A close-up photograph of a hand holding a blue ribbon, which is a symbol for Type 2 Diabetes awareness. The hand is positioned in the center, with the fingers wrapped around the ribbon. The ribbon is a vibrant blue color and is held in a way that it forms a loop. The background is a solid, light blue color, which provides a clean and professional look. The overall image conveys a sense of care and support for individuals with Type 2 Diabetes.

# **International Consensus Guidelines: Reasonable Adjustments in the Management of Type 2 Diabetes in Adults with Intellectual & Developmental Disabilities**

**International Association for the Scientific Study of  
Intellectual & Developmental Disabilities (IASSIDD),  
Health Special Interest Research Group  
2021**



## Authorship



This document has been developed by members of the International Association for the Scientific Study of Intellectual & Developmental Disabilities (IASSIDD) Health Specialist Interest Group ([www.iasssidd.org](http://www.iasssidd.org)).

The authors of these international consensus guidelines are:



Dr Laurence Taggart,  
Ulster University,  
Northern Ireland.



Dr Henrietta Trip &  
Dr Jenny Conder,  
University of Otago,  
New Zealand



Dr Lisa Whitehead,  
Edith Cowan University,  
Western Australia



Brianne Redquest &  
Yona Lunskey,  
Centre for Addiction &  
Mental Health, Canada



Jillian Scott,  
Learning Disability Team,  
Coleraine,  
Northern Ireland



Lorna Rouse,  
Faculty of Wellbeing,  
Education & Language  
Studies at the Open  
University, England



Dr Maria Truesdale,  
University of Glasgow,  
Scotland



## **Recommended citation**

Taggart, L., Tripp, H., Conder, J., Whitehead, L., Scott, J., Rouse, L., Redquest, B., Lunskey, Y & Truesdale, M. (2021) International Consensus Guidelines: Reasonable Adjustments in the Management of Type 2 Diabetes in Adults with Intellectual & Developmental Disabilities. International Association for the Scientific Study of Intellectual & Developmental Disabilities (IASSIDD): Health Special Interest Research Group.



<b>Contents</b>	<b>Page</b>
Authorship	2
Recommended citation	3
Acknowledgement & organisations that have endorsed these guidelines	5
Intended audience	11
 Aim and Objectives of the International Consensus Guidelines for Adults with Intellectual Disability and Type 2 Diabetes	 12
1. Type 2 Diabetes in the General Population	13
1.1 What is Type 2 Diabetes?	
1.2 International Context of Type 2 Diabetes Global Guidelines	
1.3 Costs of Managing Type 2 Diabetes	14
2. Type 2 Diabetes in People with Intellectual Disabilities	15
2.1 Terminology of Intellectual Disability	
2.2 Prevalence of Type 2 Diabetes	
2.3 Risk Factors for Diabetes in People with Intellectual Disabilities	16
2.4 Accessing Diabetes Health Care	
2.5 Reasonable Adjustments in Managing Type 2 Diabetes	17
3. Reasonable Adjustments for the Quality Management of Type 2 Diabetes in People with Intellectual Disability	19
3.1 Getting your blood glucose levels measured	21
3.2 Have your blood pressure measured	23
3.3 Have blood fats (cholesterol and triglycerides) measured	25
3.4 Diabetes eye screening	27
3.5 Having your feet and legs checked	29
3.6 Have your kidney function monitored	31
3.7 Get individual dietary ongoing advice	33
3.8 Getting emotional psychological support	35
3.9 Being offered a group education course	38
3.10 See specialist diabetes healthcare professionals	40
3.11 Receive good care if admitted to hospital	42
3.12 Get a free flu vaccine	44
3.13 Have the opportunity to talk about any sexual problems	46
3.14 If you smoke, get support	49
3.15 Get information & specialist care if you are planning to have a baby	49
References	51
Appendices	
Appendix 1: Evaluating a Diabetes Service: A checklist	64
Appendix 2: Additional Resources	68



## **Acknowledgement of Supporting Organisations**

The authors sincerely thank the following people and organisations for their expertise and advice which have informed the development of the:

*International Consensus Guidelines: Reasonable Adjustments  
in the Management of Type 2 Diabetes in Adults with  
Intellectual & Developmental Disabilities*

### **Supporting organisations that have endorsed these guidelines**

- International Diabetes Federation
- Diabetes Ireland
- Diabetes UK
- NZSSD – New Zealand Society for the Study of Diabetes
- Aotearoa College of Diabetes Nurses: New Zealand Nurses Organisation –  
Tōpūtanga Tapuhi Kaitiaki O Aotearoa
- Leigh Caplan, Parent, Diabetes Nurse Educator, Canada
- Margaret Hughes, Parent, New Zealand



## **Endorsement Statement: Diabetes Nurse Educator**

Dear Dr. Taggart and team,

I am thrilled to learn about the International Guidelines on Managing Type 2 Diabetes in Adults with Intellectual Disabilities. I have been working as a diabetes nurse educator for over 24 years in the field of diabetes education for healthcare providers and patients. In my role, these guidelines will help with enhancing education of other health professionals and improving patient centre care.

At the same time, I am a parent of a young man with an intellectual disability who is very involved in Special Olympics and this means I have become an engaged parent when it comes to the Healthy Athletes program.

There are gaps when it comes to prevention of diabetes with this people with intellectual disabilities and their families. The diabetes team I work with has been doing education with Special Olympic athletes to improve their knowledge and application in making better choice in their food and drink choices. We adapted the program using laminated pictures and building health plates. The participants of these events have been very engaged in wanting to learn how to improve their health.

It is important that healthcare professionals who work in the field of diabetes like myself are aware of how to adapt their approaches for patients and to work directly with caregivers. We are not trained in this at all currently and it can be challenging to find resources.

Sincerely,

Leigh Caplan RN MA CDE  
Sunnybrook Academic Family Health Team  
Toronto, Ontario  
M4N 3M5  
CANADA



## **Endorsement Statement: Parent**

8th October 2019

Thank you for the opportunity to read and comment on the International Consensus Guidelines: Reasonable Adjustments in the Management of Type 2 Diabetes in Adults with Intellectual & Developmental Disabilities.

As the parent of a child living with diabetes and an intellectual disability, I was interested in what “lay people” or unregistered as well as registered health professionals would be recommended. From my perspective, my son has numerous support workers going into his home over any given year. Their knowledge and understanding of diabetes is minimal and often inaccurate. My son has no numeracy at all. This makes assessing his blood glucose level and choosing what to do next and then judging, for example, the correct amount of medication to administer difficult if not impossible given that he is living in his own flatting situation.

This resource document is timely and welcome, written in user friendly language, and provides access to numerous resources from an international perspective, that support people and health professionals alike could access and use.

Of note, is that each time I wrote a note to myself in the margin of the document related to something I perceived as missing, I found it further on in the document, or in another section. In particular, I looked for explanations of reasonable adjustments and diagnostic overshadowing as I have found these influence and shape how the person with diabetes and an intellectual disability are assessed, treated, is communicated with, and listened to.

Regards, and thank you for this opportunity

Margaret Hughes  
New Zealand



## Endorsement Statement: New Zealand Society for the Study of Diabetes



26 March 2020

Dear Dr. Taggart and team,

Re: International Consensus Guidelines: Reasonable Adjustments in the Management of Type 2 Diabetes in Adults with Intellectual and Developmental Disabilities

Thank you for the opportunity to review the guidance developed for the care of people with intellectual disabilities and Type 2 diabetes. This guidance fills a void that has existed to date for this vulnerable population group. The guidance contained in this document will assist in raising awareness of the complexities involved in care, and the provision of more equitable and appropriate diabetes services for people with intellectual disabilities.

The guidance is written in such a way that it provides an evidence informed overview on each topic plus specific guidance and practical points and resources. I am sure it will prove to be a valuable resource for all.

Yours sincerely



Dr Helen Snell, NP, PhD, FCNA(NZ)  
President NZSSD



## Endorsement Statement:

### Aotearoa College of Diabetes Nurses: New Zealand Nurses Organisation – Tōpūtanga Tapuhi Kaitiaki O Aotearoa



10 March 2020

Roberta Milne  
CNM- Diabetes & NP  
Whitiora Diabetes Service  
Middlemore Hospital  
Auckland, NZ

#### Chairperson

International Association for the Scientific Study of Intellectual & Developmental Disabilities (IASSIDD)  
Health Specialist Interest Group ([www.iasssidd.org](http://www.iasssidd.org))

The Aotearoa College of Diabetes Nurses are happy to endorse the document called the *International Consensus Guidelines: Reasonable Adjustments in the Management of Type 2 Diabetes in Adults with Intellectual & Developmental Disabilities*. This is because the following changes have been made as recommended by New Zealand Society for the Study of Diabetes and our National group ACDN with the recommended points below.



### 1.1 What is Type 2 diabetes

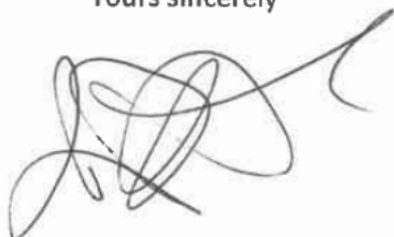
Daily management is essential in controlling blood glucose, however, many people living with diabetes are unable to maintain glycaemic control within the recommended levels for the general population. According to Diabetes UK 'Type 2 Diabetes can be lifelong and get worse over time for many, but it does not have to be like this for everyone'. Diet, exercise, stress reduction and medication management are the key mediators of glycaemic control (National Institute for Health and Care Education [NICE], 2015a) and are strongly influenced by self-management through individual behaviour and action (Whitehead, Trip, Hale, & Conder, 2016; Wilkinson, Whitehead, & Ritchie, 2011). Some people are able to stop their medication when their diabetes goes into remission which may be possible following bariatric surgery. The short and long-term effects of hyperglycemia are multiple and include microvascular changes such as retinopathy, nephropathy, and neuropathy, and macrovascular changes (e.g. heart disease) (D'Elia, Barba, Cappuccio & Strazzullo, 2011; World Health Organization [WHO], 2016).

### 1.2 International Context of Type 2 Diabetes Global Guidelines

In addition to a global guideline on diabetes management (International Diabetes Federation [IDF], 2012), evidence-based guidelines exist across many countries on the treatment of Type 2 Diabetes with a consistent focus on patient education, dietary advice, managing cardiovascular risk, blood glucose levels and as well as managing the risk of long-term complications (Diabetes Australia, 2019; Diabetes Canada, 2018; Harkins [Ireland], 2008; New Zealand Guidelines Group [NZGG], 2011; NICE, 2015a; International Diabetes Federation [IDF], 2017a; The Society of Endocrinology, Metabolism and Diabetes of South Africa [SEMDSA], 2017; UNITE for Diabetes Philippines, 2014). NICE (2015a) stated that those people with either Type 1 or 2 diabetes should have an HbA1c of under 48mmol/mol (6.5%). The guidance in New Zealand is 50-55 mmol/mol (NZGG, 2011). This reading is an indication of glycaemic control over a three-month period.

However ACDN acknowledge that all HbA1c targets should be individualised with the person with diabetes and their health care professional.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Roberta Milne', with a long, sweeping flourish extending to the right.

Roberta Milne  
Chairperson  
ACDN



## **Intended Audience**

This document is not a clinical guideline nor a definitive guide to managing Type 2 Diabetes in adults with an intellectual and developmental disability. Rather, it is intended to inform primary healthcare professionals (e.g. general practitioners, nurses, podiatrists, opticians, dietitians), hospital and specialist teams, and service providers who work directly with this. Family carers could also use the information contained within this resource to better support a person with an intellectual or developmental disability to manage their diabetes.

This document draws together the current international guidelines and evidence-based knowledge from the general population, the intellectual and developmental disability population, clinical practice, and health education into a single source, focusing upon the reasonable adjustments that can be made to support this population.

These guidelines are intended for an international audience and are positioned to inform how reasonable adjustments can be made to improve care. We hope it will be useful for clinical teams in community, primary and secondary healthcare, and also intellectual and developmental disability service providers in their discussions with funders, commissioners and diabetes services in the different jurisdictions.

Throughout this consensus guideline we provide a list of current online resources. Please note, some resources may be available from more than one site, but only one link per resource has been included and we have only included resources that are free to download, although the Easyhealth site includes resources that can be purchased.



## **Aim and Objectives of the International Consensus Guidelines**

### **Aim**

To provide guidelines for health, disability and social care professionals, and family carers, on how to make *reasonable adjustments* to support adults with an intellectual and developmental disability in managing their Type 2 Diabetes.

### **Objectives**

- 1/ To provide a succinct summary of the existing international diabetes guidelines on managing Type 2 Diabetes in the general population.
- 2/ To review the international intellectual and developmental disability literature about diabetes regarding; prevalence, risk factors, screening, assessment, management, monitoring, the identification of quality indicators and the health literacy of all in the network of care.
- 3/ To translate this evidence into international best-practice practical guidelines on the specific reasonable adjustments each country can make to identify, screen, educate, enable self-management, monitor and review Type 2 Diabetes alongside people with intellectual and developmental disability.



## **1. Type 2 Diabetes in the General Population**

### **1.1 What is Type 2 Diabetes?**

Type 2 Diabetes is a condition that develops over many years and is caused by a combination of the body becoming resistant to the normal effects of insulin and gradually losing the capacity to produce enough insulin in the pancreas. Insulin is vital in converting glucose into energy and in Type 2 Diabetes, the result is commonly hyperglycaemia (too much glucose in the blood). As a result of insulin resistance, the pancreas responds by producing greater amounts of insulin to regulate blood glucose levels; over time, these cells become dysfunctional. At diagnosis, it is estimated that an individual will have “lost” 50–70% of their insulin producing cells (Diabetes Australia, 2019).

Daily management is essential in controlling blood glucose, however, many people living with diabetes are unable to maintain glycaemic control within the recommended levels for the general population. According to Diabetes UK ‘Type 2 Diabetes can be lifelong and is progressive and may get worse over time but it does not have to be like this for everyone’. Diet, exercise, stress reduction and medication management are the key mediators of glycaemic control (National Institute for Health and Care Education [NICE], 2015a) and are strongly influenced by self-management through individual behaviour and action (Whitehead, Trip, Hale, & Conder, 2016; Wilkinson, Whitehead, & Ritchie, 2011). Some people are able to stop their medication when their diabetes goes into remission which may be possible following bariatric surgery or with substantial weight loss (ie. 15% body weight). The short and long-term effects of hyperglycemia are multiple and include microvascular changes such as retinopathy, nephropathy, and neuropathy, and macrovascular changes (e.g. heart disease) (D’Elia, Barba, Cappuccio & Strazzullo, 2011; World Health Organization [WHO], 2016).

### **1.2 International Context of Type 2 Diabetes Global Guidelines**

In addition to a global guideline on diabetes management (International Diabetes Federation [IDF], 2012), evidence-based guidelines exist across many countries on the treatment of Type 2 Diabetes with a consistent focus on patient education, dietary advice, managing cardiovascular risk, blood glucose levels and as well as managing the risk of long-term complications (Diabetes Australia, 2019; Diabetes Canada, 2018; Harkins [Ireland], 2008; New Zealand Guidelines Group [NZGG], 2011; NICE, 2015a; International Diabetes Federation [IDF], 2017a; The Society of Endocrinology, Metabolism and Diabetes of South Africa [SEMDSA], 2017; UNITE for Diabetes Philippines, 2014). NICE (2015a) stated that those people with either Type 1 or 2 diabetes should aim for an HbA1c of under 48mmol/mol (6.5%). The guidance in New Zealand is for an HbA1c 50-55 mmol/mol (NZGG, 2011). This reading is an indication of glycaemic control over a three-month period.

South Africa for example recently released their national guidelines in which an increased prevalence of Type 2 Diabetes has been reported in rural areas: Asian and non-European populations with obesity as the predominant risk factor (Diabetes Canada,



2018; The Society of Endocrinology, Metabolism and Diabetes of South Africa [SEMDSA], 2017). Support to achieve optimal management however, is thought to be only reaching the minority (IDF, 2012) due to the size and complexity of the evidence-base, the complexity of diabetes care itself, a lack of proven cost-effective resources for diabetes care and the diversity in standards of clinical practice cited as driving disparities in clinical care.

Of note, national or international guidelines for Type 2 Diabetes vary regarding whether or how people with intellectual and developmental disability are included or represented. There may be similarities in reference to other vulnerable populations with cognitive impairment and communication difficulties such as people with acquired-brain injury, stroke, severe mental illness, and dementia for example.

### **1.3 Costs of Managing Type 2 Diabetes**

In 2017, it was reported that approximately 425 million adults (20-79 years), worldwide were living with diabetes with an estimated projection of 629 million by 2045 (IDF, 2017a). According to Diabetes UK, almost 80% of the money the NHS in the UK spends on diabetes, is on treating the complications. Approximately 90% of these people have Type 2 Diabetes (WHO, 2013) leading to an increasing economic burden upon healthcare systems. According to Farag and Gaballa (2011), the global cost of treating Type 2 Diabetes is projected to increase over the next five years, reaching approximately €375 billion by 2030. Minimizing this cost while improving outcomes will be a major challenge. Unfortunately, many individuals with diabetes cannot access education programmes and therefore remain unable to make the required long-term changes in their behaviour and lifestyle that is required (Loveman et al., 2003). Improvements in outcomes will most likely come from advances in research, personalised medicine, new medications, treatments, better use of existing treatments and access to education. NICE (2015a) also states carers also need access to diabetes education programmes. However, no known cost estimates are reported specifically for people with intellectual and developmental disabilities.



