

How can Educational Psychologists, School Practitioners, and Parents/Carers Come to a Shared Understanding of and Promote the Mental Wellbeing of Children and Young People with Profound and Multiple Learning Disabilities?

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Overarching Abstract

This thesis explores how mental wellbeing for children and young people (CYP) with profound and multiple learning disabilities (PMLD) might be understood and promoted in schools. These CYP are significantly more likely to experience issues with their mental wellbeing yet receive less attention in government guidance, policy, and in research. Their dependence on others has engendered debate about the usefulness and inclusivity of general mental health definitions and how to understand and promote their mental wellbeing. One definition, concerning their ability to 'feel good and function well', may be more applicable. However, this may depend on their engagement; the critical interaction between what is happening with or around them.

Chapter 1 describes a Systematic Literature Review (SLR) exploring what approaches described in research literature enhance the engagement of these CYP. Seven studies were located, narratively described regarding impact on engagement, and visually mapped using thematic networks. Themes culminated in an overarching global theme 'Quality of Space'; the extent to which environments facilitate conditions for enhanced engagement. Findings suggest that mental wellbeing for these CYP may relate to the extent to which the environment provides the quality of space needed to enhance their engagement and ability to 'feel good and function well'.

Chapter 2 discusses the philosophical, methodological, and ethical decisions made in attempting to explore this research topic.

Chapter 3 addresses the research question: "How might Educational Psychologists, school practitioners, and parents/carers collaborate to understand and promote the mental wellbeing of CYP with PMLD?" An eclectic methodology was used involving ethnographic observation and video recordings of the CYP, as well as dialogic consultation with adults. Abbreviated Realist Grounded Theory was used to analyse consultation transcripts relating to adults' perspectives on the CYP's engagement with day-to-day activities and how these may be promoting their mental wellbeing. Findings provided a tentative model for understanding and promoting these CYP's mental wellbeing. An individualised approach to promoting opportunities for positive emotion, engagement, relationships, meaning, and accomplishments (PERMA+) was highlighted as important along with reflection on curricula and educational purpose for these CYP.

Chapter 4 reflects on the learning acquired in completing this project. This specifically outlines what the project means for me as a soon to be qualified Educational Psychologist, what the implications are for others I may encounter in both a personal and professional capacity, and appropriate next steps as a qualified researcher-practitioner psychologist.

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'My land's only borders lie around my heart.'

'Relationships of the 'I-It' kind never raise beyond the banal or trivial.' (Buber, 2004)

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Chapter 1: What Approaches Described in Research Literature Enhance the Engagement of Children and Young People with Severe or Profound and Multiple Learning Disabilities?¹

1.1 Abstract

Background

Children and young people (CYP) with severe or profound and multiple learning disabilities (S/PMLD) are more likely to experience difficulties engaging for long periods. Finding ways to facilitate their engagement is crucial in promoting their social and emotional development and their mental wellbeing. This is particularly important as they are more vulnerable to difficulties with mental wellbeing compared to other CYP.

Method

A Systematic Literature Review (SLR) was undertaken to identify approaches described within peer-reviewed research literature that enhance the engagement of these children. Data within seven identified research studies each describing approaches used or steps taken that enhanced their engagement were qualitatively synthesised. Thematic networks were then developed to visually present global, organising, and basic themes identified within data.

Findings

From the SLR, a global theme derived from organising themes across studies indicated that the quality of space was an important consideration in enhancing engagement. This included the extent to which space adhered to prescribed knowledge or afforded practitioners opportunities follow their intuition and deviate from such ideas.

¹ This SLR has been structured in line with guidance for publication in the British Journal of Learning Disabilities.

Conclusions

Quality of space may be important to the engagement of these CYP and subsequently to their mental wellbeing. This may involve consideration of the extent to which formal learning environments for these CYP are organised and informed by dominant theory and discourse (abstract space), prescribed practice (spatial practice), and the extent to which environments provide conditions for 'lived spaces' that are potentially more facilitative of their engagement and subsequently their mental wellbeing.

1.2 Introduction

The situation²

In comparison to those without learning disabilities (LD), CYP with LD are more vulnerable to mental health difficulties (Rose, Howley, Fergusson, & Jament, 2009). In the United Kingdom (UK), it is estimated that between 25 to 40 per cent of those with LD (87,550 to 140,400 CYP) will experience difficulties with their mental health, with 36 per cent (approximately 126,360 CYP) having a diagnosable psychiatric disorder (Hatton, Emerson, Robertson, & Baines, 2018; Mencap, 2020). This increased likelihood has been attributed to the cumulative risk of biological, psychosocial, and environmental factors related to having LD, including but not limited to being at an increased risk of experiencing issues with physical health, living in poverty, and having difficulties forming social relationships (Emerson & Hatton, 2007; YoungMinds, 2021).

In comparison to those described as having mild or moderate LD, cumulative risk is increased further for those with S/PMLD. These CYP are more likely to experience physical health problems, live in poverty, and be socially isolated (Pote & Goodban,

² I have chosen to structure the headings in this chapter of my thesis in line with guidance on developing a Theory of Change provided by Laing and Todd (2015, p. 4)

2007; Sheehy & Nind, 2005). They are also more likely to experience significant difficulties with cognition and communication (Bellamy, Croot, Bush, Berry, & Smith, 2010) meaning it can be difficult for them to share thoughts and feelings, interact and relate to others, or request or access support using verbal communication skills. It can also be difficult for those around them, such as family or practitioners, to accurately interpret and respond to their non-verbal forms of communication (Sheehy & Nind, 2005). Behaviours which may be communicative and intentional can often be construed as unintentional, idiosyncratic, or even 'challenging behaviour' associated with LD which can increase the likelihood that difficulties with mental health are overlooked (YoungMinds, 2021).

Definitions of mental health and mental wellbeing continue to be debated and contested in scientific and philosophical literature due to the difficulty in defining and applying terms universally across the whole population (Palumbo & Galderisi, 2020). Mercieca (2013) has suggested that, in order to find a definition of mental health and mental wellbeing that can be applied to CYP with S/PMLD, it may be necessary to consider alternatives to contemporary definitions and dominant discourse which are not always helpful or applicable. For example, contemporary definitions of mental health and mental wellbeing continue to highlight the importance of factors such as 'productivity' (WHO, 2004), 'autonomy' (Deci & Ryan, 2000), 'responsibility' (Keyes, 2006), and 'feeling good and functioning well' (Huppert & So, 2013; YoungMinds, 2021). Vaillant (2012) has suggested that more inclusive definitions of mental health that have universal applicability, particularly to those with LD who are underrepresented, should be developed.

Definitions that highlight the importance of factors listed above can be problematic as their application to CYP with S/PMLD is inextricably linked to a dependence on others due to their often-complex needs (Emerson & Hatton, 2007; Galderisi, Heinz, Kastrup, Beezhold, & Sartorius, 2015; YoungMinds, 2021). More inclusive definitions that may be less problematic for these CYP may involve a more relational understanding of mental health and mental wellbeing where dependence on others is normalised and considered important. For some, this has involved considering factors that cultivate a sense of connectedness and belonging and how this can be facilitated by meaningful activities and interactions (Nind & Strnadová, 2020;

Simmons & Watson, 2014). Such definitions suggest that, for these CYP, promoting mental wellbeing can be achieved via activities and interactions that facilitate opportunities for 'feeling good and functioning well' resulting in positive emotions, enjoyment, engagement, curiosity, safety, feeling connected, and having a sense of purpose and satisfaction (Huppert & So, 2013; Seligman, 2018; YoungMinds, 2021).

Activities and interactions that promote mental wellbeing may involve consideration of the quality of such activities and how they support 'engagement'; described for CYP with S/PMLD as the critical interaction between what is happening with them or around them (Carpenter, Carpenter, Egerton, & Cockbill, 2016). These CYP spend less time engaged with peers, adults, and materials than those without LD (Bagatell, 2012). Therefore, understanding what is effective in enhancing their engagement and how such activities help them to 'feel good and function well' is not just crucial for their education and developing skills (Steinbrenner & Watson, 2015) but also for facilitating connection to others, developing a sense of belonging, and promoting mental wellbeing (Huppert & So, 2013; Nind & Strnadová, 2020).

1.3 Method

What are we going to do about it?

The SLR focus is therefore on approaches claimed to enhance engagement of these CYP. This was developed by following guidance on Theory of Change (ToC) which is a theory-based approach used to explain the underlying psychosocial mechanisms and their potential causal impact on phenomena (Laing & Todd, 2015; Weiss, 2000).

Potential underlying psychosocial mechanisms

Careful consideration could be given to how to go about capturing and sustaining the engagement of these CYP by increasing opportunities for them to 'feel good and function well' (YoungMinds, 2021). This may involve finding ways to facilitate high quality intersubjective interactions between them and those around them (Nind & Hewett, 2012; Trevarthen & Aitken, 2001). Additionally, engagement for these children might also be enhanced by developing environments around them that are

both socially and materially responsive (Goodwin, 2019; Ware, 2004) and conducive towards associative and contingency-based learning. Increasing the quality of interactions and the responsiveness of the environment around these children has been known to reduce moments of passivity and enhance their engagement (Foreman, Arthur-Kelly, Pascoe, & King, 2004; Simmons & Watson, 2014). These are factors described as essential to promoting their mental wellbeing (Sheehy & Nind, 2005). In a sense, for these children and young people, mental wellbeing, like 'voice' (or the interpretation of their communicative intent), may well be dependent on the performance between them and their social and material worlds and how these unfold and are interpreted in context (Simmons & Watson, 2015).

Defining the SLR question

I followed Petticrew and Roberts' (2006) seven-step guidance in completing a SLR. The SLR question and the search strategy were developed using Robson's (Robson, 2011) model describing realist exploration within research and sought to answer this question:

"What Approaches Described in Research Literature Enhance the Engagement of CYP with S/PMLD?"

Robson's (2011) model focuses on the actions, mechanisms, context, and outcomes of an approach. By focusing on these, I was able to determine the following search terms for the SLR:

Table 1: SLR search terms

X (the actions)	Y (the target group)	Z (the outcomes)
approach* OR strateg* OR interven* OR method* OR design OR program* OR action OR plan* OR project OR procedure* OR tool* OR modif* OR support* OR adapt* OR adjust*	"profound intellectual and multiple disabilit*" OR "PIMD" OR "profound and multiple learning disabilit*" OR "PMLD" OR "profound intellectual disabilit*" OR "profound and multiple learning difficult*" OR "severe learning disabilit*" OR "severe and complex needs" OR "high support needs" OR "profound learning disabilit*" OR "severe learning difficult*" OR "severe intellectual disabilit*"	alert* OR engag* OR interact* OR stimulat* OR learn* OR encourag* OR activ* OR aware* OR curious OR curiosity OR initiat* OR persist* OR anticipat* OR discover* OR investig* OR affect* OR attent* OR focus* OR participat* OR motivat* OR interest*

The target group

The terms for the target group (CYP with S/PMLD) were developed by considering the different words used across international research literature when referring to these CYP (Nind & Strnadová, 2020). Although the terms 'severe learning disabilities' and 'profound and multiple learning disabilities' refer to two heterogeneous groups of CYP with defining characteristics (Imray & Colley, 2017), there is some overlap of characteristics between the two groups which is often why the terms are combined to S/PMLD when referring to these CYP (Colley, 2020). For example, CYP in both groups may share the following characteristics:

- Significant intellectual impairment.
- Reliance on those around them to interpret communicative behaviour.
- Forms of physical or sensory disability making it difficult for them to communicate and interact.
- Complex needs requiring a high level of support with aspects of their day-today routine.

Throughout this chapter, unless referring to these groups individually, I will be using the terms 'severe or profound and multiple learning disabilities' (S/PMLD) as this term is generally accepted within research literature and by UK disability advocacy groups. The term also differentiates between those with LD and those with more specific learning difficulties such as dyslexia which is unrelated (Mencap, 2021).

Although the term 'S/PMLD' is used frequently throughout research, policy, and practice relating to these two distinct groups of CYP (for example, see Colley (2020) and Hinchcliffe (2022)), there are regarded to be strengths and limitations in doing so. For example, some have suggested that there should be clear and distinct definitions for those with PMLD and SLD so that they can be separately identified, understood, and responded to (Bellamy et al., 2010; PMLD Network, 2003). It has been suggested that researchers should exercise caution when attempting to generalise findings between both groups, particularly when there is a focus on behavioural and emotional problems (Forster, Gray, Taffe, Einfeld, & Tonge, 2011). Others have suggested that there is a risk that understanding them separately rather than together as a group who 'share needs, characteristics, circumstances, and ways of living' can result in them becoming further marginalised and thusly further underrepresented in research, policy, and practice (Redmore, 2021, p. 59). In this SLR, expanding the search to identify studies related to SLD and PMLD increased the number of articles for the synthesis. Effort was made to ensure that data included in the synthesis related to CYP with SLD and PMLD that were non-verbal communicators as this was a primary interest rather than the labels used (see Table 3).

The outcomes

Although engagement has been deemed a multidimensional concept that is hard to define operationally (Kossyvaki & Curran, 2020; Newmann, 1986), for these children and young people, engagement may refer to an ability to connect with the material and social environment (Carpenter et al., 2016). This conceptualisation was used to develop search terms denoting engagement and related synonyms as the outcome of approaches used.

The search strategy

Seven academic databases were searched between October 2020 and May 2021 using the above search terms and search results can be seen in Table 2.

Table 2: Database search process

Databases searched	Search results (number of articles)
ERIC (EBSCO)	80
British Education Index	58
Ovid (PsycInfo, Medline, Embase)	358
ERIC (Proquest)	170
Web of Science	113
Total	779
Total after removing duplicates	523
Excluded after screening title and	443
abstract	
Included after screening title and	80
abstract	
Excluded after screening full text and	73
applying inclusion criteria	
Total	7

Seven articles were then screened by reading full text and were confirmed as relevant in answering the SLR question.

Table 3: Inclusion criteria for SLR

- Studies published in peer-reviewed journals between January 1st 2014 and May 1st 2021 (these dates were selected to consider how research literature during this time had responded to the Department of Health's (2015) 'Future in Mind' Green Paper which by 2020 set out to understand what is most effective in supporting and promoting the mental health of all CYP in schools).
- Studies conducted in a school or other education context in the UK or Ireland (studies thus included were felt to have taken place in a similar cultural, political, and educational context when compared to others in the western world).
- Studies that describe the impact of an intervention, approach, strategy (or related synonyms) on engagement, interaction, alertness (or related synonyms) of CYP with S/PMLD (or related synonyms) aged 0-25 that are either described as pre-verbal communicators or working below P Scale Level 4 in the areas related to communication (QCA, 2009).
- Studies published in English.
- Studies describing empirical research with a clearly identifiable qualitative methodology.

The titles and authors of the seven included studies deemed most appropriate in answering the SLR question and included to be critically appraised and synthesised can be seen in Table 5.

Critically appraising and synthesising the included studies

I followed Popay et al's (2006) guidance on Textual Narrative Synthesis (TNS) to individually appraise and collectively synthesise the seven selected studies. TNS was selected instead of other methods given its ability to aid the process of comparison between qualitative studies and approaches described (Barnett-Page & Thomas, 2009). Guidance on using TNS as part of an 'implementation review' (Popay et al., 2006, p. 12) to understand factors, facilitators, and barriers within

approaches in identified studies mirrors ideas contained within ToC (Laing & Todd, 2015) and a realist explanation of research (Robson, 2011).

Table 4: The four elements of TNS

- Developing a theory of how the intervention works, why, and for whom (see above for the psychosocial mechanisms);
- Developing a preliminary synthesis of findings of included studies (see Table 5);
- Exploring relationships within data;
- Assessing the robustness of the synthesis.

(Popay et al., 2006, p. 12)

1.4 Findings and Discussion

Exploring relationships within data

Included studies were individually appraised and coded to identify basic themes within data (Popay et al., 2006) which have been collated in Table 5. Included studies were then collectively synthesised to understand organising themes across data between included studies (Popay et al., 2006). To aid this process, themes and concepts were visually presented using Thematic Networks (Attride-Stirling, 2001) firstly as basic themes, then as organising themes that clustered characteristics across studies, and finally as an overarching global theme that encapsulates a central argument or theory across all included studies (Attride-Stirling, 2001).

Table 5: Preliminary synthesis of the seven studies located that answer the SLR question

Study and country of origin	Approach	Participants	Setting/ context	Focus	Design/ Method	Outcomes and <i>codes</i> within studies used to develop basic themes	Other notes
Study 1: Pavlicevic et al. (2014) Making music, making friends: Long-term music therapy with young adults with severe learning disabilities UK	The use of music-centred music therapy to respond to the needs of young adults with severe learning disabilities.	Stakeholders such as parents, family members, teachers, therapists, personal/ learning support assistants with direct experience of young adults with severe learning disabilities that had been involved in Nordoff Robbins Music Therapy.	A London-based clinic attached to the Nordoff Robbins Music Therapy Charity	Understanding the psychosocial needs of young adults with severe learning disabilities and how music therapy responds to these needs.	Focus groups held with two groups of stakeholders (parent/ carers and professionals) in addition to meetings with music therapists all with direct experience of young adults with severe learning disabilities. Focus groups followed three phases each with a series of questions and prepared cues and prompts (including audio and video excerpts of music therapy sessions with young adults with severe learning disabilities). Focus group discussions transcribed for the purpose of data analysis. Ideas generated in the additional meetings with the music therapists feature in the discussion and conclusion.	Music therapy increased accessibility by providing the young adults with a nonconfrontational and nonjudgemental way of engaging with others by overriding pressures and stresses arising from language limitation. Music therapy enhanced engagement and provided the young adults with communicative, emotional expressive, and relational coping strategies to counter the difficulties that are a barrier to dyadic engagements with others. Music therapy supports, extends, and elicits motivation in the young adults to engage, communicate, and exchange meaning with others to establish satisfying emotional relationships, meet a need for intimacy and understanding, as well as reduce isolation and mental ill health. Music therapy provides a safe socialising opportunity for interaction as part of a group with shared musical experiences.	
						relationships, meet a need for intimacy and understanding, as well as reduce isolation and mental ill health. Music therapy provides a safe socialising opportunity for interaction as part of a group with shared musical	

Study and country of origin	Approach	Participants	Setting/ context	Focus	Design/ Method	Outcomes and codes within studies used to develop basic themes opportunities closely linked to positive self-esteem, positive self-value, and sense of self.	Other notes
Study 2: Preece and Zhao (2015) Multi-Sensory Storytelling: A Tool for Teaching or an Intervention Technique? UK	The use of multi- sensory storytelling as an approach to contribute to curriculum access, learning, and socialisation of students with severe and profound and multiple learning disabilities.	School professionals based within special schools for students (Early Years Foundation Stage to Post-16) with severe and profound and multiple learning disabilities.	Five day/ residential special schools based in the East Midlands/ South East of England for students with a range of additional needs including severe and profound and multiple learning disabilities.	To investigate school professionals' practice of multi-sensory storytelling, what opportunities the approach provides, and what factors affect its use.	Case study methodology. Semi structured interviews carried out with school-based professionals. Observations undertaken for 18 school sessions using multi-sensory storytelling. Field notes gathered in-situ using non-participant unstructured observation techniques. Transcripts of interviews and records of observations were analysed alongside an a priori list of predetermined codes from research questions and literature.	Multi-sensory storytelling supported opportunities for socialisation/ interaction in lessons. Combined with the use of engaging objects it developed students' anticipation and facilitated their attention. It increased opportunities for interaction and exploration which provided communication opportunities. It supported development of agency/ empowerment of pupils.	Multi-sensory stories were individualised and differentiated for individual pupil needs (e.g. increasing the size of objects in line with fine motor skills).
Study 3: Griffiths and Smith (2016) Attuning: A Communication Process between People with Severe and Profound Intellectual Disability and Their Interaction Partners Republic of Ireland	The use of attuning as an approach to facilitate dyadic communication between a young person with profound intellectual and multiple disabilities and their communication partner.	Three dyads each comprising of one person with profound intellectual and multiple disabilities and their keyworker (this included one dyad comprising a young person aged 18 with profound intellectual and multiple disabilities	A non-residential special school in Ireland for children and young adults with severe and profound intellectual and multiple disabilities.	To develop a theory that explains the interaction process between people with severe and profound intellectual and multiple disabilities and others	Three dyads were recruited comprised of a person with severe and profound intellectual and multiple disabilities and their key workers. Activity sessions involving each dyad were observed and video recorded to analyse periods where interaction in each dyad was most frequent.	The overarching theory of attuning was related to a communication partner's ability to interact, engage, and respond to stimulus within the dyad. Attuning was linked to observed behaviours within the dyad related to reduced and increased levels of interaction, engagement, cooperation, and mutual attention.	Attuning is not an approach as such but a theoretical concept for understanding levels of empathy and cooperation within dyadic interaction. However, the author suggests that implications for practice could

Study and country of origin	Approach	Participants	Setting/ context	Focus	Design/ Method	Outcomes and codes within studies used to develop basic themes	Other notes
		and their keyworker).		with whom they interact.	Video recordings were transcribed and analysed to identify segments incorporating interpersonal interaction. Grounded Theory (Glaser, 1998) was applied to transcript data to compose a core theoretical category as well as related but discrete concepts that explain the overarching theory.	Persons with and without severe and profound intellectual and multiple disabilities are equal partners in attuning processes which are dynamic and can fluctuate in levels of empathy and cooperation.	include applying the concept to people with severe and profound intellectual and multiple disabilities to increase their ability to engage with, interact with, and affect things in their lives (autonomy and agency).
Study 4: Robinson, Moore, and Harris (2018) The Impact of Books on Social Inclusion and Development and Well-Being among Children and Young People with Severe and Profound Learning Disabilities: Recognising the Unrecognised Cohort UK	The impact of pleasurable engagement with books.	37 children and young people with severe or profound and multiple learning disabilities; 24 school practitioners working in Early Years or Key Stage 3 contexts; 21 parents of children participating.	Four Local Authorities within the North, South East, South West, and Midlands regions of the UK. A combination of special schools, a mainstream nursery and primary school, a child development centre within a large hospital, a children's centre, a local library, and family homes.	How is pleasurable engagement with books experienced by children and young people with severe or profound and multiple learning disabilities, how is this achieved, and what impact does this have?	Methods investigated real-life interactions and the perspectives of significant others in relation to pleasurable engagement in books. 13 semi-structured interviews were conducted with families following observation of parents/ carers and their children sharing books and reading together. 27 semi-structured interviews were carried out with practitioners following observations of individual children or groups of children in school or play settings. Observation schedules collected structured and unstructured data in-situ related to artefactual, sensory, vocalised, physical,	Personalisation of the book reading activity to experiences, sensory preferences, and additional needs of the child, making them more accessible enhanced pleasurable engagement. Enhancing the reading activity with multi-sensory and social stimuli such as song, props, and real-world artefacts increased pleasurable engagement. Interacting intensively with the child around the book was linked to increased pleasurable engagement. Stories that include repetition or repeating the same stories also led to more pleasurable engagement.	Includes a combination of approaches that are highlighted in other studies in this review (e.g. multi-sensory storytelling; Intensive Interaction)

Study and country of origin	Approach	Participants	Setting/ context	Focus	Design/ Method	Outcomes and <i>codes</i> within studies used to develop basic themes	Other notes
					and gestural interaction around a book. This was supplemented by Carpenter et al's (2016) engagement profile. Observational and interview elements of data collection were combined to provide rich triangulated qualitative data. Data from all sources underwent inductive thematic coding to form theoretical concepts.		
Study 5: Aidonopoulou-Read (2020) The Conceptualisation of a Modified Formative Assessment Model for Non-Verbal Students with Autism and Severe Learning Difficulties UK	A practical formative assessment tool which included the use of engaging resources and rewards.	Five student participants who are non-verbal diagnosed with autism and significant developmental delay.	School (no further information provided)	To examine the impact of a formative assessment model to serve as a tool for students with autism and severe learning disabilities to examine the impact of learning instruction on student behaviour and engagement.	A combination of video and observational checklists to record student reactions and assess student engagement (procedural engagement) in relation to the use of praise, tangible rewards, and engaging resources.	Student 1: no procedural engagement but examples of active engagement in response to an <i>engaging resource</i> . Student 2: signs of active engagement in later lessons in response to engaging resources and rewards but disengagement later in response to the same resources. Student 3: signs of procedural engagement in response <i>to engaging resources</i> , <i>recognition, and praise</i> . Student 4: signs of procedural and active engagement in response to engaging resources. Student 5: engagement levels were inconsistent in response to engaging resources and rewards but more stable when	Important to note individual differences between students and their ability to engage such as their sensory needs (student 3 had poor eyesight affecting his ability to engage with resources).

