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Title	How do children and young people with intellectual and/or developmental disabilities experience the therapy process when engaging with occupational therapists, speech and language therapists, and physiotherapists?
Authors	Hynes, Patrick Joseph
Publication date	2022-03-26
Original Citation	Hynes, P. J. 2022. How do children and young people with intellectual and/or developmental disabilities experience the therapy process when engaging with occupational therapists, speech and language therapists, and physiotherapists?. MSc Thesis, University College Cork.
Type of publication	Masters thesis (Research)
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Download date	2026-11-02 11:55:36
Item downloaded from	https://hdl.handle.net/10468/14523



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National University of Ireland, Cork



How do children and young people with intellectual and/or developmental disabilities experience the therapy process when engaging with occupational therapists, speech and language therapists, and physiotherapists?

Thesis presented by

Patrick Joseph Hynes

BA(Hons). MSc OT (Professional Qualification).

https://orcid.org/
0000-0002-9453-5596

for the degree of

MSc Medicine and Health

University College Cork

Department of Occupational Science and Occupational Therapy

Head of School/Department: Prof. Jeanne Jackson

Supervisor(s): Dr Helen Lynch and Dr Katie Robinson

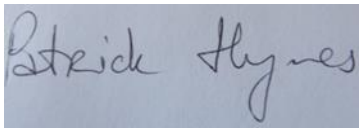
Thesis presented to University College Cork, March 2022

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DECLARATION

“This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism and intellectual property.”



_____

Name: Patrick Joseph Hynes

DEDICATION

Dedicated in memory of my dear parents

Denis Hynes (1929 – 2005)

Nora Elizabeth (Gately) Hynes (1937 – 2015)

who always listened to me as a child and instilled in me the understanding that children do have a voice.

Also dedicated to the memory of

Sr. Margaret Mary (Peg) Hynes SSJ (1933 – 2002)

&

Sr. Josephine Rita (Jodie) Hynes RSM (1934 – 2015)

who were both some of the first members of our family to obtain Masters degrees, and who throughout their lives demonstrated social justice, a passion for education, and were trailblazers in their careers and in our family.

ACKNOWLEDGEMENTS

There are a number of people who I want to acknowledge and thank on this research journey. Firstly, I want to thank both of my supervisors Dr Helen Lynch (University College Cork) and Dr Katie Robinson (University of Limerick). You both gave constant considered guidance, support, and encouragement which was always delivered with professionalism and at the right pace. Your constructive feedback was excellent and helped create within me a greater ability to develop my skills as a researcher. Your passion as researchers, supervisors, occupational scientists, and occupational therapists has been a driving force for me to continue to work on this research culminating in the production of this thesis. I also wish to thank Dr Aisling Parkes (Department of Law, UCC) for her supervision and guidance on the early part of this research journey.

Thank you to my family and friends, who encouraged, listened, and were often "just there" when needed. In particular, I want to thank my good friend Margot Barry, an occupational therapist who has always inspired me through her combined clinical work and research in occupational therapy. Indeed, it was by watching her in action in her clinical work that I decided that I would like to become an occupational therapist too. I wish to thank my friend John C. Friend Pereira, for always providing critical debate throughout the years on a range of topics. Your background in international human rights, politics and policy has always brought a level of discourse and critique to life that is outstanding, which in turn contributed to some of my thinking on this research journey.

Thank you to my employers, Treasa McAuliffe, CEO, and Máire O'Leary, former CEO, at St. Gabriel's Foundation, Limerick for accommodating me with taking unpaid study leave to facilitate my studies. Your interest in my professional development is much appreciated and is testament to your leadership of a progressive organisation.

ABSTRACT

Background: The UN Convention on the Rights of Persons with Disabilities (CRDP) was adopted by the United Nations General assembly in 2006 to protect, promote and ensure full equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. The right of all children to be heard and taken seriously constitutes one of the fundamental values of the United Nations Convention on the Rights of the Child (UNCRC). For children with disabilities the UNCRC applies, confirming the child's right to have a voice in all matters that affect them. Children with disabilities face barriers to participation and threats to enactment of their rights, including in healthcare settings such as those provided by the disciplines of occupational therapy, speech and language therapy, and physiotherapy. Children with disabilities frequently access these services. These disciplines purport to deliver client centred services in line with human rights. However, little is known about children's experiences of these therapies as voiced by children themselves.

Aim/Objectives: Through the completion of a systematic review of qualitative evidence, this study aimed to explore how children with intellectual and/or developmental disabilities experience the therapy process when engaging with occupational therapists, speech and language therapists, and physiotherapists.

Methods: A systematic search of seven databases was undertaken, and included studies were synthesised following the stages of meta-ethnography described by Noblit and Hare (1988). Databases searched were Academic Search Complete, AMED, CINAHL complete, MEDLINE, APA PsycINFO, APA PsycARTICLES, and Social Sciences Full Text (H.W. Wilson). The Preferred Reporting Items for Systemic Reviews and Meta-Analysis Protocols (PRISMA-P) checklist was used to illustrate the research strategy procedures. Searches were limited to English language publications. No limits were applied to date of publication. The Critical Skills Appraisal Skills Programme (CASP) Qualitative Studies Checklist was used to critically appraise the quality of the included papers.

Findings: Sixteen studies were included in the synthesis. Four interrelated themes were identified; "Interpersonal experience of therapy", "Who is in the driving seat? – Children's experiences of power in therapy", "The nuts and bolts of therapy: experiencing therapy in the here and now", and "Making sense of therapy".

Conclusions: The value of qualitative research can be seen in this review due to the rich data that was extracted from a range of qualitative papers. Children with intellectual and/or

developmental disabilities described how they experienced therapy sessions. Common experiences included having fun (and a desire for therapy to be more fun) and conversely boredom, discomfort and pain were also commonly experienced. Children described their interpersonal experiences and relationship with the therapist during therapy including their experiences of engagement, communication and trust and their experiences of therapist attunement. Children described how they understood therapy and its purpose, including their experiences of making progress in therapy or achieving outcomes and how therapy related to their view of themselves and their views of ability and disability. Children reported on their experiences of power in therapy, with finding suggesting that therapists often hold power over decisions and goals for therapy, and less frequently children hold power, often regarding smaller decisions. Findings point to the need for occupational therapists, speech and language therapists, and physiotherapists who work with children with intellectual and/or developmental disabilities to further create opportunities for children to be part of the decision-making process and goal setting process. Through interrogation and reflection on their practice, therapists have the potential to be poised for action to utilise a model such as Lundy's model of participation (Lundy, 2007) to ensure that children experience the full participation in therapy of having their voice heard in all matters that affect them.

OVERVIEW OF THE CHAPTERS

This thesis is laid out in five chapters as described below:

Chapter 1: Chapter one provides an introduction and background to this study. It also includes the positionality of the researcher; a literature review, that explored children's rights and voice in healthcare in general which led to the identification of the research question.

Chapter 2: Chapter 2 introduces the methodology for addressing the research question and the rationale for conducting a formal systematic qualitative synthesis, and the rationale for using meta-ethnography. It includes the search strategy; inclusion/exclusion criteria; screening of papers; and data extraction and analysis.

Chapter 3: Chapter 3 presents the findings of the meta-ethnography. It outlines the study selection including a PRISMA flowchart; the characteristics of included studies; the quality appraisal of the included papers; and the synthesis of the included studies. It outlines the four interrelated themes which were identified and labelled as "Interpersonal experience of therapy", "Who is in the driving seat? – Children's experiences of power in therapy", "The nuts and bolts of therapy: experiencing therapy in the here and now", and "Making sense of therapy".

Chapter 4: Chapter 4 presents a discussion of the study findings including considering the findings in the context of children's rights and voice; participation in decision making; goal setting; client centred practice and power; relationship with therapist and engagement; and research with children with additional needs or disabilities.

Chapter 5: Chapter 5 revisits the research question and provides an outline of the strengths and limitation of this study, implications for practice, and further research areas that warrant exploration. It concludes with a summary of the key findings.

References: All references are presented in APA 7th edition format at the end of this thesis.

Appendices The appendices contain: the terms and concepts used in describing client centred practice, the terms and concepts in academic publications discussing child participation, the PROSPERO study protocol, the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) table, the codebook of generated codes, the search terms used, and the themes mapped to concepts and ideas.

Chapter 1 Introduction and Literature review

1.1 Introduction

This thesis aimed to explore children with intellectual and/or developmental disabilities' experience of occupational therapy, speech and language therapy, and physiotherapy with a specific focus on the extent to which they have a voice in therapy, the enactment of their right of participation in decision making, and if they experience being heard in the therapy process.

Experience is defined as an event that is lived through as opposed to one that is imagined or thought about (American Psychological Association (APA), 2022). In qualitative research, experience is described as a representation and understanding of a researcher or research subject's human experiences, choices, and options and how those factors influence one's perception of knowledge (Given, 2008). Building on this concept, experience in its most fundamental sense is further described as putting us in play ourselves, modifying us profoundly in a way that after having crossed, endured, traversed experience, we will never be the same again (Romano, 1998, cited in Roth & Jornet, 2014). In the context of this research study, the experiences reported by children are the focus of attention as it relates to participation in decision making in the therapy process.

The right of all children to be heard and taken seriously constitutes one of the fundamental values of the United Nations Convention on the Rights of the Child (UNCRC) (United Nations [UN], 2009). Participation in decision making is defined as an ongoing process, including information sharing and dialogue between children and adults based on mutual respect, in which children can learn how their views and those of adults are taken into account and shape the outcome of such processes (Committee on the Rights of the Child, 2009). The government of Ireland stated its commitment to developing a national policy on the participation of children and young people's participation in decision making, to further ensure and support children and young people to express their views (Department of Children and Youth Affairs [DCYA], 2014; DCYA, 2015) which aligns with Article 12 of the UNCRC which states that a child who is capable of forming his or her own views has the right to express these views freely in all matters affecting them with their views being given due weight in accordance with the age and

maturity of the child (UN, 1989). In addition, specific to people with disabilities in Ireland, an action from the Irish National Disability Inclusion Strategy 2017 – 2021 was to deliver a model of disability services that provides support for empowering people to make decisions in their own lives (Department of Justice and Equality [DJE], 2017). It follows, that children with disabilities should participate in decision making in the therapy process when engaging with occupational therapists, speech and language therapists, and physiotherapists. However, while children have the right to be heard it does not necessarily follow children are making decisions on issues affecting them (Todres & Diaz, 2017). The principles of client-centred practice and the nature of the relationship therapists aspire to establish with children with disabilities resonates with the rights of children to participate in decision making during the therapy process. However, little is known about children's experiences of therapy and the extent to which the stated aims of therapists are realised in the enactment of therapy. Additionally, the UN Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the United Nations General assembly in 2006 to "protect, promote and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities" (UN, 2006, p.4) which is of relevance to children with intellectual and/or developmental disabilities. These conventions and rights combine to protect and promote the rights of children with disabilities to have a say in matters that affect them, including in therapy.

In response to how little is known about how children experience therapy, and to investigate this aspect of therapy further, this study explores children's experience of therapy. Firstly, a contextual background is presented with a focus on explaining the current situation regarding children with disabilities, providing an overview of therapy practice with children in Ireland, client centred practice in therapy, a rights-based perspective on child participation, concluding with an overview of child participation in healthcare. These areas all form the tenets of the literature review presented below.

1.2 Researcher positionality

I have worked for almost 30 years in disability services in Ireland. My first two employment roles were working with adults with intellectual and physical disabilities, in training centres. It was an exciting time as self-advocacy and self-actualisation were strong guiding principles within both services. Following this, I worked in a special school for 12 years where many of the children had complex disabilities. I returned to working in an adult training centre for a period and noted that some of the principles that I had seen years previously were

operationalised in the programmes and the areas of rights, voice, and choice were integrated into service delivery.

I hold a Batchelor of Arts degree (Hons) in Social Science with Social Policy and Sociology which introduced me to the social sciences and qualitative research. In 2007, I returned to university, to study for a Masters in Occupational Therapy (Professional Qualification), qualifying in 2009 as an occupational therapist. After qualifying, I held clinical positions in the areas of paediatric occupational therapy in private practice, and in a not-for-profit children's service. I progressed to holding senior clinical positions in Child and Adolescent Mental Health Services (CAMHS), and currently in a Children's Disability Network Team (CDNT). I have also worked as a lecturer in occupational therapy at two Irish universities. I also currently work as a regional placement facilitator/senior occupational therapist at an Irish university.

My academic experience, combined with my clinical experiences, occasioned in me a desire to want to explore how children experience therapy. In particular, at the outset of this project, I was interested in children's voice, agency, decision making, participation and influence in and on therapy. My personality is one of curiosity and interrogation, so it was a natural fit that I wanted to find out more about how children experience therapy and see who made decisions, who set goals, and explore if it is child centred. From my experiences of working with children with many different disabilities, I have on occasion witnessed exclusion in decision making, and observed challenges in child participation when goals were being set, and in the general areas of service development. Children's voices were often not present, or silent, when decisions about therapy were being made. Additionally, the perspectives of parents are often sought, but there is often a lack of seeking objective feedback on the experience of therapy from children themselves.

As part of the foundation work for this thesis, a number of additional pieces of work were completed prior to this study. I successfully completed a 10-credit module on International Children's Rights (LW6549) in the Department of Law at University College Cork which afforded me with a broad understanding of Article 12 of the UNCRC (UN, 1989) and its impact on children's rights including the right to have their voice heard in all matters that affect them. I also successfully completed a 5-credit module on Graduate Information Literacy Skills (PG6009) at University College Cork which was a valuable tool that furnished me with an array of skills that were relevant to my research including using research resources; evaluating

research resource results; ethics in using information; and publishing and disseminating your research.

Additionally, I presented a poster at the Children's Research Network conference in Dublin in 2017. The title of this presentation was "Remaining client centred and ensuring children's participation in occupational science and occupational therapy research". This was valuable in signposting my understanding of child friendly research.

1.3 Literature review

This literature review will present an overview of the disability sector including statistics on the prevalence of childhood disability, therapy practice with children with disabilities, concepts of client centred practice, child participation from a rights-based perspective, healthcare rights for children, all of which lead to the rationale for the current study.

There are an estimated 93 million children and young people with disabilities worldwide, but numbers may be much higher (UNICEF, 2021). In Ireland 6,230 children were registered as having a physical and/or sensory disability according to the National Physical and Sensory Disability Database (Department of Children and Youth Affairs [DCYA], 2016) and the Irish National Intellectual Disability Database (NIDD) recorded 9142 children (5-19 years) with an intellectual disability in 2016 (McConkey et al., 2019). However, these figures may not reflect the total number of children and young people with disabilities in Ireland. Data from a nationally representative sample of 13yr olds in Ireland identified that 17.36% had received a diagnosis of a developmental disability, most commonly specific learning difficulties, physical and sensory disabilities, and learning difficulties (Gallagher et al., 2020). The Irish census provides further evidence that the Irish database figures underestimate prevalence of disability as according to the 2016 Census, there are 59,086 children aged from 0 to 14 years with a disability (Central Statistics Office [CSO], 2020). Although precise Irish prevalence data is not available, a significant proportion of children and young people live with intellectual and developmental disabilities and associations between childhood disability and deleterious well-being and participation outcomes are well established (World Health Organisation [WHO], 2011; Bennett & Abi-Aad, 2018). Developmental disability is defined as a severe or chronic condition that is acquired before 22 years of age (Altman, 2001) with intellectual disability being defined as significant limitations both in intellectual functioning and in adaptive

behaviour as expressed in conceptual, social, and practical adaptive skills which occurs before the age of 18 years. (Schalock et al., 2007).

1.3.1 Therapy practices for children with a disability

In Ireland, children and young people with intellectual and/or developmental disabilities avail of therapy services as part of disability teams in the health service (Health Service Executive, 2020) in either primary care settings, for non-complex needs, or in a Children's Disability Network Team (CDNT), for complex needs (Health Service Executive [HSE], 2019). There are also several voluntary agencies funded by the HSE providing services to children in Ireland. Occupational therapists, speech and language therapists, and physiotherapists are some of the professions that make up the teams in services for children who have a disability. These professions are regulated by CORU, and all have professional codes of ethics/professional conduct which endorse service users' rights. CORU is Ireland's multi-profession health regulator with a role to protect the public by promoting high standards of professional conduct, education, training, and competence through statutory registration of health and social care professionals (CORU, 2022). Across both national and international contexts occupational therapists, speech and language therapists, and physiotherapists often work with children with disabilities in hospitals (American Speech Language Hearing Association [ASHA], 2014; World Federation of Occupational Therapists [WFOT], 2021; Irish Society of Chartered Physiotherapists [ISCP], nd), health care settings (ASHA, 2014), community settings (ISCP, nd), clinics, day and rehabilitation centres, home care programmes (WFOT, 2021), schools (ASHA, 2014; WFOT, 2021) and private practice (ASHA 2014; ISCP, nd).

These three disciplines have a distinct scope of practice. Occupational therapy is defined as a client-centred health profession concerned with promoting health and well-being through occupation (WFOT, 2021). When working with children and young people, occupational therapists focus on enabling childhood occupations such as play and school occupations and supporting development and emerging independence skills (Association of Occupational Therapists of Ireland [AOTI], nd).

Speech and language therapists provide treatment, support and care for children who have difficulties with communication, or with eating, drinking, and swallowing (Royal College of Speech and Language Therapists [RCSLT], 2021) with speech and/or language disorders being considered the most common developmental difficulties in childhood (Law et al., 2017). Physiotherapists who work with individuals with intellectual or developmental disabilities

address issues such as pain management, functional mobility or activity training, postural and respiratory support, secondary impairment prevention, assistive technology provision, and environmental modification (Friedman & Feldner, 2018) through movement and exercise, manual therapy, education, and advice (Charted Society of Physiotherapy [CSP], 2021). While each of the disciplines have distinct professional backgrounds and training, they share common features in terms of the practice context, the nature of intervention, how intervention is delivered, and the extent of involvement of service users and their families in practice.

There are many common features in the way that occupational therapy, speech and language therapy, and physiotherapy services are delivered to children with intellectual and/or developmental disabilities. This includes the overall therapy process, incorporating referral, assessment, intervention, and outcome measurement (Creek, 2003) and the complex shared context of both the client and therapist, and how this influences therapy and the changes that occur over the therapy process (Pentland et al., 2018). It also involves goal setting with the child and family as part of the therapy process (Jeglinsky et al., 2012), giving attention to family priorities and concerns in planning interventions (Marshall & Mirenda, 2002), and participation in shared decision-making involving collaborative setting to develop a care plan in a mutually respectful and trusting manner with the family (Murphy et al., 2011). Goal setting is a central feature of therapy (Wade, 2009). Other common features include where and how therapy is delivered, and the frequency, duration, and dosage of therapy. The services provided often overlap with each other (Houtrow et al., 2019) with disciplines working closely together (HSE, 2020) often in an interdisciplinary manner.

Settings where interventions for children with disabilities take place are primarily in hospital, community setting, the child's home, or in the child's school (Houtrow et al., 2019). Commonality exists between the three disciplines regarding therapy dosage, where for example, therapy for younger children may be of shorter duration, whereas children with intellectual and developmental disabilities impacted by chronic health conditions often need therapy on a more ongoing basis (Houtrow et al., 2019). Therapeutic blocks of time (Academy of Pediatric Physical Therapy [APPT], 2014) may be utilised when considering dosage of therapy. A commonly delivered dose of therapy may be for 30 to 60 minutes per week for an episode of care (Majnemer et al., 2013) depending on the resources available and the goals for therapy. In Ireland, families are often offered a six-week block of intervention as a standard approach to a provision that aims to allocate limited resources fairly (Lynch et al., 2020).