## **2. Type 2 Diabetes and People with Intellectual & Developmental Disability**

### **2.1 Terminology of Intellectual and Developmental Disability**

Intellectual and developmental disabilities (IDDs) are usually present at birth and impact the trajectory of the individuals' physical, intellectual and/or emotional development and may affect multiple body systems.

The diagnosis of intellectual disability and the corresponding level and severity is based on an evaluation which includes three core components; a standardised [IQ] intelligence quotient test (<70), an assessment of social adaptive functioning skills and evidence of the age of onset before the age of 18 (American Psychiatric Association, 2013).

Individuals who have a mild intellectual disability can achieve full independence in self-care but may have delayed language acquisition and poor academic abilities.

Individuals with a moderate intellectual disability have poorer self-care, motor skills, limited language development and rarely achieve full independence. Individuals who have a severe/profound intellectual and developmental disability have limited self-care and may also be restricted in mobility.

In this guideline the term intellectual disability and developmental disability is used (hereafter referred to IDD), and it is acknowledged that different jurisdictions may have alternate definitions and terms. In the United Kingdom for example learning disability, in North America, intellectual or developmental disability. Developmental disability represents lifelong impairment that can be intellectual, physical or both, may affect the sensory system (e.g. cytomegalovirus), nervous system (e.g. cerebral palsy, fragile X), or metabolism (e.g. phenylketonuria, congenital hypothyroidism) or be a degenerative condition (See link). Individuals with developmental disabilities may include those with some degree of cognitive and adaptive limitation, but not meet the cutoffs described within the above diagnostic criteria for intellectual disability.

It is evident that the presence and level of IDD may affect many aspects of an individual's life, including the ability to live independently, form relationships, and achieve academic and employment prospects. Furthermore, it may also limit how the person manages their diabetes in terms of a healthy diet, doing appropriate physical activity such as walking, swimming, taking blood glucose levels, adherence to medication and/or taking insulin due to their limited knowledge, understanding and/or ability to recall information and apply it in different contexts. This means people with IDD may be more reliant on family, paid carers and others to support them to exert self-determination in making healthy lifestyle choices and in the management of their diabetes (Cardol, Rijken & van Schrojenstein Lantman-de Walk, 2012a; Hale, Trip, Whitehead & Conder, 2011; Rouse & Finlay, 2016).

<https://www.nichd.nih.gov/health/topics/idds/conditioninfo/default>



## **2.2 Prevalence of Type 2 Diabetes in People with IDD**

There have been two recent systematic reviews that have examined the literature on IDD and diabetes; both reported that this population were two to three times more likely to develop Type 2 Diabetes. Furthermore, this population were also found to develop this condition at an earlier age compared to the general population (MacRae et al., 2015; McVilly et al., 2014). More recently in a study investigating the prevalence of diabetes in adults with ID and its relationship with demographic, lifestyle, independence and health factors, using a cross-sectional analysis of interview data from 1091 adults with ID from the Leicestershire Learning Disability Register from 1 January 2010 to 31 December 2016, Tyrer et al. (2020) found that the prevalence of carer/self-reported diabetes was 7.3% (95% confidence interval 5.9-90).

## **2.3 Risk Factors for Diabetes in People with IDD**

From the growing evidence, people with IDD are more susceptible to developing Type 2 Diabetes as they age due to a number of factors that are also relevant for the general population. These associated risk factors include:

- Gender
- Family history
- Age
- Ethnicity
- Obesity
- Poor diet
- Physical inactivity
- Smoking
- Alcohol

In addition, people with IDD are more likely to develop Type 2 Diabetes than other people as there is an increased chance they are:

- More likely to be obese
- More likely to be less physically active and lead a sedentary lifestyle
- Prescribed medications such as atypical antipsychotic and antiepileptics that lead to increased abdominal obesity: an independent risk factor for insulin resistance
- Lack of access / barriers to participation to engage in annual health checks, proactive health screening, prevention and health promotion activities compared to the general population.

## **2.4 Accessing Diabetes Health Care**

According to Mencap's (2012) report Death By Indifference, avoidable deaths are not uncommon and people with intellectual disability continue to die due to inequalities and inequities in the provision of primary and secondary healthcare. A study in England and Wales for example, found that the deaths of 37% of people with intellectual disabilities were preventable (Heslop et al., 2014, p. 892). Issues that contributed to this were a



lack of reasonable adjustments being made such as: the lack of listening to, and by, significant others, difficulties in assessing need, and the recognition and responsiveness to changing presentations and issues with enabling decision making. Whilst not specific to diabetes, these are some of the factors which contribute to inequalities in accessing appropriate and responsive diabetes care and, ultimately, health outcomes for people with IDD. For example, diagnostic overshadowing is common as changes in presentation are attributed to behaviour or the IDD itself rather than a health need (Ouellette-Kuntz, 2005) such as diabetes. The health literacy of direct-care staff, staff attitudes and turnover, financial costs, organisational culture, flagging systems, lack of understanding about reasonable adjustments, a lack of time and available resources, a lack of targeted education and training to individuals, health professionals and caregivers in terms of diabetes and the population concerned (Trip, Conder, Hale & Whitehead, 2016) needs to be addressed and as it relates to self-efficacy (Maine, Dickson, Truesdale & Brown, 2017). More recently, the “Counting for Something” report (Brandford, 2020) highlighted that the life expectancy for New Zealanders with ID is between 18 and 23 years less than the general population and recommends the robust system that exists in New Zealand for accurately recording, investigating and reviewing deaths of New Zealanders should also be applied to the deaths of those with ID to ensure their deaths are counted for something.

The following list identifies some considerations which may improve healthcare access for people with IDD:

- Identify people at high risk and seek to prevent Type 2 Diabetes
- Early detection to reduce complications
- Training on self-management (individual, family, carers and health workforce)
- Identify and implement Reasonable Adjustments
- Ensure a coordinator of health is allocated to individuals
- Integrated and coordinated approaches across multi-disciplinary teams as well as primary and secondary services
- Consistent approach to annual health checks
- Support and engage in advance care planning

## **2.5 Reasonable Adjustments in Managing Type 2 Diabetes**

Internationally, there are few guidelines about the management of Type 2 Diabetes which specifically consider the need for, and application of Reasonable Adjustments when supporting people with IDD. Reasonable adjustments are embedded in the Disability Discrimination Act, UK Legislation (1995) which requires adjustments be made to ensure individuals are not disadvantaged in their employment. This was superseded by the Equality Act (2010) and legally requires primary and secondary health and social care services to ensure accessibility for people with IDD and ultimately improve health outcomes. Reasonable adjustments have also been equated to the tenets of person-centred care which requires adaptations to individualize diabetes management in people with IDD (Brown et al., 2017).



Article 2 of the United Nations Convention on the Rights of Persons with Disabilities (2006) identifies reasonable accommodation to mean *“necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”*. This can be interpreted within Article 25 which identifies the need for *“appropriate measures to ensure access for persons with disabilities to health services ... [of] the same range, quality and standard of free or affordable health care and programmes as provided to other persons”*.

Diabetes UK (2017a) have recently released a *Guideline on How to Make Reasonable Adjustments to Diabetes Care for Adults with Learning Disability* and provides both information and links to resources about the following service considerations:

1. Make information accessible and user friendly
2. Provide training for all staff
3. Address social barriers
4. Involve supporters
5. Plan for and make reasonable adjustments.

The above is reflected in Kachika’s (2017) UK NHS Right Care Pathway: *‘Diabetes. Reasonable Adjustments for people with a learning disability who have diabetes’*. It specifically identifies ways in which the application of reasonable adjustments may be evidenced and the importance in relation to undertaking the following 15 indicators upon which this guideline is based (and which are linked below to Diabetes UK (2017b):

- Tests and investigations (Indicators 1-6)
- Structured support programs (Indicators 8-9, 14)
- Weight management programs (Indicator 7)
- Supported self-management of diabetes (Indicators 10-11, 13)
- Personalised care planning (Indicators 10-12, 15)

Diabetes UK (2017a) also provides a comprehensive checklist to enable individuals, family, carers, and health professionals to evaluate the diabetes service with which they are engaged (see Resources). The checklist clearly lists key elements of reasonable adjustments that services should consider in supporting the management of Type 2 Diabetes in people with intellectual disability (Appendix 1).

### **Resources:**

Diabetes UK website for people with intellectual disabilities:

<https://www.diabetes.org.uk/professionals/resources/shared-practice/for-people-with-learning-disability>

<https://www.diabetes.org.uk/resources-s3/2018-02/Improving%20care%20for%20people%20with%20diabetes%20and%20a%20learning%20disability%20-%20Fact%20sheet%202.pdf>

Diabetes symbols: [www.easyhealth.org.uk/sites/default/files/Diabetes%20symbols.pdf](http://www.easyhealth.org.uk/sites/default/files/Diabetes%20symbols.pdf)



### **3. Reasonable Adjustments for the Quality Management of Type 2 Diabetes in People with IDD**

Diabetes UK (2017b) identified 15 essential checks, tests and services, which, if received by adults with Type 2 Diabetes, may help to reduce the risk of serious diabetes complications. They are also known as the 15 Healthcare Essentials and represent the minimum level of healthcare everyone with Type 2 Diabetes deserves and should expect from their healthcare team. Measurement of the annual achievement of these 15 healthcare essentials can be used as an indicator of quality of care.

The focus of this guideline is framed upon these *15 Healthcare Essentials* (Diabetes UK, 2017b). The international guidelines contain reference to some or all of the 15 indicators and are common considerations for the ongoing assessment and monitoring of people with Type 2 Diabetes.

#### *15 Healthcare Essentials*

1. Getting your blood glucose levels measured
2. Have your blood pressure measured
3. Have blood fats (cholesterol and triglycerides) measured
4. Ensure eyes are screened
5. Having your feet and legs checked
6. Have your kidney function monitored
7. Get individual dietary ongoing advice
8. Getting emotional psychological support
9. Being offered a group education course
10. See specialist diabetes healthcare professionals
11. Receive good care if admitted to hospital
12. Get a free flu vaccine
13. Have the opportunity to talk about any sexual problems
14. If you smoke, get support
15. Get information and specialist care if you are planning to have a baby

These 15 indicators are used to frame this international consensus guideline focusing on; (a) the evidence-base for the general population, (b) the evidence-base for people with intellectual and developmental disability, and (c) what reasonable adjustments can be made to support the person with IDD to achieve these indicators. In their latest fact sheet about making reasonable adjustments for this population Diabetes UK ask the following questions (See resources: Diabetes UK, 2018):

- *Does the diabetes service have all the components it needs to ensure accessibility to and effectiveness for people with an intellectual disability?*
- *Are there systems in place to ensure individuals are assessed and the appropriate adjustments are made to meet their personal needs?*
- *Do the people in the service have the right knowledge and skills?*



## Resources:

Diabetes UK 15 Healthcare Essential: <https://www.diabetes.org.uk/Guide-to-diabetes/Managing-your-diabetes/15-healthcare-essentials>

<https://www.diabetes.org.uk/resources-s3/2018-02/Improving%20care%20for%20people%20with%20diabetes%20and%20a%20learning%20disability%20-%20Fact%20sheet%202.pdf>

<https://diabetes-resources-production.s3-eu-west-1.amazonaws.com/diabetes-storage/migration/pdf/are-you-really-getting-your-15-0912.pdf>

Diabetes UK Planning Services for People with Intellectual Disability and Diabetes: <https://www.diabetes.org.uk/resources-s3/2018-02/Improving%20care%20for%20people%20with%20diabetes%20and%20a%20learning%20disability%20-%20Fact%20sheet%204.pdf>

Turner & Emerson (2013). *Making Reasonable Adjustments for People with Learning Disabilities: IHAL England*. [http://cdn.basw.co.uk/upload/basw\\_124408-2.pdf](http://cdn.basw.co.uk/upload/basw_124408-2.pdf)

NHS RightCare Pathway: Reasonable adjustments for people with a learning disability who have diabetes: <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2017/11/rightcare-pathway-diabetes-reasonable-adjustments-learning-disability-2.pdf>

University of Leeds, England: Improving Care for People with Intellectual Disability and Diabetes: <https://www.youtube.com/watch?v=t3mubEwUFec&feature=youtu.be>

<https://www.cdc.gov/ncbddd/disabilityandhealth/features/disability-and-diabetes-prevention.html>



### 3.1 Getting your blood glucose levels measured

***What we know about the general population:*** It is recommended that adults with Type 2 Diabetes should have their HbA1c measured by a primary healthcare professional at 3-6 monthly intervals until HbA1c is stable. Monitoring continues at six-monthly intervals once the HbA1c level is stable following the implementation of lifestyle and/or blood glucose lowering therapy (NICE 2015a; NZGG, 2011; UNITE for Diabetes Philippines, 2014) and bi-annually thereafter (SEMDSA, 2017; Diabetes Ireland, 2018). Many people will use a blood glucose meter to measure their blood glucose levels. Self-monitoring of blood glucose levels for adults with Type 2 Diabetes should be determined on a case by case basis, for example, 3-5 tests per week (SEMDSA, 2017; IDF, 2005), more frequently with exercise or illness (Diabetes Canada, 2018; UNITE for Diabetes Philippines, 2014) based on medications used as treatment, or when fasting (e.g. during Ramadan). Self-monitoring is also indicated when a person has a laboratory test result indicating “unstable or poor glycaemic control - HbA1c >64 mmol/mol” (NZGG, 2011, p. 13) and is based upon the NICE (2015a) guidelines:

- The person is on insulin or
- There is evidence of hypoglycemic episodes or
- The person is on oral medication that may increase their risk of hypo-glycaemia while driving or operating machinery or
- The person is pregnant, or is planning to become pregnant
- Consideration short-term self-monitoring of blood glucose levels in adults with Type 2 Diabetes when starting treatment or to confirm suspected hypoglycemia.

Whilst cognitive issues may be a barrier to monitoring blood glucose (Diabetes Australia, 2018), and people may develop and experience disability as a result of diabetes, there is no evidence in existing clinical guidelines about the self-monitoring of blood glucose for people with IDD.

***What we know about people with intellectual and developmental disability:***

Self-monitoring in people with an IDD can be supported through ongoing education and the use of pictorial information on how to use a blood glucose meter (Reed, Ashton, Lawrence, Hollinghurst & Higgs, 2003). Some people with an IDD may also find it helpful to involve a peer, family or paid carer who can help use the meter and record results to discuss with their GP/nurse. Capillary blood glucose results are useful as the GP/nurse can determine if the person has had a hyperglycemic or hypoglycemic event (as the person with IDD may not be able to describe) and then advice or treatment can be given. Despite these attempts the national standard in many jurisdictions for blood glucose monitoring is not being met for adults with IDD (Taggart et al., 2013). Adults with IDD should also have their HbA1c measured at 3-6 monthly intervals through laboratory testing initiated through their primary care provider until HbA1c is stable (NICE 2015a).



***Reasonable adjustments:***

- Ongoing education and training for self-monitoring of capillary blood glucose
- Attend an annual health check during which HbA1c levels should be checked and monitored.
- Having the support of a family / paid carer with the person with IDD when they have their blood taken
- Use of a pictorial book with easy read to help explain what is involved in taking blood (see resources below)

***Resources:***

*[http://www.easyhealth.org.uk/sites/default/files/blood%20test%20card\\_0.pdf](http://www.easyhealth.org.uk/sites/default/files/blood%20test%20card_0.pdf)*

*<http://www.easyhealth.org.uk/sites/default/files/null/Bloodtest.pdf>*

*<https://www.diabetes.org.uk/resources-s3/2018-02/Having%20a%20blood%20test.pdf>*



### 3.2 Have your Blood Pressure measured

What we know about the general population: People with diabetes are 2-3 times more likely the risk of developing a range of cardiovascular diseases (including heart disease and stroke) compared with people who do not have diabetes (IDF, 2012). There are variations in the guidelines about the frequency of blood pressure checks. For someone with a low risk of complications, it is recommended that blood pressure should be measured at least 6 monthly (NZGG, 2011) or annually in an adult with Type 2 Diabetes (who has not previously been diagnosed with hypertension or renal disease) (Diabetes Canada, 2018; SEMDSA, 2017) and ensure lifestyle and health promotion advice is given (NICE, 2015a). A blood pressure of <140/80 mmHg is recommended (Diabetes Australia, 2018; IDF, 2017a; UNITE for Diabetes Philippines, 2014) i.e. a systolic target of 130-140 mmHg and diastolic 80-90 mmHg otherwise further assessment, treatment and closer monitoring for hypertension may be needed (Diabetes Canada, 2018; Ministry of Health, 2018; SEMDSA, 2017). Recommendations about the frequency of blood pressure monitoring for people with Type 2 Diabetes include (NICE, 2015a, p.15):

- 1 month if blood pressure is higher than 150/90 mmHg
- 2 months if blood pressure is higher than 140/80 mmHg
- 2 months if blood pressure is higher than 130/80 mmHg and there is kidney, eye or cerebrovascular damage.

