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The impact of books on social inclusion and development and well-being among children and young people with severe and profound learning disabilities: Recognising the unrecognised cohort

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TITLE: **The impact of books on social inclusion and development and well-being among children and young people with severe and profound learning disabilities: recognising the unrecognised cohort**

CONCISE TITLE: The importance of books: PMLD and SLD

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ACCESSIBLE SUMMARY

This paper shows what people with learning disabilities can get out of enjoying books and reading even when they cannot read words easily.

The writers think about how people with learning disabilities can be helped to enjoy books. They say that this can happen through reading with other people, enjoying lots of activities about books and making books part of their daily routine.

The writers also think about the way that books and stories help us to learn about the world and the people in it.

The writers are annoyed about the way that enjoyment of books by people with learning disabilities has been ignored by people.

This matters to people with learning difficulties because enjoying books, even when we cannot read words easily, can give us good feelings and help us to learn and develop,

KEYWORDS

Learning disability, inclusive literacy, reading for pleasure, engagement with books

This paper presents the findings of an original research project commissioned by BookTrust, a respected UK charity that gifts books to children, young people (CYP) and their families. It explored the impact and modus of pleasurable engagement with books among CYP with severe and profound learning disabilities and applied a critical, phenomenological stance on what it means to read through drawing on 'inclusive literacy' as a conceptual framework. Data was collected from four local areas in England and included 43 CYP aged 4-14. In keeping with a phenomenological stance, it employed interpretivist methods involving 13 deep-level interviews with families to include observations and structured play; 13 observations of CYP sharing books with others in home, play or school settings, and interviews with 27 practitioners working in a range of organisations (e.g. Portage service, advisory teams). Findings were that books had a positive impact on well-being, social inclusion and development. CYP were engaged in enjoying the content of books through personalisation, sensory stimulation, social stimulation and repetition. This affirmed the theoretical and practical approaches espoused by 'inclusive literacy' but made a critical and original

contribution to our understanding of the special place that books occupy as ordinary artefacts of literary citizenship among this cohort. The benefits of volitional reading among CYP who do not have learning disabilities are well known but the authors urge publishers and policy makers to recognise CYP with severe and profound learning disabilities as equally important, active consumers of books who have much to gain from reading for pleasure.

HIGHLIGHTS

There is strong evidence of the positive relationship between reading for pleasure and attainment, emotional and economic wellbeing.

Reading books for pleasure has strong associations with emotional and personal development including self-understanding.

This is shown to be the case across genders and socioeconomic groups but significantly less research has been done on the impact of reading books for pleasure among people with learning disabilities.

This paper provides an original account of the impact of pleasurable reading and engagement with books on children and young people (CYP) with severe learning disabilities (SLD) and profound and multiple learning disabilities (PMLD).

It demonstrates that responsive adults support pleasurable engagement with books and reading in ways that enable children and young people with reading disabilities to develop sensory, shared focus, communication, social and cultural understanding whilst also providing a basis for shared attention, closeness and wellbeing.

Provided is account of the modus of pleasurable reading and engagement with books within the conceptual frame of inclusive literacy and phenomenological conceptions of what it means to read.

Effective practices are illustrated and outlined to include recognition of the importance of multi-modal texts, personalisation and intense dyadic interaction

The paper urges policy makers and publishers to recognises CYP with SLD and PMLD as important, active consumers of books, claiming that their relative absence from consideration

of positive impacts is a sign of exclusive conceptualisations of what it means to be a literate citizen.

1. Introduction

The research was commissioned by BookTrust to evaluate the importance of books to children and young people (CYP) with severe and profound learning disabilities (SLD and PMLD). BookTrust are a respected UK charity funded by the Arts Council who have a range of book gifting programmes to meet the needs of children, young people (CYP), and their families, including those with learning disabilities. The purpose of the research was to understand the impact that books might have on a cohort who are unlikely to learn to read and write for pleasure, work, or study (Lacey, Layton, Miller, Goldbart and Lawson, 2007).

This paper forcefully rejects the notion that people with SLD and PMLD are to be considered as pitifully incompetent in their capacity to be consumers of books and unrecognisable as a cohort of literate citizens (Kliewer, Biklen, & Kasa-Hendrickson, 2006). It does this through assuming that understanding is constructed through *expressive cognition* (Hass, 2008), a term fashioned by Merleau-Ponty to explain how meaning is built through the movements and sounds of the body in the social milieu of lived experience. From this perspective, functional literacy is not a prerequisite for reading since reading is understood as a broader meaning-making activity around texts of varied types. This stance demands allegiance with phenomenological conceptions of what it means *to read* and what is meant by *text*. For this reason, a model known as *inclusive literacy* (Flewitt, Nind, & Payler, 2009, p. 213) is espoused to assume literacy as a social process for 'the development of shared meanings through diverse symbol systems in social contexts as woven into the fabric of daily practices,' rather than a set of curricula goals for skills-based competencies.

Through a review of the literature, the paper celebrates *inclusive literacy* whilst exposing a lack of attention to special place of books as artefacts for literate citizenship for CYP with PMLD and SLD in research. A methodological account describes the deployment of rigorous, qualitative methods (including observation, conversations, interviews, and focus groups) which were set within an interpretivist paradigm. These methods supported rich accounts of inclusive engagement with books among participants who included 43 CYP with learning disabilities and learning difficulties aged 3-14, 21 parents, and 24 practitioners from nursery, primary and secondary schools across 4 local authorities to cover coastal, rural, urban, and metropolitan areas. Participants were ethnically diverse and 55% of CYP were male and 45%

were female and 70% of adult participants were female and 30% were male. The local authority areas were also varied in levels of deprivation, with their income deprivation affecting children index (IDACI) ranging from 39.23 (4/353 most deprived in the country) to 18.77 (149/453 most deprived in the country) (Ministry of Housing, Communities and Local Government, 2015).The Findings are discussed in ways that will inform researchers, policy makers, practitioners, parents and other stakeholders about the value and importance of books to this cohort and how their engagement with books might best be supported.

Research Questions

As is fitting with a phenomenologically rooted conceptual framework for literacy, the study adopted an interpretivist approach to investigation of the following questions:

- What is the impact of pleasurable engagement with books among children and young people (CYP) with severe learning difficulties (SLD) and profound and multiple learning difficulties (PMLD)?
- How is pleasurable engagement with books experienced by CYP with SLD and PMLD?
- What is the modus of pleasurable engagement with books among CYP with SLD and PMLD?

The term *modus* describes the way pleasurable engagement with books is experienced by CYP with learning disabilities and the practical means by which it is facilitated. The research also explored the extent to which books have a special place in the lives of CYP with SLD and PMLD and their families.

The current treatment of these questions in the literature is explored in what follows.

