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Title: Diabetes education for adults with learning disabilities: addressing the inequalities

Authors: Dr Laurence Taggart (Ulster University) & Dr Maria Truesdale (Edinburgh Napier University, Scotland)

Introduction

Health inequalities faced by people with learning disabilities is a critically important issue for primary and secondary healthcare services. Although health inequalities are, to an extent avoidable, it is evident that existing patterns of healthcare provision are insufficient and likely to be in contravention of legal requirements under the Disability Discrimination Acts 1995 and 2005, and the UN Convention on the Rights of Persons with Disabilities (2006).

N Ireland Department of Health policies (Equal Lives, DHSSPSNI, 2005) and guidance (Learning Disability Service Framework, DHSSPSNI, 2012) have emphasised the central role of mainstream health services in meeting the health needs of this population. Understanding the determinants of health inequalities helps identify potential solutions including: making *'reasonable adjustments'* in all areas of health promotion and healthcare in light of the specific needs of this population and acting within the legal framework of the Mental Capacity Act (2005).

Changing demographics of people with learning disabilities

There have been a number of national and international studies that have examined the ageing profile of people with learning disabilities and the universal consensus is that this population in common with others are living longer and it is projected that this increased longevity will continue (McConkey et al., 2003, McConkey, 2006; DHSSPSNI, 2015). The DoH (2001) within the UK stated that life expectancy for people with learning disabilities is predicted to increase by 11% between 2001 and 2021.

Health of people with learning disabilities

People with a learning disability are exposed to a range of health conditions and social inequalities across their lifespan. These may impact on the individual and their family at any time from childhood, through transitions to adolescence, into adulthood and also into older age. International (The US Surgeons General Report, 2002) and national reports (Disability Rights Commission, 2006; MENCAP Report, 2004, 2007; Michael Report, DoH, 2008; Six Lives Report, DoH 2009), as well as regional studies (Barr et al., 1999, 2007; Devine et al., 2010; Marshall et al., 2003; McConkey et al., 2006, 2011, 2013; McGlade et al., 2009; Sowney & Barr, 2006; Taggart et al., 2007, 2010, 2012, 2013; Slevin et al., 2008, 2010, 2011, 2014) indicate that this population have poorer health compared to their non-disabled peers.

The recent Confidential Inquiry Report into the Premature Deaths of People with Learning Disabilities (Heslopp et al., 2013) in England found that people with learning disabilities died on average 20 years earlier than adults in the non-disabled population and that many of these early deaths were avoidable. Cardiovascular disease, respiratory diseases, and stomach and gallbladder cancers were the three leading causes of death for this population (Taggart & Cousins, 2014). In addition, people with a learning disability are more likely to experience a range of secondary or chronic health conditions compared to their non-disabled peers including: sensory problems (including vision, hearing and dental), constipation, thyroid problems, gastro-oesophageal reflux disease, obesity, osteoporosis, epilepsy, Type 1 and 2 diabetes, mental health problems, addictions and dementia (for a review see Emerson & Hatton, 2014; Taggart & Cousins, 2014). Many of these conditions can be prevented and/or managed more appropriately; thus improving quality of life, increasing longevity, and reducing care costs.

According to Emerson & Hatton (2014) there are four key determinants of health inequalities affecting people with learning disabilities.

- *Increased risk of health problems associated with specific genetic/biological causes of learning disabilities*
- *Personal health risks and behaviours*
- *Deficiencies relating to access to health education, health promotion and access to care*
- *Greater risk of exposure to social determinants of health.*

Diabetes and people with learning disabilities

Diabetes mellitus affects approximately 1 in 20 people and rates are predicted to increase from 177 million in 2000 to 366 million by 2030; a global prevalence rate of 6.3% (WHO, 2016). Blindness, renal failure, amputation and cardiovascular problems (stroke and myocardial infarction), are key complications of poorly controlled Type 2 diabetes, leading to premature death.

