Diabetes education resources for people with learning disabilities

Michelle Denyer

Educational resources for any individual with diabetes need to be appropriate for their needs. Unfortunately, however, there is a distinct lack of materials that are suitable for those people with diabetes who also have a learning disability. Developing resources that are understood by those with limited literacy and cognitive skills is challenging. This article outlines a project in North Derbyshire that led to the development of written resources, a group education programme, an exercise DVD and training of carers of those with a learning disability.

Nurses working in specialist fields build up their knowledge and skills over time by reflecting on how their clinical practice works with specific individuals and by learning from specific cases. Individual patients impact on the way we think and deliver care, by bringing their own ideas and ways of working and self-care to us. One such individual accessing diabetes services in North Derbyshire in the early 1990s set off a train of thinking and challenged our way of working. This individual, "Barry", was diagnosed with type 1 diabetes, but he also had Down's Syndrome. The usual ways of teaching insulin injection techniques were not appropriate, nor were the patient information leaflets. This contact with Barry started off a process to examine how we delivered care, what resources were used and what other sources of information could be accessed, from both adults' and children's resources, as well as other learning disability sources. Though a challenge, it enabled a new way of thinking and working that benefitted Barry and others.

In 2006, while working in Derbyshire (then High Peak and Dales PCT), a request was received for training of carers for those with learning disability. It was felt that rather than training one group of carers, better resources were needed that would be widely accessible to all, rather than one centre. This request led to the development of accessible written resources for patients and carers, closer working with colleagues specialising in the field of learning disabilities and the development of education materials both for groups (NICE, 2003) and multidisciplinary teams working together. Resources were developed and a training day was set up. Many of the people with learning difficulties are cared for in the private sector, so links were made via social services and private care homes so that they were included in the training provided and were able to access resource materials.

Easy-read information was designed with the involvement of people with learning disabilities and was highlighted in the Department of Health document on providing equal access for people with learning disabilities (Department of Health, 2009).

This project followed identification of a gap within the diabetes service provision both locally and nationally. Professional awareness within the local community diabetes service, as well as work undertaken examining the published evidence, identified that limited specific resources were available from national organisations for adults with diabetes and a learning disability, or limited reading skills. This, in turn, meant that this group are less likely

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Article points

1. The Department of Health has emphasised the need to provide equal access to good healthcare for people with learning disabilities. However, prior to starting this project, we found a distinct lack of quality information available to people with learning disabilities and diabetes.
2. Our team was inspired by a gentleman in our care with diabetes and Down's syndrome. We did not have the appropriate materials to teach him about insulin injection, so it was decided that we would develop some accessible reources.
3. The project involved the development of written resources, a group education programme, an exercise DVD and training for carers.

Key words

- Diabetes education
- Learning disabilities

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Page points

1. This project followed identification of a gap within the diabetes service provision both locally and nationally.
2. The aim was to ensure equity of diabetes service provision across the local health community for people with diabetes and learning disabilities.
3. The project involved collaborative working with the community learning disability nurse, as well as people with learning disabilities and their families and carers.

to access services (Glover et al, 2012). Evidence demonstrates a clear link between low literacy and poor health. In 2008, the National Literacy Trust published a paper highlighting the association between low literacy and poor health outcomes (Dugdale and Clark, 2008).

Although not underpinned by a great amount of evidence and research findings, it seemed obvious that those with learning disability would gain more from an interactive approach to education (Kolb, 1984).

The aim was to ensure equity of diabetes service provision across the local health community for this vulnerable group of people. It is a statutory requirement under the Health and Social Care Act (2008) and the Equality Act (2010) that public sector agencies make "reasonable adjustments" to their practice that will make services as accessible and effective as they would be for people without disabilities. These reports came after the start of the project and supported the idea of empowering clinicians to innovate. The *Healthcare for All: The Independent Inquiry into Access to Healthcare for People with Learning Disabilities* report (Michael, 2008) explains the need for mainstream healthcare professionals to make reasonable adjustments to their services for people with learning disabilities.

Following identification of this need, a needs assessment took place in consultation with professionals within the learning disability field and discussions were had with service users about what they would find helpful. This changed thinking about appropriate ways to present information. For example, when explaining food choices, simplicity was important. For example, we were told that a simple "yes" or "no" answer relating to certain food, or the use of ticks and crosses, is helpful rather than vague statements, such as "sometimes you can have some."

When starting such a project, it is important to work in partnership with others who have specific skills and knowledge. Working with a community learning disability nurse, we consulted with patients and carers, and produced information booklets that would address the specific needs of this group. Family and carers were also consulted about the style and delivery of the materials being developed. Community learning disability teams were approached to help identify needs of clients and professional carers. The booklets were written in a simple, accessible language and included many photographs and illustrations to help with comprehension. The booklets were presented as a story that could be personalised for different individuals.

