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Book clubs for people with intellectual disabilities: the evidence and impact on wellbeing and community participation of reading wordless books

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Abstract

Purpose – The purpose of this paper is to introduce the social and scientific rationale for book clubs, whose members read wordless books together, and give examples of storytelling with picture books in libraries and other community settings for people with intellectual disabilities and autism.

Design/methodology/approach – The authors consider the impact of book clubs reading picture books without words, alongside an understanding of the underlying neuroscience (see Table I for search strategy). The authors compare differences in the neuroscience of information and emotion processing between pictures and words. Accounts from book club facilitators illustrate these differences in practice.

Findings – Many readers who struggle with reading and comprehending words, find pictures much easier to understand. Book clubs support community inclusion, as for other people in society. A focus on visual rather than word literacy encourages successful shared reading.

Research limitations/implications – No research has been published about the feasibility and effectiveness of wordless books in community book clubs or shared reading groups. There is very little research on the impact of accessible materials, despite a legal requirement for services to provide reasonable adjustments and the investment of time and resources in developing storylines in pictures, or "translating" information into easy read formats.

Practical implications – Book clubs whose members read picture books without words are growing in number, especially in public libraries in the UK. Expansion is dependent on funding to pay for training for librarians and volunteer facilitators.

Social implications – There is a shortage of fully accessible activities for adults with intellectual disabilities in mainstream community settings with a primarily social purpose.

Originality/value – To the authors' knowledge, this is the first paper describing the theory and impact of wordless book clubs for people who find pictures easier to understand than words.

Keywords Visual literacy, Book clubs, Books Beyond Words, Information and emotion processing, Shared reading, Wordless books

Paper type General review

Background

The first known groups to use wordless books were set up in 1990 to provide bereavement counselling using the first editions of the books *When Dad Died* and *When Mum Died* in the Books Beyond Words series (Hollins *et al.*, 2014a, b, Box 1). Many of the life events and stressors identified as predictable crises in the lives of people with developmental intellectual

disabilities (Levitas and Gilson, 2001), are shown in Table I matched to relevant titles in this series. Healthy living groups now use some of the other titles in the series, and many are used in both individual and group therapy to support and explore life events commonly associated with negative impacts (Hulbert-Williams *et al.*, 2014).

These books are all co-created with people with intellectual disabilities, initially by researching the learning needs of the intended reader, and then extensively trialling the pictorial story line. Some books in the series have been part of the dissemination of scientific research into, for example, the most effective intervention following the death of a parent, but most are simply stories exploring the challenges of everyday life (Hastings *et al.*, 2016).

How do wordless books work?

Some people understand pictures better than words, and for most people, receiving information in two formats simultaneously sets up attentional competition (Hurtado *et al.*, 2014). Greenham *et al.* (2003) suggests that individuals with intellectual disabilities pay selective attention to visual and auditory (as opposed to written) information, and Jacola *et al.* (2014) found evidence for an

Table I Mapping Books Beyond Words to predictable crises[a] in the lives of people with DID

Crises in left column map to Books Beyond Words (BBW)[b] series titles in right column

Crisis	Supporting titles from BBW series
Initial diagnosis of DID	
Birth of siblings	*Sonia is Feeling Sad*
Starting school/college	*Speaking up for Myself*
Puberty and adolescence	*Susan's Growing up*; *George Gets Smart*
Sex and dating	*Falling in Love*; *Loving Each Other Safely*
Being surpassed by younger siblings	*Michelle Finds a Voice*
Emancipation of siblings	*Sonia's Feeling Sad*
End of education	*George Gets Smart*; *Speaking up for Myself*
Out-of-home placement/residential moves	*A New Home in the Community*; *Finding a Safe Place*; *Ann Has Dementia*
Staff/individual relationships	*Feeling Cross and Sorting it out*; *Enjoying Sport and Exercise*; *The Drama Group*
Inappropriate expectation	*Hug Me Touch Me*; *Making Friends*
Ageing, illness, death of parents	*When Mum Died*; *When Dad Died*
Death of peers, loss of friends	*When Somebody Dies*
Medical illness/psychiatric illness	*Getting on with Cancer*; *Ron's Feeling Blue*; *Getting on with Diabetes Type 1, Type 2, Epilepsy*; *Looking After my Heart*; *Am I Going to Die?*
Deinstitutionalization	*A New Home in the Community*; *Peter's New Home*
Traumatic events	*Jenny Speaks Out*; *Bob Tells All*; *Mugged*; *When Dad Hurts Mum*; *I Can Get Through it*; *Mugged*; *You're Under Arrest*

