

DISABLED PEOPLE'S EXPERIENCES OF THE NHS - A REPORT BY ACTION ON DISABILITY

Introduction

Action on Disability asked its members to contribute their views on the treatment they had received from the NHS. Evidence was collected by distributing a questionnaire to members and holding a hybrid in-person and online group meeting. Contributions were received from 26 disabled people.

1. Overall Experience

Overall experiences with the NHS varied significantly among members, with both positive and negative encounters.

Several members expressed satisfaction with certain aspects of the NHS. For example, one individual who moved to London in 2020 praised their local GP for being attentive and providing phone appointments that were thorough, contrasting this experience with rushed appointments in Portsmouth. Another participant shared a positive experience regarding hip surgery performed at University College Hospital (UCH) in 2020, which was well-coordinated and supported by their GP's efficient referral process. Their autistic son received comprehensive support for allergies and a deviated septum, underscoring a more positive side of NHS services.

However, despite these positive experiences, significant challenges remain. During the group meeting, multiple participants shared instances of inadequate care. One participant spoke about arriving at a hospital after informing staff in advance of their need for a hoist, only to find that the equipment wasn't available. This experience highlights the ongoing problem of insufficient preparedness for disabled patients in medical settings.

Another participant described the difficulty in accessing mental health support, sharing that they had to wait two years to transfer their care to a local service because they were considered "too complex." This issue is echoed by many who feel that mental health support is slow and insufficient. Additionally, one participant explained that GP appointments, which once were easily accessible, had become difficult to book due not only to long waiting lists but also the lack of physical accessibility at some facilities, particularly for those with mobility issues.

The poor communication between hospitals was also mentioned. Participants shared that medical records were not transferred efficiently between facilities, leading to repeated tests and unnecessary delays in receiving care. One participant recounted a troubling experience of medication errors, where they were not administered the correct tablets, including sleeping pills given at inappropriate times, which left them dazed and unable to engage in their own care.

2. Challenges or Barriers

Members identified several key barriers that prevented effective healthcare access and service delivery, with long wait times and accessibility issues being at the forefront.

At the meeting, numerous participants highlighted the challenges of navigating the NHS system. One participant explained how they had to wait over two years for an ADHD/Autism referral, and another described a nine-month wait to see a specialist at an eye clinic for deteriorating vision. In addition, an 18-month wait for a urology appointment was also mentioned. Mental health care was another area where delays were widespread, with some participants stating they had been waiting over three years for adequate support.

The physical accessibility of hospitals emerged as a significant concern. Some buildings were difficult to navigate, especially for those with mobility issues. Entrances were not always wheelchair accessible, compounding the difficulty. One participant described how they encountered severe accessibility issues at St. Mary's Hospital, where the department they were visiting was not wheelchair accessible, forcing them to wait over an hour for alternative arrangements. This delay impacted their care and highlighted the lack of accessible infrastructure in certain hospitals, a common issue for many disabled individuals navigating NHS services.

Another member shared their frustration with the NHS 111 service, which frequently redirected them to A&E, despite their health issues not warranting emergency care. Participants at the meeting echoed this frustration, pointing out that A&E departments were overcrowded and that patients often avoided them unless absolutely necessary due to long waits and uncomfortable conditions.

Dental care presented another issue. Although emergency dental treatment was accessible to one member through a special needs service at Parkview due to anaesthetic sensitivity and autism, regular treatment had to be sought from any available dentist, which did not adequately

cater to special needs. Additionally, efforts to access Dynamic Interpersonal Therapy through Back on Track were met with repeated rejections. The individual sought six sessions to manage the stress of downsizing their living situation but was told they required a longer-term service, leaving them feeling insulted and overlooked.

Errors in administration and communication were also brought up. Participants shared instances where their contact information was incorrect in NHS systems, leading to missed appointments. One participant recalled being reprimanded for lying on the floor due to weakness while waiting at A&E, further underscoring the stress and discomfort faced by disabled individuals in these settings.

