Goal Setting for Children with Cerebral Palsy: Navigating the Family Centred Practice Narrative

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Sarah Ferguson

i

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Abstract

Children with cerebral palsy often require additional support at school. Education, Health and Care Plans facilitate active collaboration between education, health care professionals and the family, to work in unison to identify goals for children with additional needs and ensure the necessary provision is in place for these outcomes to be achieved. Whilst an increasing body of knowledge is emerging relating to family centred goal setting practices for children with cerebral palsy, these studies have predominantly concentrated on clinic and community-based services with collaborative goal setting continuing to present a challenge. This research aimed to gain an understanding of perspectives from school-based educators, healthcare practitioners and parents of children who attend the school to create a resource in the form of a framework for practitioners to support collaborative goal setting.

Participatory action research and constructivist grounded theory were selected to account for my position as researcher within the organisation that I work, and the positions held by the prospective participants (co-researchers): education and health care practitioners, parents of pupils attending the school, and pupils. Creating a goal setting framework required understanding experiences and perspectives of all those involved with or impacted by goal setting practices. A participatory approach enabled the transformation of ideas for solutions into actions for change, with those for whom the changes would affect as central to decision making. Constructivist grounded theory was selected due to my already established presence in the research field and for its emphasis on explanation and understanding of social processes utilising an iterative approach to support data collection and analysis of the participatory action research. The research was carried out in three broad phases between 2019 and 2021 with each phase introducing a co-researcher group and the implementation of actions, and subsequent cycles of action and reflections directed by the group(s).

The outcome of the research resulted in the creation of the Purposeful Achievement Collaborative Engagement (PACE) goal setting framework and is offered as a resource for practitioners to address the factors identified through the research in the form of a theoretical model and practical resource. The constructivist grounded theory developed from this study: Navigating the family centred practice narrative depicts the journey that practitioners and families make, based on previous experiences, expectations, and future ambitions. Categories that underpin the theory: Competing demands on time, Importing emotions, Missing what's important, and Using the right language to inform the goal setting framework in order to initiate change and attempt to avoid occupational injustice and marginalisation.

The purpose of the framework is to raise awareness of the different aspects and considerations for setting goals within a family centred approach to practice. This aims to support practitioners with goal setting by considering a range of interlocking components to help understand behaviours and actions which can support improved collaboration. It aims to support decision making by practitioners that reflects the desires of the child and their family and by extension, promote occupational justice.

Collaborative goal setting is a challenge for practitioners and parents, as demonstrated by this research. To achieve the best possible outcome for all, school-based goal setting needs to be a collaborative process between the child, the family, education and health care professionals. Setting and progressing to further goals is a dynamic process and although the focus may be toward specific achievements, a variety of factors will impact on and influence the outcome.

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Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction to the thesis

1.1   Introduction

The findings of a blended participatory action research and constructivist grounded theory study are presented exploring goal setting practices in a specialist school for children with cerebral palsy. This chapter sets the scene for the research and begins with providing a background to the study and a reflexive account of the researcher position to demonstrate the rationale for undertaking the research. This is followed by contextualising the study, providing an overview of cerebral palsy, the potential challenges faced by the child and how having a child with cerebral palsy can risk affecting parental mental health. An overview of current approaches to managing paediatric disability, including family centred practice are discussed. Legislation that informs the rights of children who require additional support from health, social care and education practitioners as they move through education are then discussed, followed by outlining the aims and objectives for the study and structure of the thesis.

1.2   Background to the study

Goal setting for children with additional needs serves the purpose of measuring achievement and ensuring appropriate provisions are in place. It also provides a platform to build relationships between families and practitioners, between practitioners and practitioners, and to focus therapy intervention (Bexelius, Carlberg et al. 2018). Although policy and empirical research assert that goals are set in order to justify interventions, inform progress and measure change, this continues to be a challenge (Jacob, De Francesco et al. 2017) and has been experienced first-hand by the researcher.

Practicing as an occupational therapy lead working in a specialist school supporting children with motor disorders, I directly experienced the often-challenging process of setting long and short-term goals (referred to as outcomes and objectives) for the Education, Health and Care Plans which are integral to ensuring appropriate support for a child's ability to access education

(Adams, Tindle et al. 2018). I wanted to deconstruct the goal setting practices of the school in order to understand why they felt so challenging and discover if there was an alternative process to enable greater cohesion. A recognition of the need for greater cohesion was the motivating factor for undertaking this research.

1.3   The school

The school and the focus of this study uses an approach to learning whereby education and therapy staff work together in the classroom. Lessons are designed to integrate education with therapy that align with principles of conductive education, a holistic approach originally designed for children with cerebral palsy, originating from Hungary and developed by Andras Peto (Schenker, Parush et al. 2016). Specialist educators who are trained in conductive education known as conductors, form part of the staff team alongside traditional allied health professionals. Depending on the primary focus, lessons are designed collaboratively and are delivered by either an occupational therapist, physiotherapist, speech and language therapist, conductor or teacher. A recent systematic review by McAnuff, Gibson et al. (2022) found that approaches and interventions directed by school based health professionals, similar to those adopted by the school for this research, has a limited evidence base. However, it is argued that this way of working supports knowledge translation between therapy and education (Kennedy, Missiuna et al. 2020) and the purpose of this study relates to goal setting and not interventions.

1.4   Positionality of the researcher

Positionality of the researcher shapes how we enquire and interpret what we see (Corlett and Mavin 2018). When researchers acknowledge their positionality, this demonstrates an awareness of their actions and facilitates a transparency of intersubjectivity between researcher and researched (Greenbank 2003). Depending on how the researcher positions themselves philosophically, determines the position of inclusion or distance in the field and consequently will alert them to differing theoretical analysis, informing trustworthiness, and shaping the research (Finlay 2002, Birks and Mills, 2015). This research aimed to convey the multiple realities of the education and healthcare team, and the families they support and readily acknowledged that any analysis or interpretation was a co-construction between myself and

2

the participants (Lincoln and Guba 1985), highlighting the intentional and subjective awareness of reflexivity (Holmes, 2015). Occupying a position of authority, I wanted to understand more about how staff and families experienced goal setting, and if there was anything as an organisation that we could be doing differently. However, conducting research within the organisation where I work, and with people with whom I work (staff, parents of pupils and pupils), created the dilemma of selecting a methodology that could withstand my own values and world views, in addition to the research participants views (Creswell, 2003). Demonstrating active reflexivity acknowledges that qualitative research data is an interpretation, and the conscious self-awareness that reflexivity affords supports the transparency of decisions made to ensure trustworthiness of the research (Palaganas, Sanchez et al. 2017). It was therefore necessary that I embrace reflexivity throughout the research process in order to demonstrate how my self-awareness facilitated transparency of decisions made, giving meaning to the research and contextualise the creation of new knowledge (Davis 2020). The selection of methodology and the reflexive activities I undertook to ensure the research remained trustworthy and transparent are discussed further in chapter 3.

1.5   Research design

Due to my position as stated above, I assumed that I would bring my own knowledge and experience into the study and any research I carried out would need to be a co-construction between myself and the participants rather than an objective approach. Constructivist grounded theory best suited the requirements to understand and explain what was happening through a structured and systematic approach of collecting and analysing data, and would in part acknowledge that my existing experiences would influence the research (Charmaz 2014). However, my intention was for the research to be useful for the school and this required buy-in from those who would be applying it (the practitioners) and be receivers of it (parents, pupils). I therefore needed to create a collaborative relationship between myself and the team members in order to create change that would be perceived as useful. This resulted in the utilisation of participatory action research which served to facilitate a co-researcher collaboration. This meant that I could equalise the power balance by transforming participants into co-researchers (Stringer 2014). Early in the action research meetings with the practitioners, it became clear

that the challenges with goal setting related more to collaboration between practitioners, parents and their children. Although one pupil co-researcher group was created, their presence in this thesis occurs implicitly and the focus is on the interplay between practitioners and parents. It became apparent through the research process, guided by the inductive nature of constructivist grounded theory, that the parent-practitioner interactions were considered a priority for both the practitioners and the parents for improving goal setting practices, hence this is where the focus resides.

1.6   Cerebral Palsy, goals and family centred practice: a review of the context
1.6.1   Cerebral palsy

Cerebral palsy (CP) is the most frequent type of motor disorder in childhood with an estimated prevalence of one in 400 births worldwide (Colver, Fairhurst et al. 2014) and occurs as the result of an insult to the immature brain before, during or shortly after birth (Rosenbaum and Gorter 2012). Indicators of CP include missed or delayed motor milestones, asymmetry and abnormal muscle tone with a diagnosis usually received when the infant is aged between 12 and 24 months (Graham, Paget et al. 2019). The type and distribution of motor difficulties observed are dependent on the primary site of neurological insult and may affect lower limbs (diplegia), one side of the body (hemiplegia) or total body involvement (quadriplegia) with varying degrees in combinations of presentation of high tone, low tone and involuntary movement (Graham, Paget et al. 2019).

CP is primarily a disorder of posture and movement but is better understood as a complex set of conditions due to the differences and range in severity of motor involvement, and often present with additional challenges relating to cognition, speech, sensory, behaviour and perception all of which can impact on participation for learning and functional skills development (Rosenbaum and Gorter 2012).The effects of CP may affect function and participation in a variety of ways, requiring interventions provided by medical and allied health professionals ranging from supporting mobility, breath control, communication, and functional skills, including fine motor, gross motor and coordination for activities of daily living, play and school (Law, Darrah et al. 2011, Glinianaia, Best et al. 2017). Pain, sleep difficulties and fatigue found in a

4

study by (Hanes, Hlyva et al. 2019) has a significant impact on being able to engage in and sustain engagement in activities of daily living, schoolwork, and leisure. The risk of depression and anxiety is also higher compared to typically developing peers which further impacts on functional social skills for relationships (Hanes, Hlyva et al. 2019).

1.6.2 Approaches to managing childhood disability

In recent years there has been a shift in the approach to managing disability. The introduction of the International Classification of Functioning, Disability and Health (ICF) by the World Health Organisation (2002) sought to reconsider how health and disability were viewed as having either health or disability, and instead proposed that by combining the medical model of disability with the social model of disability, health could be viewed in terms of functioning in society. Emphasising how the interactions between health condition, body function, participation and contextual factors of the environment and personal factors impact on activities of choice (Figure 1), the ICF is considered a universal tool that can be used regardless of diagnosis and as a resource for guiding health policy and provision (WHO 2002).
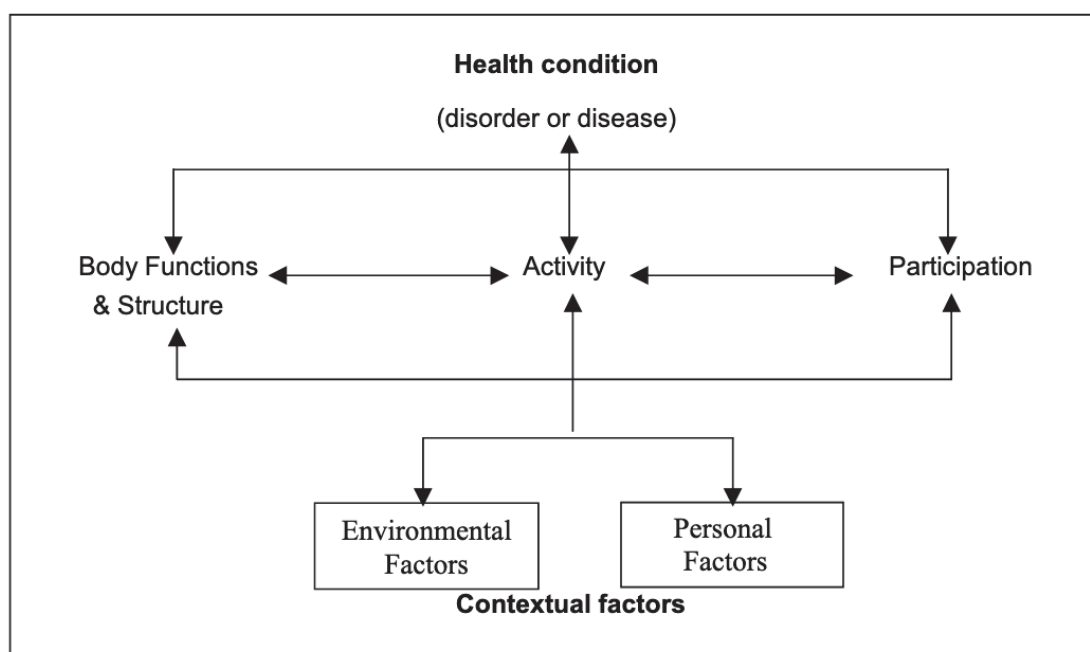
Figure 1 The International Classification of Functioning, Health and Disability Framework (WHO 2002)

The relevance of the ICF for this study is the work of Rosenbaum and Gorter (2012) who created a set of F words: function, family, fitness, fun, friends and future. These child and family

5

friendly terms each overlay the concepts of the ICF framework (Figure 2). The purpose of the F-words is to offer an alternative way of supporting children with neuro-disabilities such as cerebral palsy, their families, and practitioners. The F-words offer a strengths based approach that focuses on how participation in activity of choice can be achieved, regardless of whether it relates to home, school or the community, as opposed to focusing on attempting to remediate or reduce the effects of the disability (Rosenbaum and Gorter 2012). This framework was constructed to facilitate goal setting and intervention planning that focuses on the desires of the child across all domains of childhood occupations, emphasising that promotion of activity needs to be the focus of attention for intervention (Rosenbaum and Gorter 2012). This is because performance comes with practice and due to CP and the impact on motor skills, typical experiences associated with development may be deprived and therefore practice is limited. The F-words framework continues to evolve, with further exploration of each F-word concept, such as the role and diversity of environmental factors (the family) in family centred practice (Rosenbaum 2022).
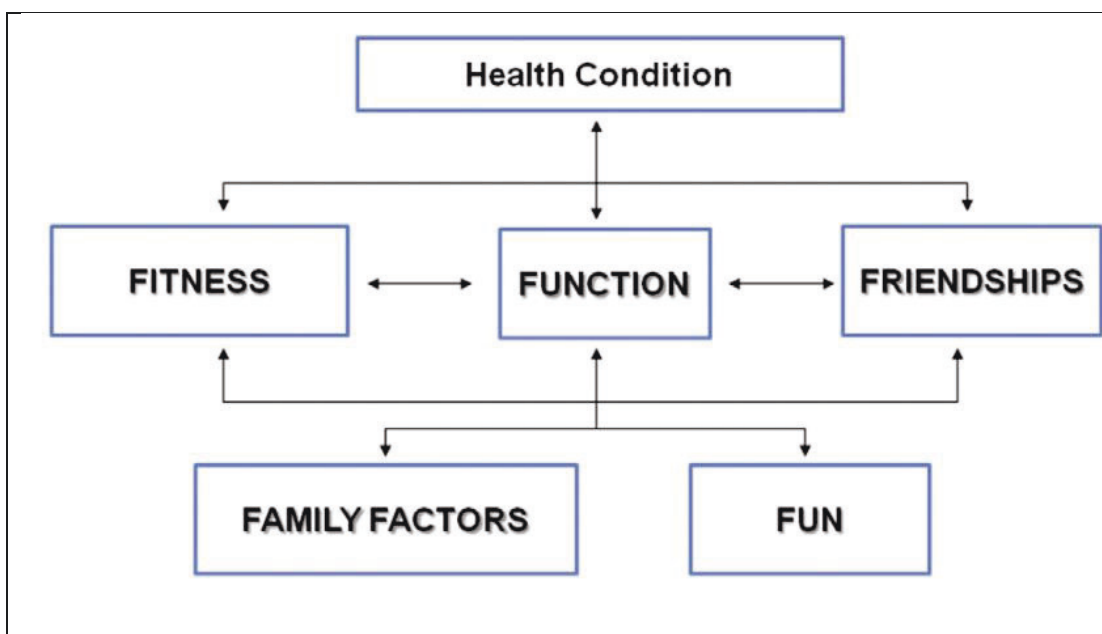
Figure 2 Adaptation of The International Classification of Functioning, Health and Disability Framework (Rosenbaum and Gorter 2012)

1.6.3   Family centred practice

Family centred practice may be defined as "based on the understanding that the family is the child's primary source of strength and support and that the child's family's perspective and information are important in clinical decision making" p.691 (Eichner, Johnson et al. 2003).

6

Family centred practice is considered effective for improving outcomes for the child and the family, increase satisfaction in service delivery and promote relationships between parents and practitioners (Eichner, Johnson et al. 2003).   Positive relationships between parents and practitioners promote collaborative goal setting and facilitate increased engagement in intervention (Forsingdal, St John et al. 2014) which can enable better outcomes for the child (Bartlett, McCoy et al. 2018). Furthermore, goals that are grounded in decisions made by the family and child are considered best practice (Novak, te Velde et al. 2021).

Family centred practice is considered gold standard practice in paediatric rehabilitation (Pritchard, Phelan et al. 2020) and is reported to enable increased engagement, satisfaction with services and enhance emotional availability of the family to deal with the variety of therapy and health services they are involved with for their child (Rosenbaum 2022). It considers the family as a unit that the child is part of, rather than focusing solely on the child (Poulsen, Ziviani et al. 2015, Davidson, Aslakson et al. 2017) and aims to remove the power imbalance of professionals as experts, elevating the family, including the child, to form a collaborative partnership in order to decide together meaningful goals and appropriate interventions (Dunst, Boyd et al. 2002). The effects of having a child with disabilities extends to all areas of personal and family life including financial, physical and mental health (Gilson, Johnson et al. 2018). Elevated parent stress, depression and suicidal thoughts especially during times of diagnosis and medical interventions, and a child's behavioural challenges can all impact on parental engagement with health services (Gilson, Davis et al. 2018, Pinquart 2018). Although family centred practice as a concept is well supported, the evidence to support its effectiveness is limited (Shields 2015) and challenges faced with implementing it include communication difficulties between the parent and practitioner, unclear roles and high workloads impacting on practitioner time available to spend with parents (Coyne 2015, Shields 2015). It is argued that for those working in school settings, practitioners have less contact with parents which may further impact family centeredness.

7

1.6.4 Legislation relevant to school age children and families

The Children and Families Act 2014, Part 3 sought to reform existing special educational needs and disability (SEND) policy for supporting children and young people in England. It emphasises the need for the child and their family to be at the centre of all collaborative decision making (DFE 2015) aligning with family centredness (Adams, Tindle et al. 2018). The Act asserts placing greater focus on improving outcomes for children and young people compared to its predecessor (the SEN Code of Practice 2001) and aims to bring together the education, health and care needs of the child through an Education, Health and Care plan (EHCP). The EHCP outlines the strengths and needs of the child, and is intended to facilitate collaboration between families, education, health, and social care to design meaningful goals (or outcomes) which may fall within the categories of communication and interaction; social, emotional and mental health; cognition and learning; and physical and sensory, to guide appropriate provision and support for the child (Pritchard-Wiart and Phelan 2018). Part 3 of The Act, the SEND code of practice (DFE 2015) stipulates that: *"Outcomes refer to the benefit or difference made to an individual as a result of an intervention at three levels" (Individual, service level and strategic). Individual outcomes – such as might be set out in an EHC plan: for example, Martha can communicate independently with her friends at playtime." 3.49 page 51*. The formulation of outcomes are of particular interest to this study because the collaboration intended between healthcare, education practitioners and families to write and agree outcomes remains a challenge (Cochrane and Soni 2020).

1.7 Research aim and objectives

The aim of this research study was to explore the dynamics and discourse that are manifest within school-based education, the healthcare team, and the families they support. To evaluate the impact of goal setting behaviours and priorities for children with cerebral palsy to develop a framework to assist practitioners with goal setting. This aim was set to be achieved through the following objectives:

- Explore processes involved for determining the focus of goals
- Examine the perceptions and attitudes of contributors to goal setting and how these compare or contrast with one another

- Explore what facilitates or acts as barriers to goal setting

1.8 Thesis structure

The remaining chapters of this thesis are organised as follows:

Chapter Two provides a concise review of goal setting practices for children with cerebral palsy. It discusses the barriers and facilitators to collaborative goal setting within a family centred practice approach and highlights the risk for occupational injustice and subsequent marginalisation.

Chapter Three presents the methodologies: Participatory action research and constructivist grounded theory, and the rationale for their use to create a blended approach.

Chapter Four presents the methods of data collection and analysis including ethical considerations and a phased approach to sampling.

Chapter Five presents the findings of the study from an action research perspective, utilising headings that developed into the categories for the grounded theory.

Chapter Six presents the grounded theory categories: Competing demands on time, Importing emotions, Missing what's important, and Using the right language, and provides a review of the literature relevant to each category.

Chapter Seven presents the discussion of the practical and theoretical components of the research and positions the grounded theory: Navigating the family centred practice narrative within the extant literature.

Chapter Eight concludes the research with the contribution to new knowledge that is the PACE goal setting framework. Recommendations for further research are presented and limitations of the study are discussed.

Chapter 2: Review of existing knowledge

2.1   Introduction

This chapter offers a critical review of literature concerning goal setting for children with cerebral palsy. The chapter begins by discussing the place of the literature review in relation to grounded theory, the search process and approach to appraisal. This is followed by situating goal setting alongside theory utilised within paediatric rehabilitation, paying particular emphasis to self-determination theory due to its suggested alignment with family centred practice (Podlog and Brown 2016). This is followed by focusing on family centred practice and the barriers and facilitators to collaborative goal setting between the practitioners, parents, and the child. Although the focus is on children with cerebral palsy, literature relating to paediatric rehabilitation in general and where relevant, adult rehabilitation is included. The review explores parent engagement and how the effects of raising a child with cerebral palsy affects engagement with practitioners when setting goals. The review also considers how different environments may affect goal setting practices on behalf of the practitioners. Occupational justice is introduced into the review as an avenue for discussion to highlight barriers and facilitators to engagement, which may impact on goal setting. The chapter concludes with identifying the gap within the existing literature that this research seeks to fulfil. Although not specifically referred to, the importance of the role of evidence-based practice is implicit within the literature review. The literature review was an ongoing process undertaken throughout the study to ensure any new literature may be included.

2.2   Positioning the literature

The timing of the literature review within a grounded theory study is historically contentious (Charmaz 2014). However, regardless of the location of the review, the aim is to remain open to the data and follow where the analytic process takes you and to avoid persuading data into pre-existing theories (Thornburg and Dunne, 2019), the epistemology of the researcher and existing knowledge of the field guides the stance adopted (Giles, King et al. 2013). Classic grounded theory (Glaser and Strauss 1967) argues that the literature review should take place after data analysis so not to influence the research or make it 'fit' into already established theory. This approach supports that researchers to go into the field with an open mind and not

be clouded by prior experience. However, Charmaz (2014) argues that putting aside prior experience or pre-conceptions is not achievable, and some preliminary knowledge of the field can be useful in determining if it is a worthwhile study and can enhance theoretical sensitivity. Furthermore, Charmaz (2014) explicitly acknowledges that the researcher is part of the research, bringing prior knowledge, experience, and beliefs (including hidden beliefs) resulting in a co-construction of knowledge between the researcher and research participants.

The position I have adopted aligns with Charmaz (2014). I believe that as an occupational therapist carrying out research in the field that I work, renders me unable to adopt an objective position whereby I will not be influenced by my prior experiences. I therefore did not believe that carrying out a review of the literature prior to engaging in the research would be detrimental to this study. The literature review adopts a narrative approach (Ferrari 2015) which focuses on the context of the studies rather than focusing on methodological rigour. This was considered an appropriate approach to take due to the research aims for this study. Appendix 1 outlines the search strategy and criteria for inclusion.

2.3   Theory relevant to goal setting in paediatric rehabilitation

The use of theory to guide decision making underpins the evidence base for goal setting which informs interventions (Craig, Dieppe et al. 2008). Understanding theories of human behaviour help guide the methods used for goal setting (Wade 2009) and theories relevant to paediatric goal setting have been explored by Brewer, Pollock et al. (2014), Pritchard-Wiart and Phelan (2018) and Pritchard-Wiart, Thompson-Hodgetts et al. (2019). One of the recurring theories is Self-determination theory (Ryan and Deci 2000) which proposes that the effects of the social environment can promote autonomy or impose control which either positively influences or negatively impacts intrinsic motivation, and affects engagement in actions (Deci and Ryan 2012), and in this case, the actions refer to goals. This theory is based on the premise that children have inherent intrinsic motivation to explore and learn about their environment (Ryan and Deci 2000). It has been applied to paediatric goal setting to help contextualise the impact and interplay between the self and the social environment for children who have additional

needs such as cerebral palsy (Poulsen, Ziviani et al. 2015, Pritchard-Wiart and Phelan 2018, Pritchard-Wiart, Thompson-Hodgetts et al. 2019).

Although practical application of the theory is limited (Pritchard-Wiart and Phelan 2018) it is argued that the underpinning components of self-determination theory reflect the ambition that practitioners aim to elicit when goal setting with families and their children as discussed by Rosenbaum (2021). Parents and family members are the primary agents of change for their children and strengthening both the child and parent voice in goal setting, makes for a more successful and meaningful endeavour for personal and professional relationships (Rosenbaum 2022) . The commitment of parents is necessary for any intervention to succeed (Phoenix, Jack et al. 2019) and as such, it is argued that the concepts of self-determination theory and the trajectory of how external motivation (provided by education and healthcare practitioners) is presented to and interpreted by parents can also potentially affect engagement. Providing the child with explicit opportunities to develop their own interests that inspire motivation aligns with the key constructs of self-determination theory: competence (feeling capable and confident to achieve goals) autonomy (choosing meaningful goals) and relatedness (feeling supported by others to achieve goals) that assume to underpin psychological health and wellbeing (Ryan and Deci 2000). These principles also align with family centred practice and serve to facilitate occupational justice. The relevance of occupational justice to goal setting is that occupational justice refers to the freedom to participate in occupations of choosing (Bailliard, Dallman et al. 2020). Taking a family centred approach aligns with promoting occupational justice as it aims to mitigate against the risk of practitioners imposing their priorities for goals, and instead emphasises the choices of the family (Bailliard, Dallman et al. 2020).

2.4   Family centred practice
2.4.1   Focus of goals

The importance of family centred practice for engagement in goal setting and overall wellbeing is widely accepted. This has been demonstrated through the work and adaptation of the ICF by Rosenbaum and Gorter (2012) who consider the family as essential to the contextual factors and serve as the 'environment' to the child. Despite the continued argument to enhance parent

13

involvement in rehabilitation (Rosenbaum 2022) collaboration between practitioners and parents to co-create goals has remained a challenge. Part of the challenge for goal focus may also be due to the diversity of physical, cognitive and emotional difficulties including depression and anxiety that a child cerebral palsy may present with (Dababneh 2013). Jacob, De Francesco et al. (2017) explored goal setting records within a mental health facility for children with learning difficulties. Findings from the study highlighted that goals were not sufficient to measure progress and were poorly recorded. Rosenbaum (2021) argues for an approach to supporting families, which although does not explicitly discuss emotional health, it implicitly addresses the potential for emotional challenges by removing the assumptions that engagement in functional activities need to be carried out in a 'normal' way. However, in a recent editorial, Rosenbaum (2022) refers specifically to emotional health requiring more attention.

By placing the emphasis on the activity and not how the activity is carried out 'normally', serves to shift attention away from the child's condition and focus on how, as an individual they can perform occupations in a way that works for them (Rosenbaum 2021). Hanes, Hlyva et al. (2019) sought to investigate the social and emotional impact on young people with cerebral palsy in order for practitioners to provide support systems that meet the needs for young adults. The study, conducted with 16 young people aged between 17-29yrs found that feeling socially connected to peers was of high importance, as was being able to participate in meaningful activities. Although this study consisted of a small sample size and interpretation needs to be met with caution, it provides insight into the experiences of young adults with cerebral palsy. This insight may assist with practitioners working with younger children and their families, and corresponds with Rosenbaum (2021) assertion that taking a strengths based approach and focusing on participation rather than remediation of challenges matches with the desires of the young person. This highlights the importance of focusing goals which inform subsequent interventions towards participation in meaningful activities for the child, but also what is considered important to the family. For parents of children whose abilities prevent them from accessing typical activities, support may be required to assist the parent with thinking about achievement and what participation for their child looks like (Rosenbaum 2021). This assumes

14

the needs for effective collaboration between the parents, child and practitioners, as a priority area for research and practice development (Rosenbaum 2022).

2.4.2 Challenges to family centred goal setting

Collaboration has been argued as being the most important principle to family centred practice (Darrah, Wiart et al. 2012), yet challenges persist. Kennedy, Missiuna et al. (2020) sought to explore the relationships between practitioners and families in 'Partnering for Change', a service model to facilitate collaboration between occupational therapists, educators and families which arose from challenges with building relationships between practitioners and parents. Their study carried out focus groups with occupational therapists and although revealed that challenges concerning the availability of practitioners and parents impacted on the collaborative relationship and the sense that some parents were not 'ready' to engage, this was not elaborated. Coyne (2015) investigated collaborative working between healthcare professionals and parents of children within a hospital environment in Ireland. Issues raised by healthcare workers included the lack of time available to spend with parents, resulting in the parents feeling overlooked and unsupported, and a lack of clarity in the role that they played in supporting their child's care.

Bexelius, Carlberg et al. (2018) explored the quality of collaborative goals set in paediatric rehabilitation centres in Sweden and reported the most problematic aspect was the time required to transfer parent aspirations into functional goals. A systematic review by Grant, Jones et al. (2022) on teletherapy delivery by health practitioners in Australia, cited time management as a barrier to providing effective and collaborative therapeutic support. Kolehmainen, Maclennan et al. (2012) explored collaborative working between healthcare practitioners and parents in Scotland. They found that challenges were associated with the time taken to facilitate cultural shifts long embedded in the organisation. Although the contexts of these studies differ to that of this research, for example, the environments (hospital, rehabilitation centres, remote services) and purpose of the services (acute or long-term rehabilitation) the demands on time appear dynamic, multifaceted, and consistent across western cultures concerning collaboration between practitioners and families. The impact of the

lack of time expressed by practitioners affects engagement, and if overwhelmed by the amount of demands placed on them, the capacity of practitioners to engage effectively with families as described by Coughlin (2021) may reduce.

The conflict between time available and family centred practice has also been reported in other studies for those working in schools as compared to home or clinic settings. Fingerhut, Piro et al. (2013) conducted interviews with occupational therapists across different settings and found that carry over from school to home and the importance of measuring progress in different environments was recognised as a challenge. Their study found that school-based therapists collaborated less with parents than other settings, citing the main reason as reduced opportunity for liaison, difficulties with contacting parents and because of this, were considered the least family centred compared with clinic or community-based therapists.

2.4.3   Collaboration and goal setting

Challenges with collaborative goal setting have been found in both paediatric and adult services. Darrah, Wiart et al. (2012) explored collaborative practice and goal setting with practitioners and parents of children with cerebral palsy. There were differences expressed by parents taking part in the study relating to how much support they needed from the practitioners, whereas some parents expressed a desire for more support, others expressed a desire for less however the reasons why were not explored. Plant, Tyson et al. (2016) explored collaborative goal setting in stroke rehabilitation and noted the challenges with patients and practitioners related to the goals of staff taking priority, and different expectations of what could be achieved. Angeli, Harpster et al. (2019) studied occupational therapists' and physiotherapists' collaborative goal setting with parents of children enrolled in an outpatient service. Data were collected from therapy files (completed by the therapists) and through parent interviews. Their study found that parents had different perceptions of the goals for therapy compared with the practitioners, which suggests that collaboration and communication between the practitioners and parents was problematic. Although this study reports that goals set by the therapists were still achieved by the child, the lack of parent voice in the goals, raises questions about what

factors created the discord and further demonstrates the practitioner priority for goals takes precedence.