Notes: [a]Adapted from Levitas and Gilson (2001) predictable crises in the lives of people with DID; [b]Books Beyond Words, London, http://booksbeyondwords.co.uk/
Source: © Bradley *et al.* (in press)

atypical pattern of functional organisation for auditory language processing in young people with Down syndrome in an fMRI study.

Hibbing and Rankin-Erickson's review of literature showed that rather than creating associated mind-images, as most proficient readers seem to do when reading, struggling readers focussed only on the decoding of words. Such mental images enhanced a reader's ability to recall information, draw inferences and make predictions from text, and readers who visualise in this way have been shown to learn two to three times as much as those whose strategy is to repeatedly re-read the text (Hibbing and Rankin-Erickson, 2003). Some students found it difficult to focus their attention or to decode words because of their limited vocabulary or background knowledge. Others did not understand critical features in the setting or spatial relationships between characters or items discussed in the text. Supporting understanding through pictures was found to resolve these difficulties, by enabling their students to identify the main idea and events of the story and to track the story's action. The pictures also helped to activate their background knowledge, reflect and make predictions about what might happen (Box 2).

Accessibility beyond words

Many readers with learning and communication difficulties struggle with reading and comprehending words at single-word level. At paragraph (story) level the cognitive demands are even greater. Reading for meaning at this level requires complex brain processing including "integration [e.g. social, emotional, and lexical information], inference, and derivation of overall meaning based on previous knowledge, as well as phonological, syntactic and semantic information" (Berl et al., 2010; Maltese et al., 2012). These activities place heavy demands on working memory and executive function processes (e.g. the need to refer, hold competing models of interpretation and prioritise key information). These are areas in which people with learning and communication difficulties are often challenged (op. cit.). The Books Beyond Words picture sequence structure enables them to explore the issues, concerns and life experiences they face as adults and, with guidance from family, supporters and professionals, can help to integrate the reader's personal engagement, contributions and interactions (Bradley and Hollins, 2013). The stories develop an understanding of the different perspectives and feelings of the characters and of the relationships involved.

What are beyond words book clubs?

The first Beyond Words community based book club was started by a direct support worker in 2009 for some of her clients, with the help of one of the authors, initially in the service provider's office, but later transferred to the community library. Since then Beyond Words Book Clubs have been set up throughout the UK, mostly in public libraries.

Box 2: Books Beyond Words

The Books Beyond Words series includes 50 titles, which address most life areas in a story format. Of particular relevance to this journal's readership are books about living a healthy life style, the ups and downs of family life and relationships, understanding life and how a community works for its citizens including the criminal justice system. Each book is "road-tested" during its development by Books Beyond Words advisers, always including people with developmental intellectual disabilities and family carers as well as relevant health and social care professionals and educators (Hastings et al., 2016). The books cover everyday experiences for people of all ages, including young people approaching the transition to adult life, and are therefore helpful for older schoolchildren and school leavers (Carpenter et al. (2016a, b). The neuroscience behind the understanding of narrative and emotion in pictures is covered elsewhere, and the books use in clinical and therapeutic settings is well established, both in one to word clinical encounters but also in groups.

The features of a Sustainable Book Club or shared reading group model include regular meetings in small groups led by a trained volunteer facilitator who ensures that book club members are involved in some of the decisions that determine the character of an individual group. These features are described by both The Reader Organisation in the UK which has begun to extend its shared reading groups to people with intellectual disabilities, and by the Next Chapter Book Clubs in the USA (Fish *et al.*, 2006), that typically meet in bookshops and café's to read literature, as well as by Beyond Words Book Clubs reading wordless books (Carmichael, 2015).

