

Empowering Voices: Examining Healthcare Access for Adults with Learning Disabilities and Autistic Adults

We heard from 104 service users, carers and healthcare professionals through a survey and 3 Café Conversations events.

We found that most participants have experienced barriers to accessing healthcare. These barriers can be broken down into 4 groups:

Staff-Related Issues



- Rude behaviour.
- Patients struggle to understand what staff say during appointments.
- Not understanding learning disabilities and autism.
- Not making reasonable adjustments to make patients more comfortable.



Patient-Centred Issues

- Feeling too afraid or nervous to get help.
- Not knowing what help is available.
- Carers are left out or ignored.
- Unsuitable spaces e.g. loud waiting rooms.



Operational Issues

- Services are hard to contact.
- Inflexible appointments.
- No follow-up care.
- Difficult to get a diagnosis.
- Staff changes



Social Factors

- Such as financial struggles, loneliness, not having a carer or carer's becoming unwell, and racial inequalities.

“It’s too confusing seeing different people every time. A lot of explaining to staff although they have notes on the system. It’s draining.”

Recommendations



1. Train healthcare staff about learning disabilities and autism, including how to use Makaton.
2. Acknowledge that disabled people often have multiple disabilities and health conditions, and that disabled people from ethnic minority backgrounds may not be treated the same as those from white backgrounds.
3. Appoint Learning Disabilities and Autism Champions to share information and monitor services.
4. Hold events about learning disabilities and autism to share information.
5. Specialist services should share knowledge with mainstream services.
6. Create a system to make sure patients access the correct service, if the service they are in cannot help them.
7. Help carers to access support.
8. Expand the Local Offer to include adults' services.
9. Check that contact details are up to date and accessible.
10. Offer different ways to contact services e.g. phone and email. Don't use withheld numbers to call patients.
11. Provide information about services online, in health locations and work with community organisations to share information.
12. Use a standard easy-read format so all documents look the same.
13. Different services should work together on an individual's care.
14. Start using the Reasonable Adjustments Digital Flag system.
15. Improve staff continuity and handovers to make referrals easier.
16. Carry out an NHS Equality Delivery System review of areas that are used by patients, using feedback from patients and carers.
17. Provide suitable areas for patients e.g. quiet waiting areas and space for wheelchairs.
18. Collect feedback from patients and carers.
19. Carry out an Equality Impact Assessment to identify inequalities, particularly for people from ethnic minority backgrounds.