Study and country of origin	Approach	Participants	Setting/ context	Focus	Design/ Method	Outcomes and codes within studies used to develop basic themes intrinsically motivated and interested in the lesson.	Other notes
Study 6: Rushton and Kossyvaki (2020) Using Musical Play with children with profound and multiple learning disabilities at school UK	The impact of musical play intervention on the play experiences of children with profound and multiple learning disabilities and the staff that support them	Five children aged 8 to 10 years old with profound and multiple learning disabilities and four school practitioners.	A special school for primary-aged children with complex needs in England.	To assess the impact of a musical play intervention on children with profound and multiple learning disabilities.	Mixed-methods case study to quantitatively assess the impact of the intervention on the children and qualitatively explore the views of school practitioners. Musical play sessions were developed using an adapted framework comprised of numerous existing practices (e.g. Intensive Interaction) as well as use of music/ playful musical instruments. Video recorded observations and focus group interviews were the main data collection methods. Data from focus group interviews underwent inductive thematic coding.	Common themes related to staff perceptions towards structured, targeted, and nonplayful learning for children which were a barrier to facilitating engagement in play. Staff felt the environment was not always conducive to focus and attention. There was a sense that staff felt playful approaches that were more child-led, spontaneous, and joyful could lead to increased engagement. Staff felt that less structured play/ more spontaneous play could jointly facilitate engagement leading to learning and increased well-being for the children.	
Study 7: Simmons (2021) The production of social spaces for children with profound and multiple learning difficulties: a Lefebvrian analysis UK	An examination of how different learning environments (specialist education settings and mainstream education settings) provide alternative	Seven children all identified by parents and teachers as having profound and multiple learning disabilities.	A combination of integrated, specialist, or mainstream nursery or school settings (with some children attending a combination of	Applying a Lefebvrian lens (analysing the impact of abstract and lived spaces as well as practices	A mixture of qualitative methods including pre- observation of children followed by focus groups and interviews with significant others (e.g. parents and teachers); participatory observation of children during activities; observational	Qualitatively different social spaces and practices within these spaces provided alternative opportunities for children with PMLD to practice and demonstrate social awareness and communication skills.	Simmons (2021, p. 15) suggests that the fluidity of social interactions are more important than geographical sites for the inclusion of children with profound and

Study and country of origin	Approach	Participants	Setting/ context	Focus	Design/ Method	Outcomes and <i>codes</i> within studies used to develop basic themes	Other notes
	opportunities for children with profound and multiple learning disabilities to engage in social interaction.		both specialist and mainstream).	within these spaces) to understand the conditions that impact on the social engagement of children with profound and multiple learning disabilities.	fieldnotes to build storied vignettes for each child; and an inductive thematic approach applying Lefebvre's 'spatial triad' to data analysis.	Interactions between specialist staff and children with PMLD in the special school spaces were typically consistent with accounts and pedagogic styles discussed in PMLD literature and were mostly dyadic as opposed to pluralistic. Comparatively, peers in the mainstream embodied a style of interaction which contrasted sharply to special school staff in that they were less pedagogic, less dyadic, and more playful (e.g. 'interacting for interaction's sake'). This increased the children with PMLD's engagement, social awareness, playfulness, alertness, and communicability. In some cases, children with PMLD sharing mainstream spaces with their non-disabled peers were able to meet their developmental targets quicker and developed new symbolic forms of communication.	multiple learning disabilities, and that considering this might be an integral component of belonging, and subsequently mental wellbeing.

Figure 1: A thematic network (Attride-Stirling, 2001) describing factors that enhance the engagement of CYP with S/PMLD

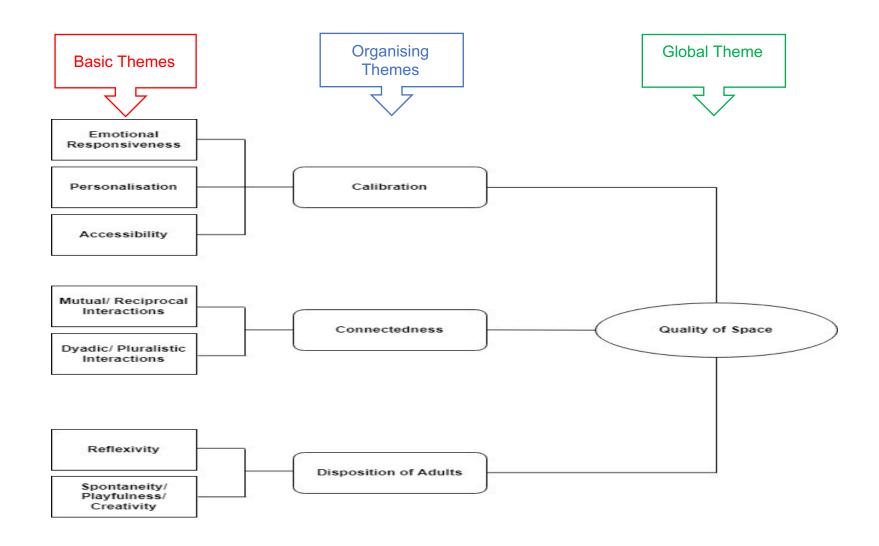


Table 6: Recap of included studies and authors

Study 1 Pavlicevic et al. (2014)
Study 2 Preece and Zhao (2015)
Study 3 Griffiths and Smith (2016)
Study 4 Robinson, Moore, and Harris (2019)
Study 5 Aidonopoulou-Read (2020)
Study 6 Rushton and Kossyvaki (2020)
Study 7 Simmons (2021)

Organising themes (OT) and constituent basic themes

OT One: Calibration (emotional responsiveness, personalisation, accessibility)

'Calibration' was chosen as an organising theme as this term best described how approaches would often have to undergo a process of personalising the activity to the individual, making it accessible to them, whilst remaining responsive to the flux and flow of levels of engagement and cooperation. This was often described as a dynamic process that required adults to calibrate their approach based on how CYP responded.

Basic themes related to 'emotional responsiveness' were discovered within all studies. Adults' emotional responsiveness and how this led to engagement was best described in Griffiths and Smith (2016). Here, the 'communicative ebb and flow' (p. 35) of engagement was facilitated by a responsive adult who could calibrate their approach based on levels of empathy and cooperation in their interactions with an individual with PMLD. Similarly, in Study 5, the emotional responsiveness of the adult, how they altered their approach and response to CYP's perceived need for emotional engagement, facilitated the engagement of CYP when other stimuli such as rewards and engaging resources had not been successful. In Study 1, music therapy sessions provided opportunities for CYP to communicate emotional needs and receive appropriate responses. Adults were emotionally responsive to these needs and during music therapy sessions prioritised them above 'the practicalities of looking after...and caring for their basic needs' which would usually take up their time (Pavlicevic et al., 2014, p. 13). Furthermore, in Study 4, the adults' emotional responsiveness and how they monitored and adjusted their approach in line with the mood of CYP during shared reading was important in enhancing pleasurable engagement with books. These examples suggest that the emotional responsiveness of those interacting with these CYP was important to monitor and sustain levels of engagement.

An 'accessibility' theme was discovered, perhaps fundamentally, within all studies as they were invariably describing approaches that had been designed with accessibility and participation for the CYP in mind. In Study 1, music therapy was described as offering 'a non-judgemental and non-confrontational stance' towards the needs of CYP and as supportive of musical engagements that help them to overcome 'the pressures and stresses arising from language limitations' (Pavlicevic et al., 2014, p. 11). In Study 3, attuning was described as an approach to supporting talk 'that did not rely on words' (Griffiths & Smith, 2016, p. 29). In Study 6, musical play was described as accessible due to 'the absence of formal language' (Rushton & Kossyvaki, 2020, p. 492). These examples suggest that accessibility was a fundamental element of approaches that enhanced CYP's engagement.

Basic themes related to 'personalisation' were also discovered across Studies 2, 4, 5, 6, and 7. Study 5 described the importance and necessity of 'knowing the

individual' and tailoring 'individualised interventions' to enhance engagement (Aidonopoulou-Read, 2020, p. 105). Study 4 described how the impact of books on the engagement of CYP was enhanced when 'a highly personalised experience which was related to developmental needs' was provided by a significant other (Robinson et al., 2019, p. 100). Study 2 described how adults were 'continually adapting, assessing, and making judgements' to personalise multi-sensory stories to enhance the engagement of CYP (Preece & Zhao, 2015, p. 437). These examples suggest that personalisation was an important feature of approaches that enhanced engagement described in studies.

Collectively, the basic themes within and between studies described above clustered to form an organising theme of 'calibration'. The engagement of CYP was often described across studies as being in a dynamic state of ebb, flux, or flow. Personalising approaches and making them accessible to CYP was not described as a single action but was a process of continuous monitoring and adjustment to maintain CYP's engagement. This was overseen by emotionally responsive adults adjusting and adapting their approach using a combination of practice-based pedagogical knowledge relating to S/PMLD and how they viewed CYP's emotional and cognitive engagement with activities (Preece & Zhao, 2015). This provides an example of how basic themes around 'emotional responsiveness', 'accessibility' and 'personalisation' clustered and formed the organising theme of 'calibration'. This organising theme was closely related to another around the 'disposition of adults' as well as the overarching global theme of 'quality of space'. Across studies, 'calibration' was affected by the reflexive disposition of adults and, importantly, the extent to which approaches created space and opportunity for this.

Findings related to the organising theme of 'calibration' appear to be in line with ideas within wider research literature relating to CYP with S/PMLD, particularly those that highlight the importance of responsive environments (Ware, 2004) and interactions (Nind & Hewett, 2012). Approaches that are personalised, accessible, and responsive to CYP appear to enhance their ability to engage with the environment and with others (Nind & Hewett, 2012). Adults that respond to CYP using individualised approaches enhance levels of engagement (Goodwin, 2019). Emotionally responsive adults appear to be better equipped to interpret the

communicative intent of CYP and can adjust their approach in line with their emotional presentation (Cluley, 2017; McCormack, 2017). Adults' ability to calibrate their approach appears to lead to engagement, which appears to be dependent on the intensity and emotional quality of activities that enhance CYP's involvement (Carpenter et al., 2011).

OT Two: Connectedness (mutual/ reciprocal interactions, dyadic/ pluralistic interactions)

'Connectedness' was selected as a second organising theme. This term best described how approaches leading to enhanced engagement often involved opportunities for CYP to engage in reciprocal dyadic or pluralistic social interactions. These interactions were often described as mutually beneficial as they led to shared moments of pleasure between CYP and adults.

Basic themes related to 'mutual/ reciprocal interactions' were discovered within Studies 1, 2, 4, 6, and 7. In Study 1, this is best described when music therapy sessions enabled CYP to 'tap into other peers...feeling and joining in' and to be 'actually a part of the group' (Pavlicevic et al., 2014, p. 13). In Study 2, multi-sensory storytelling was described as promoting socialisation and maximising enjoyment for CYP, providing them with 'a chance to come together as a group' and share in an enjoyable activity (Preece & Zhao, 2015, p. 433). In Study 4, books were described as providing CYP and those reading to them with 'meaningful, mutually gratifying social interaction' (Robinson et al., 2019, p. 99). In Study 6, a common theme related to adults' description of the 'positive experiences' of musical play for themselves and for CYP (Rushton & Kossyvaki, 2020, p. 503).

Basic themes related to 'dyadic/ pluralistic interactions' were also discovered within studies 1, 4, and 7. These terms were selected to describe examples in studies where engagement was linked to a socially interactive and often emotional interdependence between CYP and at least one other individual. In Study 1, music therapy was described as both a dyadic and pluralistic activity that provided CYP with 'shared musical experiences... bringing the kinds of values that, for these young adults, parallel socialising in the lives of their peers' (Pavlicevic et al., 2014, pp. 13-

14). In Study 4, books were described as a dyadic activity bringing benefits to CYP via 'intensive dyadic exchanges' through which pleasurable reading was sustained between adults and CYP providing 'here and now benefits' to both (Robinson et al., 2019, p. 100). In Study 7, opportunities for CYP with PMLD to mix with their mainstream peers created pluralistic social interactions that were 'joyful', 'emotionally charged', and 'mutually pleasurable' (Simmons, 2021, p. 11).

Collectively, the basic themes of 'mutual/ reciprocal interactions' and 'dyadic/ pluralistic interaction' clustered to form an organising theme of 'connectedness'. Findings related to the organising theme of 'connectedness' appear to be in line with ideas within wider research literature relating to CYP with S/PMLD that highlight the importance of primary and secondary forms of intersubjectivity (Trevarthen & Aitken, 2001) and support the use of approaches such as 'Intensive Interaction' (Nind & Hewett, 2012). Approaches underpinned by this theory explain how opportunities for shared and emotionally attuned social interactions lead to enhanced engagement via a social connection and interaction with others. A feature of approaches described involved CYP often being engaged in activities that enhance shared emotion and attention with and alongside others. In a sense, these activities enabled a form of 'coordinated companionship' (Malloch & Trevarthen, 2009, p. 32) to emerge through emotionally responsive, reciprocal and mutual social interactions.

OT Three: Disposition of Adults (reflexivity, spontaneity / playfulness/ creativity)

The third organising theme related to the 'disposition of adults'. Adults had an implicit gatekeeping role to the approaches used with CYP. Accessibility for and engagement of CYP was often dependent on personal and professional qualities and tendencies of adults across studies.

Basic themes related to adults' 'reflexivity' were discovered within Studies 2, 6, and 7. This term was selected as it best described the propensity for adults to alter their approach based on environmental and interactional information regarding levels of engagement from CYP. In Study 2, adults' reflexivity towards using multi-sensory storytelling with CYP was described as 'adapting practice in vivo' to 'adapt and individualise to the needs of the kids...through local hermeneutics' (Preece & Zhao,

2015, pp. 437-440). This was deemed essential to be able to interpret and respond to real-time information regarding CYP's engagement with stories. In Study 6, adults involved in facilitating musical play for CYP described feeling 'restricted in their opportunities to support play purely as a child-focused, spontaneously joyful activity' (Rushton & Kossyvaki, 2020, p. 505). This was reconciled by adults within musical play by 'mindfully observing the reactions and interactions of learners and following their interest' (Rushton & Kossyvaki, 2020, p. 506). Study 7 described how adults sharing space with CYP outside of typical special school environments 'abandoned specialist pedagogic styles to collectively and spontaneously live in the moment' within social spaces, which led to enhanced engagement for CYP (Simmons, 2021, p. 14). These examples suggest that when adults were more reflexive towards their gatekeeping role and were more mindful of environmental and interactional information, they were better able to respond in the moment to the ebb and flow of levels of engagement for CYP.

Basic themes related to 'spontaneity/ playfulness/ creativity' were discovered within Studies 1, 2, 6, and 7. These terms were selected to describe personal characteristics of adults and how these facilitated and enhanced CYP's engagement. In Study 2, multi-sensory storytelling was described as an approach to teaching that calls for 'intuition, creativity, improvisation and expressiveness' as prerequisite skills to make the approach beneficial to CYP (Preece & Zhao, 2015, citing Gage, 1978, p. 15). In Study 6, flexibility to be playful was described by adults as an essential feature of musical play, enabling them to be spontaneous and creative in their playful interactions with CYP. Adults felt a 'more play-led approach would be beneficial to the learners', with one adult commenting, "why does everyone and everything have to have a target? Why can't we play and then at the end of the day go "these are the things we did" (Rushton & Kossyvaki, 2020, p. 504). In Study 7, the playful disposition of adults was impacted by the nature of social spaces where interactions took place. For example, adults became playful in their interactions with CYP, demonstrating 'lots of laughter, shouting, gentle teasing, performances, physical exchanges and group-based interactions' when outside the school environment (Simmons, 2021, p. 14). These examples suggest that the space and time to be playful, spontaneous, and creative that was afforded to adults by the approaches described enhanced the engagement of CYP. It also suggests that typical

approaches used with these CYP may constrain adults' ability to be instinctive and intuitive in their approach. The examples also further support the link between organising themes and the global theme of 'quality of space' which describes how approaches described appeared to provide space and opportunity for adults to be reflexive, spontaneous, playful, and creative in how they engage CYP.

Collectively, the basic themes of 'reflexivity' and 'spontaneity / playfulness / creativity' clustered to form an organising theme of 'disposition of adults'. Findings related to the organising theme of 'disposition of adults' appear to be in line with ideas within wider research literature broadly relating to the education of CYP. For example, literature describes the importance of providing educators with space and time to be reflexive and able to respond in the moment to what they observe based on their 'craft knowledge' (Thomas, 2012) or 'informal funds' of practice-based evidence (Hedges, 2012). In the studies described above, approaches appeared to afford adults with an opportunity to break from prescribed practice related to the education of these CYP, enabling them to be increasingly reflexive and intuitive in their engagement/interaction with these CYP. These findings appear to be in line with those of Stewart and Walker-Gleaves (2020, p. 356), who indicated that the success of curricula that effectively engage CYP with S/PMLD appears to be related to adults' individuality and creativity in being the 'curriculum-in-action' for CYP.

This organising theme also highlights the importance for adults' understanding of the complex balance between their 'professional skills and knowledge and the more 'affective' dimensions of their work' (Shipton & O'Nions, 2019, p. 289). Adults supporting the engagement of these CYP might consider opportunities to be reflexive, spontaneous, playful, or creative as something that enables them to address this balance. In the studies considered in this SLR, doing so appears to have significant benefits for these CYP and those around them, including enhancing engagement with and for the CYP and helping them to develop mutually beneficial relationships with others (Watson, 2015). This organising theme can also be related to the importance of adults reflexively considering how responsive environments are to these CYP (Ware, 2004) and how approaches cultivate conditions for primary and secondary intersubjectivity (Trevarthen & Aitken, 2001) for these CYP via the spontaneous, playful, and creative disposition of adults.

Global Theme: Quality of Space

All basic themes and organising themes discussed above are interlinked and contributed to an overarching global theme of 'quality of space'. This term was selected as it best described how approaches cultivated the psychosocial conditions that led to the enhanced engagement of CYP.

The term 'quality of space' was derived from concepts discussed in Study 7 which relate to how theory and practice informs and constructs social environments around these CYP (Simmons, 2021). Study 7 utilised concepts from Lefebvre (1991) to describe and contrast social spaces and practices that were informed more or less by 'PMLD wisdom' (Simmons, 2021, p. 15) or abstract ideas relating 'to knowledge, to signs, to codes, and to frontal relations' (Lefebvre, 1991, p. 33) that are used to inform and construct social spaces for these CYP. Abstract ideas inform practices within social spaces that are commonly informed by hegemonic professional discourse and knowledge relating to the education of these CYP (Simmons, 2021).

Themes related to 'quality of space' were discovered within all included studies. In Study 1, music therapy was described as providing space and opportunities for adults and CYP that were 'seen to contrast with more standard types of specialised environments... and offer experiences of fun, enjoyment and equality, a sense of group belonging, intimacy, confidence, self-worth and dignity' (Pavlicevic et al., 2014, p. 16). This was described as being in sharp contrast with environments and approaches where a focus on development and efficacy were dominant. In Study 2, multi-sensory storytelling was described as a pedagogically flexible approach where development of CYP was not viewed as a primary concern but a 'serendipitous bonus' (Preece & Zhao, 2015, p. 436). In Study 7, 'lived spaces' which were described as being spaces where CYP could engage in mutually beneficial and emotionally charged social interactions with others were spaces where typical theory and practice related to these CYP appeared to be 'abandoned, forgotten, resisted so it does not reign supreme' (Simmons, 2021, p. 14).

When the psychosocial conditions (such as those described as basic and organising themes) that are conducive to enhanced engagement for these CYP are considered,

'quality of space' refers to the socio-material environments for these CYP. Such environments often appear to be rigidly constructed upon dominant theories, practice, and discourse around S/PMLD. This arguably leaves little room for the creation of 'lived spaces' (Lefebvre, 1991) 'where protocol is not followed, and where novel forms of engagement are allowed to emerge' (Simmons, 2021, p. 4). Approaches described in this SLR, although underpinned by evidence-based theory and practice often cited within S/PMLD literature, may have provided space and opportunities for adults to deviate from and disrupt dominant theory and practice. Approaches may have assisted adults in cultivating space and opportunities 'shaped by tension between abstract space and lived space' (Simmons, 2021, p. 4) that cultivate the psychosocial conditions that are particularly conducive to enhanced engagement for these CYP.

Assessing robustness of the synthesis

In line with the SLR's critical realist approach, the decision was made to assess the robustness of studies included. This involved subjectively assessing the methodological quality of studies included and their relevance to the focus of the SLR to gain an overall assessment of trustworthiness of the SLR synthesis (Popay et al., 2006). An adapted version of the 'Critical Appraisal Skills Program: Qualitative Studies Checklist' (CASP, 2022)' was used (See Table 7).

This process indicated that there was a high degree of quality and relevance within studies included, suggesting high overall trustworthiness of the SLR synthesis. On occasions when studies were 'marked down', this was related to lack of clarity in how methodological or ethical issues had been considered. For example, Study 5 did not appear to specify the method of data analysis which weakened the overall quality judgement. Study 3 did not appear to consider the issue of ongoing assent when involving participants with S/PMLD in data collection methods to the extent of other studies, which is often highlighted as an important consideration when conducting research involving these CYP (Harris, 2003). Study 2 did not appear to consider the impact of the researcher relationship towards adult participants and how this may have impacted data collection or interpretation to the same extent as other studies.

Table 7: CASP checklist summary (Owen-Hughes, 2021)

	Study 1	Study 2	Study 3	Study 4	Study 5	Study 6	Study 7
Was there a clear	_		_				
statement of the aims?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is a qualitative							
methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the research design							
appropriate to address the	Yes	Yes	Yes	Yes	Yes	Yes	Yes
aims?							
Was the recruitment							
strategy appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was data collected in a							
way to address the	Yes	Yes	Yes	Yes	Yes	Yes	Yes
research issues?							
Are data collection							
methods detailed?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Has the relationship							
between researcher(s)							
and participants been	Yes	Somewhat	Yes	Yes	Yes	Yes	Yes
considered?							
Have ethical issues been	V.	V.	0	V.	V.	V.	V
taken into consideration?	Yes	Yes	Somewhat	Yes	Yes	Yes	Yes
Was the data analysis	V.	V.	V.	V.	I I a de con	V.	V
sufficiently rigorous?	Yes	Yes	Yes	Yes	Unclear	Yes	Yes
Is there a clear statement	V	V	V	V	V	V	Van
of the findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is it clear how the	Vaa	Vaa	Vaa	Vac	Vaa	Vaa	Vaa
statement of the findings was reached?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
How valuable is the							
research to the SLR?	Valuable	Valuable	Valuable	Valuable	Somewhat	Valuable	Valuable
What is the overall	valuable	valuable	valuable	valuable	Somewhat	valuable	valuable
	High	High	High	High	Medium	High	High
judgement of 'quality'? How relevant is the	riigii	High	riigii	riigii	IVICUIUIII	riigii	riigii
research for the SLR?	Relevant	Relevant	Relevant	Relevant	Somewhat	Relevant	Relevant
research for the SLK?	Televalit	Televalit	Televani	Televani	Relevant	Relevant	TABLEVALIL
<u> </u>					Relevant		

1.5 Conclusion and Implications

What actions will be taken and what effect might this have?

This SLR set out to answer the question "What approaches described in research literature enhance the engagement of CYP with S/PMLD". The SLR process identified seven studies, all rated as being medium to high quality, describing approaches leading to the enhanced engagement of these CYP. Studies described a range of strategies designed to enhance these CYP's engagement, including use of music, story books, engaging and rewarding resources, particular communication approaches, and sharing social space with others. These approaches were closely examined to identify any underlying factors or psychosocial mechanisms contributing to the enhanced engagement of these CYP.

Underlying psychosocial mechanisms appeared to align with many of the hegemonic theories frequently discussed within the wider literature relating to these CYP; for example, the importance of responsive and energetic social spaces that create opportunities for emotionally attuned intersubjective interactions between them and others. Social interactions between adults and these children appeared to be characterised by 'depth of meeting and mutual openness' (Cooper, Chak, Cornish, & Gillespie, 2013, p. 71) on both an inter- and intra-personal level. For practitioners, there were examples of introspection and personal reflection in relation to their interactions with CYP. This appeared to be reflective of a kind of 'I-Thou' interaction (Buber, 2004) where these CYP were viewed as fluid, freely-choosing subjects rather than 'static', 'determined' objects (Cooper et al., 2013) or passive recipients of the world around them. This approach appeared to enhance their engagement.

Many studies appeared to highlight tension experienced by practitioners: on the one hand there was the expectation that they would follow approaches traditionally used with these CYP; and on the other hand, there was a desire for freedom and flexibility to deviate from such ideas. Approaches in studies that led to enhanced engagement appeared to be more in line with descriptions of 'lived spaces' as opposed to spatial practices dominated by 'abstract' ideas (Lefebvre, 1991) about how activities for

these CYP should be organised. Approaches did not appear to 'obey rules of consistency or cohesiveness' regarding theory and pedagogy relating to S/PMLD (Merrifield, 2013, p. 110). Descriptions of approaches suggested that activities were 'felt rather than thought' (Ibid), indicating that relationships, interaction, and positive emotion were prioritised above progress and skill development. By aligning with ideas about 'lived space', approaches were often described as providing a range of 'serendipitous' (Preece & Zhao, 2015) benefits in terms of skill development and wellbeing which fit with psychological needs theories and the importance of relationships (Lambert, 1992).

Findings also appeared to be reflective of Biesta's (2020) 'three domains of educational purpose'. For practitioners involved in the approaches discussed, the tension created by considering the quality of space for these CYP appears to relate to Biesta's (2020) ideas about the 'qualification', 'socialisation', and 'subjectification' purposes of education. For practitioners, the desire for freedom and flexibility to create spaces that promote opportunities to interact (socialisation), 'be', or 'become' (subjectification) for these CYP had to be carefully considered alongside and were at times prioritised above skill development (qualification). This approach appeared to lead to enhanced engagement.