2. Literature Review

It is important to preface the review with clarification of the term *inclusion* which is a highly problematic concept much debated in the field of disability studies. In this paper, the term inclusion is used to refer the process through which societal and more specifically, educational systems respond to diverse learners in ways that enable participation, equal opportunities, respect for difference and social justice (Florian, 2008). It places focus on the inclusion of people disabilities in ordinary life including access to cultural life - enabled through engagement with literature.

2.2: The impact of pleasurable engagement with books on CYP with severe and profound learning disabilities

This paper focusses on the impact of pleasurable engagement with books and their content (stories, poems, pictures, texts), among CYP with SLD and PMLD, noting that an individual signified by the term learning disability is a unique, contributing human being with potential for growth and development and contribution (Emmerson & Heslop, 2010). This research was conducted and is reported in ways that honour that fact. In England (the site for this study), this cohort are identified through 'a significantly reduced ability to understand new or complex information, to learn new skills' and 'a reduced ability to cope independently' (Department of Health, 2010, p. 6). Internationally, this cohort may be described as having 'intellectual disabilities' of a severe or profound nature. This descriptor is presented in the revised fifth edition of the Diagnostic Manual of Mental Disorders, DSM-V (American Psychiatric Association, 2013). Here the term intellectual disability (intellectual developmental disorder) reflects deficits in cognitive capacity that are persistent across the life span. In this paper, the term learning disabilities is regarded as synonymous with intellectual disabilities but emphasises capacity over deficit.

Questions related to this group can be better understood when set against the widespread interest in the impact of pleasurable reading on CYP *without* learning disabilities, not least because this exposes the extent to which this group been excluded from consideration. The positive relationship between pleasurable reading, educational attainment, social mobility and well-being for those who do attain functional literacy has been of considerable interest to policy makers. Clark and Rumbold (2011) explain that it is 'one important way to help combat social exclusion and raise educational standards' (Clark & Rumbold, 2011, p. 6, see also Morrisoe, 2014). Reading at home (independently and with parents/carers) is associated with higher attainment (Mullis V. , Martin, Kennedy, & Foy, 2007)) and increased general knowledge (Clark & Rumbold, 2006; Sullivan, 2015; Twist, Schagan, & Hogson, 2007) and the Organisation for Economic Co-operation and Development (2009) cite the Programme for International Student Assessment (PISA) to report the positive relationship between how often children read, how much they enjoy reading and their educational attainment. From the perspective of utility, pleasurable engagement with books can lead to higher reading attainment (De Naeghel, Van Keer, Vansteenkiste, & Rosseel, 2012) better examination grades and enhanced prospects for successful economic performance (Organisation for Economic Co-operation and Development, 2011). Using books to read for pleasure has strong

associations with emotional and personal development including self-understanding (Moje, Overby, Tysvaer, & Morris, 2008), understanding of others (Mar, Oatley, & Peterson, 2009; Vasquez, 2005) and the subjective experience of social inclusion (Billington, 2015). In summary, there is clear evidence of a link between pleasurable reading and better life outcomes for those who can read and write for themselves. It is purported that this is because that reading develops vocabulary and general knowledge in ways that accelerate cognitive development (Sullivan & Brown, 2015) and that reading provides a window to another world, giving us access to the deep inner workings of others' hearts and minds in ways that enable feelings of connectedness (Mar, Oatley, & Peterson, 2009).

Though reading for pleasure may imply some focus on reading for its own sake, the personal and economic benefits of positive engagement with books makes it a focus for policy makers in their pursuit of a more skilled, productive, and mentally healthy workforce (Department for Education and the Educational Standards and Attainment Research Department, ESARD, 2012). But what can pleasurable engagement with books do for those CYP with SLD and PMLD who are unlikely to become conventionally (or functionally) literate? In discussions about the personal and utility-oriented outcomes of reading for pleasure and engagement with books, this cohort are - at the policy level at least - unrecognised.

With significant evidence from the international literature, it can be theorised that this is because this cohort are less likely to gain independent functional literacy, less likely to attain in systems of national assessment and less likely to gain employment. Ratz & Lenhard (2013) assessed the reading stages of over sixteen hundred students with learning disabilities aged 6-21 in Bavaria and found that two thirds did not read at all and another third read at an alphabetic level that was not yet supportive of fluent reading and comprehension. In West Africa, most CYP with severe and profound learning disabilities aged 4-16, were assessed to be below the level of functional literacy (Spangenberg, et al., 2016). In England, statistics from the Learning Disabilities Observatory show that the number of adults with learning disabilities in any paid or self-employed work comprises 6% of the working population with 71% of this group working less than 16 hours a week. (Public Health England, 2016). Further theorising about the reasons for the exclusion of CYP with SLD and PMLD, it is useful to note that this cohort are a minority group. In England, 0.12% of the school population are identified as having PMLD and 0.37% as having SLD (Department for Education, 2017a; Department for Education, 2017b). The majority-focussed outcomes of reading for pleasure (such as high levels of conventional literacy and higher income) can become an irrelevance

for a cohort who, a) may never read or write, and, b) are likely to fall outside the trajectories for social mobility currently imagined by policy makers.

The non-recognition of learning disabilities in discussions about pleasurable reading may be the result of positive, inclusive assumptions. The first is that pleasurable reading is so universally impactful that it is not necessary to consider specific cohorts such as those with learning disabilities. However, the prevalence of studies focussed on gender (Hochweber & Vieluf, 2016), age group (Mol & Jolles, 2014) and socio-economic status (Chiu & McBride-Chang, 2006) show that has not been assumed. The second is that effective practices to enable pleasurable reading are universal to all with no need to consider a special pedagogy specific to learning disabilities. Where this is true it is only in the case of pleasurable reading and engagement with books since research into the impact of impairment specific approaches to reading-instruction are very prevalent (Walker & Stevens, 2016; McKenna, Shin, & Ciullo, 2015). Most studies focus on functional skills (such as word recognition and phonic decoding) and how programmes of reading instruction can be designed to support skill acquisition among people with specific impairments such as Downs syndrome ((Lemons, et al., 2015; Morgan, Moni, & Jobling, 2006) and autism (Doyle & Debelak, 2014).Theorists of inclusion would argue that this represents a societal interest in correction and remediation over the engagement of disabled people in 'ordinary' cultural activity (Goodey, 2015; Tremain, 2005).

If books do have a powerful role in improving the life outcomes of learning-disabled people, it is important to understand the nature and modus of their impact, not least to make clear that there is a cohort of literate consumers who are unrecognised and worthy of consideration.

2.2: Inclusive and non-conventional models of literacy

Though specific attention to pleasurable engagement with books as *particular* cultural tools for CYP with severe and profound learning disabilities is not widely addressed by the literature, studies of effective literacy practice for this cohort provide an authoritative insight into how this may be understood and supported.