Additional monitoring of blood pressure must be undertaken at recommended intervals in keeping with the prescription of antihypertensive medications. Despite guidelines the national standard in many jurisdictions for measuring blood pressure is not being met for adults with intellectual disability.

***What we know about people with intellectual and development disability:*** This population is at risk of elevated blood pressure (Rimmer & Yamaki, 2006) - which may be linked to specific syndromes (Wallace, 2004), however, the actual prevalence of hypertension may be in keeping with the general population (Wallace & Schluter, 2008). van de Louw, Vorstenbosch, Vinck, Penning and Evenhuis (2009) suggest that monitoring should be in keeping with the guidelines for each jurisdiction.

If the blood pressure of a person with an IDD is raised, then they will be asked to attend their GP practice for further readings. If they do not wish to do this then the community nurses with/without a specialty in Diabetes should monitor their blood pressure at home or in a relaxed environment and these results can be forwarded to the GP practice therefore providing a true accurate reading. Some people with IDD, with autism or behavioural challenges or sensory impairments for example, may refuse to engage in blood pressure monitoring for which a desensitisation program may be beneficial.



***Reasonable adjustments:***

- Attend an annual health check, as the person's blood pressure should be taken and monitored
- Having the support of a friend, family member or paid carer with the person with an IDD when they have their blood pressure taken
- Use of a pictorial book with easy read to help explain what is involved in taking blood pressure (see resources below)

***Resources:***

*<http://www.easyhealth.org.uk/sites/default/files/Blood%20Pressure.pdf>*

*<https://www.heartfoundation.org.au/your-heart/know-your-risks/blood-pressure/is-my-blood-pressure-normal>*



### 3.2 Have your Blood Pressure measured

***What we know about the general population:*** People with diabetes are 2-3 times more likely the risk of developing a range of cardiovascular diseases (including heart disease and stroke) compared with people who do not have diabetes (IDF, 2012). There are variations in the guidelines about the frequency of blood pressure checks. For someone with a low risk of complications, it is recommended that blood pressure should be measured at least 6 monthly (NZGG, 2011) or annually in an adult with Type 2 Diabetes (who has not previously been diagnosed with hypertension or renal disease) (Diabetes Canada, 2018; SEMDSA, 2017) and ensure lifestyle and health promotion advice is given (NICE, 2015a). A blood pressure of <140/80 mmHg is recommended (Diabetes Australia, 2018; IDF, 2017a; UNITE for Diabetes Philippines, 2014) i.e. a systolic target of 130-140 mmHg and diastolic 80-90 mmHg otherwise further assessment, treatment and closer monitoring for hypertension may be needed (Diabetes Canada, 2018; Ministry of Health, 2018; SEMDSA, 2017). Recommendations about the frequency of blood pressure monitoring for people with Type 2 Diabetes include (NICE, 2015a, p.15):

- 1 month if blood pressure is higher than 150/90 mmHg
- 2 months if blood pressure is higher than 140/80 mmHg
- 2 months if blood pressure is higher than 130/80 mmHg and there is kidney, eye or cerebrovascular damage.

Additional monitoring of blood pressure must be undertaken at recommended intervals in keeping with the prescription of antihypertensive medications. Despite guidelines the national standard in many jurisdictions for measuring blood pressure is not being met for adults with intellectual disability.

***What we know about people with intellectual and development disability:*** This population is at risk of elevated blood pressure (Rimmer & Yamaki, 2006) - which may be linked to specific syndromes (Wallace, 2004), however, the actual prevalence of hypertension may be in keeping with the general population (Wallace & Schluter, 2008). van de Louw, Vorstenbosch, Vinck, Penning and Evenhuis (2009) suggest that monitoring should be in keeping with the guidelines for each jurisdiction.

If the blood pressure of a person with an IDD is raised, then they will be asked to attend their GP practice for further readings. If they do not wish to do this then the community nurses with/without a specialty in Diabetes should monitor their blood pressure at home or in a relaxed environment and these results can be forwarded to the GP practice therefore providing a true accurate reading. Some people with IDD, with autism or behavioural challenges or sensory impairments for example, may refuse to engage in blood pressure monitoring for which a desensitisation program may be beneficial.



***Reasonable adjustments:***

- Attend an annual health check, as the person's blood pressure should be taken and monitored
- Having the support of a friend, family member or paid carer with the person with an IDD when they have their blood pressure taken
- Use of a pictorial book with easy read to help explain what is involved in taking blood pressure (see resources below)

***Resources:***

*<http://www.easyhealth.org.uk/sites/default/files/Blood%20Pressure.pdf>*

*<https://www.heartfoundation.org.au/your-heart/know-your-risks/blood-pressure/is-my-blood-pressure-normal>*



### 3.3 Have blood fats (cholesterol and triglycerides) measured

**What we know about the general population:** Blood fats such as cholesterol and triglycerides should be measured every year (Diabetes Australia, 2015; Diabetes Canada, 2018; Diabetes UK, 2015a; SEMDSA, 2017) and are usually part of a cardiovascular disease risk assessment from which titrated interventions may be implemented alongside recommended lifestyle adjustments (IDF, 2017; UNITE for Diabetes Philippines, 2014). According to the Diabetes UK (2018) website there are no longer specific target levels, rather a calculation is undertaken of risk based on BMI, age, gender, Diabetes Type, blood pressure and cholesterol levels. Indicators for CV assessment may also vary between jurisdictions (Ministry of Health, 2018a) and this includes considerations about ethnicity. There are no specific monitoring parameters identified for people with IDD.

**What we know about people with IDD:** As above, some people with an IDD will find it difficult to get their bloods taken for HbA1c, cholesterol and triglycerides, and therefore, will find it helpful to involve a family or paid carer present to support them. People with an IDD are at a higher risk of developing obesity and cardiovascular disease at an earlier age than the general population, and therefore - developing Type 2 Diabetes (Rimmer & Yamaki, 2006; Taggart, Coates & Truesdale-Kennedy, 2012). If dietary needs are not adhered to then this can lead to further complications with diabetes. Dietary management for people with IDD may be difficult to achieve. It can be particularly challenging for this population to understand the meaning of cholesterol, saturated fats or triglycerides and how small changes in the frequency, amount or Type of food can have a positive effect on fat intake and therefore that this can influence weight, cholesterol, insulin resistance and blood pressure. Cholesterol levels should also be carefully monitored for people not only with diabetes but who are prescribed antipsychotic medication (American Diabetes Association [ADA], 2017)

Despite these attempts the national standard in many jurisdictions for measuring blood fats is not being met for adults with intellectual disability.

#### ***Reasonable adjustments:***

All people with IDD who have diabetes should be:

- Attending an annual health check within the primary care setting, during which cardiovascular risk is assessed and a blood sample is taken and sent for laboratory testing to measure lipid levels.
- Having the support of a family / paid carer with the person with an IDD when they have their bloods taken.
- Using a pictorial book with easy read to help explain what is involved in taking bloods (see resources below).
- Referred to the dietitian where they can source expert advice for themselves, carers or staff who assist with shopping or preparation of meals.
- Education programme for catering staff in residential or day care settings.



- Educated using accessible information which may include: pictorial information about food choices that are high in (lipids) fat, food labels and use of food models about making healthier choices.
- Offered an educational program which shows how to cook basic healthy meals, trying new healthier foods which is very beneficial to any person with an IDD who is living independently and has little or no cooking skills.

**Resources:**

*[http://www.easyhealth.org.uk/sites/default/files/blood%20test%20card\\_0.pdf](http://www.easyhealth.org.uk/sites/default/files/blood%20test%20card_0.pdf)*

*<http://www.easyhealth.org.uk/sites/default/files/null/Bloodtest.pdf>*

*<https://www.health.govt.nz/publication/cardiovascular-disease-risk-assessment-and-management-primary-care>*



### 3.4 Diabetes eye screening

What we know about the general population: It is well known that eye problems (retinopathy) are a complication of diabetes and is regarded as a quality indicator of diabetes. Retinopathy is the most common form of eye problem in people with diabetes and can lead to blindness and vision problems. Research shows that those with higher HbA1c values, higher blood pressure and longer duration of having had diabetes, were more likely to develop retinopathy. Diabetic retinopathy involves changes in the tiny blood vessels that nourish the retina at the back of the eye, which if left untreated, can lead to serious vision problems. A comprehensive assessment for retinopathy should be undertaken at the time of diagnosis. Should there be no evidence of visual impairment, it is recommended that retina checks or other diabetes related conditions are undertaken regularly (Diabetes Canada, 2018) - everyone to two years (ADA, 2017; Diabetes Australia, 2015; Ministry of Health, 2016; SEMDSA, 2017; UNITE for Diabetes Philippines, 2014), otherwise, annually by an ophthalmologist or optometrist.

***What we know about people with IDD:*** Li, Wong, Park, Fricke and Jackson (2015) identified that, aside from conditions akin to the general population, people with Down syndrome, cerebral palsy and autism are at a greater risk of several additional visual and/or ocular presentations. These need to be considered when seeking eye screening for people with intellectual disability and diabetes. The many challenges faced by this population often lead to a low uptake of diabetic eye screening including practical barriers such as a lack of support to attend screening, lack of understanding around the importance of the screening process and fear associated with the screening process, concerns in relation to capacity to consent and availability of accessible information and resources for screening (Li et al., 2015).

Despite these attempts the national standard in many jurisdictions for checking eyes is not being met for adults with IDD.

#### ***Reasonable adjustments:***

In order to facilitate better eye screening Turner, Kill and Emerson (2013) developed a resource in which reasonable adjustments expected of diabetes services for people with IDD are outlined. These include examples of local procedures and refer to specific accessible resources. Additional reasonable adjustments to facilitate successful screening include highlighting a person's disability at the time of referral and allowing additional time for the screening process to take place (Pilling, 2014). Further suggested adjustments include:

- Attend an annual eye screening, the person can have their eyes checked and monitored
- Having the support of a family / paid carer with the person with an IDD when they attend the optometrist
- Use of a pictorial book with easy read to help explain what is involved in checking your eyes (see resources below)



**Resources:**

<https://www.Diabetes.org.uk/resources-s3/2018-02/Diabetes%20and%20your%20eyes.pdf>

Diabetic Eye Screening:

<https://www.Diabetes.org.uk/resources-s3/2018-02/Diabetic%20eye%20screening.pdf>

Diabetic Eye Screening and Learning Disability.pdf:

<https://www.Diabetes.org.uk/resources-s3/2019-10/Q%26Ag.pdf>

Public Health England:

[https://www.Diabetes.org.uk/resources-s3/2018-10/Diabetic\\_eye\\_screening\\_easy\\_read\\_final.pdf?](https://www.Diabetes.org.uk/resources-s3/2018-10/Diabetic_eye_screening_easy_read_final.pdf?)

Turner, Kill & Emerson (2013):

[https://www.ndti.org.uk/uploads/files/IHaL-2013\\_-01\\_Reasonable\\_adjustments.pdf](https://www.ndti.org.uk/uploads/files/IHaL-2013_-01_Reasonable_adjustments.pdf)

UK College of Optometrists Guidance on Examining Adults with Learning Disabilities:

[www.college-optometrists.org/en/utilities/document-summary.cfm/9FEB-B6A0-D054-4F9996D71008D858A59E](http://www.college-optometrists.org/en/utilities/document-summary.cfm/9FEB-B6A0-D054-4F9996D71008D858A59E)

Diabetic Retinal Screening, Grading, Monitoring and Referral Guidance (MOH, 2016):

<https://www.health.govt.nz/system/files/documents/publications/diabetic-retinal-screening-grading-monitoring-referral-guidance-mar16.pdf>



### 3.5 Having your feet and legs checked

**What we know about the general population:** Keeping active and mobile are important in preventing the progression of lifestyle related diseases. Impairment of blood or nerve supply due to high blood glucose, pressure or lipids frequently involves the feet first and a reduction in mobility is associated with pain, issues with balance and foot ulcers. Diabetic foot disease may be asymptomatic (ADA, 2017), and is mainly due to neuropathy, peripheral arterial disease, and/or infection which may be exacerbated by trauma, which can lead to ulceration and possible subsequent limb amputation. The key to managing foot problems is to prevent them from developing (NICE, 2015c). There needs to be a heightened awareness of protecting legs and feet from trauma when mobilising. This includes removing environmental hazards and ensuring patients seek advice on footwear and fitting (van Netten et al., 2018). This involves:

- Managing blood glucose levels through diet, exercise and for some, medication and awareness that the loss of sensation may be silent.
- Check feet daily: Education on foot hygiene, nail cutting, appropriate footwear, ulcer prevention and recognition of the diabetic foot (when an ulcer is present). Moisturize soles, and do not check water temperature of a bath with one's foot: If person is unable to check their own feet, ensure they have someone who can (NICE, 2015c; UNITE for Diabetes Philippines, 2014).
- Calluses, ingrown toenails or other foot injuries should be assessed and treated by a registered healthcare professional with expertise in foot care.
- Undertake a Diabetes Foot Screening & Risk Stratification assessment with a registered health professional at least every six months or more often if new symptoms present (Diabetes Australia, 2015) annually (SEMDSA, 2017) at every visit (ADA, 2017) or more often if at higher risk of complications (NZGG, 2011).

**What we know about people with IDD:** Whilst the principles are similar for people without IDD, there is limited information available regarding foot care for this population who have Type 2 Diabetes. However, it is known that individuals with Diabetes, Down Syndrome, Prader-Willi Syndrome and Smith Magenis Syndrome are all at risk of impairment in terms of pre-existing issues and/or support in regard to foot health, shape, lifestyle, obesity, and dexterity for example (Courtenay & Murray, 2015). Borst et al. (2018) also found that women with Rett syndrome may also be at risk of impaired foot health in terms of "pressure load" and symmetry in weight-bearing which may impact mobility later in life. Whilst not specific to people with diabetes, these studies present implications for the IDD population with this long-term condition.

#### **Reasonable adjustments:**

Support may be needed to undertake the following recommendations and the education provided not only to the person with IDD, but also to their family, paid carer(s) and/or significant others. As a guide, refer to previous reasonable adjustments regarding providing appropriate visual prompts or increased familiarity with engaging relevant health professionals and see below:



- Wash feet daily
- Dry well especially between the toes
- Check for broken or peeling skin
- Wear clean socks every day
- Ensure the person or their carer does a full leg, and footwear examination every month and know when and how to seek urgent review for un-healing breaks in the skin, discoloration, changes in temperature.

**Resources:**

[http://www.northerntrust.hscni.net/pdf/Diabetes\\_booklet\\_for\\_those\\_with\\_a\\_learning\\_difficulty.pdf](http://www.northerntrust.hscni.net/pdf/Diabetes_booklet_for_those_with_a_learning_difficulty.pdf)

<http://www.easyhealth.org.uk/sites/default/files/how%20to%20look%20after%20your%20feet.pdf>

<https://www.Diabetes.org.uk/resources-s3/2018-02/Keeping%20your%20feet%20happy.pdf>

<https://Diabetes-resources-production.s3-eu-west-1.amazonaws.com/Diabetes-storage/migration/pdf/Improving%2520footcare%2520economic%2520study%2520%28January%25202017%29.pdf>

<https://www.nzssd.org.nz/guidelines-documents-and-useful-links>

<https://www.nhs.uk/Livewell/fothealth/Pages/Healthyfeet.aspx>

<https://www.Diabetesaustralia.com.au/caring-for-your-feet>



### 3.6 Have your kidney function monitored

***What we know about the general population:*** It is well known that kidney function is a complication of diabetes, and therefore individuals need to be screened at least once per year. Two tests are performed to screen for diabetic kidney disease (or nephropathy). For the first test for signs of kidney disease, a urine sample can identify if protein is in the urine (albuminuria). For the second check, a blood sample is required to screen for creatinine and the glomerular filtration rate (eGFR) of the kidneys to see how well they are performing and should be monitored regularly and at least annually (ADA, 2017; Diabetes Australia, 2015; Diabetes Canada, 2018; IDF, 2017; NICE, 2014; NZGG 2011). Changes in these and other monitoring levels may be due to diabetic kidney disease, as well as medications taken for Diabetes and/or as other co-morbid conditions requiring specific and individualized management (ADA, 2017; SEMDSA, 2017). There are no specific considerations in these guidelines for people with IDD regarding monitoring kidney function.

***What we know about people with IDD:*** The majority of people over 50 years of age in this population have two or more comorbid conditions (Hermans & Evenhuis, 2014) half of whom experience polypharmacy (Zaal, van der Kaaij, Evenhuis & van den Bemt, 2013). Regardless of the aetiology for IDD, there is a higher prevalence of renal dysfunction (Lin, Lin, Hsieh, & Lin, 2010). Hence Diabetes places people with an IDD at an increased risk of renal issues. Furthermore, those who are older and/or with Down syndrome are at greater risk compared to their peers (de Winter, Echteld & Evenhuis, 2014). Of note, the monitoring of kidney function may not be routinely undertaken in adults with Type 2 Diabetes and IDD (Taggart, Truesdale & Coates, 2013; NHS Digital, 2017).

