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To cite this article: Liesje Donkin, Carrie McColl & Marleen Verhoeven (19 Aug 2026): Stakeholder views on hospitalisation of adults with intellectual disabilities in New Zealand, Journal of Intellectual & Developmental Disability, DOI: [10.3109/13668250.2026.2681222](https://doi.org/10.3109/13668250.2026.2681222)

To link to this article: <https://doi.org/10.3109/13668250.2026.2681222>



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Published online: 19 Aug 2026.



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Stakeholder views on hospitalisation of adults with intellectual disabilities in New Zealand

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ABSTRACT

Background: Community stakeholders play a crucial role in supporting the wellbeing of people with intellectual disabilities, including during hospitalisation. This study explored community stakeholder perceptions of the barriers to safe and equitable hospital care for adults with intellectual disabilities in Aotearoa New Zealand.

Method: Semi-structured interviews ($n = 9$) and anonymous online surveys ($n = 38$) were analysed using reflexive thematic analysis within an interpretive description framework.

Results: Four themes were generated: experiencing the hospital as unsafe due to structural and interpersonal discrimination; communication breakdowns that undermine care and amplify distress; distress misread as behavioural issues; and stakeholders becoming the default safety net. Across themes, discrimination emerged as the underlying mechanism shaping patient safety, communication practices, behavioural interpretations, and reliance on stakeholder vigilance.

Conclusion: These findings highlight the need for systems-level change, including improved training on working with people with intellectual disabilities, enhanced communication practices, and strengthened continuity of care to support equitable hospital experiences.

ARTICLE HISTORY

Received 3 May 2025
Accepted 25 May 2026

KEYWORDS

Intellectual disability;
hospital experiences; New
Zealand; qualitative; health
care

Intellectual disability community stakeholders are a diverse group that plays a crucial role in the lives and wellbeing of people with intellectual disabilities. This group includes community agencies, volunteer support workers, and paid professionals who support people with intellectual disabilities. Community stakeholders offer support services for people with intellectual disabilities, such as assistance with daily living tasks, advocacy, and needs assessment and service coordination across various settings, including supported living facilities and private homes. Community stakeholders thus have significant influence in promoting and facilitating a good life for people with intellectual disabilities, enabling people with intellectual disabilities to have agency over their lives and wellbeing (Windley & Chapman, 2010).

Community stakeholders may also provide support for people with intellectual disabilities during hospitalisation. Research has noted that people with intellectual disabilities are often high users of medical systems (Dunn et al., 2018), have poorer safety outcomes

(Louch et al., 2021), and experience less satisfaction within the hospital system (Iacono et al., 2014). As such, stakeholders are often crucial for people with intellectual disabilities during hospitalisation through their support and advocacy roles. Thus, community stakeholder perspectives are important because they can provide insight and expertise on the needs of people with intellectual disabilities during hospitalisation and on how hospital systems might improve their care.

To date, several studies have provided insight into the challenges that community stakeholders may experience when supporting an adult with an intellectual disability during hospitalisation (Appelgren et al., 2018; Dinsmore, 2012; Gibbs et al., 2008; Hemsley et al., 2011; Sowney & Barr, 2006; Tuffrey-Wijne et al., 2014). Key themes identified in international research include hospital staff lacking knowledge or training about intellectual disability, negative attitudes about people with intellectual disabilities in hospitals, communication barriers, inadequate care in hospital (McCormick et al., 2021), poor discharge (McCormick

et al., 2021; Parker, 2023; Webber et al., 2010), and support practices (Iacono et al., 2014). Little is known about the hospitalisation experiences of people with intellectual disabilities in Aotearoa New Zealand (NZ); however, each healthcare system may present unique challenges due to regional variations in care and support available. This study aims to explore community stakeholder perspectives on the hospitalisation experiences of people with intellectual disabilities in NZ.

Method

Research design overview

This qualitative study gathered data through free-text responses in an online survey hosted on the Qualtrics platform (Qualtrics, 2024) and through semi-structured interviews, and analysed the data using an interpretive descriptive approach (Thorne, 2016) to capture participants' subjective experiences (Thompson-Burdine et al., 2021).

Box 1. A comparison of semi-structured interview and survey questions.

Section	Semi-structured interview questions	Survey questions
Consent	Oral consent process	Digital consent process
Introduction	Introductions and relationship building	
1	Demographic information	Demographic information
2	What were your experiences of supporting an intellectually disabled adult during hospitalisation?	
3	How do you believe people with intellectual disabilities experience being hospitalised?	Can you please tell us about your views on how people with intellectual disabilities experience being hospitalised?
4	What are the biggest challenges for people with intellectual disabilities when in hospitals?	What are the biggest challenges for people with intellectual disabilities when in hospitals?
5	What things worked well for you as a support person of an adult with an intellectual disability during a hospital stay?	What are the things that make being in a hospital easier for people with intellectual disabilities – both for the person with the disability and for their caregivers/support people/and treating team?
6	What would you like to see improved to better support other support people of adults with an intellectual disability during a hospital stay?	How do systems need to change to better support people with intellectual disabilities when they are hospitalised?
7	Are there any other comments you would like to make?	Are there any other comments you would like to make?

Participants and recruitment process

Participants were recruited through email invitations sent by researchers' networks and several agencies that provide support in the intellectual disability field. These agencies were identified via internet searches between July 2022 and November 2022. No advertising to the general public was utilised.

Inclusion criteria

Although stakeholders are a broad group, this study defined community stakeholders as people working in professional roles supporting adults with intellectual disabilities in the community. These roles include residential support workers and medical/allied health staff, such as occupational therapists, nurses, and psychologists. Participants needed to understand and communicate in English well enough to read the participant information sheet, complete the informed consent process, and participate in either the online survey or the interviews. There were no exclusion criteria.

Data collection

Both interviews and the online survey included similar questions to enable comparison and integration of the datasets. The number of questions was kept small to reduce the burden on survey participants. Having few questions also enabled the semi-structured interview format, allowing further exploration of participant answers and subsequently the generation of more in-depth data and insights. A comparison of the questions from both formats is provided in Box 1.

Recording and data transformation

Interviews were conducted and recorded through Zoom (www.zoom.com) and were transcribed verbatim. All identifiable information was removed during transcription, and participants were assigned code names (e.g., CSH01) to maintain confidentiality.

