escort children and young people to activities. - At least on face value, might be incompatible with some stakeholders’ concept of participation in leisure, for example ‘leisure is not a habit’.
33. Generalise a leisure activity from one situation where the children and young people already do it, to another situation. *8.6 Generalisation of target behaviour*	We met a power chair user at the café somewhere in Yorkshire. She saw [my wife]. [My wife] goes across to have a chat. She’s quite severely disabled, so I twigged that she probably did play Boccia. So I asked the father. I said, “Does your daughter do it?” He said, “Yes, plays Boccia, but she can only play once every couple of months because it’s so far away.” And I’m like, “But you can play Boccia at home. You can play Boccia in your local leisure centre as a family.” And he was like, “I haven’t really thought about that.” (Seb, inclusive sports development advisor)	- It might be particularly acceptable and feasible to generalise sports activities from one situation to another. - It is not likely to be acceptable or feasible to generalise activities that are highly dependent on the setting, for example watching a film at the cinema would not generalise to watching a film at home on the television.

34. Grade: make attending settings or exploring activities easier, or gradually more challenging – but achievable – until children and young people successfully attend and explore. 8*.7 Graded tasks*	They maybe came to the first session for and wouldn't get out of the car. Then the next day or the next term, they would come, they'd get out of the car, they'd sit down in the sports hall, they wouldn't engage and then they'd go. So we've got a couple of examples of where that's happened but over the months and over about a period of about a year or two years, they've gone from not wanting to get out of the car to actively engaging in the camp and also actively engaging in weekly activity on the back of going to the camp. So it's kind of its taken a lot of work and a lot of effort from that person's point of view, from the parent and also from us to facilitate getting that getting that child to that level. (James, disability sports officer)	- Ensuring children, young people, and parents quickly have a positive and successful experience in new leisure activity settings is likely to increase the acceptability of grading, and the likelihood of repeated attendance. - Grading might be more acceptable and feasible if delivered within the actual activity setting, as opposed to in a different context beforehand. - Grading is particularly acceptable when it enables the middle ground to be located between too challenging and too easy.
35. Provide information from a credible source in favour of or against doing leisure activities. A credible source might be other children and young people, another parent, a certain type of professional, or a public figure. *9.1 Credible source*	Later they were saying that parents/families are a more credible source of information on accessibility, experience…parents wanting to hear about things from other families who have actually experienced it and been to the activity. (field notes, go-along interview with Thomas)	- Likely to be more acceptable to children and young people if the credible source is a friend, a peer, and/or a person with similar abilities. - Likely to be more acceptable to parents if the credible source is a peer whose child has similar abilities, or a person who is familiar with the particular activity setting. - Word of mouth between parents is particularly acceptable to parents. - Likely to be less feasible in relation to leisure activity settings whose staff (and therefore potentially quality) changes frequently.

36. Provide children and young people with material rewards, for example valued objects, for trying to participate in leisure activities, and/or making progress with participating. *10.2 Material reward (behaviour)*	So we have little smiley stickers and we have rubbers, the little erasers, and pencils and things, so these are prizes and people get these for being good. We make a big thing of it, and sometimes it's a certificate, and it's telling mum and dad how well they've done or how they might need to just watch what they're doing with this or that. (Justin, accessible activity scheme leader)	- At least on face value, might be unacceptable to many stakeholders, and incompatible with their concept of participation in leisure. For example, a belief that participation in leisure is always intrinsically motivated and can or should not be externally rewarded. - Small, developmentally appropriate, personally meaningful, and socially valued material rewards are likely to be more acceptable and feasible, for example stickers and certificates. - Might be more acceptable and relevant as a planned and short-term technique for certain children and young people, for example those struggling to attend for the first time or first few times. However, focus should remain on exploration and enjoyment as the reasons for continued attendance.
37. Provide children and young people with social rewards, for example praise, for trying to participate in leisure activities, and/or making progress with participating. *10.4 Social reward*	Normally what I do for the races is I go, “can you go get me two of your friends,” and then get them cheering while they’re doing the race, because then they feel, “Oh wow, okay, yes.” (…) I make this a big deal because for some kids this is their only major tournament they do at school. So you’ve got to make this like the Olympics. We normally get Paralympians that come down and give the medals out, which is a massive incentive. (Kate, sports development officer)	- At least on face value, might be unacceptable to some stakeholders, and incompatible with their concept of participation in leisure. For example, a belief that participation in leisure is always intrinsically motivated and can or should not be externally rewarded. However, this is to a lesser degree than providing material rewards (technique 36). - Conversely, social rewards specifically from peers, and/or in relation to children and young

		people’s efforts to attend settings and explore activities, might be more acceptable. - Developmentally appropriate social rewards are likely to be more acceptable, for example rewards that take account of the presence/absence of learning disability.
38. Provide a range of leisure activities and opportunities for children and young people. *12.2 Restructuring the social environment*	For some of the young people we didn’t have a Boccia club in the city for example so we worked with partners to establish that and again that’s key, it's working in partnership with lots of organisations cos we can’t do it all on our own, and the Boccia club was established and it’s been really successful ever since, so and that’s kind of hit a target group that we weren’t really catering too well for in the past. (James, disability sports officer)	- Likely to be more acceptable to provide a variety of activities, including but not limited to sports, e.g. music and arts. - Likely to be more feasible to be strategic, e.g. provide a small range of activities, maximise attendance, and then branch out. - Consider also providing information about available local leisure activities and opportunities (technique 14).
39. Provide leisure activities and opportunities in response to children and young people’s particular goals and priorities. *12.2 Restructuring the social environment*	Yes, we have been up to Newcastle. Joe got some funding, they are into wrestling and football, so we managed to take them up to Newcastle to see WWE wrestling and we have been to Leeds to see them as well. We used to do Christmas shopping trips on a Thursday (…) We have done cinema trips once a month and trips into town to a classic car show because they are into their cars. We even visited a local car showroom in the city that’s like sport Lamborghinis and Porches, they are really into their cars and we even managed to get a visit arranged there. Basically they decided what they wanted to do and we made it happen. (Jim, short breaks coordinator)	- To be acceptable and feasible for parents, activities should take account of the everyday practical and logistical demands that parents are managing (see Chapter 8). For example, the timing of activities should work for parents as well as children and young people. - Children and young people’s goals and priorities are partly shaped by their prior experiences of settings and activities, and what their peers are doing (see Chapter 7). Therefore, it might increase acceptability to also support their attendance at commonly

		experienced leisure activities, regardless of whether these are current goals or priorities, to provide positive experiences and inform future goals and priorities. - Children and young people's goals and priorities change, therefore ongoing discussion is likely to increase acceptability. For example, by continuously setting goals (technique 1) or exploring (technique 2) with children and young people in a particular local leisure context.
40. Restructure the social environment where leisure activities take place, for example by adapting the usual routines or rules, or organising children and young people into groups who get along well together. *12.2 Restructuring the social environment*	I mean, there is a few people, you can tell that they're not keen on each other, so again, you've got to manage that, try to keep them apart a little bit. You know that you're going to get more out of them if you've kept those two apart, if you like, as opposed to trying to get them in the same group. (Gerry, disability sports coach)	- Likely to be particularly acceptable and relevant for children and young people with social communication limitations. - Might be more acceptable and feasible to balance restructuring the social environment with providing time, space, and support for children and young people to get to know each other and learn to be together.
41. Provide opportunities for individuals to experience direct contact with children and young people with neurodisability, to reduce those individuals' anxiety and increase their empathy.	My experience of coach education in wheelchair tennis is (…) you can give them the information about wheelchair tennis and they get it because they're tennis coaches and they take it on board pretty quickly. But the barrier is they've never met a disabled person. They're not sure what language to use. (…) So I think a lot of it is confidence. […] I think experience is the only way to go because you have to meet and feel comfortable with [disabled people].	- Might be particularly helpful for workers with no previous experience of children and young people with neurodisability. - Consider also teaching/instructing workers in how to support participation (technique 25). - Consider also delivering vicarious experiences to workers (technique 29).

12.2 Restructuring the social environment	(Seb, inclusive sports development advisor)	
42. Add objects to the environment to facilitate participation in leisure, for example adding a racing wheelchair to a training session at an athletics club or adding equipment into a school playground. *12.5 Adding objects to the environment*	We would contact the [wheelchair racing] national governing body (…) and get them to support that individual, or get them to make the links with the local clubs to say actually there is a local club in [town], if you wanna link with them and if this club then says actually we haven't got anyone that's trained up in disability awareness, we haven't got a wheelchair, well that's where that other network, the governing body, maybe it's the the sports association, the local charitable arm, can then look at well can we loan a chair? Can we put funding in to get a chair? Can we look to set this session up? (…) or they can borrow one of our chairs which we've done actually, we've lent chairs to other groups to help them get started. (James, disability sports officer)	- Objects in the form of Changing Places toilets and ramps are likely to be particularly acceptable. - Likely to increase acceptability and feasibility by also teaching/instructing children, young people, parents, and/or workers how to use the objects in the context of supporting participation in leisure (technique 25). - Might be more acceptable to children and young people if the objects are novel and attractive.
43. Punish: arrange for aversive consequence contingent on the performance of an unwanted behaviour. *14.2 Punishment*	Sometimes we have to sort of say, "Right, we're going to stop Paul from coming tomorrow. Don't bring him tomorrow because there's been an incident today where this, this, this and this, has happened. We'd like you to keep him at home today." That is the sanctions that we've got. It might be that we stop someone coming altogether, depending on what the issue is. (Justin, accessible activity scheme leader)	- This technique was identified in the Delphi Stage 1 dataset. However, it was not carried forward to the survey in Stage 2 as general behaviour management was considered beyond the scope of the present research programme.

Table 8-2 Bundles of techniques commonly delivered as standalone interventions across stakeholders' different contexts

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1. Provide activity taster sessions in the form of brief experiences to introduce children and young people to leisure settings/activities.

Individual intervention techniques that may be included:

2. Explore what leisure activities children and young people might want to, by discussing their current activities and interests, making suggestions, and/or offering options of available activities.
13. Provide practical support to identify leisure activities that are locally available, accessible, and appropriate for children and young people.
14. Provide information about local leisure activities and opportunities.
35. Provide information from a credible source in favour of or against doing leisure activities. A credible source might be other children and young people, another parent, a certain type of professional, or a public figure.
23. Provide emotional support to children, young people, and/or parents, before, during, and/or after children and young people participate in leisure activities.
29. Vicarious experience: Show children and young people examples of others similar to themselves successfully attending and exploring leisure activities, to make them think they could do it too; or show parents examples of others, similar to their sons and daughters, successfully attending and exploring leisure activities, to make them think their sons and daughters could do it too.

Direct stakeholder quote illustrating the bundle:

I think what we're trying to do is to, I suppose, to take away those barriers of turning up to a sports club that you don't know anything about and not knowing what it's going to be like. By us organising it and putting our name to it, parents have got the opportunity to ask us questions, so things like we can talk to them about the accessibility of the toilets. We can provide a hoist there and those sorts of things. […] That's an example of how it works, is, for whatever reason the family weren't doing that before [sports taster day], I think there were things around that they didn't actually think that she'd be able to participate and enjoy it. They were scared of taking her, but coming along to an event where you're just trying things is a bit less intimidating, I guess, because if it doesn't work out, then you kind of walk away and you go and try something else. *(Paula, physiotherapist)*

Key messages for acceptable and feasible delivery:

- Activity tasters are likely to be more acceptable if there are local opportunities for children and young people to do the activity regularly.
- Some children, young people, and parents might need to try out the activity several times, as opposed to once.
- Sessions may be more acceptable and attractive to parents and service providers if they are well-publicised and there is good attendance.
- Some children and young people may feel overwhelmed at an activity taster session and need quiet space or other accommodations.

2. Adapt a leisure activity so children and young people can attend and explore, for example by changing when or where it's done, the space in which it's done, the objective of the activity, its duration or timing, the materials or equipment, and/or the rules of the activity.

Individual intervention techniques that may be included:

5. Problem solve: analyse the factors influencing whether children and young people participate in a leisure activity and come up with strategies to overcome barriers/increase supports to participation.

- 34. Grade: make attending settings or exploring activities easier, or gradually more challenging – but achievable – until children and young people successfully attend and explore.
- 40. Restructure the social environment where leisure activities take place, for example by adapting the usual routines or rules, or organising children and young people into groups who get along well together.
- 42. Add objects to the environment to facilitate participation in leisure, for example adding a racing wheelchair to a training session at an athletics club or adding equipment into a school playground.

