In a public library in Swiss Cottage, north London, six teenage book group members are talking about what they have been reading.

It is a romance and, as in any similar group, there is animated discussion, in this instance on the topic of sex in relationships. The difference here is that these young people have learning disabilities – some of them cannot read, while others find reading quite difficult – and the book they are reading has no words.

The story in question, Falling In Love, is one of the Books Beyond Words (BBW) series of picture books for young people and adults who find pictures easier to understand than words.

Books Beyond Words
Books Beyond Words is the brainchild of Baroness Sheila Hollins, emeritus professor of the psychiatry of disability at St George’s, University of London. In her early years as a psychiatrist, she was called to see a young man with Down syndrome who was self-injuring. He would not get out of bed and was refusing food.

‘Staff asked if I could prescribe something to get him up,’ she remembers. ‘I didn’t know of anything that could do that, so I tried to find out why he was behaving as he was. Eventually, I discovered that his father, who used to visit every Sunday, had died. Nobody had told the young man; they didn’t think it mattered because he couldn’t speak.’

Professor Hollins diagnosed a grief reaction. ‘Staff thought I was mad,’ she continues. ‘So I set out to demonstrate that you can address sensitive issues with people who are non-verbal, and I tried to find some pictures.’

Professor Hollins already had experience of using pictures to help her communicate with her son Nigel, who has a learning disability and who, as a child, did not speak. But all she could find to use with her older bereaved client was a book aimed at very young children. ‘It was about a little girl whose Grandpa was dying,’ she explains. ‘As I sat and read it to him, I thought: “This is just not right.”’

After approaching a number of publishers about the gap in the market and receiving very negative responses – the topic of a parent’s death was too sensitive to tackle in a book, they were not interested in picture books featuring older characters – Professor Hollins worked with an artist to create her own storybooks. The first, When Dad Died, now into its fourth edition, is just one of 50 BBW titles.

Beyond words
Annie Grant looks at how book clubs for older readers with learning disabilities are promoting good mental health and wellbeing.
**Pictures not words**

Books Beyond Words tell stories about important or difficult events that challenge people in their everyday lives. Topics covered include:
- Health
- Behaviour
- Healthy living
- Criminal justice
- Young people
- Abuse and trauma
- Accessing services
- Lifestyle and relationships
- Mental health and grief.

Each story is structured using pictures that communicate key messages and ideas through facial expressions, body language and colour. In the earliest titles, a single line of text accompanied each one, but today’s books contain no words.

‘We found very quickly that the words were barriers to our readers, so we removed them,’ explains Danny Curtin, BBW executive director. ‘If you write: “John gets on a bus” under the picture, that’s what the picture is. The whole point is that readers explore their own reaction to what they see – what the characters are doing, what they might be saying or feeling. If you are struggling to make sense of the text, it detracts from the pictures.’

**From therapy to community**

The first books were used mainly by mental health professionals working with individuals, but Professor Hollins believed that they could also be of great value outside the therapeutic context. ‘When the books are used in therapy, the individual is already experiencing problems,’ she says. ‘I wanted to use them to prevent problems by increasing understanding.’

It was her son’s support worker who first thought of using the books in the setting of a book club as a social activity for her clients. ‘It was a simple idea and it worked so well that we set up two more,’ enthuses Sue Carmichael, a volunteer in Kent libraries, where there are now 16 BBW book clubs. The clubs, held regularly in public libraries, are open to anyone with a learning disability.

Meeting in a public space is an important feature. ‘It’s about social inclusion and confidence – we’re out in the community and everybody sees us,’ explains Ms Carmichael. ‘It can challenge and change public perceptions of how people with learning disabilities can contribute in society. Plus, when our book group members are out and about, the library is a warm, safe place where they’re known and where they can ask for help if they need to.’

While all book clubs are organised around BBW titles chosen by their members, every club is different. ‘The range of learning disabilities is very wide, so you need to find the best way to work with the group you’ve got,’ says Ms Carmichael. ‘That might mean introducing more structure for participants with autism, or adding a sensory dimension by using objects to support the story if participants have more complex needs.’

**Students quickly learned to give and receive support and to challenge each other**

**Training**

In a book club meeting, participants take it in turns to describe what they see in each picture. A facilitator guides them through the story, creating a supportive environment in which everyone is given the space to express their thoughts on the story in their own way.

There is written guidance for facilitators at the back of each book and BBW offers training for anyone wanting to set up or facilitate a book club.

‘Working with the books is a different kind of pedagogy,’ explains Professor Hollins. ‘In the training we run, professionals read a book with adults with learning difficulties. Almost always the professional opens the book and says: “Let’s start here.” Then we ask them to give the book to the person with a learning disability and let them set the pace. Suddenly, the professional is the observer, the person with the learning disability is pointing at things and they’re talking about the pictures in a different way.’