Intervention provided by each of the three disciplines may be direct, indirect, or consultative. Direct therapy involves working directly with the child. Indirect therapy can involve providing intervention that is conducted by someone else other than the therapist. Examples include home programmes to support children with cerebral palsy to develop skills through repetition (Novak et al., 2009), with time spent practicing activities where children practice skills in their own environment (Gannotti et al., 2014), with support from their parents and other family members to carry out therapy. Consultative intervention can include providing advice and input to other professionals working with the child such as school staff. Some therapists choose consultation because they feel that support in the classroom would be of benefit to the child more than direct service once a week would (Dreiling & Bundy, 2003).

All three disciplines aim to be client centred, or person centred, and work in collaboration with the child and the child's family (WFOT, 2010; ASHA, 2022) often following the ethos of family centred practice (Dunst & Espe-Sherwindt, 2016). Child centred healthcare is defined as health care policy and practices centred on children's rights, needs, characteristics, assets and evolving capacities, taking into account children's own opinion (Council of Europe, 2011) which concurs with the concept of client centred practice. Client centred practice has been a guiding concept within occupational therapy (Hammell, 2013; Ripat, 2017) and is considered a foundational element (Ripat, 2017) and a core value of the profession (Aguilar et al., 2013). Similarly, the disciplines of speech therapy and physiotherapy aim to be client centred. Speech and language therapists treat the client as an equal partner and shares power (Leahy & Walsh, 2008) with an aim to provide person and family centred care (ASHA, 2022). In the United Kingdom, working in a person-centred manner is reported to be an under-pinning value and concept in the code of members' professional values and behaviour for physiotherapists (CSP, 2011) but full implementation of these person/family centred practice principles in daily practice of physiotherapy has proven to be difficult (Bailey et al., 2012).

Across the three disciplines there are similarities and variances in how the relationship with the child with disabilities and their family is described. In occupational therapy, the relationship is typically described as a partnership with therapists working in collaboration with children and their families in line with the principles of client-centred practice (Jeglinsky et al., 2012). How collaboration is enacted is variably described. Cahill and Beisbier recommend that occupational therapists collaborate with children by enabling opportunities for the child to be part of goal setting and decision making in the therapy process (Cahill & Beisbier, 2020) with goal setting being identified as a main component of family centred practice (Brewer et al.,

2014). Similarly, in physiotherapy it is seen as crucial to develop a collaborative relationship and therapeutic alliance, between the child, parents, and therapist (Bamm & Rosenbaum, 2008) but it is also acknowledged that there is limited research on the role of the therapeutic alliance in physiotherapy (Babatunde et al., 2017). It is also noted by Crom et al (2020) that paediatric physiotherapy implies a complex relational situation where both the child and parent are in subordinate position to the physiotherapist. In Speech and Language therapy, it is argued that person centred care should form a fundamental part of speech and language therapy therapeutic interactions (DiLollo & Favreau, 2010) and should be family centred with involvement of family members, carers, and other professionals, so that they can contribute to decisions that help to meet a child's needs (RCSLT, 2013).

Another common feature, of their work with children with disabilities by these three disciplines, is the use of play in therapy. Play is used for multiple purposes including engaging children in therapy to achieve developmental goals (Lynch & Moore, 2016), to enhance motivation, to facilitate playfulness, and assist clients in meeting play-based outcomes (Kuhaneck et al., 2013). In Occupational therapy, the use of play with children with disabilities as the means of therapy, as the outcome of therapy, and for its own sake is reported (Lynch et al., 2018; Moore & Lynch, 2018a). Studies describing the practice of physiotherapists and speech and language therapists with children with disabilities describe the use of play to support engagement with physiotherapy studies reporting on positive outcomes in intervention for children with cerebral palsy through the use of play (Buddhadev & Ary, 2012; Barton et al, 2013; Pratt et al., 2016) and speech and language therapy reporting on including the use of non-directive play in speech and language therapy (Cogher, 1999).

1.3.2 Concepts of client-centred practice

Many therapy disciplines aim to deliver client-centred or person-centred services. This type of practice is oriented towards upholding the rights of the client. While no common definition of what it means to be person-centred exists (Waters & Buchanan, 2017), generally it is described as a partnership between the therapist where the therapist finds common ground with the client (Ayres Rosa, 2009). There is consensus that client centredness is important (Little et al., 2001) but little agreement exists on what client-centredness actually means (Dwamena et al., 2012). The terms "client driven", "patient-centred", patient-focused care" are also used in relation to client centred care where individuals are partners in healthcare (Law & Mills, 1998). The client may not be just an individual person, but can also be families, organisations, or systems.

Client-centredness has its origins in psychotherapy. The concept emerged in the United States in the 1940s with the work of Carl Rodgers, a psychologist, who described client centred practice as a practice that was non-directive and focused on the client who is receiving a service. The theoretical constructs that underpin client-centred interactions evolve from learning theory and ideas about the dynamics of interpersonal relationships (Rodgers, 1951) and the non-directedness of the therapist (Rodgers, 1942).

As illustrated below in Appendix A, terms and concepts that feature in descriptions of client entered practice include: philosophy, respect, partnership, collaboration, enabling, decision making involvement, advocacy, non-directive, focused on client, cultural values, relationship, non-judgemental, phenomenological approach, problem solving, involve clients, diversity of client, client driven, autonomy, flexible, accessible, listen, values, choice(s), support, facilitate participation, provide information, comfort, focus on client goals and needs, therapeutic orientation, open communication, trust, acceptance, client in charge, agenda established by client, mastery, understanding client, control, unconditional positive regard, self-actualisation, client valued, active participants/active participation, kind therapist, recognising client expertise, recognising client knowledge, influence of power, hope, central to occupational therapy practice, responsibility, empowering, occupational centred practice, occupational beings, empathy, process, collaboration and common ground, genuine, and authentic.

Across the literature describing client centred practice, clients are described as active participants with active participation (Kang et al., 2008; Rodgers, 1950; Rodgers, 1965) and involvement in the healthcare interaction (Canadian Association of Occupational Therapists [CAOT], 1997). Client centred practice is characterised by the client having mastery (Emener, 1991), choice(s) (Baptiste, 2003; Baum & Law, 1997; CAOT, 1997; Beauchamp & Childress, 1994; Ennals & Fossey, 2017; Law & Mills, 1998), hope (Ennals & Fossey, 2017), control (Emener, 1991; Pollock & McColl, 1998), responsibility (Baptiste, 2003), and autonomy (Baptiste, 2003; Beauchamp & Childress, 1994; Law et al., 1995; Wright-St. Clair & Seedhouse, 2005). Central to client centred practice is decision making involvement (Bernard, 1995; CAOT, 1997; Fearing et al., 1998; Gage, 1995; Law & Mills, 1998; Sumsion, 2006) and equalisation of power (Ennals & Fossey, 2017) in the client therapist relationship.

Client centred practice demands that the therapist understands the client (Bandura, 1989; Bandura, 1990; Burnard & Morrison, 1991; Fleming-Castaldy, 2015), is non-judgmental (Rodgers, 1942), and holds unconditional positive regard (Rodgers, 1961) for the client.

Aligned with the concept of unconditional positive regard, therapists are required to be respectful (Ayres Rosa, 2009; CAOT, 1997; CAOT, 2002; Hammell, 2013; Institutes of Medicine, 2001; Law et al., 1995); Law & Mills, 1998); Sumsion, 2006; Szasz & Hollender, 1956; WFOT, 2010), supportive (CAOT, 1997; Hammell, 2013; Pollock & McColl, 1998; Rodgers, 1942), empathetic (Rodgers, 1949), accepting (Burnard & Morrison, 1991; Hammell, 2013), comforting (Law & Mills, 1998), and kind (Hammell, 2013).

When enacting client centred services, the therapist focuses on the client (Maitra & Erway, 2006; Rodgers, 1939; Sumsion, 2000), establishing client goals and needs (Burnard & Morrison, 1991; Institutes of Medicine, 2001; Law et al., 1997; McColl et al.,1997;), advocates for the client, and provides information to the client (CAOT, 1997; Law & Mills, 1998). Therapist attributes that contribute to empowering and enabling the client, and thus facilitate client centred practice, include being genuine (Rodgers, 1956), authentic (Rodgers, 1956), being an open communicator (CAOT, 1997; Ennals & Fossey, 2017), listening (CAOT, 1997), being non-directive (Rodgers, 1939), being accessible (Baptiste, 2003; Law et al., 1995;), and recognising client expertise and knowledge (Sumsion, 2006).

A client-centred approach or practice is accepted globally as one of the core aspects of care in any occupational therapy service (Law et al., 2001), and person-centred care is used in speech and language therapy (ASHA, 2022). Similarly in physiotherapy, there is an expectation that all members of the UK Chartered Society of Physiotherapy (CSP) should work in a person-centred way (Owen, 2013).

This section has overviewed client centeredness from a general perspective. Across the literature on client centredness, few have associated client centredness specifically to children and to paediatric settings. Yet, enabling, and enacting child participation in client centred approaches is a key feature of how therapy can be truly client centred. Furthermore, it is important to consider the importance of child participation and how it is defined. An understanding of child participation has the power to influence therapy and subsequently influence client centredness.

1.3.3 Child participation from a rights-based perspective.

The right of all children to be heard and taken seriously constitutes one of the fundamental values of the UNCRC (UN, 2009) with article 12 of the UNCRC (1989) highlighting that every child has a right to be heard and to participate in decisions that affect his or her life (UN, 1989). This includes participation in health-related matters. Article 12.1 of the UNCRC (1989) states

that “States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child” (UN, 1989). Of significance is the legal term “shall assure” which indicates that there is no leeway for discretion on the part of Sate Parties in the implementation of this right (UN, 2009) which in turn is an important factor in the implementation of the UNCRC into the legislation of any country. Another important consideration is the right to be heard to every child capable of forming his or her own views with no age limitation. This includes non-verbal forms of communication including play, body language, facial expressions, drawing and painting, through where young children can demonstrate understanding, choices and preferences (UN, 2009). Participation is viewed and defined as “ongoing processes, which include information sharing and dialogue between children and adults based on mutual respect, and in which children can learn how their views and those of adults are taken into account and shape the outcome of such processes” (Committee on the Rights of the Child, 2009, p. 3).

Facilitating the participation of children in decisions concerning them has many social, political and, in the case of healthcare, therapeutic, advantages (Kilkelly & Donnelly, 2006). Children want to be consulted, to be listened to, and to have their views taken (Children in Scotland/University of Edinburgh, 2010). Children with disabilities highly value the ability to participate in decision making. They particularly enjoy methods which are creative and fun, and they would like to have more opportunities to participate and to be kept informed of what happens (Franklin & Sloper, 2009). However, children with disabilities are less likely to be involved in decision making than other children.

An alternative view on children’s rights is presented by Guggenheim (2005) who defends parents’ rights over children’s rights, describing parent rights as “sacred” (Guggenheim, 2005 p.71). This view has the potential to stifle or at least limit children’s rights especially where there may be power imbalances or conflicts in children’s voice versus parents’ voice. Rights may be limited such as the concept of rights purported by Goldstein, Freud and Solnt (1996) who indicated that the only rights available to children should be the right to autonomous parents, the right to be represented by parents, and the right to parents who care (Goldstein, Freud & Solnt, 1996). Guggenheim (2005) further adds to this argument by suggesting that children have a right to be raised by “parents who are minimally fit and who are unlikely to make significant mistakes in judgement” in their rearing of their children (Guggenheim, 2005 p.43). This highlights the position of importance and power that is placed on parents’ rights

over children's rights. Notwithstanding this and despite critics of children's rights existing, overwhelmingly there is a commitment within law and policy to support and endorse children's rights.

Appendix B presents concepts that feature in academic publications and discussions about child participation including the impact of participation; participation as an ongoing, consultative process; where decisions are shared; with the child's views taken into consideration, including responsibility for decisions, with the child informed in advance; it should be embedded in everyday life; the child has a voice, including a voice in decision making; it should be child initiated and directed. Other features and traits include good relationships, respect, honesty, and trust. Many of these terms associated with child participation align with client centeredness. This includes giving the child a voice, being respected, having good relationships, being informed in advance, being listened to, and making shared decisions, with the child initiating and directing. It is clear that these terms and concepts are closely related within both client centredness and child participation.

It important to differentiate participation in decision-making and autonomous decision-making (Donnelly & Kilkelly, 2011). Autonomous decision making is where the child has complete control over the decisions that they are making as opposed to participation in decision making which is where the child participates in decision making but does not have full autonomy or control over the decision made. There are practical considerations, as well as philosophical struggles, encountered in the implementation of children's rights to participate (Todres & Diaz, 2017). Additionally, there are four requirements which individuals must meet to be autonomous (Dietrich, 2021). The individual must possess basic mental abilities for reasoning and judgment; they must have an adequate range of options; they must be capable of evaluating and deciding between given alternatives; and they must be free from coercion (Dietrich, 2021). This conceptualisation of autonomy raises questions with regard to what is considered the basic mental abilities that children must possess in order to be able to have autonomous decision making, what are the range of options that they are given, how they evaluate these options, and how do adults ensure that there is no coercion involved. In relation to therapy, it is most likely that decision making is more of a negotiated process rather than a process of autonomous decision making.

However, in contrast to children having full autonomy over decision making, discourse exists suggesting that children prefer shared decision making (Coyne & Harder, 2011). They suggest

that children's lives are closely intertwined with that of their families where they receive advice and guidance regarding various matters throughout their childhood (Coyne & Harder, 2011). Related to this, is the idea that while children's competence has been underestimated in the past, children still require, and desire, assistance to make healthcare decisions (Coyne, 2006). These concepts are important factors to consider in the context of children's rights and in giving children the choice of whether they actually want to be making decisions, or whether they are happy for their parents and therapists to be making the decisions.

Children face a range of obstacles in enacting their right to participation including adult indifference, tokenism, over-complex procedures, and practical barriers (for example, lack of time for proper participation, language difficulties, and insecure living conditions) (Daly et al., 2012). Additionally, children claim that opportunities and structures to enable them to participate more fully in their local community and in service provision should be improved (Daly et al., 2012). Being "corralled by adult agendas" (James & James, 2001) also impacts children's participation rights as adult needs may override the needs of the child and children may not be allowed to participate or have very limited participation.

Kilkelly and Donnelly (2006) state that "the rights of parents are given express recognition in Article 18 of the UNCRC, which also articulates the State's duty to provide appropriate assistance to parents in the exercise of parental responsibility. The principle of evolving capacity, set out in Article 5, is also relevant here insofar as it recognises the duty, right and responsibility of parents to guide their children in the exercise of their rights. According to this principle, parents, who exercise their rights on behalf of their young children, are encouraged to gradually cede these rights to their children as the child's willingness, capacity and development allows. This allows children to take on a more directly active and autonomous role in the decision-making process as they develop, although parents always retain ultimate responsibility for them, and the decisions made. In this context, it is important to note that Article 12 does not provide for all children to have the final and decisive say, but that their views be given due weight in accordance with their age and maturity in preparation for adulthood, where their right to self-determination is complete" (Kilkelly & Donnelly, 2006, p. 12).

To better support child participation in decision making, models and guidelines were developed and have gathered momentum including Lundy's model of participation (Lundy, 2007) and guidelines from UNICEF on engaging children with disabilities in decisions affecting their

lives (UNICEF, 2013). Lundy's model of participation (Lundy, 2007), which is gaining dominance in Ireland and Europe, highlights four inter-related components that are necessary to ensure that Article 12 of the UNCRC (UN, 1989) can be achieved. The components are space, voice, audience, and influence. Lundy's model of participation begins with creating a safe and inclusive space for children to express their views. This space is a pre-requisite for children to express their authentic views, without fear of rebuke and reprisal (Lundy, 2007). This is more than a physical space; it is a space for voice to be heard and appreciated and not just in a tokenistic way (Harmon, 2020). Regarding voice, children must be facilitated to express their view, with this view being listened to by the audience (Lundy, 2007). Regarding influence, the child's voice must be acted upon (Lundy, 2007).

The UNICEF (2013) guidelines on engaging children with disabilities in decisions affecting their lives (UNICEF, 2013) were developed to further enhance participation of children with disabilities in interventions and policies. The guidelines offer an overview of UNICEF's principles of a human rights-based approach, an equity agenda, inclusive development, and the promotion of a social model of disability (UNICEF, 2013). Against this backdrop, a strong focus exists on child participation in decision making, including addressing how it can be ethical and meaningful with the following standards being addressed: participation being transparent and informative where children are provided with full accessible disability sensitive and age appropriate information, voluntary, respectful, relevant, facilitated with child friendly environments and working methods, inclusive, supported by training, safe and sensitive to risk, and accountable (with a commitment to follow up and evaluation being essential) (UNICEF, 2013). Practices such as having a welcoming environment, equal opportunities for each child, building on children's strengths, and accommodating difference are also highlighted as being facilitators of inclusive participation. Additionally, UNICEF (2013) highlight three levels of engagement for children: consultative, collaborative, and child led engagement.

Another relevant model of participation was developed by Shier (2001). This five-level of participation focused on:

1. children being listened to
2. children being supported in expressing their views
3. children's views taken into account
4. children being involved in decision-making processes
5. children sharing power and responsibility for decision-making (Shier, 2001).

Furthermore, in this participation model, Shier (2001) presented three stages of commitment to these five levels of participation. These are:

1. providing openings where adults working with children and organisations become receptive to empowering children.
2. providing opportunities where adults and organisations have the funding, time, professional development, knowledge, and skills to support empowerment of children in authentic and meaningful ways.
3. obligations where adults agree to include child empowerment in organizational policy and practice, while being accountable through establishment of expectations for the adults involved and building requirements for child and youth empowerment into systems (Shier, 2001).

1.3.4 Healthcare rights for children

Both Article 12 of the UNCRC (UN, 1989) and Article 24 of the UNCRC (UN, 1989) need to be considered together to gain a true understanding of children's participation rights and voice within the context of children's rights in healthcare. Article 24.1 of the UNCRC (UN, 1989) states that "States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services" (UN, 1989), with a special emphasis on primary and preventative health care and public health education. However, tensions exist in the healthcare systems with regard to children's protection and children's participation rights. In Ireland, Article 23 of the UN (1989) stipulates that a child with disability should enjoy a full and decent life with recognition of the child having, among other things, effective access to health care services and rehabilitation services (UN, 1989).

There is a legal mandate to implement the UNCRC in the countries where it has been ratified. Limited integration of the UNCRC into Irish legislation was noted (Lundy et al., 2012) but there have been significant improvements in the State's approach to the protection and promotion of the rights of the child (Irish Human Rights and Equality Commission [IHREC], 2015). The Council of Europe (2011) have guidelines on child centred healthcare with particular emphasis on positioning children's rights, needs and resources at the centre of

healthcare activities including consideration of the child's family and the child's environment. Child centred healthcare is defined as "the health care policy and practices that are centred on children's rights, needs, characteristics, assets and evolving capacities, taking into account their own opinion" (Council of Europe 2011 p.6). There are various principles associated with child centred healthcare. These are:

- fundamental rights and children's specific rights
- dignity (with an emphasis on respect)
- participation (child gives consent or if they are not able to connect their opinion is taken into account, and child should be informed and consulted, and be given the opportunity to take part in the social decision-making process within health care)
- equitable access to quality health care (including prevention, promotion, protection, and provision of health services)
- best interests of the child (Council of Europe, 2011)

Furthermore, child friendly health care approach is underpinned by five principals (Council of Europe, 2011) which if implemented have the potential to empower children's participation rights further in healthcare. These are:

- Participation (where the child has the right to be informed, consulted, and heard)
- Promotion (where people increase control over their lives and should allow actions that allow children to become more involved in health decisions)
- Protection (limit or avoid children from being exposed to any hazard e.g. in the family, community or the health service)
- Prevention (avoid future health, social or emotions problems in order to realise human potential)
- Provision (services that contribute to health and well-being of children and families including pathway-based provision) (Council of Europe, 2011)

While complex, these principles associated with child centred healthcare share common features including a foundation in children's rights, which aligns with the UNCRC (UN, 1989), child participation where possible in decisions including being informed, consulted with, and listened to, child centred concepts (such as dignity and respect), children's access to healthcare,

and a consideration of the best interests of the child. Being listened to, concurs with Kilkelly and Donnelly's (2006) research on children's perspectives of being heard in the healthcare sector where children "consistently identified the importance of being heard by health professionals (Kilkelly & Donnelly, 2006 p. 2). The relationship between the Council of Europe (2011) principles is based on a rights perspective, which includes child participation, promotion of those rights, and child protection. Protection is commonly viewed as being provided by adults with the child as the recipient of healthcare and is usually considered as part of doing what is in the best interests of the child. This has potential to impact children's participation and in having their voice heard in healthcare. An interconnected relationship exists between child protection, and prevention of future health, social, or emotional difficulties, with the premise being that services provided should contribute to the health and wellbeing of children.