The challenges reported in these studies correspond with Smith and Kendal (2018) who explored parents of children with long term conditions and healthcare practitioner experience of collaborative working to support the child's care. Their study found that expectations between the parents and practitioners were different which impacted on collaboration. Parent needs for support from practitioners changed over time, delivery of information about their child's progress was reported as a source of frustration, and knowledge of their child were not always perceived as valued by the practitioners. In order to support practitioners with collaborative working, Smith and Kendal (2018) extended the parent-practitioner continuum originally constructed by O'Grady and Jadad (2010), see Figure 3. The continuum proposed by Smith and Kendal (2018) position the parent and practitioner roles as fluid and are guided by the practitioner adjusting their approach according to the needs of the parent. Although it refers to collaboration generally and not specific to goal setting and healthcare participants were hospital-based nurses; it is argued that goal setting is a key principle of collaboration within family centred practice and assumes that these experiences may offer some insight into potential challenges of school-based collaboration between practitioners and parents similar to those mentioned.

Phase of the relationship	HPs position	Parent position	Behaviour	Purpose
Parent/ carer overwhelmed	Directive, supportive	Wants information but may not be processed Uncertainty Grieving	Parent provides narrative of their child's condition Health professional provides information, advice and support	Immediate management of long-term condition Establish processes for long-term engagement with services
Learning how to collaborate	Receptive, present, supportive	Learning how to manage their child's long-term condition	Parent asserting self as expertise and confidence building Health professional advising, supporting, negotiating	Sharing in care decision, moving towards equality of power
Collaborative	Available, supportive	Managing their child's long-term condition with access to advice and support	Parent supported to choose how they want to work with health professionals	Collaborative practice

Figure 3 Fluid relationship between parent and health professional (Smith and Kendal 2018)

The challenges with collaboration appear to be in part, related to how practitioners engage with parents. The increasing utilisation of technology as communication is becoming a more prevalent method between school and families (Kennedy, Missiuna et al. 2020) and considered a positive means for engaging parents. Snell, Hindman et al. (2018) carried out focus groups and surveys of educators and family member's perceptions of a variety of approaches using technology including text message, social media and email, with almost half of family respondents indicating that email communications were desirable. Olmstead (2013) studied how to increase parent engagement in schools and also reported that family members reacted positively to email. Although these studies concentrated on mainstream education focusing on more general information circulation, and not exploration of child specific goals as is the focus of this research, it does highlight the ever-increasing variety of technology available for communication between schools and families.

There is a risk that replacing face to face discussion with email or other technology based correspondence may reduce engagement from parents, as parents engage most when they feel that practitioners make time available for them (Oien, Fallang et al. 2010). Furthermore, suggestions made by the participants in the study by Kennedy, Missiuna et al. (2020) were that increasing face to face communication would facilitate better collaboration. The communication approaches utilised by practitioners and how they are interpreted by the family members supports or hinders the development of trusting relationships (Gershwin 2020). It is argued that a reduced amount of time spent between practitioners and families and the communication methods used, can potentially affect the opportunities for relationships to develop and for trust to grow. Although clinical guidelines for practitioners working in intensive care units articulate that effective methods for engaging families include active listening, demonstrating empathy, and using a strengths based approach (Davidson, Aslakson et al. 2017), it is reasonable to assume that these recommendations are appropriate for all settings. However, if the relationship between practitioners and parents is compromised due to misinterpretation of any of the above communications, this poses a risk to effective and collaborative goal setting (Darrah, Wiart et al. 2012, Plant, Tyson et al. 2016, Smith and Kendal 2018)

Carnevale, Farrell et al. (2016) explored communication between parents and health care professionals in the Paediatric Intensive Care Unit (PICU) and compared parent perspectives of feeling included in decision making about their child with how health professionals interpreted how parents felt based on their actions. They found that parents and professionals have different perspectives and concerns of who to include, and how to be included in the decision-making process and this was reflected in the communication used. Although this study was focused on a PICU and communication regarding medical care, the importance of language and communication between practitioners and parents is considered highly relevant as the current study demonstrates, it can both positively and negatively affect engagement towards parent contributions and goal setting. How the parents and practitioners interpret one another's communication and if there is a misinterpretation of communication on behalf of the practitioner or parent, risks the goals being informed by the values or prior experience of the practitioners which may not align with, or miss what is important to the parents (Suc, Svajger et al. 2020). This may inadvertently add stress to parents and cause them to withdraw from engagement.

2.4.4 Parent mental health and engagement in goal setting

Parent wellbeing is associated with child outcomes (Rosenbaum 2021) yet parents of children with additional needs are at increased risk of mental health difficulties, however it is not considered routine practice by paediatric health workers to address this (Gilson, Johnson et al. 2018). Stress experienced by parents may be exacerbated and result in a disconnect (Currie and Szabo 2019) when meetings such as Education Health Care Plan annual reviews that often involve many practitioners from health and social care, are the environment for discussing a child's goals. Emotions can facilitate or hinder the development of trusting relationships (Gershwin 2020) and it is the relationship between the parent and practitioners involved in supporting their child that can influence engagement in services. Gilson, Johnson et al. (2018) explored health practitioner perceptions of supporting the mental health of mothers of children with additional needs and whether they believed it was part of their role to do so. Although the practitioners in the study acknowledged the importance of good parent mental health to support child outcomes and the frequency of parent mental health difficulties routinely experienced, the

practitioners were reactive and when they observed parents not coping, they referred them onwards for support. Although the study identified a lack of training in parental mental health and practitioners feeling conflicted between focusing on the parent rather than the child was a barrier to addressing mental health, it is argued that due to the difficulties observed being commonplace a more proactive awareness that informs routine practice may help support parent emotions.

O'Connor, Kerr et al. (2016) conducted a systematic review of the parent experience relating to assessment practices and identified that parent emotions were influenced by how practitioners discussed the abilities or disabilities of their child. Although their review focused on assessment rather than goal setting, it is argued that experiences of meetings, the number of practitioner's present and how their child's difficulties are presented can affect emotional wellbeing and either facilitate or hinder engagement of the parent. The findings in these studies with regards to the emotions experienced by the parents in different situations align with the theory of chronic sorrow. Chronic sorrow was first identified in nursing and offers a framework for understanding parent experiences of loss and responses to sadness or grief that is pervasive, periodic and reoccurring (Eakes, Burke et al. 1998). Chronic sorrow may occur when there is a discrepancy between expectations and reality, such as raising a child with a disability, which results in an altered life course to the initial hopes and desires of the family (Eakes, Burke et al. 1998). Chronic sorrow has been applied to a variety of childhood conditions and systematically reviewed by Coughlin and Sethares (2017) who sought to explore how parents of children with an illness or disability experienced grief. Findings from the review demonstrated a consistency in the parents moving through cycles of grief which were triggered by certain events. A single study by Whittingham, Wee et al. (2013) focused on parents of children with cerebral palsy, highlighting that their experiences of cyclical feelings of loss and grief were triggered by missed milestones, possibly because this acted as a reminder of achievements missed but there was little exploration into other events, such as goal setting that may trigger similar emotions.

20

Gilson, Davis et al. (2018) explored the mental health of mothers of children with additional needs relating to the support they would find beneficial. They sought to identify if there were situations that triggered increased emotional challenges and the subsequent need for professional support. Individual, in person therapeutic support was rated as preferred, although group and remote services were also considered potentially useful by parents. Emotional challenges were elevated specifically in times of developmental changes in their child and during medical interventions. The exact nature of developmental changes and medical interventions were not specified limiting interpretation, however the mental health challenges observed by practitioners and the subsequent acknowledgement by parents observed in these studies aligns with chronic sorrow theory and poses the question whether the event of goal setting also elicits similar emotional responses in parents. Furthermore, the increased use of technology to communicate, although reported as beneficial (Olmstead 2013, Snell, Hindman et al. 2018) may pose a risk and interrupt relationships that facilitate collaborative goal setting between practitioners and parents.

2.4.5 Differences in goals set between parents and children

This review so far has focused on collaboration predominantly between parents and practitioners. Family centred practice assumes that where possible, the child's voice should be heard when setting goals. According to Poulsen, Ziviani et al. (2015) children as young as five are often able to articulate what is important for them to be able to achieve, with a variety of image based methods available to practitioners to support goal setting with children such as Talking Mats (Mackay and Murphy 2012) and the Perceived Efficacy Goal Setting System (Missiuna, Pollock et al. 2006). Vroland-Nordstrand, Eliasson et al. (2016) compared the goals of children aged between 5yrs and 12yrs with the goals for them set by their parents. They found that the children had more variety of goals that focused on improvements for activities of daily living and leisure pursuits such as being able to play basketball. This served to develop peer relationships in addition to physical abilities as opposed to the parent goals that primarily focused on functional activities of daily living. The goals of the child focusing on peer relationships equates with the study by Hanes, Hlyva et al. (2019) discussed previously which

supports the child's voice to be integrated when co-creating goals. However, Vroland-Nordstrand, Eliasson et al. (2016) found there were no notable differences in goal achievement regardless of whether the goals were identified by the child or their parents. Aside from attending a neurorehabilitation clinic, there was insufficient detail to determine which profession specific disciplines were involved or the experience of the professionals in working with this population. Furthermore, the study did not discuss how much support was received or the mechanisms in place to identify goals which may or may not have influenced the outcomes.

Pritchard, Phelan et al. (2020) explored child, parent, and practitioner experiences of a child-driven approach to goal setting whereby the goals start with the activities that are meaningful to the child. The child participants ranged between 5yrs and 15yrs old and demonstrated capability to construct goals that were meaningful and potentially different to those of the parents or practitioners. Furthermore, the child-driven approach encouraged the children in the study to be more engaged with the goal setting as they highly rated the importance of feeling listened to, which increased their motivation to participate in interventions. The studies discussed were carried out with children at rehabilitation settings with a predetermined block of intervention and therefore differ from the school setting for this study. Even though achievement of goals was not necessarily influenced by whether it was set by the parent or the child, it highlights that there are differences in what is important for the child compared to their parents, and without the child's voice, parents and therapists are at risk of making assumptions that the goals are meaningful to the child (Pritchard, Phelan et al. 2020).

As previously discussed, self-determination theory is relatively under explored within paediatric rehabilitation (Pritchard-Wiart, Thompson-Hodgetts et al. 2019). It refers to individual occupations in terms of engagement through intrinsic and extrinsic motivation. This may be extended to co-occupations between the child and the parents which may account in part for why achievement of goals may not be dependent on whether the child or parents identifies them as found in the study by Vroland-Nordstrand, Eliasson et al. (2016). Co-occupations are described as mutually beneficial physically and emotionally motivating occupations engaged by two or more people (Pickens and Pizur-Barnekow 2011) for example, the parent and the

child or peer to peer. It is argued that goals which facilitate co-occupations, have shared intrinsic values based on personal interests, and are extrinsically supported by the environment and the people within it, provides the opportunities that facilitate those interests, affects motivation, engagement, and achievement. This highlights the importance of extrinsic environmental motivators, which may include the parents and the practitioners in addition to the physical environment, which aligns with the importance of the family environment. This raises the issue of the role that practitioners play when instigating collaborative goal setting and can be likened with facilitating or inhibiting occupational justice (Rosenbaum and Gorter 2012).

2.5   Goal setting in schools

The majority of this review has concentrated on goal setting and collaboration between parents and practitioners from rehabilitation services due to the limited research carried out specifically pertaining to school-based practitioners. Education, Health and Care Plans (EHCP) are provided for children who require extra support or therapeutic provision. The desire for EHCP's to be a more collaborative enterprise between practitioners and the family has received mixed responses, with the child's aspirations remaining as tokenistic (Cochrane and Soni 2020). An investigation by Adams, Tindle et al. (2018) of factors affecting engagement in the EHCP process where identifying goals, termed outcomes, is fundamental to determining the level of provision required, explored collaboration between parents and providers of health and education. Parents who took part in this study reported that success and ease of the EHCP process was dependent on the collaboration of the practitioners between each other and between the parents and the practitioners; when parents perceived communication as poor, resulting in not knowing what was happening, their stress was increased. Evidence to support the number of goals that is realistic for a child with cerebral palsy or other conditions which affect childhood development is scarce. A smaller number of goals is considered effective for targeting intervention (Law and Jacob 2013) and an exploration of the quality of goals by Bexelius, Carlberg et al. (2018) reported the average number of goals was four for each child. This review now turns to the effects of goal setting on occupational justice and potential for injustices if the child and the parents are not included or if collaboration is a challenge.

2.6   Occupational justice

Goal setting and collaborative practice also has relevance to the field of occupational science which views humans as occupational beings, places importance on what people do, and as such attempts to bridge the gap between occupation and health (Wilcock 2005). Occupations, as defined by Wilcock (2005, p8) are:

> *"Health giving when they provide choice, meaning, purpose, balance, challenge, freedom, creativity, growth, opportunity, the capacity to change or cope with the environment, satisfaction of mental, physical and social needs, as well as stimulating and enjoyable work and leisure. For pro-active health promotion and occupational fitness, occupations need to enable people to strive towards achieving personal aspirations and potential."*

The relevance of occupational science to this study is the change or difference in the typical trajectory of expected development that may be associated with a condition such as cerebral palsy, and how this can affect participation in everyday occupations resulting in opportunities presented or availability of them being different, and potentially reduced (Prellwitz and Skär 2016).

Values, beliefs and interests influence the importance placed on occupations (Durocher 2016) and subsequent opportunities made available to engage in them, may in part be directed by the goals identified, and who they are identified by, as it is the goals that determine the focus of interventions (Bexelius, Carlberg et al. 2018). It is suggested that the availability of opportunities to engage in everyday occupations may be situated within the occupational science domain of occupational justice which supports the intended outcome of social inclusion (Whiteford, Jones et al. 2018). According to Nilsson and Townsend (2010), framing everyday occupations through a lens of occupational justice serves to firstly understand, and then find ways to address and empower individuals and communities that are at risk of occupational alienation, deprivation, imbalance or marginalisation. Alienation refers to feelings of disconnectedness or isolation from society, and those with disabilities may experience alienation when engaging in activities that have little meaning to them. Deprivation refers to the

limitations of occupations available due to abilities or social location, marginalisation refers to the reduced opportunities for making choices about participation in meaningful occupations, and imbalance refers to having too many occupations or too little, that can impact on health (Townsend and Wilcock 2004). It is important to emphasise that these terms are not idiosyncratic to occupational science, it is instead the emphasis on everyday occupations and how the impact of not being able to participate in them that may lead to the injustices described above (Christiansen and Townsend 2013).

The occupational justice framework has been applied to different communities that have or do experience occupational injustices resulting in social exclusion which impacts on the ability or opportunity to perform everyday occupations. This includes the experiences of refugees experiencing occupational alienation due to the impact on resettling in an environment where transport, knowledge of welfare systems and laws are different and not well understood, patients of a forensic mental health unit experiencing occupational marginalisation due to the systems and structures of the facility, and Muslim women experiencing occupational deprivation due to discrimination within the community in which they live (Whiteford, Jones et al. 2018). A scoping review exploring the utilisation of occupational justice in practice was carried out by Malfitano, De Souza et al. (2019) and despite the diversity of populations that occupational justice has been considered with, including those with disabilities, mental health and at risk youths, the exploration of how goal setting practices for children with cerebral palsy are informed through an occupational justice perspective is yet to be fully explored.

However, studies have been carried out concerning barriers to occupational participation in children with cerebral palsy which can be related to experiences of occupational injustice. Pashmdarfard, Richards et al. (2021) conducted a systematic review of factors that influence participation in activities of daily living and leisure in children with cerebral palsy. Several themes were identified from the review and included facilitators and barriers relating to the ability of the child and the interplay between the physical environment and social support. Predictors of reduced participation in leisure and everyday occupations related to the child's motor abilities, communication, cognition, psychological wellbeing, pain, and visual

25

impairments with mobility issues found to be the most prolific determining factor. External determinants affecting participation related to the environment, transport, social support, parent stress and social economic status. The review found that participation in leisure and everyday occupations increased if the child's motor abilities were less affected. It is suggested that due to the child's increased physical ability, fewer adaptations to the environment were required which made access more readily available. Conversely, if the child's motor skills were more challenged then participation was reduced which could be due to the environment acting as a barrier.

The systematic review demonstrates how the environment can deprive a child with cerebral palsy from participating in occupations of daily living or leisure activities that would typically be available if they did not have mobility issues. Furthermore, the importance of social connection and peer relationships for young people with cerebral palsy has already been highlighted in the study by Hanes, Hlyva et al. (2019). Taking this into consideration with the findings from the systematic review by Pashmdarfard, Richards et al. (2021) and viewed through the lens of occupational justice, it could be argued that the factors affecting participation e.g. accessing the physical environment, risk occupational deprivation. This has repercussions with developing important peer relationships and social connectedness identified by Hanes, Hlyva et al. (2019) as the opportunities for interactions are reduced, which may lead to occupational alienation and marginalisation. These injustices may contribute to the prevalence of behaviour problems associated with peer relationships in children with cerebral palsy identified by Brossard-Racine, Hall et al. (2012) because the opportunities for social interactions with peers through shared meaningful occupations have been denied.

Parent stress has also been identified as a determinant to limiting occupational participation in parents as well as the child. Pashmdarfard, Richards et al. (2021) found that the increased need for support was reported to elevate parent stress and subsequently reduced occupational participation for the child. Furthermore Günal, Pekçetin et al. (2022) explored occupational balance in mothers of children with cerebral palsy. They found that due to the increased caregiving demands, the opportunity for engaging in leisure occupations was reduced which

resulted in an occupational imbalance that affected opportunities for social interactions and in turn, affected emotional health and wellbeing. This demonstrates that occupational injustices can also be experienced by parents of children with cerebral palsy. Brossard-Racine, Hall et al. (2012) also found that improved motor abilities directly related to pro-social behaviours such as caring for others and being helpful. This suggests that if the environment facilitates accessibility, the risk of occupational injustice is reduced which affords more opportunities for social development of the child resulting in fewer behavioural challenges. This in turn may help reduce parent stress, as behaviour problems in children have been related to increased stress experienced by parents (Brossard-Racine, Hall et al. 2012). As a result, this promotes occupational justice through increased opportunities for occupational participation for both the child and the parent.

It is argued that utilising the occupational justice framework supports the identification of actions taken by practitioners and how they prioritise goals and include parents and the child, may facilitate occupational justice or risk occupational injustices. Understanding the challenges faced can help support practitioners with minimising risks to occupational injustices and understand the potential barriers and consequences that impact on the lives of children with cerebral palsy and their families. Therefore, the value of considering goal setting through an occupational justice framework assists with understanding the complexities of goal setting and the resulting discourse that may influence positively and enhance social inclusion, or negatively and reinforce injustices.

2.7   Conclusion

This review has highlighted that family centred practice in paediatric rehabilitation is fluid and collaboration between the practitioners, parents and the child vary. Whilst an increasing body of research has focused on goal setting within paediatric rehabilitation generally and specifically with children with cerebral palsy, these studies have primarily concentrated on clinic and community-based therapy with limited studies concerned with school-based practitioners and collaborative goal setting. For school-based practitioners, opportunities for contact with families

is significantly reduced compared to the home or clinic based and how this is addressed by practitioners is not well documented.

This review has identified the need for exploring the facilitators and barriers to goal setting for school-based practitioners, families and children, and highlighted a need to create a resource to support family centred practice in order to enhance collaborative practice. Introducing the concepts of occupational justice has highlighted that children with cerebral palsy (and their parents) may be denied opportunities to participate in meaningful occupations for a variety of reasons and as a result, puts them at risk of experiencing occupational marginalisation, deprivation, alienation and imbalance.

This literature review has highlighted that parents and practitioners face a variety of barriers which may influence how they facilitate and engage in goal setting. Moreover, a family centred practice approach does not automatically assume that the parent and child voice is present during goal setting, which inadvertently raises the potential for occupational injustices to occur. This highlights the need for further exploration concerning goal setting to support improved practice which this research seeks to fulfil. The overall aim of this study is to explore the dynamics and discourse that are manifest in the school-based team and families, and develop a framework for practitioners to assist with goal setting and evaluation.

Chapter 3: Methodology

3.1   Introduction

The purpose of this research was twofold: 1) to understand goal setting practices from an education and healthcare practitioners, family and pupil perspective, and 2) to create a goal setting framework to support practice. This chapter justifies the decisions made for integrating two research methodologies: constructivist grounded theory and participatory action research. Grounded theory offered a dynamic approach for exploring, describing, analysing and making sense of the variety of perspectives held by education and healthcare practitioners and families

they support. Utilising explicit methodological processes predicated by inductive and abductive logic (Charmaz 2014) enabled exploration of this discourse (Breckenridge and Jones 2009). Participatory action research transitioned participants from passive informants to active co-researchers to become the agents for change (Greenwood and Levin 2007). Features of constructivist grounded theory and participatory action research that hold specific relevance to this study, and how my own, and participant positionality influenced decisions made is discussed to justify why both methodologies were required.

3.2   Reflexivity, epistemology and positionality
3.2.1   Reflexivity

Qualitative research is interpretive and outlining my philosophical position, demonstrating how I would acknowledge and account for this throughout the research was necessary to show transparency of how decisions were made and assist with ensuring a trustworthy study (Davis 2020). This called for reflexivity and asking scrutinising questions of myself throughout the research process (Palaganas, Sanchez et al. 2017, Davis 2020) such as *how has my personal and professional journey influenced the choice of research topic? How will the participants respond to me? How will I respond to the participants?* The purpose of asking such questions and being reflexive serves to contextualise how the new knowledge gained from the research is constructed, and how my presence and the experiences that I bring into the field including societal and biographical influences will shape the research (Palaganas, Sanchez et al. 2017). One way of articulating reflexivity is through keeping a journal, and I established this early in the research. Figure 4 provides an excerpt of an initial journal entry detailing my initial thoughts and appendix 14 provides a further excerpt detailing my thoughts as the research gained traction.
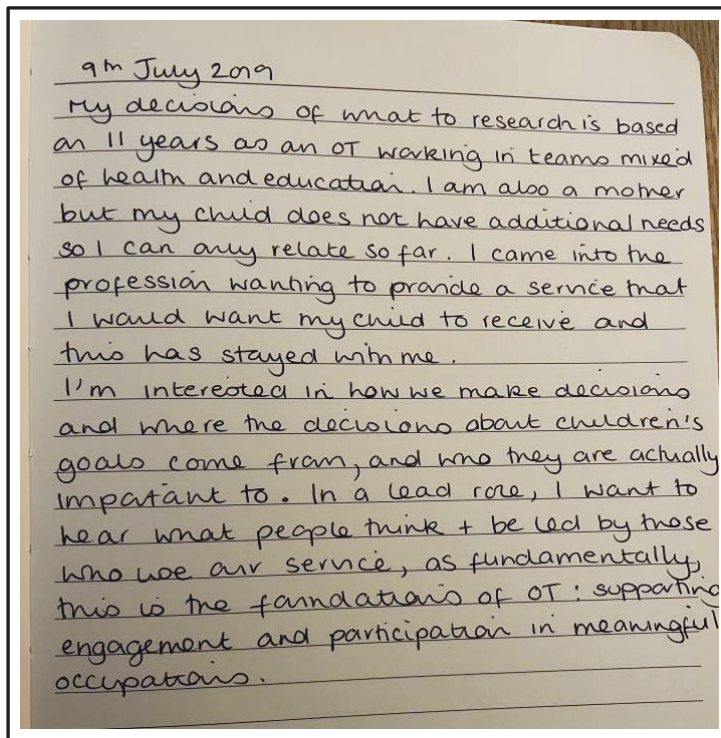
Figure 4 Reflexive journal excerpt

The early entry as shown in Figure 4 brings together my personal experiences as a mother and professional experience as an occupational therapist. It emphasises the motivation for carrying out research in this particular area, and shaped the decisions I made when considering which research methodologies would suit the questions I wanted to know relating to goal setting (Davis 2020). These decisions made are based on my own world views and beliefs about knowledge generation which is now discussed.

3.2.2 Epistemology

The professional identity of occupational therapists is regarded as complex, both historically and present day (Hooper 2006) due to the expression of different ways of knowing, or epistemology, that informs the diversity of the profession. Hooper (2006) argues that occupational therapy has strong roots in pragmatism, and how our assumptions based on these ways of knowing, inform our clinical reasoning and the choices we make. A pragmatist epistemology views knowledge generation as flexible due to it being a result of individual experience rather than a fixed set of ideas that are open to change when there are improved ways of understanding made available (Charmaz 2016). Furthermore, a pragmatist viewpoint is iterative and develops through action (Charmaz 2016). Personally, and professionally, I align

with these ways of knowledge generation and consider myself a pragmatist. As an occupational therapist, and as an individual, I hold my own knowledge lightly which for me, means that I am receptive to new knowledge as it develops through my own and other's shared experiences. I also align with a constructivist epistemology due to the client-centred approach that is fundamental to occupational therapy (Walder and Molineux 2020). The collaborative and power-sharing therapist-client relationship aligned with client-centredness supports the suggestion that a co-construction of knowledge occurs to elicit meaning and guide therapy and is a further example of reflexivity. Furthermore, as an occupational therapist working in the field for many years that I am to conduct research within, I acknowledge that the questions I ask and how I interpret what is being said, will be influenced by my own experiences in the field, hence the research findings will be a co-construction between myself and the participants (Charmaz 2014).

3.2.3   Positionality

Herr and Anderson (2005) p29, outline a six-stage continuum of researcher positions that occur between insider and outsider shown in Table 1. This model, although intended for positioning the researcher, also enabled me to consider the positionality of potential participants in the same way.

1	2	3	4	5	6
Insider	Insider	Insider(s)	Reciprocal collaboration	Outsider(s)	Outsider(s)
Researcher studies own self or practice	In collaboration with other insiders	In collaboration with outsider(s)	Insider-outsider teams	In collaboration with insider(s)	Studies insider(s)

Table 1 The insider-outsider continuum adapted from Herr and Anderson (2005)

According to this continuum there is no predominant position I believe that me or the participants occupy. The participants range from staff, parents of pupils and pupils, who all are approaching the research from differing perspectives due to their professional or personal relationship with goal setting. Depending on the group that I am collaborating with will shift my position from 2) insider collaborator with insiders (occupational therapist collaborating with education and health practitioners all working within the same organisation) to 5) outsider (due

31

to my roles of occupational therapy lead and researcher) in collaboration with insiders (education and allied health staff), to 3) insider (employee, therapist, position of management in the school attended by the pupil) collaborating with outsiders (parents of pupils) although this could also be argued as 2) or 5) based on the perceptions of the parents.

Additionally, based on how the pupils view the authority of the staff (including myself) may range from 2), 5) or possibly 6). Addressing reflexivity by assigning labels of insider or outsider and comparing differences and similarities between researcher and participants may be regarded as a superficial approach as it does not demonstrate sufficient critique of researcher identity (Kohl and McCutcheon 2015). However, this exercise demonstrates a 'messiness' of attempting to position the researcher and the research participants, highlighting that all those involved with the research occupy fluid positions which in this case, are related to personal and professional perspectives, and if ignored could impact on the integrity of the research. However, the existing knowledge and experience of the field may assist with supporting a better understanding of nuances in the discourse that may otherwise go unnoticed (Timonen, Foley et al. 2018).

3.3   Facilitating engagement and trust

I needed to acknowledge the possible tensions that could arise throughout the research regarding other commitments co-researchers may have, as this research would be an additional role or demand on time. Willingness to participate may vary, and I needed to facilitate initial and ongoing participation and engagement for this study to achieve its aims (Dworski-Riggs and Langhout 2010). I needed to be mindful that should staff, parents and pupils view me as an outsider and in an authoritative position, how much this could affect engagement. Although the primary aim was to develop a goal setting framework to support practice for the organisation, potential participants may perceive this as a self-serving project for completing academic study and be reluctant to engage if they did not consider the project as worthwhile or beneficial to them (Skeggs 2002).

In an effort to reduce how my positions as researcher, therapist and therapy lead may influence the research and encourage engagement (Coghlan 2019), utilising a methodology that seeks to elevate participants to becoming co-researchers was considered an appropriate direction to take. From here-on in, the prospective participants are referred to as co-researchers. Building trust between the researcher and co-researchers was anticipated as a key challenge, and although I am an insider, I am also an outsider which cannot be overlooked. I still needed to gain the trust of the co-researchers regarding the project, its value, and the democracy within it (Grant, Nelson et al. 2008). It was necessary that I acknowledged these multiple roles and the roles of the those involved in the research and how they would shape this study to provide a transparent account. The individual and collective perspectives could differ within and between staff, parent and pupil groups, particularly between those with professional training and those without, the interactions between the co-researchers and me, and the co-researchers between themselves would provide a stimulus for one another, determining what was said and what was not (Avgitidou 2009).

The intention of creating a goal setting framework would require understanding experiences from all perspectives of those involved with or impacted by goal setting practices. A participatory approach, enabling the transformation of ideas for solutions into actions for change and reflecting on the effectiveness as they occur would assist with eliciting the diversity of viewpoints. The emphasis of participation and collaboration was considered necessary so those involved would view the research as worthwhile, leading to fostering and maintaining engagement (Grant, Nelson et al. 2008). Utilising reflexivity to acknowledge that decisions made can influence actions of others (Finlay 2002) and attempting to equalise the power balance between researcher and researched, would address the perception that the researcher may consider them self as better positioned to understand problems (Clarke 2009).

3.4   Justifying a blended methodology

The decision to adopt two methodologies came from the need to support the generation of new knowledge for understanding, and the generation of knowledge for action (Cornwall and

Jewkes, 1995). This would serve to bridge the theory practice gap, supporting practitioners to make clinical decisions (knowledge for action) based on research evidence (knowledge for understanding) that remains a challenge within allied health practitioners (Sherratt 2005). As already discussed, the methodology would need to account for my position as researcher within the organisation that I work, and also the positions held by the participants who were staff, parents of pupils attending the school, and pupils.

The necessity for being reflexive and the ongoing awareness and acknowledgment that how as a researcher, and therapist, I am part of the research process and cannot be separated from it. My pragmatist and constructivist approach to knowledge generation, and my experiences, values and beliefs that underpin them, would also inform what I wanted to find out, and guide the way that I believed, to be the most suitable way in doing this (Davis 2020). An overview of each methodology is discussed separately, then together to explain how they complement each other, to reiterate why both were necessary for this research and to illustrate how they were blended, as opposed to being carried out side by side.

3.4.1 Constructivist grounded theory

Grounded theory is a research methodology and set of methods developed through the work of sociologists Barney Glaser and Anselm Strauss (Glaser and Strauss 1967). Drawing on explicit principles and processes for data collection and management traditionally associated with quantitative research, grounded theory aimed to raise the profile of qualitative enquiry and demonstrate that it could be of equal value as quantitative research (Glaser and Strauss 1967). Theory, as described by Glaser and Straus refers to the formulation of concepts or categories that serve to explain behaviours and social processes that are grounded in the data. Grounded theory is one of the most widely used approaches to qualitative enquiry and has evolved from its original foundations in positivism, being applied within different philosophical frameworks including constructivism (Charmaz 2014)

The evolution of grounded theory has caused the position of researcher objectivity to be challenged, and Kathy Charmaz a former student of Glaser, proposed that grounded theory

research is a co-construction between the researcher and the researched. Charmaz argued that the researcher's prior knowledge and experiences cannot be separated from the research process which contributes to the co-construction and interpretation of the phenomena being studied (Charmaz, 2014). Charmaz's work redefined the position of the researcher from an objective observer towards subjectivity and raised awareness of the researcher's role in constructing the grounded theory (Charmaz, 2000).