Direct stakeholder quote illustrating the bundle:

Getting people for the first time? I think, as we said earlier, almost taking sports to them, which could be, one of the ideas that we're trying to develop is to wherever they are. So whether it be in their local park or even literally outside their block of flats, and then making them feel comfortable. And hopefully providing sport in a way that they can continue to go. So a bit like I mentioned earlier, deliver sport in a different way, and if it's tennis and they're playing on a mini court but they're only going to play if that mini court is outside their flat, well, almost don't try and encourage them to go anywhere else. Keep them active where they are, and then maybe they'll get enough skill level or confidence to go somewhere else. (*Seb, inclusive sports development advisor)*

Key messages for acceptable and feasible delivery:

- It might be particularly acceptable and feasible to adapt existing, popular settings and activities (e.g. climbing), especially if disabled and non-disabled siblings can take part together.
- Leisure activity leaders will need to be on board with adapting activities and may need support to see the potential of/accept adaptations.

3. Do a recce: visit leisure activity settings in advance, with or without children and young people, to become familiar with it, and/or help decide if children and young people will be able to attend and explore.

Individual intervention techniques that may be included:

- 5. Problem solve: analyse the factors influencing whether children and young people participate in a leisure activity and come up with strategies to overcome barriers/increase supports to participation.
- 21. Provide workers with information about children and young people's health conditions, strengths, limitations, likes, and/or dislikes.
- 23. Provide emotional support to children, young people, and/or parents, before, during, and/or after children and young people participate in leisure activities.
- 13. Provide practical support to identify leisure activities that are locally available, accessible, and appropriate for children and young people.

Direct stakeholder quotes illustrating the bundle:

I went over and discussed the needs, and could they cope with them? It was like, "My little girl's got special needs and her behaviour can be inappropriate. She won't listen, she'll want to control the situation, but I want to expose her to this challenge, to this activity. Therefore, if you do not engage" – that's the word – "And shaking hands and giving hugs, if you understand all that but deviate to why we're here, but be friendly, be appropriate and directing if you can, and try to get her to listen." The gentleman seemed very au fait with what I was saying. The bonus to that is we'd got a timeframe when there was not many people in. That was at seven o'clock at night and he assured me it would be very quiet, so that was another tick the box; that would work. Doing a recce is ideal to go and discuss. *(Diane, mother)*

We invite parents to come with their children prior, if they've not been before, to the summer scheme starting to bring them round the centre and take away that fear of the unknown if you like. It also helps us to decide on what access needs there are and whether the young person needs one to one support, some do and some don't. *(Justin, accessible activity scheme leader)*

Key messages for acceptable and feasible delivery:

- Doing a recce might be particularly feasible if combined with an activity taster session. It is also helpful to allow parents to stay for the first few sessions at a new activity to feel comfortable that the child or young person is happy and well-supported.
- It might be more acceptable to parents and service providers if the child or young people is involved in doing the recce and making the decisions.

Table 8-3 Delphi Stage 2 stakeholder consensus on the potential effectiveness of intervention techniques for supporting participation in leisure

Intervention techniques (see table 8-1)	**Round 1 ratings (median, IQR)***					**Round 2 ratings (median, IQR)**					**Stability****
	P	AHP	R	SB/SC	Overall	P	AHP	R	SB/SC	Overall	
Consensus of ‘very effective’:											
2	1 (0.5)	1 (1)	2 (1)	1 (0.5)	1 (1)	-	-	-	-	-	-
13	1 (1)	1 (2)	2 (1.5)	1 (0.5)	1 (1)	-	-	-	-	-	-
14	1 (1.5)	1 (1)	2 (2)	1 (1)	1 (1)	1.5 (1)	1 (1)	2 (2)	1 (0)	1 (1)	-
17	1 (1)	1.5 (1)	1.5 (2)	2 (1.5)	1 (1)	1 (0)	1 (1)	1 (1)	2 (1)	1 (1)	-
18	1 (0.5)	2 (1)	2 (1)	2 (2)	1.5 (1)	-	-	-	-	-	-
19	1 (0.5)	1 (1)	2 (2)	1 (1)	1 (1)	-	-	-	-	-	-
25	1 (0.5)	1 (1)	2 (1.5)	1 (1)	1 (1)	-	-	-	-	-	-
38	1 (0.5)	1 (1)	2 (2)	1 (1.5)	1 (1)	1 (0)	1 (1)	2 (2)	1 (0)	1 (1)	-
39	1 (1)	1 (1)	2 (2)	1 (1)	1 (1)	-	-	-	-	-	-
42	1 (1)	1 (1)	2.5 (3)	1 (1.5)	1 (1)	1 (1)	1 (1)	1.5 (2)	1 (0)	1 (1)	-
Bundle 1	1 (2)	1 (1)	3 (1)	2 (2.5)	2 (2)	1 (1)	1 (1)	2 (1)	1 (1)	1 (1)	-
Bundle 2	1 (0.5)	1 (1)	1.5 (2)	1 (1.5)	1 (1)	1 (0.5)	1 (0)	1 (0)	1 (1)	1 (0)	-
Consensus of ‘effective’:											
1	2 (3)	2 (3)	2.5 (2)	2 (2)	2 (2)	3 (2)	2 (1)	2 (1)	2 (1)	2 (1)	-
4	1.5 (2)	2 (1)	2 (2)	2 (1.5)	2 (2)	2 (1)	2 (0)	2 (1)	2 (1)	2 (0)	-
5	2 (1)	2 (2)	2 (1)	1 (1)	2 (1)	-	-	-	-	-	-
8	2 (2.5)	2 (2)	2 (1)	2 (2)	2 (1)	2 (1.5)	2 (0)	2 (1)	2 (1)	2 (1)	-
10	2 (1.5)	2 (1)	2 (1)	1 (0.5)	2 (2)	2 (1)	2 (1)	2 (0)	1 (0)	2 (1)	-
16	2 (2)	2 (1)	2 (1)	2 (1)	2 (1)	-	-	-	-	-	-
22	1 (1)	2 (2)	3 (0.5)	2 (1)	2 (2)	1 (1)	2 (1)	3 (2)	1 (1)	2 (1)	-
23	1 (1)	2 (2)	2 (1)	1 (1.5)	2 (2)	1 (1)	2 (0.5)	2 (1)	1 (0)	2 (1)	-
28	2 (2)	2.5 (2)	3 (2)	2 (2)	2 (2)	2.5 (1)	2 (1)	2 (1)	2 (2)	2 (1)	-
29	2 (2.5)	1.5 (2)	2 (0.5)	2 (2)	2 (2)	2 (1)	2 (0)	2 (0)	2 (1)	2 (0)	-
31	2 (2)	2 (2)	2.5 (1)	2 (2.5)	2 (2)	2 (1.5)	2 (0)	2 (1)	2 (1)	2 (0.5)	-

34	2 (0)	2 (1)	2 (2)	2 (2)	2 (2)	2 (1.5)	2 (0)	2 (1)	2 (1)	2(1)	-
35	2 (1)	2 (2)	3 (2)	2 (1)	2 (2)	2 (0.5)	2 (0.5)	3 (1)	2 (1)	2 (1)	-
37	1 (1)	2 (1)	3 (1)	1 (1)	2 (2)	2 (1)	2 (1)	3 (2)	1 (1)	2 (1)	-
41	2 (1)	2 (2)	2 (1)	1 (1)	2 (1)	-	-	-	-	-	-
Consensus of ‘fairly effective’:											
3	4 (1.5)	4 (3)	4.5 (2)	3 (3)	4 (3)	4 (1.5)	3 (1)	4 (1)	3 (1)	3 (1)	-
24	2 (2)	3 (2)	3 (1)	3 (2.5)	3 (2)	2 (1)	3 (0)	3 (1)	3 (2)	3 (1)	-
27	3 (2.5)	2 (2)	3 (2)	3 (2)	3 (1)	3 (2)	3 (0)	4 (1)	3 (2)	3 (1)	-
30	3 (1)	3 (2)	3 (1.5)	2 (3)	3 (2)	3 (1)	3 (0)	3 (1)	2 (1)	3 (1)	-
36	3 (2.5)	3 (2)	4 (1)	3 (1.5)	3 (2)	3 (3)	3 (1)	4 (1)	3 (1)	3 (1)	-
No consensus:											
6	2 (1.5)	3 (2)	2.5 (2)	2 (2)	2 (2)	2 (2.5)	3 (1)	2 (2)	3 (2)	2 (1)	Stable
7	2 (3)	2 (2)	2.5 (2)	2 (2)	2 (1)	3 (2.5)	3 (1)	3 (1)	2 (2)	3 (1)	Stable
9	2 (2.5)	3 (2)	3 (2)	2 (1.5)	3 (2)	2 (3)	3 (0.5)	3 (2)	2 (1)	3 (1)	Stable
11	4 (2)	2 (2)	3 (2)	3 (2)	3 (2)	3 (2)	3 (0.5)	3 (0)	2 (2)	3 (1)	Stable
12	3 (2.5)	3 (2)	4 (1)	2 (1.5)	3 (2)	3 (2)	3 (0.5)	4 (1)	2 (1)	3 (2)	Stable
15	2 (1.5)	1 (1)	2 (1)	1 (3)	1.5 (1)	1 (1.5)	1 (1)	2 (1)	2 (2)	1 (1)	Stable
33	3 (2)	3 (2)	3 (1)	3 (3)	3 (2)	3 (2)	3 (0)	3 (1)	3 (2)	3 (0)	Stable
40	1.5 (1)	2 (2)	2 (2)	3 (3)	2 (2)	2 (1.5)	2 (1)	2 ()	2 (2)	2 (1)	Stable
Bundle 3	2 (1)	2 (1)	3 (2)	2 (1.5)	2 (2)	2 (2)	2 (0.5)	3 (2)	2 (1)	2 (2)	Stable
20	1 (1)	2 (2)	3 (3)	2 (2)	2 (2)	1 (1)	2 (1.5)	2 (3)	2 (1)	2 (2)	Unstable
21	2 (1.5)	2 (1.5)	3 (2)	3 (2)	2 (2)	2 (3)	2.5 (1)	3 (1)	2 (3)	3 (1)	Unstable
26	4 (5)	4 (2)	4 (1)	4 (1)	4 (1)	2.5 (2)	4 (2)	4 (1)	2 (3)	4 (2)	Unstable
32	2 (1.5)	2 (2)	4 (2)	3 (3.5)	2 (3)	2 (1.5)	3 (1)	3 (1)	1 (3)	2.5 (1)	Unstable

*1 = very effective, 7 = very ineffective, 4 = not sure, IQR = interquartile range (IQR ≤1 = consensus).
P = parents, AHP = allied health professionals, R = researchers, SB = short breaks professionals, SC = sports coaches, Overall = overall group.
**Items achieving consensus within at least three stakeholder groups and overall in round 1 were not included in round 2. Stability of ratings between rounds was calculated only for techniques that did not achieve consensus within at least three stakeholder groups and overall in round 2. Stable lack of consensus was defined as a statistically significant difference in neither the ratings of a separate stakeholder group nor the overall group between rounds 1 and 2. Unstable lack of consensus was defined as a statistically significant difference in ratings of at least one separate stakeholder group or the overall group between rounds 1 and 2.

9 Chapter 9. Reflections on involving parents and young people in the research programme

In chapters 1 and 2, I set out the real-world problem on which this research programme was based: children and young people with neurodisability are more restricted in participation in leisure than their non-disabled peers and, whilst allied health professionals in the NHS are well positioned to support participation, they have limited evidence-based intervention options from which to choose. The overall epistemic aim of the research was to generate knowledge that could usefully inform allied health interventions and potentially improve health outcomes for these children and young people. As part of a mixed methods approach, I understood that parents of disabled children and young people, and children and young people themselves, could bring considerable epistemic resources to the research programme in the form of their lived experience, tacit knowledge, and implicit theories about the research problem (95). In chapter 4, I described their contribution to the Delphi study. In this chapter, I will describe how they were involved in ‘co-producing’ parts of the research.

The National Institute for Health Research (NIHR) has defined co-production as ‘an approach in which researchers, practitioners, and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge’ (333 p.4). I was interested in whether co-production could further advance the epistemic aim of my research through meaningful, substantial, and challenging involvement of parents and young people (99, 100, 334). Two opportunities to pursue this came up within the research programme. One was a request from a conference organising committee to identify a parent who could deliver a keynote presentation at a national allied health event. The other was an idea of working with young people with neurodisability and professional artists to create artwork to share the results of the research. Together, these formed part of the data analysis, interpretation, and dissemination stages of the research process.

Although co-production was my general orientation from the outset, I was unable to identify specific guidance on how to go about doing it with parents and young people from my study population (335-338). Historically, co-production has been applied to designing public services as opposed to conducting research, and examples of individual projects tend to be specific to particular practice contexts (339-342). More recently, detailed and elegant accounts of co-produced research have been published, and the key principles and features of co-production have begun to be clarified (101, 333, 343-350). However, these had yet to emerge at the time I was exploring the topic. In the absence of a clear format, it was necessary to be inventive and improvise. In the end, the parent keynote presentation and creative arts workshops with young people appeared to be successful in that they had a positive impact on the research and the people involved (351, 352). However, I found that there was a ‘dark side’ to co-production (338). This approach was one of the most challenging aspects of the research, practically, intellectually, ethically, and emotionally. I had familiarised myself with the wider methodological literature on public and patient involvement in research, but this had not prepared me for the demands of co-production.

