healthwatch
Oldham

Your Experiences of living with a Learning Disability and Diabetes

A deeper insight into the support available in Oldham and their experience of the healthcare system - Summary Report.

June 2025

About us

Healthwatch is the statutory body created to help improve local health and social care services and make sure they work for the people who use them. Healthwatch Oldham is the local independent champion for people who use health and social care services. Our purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf; ensuring that those running services put people at the heart of care. We also provide information and advice to help people make the right decisions for their health and access support.

Our main statutory functions as local Healthwatch are:

- To obtain the views of people about their needs and experience of local health and social care services
- To make reports and recommendations about how those services could or should be improved
- To promote and support the involvement of people in the monitoring, commissioning and provision of local health and social care services
- To provide information and advice to the public about accessing these services and the options available.

We also represent the voice of local people on various health and social care forums, including the Integrated Care Board and the Health and Wellbeing Board. We're part of a national network that reports to Healthwatch England, NHS England and The Department of Health and Social Care on national health and social care trends.

Introduction

Healthwatch Oldham (HWO) have conducted research into the experience of people living in Oldham with a Learning Disability (LD) and diabetes (or pre-diabetes); providing a deeper insight into the support available in Oldham and their experience of the healthcare system. This report contains a methodology, results, desk-based research, key findings and recommendations. We welcome working collaboratively with services to explore changes that can be implemented with people with diabetes and LD.

Background:

Oldham has a total registered population of 268,256 (figures correct as of 31/10/24 and obtained from NHS Greater Manchester/Northwest Health Checks Performance data and Oldham Council). Of these:

- 19,837 of people aged 18+ had a confirmed diagnosis of diabetes (this figure includes Type 1 & Type 2),
- 21,093 of people aged 18+ had a confirmed diagnosis of NDH (non-diabetic hyperglycaemia) i.e. pre-diabetes,
- 1,490 people on the LD Register,
- 178 people on the LD register with diabetes (either type 1 or 2).

According to the Greater Manchester (GM) Tackling Diabetes Together Strategy 2022-2027 (2022), the number of people with diabetes in GM has increased from 5.7% to 7.4%, compared to 7.1% nationally (between 2009 and 2021), with Oldham prevalence rate being at 7.9% in 2021. At the time of this report being produced, it was reported that diabetes causes over 1,000 premature deaths in GM each year. The overall GM strategy is to reduce the incidence of type 2 diabetes. We hope that this report will be informative of steps that need to be taken for people with LD to achieve this goal.

Limitations:

Whilst planning this research project, we had expected a limited response via our survey for several reasons, including the additional need people with LD may have for support from a care/support worker to complete the survey. We did mitigate this by ensuring availability of an easy-read version of the survey (which was also reviewed by OPAL – an Oldham charity providing advocacy support and activities for people with LD and autism in Oldham), and prioritising focus groups to ensure we were able to gather rich intelligence. We received 20 responses to our survey over the 2 months that it was live, and we were able to reach out to 59 people with LD (and either diabetes or pre-diabetes), and 12 support workers through our focus group which mitigated the low survey numbers.

Unfortunately, the ethnicity demographics of our focus group attendees are not representative of the population of Oldham. As per the ONS Census (2021), 68.1% of Oldham’s population are White, 13.5% Pakistani, 9% Bangladeshi, 0.7% Indian, 3.4% Black (African/Caribbean), 5.3% Mixed and Other. Our focus groups were attended by white-British people. Our focus groups were helpfully organised through local day services, which draws the wider question of accessibility to local services for people from ethnic minority groups. Our surveys had a small number of non-white respondents (1 Arabic, 1 black/white Caribbean background) – equal to 20% which is still lower than the 30% non-white population in Oldham.

In addition to this, our focus groups did not involve people with LD and diabetes/pre-diabetes outside of local services, and it's difficult to say what the level of need was for those completing our surveys/if they were engaging with services. The diversification of responses (e.g., those who have their care needs met at home/are independent) is therefore limited. We did, however, try to mitigate for those who do not have the capacity to share within a focus group/survey by encouraging support workers to either complete the survey or attend the focus groups to represent their client's voice. We do understand, however, that this will never quite fully reflect the voice of those with the lived experience. We would therefore recommend further research into this area to ensure all corners Oldham's population can have their voice heard.

