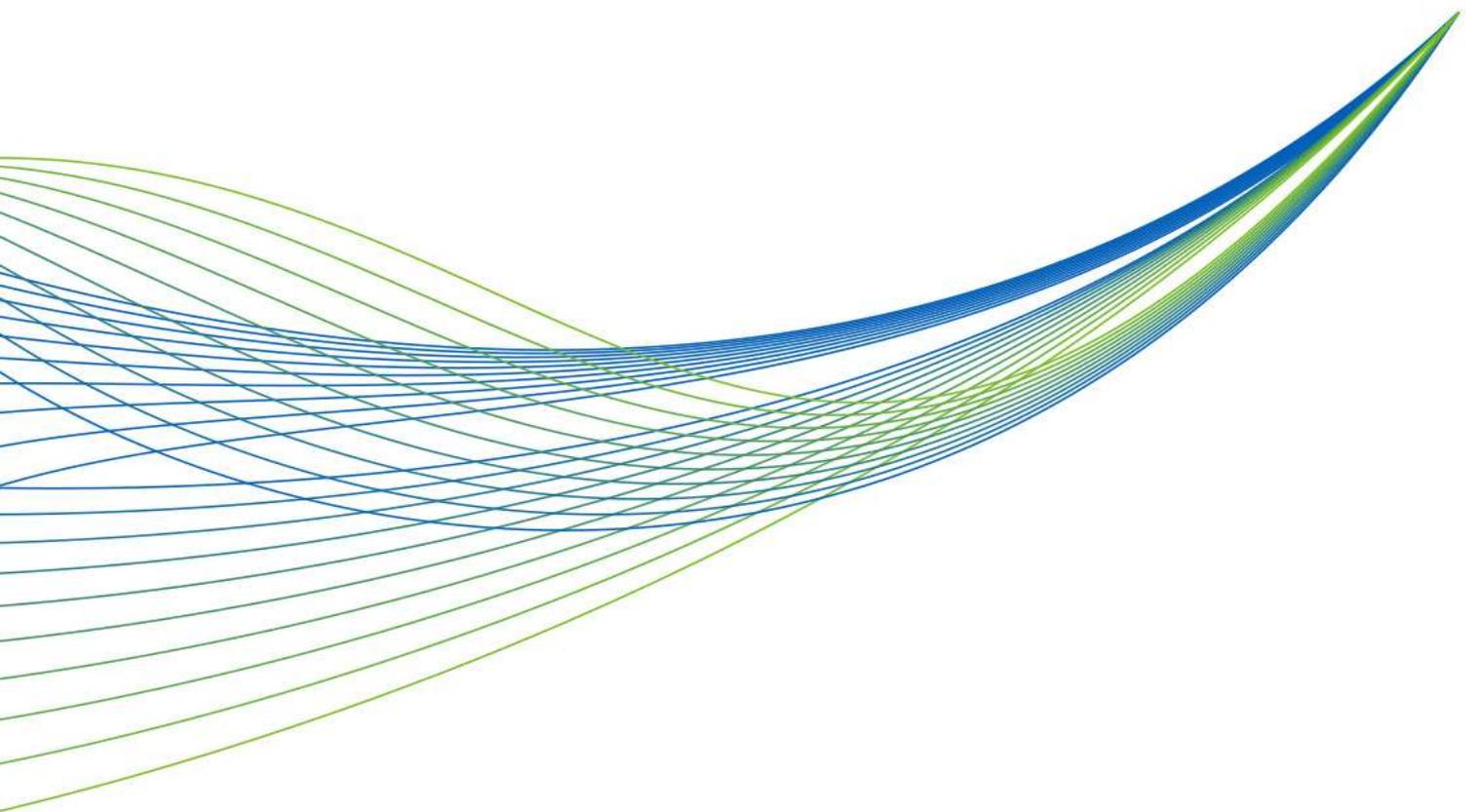


NHS RightCare Pathway: Diabetes

**Reasonable adjustments for
people with a learning disability
who have diabetes**



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2. EXECUTIVE SUMMARY

This guidance is aimed at commissioners and providers of diabetes services working with people who have a learning disability and diabetes.

The prevalence rates of both Type 1 and Type 2 diabetes were identified to be higher in people with a learning disability compared to the general population. Higher rates of obesity were also seen in people with a learning disability compared to those without.

