Beyond Words

 A manual to help understand the theory and practice

For anyone working with, supporting or just interested in those with learning disabilities and autism in education, health care, social care, and the community

Version 1 completed in 2016

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A note on terminology

Different professionals in the United Kingdom and in other countries use different terms to refer to broadly the same group of people: people with learning difficulties/disabilities, intellectual disabilities, developmental disabilities and older terminology which is now considered pejorative such as mental handicap or mental retardation. In this manual, we have chosen to use the term ‘people' to be as inclusive as possible whilst making clear that the Beyond Words method was co-developed with people with developmental learning/intellectual disabilities and people with autism (we use the term **‘people with learning disabilities’** when specifying this group).

We also follow the Beyond Words practice of using the term **‘self-advocate’** to refer to any person with learning disabilities who is active in making his or her voice heard, with or without another person acting as supporter.

Section 1 Introduction

This manual is for people who would like to know more about the Beyond Words books: why they were created, how they are created, how to enable their use as they were intended to be used (‘with fidelity’) in a variety of contexts, what training is available to support their use, and what the evidence of their impact is to date. In this first section, we cover the mission, ethos and core values of Beyond Words and briefly describe the context that explains why the books are required.

1.1 Mission, ethos and core values

Beyond Words books are stories about real life, read individually or in groups, usually with support, to allow and empower people to flourish in our often confusing, information-driven world, ensuring that their experiences and voices are understood, validated and valued.

Figure 1 The Beyond Words mission

|  |
| --- |
| **Thinking in pictures**People who can’t read or who don’t like written words are often very good at reading pictures. That’s why there are no words in our picture stories. Our books all tell a story, but they also let the reader tell their own story – the one they see in the pictures. This can tell you a lot about a person’s inner world and their understanding of situations. There is plenty to talk about and each story explores feelings and relationships as well as giving information. All the pictures used in our books are tested by people who find pictures easier than words, to make sure they are easy to understand.  **Removing barriers**For someone who struggles with words, there are a lot of barriers to getting the right health or social care and support. Even when a person with a problem reaches someone who can help, like a doctor, a social worker or a therapist, there can be communication problems and anxieties on both sides.By telling the whole story in pictures, each Books Beyond Words narrative gives people the chance to work together and explore different types of situations; for example:* everyday opportunities and experiences
* things that are about to happen, like going to hospital or appearing in court
* life decisions, like having a relationship or agreeing to an operation.
* things that have already happened, like abuse or losing someone you love.

From the Beyond Words website |

The ethos of Beyond Words is rooted in fundamental core values:

* That, as human beings, whatever our intellectual or emotional capacity or impairment, we have **a right to communicate** our feelings, thoughts, needs, wishes and desires and to be treated as **equal partners in that communication**
* That getting it right for people with learning disabilities will get it right for everyone
* That people with relevant lived experience have **a right to bring their expertise** to the table in the **co-production** of the books
* That we should respond to people’s experiences and views with **acceptance** and should **validate** these as being **legitimate and understandable** even if we hold different views
* That all people have a right to be **empowered** to make **informed choices** affecting their lives – and that the books should support this.

1.2 How the method began

The genesis of the method was rooted in personal experience and professional practice. It was driven by the Founder’s need to find a way to communicate with her son (Figure 2).

Figure 2 How Beyond Words started

|  |
| --- |
| In the 1980s Professor Sheila Hollins looked for pictures to help people with learning disabilities to understand their feelings following trauma. Almost nothing was available. Children’s picture books were on offer, but they could not help people talk about or understand adult feelings and adult experiences.Sheila had noticed how much pleasure her teenage son, who had a learning disability, got from silent movies and children's picture books. She had also found that by drawing pictures she could help her son to understand and prepare for what was happening in his life and that this reduced his anxiety. She decided that she would put picture books together herself and publish them. She began work with her son, illustrator Beth Webb, and psychiatrist Dr Lester Sireling. Our first books, When Mum Died and When Dad Died, published in 1989 are still going strong today.Books Beyond Words is now an award-winning series published by Beyond Words and edited by Professor Hollins. Professor Hollins is also the lead author for most of the series, and each book is co-authored by senior experts in the field. Fifty titles have been published since 1989, and all have been co-produced with people who find pictures easier than words, with family carers, support staff and professionals.As well as picture books, Beyond Words also offers:* regular workshops about how to use the books
* bespoke training for organisations
* help with setting up a local book club
* eBooks and translations of our supporting text in several languages.

Beyond Words is a small not-for-profit social enterprise set up in 2011. We are a spin out from St. George’s University of London where our Executive Chair, Baroness Hollins, is Emeritus Professor of the Psychiatry of Disability. The Books Beyond Words series has been helping people to understand their world since 1989.From the Beyond Words website |

1.3 The context

Struggling with understanding information and relationships is an everyday problem for more than 2% of the population in every country around the globe who have learning disabilities. In today’s world, lack of access to high quality information and difficulties in communicating with other people, mean that people with learning disabilities are **disadvantaged and excluded**. Research tells us that **people with learning disabilities face serious** **inequalities in health** (e.g., they die younger, receive poorer quality care, and have more mental health difficulties), in **socio-economic domains** (e.g., very few adults with learning disabilities have a job, families are more likely to live in poverty), in **education** (educational outcomes are poor, including difficulties with reading), and in **quality of life** (disability hate crime is common, many lack access to leisure and other activities and friendships are rare). Contributing to these inequalities are the closely related problems of: (a) **accessing and understanding information**, and (b) **communicating and sharing with other people** about both difficult problems and the everyday activities of life.

Since the 1970s-80s there has been a growing adoption of the **social model of disability** which, rather than focussing on deficits and impairments in the individual, emphasises the negative attitudes, barriers and exclusion that occurs within the systems of societies. These are the most significant factors responsible for disabling people. Physical, functional and psychological impairments do not necessarily lead to an individual being disabled or handicapped if the society and environment around them is able to respond in ways that meet their needs irrespective of differences. Sometimes however, an overzealous adherence to the social disability model has meant that significant impairments, physical and mental disease processes have been overlooked; there is a paradox in that people often need to acquire diagnostic labels in order for services to recognise and respond to their need. Beyond Words highlights very real problems that people encounter in life, including challenges to mental health and physical health and address these in an individualised way. Beyond Words enables professionals, carers, educators and others to understand the very personal nature of an individual’s life and condition.

Section 2 The unique Beyond Words method

This section begins with a summary of the drawbacks of Easy Read, the widely used and accepted current approach to making information accessible for people. Because Beyond Words seeks to do much more than give information, it is based on narrative approaches using pictures, not words, to enable expression of feelings and points of view of different characters and the use of the reader’s own imagination. This section therefore summarises the science that informs the Beyond Words method, followed by a brief description of the robust co-production process through which the books are developed, and ends with some principles underpinning how the books should be read. Together, these three aspects encapsulate the unique Beyond Words method.

2.1 Beyond Easy Read

2.1.1 The current approach

The dominant and accepted approach to making information accessible for people with learning disabilities, and to providing the context for communicating with others, is known as “Easy Read”. This approach **presents information** using **simplified text**, larger font, short sentences, shorter paragraphs to emphasise separate points, and **adds illustrations or symbols** to accompany the text.

Detailed guidance for those who produce or commission Easy Read information has been published by the UK Department of Health (DoH, 2010). The DoH guidance makes it clear that Easy Read is not the only way to communicate with/provide information for people with learning disabilities. However, within the UK national health service (NHS), approximately 80% of organisations reported using Easy Read to make information about health problems, health promotion, their rights as patients, and complaints procedures available to people with learning disabilities (IHAL, 2011).

2.1.2 No clarity about the effectiveness of Easy Read

Given the dominant position of Easy Read as a way of providing information to people, it is important to ask about the evidence base for its effectiveness. Here we review the available literature to assess the effectiveness of Easy Read and to explain why there is a need for the different Beyond Words approach.

A small research literature has emerged that both informs the presentation of Easy Read information and examines its effectiveness as a means of providing information. In an early study, Strydom and others (2001) worked with people with learning disabilities to design information sheets about medicines. Participants **preferred line drawn pictures** rather than more abstract symbols to accompany simplified text. Strydom and Hall (2001) then tested the new leaflets in a randomised controlled trial in which half of the 54 participants with learning disabilities were given verbal information only about their medications and the other half were given the verbal information and the leaflet. Knowledge about the medications was no different between these two groups suggesting that adding Easy Read information to verbal information did **not** provide additional benefit in terms of understanding. Other researchers have tested components of Easy Read material. For example, Dye and others. (2007) developed an Easy Read text passage to explain a research study that they were conducting. Participants were either read the passage and then asked consent questions, or read the passage in short sections followed by the relevant consent questions, or read the passage with accompanying photographs. Ability to consent to the research was found to be **no different** across the three conditions. In addition, only 6% of participants were able to provide evidence that they understood all of the requirements of the research study, which could be seen as the most robust criterion to determine ability to consent. Thus, none of the methods for presenting the research study information appeared to help participants’ understanding. As far as can be determined from the description of the research study, participants were not given access to a printed copy of the Easy Read text information about the research.

Poncelas and Murphy (2007) tested the effectiveness of Easy Read textual information presented with or without accompanying symbols (considered to be a part of good practice). Thirty-four adults with learning disabilities were allocated randomly to receive election manifesto information in Easy Read format without pictures, or the same Easy Read information with accompanying pictures. **No group differences** were found in relation to understanding the election manifesto information. In a further randomised trial, Hurtado and others (2014) presented full Easy Read information (following national guidelines, and including accompany pictures) versus pictures alone to adults with learning disabilities attending psychology services. For both conditions, the text information was read out loud to participants. Again, **no differences** were found in participants’ understanding of information between the two conditions. These two studies suggest that adding pictures to Easy Read text does not lead to advantages in terms of understanding. Hurtado and others did note that knowledge improved under both of their experimental conditions.

Ferguson and Murphy (2014) examined a two-stage process for testing the understanding of adults with learning disabilities about their medications. First, all 28 participants were given Easy Read information sheets including pictorial information. **No changes** in understanding were found from before the provision of the Easy Read information to afterwards. Participants then took part in three short training sessions about the reasons for prescribing the medications, the way that the medications might be to expected function, positive effects and side effects, alternatives to medication, and their individual rights. This training used **group exercises, group discussion, and a variety of methods to present information. Increases in understanding were found** after the training.

Summary

The existing research on Easy Read formats for people with learning disabilities lacks consistency in terms of design and the questions asked. Therefore, it is quite **difficult to draw clear conclusions**. Perhaps because of accepted best practice, we could locate no robust test of Easy Read information compared with non-adapted information provided to people with learning disabilities. Research results are mixed in terms of whether providing Easy Read information alone can improve understanding. Adding pictures to Easy Read text does not seem to lead to advantages in understanding. Presenting Easy Read information alone, in the absence of additional training and support may not be effective, but **it is clear that individuals with learning disabilities can improve their understanding of key issues for them with training and support** (Ferguson & Murphy, 2014) – see also Section 3.1.5 for use of pictures in research.

2.2 The science that informs the Beyond Words method

Like Easy Read, Beyond Words is an approach that can be used with people to increase understanding of key information. Unlike Easy Read, the Beyond Words method is used in the context of an interaction, or series of interactions, focused on a **picture-based** (not text-based) book. In addition, Beyond Words is not only about improving the understanding of people with learning disabilities; the books also serve other purposes. (See Section 3.1 for a description of the ways in which Beyond Words books are used). Beyond Words’ books are used in practice as a context for building relationships between people with learning disabilities and others.

