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Chapter 11

Enacting the International Vision of Inclusive Education: A UK-PMLD case study

Ben Simmons

Introduction

This chapter explores the inclusive education debate as it relates to children with profound and multiple learning difficulties (PMLD). It illuminates a fundamental tension between international policy which promotes inclusive education as a human right (UN, 2006), and the challenge of including learners with profound intellectual impairments in the current neoliberal education system (Tomlinson, 2017). This tension is examined through two interpretations of disability found in the field of Disability Studies: the medical model and the social model (Goodley 2011). A medical model interpretation holds that children with PMLD are excluded from the mainstream because they lack the intellectual ability to learn at the same pace as other children. A social model interpretation holds that children with PMLD are excluded because mainstream education has not been designed with the needs of children with PMLD in mind, resulting in a range of barriers that prevent children with PMLD from meaningful participation. Proponents of the social model of disability call for a radical reform of the education system to reflect the diverse needs of all learners, including children with PMLD (Baglieri and Shapiro, 2017; Greenstein 2016).

According to international policy, one of the key outcomes of inclusive education is social cohesion (UNESCO, 2002) defined in this chapter in terms of a sense of belonging, shared identity, and social cooperation (Fonseca *et al.*, 2019; Simmons 2020). If inclusive education is to be realised for children with PMLD, then any radical reform of the education system must begin with an understanding of how schools can foster social cohesion amongst pupils. This chapter presents research evidence that illuminates the possible conditions of social cohesion, which include specialist staff who perform a dual role of supporting the emerging communication skills of children with PMLD, whilst also providing mainstream school peers with expert knowledge about how each child with PMLD uniquely communicates. The findings also suggest that children benefit from protected time and space to experiment with communication strategies, play together, develop friendships, and share roles and responsibilities. The chapter concludes by suggesting that if inclusion is to be actualised for children with PMLD, then we need to move beyond narrow concepts of inclusion as assimilation into a neoliberal education system, and begin to reimagine inclusive education as a process of enacting the conditions that can lead to social belonging.

Inclusive education

The meaning of ‘inclusive education’ is highly contested and there are (many) competing interpretations, definitions and models (Armstrong *et al.,* Spandagou 2010). Inclusive education is often associated with diverse groups of students learning together in a mainstream school. This ‘simple’ understanding of inclusion focuses on good classroom practice whereby teachers make adaptations and adjustments so that all learners experience educational success (Hodkinson, 2016). Simple models of inclusion describe technical solutions that allow children to be assimilated into an unchanged education system (e.g. through the provision of additional resources and differentiated pedagogy). By contrast, a more radical interpretation of inclusion takes aim at the education system itself, and calls into question the meaning and purpose of education. Radical interpretations of inclusion have their roots in emancipatory movements of the 1980s and 1990s whereby parents, teachers and children expressed dissatisfaction about the two-tier education system (i.e. segregated special schools or integrative mainstream schools not designed for children with complex disabilities). A radical interpretation of inclusion is a reform programme that ultimately aims to restructure the education system (Armstrong *et al.,* 2010).

Inclusive education has received international support, particularly from intergovernmental organisations such as the United Nations and its agencies who have produced numerous documents enshrining the right of all children to a mainstream education. For example, the *Salamanca Statement* (UNESCO 1994), adopted by 92 governments and 25 international organisations set the policy agenda for inclusion on an international scale (Goodley, 2011) and declared that inclusion was ‘essential to human dignity and to the exercise and enjoyment of human rights’ (11). The *Salamanca Statement* also linked inclusion to economic benefits, claiming that inclusive education ‘improve[s] the efficiency and ultimately the cost effectiveness of the entire education system’ (ix). The *Convention of the Rights of Person with Disabilities* claimed that inclusion can ‘maximize academic and social development’ (UN, 2006: 17) whilst the *Declaration on Cultural Diversity* claimed that ‘policies for the inclusion and participation of all citizens [act] as guarantees of social cohesion, the vitality of civil society and peace (UNESCO 2002: 13). More recently, the *Incheon Declaration and Framework for Action* declared that inclusive education was ‘essential for peace, tolerance, [and] human fulfilment’ (UNESCO 2015: 7).

Despite international support for inclusive education, there is ongoing resistance to the view that mainstream education is appropriate for *all* children. For example, Mary Warnock – a champion of ‘integration’ in the 1970s (DES, 1978) –suggested that some children find it ‘impossible’ (2010: 33) to participate in mainstream schools, and that inclusion is better understood in terms of children ‘being involved in a common enterprise of learning, rather than being necessarily under the same roof’ (ibid: 32). This view has been extended to children with PMLD who are the focus of this chapter (Imray and Colley, 2017).