The above risks can be reduced by greater understanding of the needs of people with a learning disability and adapting existing lifestyle programmes to suit the needs of this population.

Addressing reasonable adjustments for those with diabetes and a learning disability will not only improve diagnosis and detection of the condition but has other benefits:

Reductions in:

- Complications arising from diabetes, e.g. amputations
- Diabetes related A&E attendances
- Visits to GP
- Missed appointments

Reasonable adjustments are seen to be particularly essential at the following:

- Tests and investigations
- Structured support programmes
- Weight management programmes
- Supported self-management of diabetes
- Personalised care planning

What this means for Commissioners:

- Know your population
- Increase uptake of Health Checks

- Avoid unnecessary hospital admissions
- Reduce lengthy hospital stay
- Support healthy lifestyle
- Supporting structured education and self-management

Key commissioning guidance for local services to make the necessary reasonable adjustments for early detection and diagnosis of diabetes in those with a learning disability, and a guide to adjustments needed for effective treatment and care planning processes, is included in this document.

It is the intention of this guidance to outline principles of reasonable adjustments that should be considered for equitable access to an optimal diabetes service by those with a learning disability. The document provides links to **intelligence, guidance, tools and examples of good practice.**

3. Background

The 2014-2015 data extracted from GP practices on 51.2 per cent of all people registered with a GP in England showed higher prevalence rates of both types of diabetes for people with a learning disability compared to the general population (Public Health England, NHS Digital, 2016).

Prevalence of Type 2 diabetes varies in the general population by ethnicity and social factors; however studies have shown individuals with a learning disability are at a higher risk of developing Type 2 diabetes (MacRae *et al*, 2015; Walwyn *et al*, 2015 and McVilly *et al*, 2014).

The reasons for higher estimates being based on the following:

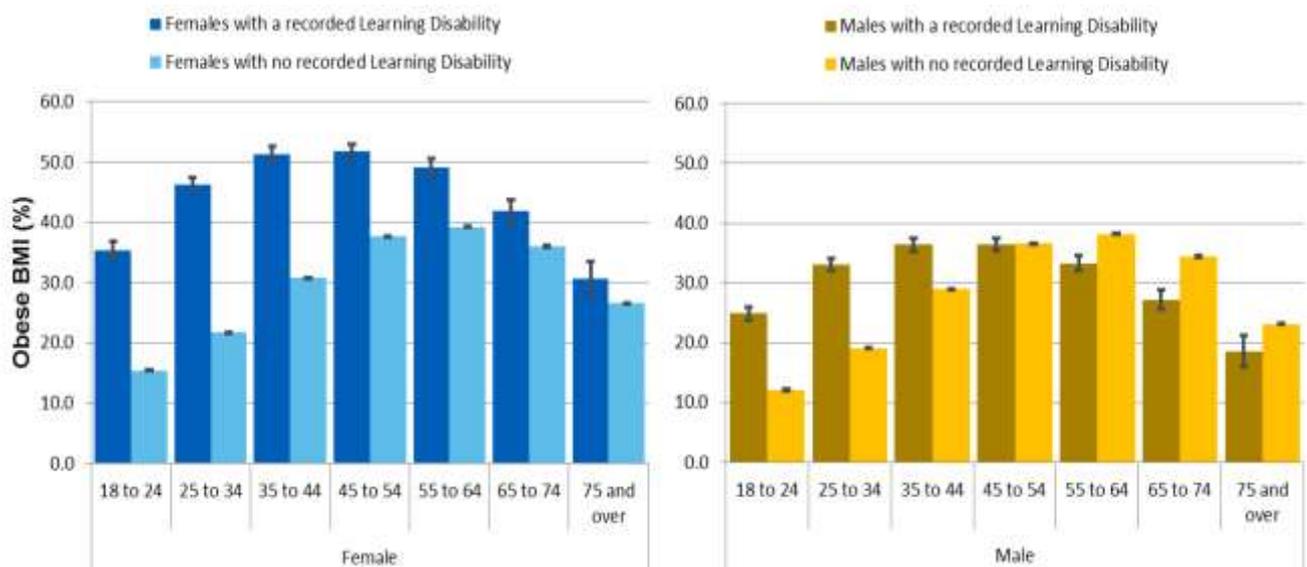
- People with learning disabilities leading a more sedentary lifestyle, undertaking low levels of exercise
- consuming high fat diets
- being prescribed high levels of antipsychotic medications, all of which can contribute to obesity (Taggart and Cousins, 2014).

