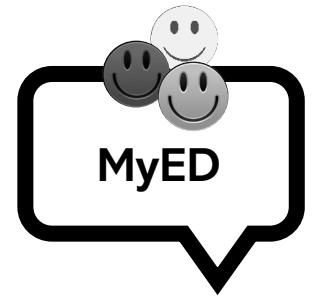


MyED Touchpoints – Disability



Summary:

People living with disability (PlwD) present frequently to all three study EDs, but hospitals lack sufficient complex service capacity for inclusive, accessible and timely care in the ED. EDs are designed to treat patients with acute illnesses on the premise that patients will only spend 4-6 hours within the ED. The ED environment is not specifically designed for the needs of PlwD, particularly those who live with a moderate to severe disability. NDIS regulations for paid carers to attend ED with PlwD need to be clarified, and an audit of communication tools available was required. Triangulating all data, the focus for codesign will be to improve communication for PlwD in the ED, specifically:

- optimal implementation and use of the “All About Me” tile developed by the Sydney Childrens Hospital Network (see Appendix 1), where a ‘jigsaw’ icon on the FirstNet screen leads ED staff to completed personal information about the PlwD.
- alternative communication of common procedures such as CT scan and IV cannulation/blood test.

Step 1.1 – Non-participant observations (NPOs)

NPOs were conducted at Mount Druitt, Blacktown and Westmead Emergency Departments. Overcapacity and long patient wait times were evident at all EDs. NPOs highlighted the lack of equipment such as wheelchairs in the EDs with staff sometimes unable to locate one when needed. Wayfinding for sight-impaired individuals was limited. Some individuals left aids at home so they wouldn’t be lost during their ED visit. Carers were observed advocating for PlwD when assistance was needed.

Step 1.2 – Interviews with Users

We conducted 36 interviews: 15 interviews with PlwD (intellectual and physical), 12 carers, and four epistemic experts. PlwD who were dependent felt staff had difficulty fulfilling their basic and specialised needs - for assistance with eating or drinking, personal hygiene, and mobilisation. If present, carers often provided physical and emotional care for PlwD when ED staff members were not available. In the absence of high levels of care and attention, carers perceived PlwD experienced distress when their needs were not met.

“It was a full roast dinner and a slice of bread. I said to the nurse, ‘she can't eat that’. The nurse said, ‘we can't get anything else from the kitchen now’. So, they were just going to let her starve all day.” Carer of PlwDSP13

Carers reported both high-level communication and poor communication (e.g. using medical language, talking to the carer only not the patient) or a lack of communication.



“One of the things my participants found most traumatising was being given needles unexpectedly. It’s like – it is actually an assault. You’re not meant to give anybody a needle or a procedure without having gained even an informal consent.” (Paid carer, 15)

PlwD and carers noted that the staff communication was rushed and perceived staff behaviour to be uncaring at times. Carers aided communication between staff and patients, providing additional time and resources (e.g. communication aids) needed for people with a disability.

“They were talking over her head. They didn’t try to communicate with her. They were talking to me. They weren’t talking to her. So they weren’t asking for consent or for anything. They were just saying ‘can we’ to me, and then they’re just putting the mask on to her after they asked me.” Carer of PlwDSP5

“Just try to be more caring and what not. Me myself, I’ve got autism, so it’s really hard for me to express myself and it’s hard for me to find the words, if that makes sense... Like they behave like they don’t care, and I know that they do, but actions speak louder than words.” PlwDFP8

ED users found the environment was loud, high stimulus, lacked accessibility and privacy, and was uncomfortable. Physical access to and within the ED was sometimes problematic, some hospitals did not have appropriate equipment which led to poor mobility and care. PlwD and carers emphasised the need for carers in the ED to help with communication, advocate for, and support physical and emotional needs of PlwD. Paid carers claimed that the NDIS funding policies did not cover their work if they were caring for PlwD in hospital and this was perceived as a significant barrier to their accompanying the PlwD to the ED.

Step 1.3 – Interviews with providers

We interviewed 50 ED staff members in total: 44 staff in 43 interviews and 6 Patient Experience Coordinators in 1 focus group. Staff recognised that basic and specialised needs of PlwD (e.g. access to appropriate food/drink, showers, toileting) were not being met in the ED. Staff reported that PlwD often had high care needs, requiring round-the-clock-care, and that they did not have the capacity to provide the level of care needed because of lack of time and higher priorities.

“I think it all comes down to time really, because I had one person with a severe Down Syndrome, intellectual disability, and his family just had to stay 24/7 because I couldn't be with him all the time, and he needed 24/7 eyes on him, or more frequent care than I could give him.” (SM48ED2)

Some staff reported that they lacked confidence and specialised equipment at hand to provide specialised care they perform infrequently for PlwD.

“We don’t have them [Percutaneous Endoscopic Gastrostomy (PEG) feeding equipment] here in Emergency. We try our best to ask some of the surgical wards upstairs to bring us down the run lines and all the [PEG tubes]. They will be like, ‘just bring it back’ but most of us here is [are] not really competent to do those.” (SM47ED2)

Staff were aware that the level of care afforded people living with a disability was inadequate for their needs, and grateful when carers, who knew their clients or family members well, were able to stay to provide specialised care for PlwD in ED. Staff recognised that the ED is not an



environment that suits the needs of people living with a disability. They noted the design of the ED environment posed physical barriers such as inadequate space for wheelchairs, doors and wayfinding are not disability-friendly). The toilet doors in the waiting room of at least one ED were swing doors, not sliding, making access difficult for some PlwD. These barriers limited staff-patient care, self-care or mobility around the ED. A high stimulus environment sometimes triggered behaviours of concern. Staff felt ill-equipped to manage behavioural issues effectively, because staff did not know the patient, and they depended on carers' knowledge of PlwD to deescalate situations quickly.

“The environment is very overstimulating in there, it’s hard on the patient and the parents or the carers, or whoever is with them, to try and keep them calm and comfortable.” (SM16ED3)

Additionally, ED lacked equipment, or available equipment was not repaired in a timely manner. Staff found it difficult to communicate where there were multiple disabilities such as hearing and sight deficits, others recognised that they needed to find alternate ways to communicate although this could be difficult in emergency situations.

“We’ve had deaf and blind people and they’re in respiratory distress and you’re there trying to hook up some really high-flow oxygen to their face and they’ve got no idea. They’re deaf and blind and have no idea what. It’s obviously a stress for them and you can’t explain it right. So oftentimes those disabled patients are difficult because I don’t think they understand what you’re doing and you’re a threat to them.” (SM25ED3)

Staff valued carer involvement when communicating with PlwD, though noted that PlwD sometimes did not have a carer. Carers acted as an intermediary when rapport could not be established or often offered a relevant medical and psychosocial history of the patient. While most patients arrived with information packs that contained useful medical and psychosocial information, many staff said that they needed the information in a synthesised and accessible format.

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