

Diabetes and people with learning disabilities: living in parallel worlds

Diabetes is estimated to be significantly more prevalent in people with learning disabilities than in the general population. Yet very little attention is given to this by researchers or health professionals

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Few researchers have investigated diabetes among people with disabilities, especially those with intellectual or developmental disability (Reichard & Stoltzle 2011, p.141).

This article examines what is known from published research about diabetes and people with learning disabilities. It is based on a review of literature and associated media commissioned by the Open University's Faculty of Health and Social Care and carried out by Jan Walmsley Associates Ltd and emeritus professor Celia Davies during 2012.

The Learning Disabilities Health Observatory, Improving Health and Lives (IHaL), has given a much-

needed impetus to research into the health issues facing people with learning disabilities in England, providing data to complement the vivid and effective campaigning by learning disability charity Mencap and other advocacy organisations. The figures IHaL has compiled give a truly appalling picture of people's health needs, something suspected for some time, but is now verified by the work of the Observatory and the Confidential Enquiry into Premature Deaths. People with learning disabilities die too early, and for reasons not necessarily associated with their impairment.

There is, however, a long way to go before a full picture emerges as to the extent of unmet health need in this group of people. Diabetes has

had little specific attention, though anecdotal information from health professionals, self-advocacy groups and Diabetes UK local activists suggests that diabetes, particularly adult onset Type 2 diabetes, is significantly underdiagnosed among people with learning disabilities. This is partly due to ignorance of symptoms among this population, and people close to them, but often compounded by diagnostic overshadowing by healthcare professionals. The result is not only unnecessarily high levels of ill health, but also costly emergency hospital admissions.

The review examined three broad areas:

- Prevalence of diabetes in the general population compared to people with learning disabilities
- The extent to which self-care and self-management approaches to managing diabetes, which put more responsibility on patients to manage their own condition, address issues of intellectual impairment
- Literature and health promotion approaches that focus on people

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The University of Manchester offers a three-year full-time or six years part-time BA (Hons) Learning Disability Studies degree. For more information go to www.manchester.ac.uk/undergraduate/courses/search2012/atoz/course/?code=00099. There is also a part-time MA in Critical Learning Disability Studies. For more information go to www.manchester.ac.uk/postgraduate/taughtdegrees/courses/parttime/course/?code=09005

with learning disabilities and long-term health conditions, including diabetes.

Prevalence of diabetes

Diabetes is a long-term condition that can have severe and life-threatening consequences. These include blindness, nerve damage and foot amputation, cardiovascular disease and kidney disease. Diabetes is found in more than 6% of the world's adult population and is one of the major causes of premature death, according to www.worlddiabetesfoundation.org. Diabetes UK estimates 2.9 million people in the UK have been diagnosed with the disease and another 850,000 are undiagnosed. The National Diabetes Audit draws on data from around 80% of general practices (GPs) in England. It suggests that in 2009–2010 as many as 4.45% of the population as a whole had a known diagnosis of diabetes, a figure rising to 5.24% among those aged 16 and over. NHS Quality and Outcomes Framework (QOF) data, compiled from GPs, yield higher figures and modelling by the Association of Public Health Observatories estimates more than 7% of adults have diabetes and suggests that for every three diagnosed there could be one undiagnosed (cited in National Diabetes Audit 2012).

If it is difficult to accurately estimate the prevalence of diabetes in the population, estimating it for people with learning disabilities is even more a matter of guess work. Difficulties of arriving at precise figures are compounded by under-diagnosis of diabetes and failure to identify learning disabilities on GP registers, not to mention lack of robust research. Emerson *et al* (2012) in the most up-to-date and comprehensive briefing paper on health inequalities were able to devote just three lines to diabetes.

It is likely that people with learning disabilities face increased

risk of Type 2 diabetes and that prevalence of diabetes will be higher than in the population as a whole. High levels of obesity and poor diet may contribute.

Emerson and colleagues cite a Dutch GP study which estimates 11% of people with learning disabilities will have diabetes compared with 6% among matched controls (Straetmans, 2007). They also cite an American study suggesting 19.4% with diabetes among people with cognitive limitations compared to 3.8% in the population as a whole (Reichard & Stolze, 2011). Meanwhile, Cardol *et al* (2012) bring together several sources to suggest the figures will be high for Down's and Prader Willi syndromes – as high as 25% for the latter – and that Type 1 diabetes could be up to 35 times higher than in the population as a whole.

