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Published online: 27 Nov 2021.

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'To start talking phonics is crazy': how parents understand 'literacy' in the lives of children with learning disabilities

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ABSTRACT

Children and young people with learning disabilities may not acquire the independent reading and writing skills which are conflated with 'literacy' in international educational policy, calling into question what 'literacy' means in the context of 'special education'. Existing literature explores teacher perspectives, but less is known about parent views. This study conducts semi-structured interviews with two mothers of learning disabled children, drawing on Critical Discourse Analysis to trace inflections of policy, theory and practice-based discourses in their talk as they attempt to construct a meaningful version of 'literacy' in their children's lives. It is argued that parents may align either with conventional discourses of autonomous literacy currently favoured in policy – which may result in disappointment at the child's 'inability' – or with more expansive notions of 'inclusive literacy' which challenge and subvert conventional understandings of literate practice. Parental positioning, subjectivity and practice are interwoven with underpinning discursive constructions of 'literacy'.

Introduction

International policy on 'literacy' teaching currently coalesces around a functionalist view of discrete, measurable skills which must be mastered for a child to enjoy full citizenship and for a country to enhance its international competitiveness in the 'global knowledge economy' (Bromley, Oakley, and Vidovich 2019, 160). For instance, the United Nations Literacy Decade (2003–2013) was launched with the reminder that literacy constitutes 'an indispensable means for effective participation in the societies and economies of the twenty-first century' (UN General Assembly 2002, 2). Reading performance is the subject of large-scale international comparisons such as the *Programme for International Student Assessment* (PISA), with media panic over 'serious economic consequences' (Morsy, Khavenson, and Carnoy 2018, 60) for countries whose scores are seen to be waning. In England, the National Curriculum for English opens with a stark warning:

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> All the skills of language are essential to participating fully as a member of society; pupils, therefore, who do not learn to speak, read and write fluently and confidently are effectively disenfranchised. (DfE 2014, 3).

This (inter)national policy direction raises important questions about the education of children and young people (CYP) with learning disabilities who may not learn to read and write independently. On the one hand, it might be argued that they are simply destined for 'disenfranchisement' and peripheral 'membership of society': cognitive deficit prevents them from acquiring literacy skills necessary for the enjoyment of full citizenship. Additionally, when literacy is conceptualised as a vehicle for social mobility and a trajectory to paid employment, it becomes easy for policymakers to dismiss it as an irrelevance in the life of learning disabled children (Robinson, Moore, and Harris 2019). On the other hand, as this paper will argue, these children can and do enjoy meaningful home literacy experiences. Their positioning in relation to literacy therefore raises important questions about the direction of current policy and the need for a more 'inclusive literacy' (Flewitt, Nind, and Payler 2009).

Existing research demonstrates that educators in special education struggle with the meaning of 'literacy' (Lawson et al. 2012; Roberts-Tyler et al. 2020). This paper is unusual in that it foregrounds *parental* understandings of 'literacy' in the lives of learning disabled CYP. Using Critical Discourse Analysis, it examines how competing discourses around 'literacy' in educational policy and practice are mobilised, adapted, or resisted by parents in order to make sense of 'literacy' in their child's life. This is important because the meaning of 'literacy' for severely disabled children is vastly under-researched in educational literature compared to their mainstream counterparts who have well-defined and evidence-based trajectories and age-related expectations (Snow 2017). Further, whilst a modest body of literature exists on home literacy *practices* with disabled children (Karaahmetoglu and Turan 2020; Westerveld and van Bysterveldt 2017), much less is known about how parents conceptualise and discursively position their disabled child as an insider/outsider to the world of 'literacy' in the first place. This paper addresses this gap in the literature.

Background

Models of literacy, models of disability

The *autonomous model of literacy* is associated with transmission teaching of skills such as decoding which will lead to independent reading and writing (Street 1995). The non-acquisition of such skills will limit the child's cognitive, social and employment prospects, irrespective of 'the social and economic conditions that accounted for their "illiteracy" in the first place' (Street 2006, 1). This results in policy emphasis on 'a narrow set of technical sub-skills' associated with independent reading and writing (Flewitt, Nind, and Payler 2009, 231) which Kliewer (2008) links to the shift towards performativity and high-stakes testing in education. Brewster (2004) draws a parallel between this autonomous model of literacy and the medical model of disability, which views disability through the lens of medicalised discourse as individual deficit. Both models share the view that failure to acquire the technical skills of literacy is a regrettable problem for the disabled child, while the concept of conventional literacy itself remains unproblematic.

In contrast, the *ideological model of literacy* (Street 1995) views literacy as a social practice which is inevitably patterned by social institutions and relations of power. It urges analysis of how and why some 'literacies' become more dominant, visible and influential than others which are subsequently devalued. In the words of Lawson et al. (2012), 'a failure to regard the literacy attempts of all people as culturally significant amounts to the marginalisation of certain individuals in relation to that culture'. (102). Similarly, Locke (2004) notes that a sociocultural approach to literacy 'allows for the observation that some versions of "literate" practice are discursively constructed as having higher status than others' (13).