There is beginning to be a better understanding of the complex processes that researchers and collaborators have to navigate in co-production contexts (338, 343, 353-356). In this chapter, I will make a modest contribution to these understandings by describing the context and emergent methods for the co-production in my research programme, and reflecting on which aspects I found particularly challenging, and why. I will also outline what the co-production contributed to the research programme and the people involved and put forward some theoretical ideas that I have found useful in processing and interpreting the experience.

9.1 Parent Keynote Presentation

9.1.1 Context

Diane and her daughter Lucy were stakeholders in Stage 1 of the Delphi study – Diane took part in a semi-structured interview, and they both took part in a go-along interview at Lucy’s weekly visit to a disability swimming session at her local swimming pool (see chapter 4). Not long after the data collection, I was asked to identify a parent who could deliver a keynote presentation at the annual conference of the Royal College of Occupational Therapists Specialist Section for Children, Young People, and Families. Diane agreed to co-produce the presentation together, and the theme was ‘a parent perspective on collaborative working.’ In this section of the chapter, I will present an extract from the presentation script, describe our co-production methods, and set out my main reflections on and interpretation of the experience.

9.1.2 Extract

‘Did you go swimming in your free time when you were a child? Do you think all children, whether or not they have disabilities, should be able to go swimming in their free time? Do you think allied health professionals can enable children to go swimming in their free time?

I want to tell you a story. My daughter is disabled. Epilepsy, global developmental delay, hip problems, feet problems, back problems, limited communication, challenging behaviour, and very sensory-led. Complex on so many levels. She loves swimming, but providing this activity has been difficult. School refused to take her swimming because of her behaviour.

Reception areas in leisure centres were a nightmare. So many people to touch, hug, and engage with. When we finally got into the changing room, she was self-harming, screaming, and hitting out. The swimming pool was another level of sensory overload. She was overwhelmed. I was trying to see this experience through her eyes, her ears. The noise, the echo, her voice became louder. But when she’s shouting, she’s not listening. I used calming gestures, distraction, I tried to get eye contact, to lead her, beckon her.

I was determined to go again. I was looking for outcomes and I felt that I had to put a lot of effort in, use a lot of tools from my toolbox. My goal was to say, “Okay, five more minutes,” and she would just come out of the water. I wanted her to get used to listening to an authoritative person in the swimming pool. That’s a win-win for me. I have to be able to transfer that responsibility to another adult, if I think they’re appropriate.

One week there was a new lady at the swimming pool. I thought she was very interesting. She might be an enabler, like me. So I shared the necessary information about my little girl. We worked together. We introduced a whole suitcase full of tools between us. There was empathy, there was care. There was problem solving: the staff made some tweaks. They don't usually allow parents on poolside, but they allowed me. It took us nine months, week in, week out, to get our child to come out of the water when asked. We never gave up, and it got hostile and it got difficult. But we did it.

Swimming is very important for my daughter's physical and mental health and wellbeing. The physiotherapist has recommended that she gets as much opportunity for swimming as possible, and she gave me information about a swimming pool with disability experience. I follow up on the lead, go along to have a look around and talk to the staff. Nobody gets back to me, there's no feedback. I find another leisure centre with a disability swim session. I take my daughter along to check out the space, check if the staff have the skills. For my daughter the swim goes really well. I was so proud of her. She listened, she cooperated, she engaged, she was responsive. All the work we had done, it was worth it.

The manager comes and knocks me off my perch. "She needs one-to-one support in the pool, that's my assessment. We can't take the risk." I can't get in the pool, so there is nobody to provide the support. I ask a social worker about support for swimming. She tells me, "I think she needs a worker to take her to the youth club each week." But what about swimming? Professionals tell me what needs to be done, and I want to collaborate. But I can't collaborate by myself.

What do we mean by collaboration? I always reach for the dictionary to define the concepts I'm interested in. "The action of working with someone to produce something. Alliance, partnership, participation, combination, association." Or alternatively, "Traitorous cooperation with an enemy. Fraternisation, colluding, consorting, sympathising, conspiring." I've experienced both these styles of collaboration in my dealings with professionals, and I prefer the first one.

Every day I aspire to be an ambassador, an advocate, an enabler, a role model, a problem solver, reflective, goal-oriented, a collaborator. I try to live my personal values of courage, perseverance, integrity, and patience. This is who I am. When you and I take action together to produce a good outcome for my daughter, then you enable me to be the person I am already trying to be. I'm already empowered. If you're my collaborator, I don't need you to empower me. But I do need you to not disempower me.'

9.1.3 Methods

In retrospect, the methods for co-producing the keynote presentation emerged as a process with four phases:

Phase 1: Seeing the potential

During the data collection for the Delphi study, Diane had spoken eloquently about her experiences as a parent and a carer. I knew she was the perfect candidate for the parent keynote presentation. She had a lot to say about both the topic for the research programme – supporting participation in leisure, and the theme for the presentation – parent-practitioner collaboration. I could see her potential to engage an audience and convey ideas and messages in a powerful way. Diane had never done any public speaking before, and she was surprised and pleased when I asked her to get involved. She was also apprehensive, but I was familiar with this particular conference, and I could assure her that these delegates would be welcoming and receptive. We had established a good relationship by this point, and she trusted my judgement. We could see that this conference was an opportunity to influence a large group of allied health professionals, and we were curious about working on something together beyond the data collection.

Phase 2: Telling stories and listening

Diane and I explored the presentation theme over the course of approximately four months and three extended face-to-face meet-ups. This phase was often uncomfortable for me for three reasons. The first was to do with how our relationship was progressing. We were revealing more and more about our experiences of parent-practitioner collaboration

– Diane as a longstanding recipient of health and social care services of varying quality, and me as a former senior practitioner and NHS service manager. Much of what we had to say was challenging and critical. By speaking frankly, we were building trust, solidarity, and investment in the co-production project. However, I was finding the role blurring unsettling. I was shifting between researcher, practitioner, colleague, confidant, advisor, pupil, and friend. This felt transgressive. Unprofessional, even. I was worried about crossing boundaries and breaching personal and professional norms.

The second reason for my discomfort was the methods we were using. As an experienced conference-goer, I had my usual way of constructing a presentation, and I thought we would get started by pinning down our key messages. Diane implicitly rejected my method. Instead, she told stories and I listened and began to fill an A3 sketchpad with mind maps. This approach did not automatically lead to a structure for the presentation. It was highly exploratory, an unfamiliar way of going about things. I was trying to work out how to channel what Diane was saying, and some of her stories were not directly relevant to our theme. It felt risky. I had to take a leap of faith, and trust that we would actually produce a presentation from this content. I was conscious of spending more time on this than I had anticipated, when I was supposed to be doing ‘real’ research. I had to resist being drawn back to the comfort of my usual methodological anchors, and the stability of more traditional ways of working where I, the ‘professional’, could control things.

The third reason for my discomfort was a sense of responsibility for it all. Would this keynote be trite, a waste of an opportunity? Would everyone shed a tear and then feel better about themselves for the rest of the day (357)? Or would we succeed in bringing conscience and critical voice to the event (334)? I had promised Diane that we could co-produce something more than just another ‘patient story’ for the delegates to ignore, and I felt responsible for delivering this. I was also worrying about my own professional reputation. Was this collaboration working? Would we create something decent? Would we even deliver the brief?

Phase 3: Breakthrough

A few weeks before the conference, Diane got in touch in touch with me about swimming. During the data collection for the Delphi study, she had described teaching her daughter to go swimming, talking at length about how ‘It took us nine months, week in, week out, […] and it got hostile and it got difficult. But we did it.’ Diane wanted her daughter to do more swimming, but she was encountering barriers from professionals. I instantly recognised that this was the centrepiece of the keynote presentation. On the surface of it, swimming is an everyday mundanity. But in fact, for Diane it was a frontier of parent-practitioner collaboration. It illustrated the best and the worst of her experiences as a parent and exposed the possibilities and limits of my role as a practitioner. Reflected upon as a critical incident, participation in swimming brought together much of our discussions over the previous months and allowed us to envisage key messages and a structure for the presentation.

To create a script, we printed chunks of data related to swimming from Diane and Lucy’s interview transcripts, wrote down key words and definitions on A4 sheets, and cut out sections of the mind maps representing stories, ideas, and ‘hooks’ to which Diane was particularly attached. We laid out our content materials on a large table and experimented with different narrative structures by physically arranging pieces in different orders to see what might work. This was exciting because we could actually see the presentation begin to take shape. Diane was braver than I was about trying out unconventional structures and styles of delivery, but I followed her lead and came up with ideas for audience participation. We were becoming more confident and feeding off each other’s enthusiasm. We finalised the script and left Diane to practise before the event.

Phase 4: Performing

I felt physically sick when I drove to collect Diane on the morning of the conference, particularly when she told me she had made some last minute (‘unauthorised’?) changes. My mind was working overtime. Could I trust Diane to keep to time? Would our content resonate with this audience? Would the experimental structural engage or confuse? On the outside, I wanted to convey to Diane that I had confidence in our collaboration, so I projected calm certainty that the keynote would go well. By the mid-morning coffee, Diane had performed the presentation to approximately 150 allied health professionals with ease, had received a standing ovation, and was working her way through a queue of conference delegates who wanted to hear more about her views and advice on parent-practitioner collaboration.

9.1.4 Interpretation

‘The whole experience was edifying, it will stay with me like a lush cashmere cloak.’ This was the text message that Diane sent to me a week after the event, about her experience of co-producing the keynote presentation. For me, her choice of words evokes sensations of enlightenment, strength, warmth, and safety. I have found it useful to reflect on Diane’s experience through the lens of ‘epistemic injustice’, and specifically ‘testimonial injustice’, as recently contextualised by Hutchison and colleagues within the arena of public and patient involvement in health research (358). Testimonial injustice is a form of epistemic injustice in which the credibility of a speaker is unfairly diminished in the eyes of the speaker’s audience, due to a prejudice on the part of the audience. The prejudice is in relation to a particular aspect of the speaker’s identity, for example their gender or social status.

From her involvement in the research programme, I was aware that Diane strongly identified as an ambassador for her own disabled daughter, and children and young people with neurodisability more broadly. As an experienced parent and carer, she has experiential knowledge – ‘jewels of wisdom’ – that would make a valuable contribution to improving health and social care services in her local area (359 p.1). However, from her perspective, local services and their constituent practitioners had consistently rejected or subverted her attempts to get involved in service improvement, an experience commonly reported by people affected by health conditions and disability (e.g. 105, 107, 359, 360-362). Drawing on my own experiential knowledge as a practitioner, I suspect that local services and practitioners judged Diane not to be credible on the basis of aspects of her identity. Specifically, Diane comes across as confident, well informed, righteous, and tenacious. I surmise that she will have been perceived as a trouble-maker, a difficult parent with unrealistic expectations of services and excessively high ambitions for her daughter (363). These prejudices rendered Diane as ‘unheard and unhearable’, and her experiential knowledge as an untapped epistemic resource (360 p.87).

Drawing on the recent theoretical work from Hutchison and colleagues, I would argue that co-producing the keynote presentation was an antidote to Diane’s experience of chronic testimonial injustice (358). The quality of our relationship removed, or at least reduced, the hierarchical barriers that contribute to testimonial injustice, and Diane’s experiential knowledge was taken not only as credible, but as valuable. She was explicitly and consciously contributing to the epistemic aim of the research, whereas it had not been possible for her to contribute to the practical aims of local services. As a practitioner academic, I perceive there to be a considerable distance between research and practice. However, there is evidence that such distinctions are less marked – or less important – to people like Diane who are contributing to research (353, 360). It is possible that Diane may in fact have felt she was contributing directly to improving local services – her main ambition as an ambassador for disabled children and young people.

I have reflected on whether the public performance of the keynote presentation in Phase 4 was particularly significant. From Diane’s point of view, a large group of allied health professionals had publicly accepted her experiential knowledge as credible and valuable, and witnessed their respected peers do the same. The responses and Tweets from conference delegates on the day, and the formal conference evaluation, evidenced at least a transient impact of the presentation on the practitioner community. In retrospect, I can see that a key function of my role was avoid the risk of further testimonial injustice and help create the conditions within which Diane’s experiential knowledge could be harnessed. I have since used our emergent method to co-produce a conference presentation with a young person with neurodisability who is also a care leaver.[19] I would argue, therefore, that some of the principles and key features of this co-production project are transferable to different people and topics, and have the potential for positive impact in other contexts.

