

Care
Opinion
Scotland

Disability in the NHS

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Oiligh na Gàidhealtachd
agus nan Eilean

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Introduction

Who am I?

My name is Iona Gibson and I am a postgraduate medical student based in St Andrews. As well as pursuing a career in medicine I also have a background in working with people who have disabilities, this led me onto wanting to dive into researching feedback from people who have disabilities about the NHS using Care Opinion.

Why research disability?

As a carer, I have watched people who have disabilities face many challenges when it comes to their health but unfortunately one of those challenges was the care provided by the NHS. Over time changes have been made in some places to make services more accessible but there is still a long way to go. Personally, I find it hard to believe more change has not happened to aid people with disabilities as they make up almost half of the Scottish population when you include long term conditions. This can be seen in a statement on NHS Ayrshire and Arran website:

“Long term conditions are health conditions that last a year or longer, impact on a person's life, and may require ongoing care and support.

The definition does not relate to any one condition, care-group or age category. Around two million people, 40 per cent of the Scottish population, have at least one long term condition and one in four adults over 16 reports some form of long term illness, health problem or disability.” (1)

This highlights that changes are crucial to make healthcare accessible to the entire population, not just 60%.

What is the Scottish Governments' ambition?

Previously society was focused on what is called the medical model which means that the person who is disabled is impaired by their condition rather than their surroundings. The Scottish government is working towards the social model which focuses on the barriers that are created by society and the environment rather than the disabled person being the problem. The Scottish government website states:

“In other words, it sees the barriers created by society, such as negative attitudes towards disabled people, and inaccessible buildings, transport and communication, as the cause of disadvantage and exclusion, rather than the impairment itself. The aim, then, is to remove the barriers that isolate, exclude and so disable the individual.” (2)

They went on to state 5 ambitions they have in order to remove the barriers which disable people. The two ambitions which are relevant to this study are:

“1. Support services that promote independent living, meet needs and work together to enable a life of choices, opportunities, and participation.

Health and social care support services are designed to meet - and do meet - the individual needs and outcomes of disabled people.”

“3. Places that are accessible to everyone.

Housing and transport and the wider environment are fully accessible to enable disabled people to participate as full and equal citizens.” (2)

These ambitions were published in 2016 as part of their publications on equalities and rights which was stated to be a plan to 2021. The research which I have conducted is to see where the key issues still remain for people with disabilities but also to celebrate what is being done well within healthcare to make it more accessible for everyone.

At the beginning of my research I read The Equality Act 2010 to understand the duty which the Scottish Government should be held to. The first thing I noticed is the definition of disability in the act:

“A person (P) has a disability if—

(a)P has a physical or mental impairment, and

(b)the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities.” (3)

This opened up my search to debilitating long term conditions alongside impairments people are born with. Having this basis for my search criteria allowed me to look widely across feedback from people who face a variety of issues in healthcare to see what similarities come up continuously in Scotland.

The criteria by law for the duty to making adjustments to be necessary is when “a disabled person is at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled” (3). This meant that I constantly had to ask myself “would this problem still have occurred if the person was not disabled” when I was reading through feedback to see if the social model is being upheld.

Methodology

Using the Care Opinion search tool, a 3 year time period between November 2019 and November 2022 was selected. This time period was chosen to give a wide array of stories but to keep them recent therefore still relevant to healthcare procedures today. The search specified only focusing on stories from NHS Scotland so it directly related to my ambition of being a doctor in Scotland, and therefore not having to compare different services and different protocols due to the geographical difference across the UK. In order to focus my search on stories regarding disability in general I used the following tag words: disability, disability access, disability awareness, mobility, disabled, access, wheelchair, disabled access, learning difficulties, walking aid, chronic illness, disabled parking, frail.

The search criteria selected generated 390 stories. The stories were then narrowed down based on a selection criteria - the story articulated why something was positive/negative in order for learning points to be taken from the story. 100 stories were selected and the analysed for themes. The most common themes which occurred and overlapped were accessibility, awareness, communication, travel and appointment type. The stories were given tags to the corresponding theme for further analysis, which is demonstrated below:

Tag	No. stories	critical	% critical	Not critical	% Not critical
Accessibility	52	43	83%	9	17%
Awareness	40	20	50%	20	50%
Communication	34	20	59%	14	41%
Travel	3	3	100%	0	0%
Appointment type	2	2	100%	0	0%

Each category was then analysed to determine what negative outcomes needed to be changed in healthcare and what positive outcomes should be implemented across Scotland. I focused of accessibility, awareness and communication as they were the biggest topics, therefore the topics having the biggest effect on people with disabilities.

I compared the critical and non-critical stories which appeared in these topics, to identify key issues that are present across the country in healthcare.

Findings

Accessibility

The most prevalent topic that came up in the search I conducted was the accessibility of healthcare for people with disabilities. The issue of accessibility varied over accessing rooms in hospital, equipment for day to day use, lack of specialist staff, disabled parking and more. This made it clear that there are still many barriers that people with disabilities face when trying to access healthcare and services that would improve their quality of life.

Staff

It is common knowledge that the NHS is underfunded and understaffed but the impact of this on healthcare is amplified for people who are disabled as there are many hurdles they face to getting the care they need. This varies from the need of porters to specialist nurses, they all have vital roles in healthcare, and without them the care of people with disabilities is severely impacted.

First of all, stories mentioned the inaccessibility of help when entering and leaving the hospital.

“My husband had to attend for an appointment. He has had a leg amputated. I dropped him off at the drop off point assuming a porter would assist while I went to park up the car. No porter helped him and he had to struggle to push his wheelchair whilst trying to walk to reach the reception area where a porter could then assist. Apparently, the porters are not allowed past the entrance doors and cannot give aid outside. This is dangerous and ridiculous! This was an accident waiting to happen and we are not young either being 74 and 75 years of age. When I questioned this I was told that hospital rules state a porter can only help to and from the entrance doors. This incident put my husband very much at risk and I was told I could have ordered an ambulance but is this not then wasting the NHS time and money? Extremely upset and angry.” - 940546

Many people who have disabilities have someone who will bring them to their appointments whether that be carers, family members or partners, but having access to a trained professional with equipment such as a wheelchair to help the patient from the disabled bays or drop off point into the hospital could make the experience far less daunting of coming to hospital. If it would be possible to have a porter arranged for the people who need it from the drop off point it could improve patient safety and prevent falls if the patient desired assistance into the facilities.