One Beyond Words Book Club facilitator reported that having a large selection of books available for everyone to review, for example on the shelves, is a great way to help people to choose. Many have chosen books about something that relates to them like epilepsy or losing their temper. Almost all groups want to read a love story as an early choice. One group made their own version of this story taking up where the book left off. Another group chose to read a book about diabetes when a member's dad was newly diagnosed (Carmichael, 2015; Hollins *et al.*, 2012). Beyond Words worked with nine Kent Book Clubs to develop three fantasy storybooks, now published in the series (Aulton and Kent Library Book Clubs, 2016; Bergonzi and Kent Library Book Clubs, 2016; Weigart and Kent Library Book Clubs, 2016).

Building interpersonal skills and working as a team

Interpersonal skills are important and offer "opportunities for inclusion into local community life and culture" as well as friendships. Maintaining friendship networks can be very difficult for people with intellectual disabilities, especially bridging the transition from school to adult life. They "often lack the opportunities and/or social skills necessary to participate in social events without adequate supports" (Fish *et al.*, 2006).

In addition to functional skills, individuals with intellectual disabilities need to gain a range of skills to enable them to participate and self-determine (Cabeza *et al.*, 2013). Beyond Words Book Clubs support the development of those team skills by giving experience, guidance and opportunities to contribute to and manage group storytelling. The book clubs provide "real life" situations in which to practice these skills on a regular basis, bringing added value to participants' daily lives (Carmichael, 2015). Bollard (2010) described the perspectives expressed by co-researchers with intellectual disabilities involved in team-working research. When asked about what made teams work badly, their responses summarised by the facilitators included:

> Poor communication and miscommunications; poor prioritisation; no eye contact; lack of respect for others' ideas; rejecting and ignoring people.

When asked about what made teams work well, their thoughts were:

> Working together, sticking together and pulling together; liking each other; talking to each other; respecting each other; clear, precise communication and use of appropriate sign language; thinking before speaking; regular meetings; good time keeping; smart appearance; being professional, kind, polite and respectful; doing things for other people; good team leadership; showing people how to do things.

They advised that professionals involved in a group needed to find out about group members' values and receive training to understand and support people with intellectual disabilities to participate (e.g. to adopt the Rights-Inclusion-Choice-Independence principles in Department of Health, 2001; Bollard, 2010).

Book club facilitators within the groups encourage these positive attitudes and skills, which are essential for the wellbeing of the members and for the sustainability of the group.

Beyond Words has developed an approach called "co-creative reading", as a form of total communication. This includes recognition of and response to gesture, body language and other physical signals, facial expressions and eye contact which is taught in Beyond Words workshops (Carpenter *et al.*, 2016b). Within the co-creative relationship, readers draw on a range of communicative skills including: recognising symbolic and literal meaning, estimating and imagining, conceptualising and negotiating.

Exploring pictures and contributing to a narrative within an existing frame of a story can promote feelings of ownership and an investment of individual creativity that is both exciting and enjoyable. Recognising feelings through our co-creative reading process and exploring different layers of the story may encourage readers to explore emotional language within the context of a narrative. The validation of individual ideas through collaboration builds confidence.

The co-creative exploration, mutual understanding and acceptance involved in creating a shared narrative, within the frame offered by the pictures, build and strengthen relationships. This co-creative approach promotes the positive feelings associated with teamwork including empathy between communication partners. They may lead to a deeper understanding of our inner emotional landscape as individuals in proximity with other readers – in pairs, in groups and in the broader social context.

The skills needed to read or listen to a story

In 2011, Wendy Lukehart, Youth Collections Coordinator for the District of Columbia Public Library, Washington, wrote:

> Wordless books offer a bounty of riches. The format is accessible to everyone regardless of language or reading ability, making the books ideal for use in international settings, classes with non-native speakers, or families with adults or children who are struggling or emergent readers […] [and] "mainstream" or "gifted" children as well […].

