MAKING MAINSTREAM SERVICES ACCESSIBLE AND RESPONSIVE TO PEOPLE WITH INTELLECTUAL DISABILITY: WHAT IS THE EQUIVALENT OF LIFTS AND LABRADORS?

Proceedings of the
Seventh Annual Roundtable on Intellectual Disability Policy

Held on December 6, 2012

Edited by
Christine Bigby and Chris Fyffe

Published by the Living with Disability Group,
School of Allied Health, Faculty of Health Sciences
La Trobe University
Bundoora, Vic. 3086 Australia

Printed by Allardice Group
Blackburn Vic. 3130

Making mainstream services accessible and responsive to people with intellectual disability:
Bundoora: Living with Disability Research Group, Faculty of Health Sciences, La Trobe University

Further copies of this document are available from C.bigby@latrobe.edu.au or online
MAKING MAINSTREAM SERVICES ACCESSIBLE AND RESPONSIVE TO PEOPLE WITH INTELLECTUAL DISABILITY: WHAT IS THE EQUIVALENT OF LIFTS AND LABRADORS?

Proceedings of the
Seventh Annual Roundtable on Intellectual Disability Policy

Held on December 6, 2012

Edited by Christine Bigby and Chris Fyffe
# Contents

Introduction ..................................................................................................................................................................3

Overview – Responsiveness of mainstream services to people with intellectual disability: Challenges for the National Disability Insurance Scheme?  
*Christine Bigby & Chris Fyffe* ........................................................................................................................................4

Specific disability services and the mainstream – what do we mean?  
*Christine Bigby & Chris Fyffe* ......................................................................................................................................11

The challenge of including and organising special support in mainstream services  
– A Swedish perspective.  
*Magnus Tideman* ..........................................................................................................................................................21

Vocational services under a National Disability Insurance Scheme.  
*Bryan Woodford* ............................................................................................................................................................29

Disability in the mainstream: Improving healthcare provided to people with intellectual disability and the role of mainstream and specialist services.  
*Jane Tracy* ......................................................................................................................................................................37

Housing people with intellectual disability under the National Disability Insurance Scheme.  
*Ilan Wiesel* ....................................................................................................................................................................47

The concept of reasonable adjustment in Commonwealth disability discrimination law and its implications for equality for persons with intellectual impairment.  
*Phillip French* ..................................................................................................................................................................54

Communication access: A journey towards inclusion for people with intellectual disability.  
*Barbara Solarsh, Hilary Johnson and Denise West* ......................................................................................................60
Introduction

The Roundtable on Intellectual Disability Policy is an annual event that is convened by the Living with Disability research group at La Trobe University in collaboration with key stakeholders interested in improving the lives of people with intellectual disability. The Roundtable is self-funding. It aims,

To provide a space for fearless debate, among interested groups, about policy within both the disability and the broader human service sectors for people with intellectual disabilities, with the intention of naming issues, clarifying concepts and ideas, exploring challenges, articulating solutions and informing practice.

The 2012 Roundtable explored the proposition that all mainstream services should be accessible and responsive to people with intellectual disability and asked how this might be done. It considered the following questions:

- What do we mean by mainstream services?
- What is the goal? What does ‘using mainstream services’ look like for someone with an intellectual disability with and without NDIS funding?
- What are the barriers that prevent people with intellectual disability using mainstream services or services from responding appropriately?
- What are the models used to make mainstream services accessible and responsive?
- What is the evidence about what works?
- Are approaches for people with intellectual disability different from those required to address access for other groups of people with disability?
- What can be learned from the models used in Education or Transport Standards or Disability Action Plans?
- Whose responsibility is it to drive change?

The papers in this collection were written to stimulate debate at the Roundtable. They are reproduced in these Proceedings together with an overview of the issues in order to generate further debate about these issues that will be fundamentally important to the long term viability of the National Disability Insurance Scheme.
Responsiveness of Mainstream Services to People with Intellectual Disability: Challenges for the National Disability Insurance Scheme?