The ideological model points to the possibility of a more expansive understanding of what constitutes 'literacy'; with attention given to the de/valuing of diverse mediums of meaning-making used by disabled people such as Braille, sign languages, pictorial symbols, communication technology, and idiosyncratic embodied communication. This appears congruent with a rights-based approach to disability, specifically the right of disabled people to 'seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice' (UN Convention on the Rights of Persons with Disabilities, Art.21). Such an approach also has parallels with the social model of disability, which urges redirection of our theoretical analysis and political efforts to the disabling features of the environment rather than individual impairment (Brewster 2004). Such a perspective might suggest that people are disabled not by their inherent 'illiteracy' but by society's ableist privileging of spoken and printed language to the exclusion of other meaning-making. Recent attempts in England to make party political manifestoes and voter guidelines available in easy-read format with symbols and photographs (Mencap 2019) might be seen as an instantiation of a social/ideological approach to disability and literacy.

These competing discourses raise important questions about the positioning of children identified as having learning disabilities who do not acquire conventional autonomous reading and writing skills. From a realist perspective, some disabled children would be considered non-literate if we subscribe to an autonomous model of literacy as skill acquisition (Lawson et al. 2012). From a social/ideological perspective, however, analysis might instead foreground how 'literacy' might be framed more inclusively.

Inclusive literacy

Sociocultural approaches to literacy have long emphasised the importance of the embodied and social interactions that occur around a text. A *literacy event* such as a shared bedtime story is defined by Heath (1982) as 'any occasion in which a piece of writing is integral to the nature of participants' interactions and their interpretative processes' (93) and where participants 'follow socially established rules for verbalizing what they know from and about the written material' (50). This concept of a literacy event is useful in foregrounding the centrality of human interaction in enjoyment of a piece of writing, although it might be criticised for anthropocentrism which neglects analysis of the materiality of the text (Brandt and Clinton 2002).

This concept of the *literacy event* has since been useful in the context of learning disability, as learners who have not acquired independent reading and writing may continue to enjoy shared reading and other interactions around texts well beyond pre-

school years. The idea of a 'text' as an anchor for the event has been extended beyond Heath's original conceptualisation of a 'piece of writing'. For instance, Lawson et al. (2012) consider it sufficient to have an interaction around an artefact 'that can cross the barriers of time' (106) such as a wordless book with pictures, a photo album, a video, an object of reference that conveys meaning, or pictorial symbols. Additionally, Heath's idea of participants *verbalising* around the text can be given a more expansive multimodal interpretation. For instance, Flewitt, Nind, and Payler (2009) describe how a disabled child demonstrates embodied idiosyncratic communication to shared reading which includes rocking in her chair, gesture, non-verbal vocalisation and eye gaze. They go on to argue:

> Recognizing and valuing the multimodal richness of all children's communicative competence, whether conventional or idiosyncratic, appears to be fundamental to nurturing all children's literacy development and to fostering inclusive literacy practices ... where they can communicate meanings, express emotion, move towards showing empathy and be valued as full members of the learning community. (Flewitt, Nind, and Payler 2009, 231).

Following 'inclusive literacy', 'reading' denotes engagement with texts which may be books but also 'any medium that participates in a sign relationship between social actors' (Robinson, Moore, and Harris 2019, 94). This 'inclusive literacy' might be described as 'multi-textual, multimodal, artefactual activities set within a social context' (Robinson, Moore, and Harris 2019, 102) where the 'text' is brought alive by a 'responsive significant other' (100). For instance, George (2020) calls upon public libraries to facilitate 'reading for pleasure' for children with learning disabilities, by providing (for example) sensory trays with hidden objects relevant to a story, or cloth books with tactile features to explore. Similarly, the practice of Multi-Sensory Storytelling (MSST), now well-known in special education, has been described as 'a powerful, practical expression of inclusive literacy' (Robinson, Moore, and Harris 2019, 95). This involves the intentional, planned provision of sensory experience to convey key concepts of a story, such as an electric fan to provide the sensation of wind or a water spray to convey rain: in this way, 'stories are not simply told but can be experienced with all our senses' (Fornefeld 2013, 78). MSST results in more attentiveness to the book and/or stimuli than regular reading for children with profound learning disabilities (Ten Brug et al. 2016).