In terms of *actions* and their *effects*, this SLR's findings provide a compelling argument that quality of space organised around these CYP should be given serious consideration to enhance their engagement. This comes at a time when engagement is becoming a key focus of the curriculum for these CYP (Standards & Testing Agency, 2020). However, this might require that practitioners be given more freedom in terms of pedagogical and curriculum flexibility to cultivate such engagement enhancing spaces. Approaches described in studies that enhanced the engagement of these CYP appeared to also lead to additional benefits for CYP in terms of their skills development, their experience of positive emotion, and their enhanced ability to connect and interact with others, enhancing their mental wellbeing by helping them to 'feel good and function well' (Huppert & So, 2013; Seligman, 2018).

Practitioners might therefore respond to the findings of this SLR by carefully considering how quality of space within the settings where these CYP spend a lot of

time help to cultivate the kinds of psychosocial mechanisms described that lead to their enhanced engagement. Since the introduction of the 'engagement model' as a statutory framework for practitioners involved in the education of these CYP (Standards & Testing Agency, 2020), we may begin to see practitioners less constrained by curricula and more led by the interests of CYP and what enhances their engagement. These SLR findings suggest that this, along with practitioners being given increased flexibility to be spontaneous, creative, and reflexive may enhance the intensity and emotional quality of engagement for these CYP (Carpenter et al., 2011). This appears to contribute to further benefits described in studies relating to skills development. This might constitute what Veck (2013, p. 626) refers to as increasing trust in the special school educator and the 'efficiency of relation' with these CYP, shifting from an overreliance on rigid pedagogies and curricula, towards a 'being with' these CYP (de Haas, Grace, Hope, & Nind, 2022).

In 2011, Carpenter et al. (2011) suggested that specialists and practitioners are 'pedagogically bereft' in terms of how to engage these CYP as learners. The findings of this SLR appear to provide some evidence of the benefits of a relational pedagogy that provides opportunities for practitioners to focus on the 'socialisation' and 'subjectification' purposes of education. This might involve less focus on espoused or abstract ideas within the S/PMLD literature and rigid curricula that prioritise accountability in terms of pupil progress and 'qualification' (Biesta, 2015). Instead, it might involve enabling practitioners, as 'the curriculum in action' (Stewart & Walker-Gleaves, 2020, p. 356), a higher degree of freedom and individuality in terms of how they relate to *and* educate these CYP.

Chapter 2: Methodological Considerations for Empirical Research

2.1 Introduction

This chapter discusses the following:

- My overarching conceptual framework.
- How the SLR focus and its findings (Chapter 1) link to the empirical research (Chapter 3).
- My world view, how this relates to the empirical research, and how this is reflected in methodological decisions.
- How the philosophical stance towards this research is reflected in methodological decisions and the analytical strategy for the empirical research.
- Ethical considerations that have influenced decisions made in conducting this research in this way.

2.2 Conceptual Framework

Why am I doing this research?

Darlaston-Jones (2007) has suggested that the role of the researcher within research processes is often overlooked, particularly in research of a positivist or empiricist nature. This is despite the researcher's role being what she describes as an inseparable component of philosophical and methodological decisions made. In line with my ontological and epistemological stance towards this research, it is important to consider the 'why me?' along with the 'what?' and 'how?' aspects of the empirical research in this thesis.

'Why me?'

My interest in researching this topic stems from both personal and professional experiences of learning disabilities (LD). Through reflection, I have come to realise the deeply personal aspect of this research. I come from a family that includes relatives who themselves have LD. I have a life-long genetic condition that makes me vulnerable to potential brain injury and LD, something I was made aware of, and subsequently came to fear, from a very young age. My interest in LD, therefore, has personal and almost existential bases. I grew up contending with a sense of fear towards the potential to develop LD should I not make careful lifestyle choices. This became even more personal in my adult life, following the sudden loss of an older sibling who had the same genetic condition which had contributed to LD. This, amongst other things, served as a personal reminder of my own vulnerability in terms of the potential to develop LD.

My professional experiences, which include working in schools with CYP with 'special educational needs and disabilities' (Department for Education, 2015) stem from an interest in education and inclusion of CYP. Such experiences provided opportunities to confront and challenge feelings contributing to an uneasiness towards LD. Working with one child in particular, who was physically disabled and non-verbal, provided opportunities to confront this sense of cognitive dissonance (Festinger, 1957), a sense of discord between thoughts, feelings, and behaviour. I did not think that how I felt, the 'affective' component of my attitude, reflected thoughts or behaviours towards CYP with LD (Triandis, 1979). Goodwin (2019, p. 54) suggests that professionals with a role that involves spending time with those with LD might initially experience a sense of discomfort in what can often be spaces that are 'still and languageless'. Seeking out these professional opportunities provided a way of challenging such feelings through spending time and sharing space with CYP with LD (Allport, 1954). These professional experiences led to an interest in attitudes towards disability/ inclusion, which was the topic of my Masters dissertation; the culmination of educational and professional experiences that affected me significantly both personally and professionally.

These personal and professional experiences have been formative. They have led to what Moore (2015, p. 5) describes as 'practical and determinative work' as part of my developing practice as a Trainee Educational Psychologist (TEP). This work, including this thesis, has been in line with my interest in social justice, educational inclusion, and relational practice. Such examples require practice to be reflexive in terms of understanding and working on oneself within the context of others (BPS, 2017). Practice and research involving vulnerable groups such as those with LD can provide such opportunities.

What and why in this time and context?

Thinking about mental wellbeing of CYP in UK schools and colleges was brought into sharper focus following the publication of the Department of Health's (2015) 'Future in Mind: Supporting the Mental Health and Wellbeing of Children and Young People' Green Paper. This included key proposals relating to improving access to effective support for all CYP, including those most vulnerable to mental health difficulties such as CYP with LD. Within proposals there is an acceptance that there are specific issues facing such vulnerable CYP, and that responding to this must include solutions that are joined up and individually tailored to needs. However, when this guidance was proposed there was the concession that more evidence was required regarding what is most effective for improving mental health in schools and colleges for all CYP. This implies that, for CYP with S/PMLD, who are frequently described as both complex and more vulnerable to mental health difficulties, we may need to go to even greater lengths to understand what is most effective. There appears to be some acknowledgement of this within the NHS "Five Year Forward Plan" (NHS England, 2016), which has suggested that more work is needed to understand how to support the mental wellbeing of these CYP, as this is a significant issue for them.

Government policy and guidance relating to the mental wellbeing of all CYP has been described as lacking relevance or practicality for those with S/PMLD (Mercieca, 2013). This is perhaps due to a lessened understanding of how the mental wellbeing

of these CYP can be both conceptualised and supported compared to other CYP (Rose et al., 2009). There is some debate regarding the extent to which these CYP can conceptualise and communicate views on abstract concepts such as mental wellbeing (Lewis & Porter, 2004; Ware, 2004) meaning that it can be difficult to ask them directly about this as we might others.

In understanding what is supportive, Doukas, Fullerton, Fergusson, and Grace (2019) have suggested that this should involve the following:

- Acknowledgement of the likelihood of issues with mental health.
- Emphasis on importance of shared responsibility/ collaboration to support them.
- Emphasis on communication standards (e.g. relational approaches, total communication, responding to 'perceived wishes/ preferences', a sense of belonging, things done with them and not to them).
- Emphasis on social and community standards (e.g. commitment to promoting social lives with family/ friends, person-centred planning of daily meaningful activity) so that they can be visible, active, and can thrive.
- Emphasis on meaningful time standards (e.g. where they can be active and can participate and engage alongside others).
- Acknowledgement of the importance of understanding what this looks like individually and how to promote this.

How and why in this way?

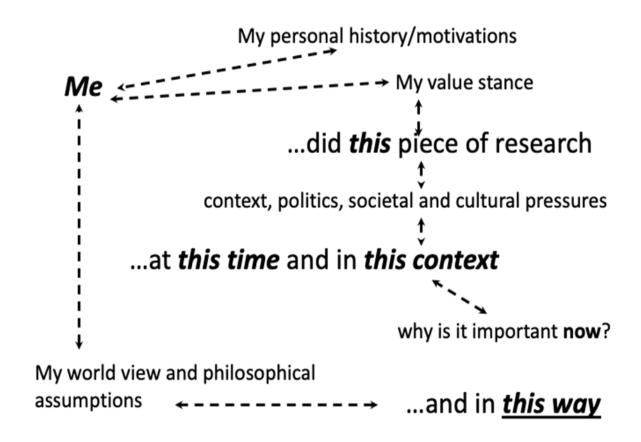
In line with my interests in social justice, educational inclusion, and relational practice, this research has been designed by following guidance about inclusive and participatory research paradigms involving these CYP. This approach has been influenced by a personal commitment to addressing power and positionality within research, collaborating thoughtfully and appropriately with those close to such issues, and speaking to them rather than for them to increase understanding and bring about meaningful change (Billington, 2006; Tolbert, Schindel, & Rodriguez, 2018). Research of this nature seeks to finds ways of meaningfully involving those

with LD in exploring matters that affect them (UN General Assembly, 2007; Unicef, 1989) and tries to move away from approaches that have traditionally made them objects of investigation (Nind, 2014). Instead, research is done with, alongside, and for them rather than to them (de Haas et al., 2022; Nind & Vinha, 2014). The hallmarks of inclusive research include finding creative ways of representing their perspective in a respectful and dignified way whilst seeking to address issues which really matter and make a difference in their lives (Nind & Vinha, 2014).

The dependence of these CYP on others means that designing research that explores such important issues in their lives might necessarily involve those who know them best such as parents/ carers and school staff (Cluley, 2017; de Haas et al., 2022). It is argued that this should not be seen as limiting the usefulness of research, but something that enhances the research by helping to interpret and respond to matters of importance that these CYP themselves may otherwise have difficulty communicating (Sheehy & Nind, 2005). Furthermore, research done in this way can address the dearth of research expertise around LD by finding meaningful ways of involving them and those closest to them as experts through lived experience (McCormack, 2017). Such research focuses on shifting the balance of power more equitably between those involved, particularly those closest to the topic. It has been suggested that this might be facilitated by assuming a position of 'methodological immaturity/naivety' (Gallacher & Gallagher, 2008). This means that those involved are 'co-researchers' rather than 'participants', who have valuable expertise that will allow knowledge and understanding to be created collaboratively.

Furthermore, it has been argued that inclusive research must consider issues of 'epistemic in/justice' (Fricker, 2007). This can involve an element of 'epistemic risk' (Skarsaune, Hanisch, & Gjermestad, 2021) in ensuring that knowledge gained from those whom inclusive research is focused on is reliably interpreted and used responsibly for their benefit. Epistemic risk also implies that research is fallible and inexact suggesting a critical approach should always be taken. Such principles align well with the guidance offered by Doukas et al. (2019) on exploring mental wellbeing for these CYP by finding ways to increase their involvement, collaborating thoughtfully with those closest to them, and ensuring such knowledge contributes to positive change.

Figure 2: The Conceptual Framework (Adapted from Parker, 2020, unpublished work)



2.3 Linking the SLR to the empirical research

The SLR in the previous chapter highlighted a range of approaches designed to enhance these CYP's engagement. When considered together, approaches were found to cultivate responsive and energetic social spaces for these CYP which appeared to fit descriptions of 'lived spaces' (Lefebvre, 1991) where relationships, interaction, and positive emotion were prioritised above progress and skill development. By enhancing engagement, these approaches appeared to lead to additional benefits for CYP in terms of their development of skills, their experience of positive emotion, and their enhanced ability to connect and interact with others. Their enhanced engagement helped them to 'feel good and function well' (Huppert & So, 2013) promoting their mental wellbeing.

The empirical research in this thesis sought to build on the findings of the SLR by further exploring the link between enhanced engagement and mental wellbeing for

these CYP. It did so by applying the SLR's global theme of 'Quality of Space' to the typical special school classroom for these CYP and considering the extent to which these spaces cultivate the kinds of psychosocial conditions for enhanced engagement promoting their mental wellbeing. The empirical research seeks to address a gap in research literature in understanding and enhancing the mental wellbeing of these CYP. This is a topic which has often been overlooked (Sheehy & Nind, 2005) and is less empirically understood within research (Jones, 2019) in comparison with other CYP. Some have suggested that the scant research that has previously focused on this area has been informed by a reductionist, deficit-based, and medicalised view of these CYP's needs (McCormack, 2017). The empirical research in this thesis adopted an inclusive, participatory, and strengths-based approach to understanding and promoting their mental wellbeing. By doing so, it sought to confront an issue related to social justice, children's rights, and inclusive education, specifically schools' role in this.

2.4 Philosophical stance

Schwartz and Ogilvy (1979, p. 19) make the assertion that 'as we think, so do we act'. This is to say that the actions we take in research are often reflective of the things we hold true about the world, the knowledge within it, and the questions we seek to answer. The conceptual framework discussed above gives an idea about some of my core values that, according to (Schwartz & Ogilvy, 1979), will have had an influence on the *who*, *what*, *how*, and *why* of this research.

For researchers, adopting a philosophical stance involves acknowledgement and clarification of *how* we are influenced by beliefs we hold about the world, the knowledge within it, and how we come to know about this (Hofer & Pintrich, 2012). This involves developing an ontological and epistemological position. To do so, Parker (2013) asserts, helps us to understand and clarify our individual world views and how these come to bear on our decisions in research related to the *how*, *what*, *who*, and the *why*. This is essential as our world view is inextricably linked with the kinds of questions we ask in research and ultimately the answers we find (Parker, 2013). Ontology requires us to ask questions about the nature of reality, whether this is something concrete, objective, and outside of individual perspective (realist-

objectivist), or something socially constructed, subjective, and likely to be influenced by individual perspective, experience, and interpretation (relativist-subjectivist) (Denzin & Lincoln, 2018; Parker, 2013). Epistemology involves using our ontological position regarding the nature of reality (is this concrete and objective or socially constructed and subjective) to formulate a way of going about knowing and understanding phenomena or an aspect of reality (Parker, 2013).

In Chapter 1, I adopted a critical realist approach to answering the SLR question. This focused on identifying what may be the causal psychosocial mechanisms enhancing these CYP's engagement. This also involved a qualitative synthesis of the perspectives of those closest to the CYP to understand how such mechanisms may enhance engagement. A critical realist approach is neither realist, relativist, objective, nor subjective. Critical realism, according to Robson (2011, p. 29), 'avoids both positivism and relativism'; it accepts that knowledge within the world exists outside of our perspective or experience, can be contested (which is anti-positivist), is fallible, and can be understood through 'taking note of the perspectives [of others]' (Robson, 2011, p. 30). Critical realism views explanations of the social world as fallible and always open to critique (Scott, 2005). The empirical research discussed in Chapter 3 adopted critical realism as an overarching meta-theory in answering the following research question:

"How can Educational Psychologists (EPs), school practitioners, and parents/carers collaborate to understand and promote the mental wellbeing of CYP with PMLD?"

This meta-theory implies the following:

- There may be some causal explanation that can help us understand and promote their mental wellbeing (e.g. things present and observable that may affect the mental wellbeing of these CYP).
- What is present and observable can be critically and fallibly considered and subjectively interpreted/understood.

 Understanding what is present and observable and deciding how this can be promoted can be a collaborative endeavour amongst people with individual insights into this phenomenon.

This suggests that an overarching critical realist ontology would be appropriate. The collaborative and subjective element of this research suggests that an interpretivist-phenomenological epistemology may also be warranted. This means that causal assumptions relating to the phenomenon under investigation (mental wellbeing) can be discussed in terms of 'the meaning and experience of behaviour in context' and how this is 'represented through the eyes of participants' (Robson, 2011, p. 25).

2.5 Methodology

Parker (2013) asserts that methodological decisions must follow the underlying thinking and planning for how our research should or should not proceed based upon our world view (our ontological and epistemological position). This determines the things we can and cannot engage with methodologically. A critical realist ontology implies that, within this research, there is an aspect of reality in the world, or a phenomenon that is real and observable. It also implies that what is present/observable may be experienced and understood differently and we might come to understand this more through an interpretivist-phenomenological epistemology.

This suggests that methodologies must be responsive to individual experience and understanding of the phenomena being explored. Within inclusive research involving these CYP, this can be challenging as their experience and interpretation of phenomena falls 'outside of the boundaries of traditional conceptions of 'talk'' (Griffiths & Smith, 2016, p. 28). Their individual experience of phenomena might be better understood through their 'expressive cognition' (Merleau-Ponty, 2002) within the 'social milieu of lived experience' (Robinson et al., 2019, p. 92). This suggests that the methodology for this research must include an element of 'epistemic risk' (Skarsaune et al., 2021, p. 318) in that the methodology must be interpretative,

phenomenological, will likely involve a high level of inference, and is fallible in attempting to understand the perspectives and experiences of these CYP.

The psychological project of this research is based on what occurs between these CYP and their relationships to others within the environments they inhabit day-to-day in school (Langdridge, 2007). This suggests a phenomenological focus on how their experience of mental wellbeing, through their engagement, is 'turned out onto the world' (Langdridge, 2007, p. 7) and interpreted by others (Simmons & Watson, 2015) regarding what this looks like and how this can be promoted. A qualitative methodology was selected and deemed most appropriate in considering the different subjective interpretations of what the CYP may be experiencing (Ponterotto, 2005). This included following some of the principles within Action Research (AR) methodology (McNiff, 2016). AR is a collaborative and iterative approach to gathering, using, and developing knowledge to generate theories about phenomena. Those contributing to the theory-generating process are encouraged to engage in a reflexive, critical, and dialogic form of discussion that moves beyond face-value interpretations (McNiff, 2016). AR principles were used as an overarching methodology with dialogue (Bakhtin, 1982), dynamic forms of consultation (Hymer, Michel, & Todd, 2002), and a 'triple hermeneutic' (Fangen, 2015) as additional layers (see Table 8).

This approach fits well with the purpose of this research, which is to critically consider the views of those closest to these CYP regarding how their mental wellbeing may be understood and promoted. It is hoped that embedding these dialogic principles within the methodology will enable the critical consideration of what is important to these CYP by co-researchers such as those that know them best and outside professionals; this has previously been highlighted as an issue in both Educational Psychology and LD literature (Figg, Keeton, Parkes, & Richards, 1996; Porter, Ouvry, Morgan, & Downs, 2001). This methodology also reflects my ontological and epistemological position in that it supports the process of subjectively and critically understanding and promoting causal mechanisms affecting the mental wellbeing of these CYP.

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Table 8: Dialogic principles embedded within the methodology

- A meeting of equals (albeit with distinct but complementary skills or 'knowledge').
- The need to question power and control and to challenge language that unhelpfully 'positions' others.
- Developing the 'expertise to become non-expert' (rather than imposing your own outsider perspective or privileging your own knowledge).
- Using dialogue with others that is reciprocal and 'enskilling' rather than unidirectional.
- 'Knowledge production' is a shared endeavour through dialogue.
- Questions draw out knowledge and solutions as a relational and 'cooperative enterprise' (Hymer et al., 2002).
- Dialogue as a form of triangulated interpretation of a 'polyphony of voices' (Bakhtin, 1982).
- The triple hermeneutic involves critically interpreting the 'double hermeneutic' (coresearchers' own interpretations of the phenomenon i.e. the processes that may be affecting these CYP's mental wellbeing) as well as their ability to freely interpret this (Fangen, 2015; Langdridge, 2007).

2.6 Analytical strategy

Realist Grounded Theory (GT) was selected as the analytical strategy (Strauss & Corbin, 1997). GT is noted for its epistemological flexibility having been used within both realist and relativist research paradigms (Oliver, 2012). GT aims to generate theories related to potential causal mechanisms inductively through an iterative process of data generation and analysis (Oliver, 2012). Compared to constructivist GT (Charmaz, 2017), critical realist GT 'seeks to make claims about an objective reality and develop contextualised theory for practical application' (Oliver, 2012, p. 377). Critical realist GT addresses both the objective reality and the subjective interpretation of it (the event and the meanings made of it; Oliver, 2012, p. 378). Critical realist GT also rejects the notion of researcher neutrality by accepting that those involved in the research may have already developed preconceived analytical concepts and generative mechanisms (Oliver, 2012) such as those discussed in the SLR.

2.7 Ethical considerations

Consent and assent

In research involving these CYP, their ability to give informed consent to participate should always be assumed until it is decided that they cannot fully understand what this involves (McCormack, 2017; Mental Capacity Act, 2005). In such cases where consent is given on their behalf, special safeguards must be in place to ensure it is safe for them to participate and they are able exercise their right to withdraw (BPS, 2021). Walmsley, Strnadová, and Johnson (2018) suggest that inclusive research involving these CYP must always begin by assuming that there will be an absence of verbal language. With this in mind, their ability to give consent is often made on their behalf so as to not exclude them from research (Rolph & Walmsley, 2006). Their assent is often viewed as an ongoing relational process (Davy, 2019) involving those closest to them monitoring them and acting in their best interests by ending their involvement should they appear distressed (Lewis & Porter, 2004).

In this research, arrangements were made to ensure the CYP were comfortably involved and adults were responsive to how they might give an indication of their assent. This included an initial informal person-centred meeting (Sanderson, 2000) with the CYP, their parents/ carers, and their key adult in school to get to know them better; to help everyone understand, as appropriate, how they would be involved (Lewis & Porter, 2004); and to understand how the CYP might non-verbally communicate to others that their involvement is causing distress (Simmons & Watson, 2015). Assent is traditionally considered an ongoing process in inclusive research rather than a single activity of giving consent (Povee, Bishop, & Roberts, 2014). Assent of the CYP was continually monitored during the CYP's involvement in data collection activities.

Power, positionality, and authorship

In inclusive research, it is important to consider power and positionality regarding how we position ourselves alongside those with whom we engage in research with, whose knowledge we privilege, and to what end (Olesen, 2011; Tolbert et al., 2018).

In considering power within research, we might consider issues around identity, representation, and positionality as this influences how we are perceived and received by others, what we choose to look at, what kinds of questions we ask in research, and our interpretations (Corbin Dwyer & Buckle, 2009; Tolbert et al., 2018). For inclusive researchers interested in social justice, it also suggests it is important to think carefully about how we position ourselves as 'social justice change agents' (Shriberg et al., 2021) and how ideas of 'self' and 'other' are critically considered and reflected in what we choose as the research focus and the wished for outcomes. In research involving these CYP, power and positionality are important considerations in relation to how findings may be representative of their 'views' and how these are reflected in decisions made on their behalf both during and after the research is completed (Fricker, 2007).

The ontological, epistemological, and methodological decisions we make in research are often affected by our ethical values (Parker, 2013). The methodology described above, in line with my ethical values, acknowledges issues around power and positionality. It does so by positioning those involved in the research as 'coresearchers' and attempting to distribute expertise more equitably via a collaborative, dialogic, and reflexive approach. To address issues of authorship, the research employed accessible and meaningful ways to conduct research with and alongside these CYP (Nind & Vinha, 2014) and encouraged critical consideration of what may be important to them alongside those who know them best (de Haas et al., 2022). To attempt to address issues around my own positioning as an 'outsider' (Corbin Dwyer & Buckle, 2009) within this research, the principles around 'cultural competence' (Campinha-Bacote, 2002) were adopted.

Table 9: Acknowledging and attempting to address issues of position and power within this research using the principles of 'cultural competence'

- Cultural Awareness self-examination of one's own biases, prejudices, and assumptions towards these CYP.
- Cultural Knowledge seeking and obtaining knowledge about these CYP.
- Cultural Skill having culturally relevant knowledge regarding these CYP and using this appropriately to understand this research topic alongside those closest to them.
- Cultural Encounters being interested and motivated to want to engage in interactions with these CYP and those closest to them.
- Cultural Desire wanting to rather than having to engage in processes to become more culturally aware about these CYP and what is important to them.

(Adapted from Campinha-Bacote, 2002)

2.8 Quality and rigour

Interpreting the views of these CYP has been described as an 'inexact science' (Ware, 2004, p. 177) as we cannot be certain of what they are communicating. Forster (2020), however, suggests that their 'voices' might be reliably interpreted by those closest to them. Lewis and Porter (2004) assert that, to maintain the quality of activities designed to elicit the views of these CYP, and to avoid tokenism, we must be able to place trust in the quality of the methods we adopt for research to be meaningful (Palmer & Walmsley, 2020). Therefore, the ethnographic observational methods used in this research (described further in Chapter 3), which are aligned with the methodology described above, made the interpretation of these CYP's 'voices' collaborative. Discussing this observational data within a dialogic and reflexive consultative space as co-researchers facilitated critical interpretation of their 'voices'. According to de Haas et al. (2022), this helps interpretation stand up to scrutiny, adding to the quality and rigour of research.

Additionally, the research went through a rigorous ethical clearance process with Newcastle University's Ethics Committee. This was to ensure that the intent and purpose of the research was warranted, clearly communicated to those invited to be

involved, and that data collection methods were both appropriate and clearly described (see Appendices A and B).