Second of all, the accessibility of at home care staff is low which is dangerous for both the patient and the staff. This could lead to a patient often recurring in hospital more than required if they cannot get access to the care package they need which puts them at risk of declining. This is made evident in quote 991210. If someone is assessed as needing 2-to-1 care but this is not accessible this puts the carers in a difficult position as they are risking hurting themselves to help someone who struggles to support themselves. Also the potential of someone who can move being made bed bound purely due to lack of staff is heartbreaking as they will become frail and decline further, therefore decreasing quality of life due to staff shortages.

“where the care falls flat is in the discharge planning stage. I was made aware of my mothers discharge on Friday afternoon - to be discharged on Monday. Which is welcomed however all was not what it seemed. The story to date is, the hospital OT was asked to assess my mums abilities on admission and devise a plan of care. Then at a later stage again asked to carry out an assessment and formulate a discharge plan. I was recently asked into a meeting with the OT who subsequently went through the discharge plan with me which included 2 carers 4 times a day and the equipment that was required. This was an increase in my mothers previous care package of one carer twice a day. I contacted Wishaw Home Support to clarify mums discharge and care package. I was advised mum wasn't for discharge on Monday but Tuesday and that the care package was for one carer 4 times a day. I advised them that the OT had assessed for 2 carers and that I had contacted the hospital social work dept only last week who confirmed that on their system mum was down for 2 carers 4 times a day. My mums care package has seemingly been downgraded despite the OT assessment stipulating 2 carers. This assessment was documented in my mothers notes. This is pretty serious and I was told by the OT that part of the assessment of requiring 2 carers was for safety reasons (use of the steady) and the difficulties getting mum in and out of bed. My mum is 12 stone and her mobility is extremely poor. She may be able to move a very short distance but she gets tired and finds it very difficult to repeat this and there are times when she can't move her legs at all and requires the steady. I have witnessed this and asked staff to document it. No one has visited my house to assess how mum would cope in it. There is 36 foot steps from the living room to the bedroom and 31 foot steps from the living room to the toilet. Mum will not be able to do this without staff using the steady. To say that mum is getting about with the use of a zimmer without any problem is simply not true. I don't believe that the reason for the downgrade in mums package of care has anything to do with the best interests of the patient. I have just spoken with my mums previous care provider, who explained that they did not have the staff to provide 2 carers for my mum and that if they were to provide her care with one carer and they couldn't manage, mum would then be cared for in bed. They also stated if the care package broke down mum would be readmitted to hospital, and advised that they had spoken to someone earlier this morning about my mother's care and made them aware of this. This is an absolutely shocking situation for my mum to be in and I truly fear for her ongoing care at home.” - 991210

Lastly, the lack of specialist nurses accessible to bridge the communication between community and specialist healthcare does impact the care of people with disabilities and chronic conditions.

“I previously had an IBD Nurse involved in my care for over 15 years, until she retired and her replacement has since left for another post and I'm not aware of the job being re-advertised. IBD Standards highlight that patients, particularly inpatients, should have access to an IBD Nurse Specialist and evidence suggests that a patient's length of hospital stay may be reduced by the involvement of an IBD Nurse in care and in follow up... an IBD Nurse has prevented several hospital admissions as they have been able to get the right care and treatment for me at the right time and also in the least restrictive environment. Hospital stays are devastating for IBD patients and incredibly anxiety provoking due to patient to toilet ratio in a dorm” - 1015588

Patients having access to specialist nurses has a large impact on them understanding their own health, learning overtime what to look out for and getting treatment before their health declines to the point of hospital admission. Specialist nurses being another point of contact alongside the GP and pharmacists when a patient with a chronic condition or disability is experiencing problems, helps give further insight on topics that might not be known well to GPs' and pharmacists. Having more medical professionals part of the patients care team gives them the best chance at a better quality of life.

Hospital grounds

The hospital grounds themselves create accessibility issues for patients, from disabled parking to the buildings themselves not being wheelchair friendly. The Scottish government made it their ambition to make public buildings accessible to people with disabilities but this sadly has not been fully effective as there are still many barriers that

patients face. Another issue is the lack of rooms available in a hospital for patients overnight but this is a harder to solve issue.

There was many stories which mentioned being unable to park in a disabled parking bay.

“I am registered disabled with a Blue Badge. I attended today at 0900 hours at Inverclyde Hospital. There were no Blue Badge spaces available and all the general parking spaces next to the hospital were full so I parked in the eastern car park and walked across to the hospital. After my appointment and returning to my car I took the time to look at the cars parked in the disabled spaces near the front door of the hospital. Six of the cars parked there were parked without Blue Badge Stickers displayed on their windows...Can you tell me how this car park is or is not monitored and whether there are any penalties applied for wrongful use?” - 968536

Many of the stories mentioned they did not see blue badges displayed in the cars parked in the disabled bays, but also some stories mentioned staff were also parking in these bays (again, without a blue badge present). The first hurdle of attending a hospital appointment for anyone is finding where to go and getting parked but this is especially anxiety inducing for someone with a disability who has to worry about how they will cope getting into the hospital building if they have to park very far away whether that be to them being frail, at risk of a fall or using mobility aids that may not cope well with the carpark terrain (possible grassy patches, cobble stones, uneven concrete).

The location of the disabled car park is also important to consider.

