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Inclusive mainstream services for people with intellectual disabilities: A relational approach

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ABSTRACT

Background: Despite growing recognition of their right for inclusion in society, people with intellectual disabilities are often excluded from mainstream services, or experience poor service outcomes.

Method: Taking a relational approach that considers the interpersonal relations and interactions that occur in mainstream service settings in Australia, this paper examines the features of services that research participants considered more inclusive.

Results: Relations between service users with and without intellectual disabilities, mainstream service staff and disability support workers in inclusive mainstream services were characterised by; respect; warm, welcoming and convivial interpersonal engagement; active listening; proactive assistance; flexibility; mediation to create a safe environment; and collaboration and shared responsibility by both mainstream staff and disability support workers in supporting a service user with intellectual disability.

Conclusions: Building on these results, we put forward a set of principles for facilitating inclusion of people with intellectual disabilities in mainstream services.

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Disability; intellectual disability; mainstream services; community participation; social inclusion

The 2006 Convention on the Rights of Persons with Disability (CRPD) recognises the right for "full and effective participation and inclusion in society" (Article 3). This includes signatory countries' responsibility to ensure people with disabilities can access and participate on an equal basis with others in all publicly available services, which we refer to here as "mainstream" services. In Australia, the primary aim of the Australian National Disability Insurance Scheme (NDIS) is to advance participants' "full inclusion in the mainstream community" (Australian Government, 2013, 3(1)(g)). The NDIS funds individualised support for people with disabilities, which can include support for community participation and for access to mainstream services. Additionally, the Australian Government funds projects that promote mainstream inclusivity under the Information, Linkages and Capacity Building (ILC) program.

Despite these investments to support mainstream inclusion, evidence suggests that people with intellectual disabilities are often excluded from mainstream services, or if they do access services, they are more likely than others to experience poor outcomes, in Australia and elsewhere (Pelleboer-Gunnink et al., 2017; Wiesel et al., 2023). Many studies highlight the significance of the skills, practices and attitudes both of staff in mainstream services and community members in shaping the inclusivity of services for people with intellectual disabilities (Abbott & McConkey, 2006; Merrells et al.'s, 2018; Pelleboer-Gunnink et al., 2017; Stancliffe et al., 2013; Terras et al., 2021). Rather than focusing on individual attributes, this study takes a relational approach that considers the interpersonal relations and interactions that occur between people in mainstream services that facilitate or obstruct inclusivity. First, we review key themes in existing literature on inclusion in mainstream services and then describe the results of our study on inclusion in mainstream housing, health, transport and community services. We focus on interpersonal relations between people with intellectual disabilities, other service users, mainstream services' staff and disability support workers. Finally, we propose seven principles for fostering inclusivity in mainstream services.

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Literature review

Rather than considering mainstream services in general, research often focusses on access to specific service sectors such as education, employment, health, or social services. However, similar barriers and enablers, often associated with staff skills, attitudes and practices, are found in different sectors. A large body of research focuses on access to mainstream healthcare services. Pelleboer-Gunnink et al.'s (2017) systematic review found that healthcare professionals generally recognise the rights of people with intellectual disabilities to be included in mainstream healthcare services. However, professionals' attitudes and practices are mixed; many lack confidence about treating people with intellectual disabilities, have stigmatising attitudes, and lack knowledge about their needs. This is often reflected in practices that restrict the autonomy of people with intellectual disabilities and misaligned expectations about capabilities, where professionals expect too little or too much of a service user with an intellectual disability.

In the context of social services, a qualitative Australian study examined people with intellectual disabilities' access to a mainstream sexual violence service (Fraser-Barbour et al., 2018). They found that staff in this service often lacked the practical skills necessary to support women with intellectual disabilities to report sexual violence. A mixed methods Australian study explored older people with intellectual disabilities' participation in community groups. It demonstrated the benefits of training staff and other participants to support the engagement of people with intellectual disabilities in groups using an "active mentoring" approach based on Active Support (Stancliffe et al., 2015). A Canadian study took a more relational approach to considering interactions between people with intellectual disabilities and staff in mainstream services (Wilton et al., 2018). Their study explored the shopping experiences of people with intellectual disabilities when they visited mainstream spaces of consumption. The authors argued that despite their transactional purpose, such service interactions – particularly if repeated over time – could become important moments of social connection and recognition for people with intellectual disabilities.