A number of key concepts, values-based principles, and theoretical ideas have been used to inform the Beyond Words approach. These ideas do not represent the totality of the rationale for the Beyond Words approach, since this has been built partly on the basis of experience from practice. However, these ideas do provide a link to key concepts and theoretical perspectives in the wider literature. Each key idea is introduced briefly below.

2.2.1 Concepts informing the Beyond Words method

Insights from psychodynamic research and practice

The Beyond Words approach is fundamentally informed by key concepts in the discipline of psychodynamic psychotherapy. The founder, Baroness Hollins, is a psychiatrist and psychotherapist. Every book to date (2015) has had at least one psychotherapist as a co-author. How people **feel** about themselves and about others and how people **relate** to each other are core elements of the story in every book. The pictures are a way of communicating about feelings and relationships in a manner that the reader can respond to. The active part of what the reader brings to the book mirrors the active participation of the client in psychotherapy, reading and narrating their personal story in the same way that a client ‘draws’ on the ‘blank canvas’ of the therapy setting. The expectation that the professional, practitioner or supporter, with whom the person with learning disabilities reads the book, will be **tuned in and empathic** to him or her and able to be aware of and reflect on the emotions engendered in the shared reading process, also mirrors an element of the role of the psychotherapist. The courageous step of addressing some serious and difficult topics in the books is also rooted in a psychotherapeutic focus on working through **two-way communication** to identify, and ultimately resolve, problematic issues and relationships.

Co-production

Beyond Words books are produced following a clear process that has developed over time (see Section 2.3). At the core of this process is a commitment to co-production (e.g., Boyle & Harris, 2009). This means more than simply involving people representative of the expected readership in the book development process; it means working together with them as **equal partners** who bring their own expertise and experience to the process, alongside other experts in the topic area of a book who bring their own perspectives to the process, as do the artists and editors. In this way, each book is co-produced and emerges from the interplay among the different expert perspectives.

Experimental developmental psychology: visual literacy and pictorial competence

Information and meaning does not need to be presented in text formats, or verbally; these can be conveyed visually, using pictures or other visual medium. Visual representation can be used as an alternative to text or talking but can also be used alongside either or both, as a medium of equal value.

The science behind the Beyond Words approach draws on the concept of **visual literacy**, a useful definition of which is:

“A group of skills which enable an individual to understand and use visuals for **intentionally communicating with others**” (Ausburn & Ausburn, 1978, p. 291).

The Beyond Words books are based on the assumption (rooted in experience) that many people with learning disabilities find pictures much easier to understand than words; and that pictures enable them to structure their understanding of the world around them. Beyond Words acknowledges that some people with learning disabilities will understand concrete objects in context better than pictures but that, for most, pictures are a powerful communication tool. Beyond Words also recognises that through repeated practice and teaching/support, people can develop visual literacy skills in a similar way to the learning of textual literacy skills. That is, just as people can be taught how to read text, they can be taught how to ‘read’ visual representations; i.e. ‘to understand and use visuals for intentionally communicating with others’ (as in the quote above).

Visual literacy skills can be thought of as a type of **pictorial competence**, defined as:

“The many factors that are involved in perceiving, interpreting, understanding, and using pictures” (DeLoache and others, 2003, p. 114).

Pictorial competence is a broader concept than visual literacy because it covers art (e.g., appreciation of art) and the social, and psychological dimensions of pictures. In developmental psychology, there is a recognition that pictures are symbolic artefacts that encompass a dual representation: the picture is an object itself, and stands for something else (DeLoache and others, 2003). To be able to use and understand pictures successfully, this duality needs to be understood.

Experimental developmental psychology research suggests that pictorial competence in infants is established by experience or exposure to material **in the context of a relationship** with a caregiver. This implies that pictorial competence in general is **a skill that can be taught**. Indeed, some research suggests that individuals with significant learning disabilities can be taught to read/understand pictures. For example, Cihok (2007) taught young people with autism to understand pictures by breaking down the skills into a series of steps: identifying the people in the pictures, identifying objects, identifying actions, and so on. Such research provides a scientific base for the Beyond Words method which involves a supporter and a reader in a working relationship, where the supporter coaches the reader in the skills of pictorial competence by using a set of open questions (set out in Figure 7, section 2. 4) very similar to the steps used by Cihok (2007).

Health research: literacy as a social phenomenon

In the field of health literacy (understanding one’s own health, health behaviours, one’s own health problems etc.), some authors consider health literacy to be, “a situated social practice…a shared resource frequently achieved collectively by groups of people, for example families” (Papen, 2009, p.19). This is a challenge to the dominant view of health literacy as an ability possessed by individuals that is transferrable to different contexts, and measurable by tests of knowledge. This **socially situated** notion of health literacy (and potentially other dimensions of understanding) has profound implications for working with people with learning disabilities.

This view of health literacy is reflected in the Beyond Words approach which is based on a strong relationship between supporter and reader, the picture book as a shared means of communicating about a focused topic, and the ability of the reader to develop understanding over time through repeated use/exposure to the book/s.

Story-telling

Stories have been part of human society in all cultures and from the earliest times The Beyond Words books each tell a story, even the ones that, on the face of it, are mainly intended to provide information. The **narrative content** is central to every book and is a key difference between a Beyond Words book and Easy Read information. The underpinning assumption is that this narrative structure, by mirroring the timeline of life (beginning, middle, end), supports communication and understanding: something happens and then some other things happen and then there is a resolution or some conclusion.

The narrative in each book also has a **relational** element. They are about feelings and how people relate to each other. In many of the books, the narrative also has a **therapeutic purpose**. There is an **emotional content**, as well as a **factual one**. This is there to support people with learning disabilities to tell their own story, ask their own questions and reflect on their feelings. It requires the professional, practitioner or carer supporting the reader to give space and time to allow this process to take place. When the book topic confronts difficult issues, such as dying, serious ill-health, domestic abuse, sexual abuse, it also requires the supporter to have patience and empathy to sit with the person through their feelings of emotional pain and upset, seeking to understand that. The pictures act as a way of communicating emotions to elicit a response from the reader. The **power of the pictures** covering difficult topics can be likened to elements of what happens in a psychotherapeutic relationship: looking at the picture is similar to naming the fear; having seen the picture, the difficult topic cannot be avoided.

2.2.2 The Beyond Words Theory of Change

The logic behind the Beyond Words books is that they are designed **to remove barriers to understanding and communication** and thus to reduce anxiety about unknown and confusing situations by providing a shared communication tool, which presents a narrative in pictures. This is encapsulated in the **logic model** set out in Figure 3.

Figure 3 Beyond Words Logic Model

The Beyond Words logic model is underpinned by the **need to remove barriers to communication** between people with learning difficulties and others, thus promoting equality of human rights and respect.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Ultimate aim** | **Aim** | **Intended outcomes** | **Hypothesis** | **Intervention activities** | **Activities** |
| To promote equality of human rights and respect by encouraging professionals/others interacting with people with learning disabilities to use the books in a way that **enables the reader** to communicate his/her feelings, needs, choices, wishes, thoughts, views and experiences and **expects the listener** to respond to these with acceptance and validation | To improve communication by removing barriers to communication between the reader (the person with learning disabilities) and the ‘listener’ (the professional/other supporter) | * Enhanced relationship between reader and professional/other supporter.

For the reader:* Experience of being a reader
* (all the books) Improved understanding/Improved communication of own feelings, thoughts, choices, desires, wishes/Reduced anxiety
* (book specific) Improved understanding/knowledge/ability to communicate own perspective in relation to the topic

For the professional/ other supporter (‘listener’):* Experience of listening and/or observing, of paying attention to the reader
* Increased empathy/increased understanding of the reader
 | That reading the books, supported by a professional/other supporter behaving in accordance with the Beyond Words ethos, will lead to positive changes.Unknowns: What ‘dosage’ is needed? (One book? Multiple books? Specific, meaningful pictures?) What period of time is required? How many repetitions of reading Beyond Words book/s are required to create the desired changes? What difference does reading in a group make? | Books are read in a range of contexts by people with learning disabilities/people who prefer pictures to words, supported, ideally\* in accordance with the Beyond Words ethos by a professional/other supporter.\*Note: Not in Beyond Words’ control | 1. Co-production of **Beyond Words books which present a narrative in pictures**2. Articulation of critical success factors about **how the reader should be supported** (‘the Beyond Words ethos’) provided:a) in writing: the Supporting Text included at end of each book b) face-to-face: the training sessions |

|  |
| --- |
| **Inputs** |
| * Create and run the organisation, Beyond Words, including group of lead people who define and articulate the ethos
* Selection of topics
* Sourcing of funding/grants to finance co-production of the books
* Co-production of books without words
* Includes involvement (and coaching/support) of people with learning difficulties affected by the topic; expert author; co-author/s; artist; editorial team; trialling groups and individuals who can facilitate trialling of the drafts
* Building and maintaining relationship with artist/s; with those working with people with learning difficulties in a range of clinical and community settings
* Link with publisher
* Marketing of the books: via website; word of mouth; at conferences; through funder networks
* Link with distributor
* Training
* Train the trainer
* Support setting up of book clubs
* Monitoring of activity
* Evaluation of training, of book clubs, of book use
 |

A theory of change is a way of encapsulating **how** the ‘service’ or ‘intervention’ **reduces risk factor/s and/or enhances protective factor/s** for the population of interest. Figure 4 is an attempt to do this for Beyond Words. It shows that the ‘books as communication tools’ is only one aspect of how and why Books Beyond Words reduce barriers to communication. The way people are trained/encouraged to use the books is also part of the Beyond Words ethos and therefore of the theory of change. Beyond Words books are designed to make the relationship between supporter or professional and the person who is reading it more equal by giving the power to hold and read and 'own' the book-without-words and the unique story they discover in it, to the reader themselves. This can be conceptualised as a process of **validation**[[1]](#footnote-2) where the person supporting the reader confirms or emphasises the relevance or personal truth of the individual’s thoughts, experiences, sensations or actions. This not only requires an accurate understanding of the individual’s perspective but also the communication to them that this “makes sense”. **The book-without-words, plus the changed power-relationship, creates an empowering dynamic. It changes the self-perception of the person with learning disabilities from ‘I can’t read’ to ‘I am a reader’.** This, in turn, changes the way people who find pictures easier than words are perceived by those around them - from passive to active players in their own lives.