9.2 Creative Arts Workshops with Young People

9.2.1 Context

Within the research programme, I worked with a participatory artist and eight young people aged 16-21 years to form ‘AniMates’, a group that makes artwork about research projects. AniMates members have first-hand experience of neurodisability, or supporting people affected by neurodisability. Together we co-produced two stages of the research programme: the data analysis and interpretation at Stage 1 of the Delphi study, and the dissemination of the overall results. In this section of the chapter, I will present a reflective case study about AniMates that I was invited to write by NIHR INVOLVE for their upcoming publication on how to co-produce research. The publication is part of a follow-up series to their current guidance on the key principles and features of co-production (333).

9.2.2 How did the key principles and features of co-producing research find expression in the research?

As a practitioner academic, I was inspired by projects where creative arts had been used for including the perspectives and skills of all stakeholders, particularly those of young people perceived as vulnerable. I had budgeted for public involvement in my original funding application, and I needed to access methodological expertise to support a co-production project. Therefore, my first step was to commission an experienced participatory artist, Lucy Barker, and orientate her to the research programme and preliminary results. Initially, Lucy and I decided to co-produce an animated film to share the results of the research programme. We chose animation

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[19] The young person is a member of AniMates, described later in this chapter. The presentation was accepted as an exhibit for Rightful Lives, the online exhibition that explores the theme of human rights and people with autism and/or learning disabilities: http://www.rightfullives.net/Videopages/Rebel-Girl.html

because of its successful impact in other co-produced research with vulnerable young people.[20]

To get people involved, we contacted individuals from my previous project (330) and began a new collaboration with Pyramid of Arts, a collective of artists with and without learning disabilities. Eight young people aged 16-21 years got involved in the co-production: three young people with neurodisability and their three personal assistants, and two artists, one of whom has a learning disability. We visited them at home to introduce the idea of the animation and gain their initial consent to be involved. The home visits helped us to start building and maintaining relationships, and to prepare an inclusive and accessible co-production environment. We practised interacting through the young people's high-tech communication aids, worked out how to operate their other assistive technologies (e.g. powered wheelchairs and hearing aids), and learned how to carry out essential support tasks safely (e.g. assisting one young person to have a drink of water). The young people were all in education, so we worked around college terms and family holidays to set the date for our first co-production workshop. We sourced a suitable venue with a Changing Place accessible toilet, level access, and parking, and booked wheelchair-accessible taxis.

The co-production took place within five one-day workshops over ten months, mostly in the school holidays and occasionally at the weekend. We made a conscious decision to include everyone's perspective. For example, we valued the contribution of personal assistants because, as well as supporting the young people to take part, they had experiences and views in their own right, and we wanted them to have a stake in the co-production. We believed that having young people as the predominant age group throughout the process would set the right tone, and create an environment where individuals could be vocal, and feel confident and in control. It was important that the young people with neurodisability could attend without their parents, and that – as much as possible – we

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[20] Breaking Through Moving On from Child Sexual Exploitation, University of York and Basis Yorkshire: https://basisyorkshire.org.uk/training-resources/breaking-through-moving-on-from-cse/

communicated and made arrangements with them directly. This was more developmentally appropriate for their age group, and we wanted to avoid adding to their parents' workload.

To help build relationships, we agreed initial ground rules, and created a giant timeline where we plotted everyone's birthdays, exams, holidays, and other important events. In the workshops, we devoted the first hour to socialising and catching up on timeline news. Between workshops, we used social media (e.g. SMS text messaging, WhatsApp groups, email, Instagram, and Doodle) to share photographs of our activities (including with parents), keep in touch with each other, and decide when and where we would next get together.

Lucy and I soon began to realise that researchers and artists bring very different knowledge and skills to the co-production table. Researchers generally use pre-determined protocols that lay out the steps they will take to deliver their aims and objectives. Artists create spaces and processes for exploring ideas, seemingly without a fixed agenda or purpose, and respond to what emerges. For our co-production, Lucy envisaged loosely structured workshops, with time built in for young people to play, experiment, bond, and process the density of the research. She was confident – and creatively, she thought it was important – to take risks and see what happened. From a researcher's point of view, this felt risky and uncomfortable. How did such flexibility and open-ended approaches fit with funded deliverables and fixed timescales? At this point, it was critical to step outside my comfort zone and be open-minded about diverse methodologies. In the end, creative approaches proved to be one of the most important mechanisms for sharing some control with the young people and giving them real responsibility within the co-production process.

The young people were confident and enthusiastic about taking responsibility and control straight away. They got started by watching a diverse selection of short animations, analysing their content, tone, accessibility, and format, and deciding on a shortlist of desirable features. They preferred animations that had a clear message and a target audience, were humorous, accessible for people with hearing loss and those with reading difficulties, and based on real-life people and places. We realised that real-life stories would be a good way of opening up the research for young people, so I went back to the research data and extracted stakeholders' quotations, stories, and examples. These were printed out on large A0 sheets and pinned onto the wall for the young people to explore in more detail. Simultaneously, the group experimented with different art forms, including light painting, animating, and printing. Combining the art with the research was refreshing. Making things gave us all time to reflect on the data and sparked off conversations about how health and social care policy and practice actually played out in the young people's day-to-day lives. They made connections between the issues in the data and their own views on leisure, short breaks, direct payments, accessibility of buildings, and rules and regulations in leisure centres. Their views challenged us to think about whether and how the results of the study might help to address the issues they were describing.

There were around six weeks between the workshops, and this gave Lucy and me time and space to take an iterative approach to the co-production. We reflected carefully on the young people's views, went back to the data for more analysis and interpretation in light of their perspectives, and planned the next workshop in direct response to their ideas. We created an ongoing dialogue by following the threads of the young people's views in and out of the data, and bringing back further quotations, stories, and examples focusing on the issues they had identified as important.

By halfway through the co-production, we were collectively taking joint ownership of key decisions, particularly the main messages for the animated film. The young people wanted to focus on tensions around 'hanging out with friends', because this topic resonated with their own experiences. On the one hand, they believed hanging out with friends to be an important aspect of participation in leisure contributing to health and wellbeing. On the other hand, within the research data they had explored problems with NHS and Social Care support for hanging out with friends (e.g. professionals' beliefs that hanging out has limited value, and that participation in sport is more important). These tensions have been highlighted in other studies, but – prior to the co-production – had not been part of my main focus. Ongoing dialogue with the young people enabled me to analyse the thread of hanging out with friends in more detail and with more nuance than I had previously. This meant that I could appreciate its importance to one of the key stakeholder groups (young people) and highlight its significance in the write-up of the research programme. In short, collectively we were respecting and valuing the knowledge of all those working on the project.

In co-production, reciprocity means that everybody benefits from working together. In this project we emphasised valuing and evaluating the impact of co-producing research, not just in terms of project outputs, but also the personal development opportunities that came about for all of us. In particular, I learned how to open up the research data and preliminary results to people outside the academic research team (i.e. me and my supervisors). On a practical level, this meant getting better at communicating in plain English, and working out how to condense a large volume of information to something that Lucy and the young people could actually access, whilst simultaneously preserving its nuance and meaning. For example, Stage 1 of the Delphi study had generated approximately 1,000 pages of interview and focus group transcripts. It was overwhelming to think about how to even start to make these data accessible and interesting. The solution emerged from listening and responding to the young people: they could relate to stories about real-life people and places, so extracting participants' verbatim stories and examples from the data set was the best place to start. Opening up the research meant I had to become less protective of the data set as a whole, and more willing to separate out individual sections and stories for scrutiny in the co-production workshops. The temptation was to try and control other people's understanding of the research. It was important – but challenging – to resist the urge to over-explain the data and give other people time to digest it all and come up with their own interpretations.

The creative arts methods we used emphasised exploring and experimenting, seemingly without a fixed agenda or purpose related to the research data and results. The idea was to embrace uncertainty, follow the threads in different directions, see what happened, and respond. For me as the lead researcher, who had responsible for delivering and managing the project and would be judged on its success, this was challenging. What would the funder and the wider academic community think about the outputs of the co-production? How was all this going to help disseminate the research? However, as the co-production progressed, the creative methods were the very aspects that freed us up to take a fresh perspective and play with the research in different ways, for example through comedy, movement, and metaphors. Although this approach was unfamiliar to me, it was natural and interesting for the young people. It played an important part in getting them involved in the process, because it encouraged expression and autonomy, and enabled them to take more control over the co-production. Sharing control with the young people generated uncertainty, which meant that a supportive and respectful relationship between Lucy and I was key. Through continuous reflection on our ideas, concerns, and anxieties, we developed a shared sense of responsibility for the success of the project and became more confident and willing to take risks.

Throughout the co-production, there was a commitment to relationship building, breaking down boundaries, and gaining a better understanding of the young people’s worlds. Lucy and I experienced first-hand the considerable logistical challenge of organising accessible co-production workshops, particularly the limited availability of level access venues with Changing Places. Although this was time-consuming and often frustrating, it was also fundamentally important to making the co-production happen, and it gave us a taste of the reality that the young people and their parents navigated each day. We learned more about how health and social care policy and practice actually played out in the young people’s day-to-day lives. These insights enabled us to explore the relevance and use of the research results and come up with new ideas for research that would inform positive changes in policy and practice.

From the outset, it was essential for the young people to get something back from the co-production, and our first priority was for the workshops to be enjoyable and challenging, as well as inclusive and accessible. We had learned to have high expectations of the young people’s abilities, and we wanted to make sure their contribution was meaningful, substantial, and challenging. We wanted to avoid falling into the trap of merely ‘entertaining’ them or asking them for feedback on – or endorsement of – research results that had already been decided upon by the adults. The co-production was an opportunity for combining academic and creative thinking, exploring young people’s perspectives on live research data, and experimenting with art forms they had not previously experienced. We believed that this approach would lead to opportunities for personal growth and development for all of us, by using and extending our existing knowledge and skills.

The co-production also provided a context for forming friendships and developing a sense of group identity. Partway through the workshops, one young person named the group ‘AniMates’ – a play on our animation work and the social aspects of getting together regularly. Two artists in the group designed an AniMates logo capturing the ideas of asking questions, having fun, voicing your opinion, making things, and being together. As a group, we socialised outside the arena of the research programme by visiting one of the young people’s first exhibitions as a solo artist and having a celebration lunch. Socialising both within and outside the workshops was pleasurable and helped strike a balance between having more challenging academic and more laid-back aspects to the co-production.

Our co-production project gradually became a springboard for new ideas about how young people can make a much greater contribution to neurodisability research. To begin to realise our ideas, we needed to be able to sustain what we had achieved in AniMates. However, I was all too aware of the challenge of keeping up momentum between funded research programmes. I successfully applied for sustainability funding from EngageFMS at the Faculty of Medical Sciences, Newcastle University, which enabled me to develop a strategic plan for maintaining and developing AniMates in the coming years. By this point, I understood the individual young people’s talents, interests, and capabilities, so the funding also enabled paid leadership roles for AniMates members on various projects. For example, two members designed a Facebook page to describe our co-produced projects, introduce AniMates to the world, curate our artwork, and get more people involved in the future.[21] One young person was interested in exploring career options in health and social care and research. She worked with me to contribute to two successful funding applications to the National Institute for Health Research[22] and the British Academy of Childhood Disability,[23] and became a paid co-investigator.

Looking towards the future, one next step is for AniMates to connect with other researchers and young people's advisory groups. We would like to further explore how meaningful and reciprocal involvement of people who are seen as vulnerable can best be embedded within, and sustained between, research programmes. We are also interested in how co-production itself could have a positive impact on young people's friendships, peer support, work experience, and employment, all of which are more restricted for young people with neurodisability. And we have started working on plans to further evaluate both the impact of our co-produced artwork and events, and of the co-production methods and processes themselves. Our animated film can be viewed at: www.facebook.com/animatesleeds.

9.3 Summary

I have described two co-production projects that made a substantial contribution to this research programme on supporting participation in leisure of children and young people with neurodisability. In this reflective account, my focus on methods for co-production adds to the emerging literature in this area, and my interpretation of the impact particularly on Diane builds on other descriptive accounts and analyses in this field (336, 364-366). I have also touched upon the impact on me as a developing practitioner academic. So far, my co-production journey has been characterised by a great deal of improvisation, uncertainty, and emotion, which I now interpret as a hallmark of its authenticity. Having lived to tell the tale, I recognise that my experience of co-production has

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[21] www.facebook.com/animatesleeds
[22] http://empower.bangor.ac.uk/index.php.en
[23] https://www.bacdis.org.uk/awards/

fundamentally changed me as a practitioner-academic, in terms of what I know, what I believe, how I think, and how I act (351, 367).

