

Books Beyond Words: Using Pictures to Communicate

Abstract

Books Beyond Words are the outcome of the Beyond Words method of putting people with intellectual disabilities and others who struggle with words at the centre of the communication exchange. Books Beyond Words are picture books, in colour that tell a story and are designed particularly for adults. The Beyond Words method has developed as a partnership involving self advocates with intellectual disabilities and those who provide every day and professional supports. In this article the creator of the Beyond Words method describes the development of the current Books Beyond Words series as well as the wide range of circumstances in which the books are helpful in ensuring people with intellectual disabilities are fully involved in meaningful exchanges with others about their day to day needs. Feedback from people using the books is also shared.

The first author of this paper has been using Books Beyond Words with clients and patients over many years with considerable therapeutic benefit. Through the interview format which follows, the second author and creator of Books Beyond Words is able to speak directly to the reader of the article about the origins, uses and ongoing development of the current series of Books Beyond Words and the Beyond Words method.

e-Interview

What Are Books Beyond Words?



*Professor Sheila
the Baroness Hollins*

Books Beyond Words (hereafter sometimes just referred to as the Books) are picture books, in colour, designed for people with learning and communication impairments, and created in partnership with the people they are designed for. They are aimed at people who struggle with words and who find pictures easier to understand. The Beyond Words method provides a communication tool to help people understand things that they find hard to understand just with words.

How Did These Books Come to Be?

Looking back I can recall two specific circumstances that highlighted in my mind that visual communication can convey shared meaning where language may be difficult for one of the communicating partners. My son has an intellectual disability and when he was facing a new experience, we found that drawings – a cartoon strip with stick figures –

Authors

Elsbeth Bradley,¹
Sheila the Baroness
Hollins²

¹ Surrey Place Centre and
Department of Psychiatry,
University of Toronto,
Toronto ON

² St. Georges
University of London,
London, UK

Correspondence

e.bradley@utoronto.ca

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really helpful in calming and preparing him for events ahead that were unfamiliar. Early in my clinical practice as a psychiatrist, I was called to see a man with Down syndrome who had started to refuse to get up in the morning, he would not eat, he was a man without any speech, and I eventually discovered that his father had died. I started trying to explain to him about his father and I looked around for pictures and any resources I could find that would enable me to get across to him that his father had died. Our first book *When Dad Died* was made out of that story because there were no resources that were relevant. From that the books have grown to cover a whole range of the aspects of people's lives.

Working with my son using pictures to assist his understanding of future events I recognised the important distinction between visual and verbal literacy. By visual literacy I mean recognising that some people understand pictures better than words and that they can *read pictures* and understand visual cues even though they may not be able to read words. Many people with intellectual disabilities and communication difficulties (e.g., autism) have documented visual/verbal discrepancies in IQ with visual understanding being a strength and visual communication preferred.

In subsequent years in our psychotherapeutic work with adults with intellectual disabilities, rather than the focus being on words as in other so-called talking treatments (e.g., more traditional psychological psychotherapies), using pictures has enabled individuals, sometimes for the first time, to share their emotional inner worlds and concerns.

Who Reads These Books?

We have discovered that a variety of people find the books helpful: (1) people with communication and learning difficulties; (2) people with literacy problems; (3) non-English speakers when there is no interpreter; (4) deaf people; (5) relatives, friends, supporters, carers, advocates; and (6) health and social care professionals, educators, criminal justice staff. In addition they have been used with some people with thought disorder and some with dementia.

When and How are Books Beyond Words Used?

People usually read the books with a supporter, a friend, a relative or a professional.

The Books can also help a professional, such as a health or criminal justice professional to be able to communicate more clearly and easily. Having the picture as a tool for engagement can make the interview just that much easier both as a way of sharing information and as a way of understanding what is going on in the mind of the person they are trying to communicate with. Pictures can also simply be a way of engaging the interest and cooperation of the person they are with.

