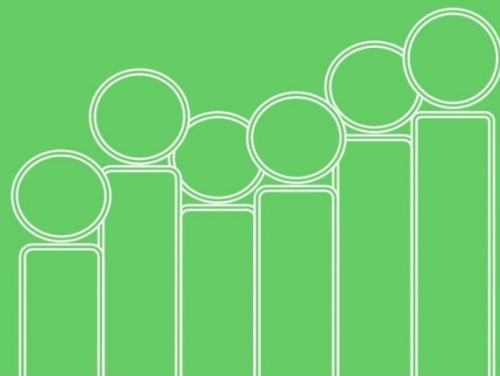


Making Reasonable Adjustments to Diabetes services for People with Learning Disabilities

Sue Turner & Eric Emerson



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IHaL – 2013 –05 Reasonable adjustments

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About the Authors

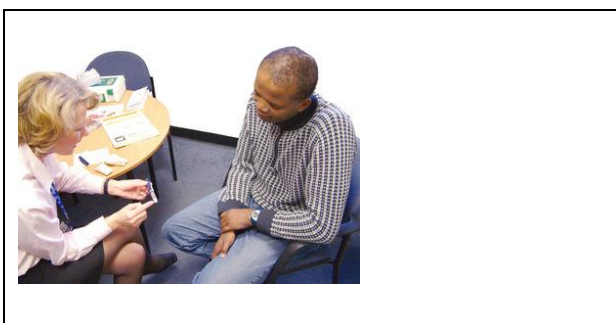
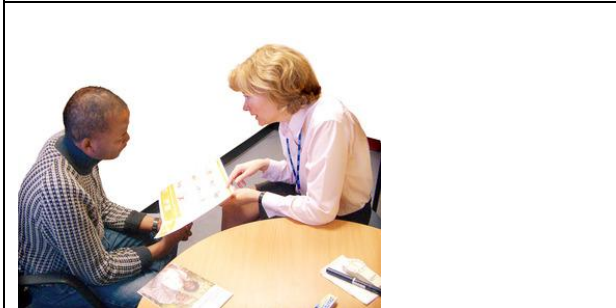
Sue Turner initially trained as a nurse for people with learning disabilities in Bristol. She has worked within training, as a Nurse Advisor in Gloucestershire, and has managed a variety of services for people with learning disabilities in Gloucestershire and Bristol including community learning disability teams. Sue was the Valuing People Lead for the South West Region for four and a half years. During this time, Sue developed the health network in the South West and introduced the health self-assessment tool to the region. She later worked closely with the Strategic Health Authority on its implementation. Sue is now leading on the Improving Health and Lives project for the National Development Team for Inclusion.

Eric Emerson is Co-Director of the Improving Health and Lives Learning Disabilities Observatory. Eric is also Professor of Disability & Health Research at the Centre for Disability Research, School of Health & Medicine, Lancaster University and Professor of Disability Population Health at the Centre for Disability Research and Policy, University of Sydney.

Acknowledgements: We would like to thank all those who contributed to this report by sending us examples of reasonable adjustments and good practice.

Easy read summary

	<p>People with learning disabilities are more likely to get diabetes than other people.</p>
	<p>It can be difficult for people with learning disabilities and family carers to get the right support with diabetes.</p>
	<p>If people do not get good support with their diabetes, they can get other health problems.</p>
	<p>The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities use them. This means they need to change their services so they are easier to use.</p>

	<p>This report has lots of information about reasonable adjustments in diabetes services. Professionals and carers can use them to get better services for people with learning disabilities.</p>
	<p>The report also has some examples of how local services have put reasonable adjustments in place so that people with learning disabilities can use diabetes services.</p>



Introduction

This report is the fourth in a series of reports written by the Learning Disabilities Public Health Observatory (LDPHO: www.ihal.org.uk) focusing on reasonable adjustments in a specific service area. The aim of these reports is to make it easier for people to find and use reasonable adjustments, and to share good practice regarding implementation of reasonable adjustments. Examples of reasonable adjustments in diabetes services were sent to us following a request to the Janet Cobb network (janet@jan-net.co.uk). We also looked at a number of websites (see resources section for details).