Chapter 3: How can Educational Psychologists (EPs), School Practitioners, and Parents/ Carers Come to a Shared Understanding of and Promote the Mental Wellbeing of CYP with PMLD?³

3.1 Abstract

Background

Children and young people (CYP) with profound and multiple learning disabilities (PMLD) are more vulnerable to experiencing difficulties with their mental wellbeing. Understanding what promotes their mental wellbeing may involve understanding their engagement, or the intensity and emotional quality of their involvement in activities in school that help them to 'feel good and function well'.

Method

Three children with a PMLD label, their parents/carers, and their school key workers from one special primary school in North West England were identified and invited to collaborate in this research to understand what promotes the children's mental wellbeing. An eclectic methodology was used involving ethnographic observation and video recordings of the children, as well as dialogic consultation with adults to critically consider what may be promoting their mental wellbeing. Abbreviated Realist Grounded Theory was used to analyse consultation transcripts relating to adults' perspectives on the children's engagement with day-to-day activities and how these may be promoting their mental wellbeing.

Findings

Findings provided a framework for how this issue can be collaboratively explored between special schools, parents/carers, and educational psychologists. Findings also provided a tentative model for understanding and promoting these CYP's

³ This empirical research chapter of my thesis has been structured in line with guidance for publication in the British Journal of Learning Disabilities.

mental wellbeing. An individualised approach to promoting opportunities for positive emotion, engagement, relationships, meaning, and accomplishments (PERMA+) was highlighted as important along with adults' ability to reflect on curricula and educational purpose for these CYP.

Conclusions

Findings highlighted the importance of consistent opportunities for these children to experience positive emotion, engagement, have relationships, a sense of meaning, and accomplishments in school, and considering this on an individual basis (PERMA+). Findings also highlighted the significance of the 'relationships' component of the PERMA+ model for these children, specifically the role that adults in school play in facilitating other components of the PERMA+ model within positive emotional spaces where the children could thrive, feel good, and function well.

3.2 Introduction

Defining PMLD

According to Bellamy et al. (2010), the term 'PMLD' is predominantly applied to describe individuals with these characteristics:

- Extremely delayed intellectual and social functioning.
- Limited to no ability to engage verbally.
- Mainly responsive to environmental cues.
- Usually reliant on familiar others to interpret communication and intent.
- Frequently associated medical or neurological condition.
- Require a highly structured environment, constant support, and an individualised relationship with a key person to achieve optimum potential.

Some terminology is common to the UK and international research literature (Nind & Strnadova, 2020). However, 'PMLD' is used throughout this chapter as a term used widely in the UK within research literature and by disability advocacy groups and charities (Mencap, 2021). This term was also most recognisable to the adult co-

researchers involved in this research. The term 'PMLD' also differentiates from more specific learning difficulties such as dyslexia which are not associated with PMLD or other learning disabilities (LD).

Mental wellbeing for these CYP

The term mental wellbeing is used throughout this Chapter. Mental health and mental wellbeing can be understood as closely related yet different concepts. Positive mental health is said to be the absence of mental health difficulties and the presence of higher levels of mental wellbeing achieved via a combination of 'feeling good and functioning well' (Huppert & So, 2013). Seligman (2018) suggested individuals' mental health and mental wellbeing are supported by opportunities to experience positive emotions such as happiness, enjoyment, engagement, curiosity, and safety; and through positive relationships, feeling connected, and having a sense of purpose and achievement. CYP with LD are more likely to experience poor mental health compared to their age peers (YoungMinds, 2021). Emerson and Hatton (2007) suggested that this is related to the cumulative risk of biological, psychosocial, and environmental factors, including the likelihood of those with LD experiencing issues with physical health, living in poverty, and having fewer social relationships. For CYP with PMLD, the risk of poor mental health is said to be even greater due to need complexity (Bellamy et al., 2010; Sheehy & Nind, 2005) which lessens opportunities for them to experience positive mental wellbeing through feeling good and functioning well. Furthermore, these CYP's communication difficulties mean it can be difficult for those around them, such as family or practitioners, to accurately identify and respond to any indication of a mental health difficulty as signs can often be overlooked or misinterpreted as idiosyncratic or 'challenging behaviour' (YoungMinds, 2021).

The debate about the generalisability and inclusivity of definitions of mental wellbeing (Palumbo & Galderisi, 2020; Vaillant, 2012) has led some to argue that conceptualisations of mental wellbeing for these CYP should acknowledge the diversity of need and the complexity of personal and contextual circumstances (Mercieca, 2013; Nussbaum & Sen, 1993). For these CYP, experiencing positive mental wellbeing may well be related to their embodied experience of what it means

to 'be' and 'do' and how this is understood and facilitated relationally by those that know them best (Nind & Strnadová, 2020). For these CYP, a phenomenological conceptualisation of mental wellbeing that focuses on individual embodied experience of 'being' and 'doing' (Goodley & Lawthom, 2008; Merleau-Ponty, 2002), acknowledging the individual and their engagement with their social and material world (Carpenter et al., 2011; Simmons & Watson, 2015) may be most helpful in both understanding and promoting what helps them to feel good and function well.

In the UK, the mental wellbeing of CYP in education was brought into sharp focus following the publication of the Department of Health's (2015) 'Future in Mind' Green Paper. This guidance offers little detail on how the mental wellbeing of CYP with PMLD can be understood or promoted in schools. Since then, a call for more evidence was made regarding what may be most effective (NHS England, 2016), with an expert group eventually established resulting in the following guidance:

Table 10: Quality standards for supporting those with PMLD (Doukas et al., 2019)

- Acknowledging the likelihood of issues with mental health for those with PMLD.
- Emphasising the importance of shared responsibility/ collaboration to support those with PMLD.
- Establishing relational approaches to enhance a sense of belonging by doing things with them and not to them.
- Promoting their social lives making them visible and active in meaningful activity alongside others.
- Understanding what this looks like for each individual.

Conceptualising engagement

Engagement as a concept has been noted for its importance in learning and also for its role in social and emotional development and developing resilience (Orley, 1996). For these CYP, moments of non-engagement can be frequent (Bagatell, 2012), ultimately affecting their ability to feel good and function well and experience positive mental wellbeing (Sheehy & Nind, 2005). Carpenter et al. (2016) suggested that this may be related to the quality of processes that support the critical interaction between these CYP and their environment. Therefore, conceptualising engagement

in this way may support an understanding of what helps them to feel good and function well.

For this research, engagement is considered a precursor or proxy measure to these CYP's ability to feel good and function well. Therefore, engagement has been conceptualised as the intensity and emotional quality of their involvement in activities in school (Carpenter et al., 2011) enabling them feel good, function well, and experience positive mental wellbeing.

3.3 Aims

The research aim was to collaborate alongside children with PMLD and those closest to them to understand how their day-to-day activities in school may promote their mental wellbeing. This was chosen as the research focus as:

- These CYP face specific issues making them vulnerable to mental health difficulties (Doukas et al., 2019; Sheehy & Nind, 2005).
- There is a gap in research and in government guidance concerning what may be helpful in understanding and promoting their mental wellbeing.
- Wider literature suggests the quality of space within these CYP's school environments may be important to consider for both their engagement and their mental wellbeing.
- Participatory and inclusive research that aims to bring about meaningful change in the lives of these CYP should find ways to involve them and those closest to them in a collaborative endeavour (Doukas et al., 2019) as we may not be able to ask these CYP directly about this (Lewis & Porter, 2004; Ware, 2004).

The research set out to answer the following question:

"How can Educational Psychologists, School Practitioners, and Parents/Carers Come to a Shared Understanding of and Promote the Mental Wellbeing of CYP with PMLD?"

3.4 Design

This research adopted a purposive sampling strategy to identify three children with a PMLD label, their parents/carers, and their school key workers from one special primary school in North West England. After confirming their interest, school was supported to begin identifying children with a PMLD label suitable for involvement in this research who are non-verbal communicators working below P Scale Level 4 in the areas related to communication (QCA, 2009).

Table 11: Pseudonyms and details of CYP and adult co-researchers

Jake (Year 3)	Paul (Year 5)	Sophia (Year 3)
Jake's Mother 'Olivia'	Paul's mother 'Catherine'	Sophia's mother 'Talia'
Jake's teacher 'Alison'	Paul's father 'Aiden' Paul's keyworker 'Janine'	Sophia's teacher 'Michelle'
	, and the second	

Pre-research meetings were arranged with the CYP, their parents/carers, and their key adults in school to discuss the research and answer any questions about their involvement. During meetings, the following person-centred questions (Helen Sanderson Associates, 2022) were used to highlight things that were important to consider during the research, discuss how the children might communicate their willingness to assent, and to aid the process of familiarisation between them and me:

- What's important to their comfort, happiness, contentment, fulfilment, and satisfaction?
- Who is in their relationship circle?
- How do they communicate ("if I do this, at this time, it usually means...")

It was explained to adults participating in the research that they would become coresearchers with me, and that this would involve exploring the day-to-day activities of the children through observational data to understand what might be important to their mental wellbeing (see Appendix A and B).

Ethical considerations

It has been suggested that the lack of research exploring the lives of people with LD is due to the difficulties often experienced in attempting to address the ethicality of their involvement (Tilley, Ledger, & de Haas, 2020). Walmsley et al. (2018) suggested that inclusive research involving these CYP must always begin by assuming that there will be an absence of verbal language. Consent is often given on their behalf so as to not exclude them from research (Rolph & Walmsley, 2006). Their assent is often viewed as an ongoing relational process (Davy, 2019) involving those closest to them monitoring them and acting in their best interests by ending their involvement should they appear distressed (Lewis & Porter, 2004).

In this research (see Appendices A, B, C and D), the children's and the adult coresearchers' involvement had been agreed with Newcastle University Ethics Committee to ensure their participation was safe and ethical. All adults received participant information sheets, co-researcher contracts, and had the opportunity to ask further questions about the research and how they and the CYP would be involved. Pre-research meetings provided an opportunity for the CYP to meet and familiarise with me prior to me spending time with them in class.

The pre-research meetings helped me understand how I might recognise and respond with other adults to any indication that the CYP were not happy to continue to participate. This was something adult co-researchers felt confident was possible for all CYP involved by inferring what they were communicating. For example, during data collection I was informed by one adult that the child I was observing appeared to be aware of me recording him and may be uncomfortable with this (see Figure 3 on Page 57). Following discussion, we decided to make video recordings more

discreetly and tried to enhance my involvement in activities so he could be more comfortable with me being there and that data could provide a more natural representation of his involvement with activities. Following these arrangements, all adults were happy to give informed consent for their own participation and were happy to allow the children to participate under the proviso that adults would monitor their ongoing assent during data collection and cease any activities should they appear unhappy.

During the pre-research meetings, it was explained to the children verbally by the adults that know them best that I would be coming into class to watch and join them in some of their day-to-day activities. The process of informing the children about the research, the nature of their involvement, and that this would involve me joining them and recording them on video, may have been enhanced by using symbolic communication methods (for example, picture communication symbols). Although the children had access to individualised communication systems throughout their involvement (as is normally the case during their day-to-day activities), these were not adapted in any way for the research. Doing so might well have enhanced their understanding of what the research involved and what to expect when I joined them in class. Furthermore, having access to symbols that could inform adults that they would wish for me to stop data collection might also have increased the ethicality of this research.

Table 12: An example of person-centred information gathered for the CYP participating in the research

Jake (Year 3)

What's important?

- Spending time with family and receiving lots of positive attention from them.
- Music and dancing to the actions in nursery rhymes.
- Having plenty of stimulation and not being bored in school.
- Being given choices of what to do/what happens in school.

Who's important?

- New school key worker.
- Old school key worker from previous class.
- Class teacher.
- The school receptionist who greets me every day.

How do I communicate?

- If I blow kisses and smile this means I am happy.
- If I hold my hands together this might mean I am nervous or anxious.
- I'll usually look towards familiar people to gauge if things are safe.

Action research

This research was designed in line the with the principles of Action Research (AR) methodology. McNiff (2016) describes AR as a collaborative endeavour between people close to phenomena. Collaboration brings together expertise to create knowledge and generate theories that can be used to bring about meaningful action. AR is a cyclical and iterative process that recognises the relationship between praxis and knowledge; collaborators can inform practice and practice can inform collaborators' knowledge and thinking about phenomena. AR is noted for its political and emancipatory characteristics as it can focus on bringing about change in people's lives by enabling collaborators to critically consider issues, such as the mental wellbeing of these CYP, how this can be understood, whether change is needed, and how this can be achieved (McNiff, 2016).

Here, the co-construction of knowledge between adult co-researchers using observational data is intended to encourage critical reflexivity (thinking critically about what data is telling us) and dialectical reflexivity (being aware of other influences on our thinking and interpretations).

Table 13: Principles of AR within this research

- **Investigation** finding out about the CYP's experiences of school by observing and interacting with them during their day-to-day activities.
- **Reflection -** bringing observational information back to adult co-researchers to begin thinking about what this may tell us about CYP's mental wellbeing.
- **Action -** observing and interacting with the CYP furthermore following collaboration with adults to gather further information.
- **Evaluation** summarising what we have come to know together about the mental wellbeing of these CYP.

Three 'cycles' of AR were used for each of the CYP (see Table 14).

Table 14: Cycles of AR incorporating data collection methods

Jake		Paul	Sophia	
Olivia (Jake's mother) Alison (Jake's class teacher)		Catherine (Paul's mother) Aiden (Paul's father) Janine (Paul's Learning Support Assistant)	Talia (Sophia's mother) Michelle (Sophia's class teacher	
Person-centred meeting (1 per child) to aid process of familiarisation (1 hour)				
Cycle 1	Observation 1 (1 hour per child) Consultation 1 (1 per child) with adult co-researchers to discuss observational data (1 hour)			
Cycle 2	Observation 2 (1 hour per child) led by prior discussion with co-researchers during Consultation 1 Consultation 2 (1 per child) with adult co-researchers to further discuss observational data (1 hour)			
Cycle 3	Observation 3 (1 hour per child) led by previous discussion with adult co-researchers from Consultations 1 and 2 Consultation 3 (1 per child) with adult co-researchers to summarise what has been discussed/ learned from observational data (1 hour)			

Ethnographic observation and use of video

I chose to use ethnographic observation (EO) for these reasons. EO provides researchers with opportunities to both observe *and* participate in data gathering processes (Nippert-Eng, 2015). EO research has previously been noted for its usefulness in exploring aspects of these CYP's lives by enabling researchers to get close to them and phenomena being explored (Geertz, 1998; Goode, 1994). EO provided a way of conducting this research more naturalistically alongside the children (de Haas et al., 2022) and allowed me to become involved in their day-to-

day activities. EO provided opportunities for me to share space with the children, get to know them and their experiences of school at first hand, and helped me to develop an understanding of them and what may be important to their mental wellbeing (Vorhaus, 2016). EO appeared to fit within the principles of AR in that data could be gathered and interpreted alongside co-researchers in an inductive and iterative manner (Lacey, 2015; Nind, 2014; O'Reilly, 2009). EO was particularly useful in helping to develop my insight into CYP's experiences which could be critically and collaboratively discussed with the adult co-researchers to develop an understanding of the children's mental wellbeing.

Figure 3: The benefits of the EO approach

"It [EO] was much more relaxed...because you had that bit of banter...and joined him with the parachute. I think that helped Paul think "I don't have to be a performing monkey". He probably felt like he was expected to do this certain thing or this certain thing. Where if he just relaxed that's the Paul you see all the time."

Janine

EO was further enhanced by making video recordings of the CYP during their day-to-day activities. Use of video has a long tradition within inclusive research and provided a way of capturing data and triangulating this with the adult co-researchers (Pearlman & Michaels, 2019). Some literature about these CYP has highlighted issues with an overreliance and sometimes skewed view of outside professionals in terms of their observations (Figg et al., 1996; Porter et al., 2001). This was also highlighted as a potential issue by parent co-researchers. Therefore, the use of video added an additional and welcome layer to the data collection in that interpretation of observational data gathered by me as the lead co-researcher could be critically considered alongside other adult co-researchers who know these children best.

The three children involved in this research were observed on three separate occasions at different points in their school day. This included two observations of morning activities with more of a curriculum focus towards promoting literacy and communication, observation during more social times such as 'snack time', and an afternoon observation of more topic-based activities. Observations at these times

provided more varied data in terms of activities the children were engaged in and how these might be promoting their mental wellbeing. Each observation lasted for the duration of a lesson which was approximately one hour. During each hour-long observation, several video recordings varying in length between thirty seconds and two minutes were made. Between five and ten video recordings per child that showed them at their most engaged were selected to take along to consultation with adult co-researchers.

Depending on the nature of the classroom activities, my role during data collection would switch frequently between participation alongside the children (during this time no video recordings or vignettes would be made), to reflection on my participation alongside them (usually in the form of written notes or 'vignettes' [see Figure 4]), to video recordings or written descriptions of something I felt was engaging for the children that I was not participating in. Collection of this data took place over a month. During each observation, EO fieldnotes were created in the form of vignettes (see Figure 4); small, detailed descriptions of what the children were doing, who was involved, how they and others were responding, and what this may mean in terms of their mental wellbeing.

Figure 4: Example of observational data shared with adult co-researchers in the form of a vignette

"Sophia was sat with three other children and two adults for snack time. She was feeding herself some yoghurt with one hand, and her other hand was propped on the table on her elbow. She occasionally opened her hand and stretched her fingers. Sophia then made a choice using a visual resource laminated on the table in front of her and selected toast. She had some toast and would occasionally appear to look around the room moving her head side to side. The room was relatively quiet and some relaxing music was playing on the speakers. Sophia appeared content. She was occasionally smiley and would vocalise. Sophia appeared to persevere [with this activity] with the choice making that she was doing with the adult using a visual well. She then chose a pear, and as she chose one of the adults said to her, "are you happy Sophia?" while she was looking side-to-side exploring the room having her snack. She continued to smile and vocalise."

EO fieldnotes and video recordings shared with adult co-researchers were helpful in providing examples of the CYP's day-to-day activities and allowed adult co-

researchers to make inferences regarding how they may be promoting the CYP's mental wellbeing. Three meetings with each group of adult co-researchers were arranged shortly after each of the three observations had been completed. To centre discussions on 'engagement' and 'mental wellbeing', adult co-researchers were provided with a reminder of the definition of each of these terms being used in the research at the beginning of all three consultations. This was so all adults could understand what was meant when such terms were used during consultation and when referring to the children's activities. 'Engagement' was defined as 'the intensity and emotional quality of children's involvement in activities' (Carpenter et al., 2011) and 'mental wellbeing' was defined as whatever makes the children 'feel good and function well' (Huppert & So, 2013).

Dialogic consultation and the triple hermeneutic

It was my intention to create dialogic space within meetings where adult coresearchers felt safe and able to engage in a reflexive, critical, and dialogic form of discussion that would move beyond face-value interpretations of EO data (McNiff, 2016). I hoped that by embedding a dialogic approach within meetings it was both safe and acceptable for adult co-researchers to debate what had been observed and reach a different conclusion (Bakhtin, 1982) regarding what the data might tell us about the children's mental wellbeing. This approach to consultation was underpinned by further consultative principles including 'dynamic forms of consultation' (Hymer et al., 2002), and a 'triple hermeneutic' (Fangen, 2015) which are described in Table 15. This provided the basis of discussion designed to engage more critically with this topic (McNiff, 2016).

Table 15: Dialogic principles embedded within co-researcher consultations

- A meeting of equals (albeit with distinct but complementary skills or 'knowledge').
- The need to question power and control and to challenge language that unhelpfully 'positions' others.
- Developing the 'expertise to become non-expert' (rather than imposing your own outsider perspective or privileging your own knowledge).
- Using dialogue with others that is reciprocal and 'enskilling' rather than unidirectional.
- 'Knowledge production' is a shared endeavour through dialogue.

- Questions draw out knowledge and solutions as a relational and 'cooperative enterprise' (Hymer et al., 2002).
- Dialogue as a form of triangulated interpretation of a 'polyphony of voices' (Bakhtin, 1982).
- The triple hermeneutic involves critically interpreting the 'double hermeneutic' (coresearchers' own interpretations of the phenomenon i.e. the processes that may be affecting these CYP's mental wellbeing) as well as their ability to freely interpret this (Fangen, 2015; Langdridge, 2007).

Figure 5: An example of embedded dialogue within discussion between adult co-researchers

Dominic - "I think there was a point where Paul almost initiated some interaction, you know, with [another child] by turning to his left, having some face-to-face contact with him and vocalising with him."

Catherine - "Is the other child over there?" [gestures to the computer screen]

Janine - "Yes that's the other child."

Catherine - "You can see his eyes looking."

Janine - "The vocalisation will probably be to the other adult "turn me over so I can face him" because that's what he wants. He might not have been vocalising to the other child; it'll have been "come on adults, you know what I want, turn me over so I can see my man."

Catherine - "Yer that's what I take from it. If he's looking and he's vocalised, to me he wouldn't necessarily be vocalising to the other child, it'd be "come on I'm telling you here what I want, do what I want!"

Dominic – "So it's really important for the adults to be kind of responsive to that? Yer? To be familiar with "what does that mean? What do you want me to do? Oh, you want me to turn you to the other child?""

Catherine - "Yeah."

Janine - "Yeah."

Discussions with adult co-researchers were a type of consultation in that new forms of knowledge and potential actions emerged from discussions around the CYP (Hymer et al., 2002) and fed into further cycles of the AR process. It was a further intention of mine that by creating dialogic space, knowledge and/or action would emerge more naturalistically as an 'incidental outcome' (Wenger, 2011) of discussion

and not something co-researchers were obliged to take away and consider/use. This was an important way of attempting to shift understanding and critically consider this issue without enforcing an outsider professional expert view which I felt would contradict the collaborative ethos of the research.

Figure 6: Example of knowledge production/action as an 'incidental outcome' of dialogue

"Lately I think we've really gotten...for myself and my husband to talk and we'd never go into that much detail and much analysis of what impact [activities] have on Sophia. But chatting through with Catherine and yourself, and you're looking at it [as an] outsider...it's really challenged me to think differently about how we do things at home."

- Talia

3.5 Analysis

Consultations with adult co-researchers were recorded using a Dictaphone and transcribed. This provided qualitative data for the final analysis using Abbreviated Realist Grounded Theory (GT, Strauss & Corbin, 1997). This approach to GT enabled the process of using data from consultations with adult co-researchers to generate theories regarding how the mental wellbeing of the CYP can be understood and promoted in school. Consultation transcripts were analysed using an open coding process to identify phenomena or concepts within data. A process of axial coding was then undertaken to begin grouping together ideas that were conceptually similar within data using the 'constant comparison' method. The final process involved rebuilding data around categories using selective coding. The Paradigm Model (Strauss & Corbin, 1990) outlined in Table 16 was used to try to explain relationships between codes and how activities might promote the children's mental wellbeing.

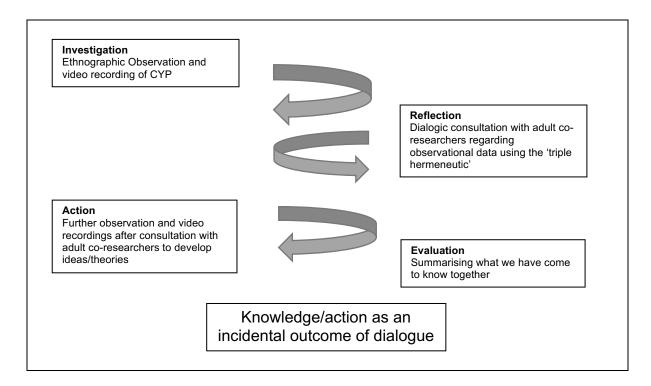
Table 16: Outlining the Paradigm Model in Grounded Theory

- Causal conditions codes relating to events, incidence, or happenings described within data that may contribute to phenomena related to their mental wellbeing.
- Phenomena codes relating to central ideas within data that may be related to their mental wellbeing.
- Context codes relating to the conditions around the CYP within which actions and strategies supportive of their mental wellbeing are taken or used.
- Intervening conditions codes relating to conditions that may facilitate or constrain the actions, interactions, or strategies related to their mental wellbeing.
- Action/Interaction codes relating to strategies devised to respond to a phenomenon under specific perceived conditions.
- Consequences codes relating to the outcome or result of conditions, strategies, actions, or interactions.

(Strauss & Corbin, 1990)

The choice to use critical realist GT was made as it was felt that deconstructing and rebuilding data using the approach outlined rather than making them fit a deductive theoretical framework from existing research may provide a means to address a significant gap in research regarding how we might understand and promote the children's mental wellbeing. The process was undertaken separately across the three conversations relating to the children and then collectively across all data from consultations. This was done to try and interpret data individually to avoid generalising across the three CYP. A collective analysis across all three data sets was done to produce a framework for theoretical generalisation to other CYP with PMLD (Smith, 2009).

Figure 7: Visual presentation of AR, EO, and dialogic principles used



3.6 Findings

3.6.1 How might we understanding mental wellbeing for these CYP?

Feeling good and functioning well

Adults across all three conversations about the CYP arrived at conceptually similar understandings of mental wellbeing for them. These appeared to fit closest with two definitions within the literature on mental wellbeing. Firstly, adults discussed activities during the school day that meet a dual objective of helping the CYP feel good and function well (Huppert & So, 2013). For example, Alison said of Jake "his understanding of the activity was a lot more so he was able to engage and kind of get it…he's enjoying the activity, and happy to be there." Alison linked opportunities for Jake to understand and engage with activities, connect with others, and experience positive emotion as helping him to feel good and function well, promoting his mental wellbeing.

