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Mainstreaming, differentiation and individualisation: inclusion of people with intellectual disability in mainstream services

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(paper co-authored with Chris Bigby, Ellen van Holstein and Brendan Gleeson)

Research questions

- What adjustments are made to include users with intellectual disabilities in mainstream services?
- How do these adjustments interact with the broader paradigms of 'mainstreaming', 'differentiation' and 'individualisation'?

Three modes of inclusion of people with intellectual disability in mainstream services: mainstreaming, differentiation and individualisation

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ABSTRACT

This paper examines the adjustments made to include people with intellectual disabilities in mainstream services. Drawing on in-depth interviews with both people with intellectual disabilities and mainstream service managers in four urban regions in Australia, the paper points to three modes of practice that are operationalised, to different degrees, when people with intellectual disabilities seek access to mainstream services: a commitment and adjustments to support inclusion of a wide range of marginalised people (*diversity and inclusion ethos*); adjustments to support inclusion of people with intellectual disabilities more specifically (*differentiated adjustments*); and, *personal support* for service users with intellectual disabilities. We argue that these three modes, at the service level, correspond in complex ways with three broader approaches to social inclusion: mainstreaming, differentiation and individualisation. Rather than contradictory modes of inclusion, our analysis suggests these approaches should be understood as complementary.

ARTICLE HISTORY

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KEYWORDS

Intellectual disability; inclusion; mainstream services; specialist services; individualisation

Points of interest

- Some mainstream services that value 'inclusion' make adjustments to their service in order to better include people from different marginalised groups. Such adjustments have mixed outcomes for people with intellectual disability, whose specific needs are not always met.
- Some mainstream services operate separate activities for users with intellectual disability. This helps them manage behavioural and communication challenges, and can help people with intellectual disability

Three paradigms in social policy (and disability policy) since the 1990s

- **Differentiation:** separate specialist services, tailored to distinct social groups
- **Mainstreaming:** integrating minority groups in services that cater for all people
- **Individualisation:** tailor services to individual rather than group preferences and needs

Differentiation

- Drivers:
 - Multiculturalism
 - Recognition
- Mechanisms:
 - Specialist services and housing
- Critiques:
 - fragmentation of society; 'super-diversity', exclusion of marginalized groups from the mainstream

Mainstreaming

- Drivers:
 - All the critiques of 'differentiation'...
 - Multiculturalism pushback
 - Austerity
- Mechanisms:
 - Deinstitutionalisation; ILC;
- Critiques:
 - Failure to recognise distinct needs of each minority group
 - Belonging

'full inclusion in the **mainstream** community' (NDIS Act 2013)

Individualisation

- Drivers:
 - Self-determination;
 - Consumer choice
- Mechanisms:
 - Individualised funding;
 - Person centred planning and support
- Critiques:
 - Failure to engage with structural societal inequalities
 - Beneficial for individuals with strong informal support

Method

- Reference group comprised of senior staff in policy and industry bodies,
- Reference group comprised of four self-advocates with intellectual disabilities
- Interviews from 2017-2020
 - Western Sydney
 - Newcastle
 - North East Melbourne
 - Geelong
- 40 people with intellectual disabilities
- 49 mainstream service staff across the four sites

Findings: Three modes of inclusion in mainstream services

- Diversity and inclusion ethos
- Specific adjustments for people with intellectual disability
- Personal support

Mode 1: Diversity and inclusion ethos

- A broad commitment to be inclusive of a diverse population of service users, and particularly those from marginalised social groups.
- Dominant in community services run or contracted by local government
- People with intellectual disability but one of various other marginalized groups targeted

Mode 1: Diversity and inclusion ethos

- Adjustments:
 - 'diversity and inclusion officers', 'outreach officers'
 - 'diversity and inclusion plans'
 - flexibility and ad hoc adjustments to activities based on specific user needs
 - 'Warm and welcoming' atmosphere
 - Smaller ratio of staff / service users
 - Facilitating a regular routine of use or ongoing membership of the service
 - Discounts and removal of fines

Mode 1: Diversity and inclusion ethos

- However, when asked how these broad ‘diversity and inclusion’ adjustments supported service users with intellectual disabilities more specifically, managers of mainstream services often responded with examples relating to people with physical or sensory disabilities, people from non-English speaking backgrounds, and children. Several participants conflated intellectual disability with autism and spoke enthusiastically about adjustments to reduce sensory overload (e.g. quiet hours).