Several studies consider the complex role of informal carers supporting people with intellectual disabilities to access mainstream services. Terras et al. (2021) noted the important role of informal carers in facilitating communication between service users and mainstream service staff. Informal carers also provided support for decision-making in relation to the use of mainstream services, such as decisions about opting out of healthcare, by filtering and explaining relevant information. Wilton et al.'s (2018) Canadian study found that for some people with intellectual disabilities, shopping was an opportunity to momentarily distance themselves from parents, while for others it was an opportunity to bond with them.

Interactions with other service users also impact experiences of inclusion of people with intellectual disabilities when using mainstream services. For example, Merrells et al.'s (2018) review found that people with intellectual disabilities' participation in leisure activities increased when service users without disability had more positive attitudes. The literature on encounters between people with and without intellectual disabilities in mainstream settings identified various ways in which such interactions are mediated by the practices of disability support staff, and the distinct characteristics of different settings (Bigby & Anderson, 2021; Bigby & Wiesel, 2015; Bredewold et al., 2020).

Several studies emphasise the importance of communication to participation of people with intellectual disabilities in mainstream services. Abbott and McConkey (2006) noted the barriers caused by the lack of information about community-based activities and services. van Holstein et al. (2022) identified initiatives to increase communication accessibility in public transport services in Melbourne. Terras et al. (2021), in a United Kingdom context, emphasise the importance of accessible information in enabling inclusion and improving mainstream health services for people with intellectual disabilities. While resources such as easy-read materials were identified as important, the authors also highlighted that access to information is a relational process, involving much more than availability of easy read material.

Other studies address more structural issues affecting the inclusion of people with intellectual disabilities in mainstream services. Abbott and McConkey (2006) note the dearth of activities and services that are open to people with intellectual disabilities. van Holstein (2021) highlights that in the context of Australian neoliberalism, many publicly funded mainstream services face pressures such as under-funding and increased administrative burdens because of compliance requirements and competitive tenders. She also noted that high staff turnover in mainstream services limited opportunities for training on disability inclusion. In another paper, van Holstein et al. (2021) suggest that the increasing intertwining of digital and physical service provision requires service users to have digital skills to make effective use of mainstream services. Wiesel et al. (2023) argue that the needs of people with intellectual disabilities are not well understood, and often

neglected in services' diversity and inclusion strategies. This is partly because, as van Holstein et al. (2022) note, people with intellectual disabilities are also rarely involved in the governance, planning and management of services. French (2013) underlines the weaknesses of Australian anti-discrimination laws, and their limited capacity to require adjustments in mainstream services. Wiesel et al. (2024) argue that in neoliberal contexts such as Australia, policy makers rely too heavily on "free market" competition between mainstream services as the main strategy to facilitate voluntary adjustments in services.

In this article, following Wilton et al. (2018), we take a relational approach to analysing inclusive mainstream service delivery. We focus primarily on interpersonal relationships, noting that these are shaped by – and in turn reproduce or reshape – the structural factors described above. Our aim is to explore the relations that emerge when people with intellectual disabilities access a mainstream service and to consider the roles that mainstream service staff play in mediating these relations. Accordingly, we focus on relationships between mainstream staff and service users with intellectual disabilities; between service users with intellectual disabilities and others service users, with and without disabilities; and the three-way relations between mainstream service staff, a person with an intellectual disability, and formal or informal supporters accompanying them. We explore the nature of these relationships, the way they are mediated by mainstream services staff, and how they facilitate inclusion in mainstream services.

Method

The study followed a qualitative design, using in-depth interviews and participant observation to collect data about factors shaping participation of people with intellectual disabilities in mainstream urban housing, health, transport, and community services. Ethics approval for the study was received from the University of Melbourne (Approval 1852372). All participants' names have been replaced with pseudonyms to protect their anonymity.

Data were collected across four sites: two in New South Wales (NSW) (Western Sydney, a subregion of the state's capital city; and Newcastle, a medium-sized city approximately three hours' drive from Sydney); and two in Victoria (North Eastern Melbourne, a metropolitan subregion of the state's capital city; and Geelong, a medium-sized city, approximately an hour's drive from Melbourne). These sites were selected to represent diverse urban contexts for mainstream inclusion. Two reference groups were formed and provided advice on research design, analysis, and dissemination. One group was comprised of senior staff in policy and industry bodies, and the other of four self-advocates with intellectual disabilities. The first met a handful of times at key project milestones, and the latter group met quarterly.

