



My Health, My Say: the experiences of people with a learning disability using local health and social care services

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Mencap defines learning disability as a reduced intellectual ability and difficulty with everyday activities for example; household tasks, socialising or managing money, which affects someone for their whole life.



Healthwatch is the consumer watchdog for health and social care in Sheffield. We're here to help adults, children and young people have a say in how local services are designed and run.



Executive summary

Mencap, the UK charity supporting people with learning disabilities, states that ‘a significant proportion of the differences in health between people with a learning disability and the general population [...] are to do with the way people with a learning disability are treated by health, mental health and social care services, as well as lifestyle factors.’¹

Issues were raised with Healthwatch Sheffield concerning the possibility that with changes in service delivery, the needs of this relatively small but vulnerable group and their access to health and social care services may be overlooked, and highlighting their continued poor health outcomes.

Healthwatch Sheffield therefore chose Learning Disability as a priority area, and sought to explore the experience of those with learning disability as they accessed doctors, opticians, chemists, hospital, and social care services. This was also contrasted with the ‘Your Health, Your Say’ survey of the general population, completed by Healthwatch in 2014.

With the help of Sheffield Mencap & Gateway, the original survey was adapted to make it suitable for people with learning disabilities. 143 responses were received.

The findings of our survey indicate that, in Sheffield, people with a learning disability are generally more satisfied with the availability of appointments and the help or treatment they receive than the general population surveyed in 2014. However, this report recommends that a number of areas are addressed to improve the help and care that people with learning disability receive from health and social care services.

A number of key themes emerged;

- 1) The attitude of staff is key to an individual’s experience of using a service.
- 2) Respondents told us that their experiences of services could be improved if more health and social care professionals had a better understanding of the needs of people with a learning disability.
- 3) Communicating and sharing information effectively is a recurring theme. Written materials need to be both appropriate and accessible.
- 4) Regular two-way communication was important to respondents, including regular social care reviews.
- 5) Many people with learning disabilities also have physical disabilities so appropriate access to services is important. A calming physical environment is ideal.

¹Mencap website: <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health-research-and-statistics/health>

- 6) Specific barriers and challenges to accessing services were highlighted as having a negative impact on those with a learning disability. These included difficulties with access to a social worker, the transition from children and young people to adult services, and variability of day care services.

This report should inform providers and commissioners of health and social care services in Sheffield, as well as being of interest to the public.



Key findings

General findings

- The **attitudes of staff are especially important** to those with a learning disability. When asked what was good about the health setting in particular, it was the kindness, patience and helpfulness of the staff that had a huge impact on people.
- Our respondents were very positive about and grateful to staff who **understood their needs and how to communicate and support them**. People with learning disabilities want to see improved levels of understanding amongst all staff, in all settings. This is equally true in health and social care settings.
- **Continuity of staff** is highly valued by respondents as it allows a relationship to be built with the person helping them and ensures they feel listened to and safe. It should be encouraged with all service providers.
- It is important to ensure that **communication materials are appropriate** for those with a learning disability.
- Health and social care settings should be **accessible for those with a physical disability as well as a learning disability**. There were repeated calls for better wheelchair access in a number of dentists, chemists and opticians in particular.

Healthcare findings

- People with a learning disability who responded to our survey had **higher levels of satisfaction with the help and treatment they received** than the general population in the benchmark survey. For doctors, dentists, opticians and hospitals, at least **90%** of respondents were positive about their experiences. This is at least **5%** higher than the benchmark population for all but opticians, where the levels were the same.
- With regard to getting **an appointment time that suited them with an optician or dentist**, those with learning disability were more satisfied than those responding to 'Your health, Your say', but less happy with getting an appointment with a doctor.

72% of people with a learning disability were able to get a doctor's appointment at a time that suited them, compared to **89%** for dentists and opticians. The benchmark levels of satisfaction were **80%** for doctors, **83%** for dentists and **82%** for opticians.

- Respondents to our survey value having a **warm, calm and clean environment**. They find waiting a long time for an appointment stressful and often prefer to go to appointments at quieter times.

Social care findings

- There were **high levels of satisfaction** with the care provided in people's homes (**83%** marked it as 'good') and day services (**80%** 'good').
- Many people were **concerned about access to social workers** and in particular being able to get help and advice when they need it. Just **47%** felt their assessment with a social worker was 'good', **32%** thought it was 'OK' and **20%** marked it as 'bad'. They want regular two-way communication and reviews of their support.
- People want better support in the **transition from children and young people services to adult services** and more support in general. In particular, they want to see improved joined up working between health and social care services. This was also mentioned in other contexts.
- There are concerns that some **day care services** are declining (though note that **80%** of people using day care services rated them as 'good'). Respondents want them to improve, particularly for those with severe and complex learning disabilities. The discrepancy with regard to the rating of day care services may relate to the particular service used by respondents.