Figure 4 Beyond Words' Theory of Change

|  |  |  |
| --- | --- | --- |
| **Risk factors** | **The books (narratives in pictures)** *plus* **the Beyond Words ethos** | **Outcomes** |
| People with learning disabilities:* struggle with text literacy
* have unequal access to education, health and other services
* experience disadvantage and exclusion
* face serious inequalities in health, living standards and quality of life.
* have difficulty in accessing and understanding information and in communicating and sharing with others both everyday activities of life and difficult problems
* have difficulty in understanding feelings and relationships.
 | People with learning disabilities are involved in co-production | People with learning disabilities *involved*: gain self-respect, validated by doing something that may help others*The books*: Narratives convey topic content in a way that increases understanding*Readers*: Increased understanding of topic. |
| The books (narrative and pictures) convey emotions | Reading the narrative and/or looking at one or more pictures validates the reader’s own and others’ emotions and lived experience |
| The books (narrative and pictures) include truthful portrayal of difficult situations  | Person with learning disabilities is acknowledged as an adult – builds self-worth; difficult situations/experiences are acknowledged as topics that can be owned and discussed – anxiety reduces |
| The books (narrative) include a resolution | Reading the narrative rehearses a problem-solving approach to life’s changes and challenges or, where applicable, an acceptance of the inevitable (e.g. death, grief, loss)  |
| Beyond Words ethos specifies that:* **the person with learning disabilities is the reader, the lead person,** i.e. setting the pace, choosing the focus of attention, creating the narrative (interpretation of the pictures)
* **the role of the professional/other supporter is to facilitate this** by:
* encouraging the reader to hold the book (if able and wishes to), to turn the pages at own pace, to create the story he/she sees or wants to tell
* active listening
* gentle encouragement, affirmation, and clarification
* acceptance and validation of the reader’s story-telling
* sensitivity in responses
* maintaining openness of the conversation through use of open question prompts
* making it clear there is no ‘right’ answer
* providing the relevant vocabulary, including for challenging topics such as ‘dying’, ‘cancer’, ‘abuse’
 | **Relationship**:* increased communication between reader and professional/other supporter
* enhanced relationship

**Reader**:* empowerment (taking the lead)
* increased understanding of emotions and of relationships
* (book specific) increased understanding of book’s topic
* communication of own feelings, thoughts, wishes, needs et cetera
* reduced anxiety/increased confidence

**Professional/other supporter:*** increased empathy with/understanding of the reader’s perspective
 |

2.3 The book development process

2.3.1 Co-production

The book development process is one that has many of the features of co-production. That is, it involves:

* recognising people as **assets** – valuing the experience, knowledge and opinions of each participant in the process
* building on people’s **capabilities** rather than focussing on deficits or needs
* working in genuine, **mutual and reciprocal** partnership with each other
* engaging peer and personal networks alongside professionals as the best way of transferring knowledge and supporting change
* blurring the distinction between professionals and recipients, and between producers and consumers of services
* enabling professionals to become facilitators and catalysts of change rather than providers of services and focussing on delivering.

2.3.2 The process in practice

The book production process in practice is now described[[2]](#footnote-3). We use a few illustrative quotations from interviews with a sample of those involved in the process.

The **idea** for a book will come from an identified need. This becomes the book’s topic. A small **editorial group** is formed made up of the editor, authors, the artist, and a small number of advisers, including one or more people with learning disabilities with lived experience of the book’s topic. That group explores and develops **the storyline**. The artist then creates a black and white version that is discussed at the editorial group to check it captures the agreed story.

“I was helping the group put the pictures in the right order and deciding what needs to go into the pictures.”

Person with learning disabilities who was a member of an editorial group

Once the editorial group are happy, these black and white drawings are tested by an **advisory group**. The advisory group includes topic experts and more people with learning disabilities. The group divides into three or four small groups who look at the pictures. The people with learning disabilities tell the topic specialists what is happening. The specialists write this down word-for-word for each picture, including any other non-verbal responses, and share them with other members of the advisory group and the publishing team. The artist changes the pictures in the light of that feedback and creates colour “roughs” which are discussed at the next advisory group.

Having self-advocates as co-authors is amazing because, if I do a drawing that [they] can’t read, or it’s a drawing they consider irrelevant, there’s no point in me drawing it.[...] Co-authoring makes the books relevant.

Artist

Once the advisory group is happy with the colour roughs, these are sent out for **trialling** by more people with learning disabilities – individuals and small groups. Again, what they say about each picture is written down, collated and fed back to the editorial team.

“That’as the good thing about it, because Beyond Words really involved us in talking about the books. ‘Nothing about us without us’ – I find that Books Beyond Words is part of that.”

Person with learning disabilities involved in trialling

Further adjustments are made by the **editorial team** **in response to the trialling feedback**. Figure 5 provides an example of how the feedback from the trialling process is used to change and develop a book. It illustrates the power given to the voice of the people with learning disabilities who have expressed their views about the ‘colour rough’ draft story.

Figure 5 Case study example of how trialling feedback is used: the domestic abuse project

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| The domestic abuse project was originally conceived as a single book with the working title “Surviving Domestic Abuse”. Feedback from trialling (recorded in a Trialling Report, and associated trialling sheets) was that:1. The book was too long or contained too many incidents

Comments included, for example:“The women thought the booklet would be very long if 50 pictures in one book, as it took us about two and a half hours to work through the story. It would be too long and tiring.”“All felt that the story was too complicated for our learners. And that it is really two stories.”1. The “safe place” ending was unclear

Comments included, for example:“Is she back at the drama group? Is she at a refuge? She is somewhere safe – is it temporary?”“Friends have come over to cheer the girl up.”“It is not clear where she has gone. It would be better if they showed her suitcase if she is going to stay there.”As a result, the authors, in conjunction with the Advisory Group, decided to respond to the first point by altering the project to make two books (Book 1: the story of the family and the abusive father; Book 2: the story of the young girl and how she gets into and out of an abusive relationship). These two books were published as “When Dad Hurts Mum” and “Finding a Safe Place from Abuse”.It was further decided to respond to the second point by resolving the main character’s storyline more clearly, emphasizing her safety and independence. To this end a new picture was added showing the girl arriving with her social worker at the outside of a new place, with her suitcase and cat to imply a long stay. One scenario – an assertiveness role play – was transferred from early in the story cycle to the latter part of the second book so that it took place in the women’s refuge and showed a growth of confidence in the character. Further pictures were added to this book to show the girl getting a job and ultimately finding a new permanent home. Example provided by Beyond Words |

At this point, the artist produces the final version. By that time, well **over 100 people** will have read and commented on the draft book. Figure 6 provides an account of how involvement in the production of a book benefitted one young woman.

Figure 6 Case study of wider benefits of co-production

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| “One of the women who was involved in the **advisory group,** who is still a resident in a specialist refuge for women with learning disabilities, was very involved in the advisory group, very articulate about what people’s experiences are and very interested in the book. She took part in the book launch. She gave a speech about the book alongside all of these big, high flying women. She said how important it had been to her to be involved in it.It was something that she talks about now as being part of her development, something that’s helped her to recover and develop self-esteem and sense of purpose, as well: that idea that she can help other people. By giving her experience and her voice, she can help other women in that situation. So that’s incredibly positive.It’s a by-product of the way that we work with people with learning disabilities: that we can equip them with that expertise as a result of them being involved with the development of a book. It’s really quite empowering I think.”Beyond Words staff member |

The process of book production, of building the story together, embodies Beyond Words’ mission, ethos and values: inclusion, co-production, communication, and empowerment. It is part of the theory of change (see Figure 4).

2.4 The Beyond Words approach to how the books should be read

**How** the books are used should also embody the Beyond Words mission, ethos and values. The fundamental principle is that **the reader is the lead person**, and wherever possible they should be encouraged to hold the book and turn the pages themselves in their own time.

The professional, practitioner or carer supporting that person is the supporter. The supporter role is to be alongside the person reading; asking that person what he or she thinks is happening in the picture. There is **no right or wrong interpretation of the story**. The reader creates the story by bringing his or her life experience to the interpretation of the pictures. The pace of reading should be set by the reader. That person may choose to look only at one picture for a shorter or longer time or perhaps only at a few pictures in the story. The way the person reads the book, whether by looking only or also by speaking aloud the story, will help the supporter to understand that person more. This new understanding then creates further scope for enhanced two-way communication between the reader and the supporter and vice-versa.

The supporter should engage in active listening – not only listening to the words spoken but also by gentle encouragement, affirmation and clarification, tuning in to the body language and mood, picking up sensitivities to specific pictures and parts of the story. The supporter should take care to be sensitive in their responses, keeping the conversation as open as possible, making it clear that there is no ‘right’ answer.

In addition, the supporter should not shy away from saying aloud the difficult words, where that is required: for example, ‘dying’, ‘cancer’ ‘abuse’. Around these topics, the way the pictures are spoken about should be clear and unambiguous.

Figure 7 How to read a Beyond Words book

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| There is no right or wrong interpretation of the pictures in a Beyond Words book. Remember it is not necessary to be able to read the words (e.g. the title, the authors).1. Some people are not used to reading books. Encourage the reader to hold the book themselves, to turn the pages at their own pace, and to read the story they see in each picture.2. Whether you are reading the book with one person or with a group, encourage them to tell the story in their own words. You will discover what each person thinks is happening, what they already know, and how they feel. You may think something different is happening in the pictures yourself, but that doesn’t matter. Wait to see if their ideas change as the story develops. Don’t challenge the reader(s) or suggest their ideas are wrong. Accept and validate their ideas.3. Some pictures may be more difficult to understand. It can help to prompt the people you are supporting by asking, ‘I wonder …’ questions; for example:* I wonder who that is?
* I wonder what is happening?
* I wonder what he (or she) is doing now?
* I wonder how he (or she) is feeling?
* Do you feel like that? Has it happened to you/ your friend/ your family?

4. You don't have to read the whole book in one sitting. Allow people enough time to follow the pictures at their own pace.5. Some people will not be able to follow the story, but they may be able to understand some of the pictures. Stay a little longer with the pictures that interest them. Adapted from the Beyond Words website |

Although Beyond Words cannot control how its books are read, the principles underpinning this relationship are included in the theory of change (see Figure 4) as a core element of how positive changes are achieved for the readers.

Section 3 Reading the books with fidelity to the method

In this section, we introduce some of the context in which Beyond Words books are used, expectations about how the books should be used in these varying contexts, and set out the current support and training offer.

3.1 Applying the Beyond Words method in different contexts

At the time of writing (2015), the main contexts in which the books were used were in:

* Therapeutic or para-therapeutic settings
* Other professional contexts
* Family or carer settings
* Libraries

This list is not exhaustive. The books can be used in other contexts too.

Currently, there are no restrictions on the use of the books. For example, there is no requirement to have attended training on the use of the books; or to be a member of a particular caring profession to use certain books. Nevertheless, it is recognised that some of the books, such as those that tackle abuse, need to be **used with care and skill** (usually with therapeutic support available) to avoid doing harm. The ‘book club sets’ do not include such books for this reason.

Working with people with learning disabilities requires a certain set of qualities, attributes and skills. Those identified during qualitative interviews with 13 Beyond Words experts are summarised in Figure 8.