Profound and multiple learning difficulties (PMLD)

‘PMLD’ is a label used in the UK to refer to children who are said to experience the severest of impairments to cognition resulting in significant developmental delay. A review of the literature in this field has demonstrated that the cognitive abilities of children with PMLD are often compared to those of the neonate or infant insofar as children with PMLD are described as operating at the preverbal stages of development (Simmons and Watson, 2014). For example, children with PMLD are understood as being pre-volitional (they lack free will or agency and cannot move with intent) (Farrell, 2004); pre-contingency aware (they do not show awareness of cause-effect relationships) (Ware, 2003); pre-intersubjective (they do not represent other people as subjects ‘like me’, and cannot differentiate between subject and object); pre-symbolic or pre-intentional (they do not intentionally communicate meaning to others) (Coupe *et al.,* 1998); and stereotypic in behaviour (they display reflexive, non-volitional behaviour) (Tang *et al.,* 2003). In addition to profoundly delayed cognitive development, children with PMLD are also said to experience a range of additional impairments, including physical impairments (Neilson *et al.,* 2000) and sensory impairments (Vlaskamp and Cuppen-Fonteine, 2007), mental health and complex medical conditions (Pawlyn and Carnaby, 2009). Hence, children with PMLD are described as being dependent on others for the most rudimentary care needs and deemed to require a lifetime of support (Tadema and Vlaskamp, 2010). With optimal intervention, it is hoped that children with PMLD will make some progress through the pre-verbal stages of development.

Relatively few children with PMLD attend mainstream schools, and it appears that the older children with PMLD get, the less likely they are to access a mainstream education. In

England it is estimated that out of approximately 9,000 children with PMLD, 82 per cent attend special school, five per cent attend mainstream primary school and three per cent attend mainstream secondary school (Salt, 2010). Lyons and Arthur-Kelly (2014: 446) suggest that segregated provision for children with PMLD is an international trend and that 'if they [children with PMLD] have access to any school education, are educated in 'special' schools or classes by 'special' educators'. Advocates of special school provision argue that children with PMLD are too cognitively impaired to engage with the mainstream and require developmentally-appropriate curricula, pedagogy, and resources found in special schools (Imray and Colley, 2017).

Conceptualising (profound) disability: the medical model and the social model

Definitions of PMLD are typically rooted in developmental psychology which present a medicalised and deficit-based account of children with the PMLD label. However, by drawing conceptual resources from Disability Studies we can redefine the meaning and location of disability, and in doing so shed new light on why children with PMLD are excluded from the mainstream. Disability Studies is a broad field of theory, research and practice that challenges the common view of disability as personal tragedy (Goodley, 2011). Its roots can be found in the disability rights movements which emerged during the 1960s when disabled people, 'like feminists, African Americans, and gay and lesbian activists … insisted that their bodies did not render them defective, [and] could even be sources of political, sexual, and artistic strength' (Neilsen, 2012:160, in Baglieri and Shapiro 2017:5). UK activists in the 1970s have been particularly influential in the development of Disability Studies, with groups such as the *Union of the Physically Impaired Against Segregation and the Disability Alliance* making key distinctions between medical and sociological accounts of disability.

The medical model of disability is the dominant perspective about disability in our society and equates disability with an 'abnormal' or 'disordered' body or mind (Baglieri and Shapiro, 2017). A disability is a professionally diagnosed condition which is characterised in terms of functional limitations, meaning that the disabled person is unable to independently perform basic tasks required to fulfil daily routines that may be taken for granted by non-disabled people (Barnes and Mercer, 2010). Societies predisposed to understanding disability through the prism of the medical model view disability as a personal tragedy which requires medical intervention (treatment, rehabilitation and/or cure) to make the body function as 'normal' as possible (Baglieri and Shapiro, 2017; Goodley, 2011). From a medical model perspective, a person's disability is the main reason for their social exclusion.

The social model of disability presents a counter-perspective to the medical model by redefining the meaning of disability and the problem to be addressed. The social model rests heavily on a distinction between impairment and disability. Impairment is described as a form of bodily, sensory or mental difference that is often defined within a medical context (Goodley, 2011). By contrast, the social model defined disability as:

> The disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (UPIAS, 1975, in Shakespeare, 2017:197).