Finally, when exploring the context of children's contemporary lives in Ireland, it should be noted that policy about children's lives is influenced and underpinned by policies such as the National Children's Strategy (Department of Health and Children (DHC) 2000) and the National strategy on children and young people's participation in decision making 2015 2020 (Department of Children and Youth Affairs (DCYA), 2015). The National Children's Strategy is based on three main goals: 1). children will have a voice in matters which affect them, and their views will be given due weight in accordance with their age and maturity, 2). children's lives will be better understood; their lives will benefit from evaluation research and information on their needs, rights and the effectiveness of services, and 3). children will receive quality supports and services to promote all aspects of their development (DHC, 2000). A whole child or holistic perspective on child development and experience, which recognises the child as an active agent in their environment is considered central to achieving these goals (Greene et al 2010). Furthermore, the vision of the National Children's Strategy emphasised "an Ireland where children are respected as young citizens with a valued contribution to make and a voice of their own; where all children are cherished and supported by family and the wider society; where they enjoy a fulfilling childhood and realise their potential" (DHC,2000 p.4). Based on the concept that this vision offers "an expressed set of values that attribute to children and young people an innate dignity as human beings deserving of respect" (Pinkerton, 2004 p.123.), this policy approach positions children as being active agents who can shape their own lives.

Having reviewed the concept and characteristics of client centredness, children's rights regarding having a voice in all matters that affect them including in healthcare, child

participation as it relates to healthcare, and the therapy processes with children with disabilities, it can be concluded that the commitment to these areas often is from the perspective of adults, including with regard to who writes policy and who researches. All these separate characteristics, including those of good practice need to be considered together. Subsequently, there is a need for research to study in detail, child participation in healthcare, and in particular in therapy to ascertain their experience. A valid starting point is to explore how children experience therapy.

1.4 Rationale for current study

As child participation is centralised as a key element of best practice in client centred therapy, there is a need to examine what is known about children's experiences in therapy. Several qualitative studies reporting children with disabilities' experiences of the therapy process exist (e.g. Crom et al., 2020; Fourie et al., 2011; King et al., 2020; Pritchard et al., 2020). Qualitative research enables in-depth understanding of how people experience their world (Carpenter & Suto, 2008) and is ideal for addressing questions of how children with disabilities experience the therapy process when engaging with occupational therapists, speech and language therapists, and physiotherapists. To the best of the researcher's knowledge, studies on children's experiences of therapy have not been to date systematically reviewed and synthesised. Therefore, this study aimed to address this gap by conducting a systematic review of evidence from children's perspective. It aimed to use an interpretative method of qualitative evidence synthesis; meta-ethnography, to synthesise the available qualitative literature on how children with intellectual and/or developmental disabilities experience the therapy process when engaging with occupational therapists, speech and language therapists, and physiotherapists. The value of this study lies in revealing what children's own reported experiences are and will allow for interrogation of professional assumptions and claims on the therapeutic relationships in the therapy process including whether children consider the process client centred. It will contribute to service development by informing how services can be more responsive to the needs of children and young people with intellectual and/or developmental disabilities from a service user perspective.

CHAPTER 2 Methods

2.1 Introduction

Chapter 2 outlines the method and methodology used in this research study. It presents a description of the methods undertaken for this study. A study protocol is also presented in Appendix C.

2.2 Method

A qualitative method was taken in this study. A qualitative approach was taken because qualitative research is rooted in interpretive perspectives that emphasise the importance of understanding, from the viewpoint of the people involved (Pope et al., 2002). A qualitative evidence synthesis, which involves synthesising multiple qualitative primary research studies (France et al., 2019), was chosen as the most appropriate method to address the research question in this study. Qualitative evidence synthesis is an umbrella term for the methodologies associated with the systematic review of qualitative research evidence, conducted either as a stand-alone review or as a part of a review of complex interventions, systems or of guideline development (Carroll, 2017). While various methods of qualitative evidence synthesis exist (Barnett-Page & Thomas, 2009), a meta-ethnographic approach was chosen as the method of qualitative evidence synthesis for this review because it is interpretative rather than aggregative (Noblit & Hare, 1988). This meta-ethnographic synthesis approach of Noblit and Hare (1988) followed guidelines on conducting a meta-ethnography that are described by Cahill et al. (2018). This qualitative evidence synthesis used a meta-ethnographic approach which followed Noblit and Hare's (1988) seven-step process/phases for conducting a meta-ethnography. These seven steps were 1) Getting started, 2) Deciding what is relevant to the initial interest, 3) Reading the studies, 4) Determining how the studies are related, 5) Translating the studies into one another, 6) Synthesising translations, and 7) Expressing the synthesis (Noblit & Hare, 1988). This approach was used because drawing together findings from multiple studies has become increasingly common and important as a source of evidence within healthcare and policy (Classen & Alvarez, 2015), while building on existing knowledge (Toye et al., 2014) and adding new knowledge. A protocol (see Appendix C) for this meta-ethnography is registered with PROSPERO registration number CRD42021261706 (Hynes et al., 2021). This review was reported in accordance with the Enhancing Transparency in Reporting the

Synthesis of Qualitative Research (ENTREQ) guidelines (Tong et al., 2012) with the guidelines' checklist presented in Appendix D.

2.3 Study protocol

A protocol for a meta-ethnographic review was developed and registered with PROSPERO. A protocol is a plan for the research that will be conducted. Protocols include the research question, team members, search strategy, databases to search, inclusion and exclusion criteria, quality assessment tool, data extraction template, and the software that will be used (Columbia University, 2021). PROSPERO is an international database of prospectively registered systematic reviews in health and social care, welfare, public health, education, crime, justice, and international development, where there is a health-related outcome. PROSPERO aims to provide a comprehensive listing of systematic reviews registered at inception to help avoid duplication and reduce opportunity for reporting bias by enabling comparison of the completed review with what was planned in the protocol (University of York, nd). This meta-ethnography is registered on PROSPERO registration number CRD42021261706 (Hynes et al., 2021). The content of this protocol for the meta-ethnographic study is outlined in Appendix C.

2.4 Methodology

2.4.1 Search strategy

The scope of a synthesis is a crucial one (Britten et al., 2002) and subsequently in this review of qualitative research, the researchers completed an extensive systematic search strategy of seven databases between May and June 2021. These databases were Academic Search Complete, AMED, CINAHL complete, MEDLINE, APA PsycINFO, APA PsycARTICLES, and Social Sciences Full Text (H.W. Wilson). The rationale for choosing these databases was to ensure that as many relevant qualitative research papers as possible were sourced.

A second search was run in November 2021 and no additional relevant papers were returned that were relevant to the review. A list of the search terms is provided in Appendix F.

To ensure methodological rigor and enable clarity and reporting of the search strategy and procedures, the Preferred Reporting Items for Systemic Reviews and Meta-Analysis Protocols (PRISMA-P) checklist (Moher et al., 2015) was used. Searches were limited to English language publications, but no limits were applied to the date of publication. The PRISMA-

checklist for systematic reviews was used to illustrate the research strategy procedures (Moher et al., 2015) which is presented in Table 1.

2.4.2 Search terms

The following search terms were used:

"AB (child OR children OR adolescent OR teen OR teenager OR youth OR young person OR young adult) AND AB (qualitative OR experience* OR perception* OR perspective* OR case stud* OR interview* OR focus group* OR participant observation OR transcript* OR ethnograph* OR phenomenol* OR grounded theor* OR grounded-theor* OR life stor* OR action research OR thematic analysis OR narrative analysis OR field stud* OR field-notes) AND AB (Occupational therap* OR O.T. OR speech and language therap* OR speech pathology* OR S.L.T. OR S.P. OR physiotherapy* OR physical therap* OR physiotherapist OR physio OR P.T. OR allied health OR rehabilitation)

2.4.3 Inclusion and exclusion criteria

Primary research studies, published in peer reviewed journals, using qualitative or mixed-methods studies reporting qualitative methods of data collection and analysis of participation, experiences, feelings, views, opinions, and experiences of children with intellectual and/or developmental disabilities of the therapy process with occupational therapists, speech and language therapists, and physiotherapists were included. Qualitative studies, where a researcher was reporting on the observed experience of how children experience the therapy process were also included once it was clear that the researcher was reporting on what they have observed the child's experience to be.

Qualitative research with children aged up to eighteen years with a diagnosis of intellectual and/or developmental disability were included.

Studies, where a method of qualitative data collection or analysis was not described, were excluded. Articles were excluded where the qualitative data from the child could be identified, such as summaries or aggregated data of parent, or teacher, or family and child experiences.

Research with adults with disabilities were excluded. Research with children without disabilities was excluded.

Systematic reviews, study protocols, and theses were excluded.

Quantitative research was excluded from this research study as these types of studies do not explore children's experiences and therefore would not have data related to the topic under investigation. The focus of the research was to synthesise more in-depth rich data that could be extracted from qualitative studies. Given that qualitative research focuses on the nuances between individuals and aims to gain in-depth information about a specific topic from the perspective of the individual (Hall & Harvey, 2018), it was considered appropriate to use qualitative research studies for this research study.

2.4.4 Screening

After the removal of duplicates, the first author (PH) screened papers by title and abstract against the predetermined inclusion and exclusion criteria. One of the supervisors (KR) screened 10% of papers by title and abstract to check for consistency. Papers included for full text review were read and screened by PH and KR. Each reviewer independently considered the paper's relevance to this qualitative synthesis and through discussion, differences of opinion were resolved. The entire screening process is presented in a PRISMA flowchart in Table 1.

2.4.5 Data extraction and analysis

Once, the search strategy was completed in each of the identified databases, the citations retrieved were uploaded to Endnote software and the duplicate citations were removed. These citations were then exported to Rayyan software, to facilitate the screening of the papers by title and abstract (Ouzzani et al., 2016). The PRISMA-P flowchart (Moher et al., 2015) was populated to present the results generated at each stage of the process and aided with ensuring that the format of study selection followed a standardised process.

Similar to the method used by O'Dea and colleagues in their study protocol (O'Dea et al., 2021), information on the characteristics of each study was collated such as citation, study setting/country, sample size, participant characteristics, aims of the study, data collection and methods, and summary of findings. Each study was read, and verbatim findings related to children's experiences, or researcher's observations of children's experiences, were extracted and entered onto QSR International's NVivo 12 software. A PDF of the relevant findings section of each study was uploaded to QSR International's NVivo 12 software to aid with the first-order constructs and second order constructs being extracted and interpreted. Codes were generated to describe and explain each of the key concepts within each study. PH and KR coded

second-order findings as they were found within each study. The codebook, outlining the codes, is reported in Appendix E. Subsequently, these interpretations and synthesis of the second-order constructs became the third-order constructs. Phase four of meta-ethnography involved determining how studies were related (Noblit & Hare, 1988). Following coding of second-order constructs, the researchers met regularly to discuss and compare their concepts and determined how the studies related to each other, and the review question. This method of identifying the similarities and differences, common concepts, and recurring concepts across the included studies became a necessary prerequisite step which informed the translation process (Noblit & Hare, 1988). Phase five involved translating the studies into each other (Noblit & Hare, 1988). Constructs were constantly compared until similarities and differences between concepts could be organised into conceptual categories to represent the third-order constructs. Similar to the research method of Britten et al., (2002), the terminology used in the original papers was used in order to remain faithful to the meaning and concepts of each study. Once preliminary conceptual categories were created, PH presented the findings to HL and KR. Through discussions, these third-order constructs were further developed and refined.

The researchers synthesised all the conceptual categories, which provided greater insight into how children with intellectual and/or developmental disabilities experienced occupational therapy, speech and language therapy, and physiotherapy.

2.4.6 Quality appraisal of the included studies

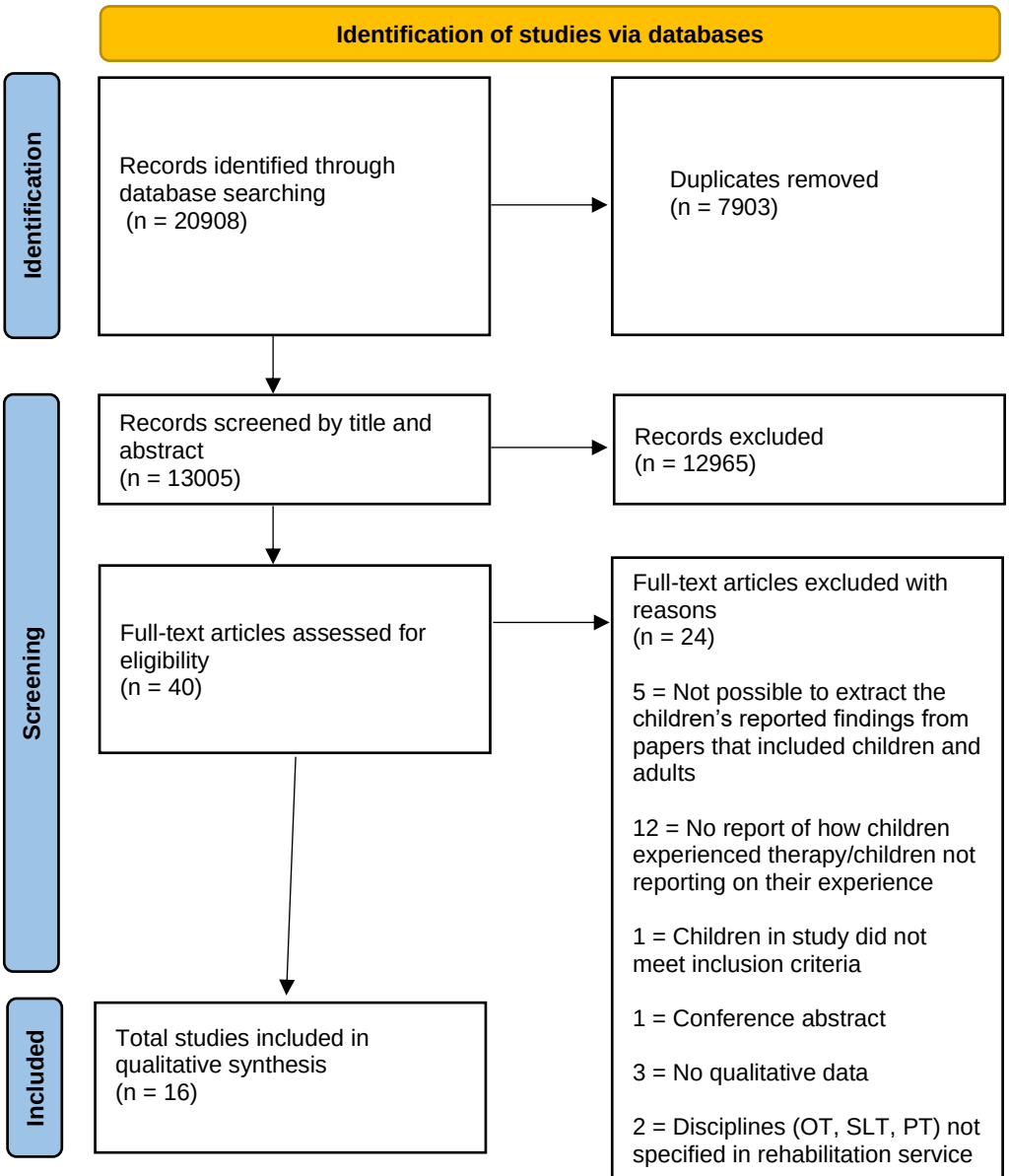
The quality of all included articles was assessed using an established critical appraisal checklist. The CASP Qualitative Studies Checklist (Critical Skills Appraisal Skills Programme [CASP], 2018) was used to critically appraise the quality of the included papers. All papers that meet the inclusion criteria were subjected to appraisal using the CASP checklist by two reviewers (PH and KR). Any differences of opinion were resolved by discussion. The quality appraisal results were then used to inform the synthesis and interpretation of the results of the study. Table 3 presents the CASP appraisal of included papers.

CHAPTER 3 Results

3.1.1 Study selection

Initial searches yielded 20908 results, 13005 after removing duplicates. Screening by title and abstract excluded 12965 results, leaving 40 studies for full text review. 16 studies met the inclusion criteria. Table 1 presents the PRISMA Flowchart diagram, detailing the entire process, which led to the inclusion of 16 studies.

Table 1: Prisma Flowchart



3.1.2 Characteristics of included studies

The characteristics of the 16 included papers are presented in Table 2. Four of the studies were conducted in the United Kingdom (Armitage et al., 2017; Clarke et al., 2001; Merrick & Roulstone, 2011; Young et al., 2006), three in Canada (Hodgetts et al., 2018; King et al., 2020; Pritchard et al., 2020), two in USA/Canada (King et al., 2019; King et al., 2021), two in Australia (Armstrong et al., 2020; Greenstein et al., 2016), one in Denmark (Andersen & Dolva, 2015), one in Norway (Bjorbaekmo et al., 2018), one in The Netherlands (Crom et al., 2020), one in Ireland (Fourie et al., 2011) and one in France (Houx et al., 2020).

In total data from 143 children, with an age range of 3 to 18 years, were included in the qualitative synthesis. Participants included children with cerebral palsy (Armstrong et al., 2020; Bjorbaekmo et al., 2018; Crom et al., 2020; Greenstein et al., 2016; Houx et al., 2020; King et al., 2019, King et al., 2020, Pritchard et al., 2020; Young et al., 2006), spina bifida (Bjorbaekmo et al., 2018; Greenstein et al., 2016; King et al., 2019), developmental co-ordination disorder (Armitage et al., 2017), combined diagnosis of developmental coordination disorder and autism spectrum disorder (Armitage et al., 2017), autism spectrum disorder (Hodgetts et al., 2018; King et al., 2019), heart surgery (Bjorbaekmo et al., 2018), psychomotor retardation (Crom et al., 2020), rare neurological condition (Greenstein et al., 2016), neuromuscular conditions (King et al., 2019; King et al., 2020), complex and multiple impairments (Young et al., 2006), physical disability (Andersen & Dolva, 2015), motor speech disorders (King et al., 2020; King et al., 2021), developmental delay (King et al., 2020), speech disorders (Merrick & Roultone, 2011), cleft palate (Merrick & Roultone, 2011), specific language impairment (Merrick & Roultone, 2011), speech and language therapy delay (Fourie et al., 2011), phonological delay (Fourie et al., 2011), communications device users (Clarke et al., 2001), intellectual disability (Andersen & Dolva, 2015), moderate learning disability (Merrick & Roultone, 2011) and no defined diagnosis (Armitage et al., 2017).

Six papers reported on children's experience of physiotherapy (Armstrong et al., 2020; Bjorbaekmo et al., 2018; Crom et al., 2020; Greenstein et al., 2016; Houx et al., 2020; Young et al., 2006), three on experiences of speech and language therapy (Clarke et al., 2001; Fourie et al., 2011; Merrick & Roulstone, 2011), three on a combination of speech and language therapy, occupational therapy, and physiotherapy (King et al., 2019; King et al., 2020; King et al., 2021), one on a paediatric setting that included physiotherapy (Andersen & Dolva, 2015), one on occupational therapy and physiotherapy (Pritchard et al., 2020), one on key stakeholders

that included speech and language therapy and occupational therapy (Hodgetts et al., 2018) and one on occupational therapy (Armitage et al., 2017).

Ten of the papers were published in the last five years.