The above risks can be reduced by greater understanding of the needs of people with a learning disability and includes adapting existing lifestyle programmes to suit the needs of this population. These approaches are further discussed in later sections of this document.

In 2016, NHS Digital in association with Public Health England, produced the first experimental GP data showing the health needs of people with learning disabilities for the year 2014-2015 (refer to **Graph A** below). The report shows higher rates of obesity (a risk factor for Type 2 diabetes) in all age groups for women with a learning disability compared to those without the disability. Higher rates of obesity were also seen in all age groups for men with a learning disability compared to those without except for ages 55 and over.

Graph A

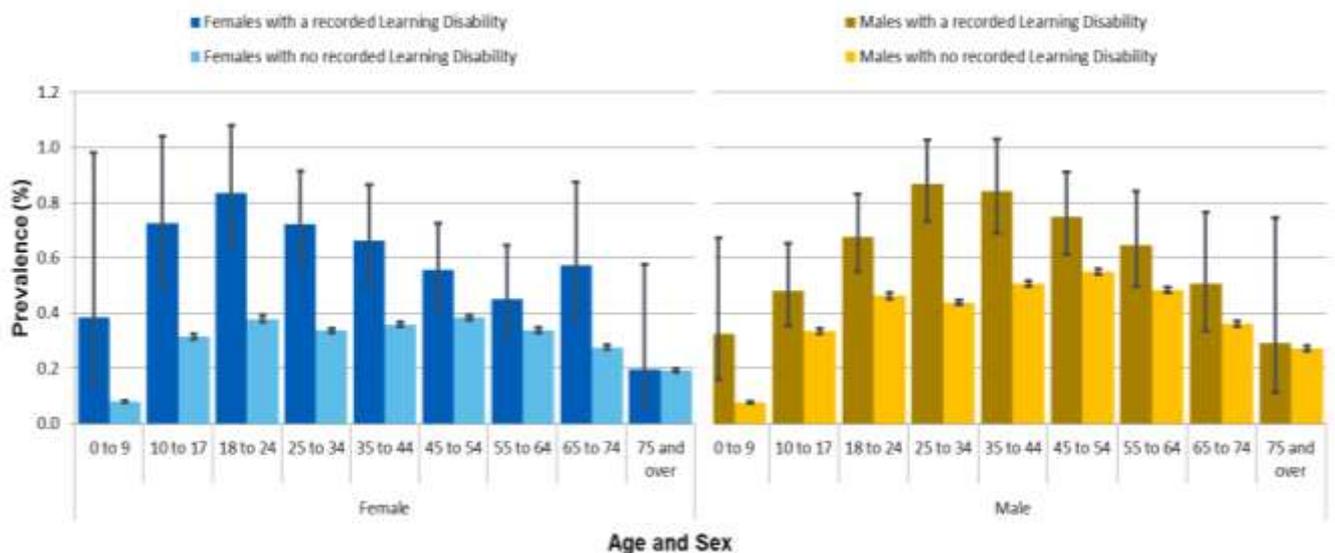
Proportion of patients with an obese BMI recorded in the 15 months to 31 March 2015 (per cent) by age, sex and learning disability status, England, 2014-15