Christine Bigby & Chris Fyffe

The capacity of mainstream service systems to meet the needs of people with disability is central to the design of the National Disability Insurance Scheme (the Scheme) and will shape the demands made upon it. The Productivity Commission (2011) warned of the cost escalation that would compromise the viability of the Scheme if it tried to compensate for the shortfalls of mainstream service systems. Heeding this advice, the scheme will only fund supports not available in the mainstream and not those that are more appropriately provided by other service systems, such as education, employment, health, housing, and public transport (National Disability Insurance Scheme Bill, 2012). Instead it will provide coordination and referral to those mainstream services, for all people with a disability including those who qualify for individual disability support funding, as well as those who do not. This paper draws together the discussion and papers from the 2012 La Trobe Roundtable on Intellectual Disability Policy which considered issues of access and responsiveness of mainstream services to people with intellectual disability, strategies for levering change in the mainstream and where responsibilities might lie for driving change. This is a timely issue as the reform of the disability system from the ground up through the Scheme provides opportunities to forge new relationships between funded disability supports and mainstream services. The focus on people with intellectual disability is warranted, as their needs are often invisible, require complex responses and have received little attention as issues of physical and sensory accessibility have dominated attempts to accommodate the needs of people with disabilities in the mainstream system (Productivity Commission, 2004).

Use of mainstream services and participation by people with disability in the mainstream life of the community have been enduring policy aims since the 1970s. During this time however, the relationship between mainstream and disability services has changed in a way that might be characterised as a shift from being parallel systems, where specialist disability services tended to separate people with disability from all aspects of the mainstream, to an increased sense of partnership, where people with a disability use both disability and mainstream systems, which work together to further social inclusion.

Being part of ‘the mainstream’ has come to be regarded as central to social inclusion, quality of life, and reducing the segregation and marginalisation of people with disabilities. For example the National Disability Strategy (Commonwealth of Australia, 2011, p.13) states;

Some people with disability and their carers need specialist supports to be able to maintain everyday wellbeing at home, and to be involved in community life … However, a key imperative is for the broader community and mainstream services and facilities that are part of ordinary Australian life to be available and fully accessible for people with disability.

Mainstream life in the community for people with disabilities should be indistinguishable from the range of opportunities and patterns of life experienced by all community members. Mainstream services can refer to buildings, public places, administrative systems such as the courts, businesses, service systems; in essence the diverse systems, processes and structures that make up communities. As relationships between mainstream and disability services have changed, a tight definition of mainstream services has become difficult; it does not necessarily mean services are identical for everyone, do not have specialists or do not have specific responses to people with disabilities. Some mainstream systems have high levels of specialism embedded within them, some of which focus on disability. The health system for example, includes specialities for population subgroups and specific conditions such as children with developmental disabilities and cerebral palsy. Some mainstream services are specifically targeted at minority or disadvantaged groups, such as public housing, or mental health of whom a significant proportion are people with disabilities. Some mainstream systems include programs specifically for people with disabilities, such as disability employment programs, as part of the employment system. In many instances these specific responses within mainstream services aim to increase participation in the community. In some instances however, as in the case of special schools for example, they segregate people with disabilities together in quasi separate systems.
within the mainstream, or in the case of some Local Government services into separate day programs or activity groups within the broader Home and Community Care Program.

Therefore, inclusion in mainstream services does not necessarily mean people with intellectual disabilities will receive high quality services or not be segregated. Evidence suggests mainstream services adopt varying ways of responding to people with intellectual disabilities, have variable capacity and motivation to respond effectively. For example, school education maintains two streams – segregated special schooling and mainstream integration, despite:

...well documented concern that special schooling legitimates the discrimination often visited upon children and young people with learning disabilities and sets the scene for subsequent disadvantage, most particularly in respect of employment (Powell & Flynn, 2005, p 400)

Disability policy suggests that the aim of using mainstream services should be to deliver to people with disability outcomes of similar quality to those expected for other service users; such as a job, housing, good health and minimum ill health, and reaching full potential for intellectual and social development, the overarching purpose being to support individual development, and social and economic participation. Yet the continued health inequalities of people with intellectual disabilities, their low rates of employment and unmet need for housing, suggest mainstream services have struggled to deliver quality outcomes (Woodford, 2013; Emerson & Durvasula, 2005; Wiezel, 2013).