Despite ongoing disputes concerning philosophical divergence from Glaser and Strauss' classic grounded theory methodology, particularly due to the proposed constructivist positionality of the researcher (Glaser 2002) there are idiosyncrasies that remain recursive regardless of the philosophical position adopted. These include the emphasis on abstract conceptualisation, the rigorous and methodological approach to analysis (although the exact processes differ), progression from inductive to abductive reasoning, and the use of constant comparative methods throughout (Bryant and Charmaz 2010).

It is the argument that the researcher and co-researchers co-construct the phenomena that is particularly relevant to this research as my positions of therapist, manager and colleague in the research field, and my own experiences of goal setting will influence how I interpret the discourse and my awareness of this presence when collecting and analysing the data (El Hussein, Hirst et al. 2014). This will allow for the research to develop through a co-construction of meaning based on actions and interactions between individuals rather than searching for objectivity (Charmaz 2014). Constructivist grounded theory was selected for its emphasis on explanation and understanding of social processes utilising a dynamic approach to data collection and analysis, and to acknowledge my already established presence in the research field.   See Figure 5 for Tweed and Charmaz (2012) visual representation of the process involved for a constructivist grounded theory.

35
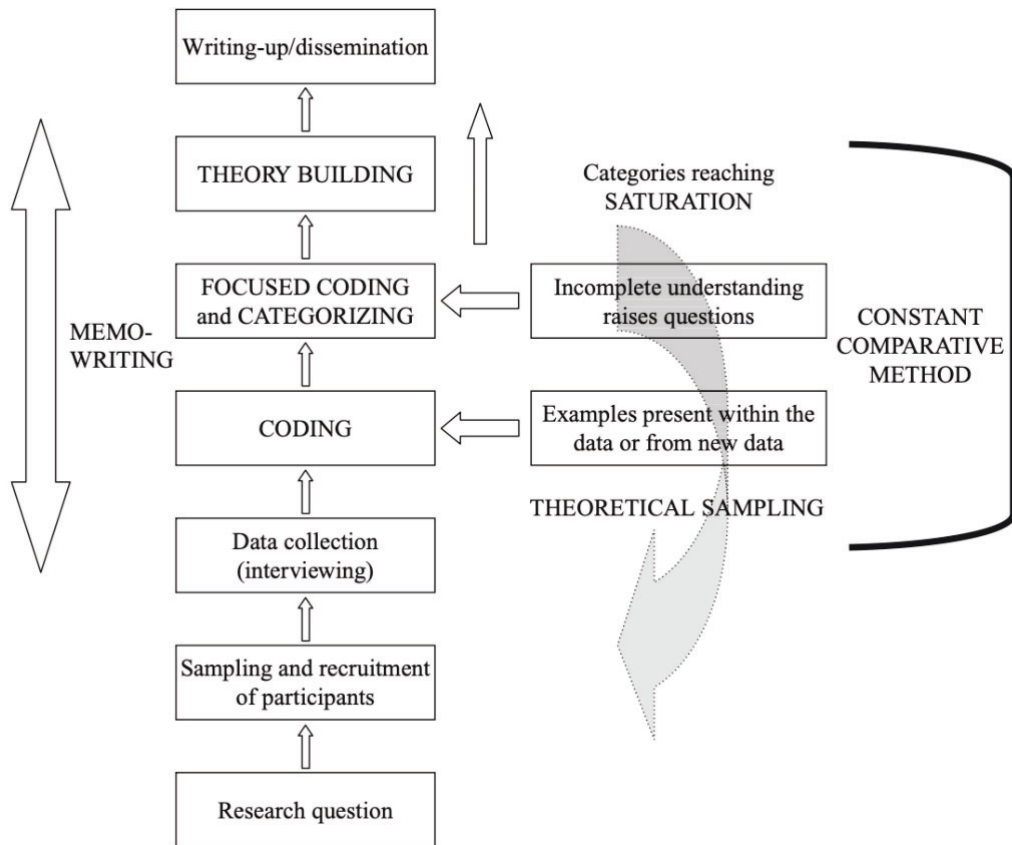
Figure 5 Visual representation of constructivist grounded theory (Tweed and Charmaz 2012)

The adoption of a constructivist approach to ways of knowing and finding out, segues with the understanding that my personal, moral and social values will also influence how I choose to approach methods of data collection and its interpretation (Berger 2015). Grounded theorists position themselves within a reflexive framework, known as methodological self-consciousness (Charmaz 2016) which affords scrutinisation of unconscious beliefs to understand how they are positioned within the research and enable transparency of how the reality is constructed (Davis 2020). Therefore, the roles I occupy and the roles of those involved in the research will collectively shape the research journey. It is my responsibility to ensure that the research is trustworthy, and by embracing methodological self-consciousness through the ongoing use of a reflexive journal as previously discussed within the research process would enable me to do this.

The ethical considerations of the research and the power dichotomy between myself as researcher and my colleagues as co-researchers, potentially serving to act as a means of recognising and addressing tensions which might occur is illuminated. The use of memos and keeping reflective field notes are a prominent component of constructivist grounded theory that are used to assist the researcher with the analytic journey and help maintain a reflexive stance (Charmaz 2014).

3.4.2   Participatory action research

Participatory action research places emphasis on participation and democracy seeking to understand or solve problems in organisations and adopts a different approach to traditional positivist research methods that are inherently hierarchical in terms of the researcher – researched relationship (Carr and Kemmis 2003). It seeks to do research 'with' a community rather than 'on' or 'to' it (Savin-Baden and Wimpenny 2007). Action research, a term coined by German American psychologist Kurt Lewin (Robson and McCartan 2017) was created with the intention of facilitating change through the voices of marginalised communities with varying emphasis on emancipation, empowerment, participation and democracy (Carr and Kemmis 2003). These variations are based on philosophical and political influences, and their application include community based action research, co-operative enquiry and action learning (Coghlan 2019). This study utilises a participatory action research approach, an evolution of co-operative enquiry which emphasises the active and ongoing contribution from participants (Coghlan 2019) and aligns with the flexible, fluid and evolving approach to understanding associated with pragmatism (Charmaz 2016).

The aims of finding solutions to problems and promote change through collaboration with the community and enhance wellbeing are central to this strand of participatory action research. Processes of action and reflection engage participants with the research and serves to offer a more enhanced understanding about the problem in question, facilitating its emergent nature (Savin-Baden and Wimpenny 2007). Furthermore, the focus on fully integrating participants into the research process offers an ethical solution when the research environment is also the

37

organisation where the researcher works as it acknowledges the potential power imbalances and positionality of both researcher and researched, which have been previously discussed.

Iterative cycles of action and reflection that build on the one that came before are fundamental to an action research approach. Figure 5 outlines the representation of action research by Stringer (2014) and although the stages of 'look', 'think' and 'act' through the different cycles of planning, implementation and evaluation appear neat and procedural, this is far from an orderly process and in real world application, steps may be repeated, reversed or even missed, depending on how the research unfolds and cycles can occur within cycles, adding to the complexity (Stringer 2014).
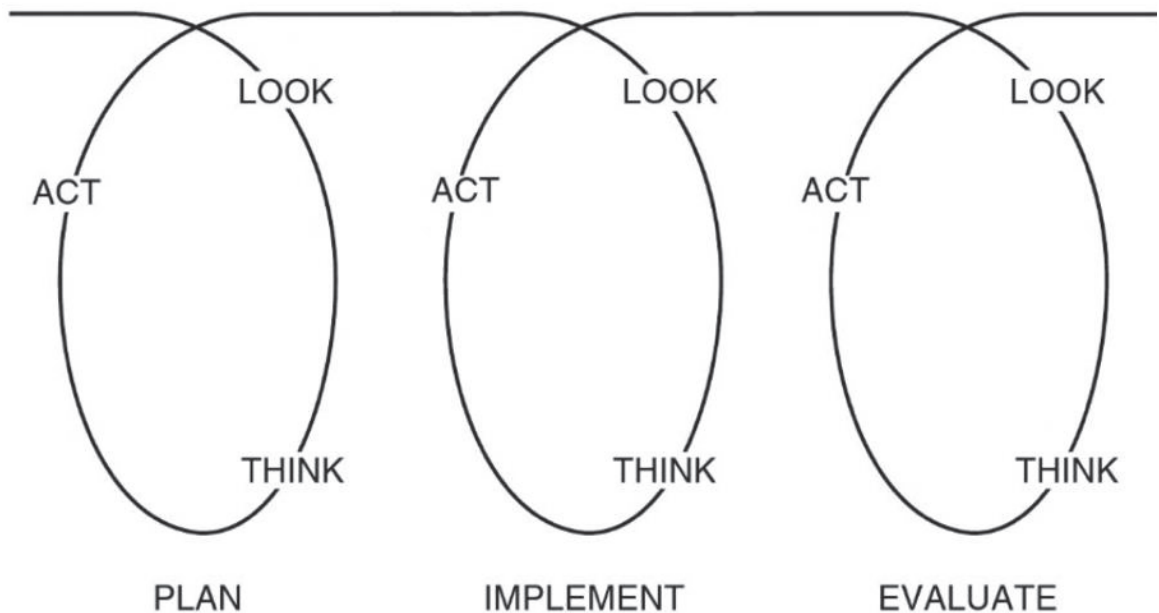
Figure 6 Action research interacting spiral (Stringer 2014)

3.5   A shared paradigm

Constructivist grounded theory and participatory action research have been well rehearsed and acknowledged as being complementary approaches to research in terms of process and theoretical assumptions (Charmaz 2016). According to Lewin's force field analysis (Willis and

38

Edwards 2014), behaviours cannot be understood unless the context of where those behaviours occur are also understood. The different 'forces' in organisations could either enable (effective time management), or prevent, (workers lacking motivation), the achievement of a desired outcome. Understanding these 'forces' could then be used to facilitate understanding the strengths of and the barriers to change management (Willis and Edwards 2014). It was anticipated that using participatory action research and constructivist grounded theory would identify the enabling and hindering 'forces' that influence goal setting practices, generate theory and simultaneously create a practical tool to improve goal setting practices. Understanding how individually and collectively, health and education practitioners, and families they support understand each other, contributes to discussion and actions undertaken by those roles. The suggestion that each share and releases their knowledge suggests that hierarchy is present, but it is also fluid based on the presence of experience and knowledge. In an effort to address these complexities, Kohl and McCutcheon (2015) argue for the ongoing discourse which contextualises knowledge and identity, respecting opinions and perspectives that are different to one another. This asserts that mutual collaboration can be a variant of reflexive analysis and involving co-researchers in this way is consistent with pragmatism and constructivism, and the co-creation of realities, adding to the transparency of the study which according to Canlas and Karpudewan (2020) is often absent in other participatory research studies.

Whereas participatory action research arguably attempts to resolve power relations and does this by investing the participants with ownership of the research, the intention of problem solving through systematic processes of enquiry are consistent with constructivist grounded theory (Charmaz 2016). Action research generates evidence that informs action, and grounded theory generates theory from the evidence gained (Dick 2007). Utilising both action research and grounded theory enables the researcher to engage directly with issues raised, and understand them theoretically in order to facilitate change (Dick 2007). Charmaz (2016) argues that grounded theory strategies offer structure and encourages scrutiny in order to critically examine hidden beliefs of the researcher (and participants) thus facilitating transparency and increased

rigour that has historically been a criticism associated with action research (Canlas and Karpudewan 2020).

However, bridging two methodologies can be problematic if their underpinning philosophical assumptions misalign (Azulai 2020). Grounded theory and action research can offer differences in philosophical underpinnings that inform the research approach, e.g. classic grounded theory described by Glaser and Strauss (1967) aligns with a positivist paradigm due to the objective stance it assumes (Charmaz 2014) and as previously discussed, constructivist grounded theory aligns with constructivism. There is also variation of action research approaches which may reside within positivism (Tekin and Kotaman 2013) or align more with constructivism and pragmatism (Charmaz 2016). This creates the potential for methodological tension when the epistemologies of the selected grounded theory and action research are not sufficiently considered and reside within opposing paradigms (Azulai 2020). For this study, the theoretical foundations seeking to illuminate multiple voices and multiple perspectives including those of the researcher and the research participants align with the principles that reside theoretically within pragmatism and constructivism (Charmaz 2016) and are therefore in philosophical alignment with one another.

3.6   A blended approach

I acknowledge that as a novice researcher, I could risk the integrity of the research if, in my efforts to use and blend these approaches meant that I omitted or failed to consider aspects of each. Furthermore, despite the published literature supporting the use of these methodologies together, I wanted to be certain that for this study, using both would not compromise and dilute the efficacy of either. During the early stages of considering whether these two methodologies would be an appropriate direction to take, I contacted Kathy Charmaz to ask her opinion. In a brief correspondence, Kathy reassured me that using these methodologies together would be an appropriate approach. See appendix 15 for an excerpt of our email correspondence.

A narrative review by Williams, Wiles et al. (2022) exploring the combination of action research and grounded theory in health research found that it was predominantly coding strategies associated with grounded theory that were used in conjunction with action research, resulting in side by side utilisation. This research aimed to extend beyond this commonly implemented side-by-side approach and adopt a blended methodology that would aim to maximise the flexibility and responsiveness associated with both, in order to meet the aims of the study and create a theoretical model for understanding, and a practical tool for use.

Figure 7 represents a visual model of blending constructivist grounded theory and participatory action research used for this study. The iterative cycles of *think, act, look,* inform and are informed by the iterations of theoretical sampling, coding, and constant comparison of data, which then re-inform the *think, act, look* stages. The iterations, although originating from separate approaches, and are situated on either side of the cycles, are blended through the practical actions, reflective discussions and theoretical insights gained. However, in practice, the iterative cycles are not neat, nor are they equal in size or focus the way that it is depicted. It is here where the role of reflexivity as previously discussed acted as a protective mechanism for the blended constructivist grounded theory and participatory action research. In addition to being reflexive regarding data collection and analysis, I also utilised reflexivity to ensure that I remained authentic to both methodologies.
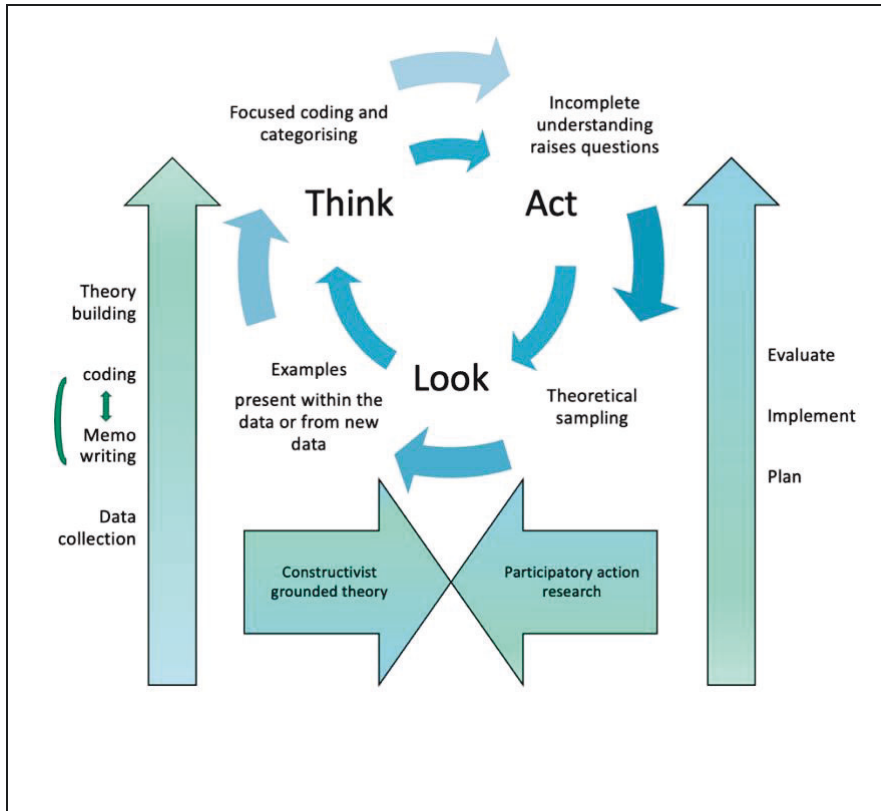
Figure 7 Adapted from Charmaz and Tweed (2012) and Stringer (2014). Visual representation of constructivist grounded theory blended with participatory action research

3.7   Data collection and analysis

Grounded theory methods for data collection and analysis are pragmatic, investigative and flexible, requiring reflexivity from the researcher to sustain attention to the field, searching for meaning in the implicit and explicit actions, and use of language (Bryant and Charmaz 2010). It is the attention to initial and focused coding, memo writing and theoretical sampling that are intrinsic to the analytic process that serves to generate explanations from the data (Charmaz 2014). Although present throughout the data analysis, abductive reasoning comes to fruition during constant comparison of categories (Birks and Mills 2017). Coding takes the form of a two-stage process, initial coding which is used to 'gain an analytic handle' on the data and creating focused codes from these initial codes to synthesise and explore them further (Charmaz 2014). The use of gerunds is integral to coding as these transfer the meaning of data into actions and supports the analytic task of explaining behaviours and processes (Charmaz 2014).

3.8   Trustworthiness

Although designed not to be used as a checklist or recipe for carrying out grounded theory research (Charmaz 2021), the systematic processes and strategies aligned with grounded theory methodology provides a scaffold to support an approach such as participatory action research where definition or guidance of methods for data collection and analysis are not well articulated (Canlas and Karpudewan 2020). There are various sources available in the literature that provide accounts of the processes of action research including problem formulation, literature review and sharing results. For example, (Kelly 2005) discusses the use of photos and Stapleton (2021) suggests the use of poetic enquiry for data analysis but neither provide detail about the processes of data collection and analysis used which could raise doubts regarding the trustworthiness of their studies. The failure to address data collection and analysis with any specificity contributes to the challenges regarding credibility, trustworthiness and rigour of this approach (Robson and McCartan 2017). Greenwood and Levin (2007) assert that trustworthiness of action research is measured in success of solutions to problems and call for the importance of workability as the method to measure success and whether a feasible or practical solution can be found to the initial problem.

The role of co-researchers participating in analysing and coding the data in action research has also come under scrutiny; Canlas and Karpudewan (2020) acknowledge that time required for participants to be engaged in the coding and analysis process is a reason for why it is conducted by the researcher, which is also true for this study. However, reflexivity of the researcher that informs the process of constructivist grounded theory acknowledges that the research is a co-construction, and the analytic journey taken is an interpretation (Charmaz 2014). Furthermore, it is argued that the iterative cycles of action and reflection naturally offers the opportunity for participants to sense check the researcher's interpretations and therefore it is argued that it is step not necessary for the participants to be directly involved with.

Although Dick (2001) argues that as action research studies develop, the methods and routes of inquiry become more defined and strengthens the study, the transparency of methods and underpinning philosophical assumptions are rarely reported. Participatory action research has

43

been further scrutinised due to the expectations placed on co-researchers (Coghlan, 2019) and how generally, although it is considered as a modern approach to research, little emphasis is given to published studies articulating how it is positioned within research paradigms (Tekin and Kotaman 2013). This makes it difficult to appreciate the theoretical assumptions that underpin the research. It appears that due to action research focusing on creating actions for change, the specific methods used for data collection and analysis are dependent on the subject of interest, which in one sense highlights the flexibility of this approach but also has resulted in the methods used and analytical frameworks lacking articulation, causing criticism with the methodological and theoretical processes. To address these deficits, this study has been positioned within a constructivist and pragmatist paradigm which provides transparency regarding the construction of knowledge. Furthermore, blending this with a constructivist grounded theory methodology aims to provide a transparent and refined process for data collection and analysis, thereby raising the profile of theory development (Dick 2001, Manuell and Graham 2017). For this study, in addition to the utilisation of reflexivity, trustworthiness was demonstrated through clear cycles of action and reflection (the research process), and the explicit processes of data collection and analysis which are all regarded as necessary criteria (Charmaz 2016, Charmaz and Thornberg 2021). Appendix 16 provides an example of an action and reflection cycle with justification for decisions made.

3.9   Conclusion

This chapter has argued that utilising both participatory action research and constructivist grounded theory methods, serves to demonstrate that the researcher's role extends beyond conveying the knowledge gained, but also helps to shape it. The implicit, explicit, and perceived power imbalances of those involved, exploration of individual and collective experience, and the utilisation of these experiences to stimulate and promote change in work practices are all necessary navigational factors. Utilising a blended methodology served to address the complexities of carrying out research in the organisation where I work, facilitating an approach to understanding goal setting, and supporting actions to enable change in working practices.

Chapter 4: Research Processes

4.1   Introduction

This chapter presents the methods of data collection and analysis and the processes employed utilising the blended grounded theory and action research. The research was completed in three phases, with each phase introducing additional co-researcher groups to the study (Figure 8). Phase 1 focused on the practitioner co-researchers, setting the scene for the entire study, outlining the key issues and priorities for change. Phase 2 began with the actions designed in phase 1 having been implemented and introduced the parent co-researcher group. Similarly, to the previous phase, phase 3 began with the actions designed during phase 2 and introduced pupil co-researcher group. The global pandemic of 2020 impacted the day to day running of the school causing a reduction in action research group meetings and a delay of rolling out new systems between March and November 2020.
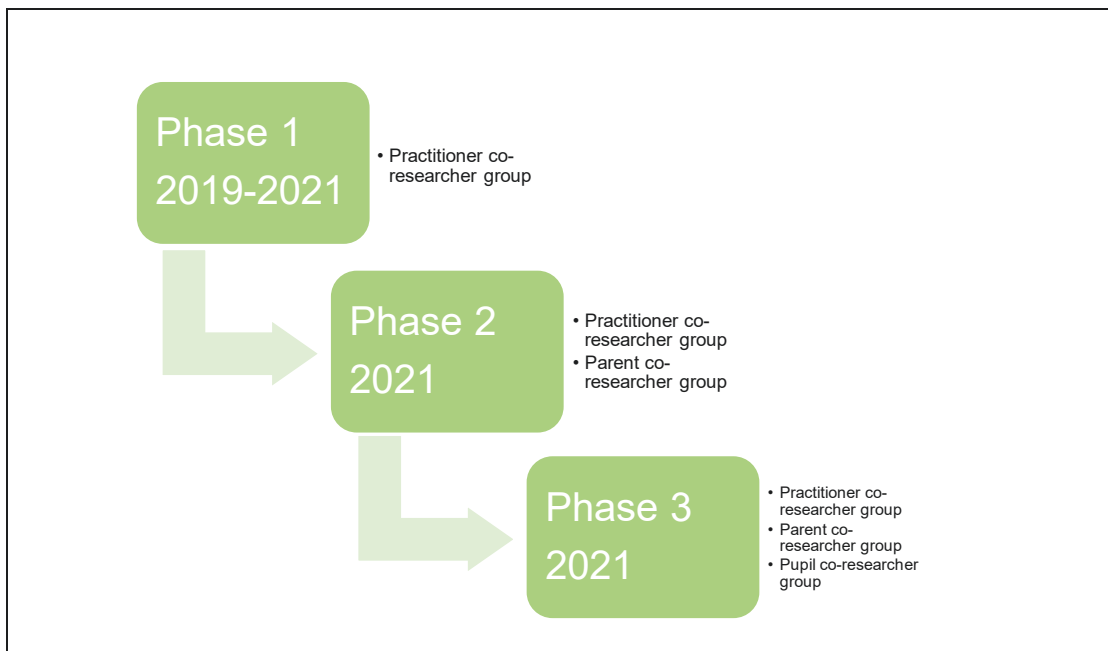
Figure 8 Phases of action research and co-researcher groups

4.2   Co-researcher criteria

One of the principal data collection methods in grounded theory is theoretical sampling, whereby the process of analysis and the constant comparison method has unearthed further questions of the data, specifically relating to the developing categories and guides where, and who to seek further information from to develop them further. This may consist of going back

to previous informants or seeking new (Charmaz 2014). In grounded theory, purposeful sampling is initially employed and "gets you started; theoretical sampling guides where you go" (Charmaz 2014, p.197). In this study, purposeful sampling began with recruiting a practitioner co-researcher group that aimed to represent each member of the education and healthcare team. Theoretical sampling guided the recruitment of the parent co-researchers and pupil co-researchers and the iterative discourse that took place with the practitioner co-researchers and parent co-researchers (Charmaz 2014).

Practitioners participating in the study met the following inclusion criteria:

- Be an employee of the research site

- To work within the school services and directly with pupils in the classroom environment

- To have experienced / participated in the goal setting process

Parents participating in the study met the following inclusion criteria:

- To be the parent (or primary caregiver) of a child who attends the research site (the school)

Pupils participating in the study met the following inclusion criteria:

- To be a pupil at the school

4.3   Procedures

The research site (the school) is where the researcher is employed making initial access to prospective participants straightforward. The school is a charity funded specialist school and carries no affiliation with the NHS therefore ethical approval was sought directly with the school. A meeting with the school CEO, Director of Education and Director of Therapy was conducted resulting in agreement for the research to take place subject to ethical approval from the University of Northampton (appendix 2). Following this meeting, ethical approval was sought and gained from the University of Northampton Research Ethics Committee. Additional ethical approval was repeated for the recruitment of parent and pupil co-researchers (appendix 3).

4.3.1 Ethics

The College of Occupational Therapy research guide: Research governance and ethics (RCOT 2022) stipulates that *"As far as possible, participants should be involved in the design, conduct, analysis and reporting of research".* Using a participatory action research approach would enable a collaborative partnership between myself and the co-researchers and would assist with mitigating against the power imbalance as I hold a position of authority at the school.

I am governed by the Royal College of Occupational Therapy (RCOT 2022) which stipulates that I must protect the interests of fellow researchers. For this study I was mindful that time management, potential conflict that could arise between co-researchers, and ownership of the resulting study outcomes would need to be managed to protect all involved. Should a safeguarding issue have arisen, the designated safeguarding officer would have been notified and the process in accordance with school policy would be enacted. Non-safeguarding issues would be directed through the HR manager in line with the school conduct policy.

In addition to the above-mentioned code of ethics, each of the allied health professions, occupational therapy, speech and language therapy, physiotherapy, as part of their registration, must abide by the Health Care Professions Council code of conduct (2016) as well as their own professional bodies which sets out expectations of how registered professionals are required to conduct themselves. Similarly, teachers must abide by the Teaching Standards (Department for Education, 2011) and conductors must abide by Professional standards for conductors in the UK (2017). Learning support assistants employed at the school do not belong to a governing body, however they must, as all staff, adhere to the school's standards of practice (2017) which sets out expectations for every employed member of staff. Issues have been highlighted regarding the ethical dilemmas due to the power imbalance and the associated risks with both parties. The research is an extension of the goal setting processes of what is already being implemented at the school and the conversations regarding goal setting were a familiar topic to all co-researchers.

4.3.2 Co-researcher recruitment

<u>Phase 1: Practitioner recruitment</u>

An information workshop concerning the intended study was presented to all staff at the research site's annual conference on Saturday 8th June 2019 (appendix 4). The information workshop consisted of an overview of the research and discussed how it matched with the school strategic plan. The information workshop included details about the goals of the research and what to expect. Although not all staff would be eligible to participate due to the specific criteria of being classroom based, it was considered relevant to inform all staff about the research, so all were aware that it was being carried out.

Following the conference, an email containing a participation information sheet which included all the information that had been presented (appendix 5) along with a consent form (appendix 6) was sent to all staff who were eligible to participate with a reply to deadline date attached. A second, reminder email was sent one week later.

Once the reply to deadline date passed, all staff who had replied to the email and returned the consent form were invited to an initial meeting in July 2019 to discuss protecting and safeguarding co-researchers. This was supported by a written agreement in the form of a Group Confidentiality Statement (GCS). The GCS was created as a collaborative exercise between myself and the co-researchers and detailed all parties' roles and responsibilities including anticipated time spent for workshops and other key aspects of the research as well as authorship considerations. This included setting up timely and specific methods to keep a record of meeting times, issues discussed, and duties assigned. The GCS outlined the boundaries, rules, expectations, anticipated outcomes e.g., a framework to assist with goal setting, and ownership/ authorship of the research (appendix 7). The Group Confidentiality Statement was constructed by adapting the Centre for Social Justice and Community draft guidelines relating to ethical principles for Community Based Participatory Research (Banks and Manners 2012). Key components from the guidelines that informed the GCS are demonstrated in Table 2.

48

1) Mutual respect: the importance of developing research relationships based on mutual respect, which entails listening to all voices and valuing diverse perspectives.

2) Democratic participation: the importance of encouraging and enabling people from a range of backgrounds (ethnicity, faith, class, gender, sexual orientation, ability, age, etc.) to play a role in the research process.

3) Personal and professional integrity: the importance of a commitment by participants to behave reliably, honestly and in a trustworthy fashion and to work within the values of the organisation.

4) Active learning: the importance of seeing the research collaboration and the process of research as learning opportunities – particularly as offering the chance to learn from each other and for critical reflection by individuals and groups on their own roles in the research process and contributions to outcomes.

5) Making a difference: the importance of research that creates beneficial outcomes for communities of place, interest or identity and works for progressive social change and social justice, including the creation of more equitable and sustainable distribution of power and resources.

6) Collective action: the importance of individuals and groups working together to achieve change - identifying common goals, while recognising and working with conflicting right and interests. Emphasising consensus building rather than division and difference.

Table 2 Group confidentiality statement key components

Phase 2: Parent recruitment

The School Curriculum Statement policy (2020/2021) sets out the school vision, mission and values. One of the seven values is 'child, family and community centred' which emphasises the importance of the voice of the child and their family in their journey through school. It was possible that a parent and a pupil co-researcher could be from the same family. There was not any instruction or expectation that parent, and pupil co-researchers could not discuss the

research with each other as doing so would present serious issues relating to safeguarding. Risks to pupils and parents, including myself as researcher were considered using the principles of ethical research with children and adults, and safeguarding procedures were put in place. Similar to the group confidentiality statement discussed for the staff as co-researchers, the same was applied to the parent and pupil co-researcher groups.

An email was sent to all prospective parent co-researchers (parents of pupils who attend the school) which contained a participant information sheet (appendix 8) and consent form (appendix 9). A follow up email was sent approximately one week later. Two parents returned the consent forms and agreed to take part. A separate information letter was sent to parents of children who attend the school to inform and reassure that there would not be any removal of services or change in provision due to the research taking place. There was a section on the letter which asked parents if they had any thoughts or questions about the research. Measures were put in place in the event of parents requesting to be involved in the research in any way, which would involve a separate ethical submission request. There were no responses to this letter and no requests made from parents to be involved.

Phase 3 Pupil co-researcher recruitment

Although ethical research with children remains a contentious issue (Ferdousi 2015), the contribution of what the child voice can offer in research is increasingly being appreciated (Borovac 2015). Pupils at the school routinely take an active role in collaborating with staff to select a relevant goal from their Individual Learning Plan (ILP) for them to work on during each session and self-evaluate their achievement using a format that is meaningful and appropriate to their cognitive ability. From here on in, 'pupil' and 'child' will be used interchangeably when referring to any child who attends the school, and 'school' will be used interchangeably with research site, depending on the context that they are discussed.