Self-care and self-management approaches

The National Service Framework for Diabetes (2001) identified improved education for self-management of diabetes as a significant way forward. Packages such as DESMOND and the Expert Patients Programme have gained significant traction.

DESMOND (www.desmond-project.org.uk) offers a suite of patient education programmes and related educator training. The differing needs of a number of specific population groups

have been recognised. Thus, for example, there are programmes for young people and new culturally appropriate measures have been launched under the heading 'A Safer Ramadan'. To date there is no structured education programme being delivered within the UK that is specifically tailored to the needs of adults with learning disabilities with Type 2 diabetes, nor one that targets the carers who support this population. Until recently there was no major initiative in this area, but Diabetes UK has recently been awarded a significant sum to address this issue (see <http://www.diabetes.org.uk/Research/Current-research/Ongoing-research/Tailored-education-for-people-with-diabetes-and-learning-disabilities/>).

Literature and health promotion approaches

In clinical research, diabetes and learning disability appear as two entirely separate clinical specialties. Clinical trials in diabetes often treat learning disability as an exclusion criterion when recruiting, which helps to keep people with learning disabilities off the radar, with little effective crossover in research or in practice. Those in the learning disability field have rarely chosen to focus on diabetes. Emerson *et al*'s review (2012) of health inequalities devoted just two references to diabetes.

The most commonly found published approaches to health

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promotion for people with learning disabilities are 'easy read' documents about diabetes, often produced by individual NHS Trusts. Just two of the many examples found are eye health and disability charity SeeAbility's specialist leaflets on eye care, which includes diabetes http://www.lookupinfo.org/carers_supporters/default.aspx and Walsall Primary Care Trust's easy reading guides: <http://www.walsalltogether.net/Libraries/Local/788/Docs/NEW%20-%20Health/Diabetes/2010%2007%2013%20-%20HF%20-%20Diabetes%20-%20Diabetes%20&%20Me%20-%20My%20Guide%20to%20Keeping%20Healthy.pdf>

Diabetes UK's principal investment in this area until recently was an educational DVD aimed at people with learning disabilities, launched in 2010. We have yet to locate any published evaluations of this initiative or indeed of the effectiveness of easy read and other health promotion literature aimed at people with learning disabilities.

Papers using qualitative methods to understand the lived experience of people with learning disabilities and diabetes begin to give a glimpse of the issues that will have to be faced if healthcare for people with learning disabilities is to address the consequences of diabetes; or preventing/diagnosing it. We quote from two recent UK studies.

Catherine Dysch and colleagues (2011) asked people with learning disabilities about how they understand and experience Type 2 diabetes. They found:

- Some people were confused about why they had it, and if it can be cured
- Some people found it difficult to remember their tablets or injections
- Some people disliked having diabetes: "I've got fed up not being the same as other people"
- Most in the study had other health problems.

Meanwhile, researchers in the Netherlands (Cardol et al, 2012) asked 17 people with mild to moderate disabilities about their diabetes. They found:

- Most people had little information, but they did have questions
- Family members with diabetes could act as role models about managing it
- Self-management was impeded by lack of information, motivation, mood and living accommodation
- Communication over diabetes with health professionals is rare.

They concluded that it is vital to educate carers, paid and unpaid, to support people in managing diabetes.

These two papers begin to unearth the considerable challenges of ensuring that people with learning disabilities and diabetes are able to manage the disease successfully, with the support of carers.

Conclusion

Research into diabetes and learning disability appears to be in its infancy. There is much to be done if we are to:

- Know how many people fall into this category
- Understand the issues faced by people with learning disabilities who have diabetes
- Design effective interventions to prevent it altogether, or to ensure early diagnosis
- Design self-management approaches that will enable them and/or their carers to manage it better.

While we have made a start in drawing together some literature from the parallel worlds of diabetes and learning disabilities, this only serves to point out how much there remains to do to fully understand the issues and to tackle them. ■

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