Forty participants with intellectual disabilities were recruited, 10 from each of the research sites, with the assistance of the reference groups and other disability advocacy organisations and disability support services. Each participant with an intellectual disability was interviewed in person. Interviews were semi-structured and explored people's experiences of the mainstream services they used. Participants were offered the option of being interviewed in the presence of another person, and several chose to be interviewed with a support worker or a relative who assisted with communication and in some cases actively participated in the interview. In the article we refer to these participants as "service users", acknowledging that in disability studies such terminology is typically used to refer to users of disability services, whereas here we use it in reference to users of mainstream services. Of the 40 participants with intellectual disabilities, 26 were women and 14 men. Their ages ranged from 18–74 years, including 17 participants aged 18–34 years; 18 aged 35–54 years; 4 aged 55–64 years; and 1 participant between 65–74 years. All participants had a mild or moderate intellectual disability and communicated verbally.

Of the mainstream service staff, 49 were recruited from services used by research participants with intellectual disabilities or from services recommended by reference group members or staff in other services as being particularly inclusive towards people with intellectual disabilities. Interviews with staff were face-to-face or online and explored their experiences of including people with intellectual disabilities in services and the types of adjustments they made, if any.

In addition to interviews, participatory observations were conducted, whereby a researcher joined a participant with an intellectual disability in their visit to a mainstream service. The researcher took notes on interactions between the participant and staff and other service users, and the participants' engagement with the activity. In 2020, Covid19 lockdowns reduced time available for data collection and the number of interviews and observations that could be conducted in-person.

All interviews were digitally recorded and transcribed by the interviewer. Transcripts and observation notes were coded thematically using Nvivo software, following a hybrid inductive and deductive approach

to the generation of codes. Initially, data were coded under broad themes of mainstream staff support practices, adjustments made in mainstream services, experiences of people with disabilities in mainstream services, and their interactions with other service users. Further codes were then developed around the types of relationships between staff, service users and disability support workers in services. The themes and sub-themes identified are described in the findings and illustrated with excerpts from the interviews and field notes.

The primary limitation of the study is the exclusion of participants with severe or profound intellectual disabilities, and those who cannot communicate verbally, due to recruitment challenges. The findings and conclusion reflect the experiences of people with mild or moderate intellectual disabilities and may not be applicable to people with more severe impairments. We return to the implications of this limitation in the conclusion.

Findings

Relations between mainstream service staff and service users with intellectual disabilities

Warm, personal, welcoming engagement

Participants with intellectual disabilities were comfortable using a mainstream service when they felt staff were welcoming, warm, and friendly. Describing mainstream services where they felt included, they often referred to staff characteristics such as being "lovely", "friendly", "gentle", "nice". For example, one participant said he thought the library was very good, and when asked what made it a good library, he said, "You meet the lovely people there" (Sydney, Jacob). Talking about staff in services, other participants said they were "lovely" at a swimming pool (Newcastle, Laura) "friendly" at a library (Sydney, Nigel) and "nice" at a health service (Newcastle, Julia). Talking about being happy with her General Practitioner (GP), Maya (Newcastle) said "she is a very gentle person and calm".

In turn, staff in mainstream services described their intentional efforts to be welcoming and the practices they used to make their service more warm and friendly. These included a "personal approach" in their own interactions with service users. For some, this meant trying to be "on first name basis" with service users and attempting to "connect" with them on a personal level. One example mentioned by staff was trying to remember service users' birthdays. Talking about their approach to service users with intellectual disabilities, another staff said:

> We're on a first name basis with them … There's a lady that comes in the winter all the time … we have a chat with her. Just how your day is going and yeah, I think that all the staff and volunteers in the office do really well with anybody with intellectual disability. We treat them with respect, and I think they enjoy it because they keep coming back to have a chat and to see what's going on. (Community service, Geelong)

This personal approach involves giving priority to relational aspects of a service experience over more transactional or instrumental aspects. One service manager described their effort to embed this approach with new volunteer staff:

> Whenever we have volunteers, particularly office volunteers, I make it really clear the most important thing in their day is just talking to the people who come in … If someone walks in and really they just want someone to talk to then just do that, don't worry about the other things you've been given to do, that's the most important thing. (Melbourne, neighborhood house)

For many mainstream service staff, as was the case for other aspects of creating inclusivity, a personal approach was simply part of good "customer-focused" service that applied to everyone. Several participants noted for example, that when they recruited new staff, they looked for skills and disposition towards this type of a personalised approach in applicants.

