

# *Diabetes and Me:* Learning disabilities and diabetes

Julia Kelly

## Article points

1. There is very little comprehensive education material available regarding diabetes education for adults with learning disabilities.
2. The Walsall Health Facilitation Team's *Diabetes and Me* information pack aims to educate people with learning disabilities on diabetes in an easy-to-read, accessible format.
3. The pack has information on what diabetes is, management of the condition and advice on diet and exercise.
4. This tool has enabled people with learning disabilities and diabetes to make their own choices and gain independence in their lives.

## Key words

- Education
- Information pack
- Learning disabilities

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There has been a lack of expertise when planning for, and meeting the health needs of, adults with learning disabilities. In particular, there is little comprehensive education material available for the teaching of diabetes to adults with learning disabilities. People with newly diagnosed diabetes have much to learn about the condition. The definitive goal of diabetes management is to enable the individual with diabetes to be self-caring. To achieve this, education is vital, beginning when a person is newly diagnosed and continuing through life. The Walsall Health Facilitation Team has sought to address this by developing the *Diabetes and Me* information pack, aimed at educating people with learning disabilities about diabetes and self-management of the condition in an easy-to-read, accessible format. In this article, the author reports on the development and use of this pack and how it has led to health and quality-of-life improvements in this population.

The White Paper *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Department of Health [DH], 2001) highlights that there is a marked lack of innovation and expertise when planning for, and meeting the health needs of, adults with learning disabilities. As with all aspects of education for this population, health education has not been seen as a priority by the NHS. This is clearly evidenced in the *Death by Indifference* (Mencap, 2007) document.

Government reports and practice documents have emphasised the need for primary healthcare and learning disability teams to work together to provide quality healthcare for people with learning disabilities. For example, the *Good Practice in Learning Disability Nursing* (DH, 2007)

guidelines highlight the need for healthcare promotion among this population.

Diabetes is a complex condition. Owing to the comprehension, communication and literacy difficulties experienced by people with learning disabilities, healthcare professionals must carefully consider what tools to use to educate people with diabetes and learning disabilities. In this article, the author discusses the challenges in caring for this population, and report their experience of implementing health education strategies to improve care for this group.

## Health education for people with learning disabilities and diabetes

The *Equity and Excellence: Liberating the NHS* (DH, 2010) White Paper sets out the Government's long-term vision for the

future of the NHS. This vision builds on the core values and principles of the NHS. The document outlines how the NHS will:

- Put patients at the heart of everything it does.
- Focus on continuously improving those things that matter.
- Empower and liberate clinicians to innovate, with the freedom to focus on improving healthcare services.

Mainstream healthcare professionals generally need to increase their skills in communication and teaching to enhance an effective health education role to people with learning disabilities. The *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities* (Michael, 2008) document describes, in length, the need for mainstream healthcare professionals to make reasonable adjustments to their care provision to this population.

People with learning disabilities need sufficient support, advice and guidance to play a larger part in service provision. In particular,

attention needs to be given to the requirements of vulnerable adults. Staff working in the learning disability service have a crucial part to play in providing specialist support to communicate effectively and monitor the individual's ability to remain involved in service decisions.

In people with learning disabilities and diabetes, information that is either not understood or misunderstood will prevent them from becoming active in the care of their own health. Low literacy and comprehension levels can be a significant challenge when non-adherence with a treatment plan occurs.

There is very little comprehensive education material available regarding diabetes education for adults with learning disabilities. Many learning disability teams around the UK have looked at projects and innovations to "fill this gap". However, these innovations are not widely spread or shared.

People with learning disabilities gain more understanding and knowledge from interactive

#### Page points

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2. In people with learning disabilities and diabetes, information that is either not understood or misunderstood will prevent them from becoming active in the care of their own health.

#### Page points

1. The definitive goal of diabetes management is to enable the individual with diabetes to be self-caring. Achieving this education is key, beginning when a person is newly diagnosed and continuing throughout their life.
2. The Walsall Health Facilitation Team identified, through local audit, that there are less educational opportunities for people with learning disabilities from mainstream services, owing to attitudes and lack of understanding demonstrated by mainstream healthcare professionals
3. The D-Day programme was not intended to encourage segregation from mainstream services for people with learning disabilities, but rather to empower the person in feeling comfortable in accessing an education programme tailored to suit their own individual needs.
4. The *Diabetes and Me* information pack was designed with service users with diabetes and specialist nurses from the diabetes team.

and participatory education models (Kolb, 1984). This is termed “experiential learning” by educationalists. Interactive education is generally more advantageous. An approach based on practice, participation and activity could be more effective than traditional health promotion material available for the generic population.

Learning disability nurses have an important role to play in teaching skills to this population. They can assist them in gaining access to healthcare services that are suited to their needs, such as diabetes services. Having the skills and knowledge to adapt mainstream health information ensures that people with learning disabilities have the same opportunities as every other member of society and thus reduces health inequalities.

Any person newly diagnosed with diabetes has much to learn. The definitive goal of diabetes management is to enable the individual with diabetes to be self-caring. Achieving this education is key, beginning when a person is newly diagnosed and continuing throughout their life. Not only may new skills such as monitoring blood glucose levels or injecting insulin have to be learnt, but these individuals also need the knowledge and understanding to make informed decisions about all aspects of living with diabetes.

Within NHS Walsall, the Health Facilitation nurses from the Walsall Integrated Learning Disability Service have developed local initiatives as part of their Pacesetters Programme in accordance with DH (2008) guidelines to address the health inequalities.