Pupils who were aged over 5 years old and who performed within typical age ranges for their cognitive ability were invited to take part in the study via an email sent to their parents. The email contained a participant information sheet (appendix 10) and consent form for the parents

(appendix 11) and a child friendly, easy read information sheet (appendix 12) and consent form (appendix 13) for the pupils. The pupil researcher group confidentiality statement was phrased in a child friendly way, for example renaming it to Group Rules as this would be a concept that all pupils were familiar with but remained in accordance with the outlined components previously described.

In addition to the identified risks associated with this research, the following policies were adhered to ensure the rights and safety of pupils and parents taking part were protected:

Child Protection Policy (2020/2021)

Data Protection Policy (2020/2021)

Equality and Cohesion Policy (2020/2021)

4.3.3   Co-researcher characteristics

Practitioner co-researchers

For this research, ideally there needed to be a representation of each profession, and where possible, there needed to be more than one from each profession to address concerns about assumptions of a sub-group based on the opinions of one person (Israel, Schulz et al. 1998). The project is made up of different groups of staff who have different experiences to offer based on their knowledge and roles within the group. For example, the therapists may report on writing the goals, whereas the learning support assistants may report on writing evaluations of the session. The benefit of an action research community is the diversity and each co-researcher brings a different perspective based on the roles that they occupy (Israel, Schulz et al. 1998). Twelve practitioners agreed to become co-researchers. Table 3 presents the characteristics of the co-researchers, including their profession and length of time employed at the school. Co-researcher names were replaced with code numbers. Not all staff were present at every meeting due to other commitments, and one staff member began maternity leave in July 2020 and was no longer able to be involved with the study.

Code	Profession	Gender	Years employed at the school
Pr 1	Speech & Language Therapist	Female	1
Pr 2	Occupational Therapist	Female	17
Pr 3	Conductor-teacher	Female	6
Pr 4	Conductor	Female	14
Pr 5	Physiotherapist	Female	3
Pr 6	Occupational Therapist	Male	4
Pr 7	Teacher	Male	2
Pr 8	Occupational Therapist	Female	6
Pr 9	Learning support assistant	Female	7
Pr 10	Conductor	Female	18
Pr 11	Physiotherapist	Female	2
Pr 12	Speech & Language Therapist	Female	20
Pr 13	Learning support assistant	Female	8

Table 3 Practitioner co-researcher characteristics

Parent co-researchers

The uptake of recruiting parents as co-researchers was low and resulted in two parents agreeing to take part. Table 4 presents the characteristics of the parent co-researchers with codes assigned.

Code	Relationship to child	Age of child
Pa 1	Mother	11
Pa 2	Mother	5

Table 4 Parent co-researcher characteristics

<u>Pupil co-researchers</u>

Similar to recruitment of parent co-researchers, the response from parents of pupils to take part in the study was low. Table 5 presents the characteristics of the pupil co-researchers with codes assigned.

Code	Gender	Age
Pu 1	Male	10
Pu 2	Female	11

Table 5 Pupil co-researcher characteristics

4.3.4   Informed and ongoing consent

Informed and ongoing consent was demonstrated through co-researchers attending meetings and engaging in activities set by the group. Should a co-researcher have no longer wished to take part in the research, they could withdraw their consent. However, any contributions they would have made up to that point would still be used in the research project and this was made clear in the participant information sheet, consent form and the group confidentiality statement.

4.3.5   Rights to anonymity

For the practitioner co-researchers, full anonymity was not possible as practitioners would know who the co-researchers were. However, the meetings were recorded with notes taken and transcribed using pseudonyms. There was at least one representative from each professional discipline and although different disciplines may have shared or had differing opinions, the profession attached to the co-researcher made them identifiable. The confidentiality agreement was designed to protect co-researcher's rights and freedom of speech. Issues discussed within the closed meeting sessions were not discussed elsewhere, unless it was an action that was to be implemented or feedback to be provided to the management team. Co-researchers were made aware before they agreed to participate that full anonymity was not possible as they would be recognisable to other practitioners not involved directly in the study. External to the

school, the only identifying features would be the profession. Detail of where in the school the co-researcher works and with whom remained confidential.

For the parent co-researchers, although remaining fully anonymous was not possible, the meetings took place remotely parent names were replaced with codes. It was not possible to maintain full anonymity of the pupil co-researchers as other practitioners would need to be involved to arrange the technology for a remote video call.

4.3.6 Data management

Data were collected using handwritten notes, typed notes and audio recording. All audio recordings were transcribed. Data were collected during co-researcher group discussions and individual reflections. Pseudonyms (codes) were used to protect the identity of the co-researchers. Dates were used to act as a record of progression. Raw data gathered from any meetings was not shared beyond the co-researcher groups and stored in line with GDPR. The co-researcher group confidentiality statements outline consent and ownership, and data generated from the study including the anticipated outcome of producing a goal setting framework would belong to the research site.

Data were stored on the cloud using OneDrive. The OneDrive account belongs to the research site and is routinely backed up. In the event of an incident, the IT services had the capabilities to restore any lost data. Any audio recordings were transcribed, handwritten notes scanned, and all data uploaded. Data was stored in one place to maintain security. As the primary researcher, I retained overall responsibility for the data. Data was preserved in accordance with the University of Northampton's Research Data Policy.

I retain sole access to the data that is stored on the OneDrive after completion of the study for up to 3 years in order that I may publish work based on the data. This was discussed with the co-researchers during the development of the group confidentiality statement. Although co-researchers did not have automatic access to the data, they could request access to the data stored. Data security was the responsibility of the IT services at the research site.

Naturalistic data collected from staff feedback forms and goal setting documents were anonymised and coded so that only staff profession was identifiable, and the school key stage of pupil related documents identifiable. There were sufficient numbers of pupils and staff in each of the groups that does not make staff or pupils easily identifiable outside of the organisation. All resources required for managing data were readily available.

4.4   Co-researcher meetings

The researcher had previous working relationships with all of the practitioner co-researchers, knew the parent co-researchers but had not directly supported their child in the classroom environment, and knew the pupil co-researchers but did not work directly with them. The practitioner co-researchers all knew each other even though they may not have worked directly together. The parent co-researchers were familiar with each-other, and the pupil co-researchers were in the same class, so they were also familiar with each other. This familiarity helped support the development of a relationship between the researcher and all action research groups and helped to ensure all co-researchers were comfortable to share their thoughts which is considered a requisite for both participatory action research and constructivist grounded theory studies (Sirca and Shapiro 2007, Birks and Mills 2017).

All co-researchers understood the aims of the research prior to taking part, and because of this, were considered as having a vested interest (Savin-Baden and Wimpenny 2007) and with the familiarity of the co-researchers between themselves, resulted in the discussions feeling informal and conversation based. The inductive principles of constructivist grounded theory require the researcher to be open minded and follow the path that the research participants lead (Charmaz 2014) which also aligns with conducting participatory action research (Dudgeon, Scrine et al. 2017). This supported the informal discussion format that took place with the groups. The pupil co-researchers were supported by a communication assistant not involved in the study to assist engagement in a way that was familiar to them. Twenty-eight co-researcher group meetings took place in total between September 2019 and June 2021 with

the majority being held with the practitioner co-researchers. Table 6 shows the distribution of co-researcher meetings.

Co-researcher group	Number of meetings
Practitioners	23
Parents	4
Pupils	1

Table 6 Number of action researcher meetings per co-researcher group

The meetings all took place during school hours and were carried out remotely, in person and a combination of both. The participatory action research meetings with the practitioner co-researchers increased in frequency during the already established periods of goal review set in November, March and June of each year. All parent and pupil co-researcher meetings were carried out remotely during school hours. Less emphasis was placed on the pupil co-researcher group as they were included towards the end of the research process and used to sense check their inclusion in goal setting.

4.5   Participatory action research processes

Each phase of the action research consisted of co-researchers reflecting on current practices, trialing new ideas in the school, and reflecting on how they worked. Changes were implemented and evaluated in line with the structure of the school review periods. The direction of the research was guided by the methods aligned with constructivist grounded theory: initial coding, followed by focused coding, memo writing and constant comparison of data to begin to generate tentative categories that were being constructed through the co-researcher group meetings, actions and reflections. See appendix 17 for examples of meeting agendas and discussion points that were generated using the processes outlined above and used as working documents during the group meetings. The content of the meetings informed the actions and further reflections. Table 7 provides an example overview of the planning, implementation and evaluation of the research concentrating on the procedures for setting goals.

Plan	Implement	Evaluate
Began with reflecting on current practices and ideas for improving what is already in place.	**November 2019** During goal review week adjust how goals are set by increasing pupil/ parent involvement.	Discussed what changed and how these changes impacted review week and quality/ focus of goals.
Plan	Implement	Evaluate
Reflected on importance of goals, who are they important to		Reflected on whole team perspectives of goal setting
Plan	Implement	Evaluate
Finding a way to address what has been discussed during evaluations, particularly around capturing everything that is important about the goal	**November 2020** Change goal setting procedures and introduce additional methods for capturing progress	

Table 7 Overview of procedures for goal setting

For each phase, there were specific actions carried out based on the issues raised. Each action was provided with clear justification to demonstrate the thought processes involved in creating them. Table 8 illustrates phases of action and reflection with the different action research stages carried out by the practitioner co-researchers.

Think (issue)	Act (Action)	Justification	Look (did it work?)	Think (issue)
1) Parent voice is not present	Sending home a letter and/or email requesting what was important for them for their child to focus on at the beginning of the goal setting period	Families would find this a useful way of communicating their thoughts and contribute to the goal setting process	Correspondence was low, parents appeared not to engage	Why don't parents engage with email?
2) Child voice is not present	Trial talking mats	Talking mats facilitates communication and understanding of pupil aspirations	More insight gained of what is important to pupils	Who's responsibility could this be to ensure it happens?
3) Not capturing everything that is being achieved through only having four goals	Create a crib sheet that can track other, discreet non goals and factors that may influence this	Capturing other areas of success or skill maintenance	This takes too long; not realistic for regular use	What is necessary to capture/ what are we looking to gain?
4) Current system of writing goals only measures how much support is required	Trial Goal Attainment Scaling (GAS)	GAS enables a systematic method of writing goals and facilitates variety in what is to be measured	Well received by the classes	How to provide training to all staff

Table 8 Phases of practitioner co-researchers' action and reflection

4.5 Analysis of data

Data was analysed consistent with constructivist grounded theory methods. Data from the participatory action research meetings were analysed line by line and were assigned initial codes. The initial codes were then reviewed and analysed, condensing them into focused codes that captured the essence of the co-researcher experiences. The use of gerunds assisted with elevating the codes from description to action, supporting the analysis whilst being mindful not to focus on generating gerunds which carries the risk of assigning meaningless codes to the data (Charmaz 2014).

The intention was to use data management software QSR NVivo 12 to support the collection, organising and coding process. However, for the researcher, this method felt too 'removed' from the data, lacked visual engagement, and felt that the voice of the co-researchers was getting lost, which Charmaz (2014) argues is a risk when analysing data. Instead, the coding process was carried out beginning with manually writing initial and focused codes against the transcripts. Figure 8 presents part of a transcript with an example of manual coding, and initial codes being transferred into focused codes.

Initial code	Excerpt from parent co-researcher transcript	Focused code
Having options Being guided confusing terminology going along with what is said Lacking confidence Disengaging + agreeing using conversation	was a hot, it's kind of hard to kind of keep up and to actually kind of engage in it, I suppose. Because it's a it's a bit abstract is a bit kind of, yeah, let's let's do that. And I'm like, Yeah, okay. Sure. I don't know. So I just I think what ▬▬ does I mean, they definitely do are. But I can't say I honestly have really engaged in it that much. I don't know why I happen. Partly because I don't, I don't feel like I'm able to confidently say what I want to happen, but also, I don't know. I think maybe maybe it wasn't face to face. I can't actually remember if I'm honest. But I think this conversation would be easier than a write down what your goals are. I think I've definitely had one where you have to kind of list a few	feeling unsure Disengaging + going along with it. Having conversations

Figure 9 Example of transcript with initial and focused codes assigned

Codes were analysed, compared, and reanalysed as new data was generated. During the analysis, codes were mapped together to explore the relationships and generate further lines of enquiry. Figure 9 presents an example of mapping codes generated from parent co-researcher meetings and exploring the relationships between them.
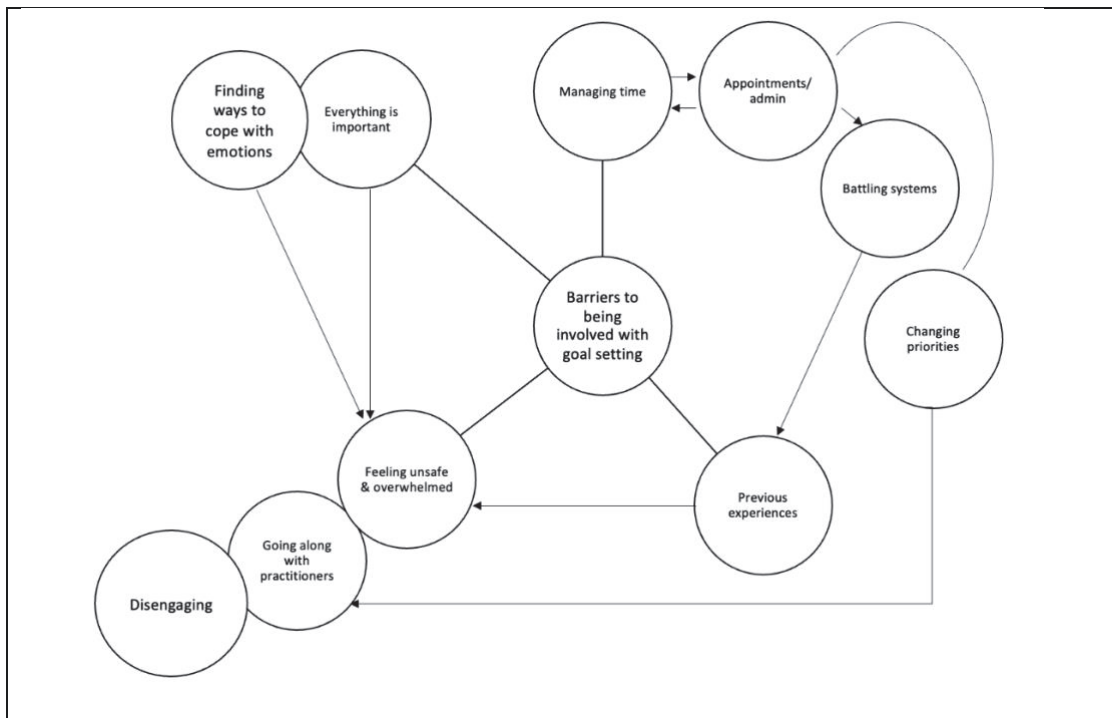
Figure 10 Exploring the relationships between codes

The iterative cycles of action and reflection dovetailed with the iterative cycles of data collection and analysis. The systematic process of constructivist grounded theory methods assisted with analysing the data generated from the participatory action research meetings and actions carried out within the school as a result of the meetings. Transcripts were re-read, and audio recordings re-listened to ensure the co-researcher voices were not lost and to maintain constant comparison of the data. Memo writing, an important component of analysis (Charmaz 2014) assisted the researcher with engaging reflexively, asking questions of the data which served to support the analytical process of transforming focused codes into theoretical codes and concepts that would develop and refine theoretical categories. Memos were written throughout the research and kept as a journal log as a way to constantly ask questions of the data and enable reflection of my own assumptions and attitudes, especially as I was conducting research in a familiar environment and had previous experience of goal setting processes. Figure 10 presents an example of a memo, demonstrating questions raised from the code relating to 'time' being investigated and analysed following on from a practitioner co-researcher meeting.

16.09.2020: Memo
It came up in the discussion today that the LSAs who are trained in Talking Mats are concerned about getting the interviews with the pupils carried out during the first review week. This does take time, but the issue of time is always there. It seems that expressions of lack of time is a form of comfort blanket, almost an excuse to account for not getting things done. What are our priorities? We say that they are the voice of the child but before its even begun there are issues raised about not having the time. What are we most concerned with? How can we do this more effectively?

Figure 11 Extract from memo following a practitioner co-researcher meeting

Taking field notes was also an important aspect of the research, serving to help describe and position events and act as a conduit for reflexivity (Montgomery and Bailey 2007). Figure 11 presents an excerpt from a field note written following a practitioner co-researcher meeting.

04.09.2019: Reflection of parent and child involvement
There is no established system of involving parents or pupils in discussions about goal setting. The pupil voice is considered as important as the parent voice but communication challenges makes this a longer process that requires training. Methods to obtain the pupils views are being used but to evaluate how they thought they did the end of that session rather than how they feel overall about their achievement of the goal. This is a tokenistic approach to gathering people views, the information that the pupil provides is not recorded anywhere. Parent collaboration is highlighted as something that is being insufficiently addressed but the processes are directing how time is used. The tension that priority should be given to the pupil and families thoughts for goals, not just agreeing to them but being involved in initial discussions. Parent meetings are arranged after the review weeks, this does not give parents the opportunity to discuss goals at the outset. Parents want to be included but they want guidance from staff who really know their child. Time to discuss goals outside of structured and process driven meetings enable the parents to be more available and willing to openly discuss the aspirations of their child.

60

Figure 12 Excerpt from field note following a practitioner co-researcher meeting

As the action research meetings progressed, codes generated directly from the data, field notes and memos were integrated, and further mapping took place. This reanalysing and reassigning codes using constant comparative analysis to locate relationships, seek out literature to position the data to ask further questions of it, and develop them into theoretical codes. This process elevated the codes into tentative categories. Figure 12 shows an example of the manual and printed focused coding being analysed and developed theoretically. This process facilitated the development of the categories and subsequent core category, providing the foundations for the goal setting framework. This image also represents the 'messiness' of the research. My attempts as a novice researcher, conducting research in the environment whilst simultaneously working as a therapist and utilising two methodologies was at times challenging. Whilst acknowledging the research would be a co-construction between myself and the co-researchers as previously discussed, I found the process of writing reflections and keeping a log of my own experiences useful in helping to maintain some objectivity of the data.

Figure 13 Example of linking codes with codes

4.6   Conclusion

This chapter has discussed the methodological processes involved for this research and the application of constructivist grounded theory to support the participatory action research. It has considered the ethical implications of carrying out a study within the researcher's place of work, with co-workers, families of pupils who attend the school and pupils themselves. It has provided an outline of the co-researcher groups and described the data collection methods and data analysis processes. The processes described demonstrate how the research was guided by the iterative cycles of grounded theory and combination of coding, memo writing, and constant

comparison of data, and the development of tentative categories were constructed from the cycles of action and reflection.

The cycles of action and reflection provided the co-researchers' with space to engage reflexively on current practices, generate ideas for improving what was already in place and being able to act on them. As the research progressed, I became more comfortable with being uncomfortable with the complexities and 'messiness' of the theoretical and practical challenges of combining grounded theory and action research. I was mindful of needing to adhere to both research approaches and at times felt unsure of what was considered participatory action research and what was constructivist grounded theory. However, they both served a purpose to help understand and contextualise the actions and reflections of the co-researchers, seeking out further lines of enquiry as they occurred and achieve the intended aim of creating a goal setting framework. The findings from the action research are now presented in chapter 5.

Chapter 5: Findings

5.1   Introduction

Chapter 5 presents the research story of the co-researcher teams' behaviours and social processes concerning goal setting and evaluation, focusing on the issues raised and theoretical concepts that underpin the development of a framework to help improve practice. It outlines the issues that were identified through the cycles of action research and how the iterative process of constructivist grounded theory methods of data collection and analysis complemented the cycles. This served to demonstrate that as the meetings progressed, issues concerning goal setting and evaluation evolved into a multidimensional interpretation of actions. In line with the inductive approaches for both action research and grounded theory, there were no pre-conceived ideas as to what this framework would look like or what it would contain, it would be a product of the co-researchers. This chapter is structured by initially presenting issues that underpin the action research story whereby practitioner and parent co-researchers, and to a lesser extent pupil co-researchers, converge and diverge regarding perceptions, assumptions, and experiences. Each issue is then explored conceptually in chapter 6 and situated within pertinent literature to discuss actions and develop theoretical concepts that underpin the development of the goal setting framework.

5.2   The co-researchers

The action research began with purposeful sampling and recruitment of the practitioner co-researcher group as they assumed responsibility for ensuring goals were set and evaluated, and, took a lead role in directing parent and pupil involvement. Each action research meeting was transcribed, employed initial and focused coding and utilised the constant comparative method of analysis in line with constructivist grounded theory principles to guide further discussions and begin to generate theoretical concepts (Charmaz 2014). This helped to make sense and grapple with what was happening during the cycles of action and reflection. As issues were identified and required further exploration, additional co-researcher groups alongside the practitioner co-researcher group were introduced by means of theoretical sampling (Charmaz 2014). The parent co-researcher group was introduced followed by the

pupil co-researcher group. The pupil co-researchers were introduced towards the latter stages of the study, offering a more subtle voice presence compared with the practitioner and parent co-researchers. Extracts from the transcripts are presented throughout this chapter to emphasise and act as examples of the multidimensional perspectives and voices of the co-researchers.

5.3 Re-framing research aims and objectives

The research aims and objectives were reframed into questions, presented in Table 6, and used implicitly to facilitate but not restrict the initial discussions. They were used in this way to act as prompts for the researcher to generate conversation rather than using a formal set of questions. The questions posed were adjusted to match language and terminology that were familiar with the co-research groups (Charmaz 2014) for example, using different terminology with the practitioner researchers who may use discipline specific language in their usual practise but avoiding jargon with parents.

To explore the dynamics and discourse that are manifest within the school based transdisciplinary team to develop a framework for goal setting and evaluation
Who determines the focus of goals?   What are the perceptions and attitudes of contributors to goal setting and how do these compare or contrast with one another?   What facilitates or acts as barriers?

Table 9 Research aim and objectives re-framed as questions

5.4 Duration of the action research

The action research spanned two and half years, and although the research element came to an end in 2021, the action research within the organisation, specific to goal setting and evaluation remains active and ongoing. As previously discussed, the global pandemic impacted the momentum of action research group meetings for some months during 2020.

5.5 Issue identification

Issues raised by the practitioner co-researchers centred on the conflict between desired and actual practice: what they wanted or believed they should be doing within the constraints of a setting that provided education and therapy, compared with what they were actually doing. The parent co-researchers described conflict between the expectations placed on them as a parent of a child with additional needs, the perception that they should understand their child's condition, and therefore know suitable goals to focus on, and how they actually felt. The pupil co-researchers contributed to the study towards the end of the action research and although were less involved with the identification of issues, their responses to the actions carried out are told through the experiences of the practitioner and the parent co-researchers.

The re-framed objectives facilitated exploration of the issues raised to assist with understanding the meaning behind them and find ways to address them. As the action research progressed, the iterative cycles gained traction, and the issues identified were organised into the following broad concepts: *Competing demands on time, importing emotions, missing what's important,* and, *using the right language.* Each of these issues is now discussed as separate entities; however, as is demonstrated in the spoken examples, the issues are intimately connected, bringing together the multifaceted perspectives of the co-researcher groups that when combined create the team that aligns with a family centred approach.

5.5.1 Competing demands on time

Assumptions about the use of time interrupted the flow of communication between practitioners and parents and featured frequently. Burdens expressed by practitioners focused on the effective use of time available for both evaluating current goals and setting new ones, and how to best capture the voice of the parents and pupils. The burdens of time expressed by parents related to the already time-consuming effects of parenting a child with additional needs, the methods which practitioners used for engaging them in the goal setting process and the emotional impact of this.

The most challenging aspect for practitioners was how to include the child and parent voice within restricted timeframes that were both internally (school) and externally (local authority) enforced deadline drivers.

The pressures of time experienced by practitioners dictated their interactions with the parents. Practitioners spoke of not having enough time or running out of time to involve the parents, reporting that as deadlines were tight, it was often the parent and pupil involvement that was excluded as this was time consuming and easier to omit. This created a source of frustration due to priorities not favouring the parent and pupil voice:

> *"whenever there's a pinch when it comes to time it seems like children and parents might get pushed out a little bit because we're short on time. We know it's easier to get some staff members opinions and then take that to develop it rather than the parents and families, but it is actually the children and the parents' opinions are vital for the goals." Pr2*

Practitioners spoke of an awareness of the impact that not including the parents had on the creation of goals, and how not providing the opportunity at the outset could influence the relationship between home and school:

> *"You're giving them goals that you've set, is that influencing that they're holding back what they really want to say or is it influencing what they want to do or not want to do?" Pr5*

For parents, the demands of parenting a child with additional needs, ranging from negotiating the myriad of medical appointments, EHCP reviews and reports, and managing the additional time required for supporting their child with activities of daily living contributed to challenges of

engaging with practitioners concerning goal setting. However, the most significant impact on parent engagement was the timing and delivery of information about their child.

Parents spoke of an awareness that practitioner time was limited but felt that they would engage better if the time available was used differently. Parents spoke of wanting support from practitioners to help them understand their child's needs and welcomed suggestions of areas that could be a focus for the goals. However, the delivery of this information influenced engagement. Parents felt that they were less engaged with the processes of goal setting when they were sent through information rather than being consulted in person. Written communication tended to include more jargon, which parents found difficult to navigate. Parents spoke of profession specific language that was often used, and if not understood, could further alienate them from feeling confident in their ability to discuss their child's needs and wanting to engage.

Digital communication, which although was perceived as a good use of time by practitioners, failed to consider how this may be received by parents and the emotional implications of this. The following excerpt is from two parents discussing digital communication versus in person:

> *"I think I would like less paperwork; I find it easier to engage if it's a conversation, but that might not be the same for everybody" Pa1*

> *"No, I would agree…you need that conversation because translation and interpretation of written words can be very different and especially for parents where their emotions are high." Pa2*

The time available dictated the actions of the practitioners which inadvertently marginalised the pupil and their family because their voice was not being heard, even though the values of the organisation aligned with a family centred ethos. Digital communication within the school evolved to become the main method of practitioner-parent liaison, this reduced the amount of

68

personal contact resulting in feelings of isolation by parents from the team supporting their child. This caused parents to feel less willing to contribute their thoughts during meetings, resulting in parents actively removing their voice from discussions. Even when parents reported to know the practitioners relatively well, receiving an email or letter asking what they would like for their child was considered a task that felt uncomfortable due to the perceived expectation that they should know exactly what they want their child to achieve.

5.5.2   Importing emotions

The emotional entanglement, and very personal journey of having a child with additional needs, including the coming to terms that their child's life experiences would likely be very different to what they imagined influenced parent interactions with practitioners and disclosure of how they honestly felt:

> *"…because you guys are the experts and I am definitely not. Also, I will come with emotions, and be like, oh, this is what I really want, and then it's not achievable. I think that would just be for me." Pa2*

Without wanting to put the parents under pressure, practitioners felt they were taking a softer approach by sending out forms for them to fill in about their child, demonstrated in this practitioner's suggestion:

> *"We want to include the parents as a first step, ideally a meeting but could send out an email, or a letter, fill out a form. Not that you want to pressure them, it's not like they must do it, more like…here's something, return it if you want." Pr3*

However, the method that parents preferred to receive or discuss information was not considered. This resulted in parents being perceived by practitioners as disengaged; and practitioners being perceived by parents as distant, suggesting a disconnect between practitioners and parents.

69

Although receiving an email was time saving, it removed the opportunity to have open discussions that would facilitate parents feeling emotionally protected to express themselves fully. The challenge of receiving a document that outlined new and evaluated goals instead of having a face to face or telephone conversation, created a barrier for parents:

"The whole process can be overwhelming and difficult to understand, it's so much easier if you can talk with someone about it." Pa2

Goals were evaluated by practitioners without parent involvement, and if a goal was not achieved, or was changed, parents spoke of not being informed why this was the case, nor feeling there was the opportunity to ask why which further impacted on engagement as described here:

"Sometimes the goals just change to something completely different, and you just see it on a piece of paper without knowing why they did change. Without talking to someone it makes it hard to know what's going on" Pa1

Annual EHCP review meetings were the only consistent forum for discussing goals. Parents expressed how the structure of the meetings influenced engagement. The meetings involved parents listening to what their child was unable to do, and then felt the expectation that they should know what an achievable goal would be. Parents spoke of a history of speaking with many practitioners before their child reached school age, and by this time, they had experienced many meetings concerning their child's difficulties. Parents described feelings of sadness during these processes and for ease, would go along with whatever the practitioners suggested:

"I feel like I'm being asked to do something that I don't really know how to do. I don't know how to set goals for him because like, you guys are the experts and know his body. I have my own goals, I know what I would like for him, I don't know if it's realistic…and so what I tend to do, which is a bit awful, but across the people who have seen him, I just say the same goal because I don't know what I'm doing." Pa1

However, practitioners actively involving parents and pupils was also influenced by previous experiences of goal setting. Whilst some practitioners spoke of parents accepting whatever was suggested for a goal resulting in little need to involve them, conversely, there had also been difficulties experienced with agreeing on what was important, and expectations were not always attainable, causing reluctance by practitioners to engage:

"There's not enough time to ask parents as well, the aspiration of the child or parent might be quite unrealistic or be sort of unrelated to what we're doing, it will be different." Pr5

5.5.3 Missing what's important

Practitioners spoke about the absence of the pupil voice in formulating and documenting goals, and once the goals were set, the potential for spontaneity felt stifled. Even though some pupils actively contributed to what they would like to concentrate on during lessons, and could self-evaluate their performance, it was perceived by the practitioners as competing with goals that had already been formulated and was a source of frustration for them. Practitioners felt that the limited number of goals permitted for each pupil narrowed down opportunities for pupils to be more engaged with what they actually wanted to do, and for some lessons, practitioners felt the goals were not relatable to the existing goals. It was during these moments that practitioners invited pupil opinion which demonstrated insight into what motivated the pupils:

"I just happened to ask [pupil] because I was like, what am I going to do with you? And she was like oh I could do my walker and I was like yeah!" Pr4

The number of goals permitted for each child was raised as an issue. Practitioners spoke of frustrations with achievements not being able to be recorded due to the narrowed focus of only having four specific goals, with only one goal being attributed to each of the EHCP outcomes, limiting the scope of what could be formally worked on. Although fewer goals made the administration aspect more manageable, there was a frustration that smaller, discreet achievements were not able to be captured. The underpinning skills of the goals which although may be small, could also be big achievements in their own right:

> *"What you (referring to a practitioner) do is so good but then we don't' do anything with what we see they can do but we're not recording it…it doesn't go anywhere." Pr6*

Practitioners wanted to be able to monitor progress over different time periods, to establish how environmental or physical conditions could impact on achievements. Variables such as how well a child slept or how different sensory inputs may help or hinder were not routinely recorded and therefore often not considered when assisting with understanding why a goal was or was not achieved.