“Having hospital appointments that span over 7 years for my special wee boy has had its stresses and strains along the way but what is so hard to comprehend is that there are still no public changing places facilities in the VHK to this day. He has ASN that requires me to be his voice - so why is it that his right and dignity (amongst many other disabilities - seen and unseen) are being dismissed and denied their basic human needs in a hospital setting? Disabled parking is still not adequate and although more parking has been provided it isn't on the doorstep to meet our needs, it is at the bottom of a hill. Clearly an afterthought in design, it really must be at the forefront in future changes and not a mere tick box exercise for those without the compassion to understand the hardships it brings. Parts of the old build are not suitable to fit a wheelchair through their doorways, or to fit into their small appointment rooms. This has to be said for orthotics, although the staff are amazing. It isn't suitable for their work environment either. A hospital appointment brings with it anxiety and dread but throw disability (seen and unseen) into the mix, well, this is heightened all the more. We need to be considered and catered for. Our lives are hard enough. Perhaps my story can't change the world and the challenges we and many others face but we can certainly share our thoughts to help raise awareness knowing that at least everyone can help change someone's world. Be that person - make a difference!” - 948848

The location of a carpark with disabled bays needs to be taken into consideration as it needs to consider how easy it is for a disabled person to get from their vehicle to the hospital entrance, therefore steep hills or uneven surfaces can make this really challenging and risky for the patient. As well as the car park location this story highlights the importance of accessibility of the hospital building layout for people who do have mobility aids and also the lack of changing facilities within hospitals can be very stressful when a person relies on another person for personal care, therefore requiring a space larger than a toilet stall for assistance. This can lead to accidents occurring, which could be easily avoided if there was adequate space for them to get changed with aid of their carers.

Another issue that often came up with regards to the hospitals themselves was the lack of rooms for patients overnight.

"My mother suffers from a degenerative brain condition... She is cognitively sound but physically she is wheelchair bound, uses machinery to transfer, cannot wash or feed herself and is unable to speak or communicate verbally. She was scheduled for PEG feeding tube insertion due to her being unable to get enough nutrition orally. We were asked to arrive at 14:00 the day before her procedure at Ward 104. My mother was extremely nervous about going into hospital as people who do not know her find it very difficult to understand her way of communicating and she was worried about her procedure. When we arrived, we were informed that there was no bed for her and directed to the relatives room. We were given no timescale for a bed being ready and waited for 6 hours (with my mother becoming agitated and upset. She was sore from sitting in her wheelchair for 6 hours) before a doctor informed us that they would put her in a bed in the corridor for the night as they couldn't free up a room. My mother was completely against this suggestion, as was I. My mother was expected to lie in a corridor with no privacy or dignity. She would have been hoisted for going to the toilet etc in her nightwear in the middle of a busy corridor, would have had no rest in the bright lights and was already incredibly nervous about her admission. Most importantly in this situation, she would have no access to a call button which would have meant that she would have been unable to summon assistance if she was in pain, needed help to move or needed the toilet as she cannot shout out or help herself. Fortunately, I was there to speak up and refuse this. If I wasn't there, she wouldn't have been able to communicate her feelings about the situation and they would have put her in the corridor despite it being wholly inappropriate...I write this not to complain about waiting for 6 hours (without her being offered a drink, we bought water for her cup) but to complain that it was suggested to leave her for the night in a corridor with no regard to her needs or abilities and no foresight of the risk and distress that that could have caused her." - 987050

This demonstrates the lack of access to rooms, therefore the horrible situations patients are left in, which is even more daunting for people who have additional needs. Leaving any patient in a corridor overnight which is bright, no privacy etc. would be uncomfortable and distressing for them but for a patient who cannot go to the toilet by themselves, cannot verbalise their needs, and not even having a call button when needing help would be detrimental to their mental and therefore physical health. This problem is not easily solved in the sense of the staff cannot magic another room for patients but arranging for someone who cares for them to take them home and give instructions if they are to have no food etc. before their procedure, so the patient can rest in their own bed and come back the following day having managed to rest in the comfort of their own home with someone present to monitor them. Not every patient will have this option or may be too sick for this, but when accessible it would be the preferred option for all parties involved.

Appointments

The accessibility of specialist appointments is lacking across the NHS which is a commonly known fact. The wait lists are incredibly long for understaffed specialist appointments which is challenging for any patient to cope with, but this can be especially trying for patients who have disabilities who already have many barriers to face, as well as struggling to get help with their health issues.

“I attended for help with severe incontinence and groin/legs/back pain since my monarc mesh op several years ago. I've developed chronic lichen sclerosis in groin/vaginal/anal areas. For years have been unable to have a sex life. I have chronic UTI'S constantly recurring. I attended the clinic, they ran some tests promised botox for incontinence as I had told them removal was a last resort. I have not heard from them since. They have not offered to locate via translabial or ct scan where in my body the mesh is. Instead they appear to have archived my suffering, perhaps because I told them removal was last resort. They have not offered or even made any attempt to help me with my current issues. I have been trying to get help from Glasgow Health board via GP and various hospitals since 2006 when my mesh was 1st inserted. Nothing has helped. The Mesh clinic at QEUH was my last hope. Instead I'm left in pain with terrible incontinence and painful lichen sclerosis and constant UTI'S They have not contacted me for over a year This affects every aspect of my life I am severely limited in many areas; social/sexual/family/excursions/shopping/travel/hobbies my life revolves around my health issues I cannot plan or enjoy any of the above because of pain and incontinence and mobility.” - 989768

Patients should not feel like they have been archived, especially when their health issues is causing incontinence, chronic pain, infections etc. and is affecting everything, therefore severely diminishing their quality of life. Leaving patients in this state without any communication or help is devastating and needs to change.

Equipment

The last issue that propped up to do with accessibility was the accessibility of healthcare equipment and appropriate maintenance of that equipment. The most prominent issue was with regards to wheelchairs.

Wheelchairs are a life-changing piece of equipment that enhances the lives of the wheelchair users as it provides them with mobility and stability. Therefore, the absence of a wheelchair or having one that does not fit that specific person would be detrimental to their health and would prevent them from being able to function to the best of their ability.