Recommendations

This report recommends;

Although many of these recommendations are applicable across organisations and individual professionals due to the integrated and complex nature of support for those with learning disability, the following matrix may be helpful.

As a Local Healthwatch, carrying out this research and analysis has helped us to consider our role in promoting and supporting the involvement of local people with Learning Disabilities in the commissioning, provision and scrutiny of local care services.

As a Healthwatch we intend to:

- Attend and participate in the Mental Health, Learning Disability and Dementia Delivery Board and the Safeguarding Customer Forum
- Develop Learning Disabilities awareness within our team
- Work with partners to increase our reach to people with Learning Disabilities and their families or carers
- Actively seek the views and experiences of people with Learning Disabilities and their families or carers
- Produce Easy Read versions of our key reports
- Produce Easy Read versions of our volunteer role descriptions
- Recruit volunteers with Learning Disabilities and their families or carers

Recommendations	Health and social care providers and commissioners	Sheffield City Council (specifically)	Health and social care professionals	Doctors	Opticians	Dentists	Chemists	Mental Health, Learning Disability & Dementia Delivery Board
1. Improve understanding of learning disability:								
1.1 Training in learning disability awareness for all health and social care staff who are likely to encounter those with a learning disability should be reviewed, and if necessary improved.	✓			✓		✓		
1.2 This should include specific training in taking calls from those with a learning disability, including communication training, for all Triage staff working in General Practice.				✓				
1.3 Health and social care professionals who work with adults and children with learning disabilities should be aware of the advice on looking after and communicating with those with a learning disability in the Mencap leaflet ‘Advice for hospitals and health professionals’ ² .	✓		✓	✓		✓		
1.4 All those working in pharmacists and opticians who may encounter those with learning disability in their roles should have a suitable awareness and understanding of their needs.					✓		✓	
1.5 The recommendation in the Healthwatch Sheffield report ‘Disabled Access to Dental Services in South Yorkshire and Bassetlaw’ ³ , that ‘dental healthcare staff are trained in disability awareness’ should continue to be taken forward and monitored.						✓		

² https://www.mencap.org.uk/sites/default/files/2016-06/Mencap_tips_for_healthcare_professionals.pdf

³ <http://www.healthwatchsheffield.co.uk/wp-content/uploads/2015/12/Disabled-Access-to-Dental-Services-Report-Final-with-response.pdf>

Recommendations	Health and social care providers and commissioners	Sheffield City Council (specifically)	Health and social care professionals	Doctors	Opticians	Dentists	Chemists	Mental Health, Learning Disability & Dementia Delivery Board
2. Appropriate and accessible information and communication:								
2.1 Health and social care organisations and the professionals within them should use appropriate written and verbal communication and should follow the Accessible Information Standard - with the five basic steps of ‘Ask, Record, Highlight, Share and Act’ (For further information see Appendix 2). All NHS and publicly funded adult social care providers have been legally required to follow the Accessible Information Standard since August 2016, and its implementation is monitored by the Care Quality Commission (CQC).	✓		✓	✓		✓		
2.2 Easy Read versions of leaflets and documents should be provided to those with learning disabilities.	✓		✓	✓	✓	✓	✓	
2.3 Healthcare organisations should review training and awareness for those staff working in a hospital setting to build skills, techniques and confidence in dealing with patients with learning disabilities and their carers, in line with the ‘The Hospital Communication Book’ ⁴ .	✓							
2.4 Sheffield City Council (SCC) should incorporate the needs of people with learning disabilities, as they seek to implement improved access to information during 2017, as outlined in their report ‘Independent, Safe and Well’ ⁵ .		✓						

⁴ <https://www.mencap.org.uk/sites/default/files/2016-06/hospitalcommunicationbook.pdf>

⁵ <https://www.sheffield.gov.uk/content/dam/sheffield/docs/social-care/Independent,%20safe%20and%20well%202016.pdf>

Recommendations	Health and social care providers and commissioners	Sheffield City Council (specifically)	Health and social care professionals	Doctors	Opticians	Dentists	Chemists	Mental Health, Learning Disability & Dementia Delivery Board
2.5 The recommendation in the Healthwatch Sheffield report ‘Disabled Access to Dental Services in South Yorkshire and Bassetlaw’, that ‘professionals should increase their awareness and understanding of communication barriers during treatment [...] and try to accommodate these needs and communicate appropriately’ should continue to be taken forward and monitored.						✓		
2.6 The recommendation in the Healthwatch Sheffield report ‘Disabled Access to Dental Services in South Yorkshire and Bassetlaw’, that ‘There are a number of other non-physical adjustments that practices should consider making. These include giving people with disabilities longer appointments or having appointments at a time when there are fewer people around, taking extra time to explain things to patients and providing large print information’ should continue to be taken forward and monitored.						✓		

