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Creators	Doherty, Alison Jayne

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RESEARCH & EVIDENCE

Alison Doherty from University of Central Lancashire with Pathways Associates (self-advocacy group) explore ways of improving healthcare from the perspectives of people with learning disabilities and / or autism

Summary

Study title: Improving healthcare for people with learning disabilities, autism or both: A co-produced research project.

Research aims: To identify the barriers and facilitators that people with learning disabilities and/or autism experience in accessing and or using healthcare for their general health.

Methods: Group discussions involving 23 people with learning disabilities and / or autism, supported by their carers, were held in January 2019.

Background

Numerous studies have shown that people with learning disabilities and/or autism have higher rates of long-term health conditions and die earlier than other people in the general population (Emerson & Hatton, 2013). Studies also show that despite this, their access to healthcare services is poor and their health needs are often unmet. There is not much research from the perspective of people with learning disabilities or autism. To address this gap a co-produced research project was undertaken in the NW of England to look at facilitators and barriers to better health care. People with learning disabilities were involved in the co-production of research design, questionnaires, and the production of easy-read research findings.

Findings

Hospitals

Participants found hospitals overwhelming, impersonal and they were a cause of anxiety for several people - *“Sometimes you have to make sure the room is a bit quiet, so you are not getting a bit anxious.”* Participants said they had been anxious about finding their way around

hospitals, which could be an “*absolute nightmare*.” Families indicated that they often needed to visit several hospitals to see different healthcare teams and this wasn’t helpful:

“All the different hospitals. Each time they are going there’s different people. That impacts. So, for my daughter, my wife and myself are supporting her. She would really struggle and her health would be impeded.”

Time

The waiting time for appointments was a barrier - “...*you can’t get an appointment. Then you have to wait about two weeks*”. How much time patients could spend with clinical staff at appointments was also raised. Some felt that they spent more time with their GP than with hospital staff, whereas others felt that they did not get enough time with either.

Communication

It was sometimes difficult to communicate what symptoms they had and people needed more time to process information, particularly if they had other disabilities such as sensory impairments and physical disabilities. They were positive about those staff who knew them well, which helped put them at ease - “*He also knows how to treat you if you are uncomfortable with certain things...*”

Some clinical and non-clinical staff did not understand their needs and some people had been treated poorly as a result - “*The way they said it. In a nasty way. ‘You have to come in at 8 in the morning to make an appointment’.*” Doctors would often talk to the carer or support worker rather than the patient, although, this was more likely to occur in hospitals. A good doctor was one who “*will look at you and talk to you not talk to the support worker because you need to know what’s going on.*” The lack of up-to-date information in easy read formats was a particular concern:

“If our son or daughter did not have us as parents going through all this material they wouldn’t be attending anything. Because they wouldn’t know.”

Not everyone had heard or had health action plans, health passports or health checks. Participants spoke of the need for consistency in accessing these through GPs.

Fear

Fear was common barrier including fear of needles, of health checks, of cancer screening and of hospitals in general. People were also embarrassed to talk about their symptoms to staff when asked - *“It’s embarrassing talking about it...Talking about bowels and stuff.”* The availability of consultation rooms in some pharmacists was a positive facilitator - *“My chemist has got a private room where you can go into and talk to the person.”*

Technology

Automated phone systems can be a barrier to making appointments, particularly when faced with multiple options. Touch screen technology was also a source of confusion. There was resistance to, and mistrust of, automated and on-line services - *“Not everyone has access to computers.”* and *“No – we don’t trust anything.”* There was a preference for face-to-face interactions and *“personal contact”*, while others welcomed the use of online tools or apps in healthcare.

Social support

Social support is an important facilitator and those lacking a support network and/or living alone may not act on health concerns:

“People who are in supported living...at times don’t receive the appropriate health care because those staff don’t support them to attend those appointments.” (Carer)

People with learning disabilities and or autism often rely on others to support them to attend appointments, therefore some allowance is needed for lack of attendance. Participants identified the need for co-ordinators to work with people with learning disabilities and or autism - *“...it comes back to that health care co-ordinator. Somebody who will act as your support. And maybe unofficially your advocate almost.”* Some had not considered using pharmacists for help and support with their healthcare.

Training

People with learning disabilities and/or autism need to know how to check for cancer symptoms and how to use medical equipment and could benefit from training. Participants also suggested the need for training for both clinical and non-clinical staff. A critical feature of any training is co-training with people with learning disabilities and/or autism. However, funding could sometimes be a barrier - *“We ask our local health nurse and she said ‘bad luck guys. There is no money in the budget to train you up to train us up’...”*

Other

The participants also spoke of barriers that were related to their condition such as a lack of home visits for people with agoraphobia. Also, some had been charged inappropriately for dental services and stated that the dental forms needed reviewing.

Conclusion

The study identifies several barriers and facilitators to better healthcare experiences for people with learning disabilities and/or autism. These often relate to how staff relate to and treat people with learning disabilities and/or autism. Raising staff’s awareness and understanding of people’s needs, for example, for information in easy read formats or allowing more time in consultations, would greatly improve the experience.

Key points

- Hospitals can be overwhelming and impersonal, and a cause of anxiety for people with learning disabilities and/or autism;
- Issues related to time, lack of understanding and awareness, communication, and technology act as barriers to healthcare;
- When staff take time to get to know people the experience is more positive;
- The study underlines the need for a healthcare co-ordinator to support better access to health services;
- People with learning disabilities and/or autism should co-design improvements to healthcare services.

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Useful links

Copies of an easy-read summary of findings are available on request from adoherty7@uclan.ac.uk

Pathways Associates: [www.http://pathwaysassociates.co.uk/partners/index.html](http://pathwaysassociates.co.uk/partners/index.html)

See Emerson, E, Hatton, C. (2013) *Health inequalities and people with intellectual disabilities*. Cambridge: Cambridge University Press.

NHS England – Learning Disabilities - <https://www.england.nhs.uk/learning-disabilities/>