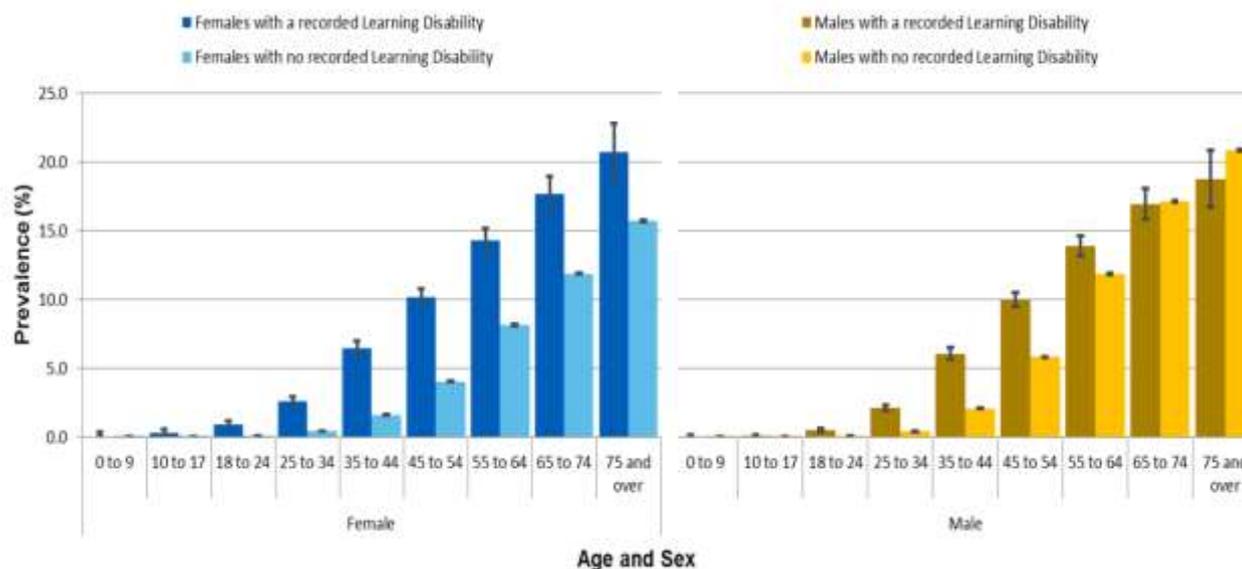
The GP data also showed that the rates for both types of diabetes are higher in people with a learning disability when compared to the general population and this is seen at all age groups (refer to **Graph B, Graph C**). For both types of diabetes, onset of diabetes is seen at an earlier age for people with a learning disability.

Graph B

Type 1 diabetes prevalence (per cent) by age, sex and learning disability status, England, 2014-15



Non-type 1 diabetes prevalence (per cent) by age, sex and learning disability status, England, 2014-15



- Down's syndrome is associated with a higher risk of autoimmune phenomenon, including Type 1 diabetes (Guaraldi et al, 2017). This may therefore account for much of the higher rates of Type 1 diabetes seen in people with a learning disability.
- Type 2 diabetes which is associated with obesity is more common in people with a learning disability than the general population. Some classes of antipsychotic drugs can also be associated with weight gain and higher risks of developing Type 2 diabetes.

The latest health data for people with a learning disability can be found at [Health and Care of People with Learning Disabilities: Experimental Statistics: 2015 to 2016](#). The data section includes an interactive tool that allows interpretation of local or CCG health data for people with a learning disability.

[The NHS RightCare Diabetes Pathway](#) describes the core components that should be present in commissioning an optimal diabetes service, from detection and diagnosis through to ongoing treatment, management and care of those with diabetes.

This guidance outlines principles of reasonable adjustments that should be considered for equitable access to the optimal diabetes service by those with a learning disability. The document provides links to **intelligence, guidance, tools**

and examples of good practice (please refer to Appendix1), where reasonable adjustments have been successfully implemented in the care and management of diabetes for people with a learning disability. This supports RightCare's approach to maximising value in terms of outcomes and costs.

This document should be used in collaboration with the [NHS RightCare Diabetes Pathway](#).

4. What are the benefits of addressing reasonable adjustments to an optimal diabetes service for people with a learning disability

Addressing reasonable adjustments for those with diabetes will not only improve diagnosis and detection of the condition but has other benefits;

There will be **REDUCTION IN:**

- 
- Complications arising from diabetes, e.g. amputations
 - Diabetes related A&E attendances
 - Visits to GP
 - Missed appointments

5. What does this mean for commissioners?

Know your population. All Commissioners should be aware of the prevalence of diabetes in people with a learning disability. The National Diabetes Audit (NDA) is a resourceful overview of the quality of diabetes care at national as well as local practice level. Commissioners should work with their GP practices to develop a local process to enhance the NDA data to have better understanding of local needs for those with diabetes.