In the included studies, interviews were primarily used for data collection. Interviews (often semi structured) were conducted with children in 13 studies (Andersen & Dolva, 2015; Armitage et al., 2017; Armstrong et al., 2020; Crom et al., 2020; Fourie et al., 2011; Greenstein et al., 2016; Hodgetts et al., 2018; King et al., 2019; King et al., 2020; King et al., 2021; Merrick & Roulstone, 2011; Pritchard et al., 2020; Young et al., 2006). Focus groups were used in three studies (Clarke et al., 2001; Hodgetts et al., 2018; Houx et al., 2020) and data collection by observation was used in three studies (Andersen & Dolva, 2015; Bjorbaekmo et al., 2018; King et al., 2019).

Based on the advice that conceptually rich data which is explanatory, or rich descriptive data which provides sufficient detail to be further developed is suitable for meta-ethnography (Sattar, Lawton, Panagioti & Johnson, 2021), all included studies were agreed upon by the three researchers as being relevant to this research. Given the broad nature of this research and the diversity of the papers used, it may appear that some studies were less relevant than others, but all included studies had rich, qualitative data that could be extracted and was deemed appropriate to the topic being researched.

Table 2: Characteristics of included studies

Author(s) **Year** **Country** **Setting**	**Article Title**	**Professionals involved**	**Participants** **Age** **Type of disability**	**Aim of study**	**Method and Methodology (study design, data collection; data analysis)**	**Summary of findings**
Andersen & Dolva, (2015) Denmark Paediatric rehabilitation centre	Children's perspective on their right to participate in decision-making according to the United Nations Convention on the Rights of the Child article 12	Paediatric rehabilitation including PT	Children (n=7) Age 7 – 14 years 4 with Physical disability 3 with intellectual disability	Aim of this study was to describe and try to capture the meaning of the children's perspective on their right to participate in decision-making together with the children's lived experiences in pediatric rehabilitation. The	Qualitative; Phenomenological hermeneutical research design; Interviews and observations; Content analysis; Systematic Interpretation	Power relationship with the therapists All children but one experienced that the therapist was the one who decided what was important for the child to learn Children experienced that parents and therapists were the ones to take greater and final decisions Children were content with not having formulated goals
Armitage et al., (2017) United Kingdom (UK)	Ingredients and change processes in occupational therapy for children: a	OT	Children (n=7) Age 7 – 11 years 3 children had no diagnosis	To explore parents' and children's views of the key ingredients of occupational therapy	Qualitative; Semi-structured interviews; Grounded theory	Performing activities and tasks' was described by the children as doing specific actions or sets of actions, in the context of therapy, especially within playful exploration or repetitive practice

National Health Service (NHS) Trust	grounded theory study		3 children had diagnosis of DCD 1 child had diagnosis of DCD and ASD 6 Parents were also interviewed	interventions for children with coordination difficulties and their parents. To explore the processes through which these ingredients might relate to the children's participation outcomes.		Repetitive practice was particularly commonly described in relation to specific skill-based activities 'Achieving' was described as successfully performing an activity (e.g. writing their name) or reaching an end point within a playful activity, a game or a competition Using performing activities and tasks within therapy sessions as a starting point for unpacking the children's descriptions of relationships, 'performing activities' were closely and directly linked to the ingredient 'achieving' Children described working hard and increasing their efforts as activities and tasks were repeatedly practiced, and persevering when performing activities and tasks in therapy in order to achieve the end point of the task The combination of performing activities and achieving was described, to result in children developing confidence in doing further activities, both within and outside of the sessions. Children described how believing that they could achieve further helped them perform activities and achieve the end points, and

						how this ultimately enabled participation across a range of situations
Armstrong et al., (2020) Australia Paediatric rehabilitation service	A qualitative analysis of the experiences of children with cerebral palsy and their caregivers in a goal-directed cycling programme	PT	Children (n=11) 10 interviews completed as child/parent/ carer diads or triads, and one child had an individual interview. Age 7 – 14 years All children had a diagnosis of Cerebral Palsy	To provide a rich and detailed account of the experiences of children with CP (GMFCS level II–IV, aged 6–18) and their caregivers who undertook an 8-week FES-cycling, adapted-cycling, and goal-directed training programme	Qualitative; Semi-structured interviews; Inductive thematic analysis	Programme that was tailored to individual's interests and goals was important to participants (e.g. ball games) Participants enjoyed setting and achieving personal goals as well as healthy competition against peers (enjoyed setting personal goals)
Bjorbaekmo et al., (2018) Norway One PT in public service 4 PTs in private practice	Which knowledge? An examination of the knowledge at play in physiotherapy with children	PT	Children (n=3) Children with either cerebral palsy or spina bifida or else had undergone heart surgery involving multiple and complex corrections in	To explore how knowledge is expressed, shared and exchanged in the practice of primary health care physiotherapy with children whose medical diagnosis	Qualitative; Observations by researcher (PT); Phenomenology	The physiotherapists and the child clients appeared caught in a kind of stagnant co-existence where their connection and contact are at a standstill and there is little exchange of knowledge between them. Children take initiative during therapy and display playful knowledge both of their body, moving capacity and of the equipment and tasks introduced.

			their first year of life Age 6 – 11 years Three anecdotes of observations from the researcher are used	suggests the need for long-term follow-up.		The physiotherapists seem to tend to emphasize physiological knowledge relating to the body, its functions and the "dangers" of pathological movement patterns.
Clarke et al., (2001) United Kingdom (UK) Education authorities	Views of young people using augmentative and alternative communication systems	SLT	Children (n=17) Young adults Median age 12 years Children who use a communication aid incorporating at least 20 symbols and/or pictures and/or written words, with language understanding at or above the two word level	To explore the perceptions of young people and children who use communication aids about speech and language therapy provision and their AAC systems.	Qualitative; Focus groups and individual interviews; Content analysis	Children expressed positive opinions concerning the role of SLTs and participation in therapy. Positive opinions centred on the characteristics of interaction between children and therapists. Negative attitudes toward therapists tended to focus on the content of activities and organizational factors Communication aid users delivered a strong message about the preferred location of therapy in school. Almost without exception, children and young adults favoured direct one-to-one therapy in a context outside the classroom.
Crom et al., (2020) The Netherlands	Between the Lines: A Qualitative Phenomenological Analysis of	PT	Children (n=10), Parents, PTs Age 3 – 17 years	To explore the opinions, perceptions, and preferences of children, parents, and	Qualitative; Semi-structured interviews; Qualitative phenomenological analysis	Trust in the therapist (relational skills and technical skills) Importance of negotiation concerning goals and tasks of the treatment

Rehabilitation setting associated with a hospital	the Therapeutic Alliance in Pediatric Physical Therapy		Cerebral Palsy, Psychomotor retardation, Orthopaedic problems, Congenital disorder, Neuromuscular disorder	physical therapists regarding the therapeutic alliance in pediatric physical therapy in a rehabilitation setting.		
Fourie et al., (2011) Ireland Speech and Language Therapy Services	A Qualitative Exploration of Therapeutic Relationships from the Perspective of Six Children Receiving Speech–Language Therapy	SLT	Children (n=6) Speech and language delay, Phonological delay Age 5 – 12 years	To elicit children's perceptions of their experiences of speech–language therapy.	Qualitative; semi-structured interviews; Interpretive Phenomenological Analysis (IPA)	The children valued the fun, games and rewards associated with interacting with their speech– language pathologists. Power - the inherent regulatory role of the clinician as an adult in relation to a child Trust The therapeutic process in terms of routines and rituals Role of SLT
Greenstein et al., (2016) Australia Community based physiotherapy service	Communication and context are important to Indigenous children with physical disability and their carers at a	PT	Children (n=5) Four children and one youth (one male, four females aged 12 to 19 years) Cerebral Palsy; Spina Bifida;	To find out what are the experiences of Indigenous children with physical disability and their carers of their community-	Qualitative; Open-ended, semi-structured, in-depth interviews; Inductive analysis	Participating children emphasised the importance of having their therapist speak to them about their condition, show them pictures and demonstrate their exercises. Positive relationship with Physiotherapist

	community-based physiotherapy service: a qualitative study		Rare neurological condition Parents were also interviewed.	based physiotherapy service? And what factors influence their experiences of the physiotherapy service and how could the service be improved?		
Hodgetts et al., (2018) Canada	Preparing for the future: multi-stakeholder perspectives on autonomous goal setting for adolescents with autism spectrum disorders	Included OTs and SLTs	Children (n=4), All 4 children had a diagnosis of ASD Age 14 – 18 years Professionals and Parents also were participants in separate focus groups	To better understand current practices and barriers to increasing autonomy in goal setting for adolescents with ASD.	Qualitative; Semi-structured interviews; Focus groups; Thematic analysis	All stakeholders said that they valued the importance of autonomy in goal setting. Children presented mixed messages about who sets goals. Adolescents were proud to share their perceived involvement in goal setting activities. Adolescents usually reported goals and goal setting in terms of the completion of concrete and discrete tasks that occur in the here-and-now.
Houx et al., 2020 France In- or	No pain, no gain? Children with cerebral palsy and their experience	PT	Children (n=18) Age 8 – 20 years Cerebral Palsy	To improve understanding of the experience of children and young adults	Qualitative study; focus groups; Thematic analysis; Inductive analysis	Participants reported that the experience of pain led to a dislike of physiotherapy. Participants perceived that physiotherapy practices were not universal and that therapists did not all have the same understanding of pain.

out-patients of paediatric physical, medical and rehabilitation centres	with physiotherapy.			with CP during physiotherapy sessions by identifying physiotherapy procedures that induced pain; where pain occurred; strategies used by both physiotherapists and participants to cope with pain; and solutions suggested by the children and young adults to alleviate or relieve pain.		Many participants equated pain with efficacy, and some suggested that pain was used by therapists to know they were being effective. Some participants discussed the impact of their relationship with their therapist on pain during sessions. The use of distraction techniques and the relationship with the physiotherapist were key elements associated with the perception and experience of pain. A few participants were positive about attending physiotherapy but most did not enjoy their sessions.
King et al., (2019) USA Canada Public and private organisations	The complexities and synergies of engagement: an ethnographic study of engagement in outpatient	OT SLT PT	Children (n=13) 7 females/6 males Age 8 – 18 years Range of diagnoses including CP, ASD, Neuromuscular conditions;	To describe people's behaviour reflecting engagement in therapy and to understand the meaning of therapy interactions from the viewpoint of	Qualitative; Ethnographic study; Participant observation; Ethnographic interviewing	Youth, caregivers, and Service Providers s all mentioned the importance of positive affect and positive relationships. This theme reflected engagement as affective and interpersonal in nature. Positive experiences in therapy and relationships enhanced engagement. Youth indicated how doing something interesting made them feel engaged.

	pediatric rehabilitation sessions		Developmental delay; Motor speech disorder; and Spina Bifida.	youth, caregivers, and SPs, using an ethnographic approach.		
King et al., (2020) Canada Outpatient services at a rehabilitation hospital	The Nature, Value, and Experience of Engagement in Pediatric Rehabilitation: Perspectives of Youth, Caregivers, and Service Providers	OT SLT PT	Youth (n=10) Service Providers Caregivers Age 8 – 18 years Cerebral palsy, neuromuscular conditions	To examine how youth, caregivers, and service providers view engagement, its value, and how it is experienced across a range of pediatric rehabilitation interventions	Qualitative; Interviews; realist method; thematic analysis	Youth indicated the value of knowing the service provider on a personal level Felt engaged Youth engaged cognitively when they saw how a therapy goal connected to their future Youth discussed connectors such as music and fun Youth discussed how having honest conversations made them feel engaged Youth discussed a sequence in which they felt they were not being listened to or included in a session, and how that led to feelings of boredom, frustration, and/or anger and cognitive disengagement, with the result that they did not pay attention and 'tuned out'
King et al., (2021) USA and Canada	Co-constructing engagement in pediatric rehabilitation: a multiple	OT, SLT, PT	Children (n=3), Professionals Parents/ Caregivers Age 8 – 15 years	To explore whether there were common engagement principles in youth rehabilitation	Qualitative; Interviews; Inductive thematic analysis	Importance of having relevant, and therefore motivating, therapy goals Importance of helping youth understand the purpose of therapy tasks Options/choice

Paediatric Outpatient Facility Regional Children's Hospital	case study approach		Male age 8 with Motor speech disorder; Female age 15 with Genetic condition involving delayed gross motor development Male age 13 with Cerebral palsy	therapy, and to consider the role of contextual conditions in the engagement experience.		Engagement can occur through feeling success or a sense of achievement Relationship was important to being engaged Comfortable and enjoyable interaction (to make it more laughter) Feeling uncomfortable Apparent lack of interest in her (client) as a person or her conversation Losing interest in the process Clients differed in what engaged them and in how they displayed engagement (Individual Variation Principle), engagement was cultivated through relationship (Relationship Principle), and it was seen as important to monitor and be attuned to the client's level of engagement (Monitoring Principle)
Merrick & Roulstone, (2011) United Kingdom (UK) Speech and Language	Children's views of communication and speech-language pathology	SLT	Children (n=11) Sample included four children with speech disorder, one child with a history of cleft palate, two with moderate learning	To explore children's views of communication and of speech-Language Pathology. The particular focus was on the children's	Qualitative, Grounded Theory Interviews	In their accounts of speech-language pathology, the children were judged by others and followed prescribed activities under the initiative and control of others. Children saw themselves as responsible for their own communication; they described speech-language pathology in terms of the social expectations of others, and saw co-operation as a matter of choice.

Therapy service			difficulties, and four with specific language impairment. Age 7 – 10 years	perspectives of communication difficulties, communication skills, and the kinds of assistance that they received		Positioned the therapist in authority relative to themselves as clients
Pritchard et al., (2020) Canada Outpatient and inpatient paediatric treatment clinics tertiary rehabilitation hospital	Child, parent, and clinician experiences with a child-driven goal setting approach in paediatric rehabilitatio n	OT and PT	Children (n=7) Cerebral Palsy Age 5 – 12 years Parents also interviewed	To explore child, parent, and clinician experiences with a child-driven approach to rehabilitation goal setting administered by therapists	Qualitative interviews; Interpretive description; Thematic analysis	Children emphasized the importance of having voice in the goal-setting process. Only they can truly understand and express the importance of their goal choices, and why they would like to work on the activities they choose to focus on for rehabilitation. Well-being was improved by a strength-based approach to goal setting Felt heard Participated in goal setting Having their own therapy goals was motivating
Young et al., (2006) United Kingdom (UK) Materially deprived inner	Decision-making in community-based paediatric physiotherap y:	PT	Children (n=11) Age 8 – 18 years 6 males and 5 females. 5 of the children were aged	To examine and compare children's, parents' and practitioners' (physiotherapist s and assistants) perspectives	Qualitative; interviews; Data were analysed using the constant comparative method	The children contrasted their lack of expertise and experience with the skills and experience of the PT or the PTA Denied having any involvement in decision making – however, when asked explicitly, when speaking in detail about their

city area of northern England.	a qualitative study of children, parents and practitioners		8–11 years, 2 were aged 12–15 years and 4 were aged 16–18 years Cerebral palsy; Several of the children had complex and multiple impairments: five attended a school for children with special educational needs (the remaining six attended various mainstream schools or colleges) and six were wheelchair users Parents also interviewed Staff focus groups	and experiences of decision-making in the context of community paediatric physiotherapy services for cerebral palsy.		experiences of PT it became clear that they did hold some influence in decision making

3.1.3 Quality appraisal

An overview of the appraisal of the included papers can be seen in Table 3. Appraisal of the included papers highlighted that all the included papers demonstrated a clear aim or objective of the research question, and all the included papers described an appropriate qualitative methodology for addressing the research question or objectives. The recruitment strategy was considered appropriate across the included studies, and the data was collected in a way that addressed the research issue. The relationship between researcher and participants was not adequately considered, or it was not easy to determine, from six of the studies (Armitage et al., 2017; Armstrong et al., 2020; Clarke et al., 2001; Hodgetts et al., 2018; Pritchard et al., 2020; Young et al., 2006). Ethical considerations were not explicitly described or explained in one of the included papers (Houx et al., 2020) and not possible to tell in one paper (Merrick & Roulstone, 2011). Data analysis was sufficiently rigorous in 15 of the included papers but it was not possible to tell in one paper (Clarke et al., 2001). All included papers had a clear statement of findings, and all included papers brought value to the research question in this synthesis.

Table 3: CASP appraisal of included papers

CASP Qualitative Research (rated as Yes, No, Can't tell)

Citation	Was there a clear statement of the aims of the research?	Is a qualitative Methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Anderse n & Dolva (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Armitag e et al., (2017)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Armstro ng et al., (2020)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes

Bjorbaekmo et al., (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Clarke et al., (2001)	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	Yes
Crom et al., (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Fourie et al., (2011)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Greenstein et al., (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hodgetts et al., (2018)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Houx et al., (2020)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
King et al., (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
King et al., (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
King et al., (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Merrick & Roulstone (2011)	Yes	Yes	Yes	Yes		Yes	Can't tell	Yes	Yes	Yes
Pritchard et al., (2020)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Young et al., (2006)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes

3.2 Synthesis (findings)

This meta-ethnographic synthesis of first and second-order constructs produced four interrelated themes (third order constructs): a) "Interpersonal experience of therapy", b) "Who is in the driving seat? – Children's experiences of power in therapy", c) "The nuts and bolts of therapy: experiencing therapy in the here and now", and d) "Making sense of therapy".

While the themes were interconnected, there were clear differences in what constituted each theme. See table in Appendix G which maps the four themes with the associated concepts and

ideas. When the initial data extracted from the original papers was being analysed and coded, the context of the richness of the data was considered. Coding is not a precise science but primarily an interpretative act (Saldana, 2013). While some codes may appear similar, there are distinctions between them in the context of telling the story of the data and the interpretation of them.

"Interpersonal experience of therapy"

This theme relates to children's interpersonal experiences and relationship with the therapist during therapy including their experiences of engagement, communication and trust and children's experiences of therapist attunement.

Children described characteristics of the therapist in positive terms including their communication style, being made feel special, and made feel that therapy is a personal experience (Clarke et al., 2001; Crom et al., 2020). Therapist communication was important to children including the timing and content of what was communicated and how it was communicated (Greenstein et al., 2016). Importance was placed on engagement through conversation in therapy (King et al., 2020) and examples of children engaging in a two-way conversation with the therapist (Bjorbaekmo et al., 2018; King et al., 2020) were given. "I can ask them questions and they'll answer me and they'll ask me questions and I'll answer" (King et al., 2020). Children reported that they were able to communicate easily with the therapist "I used to speak about me, and then when I'm done, she'd speak about her, and then me, and then her" (Fourie et al., 2011). In some cases, children experienced the use of discussion with the therapist to distract from pain (Bjorbaekmo et al., 2018; Houx et al., 2020). Other children reported on enjoying the experience of discussing treatment options in therapy and being able to talk with the therapist about different things (King et al., 2020) with another child reporting on comfort in therapy and being able to talk to the therapist if something is bothering them or needs to be changed: "if something's bothering me … if something's painful, I can always tell her" (King et al., 2019). Children reported that they discussed other things outside of therapy with the therapist also (King et al., 2021).

Trust in the relationship with the therapist was experienced by children in different ways. In two studies, children considered therapeutic alliance and trust in the therapist as important (Crom et al., 2020; Fourie et al., 2011) and reported they trusted their therapist that "she wouldn't do anything mean" (Fourie et al., 2011). Children reported trust in the technical skills of the therapist where the "therapist's insight into the developmental level of the child was

important for communication purposes and for the planning of the home program" and for the therapist to be safe (Crom et al., 2020). Interestingly, in one study, children reported that they considered the relational skills of the therapist more important than the technical skills (Crom et al., 2020). In contrast, a child experienced a lack of trust because the therapist did not follow through on a promise "My worst day going [to speech and language therapy], was when she promised me to have these pencils I liked, like she said she had them for me, she promised and then when I went she never had them there. She forgot an awful lot of times" (Fourie et al., 2011). Additionally, examples exist of where the child was not able to describe their relationship with the therapist (Fourie et al., 2011).