Kliewer et al., (2006) and Lawson, Layton, Goldbart, Lacey, & Miller, (2012, p. 101) argue that traditional conceptions of literacy as a 'set of skills related to accessing and generating written or printed text' impose a fixed, debasing, and non-literate status on people with severe and profound learning difficulties. Lawson et al. (2012), Lacey et al. (2007) and Flewitt, Nind

& Payler, (2009) assert that it is time to replace conventional conceptions of what it means to be literate with inclusive ones that are less marginalising. This movement is known as *inclusive literacy*. In contrast to conventional literacy, *inclusive literacy* (Flewitt et al, 2009) acknowledges that there are multimodal 'texts' to be read that encompass visual, digital, spatial, social, spoken and printed forms. Drawing on inclusive literacy, Lawson et al. (2012, p104) propose a range of multimodal and artefactual literacy practices to apply inclusive literacy. These enable constructive social activity around a text, where 'text' refers to any medium that participates in a sign relationship between social actors. These practices encompass the following kinds of activity:

- Traditional orthography (letter sounds, names, and graphologies)
- traditional literacy (reading, writing)
- social sight recognition (literacy in the real world, preparation for everyday living)
- use of artefacts (books, puppets, bag books, story sacks, objects, photographs, dressing up, mark making)
- pictorial and visual symbols such as ideographs, Picture Exchange Communication System (PECS) cards, facial movements, pointing, objects of reference
- sensory stimulation (touching, music, sound rhythm)
- connection of 'text' with daily life and routine (such as bath time, snack time)
- digital modes of communication (through tablets, communication aids, video, audio).

This semiotic conception of literate activity and behaviour is of value to this study for two reasons. Firstly, it enables the useful definition of pleasurable reading for people with learning disabilities as *meaningful, gratifying social exchange around a multimodal text which may include print, picture, sign, gesture, or artefact* (Flewitt, 2010). Literate activity is redefined as socially situated and co-constructed and not dependent on an individual's ability to read for themselves. In this way, inclusive literacy aligns with a phenomenological stance where a range of tools to include embodied action, construct cognitive representations of that world. Arguably, this makes it more inclusive of those CYP with learning disabilities who have not or who will not acquire functional literacy in the conventional sense. Secondly, though inclusive literacy does not place any singular focus on books as anchors for literate activity, its framing supports the proposition that books are textual modes of high yet *ordinary* standing, in which society 'embodies its people, stories, thoughts, communities, identities, and experiences' (Pahl & Rowsell, 2010, p. 2). As such, books support sign

relationships that enable reading of the wider social world even where the reading is co-constructed through dyadic exchanges between those who can and those who cannot (and may never) read. On this theme, Hollins, Egerton & Carpenter (2016) evaluated the impact of the Books Beyond Words project. This project involved the production of wordless books, developed to help adults with severe learning difficulties to explore life experiences and everyday challenges in the context of community book clubs or shared reading groups. Drawing on anecdotal evidence from book club leaders, Hollins et al. (2016) claim impact on community inclusion, demonstrating that books can be read in ways that enable modelling of social world complexities. Through acknowledging the limitations of Hollins et al. (2016) as anecdotal and small scale, it is fair to say that the academy presents little account of the impact of books (including wordless books) on a cohort of non-readers.

Nonetheless, the field of multi-sensory storytelling is well developed as a powerful, practical expression of inclusive literacy. This approach requires the pedagogue to adapt fictional works to include music, textures, smells, tastes and visual images. Mitchell and van der Gaag (2002) describe the transformative role of storytelling in enabling voice and identity formation. The authors tell the story of a young man with severe learning difficulties, Callum, who experienced a technique called 'storysharing'. For Callum, this meant creating a comic book based on his own narrative. He later moved onto reading fictional stories and developed an interest in studying drama and came to see himself as someone who should attend college rather than a day centre. Young, Lambe, Fenwick & Hogg (2011) investigated the impact of multi-sensory story telling in assisting people with PMLD to cope with sensitive personal issues. The stories (developed in a personalised way to reflect issues of concern to the individual and their families) were made available in a cardboard box with objects attached to size A3 pages accompanied by sentences of no more than eight words to be read by the story. Though not strictly in the form of an ordinary 'book' the researchers were able to evidence improvements in engagement for most participants and, from the perspective of professionals and parents/carers, an ability to cope better with a sensitive topic. Such approaches, used with attention to the sensory preferences of individuals, have proved successful across a wide range of ability in the SLD and PMLD cohort (Grove, Harwood, Henderson, Park, & Bird, 2013) and emphasise the power of stories when they are paired with *sensoried* activities (Grove, 2005; Mitchell & van der Gaag, 2002). Though the books used by CYP, parents and practitioners were mostly sensory books, picture books and highly illustrated information books, it is important to note that CYP with learning disabilities can also access much more

complex works of literature when these are adapted and made accessible through sensory activities and drama (Park, 2004; Grove & Park, 1998)

In summary, though the fields of sensory story-telling and inclusive literacy (which engages varied modalities) demonstrate positive impact, consideration of books as particular cultural artefacts has not been addressed in any great depth. The field of inclusive literacy rightly embraces a more universal conceptualisation of text and literate behaviour and in doing so creates capacity-focussed conceptualisations of what it means to read. It may however, lead to understatement of the *singularity* of books as portable, traditional, and mainstream artefacts of importance in the lives of people with learning disabilities.

3. Methodology

The research approach adopted traditional interpretivism, an approach which is concerned with understanding how social actors create meaning in their everyday practices, communications and lived experiences (Railean, Walker, Elci, & Jackson, 2016). It is traditional in the sense that adopted methods are well established in phenomenological epistemology (see 3.2).

3.1. Sampling strategy, sample, research sites and participants

BookTrust provides targeted gifting programmes to CYP with special educational needs and disabilities to include library packs for special and mainstream secondary schools and additional needs packs for young children with sensory, physical, and learning disabilities. On this basis, high participation areas were identified and from those, four LAs were selected to enable coverage of a range of contexts to include metropolitan, urban, rural, and coastal areas in the North, South East, South West, and Midlands regions of the UK. Selection was further refined through using LA level indices about population diversity and deprivation to ensure a varied sample. Take-up of BookTrust programmes was assumed a proxy for the prevalence of pleasurable reading and engagement in books and for the availability of high-quality books and reading material as provided by the charity.

In total, the research engaged eighteen children aged between 1 and 6; twenty-five CYP aged between 11 and 14 (Key Stage 3, KS3); fifteen practitioners working in early years contexts; nine practitioners working in KS3 and twenty-one parents of children between 1 and 14. The study did not include children aged 7-11 because the BookTrust gifting programmes being evaluated did not include that age group. Of the forty-three children participating in the study,

thirty-seven had severe or profound and multiple learning disabilities with the remainder having moderate learning difficulties. Since the focus was on the impact and modus of pleasurable engagement with books rather than on comparing practices and outcomes, a diverse range of contexts, age groups and participants were recruited to enhance the richness of the data. Though an opportunity sample was used, great care was taken to include a broad range of organisations, children, young people, families, and practitioners. Settings included children's centres, nursery schools, special schools, National Health Service (NHS) child development centres and Portage services. KS3 settings (in England, this refers to 11-14-year olds) were also recruited to include mainstream schools and special schools. Participants represented a broad spectrum of types and severities of learning disability. Table 1 provides a summary of the research sites and participants.