Increase uptake of Health Checks. GPs provide Annual Health Checks for people with a learning disability as part of the Directed Enhanced Service (DES). Under the Quality Outcomes Framework (QOF), GPs are also encouraged to provide a series of annual checks to monitor and improve the health of people with diabetes. The QOF recommendations by NICE help GP practices target resources as well as reduce the complications associated with diabetes such as heart disease and amputations. The diabetes QOF checks can therefore be carried out alongside the Annual Health Checks for people with a learning disability.

Avoid unnecessary hospital admissions. Diabetic crises are a common cause of hospital admissions amongst people with a learning disability, accounting for between 7 and 7.5% of these potentially avoidable admissions (Glover and Evison, 2013). In the longer term, a reduction in the incidence of diabetes and improved diabetes management has the potential to improve general health outcomes in people with a learning disability and avoid unnecessary hospital admissions.

Reduce lengthy hospital stay. Specialist care teams, for example Multi-Disciplinary Foot Care Teams (MDFTs) and Diabetes Inpatient Specialist Nurses (DISNs) play a vital role in reducing hospital stays as well as reducing complications of diabetes such as amputations. If a person with a learning disability and diabetes becomes an inpatient, expert support for these teams can be given by families/carers, learning disability specialist practitioners such as Learning Disability Nurses and/or where available Learning Disability Hospital Liaison Nurses.

A co-ordinated service between specialist learning disability services and mainstream services allows clinical discussions that achieve better results.

Supporting a healthy lifestyle. The high rates of Type 2 diabetes and obesity and extremely low levels of activity in individuals with mild to moderate learning disability contribute to significant health inequalities and need addressing. This can be tackled by improved support systems, education and community provision.

Community Learning Disability Nurses can help provide education and training to a person's network about living well with diabetes and help people access the education and support that is needed to improve outcome for the person they are supporting. Where there are capacity issues within teams, commissioners need to consider a post to build up skills and knowledge on how to manage diabetes in the local community with a particular focus on family carers and the third sector.

Supporting structured education and self-management. People with a learning disability and diabetes can benefit from personalised support with weight management, physical activity and self-management, provided as part of an adjusted evidence-based programme. Commissioners should decide how to make such services accessible to adults with a learning disability. Successful programmes adapted to meet the needs of people with a learning disability are seen to have addressed the following:

- Provision of adequate and accessible information to enable full participation
- Accommodating views of those with a learning disability
- Family/carer involvement also supporting their understanding of diabetes
- Short sessions with participants with a learning disability and their carers
- Programme rolled out over longer periods in community settings
- Realistic goal setting

(Examples, Desmond-ID **see section 8**, [ROC ACTIVE](#), [LEAN WORKSHOP](#))

6. How does a mainstream diabetes service adjust to meet the needs of people with a learning disability?

The following discussions have been derived from a variety of sources that included co-production work (focus groups, webinars) with families and people with a learning disability who have diabetes, clinical engagement with experts, health professionals working with people with learning disabilities and research. Themes identified in focus groups and webinars are shown in **Appendix2**.

Identification of diabetes

A cohort study (Dunkley *et al*, 2017) found diabetes screening uptake rates favourable in adults with a learning disability. These findings are important as screening allows early detection of previously undiagnosed type 2 diabetes and impaired glucose regulation in adults with a learning disability. As obesity is known to be a major problem, the Annual Health Check (AHC) can also be a useful screening tool to identify Type 2 diabetes in this higher risk group.

With regards to identification of diabetes in people with a learning disability;

- If a test result is within the non-diabetic hyperglycaemic range then a referral can be made into an adapted Diabetes Prevention Programme (where available) or other local lifestyle change programmes with reasonable adjustments.
- Referrals are likely to occur following an AHC or symptom presentation.
- Where obesity is a significant problem, a specific weight loss programme is indicated, rather than a more generic lifestyle programme.
- Individuals, who decline support in lifestyle change or weight loss should continue to be offered it and it is important to review capacity, explore reasons for refusal and provide reasonable adjustments if required.

The recently rolled out [NHS National Diabetes Prevention Programme](#) (NHS England, 2016), '*The Healthier You*', is a programme designed to reduce the risk of developing Type 2 diabetes in identified individuals. Some aspects of delivery of the programme may need to be adapted for people with a learning disability to improve outcomes in this population.

The National Diabetes Prevention Programme is currently looking to pilot programmes adapted for people with a learning disability and will be testing these in different areas of the UK.