Figure 8 Qualities, attributes and skills for working with people with learning disabilities

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| * Humility
* Sensitivity to others (‘have a good heart and be a decent human being’)
* Be open minded – and mindful of what the other person finds difficult, and what I find difficult myself
* Valuing others as one’s self (i.e. not being patronising; ‘see people as equal human beings’)
* Patience
* Willingness to listen (‘not just with your ears, but with your eyes and with your [...] intuition’)
* Ability to judge an appropriate response – (not clumsy, not too directive, not intrusive)
* Ability to communicate in simple, straight-forward language
* Enabling people to feel relaxed by creating a clear structure
* Recognition of the need for time to think; time to take in information
* Being friendly
 |

Source: Interviews with 13 people with expert knowledge of Beyond Words’ work

3.1.1 Using the books in a therapeutic or para-therapeutic context

The books were originally used in a therapeutic/professional context, and this practice continues. For example, **mental health professionals** use the books to work with people with learning disabilities who are, or have been, affected by the more traumatic experiences of life, such as bereavement, serious illness, or abuse. Books designed for use in this way include:

* *Bob Tells All* (Hollins & Sinason, 2015)
* *Finding a Safe Place from Abuse* (Hollins, Scotland, Blackman, 2015)
* *When Dad Hurts Mum* (Hollins, Scotland, Blackman, 2014)
* *I Can Get Through it* (Hollins, Horrocks, Sinason, 2009)
* *Jenny Speaks Out* (Hollins & Sinason, 2015)
* *Sonia’s Feeling Sad* (Hollins & Banks, 2011)
* *Ron’s Feeling Blue* (Hollins, Banks, & Curran, 2011)
* *When Dad Died* (Hollins & Sireling, 2014)
* *When Mum Died* (Hollins & Sireling, 2014)*.*

In this context, the books seem to work through the power of the pictures by enabling the person to speak about things that have happened to them – or to others they know – brought to mind by the picture. By talking about what they see happening to someone in the pictures, the reader may be more able to talk about their own, or others’, experience either directly or indirectly. Reading a Beyond Words book with a therapist or para-therapeutic supporter may enable the reader to open up about his or her own story, by responding to the story in the book and how it is similar or different to their own experience, or the experience of someone they know.

Figure 9 Descriptions of the power of the pictures of the character’s emotions

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| ‘You can describe emotions; for example, ‘he’s feeling sad’, but the actual image conveys that in a way that the person can then relate to much better and therefore can then evoke their own sadness.’‘If you were trying to have a direct conversation, [the person] might clam up but, because the story pulls them in, actually you can begin to talk about the issues at hand. I think that’s how the books work, that the projection onto the characters in the book really helps to overcome some of the maybe more protective, defensive feelings the person might have.’An author and psychotherapist |

Figure 10 gives a case study of how a book was used in a psychotherapeutic setting.

Figure 10 Case study (a) of therapeutic use: psychotherapy session

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| ‘There was a teenager with learning difficulties and autism who didn't speak to me during two years of seeing me for therapy but she always chose the same four pictures from *Jenny Speaks Out* [those on pages 8,16,19,28, reproduced with permission below]. She never followed the whole story in the book, but she quickly chose these four pictures which kind of told her own story. It was extremely helpful because I could only guess what had gone on and what her feeling state might be, but the pictures showed ... At the beginning of therapy, she’d spend more time on the first pictures, which were quite shocking, but, at the end of therapy, the last picture, of a younger woman and an older woman sitting together and looking relaxed together, that was the picture that she ended on. [...] The pictures helped to explain to me what was behind her feeling state and her behaviour so that I could talk to her and help her. We used to do a lot of craft type activities and I tried to mirror her feeling state, her mental state in my therapeutic relationship with her. The pictures helped me to understand. The impact of that was that I was able to target my intervention more appropriately because I understood a little bit more about how she was feeling, and why she was feeling that way. And there are loads of stories like that, where a therapeutic relationship has been assisted by the increased understanding that the therapist has from the patient [because of the books].’A psychotherapistIllustrations from *Jenny Speaks Out* (Hollins & Sinason, 2015) |

Figure 11 illustrates the use of the books in a para-therapeutic setting.

Figure 11 Case study (b) of para-therapeutic use; day service in a hospital setting

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| ‘I’m currently using the Books Beyond Words with a gentleman who has bipolar affective disorder. I use them in conjunction with two other bits of work, so I’ve got the NICE guidelines on the assessment and management of bi-polar; I’ve got an Easy Read version of bi-polar affective disorder but actually the thing which is of most use is this book, *Ron’s Feeling Blue,* because in *Ron’s Feeling Blue* one of the main issues that this particular gentleman has is worrying about his medication and feeling terribly low and depressed and this book has pictures in it which are about having your medication and how you work that out with your doctor and about pictures that just really describe about how people can be watching the telly and doing things, and you’re there and you’re amongst activity and you’re amongst company but, you know what, you just can’t join in. When he saw this picture yesterday he said, ‘That’s me! That’s me!’ He’s really identified with it and that’s helped us help him with his bipolar. [...] Depression is such a part of lots of mental health conditions that that [book] has been particularly useful. [...] Books Beyond Words sit in my toolkit but I use them a lot and I go back to them a lot and this is because they’re so flexible.’A learning disabilities nurse |

3.1.2 Using the books in other professional contexts

Healthcare settings

Some of the books are designed to address health issues. These are widely used in healthcare settings, such as out-patient clinics, GP surgeries and dental surgeries. Examples include:

* *Getting on with Cancer* (Donaghey, Bernal, Tuffrey-Wijne, Hollins, 2002)
* *Ann has Dementia* (Hollins, Blackman, Eley, 2012)
* *Going to the Doctor* (Hollins, Bernal, Gregory, 1996)
* *Getting on with Epilepsy* (Hollins, Bernal, Thacker, 2014).

The intention of the healthcare books is to provide information but, more than that, it is to enable the person with learning disabilities to make their views and choices known and to reduce health anxiety. The pictures and the narrative in these books model a respectful relationship between the healthcare professional or practitioner and the person with learning disabilities. In this, they are intentionally educative for the healthcare professional or practitioner. Indeed, the books have been used in the training of medical students and other professionals.

‘Sometimes doctors – not all of them, think they are better than us.’

Self-advocate

The books include those designed to prepare someone for treatments or medical investigations, such as blood tests or injections. The healthcare professional should sit with the person and go through the picture narrative at that person's pace. Their reactions and comments on the pictures will help the professional learn more about how much the person already understands and about any barriers which may prevent him or her being able to cooperate with investigations and interventions. Reading a book in this way may constitute a reasonable adjustment as required by the Equality Act 2010 to enable a person with a protected characteristic such as disability to access a public service. The Mental Capacity Act 2005 also requires health and social care professionals to take extra steps such as using pictures in the assessment of people’s capacity to consent to medical treatment or to other significant issues in their lives such as where they might live, who they might live with. Use of images that illustrate the particular issues at hand not only can enable a professional to obtain clearer insight into the person’s ability to understand, retain and weigh up information and to communicate their decision, but also can enable the professional to support someone to make an informed decision. The aim is to help him or her to think about what will happen and make sure the person understands the process and can communicate his or her feelings about it. Taking time to do this and to build understanding and reduce fear in this way can support compliance with treatment. This may even contribute to tackling health inequalities for people with learning disabilities.

The books have also been used in the context of individual social care pathways in a social care setting; for example, to help someone plan their day or their week.

The Care Quality Commission (CQC) recognised the potential of the books to support people with learning disabilities to express their views about the quality of their care. Three books were specially created for this purpose:

* *Are my physical health care needs being met?* (Hollins, Williams, Banks (Eds.), 2016)
* *Do I feel safe?* (Hollins, Williams, Banks (Eds.), 2016)
* *Am I involved in my care?* (Hollins, Williams, Banks (Eds.), 2016)

These books were introduced at a small number of initial training sessions for inspection teams, together with other information and examples of how to enhance communication with people with learning disabilities. A further session was conducted for CQC inspectors.

Judicial settings

One set of books was written to support people with learning disabilities who are involved with the judicial system. Titles in this series include:

* *Going to Court* (Hollins & Sinason, 2016)
* *Supporting Victims* (Hollins, Stone, Sinason, 2007)
* *I Can Get Through It* (Hollins, Clare, Murphy, 2016)
* *Mugged* (Hollins, Horrocks, Sinason, 2002)
* *You're under Arrest* (Hollins, Clare, Murphy, 2016)
* *You're on Trial* (Hollins, Clare, Murphy, 2016)
* *You're in Prison* (Hollins, Giraud-Saunders, Ryan, 2013)

Other titles that may also be relevant in this context include *Jenny Speaks Out* (Hollins & Sinason, 2015), *Bob Tells it All* (Hollins & Sinason, 2015), *When Dad Hurts Mum* (Hollins, Scotland & Blackman, 2014), and *Finding a Safe Place from Abuse* (Hollins, Scotland & Blackman, 2015).

The intention of these books is to enable the person to understand what is expected of them. For example, *You're in Prison* (Hollins, Giraud-Saunders, Ryan, 2013) illustrates how to cooperate with the prison regime and is designed to support early parole.

Other settings

The potential for the use of the books in school settings, perhaps especially in special schools settings has been recognised. Beginning from pilot work in one special school (Swiss Cottage School in Camden) Beyond Words has expanded its remit to include working with more schools across the country providing additional support to teachers, students, parents and support staff through its books and app. Sets of books have been created, aimed at those working with children and young people with autism and children and young people with learning disabilities.

3.1.3 Using the books in a family or carer context

Beyond Words books are used in the home setting, by families with a son or daughter with learning disabilities. Currently, little is known about how families use the books and with what results. This could be a focus of future research.

3.1.4 Using the books in a book club

The Beyond Words book clubs began from an idea formed by the supporter of Nigel Hollins, the son of the Founder. The clubs create social groups and friendship networks for adults who find pictures easier to read than words. It is an important part of the Beyond Word ethos that these clubs take place in mainstream, visible environments, such as local libraries. The clubs are intended to give traditionally socially excluded groups a voice and a place, participating within their local community. The aim is for the participants to have an enjoyable time together, to share their experiences – and, at the same time, to reduce stigma, and raise self-esteem, enabling people to shift in their self-perception from, ‘I can’t read’ to ‘I am a reader’.

Figure 12 Case study (a) of impact on a book club member

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| I often tell the story of Linda, who’s come and done the training with us. Linda’s in [a] book club and she greeted me the first time that I ever met the [book club] group. She came in with her hands on her hips (double teapot, I call it) and she just looked at me and said, ‘I don’t know why I’m here. I can’t read. Books aren’t for me. Libraries aren’t for me’. I answered her questions a bit and we persuaded her to stay and at the end of the session she was just made up [very pleased]. She said, ‘I can do this. This is good.’A Book Club facilitator |

Beyond Words has produced a [guide](http://static1.squarespace.com/static/551cfff9e4b0f74d74cb307e/t/56444e98e4b014f5dbb566e6/1447317144514/BookClubGuideA515.pdf)[[3]](#footnote-4) to setting up a Beyond Words Book Club. It describes a Beyond Words Book Club as:

“a group who regularly meet to read the Books Beyond Words series. We read the pictures as there are no words and we make up the stories between us. We have fun. We often meet in our local libraries, but you can run a book club anywhere. Some clubs run in community cafes or other community facilities. It is good to be in local places everyone uses. Currently we all meet during the daytime. Each club lasts 45 minutes to one hour, and the clubs meet every week, every two weeks or once a month.” (*How to start your own Beyond Words book club*, p4)

Experience of how books are read in book clubs suggests that new participants need time to understand how to read the pictures. Once that is established, the usual group desire is to read a whole book in a club session. The facilitator needs to make a judgement about this; sometimes it will be more appropriate to allow two or three sessions reading one book. It depends on the members’ wishes. The book clubs are intended as a recreational leisure activity. They are not intended to be a formal teaching setting, although of course they are educational in a wider sense.