The social model defines disability not in terms of bodily difference, but in terms of how society responds to those differences. Disability is a culturally, socially and politically produced form of social exclusion which stems from the way in which society creates barriers that prevent disabled people from social participation. From a social model perspective, it is society that disables people with impairments (Shakespeare, 2017). Hence, whereas the medical model locates the problem in the individual and the solution in the treatment of the individual, the social model aims to remove society's disabling barriers (Swain *et al.*, 1993).

Medical model and social model concepts of disability have been applied to the context of special and inclusive education. Special schools are conceptualised as embodying the medical model of disability insofar as children are excluded or extracted from the mainstream and treated through educational interventions until they are capable of independently participating with their non-disabled counterparts:

> Students perceived as having problems, like something broken, are sent to resource rooms, special classes, even special schools or institutions, to be repaired and later returned. Unlike a repair shop, however, many students in special education – indeed the preponderance of them never escape the special label and placement […] They stay in the repair shop (Biklen *et al.,* 1989: 8, in Baglieri and Shapiro, 2017: 6).

By contrast, the social model of disability has been aligned with inclusive education which shifts the focus away from how best to remediate disabled children to an examination of how the school environment can support or disable young people. The social model of inclusive education prioritises the removal of obstacles that prevent access to mainstream education: ‘it is about removing all forms of barriers to access and learning for all children who are experiencing disadvantage’ (Barton and Armstrong, 2001: 708). Of particular importance for those who embrace the social model is the development of diverse communities. By focusing primarily on the diagnosis and remediation of impairments the medical model limits the experiences and social opportunities of children. However, by ‘framing disability in its social dimensions, attention is instead focused on how schools and curriculum may be constructed and reformed to enable students with disabilities to gain access to learning and participation with their peers’ (Baglieri and Shapiro, 2017: 7).

From a social model perspective, children with PMLD experience social exclusion, not because of their learning impairments but because of discriminatory practices which prevent children with PMLD accessing a common curriculum. Segregated education (special schools) contribute to the oppression of disabled people by removing them from wider society. Instead of trying to change children with PMLD (curing them of their profound developmental delay), advocates of the social model of disability argue that there should be a focus on removing the barriers which prevent disabled people from participating in mainstream social life. These barriers include physical barriers to social spaces, discriminatory practices and, and private prejudice. However, a more radical reading of the social model of disability holds that inclusive education should not be understood as a simple technical solution to managing or assimilating children who struggle to ‘fit’ into an existing school system, but as an ongoing education reform programme that challenges the meaning of education (Armstrong *et al.,*2011). From this perspective, inclusive education is a doomed project unless we call into question the neoliberal ideology that shapes our current school system.

Inclusion into what? A social model critique of neoliberal education

Neoliberalism is a free market ideology that is heavily implicated in the educational policy and practice of late-capitalist, industrialised society. In such a society the production of profit is the basic organising principle of economic life, and this requires the disciplining of labour power to increase capital accumulation (Armstrong *et al.,* 2011). Businesses and employers are freed from state intervention in order to allow increased productivity and economic growth. The state is ‘rolled back’, welfare spending is reduced, and public services are deregulated, privatised, contracted out or shaped by business principles (Goodley, 2011). From a neoliberal perspective, the function of the education system is to provide a steady supply of young people who have developed work-related competencies, knowledge and dispositions that allow individuals to compete in the labour market (Tomlinson, 2017).

Central to the development of education policy is the concept of a ‘knowledge economy’ which treats knowledge as a high-value commodity (Ball, 2008). In our current economic context, knowledge is overtaking capital and energy as the primary wealth-creating asset (Greenstein, 2016). The National Curriculum (for England) (DfE, 2014) plays a central role in the knowledge economy insofar as it prescribes the body of knowledge deemed necessary for economic competitiveness. Drawing on Freire (1972), Greenstein (2016) argues that the National Curriculum presents as an objective body of facts that lends itself to the banking model of education, whereby teachers posit facts in the minds of learners who are required to patiently receive, memorise and repeat what is prescribed. Literacy and numeracy are privileged and rewarded whilst other subject such as art and dance are minimised, and the ‘vital human capacities’ (Greenstein, 2016: 50) such as love, care, and solidarity fail to be recognised or appreciated. The increasingly narrow curriculum is linked to the standards agenda, defined in terms of a continual driving up of attainment standards, workforce skills and ultimately the nation’s competitiveness in a globalised economy (Ainscow *et al.*, 2006; Hodkinson, 2016). Schools are assessed according to the collective attainment of students (the results of which are published as league tables) and schools that fail to achieve government standards are penalised through funding retention and closure (Greenstein, 2016). What emerges in this context is a fundamental contradiction for children with PMLD. On the one hand education policy advocates an inclusive education whereby diverse students are educated in the same room, with adaptation or differentiation of pedagogy, curriculum and assessment in order to make the learning objectives accessible to all. On the other hand, educational policy promotes the rapid learning of facts and the development of business entrepreneurship deemed necessary to support the economy. This leads to a narrow curriculum and a fast-paced, information processing or banking model of education which is inappropriate for children with PMLD (Greenstein, 2016; Imray and Colley, 2017). Hence, there is a mismatch between the neoliberal ideologies of schooling that aim to produce obedient citizens for the global market economy (Greenstein, 2016) and the needs of children with PMLD who are defined as not being able to cognitively engage in the National