For Sophia, Talia suggested that there was an interrelated/cyclical relationship between opportunities for Sophia to feel good and function well, and that her mental

wellbeing depended on balancing opportunities to frequently experience both together. Talia said "functioning well absolutely falls into it…and it's a calm time for her as well because she's potentially so on the go all the time…I think it's just that it gives you that break in how she functions." Talia said it was important for Sophia to develop her independence skills but for these to be balanced with opportunities for her to experience positive emotion by connecting and experiencing positive emotions alongside others.

Paul's mental wellbeing was described similarly. Janine said "the Paul that we all know and love...he's happy and he's engaged and he's interacting...all of those needs are being met." Catherine and Janine both emphasised the importance of ensuring Paul's need to feel good and function well by engaging, interacting, and feeling positive emotion was being met. Furthermore, they suggested the importance of considering Paul's needs across these areas holistically, with Catherine highlighting that "[if] one of them things are slightly off then we don't meet the whole thing of feeling well...if you picture that whole big cog, one of them just needs to be slightly out and the whole thing stops working."

Thriving

Adults also appeared to consistently conceptualise the mental wellbeing of the CYP by using the term 'thriving', also used within wider mental wellbeing literature (Csikszentmihalyi & Seligman, 2000). By using this term, adults appeared to refer to opportunities for the CYP to thrive by developing both socially and academically. For Jake, Alison suggested that activities promoting both his social and academic development are "where we get the best work from him and the best engagement...a whole class activity with everyone, and he just thrives off the energy". For Sophia, Talia linked activities that help her to engage, develop skills, and experience positive emotion to her thriving. For example, Talia said "she's getting a lot of enjoyment out of that session...it gives her not just skill...but a lot of enjoyment doing it...she's really happy and that activity fully makes her thrive." Janine suggested the importance of considering Paul's needs and ability to thrive holistically, by indicating that when "all his needs are being met, educationally, or medically, physically, emotionally, he does tend to thrive."

Weighing feeling good and functioning well opportunities

The mental wellbeing of the CYP was described as a process of considering 'feeling good and functioning well' and opportunities to thrive in a holistic and joined up sense both between home and school. All adults conceptualised this in similar ways, which all pointed towards feeling good and functioning well being cyclical, in balance, as part of a 'mechanism' and co-dependent in facilitating mental wellbeing. For Sophia, Talia suggested that "it's cyclical, that is the word. And I think they're both weighed equally as well into each other. Without one, you're not going to get the other one." Catherine and Janine further emphasised this point by suggesting "if one of them is just not working properly [Paul's] not going to thrive to the best of his abilities."

Being child-led

The importance of being child-led and taking an individualised approach was discussed in all three conversations. This indicated the importance of considering mental wellbeing by balancing opportunities for feeling good and functioning well on an individual basis for these CYP. For Jake, Alison suggested planning activities "around what we know the children prefer to do and how they prefer to engage…so we get the most out of them." For Sophia, Talia further emphasised this and suggested "other children might not get the same result out of the activity…school need to set up whatever activity that child is doing to get them to feel good about going into the activity to get the most out of them." For Paul, Janine suggested a reflexive approach was needed "to try and get a response from the children…sometimes you have to change."

3.6.2 Promoting mental wellbeing for these CYP

The PERMA model of wellbeing (Seligman, 2018) was chosen as a theoretical framework to present findings relating to how we might promote mental wellbeing for these CYP. This model was not used deductively to generate theories around these CYP's mental wellbeing. Rather, it was chosen as a framework to present findings

coherently and cohesively and due to its overall fit with theories generated following the GT analysis.

The PERMA model of wellbeing

The PERMA model is an approach to conceptualising mental wellbeing within Well-Being Theory (Seligman, 2012). Seligman (2018) has suggested that wellbeing can be understood in terms of five constituent elements:

- Positive emotion experiencing emotions such as joy, love, amusement, and gratitude whilst doing things or being with people.
- Engagement –experiencing a state of 'flow' (Nakamura & Csikszentmihalyi,
 2014) or engrossment in activities that are suitably challenging/motivating.
- Relationships feeling valued, loved, and supported through connections with others.
- Meaning having a sense of value, purpose, and worth.
- Accomplishments pursuing intrinsically motivating goals.

Seligman (2018) has suggested that the PERMA model has empirical support as a theory for understanding how to promote wellbeing. It has been suggested that this is due to how the five elements comprising overall wellbeing are distinct from each other, can be individually observed and measured, and can be seen collectively as a robust list of factors contributing to overall mental wellbeing (Goodman, Disabato, Kashdan, & Kauffman, 2018; Seligman, 2018). In considering the model's usefulness within education, Eckloff (2021) has suggested that practitioners such as educational psychologists should be cautious and conscientious in its application. Although the model presents a useful framework for conceptualising mental wellbeing, the lack of empirical research evidencing how it may be usefully applied to CYP in education means that those wishing to apply it within this context should do so tentatively (Eckloff, 2021).

Several suggestions have been made to extend its usefulness to education, including developing the model to consider CYP's views on what they think is most

important to their mental wellbeing; extending the model to consider further important constituent constructs that fall outside of the five included (e.g. PERMA+); and weighing the importance of constituent elements on an individual basis (Eckloff, 2021). Campbell (2021) has considered the usefulness of the PERMA model in considering the mental wellbeing of CYP with PMLD and outlines potential difficulties in its application. These difficulties centre mostly on the extent to which abstract concepts such as meaning and accomplishments can be applied to these CYP and how those inferring meaning on their behalf can do so without projecting their own views about what may be important. Despite this however, Campbell (2021) has suggested that a model such as PERMA may be an effective way of understanding how to consistently promote their mental wellbeing.

Using the PERMA+ model to frame these findings provided an opportunity to build on the model as a useful theoretical framework for promoting the mental wellbeing for these CYP. It did so by considering the views of adults concerning what might be important in promoting the CYP's mental wellbeing, taking a stance of epistemic risk/fallibility (Skarsaune et al., 2021) and methodological naivety/immaturity (Gallacher & Gallagher, 2008). An individualised approach to utilising the model was taken in that the five elements were considered in terms of their individual importance to the CYP, how they interact, and whether additional elements should be considered (e.g. PERMA+).

Positive Emotion

Positive emotion was a concept that featured across all three conversations. Table 17 demonstrates how this was chosen as a selective code to represent axial codes for all three CYP:

Table 17: Example of Axial/Selective Coding relating to 'Positive Emotion'

Jake	Sophia	Paul
Axial codes		
Feeling good; positive emotion; thriving; symbiotic/mutual emotional energy.	Playfulness; positive emotion; playful interaction; symbiotic; thriving; negative emotion.	Positive emotion; humour/banter; playfulness; thriving; feeling good.
Selective code: Positive Emotion		

For Jake, the 'emotional energy' code occurred most frequently under the selective code 'positive emotion'. Adults spoke about the importance of activities and interactions being high in positive emotional energy and how this facilitated Jake's engagement and his mental wellbeing. Olivia suggested that Jake "likes loud and full rooms...and everybody being happy and cheerful". Adults felt that positive emotional energy created by activities and interactions enhanced Jake's engagement and subsequently his mental wellbeing. Alison suggested that "the madder it is, the better he engages...laughing at everyone looking at what they are doing." Adults highlighted the importance of the attitude of the adult in such activities; their ability to "give themselves" to Jake, committing themselves to the playfulness of the interactions, contributing to and taking from the positive emotional space. Alison suggested Jake will "make them [be silly] and feel happy...he makes it come out of people...he'll get you to do something to give him that interaction", whilst Olivia emphasised this further by suggesting "you just give what you get from Jake, and the same goes, he just gives you what you give." These findings demonstrated Jake's volition, agency, and control over the emotional space within the classroom, and how this is a symbiotic, interdependent, and relational activity with those around him.

For Sophia, ideas denoting both positive and negative emotion were in data. Adults highlighted the importance of inferring Sophia's emotions and doing what is necessary to help her experience positive emotion. This indicated the role of adults' reflexivity/responsiveness and was described by Michelle as, "reading the child and doing what makes them tick...unless they're doing something and immersed in it...you're not going to see the success". Talia further emphasised this by suggesting "when [Sophia's] calm...she's in a happy state...her overall demeanour is different...she engages better". Sophia's positive emotion aligned with her ability to

choose/control what she was doing to follow her interests/motivations. For example, Talia said playful interaction with other CYP "makes [Sophia] happy...that's just one of her skills that she has...and she just hones in on it." Adults also indicated that positive emotion was both a facilitator and an outcome of Sophia's ability to achieve success through skill development and functioning well. For example, Talia said "if you're in the right mindset [feeling good]...you've automatically got this extra burst of energy...which means you are functioning well...each...leading into the other". For Sophia, positive emotion was described as something relational and symbiotic between Sophia and others by creating positive emotional spaces together. Talia described this as adults reading the children and creating positive emotional energy that Sophia was "feeding off". Talia suggested adults' role in this was important as they can read the children creating a "leave all your worries at the door type scenario" where activities and adults' approach create a positive emotional space.

Positive emotion featured frequently in Paul's data. Positive emotion was created jointly between adults and Paul through playful/humorous interactions. These provided a way for Paul to feed off the positive emotional energy and spontaneity of adults. Catherine said during such activities "Paul does feel good...and you can see it, it shines through him as his eyes light up...his whole expression/body language changes". Paul's experience of positive emotion via social interaction, humour, and "banter" was a feature of most activities he engaged in helping him to feel good with others. For example, Catherine suggested that "[positive emotion is] a massive part of it. And if Paul's quite excited, and you're not, that will have a negative impact on Paul." Paul was described as having a range of emotions. Adults thought that those with Paul day-to-day play an important role in being attuned and emotionally responsive to him. Adults also suggested setting Paul up to succeed in skill development activities helped him to feel good. For example, Catherine suggested that "the opportunities...to participate to the best of his ability with any of the tasks he's given" helps him to feel good.

Engagement

Engagement was a concept featuring across all conversations. Table 18 demonstrates how this was chosen as a selective code to represent axial codes for all three CYP:

Table 18: Example of Axial/Selective Coding relating to 'Engagement'

Jake	Sophia	Paul
Axial codes		
Curiosity; enjoyment; awareness; inclusion; anticipation; participation; attention; motivation; non- passive.	Anticipation; involvement; exploration; attention; interest; motivation.	Engagement; non- passive
Selective code: Engagement		

For Jake, examples of 'engagement' occurred frequently within data. Jake's engagement was regularly linked with activities that helped him feel good and function well. His engagement provided opportunities to and was facilitated by experiencing positive emotion alongside others through enjoyment of activities. For example, Alison suggested, "in a group he watches everyone around him, so because they're doing it, he's like "oh I'm going to do this now"...that's probably where we get the...best engagement." According to Alison, Jake's enjoyment of group activities means "he's watching everyone else do it...he does it and he sees them singing so he'll vocalise. And so, it progresses quicker." Jake's engagement appeared to be facilitated through his social curiosity towards others as well as adults' ability to infer his choice/preference for activities. His preferred/chosen activities were motivating and increased his awareness. Alison suggested that this was Jake "finding his own way to engage...he wanted to do it more...he's chosen it."

For Sophia, examples denoting engagement were frequently coded in data. Adults had a knowledge of what intense engagement for Sophia looked like and how they could facilitate this by helping her explore and connect to the environment and the people around her. Adults thought Sophia's engagement was better when she was allowed to explore her own interests/motivations as Alison told us: "Sophia won't just immerse herself into something, she'll walk about." There was tension between

allowing Sophia to engage through exploration of interests/motivations and supporting her to follow adult-led/curriculum focused activities with a skill development purpose. For example, Michelle said "[Sophia] was looking around the room thinking "I'm not interested in this"...and then she gets frustrated because it's not what she wants...so we're in a bit of a predicament." Data highlighted the importance of adults' familiarity, relationships, and curiosity/reflexivity towards Sophia to enable her engagement. For example, Alison suggested the importance of adults' familiarity/responsiveness towards Sophia's preference for interesting/motivating people or objects. Sophia's preferences were often viewed as "very deliberate" and "perfectly reasonable" attempts to engage/interact despite not always aligning with the purpose of activities/curricula. Talia suggested adults' being curious/reflexive about how to engage Sophia and finding a "good explanation for why she's done what she's done" by engaging/not engaging was important.

For Paul, engagement featured frequently and was reflected through codes such as non-passive, communicative, functioning well, and interests. Adults demonstrated their understanding of what facilitates Paul's engagement and highlighted the importance of following his interests/motivations, particularly for social activities with lots of positive emotion and playfulness, as well as the need to be flexible. For example, Catherine said "[if] it is something he loves...he does engage well...when he's involved in that and there is the realisation that people are looking for him." Janine added "one activity...might not work...then you try something completely different...you've got that capacity...if I know that someone's not engaged." Adults thought familiar activities enhanced Paul's ability to anticipate and remain engaged. This was facilitated through adults' familiarity with Paul and how he responds to activities. For example, Janine highlighted the importance of familiar activities that set Paul up for success by "hitting so many" of the indications that he is engaged. Adults viewed Paul as communicating a desire to engage with them and activities even during moments between planned activities when there was an increased risk of Paul becoming disengaged. Adults recognised this as Paul's desire to be socially active and used opportunities to help him engage with activities he did not enjoy that were necessary. As Janine described "[it's] an opportunity to have a good bit of banter with Paul...making the transitions [between activities] as easy as possible."

Relationships

Relationships appeared to be key across all conversations and featured frequently within data. Table 19 demonstrates how this was chosen as a selective code to represent axial codes for all three CYP:

Table 19: Example of Axial/Selective coding related to 'Relationships'

Jake	Sophia	Paul
Axial codes		
Familiarity; intimacy/touch; attunement; empathy; interaction; attitude; intersubjectivity; non- isolation.	Connection; community; symbiotic; interrelated; attunement; trust; familiarity; disposition; reflexivity; responsiveness.	Spontaneity; attitude; disposition; friendship; reflexivity; mind- mindedness; advocacy; trust.
Selective code: Relationships		

For Jake, examples highlighting the importance of relationships occurred frequently in data. Relationships appeared to provide opportunities for positive emotion and engagement leading to Jake feeling good and functioning well. Adults indicated the importance of opportunities for Jake to connect to other children and adults via activities. Adults highlighted the importance of adults' attitude towards Jake, seeing him as socially curious, being responsive to his interests, and providing him with opportunities to be with others in a positive emotional space. For example, Alison suggested that Jake "initiates that interaction...he often does". She indicated that the adult's approach to Jake was important in recognising him as social and the way that you talk to him such as "having eye contact with him...responding to him...longer interactions with them that go past the point of "this is number four, this is number five, where's four?" Alison suggested adults' relationship with Jake must be more than didactic, something echoed by Olivia who suggested adults should view their relationship to Jake "like a friendship and not just a pupil." Jake was described by adults as being emotionally responsive in his relationships with others. For example, Olivia said "I think he does care. In that video, I think he's caring for another child, and I think he's feeling 'lovey'. He's feeling 'lovey' and he wants to show that he's feeling 'lovey'." Relationships between him and others were mutual/reciprocal and intersubjective. Jake's openness towards relationships also featured, specifically

how he demonstrated agency in choosing these, and how others respond to his social disposition. For example, Alison said "[Jake] knows who he likes, and he knows who he doesn't like…so he definitely knows who is his friend." Familiarity was highlighted as both important in relation to Jake's trust in others but also as unimportant as highlighted by his social curiosity and his enjoyment of novel social interactions.

For Sophia, examples highlighting the importance of relationships were reflected in data. These emphasised the importance of connection and community between Sophia and others providing her with opportunities to be with others. For example, Talia said "all children are doing the same thing...feeding off other people's energies...all calm... [Sophia's] happy in that environment." Sophia's relationships with adults were symbiotic/mutual and emotionally attuned as Talia pointed out "adults are just a lot more tuned in" to Sophia and other CYP and "[Sophia's] feeding off the adults...if your mood's a little bit agitated...she's going to feel the same". Relationships between Sophia and adults reflected certain qualities including seeing Sophia as unique, more than a pupil, and as volitional in actions and communication. This was reflected in the adults' approach to Sophia, something summarised by Talia who said, "I think it all comes down to the demeanour of the person, the way they talk to Sophia, [they're] on her level...that has a positive factor."

For Paul, the importance of relationships was reflected through codes such as friendship, adults' disposition, advocacy, and trust. Adults highlighted Paul's social disposition. He was viewed as a friend to CYP and adults. For example, Janine described Paul as "one of the gang for us, [adults] ask his opinion on stuff". Paul was regarded as being wilful/volitional/agentic in his ability to seek/maintain friendships with others by "making himself part of...conversation". Adults' disposition towards Paul was highlighted as important, specifically their high expectations for Paul, seeing him as unique, advocating for him, and their openness towards spontaneity and playfulness. For example, in relation to their high expectations of Paul, Janine said "there is no such thing as can't". Catherine thought it was important to advocate for Paul by indicating that "there's a child in the middle [of discussions around what is best for Paul]...he needs to be heard as well". Janine added, "it gets added to the job description...you just have to let yourself go...it gets a response from him". These

features of adults' relationships with Paul enhanced his trust in them and facilitated his ability to socially interact with others.

Meaning

Meaning arose in all conversations. Table 20 demonstrates how this was chosen as a selective code to represent axial codes for all three CYP:

Table 20: Example of Axial/Selective coding related to 'Meaning'

Jake	Sophia	Paul
Axial codes		
Autonomy; control; choice; preference; voice.	Agency; autonomy; control; normalising.	Intrinsic motivation; Curriculum purpose/ meaning.
Selective code: Meaning		

For Jake, there were many examples within data of how adults viewed him as communicative and volitional; having autonomy, choice, and control over what happens. These examples highlighted how Jake, through relationships with others, exercised choice, control, and volition. This led to Jake and adults finding meaningful and purposeful ways for him to engage and interact, fulfilling his desire to be with others. For example, Alison suggested that "In everything Jake does, there's got to be a social aspect…that kind of peer-adult interaction is the basis for Jake…which is great because you can bring that socialisation into everything." Alison suggested that Jake's relationships with others were vital in enabling him to find meaning and purpose through "favourite activities, favourite lessons, favourite people".

For Sophia, the importance of meaning was reflected through data codes such as agency, autonomy, control, choice, and preference. These examples depicted Sophia as wilful/volitional. Sophia chose what to explore and who/what to engage and interact with. For example, Talia suggested that if something is not "quite grasping [Sophia's] attention" she will "see if there's something else that interests [her] a little more". Michelle suggested Sophia demonstrates agency in selecting who she wishes to interact with. For example, "[Sophia] knows who everybody is but [another pupil] is the favourite". Talia suggested that, to infer Sophia's

choices/preferences and to enable her to be wilful/volitional, her behaviour must "all be seen as communication…[to get] attention, [she's] communicated…and got a result." Adults viewed Sophia both as socially interested and with potential to develop skills. This was reflected through their relationship with her, which enabled her to be wilful/volitional, leading to her feeling good and functioning well.

For Paul, meaning was reflected in codes such as intrinsic motivation and curriculum purpose. There were examples throughout data depicting intrinsically motivating activities for Paul that promoted his autonomy, competence, and relatedness. For example, adults highlighted Paul's positive emotion/engagement during activities as helpful to skill development and providing meaning and purpose to his time in school. Catherine suggested during such activities "[Paul] does feel good...and he does function well and is able to do it...he's getting a lot from that activity." Janine suggested that although activities for Paul are almost always playful, "there is so much more, it's purposeful", which indicated that the meaning of Paul's education was more than playful social interaction. Adults' views regarding the purpose of Paul's education ranged from providing opportunities for social interaction as well as to promote skill development. Adults thought it was important to meet these purposes as well as Paul's holistic needs to provide him with a meaningful education. For example, Catherine said "as long as all of his needs are being met, educationally or medically, physically, emotionally, he does tend to thrive." Adults also spoke about the tension between being child-led and having an adult-led agenda to meet both the social interaction and skill development purpose of Paul's education. For example, Janine indicated that "[Paul's] just really engaged with [another pupil]...it's nice, and sometimes it's not appropriate...but if there's that opportunity...then we're all for it...targets might be to share an activity/take turns [which we] try to encourage if possible."

Accomplishments

Accomplishments featured frequently in all conversations. Table 20 demonstrates how this was chosen as a selective code to represent axial codes for all three CYP:

Table 21: Example of Axial/Selective coding related to 'Accomplishments'

Jake	Sophia	Paul	
Axial codes			
Accomplishment;	Skills; competence;	Curriculum; qualification;	
achievement; progress;	curriculum-balance; adult-	adult-led vs child-led.	
improvement;	led vs child-led;		
development;	communicative.		
independence; child-led			
vs adult led.			
Selective code: Accomplishments			

For Jake, adults consistently indicated the importance of skill development and curriculum progress. This included supporting Jake to persevere with activities with a skill development purpose as well as helping him to meet targets and goals. For example, Alison said "he can do it [put on a coat] himself...as he's doing it, you can see he's smiling...he's really proud of himself, it was an achievement." Adults also highlighted difficulties in meeting the skill development purpose of Jake's school experience whilst remaining child-led and responding to his preference for group/social activities. Alison said this can be "a juggling act...we're always balancing it...we have the curriculum of what we have to meet...it's finding how to get Jake to do it...what Jake wants within that." Jake's accomplishments in skill development appeared to link consistently with adults' attitude: what they viewed as the educational purpose for Jake, their passion for education, and their investment in Jake's development. For example, Alison said adults are "so proud" of Jake's development and "like to make a big deal" when he progresses. Adults viewed their role in school as "a calling" rather than a "vocation" and Alison suggested this was reflected in a shared sense of accomplishment when Jake progresses. She said "it's not just a job for the ones that might form a better relationship because they want that relationship. They want to see him progress."

For Sophia, accomplishments were linked to ideas about feeling good and functioning well. Her ability to connect to others, to interact, and to experience positive emotion were viewed as accomplishments. Adults also referenced skill development and becoming competent/independent as an essential feature of her education. For example, Talia said "[Sophia's] learning...honing in on those skills and advancing those goals...[school push] her to that next level...to function

for the real world." Adults frequently linked Sophia's accomplishments to positive emotion with both giving rise to the other, as Talia suggested "while she's doing that...she feels good about what she's doing...and we want her to function well." By supporting Sophia to achieve, adults implied that Sophia would develop purpose/meaning as wilful/volitional/social. This was facilitated by adults' reflexivity and how they would manage the space between the adult- and child-led curriculum. Talia suggested that it was important for teachers to "read those signs and clues off the children...if [the teacher] carried on with those [adult-led activities] then [Sophia's] probably not going to respond how you want her to respond." This suggested tension between the adult-led and child-led curriculum and how this meets Sophia's need for engagement, positive emotion, meaning, and accomplishment.

For Paul, accomplishments were reflected through his engagement with skill development activities as well as adults' desire to see him make progress. For example, Janine suggested "it's the process, not the product" when following Paul's interests during activities with a skill development purpose. This increased his engagement and sense of accomplishment that he had completed this more independently. Adults thought there was genuine investment in Paul's accomplishments, with Janine indicating "if he does something that it's like, "oh wow", that's a wow moment, we'll log it down." Although adults highlighted tension between facilitating opportunities for Paul to develop skills and following his interest in more social/interactive activities, they suggested that Paul's skill development could emerge serendipitously through more motivating/child-led activities. For example, Janine said Paul's targets "can just occur naturally". Catherine added to this, suggesting that when activities are less formal and more about what motivates him, "he's doing something that he finds quite useful...that will have [provided positive emotion]...because he thinks "I'm doing something really good"...he will get so much joy and satisfaction from that. But actually, he's meeting his target".

Additional considerations (PERMA+)

There were some additional topics/constructs/phenomena discussed across the three conversations that needed to be considered separately from PERMA's discrete categories. These related to individual factors likely to impact on the CYP's mental

wellbeing such as physical, medical, and sensory needs. For example, Janine said "Paul is such a happy boy. I think it shows that his physical needs, his emotional needs...are being met." Catherine added "there's a big chain, if one of them things are slightly missing...it's [affecting] the whole approach." These comments emphasise the importance of factoring in Paul's physical/medical needs as part of holistically promoting his mental wellbeing. Similar comments were made in relation to Jake. For example, Alison said "it's balancing meeting his physical needs, but giving him the ability to engage with those around him in his equipment". Alison thought Jake's physical/medical needs should not be a barrier to him being able to engage and interact with activities and people. Sophia's interest in sensory activities meant that adults had to think carefully about how to present her with opportunities to engage and interact. For example, Michelle said "we have laminated butterflies in the sensory story, and she likes ripping, tearing, eating...texture." These examples highlight the importance of factoring in CYP's individual differences when considering mental wellbeing using PERMA (Eckloff, 2021). Adults showed awareness of this, as highlighted by Janine, who said "there's very different levels of PMLD, as you know".

3.7 Discussion

Findings suggest that adults take an individualised approach to considering the intensity and emotional quality of these children's involvement in activities in school (Carpenter et al., 2011). PERMA+ provided a useful model to consider how this can lead to positive mental wellbeing. Adults in school appear to play a key role in this. Their attitude/disposition towards these children, how they perceive their role, and how they view their relationship with them appear to be significant. Adults appear to subjectify rather than objectify (Buber, 2004) these children. Relationships appear to be authentic and reciprocal. Relationships give rise to the will/volition/agency of the children (Davy, 2019).