<Insert Table 1: Summary of research sites and participants>

3.2: Methods

Methods were designed to investigate the impact and modus of pleasurable engagement in books from, a) real life interactions, and, b) the perspectives of significant others (parents/carers and professionals). This was to construct a rich account of engagement with books from multiple perspectives as is fitting with an interpretivist approach. Rigorous attention was given to designing methods that could elicit communication from CYP who could not speak. An individualistic imaging of the CYP was rejected in favour of a participatory approach that perceives all participants as *expressive* rather than *without voice* through recognising that this voice can be expressed in vocal and embodied ways through contextualised interactions (Simmons & Watson, 2015).

Deep level interviews with families

The research team conducted 13 interviews with families. They are described as deep level because they comprised three elements in pursuit of rich, triangulated qualitative data. Firstly, an observation of parents and children sharing books and reading together in their homes, local libraries, school or play settings depending on which was most comfortable and convenient for participants. Given that the research was interpretivist and focussed on every-day rituals and social exchanges, this was an important consideration in keeping with the paradigm of inclusive literacy and its phenomenological origins (see section 3). Observers used an observation schedule to collect structured and unstructured data in-situ. Though such

schedules are not interpretivist in a traditional sense, the reason for their deployment is described later. The inclusive literacy model underpinned the design of the schedule to include artefactual, sensory, vocalised, physical, and gestural interaction around the book (Lawson et al. 2012, p101) as indicators of engagement and enjoyment. For CYP, the schedule applied markers of engagement such as 'gazing at', 'vocalising about' and 'talking about' the book or book related artefact. For parents, it included markers of support, interaction, and dyadic exchange such as 'closeness', 'listening to the child' and 'talking about the pictures.'

For CYP with PMLD, a schedule was supplemented by an engagement scale based on the work of Carpenter et al. (2015) to include awareness, curiosity, investigation, discovery, initiation, and perseverance as markers of engagement. This harvested data to demonstrate embodied communication in the spirit of *expressive cognition* (Hass, 2008). The second element of the deep level interviews involved parents (or researchers where the child/young person was comfortable) conversing, playing, or interacting with children around the book to elicit further responses. A range of elicitation tools were used including puppets, drawing, objects of recognition, augmented technology, the Picture Exchange Communication System (PECS)[1], Makaton symbols and so on. Thirdly, researchers carried out a semi-structured interview with parents.

Observations of individuals and groups in school or play settings

The research team conducted 13 observations of individual CYP in school or play settings working with significant others (such as teachers or support assistants. During this time CYP would be engaged in a one to one activity where a book was being shared, read aloud, or discussed with significant others (parents and/or practitioners) and data was collected using the observation schedule described above. The research questions were also investigated using a focus group schedule or when more appropriate, an observation of a group activity led by a practitioner based on the reading and sharing of books. In total, there were seven research events involving groups to enable data collection in a range of contexts and situations.

Practitioner interviews

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[1] The Picture Exchange Communication System (PECS) allows people with little or no communication abilities to communicate using pictures. People using PECS will approach another person to give them a picture of a desired object or activity in exchange for that item or activity.

A total of 27 practitioner interviews were carried out with a range of professionals across Early Years and Key Stage 3 provision (ages 11 to 14) applying a semi-structured interview schedule using face to face or telephone modes.

Methods of data analysis and validity

During the early stages of the study, observations were video recorded and used by the research team to compare the *in-situ* records and interpretations across the research team. This was done for to serve two, somewhat discordant, purposes. The first was in the spirit of an interpretivist approach rooted in phenomenology - to deepen the research team's hermeneutic thinking and their engagement with self and others. The second was to evaluate whether there was enough commonality of interpretation to allow trustworthy enumeration of behaviour. This was in service to the funder's call for evidence about impact that would be understood by a wider, public audience. Given that researchers were also required to interpret behaviours from the observations as indications of engagement (e.g. social interaction, desire to communicate), these interpretations were also reflected upon through respondent validation for the first ten data collection events. Data was in the form of observation schedules, transcribed data (from semi-structured interviews, focus group interviews and conversations) and notes in researchers' field work journals. Data was analysed using an exploratory approach in keeping with an interpretivist, phenomenological paradigm. Inductive thematic coding (Saldana, 2011; Silverman, 2013) enumeration (Ezzy, 2002) and content analysis (Chowduhry, 2015) were used to form theories from the data and the constant comparative method (Glaser & Strauss, 1973) was applied to minimise researcher bias. The broad range of data collection sites and contexts enriched the corpus data and supported dependability, credibility, and confirmability through constructing overlapping methods in support of triangulation (Shenton, 2004; Lincoln & Guba, 1988). The most significant global themes were formed from building codes into basic themes and then into organizing themes to support theorising. Therefore, the findings that are discussed in section 4 represent the conglomeration of multiple coded events with a significant mass as illustrated in Table 2 and Table 3 (Section 4).

Ethical issues and principles

The research tools and protocols for informed consent were robustly evaluated by the Research Ethics Committee at the University of X and approved prior to commencement of the study. Researchers were always supported by parents/carers or practitioners who were

well known to the child or young person so that communication could be supported and feelings of security maximised.

To ensure an inclusive approach in keeping with the spirit of this research, if CYP did not want to engage (as demonstrated verbally or non-verbally) the activity and related data collection was halted. However, when willing, their participation was maximised through use of flexible methods such as conversations, semi-structured interviews, play, drawing, photographs, use of signs and symbols and sensory stimulation (Alderson, 2005).

4. Findings

Following a process of progressive inducting coding, categorizing and enumeration (see section 3.2), theories were formed to answer questions about impact and modus. Table 2 summarises the results of this thematic analysis. It notes the number of research events where this theme was coded and the number of participants who referred to it (during interviews) or experienced it (during observations).

<Insert Table 2: Benefits of pleasurable engagement with books: frequency of themes across the full corpus data (for the 37 children with SLD and PMLD)[2]>

Table 3 summarises evidence arising from the corpus data about the modus of pleasurable engagement with books.

<Insert Table 3: Modus of pleasurable engagement in books: frequency of themes across the full corpus data (for the 37 children with SLD and PMLD). Where the prevalence is enumerated this is based on data from interviews (what participants said) and observations (what CYP experienced)>

5: Discussion of findings

Table 2 presents evidence of the two core impacts of pleasurable engagement with books. Firstly, *well-being* (shared focus, social exchange, closeness, routines) which is evidenced in 315 coded instances. Secondly, *development* (learning about the real world, scaffolds for developmental priorities, learning to read the social/physical world, incentives for volitional communication and movement) which occurs 364 times across the corpus data.