Some public libraries in the UK are now hosting book clubs for people with intellectual disabilities where a small group of people read the pictures in one of the Books Beyond Words series together with the help of a facilitator. Through sharing their ideas and experiences in response to the pictures, the members have a real sense of belonging to the reading world. Some video clips showing the books being used are available on our YouTube channel or see www.booksbeyondwords.co.uk

Can They Be Misused?

I think it's quite difficult to misuse them, but there are some ways to use Books Beyond Words which are better than others! For example, if the person introducing the book to someone really wants to know what that person thinks and feels, then it usually works best to let them hold the book, turn the pages and tell the story they see in the pictures. It doesn't matter if it's a different story to the one that you can see – the differences will be so instructive and interesting. It's also a good idea to read the book yourself before sharing it with someone, so you don't get any surprises about the explicit nature of some of the pictures. Also the information in the text about the subject matter will prepare you for any questions you are asked about a possibly unfamiliar subject. Some of the books may be best used by therapists or specialists, but it depends on how well you know the person and whether you have an ongoing supportive or therapeutic relationship with him/her.

What is Unique About the Books

Books Beyond Words are the only books made in this way with the help of self-advocates and without any words at all to accompany the story. They are quite different from easy read documents, which have a different place in helping to convert information into an easier to understand format. Easy read documents do not tell stories and by definition they include words. Their process is completely different too, as they start with plain English and then add illustrations to support the text, whereas we start with a story told in pictures and only add words as an appendix to provide additional reference material for supporters and professionals.

What is the Process of Development From Beginning to End?

The first task after deciding on the subject for a new title is to raise the money for the production of the book. They are expensive to create, each book costing about four times the sale price to make! The artist, editor, and one or two co-authors who are specialists in the topic of the book meet for a couple of hours with two self-advocates. We think about the aims of the book and together create a storyline. The artist goes home with a storyboard – a list of about 40 pictures that we think will tell the story we have come up with.

The artist draws these pictures as quickly as she can and asks us to check them and see if they tell the story we wanted to tell. She makes any changes we request and colours the pictures. We then ask twenty or more people either working one to one or in groups to read the story and each of these stories is documented. As part of this trialling process we will also have found out a great deal about people's information needs and whether there are any problems with the pictures we have commissioned and the story we have created. If the story isn't clearly being understood as the story we wanted to tell, or people's information needs prove to be different than we had thought, then the authors and artist have to make further changes. Eventually when we are all satisfied with the story line and pictures, the artist completes them and we begin to write the supporting text that goes at the back of the book for support workers, health professionals

and others such as teachers, librarians and family members. This takes at least 18 months from our first meeting!

Have There Been Any Outcomes That Were Unexpected?

We often learn unexpected things in our trialling which can lead to picture changes or even a change in the direction of the story. During the stories we show the point of view shifting from one character to another by featuring the reactions of the different characters to the same situation. This is quite a sophisticated literary device – all accomplished in pictures without the help of words. Sometimes the reader cannot relate to all the characters but identifies just with one. In some books we have been aware of the importance of getting eye contact right to avoid any misunderstanding about the intention of one character towards another. For example, in the book *Going to the Doctor*, initially the Doctor while examining a man's abdomen, appeared to be looking "down his trousers." This was upsetting for one trialler who had been abused previously. The picture was adjusted to show the doctor maintaining eye contact with the patient during the examination.

[Note from E.B.: *Something which has caught my attention when using the Books has been the way people engage with the picture. For example for some, the nuances of colour, shade and shadows seem to resonate with previous emotional, difficult and sometimes painful experiences and they are then able to articulate more easily, and perhaps share for the first time, this distress. I have also become aware how words are quite linear and impose an agenda whereas the picture allows the person to scan the whole before focusing on what is most important and meaningful to them. In short, the pictures seem to offer more direct access to what is the priority for the person reading and to their emotions and feelings about this.*]

For Someone Who Has Experienced Trauma, Could the Books Stir up Distressing Memories and Uncontrollable Emotions?