In chapter 4, I described how the involvement of parent advisors substantively changed and improved the design of the Delphi study. The co-production projects also influenced the research programme itself, but admittedly in ways that I have found more difficult to articulate. Collaborating with Diane sensitised me to the particular challenges experienced by some children and young people with learning disabilities (see chapter 6), the amount of work parents need to put in to supporting participation in leisure (see chapters 6-7), and the creative and innovative approaches that they use (e.g. ‘doing a recce’, see chapter 8). Diane also challenged me to think differently about participation in leisure as a health outcome. I came to appreciate ‘going swimming’ as a site of potential tension, opportunity, and division, whereas formerly it was a taken-for-granted, incidental aspect of being a child or young people in the UK.

Collaborating with the young people was particularly influential on my analysis of allied health implementation of participation support. As I reported in chapter 8, it is beyond the scope of the thesis to report those results in detail. However, there was an undeniable and unsettling distance between what the young people said was important about participation in leisure (e.g. that ‘hanging out with friends’ is very important) and what the allied health professionals – on the whole – were able and willing to do to support participation in leisure (e.g. we can/will support participation in sport, but not hanging out with friends).

Co-production was my general orientation from the outset of the research programme, but throughout the research programme I have learned more about the criticisms of co-production from within the arenas of health services research, social research, and bioethics (105-107, 334, 347, 368, 369). These final points summarise some of the key lessons I have learned and the recommendations I would make to other practitioner-academics and researchers:

- Co-production – or patient and public involvement in research more broadly – is not benign. There is a need to: (i) ensure that those involved can make a meaningful, substantial, and challenging contribution, and (ii) guard against exploitation, for example where co-production may be used primarily to virtue signal for research teams, or to leverage the symbolic capital of vulnerable groups in ways that does not confer benefits onto those groups (334, 368).

- Flexibility is the cornerstone of inclusive and accessible co-production. Practicalities and logistics are a demanding but fundamentally important part of making co-production happen. It helps if researchers are ‘tolerant of messiness’ and ‘able to go with the flow’ (369 p.222).
- Interdisciplinary collaboration with participatory artists enriches co-production methods and outputs, particularly with groups of people seen as vulnerable. Being creative and making things have substantial benefits for co-production processes, outputs, and impact (370, 371). Researchers can build opportunities for diverse methodological approaches into their funding applications.
- Co-production is characterised by reciprocal relationships that bring the best out in people and support them to enact their autonomy (372, 373). However, co-production relationships, as well as processes, are often messy, emergent, uncertain, and emotional. Researchers may need to transgress traditional boundaries, and the unwritten rules about how to interact with public advisors may need to be challenged (343, 353).
- Co-production may introduce methodological and ethical complexities that will need to be carefully navigated, and critical reflection and peer support will be essential. Examples are emerging of accessible and creative approaches to preparing researchers for co-production and public and patient involvement in research more broadly (e.g. 103, 374).
- Researchers should make it a priority to look for opportunities to sustain and fund co-production relationships beyond individual research programmes, particularly with people with long-term conditions.

10 Discussion

The aim of this research programme was to develop an allied health intervention to support participation in leisure of children and young people with neurodisability. Working with diverse and experienced stakeholders, my objectives were to:

1) Develop a relevant and useful definition of participation in leisure as a health outcome,
2) Identify modifiable personal and social environmental factors that influence participation in leisure,
3) Specify intervention techniques for supporting participation in leisure,
4) Establish the extent of stakeholder consensus about the potential effectiveness of the intervention techniques,
5) Generate descriptions of acceptable, feasible ways for allied health professionals to deliver the intervention techniques in NHS settings.

In this final chapter I will summarise the key results, reflect on the programme theory and logic model in more detail, set out the implications of the research for researchers, allied health professionals, parents, and children and young people, consider the overall strengths and weaknesses, and reflect on how I have framed and conducted the research programme as a whole.

10.1 Summary of Results

My aim in this research programme was to develop an allied health intervention to support participation in leisure of children and young people with neurodisability. As I stated in chapter 4, at the outset of the research I had assumed and anticipated that I would develop one definitive intervention. However, in actual fact the main output is a comprehensive programme theory of supporting participation in leisure to be used for developing multiple interventions tailored to local contexts and diverse populations. The key components of the programme theory are the definition of participation in leisure, modifiable personal and social environmental factors, contextual factors, intervention techniques, and description of ways to deliver them. These were presented together in the form of an illustrative logic model in chapter 4 (figure 4-1, page 94) and were described in detail in chapters 5-8.

In chapter 5, I presented a definition of participation in leisure as a health outcome that was relevant and useful to a diverse group of stakeholders (objective 1). I argued that interventions to support participation in leisure should be ultimately directed towards children and young people achieving two key actions: (i) attending leisure settings and activities, and especially attending for the first time, and (ii) exploring activities, in other words getting to the point where children and young people are doing leisure activities in their broadly recognisable and conventional forms in order to discover whether they enjoy them. These actions take place in community activity settings with peers, which I identified as a particularly important context of participation in leisure, and which also may be considered an intervention target in and of itself.

In chapter 6, I described the personal factors that influence participation in leisure, and that are likely to be amenable to allied health interventions in the NHS (objective 2). When I brought together the results from the systematic review and the Delphi study, the four particularly relevant personal factors were children and young people’s emotions, goals, social role and identity, and beliefs about capabilities. I made three arguments: (i) that emotions and goals can be most usefully conceptualised as determinants of whether children and young people attend and explore leisure settings and activities, (ii) that social role and identity can be understood as an important part of the context that influences whether and how interventions for supporting participation in leisure are implemented, for example towards which leisure activities interventions are directed, and (iii) that beliefs about capabilities can be positioned primarily as an outcome of participation in leisure, but also as a key part of the process of exploring.

In chapter 7, I focused on children and young people’s social environments (objective 2), reporting six parent-related factors that influence participation in leisure: parents’ goals, beliefs about their own capabilities to support their children's participation, beliefs about the consequences of participation, beliefs about their children's capabilities to participate, detailed knowledge of local leisure activities, and emotions. I described the connections and interactions between these factors, and how they are shaped by the practicalities and logistics of parents' everyday lives. The qualitative results of the Delphi study were helpful for contextualising the systematic review results, particularly those related to parent and family leisure behaviours, and support and relationships. I also described in some detail the four features of the local leisure context likely to play an important role in whether and how participation support is implemented: the availability of accessible settings and activities, the nature of leisure and short breaks services and systems (and especially issues related to 'workers' – activity leaders, personal assistants, and carers), the social network of individuals, groups, and organisations supporting participation, and the relationships between them, and transportation services, systems, and policies.

In chapter 8, I presented a chart of intervention techniques for supporting participation in leisure (objective 3) and demonstrated that most of the techniques were evaluated as being potentially effective by most of the stakeholders (objective 4). I described acceptable and feasible ways to deliver each individual technique, as well as three cross-cutting principles for allied health professionals delivering the techniques in public service contexts (objective 5): (i) intervention techniques may be grounded in – or may extend – what is available and accessible for particular populations of children and young people in a local leisure context, (ii) practitioners should have an intimate knowledge of the leisure settings and activities with which they are connecting children and young people, and they can gain this knowledge by embedding themselves within the social network in their local leisure context, and (iii) practitioners should explicitly reflect on their implicit personal and professional value systems related to participation in leisure, as these are likely to drive which leisure settings and activities they deem it acceptable and feasible to support. I also presented several practical recommendations for building interventions using the programme theory.

10.2 Reflections on the Programme Theory and Logic Model

Articulating programme theory is a key step in complex intervention development, and throughout the research my thinking on programme theory has been primarily informed by current guidance on developing complex interventions (112, 375). A programme theory describes an intervention, states the mechanisms of change through which the intervention is hypothesised to generate its specific outcomes, and takes into account how the intervention, mechanisms, and outcomes interact with contextual factors. My programme theory is set out in detail in chapters 5-8 which, whilst important, is not conducive to its accessible presentation. Therefore, a logic model is required.

A logic model is a diagram that represents the programme theory of an intervention and illustrates the intervention itself, how it will be delivered, it's mechanisms, and its intended short-, medium-, and long-term outcomes (376). I presented the logic model representing my programme theory in chapter 4 (figure 4-1, page 94). The diagram is helpful in that it captures the key components of the programme theory. However, it does not specifically highlight the hypothesised relationships between components that I have set out in chapters 5-8. As logic models are designed to be continuously tested and refined to ensure they are clear and helpful, I have further developed my logic model to more explicitly display the direction and nature of the causal relationships that I have proposed within this thesis. The revised logic model is presented in figure 10-1 below. In terms of starting points, stakeholders' preliminary use of the programme theory to build prototype interventions suggests that, at the outset, it is usually helpful to specify the individual or populations of children and young people towards whom interventions are directed, and the leisure settings or activities that will be targeted. In the case of the latter, the exception is when the settings or activities to be attended and explored are unknown, and the point of the intervention is their identification. Otherwise, the programme theory provides multiple 'starting points' for interventions, for example focusing on a particular technique

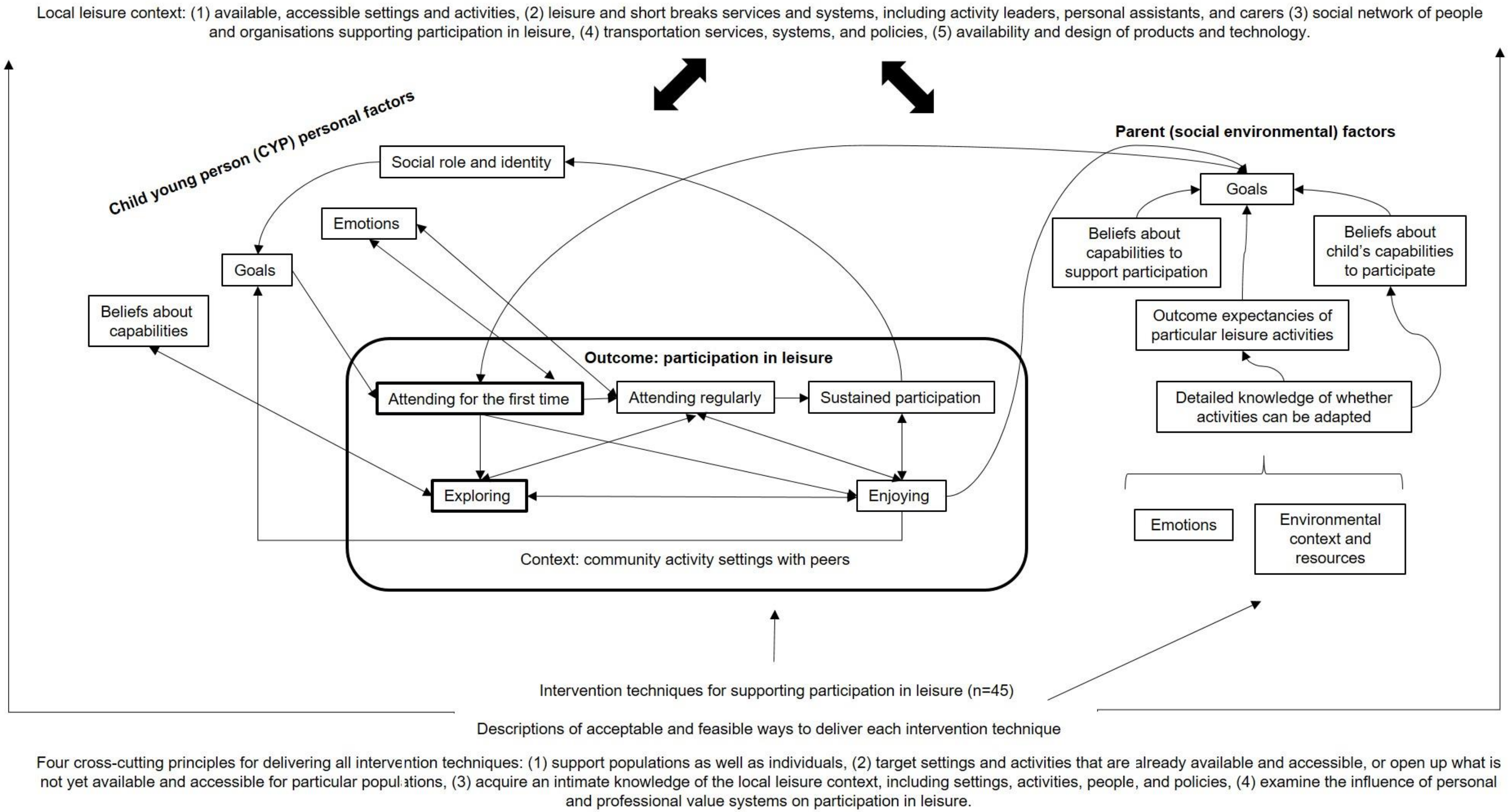

Figure 10-1 Revised logic model illustrating the programme theory for supporting participation in leisure

that is acceptable and feasible for a service to deliver within their local leisure context, or targeting a causal mechanism understood to be of particular importance for the individuals or populations a service is seeking to support.