Recommendations	Health and social care providers and commissioners	Sheffield City Council (specifically)	Health and social care professionals	Doctors	Opticians	Dentists	Chemists	Mental Health, Learning Disability & Dementia Delivery Board
3 Access to services (availability and process):								
3.1 The Mental Health, Learning Disability and Dementia Delivery Board, and all organisations involved, should continue to actively seek ways to improve uptake of Annual Health Checks for all those with a learning disability aged 14 and over (see Appendix 3 for further information).	✓			✓				✓
3.2 All health and social care organisations and professionals should promote the use of Hospital Passports for those with learning disabilities (see Appendix 3 for further information).	✓		✓	✓				
3.3 Sheffield City Council should continue to identify ways to improve the transition of those with a learning disability to adult services from those specifically for children & young people. In particular, they should implement the aspirations outlined in their report 'Independent, Safe and Well'. This includes provision of a named social worker, and the collaboration of health and social care professionals.		✓						
3.4 Sheffield City Council should adhere to standards of access to, and regular reviews by, a Social Worker for those with learning disabilities.		✓						
3.5 In the light of the proposed changes by Sheffield City Council in September 2017, the impact of the reduction in those Social Workers with a Learning Disability specialism should be monitored, and if necessary other ways of supporting these families should be explored.		✓						

Recommendations	Health and social care providers and commissioners	Sheffield City Council (specifically)	Health and social care professionals	Doctors	Opticians	Dentists	Chemists	Mental Health, Learning Disability & Dementia Delivery Board
3.6 In line with the Sheffield City Council Commissioning Strategy for services for people with a learning disability and their families 2015 - 2018 ⁶ partnership working to ensure joined up support for those with learning disabilities and their families should be improved and monitored.		✓						
3.7 Healthwatch Sheffield also supports the recommendation in the Sheffield Learning Disability Health Needs Assessment 2016 ‘that improvement programmes as part of Integrated Commissioning e.g. Active Support and Recovery, People Keeping Well consider inclusion of activity targeted to this cohort to respond to these inequalities’. ⁷	✓	✓						
3.8 The experience of those accessing Learning Disability Day Care services should be reviewed and better understood.	✓	✓						
3.9 Healthwatch Sheffield also supports the recommendation in Sheffield City Council Commissioning Strategy for services for people with a learning disability and their families 2015 - 2018 to review the effectiveness and value of the day time opportunities they commission, and to develop options for the future.		✓						

⁶ <https://www.sheffield.gov.uk/content/dam/sheffield/docs/social-care/social-care-policies/Learning%20Disabilities%20Commissioning%20Strategy%202015-2018.pdf>

⁷ <https://www.sheffield.gov.uk/content/dam/sheffield/docs/public-health/publichealthstrategyandreports/Sheffield%20Learning%20Disability%20Health%20Needs%20Assessment%202016.pdf>

Recommendations	Health and social care providers and commissioners	Sheffield City Council (specifically)	Health and social care professionals	Doctors	Opticians	Dentists	Chemists	Mental Health, Learning Disability & Dementia Delivery Board
4 Access to services (physical access):								
4.1 All pharmacists and opticians should aim for their premises to be fully accessible wherever possible.					✓		✓	
4.2 The recommendation in the Healthwatch Sheffield report ‘Disabled Access to Dental Services in South Yorkshire and Bassetlaw’, that ‘Dental practices should aim for their premises to be fully accessible wherever possible. All dental practices should aim to have a large automatic entrance door, ramps, accessible toilet facilities, hearing loops and an accessible treatment room’ should continue to be taken forward and monitored.						✓		

Background to the research

Healthwatch Sheffield is the local consumer watchdog for health and social care services. We are here to help adults, children and young people influence and improve how services are designed and run. We are completely independent and not part of the NHS or the council.

Mencap defines learning disability as a reduced intellectual ability and difficulty with everyday activities for example; household tasks, socialising or managing money which affects someone for their whole life⁸.

Concerns were expressed to Healthwatch Sheffield that despite the emphasis in Sheffield on supporting people with learning disability to improve their health, it was possible that due to the changes in services and the economic climate, the needs of this relatively small number of often vulnerable people may be overlooked due to other more visible population needs. It was also of concern that those with Learning Disability continued to experience poorer health outcomes.

Some facts and figures:

Mencap research⁹ states that

'A significant proportion of the differences in health between people with a learning disability and the general population cannot be explained by an underlying condition and are to do with the way people with a learning disability are treated by health, mental health and social care services, as well as lifestyle factors'.

The Sheffield Learning Disability Health Needs Assessment 2016¹⁰ says

'People with LD face barriers to accessing health services including problems with understanding and communicating health needs, lack of support to access services, discriminatory attitudes among health care staff and failure to make 'reasonable adjustments' to services so that they can be used easily and effectively by people with learning disabilities.'