“Our local physiotherapist referred my grandson to WestMARC aged three in 2020, requesting a wheelchair and sharing information with his mother on the type of mobility aid she was considering. At this point, my grandson could sit unsupported, but could not crawl, stand or take any steps. At assessment, WestMARC informed my daughter that they considered the requested aid an “overprescription” and instead recommended a buggy. My daughter was persuaded that this was lighter and more convenient. This was the only mobility aid he had through two years at nursery. ... At age 4 1/2 my grandson was still unable to crawl, stand or take steps. The implication of this was that school transport could not transition him safely into a taxi and a wheelchair would be required for bus transport. In addition after two years of daily use his lightweight buggy was falling to pieces. The local physiotherapist advised that WestMARC was likely to be more responsive to a family and suggested contacting them directly. ...School transport as predicted has not been possible, although his local council have made it available. We cannot use it and for the past six months have been forced to transport him to and from his specialist school, which is 5 miles from their home. It is now my belief that my grandson’s buggy may never have been an appropriate mobility aid for him and certainly quickly became inappropriate....Alternatively in the five months we waited for an appointment any contact with his local physiotherapist before he was reviewed would’ve prevented my daughter from having to retell the story of my grandson’s distressing and complex challenges. At this appointment, finally, a wheelchair was prescribed. Of course this is not really the end of the story...At his appointment, my daughter was advised that there would be a “6 to 8 week“ delay in provision of the device and of

This highlights the struggles families face when they need to go without a wheelchair. For this young boy, not having a wheelchair will have done more than just impact his mobility; travel was made difficult, starting school is daunting for any child but especially when you lack the element of independence that mobility provides.

Following on from the importance of having a wheelchair when necessary, this also means that it is vital for the wheelchair user that their wheelchair functions properly and if it breaks then they will need it fixed right away so they do not end up housebound waiting on repairs.

“I rely heavily on the use of my power chair for everyday use due to my cerebral palsy...I was enroute to a concert when my power wheelchair failed and wouldn't work. I had one of my PAs with me however this left me in a vulnerable position, which led to me being stranded in Glasgow Central Station for over 3 hours until I managed to contact a friend who was able to bring my manual wheelchair to me and take my powered one home. It was just by luck that I was able to ask my friend for assistance, she could have had other plans, it was a Saturday night after all. Due to the fact WestMARC do not currently provide an out of hours service for wheelchairs, if I hadn't been able to ask my friend, I would have had no other option but to phone the police or fire brigade for assistance. On a Saturday in the middle of Glasgow, it would have been extremely unlikely that I would have been regarded as a priority, which would have led to a longer period of me being stranded. Legally other equipment disabled people like me must use daily is serviced on a regular basis, at least annually, but this is not the case for powered wheelchairs. Repairs are only carried out as and when required. I feel this is a health and safety issue. I realise that a regular service would not totally prevent the need for repairs, but it would reduce the risk a situation like the one I described above happening because faults would be more likely be detected earlier. Furthermore, in my view, WestMARC are currently acting unlawfully and not adhering to the Equality Act 2010. Therefore, I strongly feel that an out of hours repair service and an annual service on power wheelchairs should be provided by WestMARC as a matter of course. If WestMARC can't help providing this directly then sub-contracting could be considered.” - 1005028

This story brings forward the very important point that an out of hours/emergency repairs service does not exist for power wheelchair users. People who have a car have access to emergency breakdown services as to be stranded is dangerous, so why is an emergency service for powered mobility aids not in existence? The thought of being stranded, unable to move at all without the aid of another person sounds terrifying and there is a simple solution. Unfortunately this will come down to funding, which may feel difficult to justify since the majority of the population do not require powered mobility. But for there to be no emergency service available at all is dangerous, therefore not giving the people who do use these mobility aids equal access and following the disability model, as this is regarding the wheelchair user as the problem.

Non-critical outcome

Sadly, there was not many positive stories with regardless to accessibility but a theme that did occur was when patients did get access to the equipment they need and having it tailored to them made such a positive improvement on their quality of life and mental health. For example;

"I got my new chair today! So many things I can speak about so do bear with me during this little ramble. First of all, I was quoted a 12 week wait and only waited 8 before picking the chair up today. Which is absolutely brilliant and i'm really glad that Westmarc are able to hit under the target wait times. My chair is a Quickie Argon 2 in Flamingo Glitter. I nearly started sobbing upon seeing it! It was absolutely everything I could ever ask for in a chair. It has a 3 inch camber, foldable push handles, a swing away anti tipper, a static singular footplate and the perfect sized castors (I think 3/4 inches?) I felt such a massive difference in my seating position and felt so much more comfortable in this chair. I felt like I was gliding on the ground. I tried it in the little gym hall thingie over the bricks and didn't feel a single bump. It was so incredibly smooth. The new brakes are brilliant and feel much more stable than my previous chair. It feels like i'm sitting IN the chair, instead of on top of it. It feels as if it's a part of me instead of an external accessory. And oh my goodness, cannot say thank you enough for the beautiful colour. Who knew a bright pastel pink with ACTUAL glitter would be provided by the NHS?! The colour choices are absolutely amazing and i'm so thankful I got to pick this beautiful colour. All in all, I cannot say thank you enough. This chair will (and has already in the hour I've had it) changed my life. Not only does it meet all my needs in the technical essence, but it fits my personality and I don't feel ashamed or embarrassed of my chair. If anything, I want to show the whole world!" - 936264

The excitement and enthusiasm radiates from this story, the difference access to a wheelchair suited to someones needs and also giving them the choice of colour can let them take a piece of equipment and make it their own. Having a chair which optimizes the experience for the user is so important for their independence and mobility. Going that extra mile for the patient to feel their chair meets their needs will make it so much easier for them to get around, just like you would not give an able bodied person shoes they could not walk in, you do not want to give a wheelchair user a chair they cannot move around in with ease. Story 936264 demonstrates just how important it is to have mobility aids that suit the patient.

The next theme that occurred frequently was disability awareness.

Awareness

Mobility aids

First of all, one of the aspects with regards to disability awareness was staff being aware of the importance mobility aids have to their user and the physical and mental effect of removing them from the users possession.