In the observation data, books were often a central 'text' around which other types of reading were supported. For example, Kara and Paul (parents to Joel, age 6 who has severe learning

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[2] In summary, for PMLD and SLD, there were 45 research events involving 37 CYP, 18 parents and 21 practitioners.

difficulties and a visual impairment) explained that they used books as a way of teaching Joel about the physical spaces in the outside world. They gave him plenty of time to scan the pages and paced the sharing carefully, so he had the time to map the contents of the page. They made connections between the content of the book (*Off to the Park*, a sensory book commissioned by BookTrust) and everyday life using the kind of extratextual talk described by Zucker, Cabell, Justice, Pentimonti, & Daderavek (2013). Extratextual talk occurs in interactions surrounding the story or text such as labelling, making inferences, relating what is being read to children's own lives, explaining and/or analysing before, during, and after the reading of a text. Hence, pleasurable engagement with the book became an opportunity to support Joel with other types of reading in this case, reading of the physical world. In the corpus data, there was substantial evidence that books were catalysts for meaningful, mutually gratifying social interaction supportive to development. This is evidenced by 343 instances of interaction (either described or observed) including 121 where shared focus and sustained attention occurred; 110 related to closeness and 112 where books stimulated volitional movement and communication.

Two vignettes follow as illustrations of impacts on development, well-being, and social inclusion. They are presented in the spirit of a phenomenologically situated, interpretivist study that respects data collection and presentation in the context of lived experience.

Vignette 1: Books as a catalyst for communication [Narrative based on observation data]

Rudi is six years old. He has profound and multiple learning difficulties and restricted volitional movement and communication. Branca (Rudi's mother) described Rudi as an 'Angel, because he has a good soul and a kind spirit, I can feel that about him. He is not just his disability.' When they were reading together, Branca started with a book called 'Playtime' and this had colourful pictures and textured pages, such as a doll with woolly hair and an elephant with silky ears. With hand over hand guidance from his mum, Rudi interacted with the various textures of the book, particularly enjoying the elephant's soft ears. When Branca came to the page with tactile sticky paints she showed him with vocalisations how it felt. Rudi watched and then effortfully lifted his own hands to touch them and after giving him some time to explore the page, Branca said, 'Good boy, well done' smiling broadly. She repeated this. Then she read 'That's Not My Dinosaur' and held each textured page up to Rudi to touch. He engaged with this more than the previous book and when Branca read the page 'That's not my dinosaur, his teeth are too bumpy', and held it up

to Rudi, he ran his fingers over the dinosaur's teeth (which were raised on the page) for a long while. While he was engaged with this, Branca waited and used verbal encouragers such as, 'Aaaah, what's there? Dinosaur's teeth?' and, 'Rudi, it is <u>so</u> interesting.' After a while, Branca turned the page and read 'That's not my dinosaur, its flippers are too slippery', holding the page up for Rudi to feel. Rudi became very quiet and focused on the page, spending a long time looking and feeling the scales. These ran all the way down the dinosaur's back and were made of soft felt. At one point, he looked up at his mum. His head and body went very still, and he made 'ka, ka' noises and a round shape with his mouth whilst keeping his gaze on her. Branca mirrored these movements and whispered, 'Are you trying to talk to me Rudi?' Rudi continued to make clicking noises while Branca waited and encouraged him with her own alert expression and said softly, 'Tell me something' then waited, then said 'Do you want to tell me something Rudi?' Branca looked at the researcher, smiled and raised her eyebrows, noting later that this was an important moment since she could see that Rudi was trying to communicate directly with her in a way that was new. Branca and Rudi finished sharing the book and Rudi was engaged throughout.

Vignette 2: Books triggering shared focus

George is 12 years old. He likes food, routines and talking about his pets and family. He is a friendly and sociable boy. He has an epileptic condition and has seizures often. He also has severe learning difficulties. His teacher Abbie explained that one of the consequences of this is that he gets stuck in loops of thinking and will repeat the same phrases over and over. During an observation of George, he was seen to be in one of these loops, talking about his cat and his family. One of the teaching assistants in his class, Dawn, sat with George and invited him to share 'The Really Gross Body Book' which George became engrossed with. He turned the pages and lifted the flaps. He was particularly taken with the pages about flatulence. He spoke with the researcher about these with delight. Dawn followed his lead and talked with him about the pictures he liked. He took photographs of his favourite parts, particularly liking the ones about vomit and poo and he talked about these pictures.

The vignettes enrich reporting of the findings in Tables 2 and 3 through illustration of the valuable impact of sharing of books on individual development. For Rudi, it motivated him to engage, focus, move volitionally, and communicate. He responds very positively to the language of the book, '*Where is my dinosaur*?' in ways that facilitate his understanding of everyday communication. The contribution that literature makes to inspiring engagement

with the cadences and semantics of language is important to acknowledge. When reading literature to CYP with learning disabilities, greater awareness of everyday language can be inspired such that literature is a bridge to everyday interaction rather than is more commonly assumed - that everyday language is the bridge to literature. For George in the second vignette, interaction around the book brought him out of a loop he was stuck in and engaged him in another more enriching experience. Both children were supported in this by highly responsive others who knew about each child/young person's needs. Pleasure was demonstrated through behaviours denoting enjoyment and engagement such as smiling, laughing, cuddling, sustaining attention, engaging in joint attention, intentional communication, responding and talking.

It is important to note that when children were experiencing the impact of books, they were doing this because a significant other was able to provide a highly personalised experience which was related to developmental needs. A parent, Aneesa who made the following comment:

> 'The colours of these books attract her and because she has autism…… When I am reading a story like *Mouse is small* I talk about the mouse and the elephant playing together and I show her the relationship. And when I am reading *Off to the Park*, I talk about how you must take turns on the slide. I also teach her about how to read - the direction of the words and I point to them as I go along.'

[Transcribed data from deep level interview]

This was another example of how books were being used to develop other kinds of reading, in Salima's case, reading of the *social* world. Across all age groups and types of need, the *combination of the book and a responsive significant other* brought benefits of individual, developmental relevance. Intensive dyadic exchanges emerged as the modus through which pleasurable reading was supported and sustained in support of positive impact.

Parents and practitioners rarely mentioned the grander, long term benefits of pleasurable reading (such as social mobility reported by Morrisoe, 2014 or higher reading attainment reported by De Naeghel et al., 2012). This only arose 6 times in the data. Participants were more focused on *here and now* benefits related to developmental priorities, enjoyment, and well-being. Bridget (mum to Owen who had a life limiting condition) said that books were important as a way of making life better:

'I read to him because it makes him happy. I just want him to enjoy life and because he loves me to read to him, I do it. It makes life less stressful for him even if only for a little while.'