Figure 13 Case study: a book club member describes the experience

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| When me and Carol went to [a book club] and there were all people with learning disabilities and communicated in a different way, some of them couldn’t read and the way how the book was presented it’s like, ‘This is it, this is we’re practising what we’re preaching now’. It made me so sad, in a good way, that it was working and we done this topic (I can’t remember the topic) but I remember when I talked about the topic that time, it was so touching to see, it has made a difference for people. Everybody had a say in that topic that we were talking about and it touched me to say, ‘The books are working, the books are working.’ And, if I can see that, it’s reality: the books are working and it’s made a difference because there was a lot of emotion about the book.It’s really good to have a good facilitator as well because that makes a big difference. But even talking about it, we go in sections, you would read that one and everybody would say in the group ‘What is that? What are they doing there?’ and we all discuss and you could say something, and you can say something and I could say something and then afterwards we would discuss it. Then we’d talk about something else, ‘Why is her face like that?’ and we’d discuss it. ‘Why is it?’ and all of us in this section would discuss about this topic and then afterwards we’d talk about it and we’d discuss it and then we’d go onto the other page until we finished it.One hundred percent because it was so emotional that day. Some people found it a bit difficult but the way we broke it down, everybody kind of like understood. Some people took a bit longer because of the communication but everybody discussed about it and we gradually knew the topic and what the topic was about but everybody talked about it in their own different ways and came together and we discussed it and we came up with the goods at the end of the day. A self-advocate |

The **group aspect** of the book club is important. It enables discussion about the story and also the sharing of experiences. This sharing can be validating for those who have previously felt isolated. In this loose sense, the groups can have a ‘therapeutic’ effect.

Figure 14 Case study (b) of impact on a book club member

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| I think the book club has been quite an amazing initiative actually. It’s been really interesting to see people with learning disabilities build a new relationship with books. Certainly one of my clients in therapy was in the very first area where a library book club was launched. She came into her therapy session with me, without me knowing this had happened, and was suddenly incredibly interested in books. I’d already tried to use some Books Beyond Words and other books with her in other sessions and she’d been very resistant to them because she felt they made her feel stupid and she didn’t want to look at them or open them. Then the Book Club opened in her local library and she came and told me that she’d been to this meeting and that she’d been given a card and she could take out 8 books from the library and she suddenly got very excited about the whole library experience. It moved things along in terms of suddenly books because a very useful tool for us as well, in the therapy session, but I think it gave her a further sense of belonging in her community and this place that she’d used that she’d never bothered to think that the book part of it was for her before (I think maybe they have other things going on in the place where the library is but suddenly the books were for her as well). I think that’s very powerful.An author and psychotherapist |

The book clubs, by exposing people with learning disabilities to group discussions and the ‘narrative arc’ of stories, may also be improving the expressive language of some participants: one book club facilitator noted: ‘Certainly you could tell in some of the groups [book clubs] that, within the first three months, people’s spoken language seemed more complex. They could put more ideas in.’

Monitoring and evaluation of book clubs

Beyond Words began routine monitoring and evaluation of its book clubs in 2016. Group facilitators are asked to complete an annual reflection survey, accompanied by a short survey to capture views of the group members. Results from these questionnaires will be analysed and reported regularly.

Figure 15 gives a flavour of the main findings from the 2016 survey, reflecting back on 2015.

Figure 15 Key results from the 2016 survey of book clubs

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| This survey asked book club facilitators to reflect back on activity during 2015.* 17 book club facilitators took part
* The most frequent group size was 6 members (range was from 4 to 23)

**Wellbeing*** 16 reported seeing an increase in the confidence of members, plus improved self-esteem

Illustrative comments:“Regular members have become more confident about taking part in reading the books/telling stories during the past year. One member who was very quiet at first has become much more talkative during this period [...].”“One gentleman who comes is very quiet. When he first stared attending he didn’t say anything or show any emotion. After about 6 months he started to smile, point at pictures in the book and even if only one word is said, shows he is involved in the story.”**Reading*** All 17 reported that over the book club sessions, on average, members:
	+ enjoyed reading the books
	+ engaged with the content
	+ followed the narrative/story
	+ discussed their own life experiences when interpreting the pictures
* Almost all (15 or 16) reported that over the book club sessions, on average, members:
	+ understood information conveyed by the pictures
	+ understood characters’ emotions portrayed in the story
	+ spoke about their experiences when reading the book
	+ communicated (verbally and non-verbally) more than usual during and after book club sessions

Illustrative comments:“In reading *The Drama Group*, members could recall experiences of rejection, isolation, friendship difficulties.”“Some group members with particularly complex needs are unable to follow the story or understand the content. However, I believe [the value of] this should not be measured by this alone. [...] The readers who have little communication pointing out a cat in a picture is a wonderful success.”**Book club participation*** The majority (number in brackets) reported that, on average:
	+ All members were able to participate (16)
	+ The book clubs gave members an opportunity to socialise with one another (16)
	+ Members found it easy to interact with the facilitator (16)
	+ The book club equipped members with skills to participate more fully in society (14)
	+ Members take the lead (e.g. hold the book, turn the pages) (13)

Illustrative comments:“Three members of the group live in the same house (supported living). The books have enabled them to explore ‘tension point’ in their shared lives.”“All members of our group [...] knew one another well from other activities. A new member was introduced who they had not met before and she was easily integrated. The group takes place in the children’s library, and close beside them there is a school refuser aged 12 with his tutor. Over the weeks, he has become friends with the group and has helped with some activities. They enjoy talking to him and he has certainly benefitted as well.” |

Source: 2016 Beyond Words Annual Reflection Survey

The organisation is also committed in principle to supporting other research into the impact of the book clubs. Potential areas of interest are studying changes in how group members communicate including any increase in the use of 'feeling' words, sentence length and complexity, ability to listen and respond to other members’ comments and experiences appropriately, ability to discuss ideas, to use their imagination et cetera. There is also interest in research that focuses on how trialling feedback from book club members is used to make changes to the storyline and illustrations during book production.

3.1.5 Using the books to support learning disability research

Irene Tuffrey-Wijne has, along with her research colleagues, pioneered the use of the Beyond Words books, and/or of pictures from specific Beyond Words books, in research designed to elicit views of people with learning disabilities about topics affecting them. For example, Tuffrey-Wijne, Bernal, Jones, Butler and Hollins (2006) successfully used a Beyond Words book, *Getting On with Cancer* (Donaghey, Bernal, Tuffrey-Wijne, Hollins, 2002) , “as a prompt for participants to recall and comment on their own experiences and information needs thus enabling the subsequent interview process” (p108) which focused on their experience of using the book, what parts were useful, anything not understood and anything else the participant wanted to know about their relatives’ illness (p110). In a further study (Tuffrey-Wijne, Bernal, Butler, Hollins, Curfs, 2007), a single picture of a terminally ill woman from the same book was used successfully within a nominal group technique approach to investigate the views of people with learning disabilities on end-of-life care. More recent work (for example, Tuffrey-Wijne, Giatras, Butler & Crusswell, 2012) has developed this approach further, using pictures from Beyond Words books.

This work, of importance in itself for the substantive findings, also demonstrates the power of the Beyond Words pictures, when used with fidelity to the Beyond Words method, to engage the interest of people with learning disabilities, support the sharing of information with them, and to elicit their expressions of experiences, existing knowledge, emotions and needs.

3.2 Monitoring and evaluation of book use

Beyond Words has committed to routine monitoring and evaluation of the way in which its books are used. Initially this will be done through surveying those who buy the books and following through, as far as possible, to those who use the books.

Results (Cullen, Begum, Hastings, 2016) from the first comprehensive survey of the people who buy and/or use some of the books (specifically, six named books about relationships) were **promising** but can only be viewed as suggestive rather than definitive because they were based on a small number of responses (25 completed surveys). Among other points, the results supported the theory of change (set out in Figure 4), highlighted the importance of the Supporting Text at the end of each book as a way of communicating the Beyond Words ethos and relationship-based methodology, and indicated opportunities to extend the marketing of both the books and the training in how to use the books.

3.3 The Beyond Words support and training offer

3.3.1 The support offered to those who cannot attend training

Beyond Words does not require that people attend training prior to buying, reading or supporting others to read the books. Instead, it provides three accessible ways of supporting the fidelity of how the books are used. The first is that every book contains a section entitled Supporting Text, which articulates the essence of the Beyond Words ethos and the expectations about the way in which the professional or other person will support the reader to respond to (read) the pictures.

The second way is through the [Beyond Words website](http://booksbeyondwords.co.uk/%23/about/)[[4]](#footnote-5). The website provides visual and textual information about the organisation, its products and offers guidance on how best to read or support others to read the books.

The website also contains a link to the third accessible way used to support people who cannot or do not wish to attend training in using the books: the [YouTube channel](https://www.youtube.com/channel/UCuJd8IK1K9lwVPGrZmOrOwQ). The YouTube channel contains over 20 videos about the books, including several demonstrating the books being read.

3.3.2 The Beyond Words training offer

Beyond Words has introduced a training service to help teach interested individuals how best to use the books in a one to one environment, in groups, or in Beyond Words Book Clubs. In 2015, tailor-made, book-specific training, that is, specialist book topic based training, was launched. For example, following the publication of a book entitled, *Feeling Cross and Sorting It Out* (FCASIO), a training based on challenging behaviour was offered.

Based on three participant observations of training sessions, as well as on interviews with the training manager at Beyond Words and other members of staff who have been involved in the development of the training programme, this section describes the structure, objectives and content of the training sessions.

**Aims of the training**
Both the interviews, and the training materials, reveal the two aims at the heart of the training. The first is to communicate an understanding of the Beyond Words ethos, which one interviewee referred to concisely, as ‘inclusion, communication, and equality’. It is clear that both the content, and indeed the style of delivery support this aim. The second aim relates more directly to communicating the methodology of how these books work, and how they should be used. Every training activity is designed to support this aim in part by allowing participants the opportunity to role play being the supporter and being the reader both in a one-to-one situation and in a group situation. This demonstrates how empowering reading the books can be. It can also bring about a change in perspectives about people with disabilities, about communication, emotional understanding and what it means to ‘read a book’.

Content of the training

This section firstly gives an introduction to the structure of both training programmes. After that, the focus shifts to the relationship between the ideals and ethos behind Beyond Words, and the ways in which this is translated in the training.

Both the non-specialised, and the specialised training follow, for the most part, a clear three part modular structure, beginning with an introduction and history of BW, its usages and its production process. This is followed by an active learning element, wherein the participants learn how best to use the books, through reading them in various group activities. The third module is where a clearer distinction appears between the training types. Whereas the book club trainings go further into lessons on practical use, and give the participants a taster of the various extra activities (drama-based, artistic) that they can use to complement the reading of the books, the specialised training, on the other hand, looks to develop the participants’ knowledge of the specific topic area.

Thus, participants who attended the FCASIO training were given a detailed introduction to the ‘Challenging Behaviour’ literature by behaviour expert, Nick Barratt, who is also co-author of ‘FCASIO’. In particular he focused on the ‘CAP’ Approach (Nick Barratt, 2012), a technique that can be used for positive behaviour support. CAP stands for communication, activities and predictability. This lecture-style aspect of the module was brief. After twenty minutes or so the participants were asked to read the FCASIO books in a book club style set up just as they would be asked to do in the non-specialist training.

However the subsequent activity in the specialized training highlights more clearly that this type of training is very much a mixture of both an introduction to book usage and an overview of the specific book topic. For example, in the FCASIO training, the activity invites participants to analyse the FCASIO books, using the ‘CAP’ approach to positive behaviour support.

