

“Our top three priorities”

By people with learning disabilities and the charity that supports them



“Our top three priorities” Report summary

People supported by Reading Mencap would like:

1. Staff trained on learning disabilities
2. To see the same GP, and time for the GP to listen
3. Enough, good quality, care



Reading Mencap called for:

1. Quality care needs assessments
2. Consistent and adequate care
3. The NHS to adjust for the needs of people with learning disabilities

“Sometimes they [care support workers] cancel on the day and no-one comes.”

This report is based on local listening visits carried out in February 2018. It is one of a series of short reports that Healthwatch Reading is producing in partnership with local charities, to ensure that the views and needs of people and communities who are ‘seldom heard’, are available to the NHS locally, and Reading Borough Council, to inform planning and funding of health and social care services and quality improvements to services.

Why have we produced this report?

The Quality Statements produced by Healthwatch England for measuring the impact and effectiveness of local Healthwatch include:

Community Voice and Influence - enabling local people to have their views, ideas and concerns represented as part of the commissioning, delivery, re-design and scrutiny of health and social care services;

Making a difference locally - by identifying where services need to be improved by collecting experiences of local people.

A local Healthwatch needs to formulate views on the standard of health and social care provision and identify where services need to be improved by formally or informally collecting the views and experiences of the members of the public who use them. (Healthwatch England)

Healthwatch Reading is therefore working with other local charities on a series of short 'top three issues' reports to ensure that the views and needs of people and communities who are least often heard are available to the NHS locally and to Reading Borough Council, to inform both commissioning and quality improvement in services

How did we produce this report?

Our first listening meeting was with Leslie Macdonald, Chair of Trustees, Mandi Smith, CEO and Kate Stonehouse, Family Support Team Leader at Reading Mencap.

Our second listening meeting was with Reading people with learning disabilities, at their regular Coffee Club meeting on 26 February, 2018, at Reading Mencap premises.

Part 1: What we heard from Reading Mencap

People with learning disabilities are some of the most vulnerable people in society, and they and their families and carers can often have difficulty in communicating their needs and experiences in health and care services.

These three themes emerged when we listened to Reading Mencap staff talking with us about the experiences of their clients:

1. Social care: care and support plans - getting an assessment that reflects the real needs of the individual

We heard that people with a learning disability need a high-quality assessment so that the social care plan written for them meets their needs.

It is also very important that family carers of people with a learning disability have a carers' assessment, so that their own needs can also be considered. Some people with learning disabilities live with their parents (60% of whom are retired or not working and are often frail themselves according to Reading Borough Council), or other family members, and caring responsibilities are often tiring and stressful, as well as often expensive (e.g. needing to pay for structured activity outings for the cared for person), adding to the stress that carers experience.

Other people live on their own, with some support from paid carers depending on their level of need.

We heard that the way in which social care plans are drawn up and implemented is having a serious impact on the mental health of many people with learning disabilities, who typically will experience high anxiety about forms and processes. People with learning disabilities will have very limited understanding of the process, or how what they say may affect what is put in their plan. This is resulting in social care plans that do not meet their needs.

We heard that:

- + a social care assessment is typically carried out by a social worker who has not met the person before and does not necessarily have training in learning disability
- + the assessment takes less than half a day, and lack of training in how to ask questions in the right way can mean, that a person's abilities are not correctly recorded

In one case, a person who told the assessor that they 'liked to make curry' meant that they could only make themselves a curry-flavoured instant soup. Heating up microwave meals is also deemed adequate nutrition, rather than being able to cook fresh food.

2. When social care is provided: the experience of care provided by learning disability support workers

We heard that there is a high turnover of care support staff generally, with varying abilities, in agencies that are used to support people with learning disabilities. It is a particular problem that a person with a learning disability may need to visit their GP surgery on more than one occasion to get their needs fully looked at - it can be difficult to get an appointment at a time when the person's support worker can also attend.

Care staff are often kind, but allocated care time is typically very short. This can affect the quality of the care provided.

People with learning disabilities are not able to understand fully how this might affect them, or how to try to change this so that their needs are met.

Mortality rates for people with learning disabilities are 13 years earlier for men and 20 years for women, than for people generally (University of Bristol)

We heard that care support providers may not always be providing training that makes sure that care staff really are alert to health issues for clients and that clients themselves might not be alert to these.

3. Healthcare: are the needs of people with learning disabilities understood and do services make reasonable adjustments?

Reading Mencap suggests that the following would be key reasonable adjustments:

- + surgeries ensuring that they offer appointments both for the annual health check for a person with a learning disability and for any non-routine things that are at a time when the person can be supported by someone they know
- + if a person with a learning disability does not attend a health appointment, following up with the person to call them in for an appointment can make a difference and ensure that they are seen - but that too often there is a lack of effort beyond what would be done for a person without a disability
- + taking care to obtain proper consent to treatment - it takes more time to do this well when a person has a learning disability
- + A 'lead' GP in Reading to raise awareness about the needs of patients with learning disabilities - when NHS staff are so busy, having a local 'awareness champion' could make a real difference.