[Transcribed data from deep level interview]

This is an indication of the way in which books operate within the lived experience of CYP and their families where the emphasis is on valuing the capacities and needs of individuals.

In terms of the impact of books on learning and development, Abbie, a KS3 teacher at a special school made the following comment when speaking of the importance of books in the lives of children with severe and profound learning disabilities;

'It is all about the enjoyment of the book. Our children with profound and complex needs can show their likes and dislikes through a book and books are powerful for that. We were all watching Simon [a 12-year-old boy in the class] using the book *Playtime*, the one with the sticky paints in. He loved that. He was so surprised by the stickiness, he put his nose to the picture and then tried to taste it. He was trying to work it out. The book motivated him to make some effortful movement. Our children need these kinds of sensory inputs. Books are also important for other things. As part of our sex education programme we use a book called *Where Willy Went* and we remember Cal, one of our children, looking at Dawn's [our TAs] baby bump and you could see that he was thinking 'I know where that came from' To me, this is a prime example of the importance of a book.'

[Transcribed data from semi-structured interview]

Across the 39 parents and practitioners, 34 commented on the special role that books play and there were 56 coded instances of this across the data. An example of this was from Sarah, mother to Lottie, a child with complex learning difficulties:

'Because Lottie has a heart condition, she can't move around in the world as freely as other children. Also, her tracheostomy means she cannot talk about it as freely as other children either. Books are important because they bring the wider world to life. For her because she can't talk about it, books provide common ground for us to share and understand together. They really matter to us and to the family.'

[Transcribed data from deep level interview]

Lottie's engagement with books connects her with the wider social cultural context and the 'common ground' that she has a right to occupy. Books were also described as a way of helping children learn about themselves. Sandra (mother to John, a 14-year-old who has a wide vocabulary and a liking for *Doctor Who*) showed researchers the books she had made for John throughout his life. They were stories about the things he had done with his family and in his own home. They also included stories about John and *Doctor Who's* adventures. She attributed his wide vocabulary, 'which everyone is so surprised by,' to books and noted that he 'he had learned to say his name from the books I made for him when he was younger.' Sandra said that she had 'ignored what people thought about what he could and could not do and I knew that books mattered – though they are made for John, a book is something ordinary not 'special' and ordinary really matters.'

In summary, there was evidence of the positive impact books as artefacts of importance for the well-being, development, and social inclusion of CYP with learning disabilities within the context of social exchange with significant others. This was in a context where participants noted the absence of age appropriate, sensory, and wordless books for older children with learning disabilities.

4.2: The modus of pleasurable engagement with books

The term modus is used here to describe the way in which books are subjectively experienced and the way in which social practices make them accessible to CYP with learning disabilities.

Table 3 summarises the three core themes related to modus. Firstly, *personalisation* (relating to experience, using individual sensory preferences, adapting texts, giving processing time and integrating discussions with signs and symbols) for which there were 160 coded instances. Secondly, the use of *sensory and social stimuli* to engage CYP (supplementing with sensory experiences, using props and interacting intensively with the CYP) occurring 134 times. Finally, *repetition* (using the same books or stories with repetition) for which there were 38 coded instances across the data.

There was some consensus among practitioners on the issue of how pleasurable engagement with books and reading is experienced by CYP with learning difficulties and disabilities. Differences were understood to arise from a complex set of factors inclusive of CYP impairments, sensory preferences, stages of development, personalities, and ages. Practitioners agreed that the differences in reading for pleasure for children with learning

disabilities related to *how* books were accessed. The following extracts from telephone and face to face interviews represent the nature of this consensus:

'Reading for pleasure is reading for pleasure. SEN or whatever you want to call it is largely irrelevant. You just have to make it accessible. You need to provide the right material.'

'I think [CYP with learning disabilities] can experience reading for pleasure just as much but I do think that the adaptions have to be made.'

'I think [CYP with learning difficulties] can experience reading for pleasure just as much but I do think that the adaptions have to be made such as to the colours or textures in the books.'

'It is about tapping into what is going to make that child want to open a book – every child is an individual.'

'We have two children with the same 'condition', Rett syndrome but the way they access books is totally different. The way I would share a book with each is different because they have different sensory likes and dislikes. In the end, the result is, all children can get the same amount of pleasure from a book, it is just how you get them there.'

'Any child can access any book – an adult can be the bridge''

Practitioners emphasised the importance of combining the right book with a responsive adult as a way of supporting access to pleasurable engagement.

Parents focused on the question of *how* children experienced reading for pleasure rather than i*f* they did because they assumed the latter. They tended to communicate an individuated, personalised perspective on how best to support pleasurable reading. Branca (vignette 1) said that it was a matter of tuning into what her son, Rudi, liked and responded to. Rudi had favourite books (like *That's Not My Dinosaur* and some *Thomas the Tank Engine*) and he also liked books that made noises and had music with them. Many parents talked about the importance of choosing the moment carefully. Faye and Andrew explained that with Isabella (age 6), there, 'was no middle ground' and they needed to be responsive to her mood because, 'If Isabella does not want to engage, there is no point trying'. They also knew that Isabella was much more interested in the text on pages than the pictures. In fact, she was very

drawn to print in the wider world and loved signs like 'Fire Exit' and 'Push' and so on. Therefore, Faye and Andrew were very careful not to obscure the text when they were reading to her. They also looked for books that had large text in different fonts. This is a good example of how content that might be assumed as being universally attractive to children (like pictures) is not always so. Among such a diverse population, significant others will choose and use books responsively, in ways that suit individual interests Fazina talked about her son, Arif, an energetic, lively, sociable three-year-old with Down syndrome, and how he experienced reading for pleasure.

Fazina provided a useful account of how Arif interacted with books and her descriptions were also demonstrated in the observation of Fazina and Arif reading together:

> 'He likes to feel the book and see in the books things he likes doing in his life like playing and painting. With this book *Playtime,* he likes to touch the doll's hair and he likes the pictures of the children playing. He picks the book up and he puts it down and turns the pages over and over again. I can see when he is thinking – he will go very quiet and focused - and I will listen very well because it looks like there is something he wants to say. He also likes to put the book to his mouth and if he sees something he likes he will look at me and go 'Mama' or 'Ga-ga-ga' He is trying to speak. He goes forwards through the pages and back again and he will spend a long time with books. I like books and the BookTrust means that I can have them in my home.'

> [Transcribed data from deep level interview]

The data from parents suggests that children are engaging with books on their own terms supported by responsive, significant others. The manner of engagement may be influenced by the specifics of impairment, but parents gave more weight to the individual personalities and preferences of their children when thinking about how they experience pleasurable reading and are supported in it. From the interview data with parents and practitioners, a range of suggestions about how best to support pleasurable engagement with books and reading emerged and these have been summarised in Table 3.