#### ***Reasonable adjustments:***

- Attend an annual health check would help to ensure a urine sample and blood sample are collected and the person's kidney state health and function monitored - the latter including creatinine and eGFR.
- Having the support of a family / paid carer with the person with an IDD when they have their blood taken
- Use of a pictorial book with easy read to help explain what is involved in taking a blood sample (see resources below)

#### ***Resources:***

<https://www.Diabetes.org.uk/professionals/position-statements-reports/specialist-care-for-children-and-adults-and-complications/preventing-kidney-failure-in-people-with-Diabetes>

[http://www.easyhealth.org.uk/sites/default/files/blood%20test%20card\\_0.pdf](http://www.easyhealth.org.uk/sites/default/files/blood%20test%20card_0.pdf)

<https://www.gosh.nhs.uk/parents-and-visitors/coming-hospital/if-your-child-has-additional-needs/easy-read-information-sheets>



### 3.7 Get individual dietary ongoing advice

***What we know about the general population:*** Evidence supports the effectiveness of nutrition therapy often combined with physical activity in the prevention and management of Type 2 Diabetes (Colberg et al., 2010; Gillett et al., 2012; Franz et al., 2017). This approach is recommended in many national guidelines, for example Canada (The Diabetes Prevention Program Research Group, 2018), UK (NICE, 2015a), Australia (Colagiuri, Davies, Girgis, & Colagiuri, 2009), New Zealand (Ministry of Health, 2014), South Africa (SEMDSA, 2017) and USA (American Diabetes Association [ADA], 2019). The UKPDS initial nutrition intervention was effective in lowering blood glucose after diagnosis and some people were then able to maintain target glucose control for many years by nutrition modifications alone (King, Peacock, & Donnelly, 1999; Turner, Cull, Frighi, & Holman, 1999).

All guidelines recommend a hypocaloric diet for overweight or obese people with Type 2 Diabetes in order to aim for a normal body weight or to achieve a clinically significant reduction in body weight. This means that moderately obese people need to lose at least 5% weight loss, and in some cases 15kg (or 15%) to achieve maximal benefit and a chance of remission. Severely obese people may not be able to achieve this with diet and may need bariatric surgery.

***What we know about people with IDD:*** Many people living with Type 2 Diabetes are overweight and as a population, people with IDD have higher rates of cardiovascular disease, hypertension and obesity all of which are risk factors for developing diabetes (Havercamp, Scandlin & Roth, 2004; Merrick et al. 2004; Rimmer & Yamaki, 2006; Shireman, Reichard, Nazir, Backes & Greiner, 2010, Taggart et al. 2013). In addition, whilst diet is important in managing diabetes, Bryant et al (2017) found that less than 10 percent of their sample with IDD and Type 2 Diabetes had had access to a dietitian since diagnosis. However, one small study had reported positive effects of dietetic and educational interventions in those IDD (Hunt & Stiller, 2017).

#### ***Reasonable adjustments:***

- Recommend weight loss for those with BMI >25kg/m<sup>2</sup>. A variety of dietary strategies are useful to achieve weight loss and advice should be individualized
- Offer food-based advice including advice emphasizing wholegrains, fruit, vegetables, low fat dairy products, fish, nuts and seeds and reducing red and processed meat, sugar sweetened beverages and refined or processed
- Increase physical activity and reduce sedentary behaviour
- Enlist support from family, carers and friends to support dietary changes and promote physical activity
- Referral to a dietitian
- Access to education and on-going support from the multidisciplinary team
- Encourage family and peers to adopt similar eating habits to the person with diabetes, including meal planning, grocery shopping and sharing meals



**Resources:**

<https://www.sclد.org.uk/healthy-eating-healthy-living-pack/>

<https://www.slideshare.net/PublicHealthEngland/supporting-people-with-learning-disabilities-to-have-a-healthy-diet-and-be-active>

[http://www.easyhealth.org.uk/listing/healthy-eating-\(leaflets\)](http://www.easyhealth.org.uk/listing/healthy-eating-(leaflets))

<https://www.cwt.org.uk/wp-content/uploads/2014/07/LD-TM.pdf>

<https://www.Diabetesaustralia.com.au/Diabetes-australia-app>

**Weight loss advice from National guidelines:**

	<b>Recommendation</b>
SIGN	BMI 25-35 kg/m <sup>2</sup> , aim for 5-10% weight loss BMI >35 kg/m <sup>2</sup> , aim for >15-20% weight loss
Diabetes UK	Aim for >15kg for remission, >5% for improving glycaemic control and reducing CVD risk
ADA	Weight loss of at least 5% is needed to produce beneficial outcomes in glycaemic control, lipids, and blood pressure, but more intensive weight loss (15%) may be needed
Diabetes Canada	Modest weight loss of 5-10%
EASD	Caloric intake should be reduced, and energy expenditure increased so that BMI moves towards the recommended range



### 3.8 Getting emotional psychological support

***What we know about the general population:*** Research in the general population indicates that a diagnosis of Type 2 Diabetes and living with the daily demands of the condition can have a negative psychological and emotional impact (Peyrot et al., 2005; Robinson et al., 2018; Young-Hyman et al., 2016), including increased prevalence of depression, anxiety and Diabetes distress (Ali, Stone, Peters, Davies, & Khunti, 2006; Anderson, Freedland, & Lustman, 2001). Poor emotional wellbeing has been associated with self-management difficulties (Holmes-Truscott, Skinner, Pouwer, & Speight, 2016; Lin et al., 2004; Peyrot et al., 2005) and poor health outcomes (Dalsgaard et al., 2014; Katon, 2005).

The Diabetes UK 15 Healthcare Essentials state that people with diabetes should be able to talk about any issues and concerns with specialist healthcare professionals (Diabetes UK, 2017b). Hence, international guidelines (e.g. Canada, Scotland, Australia, America and the UK) recommend the use of validated assessment tools to screen for mental health issues including depression, anxiety, diabetes distress and eating disorders both at diagnosis and on an ongoing basis (Albus et al., 2004; Ben-Yehuda, Van Hensbergen, & Fiuczynski, 2008; Herpertz et al., 2003; IDF, 2017a; IDF Guideline Development Group, 2014; Robinson et al., 2018; Scottish Intercollegiate Guidelines Network, 2010; The Royal Australian College of General Practitioners, 2016; Young-Hyman et al., 2016). Psychological interventions have been found to improve emotional wellbeing and health outcomes such as glycaemic control (Hermanns et al., 2015; Safren et al., 2014; West, Gore, DiLillo, Greene, & Bursac, 2007). Accordingly, some international guidelines recommend diabetes patients have access to psychological interventions such as CBT, motivational interviewing and stress management; these interventions should be incorporated into care plans (Albus et al., 2004; Robinson et al., 2018; Scottish Intercollegiate Guidelines Network, 2010). Some guidelines have also highlighted the psychological impact of interactions with healthcare professionals (Albus et al., 2004; IDF, 2017a; IDF Guideline Development Group, 2014; Scottish Intercollegiate Guidelines Network, 2010). For example, professionals should be culturally sensitive, adopt a non-judgmental, whole person approach and respect the individual's role in their own care. Other recommendations include the use of antidepressant medication (Albus et al., 2004; Robinson et al., 2018) and collaborative care (Robinson et al., 2018; Young-Hyman et al., 2016).

The diagnosis of diabetes has a multifaceted impact upon a person's sense of self. Hence, psychological support is needed, not only for people with diabetes throughout the trajectory of the condition, but also those in their network of support. Therefore, developing the internal and external skills and resources for coping may ease the negative correlation of diagnosis (Chew, Shariff-Ghazali & Fernandez, 2014). Young-Hyman et al. (2016) developed an assessment guide to establish psychosocial impairment for individuals and their families. A key focus of this is to recognize the clinical risk and identify considerations for appropriate contextual response. Although the above-mentioned international guidelines do not make specific mention of diabetes related psychological support for people with IDD, a recent publication by Diabetes UK suggests reasonable adjustments to emotional support for this population (Diabetes UK, 2017a) (see below).



***What we know about people with IDD:*** Research into the experience of diabetes management for people with IDD suggests there is a need for access to psychological support (Cardol, Rijken, & van Schrojenstein Lantman-de Valk, 2012; Dysch, Chung, & Fox, 2012) but little has been highlighted on the reasonable adjustments for this population. People with IDD have reported emotional distress, confusion, sadness, anger, hatred and anxiety relating to diabetes, feeling low and depressed and that they find Diabetes management difficult, frustrating and scary (Cardol et al., 2012a; Dysch, Chung & Fox, 2012; Flood & Henman, 2015; Hale et al., 2011; Rey-conde, Lennox, & McPhee, 2005; Rouse & Finlay, 2016). The reasons given include multiple restrictions around diet, the impact on opportunities for social interaction and stigma (feeling different from others). Negative emotions relating to Diabetes may impact on motivation to engage in diabetes management and medication use. Flood and Henman (2015) suggest that people with IDD may be at particular risk of developing 'diabetes distress'.

People with IDD are at a higher risk of depression, anxiety and other mental health problems (Cooper et al., 2015) and early detection for those with diabetes can improve treatment and reduce the impact (ADA, 2017). However, no studies have explored how Diabetes relates to this population and the development or exacerbation of mental health problems with the exception of Bryant et al. (2017) who found a link between elevated BMI and mood. The existing literature does not mention whether these individuals have; access to emotional or psychological support or discuss their concerns with healthcare professionals during their diabetes reviews, or if reasonable adjustments are made to support discussion of these issues with professionals or for the purposes of accessing psychological support services.

A report 'Consulting Diabetes Patients with and without Intellectual Disabilities' found that healthcare professionals prioritized information over emotional wellbeing and professionals lacked awareness of the need for emotional/psychological support (Care Quality Commission, 2016). The literature highlights barriers to psychological support services for people with IDD: diagnostic overshadowing, difficulty expressing their emotional needs to healthcare professionals, healthcare professionals may believe that people with disabilities lack enough communication skills and emotional insight necessary to take part in or benefit from psychological therapies (Kachika, 2017; National Development Team for Inclusion, 2012).

### ***Reasonable adjustments:***

Although actual examples of reasonable adjustments are scarce, a number of reasonable adjustments to emotional and psychological support for people with IDD and Diabetes have been recommended:

- Staff training in liaison between physical and mental health services
- Mental health liaison arrangements should be made with IDD services if the individual is depressed and neglects self-care
- Awareness of the danger of diagnostic overshadowing (that behaviour change can be a sign of physical and mental health difficulties)



- Provide information for people with IDD focusing on the non-medical aspects of living with diabetes
- The annual health check review should address mental health needs and concerns should be discussed with the GP or community nurse
- Diabetes also has an emotional impact on carers who should have access to appropriate respite (Dysch et al., 2012; Hillege, Gallagher, & Evans, 2013; Kachika, 2017).

Examples and recommendations for reasonable adjustments to mental health services for people with IDD may also be relevant and include:

- Ensuring good advocacy and support
- Health action plans to inform professionals on the reasonable adjustments needed and to help combat stereotypes that people with IDD will not be able to engage in or benefit from talking therapies
- Staff from different services to work together to share knowledge and skills (e.g. health care professionals seeking advice or doing joint assessments with other teams (e.g. psychologist) from specialist IDD services
- Accessible assessment tools
- Consider ways of involving people with IDD to manage their psychological and emotional wellbeing (e.g. social prescribing, peer experts and mentors, adapted Cognitive Behavioural Therapies and access to online and offline peer support groups) (National Development Team for Inclusion, 2012).

## Resources

<https://www.Diabetes.org.uk/Professionals/Resources/shared-practice/for-people-with-learning-disability>

[https://www.Diabetes.org.uk/resources-s3/2017-10/Emotional\\_and\\_Psychological\\_Support\\_and\\_Care\\_in\\_Diabetes\\_2010%20%28DUK%29.pdf](https://www.Diabetes.org.uk/resources-s3/2017-10/Emotional_and_Psychological_Support_and_Care_in_Diabetes_2010%20%28DUK%29.pdf)

<https://mentalhealthpartnerships.com/resource/reasonably-adjusted-mental-health-services-and-support-for-people-with-autism-and-people-with-learning-disabilities/>

<http://static.Diabetesaustralia.com.au/s/fileassets/Diabetes-australia/ad0cfcca-aea1-4b49-ad2e-2371671d97db.pdf>



### 3.9 Being offered a group education course

***What we know about the general population:*** Internationally, it is recommended that education is ongoing both in terms of diabetes itself as well as concepts and the practice of self-management for the people themselves and those in their network of support (ADA, 2017; SEMDSA, 2017; UNITE for Diabetes Philippines, 2014). Undertaking such education in groups can be beneficial (Diabetes Australia, 2015) as well as identifying peer-led opportunities to encourage those with diabetes to engage (Diabetes Canada Practice Guidelines, 2018). In supporting people diagnosed with Type 2 Diabetes, a few countries have developed structured self-management education programs. For example, Flinders University South Australia established a self-management programme by the same name, developed and implemented in the UK and Western Australia, DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diabetes) is a funded self-management diabetes education programme for the general population. This program is theoretically underpinned and has clearly been shown to improve biomedical and psychosocial benefits, as well as the increase in self-management strategies for those people who attend (Skinner et al., 2006; Khunti et al., 2008; 2012). There will be other structured self-management diabetes education programs in other jurisdictions.

***What we know about people with IDD:*** People with IDD rarely access structured self-management education programs for diabetes that are routinely offered to the general population (MacRae et al., 2015; Taggart, Brown & Karatzias, 2014). The specific challenges posed by this population's cognitive limitations, communication difficulties, low levels of literacy skills and learning styles have been neither recognised nor addressed in the programmes. In keeping with this, there is also a lack of attention to the support that may be needed for paid carers to understand and employ self-management concepts (Trip et al., 2016). Furthermore, until recently there have been no theoretically underpinned and robustly tested, structured diabetes self-management education programs for adults with IDD and Type 2 Diabetes in any jurisdiction.

There have been several recent developments within the UK in terms of diabetes education and people with IDD (see Taggart et al., 2018 for a full explanation of these programs). There has been one diabetes prevention program STOP (Dunkley et al., 2017) and two self-management Type 2 Diabetes education programs DESMOND-ID (Taggart et al., 2017) and the OK Diabetes program (House et al., 2018) adapted for this population. All three programs have been adapted from other theoretically informed and tested programs developed for the general population. Each program has employed co-design and co-production techniques with all stakeholders. The three programs all target the high-risk lifestyle factors that can lead to Type 2 Diabetes and contribute to poor glycaemic control, and have undertaken randomised-feasibility studies, the results of which are promising.



***Reasonable adjustments:***

- For effective diabetes self-management, people with IDD require structured education about diabetes in which the language and approach is tailored and adapted to the individual (Bell, 2005; Taggart et al., 2015; 2018), as well as feedback on what has been mastered (Maine, Dickson, Truesdale & Brown, 2017). Such approaches develop the autonomy and confidence of a person with IDD and those who support them (Cardol, Rijken & van Schrojenstein Lantman-de Valk, 2012b; MacRae et al., 2015).
- Joint clinics between primary care, diabetes services and IDD healthcare staff would inform service delivery, accessibility and continuity of care for people with intellectual disability (Brown et al., 2017).
- Peer-led education and exercise with others who have Type 2 Diabetes (Hale et al., 2011)

***Resources:***

*DESMOND-ID: <http://www.isrctn.com/ISRCTN93185560>*

*<http://www.desmond-project.org.uk/>*



### 3.10 See specialist diabetes healthcare professionals

What we know about the general population: Whilst individuals may receive exceptional primary care, it is important that they also have access to and receive community-based and/or outpatient specialist care from a range of health professionals appropriately trained in population health as it pertains to Type 2 Diabetes (Brown et al., 2017; Diabetes Canada, 2018; NICE 2015a; UNITE for Diabetes Philippines, 2014). These include but are not limited to; physicians, chiropodists/podiatrists, pharmacists, ophthalmologists, dietitians, nurses, psychologists, physiotherapists and occupational therapists, as well as endocrinologists, renal and cardiovascular specialists for example all of whom should provide timely communication and the sharing of resources (ADA, 2017; Diabetes Australia, 2015; IDF, 2017; SEMDSA, 2017). In many countries, cultural considerations need to be embedded in guidelines and consider the relevance, and accessibility of targeted healthcare for Type 2 Diabetes to both indigenous, refugee and migrant populations (Diabetes Australia, 2015; NZGG, 2011; Diabetes Canada Practice Guidelines, 2018).

What we know about people with IDD: In the UK, Valuing People (Department of Health, 2001) promotes the need for Health Facilitators to broker and enable access for people with IDD to primary, secondary and specialist healthcare services. Recommendations for service provision include flexibility with appointments, information that is accessible (e.g. pictorial information, augmentive communication) in a range of contexts (Brown et al., 2017; Doody & Doody, 2012) and ensuring the follow up of people who do not attend scheduled appointments (Castensøe-Seidenfæde et al., 2017). Facilitating appropriate communication between health, disability and social services is also important to ensure consistency and continuity of care (Brown et al., 2017; Trip et al., 2016). Balogh et al. (2015) further reported in Canada that adults with IDD are at high risk of developing and being hospitalized as the result of various complications of their diabetes than their counterparts without IDD.