> When we hire for any of our customer-facing roles we tend to do them through group interviews … we can tell from that who is going to be good with a customer, who has those skills that we need that are going to be great when we put them behind that counter to be able to cater to the customer's needs. (Arts Centre, Geelong)

Mainstream service staff actively listening to service users with intellectual disabilities

Whether staff listened and paid attention to what they were saying was important to participants' experiences of mainstream services. Positive experiences were characterised by staff actively listening to them and negative experiences by not being listened to. For example, Jane, a woman with an intellectual disability in Geelong, spoke about her positive experience in a local gym, where she felt previous staff members had treated her with "respect and dignity". She contrasted their approach to the newer staff who she felt "don't listen". Jane and her mother explained in their interview:

> [Jane's mother] So the old staff – we want to talk about the old staff who've been there for a fair while … how they treated you.
>
> [Jane] With respect and dignity … But there's new staff … They don't understand me … They don't listen.

> [Jane's mother] The new staff haven't got to understand her speech yet, that's what she's saying, and they don't listen. They don't take the time. The old staff used to. They were really supportive.

For Jane, being listened to meant staff taking time to understand her speech. Failing to listen was often reflected in the way mainstream service staff made decisions without consulting service users with intellectual disabilities. For example, in a cooking class in a neighbourhood house in Geelong, we observed mainstream staff liaising with a disability support worker about the recipe the class would cook – even asking the research observer – but not asking the service user with an intellectual disability who attended the class.

Active listening can sometime involve seeking to understand not only a service user's preferences and needs, but also making more complex assessments, for example whether the service user understands certain risks. For example, a library staff member recalled that he had been asked by a person with an intellectual disability to help fill out an application for a payday loan. The staff member explained his concerns about whether the person understood the risks of such a loan, and whether he should turn the person away, help him fill in the form, or help him understand the implications of such a loan. He said,

> I have had a gentleman with an intellectual disability who wanted me to apply for one of those payday loans for him and got quite agitated when I didn't want to have to – I could show him this is it, but I couldn't fill it all in for him. He didn't have the material for a start, thank heavens, but that's quite challenging. What do I do in this situation? This person's obviously not capable of understanding what he's committing to, but he wants me to fill this in. (Melbourne, Library)

This example highlights some of the complexities addressed in the literature about the practice of supported decision making and enabling risk (Laurens et al., 2021) which staff in mainstream services may need to grapple with, yet are unlikely to have been trained for.

Proactive, sensitive, and respectful approach in asking about needs and offering assistance

Mainstream service staff talked about the dilemma of whether and how to ask about a person's disability and need for assistance when they first access a service. From their perspective, an understanding of a person's disability could help them deliver service in a more inclusive way. However, they also acknowledged people's right not to disclose their disability, and concerns about how to ask tactfully and respectfully. They described different approaches to gaining information about service users' disabilities and support needs. Some noted that in their service, unless someone took the initiative and chose to disclose their support needs, they would not be asked about them. The downside is that the need for adjustments often only becomes apparent when something "goes wrong", as one library staff explained in relation to their policy of waiving late book return fines for people with intellectual disabilities:

> [Service users with intellectual disabilities] might slip through the cracks … Because until it becomes an issue, we don't just willy nilly go you've got a disability, we'll give you fines exempt. We treat them as every other customer until we realise that there's going to be some problems because something's come up, they've got horrendous fines on their card, they've got lost. (Library, Geelong)

Rather than asking directly about a person's disability some staff relied on signals such as a person's looks, unusual speech or behaviour, such as lack of eye contact, or the presence of a support worker or informal carer (noting mainstream service staff sometimes were unable to distinguish between a friend, relative or support worker). Some services took a more proactive approach to identifying service users' disabilities and support needs. In health services and community housing services for example, service users are often asked to fill in forms which directly ask and request details about disability. Beyond paperwork, some services – primarily in the healthcare sector – initiated conversations with service users to ask about their disability and support needs.

> They can be having an initial first meeting consult where they go through their history and have a little bit of time with the patient to be looking at what potential barriers to communication there are and how to best approach that patient as an individual, and then be having them come in with their paperwork … it really does help. (Newcastle, Health service)

Alternatively, a first conversation with a service user might ask more generally about their needs and expectations from the service, without explicitly asking about disability.

