Addressing the Shortcomings of Dedifferentiation

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People with intellectual disability have equal rights and value as citizens in society. To be included and have a comparable quality of life to other citizens, they require individual support and adjustment of social structures and processes. Support is provided informally or through disability and mainstream service systems, and mechanisms such as disability action plans, standards and anti-discrimination legislation promote adjustment of structures and processes.

Dedifferentiation means including people with intellectual disability in the broader group of people with disability rather than regarding them as a separate group for the purposes of policy, service provision and professional practices. This position paper sets out the advantages and disadvantages of dedifferentiation. It does not reach a definite positon. Rather it concludes there are benefits of differentiating people with intellectual disability from others with a disability for some issues, for particular sub-groups or at particular times. Likewise, there are benefits of dedifferentiation for some people some of the time about some issues.

The paper summaries the case for and against dedifferentiation, pointing to some of the practical implications of adopting one position or another in policy, service provision or practice. It is based on a literature review published in Research and Practice in Intellectual Disabilities which is available on open access [Clegg & Bigby, 2017]

What does Dedifferentiation mean in practice?

Dedifferentiation means legislation and policy encompasses all people with a disability rather focussing on people with intellectual disability. An example is the 2006 United Nations Declaration on the Rights of Person with Disabilities, rather than the much earlier 1971 United Nations Declaration on the Rights of Mentally Retarded Persons. It means that services may not specifically target people with intellectual disabilities and language such as 'accessible' tends to apply to all people with a disability. Staff in disability services are less likely to have specific training or skills in working with people with intellectual disability, and training programs for direct support workers are intended to encompass skills for working with all people with disabilities.

Advantages of Dedifferentiation

- Choice the label intellectual disability is stigmatising and many people with mild intellectual disability prefer to avoid it. Many people with intellectual disability, including those in self advocacy groups do not want to have a self-identity as a person with intellectual disability, a resistance to being labelled, shamed or patronised they share with many disabled or vulnerable groups. However, this is not always the case and some people with severe and multiple disabilities do welcome support related to intellectual disability when it is offered in the right way. Learning how to raise sensitive topics about intellectual impairment has been identified as a key skill for all support staff
- Advocacy it strengthens the collective voice of people with disability in advocacy to change
 oppressive structures and attitudes and raises the profile of disability issues. The United
 Nations Convention on the Rights of Persons with Disabilities has been particularly important
 in this regard and has been used to support legal challenges to discrimination and in
 generating debate about mechanisms such as supported decision making to enable people
 with intellectual disabilities to exercise legal capacity.
- Better inclusion in some mainstream services it has strengthened arguments for access and adjustment of mainstream services for people with disabilities that sometimes results in more inclusive and better services for people with intellectual disabilities. This has been particularly beneficial in the education system for primary age school children and clinical mental health services for children.
- Avoids a deficit focus by shifting the focus to all people with disability dedifferentiation
 more strongly supports a social model way of thinking about obstacles to inclusion created by
 social structures and processes rather than individual deficits.

What does Differentiation mean in practice?

Differentiation means that mainstream or disability policy or service systems have more targeted policies and services that take account of specific issues associated with intellectual disability. These may be individual and impairment specific associated with understanding how people learn, their capacity to understand ideas or language, make choices, judgments, manage social relationships or tasks of everyday living. This understanding impacts both on the type of individual support a person might need and the skills required to provide support. Alternatively, specific intellectual disability issues may be associated with structures or social processes that have a disproportionately negative impact on people with intellectual disability. These include, for example, subtle and less visible disabling barriers such as dominance of the written word to convey information, shift to multiskilling, loss of unskilled jobs, and reliance on inflexible decision-making algorithms and technologies to transact public and private business. Such understanding informs the types of adjustments required to ensure inclusion of people with intellectual disability. Differentiation also means that staff are more likely to have foundational or specialist knowledge and practice skills related to working with people with intellectual disability.

Differentiation does not necessarily mean having separate services for people with intellectual disability. It may mean specialist staff, training or adjustments that take specific account of issues relevant to people with intellectual disability within mainstream or generic disability services. However, differentiation has sometimes meant poor quality separate services.

Advantages of Differentiation

- Recognition of diversity and group specific needs recognises the diversity among people
 with disability and intellectual disability, and the breadth of specific or specialist knowledge
 and skills that may be required to provide quality support or adjust social structures and
 processes for particular sub groups. Addresses the challenges of enabling inclusion of people
 with intellectual disability that are clearly underestimated by most dedifferentiated services
 and policies
- Recognition of need for specialist knowledge and support recognises the significant and
 specialist knowledge that can be required to adequately support or adapt services to a person
 with intellectual disability. Acknowledges the difficulties and limited success in trying to
 provide in service training to generic staff in mainstream or generic disability services to
 ensure they have sufficient expert knowledge to respond effectively to some groups of people
 with intellectual disability.