Oldham Diabetes Support Pathway (for information only):

Pre-Diabetes:

The National Diabetes Prevention Programme (NDPP) (also known as Healthier You) should form part of the treatment plan for pre-diabetes and should be offered to any patient identified as NDH (pre-diabetic), this has been rolled out across GM. Other than this, patients should be provided with advice and information to self-manage their health.

Type 1 Diabetes:

Patients with type 1 diabetes should be managed by their GP and provided with education and advice. They can be referred to a specialist service, like Oldham Diabetes Service, if additional support is needed or if an insulin pump is needed. After the initial 6 months post-diagnosis, the patient should be referred to the Dose Adjustment for Normal Eating programme (DAFNE), which aims to help adults with type 1 diabetes lead as normal a life as possible, maintain blood glucose levels within healthy targets, and reduce the risk of long-term diabetes complications.

Type 2 Diabetes:

Patients who develop type 2 diabetes will usually be managed by their GP and should receive an annual diabetes review. Patients should also be referred to the Diabetes Education and Self-management for Ongoing and Newly Diagnosed (DESMOND) programme within the first 12 months; where they will be provided with risk factors and complications associated with diabetes, what happens in the body in relation to diabetes and glucose, in addition to monitoring and medication to help self-manage their condition.

Methodology

- Project planning took place from November to December 2024
- The survey went live between January and February 2025
- Focus groups were conducted between January and March 2025

The survey was compiled for people with LD and diabetes/prediabetes to better understand their experience of living with this condition and navigating the healthcare system. The survey could also be completed by a family member, carer, or support worker to represent the voice of people with LD. The survey was available online as well as in paper format and in easy-read version to ensure inclusivity. The HWO team also offered additional support either by phone or in person to anyone who needed/wanted it. We wanted the survey to enable people with LD to tell us, in their own words, what support they have received from diagnosis to the present day, and what they feel would help them manage their condition moving forwards. A total of 20 surveys were completed.

HWO also completed 4 focus groups which were held on the following dates - 22nd January 2025, 5th February 2025, 26th February 2025 and 6th March 2025. A total of 71 people attended and participated (59 people with LD (and either diabetes or pre-diabetes), and 12 support workers).

Desk-based research

The prevalence of rates of both Type 1 and Type 2 diabetes have been identified by NHS England to be higher in people with LD than the general population (NHS RightCare Pathway: Diabetes, 2017), with a suggested prevalence of 9-11% (House, et al., 2018) compared with 3.9% (Diabetes UK, 2024). It's also been found that people with LD may experience a delay in diagnosis, potentially leading to more severe health concerns (Taggart et al., 2013). Reasons for this include that people with LD typically:

- Lead a more sedentary lifestyle,
- Consume high fat diets,
- Are prescribed higher levels of prescription medications, all of which can contribute to obesity (Taggart & Cousins, 2014).

NHS England (NHS RightCare Pathway: Diabetes, 2017) have listed recommended reasonable adjustments for people with LD and diabetes, including:

- Structured support programmes,
- Weight management programmes,
- Supported self-management of diabetes,
- Personalised care planning,
- Carer involvement in healthcare assessments (especially initial assessments and diagnosis),
- Checking understanding of diabetes during diagnosis, and making reasonable adjustments to consider emotional wellbeing,
- Considering delivering parts of the initial assessment (e.g., referral for diabetic retinopathy screening) at a later appointment or conducting a phased assessment approach,
- Initial assessment meetings to be facilitated by a LD health professional (e.g., an LD nurse),
- Accessible materials to increase opportunity to make informed decisions.

NHS England have indicated that these reasonable adjustments will not only improve diagnosis and detection, but will also result in reductions to:

- Diabetes related A&E attendance,
- Visits to GP,
- Missed appointments.

In relation to the structured diabetes education courses, GM Tackling Diabetes Together strategy (2022) reported that only about one in eight diagnosed with type 1 diabetes and fewer than one in ten are reported to have attended structured education in England. The report made it clear that structured education should be available to those newly diagnosed and to people already living with diabetes who have not previously attended. The report also recognised that the person with diabetes retains the choice as to whether or not they do attend, clinicians should express the expectation that education will form part of the treatment pathway.

According to Diabetes UK, diabetes can lead to severe complications if not managed well, including strokes, heart attacks, amputations, and heart failure. It reports research which was carried out by York Health Economics Consortium evidencing that the NHS spends £10.7bn a year on diabetes, which is roughly 6% of the UK health budget. The study reports that investing more in better diabetes care may help to reduce these costs.