**Making the mainstream accessible and responsive**

The concept of ‘mainstreaming’ and ‘universal design’ are one way of achieving the policy aim that ‘all mainstream services and programs across the country – including healthcare, education, Indigenous reform and housing – address the needs of people with disability’ (Commonwealth of Australia, 2011, p13). This approach aims to design services from the outset to take into account the needs of people with intellectual disabilities, to avoid singling them out from other service users or offering special treatment. Universal design which is used commonly to address building design and physical access has the potential to be applied to aspects of communication and interface between services and their users, by for example, including standards for staff communication skills and the use of multiple modes of communication. A principle that might inform this type of design is found in the NDIS legislation in respect of the way it should operate, ‘People with disability should be supported in all their dealings and communications with the Agency so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs’ (National Disability Insurance Scheme Bill, 2012).

Issues of physical access and communication which are common to all mainstream services lend themselves to a universal approach. However, many of the problems people with disability experience using mainstream services are specific to the design and context of that service or the nature of their impairment. For example, Woodford’s (2013) paper drew out the poor design of mainstream employment program that is targeted at people with disabilities which is based on short term engagement and throughput, and fails to reflect evidence about the importance of building social engagement in the workplace or the role of long term support and workplace coaching for people with intellectual disability to gain and retain jobs. Tracy (2013) talked about the absence of systematic knowledge and awareness of intellectual disability in the curriculum design of medical and allied health professionals and consequent lack of confidence among medical practitioners, and Wiesel (2013), drew attention to the shortage of affordable housing which impacts heavily on people with intellectual disability dependent on income support payments.

These examples suggest different strategies are needed ‘to make the mainstream accessible’ depending on the mainstream service sector in question. Many of the shortcomings identified in mainstream service responses for people with intellectual disability stem from program designs that fail to take account of their needs, or in taking needs into account are poorly designed or lack the knowledge or other resources to produce good outcomes. Some shortcomings also arise from broader problems that are experienced by other service users, such as the high cost of housing or the limited scale of government investment in social housing programs. Teasing out the problems encountered by people with intellectual disability in each mainstream service sector will inform strategies to address them, as well as, in some instances, point to the potential value of strategic alliances with other groups.
The Roundtable illustrated a range of strategies used to make mainstream services more responsive to people with intellectual disability. One approach used in the health system, depicted as a triangle, is similar to the conceptualisation of primary, secondary and tertiary interventions. At the base are responses built into the design, such as a specific Medicare item to enable longer consultations by general practitioners, at the next level, availability of specialist medical practitioners to consult with general practitioners, and finally at the tip of the triangle, specialists with capacity to provide direct assessment and treatment of people with intellectual disability when necessary. In Australia, all of these elements, including identification and advocacy of the need for change to Medicare design, are located and funded outside the mainstream health care system. The Centre for Developmental Disability Health Victoria, and its equivalent in Queensland, are staffed by specialists in health care of people with intellectual disability who act as change agents in the mainstream health system from positions in Universities funded by disability systems.

Although reliance has been placed on external specialists to resource mainstream systems at multiple levels (design, pre service education, in service training, direct practice, knowledge transfer, research and advocacy) there is no reason why the same functions cannot be performed from within a system as occurs elsewhere. For example, a similar model exists already for people with a mental illness in Australia, in the health system in the UK hospitals employ disability liaison practitioners, whose role is to influence the way medical staff care for and treat people with intellectual disability, and in the Netherland a medical speciality in intellectual and development disability exists in the health system.

Another approach, reliant in Australia on external change agents, is illustrated by the Community Resource Centre (Solarsh, Johnson & West, 2013), which has a primary focus on one aspect of need, accessible communication and works across mainstream sectors. The Community Resource Centre group have developed standards for accessible communication, an international symbol awarded to recognise compliance, and provide consultancy, advice and education to mainstream services such as hospitals, and public transport authorities. Notably, this paper also talks about the multiple layers or domains that need to be considered in thinking about the responsiveness of mainstream services to people with intellectual disability. In respect of communication for example, some layers such as simple customer service enquiries lend themselves to a more universal approach designed in collaboration with specialists, whilst others such as dealing with critical life issues in a hospital may require the more direct support of a specialist to enable effective communication to occur.