Lukehart explains that people use a number of different skills in decoding and interpreting pictures meaningfully compared with reading words. Her comments mirror the experience of mental health professionals and carers who find that picture stories stimulate language and thought, and help the reader – their patient or client – to understand the different perspectives of the characters in the story. The primary aim of Books Beyond Words publications is to enable people with intellectual disabilities and autism to explore, understand and participate in their world (Bradley and Hollins, 2013). As part of this, the books inform, prepare and reassure readers. It is therefore essential that the readers are focussed on the content of the book instead of their "reading anxiety" due to worries about decoding and understanding text (Carpenter *et al.*, 2016a).

Comments from and about some members of Beyond Words Book Clubs:

> Cathy, who has Down's Syndrome, is a regular book club member where Books Beyond Words books are read. Cathy told one of the authors that she can read novels and her parents are proud of her achievements, but she doesn't get nearly as much enjoyment from them as she does from wordless books. She said: "now I know that other people have feelings just like me!".

Cathy's experience of pictures being effective in arousing emotion supports Hibbing and Rankin-Erickson's (2003) findings (Carpenter *et al.*, 2016b):

> Another book club member was initially clear that she could not read and was anxious going into the library and getting close to the books. The first experience of a story reduced this anxiety and she contributed well. She continued to attend and be a lively and reflective group member. After some time it became apparent that this person could read and write to some degree. She made a cake for a leaving party for a librarian and wrote her name out on the top. Later still she accessed literacy classes but continues to attend the book club as she enjoys it so much (Carmichael, personal communication).

Overcoming barriers to community inclusion

Although people with intellectual disabilities live in their community, they often meet with exclusion in the form of limited opportunities, patronising attitudes and segregated social experiences. Many of their fundamental community needs are neither identified nor supported. In a Next Chapter Book Club survey, members described how they had experienced people treating them as though they had an illness, discrimination, poverty, loneliness, vulnerability to abuse and violence (Fish *et al.*, 2006). Hollins (2014) observes that effective support for people with intellectual disabilities must be grounded in their real lives, and that supporters need to listen with "a different quality of attentiveness […] grounded in a basic understanding of their daily experiences". For example, opportunities for social spontaneity are often reduced for people with

intellectual disabilities due to their reliance on others for transport and support. However, people love to be asked about their ideas, feelings, and opinions, and group support is a key ingredient for life-long learning activities (Fish and Beu, 2014).

Creating a social hub

Sense (2015) have identified that "the isolation of disabled people and the obstacles they face in making friends needs to be tackled as a matter of urgency". In the 2015 Sense survey of 1,000 disabled people, 53 per cent reported feeling lonely. In total, 23 per cent of these reported being lonely on a typical day and 6 per cent that they had no friends. Nearly one in three reported seeing friends once a month or less. If this is scaled up in terms of the national population of 11.6 million disabled people (0.8 million children. 5.7 million adults of working age and 5.1 million over state pension age; Office for Disability Issues, 2014), the need for action becomes obvious.

Respondents felt that their lives would improve if there were more accessible transport (20 per cent), and more local support and social groups (17 per cent). There are also attitude issues to overcome in the community. Sense noted a recent research finding that 21 per cent of 18-34 year olds surveyed had actively avoided talking to a disabled person because they were not sure how to communicate with them.

The contribution of Beyond Words Book Clubs to social engagement

The experience of reading stories in pictures, without words, goes beyond supporting readers' health and therapeutic needs. Book clubs become a social hub for readers as well as a springboard for social activities (e.g. coffee shop socialising, theatre group membership; trips to art galleries; and the valued, everyday interactions with people within their communities; etc.). All these create the knowing, belonging, recognition, confidence in their neighbourhood and self-esteem that most people take for granted, but which are part of the habilitative programmes needed by so many adults with intellectual disabilities:

> At the end of her first session at a Beyond Words Book Club I asked Claire if it had been OK. She said she had really enjoyed it and was going to speak to her Nan that evening and tell her that she had joined a book club in the Library, and when was the next meeting. She spoke with pride (Carmichael, personal communication).

Beyond Words Book Clubs take wordless books beyond the therapeutic into the social and community domains, bringing benefits such as social connectedness and community inclusion. They are held in community venues to bridge the divide between people with intellectual disabilities and other community members, and to foster connections. Members gain familiarity with community facilities, the people who work there, and everyday community activities, such as meeting friends in a coffee shop, ordering and paying for refreshment, and interacting with other people in passing. One book club member now helps out in the library with other events as a volunteer and was featured in the local paper (Carmichael, personal communication).