Findings

Access to Structured Education Diabetes courses

As already demonstrated, at diagnosis (or within 12 months of diagnosis), patients should be referred to either Adjustment for Normal Eating (DAFNE) programme (Type 1), the Diabetes Education and Self-management for Ongoing and Newly Diagnosed (DESMOND) programme (Type 2), or the Healthy You programme (pre-diabetic) (Diabetes UK, 2024). Feedback from our participants was that this is not routinely happening.

80% of survey respondents said they were not referred to a structured education diabetes course, in addition to this, focus group participants were either not aware of these courses, or were also not referred on or after diagnosis. This issue was exacerbated by our focus group participants raising that when they were referred, there were complexities that either made it too difficult to attend (e.g., not being able to attend due to restricted accessibility of venue), or to properly engage with the course content.

"Some of the information was difficult to understand/take in for both them and myself" Focus group participant - support worker

This was viewed as a missed opportunity, both for support workers and service users. Several focus group participants commented that they have limited knowledge of diabetes, and therefore limited ability to self-manage their diagnosis; commenting that attending the diabetes courses would be helpful. This is further evidenced by our desk-based research which shows that structured education for people with LD can support self-efficiency

(Maine et al., 2018). Alongside the GM Tackling Diabetes Together strategy (2022) which evidences that structured education programmes can improve diabetes management, including, improved nutrition, physical activity, reduced smoking, and compliance with medication and care processes.

"I would like to attend the Desmond course to learn about what foods to eat and avoid, as only know to avoid sweet things" Focus group participant

"If [a referral] had happened on diabetic diagnosis, it may have made a difference on how the clients had/do manage their condition" Support worker

It was clear that accessibility to these courses is an important factor to consider, both in the form of location and content, and that support workers would also find the course content helpful. Again, this was also evidenced through our desk-based research, Mieke et al., (2012) found that support staff need training to support self-management in diabetes.

"Deliver the diabetic courses in the day centres and allow everyone to attend so everyone can benefit and not just those with diabetes" Focus group participant

"I want a better understanding of Diabetes – in a format that someone with a learning disability can understand" Survey respondent

Communication with healthcare professionals

Several participants highlighted that healthcare professionals did not communicate well with people with LD. Focus group participants (both service users and support workers) commented on healthcare professionals being too direct in their communication or not properly explaining things, which was exacerbated by not having long enough appointments.

The meant that service users felt they had been lectured to, dismissed, not had enough encouragement, and that healthcare professionals had minimised the complexity of the diagnosis for people with LD. Service users also felt that there was not enough time to discuss either concerns, or have things explained in a way that works for them.

"They sometimes don't know how to talk to people with learning disabilities, therefore don't explain things properly" Support Worker

"I have my annual health check and bloods taken to check for diabetes, but I don't really have the results properly explained to me" Focus group participant

"I was just advised to lose weight and exercise" Focus group participant

Accessible information and advice

Comments across focus groups and surveys indicated that participants felt they were not receiving accessible (e.g., visual) information from healthcare professionals and instead were given verbal information/instructions.

When asked within our survey and focus groups what would be helpful, the majority response was more accessible information (e.g., pictures, simple explanation, meal ideas, etc.,). Most of our respondents/participants said that this has not been provided to them. Some participants within our focus groups commented they have only been given verbal advice by healthcare professionals. However, some also commented that when they have been provided with written information, leaflets, or seen posters in GP practices, they have found this helpful.

A lack of accessible information meant that service users felt they had a poor understanding of their diabetes and were thus not well equipped to manage their diabetes. The GM Tackling Diabetes Together strategy (2022) describes lifestyle changes having the capacity to reduce the risk of developing type 2 diabetes by up to 58%. Therefore, if people with LD are provided with more accessible information to self-manage their condition, it could have a significant impact. The GM Tackling Diabetes Together strategy (2022) also states that information should be provided to all people living with diabetes at diagnosis, in a variety of formats to meet the needs of people with LD.

"They have not been given any leaflets about the condition or written information on diet and exercise" Support worker

"My client has a LD and Autism and struggles to understand the full extent of his diabetes" Support worker

"I recently saw a poster in the GP surgery that showed portion sizes and food that you should eat, the poster I saw made me think" Focus group participant

Experience at Diagnosis

At diagnosis, several participants commented the communication was not appropriate for someone with LD. Participants in our focus group discussed feeling confused, shocked, judged, and scared.