Fortunately, Barry was pleased to feature in the insulin booklet. The patients involved in the development of materials from the outset told us that they were very happy and proud to be consulted. Their ideas and suggestions have been incorporated into both the resources developed and the devising of a group education programme. This innovative project was one of the first of its kind. Only this year have we seen the publication of the new accessible information standard that states that health and social care services must provide information in a way that meets patients' communication needs (NHS England, 2016).

Following discussion with professional carers, it became apparent that training specifically tailored to those caring for people with learning disability was needed, rather than general diabetes courses. As a result, this was arranged and these sessions were used to develop further resources such as the "Talking to me" prompt cards for carers. These cards encourage carers to think of alternative words that people with learning disabilities could understand, rather than using complex language. Speech therapy colleagues were also consulted and advised on use of symbols, giving other agencies ideas of how to explain diabetes and words to use.

These sessions were popular and feedback was positive. They were delivered with a diabetes specialist nurse, community learning disability nurse, speech therapist, the health promotion service, podiatrist, dietitian, a practice nurse and the local North Derbyshire Diabetes UK group. A series of interactive workshops were set up within the training, asking each speciality to think of ways of communicating messages. These sessions were delivered over a five-year period.

Resources have been developed alongside the patients and carers, and with multidisciplinary input, ensuring that individual disciplines feel that resources reflect their service. Encouraging champions from different specialities definitely helped with the promotion of resources. Collaborative working helped to ensure that this project was available to professional carers both in public and private sector, with funding from the Trust.

As part of the evaluation processes, each group of

carers and patients were asked for new ideas in order to develop a local work plan to improve services. The study day for professional and personal carers received very positive feedback:

"Best study day I have been on in 27 years."

"I went to the training day with my mum and I enjoyed it very much. It helped me to understand."

"I found it hard to understand before. The way it was put over was easier for me. I liked the books with the pictures."

Over time, other diabetes care providers became part of the project, including practice nurses and GPs, public health professionals and those from the retinopathy screening service. There was also interest and support from local secondary care providers. Health promotion colleagues were involved with the group sessions and participated in the production of an exercise DVD. The public health colleagues supported the development of new resources, including a leaflet on retinal screening, as those with learning disability are less likely to access screening services. Recent data extracted from GP information systems in England also indicate higher rates of type 1 and type 2 diabetes and lower rates of retinal screening among people with learning disabilities who have diabetes (Glover et al, 2012).

The group education programme, which was first delivered in 2008, was subsequently delivered by a community learning disability centre and was improved further with the development of "My diabetes file", a personalised folder with an individual care plan and relevant leaflets. Further resources were also developed, including a resource leaflet on foot care and production of materials for group sessions. The group education programme was initially set up in one centre and went well:

"I went to the group with my carer. I showed my mum the things that we had done. It helped me to understand it [diabetes] wasn't so scary".

This centre was unable to accept external referrals to the programme, so in order to enable equal access to this service, further centres were established within the Trust, giving a choice of local venues. Links were made with the learning disability education coordinator in South Derbyshire, who has continued to be supportive with the delivery of group sessions, organising staff and venues. In 2009, negotiation for funding led to the appointment of a learning disability nurse to support delivery of diabetes group education programmes. However, these group sessions were not sustainable and this nurse is currently delivering general diabetes education sessions, with the flexibility to offer one-to-one education for those with learning disability. This has been one of the frustrations of the project and was disheartening. One of the issues has been identifying those with a learning disability or educational needs, as not all people attend learning disability centres. This may have been a contributing factor in the failure of the group education programme.

There has been a great deal of interest in this project from external organisations, including Diabetes UK and other Trusts. The Department of Health recognised this unique project in *The Way Ahead: The Local Challenge* document (Department of Health, 2007) and promoted the project's materials on their website. This led to an influx of enquiries and, unfortunately, many people were frustrated that the booklets were not easily downloadable. As a result, following negotiation, the Department of Health agreed to fund the initial printing of booklets to enable wider distribution across the country. In 2008, it was agreed that resources would be produced by the then Derbyshire County Trust. The Trust's communications team were asked for advice and decided that a graphic designer should be used. Funding of this was agreed following discussion with diabetes network leads, who were supportive of the project and production of booklets.

The resources have been used widely by others services, including the local prison service doctor and by a local dietitian who is working with older people with diabetes.

It has been suggested that the booklets could be re-used for other patient groups by simply replacing the photos with more relevant images. This option is currently being explored by our in-house communication team.

Unfortunately the resources produced have not received recurrent funding to continue with further production, but the resources are held by the community diabetes specialist nurse team in North Derbyshire and are shared as widely as possible locally, as well as being used at training

Page points

1. Collaborative working helped to ensure that this project was available to professional carers both in public and private sector.
2. As part of the evaluation processes, each group of carers and patients were asked for new ideas in order to develop a local work plan to improve services.
3. Many different healthcare professionals were involved in the project, including nurses, GPs, public health professionals and those from the retinopathy screening service.

Page points

1. The resources have been used widely by others services, including the local prison service doctor and by a local dietitian who is working with older people with diabetes.
2. Resources included written information on insulin injections and footcare, as well as a DVD on exercise, *Fit for life*.

events. Some resources are available online (see http://tinyurl.com/zmt685b); however, previous experience shows us that carers often do not access online materials.