“I contacted the SMART centre for wear and tear repairs for my day to day wheelchair I’m paraplegic. They were very pleasant and helpful as they always are. The person who attended my workplace to fix my chair was less than pleasant unfortunately. I work in a public government building and they arrived at reception which was busy with people, I greeted him and asked where his equipment was as I planned to go into the back of office area as normally happens when I get my wheelchair repaired. The repair person informed me they would be taking my chair away as they didn’t know the area so hadn’t parked conveniently close enough to bring tyres and tools in, so would be taking my wheelchair away to the van. I was concerned and asked if they were taking my chair away, the reply was to quite sternly say that they’d be taking it out to the van with them or it wouldn’t be getting repaired. 2 clear choices for me there. So I took them into the back non public area to sit in a chair, and they took my chair and said that they’d be back in 30 minutes. I said trying to be light hearted even though I didn’t feel it I’ll sit here and try not to have a panic attack. They said not to worry, no one was there to see me. I am never away from my wheelchair and found this experience horrendous. An office in the district had a bomb scare and evacuation recently. This and the humiliating way I was spoken to in front of everyone at reception played heavily in my mind for the entire 30 minutes. I don’t think it is acceptable for anyone to take a wheelchair away from their user without positive consent which in my case would be never. “- 993393

This demonstrates the importance a mobility aid has to its user, its not merely an object they own and use, it is a part of them that allows them to function and gives them their independence. Removing the aspect which gives someone their mobility and independence leaves a person stranded, filled with panic or at least discomfort, therefore this should be avoided if possible or at least have more compassion when explaining to the user why it needs to be taken away as it can cause much distress.

Appointments

Medical appointments require extra stages of planning for many people with disabilities especially if they need to organise a carer or family member to attend as well, organising transport and mental preparation for doing something out with their usual routine can be very mentally taxing. Therefore, there are more aspects that the patient needs to take into account for appointments, so when things need to change this can be quite distressing. The person with disabilities may also not have an understanding of why the medical appointment/procedure is required, therefore being in a strange environment, with strange people doing strange things can be extremely disorientating and lead to sensory overload. These factors need to be considered by healthcare staff when caring for someone with a disability.

“My young son is autistic. He was unable to cope with getting his flu vaccine at school so I arranged to take him myself...I phoned and managed to book an appointment for myself and my son. The operator confirmed this was for both his flu vaccine and primary COVID vaccine. She then provided me another number to arrange the flu vaccine for my daughter. The flu vaccine sessions for her were taking place at the same location and date of my son's appointment. We arrived and booked my daughter in and asked if my son could be seen for his appointment at the same time, as he doesn't cope well with queuing. When this was refused we asked if he could just get his flu vaccine now and we'd come back for the COVID jab. Again they said no, we would need to return in an hour for his appointment, which we did. I arrived 10 minutes early as requested but was not allowed in until 5 minutes past the appointment time. At this point my son was unsettled but coping. I booked him in and confirmed the vaccines he was getting then joined another queue. The longer we stood the more nervous and overwhelmed he became but we were managing as we had put strategies in place to comfort him. When we finally sat down with the nurse we were told it was a COVID only clinic and he could not get his flu vaccine. I explained that I had confirmed the vaccines he was getting 3 times, once on the phone and twice with the person who booked us in that morning. I also explained we had asked to get his flu vaccine at the earlier clinic and had been refused and told to come back in an hour. They spoke to their supervisor who said it could not be done. I explained again that he was autistic and there was no way I would be able to get him to do this again. They went away again and their supervisor agreed to allow us to get both vaccines and directed us to a booth. We were there for at least another 30 minutes attempting to get him to accept the vaccines.” - 997175

This story highlights just how distressing and overwhelming medical appointments can be for someone who does have additional needs. There will not always be a possibility to make adjustments, but when there is time and space available it would make a world of difference for that individual and therefore will help shape their perception of healthcare appointments in the future. As healthcare professionals, it is our duty to give each individual equal access to healthcare, but are we really managing to achieve that if we create an environment that over-stimulates and overwhelms our patients before they are even treated?

Taking into consideration the extra measures a person with disabilities may need to put in place in order to be able to attend their appointment is also a very important aspect.

“After taking time off work as an employee of NHS GG&C I attended my booked appointment for my vaccinations at the Lagoon Leisure Centre, to find centre closed! As a person with a disability it is not always easy to attend these things. On speaking to the nurse in charge she stated this was because it was too busy and at one point there was a 3 hour queue. When I went in there was maybe 10 people waiting. Time wasted for myself and my place of work, the logistics of attending resulting in nothing! Could someone not have called to inform me of the situation and cancelled before I attended or is this too sensible an option. Why is the nurse in charge allowed to just close the doors, refuse to see anybody else even though patients have booked appointments?” - 976487

For an able-bodied neurotypical individual of course there are aspects that come into consideration for medical appointments such as time off work or mode of transportation, but for people with disabilities there may be additional requirements that make getting to their appointments more difficult. For example transport may be more difficult as they may have a wheelchair or require moving additional equipment such as an oxygen tank. They may require a carer to be with them which will need additional planning on the lead up to the appointment. Medical appointments in general may be more mentally taxing due to them being out of the normal routine for that person. If a medical appointment needs to be cancelled for any patient they should be informed, but especially for those who have so many aspects they need to arrange to be able to attend in the first place.

Sensory awareness

Extra considerations for people with disabilities do not only require healthcare staff to consider the environment and timing of the appointment but how the appointment is conducted too. Sensory awareness is important with regards to both people who are hypersensitive to touch, sound etc but also how a “simple procedure” may negatively impact someone with disabilities by overwhelming them.

“Terrible experience with one of the nurses. I was having routine vaccinations and the nurse was extremely blunt and it seemed they were not trained in dealing with Autistic patients. They hurried me through the vaccines not giving me any information other than take paracetamol if it hurts, Autism trained nurses always explain exactly what is happening and help as much as possible, they also are supposed to offer a private room seeing a sunflower lanyard (which I was clearly wearing.) They were rough with the needles which were painful and bled lots, so much as so they bled through my t-shirt. They didn't apologize or anything. I'm a wheelchair user so badly done needles mean I can't push myself for a few days. This takes away my freedom and the ability to leave my bed. Thanks to this I'm going to be scared for my next vaccine appointment and will leave me unable to move for about a week.” - 956019

This story demonstrates how something as simple as receiving a vaccine can have a highly negative effect on the patient when there are extra sensory considerations required. Taking the time to talk to patients, ask about their needs if you are unsure and accommodate what you can goes a long way and could have prevented this patient from being scared to attend their next appointment.

Mode of communication

A very simple thing such as the method of communication can be overlooked as a source of anxiety for people with a variety of disabilities. It is difficult when a patient is not given a choice as this can be overwhelming and result in them not getting the care they need because they avoided making a phone call. This can be seen in the story below as it was a very anxiety provoking experience for this patient.