> I have asked people … is there something that you think I'll need to know to make the gym a more comfortable place? (Newcastle, gym)

> … when I do a registration, any event that I'm running, I'll say do you have any special dietary requirements, and then I'll say are there any … requirement, access support, … any support you need to participate in that event. (Melbourne, neighborhood house)

As a matter of course, reception staff asked service users whether they had some form of concession card in some

services with reduced fees for low-income earners. Possession of a card was then taken as an indicator that a person has a disability and might need additional support.

Following up with service users after an episode of service was another way of finding out if a service needed adjustment. As the following examples show, this approach was taken in some health services and leisure centres.

> After two weeks or three weeks my physio checks to see if I'm okay and gives me more or less [exercises]. (Geelong, Olivia)

> We don't assume. We just say you know what? It's on us to follow up. We'll just make sure we follow up with so and so just to make sure that that person gets the gym, the best out of it. (Melbourne, Leisure Centre)

An ongoing relationship with a service user allowed staff to gain a more in-depth understanding of a person's disability and support needs, although such opportunities were limited by the high staff turnover in mainstream services. However, experiences of working with different service users with intellectual disabilities had helped staff gain skills in identifying and understanding intellectual disability.

The quest to gain information to adjust services raises ethical issues about privacy. There were examples where staff sought information about service users from their support workers without their consent or information was shared both within and outside the service, without the service user's consent. Carelessness with privacy issues was evident when one of the co-authors was asked to register her personal information when she entered a neighbourhood house. She was assured the information was "just to have on file", but the form was subsequently shared with other staff and volunteers in the service.

Flexible approach

Participants with intellectual disabilities appreciated flexible application of rules by mainstream service staff. They also appreciated enforcement of rules in a respectful rather than threatening way. For example, Megan, a woman with an intellectual disability, described being politely asked by bus drivers to remove her legs from the seat to allow another person to sit:

> But if they see me like with a leg up and I'm like this, then the driver will say, excuse me can you please offer a seat to this lady? (Megan, Sydney)

Mainstream service staff acknowledged that service users with intellectual disabilities might have difficulties understanding or following rules and procedures and spoke about the need to avoid rigid enforcement. Several examples concerned rules around scheduling, such as payment due dates. Some services, such as public libraries, exempted people with disabilities from penalties on late book returns, acknowledging their financial constraints as well as difficulties related to their disability, such as forgetting due dates.

In one leisure centre, fifty free memberships were offered to people who experienced barriers to access, including people with disabilities. Free memberships were renewed every three months if the members were regularly using the centre. This rule was to ensure free memberships were allocated to people who used them, since there was a waiting list for them. However, a staff member noted the flexible approach to enforcing this rule that recognised it might be difficult for people with intellectual disabilities to meet such requirements.

> … if we do know that they have an intellectual disability or they have a carer, then we're a little bit more relaxed about them meeting those standards. Because sometimes, we've had community members not be able to go because their carer hasn't been available. You know? Things like that. So, we don't see that as a hard and fast rule … We've reinstated one of our community members who has an intellectual disability because she came and talked to us … about how she'd been unwell, there'd been something else, and she didn't realise different things. (Neighborhood house and Leisure Centre, Melbourne)

Staff also described flexible ways of accommodating individuals' needs when they did not align with the regular schedule of service delivery. For example, one spoke about trying to accommodate a person's need for a "quiet space" before a show:

> If somebody asks us to do something if we can accommodate them, we will. If somebody says we've got someone coming to see a show, they need to be in a quiet space before the show happens, we try and find a room for them to sit quietly and then come and get them once everybody [is] in the theatre. (Geelong, Art Centre)

Mainstream services staff adjusted the nature and intensity of assistance they offered to service users with intellectual disabilities based on individual need. The level of assistance ranged from doing something *for* someone; offering "hands on" assistance; to low-intensity assistance such as explaining how things work. For example, while many library users will use the computer catalogue to search for items, Jacob (Sydney) said the library staff often ran searches for him as he struggled with the small letters on the keyboard.

Flexibility was not characteristic of all relationships between people with intellectual disabilities and mainstream services, and staff in some services enforced

rules strictly. For example, a staff member was observed threatening punishment for those who took a second serving of food at a neighbourhood house event, saying they "would be made to leave". While mainstream service staff saw a flexible approach as inclusionary towards people with intellectual disabilities, it may also reflect low expectations of this group. For example, we observed the instructor of a basketball group for people with intellectual disabilities in a mainstream setting encouraging the players by removing all game-defining rules and not keeping score. This made the game accessible for some players who would not otherwise be able to engage in the game, for example because of difficulty catching or dribbling. However, the complete removal of rules denied other players the opportunity to participate in basketball more competitively, and foreclosed the potential for them to experience a rewarding sense of winning.