The recently updated guidance from the Medical Research Council on developing and evaluating complex interventions – currently in draft – points out that thinking in this field has moved on (377). Interventions may be complex not only because they have several interacting components, but also because of how they interact with the context in which they are located, which in itself can be considered a complex adaptive system characterised by unpredictable emergent properties, feedback loops, adaptation, and self-organisation of individuals and groups (303, 377). The complexity of the system highlights the importance of developing and delivering multiple interventions that target causal mechanisms at multiple levels (377). I argue that the programme theory produced in this research programme can be used to develop such multi-level interventions. Indeed, evidence is emerging that multi-level interventions have positive effects on the participation in leisure of the general population (313) and are needed for supporting participation in leisure of children and young people with neurodisability (223).

10.3 Implications for Researchers

Following on from this research programme, the most important next stages relate to testing the feasibility of using the programme to develop and evaluate interventions for supporting participation in leisure. The immediate next step is to present the components and resources of the programme theory in formats that stakeholders can actually access, engage with, and use. It will be critical to test its use with diverse stakeholders beyond those involved in this research programme. Stakeholders will require guidance and training on how to use the programme theory to build interventions, for example how to make decisions about where to intervene, at what level, and in relation to whom, and about interventions’ format, content, and delivery (109).

Feasibility testing should also explore how to evaluate the potential impact of the interventions developed and implemented using the programme theory. Key objectives of modelling the process and outcomes of the interventions will include determining how the outcome can be measured, whether the programme theory and related tools and training resources are working as intended, whether interventions are achieving short-term goals, the resource implications, and the most appropriate design for a definitive evaluation.

10.4 Implications for Allied Health Professionals

The most immediate implication for allied health professionals is the specification of 45 intervention techniques and descriptions of how they can be delivered to support participation in leisure. Some of these could be informally trialled relatively quickly in everyday practice, as they are already presented in a fairly accessible (albeit minimally engaging) format. With support and facilitation, the programme theory could stimulate allied health services to begin analysing the local leisure context in which they are operating, critically reflecting on their current place in the social network and considering what resources they can bring to the table.

More broadly, the results of the research programme should help provoke a shift in allied health professionals' perspectives about interventions for supporting participation in leisure. This would involve moving away from thinking primarily – or exclusively – in terms of clinic-based, single-level interventions for individual children and young people, to thinking more in terms of system-wide, multiple, and multi-level interventions for populations as well as individuals. Allied health professionals need not be single-handedly responsible for developing and delivering all the necessary interventions for supporting participation in leisure. However, by recognising how the social network operates within the local leisure context, they can strengthen their contribution.

More fundamentally, the research programme challenges allied health professionals to examine their own personal and professional value systems related to supporting participation in leisure. This is important because their values infiltrate their decisions about when, where, how, and with whom to intervene – and when not to do so. In my experience as a senior occupational therapist, I would argue that there is already considerable evidence of the influence of allied health professionals' values on their support for participation in leisure. This is particularly marked in relation to children and young people's physical activity. Reflecting one of the highest profile public health agendas in the UK, allied health professionals have become increasingly interested in supporting participation in physical play and leisure and have largely interpreted physical play and leisure as organised sport. This has two implications. First, it risks positioning organised sport as the only source of movement and physical activity, overlooking other sources (e.g. an art group or a walk around the shops) and excluding those for whom organised sport is inaccessible, irrelevant, or holds little appeal. Second, it risks privileging movement and physical activity as the most important or even the only reason to participate in leisure, and organised sport as the only form of leisure in which it is worth supporting children and young people to participate, or which allied health professionals can justify supporting. Physical activity and movement are critically important, but there are wide-ranging benefits of participating in a variety of leisure settings and activities, which is what children and young people with – and without – neurodisability want to do.

10.5 Implications for Parents

The research programme offers a contextualised account of parent-related factors influencing participation in leisure. The factors are situated within the practicalities and logistics of parents' everyday lives, and their wider values and priorities – both related to and beyond participation. In particular, the results highlight how parents are already actively operating within their local leisure contexts, as opposed to within the vacuum of a statutory organisation. Many parents are already trying to identify, attend, and explore settings and activities with their children, and using social media and word of mouth to find and share information. This research captures, to some extent, the work they put in and their critical contribution to the functioning of the social network.

The extent to which parents might engage directly with the programme theory is unclear, and something I am interested to explore further. On the one hand, many parents are already delivering ‘bundles’ of intervention techniques to support their children’s participation (e.g. ‘doing a recce), although I am not sure if they would conceptualise their support in this way. Would they require – or even welcome – the approach to intervention development I am proposing? On the other hand, parents want their children to participate, and are likely to support most efforts towards this goal. In particular, they are likely to support any targeting of the contextual and systemic factors that restrict their children’s participation, and to be welcoming of improved recommendations for settings and activities from practitioners with greater intimate knowledge – because this means less of their time will be wasted.

Parents are likely to be especially interested in further research about ‘workers’, i.e. activity leaders, personal assistants, and carers. This research programme has highlighted the multitude of worker-related factors potentially influencing children and young people’s participation in leisure. As with any parents, parents of disabled children and young people need to be assured that the workers supporting their children are capable. Additionally, many parents in receipt of direct payments are in the position of having to find, train, retain, and replace workers. This is demanding, and feedback from the parent advisors in the research programme indicates that research on how this can be implemented, evaluated, and optimised would be welcome.

10.6 Implications for Children and Young People

A key message from this research programme concerns the fundamental sameness of children and young people with and without neurodisability – they want to participate in, should be participating in, and enjoy the same leisure settings and activities. Importantly, this is not a novel idea, but instead lends further evidence – should it be needed – to arguments that are well-rehearsed in the wider literature. The novel contribution of the research is that the programme theory provides specific and practical ways forward for actually supporting participation in leisure, beyond that which is currently implemented and imagined in allied health professional practice in the NHS. The imperative now is to use this programme theory to develop, test, evaluate, and implement support that may make a material difference to children and young people's participation, and their wider health outcomes.

10.7 Strengths and Weaknesses of the Research Programme

I have reflected on the overall strengths and weaknesses of the research programme in light of two recent developments in complex intervention development methods: the draft updated methodological guidance from the Medical Research Council (377) and the systematic methods overview of approaches to intervention development by O'Cathain and colleagues (109).

A particular strength of the research programme was its involvement of diverse stakeholders at the different stages. To my knowledge, there are few if any studies that have brought together short breaks and allied health professionals, and I consider this combination to have significantly enriched my research. It was critical for my understanding of how supporting participation in leisure works within local authorities as well as the NHS, and for situating the research results within the short breaks policy and practice context, rather than an allied health vacuum. It would have been helpful to include local and national policy makers as a further stakeholder group. My attention to context was also a strength, given that the success of an intervention is related to the system and context in which it is implemented. I have been able to highlight the complexity and variability of local leisure contexts, and pinpoint key features that may be particularly relevant to the delivery and effectiveness of interventions.

The programme theory that I developed is built on established theoretical constructs and empirical evidence. It is well-specified, and clear in that it conceptually defines and delineates target health behaviours from their causal mechanisms and consequences. It proposes some causal relationships between components at individual, interpersonal, and community levels, and enables further hypotheses about relationships to be articulated and described in some detail. It is also fundamentally practical – it includes multiple specific intervention techniques with detailed descriptions of how they can be delivered, and these descriptions are tailored to leisure contexts and were able to be used for building prototype interventions. The techniques are likely to be helpful for specifying usual care as well as interventions for evaluation. It remains to be seen whether this programme theory is useable and testable beyond a small group of informed and committed stakeholders, and I have not gone so far as to deal with measurement of its various components. A further limitation of the research programme is its limited attention to health economic considerations, for example quantification of the value of outcomes or the potential resource consequences of intervention techniques.

10.8 Reframing the Primary Research

Having completed the thesis, I have reflected on my framing of the primary research – the focus groups and interviews, online survey, and workshop – as a three-stage mixed methods Delphi study. In chapter 4 I described how Delphi studies are conventionally characterised by multiple rounds of questionnaires in which stakeholders generate and rate evidence statements, receive feedback about group ratings, revise their ratings in the light of the feedback, and reach a pre-determined level of consensus about the topic under discussion. I also argued that, as well as questionnaires, Delphi studies have used qualitative methods such as focus groups and stakeholder meetings to enable open exploration of topics, particularly in the first 1-2 rounds of the process. For example, Berquez and colleagues conducted focus groups to generate questions for eliciting stakeholders' statements about supporting children and young people who stutter within educational environments (220). They then used the questions in subsequent rounds of an online and postal survey (220). Their study provides an illustration of qualitative data collection embedded into the early stages of a comprehensive mixed methods Delphi process. With this in mind, I framed the primary research within my overall research programme as a three-stage mixed methods Delphi study. I wanted to present a coherent and integrated research programme in which I used focus groups, semi-structured interviews, and go-along interviews to build on the systematic review and feed directly into the online survey and workshop.

On reflection, I would now argue that it is more useful to frame the focus groups, semi-structured interviews, go-along interviews, and workshop as a discrete qualitative work package, and the online survey as the substantive Delphi study. As I had planned, the qualitative research generated the content for the online survey – a provisional definition of participation in leisure and 45 intervention techniques for supporting participation in leisure. However, it also made a substantial contribution to the overall research programme that went well beyond informing the online survey. As well as generating the definition and techniques, the qualitative work contextualised the results of the systematic review, and therefore made the review more useful for the purpose of intervention development. The qualitative research also produced new knowledge about personal and social environmental factors related to participation in leisure, and features of the local leisure context that may influence and be influenced by participation in leisure. It provided valuable insights to inform how future implementation of allied health participation support might be planned and organised. In short, the qualitative research has been of central importance in developing a programme theory of supporting participation in leisure.

The scale and contribution of the qualitative results mean that it would be both important and warranted to disseminate the focus groups, semi-structured interviews, go-along interviews, and workshop in their own discrete publication, separately from the online survey. Indeed, to publish these results as merely one stage of a mixed methods Delphi study – as I had originally planned – would potentially do the results a disservice. End users of the research are likely to associate ‘Delphi study’ with the characteristic multiple rounds of questionnaires, stakeholder ratings, and levels of consensus, which would risk overlooking the qualitative results and wasting their contribution to new knowledge in this field. I envisage that it will be feasible to publish a qualitative work package separately for two reasons: (i) in chapter 4 I set out the methodological strengths of the qualitative work, including purposeful sampling of diverse expert stakeholders, the inclusion of children and young people with relatively complex neurodisability, theoretically-based topic guides, and stakeholder involvement in data analysis and interpretation, all of which bodes well for favourable peer review, and (ii) several other research programmes of relevance have separately published substantial qualitative work packages that both contributed to a Delphi survey and generated new knowledge, theory, and insight beyond the Delphi (e.g. 9, 222, 232).

10.9 What I Would Do Differently

As well as reflecting on and reframing my primary research, I have also considered what I would do differently across the overall research programme. My main thoughts here relate to the systematic review of modifiable personal and social environmental factors associated with participation in leisure (reported in chapter 3). I have mixed feelings about this review. On the one hand, I value the review's contribution to the research programme. It allowed me to argue with confidence that the existing evidence in this field – including multiple related systematic reviews – was limited and did not provide an adequate theoretical basis for intervention development. In turn, my being able to describe these limitations in detail provided a clear rationale and justification for the qualitative work package that went on to make such a substantial contribution to the overall programme theory. In addition, as an early career researcher I personally gained a huge amount of knowledge, skills, and confidence from conducting the review and leading each methodological step. On the other hand, the systematic review process was considerably longer than I had anticipated and took up much more of the available resources – primarily my time – than I had intended. There were two key reasons for this. First was the variable quality of reporting within the 18 included studies, which I have set out in detail in chapter 3, combined with the methodological challenge of meaningfully synthesising and presenting such a highly heterogeneous body of evidence. Second was the personal challenge of tackling this process as a novice systematic reviewer with limited experience of dealing with non-randomised and observational study designs.