- Avoids inaccurate or absent representations avoids the tendency to use people with mild intellectual disability as the proxies for all people. Draws attention to the types of accommodations needed to include people with intellectual disability in reference, advisory or co-production groups, and in disabled people's organisations. Increases the chance that issues for people with more severe or profound intellectual disability are acknowledged.
 Promotes a more nuanced understanding of ways of knowing about life experiences and circumstances so that other sources of expertise can be placed alongside self-reports from people with milder intellectual disabilities.
- Recognition of impairment specific barriers recognises that some barriers to access or
 participation are associated with facets of a person's impairment and draws attention to these
 and the need to make adjustments. Broadens the concept of accessibility, and counteracts the
 default position that 'access' is about visible and physical barriers.
- Enables quality alternatives to mainstream services —provides alternatives to mainstream or generalist disability services when they are not able, despite considerable policy attention, to adapt in ways that will meet the needs of some people with intellectual disability. For example, the failure of mainstream secondary schools and mental health services to include and provide quality services effectively to young people or adults with intellectual disability.
- Avoids compounding disadvantage avoids the poor outcomes in terms of service quality
 that can result from dedifferentiated service systems that group together disadvantaged
 people in one location or service.
- Enables more specific advocacy enables advocacy and self-advocacy to raise issues specific to the experiences of having intellectual disability, many of which are given limited attention or are neglected by broad disability groups.
- Identification of need and access to resources effective identification in administrative data sets will ensure good data are available to make the political case for redistributing resource to people with intellectual disability and their families. Differentiation also protects resources and opportunities intended for people with intellectual disability from being encroached on by other groups.

In summary, these arguments revolve around dilemmas of difference, how to treat a person as an individual with equal rights and expectations of a quality of life similar to other citizens without disregarding their impairment or their need for specific adaptations and support to attain equal outcomes. The core argument against dedifferentiation in favour of differentiation is that impairment matters sometimes for some people. These arguments tend to favour a critical realism understanding of disability as the interaction between factors intrinsic to the individual, and extrinsic factors arising from the wider context. For people with intellectual disability, discriminatory structures and limiting social attitudes compound the difficulties of low intellectual capacity, depriving people of rights, respect and dignity.

Conclusions

Efforts to make services and systems universally accessible and thus responsive to people with intellectual disability have made little progress, and in countries facing austerity financing have resulted in some services for this group becoming disproportionately worse. As the early days of the NDIS in Australia demonstrated, enabling people with intellectual disability to articulate their aspirations, spell out their needs, and claim necessary resources requires specialist skills: a finely tuned service system aware of communication and other difficulties associated with intellectual disability. Similarly, social inclusion requires nuanced and skilled support to counter invisible barriers posed by prejudice that fuel both exclusion and hate crimes; and to counter the problem of community members having limited contact and understanding about how to interact with people who have intellectual disability.

So policy, service systems and professionals should:

- Design different types of services for different types of people. Treat people with intellectual
 disability as members of the broad disability group wherever possible, and protect and
 develop differentiated opportunities, services and research whenever necessary.
- While service user perspectives are important, acknowledging the diversity of people with intellectual disability will ensure input is critically appraised and considered alongside other forms of knowledge to ensure that the decisions reached are sensible for all.
- Since a high proportion of people with intellectual disability also experience complex
 physical and/or mental health problems, and very often live in the most disadvantaged
 localities, different policies and support services for them need to be imagined, developed and
 examined.
- Tackle the social isolation of people with intellectual disability by emphasizing the creation and maintenance of satisfactory relationships, both in care situations and through community developments that build connections and a sense of belonging.

- Ensure that specialist opportunities and services are only segregated if necessary. They should not be less valued or poorly resourced, just tailored for the unique talents of people with intellectual disability.
- Negotiate a definition of a meaningful adult life in different cultures, so that people with
 intellectual disability can be supported to live a life of dignity without having to battle against
 other vulnerable groups for resource. Priority topics are support to experience belonging –
 looking to employment and beyond to encompass a much broader range of purposeful
 activities –and acceptable accommodation that avoids placing people with disliked others, but
 also avoids creating isolated single-person services afflicted by rapid staff turnover.