3. Accommodation of Needs

When asked how the NHS could better accommodate disabled individuals, participants offered a range of suggestions centred on improving efficiency, communication and physical accessibility.

One key suggestion from the meeting was to improve information sharing between hospitals, to avoid the unnecessary repetition of tests and consultations. Participants agreed that better integration between administrative and clinical staff could greatly improve care. One participant explained how they were sent to different hospitals across London for treatment, resulting in confusion and delays.

Accessibility was another significant issue discussed. Participants suggested that hospitals should inform wheelchair users in advance if certain departments or facilities are not accessible. This would allow patients to make alternative arrangements and avoid stressful situations like the one described by a meeting participant who faced long delays due to inaccessible facilities.

Members called for NHS staff to have a deeper understanding of chronic illnesses. Participants highlighted the need for NHS staff to be more knowledgeable about conditions such as fibromyalgia and ME, noting that many doctors lacked the expertise needed to treat these conditions effectively. Participants said that their symptoms were often dismissed and the treatments offered (like graded exercise) were inappropriate and sometimes harmful.

Another suggestion was for the NHS to play a more proactive role in helping disabled individuals access Personal Independence Payments

(PIP) and other benefits, as quicker access to these sources of income could alleviate some of the pressure on the NHS.

4. Discrimination or Lack of Understanding

Several members recounted instances of discrimination or lack of understanding from healthcare professionals. During the group meeting, multiple participants shared similar experiences.

One participant recalled being dismissed by doctors when presenting with fainting episodes, being told that the symptoms were "normal" and that nothing could be done. This echoes similar experiences described in the questionnaire, where another participant shared that their GP did not believe in their diagnosis of fibromyalgia, despite a prior diagnosis and clear symptoms.

Receptionists were also a source of frustration for many. Participants described them as sometimes being rude and unsympathetic, which added to the stress of trying to access care. One participant at the meeting explained that when they arrived early for their appointment, no one informed them that the doctor was running late, further amplifying their anxiety.

Issues around gender identity were also raised. One participant, who identifies as non-binary transgender and queer, shared that they had to repeatedly explain their identity to healthcare providers. They encountered dismissive attitudes, with one staff member even stating, "I don't care." This experience highlights the lack of understanding and respect for the diversity of patients' identities, which can negatively impact their interactions with NHS staff.

5. Improvements

Participants in both the questionnaire and the group offered several suggestions to improve NHS services for disabled individuals.

Improving staff training was one of the most common suggestions. Participants called for mandatory training on disability awareness, including the social model of disability, to help staff better understand and accommodate the needs of disabled patients. One participant suggested that training should be rolled out across all staff, including administrative workers, who are often the first point of contact for patients.

Another suggestion was better access to a range of treatments, such as hydrotherapy and ongoing physiotherapy, which were once widely offered but are now difficult to access. Participants also mentioned the need for the NHS to offer treatments like acupuncture, as recommended by NICE guidelines, especially for chronic conditions like fibromyalgia.

The issue of the accuracy of medical records was raised, with participants calling for greater transparency and access to their medical records to ensure that mistakes are corrected promptly. One participant shared their frustration with a misdiagnosis that had been recorded in their notes and the challenges they faced in trying to have it amended.

In addition to the points above, participants emphasised the need for better visual and sensory aids in hospitals. One participant with a visual impairment explained that relying on verbal directions alone was insufficient, and they recommended the use of clearer signage and tactile guidance to help patients navigate hospitals.

6. Additional Comments

One participant underscored the importance of being treated with dignity and respect, particularly in cases where they had to repeatedly explain their disability or identity. This was echoed by several participants who felt that staff attitudes needed to improve, particularly in terms of empathy and communication.

This report was written by the Project Lead for Coproduction & Disability Equality at Action on Disability, and commissioned by Victoria Brignell, former Chair of Action on Disability

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