Facilitated by the training manager, another short concluding module follows. In many ways, this took the form of a plenary and for some acted as a therapeutic experience. In the book-specific training, this focuses on participants’ experience of the topic of the book. For example, in the FCASIO training, participants were asked to use their own experiences to identify real ‘challenging behaviour situations’, and use the ‘CAP’ approach to analyse the event, as well as discussing ways in which the book itself could be used as a tool for negotiation. Similarly, in the non-specialised training’s concluding activity, the main aim is to undo the anxieties participants highlighted regarding communication difficulties, at the very beginning of the training. (This activity is discussed in greater detail later on in the section.) It also imbues elements of therapy.

Themes in the training

The themes of ‘communication, visual literacy, versatility and empowerment’ play a key role in the BW ethos, and the training is a reflection of this, the subsequent paragraphs look to explore the way in which each of these themes is translated in the training.

Communication is at the very forefront of Beyond Word’s concern. It is clear from the series of expert interviews that allowing people with learning disabilities to communicate more effectively, and enabling other people to listen more effectively to people with learning difficulties, are the organisation’s primary concerns. This ethos is translated clearly into the training programme. The first activity invites participants to share and discuss ‘barriers to communication’ that they experience in their everyday lives, and often their experiences with people who have learning disabilities. Popular responses include ‘confidence’, ‘fear’, ‘jargon’, ‘understanding’. The training facilitator then uses these pieces of paper to form a brick wall like structure. This exercise, very much functions as the ‘problem’ that the training session, and the participants are hoping to overcome. The ensuing activities present to the participants the range of ways in which the Beyond Words series are able to break down these barriers. This lesson is then firmly cemented by the final activity wherein the brick wall made with the barriers earlier in the session is discussed and then slowly dismantled.

Though in the very first titles, the Beyond Words series used some simplistic wording opposite pictures to help describe the scene, these were very quickly removed, and subsequent editions and titles have omitted the use of words in the main story. Key to this, is the concept of visual literacy, which is based on the audience’s ability to negotiate meaning from images, and indeed in one interview with a BW expert, when discussing the significance of BW training, the interviewee asserted that the BW training was distinctive as it was introducing the concept of ‘visual literacy’ to the participants. This is best highlighted by a 20-minute exercise wherein the participants are asked to analyse a famous painting by Renoir, ‘Luncheon of the boating party’. First they are asked to do this individually, then in pairs, and then as a whole group. The aim being to bring to their attention the sheer depth an image can have when extracting meaning.

‘Empowerment’ through the books, is a key theme running through both the interviews, and the training materials. The books and the reading processes are presented as tools to help empower, and include those with learning disabilities and communication difficulties. For example the bespoke training for ‘Feeling Cross and Sorting it Out’ is titled, ‘Empowering people whose behaviour challenges me’, giving the participants through its various activities practical intervention-based advice to support individuals with ‘challenging’ behaviour characteristics.

More generally speaking, the wordless picture books are presented to participants at the trainings as a means to equalise information platforms for those with and without learning disabilities, thus ensuring that everyone is ‘reading from the same page’. This is best highlighted during a training exercise, often referred to by experts, and members of the delivery team as the ‘penny dropping moment’. The activity invites the participants to sit with a partner and read a BW book together; one person will imagine s/he has a learning disability, and the other will be the supporter. In almost all instances during this stage of the exercise, the ‘supporter’ holds the book and controls the reading of the text to the person who has learning disabilities. The facilitator then requests the person pretending to have a learning disability to take hold of the book and lead the reading of the text. This changeover is that ‘penny-dropping moment’. In the subsequent group discussion, where participants are asked ‘did anything surprise you?’, many are shocked at the difference holding the book can make. Those pretending to have learning disabilities expressed feelings of anxiety and exclusion in the initial stage of the exercise, and felt more in control of the situation when they were guiding the reading and holding the book.

Versatility, and off the page use of the pictures appears to be a growing BW concern. It is certainly instilled both formally and informally in the training sessions. Participants are invited to share ways in which they have/ or could use the books in a creative way, and the facilitator himself highlighted in his interview that it is necessary to ‘use art forms to promote communication among people who find communication difficult for whatever reason.’ The more formalised aspects of this are expressed in the form of the ‘freeze frame’ activities, where participants are asked to choose a picture from a book of their choice and recreate an image of it in still life. After which they present their work to their peers, and some groups go on to create a short dialogue sequence for their characters. Informal conversations with participants revealed other versatile uses of the books, for example, one book club organiser recalled that following the reading of a criminal justice book, the group organised a local police officer to attend the book club, and talk to the participants about their experiences. Other book clubs have gone on to visit the National Gallery or produce their own books, and storylines.

Responsive training through active learning

Though formula and content are of vital importance to training, so too is the style in which it is conveyed. Given the central role communication plays in the content, it is therefore no surprise that the training is delivered in a very responsive and collective way. ‘It is about sharing’, as an interviewee reveals. The main facilitator’s style allows participants to relax and be open about the communication difficulties they encounter in their professional/personal life, and ensures that the atmosphere does not bear resemblance to the pressure of a classroom, or a boardroom, but rather embodies a sense of calm which permits participants to develop their BW understanding without fear of getting it wrong.

Most participants are adults, who come from a range of different professional backgrounds. And so some concern about creating a suitable training with suitable approach would be normal. However as highlighted by an interviewee they all have at least one thing in common- their desire to learn about BW, and in many ways this acts an equaliser amongst doctor or librarian and self advocates alike. The active learning approach also aids this balance, as it encourages participants to get to know one and other, and engages them in interesting activities and discussions. Part of this also lies in the way these participants are managed, and the style in which training is delivered. It is clear that an adaptive approach is utilised, wherein the facilitator, depending on the personalities and needs of the participants has to make a decision about the language and style used. This is particularly well highlighted by the flexible nature of the day, for example in some training sessions the ‘freeze frame’ activity has lasted for no longer than 25 minutes, where participants were perhaps less comfortable with this ‘off the page’ work, whereas on other occasions it has lasted up to 40 minutes, as on this occasion participants felt far more comfortable to develop dialogues and other scenes.

Self-advocate involvement

All trainings, regardless of topic invite self-advocates to take part. For the most part two self-advocates attend every training, sometimes more. They are invited to give an extended introduction into their role and experiences with Beyond Words. However, this is not formulaic in nature; self-advocates contribute when, where and how they would like to. Two self-advocates were interviewed as Beyond Words experts. When asked about their involvement in the Beyond Words process, both made it clear that they viewed it as very importance that self-advocate participation should not be limited to the book making process but include being at the forefront of Beyond Words training endeavours too. For example, one said:

“When you [i.e. Beyond Words] go out, you need to involve people with learning disabilities. When you’re doing your training and your presentation, you need to involve people [with learning difficulties] more. When I see somebody doing it, and he’s doing it by himself, it’s OK but when you involve the person with learning disabilities, you’re practicing what you’re preaching. [...] If you don’t need us in the presentation, what does that say?”

Self-advocate, interviewed in 2015

Alongside this moral argument, self-advocate attendance at a training has a strong practical value too: it makes for a more realistic setting, as it gives the participants a better idea of how people with learning disabilities may react to the books. This is particularly apparent in the group reading activities where, for example, the attendees will get a sense of how long the individual may want to look at a picture, or the type of questions they may need to ask to allow them to explain what is going on in the picture.

3.3.3 Training and accreditation of freelance trainers

Beyond Words began to develop its training offer from 2015 onwards. It offers training for freelance trainers, and training for those who train these trainers.

A training course has been developed to equip a pool of freelance trainers with the required knowledge, skill and ethical approach to deliver Beyond Words training of high quality, and using an interactive, experiential learning model of active training. The quality of this training is monitored by Beyond Words through supervision and support to ensure it continues to reflect the organisation’s core values and to promote the Beyond Words ethos and methods. Supervision also reflects the intention to support the wellbeing of individual trainers as well as a support mechanism for the whole freelance training pool.

In order to maintain quality and consistency a three-part training process develops appropriate skills to become an accredited Beyond Words trainer. Dissemination of the books, methodology and practice is fundamental to training.

* Part 1. Core Training

A one-day training to explore Beyond Words reading methods and our core ethos. We practise techniques used in active training and experiential learning and explore the concepts of group dynamics and ways to remain inclusive, responsive and flexible within the planned structure of training. At this point all potential trainers are asked to consider the Beyond Words ethos, methodology and training style. Should a trainee not agree with the Beyond Words ethos or feel uncomfortable delivering training in the active learning style, we still honour the trainee fee for this core day and fully understand that this style of delivery is not suited to all trainers.

* Part 2. Training Support

Trainee trainers support an accredited Beyond Words trainer on one of our regular training workshops. This is an opportunity to take part in actual training delivery. The accredited trainer will agree the level of co-delivery and type of engagement the trainee is comfortable with.

* Part 3. Supported Training

Trainee trainers lead one of the regular training workshops, supported by an accredited Beyond Words trainer.

Trainers become **accredited** on successful completion of the three-part training process and the successful delivery of a supervised independent whole-day workshop. In some cases trainee trainers may need a little more time to develop the skills required to become accredited. Support and supervision schedules are agreed with accredited trainers with a minimum of two a year. Before accreditation, trainee trainers are required to provide their own Basic DBS check or an existing DBS certificate issued within the preceding year. Once accreditation is formalised, Beyond Words will manage and pay for the DBS checks for each Accredited Beyond Words Trainer.

Once accredited, trainers are offered work according to demand and trainer availability. Every training is allocated under a separate training-specific contract. Some training workshops require a co-delivery team of lead and support trainers. These roles are clearly defined and are paid at separate fees.

Trainer Training

As Beyond Words training programmes expand and develop, accredited trainers may be trained further to themselves become trainer trainers.

3.4 Monitoring and evaluation of the training

Beyond Words has committed to routine monitoring and evaluation of its training offer. Training participants are invited to complete a questionnaire at the end of each training. During 2015, the questionnaire used was enhanced in collaboration with researchers from the University of Warwick. Results from the first five training sessions (78 participants) where this enhanced questionnaire was used were **very positive** (Cullen, Begum Hastings, 2016). Figure 16 provides a summary of key findings.

Figure 16 Key results from analysis of responses from 78 training participants

|  |
| --- |
| * The majority of trainees had not used Beyond Words books prior to the training
* Almost all participants found the training enjoyable (92%) and worthwhile (95%)
* A large majority (89%) would recommend the training to peers, colleagues or family members
* Participants reported that the training was successful in conveying core messages about why the books were developed (100%), the power of pictures to tell a story (97%), how the books allow people to tell their own story (97%) and how the books can remove barriers to learning (100%)
* A large majority (87%) viewed the core message about allowing the person with learning disabilities to hold the book as important or very important.
* Almost all participants (98%) felt confident or very confident to use the books in practice
 |

Source: Analysis Sept 2015 – January 2016: 5 training sessions

The plan is for a follow-up survey to be conducted some months later to explore the effects, if any, of the training on subsequent practice.

*Note: In 2019 face to face training was largely replaced by e-Learning with an introductory module (relevant to all users but especially book club facilitators), and a specialist module on using Books Beyond Words to support social, emotional and mental health (SEMH) in schools. A module for healthcare practitioners is in preparation.* [*https://booksbeyondwords.co.uk/training-info*](https://booksbeyondwords.co.uk/training-info)

Section 4 Research studies of impact

The intention is that, in this section, research about what happens when the books are used is summarised. This section will grow over time, as more research on the impact and use of wordless stories is conducted and published. As research evidence accumulates in peer-reviewed journals, the reference list and summaries of the findings will be added to the Manual

To date, some researchers have **used pictures from relevant books as part of their research method,** and there have been a **few small research studies** **designed to test the outcomes associated with using Books Beyond Words** to improve support and care for people with learning disabilities. In addition, there have been some **review papers** describing the Beyond Words theoretical basis with practice examples, and some project evaluation reports, usually written for the project funders (these are available on request from the office).