Literacy pedagogy in special education

Given these competing conceptualisations of 'literacy', it is unsurprising that educators of children with learning disabilities find themselves caught at a confusing interface of theoretical and pedagogical discourses. In England, the National Curriculum applies in special school classrooms (DfE 2013, para. 3.3) and special schools are subject to inspections from the same regulatory body as other schools. Lawson et al. (2012) argue that this can result in adherence to phonics-based instruction, not because of any deep conviction in its relevance or usefulness but for fear of the consequences of deviation. Also supporting the pursuit of conventional literacy is the rights-based argument that no learner should be denied explicit phonics-based instruction because of their assumed level of disability, lest low expectations become a self-fulfilling prophecy (Browder et al. 2009; Bryan 2018). On the other hand, persisting with an unattainable goal of conventional literacy could have unfortunate consequences of disengagement and frustration:

Browder et al. (2009) acknowledge the risk of leaving some students 'in a state of perpetually getting ready to read' (270); whilst Lacey et al. (2007) express doubt that students with severe learning difficulties will progress from knowledge of individual phonic sounds to generalising these skills into conventional reading and writing. For this reason, the authors are in favour of an approach which orients more towards 'inclusive literacy' for students with severe learning difficulties. Overall, it is therefore difficult for the teacher to decide whether to pursue conventional literacy skills of independent reading and writing or conversely a more sensory/experiential literacy curriculum (Roberts-Tyler et al. 2020; Schnorr 2011). This can result in an eclectic mix of approaches with no clear overarching framework to guide the literacy outcomes being pursued for a particular child (Fletcher-Campbell 2000; Lacey et al. 2007).

In the case of Down's syndrome (DS), children with this label are described as typically functioning 'in the mild to moderately impaired range of cognitive ability' (Hulme et al. 2012, 320). Pedagogical materials and academic literature often express optimism that high expectations and inclusion in mainstream education will promote better language skills and academic attainment (Snowling, Nash, and Henderson 2008); and that conventional literacy *is* an attainable goal for many children with DS, to varying degrees (Hulme et al. 2012). It has been argued that literacy instruction should be tailored to the particular profile of DS which is characterised by relative strengths in receptive language, short-term visual memory, visuospatial processing and social skills (Ratz 2013) but weaknesses in attention, working memory, hearing, speech production and phonological awareness (King et al. 2020). Given that visual skills are thought to outstrip verbal skills (Snowling, Nash, and Henderson 2008; Ricci 2011) there is an emphasis on initially teaching through a whole-word approach, for example through flashcards, rather than letter-sound relationships (Lemons and Fuchs 2010). More recently, DS reading interventions have tended to combine whole-word approaches with phonemic awareness and letter-sound correspondence, with mixed results (King et al. 2020).

In contrast, in the UK the label PMLD (Profound and Multiple Learning Disabilities; known internationally as PIMD/ Profound Intellectual and Multiple Disabilities) is associated with the greatest possible level of learning difficulty. Causation may include a range of genetic disorders, brain damage as a result of infection and other acquired brain injuries (Doukas et al. 2017). Learners with PMLD often have additional motor or visual/hearing impairments and complex health needs including seizures (Ware 2004). Relatively little literature exists to connect 'PMLD' with 'literacy' and that which does typically privileges 'inclusive literacy' such as MSST. Conversely, it has been argued that a default turn to MSST because the PMLD learner is presumed 'too disabled' for conventional literacy can become a self-fulfilling prophecy which amounts to 'denial of literate citizenship' (Kliewer, Biklen, and Kasa-Hendrickson 2006, 165). There are occasional accounts of individual children identified as having PMLD and yet acquiring conventional literacy (Bryan 2018) although some have questioned the validity of such claims (French and Marshall 2018).

Families and literacy

Research on literacy for disabled children frequently foregrounds parental home literacy *practices*, with relatively less attention to underlying discursive constructions of 'literacy'. Johnson, Bornman, and Alant (2010) find that parental input and reading environment are

comparable for disabled and non-disabled children, although the children with learning disabilities demonstrated less sustained attention and independent reading. Westerveld and van Bysterveldt (2017) argue that parents of children with autism and DS begin reading to their child at an early age and typically own at least 25 children's books, whilst van Bysterveldt, Gillon, and Foster-Cohen (2010) note that parents of children with DS engage their child in shared reading, active teaching, language games and library visits. Similarly, Burgoyne and Cain (2020) note that shared book reading is a regular feature of the home literacy environment for children with DS, although due to the child's delayed language parents may assume a directive role and limit linguistic demands. O'Leary et al. (2019) find that parents of children with autism possess in-depth knowledge of their child's strengths and interests which they mobilise to mitigate against challenging behaviour, anxiety and attention deficit. The authors argue for professional recognition of parents as 'crucial partners' (152) in the child's literacy development due to this deeply individualised knowledge and insight.

Robinson, Moore, and Harris (2019) explore the impact of books on the social inclusion, development and wellbeing of CYP with severe and profound learning disabilities. They argue for pleasurable engagement with books and reading as a deeply social, interpersonal event which can facilitate shared attention, closeness and wellbeing. According to the authors, the combination of the book and a 'responsive significant other' (100) is crucial in enabling Reading for Pleasure (RfP) at home, noting that parents make highly effective reading partners who demonstrate skill in personalisation and repetition of storytelling. The authors further observe that parents did not orient to performative ideas of literacy as a vehicle for employability and national economic prosperity. Instead, parents foregrounded here and now benefits connected to joy and wellbeing: in the words of one mother 'I read to him because it makes him happy' (100).