Data analysis

Data were converted to written format through transcription or the export of survey responses, enabling interviews and surveys to be analysed in the same manner. Seven survey participants did not specify their role as community stakeholders, so their answers were reviewed for information indicating they may fill another role (e.g., family caregiver) prior to analysis. All responses were consistent with the language of

other participants who had specified their community stakeholder role; as such, these seven participants were included in the dataset.

Interview and survey data were analysed using reflexive thematic analysis (TA; Braun & Clarke, 2006) conducted within an interpretive description framework (Thorne, 2016). This approach focused on the researchers' subjectivity and demanded a recursive and reflexive involvement with the dataset to obtain robust analysis (Braun & Clarke, 2006). TA was chosen for its widespread use in health research and for its focus on understanding people's perspectives. TA has also been used in past research with people with intellectual disabilities (Van Alphen et al., 2009) and thus appears appropriate for this study.

Data analysis involved the six phases of TA (Braun & Clarke, 2006): familiarisation through reading and re-reading the data; coding of the dataset; theme construction; review of themes; definition and refining of themes; and reporting of findings. Two coders (LD & CMcC) independently coded the data using free-coding to develop codes, patterns, and preliminary themes without preconceptions (Coates et al., 2021). Preliminary theme development was completed using the online platform, Miro (www.miro.com), which allowed codes, subthemes, and themes to be visually represented and rearranged as needed. Once the researchers had developed preliminary themes independently, they met to discuss these and achieve consensus through iterative discussion. Full consensus was achieved without the need to introduce a third coder.

Reflexivity was maintained through analytic memos and weekly team discussions throughout the study. As LD had only limited experience supporting people with intellectual disabilities during hospitalisation from a professional capacity and CMcC had none, they brought "outsider" perspectives to the analysis, providing more objectivity than if they had "insider" perspectives. MV had professional experience as a stakeholder working with the hospitalisation of people with intellectual disabilities and thus brought an "insider" perspective.

Results

Demographic characteristics

The total number of participants taking part in this study was 47, with 9 participants completing semi-structured interviews and 38 completing the online survey. Of those who completed the online survey, 63.2% ($n = 24$) identified as female, 15.8% ($n = 6$) identified

as male, 2.6% ($n = 1$) identified as non-binary, and 18.4% ($n = 7$) preferred not to indicate their gender. In terms of ethnicity, 55.3% ($n = 21$) identified as being of European descent, 7.9% ($n = 3$) identified as Asian, 7.9% ($n = 3$) identified as Southeast Asian, 5.3% ($n = 2$) were Māori, 2.6% ($n = 1$) were Pacific peoples, and 21% ($n = 8$) preferred not to report their ethnicity or identified as another ethnicity not specified. The mean age of participants was 45.37 years ($SD = 13.3$), ranging from 25 to 66. Professionally, 60.5% ($n = 23$) identified as community support workers, 10.4% ($n = 4$) were nurses, 10.4% ($n = 4$) were employed in other roles, and 18.4% ($n = 7$) did not report their profession.

Researchers generated four themes: experiencing the hospital as unsafe; the experience of structural and interpersonal discrimination, communication breakdowns undermine care and amplify distress, distress misread as behavioural issues, and stakeholders as the default safety net.

Theme one: Experiencing the hospital as unsafe: experience of structural and interpersonal discrimination

Stigma and biases were common. Stakeholders reported medical staff holding pejorative views and making assumptions about the abilities and skills of people with intellectual disabilities. People with intellectual disabilities were often regarded as lacking basic skills and were often treated in a degrading manner due to this.

I think they're labelled; I can't think of the word ... stigmatised. People were still ... I've been here 20 years, I've been in this role 14 years and people would tell me on the phone of all different senior levels as well as health-care systems, "we've got one of 'your people' on the ward". As soon as they get on the ward, 90% of them are put in a continence brief unless they can fight to not have it because they're presumed to be incontinent. So, yeah, very negative. (CSH09)

Concerns were expressed that these discriminatory attitudes led to people with intellectual disabilities missing out on medical procedures as they were presumed to be unable to cope. This meant that people with intellectual disabilities were often either offered substandard care or missed out on procedures and care that – at best – may improve their quality of life, and – at worst – negatively impact their survival if not received. Thus, people were forced to live with discomfort that would not be considered acceptable if they did not have an intellectual disability.

So, I've heard many a time that a person with a disability does not get a procedure because they are assumed

not to be able to cope with the result of the procedure, and I think that is to me, that is really, really painful. (CSH04)

I have seen many people die from poor hospital care. (CSH38)

Discriminatory attitudes directed towards people with intellectual disabilities were observed to result in poor medical treatment and increased risk of morbidity and mortality. Examples were presented where medical staff minimised the adverse outcomes of interventions experienced by people with intellectual disabilities, instead assuming that these resulted from a perceived inability of the person to communicate their needs or symptom overreporting due to a perceived inability to cope. Likewise, stakeholders who raised concerns reported that these were not taken seriously as the needs of people with intellectual disabilities were treated as “less valid” than those of other patients. These staff behaviours were believed to be a manifestation of stigma, which was traumatising for people with intellectual disabilities and their stakeholders alike, increasing anxiety around future admissions and an overall mistrust of the medical system.

And then it took me months to get listened to. Finally, he was 15 at the time, finally ended up and got corrective surgery. But even the doctor at that stage was saying to me that it was my choice. Now I just totally believe that was total discrimination, because would you let any other child walk around with your head, like with this angle, spinal cord exposed the rest of their life? (CSH07)

People with intellectual disabilities are perceived as being overlooked within the hospital system due to staff beliefs about people with intellectual disabilities. This perception was influenced by directly witnessing instances of hospital staff neglecting basic care, such as failing to recognise a patient’s need for assistance with eating and drinking, failing to ask the person which way they needed to lie in bed, and failing to turn the patient sufficiently to prevent pressure injuries. Community stakeholders linked these lapses in care to a deterioration in the wellbeing of the people they support: “I have seen many people discharged from hospital with pressure injuries because they have not been positioned regularly or correctly” (SHQ2).

Several stakeholders spoke about the experience of hospitalisation being traumatising for people with intellectual disabilities, and that people are often discharged while still unwell or with physical deterioration that requires extra support when at home. Stakeholders provided examples of significant weight loss due to being bedbound and not eating properly, bedsores, and

reduced communication skills due to the anxiety of being in the hospital. The perceived lack of adequate care increased the anxiety and distress experienced by stakeholders both during hospitalisation and at discharge and was exacerbated by inadequate communication and handover from the hospital.