The approaches in Table 3 echo those proposed by models of emergent literacy (Han & Neuharth-Pritchett, 2015; Rohde, 2015) and inclusive literacy (Lawson, Layton, Goldbart, Lacey, & Miller, 2012) since they reference multi-textual, multi-modal, artefactual activities

set within a social context. This provides further support for the validity of this movement and its practices.

5. Conclusion

This paper provided new evidence of the important contribution that books make to the well-being, development, and social inclusion of children with SLD and PMLD. In the case of the diverse sample in this study, there is evidence that books held special importance in the lives of children, young people, and their families. Most parents and practitioners allotted books special status.

Positive impacts were in the areas of *development*, *well-being,* and *social inclusion*. In the case of well-being and social inclusion, engagement with books was seen to stimulate social interaction, shared focus, and closeness.

Impacts on development were judged according to the needs and developmental priorities of individuals but included sensory processing, sensory tolerance, volitional movement, volitional communication, vocabulary, signing, spoken language, intentional communication, attention, social interaction, speaking, and the passage of time. Parents and practitioners also described the way in which books helped children to read the wider social, physical world in ways that supported their inclusion in it. In the context of the Children and Families Act, 2014 in England this finding is of significance since legislation demands positive outcomes for CYP with special educational needs with reference to health, education, employment, community inclusion, and independent living. The findings of this study support the claim that pleasurable engagement with books can support these aspirations.

The findings also support *inclusive literacy* as a frame of reference for defining literate activity as meaningful, gratifying social exchange around multimodal texts. They validate its emphasis on diverse media such as sensory stories and they also offer support for the effective purported by the inclusive literacy movement. These include the need for a responsive, significant other who can support the matching of the right book with the right engagement methods in a highly-personalised dyadic exchange. The modus for meaning making includes signs, symbols, sensory stimuli, intense dyadic interaction, extratextual talk and more traditional print-based activities where appropriate. Participants emphasised the dearth of age appropriate sensory and wordless books for older CYP with learning

disabilities. More research is needed to inform publishers how to extend their reach to include this cohort as literate consumers of books.

This paper has demonstrated that the absence of attention to books as ordinary symbols of literate citizenship is unhelpful. This needs to be redressed since books have been shown to be of special importance to the participants of this study. Sarah, a teaching assistant, made an important point about books and their *special-ordinariness.* This paper ends with Sarah's comment since her statement represents the essential relationship between books and an ordinary, included life:

> 'For children with special educational needs, who are often surrounded by 'special' resources and equipment, a book is a bit unique because it is, how can I put it, its 'normal' and what I mean is it is something 'ordinary' that people use in the wider world and that carries no 'special' stigma. It is really nice for children and families to enjoy that ordinariness. This is why books are so important.'

References

Alderson, P. (2005). Designing ethical research. In Farrell, *Ethical research with children* (pp. 27-36). Maidenhead: Open University Press.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: APA.

Billington. (2015). *Reading between the lines: the benefits of reading for pleasure, quick reads.* Liverpool: University of Livepool.

Carpenter, B., Egerton, J., Cockbill, B., Bloom, T., Fotheringham, J., Rawson, H., & Thistlewaite, J. (2015). *Engaging learners with complex learning difficulties and disabilities.* London: Routledge.

Chiu, M., & McBride-Chang, C. (2006). Gender, context and reading: A comparison of students in 43 countries. *Scientific Studies of Reading, 10*(4), 331-362.

Chowduhry, M. (2015). Coding, sorting and sifting of qualitative data analysis: debates and discussion. *Quality and Quantity, 49*(3), 1135-1143.

Clark, C., & Rumbold, J. (2011). *Young people's reading and writing: An in depth study focusing on enjoyment, behaviour, attitudes and attainment.* London: Literacy Trust.

De Naeghel, J., Van Keer, H., Vansteenkiste, M., & Rosseel, Y. (2012). The relation between elementary students' recreational and academic reading motivation, reading freuency, engagement and comprehension; a self-determination theory perspective. *Journal of Educational Psychology, 104*(4), 1006-1021.

Department for Education. (2017). *Schools, pupils and their characteristics.* London: DfE.

Department for Education. (2017). *Special Educational Needs in England.* London: DfE.

Department for Education and the Educational Standards and Attainment Research Department, ESARD. (2012). *Research evidence on reading for pleasure.* London: DfE.

Department for Education; Department of Health. (2015). *Special Educational Needs and Disability (SEND) Code of Practice: 0 to 25 years.* London: DfE and DoH.

Department of Health. (2010). *Valuing people: A new strategy for learning disability in the 21st Century.* London: DoH.

Development, O. f. (2009). *Equally prepared for life? How 15-year-old boys and girls perform in schools.* Brussels: OECD.

Doyle, K., & Debelak, A. (2014, November). Literacy instruction for students with autism spectrum disorder. *LIteracy*, pp. 1-2.

Emmerson, E., & Heslop, P. (2010). *A working definition of learning disabilities.* Durham: Improving Health.

Ezzy, D. (2002). *Qualitative analysis: Practice and Innovation.* London: Routledge.

Flewitt, R. (2010). Multimodal literacies. In J. Marsh, & E. Hallett, *Desirable literacies: Approaches to language and literacy in the early years* (pp. 122-139). London: Sage..

Flewitt, R., Nind, M., & Payler, J. (2009). 'If she's left with books she'll just eat them':Considering inclusive multimodal literacy practices. *Journal of Early Childhood Literacy, 9*(2), 211-233.

Florian, L. (2008). Inclusion: special or inclusive education: future trends. *British Journal of Special Education, 35*, 202-208.

Glaser, B., & Strauss, A. (1973). *The discovery of grounded theory: Strategies for qualitative research.* Chicago: Aldine.

Goodey, C. (2015). *Learning disability and the inclusion phobia: Past, present, future.* London: Routledge.

Grove. (2005). *Ways into literature: stories, plays and poems for pupils with SEN.* London: David Fulton.

Grove, N., & Park, K. (1998). *Odyssey Now.* London: Jessica Kingsley.

Grove, N., Harwood, J., Henderson, E., Park, K., & Bird, R. (2013). Literacy and stories in the lives of learners with SLD and PMLD. In P. Lacey, R. Ashdown, P. Jones, H. Lawson, & M. Pipe, *The Routledge Companion to Severe, Profound and Multiple Learning Difficulties* (pp. 305-315). London: Routledge.

Han, J., & Neuharth-Pritchett, S. (2015). Meaing-related and print-related interactions between preschoolers and parents dring shared boo rading and their association with emergent literacy skills. *Journal of Research in Childhood Education, 29*, 528-550.

Hass, L. (2008). *Merleau-Ponty's philosophy.* Bloomington: Indiana University Press.

Hochweber, J., & Vieluf, S. (2016). Gender differencs in reading achievement and enjoyment of reading: The role of percieved teaching quality. *The Journal of Educational research, 10*(4), 331-362.