“I got an NHS letter telling me to phone them to discuss referral appointment or I will be removed from the waiting list. I felt this is an unsafe model of practice. I am autistic and using a phone is very difficult for me to process verbal information and with this I feel inflexible - phone us within 2 weeks (minus the 4 days to took for the letter to be delivered), it puts me into confused distress. My NHS file states I am autistic, this appears to be a one fit all size authoritarian system which is taking no consideration for disability or equality. No other option or channel is given. What happened to neurodiversity? I feel this phone us or be cut off system is a dangerous risk to the health and well being of the autistic community and to other vulnerable people with social communication differences... To discuss your appointment? To an autistic person this is an open ended vagueness (to discuss what), the uncertainty is very stressful. As an autistic person, I can't process unknown information with its inferred tone which my mind can't socially measure...I feel sad, angry and full of anxiety now.” - 974970

Whether a patient has a physical problem which impacts their ability to speak or gets overwhelmed at the thought of dealing with important situations over a phone call, there should be more than one option for them to contact the healthcare provider e.g. email. Providing the element of choice can remove so much anxiety and pressure as the patient can choose the mode of communication that suits them best for them to receive the best healthcare possible. Small changes such as providing communication options can open up the accessibility of healthcare to

people with different needs rather than them being discouraged based on the communication method chosen by staff. This does come with challenges such as staff having to set up a portal just for the patients to send this information to so it does not get lost but it could have a huge impact on how the patient experiences the NHS.

Although there are many areas that show a lack of awareness for different needs across the NHS, there is also evidence to support some healthcare providers are going the extra mile for patients with additional needs. The following awareness topics will be non-critical.

Non-critical outcomes

Patients who do have additional needs may require extra time, patience and care from the healthcare staff. It makes the world of difference for the patient if the staff are understanding of their needs.

“Welcomed by Tracey. She worked so hard to make sure the chair was perfect for my sister. Despite my sister being so excited about her chair that she made it incredibly difficult for Tracey and her assistant to change anything. Working under a constant stream of don't touch that....leave my chair.....etc.... staff were brilliant...positive...caring and kind. Thank you so much.” - 1004961

This story highlights the care which was put into meeting the patients needs, working around what they were comfortable with even if it takes extra time etc. Going the extra mile not only impacts the patient at the appointment but will help their perception of future appointments. The family and/or carers appreciate so much when staff are understanding as it is insanely difficult to try and make the person they care for comfortable in an environment where they themselves do not have much control to improve the experience for the patient.

Another element that is very important to caring for patients with additional needs is still treating them like a person. This sounds simple but unfortunately people are repeatedly seen as their disability and nothing more, rather than a person who just needs extra help.

“My daughter was admitted to Medical High Dependency in St John's Hospital Livingston (NHS Lothian) due to Flu. She has cerebral palsy and was quite unwell when she arrived. I just wanted to say a massive thank you to all the nursing staff, healthcare support workers and medical staff who cared for my daughter. They treated her with dignity and respect and did not judge her quality of life by her disabilities. They kept her entertained through their great banter and the care she received was gold standard! Different to our experience in another hospital, I felt confident leaving my daughter's bedside, I knew that the staff would take good care of her and the care plan they used to understand her needs was excellent. They made her time in the ward fun, so much that she didn't actually want to be discharged which is a first for my daughter as she usually hates hospital and get so distressed. I cannot praise the nursing and health care support worker staff enough, they are all amazing!! As a mum of a daughter with complex needs, I felt listened to and reassured that my daughter was being treated with dignity and respect. The words thank you does not seem enough!” - 1003346

The importance of avoiding judgement when meeting a patient with disabilities, especially pre-judging their quality of life is so important as you have no idea what their day-to-day life is like. People function with a variety of levels of what is considered normal for them to live a happy healthy life, even if that isn't what an able-bodied neurotypical person would think. A very important element of caring for people who have a disability is the ability to enter the patient's world, see how they see things so the staff can make adjustments for appointments and treatment to be as comfortable as possible. Shaping the NHS to make healthcare equally accessible to everyone regardless of disability.

A common mode of communication in people who have learning difficulties and are nonverbal is Makaton. This is a simplified sign language which allows them to communicate with people around them, but sadly this is only a mode of communication people who are in contact with a user of Makaton tend to have even heard of it.

“I have to take my disabled son to out of hours last night. Dr Coates was finish his shift but he stayed on so he could help my son understand what was happening to him, DR Coates was Fantastic at signing makaton and my son and me feel more relaxed about being there. My son give the nurse and doctor a big cuddle after it all.” - 975069

Makaton is a very simplified language, which therefore would not take a large effort for healthcare staff to be made aware and learn basic things to say using Makaton. It is the same as in the case of a BSL user requiring signing due to lack of hearing, Makaton is helpful due to struggling to communicate verbally. A common misconception is that because someone is nonverbal it means that person does not understand what is going on and being said to them. Makaton being used in healthcare can make a massive difference to how these patients experience healthcare, giving them the equal access to understanding what is happening to them when they are unwell. Good communication was demonstrated here in story 975069 which made the appointment far less distressing for the patient. Learning Makaton should be made available to all healthcare staff.

An important aspect of treating patients who have disabilities is to enter their world, and try to expand the options available to them rather than them being restricted by a world made for able bodied people.