#### **Reasonable adjustments:**

A systematic review of international evidence on health checks for adults with IDD has been undertaken by Robertson, Roberts, Emerson, Turner and Greig (2010) which concluded that the introduction of health checks had resulted in *“the detection of unmet, unrecognized and potentially treatable health conditions (including serious and life threatening conditions such as diabetes, cancer, heart disease and dementia)”* (p. 24). The health checks also led to targeted actions to address health needs such as the promotion of healthier lifestyles. Moreover, health checks also seem to be cost-effective as early detection reduces the costs associated with managing chronic conditions (Buszewicz et al., 2014). There have been three National Institute of Clinical Excellence (NICE, 2015, 2016, 2018) guidelines within the UK, that have strongly advocated that all people with IDD should receive an annual health check. This is more so for those with Type 2 Diabetes given the potential complications that can develop from this chronic long-term condition.



Some reasonable adjustments that can be made across jurisdictions are:

- Attend an annual health check and develop a health action plan (McConkey, Taggart & Kane, 2015)
- Integrated care is needed across; service providers, care workers, GP practices, specialist diabetes healthcare professionals - particularly nurses (Hale et al., 2011)
- Podiatrists, psychologists and dietitians need to be involved not only at the time of the diagnosis of diabetes, but on an ongoing basis (CQC, 2016).
- Education is needed to improve the health literacy of health professionals (including direct support workers) within the IDD sector about diabetes (Brown et al., 2017; Hemingway, Stephenson, Trotter, Clifton & Holdich, 2015; Trip et al., 2016), but also those in the wider healthcare system about IDD (Brown et al., 2017; Cardol et al., 2012b).

These factors are applicable to and inform the care expected of health professionals both in the community as well as in the hospital setting (See 3.11).

***Resources:***

Consider using a range of the links which have been provided throughout this consensus guideline which may inform and support access to the relevant specialist services.



### 3.11 Receive good care if admitted to hospital

***What we know about the general population:*** Approximately one in six hospital beds in England are occupied by someone with diabetes (National Diabetes Inpatient Audit, 2013). In Australia, one in five admissions are as a result of foot ulcerations (Diabetes Australia, 2015), or severe, life threatening hypo or hyper-glycaemia (SEMDSA, 2017) which may be due to, or in isolation of, vomiting and diarrhoea and/or other systemic dysfunction (UNITE for Diabetes Philippines, 2014). There are risks to hospitalization for the person with Type 2 Diabetes which may include issues with nutrition (NICE, 2015a) or surgery for example (Diabetes Australia, 2015) which may impact upon glycaemic control (ADA, 2017). Good hospital care is paramount as healthcare professionals, trained specialists and specialty teams have a direct impact on the length of stay, glycaemic control and ultimately, health outcomes and readmission rates for people with Type 2 Diabetes (ADA, 2017): The latter may be as a result of discharge planning, consultation and collaboration with primary or other community-based specialist services. Note, good care also includes awareness of and responsiveness to mental health (ADA, 2017).

***What we know about people with IDD:*** According to Glover and Evison (2013) people with IDD are 70% more likely to be admitted to acute hospitals as an emergency with an ambulatory care sensitive condition. There is growing international evidence to highlight the poor care adults with IDD receive when admitted into an acute hospital. Research in the UK, Ireland, USA, Australia and New Zealand highlights that people with intellectual disability are dying approximately 20 years earlier than adults from the general population peers; many of these deaths can be avoidable if appropriate care was put into place (Heslop et al., 2013; McCarron et al., 2015; Ministry of Health, 2011; Trollor et al., 2017; US Surgeons General Report, 2002). People with IDD are more likely to be hospitalized for ambulatory care-sensitive conditions related to Diabetes (Balogh, Lake, Lin, Wilton & Lunskey, 2015; Dunn, Hughes-McCormack & Cooper, 2017). Drawing on the Department of Health's (2001) strategy on Valuing People, Doody and Doody (2012) stated that hospitals are expected to "fulfill their legal duty of care and provide appropriate levels of support" to this population.

A number of studies have highlighted the negative experiences that people with IDD experience in acute hospitals. These include: difficulty in understanding what was happening; they are provided with limited information that they can understand; they do not feel involved in the discussions and decisions which have taken place about their care; they experience confusion and fear arising from limited explanation and uncertainty about what is happening; they experience insufficient attention being given to making reasonable adjustments (e.g. addressing communication problems, difficulty in understanding and anxieties and preferences).



### **Reasonable adjustments:**

- The GAIN Guidelines (2010), Northern Ireland provide a framework for how to ensure good quality care for people with IDD as they journey through a hospital admission. These guidelines explore; positive attitudes and values held by healthcare staff; clear communication; IDD training for all hospital staff; obtaining informed written consent; preparing for an outpatient appointment; admission process and support during a hospital stay; early discharge planning; attendance at emergency care services; support for family carers; effective nutrition and hydration; assessment and management of pain; and improving the experience of children with IDD.
- Implementation of a pre-admission process (Doyle et al., 2016) would identify reasonable adjustments appropriate for the individual and includes support to develop a personalized care plan (CQC, 2016); which could be assisted through the use of technology (Haymes, Storey, Maldonado, Post & Montgomery, 2015).
- Having nurses with expertise in IDD employed within hospitals improves access and the implementation of reasonable adjustments, these are known as 'Hospital Liaison Nurses' and have been employed across England and Scotland (Ministry of Health, 2011; Turner, 2014).
- Health promotion and proactive health screening for diabetes and access to specialists in the community (for both diabetes and IDD) will reduce admissions into hospital for this population (Balogh et al., 2015; Taggart et al., 2014).

### **Resources:**

Diabetes UK have published guidelines for admission to hospital for people with intellectual disabilities: [https://www.Diabetes.org.uk/resources-s3/2018-10/Making%20Hospitals%20safe%20for%20people%20with%20Diabetes\\_FINAL.pdf?\\_ga=2.139714800.218554856.1538407708-1498355072.1474465387](https://www.Diabetes.org.uk/resources-s3/2018-10/Making%20Hospitals%20safe%20for%20people%20with%20Diabetes_FINAL.pdf?_ga=2.139714800.218554856.1538407708-1498355072.1474465387)

GAIN guidelines: <https://rqia.org.uk/RQIA/files/81/81662c46-b7bb-43a5-9496-a7f2d-919c2a3.pdf>

Glover & Evison (2013): [https://www.ndti.org.uk/uploads/files/IHAL-2013-02\\_Hospital\\_admissions\\_that\\_should\\_not\\_happen\\_ii.pdf](https://www.ndti.org.uk/uploads/files/IHAL-2013-02_Hospital_admissions_that_should_not_happen_ii.pdf)

Mencap have produced a guide to reasonable adjustments for people with an intellectual disability in hospital: <https://www.mencap.org.uk/sites/default/files/2018-06/Treat%20me%20well%20top%2010%20reasonable%20adjustments.pdf>

<https://www.mencap.org.uk/get-involved/campaign-mencap/current-campaigns/treat-me-well/treat-me-well-resources-hospital>

<https://static.Diabetesaustralia.com.au/s/fileassets/Diabetes-australia/62fe45eb-938c-47ed-b048-b15e616ceb52.pdf>



### 3.12 Get a free flu vaccine

***What we know about the general population:*** Influenza can influence blood sugar levels. It is important for people to keep eating and drinking if they develop the flu. In order to prevent complications annual flu vaccinations are recommended for people with long term conditions such as diabetes (Diabetes Australia, 2015; Diabetes Canada, 2018; Diabetes UK, 2017b; European Centre for Disease Prevention and Control, 2017; SEMDSA, 2017) including those over six months of age, and particularly those over 65 years of age (ADA, 2016; UNITE for Diabetes Philippines, 2014) and those in their network of care (European Centre for Disease Prevention and Control, 2017; UNITE for Diabetes Philippines, 2014). A number of countries include people with diabetes (and with cognitive impairment) as eligible for free annual flu vaccinations and healthcare workers (Ministry of Health, 2018b; Public Health England, 2017).

Whilst people with IDD have not been specifically identified in the above guidelines, it is recommended that those considered vulnerable in terms of age, condition and/or disease access an annual influenza vaccination.

What we know about people with IDD: People with IDD are identified as a higher risk group for influenza (Blanton et al., 2017) and coupled with diabetes, this poses a significant risk of complications such as altered blood sugar levels and pneumonia ([www.diabetes.co.uk](http://www.diabetes.co.uk)). This population is included in categories for annual influenza vaccination in many countries. For countries with seasonal campaigns, people with IDD should be encouraged to participate. Ideally the seasonal flu vaccine should be free. For tropical countries where there might not be a seasonal component to flu vaccination, health professionals should consider annual flu vaccines when appropriate. Education to assist people with IDD when seeking their consent to be vaccinated, might be aided using a video and other national health sites (see resources below).

#### ***Reasonable adjustments:***

- Annual flu vaccination for people with IDD and family/carers
- Prior to vaccination, consider watching a visual presentation, engaging the person in desensitization work, and if needed, consider using topical cream to numb injection site
- If experiencing the flu, increase the monitoring of blood sugar levels as illness may mask usual feelings related to high or low blood sugar levels
- Check with a registered health professional about taking over-the-counter medications to manage flu symptoms as this also can affect diabetes



**Resources:**

Video on flu vaccination: [www.canada.ca/flu](http://www.canada.ca/flu)

<https://www.gov.uk/government/publications/flu-vaccinations-for-people-with-learning-disabilities>

[https://www.Diabetes.org.uk/resources-s3/2017-10/Stay\\_well\\_this\\_winter\\_guide\\_2017.pdf](https://www.Diabetes.org.uk/resources-s3/2017-10/Stay_well_this_winter_guide_2017.pdf)

<https://www.Diabetesaustralia.com.au/influenza>



### 3.13 Have the opportunity to talk about any sexual problems

**What we know about the general population:** Sexual problems for men with diabetes include: erectile dysfunction, hypogonadism, ejaculatory disorders, and low testosterone (Brock & Harper, 2013; Rice, Roszler, Farrell, 2009). Sexual difficulties for women with diabetes include: painful intercourse, decreased sexual arousal, and reduced libido (Rice et al., 2009). Mention of sexuality difficulties are present within international diabetes guidelines, particularly for men and recommendations to address these include: education and support for men with erectile dysfunction, regular screening for erectile dysfunction and hypogonadism and if desired, men should be referred to a health care professional who can provide treatment (ADA, 2018; Brock & Harper, 2013; Diabetes Australia, 2015; NICE, 2015a). With regard to recommendations for women experiencing sexual problems, there appears to be much less. Although, the Australian guidelines do recommend that health care professionals discuss and manage all aspects of sexual problems (e.g. physical and emotional) and explain the benefits of lubricants (Diabetes Australia, 2015). Further recommendations for women are discussed within research studies and include: doctors should facilitate a conversation concerning sexual issues and treatment options, refer patients to appropriate health care professionals (e.g., sex therapist, social workers, marriage counselors), and follow up with patients regarding treatment options and outcomes (Rice et al., 2009).

**What we know about people with IDD:** The lack of literature on sexuality difficulties in individuals with IDD and diabetes is concerning, as sexual dysfunction can reduce quality of life, therefore this topic must be discussed and addressed (Rice et al., 2009). An exception to this is a case study conducted by Brown et al. (2012) that highlights erectile dysfunction is a concern among males with IDD and diabetes. Brown et al. suggested while treating an individual with IDD, health care professionals must consider the individual's ability to communicate and provide consent. It is also important they are provided with educational resources concerning diabetes management.

**Reasonable adjustments:** Similar recommendations should be applied to this population as those in the general population:

- In talking about sexuality for people with IDD, doctors need to keep in mind that talking about sexuality is already difficult for them. Both men and women with IDD have less knowledge about sexuality (Sinclair, Unruh, & Lindstrom, 2015), are more prone to abuse (Wissink, van Vugt, Moonen, Stams, & Hendrix, 2015), and have more conservative attitudes (Servais, 2006) than other adults. People with IDD may consider sexual health and pregnancy to be matters beyond the remit of their Diabetes care appointments (Rouse, 2019).
- Women with IDD may not know that they can talk about pain and discomfort. This makes discussing sexual problems difficult. As with other areas, visual aids, simpler language and listening without judgment is important to being able to support patients with IDD who have diabetes and are experiencing difficulties with sexuality due to the diabetes itself or the medications.



**Resources:**

*<http://static.Diabetesaustralia.com.au/s/fileassets/Diabetes-australia/94087d-fc-1aea-444e-9278-9db0e34430d1.pdf>*

*<https://www.Diabetes.org.uk/guide-to-Diabetes/life-with-Diabetes/sex-and-Diabetes>*



### 3.14 If you smoke, get support

**What we know about the general population:** Smoking is an important element in the assessment and monitoring of diabetes (ADA, 2017; Diabetes Australia, 2017; Diabetes Canada, 2018) as it increases the risk of heart disease and stroke for people with Diabetes (Haire-Joshu, Glasgow & Tibbs, 1999; UNITE for Diabetes Philippines, 2014) and circulatory issues such as peripheral neuropathy (ADA, 2017). International Diabetes guidelines (International Diabetes Federation, 2017) acknowledge widespread support for smoking cessation advice (Diabetes Canada, 2018; NZGG, 2011) inclusive of e-cigarettes (ADA, 2017) and the chewing of tobacco (IDF, 2017) at least annually (Diabetes Australia, 2015) and at every healthcare encounter (SEMDSA, 2017) when people have Diabetes.

**What we know about people with IDD:** Little is known about smoking and people with IDD, however Steinberg, Heimlich and Williams (2009) found that those who smoke “are more likely to do so if they are higher functioning, live in less restrictive environments, are male, or have co-occurring substance use disorders” (p.9). Emerson (2011) also concluded smoking was heightened for individuals not linked to IDD services, and who were therefore less likely to access health promotion activities which increased their risk or poorer health outcomes. Further, they may be more likely to experience smoking related health issues and it may be harder for them to quit compared to people with a cognitive impairment or mental health issue. The International Diabetes Federation (2017) identified that all countries recommended smoking cessation and that practitioners should use whatever programmes they have available. These programmes identify the importance of considering suitable approaches for the person and the application of reasonable adjustments as needed (Brown et al., 2017).

#### **Reasonable adjustments:**

- Always ask the person if they smoke and offer smoking cessation advice
- Access online sites for specific smoking cessation support for your country.

#### **Resources:**

<https://www.racgp.org.au/guidelines/smokingcessation>

A guide to giving up smoking for people with intellectual disabilities:

<http://www.easyhealth.org.uk/sites/default/files/null/Keep%20Yourself%20Healthy%20-%20A%20Guide%20to%20Giving%20Up%20Smoking.pdf>



### 3.15 Get information and specialist care if you are planning to have a baby

**What we know about the general population:** Complications arising from pre-pregnancy Type 1 or Type 2 Diabetes, or diabetes developed during pregnancy (gestational Diabetes) can be harmful for the mother and child regardless of the disability status. Such complications can include miscarriage, increased diabetes complications, stillbirths, and preterm delivery (Milne, 2017) and retinopathy (SEMDSA, 2017). There is concern about the rates of congenital issues for offspring of adolescents with Type 2 Diabetes hence, monitoring and counselling is indicated if planning to have a baby (Klingensmith et al., 2016). It is recommended that women seek excellent glycaemic control prior to becoming pregnant (Diabetes Canada Practice Guidelines, 2018). The information contained in 3.10 and 3.11 regarding See Specialist Diabetes Healthcare Professionals and Receive Good Care If Admitted to Hospital respectively, and indeed all of the other indicators have relevance here in terms of the level of care and oversight that is required for a woman prior to, during and post pregnancy (ADA, 2016; SEMDSA, 2017). Pregnancy planning prior to conception receiving the right care, treatment and support from health care professionals is key (Diabetes UK).

**What we know about people with IDD:** Given the higher rates of diabetes in women with IDD, than without IDD during childbearing years, it is important the potential complications and the need for specialized care is considered among this population (Tarasoff et al., 2020). Women with both IDD and diabetes may be at a further risk for complications during pregnancy, as they are more likely to neighborhoods, have more health conditions (mental health issues, obesity, epilepsy), and to take more medications, including psychotropic medications, when compared to women without disabilities (Brown et al., 2016).

Research exploring pregnancy among women with IDD is minimal and even less is known about women with diabetes and IDD who become pregnant. An exception to this is a Canadian study by Brown et al. (2016) on fertility patterns of over 21,000 women with and without IDD. This study showed that although women with IDD were nearly half as likely to have a live birth as women without a disability, rates of pre-existing diabetes were similarly low between the two groups of women, approximately 2%.