Adults appear to be reflexive towards their role as educators, companions, and facilitators. Through their relationships they co-create and jointly benefit from positive emotional spaces. These findings reflect other literature highlighting the importance of adults' disposition, connectedness between adults and children, and reflexivity.

Adults appear to play an important role in fostering intersubjectivity between themselves and children (Forster, 2020) and holding space open for this to occur (Goodwin, 2019). Adults' playful/spontaneous disposition is seen as essential to create mutually enriching emotional spaces (McKim, 2015; Watson, 2015). Reflexivity is regarded to be crucial to ensure decisions taken are responsive to the needs/views of the children (Goodwin, 2020). Adults appeared to possess vital characteristics such as empathy and reflexivity, demonstrating that they view these children as subjects with identities/personalities.

Curriculum balance appeared to be an important factor in providing appropriate opportunities for these children to both feel good *and* function well. This contrasted with wider research findings suggesting that approaches should focus on producing spaces that prioritise positive emotion, playfulness, and spontaneity (Pavlicevic et al., 2014; Preece & Zhao, 2015). Findings suggest balancing both child-led and adult-led activities may be important for mental wellbeing. Finding ways to engage these children around interest/motivations was difficult to achieve when curriculum activities prioritised skill development. Finding a balance was highlighted as important. This reflects wider research findings suggesting that adults be given opportunities to use their 'craft knowledge' (Thomas, 2012) or 'informal funds' of practice-based evidence (Hedges, 2012) regarding how to provide opportunities for these CYP to feel good and function well. This suggests prioritising a child-led approach such as the Engagement Model (Carpenter et al., 2016) ahead of, but not disregarding the importance of skill development (Strnadová & Nind, 2020) may be important.

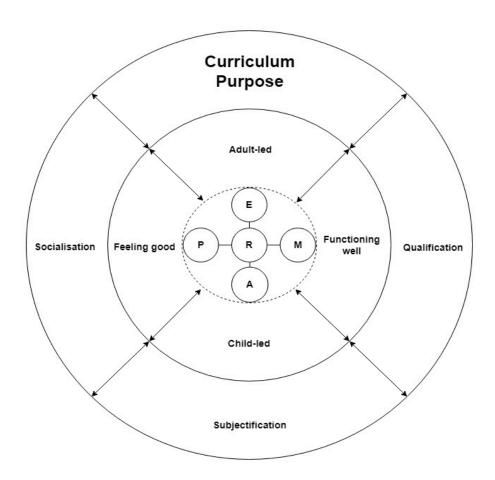
Curriculum balance appears to reflect wider research findings suggesting the importance of quality of space as impacting on the CYP's ability to feel good and function well. An overbalance towards an overly adult-led/skill development curriculum represents the idea of 'spatial practice'; how adults think curriculum activities for these CYP should be organised in line with 'abstract' PMLD ideas/theories/pedagogy (Lefebvre, 1991; Simmons, 2021). Adults appeared to highlight the importance of finding balance between adult- and child-led activities, sometimes even favouring the latter. This appeared to positively impact on the quality of space, shifting this along a continuum towards 'lived space' (Lefebvre,

1991) characterised by playfulness/positive emotion/serendipitous skill development. Adults' openness to this shift appeared to enable the children to claim/create space with others (Milner & Frawley, 2019) through their relationships with adults (Simmons & Watson, 2014).

Curriculum purpose appeared to impact the balance of child/adult-led activities and opportunities to feel good and function well. Adults frequently referenced 'socialisation' and 'qualification' educational purposes (Biesta, 2020) for these children. These emphases appeared to also impact on the shift between 'lived space' and 'spatial practice' (Lefebvre, 1991). Adults' role appeared to reflect a third purpose of 'subjectification' (Biesta, 2020). They viewed the children as active/wilful/volitional social subjects. This reflects ideas in wider literature regarding the role of adults as the curriculum in action (Stewart & Walker-Gleaves, 2020) due to their significance in meeting/facilitating the qualification, socialisation, and subjectification purposes of the children's education.

Altogether, findings emphasise the relational interdependence between adults and these children in supporting the children's mental wellbeing. This highlights the significance of relationships (Lambert, 1992) and the utility of the PERMA+ model in elucidating how relationships support other important factors in the model contributing to mental wellbeing.

Figure 8: A tentative model of research findings



3.8 Conclusion and implications

The aim of this research was to collaborate with school practitioners and parents/carers to understand and promote the mental wellbeing of children with PMLD. The research attempted to understand what promotes mental wellbeing for these children by observing and critically reflecting alongside those that know them best on their engagement with day-to-day school activities to understand how they may be promoting their mental wellbeing. Findings suggested that their mental wellbeing can be conceptualised by considering opportunities for them to 'feel good and function well' in school. Adult co-researchers consistently highlighted the importance of meeting these children's needs holistically to help them thrive.

Findings also suggested that the mental wellbeing of these children can be understood and promoted using the PERMA+ model (Seligman, 2018). This highlights the importance of consistent opportunities for them to experience positive emotion, engagement, have relationships, a sense of meaning, and accomplishments in school, and considering this on an individual basis. Findings highlighted the significance of the 'relationships' component of PERMA+ for these children, specifically the role that adults in school play. Adults played a 'subjectification' (Biesta, 2020) role for these children. Adults viewed the children as wilful/volitional, having interests and motivations towards activities and social interaction. Adults played an important role in recognising this and facilitating opportunities within positive emotional spaces where the children could thrive, feel good, and function well. Adults were also reflexive in terms of how they balanced opportunities for feeling good and functioning well to meet the 'qualification' and 'socialisation' purposes (Biesta, 2020) of the children's education, something highlighted as important by adult co-researchers.

The research and its findings provide a framework for how this topic may be explored with other CYP in other contexts in a collaborative way alongside those that know them best. The research provides an example of how special schools, parents/carers, and educational psychologists can work together to understand systemic issues affecting these CYP (Winter & Bunn, 2019). The findings present a compelling case for considering the importance of components of the PERMA+

model in understanding and promoting the mental wellbeing of these CYP on an individual basis and considering this in relation to the balance of curriculum activities in school and educational purpose for these CYP.

The findings have far-reaching implications beyond the fields of educational psychology and special education. Findings suggest that considering their mental wellbeing anywhere and at any time may begin with focusing on the significance of relationships, such as those highlighted both in this research and in wider literature. Relationships that contain 'depth of meeting and mutual openness' (Cooper et al., 2013, p. 71), and that are reflective of a kind of 'I-Thou' interaction (Buber, 2004) appear to be significant to these CYP. They are characterised by authenticity, mutuality, and interdependence. Via these relationships, adults view these CYP as fluid, freely-choosing subjects rather than 'static', 'determined' objects (Cooper et al., 2013) or passive recipients of the world around them. Such relationships appear to facilitate other components of the PERMA model enhancing the CYP's mental wellbeing. Viewing these CYP in such a way need not be confined to school but to other spaces where they may spend significant amounts of time.

3.9 Strengths and limitations

The main strength of this research is reflected in the epistemological and methodological decisions taken. Adopting an interpretative-phenomenological approach and an overarching methodology containing AR principles meant that I could attempt to understand the topic collaboratively, critically, and iteratively alongside the adult co-researchers. Altogether, this approach was reflective of the quality standards for people with PMLD (Doukas et al., 2019) highlighted in Table 10. Furthermore, a strengths-based approach in considering what may be important in promoting mental wellbeing for these CYP was taken. The findings/discussion highlight some important considerations and model (using PERMA+) an effective way of considering how to promote their mental wellbeing (Campbell, 2021). The overarching tentative model of findings (see Figure 8) combine psychological, sociological, and educational theory in attempting to understand this topic.

There are several limitations to this research which are important to acknowledge. Firstly, this research focused on generating knowledge to inform practice around individual, heterogenous CYP within a single setting (Simons, 2009). This limits the generalisability of findings to other CYP in other contexts. Despite this, the research findings do have some theoretical generalisation (Smith, 2009) and may provide an example of how this issue can be considered for other CYP in other contexts. Another limitation is the extent of the validity and concludability of findings. Although effort was made to increase trust/validity of data generation, analysis, and interpretation (Walmsley et al., 2018), a high level of inference was used throughout this research. Data analysis was complex and had to be contained within a framework to be useful/coherent. This raises questions regarding the level of epistemic risk taken (Skarsaune et al., 2021), the authorship of findings (Fricker, 2007), and whose 'views' these are (Campbell, 2021). The trustworthiness/validity of findings might have been enhanced if they were reconsidered critically and collaboratively with adult co-researchers and used to inform practice as part of an 'assess, plan, do, review' cycle. This was not possible due to time constraints but may be something other research exploring this issue might consider.

Chapter 4: A Reflexive Account of the Personal and Professional Implications As Part of the Learning Acquired in Completing This Project

In this final Chapter I wish to reflect on the following:

- How the research process affected me personally regarding to my attitude towards these CYP.
- How the research process and its findings have provided opportunity to problematise and demonstrate criticality to these CYP's education.
- How I hope the research and its implications will affect my EP practice and the profession's more generally.

4.1 How the research process has affected me personally

Earlier in this thesis, I suggested that my motivation to explore this area within my research was related to personal and professional experiences of learning disabilities (LD). This included reflection on personal experiences such as relationships with close family members with LD as well as contending with feelings towards my own medical condition which increases the potential for developing LD. It also included reflection on professional experiences such as working in schools to support CYP with different forms of special educational needs and disabilities (SEND). Throughout these personal and professional experiences there had always been a sense of discomfort and unease in some shape or form; whether this was an uneasiness towards working one-to-one with CYP, or discomfort related to trying to understand myself and my medical condition better.

Experiences throughout my professional life have, in many ways, helped me to confront and challenge such feelings; the sense of cognitive dissonance (Festinger, 1957) between my thoughts and behaviour towards these CYP (which have always been positive and well-intentioned) and the often felt (irrational) sense of discomfort. Goodwin (2019) has suggested that this sense of discomfort appears to be a common phenomenon, and is not just experienced by 'outsiders', or those with a professional relationship towards these CYP, but even family members such as

parents/carers. Goodwin (2019, p. 54) implies that this appears to be linked to a lack of experience, opportunities, and know-how for others to spend time getting to know these CYP and developing an understanding of how to bridge relationships with them across what can feel like a 'still and languageless zone'. The research within this thesis provided me with (a further) hugely valuable opportunity to confront such feelings and to begin bridging my own relationships with these CYP alongside those that know them best.

I was afforded valuable learning opportunities, both in class alongside the CYP and their key adults both participating in and observing their activities, as well as in consultation with the adult co-researchers when they often spoke openly and candidly. These learning opportunities appeared to point towards some key ideas: firstly, the importance of being curious, playful, and spontaneous with these CYP. This appears to be hugely important in providing them with opportunities to connect and relate to others and was a valuable lesson for me. Goodwin (2019) describes this approach as holding the space open to allow these CYP to become more actively engaged and responsive towards others, whereas Goodley (2020, p. 18) describes this as 'just getting on with being with one another' at the level of the mundane where we learn and relate to each other the most.

Another idea concerned thinking carefully about how to provide these CYP and those around them (such as myself) to have meaningful opportunities to connect and share space (Allport, 1954). This has potential implications for the education of these CYP and whether it is in their best interests to proceed with segregated forms of specialist education. For me, this research has been a hugely valuable opportunity to confront and reconcile these feelings of discomfort and uneasiness by learning about these CYP and spending time with them. This served to remind me of these CYP's humanity, or, to use Goodley's (2020, p. 14) words, reaffirmed 'the human at the centre of the analysis' of this research which explored their day-to-day activities in school which can often be overlooked or lost.

Before I embarked on this course of study, my interest in disability studies and educational psychology encouraged me to ask what I felt were important questions regarding how I could reconcile the dangers associated with *psychologising disability*

(Goodley, 2011) and attempting to use potentially ableist psychological theories and approaches to understand CYP with SEND and matters affecting them. This research provided me with an opportunity to be critical towards and deliberately problematise an educational issue facing these CYP (their mental wellbeing in schools).

In Chapter 1, I concluded by suggesting that we might have to take an interdisciplinary approach to understanding this issue by combining psychological, sociological, and educational theory. This might begin with what Szulevicz (2018) has described as 'asking educational questions' about problems Educational Psychologists (EPs) encounter in their work, such as considering the quality of space in which these CYP spend their time in school and how to support those around them to cultivate such spaces. Altogether, this might mean critiquing the purpose of their education (Biesta, 2015, 2020) and asking "how do we wish education to work for these CYP?". The research findings within this thesis suggest that educational purpose for the children involved is no different to other children. Adults who advocate for them (the adult co-researchers) wish for them to benefit from education as we would wish other CYP to. That is to say, for them to benefit from opportunities to be with and connect with others, and to develop and achieve. Perhaps this boils down to those advocating for them giving careful consideration to how to help them be present and connected with those around them so they can receive the same educational benefits as other CYP, suggesting utility for the tentative model developed using the findings of this research (see Figure 8).

Both in wider reading of the literature and whilst writing Chapter 1, I deliberated on how we might attempt to understand/conceptualise the mental wellbeing for these CYP. I concluded by suggesting that there is a difficulty applying more 'mainstream' models/theories of wellbeing (e.g. the WHO definition/ Self-Determination Theory) and conceded that definitions needed to be more universal/inclusive. Alternative readings of these CYP that were different from how they are typically understood and described (e.g. as 'non-volitional, unaware, mindless entities'; Simmons, 2011, p. 5) emerged from the findings of this research. These alternative readings suggested that, whilst these children could demonstrate things such as autonomy, competence, volition, agency, will, and independence, this was contingent on the

relational interdependence between them and those around them and how those around them both viewed and responded to them as social 'beings' and 'becomings' (Sheldon, 2017). I found myself questioning whether, as social beings, we can ever be completely 'self-determined' without others; or as Goodley puts it (2020, p. 16), in citing Ghai (2019) 'the self can only ever develop in relation to the other and this intertwining of self/other is key to more collectivist notions of personhood'. The research findings in this thesis indicate that considerations of self/other (reflexivity) may be a necessary relational process of understanding these CYP's identity, their personhood, and what maybe important to them in relation to their education and mental wellbeing.

Towards the completion of the thesis, I developed a tentative model (see Figure 8) for understanding mental wellbeing for these CYP using Seligman's (2018) PERMA+ model. In a sense, this journey has come full circle to a point we can tentatively apply something 'mainstream' (such as PERMA+), something that highlights the importance of interdependence in terms of sharing positive emotion, meaning, and accomplishments (essentially both being and becoming) through our relationships with others, to these CYP. There is something inclusive about that. There is also something personally fulfilling about focusing on a social justice/inclusion issue as has been considered in this thesis, focusing on perhaps one of the most marginalized groups of CYP in society, and finding something potentially universally applicable and beneficial to both to them and to their peers. Goodley (2020) has stated that there is much to learn from considering people's differences which help us to think about how we might produce a more inclusive and equitable society for all. If we are looking to improve society for all, we would do well to start by focusing on those who are most disadvantaged (Oliver, 1990). Perhaps then the 'educational question' is not about how we wish education to work for these CYP, but for all CYP. This seems a pertinent question when the findings of the SLR and empirical research in this thesis are considered. For example, how can the concept of 'Quality of Space' and the PERMA+ model for these CYP be used to produce nonsegregated educational spaces for these CYP and others to both 'be' and 'become' together?

4.2 Implications for practice (the 'so what?')

The primary implication of this research in terms of practice is as follows: this research 'presents and markets' (Winter & Bunn, 2019, p. 1) the potential role EPs can play in collaborating alongside parents/carers and special school staff regarding these CYP. Winter and Bunn (2019) have indicated that EPs' views on their role in PMLD settings seem to feature limited ideas. They have conceded that work with special schools appears to be restricted to individual statutory cases with little opportunity to consider more systemic issues facing these CYP such as their mental wellbeing.

From a very early point in devising this research it was clear that the approach to the research would have to be carefully considered to ensure those involved (the CYP, their parents/carers, school staff, and myself) were valued, respected, and were able to become involved in a meaningful way. This suggests that EPs wishing to undertake work of a similar nature within their role might necessarily consider a number of factors that I had to consider such as the availability of time and resources (Vorhaus, 2016; Young & Chesson, 2006) as well as concepts such as 'methodological immaturity/naivety' (Gallacher & Gallagher, 2008) and 'epistemic risk'. For example, Winter and Bunn (2019) have suggested that both EPs and special school staff are not confident in EPs' abilities to become effectively involved in such issues facing these CYP, that special school staff do not have knowledge of the different ways EPs might become involved, and that responsibility for such issues remains almost entirely with special school staff.

Applying 'methodological immaturity/ naivety' meant finding ways to collaborate effectively with the staff as well as parents/carers, who have valuable expertise and knowledge about these CYP, and relying on our collective skills and knowledge to guide the research. This can involve an element of 'epistemic risk' (Skarsaune et al., 2021) in ensuring that knowledge gained from those whom inclusive research is focused on is interpreted reliably and used responsibly for their benefit. This was made possible due to some of the decisions made within the research process which were necessarily eclectic and flexible. Wider reading of literature indicated that this may be needed to encourage involvement, make the research process more

inclusive, and develop a deeper understanding of the topic. Without this, there were likely to be concerns around power, positionality, and authorship within the research. For example, how were the CYP being positioned by this research? How was the power between co-researchers going to be more equitably distributed given power dynamics between researchers and participants commonly seen in research? And how can we ensure that this research was both beneficial and meaningful to these CYP and those closest to them?

To avoid tokenism, it was essential to increase the collective trust between coresearchers in the methods used to increase our understanding of this topic (Lewis & Porter, 2004). Using AR principles as an overarching framework for the methodology provided a means to build an understanding of the mental wellbeing of the CYP both inductively and iteratively (Lacey, 2015; Nind, 2014). Collaborating with adult coresearchers using dialogic consultation provided a way to tap into collective expertise shared between parents/carers, school staff, and myself. In doing so, a more critical consideration of the CYP's mental wellbeing was possible. Using EO as a data collection method made data transparent to other co-researchers increasing trust in what had been gathered. Going about the research in this manner was a priority as literature concerning these CYP indicates that outside professionals can misunderstand or misinterpret their behaviour (Figg et al., 1996). This has potential to reduce trust in outside professionals, something which was highlighted by parents/carers and school practitioners in this research. Further, literature indicates that EPs might consider ways in which they can collaborate effectively with parents/carers and special school staff by acknowledging and combining collective expertise and offering support to the benefit of these CYP (Sheehy & Nind, 2005; Winter & Bunn, 2019).

Altogether, the collaborative nature of this research and the resultant findings suggests that EPs and the EP profession might give thoughtful consideration to how they can work in partnership with special schools as well as parents/carers of these CYP to explore such issues together. This is within both the remit and skillset of EPs. One such approach may be to consider establishing 'Communities of Practice' (Wenger, 2011) alongside special schools and parents/carers to collaboratively consider this and wider educational issues for these CYP. Finding ways such as this

to work in partnership with these CYP and their families should be top of the profession's priorities if we are seeking to understand and positively affect wider systems for CYP and their families, or, as Goodley (2020, p. 13) writes, 'recentring the marginalized other as the epicentre of community from which to rethink how we live our lives *together*' [italics added].

4.3 Concluding statement

Throughout construction of this thesis and during my progress through this course of study, I have given much consideration to what it means to be a researchpractitioner psychologist. This has involved reflection on the relationship between research and practice and how this has been shaped/informed by my philosophical assumptions. I have also thought carefully about the opportunity in front of me, specifically being in a privileged position to enact/apply/bring to bear espoused psychology that resonates with me and is helpful to others in bringing about positive change. Completion of this thesis presented a valuable opportunity to reflect on these areas and consolidate such ideas; what they mean for me personally, and how this is comes to bear and reflects on others I encounter. This has meant reflecting personally and professionally in relation to how this reflects on both people and issues I encounter as an EP, a profession typically seen as social justice-oriented change agents (Shriberg et al., 2021). Perhaps then, my first act as a social justiceoriented change agent should be explore appropriate ways to disseminate the findings of this research to special schools, parents/carers, and others with an interest to inform practice around supporting the mental wellbeing of these CYP.

References

- Aidonopoulou-Read, T. (2020). The Conceptualisation of a Modified Formative Assessment Model for Non-Verbal Students with Autism and Severe Learning Difficulties. *British Journal of Special Education*, 47(1), 88-109. doi:http://dx.doi.org/10.1111/1467-8578.12290
- Allport, G. W. (1954). *The nature of prejudice*. Oxford, England: Addison-Wesley. Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative research*: *QR*, *I*(3), 385-405. doi:10.1177/146879410100100307
- Bagatell, N. (2012). Engaged moments: Mediated action and children with autism in the classroom setting. OTJR: Occupation, Participation and Health, 32(1), 258-265.
- Bakhtin, M. (1982). *The dialogic imagination : four essays*. Austin: Austin: University of Texas Press.
- Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: A critical review. *BMC medical research methodology*, *9*, 59. doi:10.1186/1471-2288-9-59
- Bellamy, G., Croot, L., Bush, A., Berry, H., & Smith, A. (2010). A study to define: profound and multiple learning disabilities (PMLD). *Journal of Intellectual Disabilities*, 14(3), 221-235.
- Biesta, G. (2015). Beautiful risk of education: Routledge.
- Biesta, G. (2020). Risking Ourselves in Education: Qualification, Socialization, and Subjectification Revisited. *Educational Theory*, 70(1), 89-104. doi:https://doi.org/10.1111/edth.12411
- Billington, T. (2006). Working with children: Assessment, representation and intervention: Sage.
- BPS. (2017). Practice Guidelines Third Edition. Retrieved from file:///C:/Users/b9055696/Downloads/BPS%20Practice%20Guidelines%20(Third%20 Edition).pdf
- BPS. (2021). BPS Code of Human Research Ethics. Retrieved from https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-%20Files/BPS%20Code%20of%20Human%20Research%20Ethics.pdf
- Buber, M. (2004). I and Thou. London: Continuum.
- Campbell, N. (2021). The intellectual ableism of leisure research: Original considerations towards understanding well-being with and for people with intellectual disabilities. *Journal of Intellectual Disabilities*, 25(1), 82-97.
- Campinha-Bacote, J. (2002). The Process of Cultural Competence in the Delivery of Healthcare Services: A Model of Care. *Journal of Transcultural Nursing*, 13(3), 181-184. doi:10.1177/10459602013003003
- Carpenter, B., Carpenter, J., Egerton, J., & Cockbill, B. (2016). The Engagement for Learning Framework: connecting with learning and evidencing progress for children with autism spectrum conditions. *Advances in Autism*, 2, 12-23. doi:10.1108/AIA-10-2015-0021
- Carpenter, B., Egerton, J., Brooks, T., Cockbill, B., Fotheringham, J., & Rawson, H. (2011). "The complex learning difficulties and disabilities research project: developing meaningful pathways to personalised learning" Project Report. Retrieved from London:
- CASP. (2022). Critical Appraisal Skills Program: Qualitative Studies Checklist. Retrieved from https://casp-uk.net/casp-tools-checklists/
- Charmaz, K. (2017). Constructivist grounded theory. The Journal of Positive Psychology.