“I asked for a referral to WestMarc for a prosthetic to help with exercise (specifically yoga) as I have a limb difference (shortened right arm) which I've had since birth. This had resulted in increasing back pain which I was hoping to limit and manage long term...The referral from my GP came back within a few weeks and was so impressed by the service from my first appointment. When I first went in, I met with a prosthetist and OT and was referred for physio. I also got cast for an arm on my first visit. They were all super supportive and eager to look at options for helping mobility/pain and increasing the type of activities I could do. I met with a physio soon after my initial appointment and was assessed and given some starter exercises to increase my mobility. I can't say enough how much that has made a difference to pain levels and general daily living...My yoga prosthetic was built and I have used it multiple times per week for yoga, Pilates and going to the gym. It's feels like a part of me and my prosthetist has been great at amending parts of the socket to fit better. I had some prosthetics when I was in Primary school but had not had any since. I really wish I had got in touch with the service earlier as having this as a tool has enabled me to access exercise classes and gym machines I've not been able to before. And has given me the confidence to go into group classes and ask how I might adapt things. I'm now in the process of getting a multi-articulating arm to use for daily activities and specialist activities such as woodwork which has opened up a whole new world of possibilities! Overall, I can't say how much I've valued the input from the team. Going from a position of having pain, not knowing how to manage that, and not knowing who to turn to get help, I'm now in a place where my mobility and general fitness is improving and I'm now looking at how I can improve daily living. Thanks so, so much guys!” - 1002050

This story displays a heartwarming example of how when healthcare staff enter the patients world they can see what would help them be able to live their best lives. This is an extreme example but it demonstrates an excellent point of how much you can increase someone's quality of life by making small alterations. The accessibility of healthcare professionals who understand the varying needs of different disabilities then projects further onto the impact they then have on the patients quality of life. Disability awareness in the NHS is a vital component of the care of our community.

Lastly, one of the most important topics with regards to disability in the NHS is communication. Communication between staff, patients and carers are vital to assure the best treatment possible.

Communication

Communication is a problem that appears consistently in care opinion stories regardless of topic, which tells us that it is an ongoing issue in the NHS which needs to be addressed. I feel this issue is amplified with regards to the disabled community as there are extra hurdles and requirements to ensure they have the best care possible.

Communication between healthcare staff

One of the crucial components to good care of people who do have additional needs is that healthcare staff relay information well between one another, especially if the patient themselves has a difficulty with communicating their needs.

“My sister has been in Queen Elizabeth Glasgow since early September with a positive diagnosis for Covid. Any infection affects her mobility and general health...When her isolation was up, a week ago, a physio rehab package was requested at New Victoria. Today I was phoned and told she doesn't meet criteria for rehab in either New Victoria or Langlands. The hospital staff were unaware that criteria had changed, so my sister has spent nearly a week in a medical bed unaware of this. I requested if Gartnavel was an option but physios have to recommend this and I have been unable to see any of them to enquire about this. I am concerned at lack of knowledge of hospital staff and the time spent before accessing rehab. With the September weekend coming up I fear the deleterious effect on my sister's mobility with a further wait. I would like to know that request is possible and has been made.” - 975844

This story is an example when poor communication between staff will impact the wellbeing of a patient, therefore delaying them getting treatment they require. Another example of this can be seen here:

Both of these stories highlight the significance of good communication between healthcare providers when the

“My mother is registered blind and has very poor mobility and also had delirium and was discharged home from ward 17 without a care package in place and no medication. The ward staff did not know who was providing the care package as the therapist had not informed them. The ambulance arrived before the medication and she was sent home without it. When I contacted the care provider who previously attended mum, they had not received any referral from the OT. I contacted the out of hours social work team who stated no referral had been received from the occupational therapist or ward. The out of hours duty worker arranged for emergency carers to put mum to bed. The volunteer service Saving Lives delivered her medication. I live 110 miles away and if I didn't come you see how she was, mum would have spent all night in her armchair where the ambulance staff left her. This was a very poor and unsafe discharge which could have been avoided with clear communication between agencies and ourselves and careful scrutiny that care was in place before discharge from hospital was implemented.” - 932910

patient has difficulties communicating on their own behalf. It can leave people in very vulnerable and dangerous situations which is unacceptable. Extra care is required in these situations, especially when they don't have a carer or family member present to advocate for them.

This leads us onto communication problems between the healthcare provider and family members or carers.

Communication between healthcare staff and family members and/or carers

Often involved in the healthcare of a patient who has disabilities there will be family members and/or carers who are vital components to ensuring they get the best care possible as their needs may be very specific or they may not be able to communicate efficiently to health professionals what they need.

“Background – My brother, suffers from COPD and is currently receiving palliative care with continuous oxygen and care at home. He lives on his own and depends on the support of myself, my daughter and his care package to help maintain some form of normality. Beginning of November 2022 – My brother was found collapsed at home on this date. We called for ambulance on 999 and he was sent to Accident and Emergency (A&E) at University Hospital Wishaw. After being initially assessed in A&E, he was admitted to the Emergency Care Unit (ECU). The next day - He was transferred to Ward 9... At the time, communication was lacking as we only found out that he was transferred after we turned up at ECU to visit him. Two days after being admitted – My daughter was called saying that he was fit for discharge from the hospital. Neither my daughter or myself had received any communication from the ward about the future plans for my brother’s care, despite the fact that we were visiting him daily. Eventually when asked, a staff nurse informed my daughter that he would be discharged in 5 days and they had assumed that the family would be responsible for his ongoing care even though he had an existing care package in place prior to his hospital stay. Given the deterioration of his health and his mobility, we were concerned that his current level of care outside hospital was insufficient...When my daughter arrived at Ward 6 to visit him, staff were unaware of who my brother was or where he was. This is appalling that family are not informed of their relative’s whereabouts within this hospital as it appears to be an issue with more than just one ward. Following the move to Ward 18, Doctors there determined that he was actually not fit for discharge. We wonder whether the constant upheaval over the weekend led to this decline. The next day – Suddenly, he was fit for discharge. He arrived home, this time by patient transport. He was home for around 15 minutes when he called me explaining that he was struggling to walk, frightened to fall and became incontinent. He was also sent home with diarrhoea. The next day – He was feeling unwell at home throughout the day. During his evening visit from his carers, he was violently sick despite not having eaten and they called my daughter concerned that he was having a seizure. My daughter asked his carers to call 999 for an ambulance immediately. Myself and my daughter rushed over where we found him covered in sick and then he had a further seizure while waiting on the ambulance. He was rushed in a blue light ambulance back to the hospital. Whilst in A&E, he had a further seizure and was extremely unwell. He spent the rest of the night in A&E and most of the following day whilst they tried find him a bed within the hospital. The next day – He was transferred to ECU in the late afternoon/early evening. I received a call from ECU informing that he was due to be moved to Ward 10, however this afternoon he was too unwell to be moved. Currently, my brother is still in hospital. Over the course of 22 days, he has been in A&E (x3), ECU (x2), Ward 9, Ward 8, Ward 6, Ward 18 and potentially Ward 10. We have grave concerns about the continuity of his care as he was moved so frequently and even greater concerns about the fact that he was discharged only to be brought back in an ambulance within 24 hours. This shameful treatment has contributed to a massive decline in his physical health and mobility. This experience has made the hospital feel like a revolving door and has been extremely unsettling for myself and my daughter.” - 1001339

This is a good example of how distressing it can be for the family and carers when there is no effective communication from health care professionals. Patients with disabilities do sometimes heavily rely on their loved ones to make sure they are safe and well, but this is an impossible job to do when health professionals are not working with you to help the patient all round.