**4.1 Research findings from outcome studies:**

**4.1.1 Bereaved adults with intellectual disabilities: a combined randomized controlled trial and qualitative study of two community-based interventions** (Dowling et al (2006).

In research with adults with learning disabilities who had experienced a bereavement, one of the interventions was delivered by mainstream bereavement counsellors who had been trained jointly by a psychiatrist and co-trainers with learning disabilities, how to adapt their typical practice for people with learning disabilities. The main adaptation was to use Books Beyond Words books as a way of discussing death and bereavement with individuals. Data for 25 participants showed improvements in psychological well-being and reductions in indicators of distress pre-post counselling, with the assessments of mental and behavioural distress reducing to the levels of non-bereaved people with learning disabilities. The use of Books Beyond Words was not the only active component of the intervention as the volunteers were all trained bereavement counsellors who brought their experience of working with bereaved adults to the one-to-one sessions. Their achievement, as described by the authors, was their ability to adapt their approach by using the books as a reasonable adjustment to assist them in listening to and talking with people with learning disabilities.

However, the main analyses lacked a control/comparison condition as only two participants completed the comparison intervention and so the original research design was effectively unsuccessful. This involved a similar intervention with the participants’ usual support worker reading the books with him or her.

**4.1.2. Wordless intervention for people with epilepsy and learning disabilities** (Mengoni 2016).

A pilot study finding a positive impact of using Books Beyond Words in clinical practice has recently been published. This involved a simple test of the added value in clinical practice of using Books Beyond Words materials. People with learning disabilities and epilepsy receiving epilepsy care as usual were compared in terms of their quality of life outcomes to people receiving care as usual alongside access to the book “Getting on with Epilepsy”. Participants were randomly assigned to the two treatment conditions. Those in the epilepsy book condition went through the material with an epilepsy nurse and were encouraged to use the book at least twice more with a carer. Carers also had access to online videos and training slides about how to use the Beyond Words books in practice. The feasibility of routine use of this BBW on epilepsy was explored, with mixed responses about the level of support the nurses thought might be needed to use the book.  For example, “The booklet could be useful for other people with epilepsy. ▸ The booklet is useful for people with difficulties with verbal communication. ▸ The booklet may be most useful when someone has just been diagnosed. ▸ The booklet may be particularly helpful to explain epilepsy to others. ▸ The time needed to use the booklet could be a barrier.”

In Table 5: “Use and acceptability of the booklet ▸ A minority of carers and participants were already familiar with Beyond Words. ▸ Most participants engaged with the booklet and could identify benefits. ▸ Control participants had differing views on the booklet after first looking at it. ▸ The booklet was used in different ways”.

A primary effect of the intervention on the behaviour and mood subscales of the ELDQOL (Epilepsy and Learning Disabilities Quality of Life Scale) was found at 4 and 20 weeks. Seizure control was a secondary outcome, assessed through completion of a seizure diary and showing a trend towards reduced seizure frequency in the intervention group. The researchers concluded that: “The acceptability and feasibility of the methodology and intervention were high among participants, carers and health professionals. Collection of economic data was found to be feasible. All feasibility criteria were fully met, or partially met and qualitative and quantitative findings indicated improvements to the recruitment and data collection procedures, thus confirming the feasibility of undertaking a definitive trial”.

**4.1.3. Promoting testicular self-examination and awareness amongst young men with intellectual disabilities (IDD): A parallel intervention randomized study** (Wilson et al 2018).

This study compared the effectiveness of Books Beyond Words as a standalone health education method (in the form of a pictorial leaflet derived from a Books Beyond Words book) with face to face teaching about testicular cancer self-examination.

The results indicated that leaflets given directly to the adult with a learning disability by a health professional and taken home to read and share with a carer or friend, produced comparable results to face to face group teaching by a learning disability nurse and a self-advocate peer. Qualitative data suggested that individuals in the Leaflet group tended to seek further information on the subject from family, friends or helpers during the six months after receiving the leaflet to a greater extent than those who received the teaching; it is possible that the leaflet assisted carers / supporters to discuss the subject more easily (Jones, Tuffrey-Wijne, Bernal, Butler, & Hollins 2007). In both groups the majority of participants reported performing testicular self-examination 6 months post intervention.

The study findings confirmed that young men with learning disabilities can benefit from health education, to improve their levels of knowledge, and skills and change behaviour. The subject of testicular self-examination and cancer is potentially embarrassing and anxiety provoking but the participants in both educative approaches, responded well and appeared to benefit without marked detrimental effects. The evidence suggested that when participants receive information in an accessible form, they can feel more confident about having influence over their health and seeking help, leading to reduced anxiety levels. This has implications for other areas of health promotion and information provision for people with learning disabilities where information may be withheld with the intent of protecting an individual from anxiety.

**4.1.4 The Open Book Project- an evaluation**

Beyond Words books were introduced to teachers and teaching assistants from 22 special schools in England and Northern Ireland through both eLearning and face to face workshops. The aim was to support social, emotional and mental health (SEMH) in the curriculum across all ages by introducing pupils to wordless books both individually and in groups. Teacher confidence increased significantly and case studies demonstrated a high level of achievement of ‘Best hoped for outcomes’ for learners. Other outcomes included the development of a wider emotional vocabulary and literacy (Egerton et al, 2020)

**4.2 Using Books Beyond Words books as a research tool:**

Professor Irene Tuffrey-Wijne has used Books Beyond Words (either an entire book, or selected pictures) as a data collection tool in a range of qualitative research studies investigating the experiences and needs of people with learning disabilities around cancer, death, dying, and bereavement. The pictures enabled the documentation of thoughts, feelings, emotional and day to day experiences of people with learning disabilities as these spontaneously arose in them when “triggered” by meaningful content (the pictures) in the presence of a facilitating listener. The use and responses to the books are illustrated below in 5 selected published papers (*direct quotes from the papers are in blue):*

## **People with intellectual disabilities and their need for cancer information** (Tuffrey-Wijne et al, 2006, Jones et al, 2007)

**Aims:** A qualitative, hypothesis generating study to investigate the cancer information needs of people with learning disabilities who were affected by cancer (either because they themselves had cancer, or a close person has/had cancer).

**Methods:** Five pairs of participants (a person with learning disabilities and a supporter, who was a staff member) were given a copy of Getting On With Cancer. Data collection consisted of non-participant observation (where the researcher observed the participants without actively participating); and audio-recording the session. In this study, the **participants** were the person with LD and the carer. The researcher gave them the book and then sat down unobtrusively in a corner to see what happened, without making any comments or suggestions. The participant looked through the book (and commented out loud on the pictures) together with their supporter.

After the session, audio-recorded semi-structured interviews were conducted separately with the participant with learning disabilities and with their supporter. Interview questions included: How did the participant experience using the book? Which parts were particularly useful? Was there anything that was not understood? Is there anything else the participant would like to know about their relative’s illness?

The **data** consisted of:

·        Field notes – descriptions by the researcher of what happened

·        Transcription of audio-recordings of the interaction between the participants

·        Plus, transcriptions of the audio-recordings of the one-to-one interviews

**Findings:** *“The book met a desperate, previously unmet need for cancer information. The participants wanted to know and understand what had happened to their parent. They had very clear ideas about what information they needed. This ranged from information about cancer, how it is caused, treatment, side effects, and what help is available, to information about coping with feelings when someone is dying, the dying process, and palliative care. The book went some way in addressing their questions, and there was marked relief when a particularly relevant picture was encountered.” (TW 2006, p111-112).*

*“Some indicated that the book had only scratched the surface for them. It would have helped some people to have even more detailed explanations and pictures about the various cancer treatments, such as radiotherapy. Several people asked for a similar book, but with a less positive outcome.”* (TW 2006, p112)

*“Apart from providing factual information, Getting On With Cancer contains pictures that show the emotional effects of cancer. The book proved to be a powerful tool in enabling people with intellectual disabilities to talk about their own personal cancer experiences... All the participants who were observed whilst reading the book with their supporter soon interspersed the story in the book with their personal experience.”* (TW2006, p113)

How much the participants were able to reflect on their own experiences depended largely on the help they received from their supporter. The researchers found that sometimes, supporters cut the participant short when s/he started talking about personal experiences. None of the supporters had any training in issues around cancer or bereavement. They could not answer some of the questions the participants with learning disabilities asked and felt out of their depth. The supporters, who knew the person with learning disabilities well, were surprised by the need and ability of the participants to talk about their experiences of cancer and bereavement.

*“There were examples of supporters becoming flustered when the person with learning disabilities began to explore their feelings and experiences around cancer. There was a tendency of supporters to move on quickly through the pages of the book, possibly missing opportunities for the person with learning disabilities to reflect on their experiences. [One participant], whose mother had recently died of cancer, looked at a picture in the book and said, ‘She looks worried, and her friend and her mum also look worried.’ [Supporter} (turning the page): ‘OK, so the next section we’re at now is ‘In the hospital’. I assume she’s been admitted.’ In [another] case, the session with Getting On With Cancer had little apparent benefit, as [supporter] cut [participant] short every time she mentioned her mother who had died some years earlier. The opposite happened when the supporter was actually trained in dealing with emotionally difficult issues:*

*‘I will use the book again in another session to find out more about what was happening to his mum. Because he didn’t like her being in hospital, he really didn’t’t.’*

*The contrast between some of the participants in this study and their ability to support complex emotional needs could have been due to the supporters’ experience and training. However, there were not enough participants to test this as a generalizable finding.”* (J 2007, p15-16)

It was after reading the book, when the participants with learning disabilities were interviewed on their own, that *“the floodgates opened, and people’s stories came pouring out. For some, it was possibly the first time that they talked about their experiences at such length. Their supporters had told us that they were coping well and never talked about their loss. In the interview with participant 3, one simple question unleashed a long reflection on what he had gone through:*

*Researcher: I want to ask you, how was it for you to read this book?*
*Participant 3: A bit sad really, some bits were. When I first knew that my mum had cancer… I found it very, very hard. I couldn’t cry, I just could not cry. I wanted to, but I couldn’t cry. Even at the funeral I just could not cry. Very, very recently, just a couple of months, I started crying…”*

*He talked, uninterrupted, for 15 minutes.” (p113)*

**Conclusions :** *“All the study participants had a substantial, unmet need for cancer information. Whatever the reasons for not having received information at the appropriate time, it was clear that they were able to understand the information if it was given in an accessible format, such as the picture book.”* (p114)

BBW had clear potential benefits for the participants in this study. It enabled them to understand what had happened to their relative/themselves and enabled them to begin to talk about their experiences and emotions. However, it was also clear that supporters need training and support themselves if they are to enable people with learning disabilities to obtain maximum benefit from the book.

## **Using Nominal Group Technique to investigate the views of people with intellectual disabilities on end-of-life care provision** (Tuffrey-Wijne et al 2007)

**Aim:** To elicit the views of people with learning disabilities on sensitive issues – in this study, on end-of-life care.