7. Tests and investigations

Reasonable adjustments should be considered for the achievement of the NICE and [NSF 9 Care Processes](#) and safe limits for the 3 diabetes treatment targets (HbA1c, blood pressure and cholesterol (See [NHS RightCare Diabetes Pathway](#), also latest [National Diabetes Audit Report 2015-2016, Care Processes and treatment targets](#))

Two key features for reasonable adjustments for tests and investigations are:-

- Use of accessible material ensures good understanding of procedure
- Always involving carers where possible.

For any tests or investigations, it is useful to know the routines of the person and to work with them in time introducing changes to their routine on the day of the test or investigation. This ensures the individual is accustomed to these changes for the day and does not get surprises.

See further guidance/examples of good practice to achieve the recommended care processes in the management of diabetes (Appendix1).

A recent report by Public Health England (2016) reported higher rates of physical and mental health problems and more problematic health behaviours for people with a learning disability when compared to those without. Having an additional health condition and the stress of illness can aggravate glycaemic control and necessitates more frequent monitoring of blood glucose and urine or blood ketones. Where multi-morbidity occurs, conflict between the recommendations for different diseases may occur, therefore shared decision making that engages with the individual and those that support them leads to decisions which patients find most appropriate to them (McCartney *et al*, 2016). This means clinicians will need to develop an individualised, person-centred approach to reviewing glycaemic control for those with comorbid conditions.

Responding to the initial diagnosis

Shock of a diabetes diagnosis with other information to be imparted could be overwhelming. It is therefore important to consider how to break any news in a way that empathises with the individual's emotional wellbeing.

- Clinicians should check the person's understanding of diabetes and be aware of their mood in response to diagnosis.
- Some parts of the initial assessment, such as discussing a referral for diabetic retinopathy screening, could be delivered better at a later appointment.
- An initial assessment meeting can be facilitated by a learning disability health professional (e.g. a Learning Disability Nurse).
- It may be necessary for the initial assessment for diabetes management that people with learning disabilities are offered a phased series of appointments.
- Part of the initial assessment is a requirement for a psychological assessment; which could be enhanced by an appropriately trained practitioner, able to make reasonable adjustments and has access to learning disability expert professionals.

Type 1 diabetes

With an increasing number of areas using community-based Diabetes Specialist Nurses to manage newly diagnosed Type 1 patients away from secondary care, it is important for these nurses to be aware of the needs of people with a learning disability. It is important to maintain consistency of care teams, particularly for successful insulin management in Type 1 Diabetes. This avoids unnecessary hospital admissions.

8. Structured support programmes

Type 2 diabetes

The [DESMOND](#) structured education programme for those with a diagnosis of Type 2 diabetes is one of a number of approaches recommended as routine.

- It has been adapted for adults with a learning disability (Taggart *et al*, 2015)
- Can be delivered in a community setting, over 6-weeks, with 1 session per week, each lasting approximately two and a half hours to the participants with learning disability and their carers.
- The DESMOND-ID programme (Taggart *et al*, 2015) had an additional education session that was aimed at family/paid carers in order to support their understanding about Type 2 diabetes and their specific role in supporting the person with a learning disability throughout the programme.
- Initial results suggest that such a multi-session education programme can be acceptable and feasible to deliver.

It is important for commissioners to work with other providers of structured education in making the necessary reasonable adaptations to meet the needs of people with a learning disability.

9. Weight management programmes

It is possible to recruit and retain people with a learning disability into weight management programmes if programmes are designed and delivered for the target population (Beeken *et al*, 2013; Harris *et al*, 2015; Hamilton *et al*, 2007).

Adults with a learning disability who are obese want to lose weight for the same reasons as do other people;

- to feel more comfortable,
- to be able to be more active, and to be attractive, as well as for the health benefits (Jones *et al*, 2015)

When commercial programmes such as Slimming World have been adapted, they too achieve good rates of weight loss in those who attend (Croot, 2016).

Physical activity and lifestyle programmes

Physical activity and lifestyle programmes can produce positive effects on outcome measures relating to health. These programmes not only reduce the associated risks with diabetes but reduce other risks to developing conditions such as coronary heart disease, known to be a major cause of death in both the general population and people with a learning disability (Public Health England, NHS Digital, 2016).