**The benefits of reading together**

BBW books are designed to be both informative and therapeutic. All are co-created with people with learning disabilities, and all have storylines that encourage readers to work together to explore different types of situations. These fall into four categories.

- Everyday opportunities and experiences, like going to the theatre, taking exercise and making friends.
- 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 a loved one.

‘Our books empower people; they give them access to information, feelings and other things which they have often been prevented from having access to,’ says Professor Hollins.

More recently, three reading for pleasure titles in a new fiction series, Picture This, have been added to the catalogue. New book clubs tend to start by reading ‘easiest’ titles, but Professor Hollins explains that, once established, groups take more challenging subject matter in their stride. ‘Members come to trust and look out for each other,’ she says. ‘As with any book club, many of the choices have something tough in them – a relationship breaks up or somebody dies unexpectedly. The challenge is in how you negotiate those things, and why shouldn’t that be the same for people with learning difficulties?’

**Community inclusion**

In a 2015 survey by the charity Sense, over 50% of disabled people, and 77% of
Reading

disabled young people, reported feeling lonely. Many expressed a wish to get out and about more to meet people. BBW book clubs provide a social hub, in which people with learning difficulties can relax, make friends and socialise. In Kent, book club membership has been a gateway to other social opportunities – from friends meeting for coffee, to drama groups and gallery trips.

Lynne Steward, a librarian in Deal, sees their book club as an important element of their mission to engage the whole community. ‘We want to appeal to people of all abilities,’ she explains. ‘Once we’ve got them engaged with books, we can offer other opportunities and keep them moving forward.’

Belonging to Deal book club changed Julie Anderson’s life. From sitting on the periphery of a group in case it was ‘like school’, Julie, who has a learning disability, gradually got fully involved and now helps run book clubs as a volunteer. She has co-authored BBW books based on her own life experiences, represented BBW at events and helps to deliver their training. ‘Without the clubs I would just be sitting at home,’ she explains. ‘The clubs have given me confidence and a social life.’

Julie, who has been through some difficult times, really values the discussions that arise from reading the BBW books. ‘It helps me to know that other people have had similar experiences to mine and that it’s all part of life,’ she says.

‘The stories address the emotional aspects of difficult events,’ confirms Professor Barry Carpenter, a BBW director. ‘Discussing them with others enables readers to express their fears and worries and helps them to understand what they are feeling. It can reduce anxiety about forthcoming events.’

Supporting transition

As part of its interest in promoting mentally healthy lifestyles, BBW has recently turned its attention to schools and the role that book clubs can play in effecting a successful transition to adulthood for older students.

‘Mental health can decline when young people leave school if there aren’t opportunities to socialise,’ explains Professor Carpenter, who is leading research on the benefits of BBW book clubs for school leavers with learning disabilities. ‘Book clubs can provide a perfect bridge between school and adult life, but it needs to be done carefully. You can run book groups in school, but if you want young people to go on to take part in community book clubs when they leave, you need to model it for them.’

Swiss Cottage School in north London has been doing just that as part of Professor Carpenter’s research project. During the first two terms of the school year, Lucy Hall, senior leader for families and inclusion, ran a weekly lunchtime BBW book group in school. During the summer term, the group relocated to the local library, where young people had a chance to get accustomed to the setting and the staff. Book groups continued to run in the library over the summer holidays, and now, as a new term begins, the hope is that young people who have just left school will still want to drop in, read with their friends and get to know new members.

Ms Hall has been particularly impressed by the way the book group has helped develop students’ social skills. ‘They quickly learned to become quite enabling of each other, to give and receive support and to challenge each other,’ she observes.

Because of the success of the project, BBW book clubs are now being rolled out at Swiss Cottage School as part of the post-16 ‘Me and My Community’ curriculum element. ‘I was blown away by how much the young people got out of it,’ says Ms Hall. ‘As well as being a great vehicle for communication and dialogue, the groups have given us a rich insight into where our young people are in their understanding of quite complex issues, and the kinds of support they might need.’

Digital content

BBW hopes that its new free-to-download app, which contains some free content and a link to its shop, will make BBW pictures and stories more easily accessible to teachers and students in mainstream and special schools. ‘You can now get books or pictures at the touch of a button on your phone, tablet or whiteboard,’ says Danny Curtin. ‘So, if a school wants to prepare pupils for emotional challenges, like dealing with relationships, or something practical, such as vaccination, they can search and access a whole range of pictures that will help.’

Back at the Swiss Cottage public library, book group members give their verdict. ‘There are really important books about love and friendship,’ says Daud, flicking back through his favourite title as he speaks. Tammy has enjoyed the experience too. ‘I’d definitely go to a book group again, even if it was in a different place,’ she concludes.

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Books Beyond Words would love to hear how your school is using the materials. Please email admin@booksbeyondwords.co.uk.

Julie Anderson (in the red kilt) helps facilitate a training session

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