“My support has been reduced because of all the cutbacks.”

Part 2: What we heard from people with learning disabilities at a Reading Mencap coffee group

We asked the group to tell us what it is like when they visit their GP or the hospital, and what it is like if someone is helping them with their care at home. Are the people who help with health and care, kind and clear in what they say? What is done well? What could be better?

We spoke with eight people with learning disabilities and one carer. Several Reading Mencap staff and volunteers were present to host the session and contributed when appropriate.

The session was facilitated by Healthwatch Reading and was a mixture of whole group discussion and informal discussion over coffee. (Some contributors use GP services outside the Reading Borough Council area that we cover - where their comments highlighted what is important to people with learning disabilities, we included them in preparing this report).

GP & other primary care services

We heard that the experiences of people with learning disabilities at GP surgeries are varied.

- + Some have good experiences with GP surgeries. They like to see the same doctor each time and they like to have enough time to explain things and for the doctor to talk to them. It is also important that the doctor listens to them.
- + Some doctors don't seem have a good understanding of learning disabilities.
- + One person had moved from Circuit Lane Surgery to another surgery because of “lack of seeing the same doctor and not feeling known”.
- + One person had found a GP to be unsympathetic about depression - they had moved to another surgery where the doctor was much more helpful.

“I can't get one [a social worker] at all.”
“Sometimes they [agency support workers] cancel on the day - no-one comes.”

It can be difficult to make an appointment at a time when the person's support worker can go to the appointment with them.

Some people feel that appointments could be given sooner - waiting several weeks to see a named doctor is difficult. Some people have to visit to visit the surgery to make an appointment because it is not easy to be understood by the receptionists on the phone. We heard that anxiety is a problem for many people with learning disabilities and that it is important to feel known, valued and understood. This can reduce the anxiety that goes with making and going to appointments. One person talked to us about using dental services and being told that they would have to pay for expensive treatment which they did not take - when in fact they would have been entitled to free NHS treatment.

Hospital

One person told us about an experience at a hospital some years ago. After their surgery they were left in a room opposite the theatre where they could see people walk in and out.

This was because the hospital could not find them a bed. They stayed there until they were discharged. They had to make their own way home on the minibus. This had not been a pleasant experience.

The few people in the group who had used hospital services generally told us they were happy with the treatment they had.

The group also discussed Health Passports (which people themselves hold to show various professionals important information). These can support and empower people, but local NHS funding for these has now stopped and GP records could be used more to hold details.

People with learning disabilities rely on their GPs to make the transition smooth for them when they have to attend hospital appointments, especially if they have no carer or support worker to bring them.



The Healthwatch Reading session at a Reading Mencap coffee group



Social care

The group told us strongly that they are not getting the support they need at home and to support them in going out.

Several have had their care needs reassessed recently, resulting in the allocated number of care hours being reduced. Most people in the group do not have a social worker and if they need to speak to one, they are getting through to a duty officer, who has no background knowledge of their needs.

People told us that things are not so good now as when there was a specialist learning disabilities team of social workers at the council.

Some told us that if care support workers were sick there was no cover for them. We also heard that care is not always provided over Bank Holidays and that this has an impact on people. One participant told us this ‘does not make me feel valued’.

Changing care providers means lots of paperwork. This is difficult for people with learning disabilities, the group told us, and reduces their choices. Sometimes they want to change who provides their care, but the process is very difficult.

Several people told us that support workers do a tremendous job. One said that they were happy to tell their care support worker what they were happy with or not.

We heard that a few of the group have their money looked after by the Deputy’s Office at Reading Borough Council.

This office does a good job of handling their

The top three issues raised by the group:
 - health & social care staff need to be better trained about learning disabilities
 - they need continuity of care at their GP’s
 - care packages don’t always meet full needs

money but it is very busy and has a long waiting list.

We heard about a positive experience of using IRiS, the alcohol and drug treatment service in Reading. The person told us that the service listened to them and had helped the person with their addiction and now they are doing really well.

Transport to and from health and other appointments can be a significant barrier to getting good access to services. We hear that travelling by public transport can be difficult. For example, staff are not always helpful when a person has physical needs that mean they need to have the access ramp lowered on a bus.

Healthwatch Reading observed in talking with this group that it is not always easy to tell that a person has learning disabilities, so staff in various services might wrongly assume a person does not have additional needs.

Conclusion

In both listening sessions it was clear how important it is for there to be a care plan that reflects and meets a person’s real needs, and how important continuity of care is, as well as training for health and care staff specific to working with people with learning disabilities.

Themes from this report, and our recommendations spanning the whole series of reports in this project, will be included in a final report in due course.

Healthwatch Reading thanks Coffee Club members and Reading Mencap staff for giving their time to share their views. Healthwatch Reading is an independent charity with some statutory powers. We can take your feedback in confidence, help you make complaints, and refer serious concerns to other agencies.



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