Taken together, these studies suggest that parents find value and pleasure in shared reading with their disabled child and draw upon their familiarity with their child to create a rewarding literacy experience. However, these findings may not be representative of parental practices internationally. For instance, Karaahmetoglu and Turan (2020)argue that Turkish parents of learning disabled children provide poor early literacy opportunities and have less positive literacy beliefs compared to the parents of typically developing children. In Malta, Mercieca and Mercieca (2009) note that the idea of academic inclusion for children with PMLD is a relatively recent and evolving phenomenon, with a strong legacy of the medical model of disability. As a result, the authors note that 'parents were amazed at the fact that we spoke of literacy with regards to their children' (58). This literature points to the importance of situating parental practices within an (inter)national context of discourses around disability, inclusion and literacy.

Methodology

Theoretical framing

This study draws upon a framework of Critical Discourse Analysis (CDA). 'Discourses' have been defined as 'sense-making stories that can be viewed as circulating in society, that are not easily attributable to a particular originary source' (Locke 2004, 5); and as 'sets of statements that construct objects and an array of subject positions' (Parker 1994, 245). A

key task of CDA is to elucidate the relationship between this wider discursive economy and the talk of individual participants. Here, it enables analysis of how diverse accounts ('discourses') of 'literacy' described previously are mobilised by families through identification, adoption, subversion or resistance in order to make sense of 'literacy' in their lives of their children. It further becomes possible to trace the implications of discursive behaviours for power, positionality and practice within the home literacy environment, 'identify[ing] the discursive constructions used by research participants and [tracing] their implications for their experiences of themselves and the world' (Willig 2008, 155).

Underpinning CDA is the question of power. Fairclough (1995) argues that discourse analysis deals with 'opaque relationships of causality and determination' which are 'ideologically shaped by relations of power and struggles over power' (132). This sits comfortably with the ideological model of literacy/social model of disability discussed earlier (Brewster 2004): real-life (in)accessibility of essential information for disabled people such as healthcare documents is ultimately shaped by literacy discourses which attribute responsibility either to the individual for their cognitive deficit or conversely to the information provider for their inaccessible dissemination format.

Setting and participants

Participants were recruited through eight special schools in the Midlands of England, who acted as gatekeepers. Five families were recruited in total, and this paper focuses on two CYP 'Gavin' and 'Matthew'. This decision was made for three reasons: to facilitate the depth of discussion required by Critical Discourse Analysis; because 'Gavin' and 'Matthew' have contrasting developmental profiles; and because the responses of Gavin and Matthew's mothers provided an interesting counterpoint in terms of their respective positioning on a conventional-inclusive literacy spectrum of aspiration.

Ethics

This study was carried out in accordance with the BERA Guidelines for Education Research (BERA 2018) and was approved by the author's University Research Ethics Committee. Written consent was obtained from a parent in each case. One young person (Gavin) was able to demonstrate understanding of the study and to give informed written consent on his own behalf using an easy-read format information sheet and consent form. Children/ young people and parents have been given pseudonyms, and potentially identifying details have been redacted.

Data generation

Semi-structured interviews explored how families experience, conceptualise and enact 'literacy' with their child. One interview was conducted with each parent through an online platform due to COVID-19 restrictions in England at the time of fieldwork; each lasted between forty and sixty minutes. The interviews were relaxed and conversational in nature, allowing parents to expand upon and explore their understandings of literacy.

Parents were invited to discuss home literacy practices, what they thought the term 'literacy' meant for their disabled child and how this compared with the experiences of any non-disabled siblings.

Additionally, the researcher offered all families the possibility of a separate interview for the child/young person with any necessary adjustments. Gavin subsequently participated in his own interview with some support from his mother. As this paper focuses on parental talk about literacy, Gavin's interview is drawn upon only occasionally where it provides further contextualising detail.

Data analysis

Data analysis was guided by the research question: *How do families understand and enact 'literacy' for and with a young person with 'learning disabilities'?* It was further informed by Critical Discourse Analysis which foregrounds how participants draw upon, reproduce, subvert or reject available understandings of the topic drawn from the wider discursive economy (Willig 2008). The analysis therefore looked for instances of how the theoretical, political and pedagogical debates around 'literacy' described above were mobilised in the talk of participants, and how such discourses opened or closed down certain subject positions and possibilities for practice.

Following transcription, interviews were analysed using NVivo 12 (QSR International Pty Ltd. Version 12) as a platform for manual coding. Each participant's interview was coded using the six-stage framework for Critical Discourse Analysis proposed by Willig (2008):

(1) **Discursive constructions**. Identification of the different ways in which the discursive object ('literacy') is constructed by participants, both explicitly and implicitly.
(2) **Discourses.** Location of the various discursive constructions of the object ('literacy') within wider discourses.
(3) **Action orientation.** What is gained by the participant from constructing the object ('literacy') in this way?
(4) **Positionings.** Identification of the subject positions offered by the discourses adopted. Discourses construct subjects (parents and children) as well as objects (literacy) and talk can position oneself and others in discursive locations from which to speak and act.
(5) **Practice.** How do the identified discourses and positionings open up/ close down certain opportunities for action?
(6) **Subjectivity.** What can be felt, thought and experienced from different subject positions? Willig (2008) cautions that this stage is necessarily speculative, since CDA views talk as active constructive work rather than a transparent window into inner mental stages.