“My mum was taken into the Langland's Building Unit at the Queen Elizabeth hospital in Glasgow in July 2022 and this place was disgusting. Firstly my mum was suffering from delirium and her mobility was walking frame aided with a companion, clearly stated on the board above her bed. One day she was taken to the bathroom, left unattended and had a fall banging her head on the hard floor resulting in blood loss. The ward nurse phoned and said my mum had fallen but there was nothing to worry about and then days later she had a scan and I was told she had a bleed in her head and there nothing to worry about either. Then my family was told that my mum had Covid, then didn't have Covid, but they had a patient who was next to my mum's bed who did. This patient was allowed to walk about the ward instead of getting put in isolation... My mum also said she was left soiled for two hours one night after asking the nurses she needed the bathroom. On another occasion during the heatwave she said the nurses put the buzzer on the wall instead of next to her resulting in her saying her mouth was stuck together as she had no fluids. Then my mum got moved into a ward down stairs and one of the senior nurses said in ear distance of my mum this was an end of life ward resulting in my mum having a panic attack which for me was very cold and unprofessional...I feel like they just dumped my mum and two days after this I thought she was going to die as her condition deteriorated. I was given no medication or equipment to help with her condition...I still feel to this day the fall quickened my mum's death and although accidents do happen ,this for me was lack of care. “- 994163

This story also demonstrates the value of family in healthcare. If the family are the people who care for the patient day to day then they are the personal experts for what that patient needs day to day. These needs are amplified when a person is unwell, which is something that should be considered when a health professional is history taking. Putting a clear picture together of what a person can and cant do for themselves, to put assistance in place drastically changes their healthcare experience. There is a duty of care, but people forget to ask what that looks like for different patients.

Communication about appointments

The way communication occurs to patients should always be simple to understand in order to make it easier for the patient. Unfortunately, it is quite common that the communication from healthcare staff to people who have disabilities does not include the information required for someone with additional needs.

This highlights that it can be distressing for communication from healthcare to not include basic things such as

“For the benefit of women invited to attend Breast Screening I would encourage them to attend, the majority of women will have the mammogram done with no problems. If you are a woman invited to attend and are a wheelchair user, in case you are unaware (I certainly was) you can attend your local mobile unit as they all have hoists suitable to be used by both Self Propelled and Transit wheelchairs. Yes, your invitation to attend will tell you if you have an access issue, are disabled or a wheelchair user to contact your local static centre, in my case WOSBS . Every mobile unit in Scotland has a hoist fitted sadly, there is no sign anywhere on the outside of the unit telling patients this, never has been nor is there any details about this in the information booklet enclosed with the invite letter. WOSBS state being in a wheelchair is ""not a barrier" to a wheelchair user. I beg to differ. Why not update information sent to patients to tell them about the availability of hoists at the point of initial contact or update the information booklet? Why is there nothing on the mobile unit, not a poster or a flyer about the availability of this asset. It is very much like for some reason you want wide its very existence. How have I been left feeling, worried upset, disgusted, struggling to believe this has happened to me, and wondering how many others have experienced the same thing” - 983388

wheelchair access. A simple fix is for health boards to include in their email/letter communication about the disability access they offer such as wheelchair access or if they have a sensory room on their premises etc. To able-bodied neurotypical people it can be hard to predict what information is important for people with additional needs, therefore this could be gathered via surveys to patients and having an EDI committee to mitigate the suggestions. The job of the NHS is to remove the barriers which stop someone from getting access to equal healthcare, therefore this could be a reasonable adjustment.

Discussion

NHS services need to be accessible. Accessibility means many things to many different people depending on their needs. The difference between a smooth trip to the hospital and a very stressful and strenuous trip can be as simple as having access to a wheelchair and porter on arrival. Staff shortages is an ongoing issue with regards to access to specialist nurses for chronic conditions to prevent hospital admission but also care staff for home care are important to prevent prolonged hospital stays. Simple things such as the accessibility of disabled parking spots and their location can make a big difference to peoples healthcare experiences such as being beside cobbled paths or being down/up a steep hill from the clinic. It is also known that hospital rooms and beds are hard to come by as they are so busy but the lack of accessibility of them for people who have disabilities it can leave them in vulnerable situations. Lastly, the accessibility of equipment such as wheelchairs can be life changing but also access to repairs services when needed is vital to this as if their chair breaks it takes away the majority, if not all, their independence.

The next topic which was explored was disability awareness in the NHS. For staff who do not have a disability or have been regularly exposed to people with disabilities, then they might not have an awareness of what is important to those who do. An example of this would be the level of importance which mobility aids have for their users. Removing mobility aids without consent can feel extremely invasive and remove independence. Also having an awareness of how places such as waiting rooms can be very overstimulating with the bright fluorescent lights, loud chatting and equipment being moved around. Another overwhelming element for some patients is the additional requirements they have for transport e.g. being able to move their additional equipment e.g. O2 tanks on public transport or making arrangements for carers to be present for the appointment.

Lastly, the topic which comes up in many areas of research is problems with communication. With regards to patients who have disabilities, they require good communication between staff so they do not need to relay their needs regularly, especially if they have communication difficulties themselves. If the patient requires care from family members or carers, it is also crucial that they receive good communication from healthcare professionals as they will be the people ensuring that patients care once they leave their appointment or hospital stay.

It is impossible to know every patients needs, I understand this. Asking the simple question "is there any additional needs you have?" can have a large impact on their perception of healthcare, even better if it is then added to their notes to make further appointments even more straightforward and accessible. We are a long way from having equality in healthcare, but I hope after reading this we are one step closer to staff being more aware of the problems faced by people who have disabilities.

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