It is however important for lifestyle programmes to:

- accommodate views of those with a learning disability
- accommodate views of staff/carers about activity targets and
- the activities and behaviour change techniques should be carried out within familiar structures and settings.

10. Supported self-management of diabetes

With support, many people with a learning disability can set goals for self-management and participate in discussions about how to achieve them.

- To achieve self-caring, education has a role, beginning from diagnosis to ongoing care.
- Family members, advocates or paid support staff can make significant contributions the effectiveness of treatment by being part of:
 - Care planning and implementation
 - Identification of areas of risk, contributing to risk management plans.
- Support staff need training in supporting self-management in diabetes (Mieke *et al*, 2012).

When planning person centred care it is essential to strike the balance between protecting an individual's health and their choices. To achieve this, the individual should be given adequate and accessible information to increase opportunity to make informed decisions. *'Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care'* (Heslop *et al*, 2013).

Type 1 diabetes

Poor glycaemic control has been reported from younger obese individuals with Type 1 diabetes, either living independently or with parents (Taggart *et al*, 2013).

- Low literacy and comprehension levels can make it difficult to learn new skills such as:
 - monitoring blood glucose levels,
 - injecting insulin or
 - learning how to use a new insulin device.
- The use of colour coded blood glucose monitors and structured education material for people with a learning disability has been seen to be helpful by community Diabetes Specialist Nurses.

Type 2 diabetes

The OK Diabetes study (Walwyn *et al*, 2015; House *et al*, 2016) developed a well-supported self-management plan involving professional support via Diabetes Specialist Nurses. The study identifies the need to establish the following elements before a supported self-management plan is devised;

- An individual's daily routine and lifestyle including current diet, social/work activity routines, food shopping and food preparation,
- Current self-reported health and self-management, identifying all supporters and helpers and who the key supporter is and their role in the life of the person with diabetes.

Goal setting should be realistic and done in collaboration with the person with a learning disability, aiming to involve the person in any change in terms good dietary practice or other lifestyle changes. Support should be given to goals suggested by the person with diabetes that are specific, simple and achievable given the person's current routines and social support (Walwyn *et al*, 2015; House *et al*, 2016).

11. Person centred care planning

For everyone with diabetes there should be an annual care plan review.

- The management of diabetes for people with a learning disability should be reflected in the Health Check Action Plan (HCAP) which is an outcome of the Annual Health Check.
- The HCAP enables people with a learning disability gain control and own their health needs and together with their GP plan how to meet these needs.
- For a person who has diabetes, the HCAP should detail how the individual's diabetes will be managed. This might involve referral to Diabetes Specialist Nurses who will together with the individual agree on goals and actions to be set out in the Diabetes Care Plan. The care planning appointment with the Diabetes team should discuss the results of the diabetes annual check including those of the [15 Healthcare Essentials](#) (Diabetes UK).
- Individuals and their carers may require more support particularly from Diabetes Specialist Nurses, Practice Nurses, GP and Community Learning Disability Teams (CLDTs).
- Address mental health needs of a person with diabetes. Any concerns should be discussed with GP or consider involving the Community Learning Disability Nurse.

12. Appendix

Appendix1

TOOLS, RESOURCES AND BEST PRACTICE

Tests and Investigations:

[Ophthalmic Services Guidance - Eye Care for Adults with Learning Disabilities](#)

[Going for a blood test book – good practice example](#)

[Diabetic Retinopathy Leaflet – good practice example](#)

[Footcare Leaflet – good practice example](#)

[Insulin injection sites – good practice example](#)

[Diabetes Plan for low blood sugar level – good practice example](#)

[Diabetes Plan for high blood sugar level – good practice example](#)

Education:

[Learning Disability guide for people with Type 2 diabetes: DIABETES UK](#)

[Pictorial Information about Type 2 Diabetes for people with a Learning Disability](#)

[Diabetes Leaflets – Easy Health](#)

[A nurse initiative in Northern Ireland](#)

Adjusted Lifestyle Programmes:

[LEAN Workshop](#)

[ROC Active – Discovering Independence](#)

Other useful links

[National Diabetes Audit 2015-2016 report](#)

[Diabetes Health Action Plan – An example](#)

[Adapted Diabetes Health Check for people with learning disabilities – good practice example](#)

[Ten top tips for helping people with learning disabilities to lose weight – good practice example](#)