For someone who has experienced something traumatic, the pictures might bring a painful memory to consciousness rather suddenly and provoke an unexpected reaction in the unsus-

pecting supporter. For this reason we advise that books about trauma should be used by people who know the individual and his or her history very well; by someone who has prepared themselves carefully before starting to share the book; and possibly by someone who has psychotherapy or counselling training depending on the circumstances. But as mentioned in answer to the previous question, sometimes people have unexpected reactions.

And How Would You Support the Person Through This?

My approach is to be guided by the wishes and pace of the reader, and only to cover as much of the story or the pictures of their choice in one reading. Some readers/patients may choose to look at a very small number of pictures that they find relevant to themselves, saying something like: "That's my story." It is important to allow enough time and not to be interrupted. It may help to have ideas of additional activities to do together such as visiting the grave of a deceased relative after reading one of the bereavement books, or looking at photos of the person who has died.

Are the Books Used in More Formal Psychotherapy – e.g., Dynamic Psychotherapy?

I have found the books a very helpful resource in both individual and group psychotherapy. In group therapy individual members are often very surprised to see how others in the group react differently to some pictures, and by listening to another person's experience, for example of being abused, empathy begins to develop. In individual psychotherapy, I recommend having a choice of books available for patients to choose from, perhaps alongside paper and crayons as one might in child psychotherapy. Their choice of a book and then choice of individual pictures can provide clues to the person's mental state and inner emotions, and support therapeutic interpretations.

Have You Encountered Any Misconceptions by Others?

Some people think that picture books are for children and that serious subjects cannot be properly explored in pictures. I think that

Books Beyond Words can roundly dispel this misconception! For example, some of the interviews shown in our training DVD are with older adults sharing books with each other and talking about how the stories mirrored their own experiences.

We received this feedback from a Book Club Facilitator: "We read *Mugged* in one session. There were people in the group who had been mugged so it was very real for them. Jane was particularly struck by the "punch" picture. She was surprised that it brought emotions up for her. It helped her think about the story and her own experiences of course but also the realisation that the pictures could move her in a way she hadn't thought possible. Up till then I think she had thought they were picture books that were interesting but just something to do."

Can Books Beyond Words be Used in Non English Speaking Countries?

Most of the subjects we cover have universal applicability. There may be variations in rituals and cultural responses to different life events, but the fundamental human feelings and responses are similar all over the world. I have read the books and they are being used in places as far afield as China, Argentina, South Africa, Sri Lanka, Pakistan, Australasia and the Netherlands. To an enquirer who says that the pictures and story told do not exactly match a similar situation in their own country, I usually suggest that they find some magazine pictures from their own country and culture to supplement the pictures in the book. After all, each book can be used as a story about someone living in another country. The reader can think about whether what happened in the story was the same as something that happened for him or her, or how it differed.

What Do People with Intellectual Disabilities Say About the Books?

There have been many spontaneous and positive comments: for example a teenage boy said that he loves stories but had never read a story himself until his Mum gave him "Falling in Love." Another woman said: "they're bright and colourful – I like that." An older man said that he liked reading stories about things that had

happened to him. This man had been mugged, and he said it helped to know that other people had been mugged too.

What Do Clinicians Say About the Books?

Feedback from clinicians is excellent. In one psychiatric unit titles in the series are included in the care plans of all of the patients, with each person being encouraged to choose a book about an area of life they are struggling with. A nurse wrote "a man whose mother died two years ago was admitted to hospital with severe depression – he is finding *When Mum died* very useful in 1:1 sessions with me. In just a short time he can look through it and make comments without crying. Now he has started to talk about his relationship with Mum – it's very moving."

In weekly psychotherapy, clinicians report significant changes in their patients' behaviour and mood when they introduce the Books in a session. One psychologist reported, "When J holds the book and turns the page, she is in

control of the pace of disclosure of her story and her feelings. She may start off telling the story of the character in the book, but invariably she ends up talking about herself and her story."

Which Book Is Your Favourite?

There are 39 books now, although some are out of print and we are seeking funding to reprint them. My favourite is *George Gets Smart* – it is beautifully illustrated and most people laugh at some point during the story – especially as they follow the behaviour of George's cat!

Do You Need Training to Use the Books?