Some children experienced limited interest from the therapist. This was seen where a child was concerned with the relevance of her goals in therapy and felt the therapist did not always show interest in the child (King et al., 2021) with another child feeling that the therapist was not interested in her during therapy (King et al., 2021), and limited attention paid to what the child was doing in therapy by the therapist (Bjorbaekmo et al., 2018). In some cases, it was experienced that the therapist was not attuned to the child (Bjorbaekmo et al., 2018; Houx et al., 2020).

Children perceived the therapist negatively in some cases when they were experiencing discomfort and "sometimes you get the impression that [therapists] are sadistic" (Houx et al., 2020). Another child equated a bad therapist with not having fun in therapy (Fourie et al., 2011). Children experienced and noticed the physical characteristics of the therapist and used this as a way of describing whether they liked the therapist or not as indicated by an eight year old child in the study by Fourie et al (2011), who reported that she "didn't like her [the speech and language therapist's] nails, 'cause they were kinda blacky…'cause her nail polish was blacky and red'" (Fourie et al, 2011, p.319).

Reports of therapists supporting and not supporting engagement in therapy were common (King et al., 2019; King et al., 2020; King et al., 2021). Therapists engaged the child in therapy, with an example of the child reporting the interaction being comfortable and enjoyable (King et al., 2021) with different levels of engagement identified in therapy (King et al., 2019). Children viewed engagement as important which added value to therapy and working together with the therapist helped with motivation (King et al., 2020). While children reported different experiences on what engaged them in therapy, importance was placed on the therapist being attuned to the child and monitoring how the child was doing in therapy (King et al., 2021).

Different aspects of the child therapist relationship were reported across studies. Associations between relationships and collaboration to support engagement in therapy were experienced (King et al., 2019) with different aspects of the relationship with the therapist being reported on across studies. Children considered the relationship with the therapist important to being engaged in therapy, including a child reporting on being aware of how the therapist engaged him where "every time I get upset we read a book" (King et al., 2021). Children experienced a friendly relationship with the therapist (Fourie et al., 2011; King et al., 2019) with positive rapport being reported on by another child (Fourie et al., 2011). Children reported on the importance of good positive relationships with their therapist (Houx et al., 2020; King et al., 2019). Children wanted a consistent therapist, valuing the relationship that they had with the therapist (Greenstein et al., 2016), including value being placed on personal relationships within therapy, being engaged in the therapy process and understanding it (King et al., 2020). Children placed value on knowing the therapist on a personal level and feeling engaged through conversation with the therapist (King et al., 2020). Engagement in therapy was experienced through different connections including personal connection, goal connection, and activity connection (King et al., 2020). Children experienced therapy differently to each other based on the therapist and personalisation of therapy including engagement strategies (King et al., 2021).

"Who is in the driving seat? – Children's experiences of power in therapy"

While the previous theme focused on the child's experience of the relationships within therapy, this second theme relates to children's experiences of power in therapy. Finding suggest therapists often hold power over decisions and goals for therapy, and less frequently children hold power, often regarding smaller decisions.

Children reported viewing the therapist as an "expert" in many studies (Andersen & Dolva, 2015; Bjorbaekmo et al, 2018; Fourie et al., 2011; Houx et al., 2020; Young et al., 2006). In some studies, the domain of this expertise was not explicitly described, however in two studies it was reported that children viewed the therapist as expert of the normalisation process regarding the child's disability (Andersen & Dolva, 2015; Young et al., 2006).

Various experiences regarding decision making were reported by children in relation to the therapy process. Multiple studies reported that children were accustomed to the therapist making decisions (Andersen & Dolva, 2015; Bjorbaekmo et al., 2018; Crom et al., 2020; Young et al., 2006). Findings from a researcher observing a physiotherapy treatment session noted that the therapist decided on what was happening and led the therapy activity

(Bjorbaekmo et al., 2018). Several studies noted that children lacked experience in decision making in therapy (Andersen & Dolva, 2015; Young et al., 2006). When children did contribute to decision making it was often in relation to small decisions such as making little changes to the intervention (Andersen & Dolva, 2015; Fourie et al., 2011; Hodgetts et al., 2018; Young et al., 2006) one study reported that the initiative came from the child when they were making major decisions (Andersen & Dolva, 2015). Examples of the child participating in decision making include where a child suggested a change in her intervention by "suggesting changing her special working chair at school with a regular office chair more like the classmates' chairs" (Andersen & Dolva, 2015).

In one study, children reported that they wanted to have some say in the decision-making in therapy (Crom et al., 2020). However, in other cases, children were happy with limited participation in decision making in therapy (Andersen & Dolva, 2015) and children did not always know the outcome of decisions made in therapy (Andersen & Dolva, 2015).

In one study, some children described the therapist having the power and being in authority in the therapy process (Merrick & Roulstone, 2011). In this study, some children followed prescribed activities in therapy (Merrick & Roulstone, 2011) and in a further study children perceived therapy as mandatory indicating that someone else had the power over deciding that therapy had to happen (Fourie et al., 2011). Importantly, the "power relationships with teachers and therapists were mitigated when difficulty was attributed to the task….rather the child's inability" (Merrick & Roulstone, 2011). The experience of children being empowered in therapy was also reported in one study such as an example of a child who reported that the therapist taught him a technique to help him remember words and "got him fixed up" (Merrick & Roulstone, 2011). Some children viewed themselves as being the power holders where they solve their own problems through their own effort where skills improve with practice (Merrick & Roulstone, 2011).

Examples of children being active rather than passive during therapy included children making requests during therapy including where "some participants would ask the therapist to stop if the stretching was too painful" (Houx et al., 2020).

The power dynamic in therapy was also illustrated by child avoidance of negative conversations with the therapist and not feeling comfortable enough to have negative conversation with the therapist. For example, one child reported "Well, how should I say this … My therapist thinks I do those exercises at home, but very often I forget to do them … I

don't like to do exercises at home. Then when I did exercise at home one time, she now thinks I always practice at home. She says that things are going very well." The child did not feel comfortable enough to bring such feelings into the conversation with the therapist (Crom et al., 2020).

Across the studies the extent of children's choice and control over what happened during therapy sessions was varied. In one study, a child reported having some choice and control over what happened in therapy "sometimes he directs me. Sometimes I direct him" (King et al., 2021), with other situations being reported where the therapist led the therapy (directs the child) and other times the child leads the therapy (directs the therapist) in therapy (King et al., 2021) with the child and therapist having an equal say (Andersen & Dolva, 2015). Children reported where the therapist provided the child with choices during therapy such as getting something that they liked in therapy (Fourie et al., 2011) and choice about attending therapy (Fourie et al., 2011) was reported. In contrast, other children felt that they had no choice but to attend therapy (Fourie et al., 2011; Houx et al., 2020), with child acceptance of therapy without questioning it (Andersen & Dolva, 2015). Children took initiative in making some choices in therapy such as a child engaging in self-initiated play in therapy (Bjorbaekmo et al., 2018).

Studies reported experiences of children both being listened to and not being listened to in therapy. Children experienced being listened to in therapy for example where a child reported pain in therapy and the therapist listened and changed therapy "if something's painful, I can always tell her ……and we can change what we are doing" (King et al., 2019). Similarly, with regard to pain in therapy, children alerted the therapist and were listened to (Andersen & Dolva, 2015; Houx et al., 2020; Young et al., 2006) and "some therapists pulled more gently or changed the exercise if the child said it was too painful" (Houx et al., 2020). This was also apparent where the child reported that the therapist changed activities when the child became tired where "he sees that I am tired (unclear) and I can't continue, the…he just stops it" (King et al., 2021). Children experienced a desire to be listened to regarding changing activities in therapy by making suggestions about how therapy could be improved (e.g., pain relief, shorter sessions, or milder stretching in the session) (Houx et al., 2020). Children indicated where they would like therapy to happen (e.g. one to one therapy outside of the classroom) (Clarke et al., 2001) and children viewed cooperation as a matter of choice regarding therapy (Merrick & Roulstone, 2011). Some children reported not being listened to in therapy and it was clear that the power laid with the therapist (Houx et al., 2020; King et al., 2020) which led to anger,

boredom, frustration, and lack of engagement as evidenced by a comment from a child who stated, “nobody listens to me” (King et al., 2020).

Additionally, specific to therapy, children reported the importance of having a voice in the therapy process as they can only be ones to truly understand their goal choices (Pritchard et al., 2020). Children valued autonomy in goal setting and were proud of this (Hodgetts et al., 2018) and wanted to be part of the goal setting process where they could tell the therapist about themselves and their goals “I really want to ask about my goals, cause I really want them to know my life” (Pritchard et al., 2020). Children stressed the importance of negotiating goals in therapy (Crom et al., 2020) and enjoyed setting and achieving goals in therapy (Armstrong et al., 2020). Children felt valued and heard when they had opportunity to set their goals in therapy (Pritchard et al., 2020) and the child’s goal was a key motivator for therapy (King et al., 2021; Pritchard et al., 2020). Goal setting was experienced by children as a co-constructed process in (Pritchard et al., 2020) with parents and children often identifying different goals for therapy but often it was the child’s goal that was focused on (Pritchard et al., 2020) including where a child had opportunity to build on strengths in therapy through setting goals (Pritchard et al., 2020).

Despite multiple studies emphasising the importance of children setting goals for therapy, children presented mixed messages in one study about who set goals for therapy with reports from one child that a goal is something you are told to do and later a goal described as something you “you pick for yourself” (Hodgetts et al., 2018).

This theme related to children’s experiences of power in therapy. Findings suggested that therapists often hold power over decisions and goals for therapy, and less frequently children hold power, and when they do hold power it is often regarding smaller decisions.

“The nuts and bolts of therapy: experiencing therapy in the here and now”

The two previous themes focused on relationships within therapy and power within therapy. This third theme relates to how children experienced therapy sessions. Common experiences included having fun (and a desire for it to be more fun) and conversely boredom, discomfort and pain were also commonly experienced.

Children reported enjoyable, playful interactions and fun and laughter in therapy in eight studies (Armitage et al., 2017; Armstrong et al., 2020; Crom et al., 2020; Fourie et al., 2011; Greenstein et al., 2016; King et al., 2019; King et al., 2020; King et al., 2021). In two studies

some children reported that they would have liked more play in therapy (Fourie et al., 2011) and more fun in therapy, "to make it more laughter" (King et al., 2021).

Children liked when therapy was individualised to them and their needs (Armstrong et al., 2020) while doing something interesting made them feel engaged in therapy as indicated by a child who reported "I get to do something that I don't normally do ….like a new thing" (King et al., 2019). This concept of enjoyable therapy being novel was further reported on in a study focused on the use of functional-electrical stimulation (FES)-bikes in therapy (Armstrong et al., 2020). Winning at an activity or a game in therapy was also described as fun or enjoyable (Armitage et al., 2017; Armstrong et al., 2020; Fourie et al., 2011).

Children in three studies described therapy as routine (Bjorbaekmo et al., 2018; Fourie et al., 2011; Merrick & Roulstone, 2011) and in some cases repetitive (Armitage et al., 2017). Routine and ritual elements of therapy are illustrated in this child's descriptions of the opening and closing ritual of the sessions "Every time I went I had to hang up my coat there, [points] and then I would sit down here . . . It was always the same, and after, I got two stickers, but I didn't put them on my head, I put them in my folder" (Fourie et al., 2011).

Children's experiences of therapy also included the therapy environment/setting and how it was set up. In one study, children described how transferring into and out of their wheelchair for therapy took a lot of time; "you would spend the whole session getting in and out of the wheelchair" (Houx et al., 2020). In a further study, the tables and chairs in the therapy room were noted by an observer to be "set up to optimize eye contact" (King et al., 2021). Only one study reported children's experiences of being involved in the setting up of the therapy session (Bjorbaekmo et al., 2018).

The sensory experience of therapy was reported on in a small number of studies. In one study a child, describing their experience of a FES-cycling intervention where electrodes and the stimulation were experienced as being "really ticklish" and "sticky" (Armstrong et al., 2020). Other forms of discomfort, fatigue or pain was experienced by children in therapy across three studies (Armstrong et al., 2020; Houx et al., 2020; King et al., 2021). Children used various strategies to manage the pain that they experienced in therapy including internal strategies and distraction techniques to help when therapy hurt (Houx et al., 2020). In this case, while children wanted pain free therapy, some were concerned that it may not be effective (Houx et al., 2020).

Some children described therapy as a negative experience, while other children reported negative attitudes towards the content of therapy (Clarke et al., 2001; Houx et al., 2020) with most not enjoying physiotherapy in the study by Houx and colleagues as children experienced therapy as boring, tiring, and painful. Other children reported being bored in therapy, as reported by one child who stated, "sometimes I get bored after a while when we're doing the same thing", while other children experienced therapy exercises as being boring (Greenstein et al., 2016; Houx et al., 2020). Others reported becoming tired and losing interest in therapy with one child experiencing "pretty much by the time we are done I was really tired" (King et al., 2021). In one study, some children reported being nervous about attending therapy (Fourie et al., 2011).

As outlined above, this theme related to how children experienced therapy sessions including the negative experiences that children had of the therapy experience including wanting it to be more fun, the sensory experience of therapy, how the therapy environment was set up, the routine of therapy, the individualisation of therapy, and the fun aspect of therapy.

"Making sense of therapy"

This final theme is different to the previous theme of how children experienced therapy. This theme relates to how children understood therapy and its purpose, including their experiences of making progress in therapy or achieving outcomes and how therapy related to their view of themselves and their views of ability and disability.

Children reported an understanding of the purpose of therapy as linked to goals or their participation, or their improvement or development and their future in multiple studies (Armitage et al., 2017; Armstrong et al., 2020; Hodgetts et al., 2018; Houx et al., 2020; King et al., 2020; King et al., 2021; Pritchard et al., 2020). Two studies specifically noted children's clear understanding of their goal for therapy (King et al., 2021) and ability to recall their goals for therapy easily (Pritchard et al., 2020) and in multiple studies therapy goals were described as future orientated (Armitage et al., 2017; Armstrong et al., 2020; Hodgetts et al., 2018; King et al., 2020; King et al., 2021).

Analysis by King and colleagues (2020) revealed that engagement in therapy included connection to the therapy goal or vision, illustrating the importance of youth seeing the value or potential of a course of action. Children did not universally, however, report clarity about the purpose of therapy, or goals across the included studies, with some reporting confusion

about why they were attending therapy or lack of understanding of the therapists' role (Fourie et al., 2011; King et al., 2021). The following is an example of lack of clarity about the purpose of therapy: "Bridget [child], who was taking part in a planning session with Holly (OT), was not sure what the meeting was about ("I was just told to come and I came") and was confused when Holly moved back and forth in discussing Bridget's goals and job tasks with her" (King et al., 2021). In another study, children with intellectual disabilities did not view intervention having a specific purpose in contrast to the children with physical disabilities in the same study (Andersen & Dolva, 2015).

Accounts of making progress in therapy or achieving outcomes were common despite in some cases it being hard work or painful (Armitage et al., 2017; Armstrong et al., 2020; Houx et al., 2020; King et al., 2021; Merrick & Roulstone, 2011; Pritchard et al., 2020). Children reported that they experienced positive outcomes from therapy, such as feeling fitter and improved functional independence which was associated with improved participation and confidence in home school and community activities (Armstrong et al., 2020). Children in one study, drew on a discourse of learning where they described communication as a skill to be practiced and mastered and Speech and Language Therapy as a means of doing this in some cases. One child described how his speech had ''got a bit better'' as he could ''say better words'' since starting speech language pathology, and he attributed the improvement to the practice he had done (Merrick & Roulstone, 2011).

Positive experiences of achievement or progress were not universal. In one case a child attributed none of their improved outcome to the clinician or the therapy (Fourie et al., 2011) and in another study some children doubted the effectiveness of therapy (Houx et al., 2020). In one further study, some children described themselves as solving communication problem through their own efforts such as recognising their mistakes and putting them right as opposed to improving due to therapy (Merrick & Roulstone, 2011).

Children's views and experiences of therapy and the reason they attended therapy related to their view of themselves and their views of ability and disability. In multiple studies children describe improvement in ability, function, and participation as a result of therapy. These studies reflect findings in the study by Merrick and Roulstone (2011) where a discourse of impairment was identified in children's accounts where they described speech, language and communication needs (SLCN) in terms of deficits requiring treatment, seeing SLCN as a weakness on their part in comparison with their peers communication which they regarded as

normal. Similarly, in another study, children reported they attended Speech and Language therapy because of their difficulties with speech, as described by one child, Mary, who needed Speech and Language therapy as ". . when I opened my mouth I didn't know how to say kitchen, I said 'picthen,' and I didn't know how to say pigeon, I said 'wigeon' (Fourie et al., 2011). A similar interpretation was revealed in accounts of children with physical disabilities in one study, who perceived intervention as meaningful as it represented a hope of achievement toward "becoming normal" (Andersen & Dolva, 2015).

In contrast children using a discourse of behaviour, where speech and language pathology was described in terms of the social expectation of others as opposed to as an individual deficit of the child, reported that they did not see themselves as having an impairment and thus saw no point in attending therapy, or saw co-operation with Speech and Language as a matter of choice (Merrick & Roulstone, 2011).

In summary, this theme related to how children understood therapy and its purpose, including their experiences of making progress in therapy or achieving outcomes and how therapy related to their view of themselves and their views of ability and disability.

Chapter 4 Discussion

4.1 Discussion

This synthesis used an interpretative method of qualitative evidence synthesis; meta-ethnography, to synthesis the available qualitative literature on how children with intellectual and/or developmental disabilities experience the therapy process when engaging with occupational therapists, speech and language therapists, and physiotherapists. Findings reveal important insights into how children experience occupational therapy, speech and language therapy, and physiotherapy. Four interrelated themes were identified and labelled as "Interpersonal experience of therapy", "Who is in the driving seat? – Children's experiences of power in therapy", "The nuts and bolts of therapy: experiencing therapy in the here and now", and "Making sense of therapy". Across the studies in this review, participants reported on a variety of experiences of the therapy process including their lived experiences during therapy sessions, how they experienced the relationship with their therapist, how they understood therapy in the context of their broader lives and selves, and their experience of power relations within therapy including goal setting and making decisions.

4.1.1 Children's rights and voice

Considering the synthesis finding from a children's rights perspective, and in the context of children having a voice in all matters that affect them as endorsed in Article 12 of the UNCRC (UN, 1989), there is evidence across the synthesis that children are listened to but often regarding smaller decisions and matters. This was seen for example when they experienced pain or discomfort in therapy, children used discussion with the therapist to distract from their pain (Bjorbaekmo et al., 2018; Houx et al., 2020; King et al., 2019). Additionally, they discussed treatment options in therapy (King et al., 2020) and through discussion with the therapist changed their intervention (Andersen & Dolva, 2015). With a legal duty to listen to children (Kilkelly & Donnelly, 2006), Article 12 of the UNCRC highlights the role of the child as an active participant in the promotion, protection, and monitoring of his or her rights (UN, 1989). This is important to consider when interpreting the findings of this synthesis, especially given that participation is defined as an ongoing process, which includes information sharing and dialogue between children and adults based on mutual respect, and in which children can learn how their views and those of adults are considered and shape the outcome of these

processes (Committee on the Rights of the Child, 2009). Some evidence of information sharing was seen in this synthesis with examples of children engaging in two-way conversations with the therapist (Bjorbaekmo et al., 2018; King et al., 2020). Additionally, evidence of a child having some choice and control over what happened in therapy was reported in the findings of King and colleagues where "sometimes he directs me. Sometimes I direct him" (King et al., 2021).