"It was a shock I was on my own at the appointment, couldn't take everything in that they told me and didn't give me any information to take away" Service user

"My client said that they felt judged and told off by their GP, it didn't sound like the communication was appropriate for someone with a learning disability" Support worker

This resulted in some patients saying they were not able to understand nor digest their diagnosis.

"I got diagnosed when I had just come back off my holiday and went to see the GP by myself, I was very scared and didn't understand what they were telling me. I felt I needed more support and still do" Service user

It can be daunting and overwhelming for people with LD to absorb information regarding a health need, especially when they do not have trusted support or someone who understands how to effectively communicate with them. Sometimes information needs to be delivered in phases, or over longer appointments to increase levels of person-centred care.

Access to specialist support

There seemed to be a lack for ongoing specialist support, e.g., diabetic nurse, for those on an annual check-up plan. Several patients responded that they would benefit from ongoing specialist support to manage their diabetes/health if pre-diabetic.

For those who participated in our survey/focus groups, this meant that there was an increased reliance on their support workers (despite support workers feeling as though the lack adequate knowledge), and an over-reliance on self-management when they do not feel equipped to do so.

"I have always had to look out for myself as after any review a lot can happen in 12 months" Focus group participant

"I know I need to do some exercise, but I haven't been given any medical direction/support around this" Focus group participant

"The day care centre staff do support us to take care of ourselves, promoting walking, exercise and fitness, along with education about different food types" Focus group participant

"If myself and the people I support could attend one of the diabetic courses this would be great, and help us all to manage the condition more effectively and understand what diabetes actually is" Focus group participant - support worker

To overcome this, additional consideration should be given to the Health Check Annual Plan (HCAP) for people who have LD, with a particular focus on additional support they may need from Diabetes Specialist Nurses/Community Learning Disability Teams (CLDTs) or equivalent. To establish this, a full review of the person's daily routine and lifestyle, including diet, activities, food shopping and food preparation should take place.

Conclusion

In conclusion, it's firstly important to state that there are some positive experiences for people with LD and diabetes/pre-diabetes. Including, the high rates of annual health checks. However, our findings highlight key challenges which are negatively impacting the ability for people with LD to prevent, self-manage, and access appropriate support.

Our key findings include the following:

- Access to Structured Diabetes Education Courses
- Communication with healthcare professionals
- Accessible information and advice
- Experience at diagnosis
- Access to specialist support

These findings have been used to guide and create our recommendations. Our recommendations are what we consider to be realistic and achievable to help create a positive impact for patients, clinical staff and teams, and the system more widely. We hope that these recommendations would support not only the experience that people with LD have but also work towards preventing either diabetes or the progressiveness of diabetes and thus reducing costs and impact on the healthcare system. Therefore, we hope that healthcare services, providers and commissioners in Oldham can act on these recommendations. Our Healthwatch commitment is to monitor progress and revisit in 12 months to see if changes have been made.

Recommendations

Access to Structured Education Courses

1. At the point of diagnosis or within 6-12 months, all people with LD should be referred to the relevant structured education diabetes course and provided with additional support to increase accessibility. Including a review of the content to ensure the courses are accessible for people with LD and the offer of bespoke arrangements for where the course held
    - In addition to this, we would recommend an additional education option aimed to support workers/families to support their understanding of diabetes and their specific role in supporting the person with LD that they care for

Experience at Diagnosis

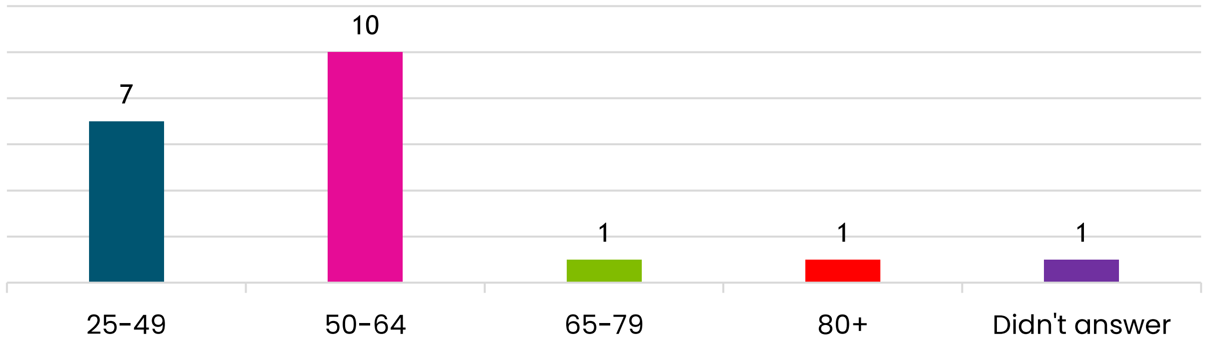
2. Before the initial GP appointment, people with LD should be provided with reasonable adjustment options, including:
   - Phased and/or extended appointments
   - Invitation for support worker/carer to be present
   - Facilitation through an LD professional