Mode 1: Diversity and inclusion ethos

- While some of these adjustments may have positive impacts for some service users with intellectual disability, they can also have negative consequences.

- Facilitator: So, do you find the library welcoming and a fun place?
- Danielle: Yeah, it's good there. It's good there.
- Facilitator: It's good there? That's nice. Okay.
- Danielle: We normally just go to the children's section. We just hang out in there, in the children's section.
- Facilitator: Okay. What do you like there?
- Danielle: Oh, there's lots of computers and there's colouring pictures and crayons and things to do.
- (Danielle, Geelong)

Mode 2: Adjustments by mainstream service to enable participation of people with intellectual disability

- targeted adjustments to their program design, management and delivery in order to enable participation of service users with intellectual disabilities.
- Often following direct encounter with service users with intellectual disabilities leading services to understand the need for adjustments
- Focused in particular on communication and behaviour management

Mode 2: Adjustments by mainstream service to enable participation of people with intellectual disability

- Adjustments:
 - Developing communication access aids and resources
 - Training of staff
 - Inductions
 - Separate activities for people with intellectual disability

Mode 2: Adjustments by mainstream service to enable participation of people with intellectual disability

- Facilitator: Okay, so who do you go to the bowling with?...How many of you go?
- Lisa: About four.
- Facilitator: Okay, so you'll have staff ...or other people there?
- Lisa: Just with people with disabilities.
- Facilitator: Do you chat people who are playing lanes or do you stay in your group? What's it like?
- Lisa: We stay with our group...
- Facilitator: Would you like to play against other people? Or are you happy the way it is?
- Lisa: Just happy the way it is.
- (Geelong, Lisa)

Mode 2: Adjustments by mainstream service to enable participation of people with intellectual disability

*I don't think I would have started a disability-specific program but it is one that I've inherited... I think our role is to be mainstream and inclusive. I think it's not our role to be offering disability-specific. I think it's what's unique about us is that people with disabilities can engage in mainstream services...[but] I'm not going to stop that class because the people who come really enjoy it and I get a lot of really positive feedback from the participants. They have a really lovely time.
(Melbourne, Community 2)*

Mode 3: Personal support

- personal support (formal and informal) for person to be able to access and use mainstream services.

Mode 3: Personal support

- Very different levels in access to, and quality of, personal support for people with intellectual disability in mainstream services
- Lack of clarity about division of roles and responsibilities between mainstream service staff and personal supporters
 - Sometimes all responsibility transferred to personal supporter
 - Sometimes personal supporters 'disappear' and are not involved
- But also some examples of good collaboration – structured or impromptu – between mainstream staff and personal supporters

Mode 3: Personal support

We find that users that come with a carer, a lot of times the carer is not involved while they're here. (Melbourne, Sports 2)

[did] that one-to-one support worker did come and fulfil those one and a half hours that they're meant to ... How is that being monitored? Is that being provided? Who is keeping a close eye on that? (Melbourne, Health 3)

The carer stopped coming after one session and then this person became really problematic and threw the whole [service's] volunteers into high stress, should we say, because he wouldn't - he wasn't listening. (Geelong, Community 1)

Mode 3: Personal support

But we usually walk people over [from the community centre to the sports facility]. Literally, we get out and we just walk them across when they have their first meeting with staff. Hey, this is so and so and this is the staff. (Melbourne, Community 1)

Conclusion

Modes of inclusion at the service level

Diversity and inclusion ethos

Specific adjustments for people with intellectual disability

Personal support

Paradigms of inclusion

Mainstreaming

Differentiation

Individualisation

Thank you!

Read more:

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