There is some evidence of information sharing between therapists and children in this synthesis but often on smaller matters within therapy such as changing an aspect of the intervention such as the example reported by Andersen and Dolva, (2015) where a child advised her therapist that she wanted a different type of chair. Another example is highlighted where a child reported on enjoying the experience of discussing treatment options in therapy and being able to talk with the therapist about different things (King et al., 2020). Children reported understanding the purpose of therapy as linked to goals or their participation, or their improvement or development and their future in multiple studies (Armitage et al., 2017; Armstrong et al., 2020; Hodgetts et al., 2018; Houx et al., 2020; King et al., 2020; King et al., 2021; Pritchard et al., 2020). Notwithstanding these examples, evidence of participation shaping the outcomes of decisions was not explicitly found across the experiences of children reported in this synthesis, and it is unclear how decisions made by the children impacted overall outcomes and decisions in therapy. This finding contradicts the concept of participation being embedded in everyday life (Percy-Smith, 2010; Percy-Smith, & Thomas, 2010) and it is unclear if the children felt that participation was embedded in their therapy experience. Children did not universally report clarity about the purpose of therapy, or goals across the included studies, with some reporting confusion about why they were attending therapy or lack of understanding of the role of the therapist (Fourie et al., 2011; King et al., 2021).

This synthesis raises important issues in terms of children's experience of decision making. Several studies noted that children lacked experience in decision making in therapy (Andersen & Dolva, 2015; Young et al., 2006). In some cases, children were happy with limited participation in decision making in therapy (Andersen & Dolva, 2015) and children did not always know the outcome of decisions made in therapy (Andersen & Dolva, 2015). It is interesting to note that in occupational therapy Yerxa (2005) claims that "authentic occupational therapy means involvement of both the client and the occupational therapist" (p.138). This resonates with that finding that children considered the relationship with the therapist important to engagement in therapy, including where a child reported on being aware

of how the therapist engaged him where “every time I get upset we read a book” (King et al., 2021).

Lundy’s model of participation (Lundy, 2007) is a valuable lens through which to view true participation in decision making as it provides a way of conceptualising the process of a child's right to participation through the provision of the four pillars of space, voice, audience, and influence. Applying Lundy’s model to this synthesis, it becomes apparent that children had some space to be heard, a voice on smaller matters, and an audience namely in the context of therapists. However, the influence of their voice was not clear from children’s reports in the included studies. For truly comprehensive participation to occur, this aspect of how children experience therapy requires attention to ensure that children are fully listened to and have full participation rights. Additionally, identifying the views of children is an essential part of the process of outcome measurement (Clarke et al., 2001) in therapy. Children are viewed as valuable, knowing beings in the here and now, as opposed to immature beings on the road to becoming mature adults (Qvortrup, 2009 cited in Bjorbaekmo, 2018). This idea of children having a voice in the here and now regarding matters that affect them needs to be endorsed to a greater extent. This would also reduce the risk of adultism in the context of children’s lives when they are exerting their voice and participating in decision making. Adultism is seen as a prejudice where negative power is exerted by adults over children (Stafford et al., 2021). However, it should be noted that there may be times where children may be happy with adults making decisions for them, or where they are happy with some participation in decision making. As noted in the literature review above, three levels of engagement exist for children: consultative, collaborative, and child led engagement (UNICEF, 2013). These three levels are considered appropriate depending on the context and there is often over-lap between the levels (UNICEF, 2013). However, as healthcare decisions are not always straightforward and can vary depending on the situation, children often want to participate in discussions about their care but would rather not bear full responsibility for decision making (Coyne, 2017).

4.1.2 Participation in decision making

This synthesis illustrates the children in some studies reported some involvement in decision-making in the therapy process, but in other papers limited or no participation in decision making was reported. These findings are echoed in several other studies (Andersen & Dolva, 2015; Stafford et al., 2003). Many included studies reported that children were accustomed to the therapist making decisions (Andersen & Dolva, 2015; Bjorbaekmo et al., 2018; Crom et

al., 2020; Young et al., 2006) and the therapist decided on what was happening and led the therapy activity (Bjorbaekmo et al., 2018) suggesting that therapists are the power holders in this aspect of the therapy. Other studies in this synthesis noted that children lacked experience in decision making in therapy (Andersen & Dolva, 2015; Young et al., 2006). This poses the question as to whether there may be an underlying assumption that the therapist knows best and is considered expert. Interestingly, adult assumptions about the capacity of children and young people to form views have in the past resulted in a questioning of children and young people's ability to make decisions in a way deemed rational and reliable (Alderson, 2008).

Therapists should facilitate the participation of children and young people in all aspects of having their voice heard. Having a consistent therapist and the quality of the therapist child relationship can enable this. Findings from the synthesis indicated that children wanted a consistent therapist (Greenstein et al., 2016) and valued the relationship that they had with the therapist (Greenstein et al., 2016; King et al., 2020).

Representation and voice do not on their own necessarily confirm the extent or quality of their influence on decisions (Forde et al., 2017). In their paper, Young and colleagues indicate that there is a need for a greater understanding of the shared decision-making process (Young et al., 2006). This synthesis supports this need for a greater understanding of shared decision making. For example, the importance of children setting goals for therapy is well established, however findings included children presenting mixed messages about who set goals for therapy (Hodgetts et al., 2018), and a further included study reported that children wanted to have some say in the decision-making in therapy (Crom et al., 2020). The development and employment of a wide range of mechanisms is recommended to facilitate participation across different groups and contexts, and children should always get feedback on whether their views have had an impact, and in what way, and professionals working directly with children should be trained to listen to children and support their participation rights (Daly et al., 2012).

Another important aspect to consider is whether children can opt in or out of decisions made in the therapy or opt in or out of therapy. In their paper, Young et al., (2006) suggest that children are often restricted regarding negotiating how interventions are implemented in therapy. Despite this, there is evidence in this synthesis that children had some agency in regard to the intervention provided such as the example where the child leads therapy (directs the therapist) (King et al., 2021) and other times where the child and therapist have an equal say in therapy (Andersen & Dolva, 2015). However, a full equalisation of power (Ennals & Fossey,

2017) is not evident across this synthesis. Power is an aspect of the therapy relationship that needs to be considered. Falardeau and Durand (2002) assert that in social sciences the "use of power in a relationship is sometimes perceived as negative, improper, excessive, repressive and even coercive" (Falardeau & Durand, 2002 p. 138), with every interaction within a relationship involving the exercise of power (Emerson, 1962, cited in Falardeau & Durand, 2002), and the exercise of power in the therapist and client relationship being impossible to escape (Falardeau & Durand, 2002). The consideration of power being inevitable within the therapeutic relationship needs to be considered in the context of acknowledging power imbalances, while at the same time giving consideration to listening to all stakeholders in the therapeutic relationship, especially children. This is a delicate balance and one that requires therapists to adopt a children's rights-based approach as an integral part of therapy practice and approach as part of their clinical and professional reasoning.

Various guidelines and policies exist regarding engaging children with disabilities in decision making (DCYA, 2015; UNICEF, 2013) and for effective consultation with people with disabilities (National Disability Authority [NDA], 2002). UNICEF (2013) provide guidelines on engaging children with disabilities in decisions affecting their lives and assert that for children with disabilities to express their views freely, they must be provided with information that's relevant, accessible, appropriate, and made available in formats and at a level which they can understand (UNICEF, 2013). Additionally, they must also be provided with space to express their views and be afforded the time, encouragement, and support to enable them to develop and articulate their views clearly and with confidence (UNICEF, 2013). They must also be provided with safety to explore and express their views without fear of criticism or punishment. These guidelines from UNICEF correlate with models of participation including Lundy's (2007) model of child participation in decision-making, and the five level model of participation developed by Shier (2001).

In research on children's views of communication and speech and language therapy, Merrick and Roulstone (2011) reported that children saw themselves as social actors with power to make choices and determine their own behaviour fitting with the view of recognising children's agency and what children can do as children. (Merrick & Roulstone, 2011). This would not align with the view of children with disabilities in a Scottish study, many of whom expressed a feeling of not being listened to even if they were asked (Stafford et al., 2003).

4.1.3 Goal setting

Collaborative goal setting is a core component and feature of paediatric rehabilitation and therapy (Jeglinsky et al., 2012; Pritchard et al., 2020). There is evidence of children reporting being part of goal setting in this synthesis. For example, children enjoyed setting and achieving goals in therapy (Armstrong et al., 2020) with children feeling valued and heard when they had opportunity to set their goals in therapy (Pritchard et al., 2020). Vroland Nordstrand (2015) highlights that children's perspectives are of importance, and to give greater consideration to children's needs, children need to be involved in the goal-setting process. This is an essential ingredient in therapy including as Pritchard et al., (2020) report, there is a positive link between child identified goals and their increased motivation for participation in therapy. Furthermore, in their paper King and colleagues discuss how client ownership of goals is influenced through client engagement (King et al., 2020). Additionally, in the paper by Andersen and Dolva, they conclude that children need to be informed by health professionals of the opportunity to participate in decision making in paediatric rehabilitation (Andersen & Dolva, 2015). This synthesis reveals that children experience goal setting and decision making in different ways. For example, children valued autonomy in goal setting and were proud of this (Hodgetts et al., 2018) and they wanted to be part of the goal setting process where they could tell the therapist about themselves and their goals (Pritchard et al., 2020). Hudson (2012) argues that for decision making to be authentic in relation to children's rights, a comprehensive dialogue is required on what decision making is regarding age-relevant terms and its practical importance to children's rights in early education and childcare environments. However, in some cases, children prefer shared decision making (Coyne & Harder, 2011) where children still require, and desire, assistance to make healthcare decisions (Coyne, 2006). This should be considered in the context of children's rights and in giving children the choice of whether they want to be making decisions, or whether they are happy for their parents and therapists to be making the decisions. This argument is also relevant to therapy services delivered to children with intellectual and/or developmental disabilities.

As noted earlier, it is likely that are times when children will not want to make decisions and this needs to be acknowledged and accommodated too. Adults may want to protect and share decision-making with a child based on the perspective of the healthcare situation departing from the child's actual competence and voiced, or demonstrated, desire and rights (Coyne & Harder, 2011) and the ability of the child to make decisions, keeping in mind how realistic is it at times to have the child influencing therapy.

However, embedding a client centred approach is relevant to this debate and if utilised properly should support the child to make decisions, or at the very least place the child at the centre of the therapy process. Recognising client experience and knowledge (Sumsion, 2006) is another way to embed and support this process.

4.1.4 Client centred practice and power

Considering the findings of this synthesis from a child centred or client centred perspective, children's accounts confirm power relations and power dynamics exist. For example, the power dynamic in therapy was illustrated by child avoidance of negative conversations with the therapist about not liking the exercises that were provided and not doing the exercises at home, but not feeling comfortable enough to have the negative conversation with the therapist (Crom et al., 2020). There are many aspects that influence client centred practice in therapy such as the therapist having a duty of care to provide a service whether the child is interested in what the care consists of or not, and pragmatics such as the employment setting of the therapist. It is important to consider the contextual factors of the power relationship which aligns with the impact of the employment setting on occupational therapists' ability to be client-centred (Bennett Mortenson & Dyck, 2006). Furthermore, while a therapist may report they are client centred and work in a collaborative manner, clients may in fact feel that they were not sufficiently involved in setting goals in therapy (Wiart et al., 2010) or indeed in the therapy process. Specifically in occupational therapy, this is further considered by Hammell (2013) who asserts that there have been few attempts to determine whether clients perceive occupational therapists to be practicing in a client centred way despite the profession purporting to be client centred and asks if the profession's commitment to client centredness is evident in practice. Having mechanisms in place where the client centredness of a service and decision-making involvement of clients is embedded in services evaluations would be of benefit to service users. The principles of client centredness and priorities in services needs to be more explicitly communicated to the service users, as often these kinds of commitments are not seen. It would also provide a lens to ascertain how client centred a service is in its practices or not.

Evidence of client centred practice is seen in some of the reports by children in this synthesis. This is seen where children felt listened to (Andersen & Dolva, 2015; Houx et al., 2020; King et al., 2019; Young et al., 2006), had some choice and control over what happened in therapy (King et al., 2021), and discussed treatment options in therapy and were able to talk with the therapist about different things (King et al., 2020). This would align with concepts of client

centred practice where the client is listened to (CAOT, 1997) and information is provided to the client (CAOT, 1997; Law & Mills, 1998). However, contemporary discourse on client centred practice suggests that occupational therapists need to further embrace collaborative relationship focused practice to attend to the relational aspects of practice (Restall & Egan, 2021). Thus, there is scope for greater involvement of children in what they perceive as being client centred, and ultimately in embedding client centred practice into therapy.

While this synthesis provided discussion on client centred practice, it did not illuminate the tension that may exist between child centred or client centred practice and family centred practice. It may be that children do not note the possible tension that may exist, or that it was not something that was explored in the included papers.

4.1.5 Relationship with therapist and engagement

Children saw the relationship with the therapist as important with children reporting both positive and negative experiences of this. Therapeutic alliance reflects the relationship between the client and therapist including agreement on goals, tasks, and the quality of the bond between clients and the therapist (Bordin, 1979). The synthesis findings on therapeutic relationship, and therapeutic alliance, align with the view that the therapeutic relationship is one of the most important dimensions of treatment interactions (Finlay, 2004; Fourie, 2009; Fourie, 2011), while involving children in the therapy journey (King et al., 2020), and creating a warm and enjoyable therapeutic environment and engaging in tasks together enhances engagement (King et al., 2019). This therapy journey should create connection, enhance positive affect, and motivation (King et al., 2020). Understanding engagement as a complex, transactional, and multidimensional construct (Bagatell, 2012) is essential in the therapeutic relationship, and engagement is a relational, dynamic, and contextualised (King et al., 2021). Subsequently, as highlighted in this synthesis, engagement can have a powerful influence on the relationships in the therapy process. For example, children viewed engagement as being motivating and important which added value to therapy and working together with the therapist (King et al., 2020). This concurs with how engagement can influence the comfort and smoothness of the therapeutic process (King et al., 2020). It further concurs with the findings by D'Arrigo and colleagues who conducted research with occupational therapists on their perspective of the nature of child engagement, which concluded that helping the child feel safe, through the provision of meaningful experiences, and being flexible and responsive were a valuable way to connect and support child engagement (D'Arrigo et al., 2020). Levels of engagement, and

its influence on how children experienced therapy, were found in this synthesis. Indeed, King et al., (2019) suggest that engagement in therapy is a change inducing construct and has an influence on the relationships and collaboration in the therapy relationship.

Fun in therapy was reported as being experienced and desired in this synthesis. Kilkelly and Savage (2013) claim that play is a vital part of the child friendly approach to healthcare. Given that play and playfulness can help with developing relationships, playfulness within therapy has the potential to influence how children positively experience therapy, including the therapeutic relationship with the therapist. Playfulness is a state of mind, and one that is established within a relationship (Youell, 2008) and is valuable to consider in therapy. In this synthesis children state that they wanted therapy to be more fun (Fourie et al, 2011). Increasing playfulness is likely to increase the sense of fun in therapy. Fun and play in therapy further concur with the finding on research conducted by Costa and colleagues who reported that joy through engagement in personally meaningful activities were main motivators for children with developmental disabilities to choose their goals for intervention (Costa et al., 2017). Fun is also seen as being the provider of regulation for children and helps with their focus on what is relevant in their environment (van der Kolk, 2005).

A need for trust in the therapist and therapy was reported by children in studies in this synthesis. This is illuminated by Crom et al., (2020) who, in reporting on therapeutic alliance in physiotherapy, found that children expressed a need for trust and open communication with negotiation being of importance, and asserts that therapists should monitor the trust that is in therapy and be responsive to discomfort, tension or dissatisfaction in therapy (Crom et al., 2020). Trust is seen as a client centred factor (Burnard & Morrison, 1991; Rodgers, 1942). In contrast to fun and trust, pain and discomfort was experienced by some children in this synthesis. Children's coping strategies with pain in therapy are likely to be affected by how children perceive the need for the pain in therapy. For example, in one included study, some saw pain as an indicator of effectiveness, whereas others were sceptical about its benefits (Houx et al., 2020). Pain and discomfort in therapy is likely to negatively impact on the child's experience of therapy and subsequently it could be counter-productive to how a child may perceive client centred therapy. In a meta-analysis that examined the alliance-outcome correlation between adolescents who had a mental health difficulty, and their therapist, alliance was significantly related to treatment success for these adolescents (Murphy & Hutton, 2018). While similar evidence in the field of intellectual and developmental disabilities does not exist, the therapeutic relationship is potentially even more important in child orientated therapy than

in adult oriented therapy because children do not necessarily initiate treatment (Bickman et al., 2004).

How the child views themselves was reported in this synthesis and is likely to influence their perspective of how they experience therapy, and subsequently their relationship with the therapist. This aligns with the concept of the child having a care need that occurs within a particular context, which is influenced by the personal characteristics of the child (Crom et al., 2020). It also aligns with the concept that children have agency over how they view themselves as participating in therapy. Merrick and Roulstone, (2011) reported that children were active themselves in improving their ability over times through practicing and mastering new skills. There is a correlation between therapeutic alliance and motivation which in turn is likely to enhance motivation to practice and master skills (Merrick & Roulstone, 2011).

4.1.6 Research with children with additional needs or disabilities

Research methods used across the studies were predominantly interviews with children (including three papers that reported on focus groups) with three of the studies utilising observation as a method. Only sixteen qualitative research papers met the inclusion criteria for this synthesis which is a small number when considering the number of children who attend therapy worldwide. The scope of this study included children with intellectual and/or developmental disabilities with a wide range of conditions represented across the studies. However, an absence of data on children with severe intellectual disabilities was evident, which is in congruence with children who have intellectual disability experiencing higher healthcare utilisation than their peers and yet their voice being rarely sought in their healthcare experience (Mimmo et al., 2020). It was also not possible in this synthesis to identify differences across children's experiences of various types of therapy. Further research on children's experience of therapy is warranted as it aligns with calls for children and youth participation being drawn upon for their expertise thus enabling them to exercise their rights as citizens (Checkoway, 2011) and adds to existing discourse on healthcare provision including the importance that is placed on child friendly healthcare (Council of Europe, 2011). Additionally, children with disabilities are particularly disadvantaged when it comes to having their rights upheld and having the opportunity to participate.

Future research could consider a broader range of methodologies including arts-based and participatory methods as children with disabilities enjoy research methods which are creative and fun, and they would like to have more opportunities to participate and to be kept informed

of what happens (Franklin & Sloper, 2009). More engaging, creative participatory methods of research would be beneficial in gathering a wider range of children's experience which would have the potential to be more inclusive especially for children with more complex needs or with communication difficulties. While the methods used in each of the included papers may have been appropriate for the aim of each individual study, for future research greater attention to a wider range of methods that could capture children's voices would be useful such as the mosaic approach which includes a variety of methods to listen to children's voice (Clarke, 2017).

This synthesis illustrates that the various research studies conducted appear to be researcher driven and it is not apparent from any of the studies whether children were involved in designing the research questions or the research methodologies. This contrasts with what is recommended in ethical research with children. The idea of children as co-researchers (Lundy & McEvoy, 2012) would help ensure that children's voice and participation is active throughout research that involves children. An example of children being co-researchers is presented by Graham and colleagues where involvement of children who had physical disabilities and communication difficulties helped with a research study design for a study on the experience of play for 6 to 12 year old children with cerebral palsy (Graham et al., 2017). Examples such as this need to be replicated throughout research with children.

Chapter 5 Conclusion

5.1 Introduction

This study aimed to explore children with intellectual and/or developmental disabilities' experience of occupational therapy, speech and language therapy, and physiotherapy with a specific focus on the how much they appear to have a voice in therapy, and enactment of their right to be heard in the therapy process. It used an interpretative method of qualitative evidence synthesis, meta-ethnography, to synthesis the available qualitative literature on how children with intellectual and/or developmental disabilities experience the therapy process when engaging with occupational therapists, speech and language therapists, and physiotherapists. The value of this study lay in revealing what children's own reported experiences were and allowed for the interrogation of professional assumptions and claims on the therapeutic relationships in the therapy process including whether children consider the process client centred. Considering that the right of all children to be heard and taken seriously constitutes one of the fundamental values of the UNCRC (UN, 2009), and with participation in decision making being defined as an ongoing process, including information sharing and dialogue between children and adults (Committee on the Rights of the Child, 2009), this thesis contributes to a greater understanding of this through the meta-ethnographic synthesis that was completed. This meta-ethnographic synthesis of 16 qualitative research studies produced four interrelated themes a) "Interpersonal experience of therapy", b) "Who is in the driving seat? – Children's experiences of power in therapy", c) "The nuts and bolts of therapy: experiencing therapy in the here and now", and d) "Making sense of therapy". In this concluding chapter, the strengths and limitations of this study are outlined, implications for practice are considered and outlined, future research is addressed, and the chapter concludes with the key findings of this study.