The Disability Discrimination Act (DDA) 1995, however, states

'It is unlawful for healthcare providers and social services such as; doctors' surgeries, dental surgeries and hospitals, to subject disabled people who wish to use those services to disability discrimination; this includes failing to comply with

⁸ <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>

⁹ <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health-research-and-statistics/health>

¹⁰ <https://www.sheffield.gov.uk/content/dam/sheffield/docs/public-health/publichealthstrategyandreports/Sheffield%20Learning%20Disability%20Health%20Needs%20Assessment%202016.pdf>

the important duties to make reasonable adjustments and to provide reasonable ancillary aids and services, such as, where needed and where it is reasonable to provide it, sign language interpreters, hearing loops and publications in different formats’.

The Sheffield Learning Disability Health Needs Assessment 2016 shows that

- Sheffield has **1938** adults with Learning Disability (LD) currently using SCC services and **3265** people (adults and children) with LD known to the case register.
- Based on national estimates, it is estimated that there are **12 000** people with learning disabilities or difficulties in Sheffield, the majority of whom are not eligible for, or would not require statutory service provision.
- The evidence also shows that there is *‘disproportionate prevalence and poorer outcomes from preventable and care-sensitive long-term conditions for people with LD’*.
- Much of the data available relates to the ‘registered’ LD population, but *‘this is only 20% of the overall population estimated to have some level of LD or learning difficulties in Sheffield. This wider population with LD or learning difficulties may also experience adverse outcomes - particularly in relation to being able to access and benefit from services.’*

We discovered other facts pertinent to this work in the national Mencap data:

- **40%** of people with a learning disability reported a difficulty using health services, compared to **18%** of people with no chronic health condition or impairment.
- **75%** of GPs have received no training to help them treat people with a learning disability.
- **7 out of 10** families have reached or come close to ‘breaking point’ because of a lack of short break services.
- **50,000** adults with a learning disability are supported by day care services.

Research methodology

A Healthwatch Sheffield survey of the general population, ‘Your Health, Your Say’, was carried out in 2014 which captured people’s experiences of access to doctors, opticians, chemists, hospitals and social care services.

We decided to follow the same format for this work to allow us to use the 2014 survey as a benchmark, comparing the experiences of people with a learning disability with the general population.

With the help of Sheffield Mencap & Gateway, the original survey was adapted to ensure it was suitable for people with learning disabilities (see Appendix 1).

The survey questions focused on patients’ ability to get an appointment that suited them; if the treatment, care and service were satisfactory; and areas for potential improvement in health and social care services.

We also asked whether the person with a learning disability had completed the questionnaire themselves or with the help of a family member, support worker or someone else.

Questions were a combination of multiple choice, yes/no answers and comment sections to expand on patient experiences. The survey was made available online and an easy-to-read print format was used extensively.

The survey was open between April and September 2016 and Sheffield Mencap & Gateway helped with the distribution and supporting people who needed help to complete the questionnaire. 143 responses were received.

Demographics

The majority of respondents categorised themselves as White British (91%). Ethnicity was a free-text question in this survey, and other respondents classified themselves as Hindu, Pakistani, Asian British, Black Caribbean and Black British.

139 respondents told us their age. Almost half (48%) were between 40 and 64 years old. 12% were in the 16-25 age group and 4 respondents (3%) were over 80.

We asked people for the first part of their postcode and this showed that respondents were spread throughout Sheffield.

Just over half the surveys (51%) were completed with the help of a family member, while 20% completed the survey themselves. The rest were completed either with the help of a support worker (12%) or someone else (17%).

Detailed findings

The survey looked at five health-related services:

- Doctors (General Practice)
- Opticians
- Dentists
- Chemists
- Hospitals (we did not differentiate between inpatient and outpatient)

And Social Care (Supported Living, Respite, Day Services, Care at Home, Assessment by a Social Worker).

The survey also asked for more general views on health and social care services, and the things that respondents would wish to change.

Health-related services:

Doctors

All but six people (a total of 137), had been to the doctor in the last 12 months.

a. Did you get an appointment time that suited you?

72% of respondents were happy with their appointment time (although when asked in a later question what would make going to the doctor better, 37% said getting an appointment or waiting times).

5% were unhappy about appointment times and the remaining 23% said they sometimes got the appointment they wanted. These results were lower than the benchmark findings where 80% were happy with their appointment time.

b. Did you get the help or treatment you needed?

The results were very positive. 93% agreed that they had received the help or treatment that they needed. 7% disagreed. This was higher than the general population where 87% agreed.

c. What are the good things about your doctor's surgery?

People were particularly positive about the attitudes of staff. 39% of respondents made comments about the staff being friendly, reassuring, accommodating, caring, helpful, polite, kind and patient.