5.5.4   Using the right language

Finding ways to support parents and facilitate engagement, whilst being mindful of deadlines were central to the next series of meetings. Practitioners spoke of creating a sense of shared ownership of goals between parents, pupils and practitioners, and creating an environment that each stakeholder could provide or receive the support that met each individual's needs. Discussions concerning goals in general, and the need to make them more relevant to the family were assumed to naturally facilitate more conversation and increase interaction with parents as this would create a collaborative ownership of the goals, rather than have school as the main focus:

> *"Taking your dream and having someone help to unpick what is important at that moment…having these conversations with someone who really knows the child." Pa1*

This shifted the focus from practitioners initially wanting to capture the influencing factors of goal achievement to being more intentional with articulating the underpinning components of the goal, re-framing them into smaller steps, how these could be achieved and ideally, developing these with the parents. It was hoped that focusing more on the achievements, and how steps towards them could be integrated into daily life in different ways would enable parents to feel that the goals were more accessible and relevant. This in turn would support the development of parent's understanding of their child's condition, to feel more emotionally secure and develop trusting relationships with staff.

The type of language used was important to parents as was acknowledging that they can feel vulnerable in large group situations when their child was discussed. Parents again spoke of needing to feel safe in order to then be able to engage honestly with practitioners. When asked about the timing of discussing goal setting that usually occurred during annual review meetings with many practitioners, parents felt that the current system did not facilitate engagement. This parent describes how she felt about being asked to comment on her child after she had listened to various practitioners discussing the challenges preventing participation:

> *"Emotions can get in the way of answering that realistically, I don't have an answer for when is best to talk about goals, but I would say definitely not at the end of the meeting when you've just heard how hard everything is…If you've been in the review meetings, they can be really awful, because you spend an hour talking about how your child finds things difficult…and you know, it's just awful to then be asked what do you want for your child?"Pa1*

For this parent, the language that practitioners used, implied an expectation to think of her child in the same way they did which she found difficult as expressed here:

73

"As a parent, I find it hard to be objective…because when you fall pregnant, you have this picture as soon as you know, of what your child's future will be, like right up to marriage and beyond. So, when it's not that you have to really battle with that image still…because it's a grieving process. So it's really hard to be objective when there's part of you still grieving. And I think it's a lifelong grief, that does pop up at times. So it's this, you need to really feel safe and secure with the people asking to be able to give an answer that is honest" Pa2

The current system of goal setting and evaluation occurred through a method idiosyncratic to the school and had been utilised for a number of years. The measure of success was based on support from an adult rather than focusing on independence of the child. Although a reduction in support may be a way of measuring achievement for some goals, it was considered not appropriate for all. Practitioners argued that using a widely known and established method of writing goals, such as Goal Attainment Scaling (King, McDougall et al. 2000) would better support clearer measurements of change.

The timing of writing and evaluating goals was also a challenge for practitioners. The current goal setting system of evaluating and setting new goals were ring-fenced to specific points during the school year and frequently did not align with the annual EHCP reviews which occurred throughout the year. However, some practitioners who also had the role of team leader, welcomed the structure of specific times to review and set new goals because this ensured that the tasks were completed, and deadlines were met:

"Can I just say as a teacher team leader it's useful because when you get to annual review, you're not chasing people to fill in the bits in the individual learning profile" Pr4

5.6 Conclusion

This chapter has focused on the story and findings of the research. The demands on time were central to how practitioners set and evaluated goals, and how they included the family voice which caused tension between what practitioners wanted to be able to do and what was feasible within the constraints. However, the electronic systems of communication utilised by the practitioners to make the processes more succinct and manageable within the time available, did not meet the emotional availability of the parents. They preferred in person communication, demonstrating that the timing of asking about goals is linked with how using language facilitates or hinders engagement from parents. The concepts: *competing demands on time, importing emotions, missing what's important,* and *using the right language* captured the essence of the story told by the action researchers. Chapter 6 analyses and positions the story whilst providing a background to the theoretical areas that structure the proposed grounded theory: Navigating the Family Centred Practice Narrative.

Chapter 6: Analysis

6.1   Introduction

This chapter presents the grounded theory aspect of this research, providing a concise analysis of the categories introduced in chapter 5 that underpin the core category titled Navigating the Family Centred Practice Narrative. The categories: *Competing demands on time, Importing emotions, Missing what's important,* and *Using the right language* are initially discussed separately to analyse and define their position within the research. Each category is explored to understand how actions or interactions between practitioners, parents and pupils may act as determinants for enabling or disabling participation in constructing meaningful goals. This is discussed in relation to promoting social inclusion or risk leading to occupational injustices associated with marginalisation, alienation, deprivation, or imbalance (Townsend and Wilcock 2004).

The categories are presented utilising direct quotes from the raw data from which they arose, thus demonstrating that they are grounded in the data. The chapter concludes with demonstrating the relationship between the categories and connects them to present the grounded theory (Figure 13). This leads to the suggestion that depending on *who* is involved and *how* it is orchestrated, goal setting may be viewed as a catalyst for facilitating or hindering occupational justices. This serves to underpin the foundations of the goal setting framework which is then discussed in chapter 7.
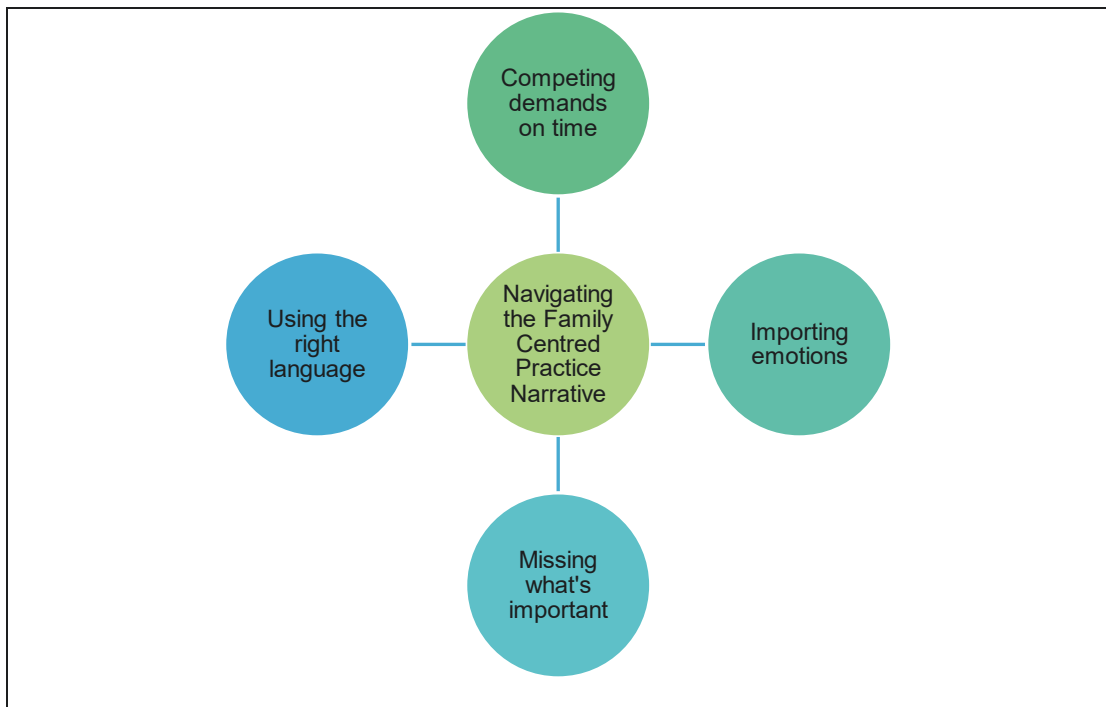
Figure 14 Representation of subcategories and the core category

6.2 Category 1: Competing demands on time

The competing demands on time experienced by practitioners and the impact of their decisions generated conflict between expectations and the reality of being able to deliver a family centred service that according to Al-Motlaq, Carter et al. (2019) is fundamental to paediatric rehabilitation. The competing demands on time may be seen to become polarised between time as linear or objective, such as "clock time" and relational, subjective experience. It is acknowledged that they are experienced simultaneously and not as an either/ or (Shipp and Jansen 2021), for the purposes of describing the competing demands on time, the dominant form of time that appears to affect the practitioners or parents is the focus of analysis. The competing demands on time considers the interactions between the parents and the practitioners but also between the practitioners themselves. It must be noted that the dominant form of time informing practitioners is that of objective 'clock time' whereas parents are informed more by subjective time which appears as the dominant form, even when practitioners are conscious of taking onboard the views and input of parents and children.

Objective time is represented by the deadlines imposed by the organisation which dictates that practitioners have a finite time available to set goals. Within the organisation the timeframe allotted for goal setting is two weeks. The use of time by practitioners is therefore mediated by how much objective time is available and how the priorities are structured. The question of who to involve and the organisation-imposed deadlines both influence the goal setting process and become accelerated as the deadline approaches. Figure 14 demonstrates an example of a visual representation of 'Competing demands on time'.
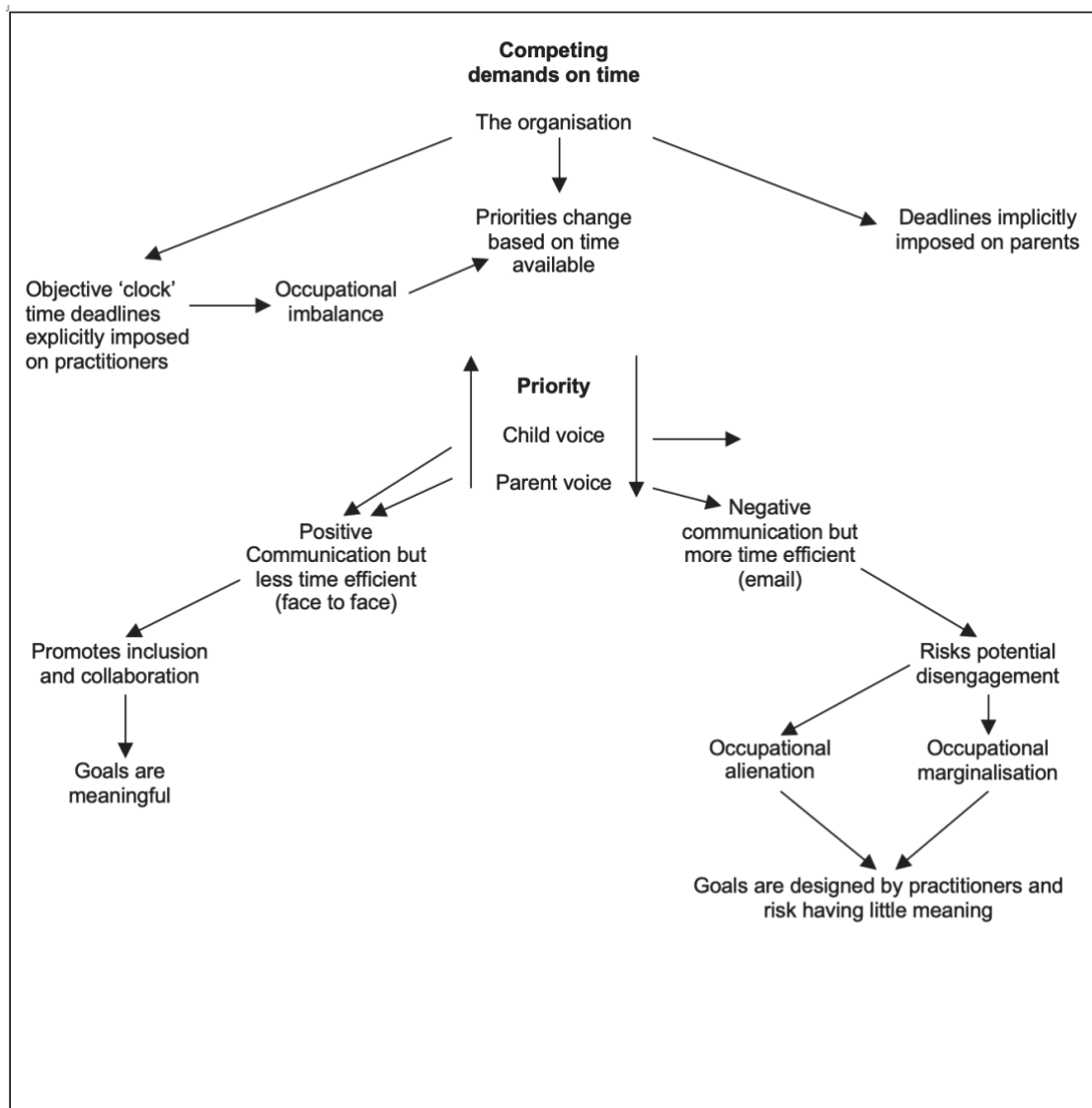
Figure 15 Visual representation of Competing demands on time

Studies that have referred to time as a barrier to practitioner – parent collaboration, from the perspective of the practitioners, focus on the objective and deadline driven effects of time, citing lack of time (Coyne 2015), time available to transfer ideas into functional goals (Bexelius, Carlberg et al. 2018) and time management (Grant, Jones et al. 2022). The parent and child's opinion and their contributions to goal setting although valued, adds extra demands on time which becomes problematic for practitioners. Working practices are influenced by the organisations where practitioners work (Jackson 2015) and demands on objective time appear to further influence priorities which again leads to the tensions of what to prioritise. The demand on time also affects collaboration between practitioners and highlights how objective time, and the availability of time influences collaboration as described by this practitioner:

"Getting together it can be quite difficult because these goals really rely on a lot of collaboration with teachers and therapists, and it's difficult with part time staff, working different days, not all of us being able to meet." Pr7

The concept of subjective time appears to compete with organisational deadlines, and the evidence-base that underpins supporting the inclusion of parents and children in decisions (Brewer, Pollock et al. 2014). The challenges of time pressures directed by individual roles and responsibilities and the culture of the organisation resulting in frustrations concerning the different prioritisation of time was expressed by some practitioner co-researchers. A dialogue between these practitioners demonstrates the conflict between what was considered important and necessary compared with what was considered achievable and realistic. This practitioner considers the practicalities of goal setting and the parent and pupil involvement:

"The biggest concern for me is the students and the families input into the goals. Often because of time pressures, they're not a priority. I think the priority and the goals should come from dialogue with the children and the families". Pr6

79

This practitioner reflects on the processes that influences whether or not the pupils are included:

"I find that having three assessments throughout the year for all the students adds pressure and stress, I find it awkward that we assess all of them at the same time, and because of this, the attention we end up giving to the children is diminished." Pr4

This practitioner, who has an additional management role of team leader takes a different perspective and considers the benefits of the processes in place:

"Can I just say, as the teacher-team leader three times in the year is useful because when you go to the annual review you are not chasing people to fill in their parts of the paperwork that you have to present to parents and the local authority. So that's a huge amount of work saved as it saves me chasing people because previously it was a very big job to get the paperwork completed in time." Pr3

Challenges faced by school based practitioners aligning their practice to a family centred approach due to conflicts on time demands has also been reported by Fingerhut, Piro et al. (2013). School based therapists typically have less contact with parents compared to clinic or home-based settings and children with EHC plans are increasingly travelling to school on transport provided by the local authority. This removes the opportunities for incidental parent – practitioner relationships to form and impacts on parent experiences of interactions with practitioners. The impact of the lack of time spent between practitioners and parents and how this affects parents understanding their role for supporting their child is reflected in the study by Coyne (2015) and demonstrated through this parent's reflection of previous experience of health professionals:

"We always try to understand as much as possible. We were really lucky when she was born, she was in hospital and they said to us, ask questions, never stop asking questions, try and understand everything. So we did, and yet we experienced another

hospital and they weren't anything like that. It was like, we do this and you just come

in and do the parent bit." Pa1

The methods of communication, such as email to replace face-to-face meetings when time is limited, is appealing and in principle may tentatively act as a compromise serving to demonstrate collaboration, a key characteristic of family centred practice (King and Chiarello 2014). Although this may be appropriate for some, there remains a risk of parents feeling overburdened (Al-Motlaq, Carter et al. 2019) which may be further exacerbated by the communication methods utilised. Historically, digital methods for communication were considered a risk to further marginalising already marginalised groups due to poor internet connection and access to equipment (Dodsworth, Bailey et al. 2013). However, the general increase in usage of digital technology as means of communication has accelerated rapidly due to the global pandemic in 2020 with guidance to stay at home elevating the use of technology for communication (Nguyen, Gruber et al. 2020). It appears that the processes which parents receive information, and the purpose of the communication is what influences engagement and if perceived negatively risks disassociation and self-imposed alienation from goal setting.

One parent described the how the responsibility of being asked her opinion about what she would like her child to achieve via an email demonstrated the mismatch between communication purpose and communication method which caused her to disengage and is suggestive of self-imposed alienation:

"I can't say I've honestly engaged in it that much, partly because I don't feel like I'm

able to confidently say what I want to happen, it wasn't face to face I think a

conversation would be easier than writing it down". Pa1

In this instance, the method of communication caused the parent to withdraw, and *"just go along with it" Pa1* effectively alienating herself, and her child from collaborative goal setting.

81

Replacing face to face discussions with emails that are directed by demands on time may present as an appropriate compromise. However, this omits to value how information is received, and the expectations experienced by the receiver which eliminate the nuances of body language and empathy that facilitates trust and nurtures collaborative partnerships (Korstjens, Mesman et al. 2021).

A synthesis of the literature and researcher responses supports the contention that time is not linear and although the organisations set rigid deadlines, the difference between clock time and relational time needs to be considered within the goal setting process. Practitioners need to negotiate objective time demands that are externally imposed as this affects the relationships that can be formed with parents, as well as inter practitioner relationships which may disempower and disengage and is contrary to family centred practice (King and Chiarello 2014). Greater emphasis is required by practitioners on the subjective time under which parents appear to operate. The lean towards subjective time by parents is demonstrated through the parent co-researcher quotes presented throughout this study that places emphasis on spending time *with* practitioners to discuss goals rather than *how* to use time most efficiently. This aligns with similar findings by Coyne (2015) who reported time use by practitioners acted as a barrier to collaboration.

The increased demands placed on parents of children with additional needs includes the number of appointments and the often ongoing support or supervision for activities of daily living (McCann, Bull et al. 2012). These additional time demands have been found to impact on the amount of leisure time available to parents (Van der Putten and Vlaskamp 2016) and although the parent co-researchers in this current study did not explicitly discuss how their wellbeing was affected due to the additional demands on their time, having reduced leisure time potentially restricts the opportunity for participating in occupations that support health and wellbeing of the parent (Van der Putten and Vlaskamp 2016). Furthermore, low self-esteem and perceived stigma associated with having a child with disabilities can induce parent isolation (Cantwell, Muldoon et al. 2015) which may further limit opportunities for parents to engage in

82

occupations that support wellbeing, including those which offer peer or family support and which can help reduce parent stress (Wang, Huang et al. 2020).

The competing demands on time appear to act as a stimulus that restricts opportunities for parents to participate in occupations of personal or social interest and potentially risks occupational deprivation and self-isolation leading to self-imposed occupational alienation. This subsequently affects opportunities for relationships and social supports that would otherwise serve to facilitate improved mental health and reduce stress.

The effects of the time available that are imposed by the organisation and filtered through to how practitioners engage with families may be comparable to the practitioners experiencing occupational imbalance and having 'too much' to do resulting in actively removing or adjusting the means for engaging parents. Thus, reducing the opportunities for parent voices concerning goals that were meaningful to them to be heard and effectively caused the parents to become marginalised. Furthermore, if the methods of engagement utilised by practitioners, due to the time saving efforts did not meet the expectations of the parents, this leads to a sense of isolation and disconnectedness resulting in them being unable to share what was important. This may result in disengagement and invoke a sense of occupational alienation from the community (the school) of which they and their child are members of (Stadnyk, Townsend et al. 2013).

This category has demonstrated that how practitioners use time, has the ability to strengthen or weaken relationships, the potential to increase or decrease collaboration and family centredness, and promote occupational justices or injustices. It is argued that the purpose of the communication relating to goal setting and the level of interaction assumed should drive the method used and not be dictated by the objective time available. It is postulated that if time available dictates the delivery of information and does not match with the communication method and expectations that parents feel able to cope with, attempts made by practitioners of being family centred are compromised and instead risks disengaging parents, inadvertently leading to occupational injustice and marginalisation.

6.3   Category 2: Importing emotions

The category of importing emotions refers to the manifestation of parent emotions during the process of goal setting and how this affects perceived and actual engagement. It is the suggestion that the processes of goal setting, may for some parents, elicit increased feelings of loss and grief due to the very nature of devising a goal; that it is to work towards something that is not yet achieved, for example typical milestones that have been missed. Uncertainty for the future may be entwined in grief and the sense of loss for parents of children with cerebral palsy (Fernández-Alcántara, García-Caro et al. 2015). The coming to terms and uncertainty associated with having a child with additional needs and realising that the otherwise taken for granted expectations relating to typical development is altered and was highlighted during a conversation between the parent co-researchers. This parent describes the internal, yet pragmatic conflict between desires for their child and what may be realistic:

"Sometimes there's a conflict between what we can realistically expect to be achieved, or what could be and then what, as a parent you want. Obviously, I want him up and walking and running around, but I know that's not a good idea though." Pa1

Whereas this parent describes how to manage between expectations and aspirations prior to learning of their child's challenges compared to what they now know and what might be:

"Okay, because I get what you're saying. It's a struggle between a parent and your kind of parental instincts. Like before you have your child, when you finally get pregnant, you have this idea. And it's a struggle between that and what is now reality and what's actually realistic." Pa2

Goal setting requires looking to the future, with current practice recommendations geared toward a strengths-based development approach that focuses on functional outcomes (Rosenbaum 2021). However, if parents are in a position of uncertainty, and between states

84

of what they hope for and what is realistic for their child to achieve, the risk of goal setting becoming a trigger event for emotions relating to chronic sorrow may affect the parent's emotional availability to engage. This could inadvertently lead to self-marginalisation as they remove themselves from being involved in decisions about their child. Figure 15 demonstrates a visual representation of *Importing emotions*.

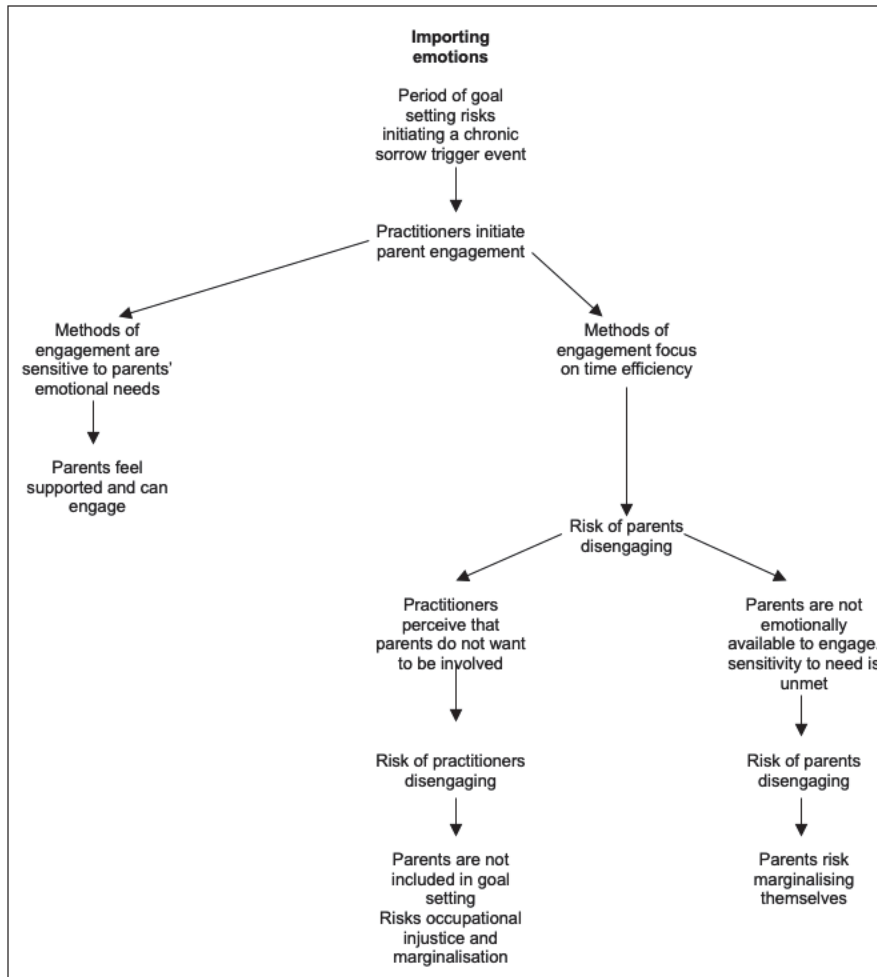*Figure 16 Visual representation of Importing emotions*

The trigger events may also be exacerbated if parents have younger children who are typically developing and surpass the abilities of the child with additional needs. This parent describes their experience of noticing when their child's younger sibling is physically more able and the emotional impact that this has:

"It's that feeling that you try to push away, when you go to that stage where you're like, I just want them to be, I hate to say the word, but normal. It's fleeting moments but I think everyone would be lying if they said they didn't have those moments, knowing that my child would really love to be able to walk and run around like her younger sister and do everything that 11 year olds do." Pa2

Negative emotions associated with chronic sorrow (Eakes, Burke et al. 1998) such as grief and loss are prevalent in parents of children with disabilities and although comparatively limited evidence exists, parents are still able to manage these feelings and demonstrate positivity, strength and optimism for the future (Kearney and Griffin 2001). This was supported in the research by a parent talking about their child's achievement and the joy it brought:

"And actually, when something happens, it's that that you're more excited about it so the other day, my child wrote her name really legibly, like you could make out every letter, and I was so excited, and that might be nothing to most parents but for us it was like we just won a marathon or won first place at something." Pa2

This combination of positive and negative emotions, conceptualised into a model of 'joy and sorrow' has been explored in the work of Kearney and Griffin (2001) who assert that parents associate the joy of experience with their child, and are influenced negatively by 'others' e.g. by the judgement of strangers, that is society. Kearney and Griffin (2001) argue that joy and sorrow experienced by parents of children with disabilities are influenced by one another and do not exist in isolation. From this, it can be argued that the experiences of joy and sorrow in two spheres: the social (what others think) and the physical (environmental barriers).

Physical or environmental barriers within society can limit participation, such as wheelchair or disability inaccessible playgrounds can reinforce the parental experience of loss due their child missing out (Prellwitz and Skär 2016). This may be considered in terms of occupational deprivation and occurs as a result of the environment not supporting the engagement in

86

childhood occupations that are available to others (Stadnyk, Townsend et al. 2013). It is suggested that this deprivation may lead to occupational alienation for the parents as well as the child. If the physical environment does not support the child's abilities, this risks the child being unable to engage in activities the same as their peers which potentially limits opportunities for social interactions and social skills development (Rodger and Ziviani 2006). Furthermore, if the environment is not supportive of opportunities for otherwise typical co-occupations between the parent and the child such as pushing or being pushed on a swing in a play park due to accessibility, it could potentially reinforce feelings of chronic sorrow and be exacerbated by seeing other parents and children sharing occupations that they cannot.

The impact of reduced opportunities for social skills development and the increased potential of challenging behaviour by the child, risks increasing parent stress and render the parent to be less emotionally available to relate to their child which may negatively influence the parent-child relationship (Barfoot, Meredith et al. 2017). As a result, this may affect parent engagement in tasks such as goal setting if the parent finds it challenging to relate to their child and manage the needs they have (Rudebeck 2020). This may lead to self-imposed occupational marginalisation and alienation. Conversely, if the playground is accessible, the opportunities for peer interactions are afforded, co-occupations attainable and parental experience elicits joy. The outcome of occupational justice is social inclusion and this would be facilitated as the parent is observing and able to participate and engage in otherwise typical co-occupational experiences which serves to positively influence the wellbeing of the parent and the child (Rudebeck 2020).

The chronic sorrow framework (Eakes, Burke et al. 1998) suggests methods of management to address emotional balance and to assist families as they move through cycles of grief. Normalising chronic sorrow and acknowledging it as part of the parent experience of having a child with additional needs has been advocated alongside the importance of developing trusting relationships between practitioners and parents (Eakes, Burke et al. 1998, Coughlin and Sethares 2017) and is consistent with the emotional safety that this parent described to facilitate their inclusion in collaborating with practitioners to develop their child's goals:

87

"This is your guy's professional world. And you're obviously and quite rightly, not emotional, about, you know, the children's goals and all that. But just to keep in mind actually, the parents that you're asking might be, so it's just that kind of initial awareness that this might be a sensitive conversation." Pa1

Although this study has focused on mother experiences as both parent co-researchers were mothers, it is important to highlight that according to Coughlin and Sethares (2017), fathers experience chronic sorrow differently to mothers. Reasons for this are possibly because mothers tend to take more of a management role of their child's condition such as attending appointments but also for some, feel a responsibility for their child's difficulties (Coughlin and Sethares 2017). The articulation of emotions expressed by fathers of children with additional needs explored by Pelchat, Lefebvre et al. (2003) were identified as different to those of mothers, as fathers were more reluctant to express themselves emotionally. Priorities relating to the father's role in the everyday childhood occupations of their child may also be different if the father sees his role as provider and instead focuses attention on fiscal responsibility (Pelchat, Lefebvre et al. 2003). It remains unclear how the impact of differing parent roles can facilitate or potentially inhibit child and family occupations when the child has cerebral palsy, including the risks and subsequent impact on opportunities that afford occupational justice.

Supportive people help promote health, wellbeing and social relationships of young people with cerebral palsy (Hanes, Hlyva et al. 2019) and if a parent feels supported and better able to cope, then they are in a better position to support their child and experience joy (Majnemer, Shevell et al. 2008). However, if a parent is emotionally unavailable due to feelings of loss and uncertainty aligned with chronic sorrow, expressing desires for their child through an event such as collaborative goal setting may exacerbate negative emotions and may be more challenging.

6.4   Category 3:   Missing what's important

This category may be understood through the concepts of self-determination theory (Ryan and Deci 2000) as previously discussed, and the how motivations of the child, parent and practitioner relationship interrelates as individuals and a collective, and influences collaboration within a family centred approach. Self-determination theory has previously been aligned with paediatric goal setting (Poulsen, Ziviani et al. 2015, Pritchard-Wiart, Thompson-Hodgetts et al. 2019) and highlights the relevance of external and internal motivations for perseverance and goal achievement, yet its application to practice is limited (Pritchard-Wiart and Phelan 2018).

This study positions 'missing what's important' as a dynamic process between individuals and groups, how the intrinsic and extrinsic motivations each affects the other and considers the social environment as dynamic and changing depending on the position held by the parent, child, and practitioners. The absence of the child's voice in setting and evaluating their goals impacts on the availability of understanding their intrinsic motivations and relies solely on the extrinsic motivations of the practitioners and the parents (Poulsen, Ziviani et al. 2015).The external directive of a limited number of goals and specific points in time to evaluate the goals were, by nature extrinsic motivators of goal setting. These imposed pressures were beyond the control of the practitioners and were passed over as imposed pressures onto the parents and passed through as goals set for the pupils. This domino effect influenced the behaviours of the practitioners, the parents and ultimately the child. Figure 16 provides an example of the visual representation of the intricacies and interplay between intrinsic and extrinsic motivation and how this affects the parent and child voice when deciding goals.