All this increases independence, access to community facilities and the likelihood of opportunities for work and has many of the hallmarks of a recovery approach to mental health.

Incentives to continue reading such as the six-book challenge offered by some libraries may be positive, but are best introduced once a group is well established as the goal might initially seem too difficult if books have not previously been a part of members lives. The schemes typically award certificates and small rewards such as mugs and bags on completion of reading six books (Carmichael, 2015).

The book clubs are facilitated by a leader who guides, encourages, draws out, supports, includes, models, enables and mediates thinking, reflection, contributions and appropriate social interactions. They aim to create an experience that is non-threatening and minimally directive (Carmichael, 2015). In line with Cassady's (1998) advice, the Beyond Words Book Club leader takes the role of coach and collaborator. He or she listens and observes, sometimes interacting, sometimes prompting when needed. Leaders may model how the book pictures tell a story, but also give readers space to use their own way of expressing themselves in a safe and supportive situation without being "corrected" or told what to look at (Cassady, 1998).

In some cases, reading wordless books can have a very fast and profound impact:

> During a pop-up book club at the Mental Wealth Festival at the City Lit in 2015, some students on a course for adults with intellectual disabilities joined in. One young man, accompanied by his tutor, joined a small group that had just started reading a book. The participants were taking turns to say how they thought the story was unfolding. At his turn, the young man spoke very quickly with a stream of consciousness style of speech, describing objects in the pictures and comparing things he recognised to his own life. The young man's tutor later told the book club facilitator that this particular man had been in her classes for about a year and had not spoken to her at all (Smagala, personal communication).

Longer-term benefits are described in groups after members have become comfortable in a trusting environment. After one book club had been running for about a year the members decided they wanted to read a "difficult" story. One member chose "Am I Going to Die" for the group to read (Tuffrey-Wijne *et al.* 2009):

> When we had finished he told us his sister was dying. The group was very supportive and impressed that he had felt able to share this with us. The group subsequently has felt able to discuss some other difficult things in their lives around death and suffering, but they also helped write a story about a trip to the beach, which was fun (Carmichael, personal communication).

A nurse therapist specialising in working with people with intellectual disabilities and autism describes the impact of a book group in a mental health day service for everyone participating showing how Beyond Words Book Club can also have a therapeutic purpose:

> Beyond Words is something additional to education […] something, which takes us back to notions of equality and of empowerment […] essentially something, which is personally meaningful. A person may be able to reframe themselves in the light of the expression of their own stories; presenting a new, more skilled and empowered version of who they now are. Importantly the story, and our understanding, will be authored and led by the reader. An important element in our working definition of empowerment is its group dimension […] a sense of connectedness with other people. Our book groups [and 1:1 sessions] are an excellent vehicle for this […] the shared development of a narrative can flatten the power differentials that often exist between us all (Williams, 2013).

Cassady (1998) identifies the following reader freedoms in book clubs and warns leaders not to inhibit speakers by continual correction and questioning. Cassady states that the oral story-telling experience should include:

Freedom from word decoding enabling the reader to engage with higher order thinking within a more complex story.

Freedom from a required form of expression leading to more complex talk and more connections made inside and outside the story.

Freedom to apply emotion and influence the plot to create a flexible and meaningful story or to interpret the scenario from their own emotional context.

Freedom to identify with the characters, thus encouraging readers to develop their social imagination and empathy.

Conclusion

Many readers with learning and communication difficulties struggle with reading and comprehending words but find pictures much easier to understand suggesting that some people have better visual literacy than word literacy. The abilities of people with intellectual disabilities and autism are often underestimated, leading to low self-esteem and self-agency (Salman, 2014). Clubs and groups have been shown to raise people's sense of achievement and quality of life. Clubs and groups challenge and change community and staff perceptions and expectations of how people with intellectual disabilities can live and contribute to their community. Book clubs are providing an effective way to support community inclusion. This paper concludes that the theoretical evidence for visual literacy supports the growing anecdotal evidence for the effectiveness of wordless books, but that there is ample scope for further research.

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