#### **Reasonable adjustments:**

There is no specific information for women with diabetes and IDD who are pregnant. Recommendations for women in the general population with pre-existing Diabetes are present within the Canadian, American, and United Kingdom guidelines. Suggestions concerning preconception care include:

- Educating women of the potential risks associated with pregnancy as well as the risks associated with specific medications (such as ACE inhibitors or statins) and the use of effective contraception to avoid unplanned pregnancy
- Women should be advised to monitor blood glucose levels and achieve blood glucose levels < 5.0 mmol/l before meals and, 6.8 mmol/L two hours after meals, have an HbA1c, 40 mmol/mol prior to conception and monitor their weight.



- The importance of planning a pregnancy including early commencing of folic acid supplements, as per national guidelines and having an eye exam prior to pregnancy were also highlighted under preconception care
- During pregnancy, women should continue to monitor their weight, eyes, and blood glucose levels
- It is very important that women are cared for within secondary care specialist Diabetes and pregnancy multidisciplinary team service and are offered and included in the process of monitoring the fetus in terms of growth and well-being

Similar approaches should be applied to women with IDD; however adjustments may be necessary. For example:

- It is essential for women with IDD and diabetes to receive information and specialized care if they plan to have a baby to minimise and prevent diabetes related complications
- Medical professionals need to ensure women with IDD and diabetes who get pregnant have a thorough understanding of all information conveyed to them.
- Medical professionals should encourage these women to discuss any concerns they may have so that they can be addressed and be supported at appointments, particularly if appointments involve drawing blood or other invasive procedures
- Women with IDD may also need to be informed, prepared for and supported prior to appointments, particularly if appointments involve drawing blood
- It is also important to ensure women with IDD have the support of a social network (e.g. caregiver, husband) and if desired, that these individuals accompany her to medical appointments and participate in perinatal care appointments.

### **Resources:**

Diabetes in pregnancy: management from preconception to the postnatal period. <https://www.nice.org.uk/Guidance/>

Diabetes in pregnancy: management from preconception to the postnatal period. <https://www.nice.org.uk/Guidance/NG3>

<https://www.Diabetes.org.uk/guide-to-Diabetes/life-with-Diabetes/pregnancy>

<https://www.Diabetes.org.uk/professionals/resources/resources-to-improve-your-clinical-practice/information-prescriptions-qa/information-prescription--Diabetes-contraception-and-pregnancy>

<https://www.Diabetes.org.uk/guide-to-Diabetes/life-with-Diabetes/pregnancy/during-pregnancy>



## References

- Albus, E. C., Kulzer, B., Petrak, F., Kruse, J., Hirsch, A., & Herpertz, S. (2004). *The German Diabetes Association Clinical Guideline: Psychosocial Factors and Diabetes Mellitus*. Retrieved from [http://www.Diabetes-psychologie.de/downloads/English\\_Praxisleitlinie.pdf](http://www.Diabetes-psychologie.de/downloads/English_Praxisleitlinie.pdf)
- Ali, S., Stone, M. A., Peters, J. L., Davies, M. J., & Khunti, K. (2006). The prevalence of co-morbid depression in adults with Type 2 Diabetes: A systematic review and meta-analysis. *Diabetic Medicine*, 23(11), 1165–1173. <https://doi.org/10.1111/j.1464-5491.2006.01943.x>
- American Diabetes Association (2016). Standards of medical care in diabetes—2016. *Diabetes Care*, 39(suppl 1), S1-S106.
- American Diabetes Association (2012). Standards of medical care in diabetes. *Diabetes Care*, 35, S11-S63.
- American Diabetes Association. (2018). Standards of medical care in diabetes-2018. *The Journal of Clinical and Applied Research and Education*, 41 (1). S105-S118.
- American Diabetes Association (2008). Nutrition recommendations and interventions for diabetes: A position statement of the American Diabetes Association. *Diabetes Care*, 31, S61-S78.
- American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders, 5th Edition: DSM-5. Virginia, USA: Author.
- Anderson, R. J., Freedland, K. E., & Lustman, P. J. (2001). The prevalence of comorbid depression in adults with diabetes: A meta-analysis. *Diabetes Care*, 24(6), 1069–1078. <https://doi.org/10.2337/diacare.24.6.1069>
- Balducci, S., Zanuso, S., Cardel, I. P., Salvi, L., Mazzetelli, G., Bazuro, A., ... & The Italian Diabetes Exercise Study (IDES) Investigators (2012). Changes in physical fitness predict improvements in modifiable cardiovascular risk factors independently of body weight loss in subjects with Type 2 Diabetes participating in the Italian Diabetes and Exercise Study (IDES). *Diabetes Care*, 35, 1347-1354.
- Balogh, R.S., Lake, J.K., Lin, E., Wilton, A., & Lunsby, Y. (2015). Disparities in diabetes prevalence and preventable hospitalizations in people with intellectual and developmental disability: A population-base study. *DIABETIC Medicine*, 32, 235-242. doi: 10.1111/dme.12573
- Bazzano, A.T., Zeldin, A.S., Shihady Diab, I.R., Garron, N.M., Allevato, N.A., Lehrer, D. and the WRC Project Oversight Team (2009). The health lifestyle change program: A pilot of a community-based health promotion intervention for adults with developmental disabilities. *American Journal of Preventive Medicine*, 37(6S1), S201-S208.
- Bell, D.M. (2005). Over the sea and far away: Ways of overcoming some of the difficulties arising in work with adults with learning disabilities living in geographical isolation in the United Kingdom. *British Journal of Learning Disabilities*, 33, 180-197. doi: 10.1111/j.1468-3156.2005.00312.x
- Ben-Yehuda, M., Van Hensbergen, E., & Fiuczynski, M. (2008). Minding the gap. *ACM SIGOPS Operating Systems Review*, 42, 1–3. <https://doi.org/10.1145/1400097.1400098>



- Blanton, L. B., Alabi, N., Mustaquim, D. et al. (2017). Update: Influenza activity in the United States during the 2016–17. Season and composition of the 2017–18 influenza vaccine. *Morbidity and Mortality Weekly Report*, 66(25), 668-676.
- Borst, H.E., Townend, G.S., van Eck, M., Smeets, E., van den Berg, M., Lann, A., & Curfs, L.M.G. (2018). Abnormal foot position and standing and walking ability in Rett syndrome: An explanatory study. *Journal of Developmental and Physical Disability*, 30, 281-295. doi: 10.1007/s10882-017-9585-6
- Brandford, S. (2020). Counting for Something – How New Zealand agencies record, investigate and review deaths of people with intellectual disability”. Wellington, New Zealand.
- Brock, G., & Harper, W. (2013). Canadian Diabetes Association 2013 Clinical practice guidelines for the prevention and management of diabetes in Canada: pharmacologic management of Type 2 Diabetes. *Can J Diabetes*, 37(suppl 1), S61-S68.
- Brown, M., Duff, H., Boyd, M., & Shaw, J. (2012). Management of erectile dysfunction in adult men with learning disabilities and diabetes. *Diabetes & Primary Care*, 12 (2), 120-126.
- Brown, H.K., Lunskey, Y., Wilton, A.S., Cobigo, V., & Vigod, S.N. (2016). Pregnancy in women with intellectual and developmental disabilities. *J Obstet Gynaecol Can*, 38 (1) 9-16.
- Brown, M., Taggart, L., Karatzias, T., Truesdale, M., Walley, R., Northway, R., ... Davies, M. (2017). Improving diabetes care for people with intellectual disabilities: A qualitative study exploring the perceptions and experiences of professionals in diabetes and intellectual disability services. *Journal of Intellectual Disability Research*, 61(5), 435-449. doi: 10.1111/jir.12369.
- Bryant, L.D., Russell, A.M., Walwyn, R.E.A., Farrin, A.J., Wright-Hughes, A., Graham, E.H., ... House, A.O. (2017). Characterizing adults with Type 2 Diabetes mellitus and intellectual disability: Outcomes of a case-finding study. *Diabetic Medicine*, 35(3), 352-359. doi: 10.1111/dme.13510
- Buszewicz, M., Welch, C., Horsfall, L., Nazareth, I., Osborn, D., Hassiotis, A., ... Strydom, A. (2014). Assessment of an incentivised scheme to provide annual health checks in primary care for adults with intellectual disability: A longitudinal cohort study. *Lancet Psychiatry*, 1(7), 522-30. doi: 10.1016/S2215-0366(14)00079-0.
- Canadian Diabetes Association Clinical Practice Guidelines Expert Committee (2013). Diabetes and pregnancy. *Canadian Journal of Diabetes*, 37(1), S168-S183.
- Canadian Diabetes Association Clinical Practice Guidelines Expert Committee (2008). Canadian Diabetes Association 2008 Clinical practice guidelines for the prevention and management of Diabetes in Canada. *Can J Diabetes*, 32, S95-S98. <http://www.Diabetes.ca>
- Cardol, M., Rijken, M., & van Schroyen Lantman-de Valk, H. (2012a). People with mild to moderate intellectual disability talking about their diabetes and how they manage. *Journal of Intellectual Disability Research*, 56(4), 351-360. doi: 10.1111/j.1365-2788.2011.01472.x
- Cardol, M., Rijken, M., & Van Schroyen Lantman-de Valk, H. (2012b). Attitudes and dilemmas of caregivers supporting people with intellectual disabilities who have diabetes. *Patient Educ Couns*, 87, 383–388.



- Care Quality Commission. (2016). *My diabetes, my care*. Retrieved from <http://www.cqc.org.uk/content/my-Diabetes-my-care-community-Diabetes-care-re-view>
- Castensø-Seidenfæde, P., Jensen, A.K., Smedegaard, H., Hommel, G.R., Pedersen-Bjergaard, U., & Teilmann, G. (2017). Clinical, behavioural and social indicators for poor glycaemic control around the time of transfer to adult care: A longitudinal study of 126 people with Diabetes. *DIABETICMedicine*, 34, 667-675. doi: 10.1111/dme.13318
- Chew, B-H., Shariff-Ghazali, S., & Fernandez, A. (2014). Psychological aspects of diabetes care: Effecting behavioral change in patients. *World Journal of Diabetes*, 5(6), 796-808. doi: 10.4239/wjd.v5.j6.796.
- Colagiuri, S., Davies, D., Girgis, S., & Colagiuri, R. (2009). *National evidence based guideline for case detection and diagnosis of Type 2 Diabetes*. Canberra: Diabetes Australia and the NHMRC. Retrieved from <http://static.Diabetesaustralia.com.au/s/fileassets/Diabetes-australia/af2389ea-8f61-4c54-82d6-77ab07f03597.pdf>
- Colberg, S.R., Sigal, R.J., Fernhall, B., Regensteiner, J.G., Blissmer, B.J., Rubin, R.R., Chasan-Taber, L., Albright, A.L., Braun, B. (2010). Exercise and Type 2 Diabetes: The American College of Sports Medicine and the American Diabetes Association: Joint position statement. *Diabetes Care*, 33(12), 2692-6.
- Cooper, S.A., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., Sullivan, F., & Morrison, J. (2015). Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC Fam Pract*, 16, 110. doi: 10.1186/s12875-015-0329-3.
- Coppell, K. J., Abel, S. L., Freer, T., Gray, A., Sharp, K., Norton, J. K., ... & Whitehead, L. C. (2017). The effectiveness of a primary care nursing-led dietary intervention for preDiabetes: a mixed methods pilot study. *BMC Family Practice*, 18(1), 106.
- Courtenay, K., & Murray, A. (2015). Foot health and mobility in people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 12(1), 42–46. doi: 10.1111/jppi.12105
- Dalsgaard, E. M., Vestergaard, M., Skriver, M. V., Maingdal, H. T., Lauritzen, T., Borch-Johnsen, K., ... Sandbaek, A. (2014). Psychological distress, cardiovascular complications and mortality among people with screen-detected Type 2 Diabetes: Follow-up of the ADDITION-Denmark trial. *Diabetologia*, 57(4), 710–717. <https://doi.org/10.1007/s00125-014-3165-4>
- D'Elia, L., Barba, G., Cappuccio, F.P., & Strazzullo, P. (2011). Potassium intake, stroke, and cardiovascular disease a meta-analysis of prospective studies. *J Am Coll Cardiol*, 57(1), 1210-1219. doi: 10.1016/j.jacc.2010.09.070.
- Department of Health (2001). *Valuing people: A new strategy for learning disability for the 21st century*. Retrieved from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/250877/5086.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf)
- de Winter, C.F., Ehteld, M.A., & Evenhuis, H.M. (2014). Chronic kidney disease in older people with intellectual disability: Results of the HA-ID study. *Research in Developmental Disabilities*, 35(3), 726-732. doi: 10.1016/j.ridd.2013.11.005



- Dhindsa, S., Miller, M.G., McWhirter, C.L., Mager, D.E., Ghanim, H., Chaudhuri, A., & Dandona, P. (2010). Testosterone concentrations in diabetic and nondiabetic obese men. *Diabetes Care*, 33, 1186.
- Diabetes Australia. (2019). Type 2 Diabetes. Retrieved from: <https://www.Diabetesaustralia.com.au/Type-2-Diabetes>.
- Diabetes Australia. (2015). General practice management of Type 2 Diabetes – 2014–15. Melbourne: The Royal Australian College of General Practitioners and Diabetes Australia, 2014. Retrieved from: <https://static.Diabetesaustralia.com.au/s/fileassets/Diabetes-australia/5ed214a6-4cff-490f-a283-bc8279fe3b2f.pdf>
- Diabetes Canada Clinical Practice Guidelines Expert Committee (2018). Diabetes Canada 2018. Clinical practice guidelines for the prevention and management of Diabetes in Canada. *Can J Diabetes*, 42, S1-S325.
- Diabetes Ireland (2018): Model of Integrated Care for Patients with Type 2 Diabetes A Guide for Health Care Professionals (Clinical Management Guidelines. <https://www.hse.ie/eng/about/who/cspd/ncps/diabetes/moc/model-of-integrated-care-type-2-diabetes-2018.pdf>
- Diabetes UK (2017a). Guide to how to make reasonable adjustments to Diabetes care for adults with a learning disability. Retrieved from <https://www.Diabetes.org.uk/Professionals/Resources/shared-practice/for-people-with-learning-disability>
- Diabetes UK (2017b). 15 Healthcare Essentials: Getting the care you need. Retrieved [www.Diabetes.org.uk/Guide-to-Diabetes/Managing-your-Diabetes/15-health care-essentials](http://www.Diabetes.org.uk/Guide-to-Diabetes/Managing-your-Diabetes/15-health-care-essentials)
- Doody, C.M., & Doody, O. (2012). Health promotions for people with intellectual disability and obesity. *British Journal of Nursing*, 21(8), 460-467.
- Doyle, C., Bryne, K., Fleming, S., Griffiths, C., Horan, P., & Keenan, P.M. (2016). Enhancing the experience of people with intellectual disability who access health care. *Learning Disability Practice*, 19(6), 33-38. doi: 10.7748/ldp.2016.e1752
- Dunkley, A.J., Tyrer, T., Doherty, Y., Martin-Stacey, L., Patel, N., Spong, R., Makepeace, C., Bhaumik, S., Gangadharan, S.K., Yates, T., Davies, M.J., & Khunti, K. (2017): Development of a multi-component lifestyle intervention for preventing Type 2 Diabetes and cardiovascular risk factors in adults with intellectual disabilities. *Journal of Public Health*, 40(2), e141-e150. doi: 10.1093/pubmed/idx067
- Dunn, K., Hughes-McCormack, L., & Cooper, S-A. (2017). Hospital admissions for physical health conditions for people with intellectual disabilities: Systematic review. *Journal of Applied Research in Intellectual Disabilities*, Supp1, 1-10. doi: 10.1111/jar.12360
- Dysch, C., Chung, M. C., & Fox, J. (2012). How do people with intellectual disabilities and diabetes experience and perceive their illness? *Journal of Applied Research in Intellectual Disabilities*: 25(1), 39–49. <http://doi.org/10.1111/j.1468-3148.2011.00641.x>
- Emerson, E. (2011). Health status and health risks of the “hidden majority” of adults with intellectual disability. *Intellect Dev Disabil*, 49(3), 155-165. doi: 10.1352/1934-9556-49.3.155.
- European Centre for Disease Prevention and Control (2017). *Seasonal influenza vaccination in Europe – Vaccination recommendations and coverage rates for*