Books Beyond Words does offer training in the UK and is always willing to train facilitators from other countries. Whilst some excellent communicators seem to be able to understand the books and their potential very quickly, for someone to become familiar with the full range of ways they can be used would be easier through training. But anyone can use a book on a one to one basis without training by sim-



Figure 1. *George Gets Smart*
© Sheila Hollins and Lisa Kopper
www.booksbeyondwords.co.uk



Figure 2. *George Gets Smart*
© Sheila Hollins and Lisa Kopper
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ply reading the guidance provided at the back of each book and by looking at the video and other guidance on our website.

What Plans for the Future Do You Have for Books Beyond Words?

Beyond Words is developing eBooks and also translating the guidance notes into several different languages. These will be available from

our website. Clinicians, therapists and supporters who have learned how to use pictures and stories with clients and patients, are themselves finding pictures to create stories to communicate with these clients and patients about other experiences too. What we have identified is a Beyond Words method of putting people with intellectual disabilities at the centre of the communication/consultation.

Titles Published Between 1989 and 2012

Books Beyond Words are stories told in pictures: (1) to provide information; (2) to check for understanding; (3) to explore feelings; (4) to share experience; and (5) to support decision making.

Physical Health

1. Am I Going to Die?
2. Getting On With Cancer
3. Looking After My Heart
4. Getting on with Type 1 Diabetes
5. Getting on with Type 2 Diabetes
6. Getting on with Epilepsy (currently out of print)
7. When Somebody Dies (currently out of print)

Mental Health and Trauma

8. Sonia's Feeling Sad
9. Ron's Feeling Blue (second edition)
10. Ann Has Dementia
11. Bob Tells All (currently out of print)
12. I Can Get Through It
13. Jenny Speaks Out (second edition)
14. When Dad Died (third edition)
15. When Mum Died (third edition)
16. Hug Me Touch Me (currently out of print)
17. Making Friends (currently out of print)

Health Screening

18. Keeping Healthy "Down Below"
19. Looking After My Balls
20. Looking After My Breasts

Health screening leaflets on bowel screening, having a colonoscopy, breast and cervical screening are also available online

Lifestyle

21. Susan's Growing Up
22. George Gets Smart
23. Loving Each Other Safely
24. Enjoying Sport and Exercise
25. Food ... Fun, Healthy and Safe
26. Falling in Love
27. Peter's New Home (currently out of print)
28. A New Home in the Community (currently out of print)

Using Services

29. Going to Out-patients
30. Going to the Doctor
31. Going into Hospital
32. Michelle Finds a Voice
33. Speaking Up for Myself

Criminal Justice System

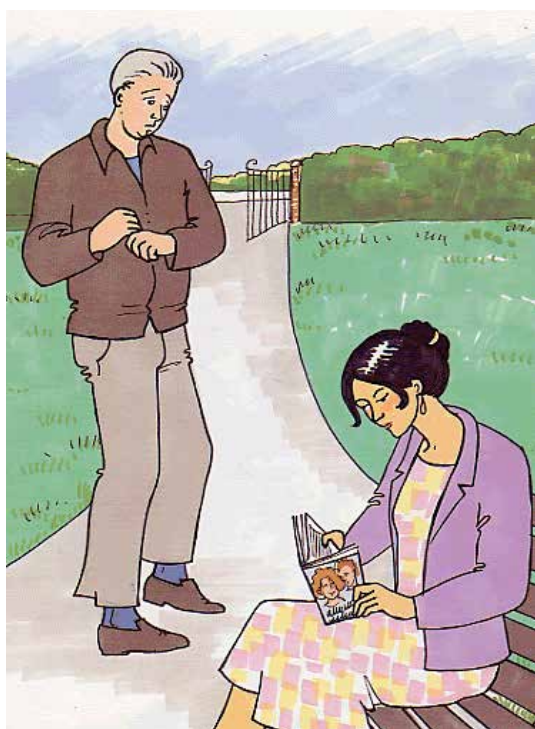
34. Mugged
35. Supporting Victims
36. Going to Court (replaced by Supporting Victims but still relevant for some overseas countries with similar Criminal Justice Services)
37. You're under Arrest (currently out of print)
38. You're on Trial (currently out of print)
39. You're in Prison (in preparation)



“When we are able to use the Books Beyond Words it then becomes a two way conversation with the patient so we can show them the pictures of what going to happen, we can talk them through it we can ask them what they understand about what they see and how that makes them feel; whether it makes them feel scared or whether it makes them feel anxious. And so we can explore those feelings with them and then try to reassure them about any of the anxieties they may be having; but also clarify any of the things that may be going to happen that they don’t fully understand.”