Relations between service users with and without intellectual disabilities

Convivial encounters

Several participants with intellectual disabilities commented on the "friendly" encounters they had experienced with other service users, both with and without intellectual disabilities, and there were many examples of positive interactions between service users. Rachel, in Geelong, described the friendly interactions she experienced in an art group, saying about people in the group, "Yeah, [really] friendly and nice and positive, that's great and that everybody loves the same art that you're in the group with". Her experience of engaging with other participants around a shared interest, resonated strongly with recent literature on convivial encounters between people with and without intellectual disabilities (Bigby & Anderson, 2021; Bigby & Wiesel, 2015). Similarly, Dina described the sense of belonging in a crowd, when attending Australian Football League matches at the Melbourne Cricket Ground, saying, "I like being a part of the crowd, yeah, being a part of everyone. Everyone that's going to the footy, I like going to the footy. I like being a part, I like wearing my guernsey". A sense of membership in a club – indicated through the guernsey – can reinforce conviviality.

Mainstream service staff also identified how engagement in shared activities increased the degree of comfort in the social interactions between people with and without intellectual disabilities:

> you might never have sat in a learning situation next to somebody with a disability, so as a student, you're going to have to learn how to have those conversations … but it's amazing how quickly those groups interact and integrate as well, because it's quite a safe space … They don't just come and learn how to make pots, they interact with people that they've never had to. (Melbourne, neighborhood house)

The quote above highlights a form of reciprocity which can exist in relations between service users with and without disabilities, where the encounter with difference and the experience of learning that comes with it, is beneficial for all.

Challenging encounters

Mediating conflicts and tensions between service users to ensure services felt welcoming and safe for everyone was described by mainstream service staff as part of their work. As a staff member explained,

> we've had some clashes sometimes with community members who are quite heightened at the time, their mental health is really unwell … But if you're heightened and you don't understand anyone else, you're in your own zone about your own issues, you know, "fuck you". "What the fuck?" We're like whoa, whoa, whoa. So, it's like constant education. But then it gets to a nice point where people actually understand where everybody is at … We've talked to them about what's okay and what's not okay behaviour. (Melbourne, neighborhood house)

> This is a safe and welcoming space. So anyone who doesn't adhere to that safe and welcoming space, we're on it. If it continues, they're out … sometimes we've had a couple of older ladies who get very angry and will leave. [They] will kick up and leave because it's too noisy for them. They blame the students with disability. (Melbourne, neighborhood house)

Staff in some services commented that enforcing behavioural norms to ensure a "welcoming" space could sometimes mean, as a last resort, removing service users with intellectual disabilities who were too noisy and interfering with the enjoyment of others:

> If they're shouting, then we would come up and say we need to keep this down, we'll negotiate with the carer. The worst-case scenario is when we have to ask them to leave. (Geelong, library)

One staff member recalled that, on one occasion, staff had called police to assist in removing a service user with an intellectual disability. Some staff described pressures from other service users to remove people with intellectual disabilities from activities. For example, several participants with intellectual disabilities mentioned their preference to use the children's books section in libraries, where books and other resources were more aligned with their literacy skills and interests than in the adult section. However, one librarian

pointed out that some parents of children were not comfortable seeing an adult participate in areas and activities dedicated to children.

> [During] children's story time … the person with the intellectual disability will probably enjoy listening to the story, the child probably won't even notice it, but the parents tend to go oh, what's happening here? … We have enough trouble with adult men sitting in the children's area as it is. (Geelong, library)

Several participants with intellectual disabilities described instances where they had been removed from a mainstream service but were not able to fully explain why this had occurred.

Relations between mainstream service staff and disability support workers

Mainstream service staff described the need for skilful collaboration with support workers of service users with intellectual disabilities to ensure services were inclusive.

There were examples of collaborative relationships, where mainstream service staff and disability support workers worked together to support a person with an intellectual disability in an activity. Nina, for example, described how in her gym, the staff and disability support workers "all help together". Some mainstream service staff described working with support workers, by guiding them, offering advice, and "building a relationship" with them. A swim teacher in a public pool told us:

> There were three carers holding a person. I'm thinking that must be killing you guys. … I said, "oh don't know if it's any use to you but I've got these noodles" [flotation devices] … . So now they use it all the time they come in. (Geelong, Leisure centre)

In some cases, disability support workers proactively engaged mainstream service staff trying to ensure they work effectively with a service user with an intellectual disability. In one observation, during a fitness class in Melbourne, the gym trainer provided personal feedback and instructions to most participants in the class, while ignoring incorrect postures and moves by Hannah, a participant with an intellectual disability (reflecting low expectations, as discussed in an earlier section). In response, Hannah's support worker subtly asked the trainer to give Hannah more direct feedback and instructions.