The LDPHO is one of the small number of specialist public health observatories that cover England. It was established by the Department of Health in April 2010 in response to a recommendation made by the *Michael Inquiry* into access to health care for people with learning disabilities.¹ The LDPHO is a partnership between the North East Public Health Observatory (the contract holder), the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. From April 1st 2013 the LDPHO will become part of Public Health England.^a

Learning disability refers to a significant general impairment in intellectual functioning (typically defined as having an IQ of less than 70) that is acquired during childhood.² In England approximately 1.2 million people have learning disabilities (290,000 children, 900,000 adults).³

People with learning disabilities have significantly higher rates of mortality and morbidity than their non-disabled peers.³⁻⁷ The importance of actively addressing the health inequalities experienced by people with learning disabilities has been highlighted by a series of reports from: the Disability Rights Commission;⁵ Sir Jonathan Michael's independent inquiry into the healthcare of people with learning disabilities;¹ the Parliamentary, Health Services and Local Government Ombudsman;⁸ the House of Lords and House of Commons Joint Committee on Human Rights;⁹ the Department of Health;¹⁰⁻¹⁴ and Mencap.^{15,16}


It is a statutory requirement under the Equality Act 2010 and the NHS and Social Care Act 2008 that public sector agencies make 'reasonable adjustments' to their practice that will make them as accessible and effective as they would be for people without disabilities. Reasonable adjustments include removing physical barriers to accessing health services, but importantly also include making whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities.¹⁷⁻²¹ A database of 'reasonable adjustments' made by health agencies is maintained by the LDPHO.^{22b}

This legal duty for health services is 'anticipatory', meaning that health service organisations are required to consider in advance the adjustments people with learning disabilities will require, rather than waiting until people with learning disabilities experience problems using health services.

The NHS Equality Delivery System provides a framework of questions for all parts of the health service in relation to all protected groups. In its 'Grades Manual' it sets out four overarching goals and invites NHS organisations to identify evidence about their progress in relation to these.²³ The

^a<https://www.gov.uk/government/organisations/public-health-england>

^b<http://www.improvinghealthandlives.org.uk/adjustments/>



first two (better health outcomes for all, and improved patient access and experience) ask healthcare organisations to look for evidence of how members of protected groups (the term used in the Equality Act) are faring in terms of their health and their use of health services. Answering these questions comprehensively, systematically and regularly requires that health service information systems identify people in the protected groups so comparisons can be made. In addition to exploring substantive questions that should be asked, the Equality Delivery System also discusses the need to discuss the ways arrangements are made to do this directly with members of all the protected groups themselves.

More generally, the importance of strategies to reduce health inequalities taking account of the specific situation and characteristics of high risk and marginal groups (such as people with learning disabilities) has been highlighted by the Health Select Committee, the National Institute for Clinical Excellence, The Marmot Review and the on-going World Health Organisation review of strategies to address health inequalities in Europe.²⁴⁻²⁷ The UK has also entered into international obligations to progressively realise the right to health of people with disabilities and to take specific measures to address the health inequalities faced by vulnerable groups such as people with learning disabilities.^{28,29}

Diabetes and people with learning disabilities


Increased rates of diabetes among adults with learning disabilities have been reported in population-based studies undertaken in the Netherlands, USA and Canada.³⁰⁻³³ Recent data extracted from GP information systems in England also indicate higher rates of Type 1 and Type 2 diabetes and lower rates of retinal screening among people with learning disabilities who have diabetes.³⁴ A recent questionnaire-based survey in Northern Ireland reported high rates of glycaemic control and poor diabetes management among people with learning disabilities.³⁵ Poorer quality diabetes management among people with learning disabilities has also been reported in the USA.³⁶

The higher rate of Type 2 diabetes among people with learning disabilities is likely to be related to their increase risk of: obesity, particularly among women, people with Down's syndrome, people of higher ability and people living in less restrictive environments;^{34, 37-45} poor diet;³⁹ and sedentary lifestyle.^{38-40, 46}