Although family centred practice may be considered an extrinsic motivation and potentially damaging to intrinsic motivation because it is an imposed way of working (Ryan and Deci 2000), it is considered a positive extrinsic motivator that is also embedded intrinsically as demonstrated by this practitioner:

"And even getting children's opinions of how they feel they are doing, that's a bit of data we don't capture which I think we should. It's our opinion about how they've done and one of our things we want to improve on is putting the child at the centre of their goals." Pr6

This parent also compared her experiences of goal setting at a previous school compared with this school and alludes to the relational aspect to motivation of the practitioners to include the parents:

"Before we came here, we weren't given an option…we were told, this is what we think this outcome should be, and we'd just sit there and nod." Pa1
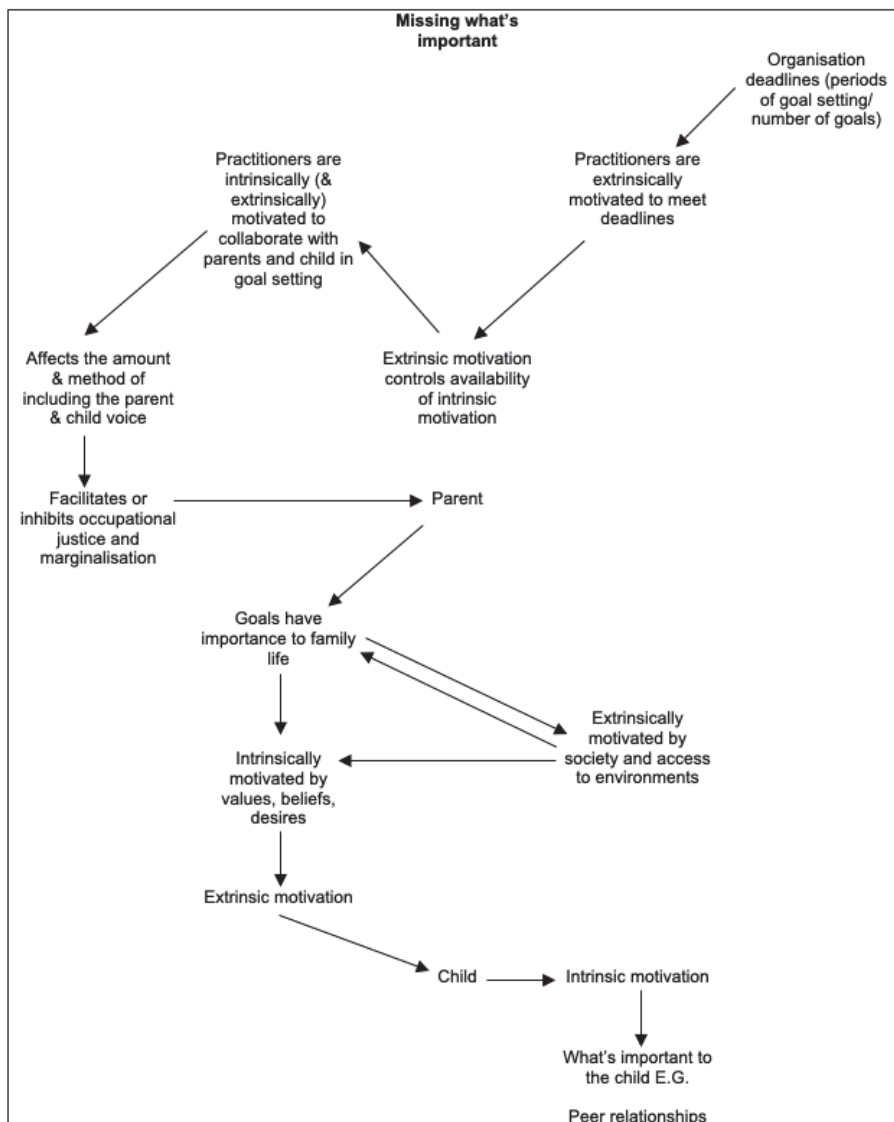
Figure 17 Visual representation of Missing what's important

This highlights the importance of extrinsic environmental motivators, which for this study may include the parents and the practitioners in addition to the physical environment, which aligns with Rosenbaum and Gorter (2012) who highlight the importance of the family environment. This raises the issue of the role that practitioners play when instigating collaborative goal setting and can be likened with facilitating or inhibiting occupational justices. It is suggested that the decisions made by practitioners due to the occupational imbalance of having too much to do, resulting in not including the voice of the parent, may generate in parents the sense of disengagement and reduce opportunities for collaboration risking occupational alienation and marginalisation.

The externally motivated pressures of having a limited number of goals to be achieved within specific and pre-determined timeframes, acted as a suppressant to the intrinsic motivations of the practitioners who wanted to be led more by the child, and by the parents, which if enforced would reduce the risk of occupational alienation and marginalisation. Spaces for spontaneity within the structured school environment facilitated the intrinsic motivation of the child, which enabled practitioners to observe achievements that were not aligned with a specific goal. The frustrations experienced as a result of these observations and how the extrinsic and imposed motivators reduced possibilities of recording what the child was achieving, shows in this conversation between practitioners discussing potential ways to resolve this:

"We set goals for each child that will be reviewed but there's so much else going on that because we've stuck to these goals, we're not capturing that richness." Pr11

"If we're trying to capture the richness of what we're doing, do we need more goals or do we need to be able to capture what we're doing within one goal but have loads of different aspects to it?" Pr2

"What if we can make the goal bigger to capture that richness, and not have the pressure of changing it termly? is that a good expectation? we could keep the amount of goals that we have but make it longer term?" Pr3

The external motivators of being required to set a specific number of goals with or on behalf of their child was also a challenge for parents and the intrinsic motivation in terms of the competency or sense of responsibility for identifying what was most important is shown by this parent:

92

"All of it's a priority and everything is important. I want him to eat with a spoon, I want

him to go to the toilet, I want him to sit up straight, I want all of that". Pa1

It is perhaps challenging to create a small number of goals because of the complexity and diverse challenges associated with cerebral palsy combined with command for goals to be specific, measurable, achievable, realistic and timebound (SMART). Although the SMART approach is still considered a robust method for goal setting with children (Bexelius, Carlberg et al. 2018), the extrinsic imposition that determines the quantity and rigidity of goals reduces the observable fluidity of motivation. Furthermore, the *"richness"* discussed by practitioners is not captured and highlights the priority for eliciting the child's views in order to find out what is important to them.

Self-determination theory refers to individual occupations in terms of engagement through intrinsic and extrinsic motivation. Co-occupations are described as mutually beneficial physically and emotionally motivating occupations engaged by two or more people (Pickens and Pizur-Barnekow 2011) for example, the parent and the child or peer to peer. It is argued that goals which are also co-occupations that have shared intrinsic values, based on personal interests, and are extrinsically supported by the environment and the people within it, provide the opportunities that facilitate those interests, affecting motivation, engagement, and achievement.

The goals need to have relevance to home as well as school (Bexelius, Carlberg et al. 2018). Goals can be structured so that the school environment supports a good balance of extrinsic and intrinsic motivation due to the availability of specialist equipment to facilitate increased independence for using the toilet. However, if the home environment does not have the same equipment, this will impact on the intrinsic motivation on the child and the parents to work towards achieving the goal. The intrinsic motivation of the child to want to use their fork at school because they are also extrinsically motivated by observing their peers using a fork, may

be diminished within the home environment because the extrinsic motivation of their peers is missing. The importance of this is demonstrated by this parent:

"My child can eat with a spoon and fork at school, not at home, he won't. But it's important though that they know that he's not doing it at home because it needs to be achieved in all settings" Pa2.

In this example, it may be assumed that the goal for the child was the engagement in the co-occupation of having lunch with his peers which resulted in the functional outcome of using a fork. However, when the goal of the child is removed, so is the motivation to use the fork. This highlights the importance of eliciting the child's views when creating goals and finding out what is important for them. Making assumptions concerning the motivations of a child can potentially lead to problematic behaviours at home and elevate parent stress (Brossard-Racine, Hall et al. 2012, Rudebeck 2020). This may result in disengagement from goal setting by the parents because it offers little relevance to home life and may be comparable to self-imposed marginalisation or alienation. Furthermore, if the child's views are not well understood concerning what is important for them at home or at school, and the opportunities are not made available, then this risks occupational injustices of deprivation. This could act as a catalyst for challenging behaviours and mental health problems because participation in occupations of choice is restricted. However, when co-occupations between the child and the parents do align, it may account in part for why achievement of goals may not be dependent on whether the child or parents identifies them (Vroland-Nordstrand, Eliasson et al. 2016).

The commitment of parents is necessary for any intervention to succeed (Phoenix, Jack et al. 2019) and as such, it is argued that the concepts of self-determination theory and how external motivation (provided by the practitioners) is presented to and interpreted by parents, can also potentially affect engagement and collaboration. Furthermore, if the goals are challenging to facilitate at home, as per the example above, then parents may be more likely to disengage and withdraw from collaborative goal setting. This suggests that when goals are set, the

94

environment, both physical and social should be considered as determinants for facilitating or preventing occupational justice (Hocking 2017) and if not, can risk self-imposed marginalisation by the parents. Parents and family members are the primary agents of change for their children and strengthening both the child and parent voice in goal setting, makes for a more successful and meaningful goal achievement (Rosenbaum 2022) that facilitates occupational justices necessary for social inclusion. The environment is also a necessary consideration as it includes both physical and social factors, and the ability to participate and promote engagement in everyday occupations is dependent on the context in which they reside (Mandich and Rodger 2006). This category highlights the need for the goals to be developed collaboratively but as has been discussed above, it is suggested that the discrepancy of how the environment supports both intrinsic and extrinsic motivation (at home or school) can promote or prevent occupational justices.

6.5   Category 4: Using the right language

Using the right language refers to how the delivery of and responses to methods of communication can help shape relationships that serve to facilitate or hinder collaborative goal setting. Parents of children with disabilities have more frequency of interactions with healthcare practitioners (Smith and Blamires 2022) and these interactions, including how a child's skills are framed, may either negatively or positively influence engagement (O'Connor, Kerr et al. 2016). This creates the risk of a disconnect or withdrawal if the parent does not feel listened to (Currie and Szabo 2019). Figure 17 presents a visual representation of 'Using the right language', demonstrating the trajectory of processes that can facilitate or inhibit occupational marginalisation. Communication between practitioners and parents, and how this affects parent engagement can be a barrier to collaboration within family centred practice (Smith and Kendal 2018). The mismatch in expectations, based on the misinterpretation of communication may be understood applying the theory of meta communication.

Using the right
language

Language &
communication
used by
practitioners

↓

Informs balance of
power &
expectations

↓

Facilitates or
hinders trust

↓

Risks occupational ← Risks ← Shapes → Facilitates → Facilitates
injustice and   disengagement   collaborative   engagement   occupational justice
marginalisation   relationships
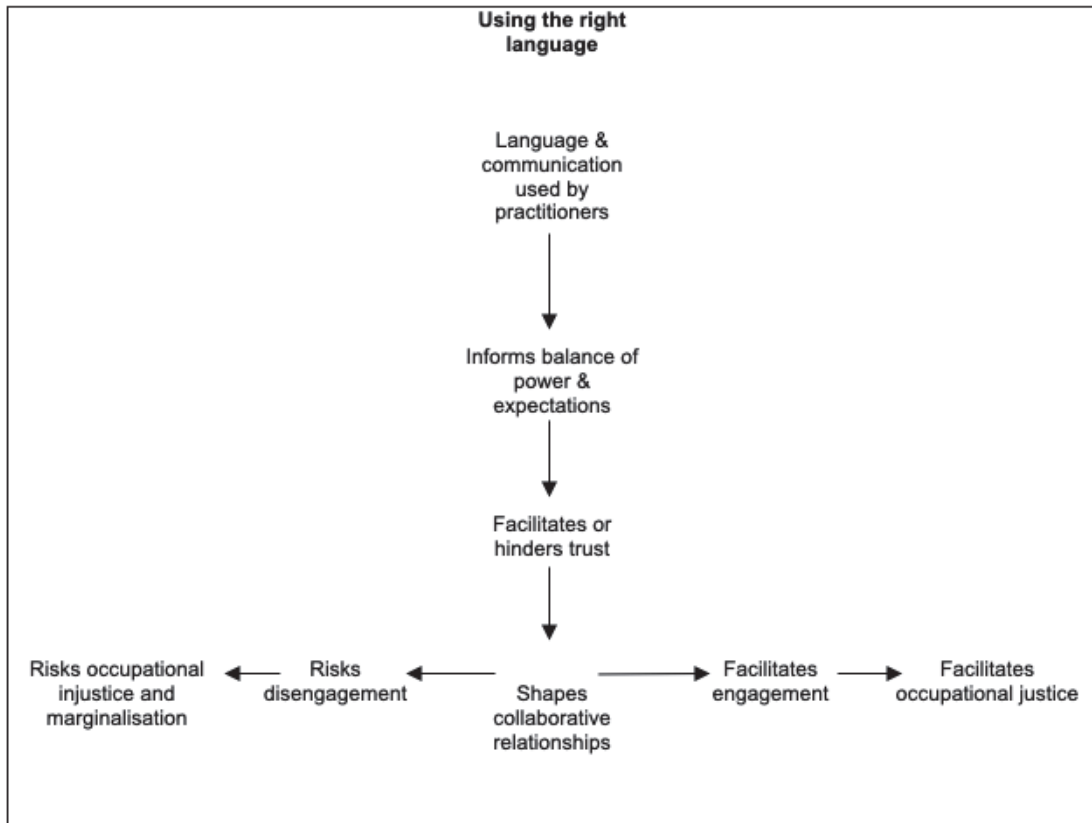
Figure 18 Visual representation of Using the right language

The premise of meta communication as described by Bateson (1972) in his essay : A Theory of Play and Fantasy, is that beyond the explicit words used, language operates on two further levels of abstraction: the type of language used and the relationship between the communicators. Bateson's essay exemplifies this through his observations of monkeys playing and how they interpret actions as play rather than hostile, even when the physical behaviours potentially look the same. The relevance of metacommunication to this study is how practitioners' reactions to time pressures and meeting deadlines, directed how they communicated with parents. The implication of altered communication was demonstrated by this parent when comparing written information with speaking in person:

"Seeing things written down, it can be really hard. Having a conversation with somebody, we get a chance to kind of ask questions or have it just explained a bit easier and in kind of normal language, not report language. You can kind of get to

grips with what's been going on, what has worked well, and also why perhaps things

hadn't worked out as opposed to just reading it" Pa1

The use of language can influence attitudes and behavioural responses (Dickinson, Guzman et al. 2017) which suggests that language used by practitioners to communicate with parents may have aligned more with the metacommunication that practitioners used between one another. This altered the practitioner – parent relationship and affected how parents engaged in goal setting. This may have unintentionally raised the expectations for parents to receive information about their child using language that assumed a position of objectivity, conflicting with their desires for a more emotionally supportive relationship that acknowledged their subjective experience of being a parent. It is suggested that if the language used by practitioners has a negative effect towards parents feeling emotionally supported, this may cause disconnection and isolation on behalf of the parent who may choose to withdraw, resulting in self alienation and self-imposed marginalisation.

This concurs with the assertion by Smith and Kendal (2018) who found that practitioners mediate the balance of power within family centred practice, and their methods of communication affect collaboration. In their study, practitioners sought to empower parents through the responsibility of sharing of care planning. However, for some parents this was misinterpreted and received as an unwanted burden on an already challenging home life. Although communication was raised as an issue concerning collaboration in family centred practice, Smith and Kendal (2018) did not elaborate on reasons for why this may be. This raises questions concerning how the balance of power portrayed by practitioners, may act as facilitators or barriers to engagement and related occupational justices.

The influence of language on developing trust between practitioners and parents also facilitates collaborative relationships (Kasper 2019). The language used by practitioners can facilitate parents feeling emotionally secure so they can express how they feel about their child's abilities and articulate what they would like them to be able to achieve, demonstrated by this parent's response:

97

"It is a lot easier if you have a really good emotional relationship there with the person who's asking you, or all the people that are present know your child really well" Pa1

Furthermore, trusting relationships are facilitated by empathy (Reeder and Morris 2021). Howick and Rees (2017) argue that the role of empathy in communication among healthcare practitioners is not allocated the attention that it deserves. They assert that a therapeutic relationship that is empathetic should be considered an intervention in its own right which corresponds with Reeder and Morris (2021) who argue that developing a connection with parents serves to understand and gauge their readiness for receiving practical information about their child's condition. They propose that instead of a blanket approach to providing information with the expectation that the parents are emotionally able to cope, collaboration should be emphasised less, and guided more by the practitioner until they feel the parent is emotionally ready.

This further demonstrates the role that practitioners assume for mediating the balance of power as discussed by Smith and Kendal (2018) and the practical utility of being led by the needs and emotional readiness of the parent may be restricted by the competing demands on time, including administrative tasks and deadlines (Howick and Rees 2017). Although finding time in an already time limited environment may be challenging, this parent sums up how adopting an empathetic approach to communication generally, can alter how practitioners deliver information:

"I think sometimes the role and where we're coming from changes automatically, the way we speak, the language we're using and I think if you approach from a more empathetic role, your language automatically changes" Pa2

Using the right language, also refers to eliciting the views of the child. Family centred practice assumes that the child voice is integral to effective goal setting as the goals and related

98

interventions will have more meaning and promote increased engagement (D'Arrigo, Copley et al. 2020). However, research conducted with children setting their own goals is limited (Pritchard-Wiart and Phelan 2018) and it has been suggested by Pritchard, Phelan et al. (2020) that the reasons for this are that children may identify goals that are unachievable which may cause uncertainty for parents or practitioners to know how to sympathetically address them. However, in their study, Pritchard, Phelan et al. (2020) found that parents embraced their child's involvement in setting goals, but still wanted the support from practitioners to help frame them due to uncertainty of how achievable or realistic the goals might be. The concern of whether a child's goals would be achievable were also reflected in this study when a parent talked about her child, highlighting that it was the way in which the child was asked:

"In the school before here, they asked the child directly: what do you want to be able to achieve this year. I think it's really hard because they're going to come up with something that's not necessarily achievable. It's more of a dream. In my experience, whatever my child's frustration is at the time will be what she wants her goal to be." Pa2

As part of the participatory action research component of this study, practitioners created goals with pupils using an approach that facilitated the child to be able to elaborate on what was meaningful to them, rather than asking a direct question, and elicit what was important to the child, as demonstrated by this practitioner's response:

"(Child) as I recall, his first goal was about walking, and he was quite clear that he'd had that discussion with lots of people. But when we just kind of went through, you know, out of all of these things you do at school, is there anything else that you want to work on? And the interesting bit was that it was only going through the talking mat that he came up with the fact that he would like to be able to have more privacy in his personal bathing routine." Pr12

99

It is suggested that providing the opportunity to build rapport and trust between the practitioner and the child (D'Arrigo, Copley et al. 2020) and between the practitioner and parents (Reeder and Morris 2021) facilitates effective metacommunication that takes into account the explicit use of language, the type of language used and the relationships between communicators to enable trusting relationships that support collaborative goal setting. The use of language is embedded within occupational justice, and how framing or emphasising ability or disability can impact on engagement (Wolbring and Chai 2016) and highlighted in both the parent experiences and practitioner discussion concerning the process of goal setting with a pupil in this study. As discussed above, where the child's voice was included using talking mats, a widely applied method for those with additional needs for assisting a child to communicate their desires and ideas using a mat and symbols (Mackay and Murphy 2012), it facilitated discussion that led to the emergence of previously unknown areas of importance and independence in occupations of self-care. This led to the potential promotion of occupational engagement in school activities such as independence in getting changed for a swimming lesson and therefore identified the potential for alienation that may otherwise have occurred.

6.6   The grounded theory: Navigating the family centred practice narrative

The core category of this grounded theory 'Navigating the family centred practice narrative' represents goal setting as multifaceted and contributes to shaping the ongoing journey that children with cerebral palsy, along with their parents, and practitioners travel together. The journey is guided by a series of **navigating** instruments directing the boat that is carrying the cargo of goals to their destination and serve different functions that contribute to the overall direction of travel. The instruments for navigation are the team made up of educators, therapists, pupils, and their families, all finding their way across the sea as individuals and as a collective. It is the combination of experiences, expectations, aspirations, and the interplay of understanding of one another's journey that influences the direction of travel, how the goals are devised, and the importance or meaningfulness that is understood and attached to them. **Family centred practice narrative** represents the family centred approach adopted by the school and may be understood as the 'sea' that is navigated by the boat's instruments. In the sea there are undercurrents which represent *Competing demands on time, Importing emotions,*

Missing what's important and *Using the right language*. The undercurrents are present and known about, but if they are ignored or misunderstood, the navigating instruments, that is the presence or lack of parent, child, or practitioner voice, risk the boat going off course into the murky waters of occupational injustice, leading to the shores of marginalisation, deprivation, imbalance, and alienation. A visual representation of the grounded theory is presented in Figure 18. The introduction of this grounded theory demonstrates that interactions between practitioners, parents and children can influence occupational justices or injustices in terms of goal setting. The ensuing justices are considered outcomes that are based on the opportunities presented, whether physically or socially and whether individual or collective desires for achievement are possible through these opportunities (Durocher 2016).

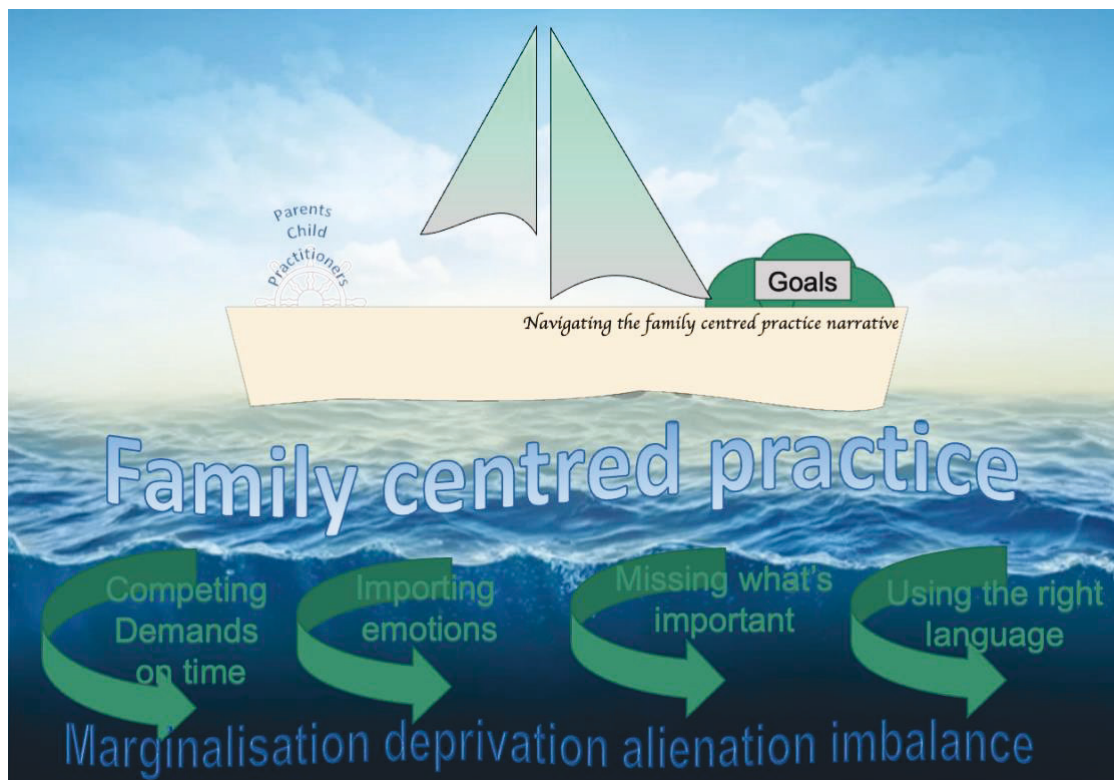*Figure 19 Visual representation of the grounded theory: Navigating the family centred practice narrative*

6.7   Conclusion

This chapter has taken the four categories originally identified in chapter 5, grounded them within the raw data and analysed them within existing literature, in an attempt to highlight the issues that can occur during the goal setting process. The simultaneous methods of data

collection and analysis, and the constant comparative method synonymous with grounded theory (Charmaz 2014) guided how each category was crafted and inductively led by the data. Category 1: *Competing demands on time* highlighted the dominance of objective time and how this influenced the priorities of the practitioners and guided their actions towards parents and pupils. Category 2: *Importing emotions* discussed the relevance of chronic sorrow to goal setting and how this theory can help explain the engagement of parents. Category 3: *Missing what's important* considered how self-determination theory can help explain the effects of intrinsic and extrinsic motivations on goal setting. Finally, category 4: *Using the right language* drew on metacommunication to also assist with understanding what facilitated engagement. These categories all interrelate and impact on one another, through the grounded theory of navigating the family centred practice narrative and can either facilitate occupational justice experienced by the child and their parents or inadvertently serve to create injustice that may lead to occupational marginalisation, imbalance, alienation, or deprivation.

The thesis now turns to chapter 7 and moves to discussing and positioning the grounded theory and underpinning categories within the extant literature. It provides the shift from theoretical to practical application of the research and demonstrates the benefits of utilising a blended methodology to create a practical resource, presented in chapter 8 that can be used by practitioners to support goal setting with children and their families.

Chapter 7: Discussion

7.1   Introduction

This chapter presents the theoretical and practical components of the research and lays the foundations for chapter 8 which introduces the PACE goal setting framework that is offered as the application to practice and contribution to new knowledge. The chapter begins with presenting the trajectory of the action research which served to underpin the practical element of the framework, synthesising actions initiated by the co-researchers that were trialled alongside subsequent reflections on these actions. A transparent account is offered of how in some instances the actions had a positive influence and facilitated goal setting practices, but also highlights instances when changes enacted did not meet expectations. The grounded theory and underpinning categories introduced in chapter 6, that developed through the iterations of action and reflection are then discussed within the extant literature previously reviewed in chapter 2, drawing on additional pertinent sources of relevance and provides the foundations for the theoretical components of the goal setting framework.

7.2   Practical foundations of the goal setting framework

The actions proposed by the co-researchers attempted to address the issues identified and discussed in chapters 5 and 6. The cycles of actions that took place over the course of the research are presented in Table 7 along with justification for the decisions made, followed by reflections that informed subsequent actions in the phases that they occurred.

Phase	Co-researchers involved	Actions
1	Practitioner co-researchers	**1) Improve parent contributions** **A letter and email to be sent home to a set of parents from each class, containing a broad question what they would like for their child to achieve that academic year.** It was assumed by practitioners that this would be the preferred method for parents because they could complete at a time that suited them and would also be the most time efficient method for practitioners **Reflection: Technology based communication for goal setting was ineffective and the response rate was low**
		2) Improve pupil contributions **One pupil from each class, who it was believed were able to understand the purpose of personal goal setting to be selected to trial the Talking Mats approach with a staff member trained in this method.** A talking mats approach (Mackay and Murphy 2012) was considered an appropriate method for obtaining the pupil voice as these were already used within the school during activities not relating to goal setting and would therefore be familiar to staff and pupils. Talking mats is a low tech communication method that uses symbols to help individuals with communication impairments articulate their opinions and is considered as an effective way to assist with goal setting (Bornman and Murphy 2006) **Reflection: This was considered effective and insightful but also time consuming which may affect routine implementation**

		3) Structure of goals **Practitioners select one pupil from each class to re-frame a goal that had been created using the current system into a GAS format.** Some practitioners who were already familiar with the internationally recognised and frequently used method of goal attainment scaling (GAS), which is also regarded as a successful goal setting tool for children with motor disorders (Steenbeek, Gorter et al. 2011) were keen to use this in replace of the current home-grown method in place. Although GAS has evolved and been modified over time, the main premise remains that it offers a systematic way of measuring change and includes the ability to monitor progression as well as regression, and focuses on one variable where the change is measured (Steenbeek, Gorter et al. 2011) **Reflection: Worked well, prepare to implement across the school**
		4) Capturing discreet achievements **Design a crib sheet that could be used throughout the school day.** The purpose of the crib sheet was twofold: 1) to record small achievements directly or indirectly relating to the pupil's specific goals and 2) documenting factors relating to the environment (noisy classroom, time of day etc.) or the presenting health of the pupil such as tiredness that may affect goal engagement and subsequent goal achievement **Reflection: Too time consuming, removes time spent with pupils**
2	**Practitioner co-researchers** **Parent co-researchers**	**1) Design a resource that can support practitioners with collaborative goal setting** **Develop a framework to be used by practitioners to assist with setting goals.** The priority of the framework was to ensure that parent, practitioner and where appropriate, pupil voice were considered, and provide a system that was flexible to meet the needs of the families and their individual situations regardless of the ability of the child. Parent co-researchers to take a lead with developing the framework which was welcomed by the practitioner co-researchers

		Reflection: Parent co-researchers and practitioner co-researchers feel collaborative and positive about this. Practitioners believe that this will be a useful and usable resource to use with all families. Parent co-researchers feel this resource will assist families with goal setting
		2) Capturing discreet achievements **Design a way of charting discreet skills and ways practitioners could integrate them into the daily routine.** Any additional administration processes needed to be viewed as time worthy, valuable, and worthwhile. The concept of the key skills and opportunities for learning tool was created from the desire by both practitioner-co researchers and parent co-researchers to capture more than just the goal and be able to celebrate other smaller successes. The key skills and opportunities for learning language was designed to remove the barriers of profession specific terminology so that it was accessible to all and would segue with the GAS system. The development of the key skills and opportunities for learning was a combined collaboration between parent and practitioner co-researchers. Although the two groups were unable to meet, collaboration was achieved through a series of meetings by both groups with the primary researcher acting as a conduit for the collaborative process **Reflection: Works well, integrate into framework**
		3) Structure of goals **Whole school training and implementation of GAS.** The training of GAS to all school staff was provided over two days during the already designated goal setting and evaluation period. It was believed that staggering the introduction of new systems to staff and introducing GAS before other changes would facilitate increased engagement and willingness to adapt practices that had been in place for many years, hence the introduction during phase 2 and pre-roll out of any other anticipated changes **Reflection: Well received by all staff, to replace current system with GAS**
3	**Practitioner co-researchers**	The pupil co-researcher group appeared significantly less in the study and took on the role of 'sense checking' the methods of expressing their opinions and how they wanted to be included in the goal setting process. During phase 3, the goal attainment scaling system had been rolled out successfully and talking mats were used routinely to understand what was important for the

	Parent co-researchers **Pupil co-researchers**	pupils. Once the key skills and opportunities for learning tool had been presented to all co-researchers and opportunities for feedback were facilitated, it was introduced throughout the school. The focus of phase 3 was to continue with developing and refining the goal setting framework with the practitioner, parent, and pupil co-researchers, and then presenting it to school teams to use. **Phase 3 is an ongoing process of evaluating the systems in place and making adjustments as new ideas emerge.**

Table 10 Phases of action and reflection

7.3 Theoretical foundations of the goal setting framework

This research has found that central to goal setting is collaboration, which historically (Eichner, Johnson et al. 2003) and currently (McCarthy and Guerin 2022) is argued to be one of the key principles of family centred practice. In this study the combination of time available to practitioners and their response to this, such as changing the way they interacted with parents resulted in a misalignment of expectations and created a barrier towards parental engagement. The methods used when time was limited (for example emails), changed the language and communication. This altered and restricted the connection between practitioner and parent that was considered necessary to facilitate the emotional security and empathic relationships which act a basis for trust and collaboration. The actions of the practitioners either facilitated or diminished the opportunity for the pupils to express their desires which acted as a support or hinderance to eliciting or understanding intrinsic or extrinsic motivations and resulting behaviours. Each action that the practitioners took could act implicitly or explicitly as a facilitator or barrier to goal setting and potentially restrict opportunities for engaging in meaningful everyday occupations. The restricted opportunities reinforces the everyday stress associated with occupational deprivation and marginalisation experienced by those with disabilities (Bartolac and Sangster Jokić 2019).