Respondents also valued it when staff greeted them by name, when staff had an understanding of learning disability and being able to get regular check-ups and appointments quickly.

Several people mentioned the environment, for example the surgery being clean, warm, and tidy.

"Staff know my name without me saying."

"All the doctors are very good at listening"

"They send me letters with big writing and pictures. They explain in letters about things - like why I should have a flu jab."

"I can go when the surgery is quiet and not busy - I don't like it when there are lots of people."

d. What would make getting help from your doctor's surgery better?

The most prevalent area for improvement, mentioned by 37% of respondents, was the availability of appointments, and the waiting times once at the surgery.

Other suggestions included doctors taking more time to listen and being seen by a doctor who knows them or is familiar with learning disabilities.

Several respondents said that the availability of parking, physical distance to a surgery and being able to get a home visit would make getting help from the doctor's surgery better.

Another issue identified was that having a triage system can be a barrier to getting an appointment as people find it difficult to explain problems clearly.

“I want to see a doctor that knows me and my history, not just reading my notes, as communication can be difficult.”

“Someone taking the time to get to know how to speak to people with a learning disability and not to just work through a list of questions I don't understand.”

“They have a triage system and if you aren't good at explaining your illness /difficulty you can easily not get an appointment or one a long date ahead.”

Opticians

109 people responded to questions about visiting the optician.

a. Did you get an appointment time that suited you?

89% of respondents said they had received an appointment at a time that suited them compared to 82% in the benchmarking survey. 4% were unhappy about the appointment time they had been given.

b. Did you get the help or treatment you needed?

Almost everyone (93%) was positive about the help or treatment they had received with 7% making negative comments. These figures were the same as the 2014 benchmark data.

c. What are the good things about your opticians?

As with visiting the GP, 40% of people commented on the positive attitude of staff. Others mentioned that their optician was good at meeting their needs, for example having the appointment downstairs or allowing extra time for the appointment so they didn't feel rushed. Several people valued receiving a reminder that their appointment was due, and having a clean and tidy environment.

“They are very understanding and will put one letter at a time on the screen for me.”

“They make sure I get a consulting room downstairs (I don't like stairs). They are friendly and understand my learning disability.”

d. What would make getting help from your optician better?

A number of respondents made suggestions for improvements, but no consistent themes emerged. Ideas included being able to have an eye test at home or closer to home, improved accessibility such as having more room for a wheelchair, more help finding the right glasses and trying to make it a more pleasant experience.



“When at opticians sometimes light in my eye is too bright”

“If it was closer to where I lived (there is a branch closer but they are not as good with me)”

Dentists

Almost everyone, 130 out of 143, responded to the section about going to the dentist.

a. Did you get an appointment at a time that suited you?

As with doctors and opticians, most people (89%) said that their appointments were at a time that suited them, which was slightly higher than the benchmark survey (83%).

b. Did you get the help or treatment you needed?

Almost everyone (95%) felt that they had received the help or treatment that they needed. Again, the results from those with a learning disability were more positive than the general population (90%).

c. What are the good things about your dentists?

As with doctors and opticians, the most commonly mentioned factor was the attitude of the dentist (46%). In addition to being helpful and understanding, people mentioned that their dentist was good at explaining the treatment or was humorous, encouraging and gentle.

Again, people appreciated those dentists with an understanding of people with learning disabilities and dentists who showed patience. Others liked being able to see the same dentist every time, so they got to know each other.

Respondents also mentioned getting help and advice on keeping their teeth clean and avoiding treatment which could be distressing, for example using needles.



“Fantastic, really good, he makes me laugh”

“The people there have known me a long time and everyone is nice to me.”

“Reassuring me because I get nervous and they tell me what is going to happen next”

d. What would make getting help from your dentist better?

There were a number of comments about the dentist having an understanding of learning disability and be able to communicate better. Several people mentioned getting appointments and ensuring they run on time. Improved wheelchair access was also mentioned.

“If I could understand what they were saying to me”

“They do not know how to deal with my needs”

“It’s too small for my wheelchair and far from home but I can’t get on my nearest dentist’s list.”

Chemist

This section was answered by 102 people who had visited their local pharmacy in the last year.

a. Did you get the help or treatment you needed?

89% of those who answered this question felt they had received the help or treatment that they needed while the other **11%** disagreed. 89% is a higher figure than for doctors, dentists and opticians, and slightly lower than the benchmarked figure of **93%**.

b. What are the good things about your chemist?

People appreciated the attitude of staff being friendly, polite and helpful, and a number had built up a good relationship with the staff in their local pharmacy. Others liked that it was close to home and prepared and delivered medication on time and some had an understanding of learning disability.

“They understand me and my needs.”

“They are very, very friendly and are aware of my disabilities. They always take time to talk to me.”

“It is close to home and the staff know me very well. They are kind people.”

c. What would make getting help from your chemist better?