– Joanne Bratchell, Lead Nurse,
Pre-Op Assessment, St George’s Hospital,
London, UK

Figure 3. Going into Hospital © Sheila Hollins and Lisa Kopper www.booksbeyondwords.co.uk



“Reading a book is such an intrinsic part of most children’s and adults’ lives that the pain and shame of feeling excluded from that world is hard for people to imagine. Books Beyond Words allows the pleasure of holding a book and reading it seriously, books on the deepest issues in life, friendship, loss, death, trauma, hygiene, romance, without a single word to impede the process.”

– Dr. Valerie Sinason, Psychoanalyst and
Director of the Clinic for Dissociative Studies,
London, UK, 2012

Figure 4. Making Friends © Sheila Hollins and Lisa Kopper www.booksbeyondwords.co.uk



“... perhaps sometimes there is a misapprehension amongst people that those with intellectual disabilities will not understand complicated and anxiety provoking subjects.

But of course they are living lives that are affected by those things everyday; and to have a really straightforward tool that covers in such a detailed and in-depth way, often really painful difficult to think about subjects, I think is really helpful and I think could be quite a surprise to people who have just stumbled upon them [the Books] for the first time.”

– Dr. Noelle Blackman
from www.booksbeyondwords.co.uk

“The Books Beyond Words series offers a wonderful resource to use in therapy sessions. It is often hard for clients to find the words to tell what they have experienced or what is worrying them. As a therapist I often choose some of the pictures from the books and provide them as a prompt to help the person tell me. Eventually with the help of the books they are able to share with me their own story.”

– Dr. Noelle Blackman,
Drama Therapist and Chief Executive
of RESPOND, a UK National charity
providing psychotherapy for people with
intellectual disabilities, 2012

Figure 5. Ron’s Feeling Blue © Sheila Hollins and Lisa Kopper www.booksbeyondwords.co.uk

Key Messages From This Paper

People with disabilities: “I thought I couldn’t read, but SH showed me that I can! I can read a few words but with these books I don’t have to read any words at all. It’s wonderful.” Self advocate and book club member.

Care providers: “Books Beyond Words help me to know what she is worrying about and how much she already knows about a situation. When a friend of hers died, the book *When Dad Died* helped us to prepare her for his funeral. Without it, I don’t think we would have supported her to go on the day.” A mother.

Professionals: “It is a penny dropping moment – both for you and the person themselves – you because you understand the power of pictures to explain and for them – because a new experience has been opened up and they feel better

prepared, better able to cope.” (Hollins; www.booksbeyondwords.co.uk)

Policymakers and service commissioners: Books Beyond Words help people who find written words difficult to understand to belong fully in their community. This includes people with intellectual disabilities, those who are non-English speaking, who are deaf, or who have literacy problems.

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Elsbeth Bradley, PhD FRCPC FRCPsych,
Associate Professor,
Department of Psychiatry,
Faculty of Medicine,
University of Toronto,
Psychiatrist-in-Chief,
Surrey Place Centre,
2 Surrey Place,
Toronto, ON Canada M5S 2C2
e.bradley@utoronto.ca

Professor Sheila the Baroness Hollins,
FRCPsych FRCPCH FRCP FCMSA,
Executive Chair,
Beyond Words and
Emeritus Professor of Psychiatry of Disability,
St Georges University of London,
6th Floor Hunter Wing,
Cranmer Terrace,
London, SW17 0RE UK
c/o dduncan@sgul.ac.uk

Other Resources

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