The challenges with collaboration in family centred practice have been reported in existing literature. McCarthy and Guerin (2022) identified discrepancies between qualitative and quantitative data regarding collaboration. The quantitative data aligned with parents agreeing that they were in a collaborative partnership with practitioners, however the qualitative data contradicted this which caused a query whether collaboration was misinterpreted as parents agreeing with activities set by practitioners, equating with the idea of 'going along with it', as noted by one of the parent co-researchers in this study. Smith and Kendal (2018) found that although practitioners and families had expectations of collaborative working, their expectations were misaligned which caused tension and engagement by parents to fluctuate if their expectations were not met. The authenticity of collaboration between parents and teachers termed "contrived collaboration" by Tschannen-Moran (2001) questions whether the

collaboration in schools has been thwarted by a perceived authenticity of collaboration and how teachers believe that parents can contribute to the school.

From these studies, and identified in the current study, there appears to be an underlying challenge to collaboration across health and education settings which may be in part, related to trust, as argued by Gregory and Austin (2016) that trusting relationships are the foundations for collaboration. Trust facilitates self-efficacy because if the stake holders, who could be parents, the child or practitioners feel trusted, they can shift their focus to growth and what can be achieved, rather than focusing inwardly on self-preservation and being defensive (Tschannen-Moran 2001). Parents need to trust the practitioners and they also need to feel trusted, so they can engage authentically in goal setting. In similar findings to the current study, for the trust to develop, Likis (2013) argues that the use of language can help facilitate or hinder this and it is the choice of words, including professional jargon and whether they are framed positively or negatively which inform others about attitudes and beliefs (Likis 2013). Taking this into consideration with the parent-practitioner relationship for goal setting, the use of language and trusting relationships may be associated with the power balance or perceptions of power which directs the collaboration. Cohen and Mosek (2019) explored the attitudes towards power and how this affected relationships between professionals (who, in their study, were predominantly social workers) and parents they supported, framing their findings within the matrix of power relations as described by Tew (2006).

The matrix of power relations is divided into productive modes of power and limiting modes of power, with each mode containing a 'power over' and 'power together' relationship between parent and professional. Cohen and Mosek (2019) found that from the perspective of the parents, the jargonistic language used by the professionals, and their approaches towards parent knowledge, created a disconnect and resulted in a feeling of dependency on the professionals. However, the professionals spoke of needing to offer parents protection and reported an expectation placed on parents to know what was best for their child. Cohen and Mosek (2019) aligned these findings with what Tew (2006) defined as limiting modes of power (oppressive power and collusive power) suggesting that the actions and language of the

professionals inadvertently directed the relationship and subsequently hindered positive engagement with the parents. This has also been reported by Currie and Szabo (2019) and is suggested that if the parents felt disengaged or disempowered due to the actions of the professionals, this risks occupational injustice and potential for occupational marginalisation as the parent voice or opinion is suppressed.   Experiences described by the parents in this study relate to general engagement rather than specifically goal setting and were community based which is different to the current research. However, it demonstrates the potential risk of occupational injustices and marginalisation are in part, dependent on the balance of power between the practitioners and parents. As such, the relevance of occupational justice and the consequence of reduced opportunities resulting in occupational injustices of marginalisation, imbalance, alienation, and deprivation is a worthwhile perspective to adopt. Utilising reflexivity and raising awareness of how practitioner behaviours, even when the intentions are good, as demonstrated in this study, can unintentionally elicit injustices when engaging in goal setting.

Mejía and Hooker (2017) argue that identity is shaped by the goals we choose and a child achieving their goal can be reflective of successful parenting goals. Although this was not made apparent during this research or raised as an issue, it may to some extent be applied to goals set by practitioners which reflect their own values rather than those of the families they support (Brewer, Pollock et al. 2014). This tension is another example of the power disparity previously referred to in the work of Cohen and Mosek (2019) because if practitioners miss cues from the parents, if there is a disconnect in the language or communication style, or not enough time to include the parent or child voice, then the practitioner assumes the responsibility for the goal which then risks the goal having less meaning for those it is intended for. This again highlights the need for practitioners to be aware of how their actions may result in occupational injustices towards those that they are working to support.

The active pupil voice in this research was less than hoped for which is acknowledged as a limitation to this study. However, the priority actions devised by the practitioner co-researchers consisted of raising the pupil profile during the goal setting process and ensuring their voice could be heard and opinion expressed, which offered some insight.   The voices of the pupils

110

that were conveyed through this aspect of the study and through the parent co-researcher discussions, although implicit, supports the findings of Vroland-Nordstrand, Eliasson et al. (2016) and Hanes, Hlyva et al. (2019) that peer relationships are important and in part, may account for in some instances why a child may willingly engage in an activity at school but not at home.

This suggests that when deciding goals on which to focus, the context of the environment in which the child is engaging needs to be considered in order to understand their motivations more fully. Furthermore, this corresponds with the relationship between intrinsic and extrinsic motivations on goal perseverance and achievement as referred to in self-determination theory, and supports the assertion by Pritchard, Phelan et al. (2020) that observations of the child's motivations in addition to their communicative expressions serves to gain more understanding of what is meaningful to them. It is argued that this enables those supporting the child at home or school, whether parents or practitioners, are then better positioned to facilitate engagement and achievement of their self-determined goals and avoid the potential for misinterpretation.

7.4 Conclusion

This chapter has discussed the practical and theoretical elements of the research and has presented the foundations that informed the development of the PACE goal setting framework. It has presented the trajectory of the participatory action research, demonstrated the cycles of action and reflection, and outlined the timeline of events that unfolded during the research which informed the practical component of the goal setting framework. This was followed by positioning the grounded theory within the existing literature, highlighting the facilitators and inhibitors that can influence collaborative goal setting. This chapter has demonstrated that by considering collaborative goal setting through the lens of occupational justice, brings to the foreground the risks of provoking unintended outcomes of alienation, marginalisation, imbalance, and deprivation if practitioners misinterpret the actions of the parents, or are not aware of how their actions can influence parent behaviours. This chapter has laid the foundations for the final chapter, presenting the contribution to new knowledge which is the PACE goal setting framework.

111

Chapter 8: Conclusion

8.1   Introduction

This chapter introduces the PACE goal setting framework and offers a contribution to new knowledge. The framework is a product of blending constructivist grounded theory with participatory action research and has resulted in a practical resource for practitioners that is underpinned by theory. The theoretical component of the framework is informed by the grounded theory: Navigating the family centred practice narrative presents each of the four categories: *Competing demands on time, Importing emotions, Missing what's important and Using the right language*, linking them to theories of time, chronic sorrow, goal setting and meta communication with the risks to occupational justice. It is designed to be a supportive resource for practitioners to encourage reflexivity and raise awareness of how their actions and approaches to collaborative goal setting can influence engagement of the parent. The practical component of the framework, developed through the participatory action research is the resource that acts as a prompt for practitioners for use in everyday practice when engaging in collaborative goal setting. The chapter concludes with discussing the limitations of the research, makes recommendations for further research and finishes with the closing summary of the entire study.

8.2   The contribution to new knowledge: The PACE Goal Setting Framework

The PACE goal setting framework offers an alternative approach for practitioners concerned with family centred, collaborative goal setting for children with cerebral palsy. It combines theory grounded within the data that arose from the actions of those who it is designed for use with, and to be used by and serves to provide a resource that links theory with practice. To achieve the best possible outcome, school-based goal setting needs to be a collaborative process between the child, their family, education, and health care professionals. Setting goals and progressing on to further goals is a dynamic process and although the focus may be toward specific achievements, a variety of factors will influence the outcome. The PACE goal setting framework is offered as a resource for practitioners to address these factors identified through the research in the form of a theoretical model (Figure 19) and practical resource (Figure 20).

The purpose of the framework is to raise awareness of the different properties and considerations for setting goals within a family centred approach. The intention of the framework is to enable practitioners to consider a range of interlocking components to help understand behaviours and actions which can support improved ways of collaborative goal setting. It aims to support decision making by practitioners that reflects the desires of the child and their family and by extension, promote occupational justice. Although the use of GAS and Talking Mats were included as actions and introduced to the school as routine methods to use, they are not discussed explicitly as part of the framework, but they are implicitly integrated.

The methods that practitioners use to engage the parents and the child, and by knowing what is important for them to want to achieve, can facilitate the opportunities for participation in relevant and meaningful interventions and as such promote occupational justice. However, in order to do this, knowing what is important to the child and the parents is the first stage and requires awareness from the practitioners. Part of the study conducted by Cohen and Mosek (2019) was an exercise in reflexivity by the practitioners to be more aware of how their assumptions, attitudes and expectations influenced their actions with those they support. It is suggested that if practitioners can actively engage reflexively as part of their day to day practice, it may reduce the unconscious behaviours which influence the power balance that have the potential to fuel occupational injustices (Hocking 2017).

The theoretical model of the framework is designed to support practitioners by bringing reflexivity into the mainstream of everyday practice, similar to the assertion by Kohl and McCutcheon (2015) who although are referring to researchers, encourage reflexivity to become part of usual 'every day talk'. This is considered an appropriate way to address the complexities identified in this research concerning collaborative goal setting between practitioners, parents, and the child where there is the potential for occupational injustices to occur as a result of practitioner or organisational imposed decisions. It is argued that utilising reflexivity alongside other methods of clinical reasoning may support practitioners with being mindful of how decisions made can inform effective collaborative goal setting. Each of the categories that structure the grounded theory can be utilised to stimulate practitioner thought processes,

113

bringing to the foreground how decisions we make based on how our attitudes and values can influence, and be influenced by the behaviours of others (Finlay 2002). It is argued that this supports practitioners to be intentional in their actions towards effective collaboration with the child and their family (Novak, te Velde et al. 2021) and serves to demonstrate transparency with the selection of relevant interventions which can then be evaluated for use based on the best available evidence (Taylor 2007).

The framework is divided into four quadrants: Purposeful, Achievement, Collaborative and Engagement. These terms were assigned by the co-researchers to capture the essence of goal setting with each quadrant underpinned by the theories highlighted by the research. These terms are also used as headings for the practical tool with questions designed by the co-researchers to be used as prompts and ensure each of the key points highlighted in the theoretical model are addressed. For example, mental health problems are frequently observed in parents of children with conditions such as cerebral palsy but are not routinely addressed (Gilson, Johnson et al. 2018). It is argued that by raising the awareness of practitioners to chronic sorrow theory and normalising how goal setting may act as a trigger event, can support the practitioner-parent interactions, promote relationships and facilitate honest discussions. The practitioner can then use this insight to adjust the support they provide as suggested in the fluid relationship model proposed by Smith and Kendal (2018). It is argued that this series of events will then serve to promote better mental health of the parents, which in turn serves to promote improved outcomes for the child (Rosenbaum 2021). In this instance, the theoretical model of the framework raises **awareness** of **chronic sorrow theory**, and highlights that parents and children are potentially at risk of **occupational marginalisation**, **deprivation,** and **alienation** if their emotional needs are not sufficiently recognised. The practical resource considers the chronic sorrow theory and risks of occupational injustices, transferring them into prompt questions for practitioners that offers a functional means for ensuring goals support **engagement**.

PACE Goal Setting Framework
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Action research categories	Are influenced by	Grounded theory categories	Identified risks to occupational justice (May be externally or internally imposed)	Risks are mitigated	Key points	Associated theories
Purposeful	→	Missing what's **important**	Alienation Marginalisation Deprivation Imbalance (Practitioner)	→	Intrinsic/ extrinsic motivation	Self-determination theory
Achievement	→	Competing demands on **time**	Alienation Deprivation Imbalance (Practitioner)	→	Time use is considered differently	Objective vs subjective time
Collaborative	→	Using the right **language**	Alienation Marginalisation	→	Empathy	Meta-communication
Engagement	→	Importing **emotions**	Marginalisation Deprivation Alienation	→	Awareness	Chronic sorrow

Figure 20 The PACE goal setting framework (theoretical model)

The PACE Goal Setting Framework

This framework has been created from an action research study involving [ ] school staff and the families that we support. It is intended to be used as a framework to guide the decisions made for goal setting and ensure that we can support pupils who attend Pace, realise and fulfil their potential.

This framework is designed to support the process of goal setting. To achieve the best possible outcome, goal setting needs to be a collaborative process between the child, their family, education and health care professionals.

Instructions for use

The framework has been divided into four sections:

P	purposeful
A	achievement
C	collaborative
E	engagement

Pupil initials: [ ]
Goal: [ ]

Purposeful

What purpose does this goal serve for the child or young person?
[ ]

Collaborative

C. How are goals being created using a transdisciplinary team approach? What methods are being used?
[ ]

C. How has the parent been involved with formulating this goal?
[ ]

C. How has the child/ young person been involved with formulating this goal?
[ ]

1

Achievement

A. How can this goal progress?
[ ]

A. Is this goal realistic within the specified timeframe?
[ ]

A. Is the baseline clearly defined?
[ ]

A. Is the expected outcome clear?
[ ]

A. What variable is being measured?
[ ]

A. Is the scaling clear?
[ ]

A. What are the key skills?
[ ]

A. What are the opportunities for learning?
[ ]

Engagement

E. 24hour curriculum: how does it fit into home and school; how can it be worked on in different environments? If the goal cannot be worked on at home, can parts of it be?
[ ]

Next steps

What actions are required?
[ ]

2

Figure 21 The PACE goal setting framework (practical resource)

116

8.3   Limitations of the Study

Throughout the research journey, limitations of the study arose and are now discussed. The first limitation is in the form of a reflection of being a novice researcher and offers a transparent account of my experience, and how I attempted to overcome the potential issues that could arise. This is followed by discussing limitations relating to recruitment and participation, and how this could have influenced the research outcomes.

Utilising an approach such as action research that aligns pragmatically with researching within an organisation where the researcher is also an employee (Coghlan 2019) presents challenges and conscious decisions were made throughout the course of the research to minimise risks and maximise engagement and motivation. It was only once the action research meetings began that the potential for power disparity, similar to that raised by Cohen and Mosek (2019) became apparent. The actions carried out during the study were predominantly orchestrated by the practitioner co-researchers. It is acknowledged that as the most amount of time was spent with the practitioner co-researchers, this unintentionally risked creating a power disparity between them and the parent co-researchers as the practitioner co-researchers had more opportunity for discussing and initiating actions. However, it is suggested that as the practitioners (guided by organisational and legislation policy) initiate and orchestrate goal setting processes, they were integral to ideas becoming actions and were necessarily positioned as the initial co-researcher group.

As the action research meetings progressed, I became aware of the risk that due to carrying out this project within an organisation where others that were not co-researchers would potentially be affected by the actions initiated, could risk a power disparity and although the co-researchers may have 'buy in' to the activities, the other practitioners within the school may perceive this as an unjust imbalance of power. I was also aware that decisions made by the co-researchers, although permitted during the preliminary stages of this research may cause tension with the senior management team of the school who were not directly involved in the study. To mitigate this, regular meetings were held with myself and senior team members to discuss what was being proposed so that any queries could be discussed as they arose. To

117

address the potential for power disparity between the action researchers and the rest of the school practitioners, communication remained transparent, and any planned activities were openly discussed using email, team meetings and whole school meetings.

The sizes of the parent co-researcher groups and pupil co-researcher groups were a limitation to this study. Despite attempts at recruiting parent co-researchers, although there was interest in the study and initial interest in participation, the uptake was low. A contributing factor to the low uptake may relate to one of the overarching themes of this research and the already competing demands on time. The uptake of the pupil co-researcher group was also low which likely affected the 'sense' of being in a group and willingness of pupils to share their ideas. The parents were the gatekeepers to the pupils, and it was unclear why the responses were limited. Despite this, it is important to acknowledge that the pupil voice was presented through the activities orchestrated by the practitioner co-researchers.

The parent co-researcher group consisted of mothers only. Although it is reported that mothers are often the primary care givers and attend appointments more frequently with their child, the opinions of fathers have not been heard in this research and if they had, it may have altered the findings and subsequent analysis. The practitioner co-researchers were predominantly female which although may be representative of an education and healthcare setting, if there were more male co-researchers in the study, it may or may not have altered the direction of discussion.

The research site where the study was conducted has a high practitioner-pupil ratio and the practitioners spend more time in the classroom with other practitioners than perhaps in other settings. Although this is not a limitation per se, it is acknowledged that the environment where the research took place is different to other special schools due to its specific cohort and as this was a qualitative study, it is not possible to make generalisations from the conclusions drawn.

Goals are set for children and young people within the parameters of their Education, Health and Care Plan (EHCP) and although this was discussed early on to contextualise the research,

118

there has been minimal reference to it. The aim of the research related to goal setting, which is a key component of the EHCP and determining the additional education or health care provision required for the child. However, the EHCP did not feature specifically in any discussions with the co-researchers and was therefore not addressed. This has been identified as a limitation to the study because had it been intentionally raised the action research and grounded theory may have unearthed different topics for exploration.

8.4   Recommendations for further research

The importance of context and participation in working towards goals relates to peer relationships, and has been highlighted as one of the 'F Words' named 'friends' described by Rosenbaum and Gorter (2012) in their adaptation of the International Classification of Functioning as discussed in chapter 1. Rosenbaum (2022) argues that the emphasis remains for goals to address physical achievements for children with cerebral palsy and emphasises the need to address the other constructs. More specifically, reference is made to the 'family' and finding ways of integrating the 'F Words' into other frameworks to support exploration of the emotional health of the child. This research, although not concentrating on specific types of goals, has identified that the importance of peer relationships reported in the existing literature, and the context in which the goals are set, is an area that requires further exploration. Carrying out research with young adults or teenagers with cerebral palsy and exploring self-determination theory alongside the 'friends' F-word within an occupational justice framework may offer insight into the discord between goals, external and internal motivators and the social environment and explore how occupational justices may be facilitated or limited.

Practitioner co-researchers in this study sought time saving methods as one of the first actions but this was met with unexpected disengagement. This disparity in expectations between the practitioners and parents, and how this affects collaborative working, risking disengagement has been reported previously including how much support for goal setting is offered compared with how much is expected (Darrah, Wiart et al. 2012), the perception from parents that practitioner goals take priority (Plant, Tyson et al. 2016) and parents being unaware of what their child's goals were (Angeli, Harpster et al. 2019). It is suggested that the practitioner co-

researcher focus on time saving methods did not account for how this might be received by the parents. It was only when the parent co-researchers reported how the methods or styles of communication utilised by practitioners elicited emotional discomfort, expressions of uncertainty and pressure to respond objectively during discussions about their child's goals that the practitioner co-researchers were able to reflect and be guided by the parent co-researchers' preferences and adapt their approach. Although other studies previously discussed regarding communication methods utilised by health and education practitioners reported positive parent engagement using technology (Olmstead 2013, Snell, Hindman et al. 2018) determining parent engagement through the methods used by practitioners appears not to be straightforward. It is possible that other influencing factors such as the emotional availability of the parent, how supported they feel and the support they need from practitioners as highlighted in this research is more informative of how parents respond to communication methods available to them. With the ever-increasing use of technology to support communication, further research focusing on communication methods and parent engagement is required.

This research shows similarities with previous published studies discussed in chapter 2. The lack of time is considered problematic by healthcare practitioners (Kolehmainen, Maclennan et al. 2012, Bexelius, Carlberg et al. 2018, Grant, Jones et al. 2022). Specific issues concerning the lack of time available to spend with families impacting on effective collaborative relationships raised by health workers in Coyne (2015) and Kennedy, Missiuna et al. (2020) and school based practitioners in Fingerhut, Piro et al. (2013) resonate with this study and how the time available influences practitioner decisions which affect interactions with families. None of the above-mentioned studies elaborate on these challenges or offer alternative suggestions. It appears that for these studies and this research, not having enough time is possibly an accepted problem that is inherent in the systems in which practitioners work. Further research is required to explore the concepts of objective and subjective time with practitioners in daily practice and how this affects interactions and decisions made.

The parent co-researchers were all mothers and therefore the father perspective is not considered which is acknowledged as a potential limitation of this study. The priorities of daily

occupations assumed by fathers of children with cerebral palsy, how they see their role and how this may facilitate or inhibit self-imposed occupational injustices and how they may differ from experiences of mothers requires further attention.

8.5   Conclusion

Collaborative goal setting is a challenge for practitioners as well as parents and was demonstrated through the iterations of constructivist grounded theory and participatory action research. Cerebral palsy is a complex condition that affects each individual differently and can affect all areas of self-care, leisure and learning. Although this research focused on the components of goal setting and not explicitly discussed goals in relation to cerebral palsy, the parent co researchers were parents of children with a diagnosis of cerebral palsy and the school practitioners supported pupils with this condition. This implies that all the discussions which took place, between all co-researchers were discussed with cerebral palsy in mind.

The research aimed to gain an understanding of perspectives from school-based educators, healthcare practitioners and parents of children who attend the school in order to create a holistic framework for practitioners to support collaborative goal setting. A participatory approach enabled the transformation of ideas for solutions into actions for change, with those who the changes would affect as central to the decision making, serving to mitigate the power imbalance between researcher and researched. Constructivist grounded theory was utilised for its emphasis on explanation and understanding of social processes - a dynamic approach to support data collection and analysis. The constructivist approach was considered most appropriate due to my already established presence in the research field and insider knowledge, recognising that any research findings would be a co-construction between myself and the co-researchers.

The resulting goal setting framework demonstrates the practical application and implications of this research for practitioners, regardless of whether they work in education or health, to support goal setting through a series of prompts to ensure the needs and desires of the child and parents are considered. The grounded theory developed through this study: Navigating the

family centred practice narrative depicts the journey that practitioners and families make, based on previous experiences, expectations and future ambitions. Categories that underpin the theory: Competing demands on time, Importing emotions, Missing what's important, and Using the right language inform the theoretical component of the goal setting framework and serve to facilitate practitioner reflexivity in order to meet the individual needs of the family in order to recognise and avoid occupational injustices.

Family centred practice implies that those who receive services from practitioners should be active agents in determining goals and subsequent interventions. It is argued that utilising the occupational justice framework supports the identification of potential occupational injustices in vulnerable populations such as children with cerebral palsy and will support the formulation of goals that address or aim to prevent these injustices. The concepts of marginalisation, alienation, deprivation and imbalance have been integrated throughout this research in an attempt to highlight their relevance and risk to collaborative goal setting. The presence of justice and risk of occupational injustices occurring may be aligned with facilitating or hindering the engagement of those to whom the goals matter most, that is, the child and the parents.

This research has identified facilitators or hinderances to family centred practice, where collaborative goal setting is key. It adds to the existing literature arguing that goal setting is a complex dynamic that is driven by the practitioners. The focus of goals appears to be determined by how practitioners approach communication with parents and whether this matches their emotional needs for support at any given time. In an effort to address these complexities, the PACE goal setting framework has been developed that offers a theoretical model supporting practitioner reflexivity and a practical resource that can be used to ensure goals are collaborative in their design and have meaning to all concerned. This study has contributed to new knowledge by interlinking the prominent theories of chronic sorrow, meta-communication, self-determination, and concepts of time within the context of collaborative goal setting and occupational justice, creating a framework that incorporates these concepts into an informative and readily accessible resource for practitioners.

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125

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Appendices

Appendix 1: Literature review search strategy

The literature review was undertaken by Electronic database searches accessed through the extensive University of Northampton Electronic Search Online (NELSON) and Google Scholar. Grey literature was accessed through The Royal College of Occupational Therapy. Ongoing searches of literature were carried out for the duration of the study to ensure any new literature may be included.

Inclusion criteria consisted of published research reports available in electronic databases to present (2022) and articles published in the English Language. Articles relevant to goal setting, family centred practice, collaborative goal setting, cerebral palsy and schools were considered for review.

Appendix 2: Research site ethical approval

The Pace Centre
Coventon Road
Aylesbury
BUCKS
HP19 9JL

Tel: 01296 392739
Fax: 01296 334836
info@thepacecentre.org
www.thepacecentre.org

27th February 2019

Research Proposal - Collaborative goal setting for children with cerebral palsy: a transdisciplinary team approach

To the Ethics Committee at Northampton University,

I am writing with respect to Sarah Hyde's research proposal, 'Collaborative goal setting for children with cerebral palsy: a transdisciplinary team approach' to give my consent, and Pace's full support, to the project that Sarah has outlined.

This consent is given subject to ethical approval for the study from the University of Northampton.

Yours faithfully,

Ian Sansbury
Chief Executive

Appendix 3: Research site ethical approval parent co-researchers and pupil co-researchers

The Pace Centre
Coventon Road
Aylesbury
BUCKS
HP19 9JL

Tel: 01296 392739
Fax: 01296 334836
info@thepacecentre.org
www.thepacecentre.org

7th January 2021

Research title - Collaborative goal setting for children with motor disorders: a transdisciplinary approach

To the Ethics Committee at the University of Northampton,

I am writing with respect to Sarah Hyde's ethics application, "Collaborative goal setting for children with motor disorders: a transdisciplinary approach" to give my consent, and Pace's full support for the research Sarah is undertaking.

This consent is given subject to the ethical approval from the University of Northampton.

Yours faithfully,

Ian Sansbury
Chief Executive
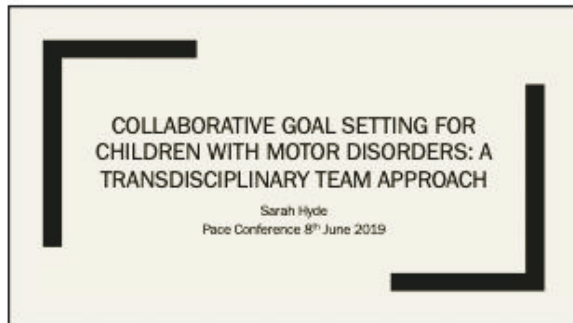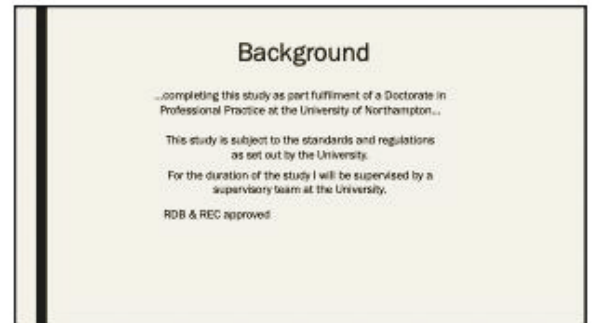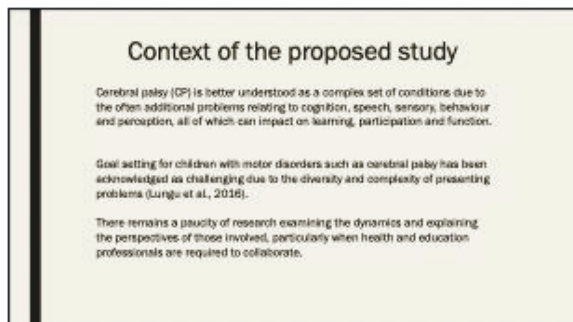
Methods

Participatory Action Research (PAR)

Approach to research with the goal of creating change through the knowledge that is produced (Kelly, 2005).

Participants become part of the research team and adopt the position of co-researcher. (Bradbury and Reason 2001).
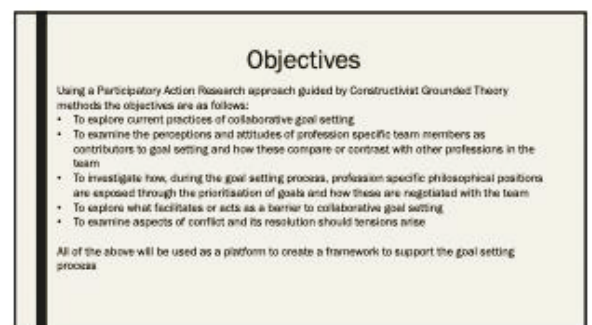
PAR is an approach to research in communities (Pace) that emphasises **participation, action** and **reflection**. It emphasises collective inquiry and experimentation grounded in experience.

Constructivist Grounded Theory

Selected to guide data collection, analysis and theory generation in order to investigate the social processes (behaviours, actions, interactions) to find out 'What's happening here?' (Glaser in Charmaz 2014)

Grounded theory involves the collection and analysis of data. The theory is "grounded" in actual data, which means the analysis and development of theories happens after you have collected the data.

7

Now what?

Recruitment
- Ideally two staff from each profession

First meeting:
- Devise a Group Confidentiality Statement that will set out the group responsibilities and boundaries of the research
- Plan dates and times for future meetings

Subsequent meetings:
- Planning, action, reflection
There will be workshops and break out groups organised that co-inside with goal assessment periods during the summer term of academic year 2018-19, full academic year 2019-2020 and the autumn term academic year 2020/2021. The purpose of these workshops is construct activities (determined during the workshops) to be carried out and reflected on during the already established assessment cycles that are currently undertaken three times per year. Workshops and breakout groups will be audio recorded and you can choose whether to audio record or write/ type your reflections.

8

Taking part

Taking part is entirely voluntary. If you decide to take part you will be asked to sign a consent form to confirm that you understand the project and are happy to participate.

If you decide to take part and then change your mind, you are free to withdraw from the study at any time without prejudice. However, it cannot be guaranteed that information that you have provided prior to your withdrawal will not be used in the research as your contributions may have guided further conversations or areas of discussion.

There is no payment for involvement. Time will be made available during the working week for all activities relating to the research to be carried out.

9

Benefits of taking part

Opportunity to actively be involved in research to share experiences.

Engage in creating change in processes by developing a framework for goal setting.

The information obtained from this study will be used for developing a framework that will be used to inform the goal setting practices at Pace and possibly further afield in other establishments that cater for children with motor disorders.

10

Risks

Possible disadvantages to taking part in the study is the time required to take part in group workshops and reflections.

However, all workshops and tasks required of the research will be carried out during typical working hours and time will be allocated during the week to accommodate the research project, so it does not impact on your regular duties.

11

What will happen to the results of the study?

The results from this study will be used to develop a framework that assists with goal setting that will be used to inform our practice at Pace, and to produce a final report to fulfil the requirements of the doctorate.

Additionally, I will publish within appropriate journals elements of the research and the findings. It is hoped that the resulting framework will be made available to other organisations who offer support to children with motor disorders.

Individual information will not be given to any other party.

12

137

Questions
?
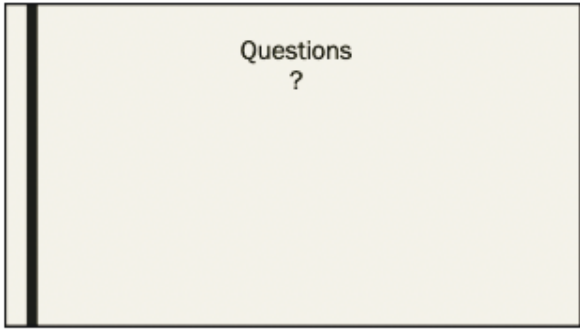
13

Appendix 5: Practitioner co-researcher participant information sheet

UON University of Northampton

Co-researcher (Participant) Information Sheet

This information sheet is for participants who may volunteer to join the research as co-researchers with Sarah Hyde, into collaborative goal setting.

I (the researcher) would like to invite you to join the research study I am conducting on goal setting for children with motor disorders. Before you decide whether you wish to participate, it is important for you to understand why the study is being conducted and what it will involve. Please take some time to read the information provided and discuss it with others if you wish. This information sheet is not intended to replace any discussion about the research. Please ask if there is anything that is not clear, or if you would like more information.