These gaps in basic care reinforced stakeholders’ perceptions that people with intellectual disabilities can be invisible to hospital staff. Deteriorations and further complications were attributed to insufficient care and considered preventable by some community stakeholders. When eating or drinking needs were not attended to, community stakeholders described this as contributing to instances of avoidable harm. These deteriorations were considered to be preventable, with one participant noting: “people leave hospital with pressure injuries or don’t leave because they acquire hospital pneumonia” (SHQ4).

Conversely, when staff had high levels of skill, low levels of discriminatory attitudes and offered positive experiences for people with an intellectual disability, procedures could be less aversive when conducted in the hospital than in the community. Hospital treatment could thus offer a feeling of safety and reassurance, and sometimes enjoyment for people with an intellectual disability:

Some people actually love to go to hospital because they get attention “Am I going to go to hospital?” And other people, it’s really bewildering for them. (CSH08)

Theme two: Communication breakdowns undermine care and amplify distress

Although Theme Two focuses on communication processes, these breakdowns occurred within a wider discriminatory context that normalised poor information exchange with people with an intellectual disability and their stakeholders; thus, discrimination again operated as the mechanism enabling communication failures to undermine care.

Effective communication was seen as pivotal to providing appropriate health services for people with intellectual disabilities. Community stakeholders described a variety of issues with communication, indicating that “hospital staff don’t know how to communicate with a person with an intellectual disability” (CSH08) and that “[People with intellectual disabilities]’s style of communication is poorly understood by the hospital” (CSH04). When people with intellectual disabilities struggled with verbal communication, this increased the time that community stakeholders needed to provide support to the person with an

intellectual disability during admission. While the majority of stakeholders were happy to offer this support, doing so increased the burden that they experienced and thus their frustration that the hospital system was not adequately prepared to support people with intellectual disabilities.

Other community stakeholders described the confusion experienced by people with intellectual disabilities post-operation, when they were only given brief written notes about what to collect from a pharmacy, with instructions to call their general practitioner (GP) if needed. This lack of information created confusion about dosage instructions, things to be aware of, and possible medication interactions. Providing accessible information in an easy-to-read format, connecting with a pharmacist who understands intellectual disability, or having the support of a disability liaison service in hospitals were steps that stakeholders identified to reduce these barriers and move towards an enabling society. Similarly, as many community service providers are not medically trained, having the hospital or pharmacy provide more straightforward information on medication management would benefit many providers, improve continuity of care, and foster better practices overall.

I suppose the system is too task orientated and too busy to take the time for this group of people to explain it in their own language or by pictures or diagrams or any other means that they may be able to understand. (CSH01)

Adequate pain assessment was identified as a potential difficulty, as some people living with an intellectual disability may have a reduced capacity to verbalise their pain. Similarly, a lack of knowledge about how people with intellectual disabilities may express pain (if they struggle with verbal communication) often led to misunderstandings about the cause of their behaviours, which was a non-verbal expression of the pain or a minimisation of their pain.

Communication between the hospital and community supports was also an issue. One community stakeholder expressed frustration with a lack of guidance on pain relief after discharge, stating that more explicit instructions would be beneficial. A lack of clear instructions led to confusion about appropriate medication use, which carries significant risk and increases the likelihood of the person with an intellectual disability experiencing poorly managed pain.

And so, it's really ... you want almost like guidelines from the hospital in terms of instead of going "hey, here's some pain medication," going "hey, we're expecting that the person would most likely have a pain at level eight for like one day, then it goes down to six. So, give the medication this amount" rather than

saying, here's the medication that's given as needed, because that person doesn't have the ability to tell me when it's needed. (CSH05)

Stakeholders consistently recognised the need for continuity of care and sufficient handover of information at both admission and discharge. Some stakeholders found that when they provided detailed information about a patient's specific requirements, hospital staff did not always appear to have read it – despite their intention being to improve communication and, subsequently, the experience of hospitalisation for everyone.

At our service we have a sheet about the person, "the things I like" ... I dislike this ... And you might send it along with the person, but staff don't read it. It's a profile we can supply that and do, but things get lost in translation. You might give information to one person, and it doesn't get passed on. And people don't go back. Staff don't go back and read. (CSH08)

Stakeholders perceived that, due to hospital pressures, people with intellectual disabilities were often discharged before they were well enough to go home; often without consultation and communication with the community supports. Sometimes discharge planning seemed rushed, with little consideration of the support available at home.

Biggest challenges? I would say the biggest challenges would be discharging. So, probably for us, discharging when there's not really a conclusion to what's going on for a person. And I understand why hospitals need to discharge at that point because the person is stable. But it's a real concern where someone has this big event and it's kind of a bit uncertain as to how to support someone going forward. (CSH05)

Stakeholder reflected frustration that their efforts were being overlooked, and a perception that the medical team's lack of care and communication during both the admission and discharge increased the burden and expectations on community stakeholders. Similarly, communication issues within the medical team affected care when information was not transferred from one shift to the next. In some instances, a lack of information sharing led to crucial care information, such as medication requirements, being missed. Stakeholders often felt anxious about how this lack of continuity of care would impact patient safety and wellbeing, both during admissions and at the information handover around discharge.

Several stakeholders attributed this inadequate planning to a lack of communication between services and hospitals not understanding that community settings did not employ medical professionals. When medical practitioners were part of the stakeholder team, it was

believed that community teams had greater power to prevent early discharge than teams composed solely of support workers without seniority or medical training. This created a pattern in which those less equipped to cope with an early discharge were more likely to experience it.

In some cases, they want to send people home and it's too early. Like, they want to send people home when they haven't got back to the baseline that they were at when they entered hospital. So, we might not have the resources we need then to care for them when they get home. So, you have to be really quite strong in those circumstances and say, actually, I'm not taking them back home at the moment. (CSH01)

Community stakeholders empathised with hospital staff about the impact of communication difficulties. They recognised that working with people with intellectual disabilities can be challenging, particularly due to diversity in presentations, and that staff were poorly equipped to provide effective care for intellectual disability. However, poor staff communication indicated a missed opportunity to understand the person with an intellectual disability, and this was related to a lack of person-centred care during hospitalisation.