Curriculum. What emerges from this tension is a view that inclusion for children with PMLD is impossible because of the pathology of ‘PMLD’.

From a social model perspective, the failure to include children with PMLD stems not simply from a lack of appropriate ‘environmental’ adaptations, but from an education system that prioritises the acquisition of subject knowledge, competition between individuals, schools and nations, and the segregation of children who cannot keep up with similarly aged peers. Such a system works against the goal of creating social cohesion through inclusive education (UNESCO, 2002) by creating the conditions of exclusion for certain groups of children (such as children with PMLD).

If a key goal of inclusion is to maximise social development and tolerance (UN, 2006; UNESCO, 2015) then an examination of how the education system can support the social inclusion of children with PMLD is needed. The following section describes a research project that examined the social opportunities that children with PMLD can experience across both mainstream schools and special schools, which in turn sheds light on the complexity of social inclusion.

Refocusing the inclusion debate: researching the social

The research presented in this chapter comes from a three-year research project funded through a British Academy Postdoctoral Fellowship (2014-17) which investigated the social inclusion of children with PMLD who experienced both special and mainstream educational opportunities. The research aimed to (i) investigate how different educational settings (mainstream and special) afforded different opportunities for social interaction, (ii) examine how children with PMLD respond to different opportunities, and (iii) explore how different opportunities impact on the growth of social awareness and communication skills of children with PMLD. The data presented is based on an analysis of three children with the pseudonyms of Emma, Harry, and Charlie. Emma was five years old; Harry was eight years old, and Charlie was ten years old during data collection. Emma and Harry attended the same special school in England and were educated in the school’s PMLD class. The PMLD class doubled up as a reception class for younger children with special educational needs. For the purposes of this project, Emma and Harry attended an age-equivalent class in a local mainstream school for one day a week (these placements were set up for the project, but continued after the project had ended which indicates their successful nature). Each child was observed once a week in the mainstream school and once a week in a special school for ten weeks (20 observations per child). Emma and Harry participated in the project at different times (Emma in the autumn term, and Harry in the winter). A special school teaching assistant (SSTA) accompanied Emma and Harry on each visit. Charlie's entire class attended mainstream school one afternoon a week. All the staff from Charlie's class supported the mainstream placement. Charlie's school had been running mainstream placements for all children for many years.

The methodology resembled a participatory or ethnographic approach which has been described extensively elsewhere (e.g. Simmons and Watson, 2014, 2017; Simmons, 2018). Prior to undertaking fieldwork, the researcher engaged in pre-observation focus groups with school staff and semi-structured interviews with the children's parents. The aim was to explore the children's interests, abilities and methods of communication by consulting those who knew the children intimately. This led to the development of an initial lens through which to interpret and understand the children's action. Participatory observation was undertaken to develop understandings of the children's behaviours by working with them in context. Participatory observation helped the researcher to develop trust and rapport with members of staff and provided the researcher with opportunities for informal discussion with staff in real time. These informal conversations allowed the researcher to share and discuss his interpretations of Charlie, Harry and Emma's actions, ask questions and seek out staff members' expertise and wisdom (e.g. to resolve the researcher's confusion about the meaning of newly-observed or unexpected behaviours).

Research data primarily consisted of written fieldnotes or 'vignettes' composed during periods of non-participatory observation. Vignettes are rich and prosaic renderings of fieldnotes about social interactions. They have a story-like structure and adhere to chronological flow. Vignettes are restricted to a particular place, time, and actor (or group of actors), and can vary from a few lines of descriptions to several paragraphs. When opportunities for social interaction were observed, the researcher would write detailed, descriptive accounts as the interaction unfolded, paying attention to who initiated the interaction and how, the actions of the interactive participants over time and contextual variables such as location, context of the interaction and the objects involved. The data was thematically analysed, the findings of which are presented below.