**Method:** A single picture from the book Getting On With Cancer was used. It was an image of “Veronica” sitting in front of a window in an armchair covered by a blanket, with a small dog on her lap. It was shown to 14 people with mild/moderate learning disabilities (two groups of four and one group of six), all with verbal skills; some lacked literacy skills. The picture was accompanied by the following verbal statement from the researchers: *“This is Veronica. Veronica is very ill. She is not going to get better. The doctor knows that she is going to die. What do you think people could do to help Veronica?”* The researchers stressed that Veronica was not real – this was a story.

**Results:** The question, and the picture, elicited a mean of nine individual responses (range 4-16). Once identical responses were eliminated, the three groups produced 25, 17 and 15 ideas respectively. All group members where then invited to ‘vote’ for their top 5 ideas. This resulted in a group consensus on what could help someone who is terminally ill.

*“Participants appeared to have varying approaches to answer the question. Some searched the picture for clues to what Veronica might want, resulting in suggestions such as ‘close the window, give her a drink, keep her warm, go to bed, someone to look after her dog when she goes to hospital’. Others seemed to remember what happened when they themselves had been ill: ‘give her a magazine, send cards and flowers, watch TV’. A few participants based suggestions on their experiences of the terminal illness of someone close to them, for example: ‘Go into a nursing home’ and ‘Support the parents because they are going to lose a daughter’.”* (p84)

**Conclusions:** Using just a single picture from BBW was remarkably effective in eliciting a very wide range of responses from people with learning disabilities. The fact that this was a story reassured the participants and enabled them to come up with ideas that resonated with their own experiences.

### 4.2.3 People with intellectual disabilities who are affected by a relative or friend with cancer: a qualitative study exploring experiences and support needs (Tuffrey-Wijne et al, 2012)

**Aim:** To explore the experiences of people with learning disabilities who have a relative or friend with cancer, and to identify their support needs.

Methods: Participants were 21 adults with learning disabilities who had a relative/friend with cancer, now or in the past; 17 took part in 3 focus groups (of 6, 6 and 5 participants respectively) and 4 took part in a face-to-face interview. The participants mentioned 40 cancer patients between them; 35 of these had died. Each focus group met four times, as follows: Meeting 1: Introduction. Meeting 2: A short slide show with selected pictures from When Dad Died. The researchers asked the group to tell the story but ensured that the following story emerged so that all participants were exposed to the same explicit content: ‘This is Jim. Jim’s father is taken ill and goes into hospital. His mother is crying because she is told that the father has cancer. Jim looks sad and worried.’ The group was then asked: “What is Jim worried about? What would help Jim?” Meeting 3: Flexible, as each group had different needs and wishes. One group wanted the researchers to explain facts about cancer. One group wanted to look at more pictures and stories from Books Beyond Words to discuss. One group wanted more time to talk about their experiences. Some role-play was included, based on the experiences of ‘Jim’ from the pictures. Meeting 4: Nine cards of pictures from Books Beyond Words were prepared, representing the various strategies that participants had said would help them. Participants were then asked to rank the ‘top five’ ideas in order of preference, following Nominal Group Technique principles. Face to face interviews: The researcher used pictures from When Dad Died to support the interview schedule.

**Results:** The data collection methods were effective in eliciting a wide range of experiences. When presented with the pictures of When Dad Died, which left it open whether or not Jim had been told about his father’s illness, participants were clear about what was worrying Jim: “Nobody’s told him”. In all groups, this elicited lively discussion about their own experiences of not protected from information about their loved one’s illness and dying. The participants also talked about their difficulties in coping with cancer and loss; their lack of understanding what cancer actually was; and their need to have someone to talk to. Prompted by thinking about Jim’s needs, they were also able to suggest a wide range of support strategies.

*“At the end of the final focus group session, when asked what it had been like to take part in the study, participants’ responses were overwhelmingly positive. Although it had been difficult and sometimes painful to talk about the issues raised, they were glad they had done so. For any, it was the first time they had an opportunity to talk about cancer and how it had affected them… They especially liked the fictional stories [Books Beyond Words], the voting, and the opportunity to share with others and find out that ‘you’re not the only one’.”* (p 516-517)

**Conclusion:** *“Our study found that showing people with ID just a few relevant pictures of situations that bore similarities to their own, and inviting them to voice their comments and questions, was a very effective way of eliciting concerns. Existing pictorial resources could therefore be used flexibly in a clinical setting to support not only people with ID who have cancer, but also cancer patients’ family and friends with ID. However, accessible cancer information is of limited use unless people with ID have access to someone who recognises their information need, wishes to meet this need, and knows how to meet it (including finding the accessible materials). Most people with ID are unable to access information on their own. Pictures and easy-read resources can be an invaluable tool, but they are only as good as the people using them.”* (p517)

### 4.2.4 Developing guidelines for disclosure or non-disclosure of bad news around life-limiting illness and death to people with intellectual disabilities (Tuffrey-Wijne et al., 2013)

**Aim:** To develop a model/guideline for breaking bad news to people with learning disabilities.

Methods: Focus groups with 21 people with mild/moderate learning disabilities. This was part of a larger study of 109 participants, also including focus groups of family carers and professionals. BBW was used with the group of people with learning disabilities only; the methods and findings are only briefly described in the published papers, as follows: People with intellectual disabilities were asked their opinion about a fictional character, John, who was very ill and whose doctor know he was going to die of his illness. To support this, pictures from Am I Going To Die? were used.

**Results:** “Responses about whether or not [John] should be told about his condition were mixed and appeared to be based on their own personal preferences if they were to find themselves in John’s shoes. Most were able to state these preferences clearly, with several participants able to give considered responses.” (p234) [on p236 of this paper, there are two extended transcripts of the focus group discussion about the BBW pictures, demonstrating the wide range of opinions and experiences it elicited]

**Conclusions:** As in the previous study, pictures from BBW were highly effective in enabling people with learning disabilities to express their opinions and share their experiences.

## **Doing it together** (Butler, Cresswell, Giatras, & Tuffrey-Wijne, 2012)

In this paper, the four researchers who carried out the two focus group studies (including two co-researchers with learning disabilities) reflect on their experiences, including the experience of using BBW pictures within their research. Here is a quote from one of the co-researchers, who helped facilitate the focus groups:

“People really liked it when we did the made-up stories. I think they can relate to stories. They can associate it with their lives. They say things like ‘I was like that’ or ‘my dad was like that’. The support staff often had an expression of shock, horror and amazement on their faces, as if they were saying, ‘This person never said this before. I never heard them say that.’” (p140)

**4.3. Review papers**

Four review papers have been published that explore the neuroscience behind the understanding of narrative and emotion in pictures (Hollins et al 2017; Carpenter et al, 2016a and b) and the contexts in which Books Beyond Words have been found to be helpful (Hollins et al 2016). These two perspectives are informing each other. Use of the books in clinical and therapeutic settings is now well established. The experience of reading stories in pictures, without words, however goes beyond readers immediate health and therapeutic needs as is being demonstrated by the development of Books Beyond Words Book Clubs; the latter now available in many locations across the UK (details available on <https://booksbeyondwords.co.uk/book-clubs>)

Book Clubs take wordless books into the social and community domains bringing benefits such as social connectedness, community inclusion, confidence and empowerment through shared learning about everyday life experiences. Personal accounts of adults with learning disabilities using Books Beyond Words in these different therapeutic and every day community contexts, help to guide the neuroscience explorations. Neuropsychological research is illuminating how readers struggling with language focus on decoding of words rather than being able to create their own mind images from the symbolic content of the words. Pictures skip the need to decode and thus permit the individual to engage with the emotional content in the picture, which in turn will bring to (their) mind their own emotional experiences. Many with learning disabilities have high levels of stress in their lives, as well as high levels of past adversity and traumatic experiences. Language barriers can further isolate them to suffer in silence – or as is now being recognized, engage in behaviours of distress (sometimes referred to as behaviours that challenge).

Effective emotional engagement such as is facilitated with Books Beyond Words, enable readers to access and reappraise emotions and events they have experienced in the past, as well as to increase their social understanding of other people. The links between meaningful emotional engagement, affect regulation and triggers of mental distress, are active and emerging areas of neurobiological research.

As these review papers demonstrate, Books Beyond Words offer the opportunity to inform this research with accounts from people with learning disabilities about their emotional experiences, as well as inform about the roles of meaningful communication (and attachment) in affect regulation and mental well-being.

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### BOOKS BEYOND WORDS (Series Editor: Sheila Hollins)

(All ‘Books Beyond Words’ are now published under the imprint of Beyond Words, London and are available in print and e-book formats (including some foreign language versions). <http://www.booksbeyondwords.co.uk>). The BW Story App is available from the App Store or Google Play for IOS and Android platforms, respectively. Also available for download to desktop via Windows.

**Coronavirus PDFs created 2020-2021- available to download free**

HOLLINS, S,. HOLLINS, N. Illustrator Lucy Bergonzi (2020). Beating the Virus.

HOLLINS, S. Illustrator Lucy Bergonzi (2020). Having a Test for Coronavirus (home testing and drive through testing)

HOLLINS, S. Illustrator Lucy Bergonzi (2020). Having a Vaccination for Coronavirus

HOLLINS, S. Illustrators include Beth Webb, Lucy Bergonzi, Catherine Brighton (2020). Good days and Bad Days during lockdown.

HOLLINS, S., SINASON, V. AND GRANT, M. Illustrator Lucy Bergonzi (2020). When it’s not safe to stay at home: a guide to supporting people at risk of abuse during coronavirus.

HOLLINS, S. and TUFFREY-WIJNE, I. (2020). Jack plans ahead for Coronavirus: a guide for family and carers

HOLLINS, S. and TUFFREY-WIJNE, I. (2020). When someone dies from coronavirus: a guide for family and carers

HOLLINS, S. and TUFFREY-WIJNE, I. (2020). Let’s talk about ….. when someone is ill or dies from Coronavirus. Online support for people with learning disabilities.

HOLLINS, S., WATSON, C. and EMMETT, M. Illustrator Beth Webb (2020). Understanding Covid-19 in secure settings.

See download link: <https://booksbeyondwords.co.uk/coping-with-coronavirus>

**Health screening leaflets commissioned by the UK NHS National Screening Service**

On Breast Cancer Screening, Cervical screening, Bowel Cancer Screening.

See download link: <https://booksbeyondwords.co.uk/#/resources-dl/>

**Books available in print and digitally**

1. CARPENTER, B, ERSKINE A and HAWKES, J. Illustrator Charlotte Firmin. (2020). *Lenny and Lucy in Lockdown.* London: Beyond Words.
2. CARPENTER, B, ERSKINE A and HAWKES, J. Illustrator Charlotte Firmin. (2020). *Lenny and Lucy return to school.* London: Beyond Words.
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1. Validation is a fundamental concept in dialectical behavioural therapy (a therapy first developed by Marsha M Linehan). [↑](#footnote-ref-2)
2. The development of one book, *Getting On with Cancer* (Donaghey, V. and others, 2002) is described in Tuffrey-Wijne, I. and Bernal, J., 2003, *Leaning Disability Practice*, 6 (5), 10-15. [↑](#footnote-ref-3)
3. 2015 version [↑](#footnote-ref-4)
4. Hyperlinks to website and YouTube channel correct at June 2016. [↑](#footnote-ref-5)