Again, no consistent themes emerged, but the areas for improvement that were mentioned included avoiding waiting for out of stock medication, better opening times (on a Saturday) and improving physical accessibility.



“It’s too small for my wheelchair so needs to be bigger.”
“High Street chemists don’t always understand my disabilities because they are not physically obvious.”

Hospital

Around 80 people had visited a local hospital in the last 12 months.

a. Which part of the hospital did you go to / have your treatment at?

76 people responded to this question and had attended various departments at a number of local hospitals (adult and children's). The most commonly visited were Accident and Emergency (21%) and Outpatients (21%). Others mentioned were the Eye Clinic; ENT (Ear, Nose and Throat); surgery; audiology; neurology; orthopaedics; X-Ray; cardiology; haematology and urology.

b. Did you get the help or treatment you needed?

Of the 81 people that answered this question, 94% felt that they had received the help or treatment that they needed, while the remaining 6% disagreed. People with a learning disability were more positive than the benchmarked group (85%).

c. What are the good things about the hospital?

31% singled out staff who were helpful, kind, friendly and polite. Others mentioned that the staff they met understood the anxieties of people with learning disabilities and were good at explaining what was going on. A number of people mentioned being happy with the diagnosis and treatment, and the fact that it made them feel better.



“Everyone is very helpful and kind to me. They explain what they’re doing and why.”

“Very helpful. Making a cup of tea.”

“They hold my hand”

“It has things I like, Teletubbies and something special.”

d. What would make getting help from hospital better?

Many of the suggestions were about accessibility and especially transport - public transport and parking accessibility and cost.

Others were unhappy having to wait a long time to be seen and felt that more staff need to understand learning disability.

“Some of the doctors do not know how to treat me with my special needs and also some of the nurses”

“Just an understanding that I can become upset by new environments and situations”

“I’m very frightened about going to the adult hospital. They won’t let my parents stay. It makes me very upset and frightened.”

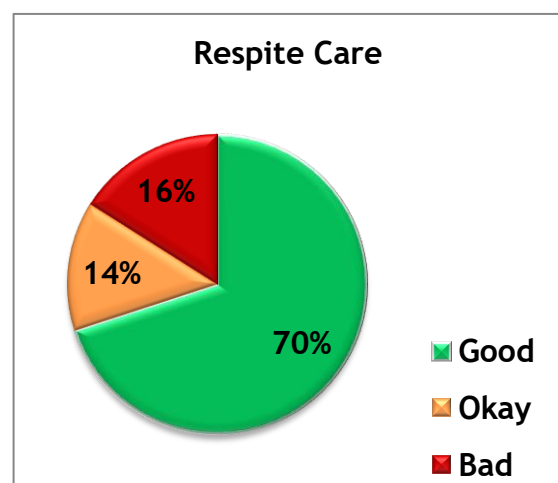
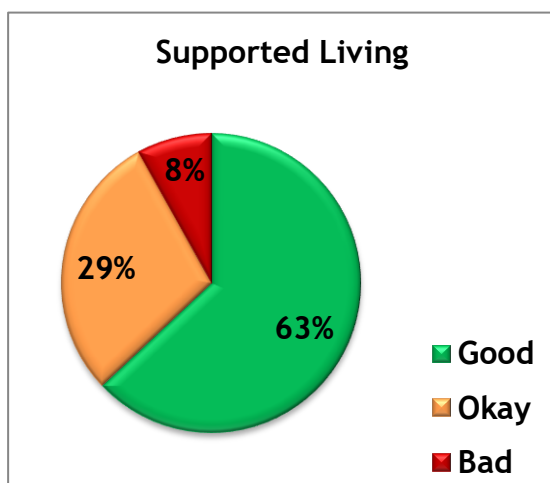
“It’s difficult to park so I would like more disabled parking spaces.”

Social Care Services:

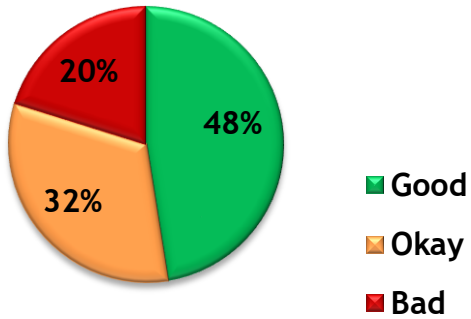
Respondents were asked to rate five areas of social care services as being good, okay or bad. The areas were supported living, respite, day services, care in your home and assessment by a social worker.

The services with the highest ‘good’ rating were Care in the Home (83%) and Day Services (80%). At the other end of the scale, ‘Assessment by a Social Worker’ was only rated good by 47% and 20% thought it was bad. This was strongly reflected in the free text or open questions with the availability and accessibility of Social Workers being mentioned repeatedly as needing improvement.