5.2 Strengths and limitations

A major strength of this study is its novelty. To the best of the researchers' knowledge, this is the first meta-ethnography to focus on how children with intellectual and/or developmental disabilities experience the therapy process when engaging with occupational therapists, speech and language therapists, and physiotherapists. This synthesis provides an insight into children's

lived experience of therapy and provides their perspective of what therapy is like for them. Research that examines children's perspectives of their lives is essential for improving their lives (Moore & Lynch, 2018b) and respecting children's perspectives gives us an insight into what children consider important (Visnjic Jevtic & Visković, 2021).

While a strength of this study was the robust conduct of the review, including the use of PRISMA guidelines (Moher et al., 2015) and the use of the CASP appraisal tool (CASP, 2018), the phenomenon of interest that was examined in this review was broad and thus difficult to categorise easily. The diversity of papers included meant that, while there was a rich volume of children's experiences of therapy, the therapy setting, and disciplines varied. Another limitation of this review is the lack of inclusion of non-English language papers, thus potentially excluding a greater diversity of experiences of children.

In research, the researcher brings with them potential biases due to their personal and professional experiences (Berger, 2015; Stanley, 2015) and this something that was given consideration. Resultant from this, a strength of this study was the strict adherence to the methodological process which was aided by having a strong protocol in place. The quality of all included articles was assessed using the CASP Qualitative Studies Checklist (CASP, 2018). All papers that met the inclusion criteria were subjected to appraisal using the CASP checklist by two reviewers. Differences of opinions were resolved by discussion. Additionally, the researcher reflected on his position in this research especially with regard to working with children and their families. The researcher ensured that when developing the research question that it was based on an identified gap in the research literature and not solely based on a gap noted by the researcher in their clinical work.

5.3 Implications for practice

This findings from this paper are relevant to contemporary health and social care practice. Findings point to the need for occupational therapists, speech and language therapists, and physiotherapists who work with children with intellectual and/or developmental disabilities to further create opportunities for children to be part of the decision-making process and goal setting process. Through interrogation and reflection on their practice, therapists have the potential to be poised for action to utilise a model such as Lundy's model of participation (Lundy, 2007) to ensure that children experience the full participation in therapy of having their voice heard in all matters that affect them. In Ireland, Hub na nÓg Young Voices in

Decision Making (2021) has developed a set of good practice principles on how to engage with children and young people and ensure that their voices can make a difference or have an impact on decision-making. These include ensuring financial and human resources are in place; identifying and naming how children's views will be used; identifying and naming how decisions that are taken will be fed back to children; reporting on the views of children and avoid adult interpretations of their views; and ensuring that children play a prominent role in presenting their own views at relevant events (Hub na nÓg Young Voices in Decision Making, 2021). Utilising a framework such as this has the potential to ensure children's voices are heard in areas such as occupational therapy, speech and language therapy, and physiotherapy service provision.

The findings also highlight the importance of the therapeutic relationship within therapy and this needs to be constantly considered to ensure that therapists embed client centred practice into their therapy. This has never been more at risk than in services that are under-funded or under-resourced. Due consideration needs to be given to how client centred practice can be a constant in therapy so to dovetail with what children report including having trust in the therapist, having fun in therapy, being able to discuss therapy with the therapist, and goal set.

There is also a need to consider training, on children's rights, for the adults who work with children in the areas of occupational therapy, speech and language therapy, and physiotherapy. Incorporating this training into undergraduate and postgraduate university programmes in these disciplines would be advantageous to educate on, and promote, children's rights in the provision of therapy. This training should include the provision of training on children's rights to have their voice heard, and training on children participation in decision making. This aligns with the recommendations made by Forde et al. (2017) who suggest that there is a need for training in participation of adults working with children and young people in home school and community settings. Given the breadth of service delivery by occupational therapy, speech and language therapy, and physiotherapy this is wholly relevant.

5.4 Future research

Further child led and child directed research is required to gather a greater understanding of children's experiences of therapy that is provided by occupational therapists, speech and language therapists, and physiotherapists. A variety of creative methodologies is needed to gather these experiences of children across every life stage of childhood. This includes arts-

based and participatory methods, because children with disabilities enjoy research methods which are creative and fun (Franklin & Sloper, 2009). Engaging creative participatory methods of research could facilitate the gathering of a wider range of children's experience which would have the potential to be more inclusive especially for children with more complex needs or with communication difficulties. As previously indicated, while the methods used in each of the included papers may have been appropriate for the aim of each individual study, for future research greater attention to a wider range of methods that could capture children's voices would be useful such as the mosaic approach which includes a variety of methods to listen to children's voice (Clarke, 2017).

Future research should include children as co-researchers and children should be co-creators of the research agendas. This is in congruence with the conclusion of a theoretical exploration on "remaining client centred and ensuring children's participation in occupational science and occupational therapy research" presented by Hynes et al., (2017) at the Children's Research Network conference which indicated that not only do children have a part to play in their decision to participate in research, but they should also have a part to play in deciding what should be researched, and also be informed of the findings.

This study focused on children with intellectual and/or developmental disabilities. Completion of a similar review with children without intellectual or developmental disabilities who attend occupational therapists, speech and language therapists, and physiotherapists would contribute to the already developing discourse in this area. There would be benefit in drawing on comparisons and differences between how children without intellectual and developmental disabilities, and children with intellectual and/or developmental disabilities, experience therapy.

Another area of research that deserves greater attention is family centred practice and child (client) centred practice. It would be beneficial to investigate if any tensions exist regarding child voice and participation in decision making when there may be competing agendas between family centred practice and child (client) centred practice.

5.5 Conclusion:

Rights based healthcare, and children's voice in healthcare, has gathered considerable discussion in contemporary healthcare discourse. The right of all children to be heard and taken seriously constitutes one of the fundamental values of the UNCRC (UN, 2009) with article 12

of the UNCRC (1989) highlighting that every child has a right to be heard and to participate in decisions that affect their life (UN, 1989). Additionally, the Council of Europe (2011) have guidelines on child centred healthcare where particular emphasis is placed on positioning children's rights, needs, and resources at the centre of healthcare activities. Child centred healthcare is where health care policy and practices are centred on children's rights, needs, characteristics, assets and evolving capacities, taking into account their own opinions (Council of Europe, 2011). Within child friendly healthcare, child participation is a vital component if it is to be truly inclusive of the child's voice. Child participation is viewed and defined as an ongoing process, including information sharing and dialogue between children and adults based on mutual respect, in which children can learn how their views and those of adults are taken into account and shape the outcome of such processes (Committee on the Rights of the Child, 2009). Facilitating the participation of children in decisions concerning them has many social, political and, in the case of healthcare, therapeutic advantages (Kilkelly & Donnelly, 2006). Based on this, it follows that, gaining an understanding of how children with intellectual and/or developmental disabilities experience occupational therapy, speech and language therapy, and physiotherapy would add to this discourse.

This meta-ethnographic synthesis of 16 qualitative research produced four interrelated themes a) "Interpersonal experience of therapy", b) "Who is in the driving seat? – Children's experiences of power in therapy", c) "The nuts and bolts of therapy: experiencing therapy in the here and now", and d) "Making sense of therapy". The value of qualitative research can be seen in this review due to the rich data that was extracted from a range of qualitative papers. Children with intellectual and/or developmental disabilities described how they experienced therapy sessions. Common experiences included having fun (and a desire for it to be more fun) and conversely boredom, discomfort and pain were also commonly experienced. Children described their interpersonal experiences and relationship with the therapist during therapy including their experiences of engagement, communication and trust and children's experiences of therapist attunement. Children described how children understood therapy and its purpose, including their experiences of making progress in therapy or achieving outcomes and how therapy related to their view of themselves and their views of ability and disability. Children reported on their experiences of power in therapy, with finding suggesting that therapists often hold power over decisions and goals for therapy, and less frequently children hold power, often regarding smaller decisions. Evidence of participation shaping the outcomes of decisions was not explicitly found across the experiences of children reported in this

synthesis, and it is unclear how decisions made by the children impacted overall outcomes and decisions in therapy. This study contributes to service development by informing how services can be more responsive to the needs of children and young people with intellectual and/or developmental disabilities from a service user perspective.

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Appendices

Appendix A: Terms and concepts used in describing client centred practice

Appendix B: Terms and concepts in academic publications discussing child participation

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Appendix A:

Terms and concepts used in describing client centred practice

Terms and concepts used in describing client centred (patient centred, person centred, child centred):					
Philosophy (Law et al.,1995)	**Respect** (Ayres Rosa, 2009; CAOT, 1997; CAOT, 2002; Hammell, 2013; Institutes of Medicine, 2001; Law et al., 1995; Law & Mills, 1998; Sumsion, 2006; Szasz & Hollender, 1956; WFOT, 2010)	**Partnership** (Baptiste, 2003; Baum, 1998; CAOT, 2002; CAOT, 2013; College of Occupational Therapists, 2010; Ennals & Fossey, 2017; Law et al., 1995); Law & Mills, 1998); Sumsion, 2000; Sumsion, 2006; WFOT,2010)	**Collaboration** (CAOT, 1997; Chewning & Sleath, 1996; Hammell, 2013)	**Enabling** (Baptiste, 2003; CAOT, 1997; Law et al.,1995; Law & Mills, 1998; Szasz & Hollender, 1956)	**Decision making involvement** (Bernard, 1995; CAOT, 1997; Fearing et al., 1998; Gage, 1995; Law & Mills, 1998; Sumsion, 2006)
Advocacy (CAOT, 1997)	**Non-directive** (Rodgers, 1939)	**Focused on client** (Maitra & Erway 2006; Rodgers, 1939; Sumsion, 1999)	**Cultural values** (Rodgers, 1951)	**Relationship** CAOT, 2002; Hammell, 2013; Pollock & McColl, 1998; Rodgers, 1951)	**Non-judgemental** (Rodgers, 1942)
Phenomenological approach (Cain, 1990)	**Problem solving** (CAOT, 1997; Law & Mills, 1998; Rodgers, 1942)	**Involve clients** (CAOT, 1997)	**Diversity of client** (Baptiste, 2003; Law et al., 1995; Law & Mills, 1998)	**Client driven** (Gage, 1995)	**Autonomy** (Baptiste, 2003; Beauchamp & Childress, 1994; Law et al., 1995; Wright-St. Clair & Seedhouse, 2005)
Flexible (Baptiste, 2003; Law et al., 1995; Law & Mills, 1998)	**Accessible** (Baptiste, 2003; Law et al., 1995)	**Listen** (CAOT, 1997)	**Values** (CAOT, 1997; Institutes of Medicine, 2001)	**Choice(s)** (Baptiste, 2003; Baum & Law, 1997; Beauchamp & Childress, 1994); CAOT, 1997; Ennals & Fossey, 2017; Law & Mills, 1998)	**Support** (CAOT, 1997; Hammell, 2013; Pollock & McColl, 1998; Rodgers, 1942)
Facilitate participation	**Provide information** (CAOT, 1997;	**Comfort** (Law & Mills, 1998)	**Focus on client goals and needs**	**Therapeutic orientation**	**Open communication** (CAOT, 1997;

(CAOT, 1997; Law & Mills, 1998)	Law & Mills, 1998)		(Burnard & Morrison, 1991; Institutes of Medicine, 2001; Law, et al., 1997; McColl et al., 1997)	(McColl et al., 1997)	Ennals & Fossey, 2017)
Trust (Burnard & Morrison, 1991; Rodgers, 1942)	**Acceptance** (Burnard & Morrison, 1991; Hammell, 2013)	**Client in charge** (Pollock & McColl, 1998)	**Agenda established by client** (Pollock & McColl, 1998)	**Mastery** (Emener, 1991)	**Understanding client** (Bandura, 1989; Bandura, 1990; Burnard & Morrison, 1991; Fleming-Castaldy, 2015)
Control (Emener, 1991)	**Unconditional positive regard** (Rodgers, 1961)	**Self – actualisation** (Maslow, 1968)	**Client valued** (CAOT, 2002; Hammell, 2013)	**Client in context** (Baptiste, 2003; Ennals & Fossey, 2017; Fleming-Castaldy, 2015)	**Active participants/active participation** (Kang et al.,2008; Rodgers, 1950; Rodgers, 1965)
Kind therapist (Hammell, 2013)	**Recognising client expertise** (Sumsion, 2006)	**Recognising client knowledge** (Sumsion, 2006)	**Influence of power** (Ennals & Fossey, 2017)	**Hope** (Ennals & Fossey, 2017)	**Central to OT practice** (Ennals & Fossey, 2017)
Responsibility (Baptiste, 2003)	**Empowering** (Sumsion, 2000)	**Occupation centred practice** (Fisher, 2013; Gupta & Taff, 2013)	**Occupational beings** (Gupta & Taff, 2013)	**Empathy** (Rodgers, 1949)	**Process** (Maitra & Erway, 2006)
Collaboration and common ground (Ayres Rosa, 2009)	**Genuine** (Rodgers, 1956)	**Authentic** (Rodgers, 1956)			

Appendix B:

Terms and concepts in academic publications discussing child participation

Terms associated with child participation				
Ongoing process (Committee on the Rights of the Child, 2009)	**Information sharing** (Committee on the Rights of the Child, 2009)	**Intergenerational dialogue** (Committee on the Rights of the Child, 2009; Wyness, 2012)	**Giving child a voice** (Department of Health and Children [DHC], 2000)	**Child's views taken into account** (Committee on the Rights of the Child, 2009) (Shier, 2001)
Child as a rights holder	**Respect** (Committee on the Rights of the Child, 2009)	**Voice in decision making/involved** (DCYA, 2015)	**Embedded in everyday life** (Percy-Smith, 2010; Percy-Smith, & Thomas, 2010).	**Good relationships** (Daly et al., 2012)
Honesty (Daly et al., 2012)	**Trust** (Daly et al., 2012)	**Impact of participation** (Daly et al., 2012)	**Informed in advance** (Daly et al., 2012)	**Ladder of participation** (Hart, 1992)
Consultation (Hart, 1992)	**Child-initiated and directed** (Hart, 1992)	**Shared decisions** (Hart ,1992)	**Child listened to** (Shier, 2001)	**Child is supported to participate** (Shier, 2001)
Responsibility for decisions (Shier, 2001)				

Appendix C:

PROSPERO Study Protocol

Citation

Patrick Hynes, Helen Lynch, Katie Robinson. How do children and young people with intellectual and/or developmental disabilities experience the therapy process when engaging with occupational therapists, speech and language therapists, and physiotherapists: A qualitative evidence synthesis. PROSPERO 2021CRD42021261706 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021261706

Review question

How do children with intellectual and/or developmental disabilities experience the therapy process provided by Occupational Therapists, Physiotherapists, and Speech and Language Therapists?

Searches

A systematic search the following databases from inception for English language publications was conductedin June 2021:

- Academic Search Complete
- AMED
- CINAHL complete
- MEDLINE
- APA PsycINFO
- APA PsycARTICLES
- Social Sciences Full Text (H.W. Wilson)

Results of database searches will be imported into Rayyan software and duplicates removed.A PRISMA flow diagram will be populated throughout the process.

The reference lists of all included studies will be reviewed to identify potential further studies for inclusion.Only peer reviewed journal articles published in English language will be included.

The search will be re-run prior to the final analyses.

Types of study to be included

All qualitative or mixed-methods studies reporting qualitative methods of data collection and analysis of participation, experiences, feelings, views, opinions, and experiences of children with developmental and/orintellectual disabilities of the therapy process with Occupational Therapists, Speech and Language Therapists, and Physiotherapists. Qualitative studies, where a researcher is reporting on the observed experience of how children experience the therapy process will also be included once it is clear that the researcher is reporting on what it is they have observed the child's experience to be.

Studies, where a method of qualitative data collection or analysis is not described, will be excluded. Articles will be excluded where the qualitative data from the child cannot be identified, such as summaries or aggregated data of parent or teacher or family and child experiences.

Condition or domain being studied

The experiences of children with intellectual and/or developmental disability. Intellectual disability is defined as neurodevelopmental disorders that begin in childhood and are characterized by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living (American Psychiatric Association, 2013), with developmental disability being defined as a severe or chronic condition that is acquired before 22years of age (Altman, 2001).

Participants/population

Inclusion:

Children aged up to eighteen years with a diagnosis of intellectual and/or developmental disability.

Exclusion:

Adults with disabilities will be excluded. Children without disabilities will be excluded.

Intervention(s), exposure(s)

The focus of this qualitative review is on how children and young people with intellectual and/or developmental disability of experience Occupational Therapy, Physiotherapy, and Speech and LanguageTherapy services.

Comparator(s)/control

Not applicable

Context

Experiences of children living in in community, residential/ institutional/ hospital settings will be included.

Main outcome(s)

The review aims to

1. Synthesise and integrate the findings of individual qualitative studies to advance the conceptual understanding of how children with intellectual and/or developmental disabilities experience therapydelivered by Occupational Therapists, Physiotherapists, and Speech and Language Therapists.

2. Inform health service delivery, and the development and implementation of services, where children's experience of therapy with Occupational Therapists, Physiotherapists, and Speech and Language Therapistsis considered.

Additional outcome(s)

None

Data extraction (selection and coding)

Results of database searches will be imported into Rayyan software and duplicates removed.

A PRISMA flow diagram will be populated through the process.

Two members of the research team will screen 10% of all results by reviewing titles and abstracts againstthe following inclusion criteria:

- Qualitative study reporting use of recognised methods of qualitative data collection and analysis

• Participants are children aged up and including 18 years of age, or if there is a mixed sample in age,include if data on children and those up to including 18 years of age can be independently extracted.

• Participants have intellectual and/or developmental disability.

• Study findings report on the experience of engaging in / receiving assessment / intervention fromOccupational Therapists, Physiotherapists, and Speech and Language Therapists

Disagreements will be managed through discussion or involvement of a third member of the team. All resultswill be screened by lead author (PH).

All included studies will be read in full (full text review) to ensure they meet all inclusion criteria by twomembers of the team.

The reference lists of all included studies will be reviewed to identify potential further studies for inclusion.

Data will be extracted from included studies by two members of the team independently using a custom dataextraction form.

Data on the following will be extracted: author, year of publication, study setting/country, number of participants, participant characteristics (age, disability type), setting (community, institutional/hospital), aimsof the study, study design, data collection, data analysis and major findings, citation.

First and second order constructs (participant quotes and authors interpretations) will be extracted from allincluded papers and imported into NVIVO software for analysis.

Risk of bias (quality) assessment

The quality of all included articles will be assessed using an established critical appraisal checklist. The CASP Qualitative Studies Checklist (CASP, 2018) will be used to critically

appraise the quality of the included papers. All papers that meet the inclusion criteria will be subjected to appraisal using the CASP checklist by two reviewers (PH and HL or KR). Any differences of opinions will be resolved by discussion andthe involvement of a third reviewer (HL or KR) if necessary. The quality appraisal results can then be used toinform the synthesis and interpretation of the results of the study.

Strategy for data synthesis

Meta-ethnography will be used to synthesise and evaluate the results of the included studies. Noblit and Hare's (1988) seven-step process for conducting a meta-ethnography will be used. These seven steps are:

1. Getting started
2. Deciding what is relevant to the initial interest
3. Reading the studies
4. Determining how the studies are related
5. Translating the studies into one another
6. Synthesising translations
7. Expressing the synthesis

The rationale for selecting the above method is to ensure that there is a structured manner in synthesisingthe data and it demonstrates a consistent approach to the data synthesis.