Findings

Special school interactions: teaching to communicate and care-based routines

Each child participating in the research was described by teaching staff as functioning at the pre-verbal stages of communication. Given this, teachers and teaching assistants regularly focused on developing children's emerging social cognition and communication skills. Daily routines involved staff working one-to-one 'dyadically' with children and encouraging them to express a preference for an object or event (e.g. Emma was asked to smile at food to express 'want', or to turn away from food to express 'not want'). Children were sometimes asked to make a choice between two objects (e.g. Charlie was encouraged to choose between a flashing ball or a tambourine by prolonged looking at an object). Some children were encouraged to request prolonged access to an object or event by vocalising (or rather, shouting) upon request. (e.g. staff would lay Harry down on a trampoline and bounce him up and down until he laughed. They would then stop bouncing until he loudly shouted, at which point the bouncing would resume). In each of these examples the teaching staff aimed to develop children's awareness that they can have control over the physical environment by communicating their preferences and choices to others. If the children failed to express a preference, choice, or request for more, teaching staff would employ a range of prompts, including verbal prompts (e.g. repeating a question using dramatic intonation: "Do you want *more* bouncing, Harry?"), gestural and visual prompts (e.g. staff would wiggle two objects in front of Charlie's face to get his attention), and physical prompts (e.g. staff dabbed yogurt on Emma's lips to see if she would lick her lips with delight or express disgust at the flavour). The vignette below embodies this style of interaction:

> It's lunchtime and Charlie is wheeled to the end of the table. The other children around him open up their lunchboxes and begin to eat. Charlie stares at the ceiling and appears to be daydreaming. The TA [teaching assistant] sits down beside him, suggests that Charlie must be hungry, then holds up two pictures – a yogurt and a drink bottle. She tries to get his attention by clearing her throat ("ahem!"), repeating and singing his name (|Charlie, Charlie, Chaaaaarlie….") and tapping her feet on the ground. He continues to stare at the ceiling until the TA tickles his tummy, which makes him jump and gasp. He looks forward and has a grumpy expression on his face. The TA chuckles at his response. She asks him if he would like a drink or a yogurt. Charlie doesn't appear to choose anything so she wiggles the water bottle in front of his face, then a spoon. Charlie shouts, and his gaze moves between the children eating and the objects in front of

> his face. He stares at the drink bottle and licks his lips. The TA celebrates ("Good choice, Charlie!") and puts the bottle to his lips. He drinks.

In addition to a formal dyadic approach to teaching communication skills during lesson time, special school staff regularly engaged in a range of care-based routines such as providing comfort to children by massaging aching arms and legs, helping children eat and drink, get changed, go to the toilet, and administer medication. The above vignette demonstrates how care-based routines provided a context for teaching communication skills. However, not all interactions aimed to teach communication skills, care-based routines often revolved around reassurance (e.g. Staff would offer verbal reassurance, speak in a soothing tone, and narrate what was happening (e.g. "We're just clipping you in the hoist, Harry. Are you ready? One, two, three… up we go…"). Staff described an on-going 'battle' with managing the side-effects of medication. Whilst medication was deemed imperative to sustain bodily functioning and reduce discomfort, it also made the children heavily drowsy. Staff would attempt to negate the effects of the medication by singing to children, talk to them using dramatic intonation, 'shake-to-wake' (e.g. rubbing and shaking limbs) as well as other forms of physical stimulation including massage. This frustrated children who verbally protested (they exhibited startle responses before shouting out loud in a grumpy manner and turning away from staff trying to wake them).