I found those sorts of things quite distressing, and it must be distressing for the person because if they can't even communicate what sort of diet they want, which is their foods, what are they able to communicate in a hospital setting? Are they able to communicate pain? Are they able to communicate who they want next to the bed? Whether they want the parent involved or you know? Yeah, communication is a big one and I think people often don't consider their communication style. (CSH04)

The majority of participants recognised that the issues described were exacerbated by a lack of staff training about how to work with someone with an intellectual disability, a lack of general understanding about intellectual disability, and a lack of experience. A lack of training often resulted in patient behaviour being labelled as aggressive or difficult rather than a manifestation of anxiety or distress, resulting in staff avoiding the patient or not seeking to resolve the underlying cause. This in turn resulted in further lapses in care and increased the distress experienced by both stakeholders and people with intellectual disabilities.

I find medical students come in in their first year as House Officer medical students who have no knowledge of disability and they're working with them in the hospital. They couldn't even tell you a disability. (CSH09)

Communication issues were indicated as both contributing to the discriminatory attitudes of hospital staff

and reinforcing feelings of mistrust towards the hospital system for people with intellectual disabilities. Stakeholders recognised that structural and system factors may influence staff interactions with people with intellectual disabilities and that systemic change is needed to create sustainable changes in care.

Theme three: Distress misread as behavioural issues

Distress was repeatedly misinterpreted as "behavioural issues" as discriminatory assumptions positioned people with an intellectual disability as inherently difficult or uncooperative, shaping how staff interpreted emotional expressions and how care responses were delivered. Several participants noted that some people with mild intellectual disabilities recognised they were treated differently from others in the hospital, which contributed to their discomfort and distress around admissions. Differences in treatment could upset the person they were supporting, particularly when the difference was a manifestation of negative biases about people with intellectual disabilities.

Overall, there was a perception that many people with an intellectual disability felt confused or scared when in the hospital, and this was exacerbated by the lack of familiarity with the environment or the behaviour of staff.

They're frightened. They're scared. If they've got a mild intellectual disability, they know they're going to be labelled. They don't want to come. I think for people with a more moderate to severe disability, it is very frightening, very scary. (CSH09)

People with intellectual disabilities were described as "not your average consumer of healthcare" (CSH02) due to a perception that they would struggle with being confined to a bed, room, or ward. Several participants indicated a preference for people with intellectual disabilities to be placed in rooms alone. The rationale for this varied, from consideration for other patients to a perception that people with intellectual disabilities would not cope with being around strangers.

Being removed from their usual environments and having to stay somewhere new if they can have their own room, that I would think is ideal. But if it's not possible, that would be even worse because they have to be together with strangers. So that would be a bit of a struggle. (CSH03)

Stakeholders believed that many people with intellectual disabilities had coping strategies that did not align with being in the hospital and that – due to the often acute nature of admissions and sometimes of discharge

– there was little planning about which strategies could be adapted for this context. Stakeholders perceived that, without access to their typical coping strategies, people with intellectual disabilities were more likely to experience increased distress and irritation, which could impact other patients. Additional exacerbating factors for distress included being in unfamiliar surroundings, meeting new people, or the person with an intellectual disability picking up on the anxiety of their stakeholders. Behavioural challenges were more likely to occur when people with intellectual disabilities felt lonely, anxious, frustrated, or unable to cope. Therefore, incorporating coping strategies into care plans and admission planning was indicated as a way to reduce behavioural incidents during hospitalisation. Likewise, recognising the underlying emotional driver for the behaviour was identified as a way to manage patient distress and subsequent behaviours. However, stakeholders noted that often hospital staff did not have the skills to support this, that systemic barriers appeared to limit reasonable adaptations, and that the resources provided to medical wards were not always available despite their clear intent for use.

Theme four: Stakeholders as the default safety net

Stakeholders became the default safety net because discriminatory structures and assumptions normalised lower vigilance, reduced accountability, and inadequate care for people with an intellectual disability. Thus, shifting responsibility for safety onto community supporters rather than onto hospital staff. As a result of the lapses in care, stakeholders held a sense of mistrust about the level of care people with an intellectual disability received in the hospital.

Being in a hospital was considered a vulnerable experience for all people, but more so for people with intellectual disabilities. As such, stakeholders felt that people with intellectual disabilities could not be left alone in the hospital, leading to heightened anxiety for caregivers during admissions.

Well, I think being in hospital is a vulnerable place for all people, not just people with disabilities, but for people with learning disabilities it's probably doubly, triply vulnerable. And I would suggest that you never leave a loved one alone in hospital. That's the one thing we're saying. (CSH07)

Anxiety stemmed from a range of concerns. In addition to the experience of stigma and discrimination, stakeholder concerns included: a perceived lack of basic care practices (such as turning a patient

regularly or ensuring they were able to eat); important information being missed or overlooked, due to communication breakdowns or hospital staff not reading the information provided by stakeholders; inconsistencies between departments and wards; and perceptions that hospital staff had insufficient knowledge of intellectual disability to provide adequate care. Some participants described specific instances of insufficient care or neglect that supported these concerns.

They would put the meal in front of them, but they don't feed people and so the person isn't fed. So, the meal is still sitting there, you can go in later and the meal is still sitting there, so no one's actually fed the person. (CSH06)

The mistrust felt by stakeholders manifested as a need to protect the people with intellectual disabilities who they were supporting. Some participants mentioned wanting to get a “lay of the land” and identify who the senior clinician was when people they supported were hospitalised, to prepare and facilitate communication. This behaviour signalled that someone was watching and supporting the people with intellectual disabilities, thus attempting to both keep hospital staff accountable and also to facilitate support.

I do get concerned when people from our service have to go to hospital, and I do worry about them. And I make a point of getting up as often as I can to visit, just to get a lie of the land and see what the staff are like and see what the charge nurse is like and that kind of thing. But generally, I don't think hospitals are prepared to care for a person with a disability. They try, but somebody with a disability actually needs somebody there looking out for them. (CSH08)

Additionally, mistrust and an anticipation of inadequate care meant that stakeholders felt obligated to provide extra support staff to be present during admissions to ensure the people with intellectual disabilities remained safe, burdening their services or themselves. This desire to protect the people they care for sometimes placed stakeholders at odds with the medical team; they felt unheard, had to be persistent about the needs of the person with an intellectual disability, and did not receive adequate information to facilitate safe care themselves. Feeling at odds with the medical team reinforced some stakeholder views about not being included in or seen as an important part of care planning, leading to a self-perpetuating cycle of frustration and feelings of exclusion.