As advised, by Noblit and Hare (1988) all studies will be read several times in full. Key quotations, metaphors, and concepts related to children with intellectual and/or developmental disabilities' experiences of the therapy process with Occupational Therapists, Physiotherapy, and Speech and Language Therapists willbe extracted using the words and explanations provided by the authors or the selected articles (second-order constructs). The coding and data extracted will be reviewed by the first researcher (PH) and a combination ofthe other researchers (HL and KR). Then the three researchers will

collaborate together to discuss differences and congruence's in their analyses and identify, consolidate and synthesise emerging themes.

Analysis of subgroups or subsets

Not applicable

Contact details for further information

Patrick Hynes 115223530@umail.ucc.ie

Organisational affiliation of the review

University College Cork www.ucc.ie

Review team members and their organisational affiliations

Mr Patrick Hynes. University College Cork

Dr Helen Lynch. University College Cork

Dr Katie Robinson. University of Limerick

Type and method of review

Narrative synthesis, Synthesis of qualitative studies, Systematic review

Anticipated or actual start date

10 June 2021

Anticipated completion date

10 December 2021

Funding sources/sponsors

None

Grant number(s)

State the funder, grant or award number and the date of award

Conflicts of interest

None

Language

English

Country

Ireland

Stage of review

Review Ongoing

Subject index terms status

Subject indexing assigned by Centre for Reviews and Dissemination (CRD)

Subject index terms

Medical Subject Headings (MeSH) headings have not been applied to this record

Date of registration in PROSPERO

19 July 2021

Date of first submission

18 June 2021

Stage of review at time of this submission

Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may beconstrued as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will addpublication details in due course.

Versions

19 July 2021

19 July 2021

Appendix D:

Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) checklist

No	Item	Guide and description	Response (Page No. in manuscript)
1	Aim	State the research question the synthesis addresses.	Aims: 1. Systematically search the qualitative literature to identify studies reporting on the experiences of children with intellectual and/or developmental disabilities on occupational therapy, speech and language therapy, or physiotherapy. 2. Perform a meta-ethnography to synthesise the included studies with a view to identifying new insights and describing user experience. See Introduction: (Abstract p.3; Introduction p.6 and p.23).
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology *(e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).*	Meta-ethnography (Abstract, p.3; Methods, p.24).
3	Approach to searching	Indicate whether the search was pre-planned (*comprehensive search strategies to seek all available studies)* or iterative (*to seek all available concepts until they theoretical saturation is achieved)*.	Pre-planned. See "Search strategy" (Method, pp.25-26).
4	Inclusion criteria	Specify the inclusion/exclusion criteria *(e.g. in terms of population, language, year limits, type of publication, study type).*	See "Inclusion and exclusion criteria" (Method, pp. 26-27). See "Search terms" (Method p.26, and Appendix F. p.125).
5	Data sources	Describe the information sources used (e.g. *electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar)*	See "Method" (Abstract, p. 3) "Search strategy" (Method, pp.25-26).

No	Item	Guide and description	Response (Page No. in manuscript)
		hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	
6	Electronic Search strategy	Describe the literature search *(e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits)*.	See "Search strategy" (Method, pp.25-26).
7	Study screening methods	Describe the process of study screening and sifting *(e.g. title, abstract and full text review, number of independent reviewers who screened studies).*	See "Screening" (Method, p. 27).
8	Study characteristics	Present the characteristics of the included studies *(e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).*	See "Characteristics of included studies". This information is included in narrative and table form (Results, pp.30-31; Table 2, pp.32-42).
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion *(e,g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).*	See "Study selection" (Results, p.29 and PRISMA flowchart p.29).
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings *(e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).*	See "Quality appraisal" (Methods, p.28; Results: pp.43-44).
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings *(e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope* [25]*; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).*	See "Quality appraisal" (Methods, p.28; Results: pp.43-44). Critical Skills Appraisal Skills Programme (CASP) (2018). CASP Qualitative Studies Checklist. Available: https://casp-uk.b-cdn.net/wp-content/uploads/2018/03/CASP-

No	Item	Guide and description	Response (Page No. in manuscript)
			Qualitative-Checklist-2018_fillable_form.pdf
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	Appraisal conducted independently by two reviewers. Consensus was sought. See "Quality appraisal" (Method, p.28).
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	No articles were excluded on the basis of quality assessment alone. See "Quality appraisal (Results, pp.43-44; Table. 3 Quality appraisal).
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? *(e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).*	The whole manuscript was read, and verbatim findings related to children's experiences, or researcher's observations of children's experiences, were extracted and entered into computer software. See "Data extraction and analysis (Method, pp.27-28).
15	Software	State the computer software used, if any.	QSR International's NVivo 12 Software. See "Data extraction and analysis" (Method, pp. 27-28).
16	Number of reviewers	Identify who was involved in coding and analysis.	See "Data extraction and analysis" (Method, pp.27-28).
17	Coding	Describe the process for coding of data *(e.g. line by line coding to search for concepts).*	See "Data extraction and analysis" (Method, pp. 27-28).
18	Study comparison	Describe how were comparisons made within and across studies *(e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).*	See "Data extraction and analysis" (Method, pp. 27-28).
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	Inductive, see "Data extraction and analysis" (Method, pp.27-28).
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation.	Quotes from participants were drawn from the included studies and used to illustrate themes and used throughout the results section (See Results, pp.45-54).

No	Item	Guide and description	Response (Page No. in manuscript)
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. *new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).*	(See Results, pp.45-54; Discussion, pp.55-65).

Appendix E:

Codebook of coded data

Children's experience of therapy synthesis

Themes:

1. "Who is in the driving seat?" – how children experience the power dynamic in therapy.
2. ""Interpersonal experience of therapy" – how children experience engagement, communication and trust in the therapy experience, including their relationship with the therapist, therapist attunement, and interest or lack of interest of the therapist.
3. "The nuts and bolts of therapy: experiencing therapy in the here and now" – children's lived experience of therapy (fun, enjoyment, play, boredom, routine of therapy, emotional experience of therapy)
4. "Making sense of therapy" – children's experience of the purpose of therapy, understanding why they were in therapy, how they see themselves in the bigger picture of therapy, and having a disability.

Codes

Name	Description	Files	References
Association between relationships and collaboration to support engagement in therapy		1	2
Child acceptance of therapy without questioning it		1	1
Child accustomed to the therapist making decisions and grateful or thankful to therapist		4	7
Child alerting therapist to pain or discomfort		3	3
Child and therapist had equal say in intervention		1	1
Child and therapist relationship including		4	10

Name	Description	Files	References
therapist as expert and therapist having power			
Child avoiding negative conversation with therapist and not feeling comfortable enough to have negative conversation with therapist		1	1
Child being successful and being able to achieve within therapy was important for child		2	4
Child can report pain in therapy and therapist listens and changes therapy		1	1
Child concerned with the relevance of her goals in therapy and felt that therapist did not always show interest in child		1	1
Child considers goal setting as important and motivator for therapy		1	1
Child considers relationship with therapist important		1	1
Child described problem associated with their disability as requiring therapy and see the difficulty as a deficit		1	1
Child describes having fun in therapy and laughing		1	1
Child describes having two-way conversation with therapist which helps with engagement in therapy		1	1
Child describes workings of therapy and how it evolves as the child gets older		1	2

Name	Description	Files	References
Child desire for therapist to be safe and for the child to feel safe in therapy		1	1
Child desire for trust in relationship skills with therapist		1	2
Child did not try to use distractions techniques or coping strategies when therapy hurt		1	1
Child disappointed with the therapy experience and felt that child's progress had nothing to do with therapy		1	1
Child does not feel listened to in therapy		1	1
Child doubting effectiveness of therapy		1	1
Child engages in self-initiated play in therapy		1	3
Child engages in two-way social conversation with therapist		1	1
Child enjoyed therapy sessions and described them as being fun		6	14
Child enjoys setting and achieving goals in therapy		1	1
Child equates bad therapist with not having fun in therapy		1	1
Child experienced fatigue and required physical assistance to engage with therapy programme		1	1
Child experienced pain or discomfort during therapy		1	3

Name	Description	Files	References
Child experienced various barriers to being able to engage with therapy eg personal and environmental factors		1	1
Child experiences therapy process as a routine		2	5
Child expressed that they are happy with goal because they know they will get better at the task (that goal is set for)		1	1
Child expressing desire for operational and linguistic aspect of therapy rather than social or strategic aspect of therapy		1	1
Child feels that therapist was not interested in her during therapy		1	2
Child feels that therapist was not interested in her on a personal level in therapy		1	1
Child felt able to participate in range of activities in and outside of therapy		1	1
Child felt no choice but to attend therapy		2	3
Child felt they were making progress in therapy despite it being hard work		1	1
Child felt valued and heard when they had opportunity to set their goals in therapy		1	1
Child focuses on the tasks within therapy		1	1
Child found therapy competed with other activities or tasks that they		1	1

Name	Description	Files	References
had to do (such as school or fun activities)			
Child had choice about attending therapy		1	1
Child had desire for trust in technical skills of therapist		1	2
Child had no new ideas for therapy		1	1
Child happy with limited participation in decision making in therapy		1	2
Child has clear understanding of goal for therapy		1	1
Child has friendly relationship with their therapist		1	1
Child has increased level of engagement in goal setting in therapy		1	1
Child having opportunity to explain their own goals for therapy in their own words		1	1
Child helps with setting up therapy session		1	1
Child in an adult dominated environment but the power relationship with the therapist was mitigated when the focus on difficulties was attributed to tasks, rather than the child's own difficulties or inability to do something		1	1
Child indicating where they would like therapy happen (eg one to one therapy outside of classroom)		1	1

Name	Description	Files	References
Child inexperienced with regard to deciding what to do in therapy		2	5
Child is familiar with aspects of the therapy routine		2	4
Child is the only one who can truly understand what goals they would like in therapy		1	1
Child liked when therapy was individualised to them and their needs		1	2
Child link performing activities in therapy with sense of achievement		2	3
Child made suggestions about how therapy could be improved (eg pain relief, shorter session, milder stretching in session)		1	3
Child making request during therapy		1	1
Child masters skill through persevering in therapy		1	1
Child motivated because therapy was fun		1	1
Child motivated by having their own therapy goals		1	1
Child not able to describe the relationship with the therapist		1	1
Child not clear about who set goals		1	1
Child noticed physical characteristics of therapist and used this as a way of describing whether they liked therapist or not		1	1

Name	Description	Files	References
Child perceived the therapy intervention as being novel		1	1
Child perceives therapy as mandatory indicating that someone else had the power over deciding that therapy had to happen		1	1
Child placed importance on having their therapy explained to them by therapist		1	1
Child places importance on fun, choice, achieving success and working hard in therapy		1	1
Child places value on knowing therapist on a personal level and feeling engaged through conversation with therapist		1	1
Child positive about attending therapy despite not enjoying it		1	1
Child positive about characteristics of therapist including communication style, being made feel special, and made feel that it is a personal experience		2	2
Child recognising that they have a difficulty (disability)		1	1
Child report on importance of good relationship with their therapist		1	1
Child report on physical aspect of what therapy intervention involved		1	1
Child reported being confused as to why she was		1	1

Name	Description	Files	References
in therapy and what it was about			
Child reported choosing how to act with regard to using therapy strategies provided to them		1	1
Child reported enjoying discussing treatment options in therapy and being able to talk with therapist about different things		1	1
Child reported enjoying playful interactions in therapy		1	1
Child reported feeling uncomfortable in therapy		1	1
Child reported having some choice and control over what happens in therapy		1	1
Child reported not having trust in therapist (due to therapist not following through on a promise)		1	1
Child reported that doing something interesting made them feel engaged in therapy		1	1
Child reported that therapist changes activities when child becomes tired		1	1
Child reported that they did not see themselves as having impairment and thus saw no point in going to therapy		1	1
Child reported that they had opportunity to build on strengths in therapy through setting goals		1	1

Name	Description	Files	References
Child reported that they were not bored in therapy		1	1
Child reported the importance of the child having a voice in therapy process		1	1
Child reported the importance of understanding the goal setting process in therapy		1	1
Child reported while nervous about going to therapy, it was fun, and she understood why she needed therapy		1	1
Child reported working hard in therapy session		1	1
Child reporting on having choice in getting something that they liked in therapy and therapist gave child choices		1	1
Child reports being aware of how therapist engages him in therapy (relationship with therapist)		1	1
Child reports being bored in therapy		1	1
Child reports being frustrated and angry when they do not get heard in therapy		1	1
Child reports being interested in therapy because goal was relevant and motivating		1	1
Child reports being tired and losing interest in therapy		1	1
Child reports lack of experience in decision making		1	1

Name	Description	Files	References
Child reports on feeling welcomed by therapist in therapy and friendliness of therapist		1	1
Child reports on importance of positive affect and positive relationships in therapy		1	1
Child reports on therapist having power in therapy but described the way therapist used power as being positive		1	2
Child reports that child discusses other things outside of therapy with therapist (relationship with therapist)		1	1
Child reports that therapist wants child to do their best in therapy (but not above child's limit)		1	1
Child saw goal as something that was future orientated and had a function		5	7
Child saw therapy as being a place where they could practice and improve their ability		1	1
Child saw therapy as important to help them		1	2
Child sees their problem (disability) as being within themselves and not as a consequence of social context or others behaviour		1	1
Child sees therapy as important despite pain associated with therapy		1	1
Child talks about comfort in therapy and being able to		1	1

Name	Description	Files	References
talk to therapist if something is bothering child or needs to be changed			
Child took initiative in making a major decision		1	1
Child used discussion with therapist to distract from pain in therapy, but this was not effective for all children		1	1
Child valued autonomy in goal setting in therapy and were proud of this		1	3
Child view cooperation as a matter of choice regarding speech and language therapy		1	1
Child views themselves as being responsible for their own communication (speech difficulties) and saw speech therapy as social expectations of others		1	1
Child views therapist (physiotherapist) as expert on their condition and therefore leave decisions to therapist to make		1	1
Child views therapist as expert of normalisation process regarding child's disability		2	4
Child wanted pain free therapy but concerned that it may not be as effective		1	1
Child wanted therapy to be more fun (more laughter)		1	1
Child wanted to have some say in decision making in therapy		1	1

Name	Description	Files	References
Child wants consistent therapist and valued the relationship they had with therapist		1	1
Child wants to be part of the goal setting process and tell the therapist about themselves and their goals		1	1
Child winning at activity or game in therapy		3	3
Child would have liked more play in therapy		1	1
Children consider therapeutic alliance and trust in therapist as being important		2	6
Children describe not being listened to in therapy and this led to boredom, frustration and lack of engagement		1	1
Children describe themselves as solving their own problems through their own effort where skills improve with practice		1	1
Children describe therapist as having the power and being in authority in the therapy process		1	1
Children described their speech and language difficulties and saw improvement over time through practice and mastering of new skills from therapy		1	1
Children experience therapy differently to each other based on the therapist and personalisation of therapy		1	1

Name	Description	Files	References
including engagement strategies			
Children have differing opinions on effectiveness of therapy		1	1
Children judged by others in power and follow prescribed activities in therapy		1	1
Children positive about role of speech and language therapist and participation in therapy		1	1
Children reported on how events in therapy made them feel and how this impacted motivation, engagement and expectations		1	1
Children stress importance of negotiating goals in therapy		1	2
Children view engagement as important and adds value to therapy and working together with therapist helped with motivation		1	1
Children were able to recall their goals for therapy easily		1	1
Children were active in the therapy process themselves and were empowered by other people who taught them how to do things		1	1
Children were different in what engaged them in therapy but therapist being attuned to child and monitoring how child was doing was important		1	1
Child's goal a key motivator for therapy		1	1

Name	Description	Files	References
Child's perception of their therapist		1	1
Child's trust in therapist may have only come about in the therapy context and relationship will end with ending of therapy		1	1
Child's uncertainty about outcome of decision		1	4
Communication was important for children including the timing and content of what was communicated and how it was communicated		1	1
Different levels of engagement identified in therapy		1	1
Engagement at different levels seen as important in therapy		1	1
Engagement in therapy has different connections including personal connection, goal connection, and activity connection		1	1
Engagement in therapy is seen as complex and can be seen in multiple ways in therapy		1	1
Example of child being able to communicate easily with therapist		1	1
Example of child finding therapy session boring		2	2
Example of child negative towards content of therapy		2	2

Name	Description	Files	References
Example of child not fully understanding the role of the therapist		1	4
Example of child not listened to in therapy		1	1
Example of child participating in small decisions		4	5
Example of child participation in decision making in therapy		1	3
Example of child understanding why they had to engage in therapy		1	1
Example of child using internal strategies to help manage pain in therapy session		1	1
Example of positive rapport between therapist and child in therapy		1	1
Example of where therapist listened to child		1	1
Examples of children reporting positive outcomes from therapy		1	2
Explanation of what is happening in therapy important for some children and less important for other children		1	1
Goal setting in therapy is a co-constructed process for children		1	1
Goals help child with remain focused on therapy		1	1
Importance of providing child with explanation of therapy, otherwise child will not		1	1

Name	Description	Files	References
understand the purpose of therapy			
Importance placed on engagement through conversation and collaboration		1	1
Limited attention paid to what the child is doing in therapy by therapist		1	3
Parents and child identify different goals for therapy but often it was child's goal that was focused on		1	1
Parents or therapist make final decision for therapy		1	8
Physical set up of therapy room can influence how therapy is performed		1	1
Practical issues such as getting in out of wheelchair impacts child's experience of therapy		1	1
Repetitive nature of therapy intervention experienced by child		1	2
Therapist decides on what is happening and leads therapy activity		1	5
Therapist engages child in conversation while working on therapeutic intervention (potentially to distract child from physical aspect of intervention)		2	4
Therapist engages child in therapy and child reports that interaction is comfortable and enjoyable		1	1

Name	Description	Files	References
Therapist leads therapy (directs child) and other times the child leads therapy (directs the therapist) in therapy		1	1
Therapist not attuned to child's needs in therapy		2	7
Therapist provided child with choices during therapy		1	1
Therapy was meaningful for the child		1	1
Value placed on personal relationships within therapy, being engaged in the therapy process and understanding it		1	1

Appendix F:

Search terms used

Search Alert: "AB (child OR children OR adolescent OR teen OR teenager OR youth OR young person OR young adult) AND AB (qualitative OR experience* OR perception* OR perspective* OR case stud* OR interview* OR focus group* OR participant observation OR transcript* OR ethnograph* OR phenomenol* OR grounded theor* OR grounded-theor* OR life stor* OR action research OR thematic analysis OR narrative analysis OR field stud* OR field-notes) AND AB (Occupational therap* OR O.T. OR speech and language therap* OR speech pathology* OR S.L.T. OR S.P. OR physiotherapy* OR physical therap* OR physiotherapist OR physio OR P.T. OR allied health OR rehabilitation) Published Date: 19810101-20211231 AND Apply equivalent subjects on 2021-04-30 02:20 PM"

Appendix G:

Themes mapped to concepts and ideas

Theme	Concept and ideas
"Interpersonal experience of therapy"	Children's interpersonal experiences and relationship with the therapist during therapy Children's experiences of engagement in the therapy relationship Children's experiences communication in the therapy relationship Children's experiences trust in the therapy relationship Children's experiences of therapist attunement
"Who is in the driving seat? – Children's experiences of power in therapy"	Children's experiences of power in therapy Children experiences of therapist often holding power over decisions and goals for therapy Less frequently children experiencing holding power and it is often regarding smaller decisions
"The nuts and bolts of therapy: experiencing therapy in the here and now"	How children experienced therapy sessions Children experiencing fun (and a desire for it to be more fun) Children experiencing boredom, discomfort and pain in therapy
"Making sense of therapy"	How children understood therapy and its purpose Children's experiences of making progress in therapy or achieving outcomes Children interpreting how therapy related to their view of themselves and their views of ability and disability