- Cluley, V. (2017). Using photovoice to include people with profound and multiple learning disabilities in inclusive research. *British Journal of Learning Disabilities*, 45(1), 39-46. doi:10.1111/bld.12174
- Colley, A. (2020). To what extent have learners with severe, profound and multiple learning difficulties been excluded from the policy and practice of inclusive education? *International Journal of Inclusive Education*, 24(7), 721-738. doi:10.1080/13603116.2018.1483437
- Cooper, M., Chak, A., Cornish, F., & Gillespie, A. (2013). Dialogue: Bridging personal, community, and social transformation. *Journal of Humanistic Psychology*, 53(1), 70-93.
- Corbin Dwyer, S., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International journal of qualitative methods*, 8(1), 54-63.
- Csikszentmihalyi, M., & Seligman, M. (2000). Positive psychology. *American psychologist*, 55(1), 5-14.
- Darlaston-Jones, D. (2007). Making connections: The relationship between epistemology and research methods. *Special Edition Papers*, 19(1), 19-27.
- Davy, L. (2019). Between and Ethic of Care and an Ethic of Autonomy. *Angelaki*, 24(3), 101-114. doi:10.1080/0969725X.2019.1620461
- de Haas, C., Grace, J., Hope, J., & Nind, M. (2022). Doing Research Inclusively: Understanding What It Means to Do Research with and Alongside People with Profound Intellectual Disabilities. *Social Sciences*, 11(4), 159. Retrieved from https://www.mdpi.com/2076-0760/11/4/159
- Deci, E., & Ryan, R. M. (2000). The "What" and "Why" of Goal Pursuits: Human Needs and the Self-Determination of Behavior. *Psychological Inquiry*, 11(4), 227-268. doi:10.1207/S15327965PLI1104 01
- Denzin, N. K., & Lincoln, Y. S. (2018). *The SAGE handbook of qualitative research* (Fifth edition.. ed.): Thousand Oaks, California: SAGE.
- Department for Education. (2015). Special educational needs and disability code of practice: 0 to 25 years. London: UK Government Retrieved from https://www.gov.uk/government/publications/send-code-of-practice-0-to-25
- Department of Health. (2015). Future in Mind: Promoting, protecting and improving our children and young people's mental health and wellbeing. London: UK Government/ NHS England Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachme nt data/file/414024/Childrens Mental Health.pdf
- Doukas, T., Fullerton, M., Fergusson, A., & Grace, J. (2019). Quality standards for people with profound and multiple learning disabilities (PMLD/PMID). *Journal of Intellectual Disability Research, 63 (7)*, 818. Retrieved from https://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=emexa&AN=628696500
- http://library.ncl.ac.uk/openurl/?sid=OVID&isbn=&issn=1365-2788&volume=63&issue=7&date=2019&title=Journal+of+Intellectual+Disability+R esearch&atitle=Quality+standards+for+people+with+profound+and+multiple+learnin g+disabilities+%28PMLD%2FPMID%29&aulast=Doukas+T.&spage=818
- Eckloff, L. (2021). *Pupil perceptions of wellbeing: a positive psychology perspective during a pandemic.* (Doctorate in Educational Psychology). University of Cardiff, University of Cardiff.
- Emerson, E., & Hatton, C. (2007). The Mental Health of Children and Adolescents with Learning Disabilities in Britain. Retrieved from https://www.mentalhealth.org.uk/sites/default/files/mh_children_adolescents.pdf

- Fangen, K. (2015). Qualitative Research. Retrieved from https://www.forskningsetikk.no/en/resources/the-research-ethics-library/methods/qualitative-methods/?msclkid=50cd9588b5a811ec99abef06b41b3fcd
- Festinger, L. (1957). A theory of cognitive dissonance (Vol. 2): Stanford university press.
- Figg, J., Keeton, D., Parkes, J., & Richards, A. (1996). "Are they talking about us?" (How EPs describe the views of children). *Educational and Child Psychology*, 13, 5-13.
- Foreman, P., Arthur-Kelly, M., Pascoe, S., & King, B. S. (2004). Evaluating the Educational Experiences of Students with Profound and Multiple Disabilities in Inclusive and Segregated Classroom Settings: An Australian Perspective. *Research and Practice for Persons with Severe Disabilities*, 29(3), 183-193. doi:10.2511/rpsd.29.3.183
- Forster, S. (2020). Approaching a Person with Profound Intellectual and Multiple Disabilities: What do you think, what do you do? In *Belonging for People with Profound Intellectual and Multiple Disabilities* (pp. 133-158): Routledge.
- Forster, S., Gray, K., Taffe, J., Einfeld, S., & Tonge, B. (2011). Behavioural and emotional problems in people with severe and profound intellectual disability. *Journal of Intellectual Disability Research*, 55(2), 190-198.
- Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*: Oxford University Press.
- Galderisi, S., Heinz, A., Kastrup, M., Beezhold, J., & Sartorius, N. (2015). Toward a new definition of mental health. *World Psychiatry*, 14(2), 231-233. doi:10.1002/wps.20231
- Gallacher, L.-A., & Gallagher, M. (2008). Methodological immaturity in childhood research? Thinking throughparticipatory methods'. *Childhood*, *15*(4), 499-516.
- Geertz, C. (1998). Deep hanging out. The New York review of books, 45(16), 69-72.
- Ghai, A. (2019). Rethinking disability in India: Routledge India.
- Glaser, B. G. (1998). *Doing Grounded Theory: Issues and Discussions*. Mill Valley: California: Sociology Press.
- Goode, D. (1994). A World without Words: The Social Construction of Children Born Deaf and Blind (Philadelphia, PA: Temple).
- Goodley, D. (2011). Disability studies: an interdisciplinary introduction. London: SAGE.
- Goodley, D. (2020). Disability studies and human encounters. *Indian Journal of Critical Disability Studies*, *1*(1), 12-21.
- Goodley, D., & Lawthom, R. (2008). Disability Studies and Psychology: Emancipatory Opportunities. In S. L. Gabel & S. Danforth (Eds.), *Disability & the politics of education : an international reader*. New York: Peter Lang.
- Goodman, F. R., Disabato, D. J., Kashdan, T. B., & Kauffman, S. B. (2018). Measuring well-being: A comparison of subjective well-being and PERMA. *The Journal of Positive Psychology*, 13(4), 321-332.
- Goodwin, J. (2019). Sharing an aesthetic space of refuge within a school for pupils with profound and multiple learning disabilities. (Ph.D). University of Winchester,
- Goodwin, J. (2020). On 'being'together as belonging: Inside golden tent. In M. Nind & I. Strnadová (Eds.), *Belonging for People with Profound Intellectual and Multiple Disabilities* (pp. 59-74): Routledge.
- Griffiths, C., & Smith, M. (2016). Attuning: A Communication Process between People with Severe and Profound Intellectual Disability and Their Interaction Partners. *Journal of Applied Research in Intellectual Disabilities*, 29(2), 124-138. doi:10.1111/jar.12162
- Harris, J. (2003). Time to make up your mind: why choosing is difficult. *British Journal of Learning Disabilities*, 31(1), 3-8. doi:https://doi.org/10.1046/j.1468-3156.2003.00181.x

- Hatton, C., Emerson, E., Robertson, J., & Baines, S. (2018). The mental health of adolescents with and without mild/moderate intellectual disabilities in England: Secondary analysis of a longitudinal cohort study. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 768-777. doi:https://doi.org/10.1111/jar.12428
- Helen Sanderson Associates. (2022). Person-centred thinking tools. Retrieved from http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/
- Hinchcliffe, V. (2022). The Rochford review, pre-key stage standards and the engagement model what does it all mean to schools for children with SLD and PMLD? *Support for Learning*, 37(1), 62-79. doi:https://doi.org/10.1111/1467-9604.12395
- Hofer, B. K., & Pintrich, P. R. (2012). Personal epistemology: The psychology of beliefs about knowledge and knowing: Routledge.
- Huppert, F. A., & So, T. T. C. (2013). Flourishing Across Europe: Application of a New Conceptual Framework for Defining Well-Being. *Social Indicators Research*, 110(3), 837-861. doi:10.1007/s11205-011-9966-7
- Hymer, B., Michel, D., & Todd, L. (2002). Dynamic Consultation: Towards process and challenge. *Educational Psychology in Practice*, 18(1), 47-62. doi:10.1080/02667360120122813
- Imray, P., & Colley, A. (2017). Inclusion is Dead: Long Live Inclusion (1 ed.): Routledge.
- Jones, C. (2019). "All the small things": research exploring the positive experiences of teachers working with pupils with profound and multiple learning difficulties. (D.Ed.Psy). Cardiff University, Cardiff. Retrieved from https://ethos.bl.uk/OrderDetails.do?did=1&uin=uk.bl.ethos.794736
- Keyes, C. (2006). Subjective Well-Being in Mental Health and Human Development Research Worldwide: An Introduction. *Social Indicators Research*, 77, 1-10. doi:10.1007/s11205-005-5550-3
- Kossyvaki, L., & Curran, S. (2020). The Role of Technology-Mediated Music-Making in Enhancing Engagement and Social Communication in Children with Autism and Intellectual Disabilities. *Journal of Intellectual Disabilities*, 24(1), 118-138. doi:http://dx.doi.org/10.1177/1744629518772648
- Lacey, P. (2015). Developing the thinking of learners with PMLD. *PMLD Link*, 27(2), 43-47. Laing, K., & Todd, L. (2015). *Theory-based Methodology*. Research Centre for Teaching and Learning: Newcastle University.
- Lambert, M. J. (1992). Psychotherapy outcome research: implications for integrative and eclectic therapists. In J. C. Norcross & M. R. Goldfried (Eds.), *Handbook of Psychotherapy Integration* (1st ed., pp. 94-129). New York: Basic Books.
- Langdridge, D. (2007). *Phenomenological psychology: Theory, research and method*: Pearson education.
- Lefebvre, H. (1991). The production of space. Oxford, UK: Blackwell.
- Lewis, A., & Porter, J. (2004). Interviewing children and young people with learning disabilities*: guidelines for researchers and multi-professional practice. *British Journal of Learning Disabilities*, 32(4), 191-197.
- Malloch, S., & Trevarthen, C. (2009). Communicative musicality. *Exploring the basis of human companionship*, 1752-0118.2009.
- McCormack, N. (2017). Making Memory Sites: Extending opportunities for people with profound and multiple learning disabilities to participate in life story work. (PhD). University of East London,
- McKim, J. (2015). Pause, play, rewind. PMLD Link Journal, 27(3), 23-26.
- McNiff, J. (2016). You and your action research project: Routledge.

- Mencap. (2020). Children, research and statistics. Retrieved from <a href="https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/children-research-and-statistics/children-research-and-statistics#:~:text=There%20are%20approximately%20351%2C000%20children,more%20than%20just%20learning%20disability.
- Mencap. (2021). About profound and multiple learning disabilities. Retrieved from https://www.mencap.org.uk/sites/default/files/2016-11/PMLD%20factsheet%20about%20profound%20and%20multiple%20learning%20disabilities.pdf
- Mental Capacity Act. (2005). Mental Capacity Act 2005. Retrieved from https://www.legislation.gov.uk/ukpga/2005/9/contents
- Mercieca, D. (2013). Living Otherwise, Students with Profound and Multiple Learning Disabilities as Agents in Educational Contexts: Springer.
- Merleau-Ponty, M. (2002). Phenomenology of Perception: Routledge.
- Merrifield, A. (2013). Henri Lefebvre: A critical introduction: Routledge.
- Milner, P., & Frawley, P. (2019). From 'on'to 'with'to 'by:'People with a learning disability creating a space for the third wave of inclusive research. *Qualitative Research*, 19(4), 382-398.
- Moore, C. (2015). Socrates and Self-Knowledge: Cambridge University Press.
- Nakamura, J., & Csikszentmihalyi, M. (2014). The concept of flow. In *Flow and the foundations of positive psychology* (pp. 239-263): Springer.
- Newmann, F. M. (1986). Priorities for the future: Toward a common agenda. *Social Education*, 50(4), 240-250.
- NHS England. (2016). *The Five Year Forward View for Mental Health*. England: NHS England Retrieved from https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf
- Nind, M. (2014). What is inclusive research?: A&C Black.
- Nind, M., & Hewett, D. (2012). Access to communication: developing basic communication with people who have severe learning difficulties. In.
- Nind, M., & Strnadová, I. (2020). Changes in the Lives of People with Profound Intellectual and Multiple Disabilities. In M. Nind & I. Strnadová (Eds.), *Belonging for People with Profound Intellectual and Multiple Disabilities* (pp. 1-22). London: Routledge.
- Nind, M., & Vinha, H. (2014). Doing research inclusively: Bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities*, 42(2), 102-109.
- Nippert-Eng, C. (2015). Watching closely: A guide to ethnographic observation: Oxford University Press.
- Nussbaum, M., & Sen, A. (1993). *The Quality of Life*. Oxford: Oxford: Oxford University Press.
- O'Reilly, K. (2009). Visual ethnography. Key concepts in ethnography, 221-227.
- Olesen, V. (2011). Feminist qualitative research in the millennium's first decade. *The Sage handbook of qualitative research*, 129-146.
- Oliver, C. (2012). Critical realist grounded theory: a new approach for social work research. *The British Journal of Social Work, 42*(2), 371-387. doi:10.1093/bjsw/bcr064
- Orley, J. (1996). World Health Organization: Programme on Mental Health. *Journal of Mental Health*, 5(3), 319-322. doi:10.1080/09638239650036983
- Owen-Hughes, H. (2021). *CASP checklist summary variation*. Education, Communication and Language Sciences. Newcastle University.
- Palmer, C., & Walmsley, J. (2020). Are People with Profound and Multiple Learning Disabilities and Their Families Welcome in the Wider Learning Disability

- Community? In *Belonging for People with Profound Intellectual and Multiple Disabilities* (pp. 129-132): Routledge.
- Palumbo, D., & Galderisi, S. (2020). Controversial issues in current definitions of mental health. *Archives of Psychiatry and Psychotherapy*, 1, 7-11.
- Parker, R. (2013). Educational psychology practice as research: a little regarded aspect of Cyril Burt's legacy. *Educational & Child Psychology*, 30(3), 84-95.
- Pavlicevic, M., O'Neil, N., Powell, H., Jones, O., & Sampathianaki, E. (2014). Making Music, Making Friends: Long-Term Music Therapy with Young Adults with Severe Learning Disabilities. *Journal of Intellectual Disabilities*, 18(1), 5-19. doi:http://dx.doi.org/10.1177/1744629513511354
- Pearlman, S., & Michaels, D. (2019). Hearing the Voice of Children and Young People with a Learning Disability during the Educational Health Care Plan (EHCP). Support for Learning, 34(2), 148-161. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=EJ1219328&site=ehost-live

http://dx.doi.org/10.1111/1467-9604.12245

- Petticrew, M., & Roberts, H. (2006). Systematic reviews in the social sciences: a practical guide. Malden, MA: Blackwell Pub.
- PMLD Network. (2003). *Valuing People with Profound and Multiple Learning Disabilities* (*PMLD*): PMLD Network.
- Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of counseling psychology*, *52*(2), 126.
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., . . . Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme Version, 1*, b92.
- Porter, J., Ouvry, C., Morgan, M., & Downs, C. (2001). Interpreting the communication of people with profound and multiple learning difficulties. *British Journal of Learning Disabilities*, 29(1), 12-16.
- Pote, H., & Goodban, D. (2007). A mental health care pathway for children and young people with learning disabilities: A resource pack for service planners and practitioners: CAMHS Publications.
- Povee, K., Bishop, B. J., & Roberts, L. D. (2014). The use of photovoice with people with intellectual disabilities: Reflections, challenges and opportunities. *Disability & Society*, 29(6), 893-907.
- Preece, D., & Zhao, Y. (2015). Multi-Sensory Storytelling: A Tool for Teaching or an Intervention Technique? *British Journal of Special Education, 42*(4), 429-443. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=EJ1089624&site=ehost-live

http://dx.doi.org/10.1111/1467-8578.12116

origsite=gscholar&cbl=2026366&diss=y

- QCA. (2009). The P Scales. Level descriptors from P1 to P8. Retrieved from https://dera.ioe.ac.uk/2627/7/P_scales_level%20descriptors_2009_Redacted.pdf
- Redmore, N. (2021). Day Service Culture from the Perspective of Autistic Adults with Profound Learning Disabilities: A Methodological Development and Empirical Study in the Space of Autism and Profound Learning Disability. (PhD). Open University, Open University. Retrieved from https://www.proquest.com/openview/371ee83dfeffadf1deb491763af49a01/1?pq-
- Robinson, D., Moore, N., & Harris, C. (2019). The Impact of Books on Social Inclusion and Development and Well-Being among Children and Young People with Severe and

Profound Learning Disabilities: Recognising the Unrecognised Cohort. *British Journal of Learning Disabilities*, 47(2), 91-104. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=EJ1213431&site=ehost-live

http://dx.doi.org/10.1111/bld.12262

- Robson, C. (2011). Real world research: a resource for users of social research methods in applied settings (3rd ed., ed.). Chichester: Chichester: Wiley.
- Rolph, S., & Walmsley, J. (2006). Oral History and New Orthodoxies: Narrative Accounts in the History of Learning Disability. *Oral history (Colchester)*, 34(1), 81-91.
- Rose, R., Howley, M., Fergusson, A., & Jament, J. (2009). Mental health and special educational needs: exploring a complex relationship. *British Journal of Special Education*, 36(1), 3-8. doi:10.1111/j.1467-8578.2008.00409.x
- Rushton, R., & Kossyvaki, L. (2020). Using Musical Play with children with profound and multiple learning disabilities at school. *British Journal of Special Education*. doi:10.1111/1467-8578.12334
- Sanderson, H. (2000). Person-centred planning: key features and approaches. Retrieved from http://www.familiesleadingplanning.co.uk/documents/pcp%20key%20features%20and%20styles.pdf
- Schwartz, P., & Ogilvy, J. A. (1979). The emergent paradigm: Changing patterns of thought and belief: SRI International Menlo Park, CA.
- Scott, D. (2005). Critical realism and empirical research methods in education. *Journal of philosophy of education*, 39(4), 633-646.
- Seligman, M. (2012). Flourish: A visionary new understanding of happiness and well-being: Simon and Schuster.
- Seligman, M. (2018). PERMA and the building blocks of well-being. *The Journal of Positive Psychology*, 13(4), 333-335.
- Sheehy, K., & Nind, M. (2005). Emotional well-being for all: Mental health and people with profound and multiple learning disabilities. *British Journal of Learning Disabilities*, 33. doi:10.1111/j.1468-3156.2004.00290.x
- Sheldon, J. (2017). The pedagogy of the student: Reclaiming agency in receptive subject-positions. *Journal of Curriculum Theorizing*, 32(1).
- Shriberg, D., Nygaard, M. A., Carlock, K., Wood, M., Brahm, A., Flores, H., & Melfi, E. P. (2021). A Qualitative Study of School Psychologists' Perceptions of Social Justice. *School Psychology Review*, 1-14. doi:10.1080/2372966X.2021.1960125
- Simmons, B. (2011). *The PMLD ambiguity: articulating the life-worlds of children with profound and multiple learning difficulties.* Paper presented at the Nordic Network on Disability Research (NNDR) 11th Research Conference.
- Simmons, B. (2021). The production of social spaces for children with profound and multiple learning difficulties: a Lefebvrian analysis. *British Journal of Sociology of Education*, 1-17.
- Simmons, B., & Watson, D. (2014). The PMLD Ambiguity: Articulating the Life-Worlds of Children with Profound and Multiple Learning Disabilities.
- Simmons, B., & Watson, D. (2015). From individualism to co-construction and back again: Rethinking research methodology for children with profound and multiple learning disabilities. *Child Care in Practice*, 21(1), 50-66.
- Simons, H. (2009). Case study research in practice: SAGE publications.
- Skarsaune, S. K. N., Hanisch, H. M., & Gjermestad, A. (2021). Self-Determination: What can we Learn from Persons with Profound Intellectual and Multiple Disabilities?
- Smith, J. A. (2009). *Interpretative phenomenological analysis : theory, method and research*. Los Angeles

- London: Los Angeles London: SAGE.
- Standards & Testing Agency. (2020). The Engagement Model: Guidance for Maintained Schools, Academies (Including Free Schools) and Local Authorities. UK Government Retrieved from
 - https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachme nt data/file/903458/Engagement Model Guidance 2020.pdf
- Steinbrenner, J. R. D., & Watson, L. R. (2015). Student engagement in the classroom: The impact of classroom, teacher, and student factors. *Journal of Autism and Developmental Disorders*, 45(8), 2392-2410.
- Stewart, C., & Walker-Gleaves, C. (2020). A narrative exploration of how curricula for children with profound and multiple learning difficulties shape and are shaped by the practices of their teachers. *British Journal of Special Education*, 47(3), 350-375. doi:10.1111/1467-8578.12313
- Stewart, C., & Walker-Gleaves, C. (2020). A narrative exploration of how curricula for children with profound and multiple learning difficulties shape and are shaped by the practices of their teachers. *British Journal of Special Education*, 47(3), 350-375. doi:10.1111/1467-8578.12313
- Strauss, A., & Corbin, J. (1990). Basics of Qualitative Research: Grounded Theory Procedures and Techniques. . London: Sage.
- Strauss, A., & Corbin, J. M. (1997). Grounded theory in practice: Sage.
- Strnadová, I., & Nind, M. (2020). Belonging and People with Profound Intellectual and Multiple Disabilities: Pushing the boundaries. In *Belonging for People with Profound Intellectual and Multiple Disabilities* (pp. 196-209): Routledge.
- Szulevicz, T. (2018). Psychologists in (Neoliberal) Schools What Kind of Marriage? *Integrative psychological & behavioral science*, *52*(3), 366-376. doi:10.1007/s12124-018-9444-8
- Tilley, L., Ledger, S., & de Haas, C. (2020). Enabling People with Profound and Multiple Learning Disabilities to Belong in Public and Community Archive Collections. In M. Nind & I. Strnadová (Eds.), *Belonging for People with Profound and Multiple Learning Disabilities*. London: Routledge.
- Tolbert, S., Schindel, A., & Rodriguez, A. J. (2018). Relevance and relational responsibility in justice-oriented science education research. *Science education (Salem, Mass.)*, 102(4), 796-819. doi:10.1002/sce.21446
- Trevarthen, C., & Aitken, K. J. (2001). Infant intersubjectivity: Research, theory, and clinical applications. *The Journal of Child Psychology and Psychiatry and Allied Disciplines*, 42(1), 3-48.
- Triandis, H. C. (1979). *Values, attitudes, and interpersonal behavior*. Paper presented at the Nebraska symposium on motivation.
- UN General Assembly. (2007). Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly. Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html
- Unicef. (1989). Summary of the UNCRC. Retrieved from https://www.unicef.org.uk/rights-respecting-schools/wp-content/uploads/sites/4/2017/01/Summary-of-the-UNCRC.pdf
- Vaillant, G. E. (2012). Positive mental health: is there a cross-cultural definition? *World Psychiatry*, 11(2), 93-99. doi: https://doi.org/10.1016/j.wpsyc.2012.05.006
- Veck, W. (2013). Martin Buber's concept of inclusion as a critique of special education. *International Journal of Inclusive Education*, 17(6), 614-628.
- Vorhaus, J. (2016). Giving Voice to Profound Disability. London: Routledge.

- Walmsley, J., Strnadová, I., & Johnson, K. (2018). The added value of inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 751-759. doi:https://doi.org/10.1111/jar.12431
- Ware, J. (2004). Ascertaining the views of people with profound and multiple learning disabilities. *British Journal of Special Education*, *32*, 175-179.
- Watson, D. (2015). 'Go-getters' and'clever little cookies': a multi-method study of playfulness in children with profound and multiple learning disabilities (PMLD). (PhD). University of Bristol, Retrieved from https://ethos.bl.uk/OrderDetails.do?uin=uk.bl.ethos.682682
- Weiss, C. H. (2000). Which links in which theories shall we evaluate? *New directions for evaluation*, 2000(87), 35-45.
- Wenger, E. (2011). Communities of practice: A brief introduction.
- WHO. (2004). Promoting mental health: concepts, emerging evidence, practice: summary report / a report from the World Health Organization, Department of Mental Health and Substance Abuse in collaboration with the Victorian Health Promotion Foundation and the University of Melbourne. In. Geneva: World Health Organization.
- Winter, S., & Bunn, H. (2019). Work to Be Done? A Survey of Educational Psychologists' Contribution to Special Schools for Profound and Multiple Learning Difficulties. British Journal of Special Education, 46(1), 53-75. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=eric&AN=EJ1210025&site=ehost-live
- http://dx.doi.org/10.1111/1467-8578.12252
- Young, A. F., & Chesson, R. A. (2006). Obtaining views on health care from people with learning disabilities and severe mental health problems. *British Journal of Learning Disabilities*, 34(1), 11-19.
- YoungMinds. (2021). Children and Young People with Learning Disabilities: Understanding their Mental Health. Retrieved from https://www.mentalhealth.org.uk/sites/default/files/children-and-young-people.pdf

Appendices

Appendix A: School Practitioner Research Information Sheet

Action Research Project Invitation

My name is Dominic Fitzpatrick, and I am a Trainee Educational Psychologist. I would like to invite you to participate in a project to explore the mental health of children and young people with Profound and Multiple Learning Disabilities (PMLD).

The invitation involves you, a school practitioner working to support and educate children and young people with PMLD, becoming a co-researcher alongside the child you support, their parent/carer, and myself. Together as a research team, we will explore and investigate the kinds of things the child you support does day-to-day in school that supports their mental health. By doing this we will learn more about what is important to their mental health and what can be done to support this moving forward.

The child you support will be involved in this research too. This will involve them being observed by me during their day-to-day school activities. Your involvement will also include discussions as part of a team alongside myself and the child's parent/carer about what we can learn from the observation of the child, how they respond to the activities they are involved in day-to-day, and what is effective in improving their mental health.

I hope that this research will help us to better understand how we can all work together effectively to support the mental health difficulties experienced by children and young people with PMLD. If you are interested in becoming a co-researcher as part of this project, then please read the information on the following pages.

Project Information Sheet

Dear .

My name is Dominic Fitzpatrick, and I am a Trainee Educational Psychologist based in Manchester. I currently work in local schools in the Bolton area and I am in the second year of an Applied Doctorate in Educational Psychology course at Newcastle University.

I am about to begin a research project to explore the mental health of children and young people with Profound and Multiple Learning Disabilities (PMLD). For my research, I would like to explore this alongside the people that know these children best, such as their parents and carers and the adults that support them in school. The research is being supervised by Dr Richard Parker at Newcastle University and the project has been approved by Newcastle University's Research Ethics Committee.

In the United Kingdom, mental health is an important topic in schools at the moment. Schools are understanding more what can be done to support children and young people with their mental health. Despite this, less is understood about how children and young people with PMLD can be supported with their mental health. This is an important area as children and young people with PMLD are often likely to have difficulties with their mental health. I hope that the findings of this research will be used to help Educational Psychologists like me, school staff like you, as well as parents and carers understand what can be done to support the mental health of pupils with PMLD.