Hollins, S., Egerton, J., & Carpenter, B. (2016). Book clubs for people with intellectual disabilities: The evidence and impact on wellbeing and community participation of reading wordless books. *Advances in Mental Health and Intellectual Disabilities, 10*(5), 275-283.

Kliewer, C., Biklen, D., & Kasa-Hendrickson, C. (2006). Who may be literate? Disability and resistance to the cultural denial of competence. *American Educational Research Journal*, 163-192.

Lacey, P., Ashdown, R., Jones, P., Lawson, H., & Pipe, M. (2015). *The Routledge companion to severe, profound and multiple learning difficulties.* London: Routledge.

Lacey, P., Layton, L., Miller, C., Goldbart, J., & Lawson, H. (2007). What is literacy for students with severe learning difficulties? Exploring conventional and inclusive literacy. *Journal of research in special educational needs, 7*(3), 149-160.

Lawson, H., Layton, L., Goldbart, J., Lacey, P., & Miller, C. (2012). Conceptualisations of literacy and literacy practices for children with severe learning difficulties. *Literacy*(46), 101-108.

Lemons, C., King, S., Davidson, K., Puranik, C., Al Otaiba, S., Fulmer, D., . . . Fidler, D. (2015, 12 2). Developing an early reading intervention aligned with the Down syndrome behavioural phenotype. *Focus on autism and other developmental disabilities*. doi:10.1177/1088357615618941

Lincoln, Y., & Guba, E. (1988). *Naturalistic Enquiry.* London: Sage.

Mar, R., Oatley, K., & Peterson, J. (2009). Exploring the link between reading fiction and empathy: Ruling out individual differences and examining outcomes. *Communications - European Journal of Communication Research, 34*(4), 407-428.

McKenna, J., Shin, M., & Ciullo, S. (2015). Evaluating reading and mathematics instruction for students with learning disabilities. *Learning Disability Quarterly, 38*(4), 195-207.

Ministry of Housing, Communities and Local Government. (2015). *English Indices of Deprivation 2015: Summaries at Local Authority Level.* London: MoHCLG. Retrieved 11 20, 2018, from http://opendatacommunities.org/data/societal-wellbeing/imd/indicesbyla

Mitchell, J., & van der Gaag, A. (2002). Through the eye of the cyclops: Evaluating a multisensory intervention programme for people with complex disabilities. *British Journal of Learning Disabilities, 30*(2), 159-165..

Moje, E., Overby, M., Tysvaer, N., & Morris, K. (2008). The complex world of adolescent litracy: Myths, motivatios and mysteries. *Havard Educational Review, 78*(1), 107-154.

Mol, S., & Jolles, J. (2014). Reading enjoyment amongst non-leisure readers can affect achievement in secondary school. *5*.

Morgan, M., Moni, K. B., & Jobling, M. A. (2006). Code-Breaker: Developing Phonics With a Young Adult With an Intellectual Disability. *Journal of Adolescent & Adult Literacy*(50), 52-65.

Morrisoe, J. (2014). *Literacy changes lives, 2014: A new perspective on health, employment and crime.* London: National Literacy Trust.

Mullis, V., Martin, M., Kennedy, A., & Foy, P. (2007). *Students' reading attitudes, self concept and out of school activities.* Massachusetts: TIMMS and PIRLS International Study Centre.

OECD. (2014). *A teacher's guide to TALIS 2013.* Paris: OECD. Retrieved May 29, 2017, from https://www.oecd.org/edu/school/TALIS-Teachers-Guide.pdf

Organisation for Economic Co-operation and Development. (2011). *PISA 2009 at a glance.* Paris: OECD.

Pahl, K., & Rowsell, J. (2010). *Artifactual literacies: Every object tells a story.* New York: Teachers' College Press.

Park, K. (2004). *Interactive storytelling: Developing Inclusive stories for children and adults.* London: Routledge.

Public Health England. (2016). *Learning Disabilities Observatory: People with learning disabilities in England: Main report.* London: Public Health England. Retrieved August 22, 2018, from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf

Railean, E., Walker, G., Elci, A., & Jackson, L. (2016). *Handbook of research on applied learning theory and design in modern education.* Hershey, PA: IGI Global.

Ratz, C., & Lenhard, W. (2013). Reading skills among students with intellectual disabilities. *Research in developmental disabilities, 34*(5), 1740-1748.

Rohde, L. (2015). *The comprehensive emergent literacy model*. Retrieved 4 19, 2017, from Sage Open: http://sgo.sagepub.com/content/5/1/2158244015577664 Accessed 5/5/2016

Saldana, J. (2011). *Fundamentals of qualitative research.* Oxford: Oxford University Press.

Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*(22), 63-75.

Silverman, D. (2013). *Doing qualitative research: a practical handbook.* London: Sage.

Simmons, B., & Watson, D. (2015). From individualism to co-construction and back again: Rethinking research methodology for children with profound and multiple learning difficulties. *Child Care in Practice, 21*(1), 50-66.

Spangenberg, K., Corten, L., van Rensburg, W., Kilian, E., McKenzie, J., Vorster, H., & Jelsma, J. (2016). The validation of an educational database for children with profound intellectual disabilities. *African Journal of Disability, 5*(1), 1-11.

Sullivan, A. (2015). The life-long benefits of reading for pleasure. *The School Librarian*, 5+.

Sullivan, A., & Brown, M. (2015). Reading for pleasure and progress in vocabulary and mathematics. *British Educational Research Journal, 41*, 971-991. doi:doi:10.1002/berj.3180

Tremain, L. (2005). *Foucault and the government of disability.* Michigan: University of Michigan Press.

Twist, L., Schagan, I., & Hogson, C. (2007). *Progress in International Reading Literacy Study (PIRLS): Reader and reading national report for England, 2006.* London: National Foundation for Educational Research (NFER) and the Department for Children, Schools and Families.

Vasquez, J. (2005). Ethic identity and Chicano litrature: How ethnicity affects reading and rading affects ethnic consciousness. *Ethnic and Racial Studies, 28*(5), 903-924.

Walker, M., & Stevens, E. (2016, February 1). Reading instruction for students with learning disabilities: An observation study synthesis (1980-2014). *Learnign Disability Quarterly*. Retrieved April 21, 2016, from https://doi.org/10.1177/0731948716633868

Young, H., Lambe, L., Fenwich, M., & Hogg, J. (2011). Multi-sensory storytelling as an aid to assisting people with profound intellectual disabilities to cope with sensitive issues; a multiple research methods analysis of engagement and outcomes. *European Journal of Special Needs Education, 26*(2), 127-135.

Zucker, T., Cabell, S., Justice, L., Pentimonti, J., & Daderavek, J. (2013). The role of frequent interactive prekindergarten shared reading in the longitudinal development of language and literacy skills. *Developmental Psychology, 49*(8), 1425-1439.