Outside of the special school: the fluidity of staff interaction styles

Whilst the weight of the data suggests that staff interactions in the special school were largely functional (i.e. oriented towards the development of children's emerging communication skills) and/or care-based, the interactive style changed during school trips or when supporting children with PMLD in the mainstream. When on school trips (e.g. to the beach or woods), staff interactions were more pluralistic or group-based (e.g. involving children and several members of staff interacting at the same time). These interactions were playful in nature and incorporated games (e.g. playing 'Piggy in the middle' by throwing a beach ball over Harry) or teasing (e.g. during a trip to the beach staff sang "dip him in the sea!"). There was clear evidence of group effect, meaning that the group as a whole were excited, smiling and/or laughing. These playful interactions lacked pedagogic purpose, were often spontaneous (not timetabled or planned) and joyful in nature:

> Harry is lying on the beach and having fun. The teacher pretends to jump on Harry before hovering above him on all fours. He smiles lots and verbalises

> loudly whilst looking up at the teacher above him. The sun comes out from behind a cloud and Harry jumps. He vocalises and smiles, whilst changing the modulation of his voice ("lalalala-ug-aaaaaah"). Harry is engaged in group affection - he is the focus of interaction and affection and looks around at the staff. Staff around him joke and ask if he's having fun. Harry responds by smiling and vocalises loudly and the staff laugh. A teaching assistant pours warm sand over Harry's feet and she giggles. He continues smile and vocalises ("aaaaah").

In the above vignette Harry is excited and focused on the adults around him. Harry is not simply surrounded by a group, but the group form around him because of his interactions with the teacher. He acts as a beacon or focus of attention (the subject of affection) and the adults near appear mutually engaged and happy.

Whilst the interactions between Harry and special school staff during school trips can be described as informal and playful, interactions between school staff and children with PMLD in the mainstream school were functional and pedagogical in nature. Whilst some interactions resembled those described in the special school (i.e. development of communication skills and care-based routines), a central theme that emerged during analysis of the mainstream data was 'narrated bodily appropriation'. Narrated bodily appropriation refers to a particular style of dyadic physical interaction whereby the Special School Teaching Assistant (SSTA) would move or control Charlie, Harry or Emma's body (or, more specifically, body parts such as limbs) in accordance with the contextual demands of the situation. If a teacher asked a question, the specialist staff would raise the hands of children with PMLD to indicate a response (e.g. the SSTA raised Harry's hand when the teacher asked the class "Who would like to play outside?"). During literacy the SSTA would play an audiobook for Emma whilst holding Emma's finger to point to the words and pictures on the physical page. The SSTA raised Charlie's hand and hit them on a drum during music. The physical control of children's limbs was also observed during care-based interactions. If Emma's 'ticks' appeared to be resulting in harm (e.g. her skin began to redden after rubbing her face too much) the SSTA would put splints on Emma's arms to prevent her from reaching her nose. Charlie would slump in his chair and put his chin on his chest when he was tired and/or uninterested, and his SSTA would sit him up and sometimes hold his head up so he would face whoever or whatever he was meant to be paying attention to (a teacher, an interactive whiteboard, etc.) These forms of interaction were typically narrated, meaning that the interactions were accompanied by a description of what was about to happen and why. The SSTA would also issue verbal instructions (e.g. “Sit up please”), ask questions (“Did you like the story?”) and offer lots of praise (e.g. “Good looking, Harry!”).

Peer interaction in the mainstream: embodying specialist styles and naturalistic engagement

During the research project there was very little observed interaction between the children with PMLD and other children in the special schools, outside of greetings or farewells at the beginning or end of the day. By contrast, the research data described a range of interactions between children with PMLD and the mainstream children. The special school teaching assistants (SSTAs) played a central role in supporting these interactions, particularly at the beginning of the project. SSTAs would support interaction by sitting children with PMLD next to mainstream peers and giving the PMLD children the same material to use (pens, paper, musical instruments, rulers, paintbrushes, jigsaw pieces). The SSTAs would celebrate the mainstream school peers’ achievements with the children with PMLD (e.g. when a group finished completing a jigsaw puzzle in a reception class, an SSTA raised Emma’s hands and cheered, or told peers that Emma liked her paintings). Peers would be invited to sit beside children with PMLD and given explicit communication strategies to help peers interact with PMLD children (e.g. “Tell her your name.” “Tell her what you’ve done today”. “Can you choose a story for Emma?”). The SSTAs suggested how to play with the PMLD children (e.g. “Can you roll the ball to Emma?” “Emma likes to have her hands held”). Sometimes the SSTAs would provide manual support for the children with PMLD so that they could participate in other children’s games (e.g. Charlie was sitting on the carpet, leaning back on the SSTA so she supported his weight, whilst she helped Charlie roll a ball to other children hand-on-hand). Peers received praise and encouragement for interacting with children with PMLD, and the SSTA would answer children’s questions (e.g. “Why is she in a wheelchair?” “Can Harry speak?” “Does Charlie understand what he’s supposed to do?”). Sometimes the SSTA would play games that attracted the attention of groups of children (such as Emma’s SSTA blowing bubbles in the playground). What emerged from this explicit support was a style of peer interaction that was specialist in nature. Without seeking permission, peers began to assume the role of the SSTA during lessons and employ similar interaction strategies as the SSTAs. For example, peers began to help children with PMLD through hand-on-hand support during writing or painting, engaged in ‘shake-to-wake’ (e.g. rubbing the shoulders, or wiggling the arms and legs of sleepy PMLD children to wake them up), and began to use verbal and physical prompts if the children with PMLD did not respond in a desired way (e.g. Harry was asked whether he would like to taste pineapple or banana, and when he did not respond the children repeated the question in more dramatic tone, provided time for Harry to reply, etc.).