In two recent systematic reviews, the prevalence rates of Type 2 diabetes in people with learning disability was higher compared to the non-disabled population, reported to be between 8.3%-8.7% (McVilly et al., 2014; Macrea et al., 2015). The reasons for such higher estimates are based upon the increasing life expectancy of this population, people with learning disabilities leading a more sedentary lifestyle, undertaking low levels of exercise, consuming high-fat diets and being prescribed high levels of anti-psychotic medications: all of which can contribute towards obesity (Hanna et al., 2011; Emerson & Hatton, 2014, Taggart & Cousins, 2014). Reichard & Stozle (2011) reported that there is an earlier onset of diabetes amongst individuals with learning disabilities. Furthermore, the detrimental impact of diabetes may be greater for this population, due to the poor capacity to communicate effectively and self-manage the symptoms (Cardol et al. 2012).

Monitoring diabetes in people with learning disabilities

A number of studies have reported that diabetes monitoring for people with learning disabilities and diabetes is poor. Lennox et al. (2007) in Australia found that a considerable number of people with learning disabilities living in the community who had diabetes and were obese were neither identified nor managed. Taggart et al. (2013) in N Ireland found that many people with a learning disability who had diabetes did not have an annual review of their HbA1c, cholesterol levels, BP, BMI or micro-albuminuria, as well as low levels of diabetic retinopathy screening, all conditions that are routinely assessed for change and management review. On average, people with a learning disability have fewer opportunities to actively engage in the diabetes self-management education programmes that are routinely offered to the non-disabled population (Taggart et al., 2014).

Structured diabetes self-management education programmes

National and international guidelines have been developed across westernized countries to enhance the prevention, early detection, and management of diabetes. Within the UK, there are a number of documents that are important in setting the key performance indicators of good diabetes management (DH, 2007; Diabetes UK, 2011; NICE 2011).

In the UK, adults with diabetes are encouraged where possible to attend structured self-management education programmes such as DAFNE for Type 1 diabetes (www.dafne.uk.com) or DESMOND for Type 2 diabetes (www.desmond-project.org.uk) as part of good practice. However, structured education programmes are not routinely offered to people with learning disabilities (Slowie et al., 2010; Taggart et al., 2013, 2014). These programmes have neither recognized nor addressed the specific challenges posed by this population's cognitive deficits, communication difficulties, low levels of literacy skills and learning styles. Wilson and Goodman (2011) in England found that adults with mild/moderate learning disability and co-morbid physical health conditions (i.e. type 2 diabetes, arthritis, hypertension) could successfully participate in appropriately modified chronic disease self-management programmes.

Modification for DESMOND for adults with a learning disability

With funding from Diabetes UK researchers, clinicians and adults with a learning disability from across N Ireland came together to look at how they could make reasonable adjusts to the national DESMOND education programme. The original DESMOND education programme was delivered to two groups of adults with a learning disability with Type 2 diabetes and their family/paid carers (if appropriate). The participants offered feedback on what worked well and what needed changing.

A new DESMOND-ID education programme was founded based upon self-management and empowerment, and covered the following topics: what is diabetes, food choices, monitoring, physical activity, risks and complications and a self-management plan. The education programme is based upon a 7-week programme, each session lasting two and a half hours delivered by two trained educators. The programme has an additional, separate introductory education session that was aimed at, and held separately for, family/paid carers in order to support their understanding about Type 2 diabetes and how it is managed. Carers gained an understanding of how the DESMOND-ID programme works and their specific role in supporting the person with a learning disability throughout the programme.

Results of a pilot feasibility study

This seminar discusses the results of a pilot feasibility study of the DESMOND-ID self-management education programme compared to routine care for adults with a learning disability that was undertaken in N Ireland, Scotland and Wales. We will illustrate how making reasonable adjustments to structured education programmes can support individuals with a learning disability, and other cognitive disability populations, to increase their knowledge and understanding of diabetes resulting in better self-management and improved glycaemic control with the support of their family and/or paid carer.