The vital role of support people was a recurring theme. Stakeholders suggested that when carers can be present at the hospital “those types of admissions can be more successful” (CSH08). Carers provided

familiarity and advocacy for people with intellectual disabilities, as well as expertise on the patient that can be useful to hospital staff. One community stakeholder related the impact of supporting people with intellectual disabilities: “having a carer with them at the bedside; it makes a huge difference in terms of the anxiety and in terms of the communication. To me, that is the solution to it” (CSH04). Additionally, community stakeholders identified that hospitals often work quickly to assess and discharge patients, which can disadvantage people with intellectual disabilities if they do not have a support person present to advocate for them. This framing of the situation indicates that stakeholders may empathise with the hospital system and may reflect on how they make sense of the needs of a vulnerable group being overlooked.

I guess what is happening in the hospital is that they have to do these assessments quickly and they need the beds, and there are not that many beds. So, people have to move through quickly, so they definitely have a disadvantage, especially if there’s no one there to support them and advocate for them. (CSH03)

Stakeholders perceived hospital staff as assuming that people with intellectual disabilities were discharged to facilities with medical staff when, in reality, many community providers employ non-medical support workers who are often ill-equipped to care for unwell residents. These assumptions created additional pressure for community stakeholders, some of whom were facing industry-wide staff shortages and funding barriers that prevented them from providing additional staff to support when someone was hospitalised. This pattern of beliefs and behaviour led to poor continuity of care, which could increase the likelihood of further complications and readmissions.

When people with intellectual disabilities needed to be assertive to receive the care they needed or to communicate their desires, stakeholders believed that medical staff often minimised these requests as “difficult behaviour.” Because of this, stakeholders needed to be present to advocate throughout the hospital experience in order to ensure that people with intellectual disabilities received appropriate care. The implication was that, without a constantly present advocate, a person with an intellectual disability would not be listened to, respected, or included in their care planning. Thus, the issues experienced were not due to a lack of ability of people with intellectual disabilities, but instead the lack of ability of medical staff to see past their own biases.

Community stakeholders described the stress and dangers associated with hospitals prematurely

discharging people with intellectual disabilities during a time of industry-wide staff shortages; they were a safety net for both the person with an intellectual disability and for the hospital. Many providers described situations where there were not enough staff in a house to ensure safe discharge or to attend to the ongoing medical needs of the person with an intellectual disability. The stress of supporting unwell people without sufficient staff numbers was indicated as increasing the risk of avoidable harm and unplanned hospital readmissions – outcomes that could have been prevented through adequate communication and discharge planning.

Several community stakeholders described the utility of having a specialist disability role within the hospital system. It was a point of frustration for some that NZ does not have a pathway to specialised intellectual disability training like other countries do, where specialised disability support staff are responsible for duties such as the management and administration of person-centred care, liaison, education, advocacy, and facilitating effective communication between the patient, treating teams, and family or community stakeholders (Bur et al., 2021). It was noted that some hospitals in NZ had employed a type of disability support person, but this did not appear to be consistent across hospitals.

Absolutely every hospital should have a disability equity lead that is informed when someone with a disability is admitted to support them on their journey and to navigate consent issues. They should adopt the flower lanyard used in some [district health boards] to identify people with disabilities that may need extra support. (SHQ1)

Community stakeholders described the significant impact of healthcare assistants and “watch people” who had previously worked in the disability sector, as they played a valuable role in supporting people with intellectual disabilities in the hospital environment. Introducing formal disability liaison nurses across hospitals was indicated as an especially helpful way to improve the hospital system for people with intellectual disabilities.

Community stakeholders expressed a desire to see a formal advocacy or specialist role rolled out in hospitals to provide support and monitor care, especially in case stakeholders were unable to be present. Thus, stakeholder responses indicated that they placed high trust in these roles. Having intellectual disability liaison nurses available was also viewed as a way to support hospital staff and encourage confidence in working with people with intellectual disabilities

through professional modelling and real-time education. It was believed that other staff would learn by proxy, thereby improving their broader knowledge, skills, and confidence to support people with intellectual disabilities.

Hospitals would benefit from Disability Liaison Nurses to work with ward staff, and the community supports to ensure good treatment outcomes for the person and safe transition back to the community. (SHQ4)

Discussion

Community stakeholders expressed significant concerns about hospitals failing to provide basic care to people with intellectual disabilities during hospitalisation, such as a lack of assistance with eating, toileting, showering, and sleeping positions. Instances of harm to patients and deteriorations in health were linked to lapses in basic care. Community stakeholders viewed hospital staff as lacking knowledge about intellectual disability and about how to adjust their communication to suit the needs of people with intellectual disabilities. Failures to keep patients safe and disruptions to continuity of care after discharge were attributed to this lack of knowledge about intellectual disability. Community stakeholders wanted better discharge planning to support continuity of care and patient safety after hospitalisation, including more straightforward guidelines about administering pain medication.

Participants believed that hospital staff lack an understanding of where people with intellectual disabilities live: they stated that hospitals assume patients are released to facilities with medical staff, whereas most people with intellectual disabilities live in the community and may or may not have access to medically trained staff. The literature supports this view that general hospital staff may not understand the level of care community stakeholders can provide for recently discharged patients (Webber et al., 2010). Community stakeholders also described difficulties obtaining the information necessary to provide safe post-discharge care. This places an extra burden on community stakeholders and contributes to unsafe care and adverse health outcomes for people with intellectual disabilities. In research by Webber and colleagues (2010), group home support staff reported similar pressures to take residents home despite the facility's inability to provide appropriate 24-hour care; a finding also noted by Parker (2023).

The importance of ensuring individualised, compassionate, and patient-centred care was interwoven with all themes. When care was individualised to the unique

needs of the person with an intellectual disability, participants indicated that this led to better outcomes. Seeing the person behind the intellectual disability or behaviour and becoming familiar with people with intellectual disabilities reduces fear and builds confidence (Hay et al., 2024), increasing the quality of care provided and facilitating the conditions necessary to deliver individualised, patient-centred care (McCormick et al., 2021). This is particularly effective when people with intellectual disabilities are meaningfully included in the training (Ee et al., 2022). Helping hospital staff to understand the behaviours of people with intellectual disabilities, and to develop a non-judgemental, humanising, and compassionate stance can improve care practices (Iacono et al., 2014; Sowney & Barr, 2006) and can reduce the discrimination (Ali et al., 2013) and stigmatisation that is commonly seen amongst health-care professionals (Pelleboer-Gunnink et al., 2017).