In common with many qualitative approaches, CDA acknowledges the subjectivity of the researcher. Establishing rigour and trustworthiness remains important, although not in the 'neopositivist' sense of (for example) validating analytic decisions through inter-rater reliability (Braun and Clarke 2020). This study adopts several measures from the qualitative rigour framework for CDA proposed by Mullet (2018). Member checking took

place by sharing with participants both initial interview transcripts as well as a draft copy of this article prior to publication for the purposes of enabling dialogue about the direction of my emergent analysis. The data analysis was also shared and discussed with research peers in conferences and seminars. The researcher maintained a self-reflective journal throughout the research process which was a useful space for exploring the intersections between fieldwork experiences, the data generated and researcher positionality (Ortlipp 2008). Additionally, researcher positionality and data analysis procedures are explicitly articulated within this paper.

Researcher reflexivity

Disclosure of my own positionality as a parent of two children with learning disabilities can be helpful in establishing rapport with other parents of disabled children, as I have discussed elsewhere (Doak 2021). In the current study I again made the decision to disclose this aspect of my life to participants before the interviews. Participants did not tend to ask about my own parenting experiences during their interviews, although some did during informal exchanges before and after recording.

According to Wilkinson and Kitzinger (2013), feminist researchers typically manage their 'insider' status by minimising it, utilising it, maximising it, or incorporating it. In this study I might be said to 'utilise' my 'insider status': I did not incorporate myself or my children into the study as an autoethnographer might do, but the shared parenting experience was disclosed and brief moments of orientation to this commonality are evident throughout the transcripts. I have argued elsewhere that literature which is typically dominated by the professional voice can rapidly problematise parents of disabled children who do not appear to offer unequivocal 'buy-in' to the professional perspective, rather than attempting to explore the emic family perspective on its own terms (Doak 2021). Establishing the study as parent-led therefore felt epistemologically important as a counterpoint to this dominant professional perspective, since parents of disabled children may feel subject to the scrutiny and evaluation of the professional gaze and therefore to the positionality of the researcher (Ryan and Runswick-Cole 2009).

Findings and discussion

The findings from this analysis are presented as two individual case studies. In each case, I begin by providing some contextualising detail of the reading/writing activities undertaken with each child before exploring parental discourses around 'literacy'.

Gavin

Gavin was sixteen years old and had Down's syndrome, Autism Spectrum Disorder and Moderate Learning Difficulties (MLD). Gavin could engage verbally in conversation expressing his views and preferences with enthusiasm: for instance he described how he loves Harry Potter films because *'it's really dark . . . it gets a bit violent with Lord Voldemort and stuff'*. Many instances were shared of Gavin engaging deeply with complex storytelling through cinema, theatre performances, television and DVDs: as his mother Rachael commented, *'Gavin tends to access stories through films nowadays'*. Gavin also

enjoyed collecting and revisiting photos and videos which documented events in his life: as he explained, old photos *'made me go back into being a kid again'*. He enjoyed taking 'selfies' on his new phone, created vlogs (video logs), and wondered if someday he might be a YouTube star.

'Literacy' viewed through a more expansive lens as meaning-making involving the 'enduring representation' of an artefact (Lawson et al. 2012, 106) encompasses these activities as literate: Gavin engaged enthusiastically with the (re)telling of stories through multiple media. However, if 'literacy' is understood as the 'narrow set of technical sub-skills' associated with autonomous reading and writing (Flewitt, Nind, and Payler 2009, 231) then Gavin's 'literacy' had its limits. In what seems to have become a laborious process, Gavin was able to write short passages with adult prompting and reminders to leave spaces between words, and he often wrote with phonetic spelling. When he was unable to attend school due to COVID-19 restrictions in England, Gavin's mother supported him to compile a 'lockdown diary' of family photos with brief written commentaries underneath:

> I wanted to catalogue what he was doing during lockdown, plus he was getting his literacy skills in, plus he was getting his reading skills in, plus he was having to think about what was happening in the picture. Because I wanted him to do the thinking, to then write down what it was.

Gavin's school sent home reading books from the Oxford Reading Tree series (Hunt 2011), designed for use with emergent readers between the ages of four and seven. Rachael commented *'the reading books he brings home tend to be at the right level for him … sort of stretch him enough'*. Additionally, she explained *'He knows the first 100 high frequency words now I think. I think he reads like a 6–7 year old on the whole'*.

A disparity appeared to have developed between Gavin's sophisticated meaning-making through verbal and audiovisual modalities and his comparatively limited meaning-making through reading and writing. Perhaps as a result, Gavin now appeared less than enthusiastic about developing conventional literacy skills, describing reading as *'very hard'*. Rachael confirmed that *'he wouldn't just go and write without being directed'*, and *'I think he sees it very much as I'm having to learn to read'*. This is reminiscent of Browder et al.'s (2009) description of children left 'in a state of perpetually getting ready to read' (270): Gavin had been working on reading books designed for younger learners for many years and it was admirable that this perseverance had resulted in some emergent reading skills, but not to the extent that would permit access to the complex stories for (young) adults he enjoyed through multimedia.