Accessible Information and Advice

3. Patients with LD should be provided with easy-read information, with simple explanations, visual information (e.g., diagrams of meal ideas) at each healthcare appointment, to support self-management.

Demographics (survey respondents)

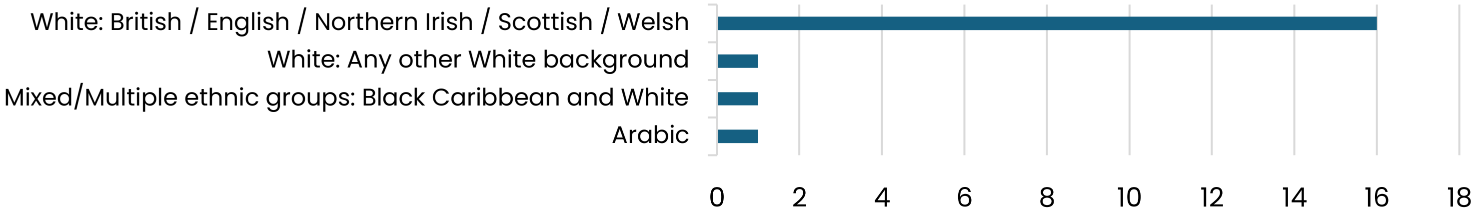
Age:



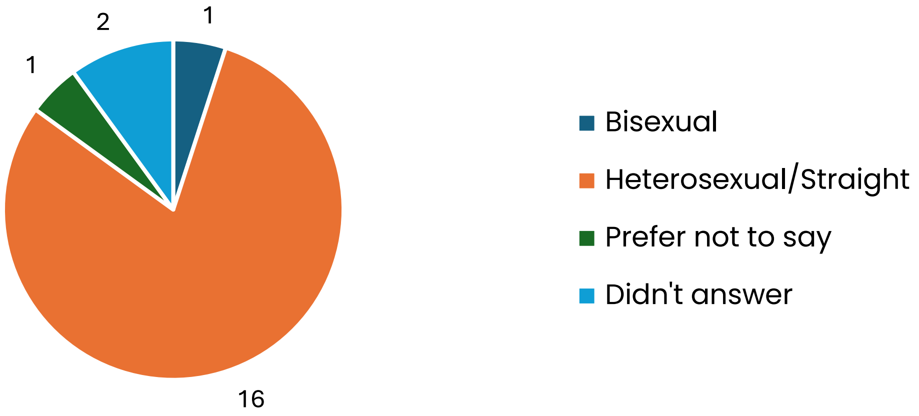
Gender:

85% (17) of respondents were female and 10% (5) were male, 5% (1) did not answer the question. All respondents had the same gender identify at birth.

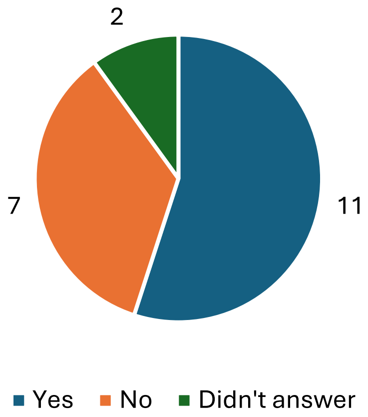
Ethnicity:



Sexual orientation:



Do you have a disability?



Where do you live?

Respondents mostly lived in **Chadderton and Oldham** (20% each). **Hollinwood**, **Royton**, and **Shaw and Crompton** were each reported by 10% of participants. Smaller proportions resided in **Coldhurst**, **Hathershaw**, **Holts Estate**, Mossley, or **Waterhead** (5% each). A minority did not specify their area (5%).

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