The importance of effective communication between stakeholders and hospital staff was highlighted by recent findings that poor patient care outcomes were correlated with ineffective communication between caregivers and hospital staff (Charles, 2020; Kelleher et al., 2023; McCormick et al., 2021). Poor communication has been found to increase risk in people with learning disabilities and may be linked to unplanned hospital readmissions (Liao et al., 2022; Wilson et al., 2024). Although this relationship is not unique to intellectual disability, people with intellectual disabilities are particularly vulnerable (Liao et al., 2022).

A lack of training and hospital pressures were factors noted to exacerbate difficulties with hospitalisation. Specifically, participants raised issues of staff not understanding that behaviours may be signs of distress, poor intellectual disability-adapted communication skills, and a general lack of knowledge and exposure to people with intellectual disabilities. Training was indicated as a way to reduce fears that hospital staff might have about supporting people with intellectual disabilities. Research has also suggested that training may improve attitudes towards people with intellectual disabilities (Iacono et al., 2014; Sowney & Barr, 2006), which are noted to be less favourable than attitudes towards people without intellectual disabilities (Kelleher et al., 2023).

Community stakeholders expressed a strong desire for intellectual liaison nurse roles to be established within hospitals to better facilitate management and administration of person-centred care. These roles can provide liaison, education, advocacy, and mediation between patients, treating teams and carers, and ensure that communication is adjusted to the individual patients' capacity (Bur et al., 2021), thus providing an opportunity for better support, liaison, and mitigation

of some of the issues experienced by our participants. This echoes the New Zealand Disability Strategy (2016), which recommended that hospitals in NZ have disability policies and guidelines that may include a disability support representative (Office for Disability Issues, 2016). These roles, where they exist, include support for physical, sensory and intellectual disability, which may cause tension due to limited resource availability.

However, the expectations on this role may be greater than what can be achieved. Certainly, emerging international evidence shows that variations in the services provided by this role are heavily influenced by the service in which nurses are placed, and may result in limited to no change in staff confidence and capacity or patient access to safe care (Oulton et al., 2019). Subsequent reviews have highlighted that further research is required to determine the effectiveness of disability liaison nurses (Doody et al., 2023; Mafuba et al., (2023)). In addition, there needs to be greater role visibility in the hospital context, including an emphasis on the unique contribution of the role to enhance outcomes (Doody et al., 2023). Thus, disability liaison nurses are only one piece of the puzzle for improving experiences and outcomes for people with intellectual disabilities during hospitalisation. Instead, a complete solution would include disability liaison nurses, promotion and support of these roles, better integration of content in undergraduate syllabi, and ongoing professional development.

Finally, this study highlights the need to strengthen the agency of community stakeholders to advocate more effectively for people with intellectual disabilities during hospitalisation. However, this advocacy needs to be balanced with the person with an intellectual disability's right to self-determination – their autonomy to express their own wants and needs and to not be overshadowed. Future work must be done in this space to change healthcare systems and improve workforce development to embed authentic patient-centred care, improve safety and quality, and create structures that enable shared decision-making in a three-way partnership between the person with an intellectual disability, their supports, and their healthcare team. Multi-level interventions, such as inclusive training on working with people with intellectual disabilities and organisational policies that prioritise collaboration, are essential to achieve this balance.

This study adds to the literature by providing an analysis of the experience of hospitalisation for people with intellectual disabilities in NZ, as perceived by community stakeholders. It specifically identifies discrimination as the underlying mechanism shaping

experiences across safety, communication, and behavioural interpretation, and explains how structural discrimination and communication failures interact to create preventable harm. This further clarifies why community stakeholders serve as de facto safety nets during acute hospitalisation, helping prevent harm. Therefore, highlighting the need for systems-level changes to better support people with an intellectual disability during hospitalisation, including better training about working with people with intellectual disabilities, enhanced communication skills, and improved continuity of care between community services and hospitals.

Limitations

Seven participants did not provide their profession; thus, it is hard to confirm their specific roles as community stakeholders. However, this was deemed to be of minimal risk to the project given the large sample size, which reduced its impact, and the targeted recruitment method, which increased the likelihood that participants were part of the desired sample group. Similarly, information was not collected about the level of intellectual disability with which participants worked. This may have a significant bearing on their experiences and the views they presented. As such, future research could explore whether stakeholder and patient experiences vary by level of disability.

It is noted that participants' views may not be representative of stakeholders across NZ or worldwide and are likely to vary by region. The study's proximity to the COVID-19 lockdowns may also have impacted the data; the pandemic may have influenced stakeholders' experiences due to reduced staffing levels in facilities, greater responsibilities for stakeholders, more complex access to medical care, and greater difficulties obtaining prescriptions and equipment. Finally, the reflexive lenses of the researchers will have impacted the interpretation of the data.

Directions for future research

Several community stakeholders indicated nursing as their profession. While this study focused on care workers and included the nurses employed by these agencies, who were naturally drawn to the topic, these nurses often hold supervisory positions and support care staff at their residences and facilities – a role different from hospital nursing. Exploring the perspectives of NZ hospital medical staff would build on the international literature (Appelgren et al., 2018; Ee et al., 2022; Pelleboer-Gunnink et al., 2017; Sowney & Barr,

2006) and deepen understanding of the challenges and barriers to effective change.

Previous studies have found that a lack of familiarity or knowledge about intellectual disability can affect healthcare professionals' clinical confidence (Ee et al., 2022; Sowney & Barr, 2006). This may have ramifications for the quality of care provided to people with intellectual disabilities; understanding the perspectives of NZ medical staff would therefore be a useful avenue for future research. This study also identified a perception amongst community stakeholders that NZ's universities and training institutions do not provide sufficient training about intellectual disability to medical students. This is not limited to NZ; it is an issue internationally (Trollor et al., 2018; Trollor et al., 2020; Vi et al., 2023) and highlights an urgent need and an opportunity for future research and intervention. Similarly, participants of the study described a lack of professional development about intellectual disability in the healthcare sector more broadly. Future research could recruit participants from medical training facilities to provide further insights into the state of training and education on intellectual disability in NZ, and to assess whether policy or institutional changes could be made.

Future work could also examine whether existing international resources such as the Australian Framework for Quality Hospital Care for People with Intellectual Disabilities (Bigby et al., 2018; Hospital Inclusion, n.d.; Iacono & Bigby, n.d.) could be co-adapted with Māori as *tāngata whenua* (the Indigenous people), community stakeholders, and hospital staff to produce a culturally responsive, NZ-specific training and practice resource and to evaluate its impact on staff confidence, communication practices, and patient outcomes.