Rachael's thinking on literacy reflected dominant discourses of literacy as autonomous reading/writing skills (Department for Education [DfE] 2013). When asked what literacy means to her, she replied *'reading and writing I think, simply … '* Later, she reflected on whether this understanding resulted from her professional background in education*: 'I guess I'm programmed to say reading and writing'*. Initially, Rachael had been hopeful that a high level of autonomous reading and writing was a feasible goal for Gavin:

> You go on these courses when you have a child with Down's syndrome … it's all about, you must have high expectations of them, they are perfectly capable of reading … teaching children with Down's syndrome phonetically, you know as in breaking down words and

everything else, isn't the way to go. You go for the whole word approach, because they're visual learners as well . . . We've got a friend, the two of them have grown up together . . . she'll read Harry Potter, she's an avid reader . . . there's very little that she can't read.

Through the lens of CDA, this initial alignment with these combined discourses – literacy as autonomous reading/writing, and children with DS as capable of literacy thus defined – had implications for action orientation, positioning, practice and subjectivity in Gavin's earlier years. It positioned Gavin as a capable learner who could remain in mainstream education (Gavin began his schooling in a mainstream school). It gave Rachael agency and competence as an education professional who could draw upon her knowledge of literacy pedagogy to ensure her son's progress. The task of teaching Gavin to read and write ('action orientation') was constructed as feasible, although requiring some additional knowledge about adapted literacy practices for DS. In terms of subjectivity, it provided what I recognised as a much-needed dose of hope, direction and optimism in the post-diagnosis period and the reassuring promise of Gavin's continued insider status in an inclusive classroom.

Nevertheless, as time went on it became apparent to Rachael that Gavin might not follow this trajectory:

So right okay, you do all these things . . . you do all the reading, and you do all the writing. And then there just comes a point for me, because I was banging my head against a brick wall it felt like. That there has to be a point of realisation where you go, well actually, my child's not going to do that. So why would I beat myself up about it going, well my child still can't read . . . you have to lower your expectations for your own self-preservation really.

Rachael continued her efforts to support Gavin's reading and writing: for instance, she still motivated Gavin to read by asking him to fetch a book, she encouraged him to point to words as she read, and she scaffolded his reading by supplying the *'tricky words'* that he didn't recognise. Efforts also continued to support his writing, as in the lockdown diary described above. Rachael also valued wider literacy experiences for Gavin which might be described as *literacy events* (Heath 1982): these included attending theatre performances, performing enactments of stories, using props and dressing up for World Book Day. These sustained efforts are consistent with previous literature arguing that parents of disabled children invest a great deal of effort into creating a bespoke home literacy environment (Westerveld and van Bysterveldt 2017; O'Leary et al. 2019). However, understandably there was a struggle to reconcile the present reality with the loss of previous literacy ambitions:

I was desperate for him just to be a competent reader . . . I'm not sure that he'll ever have that desire to pick up a book and just read it now. I almost feel like we've gone past that stage.

The shift in discursive alignment appears partial here: while Rachael had moved away from the optimistic discourse of autonomous literacy for all suggested by DS pedagogical materials, there was still broad alignment with the idea of autonomous reading and writing as the optimum literacy outcome. As Gavin had only partially achieved this aspiration, Rachael had been led to the reluctant conclusion that *'his inability, I think, stops him accessing [literacy] fully'*. This is consistent with the argument of Brewster (2004) that if 'literacy' is conceptualised as autonomous skill, non-acquisition must be explained through a medical model of disability. Nevertheless, Rachael remained committed to

Gavin's ongoing progress – *'he's definitely improving all the time'* – and proud of his many achievements in other areas including spoken language, drama performances, as well as his self-confidence and zest for life.

Matthew

Matthew was a nine year old boy identified as having Profound and Multiple Learning Disabilities (PMLD) resulting from a genetic developmental disorder. Matthew did not have independent reading and writing skills, nor did he communicate verbally but rather through embodied multimodal communication such as vocalisation, proxemics (use of distance), posture, gesture and facial expression. At school, Matthew was being encouraged to make simple choices through selecting a photograph of an item that he wanted. Matthew's school had also been working with the idea of family photos as an 'enduring representation' of meaning (Lawson et al. 2012, 106): a recent homework project involved Laura compiling a family tree containing photos of everyone in Matthew's extended family. Laura noted that although Matthew could recognise family members whilst physically present, she was not certain whether he could transfer that recognition to a two-dimensional photo. Reflecting on the school's approach to literacy, Laura noted '*I don't think they use books a great deal'*, preferring interactive whiteboard activities or sensory experiences.