Mainstream services staff sometimes complained about disability support workers who drop off a service user with an intellectual disability and leave all the support for that person to mainstream service staff. In contrast, some staff were concerned that the presence of support workers could be disruptive. For example, one neighbourhood house staff member commented that they sometimes ask support workers to leave, to prevent such a dynamic:

> Some of them [disability support workers] are doing it for them, doing for their clients, rather than supporting their clients which makes her really cross and she sends them out of the room. Sometimes I see them sitting out there because they've been banned. (Melbourne, neighborhood house)

One risk of staff trying to establish a collaborative relationship with support workers was that they communicated with them rather than directly with the service user. For example, a common practice in some services was to collect information about a person's needs by asking their support worker. As one staff member said,

> So that's really all [the information] I get … and the rest is me fact finding. So, you're the carer of Harry, can you tell me more about Harry please? What are the things I need to look out for? What are his behaviors? If this happens, what do I do? (Leisure service, Melbourne)

Permission was not always sought from service users to talk to support workers about them. One staff member in a community centre mentioned she asks support workers to fill in forms with personal details of service users with intellectual disabilities, and then reflected during the interview:

> I wonder if this is actually okay? Can you actually ask people that? I don't know if that is actually a violation of privacy. (Community centre, Geelong)

Some staff were conscious of these issues and were trying to communicate directly with the service user, while also engaging the support worker in the conversation where needed. The comments of one participant with an intellectual disability highlighted the dynamic nature of the relationship between a service user, their supporter, and mainstream service staff. She described her difficulty in asking for help from staff in a gym when she did not know any of the staff well, saying it was easier for her to seek help from her support worker. However, she said that as she gets to know staff over time, she might feel more confident to engage with them directly, rather than with her support worker.

Discussion

From features to principles of inclusive mainstream services

Relationships in mainstream services considered to be inclusive by research participants shared some common

features, which we propose constitute principles for facilitating inclusivity in mainstream services. In the rest of this section, we discuss each of these principles in turn:

Respect – Staff in inclusive mainstream services show respect for service users' dignity, privacy and autonomy. This includes actively listening to people with intellectual disabilities; involving them in decisions about service delivery; and respecting their privacy, especially when collecting or sharing information about their support needs. To manage the complexity of putting this principle into practice, work with mainstream staff will be necessary, for example around adapting and applying approaches to enabling risk and supported decision-making (Bigby et al., 2022) to the context mainstream services. Collaborative relationships between mainstream service staff, carers and disability support workers accompanying a service user with an intellectual disability may also help in overcoming these challenges (see "shared responsibility" principle below).

Warm, welcoming and convivial interpersonal engagement – Staff in inclusive mainstream services engage with service users with intellectual disabilities in a warm and welcoming way and create an atmosphere of friendliness. For example, they show a personal interest in service users, and engage on a first-name basis. These types of engagement accord with Wilton et al.'s (2018) observation that relations between service staff and users are not merely transactional and can be meaningful for people with intellectual disabilities. They reflect some of the practices that Edvardsson et al. (2005) found can make a hospital ward feel more "welcoming", when service users feel they are being expected, seen, and invited.

Staff in inclusive mainstream services help to facilitate convivial encounters between service users with and without intellectual disabilities. They do this by prioritising interpersonal encounters as a goal of service delivery; by proactively facilitating opportunities for encounter and conviviality between diverse service users with and without intellectual disabilities, for example through shared rather than separated spaces and activities, and; by supporting and mediating interactions. Many of the strategies that mainstream service staff could use to enhance convivial (and to some extent reciprocal) interactions between service users are identified in the literature on convivial encounters as a means of social inclusion (Bigby & Anderson, 2021; Bigby & Wiesel, 2015; Bredewold et al., 2020). They are also found in the disability practice literature on Active Support as a means of supporting engagement in meaningful activities and social interaction (Bigby, 2024).