Conclusion

This study explored community stakeholders' perspectives to better understand how adults with intellectual disabilities experience hospitalisation in NZ and to identify barriers to safe and equitable care. Stakeholders consistently described structural and interpersonal discrimination, communication breakdowns, misinterpretation of distress, and the need to act as default safety nets, all of which contributed to preventable harm and mistrust in the hospital system. Communication difficulties – with both hospital staff and the person with an intellectual disability – were viewed as particularly consequential, influencing patient safety, care quality, and continuity of care. Lapses in communication and basic care practices left people with an intellectual disability vulnerable, reinforcing stakeholders'

perceptions that the hospital system was not adequately prepared to meet their needs. In this context, stakeholders felt compelled to remain closely involved during hospital admissions to ensure safety, advocacy, and appropriate care. The findings highlight the urgent need for systems-level improvements, including better training in intellectual disability, strengthened communication practices, and clearer care pathways to reduce discriminatory practices and support equitable hospital experiences for people with an intellectual disability.

Reflexive self-description

LD is a dually qualified health and clinical psychologist who has worked in private practice, at a tertiary specialty service, and secondary mental health services, including with people with cognitive impairment and intellectual disabilities. She has experience in designing, overseeing, and undertaking qualitative research. CMcC, a researcher, was a postgraduate student with no prior knowledge or experience of intellectual disability. MV is a clinical psychologist with specialist knowledge of intellectual disability who has authored several chapters and articles on the topic. She has also worked in mental health services and with people with intellectual disabilities.

Acknowledgements

We wish to acknowledge and thank our participants who participated in this study. LD: Conceptualisation, Data curation, Formal analysis, Investigation, Methodology, Project administration, Supervision, Writing – Original Draft, Writing – Review & Editing; CMcC: Data curation, Formal analysis, Investigation, Writing – Original Draft, Writing – Review & Editing; MV: Conceptualisation, Formal analysis, Writing – Original Draft, Writing – Review & Editing. This study was approved by the Auckland University of Technology Ethics Committee (AUTEC reference 22/131, approved 18/11/2022).

Author contributions

CRedit: **Liesje Donkin:** Conceptualisation, Data curation, Formal analysis, Investigation, Methodology, Supervision, Writing – original draft, Writing – review & editing; **Carrie McColl:** Data curation, Formal analysis, Writing – original draft, Writing – review & editing; **Marleen Verhoeven:** Conceptualisation, Supervision, Writing – review & editing.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Data availability statement

Data is not publicly available but may be shared upon reasonable request to the corresponding author.

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References

- Ali, A., Scior, K., Ratti, V., Strydom, A., King, M., & Hassiotis, A. (2013). Discrimination and other barriers to accessing health care: Perspectives of patients with mild and moderate intellectual disability and their carers. *PLoS One*, 8(8), e70855. <https://doi.org/10.1371/journal.pone.0070855>
- Appelgren, M., Bahtsevani, C., Persson, K., & Borglin, G. (2018). Nurses' experiences of caring for patients with intellectual developmental disorders: A systematic review using a meta-ethnographic approach. *BMC Nursing*, 17(1), Article 51. <https://doi.org/10.1186/s12912-018-0316-9>
- Bigby, C., Douglas, J., & Iacono, T. (2018). *Enabling mainstream systems to be more inclusive and responsive to people with disabilities: Hospital encounters of adults with cognitive disabilities. Report for the National Disability Research and Development Agenda*. Living with Disability Research Centre, La Trobe University. <https://doi.org/10.26181/20760376>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp0630a>
- Bur, J., Missen, K., & Cooper, S. (2021). The impact of intellectual disability nurse specialists in the United Kingdom and Eire Ireland: An integrative review. *Nursing Open*, 8(5), 2018–2024. <https://doi.org/10.1002/nop2.690>
- Charles, M. L. (2020). Communication experiences of family caregivers of hospitalized adults with intellectual and developmental disabilities: A qualitative study. *Nursing Open*, 7(6), 1725–1734. <https://doi.org/10.1002/nop2.557>
- Coates, W. C., Jordan, J., & Clarke, S. O. (2021). A practical guide for conducting qualitative research in medical education: Part 2-coding and thematic analysis. *AEM Education & Training*, 5(4), e10645. <https://doi.org/10.1002/aet2.10645>
- Dinsmore, A. P. (2012). A small-scale investigation of hospital experiences among people with a learning disability on Merseyside: Speaking with patients and their carers. *British Journal of Learning Disabilities*, 40(3), 201–212. <https://doi.org/10.1111/j.1468-3156.2011.00694.x>
- Doody, O., Hennessy, T., Moloney, M., Lyons, R., & Bright, A.-M. (2023). The value and contribution of intellectual disability nurses/nurses caring for people with intellectual disability in intellectual disability settings: A scoping review. *Journal of Clinical Nursing*, 32(9-10), 1993–2040. <https://doi.org/10.1111/jocn.16289>
- Dunn, K., Hughes-McCormack, L., & Cooper, S. A. (2018). Hospital admissions for physical health conditions for people with intellectual disabilities: Systematic review. *Journal of Applied Research in Intellectual Disabilities*, 31(S1), 1–10. <https://doi.org/10.1111/jar.12360>
- Ee, J., Stenfort Kroese, B., & Rose, J. (2022). A systematic review of the knowledge, attitudes and perceptions of health and social care professionals towards people with learning disabilities and mental health problems. *British Journal of Learning Disabilities*, 50(4), 467–483. <https://doi.org/10.1111/bld.12401>
- Gibbs, S. M., Brown, M. J., & Muir, W. J. (2008). The experiences of adults with intellectual disabilities and their carers in general hospitals: A focus group study. *Journal of Intellectual Disability Research*, 52(12), 1061–1077. <https://doi.org/10.1111/j.1365-2788.2008.01057.x>
- Hay, G., Wilson, N. J., Ong, N., Benson, P., & Gallego, G. (2024). Educating the educated: The impact of educational interventions on knowledge, attitudes and confidence of healthcare professionals in caring for patients with intellectual disability: A systematic review. *Journal of Intellectual & Developmental Disability*, 49(2), 134–145. <https://doi.org/10.3109/13668250.2023.2243771>
- Hemsley, B., Balandin, S., & Worrall, L. (2011). The “Big 5” and beyond: Nurses, paid carers, and adults with developmental disability discuss communication needs in hospital. *Applied Nursing Research*, 24(4), e51–e58. <https://doi.org/10.1016/j.apnr.2010.09.001>
- Hospital Inclusion. (n.d.). Framework for quality hospital care for people with intellectual disabilities [Online learning resource]. Retrieved May 19, 2026, from: <https://www.hospitalinclusion.au/>
- Iacono, T., & Bigby, C. (n.d.). *Quality hospital care for people with intellectual disabilities*. Living with Disability Research Centre, La Trobe University. Retrieved May 19, 2026 from: <https://www.hospitalinclusion.au/>
- Iacono, T., Bigby, C., Unsworth, C., Douglas, J., & Fitzpatrick, P. (2014). A systematic review of hospital experiences of people with intellectual disability. *BMC Health Services Research*, 14(1), 505. <https://doi.org/10.1186/s12913-014-0505-5>
- Kelleher, E., Martin, A.-M., Caples, M., & Wills, T. (2023). Acute service and disability service providers experiences of joint working to improve health care experiences of people with an intellectual disability compared to non-joint working: A mixed-method systematic review. *Journal of Intellectual Disabilities*. Advance online publication. <https://doi.org/10.1177/17446295231209345>
- Liao, P., Vajdic, C. M., Reppermund, S., Cvejic, R. C., Watkins, T. R., Srasuebkul, P., & Trollor, J. (2022). Readmission and emergency department presentation after hospitalisation for epilepsy in people with intellectual disability: A data linkage study. *PLoS One*, 17(8), e0272439. <https://doi.org/10.1371/journal.pone.0272439>
- Louch, G., Albutt, A., Harlow-Trigg, J., Moore, S., Smyth, K., Ramsey, L., & O'Hara, J. K. (2021). Exploring patient safety outcomes for people with learning disabilities in acute hospital settings: A scoping review. *BMJ Open*, 11(5), e047102. <https://doi.org/10.1136/bmjopen-2020-047102>
- Mafuba, K., Chapman, H. M., Forster, M., Chester, R., Kiernan, J., Kupara, D., & Kudita, C. (2023). Understanding the contribution of intellectual disabilities nurses: Paper 1 of 4 – Scoping literature review. *Journal of Intellectual Disabilities*, 30(2), 275–304. <https://doi.org/10.1177/17446295231220432>
- McCormick, F., Marsh, L., Taggart, L., & Brown, M. (2021). Experiences of adults with intellectual disabilities accessing