Laura enjoyed reading books with Matthew, describing how she selected books based on his preference for *'bright colours, big pictures and noises'*. He also liked books containing nursery rhymes (because they can be sung rather than read) and books containing familiar characters from children's television. Matthew responded well to dramatic variations in pitch and tone when reading: Laura described how *'we changed the voices, we changed the tempo, we changed the volume, just so that he can understand that there was a story there, it's not just pictures'.*

Parents of non-verbal disabled children can become deeply attuned to the nuances of their child's embodied multimodal communication such as posture, gesture, facial expression and vocalisation (Doak 2021). Laura described how she drew on such knowledge to assess Matthew's level of engagement with a book:

> I just give him a choice of books, and then he'll just grab which one that he wants. Eye contact, obviously looking at the book. Physical contact, so he wants to hold the book, he wants to be close to the book. He will verbalise and make what we would call happy noises, and jiggley . . . If he didn't enjoy it, he would just shuffle away . . .

This description of Matthew as a competent conveyor of feelings about books is consistent with Flewitt, Nind, and Payler (2009) description of 'a symbolic being, able to express precise meanings albeit in non-linguistic and non-conventional modes' (230).

Laura indicated that the shared reading was a precious time in their day, a time of emotional and physical closeness that she valued:

> We sit together, it's good one to one time. So we normally, we sit on the floor or on the sofa, have a little snuggle up . . . we just have a little snuggle, and have a little read. It's good, it's a nice time.

Laura and Matthew's reported experience is consistent with Robinson et al.'s (2019) description of shared reading as 'a basis for shared attention, closeness and well-being' (92). However, it also brought practical challenges:

> They need to be board books; they need to be very robust. He can chew through a book within minutes . . . So it's part storytelling, part wrestling I think with him.

This bespoke personalisation of the shared reading experience is consistent with the observation of O'Leary et al. (2019) that parents draw extensively upon their deep knowledge of their child to make a literacy event meaningful. Laura could be said to function as a 'responsive significant other' (Robinson, Moore, and Harris 2019), demonstrating skill in her selection of shared reading material and the personalisation, repetition and delivery of the storytelling to maximise Matthew's engagement.

When asked what she understood by 'literacy', Laura initially turned to the experiences of her non-disabled children:

> I would associate literacy with perhaps the work that I do with [Matthew's sister] in her school . . . Reading books, understanding stories, reading more and more complicated words, sentences . . . and it is things like how sentences are made and what they're made of, punctuation, that sort of thing. It's all unpacked into almost like the mechanics of story writing.

I was interested to explore with Laura the argument that this form of conventional literacy teaching should be universally offered irrespective of disability, including to learners with PMLD (Kliewer, Biklen, and Kasa-Hendrickson 2006; Bryan 2018). Laura's response was immediate and emphatic rejection:

> I wish I could say it would be beneficial to Matthew, but it wouldn't . . . We don't know whether he understands any words at all really, even words that we use all the time. So to start talking phonics is crazy, and immensely frustrating and demoralising I think probably, from our point of view with him.

This response echoes the doubts expressed by Lacey et al. (2007) that students with severe learning difficulties will progress with phonics-based instruction and achieve autonomous reading. Nevertheless, Laura does not conclude that Matthew is 'illiterate' or limited in his ability to partake of literacy.

> [Matthew's sister] asked me a very interesting question yesterday, she said, 'if I do reading and writing at school, what does Matthew do?' And I said . . . 'while you read, while you do your reading and you sit and do maybe independent reading . . . they'll have props to understand the books that they're reading, or the story'. And it's important for her to understand as well, that . . . it's a different way of understanding literacy, but it's still literacy.

Further discussion suggested that Laura understood this 'different way of understanding literacy' with Matthew as consisting of five dimensions. Firstly, there is the *social, emotional and physical closeness* described previously: reading is embedded in a 'snuggle up' on the sofa that foregrounds sharing meaning through an artefact (a book). Additionally, the ideas of *immersion, enjoyment, interactivity* and *sensory/physical experience* were foregrounded as fundamental to Matthew's 'literacy' experience:

> For him, it's being immersed in that story. So in terms of enjoyment really. So him looking at books and enjoying the sounds, enjoying the colours, enjoying the experience, it's an experience for him. So I would say literacy for him is about joining, proactively joining in, in a story which is being told on the white board with musical instruments, or with sensory or tactile references, or whatever that happens to be . . . I think with the physical markers, like you know, water sprays, and it's an immersive experience, and he understands that.

Laura further reflected on alternative purposes or goals of 'literacy' for Matthew beyond independent reading and writing:

> So rather than reading, I would see [literacy] as understanding . . . I think it's understanding a story, and making, perhaps making the differentiation between what he is living and a story . . . it's about understanding the world better, and his place in it.

For example, Matthew sometimes got upset if he was taken somewhere but hadn't understood the planned destination in advance. Laura hoped to address this by attaching pictures to his wheelchair of frequent destinations which could be used for reference, commenting *'literacy comes into all that doesn't it, it's about understanding . . . '* This understanding of literacy is reminiscent of the idea of pictures as 'enduring representation' of meaning (Lawson et al. 2012); as well as containing traces of the rights-based approach to accessible information and ideas (UN 2006).