Invitation

I would like to invite you to participate in this project. The project will use an approach called 'action research'. This kind of research encourages people to work together to understand an issue and to take action to make positive changes. Those who would like to participate will become a co-researcher as part of a small team. Together, co-researchers in the team will try to understand this issue better and what actions can be taken that are helpful.

What will happen?

As a co-researcher, you will be asked to take part in a series of observations involving you and the child you support in your school. There will also be some sessions where we meet with parents/ carers as co-researchers and will involve some discussion about the child's day-to-day activities, their experiences of school, how these impact on their mental health, and what might be done to support this moving forward. These discussions will involve the following:

Investigation (finding out about the child's experiences of school by observing and interacting with them alongside you during the school day)

Reflection (bringing information from the observation of the child back to coresearchers in the team to begin thinking about what this says about the child's mental health)

Action (trying different things to support the child's mental health based on what we have learnt so far)

and Evaluation (summarising what we now know after investigating, reflecting, and taking action)

To understand this better, you will be asked to contribute your views on what you think the information we gather says about the child you support and what is important to them. Discussion will take place either as part of the team or individually with myself in an interview and will be audio recorded. The utmost sensitivity will be given to ensure you are comfortable whichever way you are invited to participate as a co-researcher. You will be supported to ensure that you are able to actively participate as a valued co-researcher to make a contribution to the project.

How will the child participate?

The child will participate in the project by being observed by me during their normal day-to-day routines and activities in school whilst supported by you. During the observation, I will be gathering information on what activities they are involved in, what they are doing, what other people are doing (e.g. you and other adults/children), what's happening around them, and how they appear to be responding to this. In order to make the observation feel more natural for the child, I might also participate in the activities you facilitate for the child. As we learn more about how the child responds to different activities and what appears to be more supportive of their mental health, we may change or alter some of the activities. By observing the child in their normal school routine and how they respond to different activities, the child can give us a view or indication as a co-researcher as to what is important to them and helpful in supporting their mental health.

Once you have fully understood the project and what it involves, you will be invited to give your consent to participate as a co-researcher. Although the child might not be able to indicate to us whether or not they wish to participate, we will both continually monitor the child to ensure they are happy to be observed during their activities. If at any point during the project we become concerned about the child, we will make the decision to stop the child being a part of the project at any time to protect them. Should this happen, any information relating to you or the child's involvement can be removed from the project.

Data collection

Data will be collected in the following ways during this research project:

Observation notes and checklists

Observation notes will be compiled and checklists will be completed during the observation of the child you support during their day-to-day activities in school. This

data will only be shared with you, the child's parent/ carer, me, and my research supervisor. No one else will see this information. These data will be recorded by hand and scanned electronically so that they can be stored securely on an encrypted computer. The original copies will be destroyed. To provide further security, any identifying information such as names will be replaced by pseudonyms. Scanned electronic observation notes and checklists will be kept for 12 months following the research and then deleted.

Use of video

Observations of the child you support might be video recorded so that there is a record of their activities. The video recordings can be watched by co-researchers (you, me, and the child's parent/carer) to understand how the child you support responds to different activities they are involved in. Looking at these videos together with the people that know the child well (you and their parent/carer) will make it easier to interpret what the child may be communicating as important. Permission for the use of video will be sought from the child's parent/ carer. The video files will be saved with no identifying information and stored safely on an encrypted computer. It will only be viewed by me, my research supervisor, you, and the child's parent/ carer for the purposes of this research. Video recordings will be anonymously transcribed into written notes shortly after the recording and then deleted. Transcripts will be stored for 12 months following the research and then deleted.

Consultation/ interview notes

Consultation notes will be compiled during any discussions that take place between adult co-researchers (me, you, and the child's parent/ carer) either in the research group or in an interview. These data will be recorded by hand and scanned electronically so that they can be stored securely on an encrypted computer. The original copies will be destroyed. To provide further security, any identifying information such as names will be replaced by pseudonyms. These data will be stored for 12 months following the research and then deleted.

Audio recording

Consultations between adult co-researchers in the research group or in an interview will also be recorded using an audio recording device. The audio files will be saved on a separate encrypted computer using a filename that does not include any identifying information so that it cannot be linked with any other saved information. The audio recordings will be anonymously transcribed into written notes shortly after recording and then deleted. Transcriptions will be saved for 12 months following the research and then deleted.

Response to COVID-19 restrictions

Video conferencing software

It may be necessary to adjust the way in which this project is conducted should there continue to be restrictions placed upon daily activities (e.g. physical distancing). This would mean that some of the research activities, such as consultations and

interviews alongside co-researchers, may not be conducted face-to-face, and alternative arrangements to conduct these online using video conferencing software like Microsoft Teams or Zoom may be required. If this is the case, online consultations and interviews may be recorded using the record feature on the software so that discussions can be recorded and analysed more easily as part of the research. There is no obligation to have the video active during these activities and not showing video would not affect the quality of the research. You will be asked to give your consent to have consultations and interviews you are involved in recorded using Microsoft Teams or Zoom. Only my research supervisor and I will see these video recordings as part of the analysis of discussions. Any video files will be transcribed shortly after they are recorded and then deleted. Transcriptions will not include any information that identifies you, the child, or their parent/carer, and will saved on an encrypted computer using a filename that does not include any identifying information for 12 months following the research and then deleted.

Time commitment

It is anticipated that there will be at most four meetings with myself and/or coresearchers which will last no longer than 1 hour 30 minutes each. It is envisaged that your overall time commitment to the project will be at least five hours over a period of three months.

Your rights as a co-researcher/ participant

As a co-researcher/ participant, you can exercise any of the following rights at any point during the project:

You may decide that you wish to stop being a part of this action research project at any time without giving an explanation.

You have the right to ask at any point that any information relating to you be withdrawn from the project and destroyed without giving an explanation.

You have the right to omit or refuse to answer or respond to any question that is asked of you in either discussions with co-researchers in the team or during an interview with me.

You have the right to have any questions you have about this research and any procedures involved fully answered to the point understand and are happy.

Should you have any further questions after reading this information sheet then please feel free to contact my research supervisor or myself to have them answered. Our contact details can be found at the end of this document.

Benefits and risks

I hope that this research will provide information on how Educational Psychologists, schools, children and young people with PMLD as well as their parents and carers can work together effectively in order to understand and support the mental health of children and young people with PMLD. We will not know the benefits of this research

until the end of the project. It is unlikely that this research will pose any great risk to those participating as co-researchers. However, the participation of the child you support in the observation activities may result in them experiencing mild discomfort due to the presence of someone unfamiliar to them. I am confident that, should this be the case, my experience in supporting and educating children and young people with additional needs will enable me to deal with any issues that arise sensitively and supportively alongside you as the child's key worker. It is also possible that you might experience some mild discomfort discussing topics around the support needs or mental health of the child you support. Again, should this occur, I am confident that discussions either in the team or in interviews with myself will be treated sensitively and supportively. If needed, I would be happy to discuss any concerns outside of research activities and may be able to signpost to others that can help. Discussions in the team or in interviews will be recorded using an audio device so it is easier for me to document what we talk about as a team. Experiencing mild discomfort whilst being audio recorded is perfectly normal. Should you experience this it will be accepted and acknowledged as a normal reaction to being audio recorded and you will be reassured of this by me.

Confidentiality and anonymity

Any information gathered as part of your participation in this research will be treated confidentially and only be accessible to other co-researchers (you, the child's parent/ carer, myself, and my research supervisor). The completed consent form/ coresearcher contract will be electronically scanned and saved to an encrypted computer and the original will be destroyed. These will be kept for 12 months following the research and then deleted. Other information gathered in data collection, apart from video and audio recordings, that makes you, the child you support, your school, or the child's parent/ carer identifiable will be anonymised (names will be replaced by pseudonyms). Audio and video recordings will be saved on a separate encrypted computer using a filename that does not include any identifying information. Audio and video recordings will be transcribed using pseudonyms. Should you deem it appropriate, you may be acknowledged by name in any published accounts of this research, as long as this is of benefit to individuals. Newcastle University, and/ or the Local Authority. The data collected from this research may be used for the purposes of presentation at conferences or publication. All data will be anonymous unless you have agreed to be named. Any account excerpts used in presentations will not identify participants or school establishments by name.

Data management

Newcastle University will act as the data controller for this study. You can find out more about how Newcastle University uses your information at http://www.ncl.ac.uk/data.protection and/or by contacting Newcastle University's Data Protection Officer (Maureen Wilkinson, rec-man@ncl.ac.uk). If you wish to raise a complaint on how your personal data has been handled, you can contact our Data Protection Officer rec-man@ncl.ac.uk who will investigate the matter. If you are not satisfied with the response or believe personal data has been processed in a way that is not lawful, you can complain to the Information Commissioner's Office (ICO) https://ico.org.uk/make-a-complaint/

Safeguarding

It is important that any research involving children balances the aims of the research with the safety and wellbeing of the children (NSPCC, 2020). All adults involved in this research have a shared responsibility to ensure that the children are respected and able to participate in a safe way. The welfare of the children should take priority over the research. If any adult involved in the research becomes concerned that a child might have experienced or be at risk of abuse, then this should be shared as a matter of urgency with the Designated Safeguard Lead within the child's school.

Co-researcher contract

The co-researcher contract (see separate form) is a written agreement that details the ways in which co-researchers (the adults involved) are expected to conduct themselves throughout the project. By agreeing and abiding by the co-researcher contract we can be sure that all co-researchers are able to participate in a respectful and collaborative manner.

Contact information

If you have any questions about this research project at any time, then please contact me:

by telephone or by email

Alternatively, if you have any questions, concerns, or complaints that you would prefer to direct to my research supervisor at Newcastle University please contact Dr Richard Parker on

Thank you very much for taking the time to read this information. Yours faithfully,

Dominic Fitzpatrick

Appendix B: Parent/ Carer Research Information Sheet

Action Research Project Invitation

My name is Dominic Fitzpatrick, and I am a Trainee Educational Psychologist. I would like to invite you to participate in a project to explore the mental health of children and young people with Profound and Multiple Learning Disabilities (PMLD).

The invitation involves you and your child becoming co-researchers alongside your child's school key worker and myself. Together as a research team, we will explore and investigate the kinds of things your child does day-to-day in school that supports their mental health. By doing this we will learn more about what is important to their mental health and what can be done to support this moving forward.

Your child's involvement in this research will include being observed by me during their day-to-day school activities. Your involvement will include discussions as a team alongside myself and your child's key worker about what we can learn from your child, how they respond to the activities they are involved in day-to-day, and what is effective in improving their mental health.

I hope that this research will help us to better understand how we can all work together effectively to support the mental health difficulties experienced by children and young people with PMLD. If you are interested in becoming a co-researcher as part of this project, then please read the information on the following pages.

Project Information Sheet

Dear Parent/ Carer,

My name is Dominic Fitzpatrick, and I am a Trainee Educational Psychologist based in Manchester. I currently work in local schools in the Bolton area and I am in the second year of an Applied Doctorate in Educational Psychology course at Newcastle University.

I am about to begin a research project to explore the mental health of children and young people with Profound and Multiple Learning Disabilities (PMLD). For my research, I would like to explore this alongside the people that know these children best, such as their parents and carers and the adults that support them in school. The research is being supervised by Dr Richard Parker at Newcastle University and the project has been approved by Newcastle University's Research Ethics Committee.

In the United Kingdom, mental health is an important topic in schools at the moment. Schools are understanding more what can be done to support children and young people with their mental health. Despite this, less is understood about how children and young people with PMLD can be supported with their mental health. This is an important area as children and young people with PMLD are often likely to have difficulties with their mental health. I hope that the findings of this research will be used to help Educational Psychologists like me, school staff, as well as parents and carers understand what can be done to support the mental health of pupils with PMLD.

Invitation

I would like to invite you to participate in this project. The project will use an approach called 'action research'. This kind of research encourages people to work together to understand an issue and to take action to make positive changes. Those who would like to participate will become a co-researcher as part of a small team. Together, co-researchers in the team will try to understand this issue better and what actions can be taken that are helpful.

What will happen?

As a co-researcher, you will be asked to take part in a series of sessions in your child's school. These sessions will involve some discussion with your child's key worker and myself about your child's experiences of school, how these impact on their mental health, and what might be done to support this moving forward. These discussions will involve the following:

Investigation (finding out about your child's experiences of school by observing and interacting with them during their school day)

Reflection (bringing information from the observation of your child back to coresearchers in the team to begin thinking about what this says about their mental health)

Action (trying different things to support their mental health based on what we have learnt so far)

and Evaluation (summarising what we now know after investigating, reflecting, and taking action)

To understand this better, you will be asked to contribute your views on what you think the information we gather says about your child and what is important to them. Discussion will take place either as part of the team or individually with myself in an interview.

The utmost sensitivity will be given to ensure you are comfortable whichever way you are invited to participate as a co-researcher. You will be supported to ensure that you are able to actively participate as a valued co-researcher to make a contribution to the project.

How will my child participate?

Your child will participate in the project by being observed by me during their normal day-to-day routines and activities in school. During the observation, I will be gathering information on what activities they are involved in, what they are doing, what other people are doing, what's happening around them, and how they appear to be responding to this. In order to make the observation feel more natural for your child, I might also participate in your child's activities alongside them and their key worker. As we learn more about how your child responds to different activities and what appears to be more supportive of their mental health, the activities they are involved in during observation may change to try and promote this further. By observing your child in their normal school routine and how they respond to different activities, your child is giving us a view as a co-researcher as to what is helpful in supporting their mental health.

Once you have fully understood the project and what it involves, you will be invited to give your permission for your child to participate. Although your child might not be able to indicate to us whether or not they wish to participate, as a team we will continually monitor your child to ensure they are happy to participate and be observed. If at any point during the project we become concerned about your child, we will make the decision to stop your child being a part of the project at any time to protect them. Should this happen, any information relating to you or child's involvement can be removed from the project.

Data collection

Data will be collected in the following ways during this research project:

Observation notes and checklists

Observation notes will be compiled and checklists will be completed during the observation of your child during their day-to-day activities in school. This data will only be shared with you, your child's key worker, me, and my research supervisor. No one else will see this information. These data will be recorded by hand and scanned electronically so that they can be stored securely on an encrypted computer. The original copies will be destroyed. To provide further security, any identifying information such as names will be replaced by pseudonyms. Scanned electronic observation notes and checklists will be kept for 12 months following the research and then deleted.

Use of video

Observations of your child might be video recorded so that there is a record of their activities. The video recordings can be watched by co-researchers (you, me, and the child's key worker) to understand how your child responds to different activities they are involved in. Looking at these videos together with the people that know the child well (you and their key worker) will make it easier to interpret what the child may be communicating as important. The video recordings can be watched by co-researchers to understand how your child responds to different activities they are involved in. You will be asked to give your permission for your child to be recorded in their daily activities with their key worker. The video files will be saved with no identifying information and stored safely on an encrypted computer. It will only be viewed by me, my research supervisor, you, and your child's key worker for the purposes of this research. Video recordings will be anonymously transcribed into written notes shortly after they are recorded and then made available to you before they are deleted. Transcripts will be stored for 12 months following the research and then deleted.

Consultation/ interview notes

Consultation notes will be compiled during any discussions that take place between adult co-researchers (me, you, and your child's key worker) either in the research group or in an interview. These data will be recorded by hand and scanned electronically so that they can be stored securely on an encrypted computer. The original copies will be destroyed. To provide further security, any identifying information such as names will be replaced by pseudonyms. These data will be stored for 12 months following the research and then deleted.

Audio recording

Consultations between adult co-researchers in the research group or in an interview will also be recorded using an audio recording device. The audio files will be saved on a separate encrypted computer using a filename that does not include any identifying information so that it cannot be linked with any other saved information. The audio recordings will be anonymously transcribed into written notes shortly after recording and will then be deleted. Transcripts will be stored for 12 months following the research and then deleted.

Response to COVID-19 restrictions

Video conferencing software

It may be necessary to adjust the way in which this project is conducted should there continue to be restrictions placed upon daily activities (e.g. physical distancing). This would mean that some of the research activities, such as consultations and interviews alongside co-researchers, may not be conducted face-to-face, and alternative arrangements to conduct these online using video conferencing software like Microsoft Teams or Zoom may be required. If this is the case, online consultations and interviews may be recorded using the record feature on the software so that discussions can be analysed more easily as part of the research. There is no obligation to have the video active during these activities and not showing video would not affect the quality of the research. You will be asked to give your consent to have consultations and interviews you are involved in recorded using Microsoft Teams or Zoom. Only my research supervisor and I will see these video recordings as part of the analysis of discussions. Any video files will be transcribed shortly after they are recorded and then deleted. Transcriptions will not include any information that identifies you, your child, or their key worker, and will saved on an encrypted computer using a filename that does not include any identifying information for 12 months following the research and then deleted.

Time commitment

It is anticipated that there will be at most four meetings with myself and/or coresearchers which will last no longer than 1 hour 30 minutes each. It is envisaged that your overall time commitment to the project will be at least five hours over a period of three months.

Your rights as a co-researcher/ participant

As a co-researcher/ participant, you can exercise any of the following rights for yourself or your child at any point during the project:

You may decide that you and your child wish to stop being a part of this action research project at any time without giving an explanation.

You have the right to ask that any information relating to you or your child that has been gathered and used to that point be withdraw from the project and destroyed.

You have the right to omit or refuse to answer or respond to any question that is asked of you in either discussions with co-researchers in the team or during an interview with me.

You have the right to have any questions you have about this research and any procedures involved fully answered to the point understand and are happy.

Should you have any further questions after reading this information sheet then please feel free to contact my research supervisor or myself to have them answered. Our contact details can be found at the end of this document.

Benefits and risks

I hope that this research will provide information on how Educational Psychologists, schools, children and young people with PMLD as well as their parents and carers can work together effectively in order to understand and support the mental health of children and young people with PMLD. We will not know the benefits of this research until the end of the project.

It is unlikely that this research will pose any great risk to those participating as coresearchers. However, the participation of your child in the observation activities may result in them experiencing mild discomfort due to the presence of someone unfamiliar to them. I am confident that, should this be the case, my experience in supporting and educating children and young people with additional needs will enable me to deal with any issues that arise sensitively and supportively alongside your child's key worker.

It is also possible that you might experience some mild discomfort discussing topics around your child's needs or mental health. Again, should this occur, I am confident that discussions either in the team or in interviews with myself will be treated sensitively and supportively. If needed, I would be happy to discuss any concerns outside of research activities and may be able to signpost to others that can help. Experiencing mild discomfort whilst being video or audio recorded is perfectly normal. Should you experience this it will be accepted and acknowledged as a normal reaction to being video or audio recorded and you will be reassured of this by me.

Confidentiality and anonymity

Any information gathered as part of yours and your child's participation in this research will be treated confidentially and only be accessible to other co-researchers around your child (you, your child's key worker, myself, and my research supervisor). The completed consent forms/ co-researcher contracts will be electronically scanned and saved to an encrypted computer and the original will be destroyed. These will be kept for 12 months following the research and then deleted.

Other information gathered in data collection, apart from video and audio recordings, that makes you, your child, your child's school, or your child's key worker identifiable will be anonymised (names will be replaced by pseudonyms). Audio and video recordings will be saved on a separate encrypted computer using a filename that does not include any identifying information. Audio and video recordings will be transcribed using pseudonyms. Should you deem it appropriate, you may be acknowledged by name in any published accounts of this research, as long as this is of benefit to individuals, Newcastle University, and/ or the Local Authority. The data collected from this research may be used for the purposes of presentation at conferences or publication. All data will be anonymous unless you have agreed to be named. Any account excerpts used in presentations will not identify participants or school establishments by name.

Data management

Newcastle University will act as the data controller for this study. You can find out more about how Newcastle University uses your information at http://www.ncl.ac.uk/data.protection and/or by contacting Newcastle University's Data Protection Officer (Maureen Wilkinson, rec-man@ncl.ac.uk). If you wish to raise a complaint on how your personal data has been handled, you can contact our Data Protection Officer rec-man@ncl.ac.uk who will investigate the matter. If you are not satisfied with the response or believe personal data has been processed in a way that is not lawful, you can complain to the Information Commissioner's Office (ICO) https://ico.org.uk/make-a-complaint/

Safeguarding

It is important that any research involving children balances the aims of the research with the safety and wellbeing of the children (NSPCC, 2020). All adults involved in this research have a shared responsibility to ensure that the children are respected and able to participate in a safe way. The welfare of the children should take priority over the research. If any adult involved in the research becomes concerned that a child might have experienced or be at risk of abuse, then this should be shared as a matter of urgency with the Designated Safeguard Lead within the child's school.

Co-researcher contract

The co-researcher contract (see separate form) is a written agreement that details the ways in which co-researchers (the adults involved) are expected to conduct themselves throughout the project. By agreeing and abiding by the co-researcher contract we can be sure that all co-researchers are able to participate in a respectful and collaborative manner.

Contact information

If you have any questions about this research project at any time, then please contact me:

by telephone or by email

Alternatively, if you have any questions, concerns, or complaints that you would prefer to direct to my research supervisor at Newcastle University please contact Dr Richard Parker

Thank you very much for taking the time to read this information.

Yours faithfully,

Dominic Fitzpatrick

Appendix C: Consent form/co-researcher contract

Participant consent form and co-researcher contract

 I fully understand what this action research project involves [] 	
 Any questions that I have had that relate to the project have been answered 	ł
fully []	
 I understand what my participation and the participation of my child involves 	;
I understand the risks and benefits to both my mine and my child's	
participation in this action research project and what will be done to make everyone safe []	
 I understand how data gathered as part of mine and my child's participation 	in
this action research project will be stored and used and that this may include the use of both audio and video recording of discussions I participate in and my child's activities during the school day []	
 I give my informed consent to participate as a co-researcher as part of this action research project [] 	
 I give consent for my child as their parent/carer to participate in this action research project, understand what their participation involves, and understand that their ongoing 'assent' or willingness to participate will be continually monitored throughout the research [] 	nd
1st parent/ carer co-researcher name	
2nd child/ young person co-researcher name	
	
Date	
Co researcher contract	
Co-researcher contract As a co-researcher in this action research project, it is important to acknowledge the	ne

able to participate and make a valued contribution to the project:

Respect and Open Communication

1. Group members agree to communicate respectfully and openly with one another throughout the project. In particular, this means that they agree, individually and collectively, and sincerely to seek (a) agreement about the ideas and language used, (b) mutual understanding of one another's points of view, and (c) unforced

following protocols which have been put in place to ensure all co-researchers are

consensus about what to do under the circumstances that exist when a decision about what to do is needed.

- 2. Each group member agrees to respect the rights of others to withdraw from the project at any time, or to decline participation in particular aspects of the study, or to have information they have provided removed from any reports emanating from the study. Group members agree to respect the right of any group member to withdraw from the group, the study, or part of the study.
- 3. Group members agree to be open with other group members if they think the research is having a negative impact on the group, on them personally, or on the children involved as co-researchers.

Access to Empirical Material

- All group members around participating children (that is, their parent/ carer, teacher, the main researcher only) will have access to empirical material/transcripts that are generated or collected within the context of the group meetings (that is, as 'common empirical material').
- Access to material that is collected outside of group meetings, but that directly involves group members (for instance in observations of children or face to face interviews with parents/ carers) will be restricted to those collecting the information and those about whom it is collected, unless the group members concerned negotiate for such material to be released to the group for the purposes of analysis or discussion (for example, at a group meeting). Group members agree that where others are involved (such as participating parents/ carers who may appear in audio-recorded interviews), such release of empirical material to the group will occur only with the consent of those involved.
- Group members agree that if they wish (for their own publications and/or research purposes) to use common empirical material generated within this project, they need to negotiate that with members of the group.

Reflecting on the Research Process

- In order to ensure that the research process does not compromise the integrity of the group, or impact negatively on those involved, group members agree to periodically review (as a group) how the research is unfolding and impacting on the group and the individual group members.

 Changes to Group Membership
- Group members agree that, if new members join the group during the project, the new members will be invited to take part in the research and written informed consent will be obtained before they become involved. Group members agree that the new group members will be required to agree to these group protocols.
- Group members agree that if one or more of the group members no longer wish to be involved in the study, then other group members respect that group member's right to determine what of his or her previous statements can be used in the research.

Representation

- If not directly involved in the writing of reports about the initiative, group members will be given an opportunity to check that the work and comments of the group are fairly, relevantly and accurately represented in any reports of the research.
- Group members agree that, if they feel that representations relating to them are not fair, relevant or accurate, they will negotiate with the authors of the report, and with other members of the group, to resolve the issue, keeping in mind the principle of respect and open communication.

• The authors of any reports about the work of the group will notify the group about the writing and the existence of the reports and will give group members access to the report and, so far as is practicable, will make copies available to group members on request.

Mediation

• In the very unlikely event that there is conflict/relationship breakdown (between group members) that cannot be resolved and that is detrimental to the project and/or wellbeing of group members, group members agree that a credible and neutral person, such as the school's appointed Educational Psychologist, will be asked to act as mediator to help those concerned work through the issues.

Certification of agreement

I voluntarily give consent to my participation in this action research project. In

providing consent, I agree that my participation in the project will be in accordance
with group protocols highlighted above.
Co-Researcher:
Name:
Position:
Contact information (telephone number/ email address)
,

Appendix D: Photographic examples of the analytical process using Realist Grounded Theory