#### Health education in Walsall

The Walsall Health Facilitation Team identified, through local audit, that there are less educational opportunities for people with learning disabilities from mainstream services, owing to attitudes and lack of understanding demonstrated by mainstream healthcare professionals.

The team delivers education to people about self-managing their diabetes. In particular,

the D-day group is for adults with learning disabilities who have diabetes. The course takes place over six consecutive weeks – each weekly session lasts 1.5 hours. The Health Facilitation Team established this programme in 2009, with the aim of equipping people and their carers with knowledge and skills appropriate to their level of understanding and to improve self-management of diabetes. Referrals for this programme are made directly from service users, carers or the diabetes specialist team. Groups are run in a variety of settings including local health centres, day services and residential homes.

The D-Day group runs alongside mainstream services, with collaborative working between professionals from learning disability services and other healthcare services. This programme was not intended to encourage segregation from mainstream services for people with learning disabilities, but rather to empower the person in feeling comfortable in accessing an education programme tailored to suit their own individual needs.

#### Diabetes and Me

Diabetes health education should involve giving simple, clear advice. Information should be given with respect and empathy. The individual’s ability, disability, comprehension, age, culture and social circumstances need to be taken into consideration. General information and education materials on diabetes are available from many sources but easy-to-read, accessible materials are scarce. Through involvement with the Pacesetters Project – a partnership between local communities who experience health inequalities and the DH – the Walsall Health Facilitation Team developed the *Diabetes and Me* information pack, which aims to educate people with learning disabilities on diabetes in an easy-to-read, accessible format. It was designed to support and complement the general diabetes information available. The pack was designed with service users with diabetes and specialist nurses from the diabetes team.

The pack complements the D-Day group programme using the principles of health action planning as its core. It can be used as a workbook for each individual attending the group, using the information as a learning tool and using the Health Action Plan book to plan and record the lifestyle choices they are going to make as well as record how this is impacting and improving their general health and wellbeing.

The pack has seven subdivisions:

- *My guide to keeping healthy with diabetes* – an A5 leaflet briefly outlining diabetes in simple words and pictures, with advice on diet and exercise.
- *My diabetes profile and management plan* – an A5 booklet that can be carried easily around with information on the individual's diet plan, medication, first aid, and signs and symptoms of ill health contributing to their diabetes.
- *Understanding diabetes* – an A5 glossary explaining the common medical jargon that is regularly used.
- *Contact sheet* – for users to self-refer to Health Facilitation services.
- *I have diabetes* – an A4 booklet explaining diabetes in clear, accessible language and photographs. Information is given in step-by-step “photo stories” on monitoring blood glucose levels, insulin administration and foot care.
- *Visiting the doctor or nurse* – an A4 booklet illustrating what will happen at health checks specific to diabetes monitoring (e.g. height, weight, foot care, etc). This section aims to remove the fear of the unknown that people with learning disabilities experience when attending healthcare appointments.
- *My health action plan for diabetes* – an A4 workbook explaining health issues such as healthy eating, activities and sport, health checks with columns to record “what I do now” and “what I am going to do”. This empowers people with learning disabilities on making choices regarding their health and lifestyle.

### Success so far

Uptake and interest in the group has been excellent. Each D-Day group is evaluated using an evaluation form, and groups are flexible to meet the skill and needs of members. Suggestions are welcome both from service users and healthcare staff, and groups are fully subscribed and people regularly ask to attend again. Feedback from carers and providers has been positive.

Learning disability services across the country network and share good practice. The pack was launched at an event in Walsall in March 2009 and this was well attended by health facilitation teams nationally. Requests for copies of the pack have been made from across the country. Although resources of the pack do not allow for all other services to have unlimited amounts of the pack, many services are now using it as a model to develop similar resources. Thus, the pack has been well received, with >700 being distributed across Walsall and to other learning disability services

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nationally. Below is an example of typical feedback comments from practitioners:

*“We were very impressed with the packs and wondered if we could take you up on your offer of further copies as they would be very useful for the service users we work with for whom diabetes is a common issue.”*

Health facilitation nurses work closely with GP practices and specialist mainstream services. Feedback from these professionals has shown that the use of *Diabetes and Me* pack has enabled people with learning disabilities to have more understanding about their diabetes and episodes of ill health have reduced. Attendance at health checks and adherence with treatment plans is improving. Rapport and collaborative working between specialist learning disability nurses and mainstream healthcare providers to make reasonable adjustments to the care of adults with learning disabilities has also improved.

### Conclusion

Evidence suggests that effective service user engagement leads to increased satisfaction, positive outcomes and improved healthcare professional–user relationships. Gathering views on how services work for those we support, helps us to plan for the future, by taking into account the needs of service users.

This project has demonstrated that:

- The views of service users and the public can be shown to have been sought and captured in a more systematic way.
- There is a direct and demonstrable impact on service experience, service provision and on quality.
- There was a good response to the D-Day groups.

The Walsall Learning Disability Service has a demonstrably strong record of achievement in the area of service user involvement and engagement. Their strategy/action plan outlines their aspiration to continuously improve and outlines some of their key activities in place and how they are looking

to further develop them. They believe it is important to ensure service user engagement is vital and innovative and continues to evolve.

Service users have an important role to play in the design and delivery of learning disability and diabetes services. This should lead to more accessible inpatient services and, ultimately, improve the service user’s health and quality of life. Organisational attitudes need to be readjusted to enable participation. The Walsall Learning Disability Service has invested in supporting adults with learning disabilities an diabetes by producing the easy-to-read diabetes self-management tool. This tool has enabled this population to make their own choices and gain independence in their lives through engaging with other service users and with healthcare professionals to make their thoughts and ideas known. ■

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