Resources developed (*Figure 1* and *Figure 2*)

- A photographic chart was developed showing insulin injection sites, with written guidance for staff. Individuals are able to record which sites they have used.
- A reminder chart for carers giving insulin.
- A photographic footcare leaflet was devised with the podiatrist.
- An interactive body to see treatment of hypoglycaemia. This was a material "body" that was attached to the trainer. The trainer could then attach body parts and food to it to demonstrate how the body and diabetes treatment works.
- Retinopathy screening leaflet.
- Visual care plans, with agreed actions for patients.

A training package was also developed to educate family members and carers on how to administer insulin. This then enabled the patients to continue attendance at their learning disability centres. This training package has also proved useful in educating other non-registered nurses in the practice of administering insulin and has been used across the Trust.

Figure 1. Many different resources were developed.

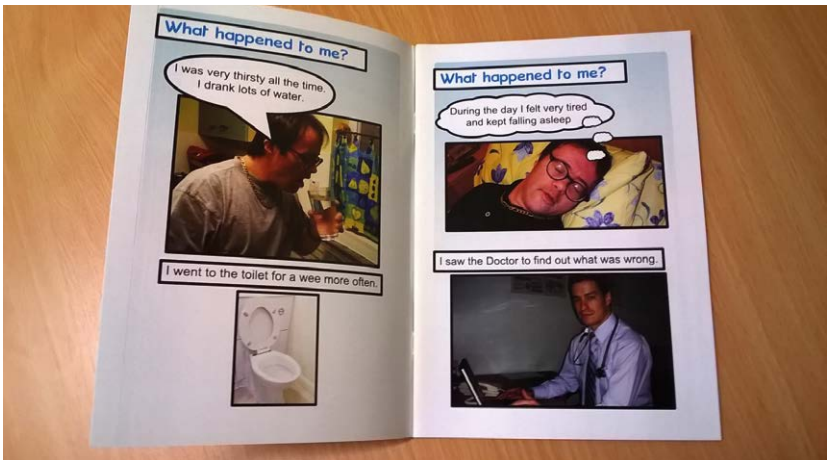

Figure 2. Easy-read leaflets were developed in consultation with people with learning difficulties.

Development of the project and funding issues

This project began with the remit of developing accessible resources for those with learning disability. Demand quickly increased following the promotion of the booklets through the Department of Health. In terms of securing more funding, local diabetes leads and commissioners were approached and financial backing was approved. However, it is was challenging to keep both a local picture and also be aware of national need, and to keep up with promotion and production of resources.

A non-restrictive educational grant was applied for from a pharmaceutical company, Takeda, to support the development of the group resources. This enabled production of an exercise DVD *Fit for Life*, which was named by the patients involved in filming. The DVD included a short introduction about diabetes and then demonstrated chair-based exercises that the patients could copy. The DVD also showed other exercise, such as walking in a group.

The booklets were developed by changing the images used. The original documents used publicly available images, but it was felt that it would be more appropriate to use images of local patients. This process also involved the development of a consent form for people with learning difficulties to consent to the use of their picture.

Conclusions

The main benefit of this project was to recognise the needs of this vulnerable group of patients. Furthermore, the project raised awareness among

commissioners and healthcare providers regarding the educational needs of these individuals.

National interest in the resources produced highlighted the desperate need across the UK for these materials. Diabetes UK have since developed some resources for those with learning disability (Diabetes UK, 2016). Some resources are also on the Public Health England website (2013).

Furthermore, the number of requests from other Trusts to deliver this training further illustrates that many areas in the UK have identified gaps in their services, as suggested by Kelly (2011).

Unfortunately, due to changes within the Trust, it was decided that the education for carers of those with learning disability had not been properly commissioned and could not continue to be offered. Carers are now directed to our in-house general training on diabetes, but this does not really address the needs of the carers of those with learning disability. The local Diabetes UK group valued the sessions and we hope will continue to deliver them.

Although it is recommended that all people with learning disabilities receive a health check, we know that not everyone does. For example, only approximately 50% of people with learning disabilities in Derbyshire receive a regular health check. Furthermore, we suspect that given the high level of obesity in this population, diabetes often goes undiagnosed. We hope that the diabetes easy-read documents and educational packs that have been produced can be used to support health action planning (Public Health England, 2016).

Making resources easily available to staff has been one of the biggest challenges. Support continues however, with the local North Derbyshire and Hardwick Commissioning Group continuing to promote resources via the *MAP of medicine*, which can easily be accessed by Practice staff.

Locally the issue of training of staff continues to need to be addressed and this, in turn, would also support some of the educational needs of individual clients.

A important lesson that we have learnt during the development of this project is that healthcare professionals should be open to new ways of working. We should be influenced by the people with diabetes that are in our care and should ensure that we deliver a service that meets each individual's specific needs. We are particularly grateful to Barry, who inspired this project and has changed our way of working for the benefit of all people with diabetes. ■

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