People with learning disabilities are more likely than the general population to be admitted to hospital as an emergency with complications of diabetes. This is an Ambulatory Care Sensitive Condition (ACSC), meaning that it is a condition which can normally be treated effectively in primary care. Admission to hospital for ACSCs indicates potential weaknesses in primary care that need addressing.⁴⁷

Diabetes services and people with learning disabilities

This section describes some of the general guidance and resources available to support people with diabetes. People with learning disabilities should be able to access diabetes services, with appropriate reasonable adjustments, in the same way as everyone else. National Institute for Clinical Excellence (NICE) guidance for the clinical management of diabetes in adults is available at:



<http://guidance.nice.org.uk/QS6> . The Diabetes UK website contains a range of helpful information on diabetes; see: www.diabetes.nhs.uk/. A commissioning guide for people with learning disabilities and diabetes is available at:

http://www.diabetes.nhs.uk/commissioning/nhs_diabetes_commissioning_guides/

DESMOND is the name of a family of programmes designed to support self-management in Type 2 diabetes care. See: <http://www.desmond-project.org.uk/276.html> . The programme is being adapted for people with learning disabilities.

The Public Health Outcomes Framework for 2013 – 16⁴⁸ includes an indicator for recorded diabetes under Health Improvement.

A diabetes outcomes versus expenditure tool (DOVE) has been developed by Yorkshire and Humber Public Health Observatory. See: www.yhpho.org.uk/dove

Consent and capacity

Consent must be sought prior to any investigation or treatment. The Mental Capacity Act 2005 sets out the law regarding capacity and consent and is underpinned by five key principles which must be considered when assessing capacity:

- A person must be assumed to have capacity unless it has been clearly established that they lack capacity regarding the specific decision under consideration at that point in time.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he/she makes what is considered to be an unwise decision.
- An act done, or decision made, under the Mental Capacity Act for or on behalf of a person who lacks capacity must be done, or made, in his/her best interests.
- Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

The Mental Capacity Act Code of Practice can be downloaded from: www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

There is a helpful guide for family carers on the Mental Capacity Act at www.hft.org.uk/Supporting-people/family-carers/Resources/MCA-guide/

Resources

The following sub-sections include some examples from practice, and resources and links to other easy read resources, which can be found on the Easyhealth site: www.easyhealth.org.uk; the picture of health site: www.apictureofhealth.southwest.nhs.uk; the SeeAbility website: www.seeability.org; the Diabetes UK website: www.diabetes.org.uk; and the LDPHO reasonable adjustments database www.ihal.org.uk/adjustments/.

Please note, some resources may be available from more than one site, but we have only included one link per resource, and we have only included resources that are free to download, although the Easyhealth site includes resources you can buy.