- eight influenza seasons (2007–2008 to 2014–2015). Retrieved from <https://ecdc.europa.eu/en/publications-data/seasonal-influenza-vaccination-europe-vaccination-recommendations-and-coverage-2007-2015>
- Farag, Y.M., & Gaballa, M.R. (2011). Diabetes: An overview of a rising epidemic. *Nephrol Dial Transplant*, 26(1):28–35.
- Flood, B., & Henman, M. (2015). Case study: Hidden complexity of medicines use. information provided by a person with intellectual disability and Diabetes to a pharmacist. *British Journal of Health Psychology*, 43(3), 234–242. <http://doi.org/10.1111/bld.12121>
- Franz, M.J., MacLeod, J., Evert, A., Brown, C., Gradwell, E., Handu, D., Reppert, A., Robinson, M. (2017). Academy of Nutrition and Dietetics Nutrition Practice Guideline for Type 1 and Type 2 Diabetes in Adults: Systematic Review of Evidence for Medical Nutrition Therapy Effectiveness and Recommendations for Integration into the Nutrition Care Process. *J Acad Nutr Diet.*, 117(10), 1659-1679.
- Gillett, M., Royle, P., Snaith, A., Scotland, G., Poobalan, A., Imamura, M., Black, C., Boroujerdi, M., Jick, S., Wyness, L., McNamee, P., Brennan, A., & Waugh, N. (2012). Non-pharmacological interventions to reduce the risk of diabetes in people with impaired glucose regulation: a systematic review and economic evaluation. *Health Technol Assess*, 16(33), 1-236. doi: 10.3310/hta16330.
- Haire-Joshu, D., Glasgow, R. E., & Tibbs, T. L., (1999). Smoking and Diabetes. *Diabetes Care*, 22(11) 1887-1898; doi: 10.2337/diacare.22.11.1887
- Hale, L.A., Trip, H.T., Whitehead, L., & Conder, J. (2011). Self-management abilities of Diabetes in people with an intellectual disability living in New Zealand. *Journal of Policy and Practice in Intellectual Disabilities*, 8(4), 223-240.
- Harkins, V. (2008). *A practical guide to integrated Type 2 Diabetes care*. Retrieved from [https://www.indi.ie/images/public\\_docs/539\\_A\\_Practical\\_Guide\\_to\\_Integrated\\_Type\\_II\\_Diabetes\\_Care\[1\].pdf](https://www.indi.ie/images/public_docs/539_A_Practical_Guide_to_Integrated_Type_II_Diabetes_Care[1].pdf)
- Havercamp, S.M., Scandlin, D., & Roth, M. (2004). Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. *Public Health Rep*, 119(4), 418-426. doi: 10.1016/j.phr.2004.05.006
- Haymes, L.K., Stoery, K., Maldonado, A., Post, M., & Montgomery, J. (2015). Using applied behavior analysis and smart technology for meeting the health needs of individuals with intellectual disabilities. *Developmental Neurorehabilitation*, 18(6), 407-419. doi: 10.3109/17518423.2013.850750
- Hemingway, S., Stephenson, J., Trotter, F., Clifton, A., & Holdich, P. (2015). Increasing the health literacy of learning disability and mental health nurses in physical care skills: A pre and post-test evaluation of a workshop on Diabetes care. *Nurse Education in Practice*, 15, 30-37. doi: 10.1016/j.nepr.2014.08.003
- Hermans, H., & Evenhuis, H.M. (2014). Multimorbidity in older adults with intellectual disabilities. *Research in Developmental Disabilities*, 35(4), 776-783. doi: 10.1016/j.ridd.2014.01.022.
- Hermanns, N., Schmitt, A., Gahr, A., Herder, C., Nowotny, B., Roden, M., ... Kulzer, B. (2015). The effect of a Diabetes-specific cognitive behavioral treatment program (diamos) for patients with Diabetes and subclinical depression: Results of a randomized controlled trial. *Diabetes Care*, 38(4), 551–560. <https://doi.org/10.2337/dc14-1416>



- Herpertz, S., Petrak, F., Albus, C., Hirsch, A., Kruse, J., & Kulzer, B. (2003). Evidence-based Guidelines of the German Diabetes Association: Psychosocial Factors and Diabetes Mellitus.
- Heslop, P., Blair, P.S., Fleming, P., Houghton, M., Marriott, A., & Russ, L. (2014). The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: A population-based study. *Lancet*, 383, 889-895. [http://dx.doi.org/10.1016/S0140-6736\(13\)62026-7](http://dx.doi.org/10.1016/S0140-6736(13)62026-7)
- Hex, N., Bartlett, C., Wright, D., Taylor, M., & Varley, D. (2012) Estimating the current and future costs of Type 1 and Type 2 Diabetes in the UK, including direct health costs and indirect societal and productivity costs. *Diabetic Medicine*, 29(7), 865-862. doi: 10.1111/j.1464-5491.2012.03698.x.
- Hillege, S., Gallagher, S., & Evans, J. (2013). The challenges for families managing an adolescent with an intellectual disability and Type 1 Diabetes. *Australian Journal of Advanced Nursing*, 30(3), 26–32.
- Holmes-Truscott, E., Skinner, T. C., Pouwer, F., & Speight, J. (2016). Explaining psychological insulin resistance in adults with non-insulin-treated Type 2 Diabetes: The roles of Diabetes distress and current medication concerns. Results from Diabetes MILES - Australia. *Primary Care Diabetes*, 10(1), 75–82. doi: 10.1016/j.pcd.2015.06.006
- House, A., Bryant, L., Russell, A., Wright-Hughes, A., Graham, L., Walwyn, R., Wright, J., Hulme C., O'Dwyer, J., Stansfield, A., Ajjan, R. & Farrin, A. (2018a). A randomised controlled feasibility trial of supported self-management in adults with Type 2 Diabetes and a learning disability: OK Diabetes. *Diabetic Medicine (in press)*.
- Hunt, K., & Stiller, K. (2017). Dietetic and educational interventions improve clinical outcomes of diabetic and obese clients with mental impairment. *Nutrition & Dietetics Journal of the Dietitians Association of Australia*, 74(3), 236-242. doi: 10.1111/1747-0080.12340
- International Diabetes Federation. (2017a). Recommendations For Managing Type 2 Diabetes In Primary Care - 2017. Retrieved [www.idf.org/managing-Type2-Diabetes](http://www.idf.org/managing-Type2-Diabetes)
- International Diabetes Federation. (2017b). *Clinical Practice Recommendation on the Diabetic Foot-2017*: A guide for health care professionals. ISBN: 978-2-930229-86-7
- International Diabetes Federation (2005). *IDF clinical guidelines task force. Global guideline for Type 2 Diabetes*. Brussels: International Diabetes Federation.
- International Diabetes Federation Guideline Development Group. (2014). Global guideline for Type 2 Diabetes. *Diabetes Research and Clinical Practice*, 104, 1-52. <https://doi.org/10.1016/j.diabres.2012.10.001>
- International Diabetes Federation Clinical Guidelines Taskforce. (2012). *Global guideline for Type 2 Diabetes*. Retrieved from <https://www.iapb.org/wp-content/uploads/Global-Guideline-for-Type-2-Diabetes-IDF-2012.pdf>
- Kachika, J. (2017). *NHS RightCare Pathway: Diabetes - Reasonable adjustments for people with a learning disability who have Diabetes*. Retrieved from <https://www.england.nhs.uk/rightcare/products/pathways/Diabetes-pathway/>



- Katon, W.J. (2005). The association of comorbid depression with mortality in patients with Type 2. *Diabetes Care*, 28(11).
- Kelly, J. (2011). Diabetes and me: Learning disabilities and Diabetes. *Journal of Diabetes Nursing*, 15(8), 308-312.
- Khunti, K., Gray, L.J., Skinner, T., Carey, E., Realf, K., Dallosso, H., ... Davies, M.J. (2012). Effectiveness of a Diabetes education and self-management programme (DESMOND) for people with newly diagnosed Type 2 Diabetes mellitus: three-year follow-up of a cluster randomized controlled trial in primary care. *BMJ*, 344, e2333. doi: 10.1136/bmj.e2333.
- Khunti, K., Skinner, T.C., Heller, S., Carey, M.E., Dallosso, H.M., Davies, M.J., & DESMOND Collaborative (2008). Biomedical, lifestyle and psychosocial characteristics of people newly diagnosed with Type 2 Diabetes: baseline data from the DESMOND randomized controlled trial. *Diabet Med*, 25(12), 1454–1461. doi: 10.1111/j.1464-5491.2008.02620.x.
- King, P., Peacock, I., & Donnelly, R. (1999). The UK prospective Diabetes study (UKPDS): Clinical and therapeutic implications for Type 1 Diabetes. *Br J Clin Pharmacol*, 48(5), 643-648. doi: 10.1046/j.1365-2125.1999.00092.x
- Klingensmith, G.J., Pyle, L., Nadeau, K.J., Barbour, L.A., Goland, R.S., Willi, S.M., ... TODAY Study (2016). Pregnancy outcomes in youth with Type 2 Diabetes: The TODAY study experience. *Diabetes Care*, 39(1), 122-129. doi: 10.2337/dc15-1206
- Legislation Government UK (1995). *Disability discrimination act*. Retrieved from <http://www.legislation.gov.uk/all?title=disability%20discrimination%20act%20>
- Legislation Government UK (2010). *Equality act*. Retrieved from <https://www.legislation.gov.uk/ukpga/2010/15/contents>
- Li, J.C.H., Wong, K., Park, A.S.Y., Fricke, T.R., & Jackson, A.J. (2015). The challenges of providing eye care for adults with intellectual disabilities. *Clinical and Experimental Optometry*, 98, 420-429. doi:
- Liang, H., Kennedy, C., Manne, S., Hsiang-Ling Lin, J., & Dolin, P. (2015). Monitoring for proteinuria in patients with Type 2 Diabetes mellitus. *BMJ Open Diabetes Research and Care*, 3, e000071. doi:10.1136/bmjdr-2014-000071
- Lin, E. H., Katon, W., Von, K. M., Rutter, C., Simon, G. E., Oliver, M., ... Young, B. (2004). Relationship of depression and Diabetes self-care, medication adherence, and preventive care. *Diabetes Care*, 27(0149–5992), 2154–2160. <https://doi.org/10.2337/diacare.27.9.2154>
- Lin, J.D., Lin, L.P., Hsieh, M., & Lin, P.Y. (2010). Preliminary findings of serum creatinine and estimated glomerular filtration rate (eGFR) in adolescents with intellectual disabilities. *Research in Developmental Disabilities*, 31(6), 1390-1397. doi: 10.1016/j.ridd.2010.06.021
- Loveman, E., Cave, C., Green, C., Royle, P., Dunn, N., & Waugh, N. (2003). The clinical and cost-effectiveness of patient education models for Diabetes: A systematic review and economic evaluation. *Health Technol Assess*, 7(22), iii,1–iii190
- Lunsky, Y., & Konstantareas, M.M. (1998). The attitudes of individuals with autism and mental retardation towards sexuality. *Educational and Training in Mental Retardation and Developmental Disabilities*, 33, 24–33.



- Maine, A., Dickson, A., Truesdale, M., & Brown, M. (2017). An application of Bandura's 'four sources of self-efficacy' to the self-management of Type 2 Diabetes in people with intellectual disability: An inductive and deductive thematic analysis. *Research in Developmental Disabilities*, 70, 75-84. doi: 10.1016/j.ridd.2017.09.004
- MacRae, S., Brown, M., Karatzias, T., Taggart, L., Truesdale-Kennedy, M., Walley, R., ... Davies, M. (2015). Diabetes in people with intellectual disabilities: A systematic review of the literature. *Research in Developmental Disabilities*, 47, 352-274. doi: 10.1016/j.ridd.2015.10.003
- McCarron, M., Carroll, R., Kelly, C., & McCallion, P. (2015). Mortality rates in the general Irish population compared to those with an intellectual disability from 2003 to 2012. *Journal of Applied Research in Intellectual Disabilities*, 28, 406-413. doi: 10.1111/jar.12194
- McConkey, R., Taggart, L., & Kane, M. (2015). Optimizing the uptake of health checks for people with intellectual disabilities. *Journal of Intellectual Disabilities*, 19(3), 205-214. doi: 10.1177/1744629514568437.
- McVilly, K., McGillivray, J., Curtis, A., Lehmann, J., Morrish, L., Speight, J. (2014). Diabetes in people with an intellectual disability: a systematic review of prevalence, incidence and impact. *Diabetes Medicine*, 31(8), 897-904. doi: 10.1111/dme.12494
- Mencap. (2012). Death by indifference: 74 deaths and counting A progress report 5 years on. Retrieved from <https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf>
- Merrick, J., Davidson, P.W., Morad, M., Janicki, M.P., Wexler, O., & Henderson, C.M. (2004). Older adults with intellectual disability in residential care centers in Israel: Health status and service utilization. *American Journal on Mental Retardation*, 109(5), 413-420.
- Michael, J., & Richardson, A. (2008). Healthcare for all: The independent inquiry into access to healthcare for people with learning disabilities. *Tizard Learning Disability Review*, 13(4), 28-37
- Milne, N. (2017). Managing Diabetes in women during preconception and pregnancy. *Clinical Pharmacist*, 9(9). Retrieved from <https://www.pharmaceutical-journal.com/learning/cpd-article/managing-Diabetes-in-women-during-preconception-and-pregnancy/20203468.cpdarticle>
- Ministry of Health. (2018a). *Cardiovascular disease risk assessment and management for primary care*. Wellington, New Zealand: Ministry of Health. Retrieved from [https://www.health.govt.nz/system/files/documents/publications/cardiovascular-disease-risk-assessment-management-primary-care-feb18-v4\\_0.pdf](https://www.health.govt.nz/system/files/documents/publications/cardiovascular-disease-risk-assessment-management-primary-care-feb18-v4_0.pdf)
- Ministry of Health. (2018b). *Influenza*. <https://www.health.govt.nz/our-work/preventative-health-wellness/immunisation/influenza>
- Ministry of Health. 2016. *Diabetic retinal screening, grading, monitoring and referral guidance*. Wellington, New Zealand: Ministry of Health.
- Ministry of Health. (2014a). *Quality standards for Diabetes care toolkit*. Wellington, New Zealand: Ministry of Health. Retrieved from <https://www.health.govt.nz/system/>



- files/documents/publications/quality-standards-for-Diabetes-care-toolkit-2014-nov14-v2.pdf
- Ministry of Health. (2014b). *The New Zealand guidelines for helping people to stop smoking*. Wellington, New Zealand: Ministry of Health. Retrieved from <https://www.health.govt.nz/system/files/documents/publications/nz-guidelines-helping-people-stop-smoking-jun14.pdf>
- Ministry of Health. (2013). *Providing health services for people with intellectual disability: Case studies of programmes and tools used in New Zealand*. Wellington, New Zealand: Ministry of Health. Retrieved from <https://www.health.govt.nz/system/files/documents/publications/providing-health-services-for-people-with-intellectual-disabilities-in-new-zealand-case-studies-dec13-v2.pdf>
- Ministry of Health. (2011). Health indicators for New Zealanders with intellectual disability. Wellington: Ministry of Health
- National Development Team for Inclusion. (2012). *Reasonably adjusted? Mental health services and support for people with autism and people with learning disabilities*. Retrieved from <https://mentalhealthpartnerships.com/resource/reasonably-adjusted-mental-health-services-and-support-for-people-with-autism-and-people-with-learning-disabilities/>
- National Institute for Health and Care Education. (2015a). Type 2 Diabetes in adults: management. Retrieved from: <https://www.nice.org.uk/guidance/ng28/resources/Type-2-Diabetes-in-adults-management-pdf-1837338615493>
- National Institute for Health and Care Education. (2015b). *Diabetes in pregnancy: management from preconception to postnatal period*. Retrieved from: <https://www.nice.org.uk/guidance/ng3/chapter/1-Recommendations#intrapartum-care-2>
- National Institute for Health and Care Education. (2015c). *Diabetic foot problems: Prevention and management*. Retrieved from <https://www.nice.org.uk/guidance/ng19/resources/diabetic-foot-problems-prevention-and-management-1837279828933>
- New Zealand Guidelines Group. (2011). *Guidance on the management of Type 2 Diabetes 2011*. Wellington: New Zealand Guidelines Group. Retrieved from: <http://baynav.bopdhb.govt.nz/media/1315/Diabetespathwaycomplications-nzgg-management-of-Type-2-Diabetes-web-v2.pdf>
- National Institute for Health and Care Education. (2014). Chronic kidney disease in adults: Assessment and management. Retrieved from <https://www.nice.org.uk/guidance/cg182>
- NHS Digital. (2017). National Diabetes Audit, 2015-2016 Report 1 : Care Processes and Treatment Targets Learning Disability - Supplementary Information, (January), 1–22. Retrieved from <http://www.content.digital.nhs.uk/catalogue/PUB22607>
- Oullette-Kuntz, H. (2005). Understanding health disparities and inequities faced by individuals with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 18, 113-121.
- Pastors, J.G., & Franz, M.J. (2012). Effectiveness of medical nutrition therapy in Diabetes. In: Franz MJ, Evert AB (eds). *American Diabetes Association guide to nutrition therapy for Diabetes*. 2nd ed. Alexandria, VA: American Diabetes Association; pp 1-18.