- acute hospital services: A systematic review of the international evidence. *Health & Social Care in the Community*, 29(5), 1222–1232. <https://doi.org/10.1111/hsc.13253>
- Office for Disability Issues. (2016). *New Zealand disability strategy 2016–2026*.
- Oulton, K., Wray, J., Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M., & Gibson, F. (2019). Learning disability nurse provision in children's hospitals: Hospital staff perceptions of whether it makes a difference. *BMC Pediatrics*, 19(1), 192. <https://doi.org/10.1186/s12887-019-1547-y>
- Parker, K. (2023). *A qualitative exploration of the experiences of the hospital discharge process, via the Transforming Care Agenda* [Major research project, Canterbury Christ Church University]. Canterbury Christ Church University Research Repository.
- Pelleboer-Gunnink, H., Van Oorsouw, W., Van Weeghel, J., & Embregts, P. (2017). Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: A systematic review. *Journal of Intellectual Disability Research*, 61(5), 411–434. <https://doi.org/10.1111/jir.12353>
- Qualtrics. (2024). *Qualtrics XM*. www.qualtrics.com
- Sowney, M., & Barr, O. G. (2006). Caring for adults with intellectual disabilities: Perceived challenges for nurses in accident and emergency units. *Journal of Advanced Nursing*, 55(1), 36–45. <https://doi.org/10.1111/j.1365-2648.2006.03881.x>
- Thompson-Burdine, J., Thorne, S., & Sandhu, G. (2021). Interpretive description: A flexible qualitative methodology for medical education research. *Medical Education*, 55(3), 336–343. <https://doi.org/10.1111/medu.14380>
- Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice (2nd ed.)*. Routledge.
- Trollor, J. N., Eagleson, C., Ruffell, B., Tracy, J., Torr, J. J., Durvasula, S., Iacono, T., Cvejic, R. C., & Lennox, N. (2020). Has teaching about intellectual disability healthcare in Australian medical schools improved? A 20-year comparison of curricula audits. *BMC Medical Education*, 20(1), 321. <https://doi.org/10.1186/s12909-020-02235-w>
- Trollor, J. N., Eagleson, C., Turner, B., Salomon, C., Cashin, A., Iacono, T., Goddard, L., & Lennox, N. (2018). Intellectual disability content within pre-registration nursing curriculum: How is it taught? *Nurse Education Today*, 69, 48–52. <https://doi.org/10.1016/j.nedt.2018.07.002>
- Tuffrey-Wijne, I., Goulding, L., Giatras, N., Abraham, E., Gillard, S., White, S., Edwards, C., & Hollins, S. (2014). The barriers to and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospitals: Evidence from a mixed-methods study. *BMJ Open*, 4(4), e004606. <https://doi.org/10.1136/bmjopen-2013-004606>
- Van Alphen, L., Dijker, A., Van Den Borne, H., & Curfs, L. (2009). The significance of neighbours: Views and experiences of people with intellectual disability on neighbouring. *Journal of Intellectual Disability Research*, 53(8), 745–757. <https://doi.org/10.1111/j.1365-2788.2009.01188.x>
- Vi, L., Jiwa, M. I., Lunskey, Y., & Thakur, A. (2023). A systematic review of intellectual and developmental disability curriculum in international pre-graduate health professional education. *BMC Medical Education*, 23(1), 329. <https://doi.org/10.1186/s12909-023-04259-4>
- Webber, R., Bowers, B., & Bigby, C. (2010). Hospital experiences of older people with intellectual disability: Responses of group home staff and family members. *Journal of Intellectual & Developmental Disability*, 35(3), 155–164. <https://doi.org/10.3109/13668250.2010.491071>
- Wilson, H., Donkin, L., Harrison, J., Brackley, K., Lim, A. G., & Chan, A. H. Y. (2024). 'I didn't want to go home': Patient-identified modifiable risk factors associated with hospital readmission: A qualitative study. *A qualitative study. Psychology & Health*, 41(1), 76–95. <https://doi.org/10.1080/08870446.2024.2391912>
- Windley, D., & Chapman, M. (2010). Support workers within learning/intellectual disability services perception of their role, training and support needs. *British Journal of Learning Disabilities*, 38(4), 310–318. <https://doi.org/10.1111/j.1468-3156.2010.00610.x>