Helping people understand about diabetes

Supporting people to understand diabetes	<p>Type 2 diabetes – living a healthier life A film for people with Type 2 diabetes who have learning disabilities by Diabetes UK www.diabetesdvd.org.uk/</p> <p>Structured diabetes education pack for people with learning disabilities and family carers Northamptonshire Teaching PCT www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=174</p> <p>Diabetes (Type 2). A guide for people with learning disabilities and carers Berkshire West PCT www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=106</p> <p>Getting started with Type 2 diabetes A leaflet by the dietitians – Bristol NHS Primary Care Trust www.easyhealth.org.uk/sites/default/files/getting%20started%20with%20Type%20%20Diabetes_0.pdf</p> <p>Diabetes A leaflet by the Isle of White Healthcare NHS Trust www.easyhealth.org.uk/sites/default/files/diabetes_2_0.pdf</p> <p>Diabetes A leaflet by Shropshire County Primary Care Trust www.easyhealth.org.uk/sites/default/files/diabetes_1_0.pdf</p> <p>Diabetes A leaflet by the Foundation for People with Learning Difficulties, Prodigy and Easyhealth www.easyhealth.org.uk/sites/default/files/Diabetes%20-%20EH.pdf</p> <p>Diabetes symbol ABC cards www.easyhealth.org.uk/sites/default/files/Diabetes%20symbol%20ABC%20cards.pdf</p> <p>Diabetes A film using British Sign Language by the British Heart Foundation www.easyhealth.org.uk/content/diabetes-1</p>
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	<p>Diana has diabetes – from ‘Getting better in hospital’. An animation by Leeds Animation Workshop www.easyhealth.org.uk/content/diana-has-diabetes-getting-better-hospital</p> <p>Jo’s story – parts 1& 2. Signs and symptoms of diabetes in people with learning disabilities A film by NHS Swindon www.easyhealth.org.uk/content/jos-story-part-1 www.easyhealth.org.uk/content/jos-story-part-2</p> <p>Diabetes blood test A film by NHS Choices www.easyhealth.org.uk/content/diabetes-blood-test</p> <p>What is diabetes? A leaflet by North Somerset Council & NHS www.apictureofhealth.southwest.nhs.uk/primary-care/illnesses/</p> <p>Insulin injection sites (to help people rotate their insulin injection sites) A leaflet by Derbyshire Community Health Services NHS Trust www.improvinghealthandlives.org.uk/adjustments/?adjustment=256</p> <p>Foot-care leaflets Leaflets by Derbyshire Community Health Services NHS Trust www.improvinghealthandlives.org.uk/adjustments/?adjustment=257</p>
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Helping people with learning disabilities understand diabetes in Nottinghamshire

In Nottingham City and the Broxtowe, Rushcliffe and Gedling areas of Nottinghamshire County, there is a four week educational training programme called Juggle, for people with type 2 diabetes who don't take insulin. Juggle is a structured diabetes education programme that meets the requirements set down by NICE and the Department of Health for the education of adults with diabetes. The curriculum has been adapted to meet the needs of people with a learning disability, and the service runs programmes specifically for people with learning disabilities and their carers. A health facilitator supports the programme by meeting the participants before the programme, attending the sessions and following up any issues that are highlighted with individuals.

For further information about the Juggle service please contact: Helen Ramwell, Juggle Programme Coordinator, tel: 0115 8834335, email: helen.ramwell@nottinghamcitycare.nhs.uk

Helping people with learning disabilities understand diabetes in Northamptonshire

In Northamptonshire, work with the Diabetes Team began in 2007 to improve access to their services for people with learning disabilities. 'Looking after me and my diabetes' is a short course for people with learning disabilities who have either type 1 or type 2 diabetes. The course was developed by the Diabetes Team in conjunction with the Strategic Health Facilitators and Community Teams for People with Learning Disabilities (CTPLD's). The course is now funded as part of overall diabetes education. The course is a structured education package based on the principles of self-management and is being run three times a year at various locations across Northamptonshire. Session plans are available at: www.ihal.org.uk/adjustments/index.php?adjustment=174 . It is an accessible course which means easy words, pictures and lots of other visual aids are used during the sessions to aid communication and understanding. The course content covers:

- What diabetes is;
- Healthy eating;
- Physical activity;
- Medication management;
- The importance of health checks.

During the course participants can start a Health Action Plan for managing their diabetes: www.ihal.org.uk/adjustments/index.php?adjustment=175 . Carers or supporters on the course are asked to complete a support plan with regard to how they are going to support the person with their diabetes. It is beneficial that the person with a learning disability chooses a carer or supporter to come with them to the course. The person should choose a key person in their lives, who is able to offer support outside of the course and in the long term. The course is delivered by the Diabetes Team with support from Community Learning Disability Nurses or Strategic Health Facilitators. Many of the Diabetes Team have now been trained to deliver the course and are very skilled in working with people with learning disabilities.

The course is well established and has been running since 2008. Initially, people who attended were usually those who had been living with diabetes for many years. Over the last 2 years more of those attending have been newly diagnosed. Referrals come from a variety of sources including practice nurses and Community Learning Disability Nurses.