On reflection, it is difficult to judge whether the review's contribution to the overall research programme and my development as a researcher was worth the large proportion of the available resources that it consumed. However, I have certainly considered the opportunity cost associated with the review. Specifically, I did not progress as far as creating an accessible intervention manual that could be used for knowledge mobilisation and implementing and evaluating participation support. I would have liked to extend the co-design workshop with multidisciplinary practitioners and, working with designers, to produce a manual for allied health services on building participation interventions, analysing local leisure contexts, and critically reflecting on personal perspectives and values related to supporting participation. It may have been useful and interesting to further develop and specify prototype interventions as priority candidates for future evaluation. I also would have liked to conduct some preliminary feasibility testing of the manual with stakeholders not previously involved in the research, and work with methodologists to explore outcome measurement, plan more comprehensive mixed methods feasibility testing and piloting, and generate design ideas for a definitive evaluation of the manual, including but not limited to a randomised controlled trial. To have such outputs prepared would have been valuable for moving the research on within future funding applications. It may have been possible to make more progress with these outputs had I conducted the systematic review more efficiently, for example by ensuring maximum use of all existing reviews and intervention studies both within and beyond allied health.

10.10 Reflexivity Throughout the Research Programme

Reflexivity refers to a form of methodological self-consciousness exercised throughout the research process and enacted through, for example, the researcher continuously questioning and making explicit their own philosophical and political assumptions, showing awareness of and taking into account the dynamics between themselves and participants, and considering how their own standpoint and social identity may be affecting data collection and analysis (87, 378, 379). I have considered how my beliefs about stakeholder involvement and identity as a clinical lead allied health professional may have played out during the research.

In chapter 2 I set out my belief that wide stakeholder involvement would improve the quality and outputs of the research by ensuring it generated knowledge that was congruent with real-world contexts. In particular, I believed that children, young people, and parents would bring considerable epistemic resources to the research programme, in the form of lived expertise, tacit knowledge, and implicit theories about the research problem. More fundamentally, I also described how I was ethically committed to achieving diverse stakeholder involvement throughout the research process. My position on this reflects the substantive values that are important to me, related to including and representing disabled children and young people and their families in research, and treating them with fairness, respect, and dignity.

At the time of conducting the research, I could clearly see how these beliefs and values were driving my approach to sampling and recruitment, data collection, and data analysis. Appendix B describes my efforts to recruit, meaningfully consent, and involve children and young people with learning disabilities. In chapter 4 I included some brief reflections on how I tried to make the go-along interviews a safe and positive experience for participants, and I described how parent advisors informed the practical research design. Chapter 9 includes an elaborate description and analysis of how I successfully included young people and a parent in two embedded co-production projects. However, as I reflect back on how my beliefs and values were driving the research, I can see that I could have been more strategic and methodologically critical as well as ethical, specifically in relation to the co-production projects. The co-production changed and developed me as a practitioner researcher and was a positive experience for those involved, but I have found it difficult to clearly articulate its contribution to the research programme in practical terms. This unsettles me, as the co-production projects were challenging and time-consuming processes.

My identity as a clinical lead occupational therapist brought advantages and disadvantages to the research and I have found it interesting and useful to reflect on how my professional perspective has changed throughout the overall process. Being a senior allied health professional went some way to providing me with good access to people, networks, and events during the research. In table 4-1 I set out my recruitment strategy for each of the stakeholder groups. Recruitment avenues included local schools, educational services, short breaks and leisure services, and parent groups in the North of England near where I have practiced as an occupational therapist, as well as national allied health and disability sports networks with which I had previously connected in the context of my wider professional role. It was extremely useful to be an ‘insider’ when it came to recruitment. Knowing about these recruitment avenues and connecting with them through the existing relationships I had built up over my career made recruitment go more smoothly. It is noteworthy that the recruitment strategy for teaching assistants was unsuccessful and that this was a group with whom I had built few prior relationships and to whom I struggled to gain access.

As an experienced occupational therapist, I was also able to anticipate to some extent what the allied health professionals would want to talk about in the qualitative data collection. This was helpful because I anticipated that they would want to talk at length about the immediate implementation challenges they face in their local practice contexts, for example the barriers of limited time, limited funding, a complex commissioning landscape, lack of strategic leadership etc. These are important and relevant issues, but to deliver my research objectives I primarily needed them to generate intervention content (a specified outcome, theoretical mechanisms, intervention techniques, descriptions of delivery and context etc.). My instinct about how our conversations might play out enabled me to carefully plan data collection, for example by building in protected but limited time for people to vent about implementation challenges, and using explicit golden rules to set discussion parameters and shift the focus in different directions.

My professional identity was also a challenge that needed to be managed during the research programme. As a senior practitioner, I have a reputation for being relatively outspoken about the occupational therapy profession and our service delivery models in the NHS. As a manager and clinical lead, it is my practice to challenge as well as support my direct reports and clinical supervisees. Throughout data collection, I was aware of my tendency to be rather critical of the allied health participants when they proposed what I perceived to be parochial or professionally self-serving ideas. At the time I saw this as unhelpful – and potentially dangerous – territory and I made efforts to progress past my frustrations with support and challenge from my supervisors and peers. However, on reflection, I think this was in part a useful refusal to see supporting participation in leisure as primarily the domain of allied health professionals. Throughout the research I encountered professional and service user participants who were deeply embedded in their local leisure contexts, or on the outside looking in, and many shades in between those two perspectives. Allied health is a relatively new kid on the block – albeit a very well-placed and potentially useful one – when it comes to supporting participation. I believe my tendency towards the critical meant that I became open to developing – and have thus now developed – a programme theory and interventions with applicability both within and beyond allied health.

10.11 Conclusions

This research programme generated a programme theory containing practical resources for building evidence- and theory-based interventions for supporting participation in leisure of children and young people with neurodisability. The next steps are to investigate the ways in which stakeholders can best interact with these outputs, and the acceptability, feasibility, and effectiveness in community NHS settings of the interventions they build. If the outputs are found to be accessible, and the interventions effective, there is the potential for a fundamental shift in the nature of allied health interventions for supporting participation, and an improvement in health outcomes of children and young people with neurodisability.

Appendix A – MEDLINE Search Strategy

MEDLINE (Ovid), 1946 – November 2015, searched 6 November 2015

Terms for children with disabilities:

1 Disabled Children/ or disab* child*.mp.

2 disab* student*.mp.

3 1 or 2

Terms for disabilities

4 disab*.mp.

5 multip* disab*.mp.

6 special need*.mp.

7 physical* disab*.mp.

8 Chronic Disease/ or chronic disease*.mp.

9 communication limit*.mp.

10 exp Communication Disorders/

11 additional need*.mp.

12 complex communication need*.mp.

13 Mobility Limitation/ or mobility limit*.mp.

14 Developmental Disabilities/ or developmental* disab*.mp.

15 exp Intellectual Disability/ or intellectual* disab*.mp.

16 cerebral palsy.mp.

17 exp Brain Damage, Chronic/

18 brain injur*.mp.

19 Brain Injury, Chronic/

20 acquired disab*.mp.

21 motor disorder*.mp. or exp Movement Disorders/

22 Motor Skills Disorders/

23 ataxi*.mp.

24 degenerat* dis*.mp.

25 exp Heredodegenerative Disorders, Nervous System/

26 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25

Terms for child:

27 child*.mp. or Child/

28 26 and 27

29 3 or 28

Terms for participation:

30 (Participat* or involv* or join* or engag* or tak* part or took part or barrier or facilitat* or attend* or pursu* or occup* or undertak* or include* or inclus*).mp.

Terms for leisure:

31 (Leisure or recreation or activit* or sport* or play* or relax* or friend* or exercis*).mp.

32 exp Leisure Activities/

33 exp Exercise/

34 Social Participation/

35 Friends/

36 Social Networking/

37 31 or 32 or 33 or 34 or 35 or 36

38 29 and 30 and 37

Limits for publication date:

39 38 and 2001:2015.(sa_year).

Key: / = MeSH heading (translated in other databases where possible), exp = explode the MeSH heading, * = truncation, mp = title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier

Appendix B – Reflections on the Recruitment Strategy

Focusing on Thomas, this reflective memo highlights the theoretical, ethical, and practical issues I encountered during the recruitment strategy for children and young people at Stage 1 of the Delphi study (see chapter 4).

I began the process of negotiating consent for Thomas to take part in the study by meeting with J and A, two teachers in one of the special schools I'm working with. This was the first level of gatekeeping for recruiting children and young people (CYP). I explained very broadly what the study was about and let them know which CYP I was wanting to invite to take part (i.e. CYP with communication and mobility difficulties, aged roughly 8-12 years). They both immediately had ideas and enthusiasm about which of their students would be 'great' for the study. These collaborators knew many of the CYP well and had strong ideas about who would be 'great'. Their judgements seemed to be based on (in no particular order, and not necessarily applying to all three collaborators): (i) CYP who experienced a lot of physical disabilities but whose communication abilities were very good – these CYP were thought to have a unique and important perspective that they were able to readily share; (ii) CYP with whom the collaborator had a strong, positive (present or past) working relationship – the collaborators seemed to really value these CYP in terms of their shared relationship; (iii) CYP of parents with whom the collaborator had a strong, positive relationship (usually present); and/or (iv) CYP whose stories and life experiences particularly stood out, e.g. because of the circumstances in which they had acquired their disabilities.

I was reflecting that, even at this early stage, the research results are being shaped by these conversations about who would be 'great' for the study. This is a double-edged sword: local collaborators are in a good position to support purposeful sampling and to decide who would be 'great'. But, these judgements may also serve to inadvertently exclude people who might not be 'great', but may well be appropriate, able, and willing to take part. I know as a clinician that some CYP are less likely to be thought of as 'great' for a study, for example because of the nature of their impairments, or because service providers have found it difficult to interact with their parents. I think the impairment aspect was less of an issue in this scenario, as all the CYP had fairly significant intellectual and communication difficulties by virtue of their being in a special school.

J and A initiated thinking aloud and telling me details about some of their students. I think they implicitly understood our conversations to be confidential and privileged as they were taking place within the actual school building, and perhaps also because they know I work for the NHS locally (although I haven’t worked as an occupational therapist with either of them). I was trying to be mindful of confidentiality, and I thought at the time whether I should stop them from giving me details; but I didn’t do this, because I thought it would be intrusive, and would undermine our relationship- and trust-building. I thought it was reasonable of them to presume confidentiality, and to presume that I had the necessary approvals to be there having these private conversations (one of them later explicitly checked with me that I had approval from the head teacher, and I emailed them both a copy of the approval). I thought the onus was on me to maintain the confidentiality and enable them to openly and confidently discuss the study (albeit in a private space).

On further discussion about different CYP, it was clear that many of those who sprung to the minds of J and A (and P) did not meet the inclusion criteria, e.g. because they could walk independently, or were outside the age range. This included some of the CYP who would be ‘great’, which seemed to be disappointing for the collaborators. They were attached to the idea of those CYP taking part, I think. I reminded J and A of the criteria, and afterwards I sent them both an email with a flyer they could print out to remind them of the age range and of what I was meaning by communication and mobility difficulties. I let them know we did have some flexibility, not least because I wanted to make sure I actually recruited some CYP within the timeframe. We agreed that they would have a think about who to invite, and that I would call back to school a week later to see who they had come up with. (We had agreed that we wouldn’t share details via email.)

When they were describing CYP to me, it became clear that many of them were going to have quite significant intellectual disabilities, along with their communication limitations. My starting point was a commitment to an inclusive, participatory approach in general across the study. The topic is, in part, about CYP with intellectual disabilities, so I thought the onus was on me to make sure some CYP from that population were meaningfully involved, and the onus was not on the CYP to be ‘able’ to take part. I thought that, if I didn’t include those CYP in a meaningful way, the study would be at worst a failure (in ethical and ideological terms, and in terms of relevance to this population) and at best a cop-out. In this regard I’ve been influenced by the ideas and issues captured by Nind and Vinha in their works on inclusive research (102, 380). Having said that, I acknowledge that, when drafting the protocol, much of my effort went into planning how to include CYP with disabilities in general, as opposed to CYP with intellectual disabilities specifically (although I did consider this group broadly). So, it’s a reasonable criticism that my commitment in principle to including these CYP was not matched by a comparable level of action in the planning stage. And taking that further, is it sufficient to simply ensure the ‘presence’ of some of these CYP in the study? I think their presence is important, but I need to be careful to remember that, taken on its own, this could be considered fairly superficial – a tick-box exercise. So, I need to think more about the involvement of these CYP throughout the whole research cycle.