- Peyrot, M., Burns, K.K., Davies, M., Forbes, A., Hermanns, N., Holt, R., ... Skovlund, D.E. (2013). Diabetes attitudes wishes and needs 2 (DAWN2): A multinational, multi-stakeholder study of psychosocial issues in Diabetes and person-centred Diabetes care. *Diabetes Res Clin Pract*, 99(2), 174-184. doi: 10.1016/j.jdiabres.2012.11.016.
- Pilling, R. (2014). Diabetic eye screening in people with learning disabilities: Improving access. *Journal of Diabetes Nursing*, 18(5), 199–202
- Reed, J.A., Ashton, H., Lawrence, J.M., Hollinghurst, S., & Higgs, E.R. (2003). Diabetes self-management: How are we doing? *Pract Diab Int*, 20(9), 318-322.
- Rey-Conde, T., Lennox, N., & McPhee, J. (2005). Diabetes and Intellectual Disability - Perceptions from People with Disability and their Supporters. Retrieved from <http://espace.library.uq.edu.au/view/UQ:9458>
- Rice, D., Roszler, J., & Farrell, J.A.B. (2009). Diabetes and sexual health. In: K. Weinger & C.A. Carver (Eds.), *Educating your patient with Diabetes. Contemporary Diabetes*. New York: Humana Press
- Rimmer, J.H., & Yamaki, K. (2006). Obesity and intellectual disability. *Ment Retard Dev Disabil Res Rev*, 12, 22-27.
- Robertson, J., Roberts, H., Emerson, E. (2010). Health checks for people with learning disabilities: A systematic review of evidence. Stockton on Tees: Learning Disabilities Observatory.
- Robinson, D. J., Coons, M., Haensel, H., Vallis, M., & Yale, J-F. (2018). 2018 Clinical practice guidelines Diabetes and mental health Diabetes. Canada Clinical Practice Guidelines Expert Committee. *Canadian Journal of Diabetes*, 42, S130–S141. <https://doi.org/10.1016/j.cjcd.2017.10.031>
- Rouse, L., & Finlay, W.M.L. (2016). Repertoires of responsibility for Diabetes management by adults with intellectual disability and those who support them. *Sociology of Health & Illness*, 38(8), 1243-1257. doi: 10.1111/1467-9566.12454
- Rouse, L. (2019). *The social construction of quality Diabetes care appointments in primary care by adults with mild-to-moderate learning disabilities, Their supporters and healthcare professionals*. The Open University, Milton Keynes. Unpublished thesis.
- Safren, S. A., Gonzalez, J. S., Wexler, D. J., Psaros, C., Delahanty, L. M., Blashill, A. J., ... Cagliero, E. (2014). A randomized controlled trial of cognitive behavioral therapy for adherence and depression (cbtad) in patients with uncontrolled Type 2 Diabetes. *Diabetes Care*, 37(3), 625–633. <https://doi.org/10.2337/dc13-0816>
- Scottish Intercollegiate Guidelines Network. (2010). Management of Diabetes. *SIGN Guidelines [116]*, (November), 1–154. <https://doi.org/10.1016/B978-0-443-10081-9.00010-5>
- Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 48–56.
- Shireman, T.I., Reichard, A., Nazir, N., Backes, J.M., & Greiner, K.A. (2010). Quality of Diabetes care for adults with developmental disabilities. *Disability and Health Journal*, 3, 179-185.
- Sinclair, J., Unruh, D., Lindstrom, L., & Scanlon, D. (2015). Barrier to sexuality for individuals with intellectual and developmental disabilities: A literature review. *Education and Training in Autism and Developmental Disabilities*, 50(1), 3-16.



- Skinner, T.C., Carey, M.E., Cradock, S., Daly, H., Davies, M.J., Doherty, Y., ... DESMOND Collaborative (2006). Diabetes education and self-management for ongoing and newly diagnosed (DESMOND): Process modelling of pilot study. *Patient Educ Couns*, 64(1-3), 369-377.
- Smith West, D., Gore, S., DiLillo, V., Greene, P., & Bursac, Z. (2007). Motivational interviewing improves weight loss in women with Type 2 Diabetes. *Diabetes Care*, 30(5), 1081–1087. <https://doi.org/10.2337/dc06-1966>.Clinical
- Steinberg, M.L., Heimlich, L., & Williams, J.M. (2009). Tobacco use among individuals with intellectual or developmental disabilities: A brief review. *Intellect Dev Disabil*, 47(3), 197-207. doi: 1352/1934-9556-47.3.197
- Taggart, L., Brown, M., & Karatzias, T. (2014). Diabetes. In L.Taggart, & W.Cousins (Eds.), *Health promotion for people with intellectual disabilities*. (pp. 69-76). Maidenhead: Open University Press/McGraw-Hill Publishers.
- Taggart, L., Coates, V., & Truesdale-Kennedy, M. (2012). Management and quality indicators of Diabetes mellitus in people with intellectual disabilities. *Journal of Intellectual Disability Research*, 57(12), 1152-1163. doi: 10.1111/j.1365-2788.2012.01633.x
- Taggart, L., Coates, V., Clarke, M., Bunting, B., Davies, M., Carey, M., ... Karatzias, T. (2015). A study protocol for a pilot randomised trial of a structured education programme for the self-management of Type 2 Diabetes for adults with intellectual disabilities. *Trials*, 16, 148-156. doi: 10.1186/s13063-015-0644-y
- Taggart, L. & Cousins, W. (eds)(2014). *Health promotion for people with intellectual and developmental disabilities*. Open University Press.McGraw-Hill Publishers: Maidenhead, England.
- Taggart, K., Truesdale, M., Carey, M.E., Martin-Stacey, L., Scott, J., Bunting, B., ... Clarke, J.M. (2018). Pilot feasibility study examining a structured self-management Diabetes education programme, DESMOND-ID, targeting HbA1c in adults with intellectual disabilities. *Diabetic Medicine*, 35, 137–146. doi: 10.1111/dme.13539
- Taggart, L., Truesdale, M., Dunkley, Al., House, Al., & Russell, A. (2018). Health promotion and wellness initiatives targeting chronic disease prevention and management for adults with intellectual and developmental disabilities: Recent advancements in Type 2 Diabetes. *Current Developmental Disorders Reports*, 5C(3), 132-142. doi: 10.1007/s40474-018-0142-5
- Taraasoff, L.A., Lunsky, Y., Chen., S., Guttman, A., Havercamp, S.M., Parish, S.L., Vigod, S.N., Carty, A. & Brown, H.K. (2020). Preconception health characteristics of women with disabilities in Ontario: A population-based, cross-sectional study. *J Womens Health (LArchmt)*, 29(12): 1564-1575.
- The Diabetes Prevention Program Research Group (2005). Impact of intensive lifestyle and metformin therapy on cardiovascular disease risk factors in the Diabetes Prevention Program. *Diabetes Care*, 28, 888-894.
- The National Collaborating Centre for Chronic Conditions. (2009). *Type 2 Diabetes: the management of Type 2 Diabetes. NICE clinical guideline*. London: Royal College of Physicians. Retrieved from <http://www.nice.org.uk/nicemedia/pdf/CG87NICEGuideline.pdf>.



- The Royal Australian College of General Practitioners. (2016). *General practice management of Type 2 Diabetes 2016-2018. The Royal Australian College of General Practitioners*. Retrieved from <https://static.Diabetesaustralia.com.au/s/fileassets/Diabetes-australia/5d3298b2-abf3-487e-9d5e-0558566fc242.pdf>
- The Society for Endocrinology, Metabolism and Diabetes of South Africa Type 2 Diabetes Guidelines Expert Committee (2017). The 2017 SEMDSA guideline for the management of Type 2 Diabetes guideline committee. *Journal of Endocrinology, Metabolism and Diabetes of South Africa*, 21(1)(Supplement 1): S1-S196.
- Trip, H., Conder, J., Hale, L., & Whitehead, L. (2016). The role of key workers in supporting people with intellectual disability in the self-management of their Diabetes: A qualitative New Zealand study. *Health and Social Care in the Community*, 24(6), 789-798. doi: 10.1111/hsc.12262
- Trollor, J., Srasuebkul, P., Xu, H., & Howlett, S. (2017). Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open*, 7, e013489. doi:10.1136/bmjopen-2016-013489
- Tuffrey-Wijne, I., Goulding, L., Giatras, N., Abraham, E., Gillard, S., White, S. ... Hollins, S. (2014). The barriers to and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospitals: Evidence from a mixed-methods study. *BMJ Open*, 4, e004606. doi:10.1136/bmjopen-2013-004606
- Turner, R.C., Cull, C.A., Frighi, V., & Holman, R.R. (1999). Glycemic control with diet, sulfonylurea, metformin, or insulin in patients with Type 2 Diabetes mellitus: progressive requirement for multiple therapies (UKPDS 49). UK Prospective Diabetes Study (UKPDS) Group. *JAMA*, 281(21), 2005-2012.
- Turner, S. (2014). Improving care for people with learning disabilities. *Nursing Standard*, 29(12), 53-59.
- Turner, S., Kill, S., & Emerson, E. (2013). Making reasonable adjustments to eye care services for people with learning disabilities. Lancaster UK: Learning Disabilities Observatory
- Tyrer, F., Ling, S., Bhaumik, S., Gangadharan, S. K., Khunti, K., Gray, L. J., & Dunkley, A.J. (2020). Diabetes in adults with intellectual disability: prevalence and associated demographic, lifestyle, independence and health factors. *Journal of Intellectual Disability Research*, 64(4), 287-295.
- United Nations (2006). *Convention on the rights of persons with disabilities. Optional protocol*. Retrieved from <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- UNITE for Diabetes Philippines (2014). Philippine practice guidelines on the diagnosis and management of Diabetes mellitus. Retrieved from <https://www.pcp.org.ph/documents/PSBIM/2017/Diabetes-United-for-Diabetes-Phil.pdf>
- van Netten, J.J., Lazzarini, P.A., Armstrong, D.G., Bus, S.A., Fitridge, R., Harding, K., Kinnear, E., Malone, M., Mena, H.B., Perrin, B.M., Postema, K., Prentice, J., Schott, K-H., & Wraight, P.R. (2018). Diabetic foot Australia guidelines on footwear for people with Diabetes. *Journal of Foot and Ankle Research*, 11(2), doi: 10.1186/s12047-017-0244-z



- Wallace, R.A. (2004). Risk factors for coronary artery disease among individuals with rare syndrome intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities* 1, 42–51.
- West, D.S., DiLillo, V.m Bursac, Z., Gore, S.A., & Greene, P.G. (2007). Motivational interviewing improves weight loss in women with Type 2 Diabetes. *Diabetes Care*, 30(5), 1081-1081.
- Whitehead, L. C., Trip, H. T., Hale, L. A., & Conder, J. (2016). Negotiated autonomy in Diabetes self-management: the experiences of adults with intellectual disability and their support workers. *Journal of Intellectual Disability Research*, 60(4), 389–397. doi: 10.1111/jir.12257.
- Wilkinson, A., Whitehead, L., & Ritchie, L. (2011). Factors influencing the ability to self-manage Diabetes for adults living with Type 1 or 2 Diabetes. *Int J Nurs Stud*, 51(1), 111–122.
- Wissink, I.B., van Vugt, E., Moonen, X., Stams, G-J.J.M., & Hendrix, J. (2015). Sexual abuse involving children with an intellectual disability: A narrative review. *Research in Developmental Disabilities*, 36, 220-35.
- World Health Organization (2016). *Global report on Diabetes*. Retrieved from [http://apps.who.int/iris/bitstream/handle/10665/204871/9789241565257\\_eng.pdf;jsessionid=F3F53A9E5D0E3A50BA8556F78667C596?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/204871/9789241565257_eng.pdf;jsessionid=F3F53A9E5D0E3A50BA8556F78667C596?sequence=1)
- World Health Organization (2013). *Diabetes factsheet*. Geneva: World Health Organization. Retrieved from <http://www.who.int/en/news-room/fact-sheets/detail/Diabetes>
- Young-Hyman, D., de Groot, M., Hill-Briggs, F., Gonzalez, J.S., Hood, K., & Peyrot, M. (2016). Psychosocial care for people with Diabetes: A position statement of the American Diabetes Association. *Diabetes Care*, 39, 2126-2140.
- Zaal, R.J., van der Kaaij, A.D., Evenhuis, H.M., & van den Bemt, P.M. (2013). Prescription errors in older adults with an intellectual disability: Prevalence and risk factors in the Health Ageing and Intellectual Disability Study. *Research in Developmental Disabilities*, 34(5), 1656-1662. doi: 10.1016/j.ridd.2013.02.005



## Appendix 1. Diabetes UK (2017a, p. 8-10)

---

### Evaluating a Diabetes service: A checklist

Use this checklist to help you evaluate how well a service is doing in making reasonable adjustments. It's also important to get feedback from people with a learning disability and their supporters to find out what they think about the service and what could be improved.

<b>1. Accessible (easy read) materials</b>	
<b>How to access and use services</b>	<b>CHECK</b>
Simple letters offering an appointment or explaining a referral	
Explanations about how to contact a service and make an appointment	
Importance of attending appointments and annual review	
Advice about how to get there – including help available with transport/ mobility problems	
What Diabetes is in simple terms and how it affects the body	
Having a blood test and home blood glucose checking	
Taking medication and the importance of adherence Injections and insulin pump	
Looking after feet, skin and eyes – and why this is important	
Hypoglycaemic episodes – what they are and what to do about them	
Risk of complications and how to prevent	



<b>Explaining the need to change and how to make changes</b>	<b>CHECK</b>
Reasons to lose weight	
Healthy eating – what that means and making healthy food choices	
How to lose weight	
Simple steps to increase activity	
Managing Type 2 Diabetes	
Managing Type 1 Diabetes	

<b>Supporting behaviour change</b>	<b>CHECK</b>
Helping with goal setting and getting support from healthcare professionals	
Monitoring progress and feedback	
The important role of supporters in making change happen	



## 2. Staff training

Is there documented evidence of staff training in the following areas	Check
<b><i>For all staff:</i></b>	
What is a learning disability	
Health needs of people with a learning disability – physical and mental health The Equality Act 2010 and requirement for reasonable adjustments	
The Accessible Information Standard	
What is meant by ‘reasonable adjustments’	
Communicating effectively with people with a learning disability	
Mental Capacity Act; assessing mental capacity and gaining consent	
The importance of working with caregivers and supporters	
<b><i>For staff supporting behaviour change:</i></b>	
Helping with goal setting	
Monitoring progress and feedback	
The important role of supporters in making change happen	



### 3. Practical support for accessibility

Is there documented evidence	Check
Providing or funding transport for those with travel difficulties	
Availability of communication aids	
Providing access for people with mobility problems	
Availability of longer appointments	
Provision of support or advocacy for people with a learning disability	
Financial support for out of pocket expenses	
Communicating effectively with people with a learning disability	

### 4. Monitoring services

Is there evidence that the service is monitoring and reporting on its use by people with a learning disability	Check
<b><i>Monitoring service use:</i></b>	
Recording of initial contacts made for adults with learning disabilities Recording of involvement of supporters	
Recording of follow up contacts made (number of visits or contacts)	
Recording of materials provided	
<b><i>Monitoring of referrals to relevant services:</i></b>	
Structured education for Type 2 Diabetes	
Lifestyle weight-management	
Bariatric surgery	



## Appendix 2. Additional Resources

---

### Diabetes Management

<https://static.Diabetesaustralia.com.au/s/fileassets/Diabetes-australia/dc8758f6-d410-41bd-8cf0-2dfe3b5df92f.pdf>

Type 2 Diabetes – Living a healthier Life. DVD on Diabetes for adults with intellectual disabilities and Diabetes: <http://www.Diabetesdvd.org.uk>

Meet Pete the Pancreas: <http://bit.ly/1KpnK6x>

Type 2 Diabetes: Pictorial information Type 2 Diabetes for people with a learning difficulty.

[http://www.northerntrust.hscni.net/pdf/Diabetes\\_booklet\\_for\\_those\\_with\\_a\\_learning\\_difficulty.pdf](http://www.northerntrust.hscni.net/pdf/Diabetes_booklet_for_those_with_a_learning_difficulty.pdf)

Easy read booklet for people with Type 2 Diabetes: <http://bit.ly/1GB3MEI>

Easyhealth.org.uk Diabetes leaflets: <http://bit.ly/1JNxK8W>



## **Reasonable adjustments**

*Link to the legislative guidelines for reasonable adjustments in the UK*

<https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities>

Diabetes UK (2017a). *How to make reasonable adjustments to Diabetes care for people with a learning disability.*

<https://www.Diabetes.org.uk/resources-s3/2018-02/Diabetes%20UK%20-%20How%20to%20make%20reasonable%20adjustments%20to%20Diabetes%20care%20for%20adults%20with%20a%20learning%20disability.pdf>

*Links to guidelines for recommended clinical pathways in addressing issues related to Diabetes and healthy living:*

<http://webarchive.nationalarchives.gov.uk/20160831134218/http://www.improvinghealthandlives.org.uk/adjustments/index.php>

Turner, S., & Emerson, E. (2013). Making reasonable adjustments or Diabetes services for people with learning disabilities. Retrieved from:  
[https://www.ndti.org.uk/uploads/files/IHaL-2013\\_-01\\_Reasonable\\_adjustments.pdf](https://www.ndti.org.uk/uploads/files/IHaL-2013_-01_Reasonable_adjustments.pdf)

## **Smoking Cessation Guidelines**

*Smokefree New Zealand has a range of tools for people to learn about tobacco smoking. Whilst none are aimed specifically at people with learning disability, some could be used without adaptation for those with a mild impairment – particularly the interactive tools.*

[www.smokefree.org.nz](http://www.smokefree.org.nz)

<https://www.health.govt.nz/system/files/documents/publications/nz-guidelines-helping-people-stop-smoking-jun14.pdf>

*United Kingdom has the link to find local face-to-face counselling for smoking cessation.*

<https://www.nhs.uk/smokefree/help-and-advice/support>