Whilst peers developed specialist communication strategies to engage with PMLD children, they also engaged in their own rich and diverse forms of communication, particularly as they became more confident over time. The theme of ‘interaction-for-interaction’s-sake’ describes this data. During this style of interaction mainstream peers would recontextualise classroom resources in order to interact with PMLD children. For example, they would tickle Harry’s nose with a paint brush to gain his attention or make animals out of playdough for Harry to squeeze. Charlie was given a tambourine during a music lesson and played ‘tug of war’ with peers who attempted to prise it from his hands (resulting in much laughter from both Charlie and peers). Peers would play ‘hide and seek’ or ‘tag’ with and through PMLD children, sometimes running away in the playground pushing the children with PMLD so they would not get caught, or hiding behind their wheelchairs. Harry and Emma became the audience for peers who sang, danced, and pulled silly faces to make Harry and Emma laugh. During these interactions Harry (and eventually Emma) were excited, alert, smiling and observant. Peers in the mainstream would give children with PMLD objects of affection (friendship bracelets, daisy chains, home-made cards, party invites) and interact in physical and affectionate ways (e.g. hugging children with PMLD, stroking their arms whilst saying “hello”, putting their ears on Harry’s chest to determine if he was hiccupping or pay attention to how tense his body was during hugging. Children would rub Harry’s arms to help warm him up, tuck in Emma’s poncho if it started to rain, and report if Charlie was being sick.

Physical exchanges sometimes appeared subversive. During carpet time, peers were expected to sit still and quietly whilst watching and listening to the teacher. Whilst peers typically did this, they still engaged with Harry and Emma in non-verbal ways, such as holding their hands, rubbing their legs, resting against their wheelchairs and legs, using Harry’s out-stretched legs as a ‘table’ to rest their whiteboards on. Harry would watch children raise their hands, locate the source of children speaking, and become increasingly happy and eventually shouting out in excitement. During these moments Harry began to develop new forms of symbolic communication – he would straighten his arm out and open his palm which was taken as an attempt to initiate interaction. Children would hold his hand and stroke his palm, much to Harry’s delight.

Discussion

This chapter has described the tension between the international vision of inclusive education (e.g. UN, 2006; UNESCO, 2015) and the idea of a neoliberal education which creates the conditions for *exclusion* (Greenstein, 2016; Tomlinson, 2017). The extent to which inclusion is achievable for children with PMLD is called into question when debate about inclusive education revolves around a ‘simple’ definition of inclusion which involves making adaptations to classroom environments to support the participation of children with PMLD in the enterprise of subject knowledge acquisition (Imray and Colley, 2017; Warnock 2010). This simple definition of inclusion risks invoking a medical model of disability which suggests that no amount of environmental adaptations can facilitate children with PMLD acquiring subject knowledge at the same rate as their non-disabled counterparts. If inclusion means the assimilation of children with PMLD into an unchanging neoliberal mainstream education then the inclusion project may never succeed.