Mediated to create a safe environment – Staff in inclusive mainstream services mediate relations between service users to create a safe space where everyone is free of violence and abuse. Mainstream service settings can be sites where people with intellectual disabilities experience aggression, abuse or other exclusionary attitudes by other service users. At times, service users with intellectual disabilities can also interact in ways that threaten other service users (with and without disabilities), and staff. Wherever possible, staff take action to prevent or stop aggressive behaviour by some users and its negative effects on others. They can prevent conflict and abuse by initiating more convivial relations, and by building a shared understanding of each other's needs. Where possible, mainstream services staff need to collaborate with other supporters of the person, to identify ways to manage conflict and abuse, for example, through positive behaviour support (see "shared responsibility" principle below). Running separate activities for service users with intellectual disabilities, or removing a person from the service altogether, risks furthering the exclusion of people with intellectual disabilities. However, where staff are unable to protect the safety of other service users, it can be justifiable to temporarily remove someone from a service as a last resort.

Active listening: Staff in inclusive mainstream services actively listen to service users with intellectual disabilities and take the time to overcome communication difficulties. Listening is a crucial element of communication accessibility, which occurs "when everyone can get their message across" (Solarsh & Johnson, 2017). The concept of "active listening" challenges the perception of listening as a passive process, instead highlighting the active labour of paying attention to diverse forms of verbal and non-verbal expressions, while also actively showing genuine interest (Martin & Jones, 2023, p. 19). Active listening can also sometimes involve staff making use of other communication aids and resources. Importantly, communication accessibility training for staff can improve effective communication with people with diverse communication abilities. However, accessible communication is a relational process and much more than a technical adjustment (Terras et al., 2021).

Proactive assistance – Staff in inclusive mainstream services take the initiative to offer assistance and ensure that service users are aware where and how they can ask for support and feel comfortable to do so. Staff ask service users about their needs in a proactive, but respectful and tactful way, that enables but does not force their disclosure about disability (Rocco, 2001). Proactive assistance also involves checking in and following up after

service delivery, to ensure needs have been satisfied. This principle resonates with Jackson and Read's (2008) argument on the need for proactive approaches in treatment for people with learning disabilities in mainstream healthcare services, which includes proactive collection of information prior to admission, and maintaining continuity of care following discharge.

Flexibility – Staff in inclusive mainstream services engage with service users with intellectual disabilities in flexible ways. This includes for example, not rigidly enforcing rules that a person will struggle to comply with because of their disability. However, staff should avoid engaging service users with intellectual disabilities in ways that reflect low expectations (see also Pelleboer-Gunnink et al., 2017). Flexibility also involves adjusting the intensity of assistance staff provide in response to individual needs. More intensive "hands on" assistance is provided for some, and low-intensity assistance – such as explaining how things work – to others, depending on need. This way, service users exercise control over the level of assistance they receive.

Collaboration and shared responsibility – In inclusive mainstream services responsibility for inclusion and effective participation is shared, and not an exclusive responsibility of either mainstream staff or carers/support workers. This requires mainstream service staff and carer/supporters to coordinate and negotiate formal or informal rules about how they work together. While shared responsibility is best practice, mainstream services should not deny service on the basis that a person does not have a support worker or carer with them. They are legally required to make reasonable adjustments to enable any person to use their service (French, 2013), and inclusive services will go beyond these minimal requirements. Mainstream services can also assist connecting people with advocacy groups to ensure that they gain access to disability support if this is necessary to access their service.

Conclusion

In conclusion, taking a relational approach, this paper considered the web of relations that occur in mainstream services between people with intellectual disabilities, other service users, mainstream service staff, and carers or disability support workers. Examining these relations, we proposed a set of broad principles for improving the inclusivity of mainstream services for people with intellectual disabilities. The principles interconnect and overlap in various ways, but each offers a distinct lesson for practice. These principles also align well with person-centred active support, which is typically applied in specialist disability services.

Our empirical analysis demonstrates that the principles proposed are applicable across different sectors of service delivery. Across many different service types, there are common structural barriers to implementing these principles in practice, such as funding pressures (van Holstein, 2021), and reliance on a casualised workforce (Wiesel et al., 2023). Yet, further research around these and other challenges is required to gain necessary insight into implementing each principle in different types of mainstream service.

Furthermore, the principles proposed are not comprehensive, and reflect the scope and limitations of our study that has focused on practices that are already in place in the services included in the study. Another limitation is the focus on the experiences of people with mild or moderate intellectual disabilities, and further research is also required to understand the inclusion of people with severe and profound intellectual disabilities, who are likely to experience additional and more significant barriers to use of mainstream services.

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