This conceptualisation of a 'different literacy' for Matthew, both in form and purpose, appears aligned with the discourse of 'inclusive literacy' (Flewitt, Nind, and Payler 2009). Laura's talk was inflected with ideas from Multi-Sensory Storytelling (Grace 2014; Ten Brug et al. 2016) about the sharing of meaning through artefacts and sensory experience as well as sociocultural understandings of complex entanglements between literacy, relationships and intersubjectivity (Heath 1982). This has important consequences for subject positioning: Matthew was not excluded from the world of 'literacy' due to 'inability' but rather partook of literacy in a different and equally valid way, whilst Laura had agency in providing bespoke and meaningful home literacy practices for both Matthew *and* his siblings. Matthew was also positioned as agentic, making active choices and expressing clear preferences about books through his embodied multimodal communication described above, and it was emphasised to his siblings that he occupied an equally important position as a learner and consumer of books. The implications for practice are illustrated in Laura's description of a mutually satisfying shared reading experience: it was clear that Matthew was perceived as a literate being who engaged with and benefitted from regular shared reading. Laura's home literacy practice with Matthew contrasts with the low enthusiasm for shared reading reported amongst parents of children with PMLD in other countries (Karaahmetoglu and Turan 2020; Mercieca and Mercieca 2009) and might indicate that 'inclusive literacy' is now a relatively well-established discourse in England which is inflecting PMLD pedagogical practice both in special school classrooms and in family homes. In terms of subjectivity, this 'different literacy' discourse may have served to insulate Laura from the disappointment experienced by parents who initially hope that a trajectory of conventional literacy *may* be within reach: perhaps due to the nature of Matthew's disabilities, Laura had unequivocally rejected conventional literacy as a desirable or realistic goal.

Concluding remarks

Education policy in England and internationally places increasing emphasis on notions of performativity, quantification and benchmarks, with literacy as a driver of international economic competitiveness. Embedded within this system are families, like the two described in this study, who must somehow make sense of 'literacy' in a context where some of their children are following normative trajectories in literacy development and others are not. This raises complex questions for such families about what it is to be a 'literate' being, of belonging, (dis)enfranchisement, and the very purpose of education.

Both Rachael and Laura were mothers who cared deeply about their children's education and wellbeing, who considered 'literacy' as a meaningful part of their disabled child's life, and consistent with previous literature (Westerveld and van Bysterveldt 2017; O'Leary et al. 2019) both went to considerable efforts to create bespoke home literacy environments based on their extensive knowledge of their child. Both undertook discursive work to make sense of their child's positioning outside of normative literacy trajectories and the subsequent meaning of the term 'literacy'. Given the very different diagnoses and educational labels ascribed to Gavin and Matthew, it is understandable that this work should take each mother in a different direction. For Rachael, Gavin had partially attained conventional literacy skills although not to the extent which had been hoped, which left him on the periphery of insider/outsider status in the (conventionally) literate world. This periphery is a liminal space which was not always comfortable for his mother and could be explained only by a medical model reading of Gavin's individual 'inability' (Brewster 2004). By way of contrast, for Laura, the prospect of independent reading and writing was dismissed at an earlier stage with phonics-based teaching rejected as 'crazy' and potentially 'demoralising'. This led Laura to align with more expansive, sociocultural discourses around literacy: her talk was inflected with traces of 'inclusive literacy' including the value of immersive, sensory-based meaning-making and the social/emotional contextualisation of a shared literacy event.

A limitation of this study is that it reports on the experiences of only two families, and in both cases the disabled child attended an English state-funded special school. Further research is needed to explore family perspectives on literacy for disabled children who attend mainstream schools, home educated children, and children in other countries. Additionally, the study explores parent perspectives at one particular point in time, whilst a more longitudinal study might yield useful insights into evolving perspectives on literacy throughout the child's development.

This study is unusual in foregrounding not only home literacy practices of families of disabled children but also their engagement with competing discourses around the very meaning of 'literacy'. This has important implications for educators, policymakers and families. For educators, it provides an opportunity to reflect on how competing discourses and uncertainty around the enactment of 'literacy' pedagogy in special education infuse everyday family literacy practices (Roberts-Tyler et al. 2020; Schnorr 2011). It also functions as an important illustration of how families take 'literacy' seriously despite their child's uncertain trajectory and are indeed 'crucial partners' (O'Leary et al. 2019, 152) in a child's literacy development. For policymakers, it highlights the ways in which young people such as Matthew and Gavin, who each have rich and rewarding relationships with literacy, are carelessly relegated to a life of inevitable 'disenfranchisement' by a relentlessly

performative system which values only independent reading and writing. It also suggests that more care could be taken to create inclusive literacy experiences including sensory and tactile resources for learners like Matthew (George 2020) and possibly the creation of more age-appropriate reading materials for learners like Gavin which would allow him access to the complex stories he currently enjoys through multimedia. For families, it is hoped that this study begins a conversation about literacy which (re)values parental expertise and knowledge in the selection, sharing and (re)telling of stories in ways which bring joy, shared meaning and understanding to the lives of disabled children.

Acknowledgments

Disclosure statement

Funding

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