The title of the study is...
"Collaborative goal setting for children with motor disorders: A transdisciplinary team approach

The purpose of this study is...
...to develop a framework that assists education and healthcare staff with the process of goal setting. It is important that we develop a framework that considers the combined perspectives of educators and therapists to ensure that goals are holistic and in line with Pace school strategic plan.

The researcher is...
...Sarah Hyde, BA (Hons), PgDip OT, MSc. Occupational Therapy Lead for Pace School Services. Contact details: 01296 392739. Email sarah.hyde@thepacecentre.org

I am completing this study as part fulfilment of a Doctorate in Professional Practice at the University of Northampton. This study is subject to the standards and regulations as set out by the University. For the duration of the study I will be supervised by a supervisory team at the University, if at any time you have concerns regarding my conduct or your experience as co-researcher please contact Alasdair Gordon-Finlayson at alasdair.gordonfinlayson@northampton.ac.uk who is part of the team who supervise me. If you have any concerns regarding your experience as co-researcher from an employee of Pace perspective and would like to discuss these, please contact Fiona Jones, Human Resources Manager at Fiona.jones@thepacecentre.org.

Why have I been chosen?
You have been asked to take part in the study because you are an employee of Pace, work within the school services and have experienced / participated in the goal setting process.

Do I have to take part?
Taking part is entirely voluntary. If you decide to take part, you will be asked to sign a consent form to conform that you understand the project and are happy to participate. If you decide to take part and then change your mind, you are free to withdraw from the study at any time without prejudice. However, the information that you have provided prior to your withdrawal will still be used in the research as your contributions may have guided further conversations or areas of discussion.

There is no payment for involvement. Time will be made available during the working week for all activities relating to the research to be carried out.

1

What will my participation involve?
Once you have agreed to take part in the study a mutually convenient time will be arranged for all co-researchers to meet together and devise a group confidentiality statement that will set out the group responsibilities and boundaries of the research including confidentiality, interpretation of results, ownership and publication of results. There will be workshops and break out groups organised that co-inside with goal assessment periods during the summer term of academic year 2018-19, full academic year 2019-2020 and the autumn term academic year 2020/2021. The purpose of these workshops is construct activities (determined during the workshops) to be carried out and reflected on during the already established assessment cycles that are currently undertaken three times per year. I will audio record the workshops and breakout groups and you can choose whether to audio record or write/ type your reflections.

What are the possible benefits of taking part?
The information obtained from this study will be used for developing a framework that will be used to inform the goal setting practices at Pace and possibly further afield in other establishments that cater for children with motor disorders.

What are the possible risks or disadvantages of taking part?
Possible disadvantages to taking part in the study is the time required to take part in group workshops and reflections. However, all workshops and tasks required of the research will be carried out during typical working hours and time will be allocated during the week to accommodate the research project, so it does not impact on your regular duties.

What if something goes wrong?
If you have any concerns about any aspect of the way you have been approached or treated during the course of this study, then please contact Alasdair Gordon-Finlayson at alasdair.gordonfinlayson@northampton.ac.uk or Fiona Jones, Human Resources Manager at Fiona.jones@thepacecentre.org.

Will my information be kept confidential?
The developed framework will be an outcome of the research project. Your individual input into these aspects will remain confidential.
All the information collected for this study will be anonymised and stored securely on a double password-protected computer. All paper-based documents will be scanned and stored on the computer. Original paper copies will be shredded and destroyed.

What will happen to the results of the study?
The results from this study will be used to develop a framework that assists with goal setting that will be used to inform our practice at Pace, and to produce a final report to fulfil the requirements of the doctorate. Additionally, I will publish within appropriate journals elements of the research and the findings. It is hoped that the resulting framework will be made available to other organisations who offer support to children with motor disorders. However, individual information will not be given to any other party.

2

Who has reviewed the study?
This study has been reviewed and approved by the Research Ethics Committee and Research Degrees Board, University of Northampton and Pace employee's Ian Sansbury, CEO, Lindsay Hardy, Director of Therapies and Claire Smart, Director of Education and Headteacher.

What happens next?
There is a consent form attached to this information sheet. Should you wish to take part, please complete and return the form by [DATE].
Your engagement in the research is entirely voluntary and is in addition to your usual working role. If you choose to participate in the research, once you have returned the consent form to me I will arrange a date and time for all co-researchers to get together and establish ground rules that set the scene for future meetings including organising agreed times for future meetings and confidentiality.

If you have any questions or would like to discuss further, please do not hesitate to contact me.
Sarah
Email: sarah.hyde@thepacecentre.org

Thank you for considering taking part in this study.

Appendix 6: Practitioner co-researcher consent form

Consent form

Collaborative goal setting for children with motor disorders: A transdisciplinary team approach

Please read each statement below and then confirm that you agree or disagree by placing your initials in the appropriate box.

	Yes	No
I have read and understood the information provided to me in the information sheet.		
I have had an opportunity to ask questions about this research.		
I agree to the workshops and breakout group discussions being audio recorded.		
I understand that I can decline to answer any questions.		
I understand that I cannot withdraw my answers in part or full, anytime.		
I agree to anonymised quotations being used in any scientific presentations or publications of this work.		
I agree to my data being used for this research project only.		
I agree to my data being used in any subsequent work that builds on this current project.		

Signature and date of person giving consent (the co-researcher).

_____

Signature and date of person obtaining consent (the researcher).

_____

1

Appendix 7: Group confidentiality statement

Pace

<u>Co-Researcher</u>
<u>Group confidentiality statement</u>

<u>Confidentiality agreement:</u> This agreement is a contract for confidentiality among the members of the group named below whose purpose is to take part as co-researchers for the study titled: Goal setting for children with motor disorders: A transdisciplinary team approach. You have the right to confidentiality and privacy by the group. Confidentiality within the group setting is a shared responsibility of all members and is based on mutual trust and respect.

Refer to Pace Safeguarding and Whistleblowing policies for legal and ethical exceptions to confidentiality.

<u>Additional group agreements:</u>
1. All group sessions (workshops) will be audio recorded
2. Time dedicated will be for one hour per fortnight (1.45-2.45) on Wednesdays. This will be put in the Pace main calendar.
3. Consultation with class groups regarding any actions to be carried out will take place on both sites (primary and secondary) during Wednesday after school meetings. Staff providing the information at these meetings will be agreed beforehand.
4. If a co-researcher is unable to attend the workshop they must let a fellow co-researcher know either by telephone/ email/ in person who can pass on this information to the group.
5. The work for this project will only be conducted during school working hours / allocated time for workshop meetings.
6. Meetings to be held on alternative sites. The site where the meeting is not held will join via teams.
7. Any consultation with class groups will be carried out to primary and secondary sites as a whole (at either site)

By my signature below, I indicate that I have read carefully and understand the group agreements and that I agree to its terms and conditions. I have asked and had answered any questions I have concerning these group agreements and am aware that signing the agreement is required for my position as coresearcher. I am also aware that refusing to sign this agreement will exclude me from participating as a co-researcher.

Signatures of co-researchers   Date

XXXXX _____   _____

XXXXX _____   _____

XXXXX _____   _____

XXXXX _____   _____

XXXXX _____   _____

xxxxx _____   _____

xxxxx _____   _____

xxxxx _____   _____ ☐

xxxxx _____   _____

xxxxx _____   _____

xxxxx _____   _____

Signature of principle researcher   Date

Sarah Hyde _____   _____

Appendix 8: Parent co-researcher participant information sheet

Parent co-researcher (Participant) Information Sheet

This information sheet is for parents of pupils who may volunteer to join the research as co-researchers with Sarah Hyde, into collaborative goal setting.

I (the researcher) would like to invite you to join the research study I am conducting a study on goal setting for children with motor disorders. Before you decide whether you wish to participate, it is important for you to understand why the study is being conducted and what it will involve. Please take some time to read the information provided and discuss it with others if you wish. This information sheet is not intended to replace any discussion about the research. Please ask if there is anything that is not clear, or if you would like more information.

The title of the study is…
"Collaborative goal setting for children with motor disorders: A transdisciplinary team approach"

The purpose of this study is…
…to develop a framework that assists education and healthcare staff with the process of goal setting. It is important that we develop a framework that considers the combined perspectives of pupils, parents, educators and therapists to ensure that goals are holistic and in line with Pace's values.

The researcher is…
…Sarah Hyde, BA (Hons), PgDip OT, MSc. Occupational Therapy Lead for Pace School Services. Contact details: 01296 392739. Email sarah.hyde@thepacecentre.org

I am completing this study as part fulfilment of a Doctorate in Professional Practice at the University of Northampton. This study is subject to the standards and regulations as set out by the University. For the duration of the study I will be supervised by a supervisory team at the University, if at any time you have concerns regarding my conduct or your experience as co-researcher please contact Alasdair Gordon-Finlayson at alasdair.gordonfinlayson@northampton.ac.uk who is part of the team who supervise me. If you have any concerns regarding your experience as co-researcher from an employee of Pace perspective and would like to discuss these, please contact Fiona Jones, Human Resources Manager at Fiona.jones@thepacecentre.org.

Why have I been chosen?
You have been asked to take part in the study because you are a parent of a pupil who attends Pace.

Do I have to take part?
Taking part is entirely voluntary. If you decide to take part you will be asked to sign a consent form to conform that you understand the project and are happy to participate. If you decide to take part and then change your mind, you are free to withdraw from the study at any time without prejudice. However, it cannot be guaranteed that information that you have provided prior to your withdrawal will not be used in the research as your contributions may have guided further conversations or areas of discussion.

There is no payment for involvement. All group meetings will take place virtually via Microsoft Teams.

What will my participation involve?
Once you have agreed to take part in the study a mutually convenient time will be arranged for all co-researchers to meet together and devise a Confidentiality Statement that will set out the group responsibilities and boundaries of the research. There will be workshops that co-inside with goal assessment in the spring term of the academic year 2020/21. The purpose of these workshops is to

reflect on a goal setting framework that will be being piloted at Pace during this time. I will audio record the workshops and will store the recordings on a secure device. Once notes have been made from the audio recordings to check that no information has been missed, it will be deleted.

What are the possible benefits of taking part?
The information obtained from this study will be used for developing a framework that will be used to inform the goal setting practices at Pace and possibly further afield in other establishments that cater for children with motor disorders.

What are the possible risks or disadvantages of taking part?
Possible disadvantages to taking part in the study is the time required to take part in group workshops. However, all workshops and tasks required of the research will be carried out virtually via Microsoft Teams which means that you do not need to travel anywhere. Workshops will be limited to one hour maximum and there will be the option of attending during school hours or in the evening at 6PM – whichever is most convenient for you. Specific days for the workshops taking place going forwards will be reached by consensus during the first meeting.

What if something goes wrong?
If you have any concerns about any aspect of the way you have been approached or treated during the course of this study, then please contact Alasdair Gordon-Finlayson at alasdair.gordonfinlayson@northampton.ac.uk or Fiona Jones, Human Resources Manager at Fiona.jones@thepacecentre.org.

Will my information be kept confidential?
The developed framework will be an outcome of the research project. Your individual input into these aspects will remain confidential.
All the information collected for this study will be anonymised and stored securely on a double password-protected computer. All paper-based documents will be scanned and stored on the computer. Original paper copies will be shredded and destroyed. Information discussed will remain confidential however, in-line with safeguarding policy 2020/2021 if you share information about imminent harm or danger to yourself or others, the safeguarding protocol will be followed.

What will happen to the results of the study?
The results from this study will be used to develop a framework that assists with goal setting that will be used to inform our practice at Pace, and to produce a final report to fulfil the requirements of the doctorate. Additionally, I will publish within appropriate journals elements of the research and the findings. It is hoped that the resulting framework will be made available to other organisations who offer support to children with motor disorders. However, individual information will not be given to any other party.

Who has reviewed the study?
This study has been reviewed and approved by the Research Ethics Committee and Research Degrees Board, University of Northampton and Pace employee's Ian Sansbury, CEO, Lindsay Hardy, Director of Therapies and Claire Smart, Director of Education and Headteacher.
What happens next?
There is a consent form attached to this information sheet. Should you wish to take part, please complete and return the form by [DATE].
Your engagement in the research is entirely voluntary and your choice to either participate or not, will not affect or influence how I or any other staff engage with you about any other matters relating to the school or your child.

If you choose to participate in the research, once you have returned the consent form to me I will arrange a date and time for all co-researchers to get together and establish ground rules that set the scene for future meetings including organising agreed times for future meetings and confidentiality.

If you have any questions or would like to discuss further, please do not hesitate to contact me.
Sarah
Email: sarah.hyde@thepacecentre.org

Thank you for considering taking part in this study.

Appendix 9: Parent co-researcher consent form

Consent form

Collaborative goal setting for children with motor disorders: A transdisciplinary team approach

Please read each statement below and then confirm that you agree or disagree by placing your initials in the appropriate box.

	Yes	No
I have read and understood the information provided to me in the information sheet.		
I have had an opportunity to ask questions about this research.		
I agree to the workshop discussions being audio recorded.		
I understand that I can decline to answer any questions.		
I understand that I can withdraw from the group at any time but any contributions I have made up to this point will still be used.		
I agree to anonymised quotations being used in any scientific presentations or publications of this work.		
I agree to my data being used for this research project only.		
I agree to my data being used in any subsequent work that builds on this current project.		
I understand that I will act in accordance with the school safeguarding and whistleblowing policies. Information discussed will remain confidential however, in-line with safeguarding policy 2020/2021 if I share information about imminent harm or danger to myself or others, the safeguarding protocol will be followed.		

Signature and date of person giving consent (the co-researcher).

_____

Signature and date of person obtaining consent (the researcher).

_____

1

Appendix 10: Pupil co-researcher participation sheet (for parents/ carers)

UON University of Northampton

Pupil Participant Information Sheet
(For Parents/ carers)

This information sheet is for parents of pupils who may choose for their child to participate in a discussion relating collaborative goal setting.

I (the researcher) would like to invite your child to join the research study I am conducting on goal setting for children with motor disorders. Before you decide whether you wish your child to participate, it is important for you to understand why the study is being conducted and what it will involve. Please take some time to read the information provided and discuss it with others if you wish. This information sheet is not intended to replace any discussion about the research. Please ask if there is anything that is not clear, or if you would like more information.

The title of the study is...
Collaborative goal setting for children with motor disorders: A transdisciplinary team approach

The purpose of this study is...
...to develop a framework that assists education and healthcare staff with the process of collaborative goal setting. It is important that we develop a framework that considers the combined perspectives of educators, therapists, pupils and parents to ensure that goals are holistic and meaningful to all involved.

The researcher is...
...Sarah Hyde, BA (Hons), PgDip OT, MSc., and Occupational Therapist at Pace. Contact details: 01296 392739. Email sarah.hyde@thepacecentre.org

I am completing this study as part fulfilment of a Doctorate in Professional Practice at the University of Northampton. This study is subject to the standards and regulations as set out by the University. For the duration of the study I will be supervised by a supervisory team at the University, if at any time you have concerns regarding my conduct or your experience as co-researcher please contact Alasdair Gordon-Finlayson at alasdair.gordonfinlayson@northampton.ac.uk who is part of the team who supervise me. If you have any concerns regarding your experience as co-researcher from an employee of Pace perspective and would like to discuss these, please contact Fiona Jones, Human Resources Manager at Fiona.jones@thepacecentre.org.

Why has my child been chosen?
Your child is being asked to take part in the study because they currently attend Pace.

Does my child have to take part?
Taking part is entirely voluntary. If you decide your child can take part, you will be asked to sign a consent form to conform that you understand the project and are happy for your child to participate. Your child will then be invited to a group discussion with peers who have also been given consent to participate, to receive the information about the project and decide whether they would like to be involved. If your child agrees to participate, they will indicate this by marking the 'tick' on the form provided to them. If your child chooses not to participate, they will indicate this by making a mark on the 'X'.

149

University of Northampton

If you decide that your child can take part or if the child agrees to take part and then either of you change your mind, you are free to withdraw your child from the study at any time without prejudice but any information they have provided up to this point will still be used.

What will my child's participation involve?
Once you have agreed and your child has agreed to take part in the study, a mutually convenient time will be arranged during the school day. All meetings will be held remotely using MS Teams.
The information gathering sessions will be carried out during school hours. These will be carried out as a group with other familiar staff present and not on an individual basis with the researcher. The goal setting and evaluation framework will be shared with the group using visual representations and discussion. The pupils will be encouraged to say what they think about the proposed framework and provide any other ideas that they may have. The session will take no more than 30 minutes and will be led by Sarah Hyde.
A mutually convenient time will be arranged for all participating pupils to meet together and devise a set of rules that will set out the group responsibilities and boundaries of the research. There will be workshops that co-inside with goal assessment in the spring term of the academic year 2020/21. The purpose of these workshops is to reflect on a goal setting framework that will be being piloted at Pace during this time.
Due to the nature of this research, it is not possible to exactly determine how many sessions will be required however it is anticipated that there may be up to three group sessions. These sessions will not take place more than once per week.

I will record the workshops and will store the recordings on a secure device. Once notes have been made from the recordings to check that no information has been missed, it will be deleted.

What are the possible benefits of taking part?
The information obtained from this study will be used for developing a framework that will be used to inform the goal setting and evaluation practices at Pace and possibly further afield in other establishments that cater for children with motor disorders.

What are the possible risks or disadvantages of taking part?
The possible disadvantages of taking part is the time required to take part in the group discussion which may have otherwise been used for other school-based activities.

What if something goes wrong?
If you have any concerns about any aspect of the way you or your child have been approached or treated during the course of this study, then please contact Alasdair Gordon-Finlayson at alasdair.gordonfinlayson@northampton.ac.uk or Fiona Jones, Human Resources Manager at Fiona.jones@thepacecentre.org or Claire Smart, Headteacher and Designated Safeguarding Lead at Claire.smart@thepacecentre.org.

Will the information be kept confidential?
All the information collected for this study will be anonymised and stored securely on a password-protected computer. All paper-based documents will be scanned and stored on the computer. Original paper copies will be shredded and destroyed. Information discussed will remain confidential however, in-line with safeguarding policy 2020/2021 if pupils share information about imminent harm or danger to themselves or others, the safeguarding protocol will be followed.

What will happen to the results of the study?
The results from this study will be used for research purposes to develop a framework that assists with goal setting and evaluation, and to produce a final report. Additionally, I will publish within appropriate journals elements of the research and the findings. However, individual information will not be given to any other party.

Who has reviewed the study?
This study has been reviewed and approved by the Research Ethics Committee and Research Degrees Board, University of Northampton and Pace employee's Ian Sansbury, CEO, Lindsay Hardy, Director of Therapies and Claire Smart, Director of Education and Headteacher.

If you have any questions or would like to discuss further, please do not hesitate to contact me.
Sarah
Email: sarah.hyde@thepacecentre.org

Thank you for considering your child with taking part in this study.

Appendix 11: Parent co-researcher consent form

Consent form

Collaborative goal setting for children with motor disorders: A transdisciplinary team approach

Please read each statement below and then confirm that you agree or disagree by placing your initials in the appropriate box.

	Yes	No
I have read and understood the information provided to me in the information sheet.		
I have had an opportunity to ask questions about this research.		
I agree to the workshop discussions being audio recorded.		
I understand that I can decline to answer any questions.		
I understand that I can withdraw from the group at any time but any contributions I have made up to this point will still be used.		
I agree to anonymised quotations being used in any scientific presentations or publications of this work.		
I agree to my data being used for this research project only.		
I agree to my data being used in any subsequent work that builds on this current project.		
I understand that I will act in accordance with the school safeguarding and whistleblowing policies. Information discussed will remain confidential however, in-line with safeguarding policy 2020/2021 if I share information about imminent harm or danger to myself or others, the safeguarding protocol will be followed.		

Signature and date of person giving consent (the co-researcher).

_____

Signature and date of person obtaining consent (the researcher).

_____

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Appendix 12: Pupil co-researcher participant information sheet

<u>Pupil co-researcher (Participant) Information</u>
This information sheet is for pupils who may volunteer to join the research as co-researchers with Sarah Hyde, into collaborative goal setting.

<u>The title of the study is…</u>
"Collaborative goal setting for children with motor disorders: A transdisciplinary team approach"

I am asking if you would be interested in taking part in a project. Before you decide if you would like to join in, it is really important that you understand what the project is about, why it is being done and what it would involve for you.

If something isn't clear or if you have any questions, please ask to speak to me or you can ask your parents to phone or email me.

<u>Why is this project being done?</u>
This project is being done so we can be better at setting and checking goals at school. It is important that we hear what pupils, parents and staff think.
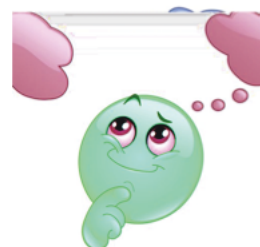
I would like you to take part in a project that involves a group of pupils working together to share their ideas about how we set and check the goals.

<u>Why have I been chosen?</u>
You have been asked to take part in the study because you are a pupil at Pace.

<u>Do I have to take part?</u>
No, you don't. It's your choice whether you want to come to the meetings and join in. If you decide to come to a meeting and then

change your mind, you are free to leave the meeting, or you can stay but don't have to say anything.

If you do talk during the meeting and then decide that you no longer want to take part, that is ok but what you have said might still be used.

All group meetings will take place during lunch time play (but will not take up all of it) and will not happen more than once a week.

What will happen if I take part?
We will meet on MS Teams on the computer. The time will be arranged to fit around your lessons.

We will decide some group rules e.g. take turns to speak, and everyone will agree to them.
I will ask a couple of questions about your goals and how we check on them. I will ask you if there is anything that you think is good or if there is anything that could be done differently.

I am going to record the meetings we have so that I don't forget anything that is said. If there is something that you want to tell me but don't feel comfortable saying it in front of the group then you can tell me or another member of staff afterwards.

Before we get together you and your parents will be able to ask any questions you may have. If you would like to take part and your parent says it's okay, then they will sign and send a form back to school.

Is there anything I need to be worried about if I choose to take part?
The project is about seeing what people think about how we set and check goals at school. It might be that some people do not agree with what each other is saying which might cause an argument. To try and stop this happening, I will only ask questions about what everyone likes, or what could be done differently. You will know all of the other pupils taking part in the project.

If anything does worry you about the project, please talk to your parents, class teacher or any other member of staff who will be able to help you.

Do I get anything for taking part?
You won't get anything, but you will be able to tell everyone what you think about how we check goals at school.

What happens to the results of the project?
The project you are involved in is part of a bigger project about goal setting and will be shared with adults at the university I am studying at, and maybe in the future, shared with other schools to help them with their goals.

Will anyone who reads the project know who I am?

What you say will be used for a written piece of work. Although you go to the school where the project is taking place, not all pupils will take part so it will be very difficult for anyone outside of Pace or your family to know. No one apart from me will listen to the recordings and once I have finished making notes from them, they will be deleted. It cannot be promised that anything you say will not be shared with anyone else.

No photographs of you will be taken during the meetings.

What happens next?

If you would like to take part, you will be given a piece of paper and asked to mark the 'tick' to show that you do want to take part or mark the 'X' to show that you do not want to take part. Once I know who is taking part, I will arrange a time for us to all get together.

Thank you for your time and thinking about taking part in this study.

Appendix 13: Pupil co-researcher consent form

Pupil consent to join the co-researcher group team

Collaborative goal setting for children with motor disorders: A transdisciplinary team approach

Please read each statement below and then confirm that you agree or disagree by placing your initials in the appropriate box.

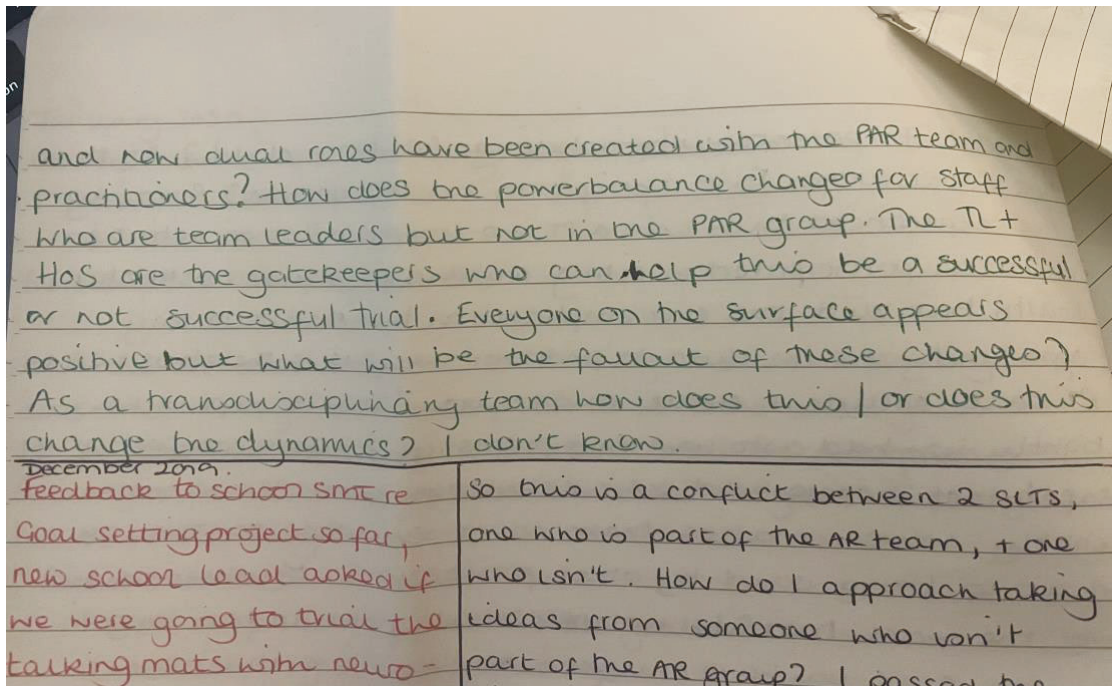| I would like to take part in the project	I do not want to take part in the project
✓	✗

Please read the statement below and confirm that you understand that you can change your mind if you decide to take part in the project.

I understand that I can change my mind if I decide that I no longer want to take part	I understand that it cannot be promised that anything I say will not be discussed with anyone else

Name of pupil: _____

Signature and date of person obtaining consent (the researcher).

_____

1

Appendix 14: Journal entry demonstrating reflexivity

and new dual roles have been created with the PAR team and practitioners? How does the powerbalance changed for staff who are team leaders but not in the PAR group. The TL + HoS are the gatekeepers who can help this be a successful or not successful trial. Everyone on the surface appears positive but what will be the fallout of these changes? As a transdisciplinary team how does this / or does this change the dynamics? I don't know.

December 2019.	
feedback to school SMT re Goal setting project so far, new school lead asked if we were going to trial the talking mats with neuro-	So this is a conflict between 2 SLTs, one who is part of the AR team, + one who isn't. How do I approach taking ideas from someone who isn't part of the AR group? I passed the

Appendix 15: Excerpt from email correspondence with Kathy Charmaz

From: Sarah Hyde <sarah.hyde@thepacecentre.org>
Sent: Wednesday, February 6, 2019 2:17 PM
To: kathy.charmaz@sonoma.edu
Subject: Grounded theory and cooperative inquiry

Dear Kathy
I'm currently In the third year of a Doctor of Professional Practice (I'm a paediatric occupational therapist). My research interest is transdisciplinary team goal setting for children with cerebral palsy. There is very little research in this area and I am proposing that grounded theory methodology is the most appropriate vessel for this study. I hold a management position in the facility I will be researching which brings with it many ethical dilemmas. One way to mitigate this is to engage the participants in the research process and use a cooperative inquiry action research approach. I'd be really keen (and eternally grateful!) to know your thoughts about using grounded theory with cooperative inquiry.
Many thanks in advance,
Sarah Hyde
Occupational Therapy Lead, School Services
The Pace Centre

For information about PACE, visit our website at www.thepacecentre.org

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The PACE Centre Ltd
Coventon Road
Aylesbury
Bucks
HP19 9JL
Registered Charity No. 1011133

From: Charmaz <charmaz@sonoma.edu>
Sent: 07 February 2019 00:42
To: Sarah Hyde
Subject: RE: Grounded theory and cooperative inquiry

Dear Sarah,

Your project sounds very interesting. I like projects that use grounded theory with cooperative inquiry. Look up Cherry Hense on the Internet for her work with community-based participatory action research. She's Australian.

Best wishes,
Kathy

Appendix 16: Demonstrating trustworthiness through explicit action research cycles

Reflection	Action	Justification	Reflection based on action
1) Parent voice is not present	1) Sending home a letter and/or email requesting what was important for them for their child to focus on at the beginning of the goal setting period	Families would find this a useful way of communicating their thoughts and contribute to the goal setting process	The response rate was low, needed to reconsider how to engage parents differently
2) Child voice is not present	2) Trial talking mats, one child per class	Talking mats facilitates communication and understanding of pupil aspirations	This worked as a good way for eliciting what was important for pupils
4) Not capturing everything that is being achieved through only having four goals	4) Create a crib sheet that can track other, discreet non goals and factors that may influence this	Capturing other areas of success or skill maintenance	This took too much time to complete, needed to reconsider
3) Current system of writing goals only measures how much support is required	3) Trial Goal Attainment Scaling (GAS) with one child per class	GAS enables a systematic method of writing goals and facilitates variety in what is to be measured	Positively received by class members who were in support of using it

Appendix 17: Example of co-researcher group meeting agenda with discussion points

4th September 2019		
Agenda & discussion - Practitioner co-researcher group		
Discussion points	Summary of narrative	Why is this? What can we do to make things different? (To be completed during the meeting)
Child & family involvement	Classes run out of time, parents and pupils are the last to be asked about goal setting and if time is running out it is this aspect that is dropped. Priority should be the child and family thoughts. Not just agreeing to the goals but being involved in initial discussions. Talking mats was discussed previously to use with pupils but it didn't get embedded. Using talking mats requires training.	The parent meetings are organised after the goals are set rather than before. There are too many formal ax weeks. The ax system does not cater for collecting children or family view. Make a difference: Step one with goal ax and developing is get information/involvement from children and parents Introduce talking mats Could we put a baseline of parent/ student view at the start of each year?
Communication	There needs to be clarity within the team meetings about what is to be recorded and what the actual goal is, including use of technology appropriately.	
Goals & SMART measures	Staff might be working towards aspects of the goal during lessons, but it is difficult to record on trackers because it doesn't make sense for grading criteria.	Pace goal measurement frequently does not line up with goals. For example, anytime a student's level of support/facilitation is stipulated in the goal it is tricky to

	task (smart measure). Lack of clarity of how to use ax weeks to their best function. We need to have baselines but if they happened in the first term all the goals would change by the new staff. The process and structures need tweaking.	
Periods of assessment	3 times or specific times for ax are useful for teacher/ TL otherwise find yourself chasing staff for info when ARs are due. We need to be flexible and reactive to what is going on with a particular child. They may have surgery / be unwell and we need to accommodate this/ modify goals rather than waiting for ax week and commenting that it wasn't able to be worked on. Some goals are short and others will take longer to achieve, what we do and how we monitor progress needs to reflect this. Setting longer term goals which can then be reviewed at different periods.	Carried out at the same time or not?
Time pressures	Sometimes there isn't much time between ax periods to work sufficiently on a goal. We are currently expecting a pupil to achieve a goal each term but at Easter particularly there states a lot of 'continue to work on goal'.	Could there be one goal (or goals) that is driven by parents/ child (which relates to outcomes) and smaller, splinter goals emanating from that which would be worked on throughout the year.