A week later, I called back into school to see J and find out which CYP they had identified for the study. She and A had come up with three names who they believed met the inclusion criteria. We agreed that I would post hard copies of the recruitment packs to school, and J would send them to the parents. At the meeting and in follow-up emails, J and I talked about how to send the packs out. J wanted to telephone the parents to let them know the packs were coming, and that their CYP had been ‘hand-picked’, and to remind them to send the consent forms back. I immediately let J know that there was no need to telephone them, and that I didn’t want them to feel under pressure – it was important that they felt able to say no without any worries about negative consequences. On reflection, this was an interesting moment and probably highlights the different positions that J and I were taking on this. On the surface, J seemed to be thinking in terms of practicalities and ‘getting the job done’ – i.e. getting consent from these parents. I seemed to be thinking in terms of ‘the rules’ – i.e. implementing the process approved by the ethics committee – but I also thought I was the one who was thinking more ‘ethically’. Specifically, I thought it was ‘ethical’ not to put pressure on people, not to bother them, and to make sure they felt 100% able to say no. Maybe J and I had different positions on what is ‘ethical’, that perhaps reflect the organisational/institutional cultures we were coming from. We didn’t discuss this openly, so this is all supposition, but here’s my thinking. The issue at stake was one of ‘autonomy’: the right to self-governance, independence, freedom from external influence. The right to make one’s own decision about whether or not to take part in the study. I was operationalising this in arguably quite a ‘medical’ paradigm. J saw nothing wrong with ‘chivvying along’ the parents, and I can understand this. She had hand-chosen the CYP because they met the criteria and because she thought they would like to be involved (and she knows them well) and she thought their parents would like them to be involved. Further, I think she thought the parents would be pleased their CYP had been hand-picked – and why wouldn’t they? In my experience, parents of CYP with learning disabilities are indeed often pleased to see their CYP given the opportunity to be involved, possibly because they are so often excluded. So, what’s wrong with ‘chivvying’? Parents are busy, and we all appreciate a reminder, and schools are always sending out forms and reminding parents to send them back, so this would be quite a similar thing. Maybe J was (implicitly, subconsciously?) working to a more ‘relational’ view of autonomy, where people exercise their autonomy and agency within supportive social networks, not in an individualised ‘vacuum’ (373, 381-383).

Nind and colleagues have written about the idea of distributed competence, in the context of young children with learning disabilities and the ways in which they enact their agency (384). They cite work on parents with learning difficulties that maintains that competence may be better seen as a distributed feature of parents' social network, rather than as an individual attribute. Competence as a product of social and relational networks. A more relational and interdependent stance on competence. They apply this idea to the fitness to learn of young CYP with learning disabilities and argue that it's a shared competence that is hugely reliant on context. They give examples of how the young children negotiated their agency through distributed competence, which was played out by others providing sensitive support.

Thomas's parents represented the second level of gatekeeping for recruiting CYP. Parents acting as gatekeepers.(385) They returned the consent form saying that I was permitted to go and seek consent from Thomas. In line with work from Flewitt (386) I considered this to be 'provisional' consent. The next step was to get Thomas's consent. I spoke to Thomas's class teacher C, and we discussed a good time for me to come in and get to know Thomas a bit. We decided that I would come in for a couple of hours at the start of the school day and stay until just after morning break. I explained that I was trying to take his consent, which she seemed to understand and accept. I also explained that I would be thinking about good ways to include Thomas in the study, from a communication and understanding point of view. This would apply to taking his consent and collecting data from him. We talked about how Thomas communicates formally – he is just beginning to use symbols to make choices. This immediately told me that I would need to think carefully about data collection.

I had stated in my protocol that I would use person-centred, accessible, and creative approaches to taking children's informed consent. However, the example I provided would not be appropriate for Thomas, as it would be too demanding in terms of his understanding, expression, and attention. So, I adopted a number of principles. First, it was important for people who know Thomas well to be involved in the 'informed consent', because they could help me interpret his communication, for example if he was feeling uncertain, unhappy, or if he didn't like me, or wanted to do something else. These people were the class teacher and teaching assistants and were an example of a consent network. Some of thinking on this is summarised by Nind (380). Second, I was conscious that Thomas's consent would be expressed moment-by-moment, and I understood it could change several times throughout the course of our interactions (386). In that regard, I couldn't assume that an initial consent would last forever, so I would need to remain vigilant, including during data collection when parents would be present – the consent network would be extended at that point. Third, what was I meaning by consent? Usually with people with learning disabilities, consent is considered in terms of capacity/competence. My assumption was that Thomas would not be competent to provide an informed consent to take part in the study, but that he would be competent to provide an informed consent to spend time with me. And that he would trust his consent network to decide whether the specific things I was wanting to do were ok for him. Having said that, I didn't want to use that as a cop out, or to have too low expectations from Thomas. I thought it was important that he actively experienced the interactions with me as positive (at best) and unintrusive (at worst). It's not enough that he 'doesn't mind me being there', as this is placing him in a passive role of a person who merely tolerates things. Thomas – like most children, and in his own way – will probably be curious and social. So, I need to work to have a relationship with him, in which he has an active role (e.g. as a player, an interactor, a decider, a person with autonomy and agency).

The next step was visiting school to gain initial and ongoing consent from Thomas. I arrived in class shortly before him. One of the teaching assistants pushed him in in his wheelchair and sorted his coat out etc. A few of the children always go up to Wake Up Shake Up (WUSU) in the main hall – lots of schools do this first thing in the morning with at least some of their classes. I said that I'd go too and would spend time with Thomas. I noticed that he has a self-propelling wheelchair, so I was asking the teaching assistant whether he wheels himself – he does. We went along the corridor, into the lift, upstairs, and into the main hall. I was being conscious of going slowly, taking our time, encouraging him to wheel himself, letting him stop and look at the stuff he wanted to look at. I suspect the teaching assistant thought I was a bit over the top – they have a schedule to keep. I tried to ignore that (respectfully) and just continue hanging out with Thomas. I talked to him a bit, did lots of smiling. We went into the hall and the music videos are projected up onto the wall. I stayed with Thomas and we were dancing to the songs. He doesn't make too much eye contact. Sometimes he copied my movements – or maybe it's the same music and movements every day and he knows them! He was laughing a bit, he seems to like WUSU. He was definitely having a good dance, and sometimes stopping to watch, look around. Then the slow music came on. Everyone else was sitting or lying on the floor so that's what I did, I sat down next to Thomas in his wheelchair. After a while, Thomas wheeled himself off slowly around the room, looking into the glass of the staff room door, looking at stuff on the walls. I thought about whether to go too, then decided not to push into his space too much – maybe he wanted to get away from me / other people. I stayed sitting on the floor but was turning around to look at him. He waved over at me a few times and I waved back. I was glad I hadn't followed him, I think he was just having a look around. I was glad that he was wheeling himself to wherever he wanted to go, that's up to him. I think some of the staff were looking, I'm not sure. Maybe they thought I should bring him back. I resisted this perception – it's not up to me to control his movements (or any of us, certainly not in that situation). I think afterwards people were saying he's nosey (in a nice way) and likes to look around – maybe he does that in WUSU every day. It was time to go and I was encouraging him to wheel himself back to class. He was surprisingly good at self-propelling slowly (why surprisingly?). Outside the hall, he was having a look around, slowly going in the opposite direction to class. I think he was wanting to go and 'say hello' to a woman at the photocopier. I let him go where he wanted, I think the teaching assistant was twitching a tiny bit. I was determined not to take hold of his push-handles and take him to class, but I definitely felt a pressure to do this. The TA and I then started gesturing and verbally encouraging him towards the lift. He was happy enough to go along with that, he clearly likes to have a bit of time to look around and process in these situations. I was delighted with his independent mobility. He wheeled mostly back to class, with a little bit of chivvying along from the teaching assistant.

In class, I spent a little bit of time with each of Thomas's classmates. I thought this was important for building relationships with the teaching staff, and not being too intensely on top of Thomas when I don't really know him yet (might be disruptive for him). Thomas had a snack supported by another teaching assistant, and she as practising some picture exchange symbols (i.e. she prompts him to touch the drink symbol for more, then when he does it she passes him a drink). We played together with a plastic musical toy – Thomas was exploring it and I was making noises and commenting. Then we all sat around in a circle and sang the hello song. I supported another child in the class but I could see what Thomas was doing most of the time. Then we did a brief spell of intensive interaction (working in pairs to look at each other and imitate the children's expressions, actions, noises, words). The children all love one particular teaching assistant, so I was trying to help her out! When it was time for play outside, I encouraged Thomas to wheel himself across the classroom and come outside, which he did. When we were outside we played a bit of ball and did a bit of moving about. There wasn't really any play equipment. Then we went back into class after about 15 minutes.

The class teacher let me read the home school diary – this is something they have in all schools for these children, where the teaching staff and parents can pass info and updates back and forth. It was a lovely read, an intimate window into how they work together to care for Thomas – nicer than ones I've seen in other schools, rich interactions, real efforts having been made. I learned that Thomas does lots of activities with his parents during half term – he went to the shopping centre South of the city, the Railway museum in a neighbouring city, and somewhere else I can't remember now – possibly the media museum in another city. I put a note in the diary to let parents know I have been into school, what I'd done with Thomas, and also put my number in there asking them to give me a quick call about arranging a go-along interview.

Appendix C – Delphi Stage 2 Questionnaire

Supporting participation in leisure of children and young people with disabilities

Thank you for taking part in this survey, which is part of our wider research programme. We're creating a practical, flexible manual for supporting participation in leisure of children and young people with disabilities.

In this survey, you're part of an expert panel that includes parents, allied health professionals (occupational therapists, physiotherapists, and speech and language therapists), professionals working in short breaks and leisure services, sports coaches, artists, and researchers. We'll be exploring your opinions about different techniques for supporting participation in leisure.

You can refer back to the Participant Information Sheet at any time.
Please remember:

- ☑ Your answers are strictly confidential and will be stored securely
- ☑ There are no right or wrong answers – we're interested in your opinions
- ☑ You can save your answers and come back later. To do this, just close your internet browser. Then, click on the survey link again **from the same device**, and it will take you back to where you left off.
- ☑ In one week, we'll send you a reminder to complete the survey
- ☑ In 2-3 weeks, we'll send you anonymised feedback on everyone's opinions
- ☑ There are 2-3 surveys in total over the next few weeks

If you have any questions, please do not hesitate to contact Jennifer McAnuff
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A definition of participation in leisure

We need a definition of participation in leisure to guide our wider research programme. Together with parents, professionals, and children and young people, we've developed a provisional definition:

"For children and young people with disabilities, participation in leisure takes place within freely-chosen activities, in the community, with peers. Participation in leisure involves: doing or attending a leisure activity for the first time; learning to do the activity successfully, which might happen straight away or might take longer; and enjoying the activity."

How **relevant** is this definition? In other words, does it capture the aspects of participation in leisure that you think are important?

1. Completely irrelevant	2. Irrelevant	3. Fairly irrelevant	4. Not sure how relevant	5. Fairly relevant	6. Relevant	7. Extremely relevant

Any other comments? (Free text comments)

We're creating a manual for supporting participation in leisure of children and young people with disabilities. In the future, we'll want to investigate whether the manual is effective. To do this, we'll need to measure whether children make progress after the manual is used.

Would it be **useful** to measure whether children and young people make progress with doing or attending activities for the first time, learning to do activities successfully, and enjoying activities? How **useful** would it be?

1. Completely useless	2. Useless	3. Fairly useless	4. Not sure	5. Fairly useful	6. Useful	7. Extremely useful

Any other comments? (Free text comments)

Techniques for supporting participation in leisure

Instructions

Together with parents, professionals, and children and young people, we've identified 45 techniques for supporting participation in leisure. By techniques, we mean specific, practical actions that could be carried out by adults, peers, or potentially children and young people themselves. For example, providing information about local leisure activities and opportunities, or providing activity taster sessions to introduce children and young people to leisure activities.

We want to ask your opinion about the techniques. Please consider:

- How **effective** would the technique be for supporting participation in leisure? Of course, this might depend on the situation. But to keep the survey shorter, consider how effective it would be for most children and young people in general, assuming it's carried out appropriately.
- In this survey, we're not particularly focusing on whether people would be **able and willing** to engage in the technique. For example, whether enough resources are available to do the technique, or whether people would be comfortable with it. We'll cover that in the next survey.
- **Please give an answer for every technique**. If you're not sure about the effectiveness of a technique, answer 'Not sure how effective'. If you're unable to rate a technique, answer 'Unable to rate', and tell us why.
- There is space under each technique to make any further comments.

People in the wider research programme have talked a lot about the importance of: (i) **workers being warm, caring, trustworthy, and good listeners**, (ii) **equipment, technology, and adaptations**, and (iii) **health, leisure, and transport services/policies**. To keep the survey shorter, we haven't included these, as they're mostly essential. But they are included in the wider research programme.

Remember: you can save your answers and come back later. Just close your internet browser, then click on the survey link again **from the same device**, and it will take you back to where you left off.

1. Provide information about local leisure activities and opportunities.

For supporting children and young people to **do or attend an activity for the first time**, **learn to do the activity successfully**, and/or **enjoy the activity**, this technique would be:

1. Very ineffective	2. Ineffective	3. Fairly ineffective	4. Not sure how effective	5. Fairly Effective	6. Effective	7. Very effective

☐ Unable to rate this technique because:

Any other comments about this technique?

(All subsequent intervention techniques were presented in the same way.)

Thank you very much for completing the first survey!

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