Further training resources can be found at: www.ihal.org.uk/adjustments/index.php?adjustment=174

For further information please contact: Kathryn.Joseph@northants.nhs.uk

Type 1 Diabetes – a family carer’s experience

My son, who has learning disabilities, was diagnosed with Type 1 Diabetes when he was nine years old. It took a couple of weeks to diagnose, as at first the GP thought it was a urinary tract infection. Diagnosis can take a long time for some young people and they can become very ill before the correct diagnosis is given. It is really important for families and GPs to be aware of the signs and symptoms of Type 1 diabetes, so that it can be picked up early. There are significantly higher cases of Type 1 diabetes in disabled children who have a lower immune system, as in my son’s case, he caught a virus which killed the cells in his pancreas.

When my son was first diagnosed, it was really difficult as he doesn’t like needles and had always had to be held down for his annual blood test for an underactive thyroid. The first thing the A+E Dept did when he was sent to hospital by the GP as he tested positive for diabetes, was to hold him down for a blood test and the insulin injections he now needed. He had to have numerous finger prick tests and 2 injections a day and we were in hospital for a week. This was because I needed to be able to give him the injections on my own in order to go home. They tried to organise community support to help with this, but this didn’t happen as the hospital was not in the same Health Authority as where we live, which seemed to make liaison more difficult.

After a few days I realised the only thing the staff could think of was to hold him down to take bloods, do finger pricks and give insulin. Eventually I suggested we make some picture cards (pecs) for him which helped to explain why he had to have injections now and also gave him incentives to sit still to have them. Some play therapy was incorporated but it was sporadic and not really age appropriate. We should have been given advice and counselling at the beginning. My son needed people trained in learning disabilities and communication techniques to help him. It must have been very expensive for us to be in hospital for a week, when it would only be a couple of days for other people. There is a learning disability team at the hospital but they only work with adults and so didn’t get involved. It is a good example of how adult and children’s services should work together. I think things would have been better if he had access to therapy for his needle phobia and this should have been available in the hospital with joined up treatment when he went home. I have tried to get some therapy for him through various services but four years later he still has had limited input.

For the last six months my son has been injecting himself. With better support this could have happened much earlier on. We are planning to move on to an insulin pump. There is one called an Omnipod which doesn’t have tubes and is waterproof. It looks a bit like a computer mouse and can be stuck on to the body. It also has a remote controller. My son did a trial for one week with a dummy one and now he is going to have the real one. Again, this is something that staff and parents need to know about as it can make life much easier for everyone.

Diabetes UK have been really helpful, but we only found out about them after a long time. It would have been helpful if we had been told about them at the beginning. They do family support weekends. They are not specifically for parents of children with learning disabilities, but it was really helpful for my son to see other children injecting themselves. I think he thought he was the only one until then.

Helping people with diabetes plan

The following section includes a number of health plan templates that can be used with people with learning disabilities to support them to manage their diabetes.

Health action plans and other plans	<p>Health Action Plan for people with diabetes Northamptonshire Teaching PCT www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=175</p> <p>Type 2 diabetes and coronary heart disease risk assessment care plan A leaflet by the Isle of White Healthcare NHS Trust www.easyhealth.org.uk/sites/default/files/type%20diabetes%20and%20coronary%20heart%20disease%20risk%20assessment%20care%20plan.pdf</p> <p>Diabetes – plan for low blood sugar levels Leaflets by Barnet and Chase Farm Hospitals NHS Trust http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=253</p> <p>Diabetes – plan for high blood sugar levels Leaflets by Barnet and Chase Farm Hospitals NHS Trust www.improvinghealthandlives.org.uk/adjustments/?adjustment=252</p> <p>Your diabetes information Hand held health record by Solent NHS Trust www.improvinghealthandlives.org.uk/adjustments/?adjustment=255</p>
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Diabetes and eye care

Diabetic retinopathy is a common complication of diabetes. It occurs when high blood sugar levels damage the cells at the back of the eye, known as the retina. If it is not treated, it can lead to blindness, and therefore needs to be recognised and treated early.