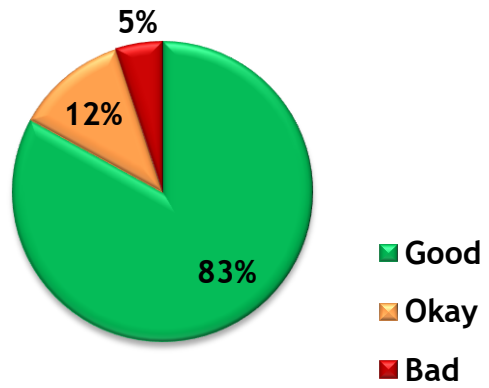
The results were as follows;



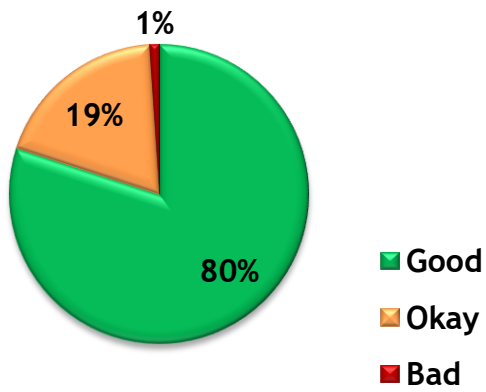
Assessment by a Social Worker



Care in Your Home



Day Services



Other questions

Q1: If you could change something about the health and social care services in Sheffield, what would you change?

We received feedback on a number of areas but the main themes were:

- The need for regular reviews and assessment, whether in day, home or residential care.
- The importance of professionals understanding the needs of people with a learning disability.
- Being able to access help and advice when needed, particularly from social workers.
- Better signposting of services with proactive help and advice and with more information available.
- Improved and regular communication.

Smaller numbers of respondents mentioned the following;

- Continuity of staff, whether at the doctors, with their carer or at day centres with people who understand the individual.
- More advanced notice of change coupled with a better understanding of the stress and anxiety this can cause.
- Improved day care services, particularly for those with severe and complex learning disabilities.
- Increased help in the transition from children and young people services to adult services including joint planning from both health and social services.
- Shorter waiting times for all services.
- More social groups for young people.
- Appropriate and timely care plans.
- A better understanding and interest in visual impairment.
- Improved access to mental health services.



“Just having to deal with one person who knows me and my situation.”

“To have a Social Worker to help me and my Mum and Dad and family to access services available to me for my future.”

“Real training needed to gain knowledge about learning disability and how it affects patients and those who care for them. Constant worry for parents about who will care and who will know how to treat our sons / daughters when we are not here.”

Q2. Is there anything else you'd like to tell us about the health and social care services in Sheffield?

Of the 51 comments in response to this question, **20%** were positive, **45%** negative with the rest being a mixture of positive, negative or neutral comments.

Positive themes:

- Individuals and organisations within health and social care services have been helpful, kind and caring.
- Although sometimes it is difficult to access services, once they are in place many are very good.



“I do voluntary work 2 days a week at Heeley City Farm, I am really happy doing this and hope I can carry on in the future.”

“I love my favourite supports - polite friendly, makes me laugh.”

Negative themes:

- Difficulty accessing social workers.
- Increased training for staff to understand the needs of people with learning disabilities.
- More joined up working between professionals, especially between health and social care.
- Ensure letters and information are accessible and appropriate for those with learning disabilities.
- People feel that Day Services have deteriorated, and should include appropriate, meaningful activities for those with learning disabilities.
- More help with the transition from children and young people to adult service.

“We are a family with two sons who have severe learning disabilities and since they have become adults we have to search for everything ourselves.”

“Just been for annual health check - Doctor was kind but don't think she had much of a clue about people with a learning disability - frightening.”

“Much more training needed of staff in NHS to raise awareness of people with learning difficulties and the everyday challenges they face.”

“They should send us letters and information that we can read. I can read a few words. I am sending you a copy of a letter that adult hospitals has sent me. I don't know what it says - I can only read my name. This is not good at all.”

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Appendix 1: Survey Questions

General Questions

1. How old are you?
2. What is your ethnicity?
3. How many people do you live with?
4. What is the first part of the postcode where you live?
5. How many people under 16 years old live in your house?
6. How many people with a learning or physical disability or long term illness live in your house?

Doctors

1. What is the name of your doctor's surgery / practice?
2. Have you been to see anyone at your doctor's surgery in the past 12 months?
3. Did you get an appointment at a time that suited you?
4. Did you get the help or treatment you needed?
5. What are the good things about your doctor's surgery?
6. What would make getting help from your doctor's surgery better?

Opticians

1. What is the name of your optician?
2. Have you been to see anyone at your optician in the past 12 months?
3. Did you get an appointment at a time that suited you?
4. Did you get the help or treatment you needed?
5. What are the good things about your opticians?
6. What would make getting help from your opticians better?