However, if definitions of inclusive education embody a more radical social model interpretation which calls into question the very meaning of education, then we can begin to imagine alternative arrangements. Radical inclusionists call for a reform of the education system as a whole to reflect the diverse learning needs of all children, including children with PMLD (Baglieri and Shapiro, 2017; Goodley, 2011). If we begin with the idea that inclusive education aims to foster social cohesion, as suggested by international policy (UNESCO, 2002), then for inclusion to succeed we need to develop understanding of the conditions that lead to social cohesion. In this chapter social cohesion was defined in terms of a sense of belonging, shared identity, and social cooperation (Fonseca *et al.*, 2019; Simmons, 2020). The research findings presented above suggest that this requires deployment of specialist staff who can support the emerging communication skills of children with PMLD, whilst also providing mainstream school peers with knowledge about the communication strategies of children with PMLD. This led to mainstream peers supporting Harry, Emma and Charlie by assuming the role of a specialist TA (e.g. by providing hand-on-hand support, or engaging in care-based routines such as tucking in Emma’s poncho in the cold weather). However, the findings also suggest the importance of providing children with protected time and place to experiment with communication strategies, play together, develop friendships, and share roles and responsibilities. Mainstream peers played games with Harry, Emma and Charlie, sang and danced for them, gave them objects of affection, and engaged in physical interaction such as hugging, stroking arms and playing tug-of-war. The children with PMLD responded positively, with smiles, laughter, increased openness to mainstream peers and clear evidence of increased alertness. Descriptions of such social inclusion are largely absent from the inclusion debate for children with PMLD, though they appear to offer much promise for thinking about the meaning of social cohesion and how this can be supported.

One of the arguments for the segregation of children with PMLD is that special school staff have training and expertise to work with profoundly disabled children. However, the findings of this research suggest that specialist staff were not consistent in their interaction style with children with PMLD, but instead appeared to be influenced by the context of the interaction. The special school staff interactions were timetabled (planned for), normative (in the sense of developing children's interaction ability according with an early developmental stage), and functional (the interactions aimed to help children develop communication skills). During school trips the interactions were playful, spontaneous, and rarely embodied the pedagogical style of interaction found in the special school. By contrast, in the mainstream school the specialist staff attempted to support children with PMLD to access the mainstream curriculum (e.g. through narrated bodily appropriation, such as hand-on-hand support with writing). These different interactive styles appear to emerge under different environmental conditions. Staff interactions in different schools (mainstream/special) were shaped by the routines, objects, and curriculums on offer. However, during school trips and away from routines practices, curricular, and the material infrastructure of both the mainstream school and the special school, the staff appeared to be 'freer' or more playful, they laughed more, and engaged with children with PMLD in a similar manner to that of mainstream children. This suggests that the material environment influences the nature or style of staff interaction. More research is needed to examine this relationship further, and to explore how environments also constrain and support social interaction opportunities between children with PMLD and mainstream peers.

Conclusion

This chapter has introduced social complexity to debates about whether children with PMLD are 'includable'. It has suggested that arguments that focus on physical place (either a mainstream school or a special school) overlook rich variations in social participation that occur when staff engage outside of special school contexts, and the ways that mainstream peers and special school staff can create engaging social environments for children with PMLD. The chapter has supported a radical social model perspective of inclusion which calls into question the neoliberal focus of education which emphasises a competitive approach to subject knowledge acquisition. If UNESCO's vision of inclusion is to be taken seriously then we need to move beyond binary models of education that separate children according to 'type', and begin to develop understandings about the conditions that lead to social belonging. To date there has been no published research that has examined inclusive education for children with PMLD from a radical social model perspective. This chapter calls for more theoretical and empirical work to develop this view further.

Questions for discussion

What is your definition of 'inclusive education'? To what extent do you agree with the definitions given in this chapter?

According to international policy makers, inclusive education leads to social cohesion. What does social cohesion mean to you, and how could inclusive education lead to social cohesion?

Children with PMLD are defined as belonging to the earliest, pre-verbal stages of development. What could be the benefits of including children with PMLD in a mainstream school?

Can an education system rightfully claim to be 'inclusive' if it provides special schools for children with special educational needs?

Summary points

- Inclusive education has been a key focus of international education policy since the 1990s. Policy makers claim that inclusive education plays a central role in enhancing society, particularly with regards to social cohesion, tolerance, and peace.
- However, not all children have been successfully included in mainstream schools, and in certain countries (like the UK) special schools continue to exist.
- Children with profound and multiple learning difficulties (PMLD) belong to the group who present the biggest challenge to inclusive education. Some commentators argue that children with PMLD are too intellectually impaired to meaningfully participate in

mainstream schools and thus require specialist settings which offer specially trained staff, better material resources, and a tailored curriculum and pedagogy.

- A radical social model perspective of inclusive education holds that the problem lies not with children with PMLD, but with the neoliberal education system that narrowly frames education in terms of subject knowledge acquisition. A radical perspective of inclusion calls for the redesign of the entire education system to reflect the diverse needs of all learners.
- This chapter presents research that appeals to a radical vision of inclusion. It examines the conditions that lead to social inclusion, and suggests that successful models of inclusive education must focus on developing a sense of belonging, shared identity, and social cooperation across diverse peers.

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