Diabetes and eye care	<p>Diabetes and your eyes SeeAbility information sheet www.seeability.org/myeyecare/eye_conditions/diabetes_and_your_eyes.aspx</p> <p>Diabetes screening test A fact sheet from SeeAbility about diabetic eye screening appointments www.seeability.org/myeyecare/eye_conditions/diabetes_screening.aspx</p> <p>Diabetes and eye care SeeAbility - Information for carers and supporters www.seeability.org/eyecare_hub/carersandsupportersinfo/eye_problems/diabetes.aspx</p> <p>Diabetes care – taking care of your eyes Leaflet by the Cheshire and Wirral Partnership NHS Foundation Trust www.easyhealth.org.uk/sites/default/files/Diabetes%20care%20-%20taking%20care%20of%20your%20eyes.pdf</p> <p>Diabetic retinopathy leaflet Leaflet by Derbyshire Community Health Services NHS Trust www.improvinghealthandlives.org.uk/adjustments/?adjustment=258</p>
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Helping people with learning disabilities access diabetic retinopathy – Teignbridge and Torbay

Identifying people with learning disabilities

The Failsafe co-ordinator (retinal screening service – Torbay Hospital) contacted all GP surgeries (targeting the person who is responsible for sending them the list) and asked them to identify patients on the list who have a learning disability. Having this information enables the screening team to give longer appointments and send out easy read information. The co-ordinator identified 57 people with learning disabilities who are eligible for screening, 15 of whom have either not attended their appointments or have had unsuccessful screening. Further work is happening to cross-reference the learning disability register and those known to have diabetes. The aim is to audit how many more people were able to have successful screening following targeted intervention.

Planning for a successful appointment

The co-ordinator has been able to send out lists of those people who will be having screening over the coming 4-6 months. This enables the primary care liaison nurses to identify those individuals who need further de-sensitisation work / additional support to attend and have successful screening.

Referral to the eye clinic

Previously, if someone has had unsuccessful screening in the local surgery / hospital, an automatic referral has been made to the eye department. However, the co-ordinator is hoping to delay referral until a second 'attempt' can be made following further input / support from the Learning Disability Team. She can refer anyone to the team who needs additional work / de-sensitisation. There may also be people who are now seen in the eye clinic who could be seen locally given the right support. This would free up more clinical appointments in secondary care for people who need it most.

Invitation letters

Initial invitations to attend for screening are currently sent out via a third party mailing system which means that a standard letter is sent out to everyone. This could be one of the reasons someone has not attended, as they may not have understood the letter. The primary care liaison nurses are developing an easy read invitation letter that the local screening service can send out following 'no reply' to initial contact. This is being considered by the Disability Equality Action Group at Torbay Hospital.

Easy read information

The primary care liaison nurses have developed a draft easy read booklet that takes a person through the process of having retinal screening undertaken, using photos of local services throughout.

For further information please contact: Katy.Welsh@nhs.net

Pictures relating to diabetes

Easy read materials	Diabetes symbols www.easyhealth.org.uk/sites/default/files/Diabetes%20symbols.pdf
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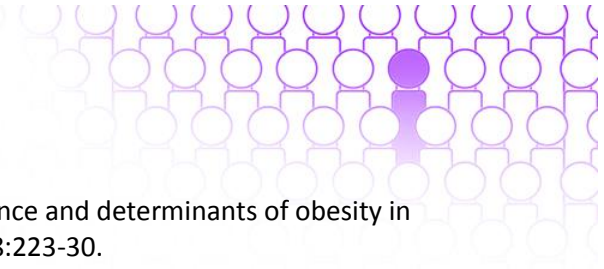
Conclusion

People with learning disabilities are more likely to get diabetes than their non-disabled peers. They are also more likely to be admitted as an emergency admission for diabetes related complications, an ambulatory care sensitive condition (ACSC). ACSCs should be treatable in primary care, indicating a potential weakness in primary care services for people with learning disabilities. CCGs should check on the situation in their area, and take appropriate action to improve access to primary care services, should they find there is a problem. Not only will this improve the quality of care for the individual and their family, but it will avoid expensive and unnecessary hospital admissions. The resources in this guide are designed to improve access to primary care and diabetes services, and can aid CCGs in this task.

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