Dentist

1. What is the name of your dentist?
2. Have you been to see anyone at your dentists in the past 12 months?
3. Did you get an appointment at a time that suited you?
4. Did you get the help or treatment you needed?
5. What are the good things about your dentist?

6. What would make getting help from your dentist better?

Chemist

1. What is the name of your chemist?
2. Have you been to see anyone at your chemist in the past 12 months?
3. Did you get the help or treatment you needed?
4. What are the good things about your chemist?
5. What would make getting help from your chemist better?

Hospital

1. Have you been to hospital in the past 12 months?
2. Which part of hospital did you go to / have your treatment at? For example the surgery ward, the emergency room, the paediatric ward, the dialysis ward.
3. Did you get the help or treatment you needed?
4. What are the good things about the hospital?
5. What would make getting help from hospital better?

Social Care Services

Have you been to or used any of the services below?

If yes, please tick the box to say if they were good, bad or okay.

1. Supported Living
 - a. Good
 - b. Okay
 - c. Bad
2. Respite
 - a. Good
 - b. Okay
 - c. Bad
3. Day Services
 - a. Good
 - b. Okay
 - c. Bad
4. Care in your home
 - a. Good
 - b. Okay

- c. Bad
5. Assessment by a Social Worker
- a. Good
 - b. Okay
 - c. Bad

Other Questions

1. If you could change something about the health and social care services in Sheffield, what would you change?
2. Is there anything else you would like to tell us about the health and social care services in Sheffield?

Appendix 2: The Accessible Information Standard

Quick Prompt:

There are five basic steps which make up the Accessible Information Standard:

1. **Ask:** identify / find out if an individual has any communication / information needs relating to a disability or sensory loss and if so what they are.
2. **Record:** record those needs in a clear, unambiguous and standardised way in electronic and / or paper based record / administrative systems / documents.
3. **Highlight:** ensure that recorded needs are ‘highly visible’ whenever the individual’s record is accessed, and prompt for action.
4. **Share:** include information about individuals’ information / communication needs as part of existing data sharing processes (and in line with existing information governance frameworks).
5. **Act:** take steps to ensure that individuals receive information which they can access and understand, and receive communication support if they need it

NHS England: Accessible Information: Implementation Guidance 2015

Further information, including the full standard, can be found at
<https://www.england.nhs.uk/ourwork/accessibleinfo/>

The following video, produced by Healthwatch England, ‘The Accessible Information Standard - What you can expect from services’ may also be useful;
<https://tinyurl.com/y9vz8f7n>

Appendix 3: Annual Health Check and Hospital Passport

Annual Health Check

‘The Annual Health Check scheme is for adults and young people aged 14 or above with learning disabilities who need more health support and who may otherwise have health conditions that go undetected.’

Who will get an Annual Health Check?

‘People aged 14 and over who have been assessed as having moderate, severe or profound learning disabilities, or people with a mild learning disability who have other complex health needs, are entitled to a free annual health check.’

What are the benefits of an Annual Health Check?

‘People with learning disabilities often have difficulty in recognising illness, communicating their needs and using health services. Research shows that regular health checks for people with learning disabilities often uncover treatable health conditions. Most of these are simple to treat and make the person feel better, while sometimes serious illnesses such as cancer are found at an early stage when they can be treated.

The Annual Health Check is also a chance for the person to get used to going to their GP practice, which reduces their fear of going at other times.’

Is it compulsory to have an Annual Health Check?

‘No. All parts of the health check are voluntary. Anyone who is having the health check, or their carer, can ask the GP or practice nurse for more information about the process. The patient can then give their consent before any tests or procedures are carried out.’

How many people have Annual Health Checks?

‘In 2013-14, 44.2% of eligible adults with a learning disability had a GP health check. This means that more than half of people who could have one are missing out.’

<http://www.nhs.uk/Livewell/Childrenwithalearningdisability/Pages/AnnualHealthChecks.aspx>

Hospital Passport

‘A hospital passport provides key information about a patient with a learning disability, including personal details, the type of medication they are taking, and any pre-existing health conditions.

The passport also includes important information about how a person communicates and their likes and dislikes, which can be crucial when they are first admitted to hospital.

This can include any communication aids and how they can be used so that health staff can communicate in a way that is best understood. They can also show how the person expresses things such as happiness, sadness, pain and discomfort.

Hospital passports can have a big impact on the treatment and care that you or the person you’re supporting gets. They enable health staff to understand the needs of the individual, and help them make the necessary reasonable adjustments to the care and treatment they provide.’

<https://www.mencap.org.uk/advice-and-support/health/our-health-guides>

The following Case Study video shows how valuable Hospital Passports are, and how they have helped one person with learning disabilities;

<https://youtu.be/jhN-EyMJWg4>