[Diabetes UK Learning disability section](#)

Appendix2

FEEDBACK FROM CO-PRODUCTION WORK WITH FAMILIES/CARERS AND PEOPLE WITH A LEARNING DISABILITY WHO HAVE DIABETES

Theme	Person with a learning disability	Parent/Carer
Understanding of food choices	<p>'I can eat fruit but can't eat crisps – it's difficult to not eat the things the doctor said not to'</p> <p>'I don't know what to eat or how to control it. I wasn't given a diet sheet'</p> <p>'Dieticians and sheets don't always work – if you don't know what moderation is then you can't do it'</p>	<p>'I had to be very creative with making food appealing, and introduce new food in miniscule amounts'</p> <p>'Diet problem largely relates to X knowing that he needed sugar and then eating whole bag of sugar babies because he has poor ability to judge quantities!!!'</p> <p>'Our son X, who had Cystic Fibrosis and Spina Bifida from birth so his CF related diabetes diagnosis at 15 years old was just another complication. Cystic Fibrosis diet is a nightmare so it makes any other diets difficult'</p>
Management of diabetes	<p>'My mum makes appointments for me and comes with me'</p> <p>'I do have support but it could be better – not sure how though'</p>	<p>What works well? 'Being able to get in contact with someone such as a nurse or doctor if and when needed'</p> <p>'I've always found the most difficult thing is managing diabetes with someone who can't communicate as easily as your average person. How can X say whether she feels ok or not. We rely on</p>

Theme	Person with a learning disability	Parent/Carer
		<p>lots of blood tests - and that leads to very sore fingers!</p> <p>'Regarding clinics we have had the diabetic nurse to school and home - they can do the HbA1c with a mobile machine too'.</p>
Person-centred care		<p>'X functions best in a structured regime so he has a written daily routine which he, and any support staff, refer to. This sets out timing and dosages for insulin injections and times when to take blood tests'.</p>
Access to and giving information	<p>'Everyone should have an easy read diet sheet given to them so they know what to and what not to eat'</p> <p>'I can't read the letters that they give me – especially the complicated words'</p> <p>'My support worker reads my letters'</p>	<p>'There was very little information. I got carrier bags of books from the library'</p>
Tests and Investigations	<p>'I am supposed to have a blood test every four weeks but it's easy to miss some tests.'</p> <p>'I am not sure when I am due for a test'</p>	

Theme	Person with a learning disability	Parent/Carer
	'It's easier to have the test done when my support worker is there – they can talk to the doctor'	
Treatments	<p>'I don't like eye-drops – they hurt'</p> <p>'I only tell my mum to stop if it hurts – I won't tell the doctors'</p> <p>'I forget to take my medication'</p> <p>'I put reminders up around my house to help me remember'</p> <p>'My support worker rings me to remind me or I set an alarm on my phone to remember to take my pills'</p>	
Referrals and appointments	<p>'I don't like waiting hours to get a blood test'</p> <p>'I am not good at keeping my Chiropody appointments'</p>	'For seeing the consultant ask ahead for the first appointment so you are straight in is my only suggestion - get to know 1 consultant well who is sympathetic to the extra needs, make these known in writing'.
Inpatient issues	<p>'It can be daunting or overwhelming in hospital'</p> <p>'It is good if they let you</p>	'I struggle getting my daughter to cope with the clinics as she associates

Theme	Person with a learning disability	Parent/Carer
	<p>choose which room to go into – I don't like all the rooms'</p> <p>'I don't like being crowded round by lots of different people – I worry about what is being said'</p>	<p>hospitals with her admission for diagnosis which was very traumatic'</p>
Multi-professional working		<p>'Diabetes professionals may have the expertise about the condition but are unlikely to have had much training in learning disability, and can therefore give complicated instructions'.</p> <p>'The second tip is to build a small expert team around your child. Try to minimise the number of different consultants, diabetes nurses as getting to know how your child's diabetes affects them, particularly if they find communication difficult, requires familiarity over a period of time'.</p>
Tips for doctors/nurses	'Talk to you and not the support worker – they can seem rude'	

Theme	Person with a learning disability	Parent/Carer
	<p>'Sometimes they assume you know something or can read it when you can't'</p> <p>'Big print or helping read through it would help'</p>	

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