Other examples illustrated similar strategies to those explained by Solarsh et al. where disability professionals or services outside a mainstream system acted as a catalyst in one form or another to encourage or support mainstream services to be more accessible to people with intellectual disability. The Independent Third Person program in Victoria for example where volunteers are supported by one government agency (Justice), to ensure another, the police force conducts interviews that take account of a person’s intellectual disability. Other types of less common responses were change generated from within a system, such as the establishment of a specialist unit in the NSW police service to increase its capacity to respond to people with disability. There were several examples too of initiatives by Universities and colleges to adapt curriculum and provide specialist support to enable students with intellectual disability to undertake modified courses and mix socially with other students. Few examples were given however of the application of mandated and more generalised mechanisms such as Disability Action Plans used to address the specific needs of people with intellectual disability.

All the approaches identified, illustrate, 1) the need to address the multiple layers within organisations that impact on responsiveness, 2) the co-existence of strategies required to ensure complex as well as more straightforward needs are met, and 3) the necessity of accumulation and access to specialist knowledge both about the relevant mainstream program and issues associated with people with intellectual disability in order to design responsive mainstream services or bring about change in mainstream system. For example, it was only through a depth of knowledge about the primary health care system and health of people with intellectual disability, that the type of change necessary to the Medicare system was identified, provision of consultancy to medical professionals about special health issues of people with intellectual disability requires access to and the opportunity to develop experienced practitioners with specialist knowledge of intellectual disability, health and disability service systems.
Policy needs research

Despite the consistent policy direction about using mainstream services and the many examples of specific responses generated from within and outside mainstream services to address the needs of people with intellectual disability, there is remarkably little Australian research that documents their experiences in using mainstream services or evaluates the effectiveness of strategies to address their needs. While there is, for example a body of work on access to primary health care for people with intellectual disability there is scant knowledge about the acute care or geriatric system. Much work remains to understand problems and interventions. Systematic research on these issues and large scale data will assist to develop effective evidence based strategies, and draw attention to the scope and nature of the problems that exist. Monitoring experiences and outcomes through more detailed collection of data about different groups of people with disability can provide powerful motivation for change. In the UK for example a major scandal about the premature deaths of six people in hospitals led to several government enquiries that focussed attention of the failure of health services to meet the needs of people with intellectual disability (Mencap, 2007). It led to a raft of initiatives taken by the health system, to change processes and practices as well as monitor outcomes through a Health Observatory and confidential enquiry into deaths (for example, Emerson et al., 2012; Turner & Robinson, 2011; http://www.improvinghealthandlives.org.uk).

Is ‘reasonable adjustment’ sufficient?

One means of driving change has been anti-discrimination legislation, which has had some success in relation to physical accessibility. French's paper (2013) argued however that it is poorly framed to ensure services take account of the needs of people with intellectual disability and has largely failed to impact on their life circumstances. Anti-discrimination legislation prohibits direct and indirect discrimination on the basis of disability, requiring service systems to make reasonable adjustment to accommodate disability to ensure people with disability are not treated less favourably than others. His analysis suggests the impact of the legislation is limited not only by the proviso that adjustment need only be ‘as far as possible’ and not ‘cause unreasonable hardship’ to the duty bearer, but also because of the inherent weakness of the concept of ‘reasonable adjustment’. He argues that the formal equality paradigm that underpins the Disability Discrimination Act seeks only to ensure a person with disability is treated the same as others with similar circumstances, which means in effect their disability is disregarded, or in the case of indirect discrimination unreasonable requirements are not imposed which would be disadvantageous. The formal equality paradigm relies on normative comparisons between people with and without a disability, which is particularly problematic in the case of people with intellectual disability whose circumstances and characteristics often fall well outside the norm. The test that a person with disability is not treated unfavourably or even less favourably compared to others does not go so far as to require that they be treated differently and positive action be taken to address their disability related need and advance their interests. For example, the case of Purvis v State of New South Wales (High Court, 2003) illustrated the onus on a school to treat a student disability in the same way as any other students, rather than take positive steps to address the students behaviour that was associated with his disability.

French’s (2013) argument suggests that to be an effective driver of change for people with intellectual disability, legislation must be based on the concept of substantive equality that would require mainstream services to recognise rather than disregard disability, and take positive or exceptional measures to adjust a service to meet their needs. Foreshadowed new equity legislation French suggests will redress some of the weakness of the current anti-discrimination but will still only require reasonable adjustment rather than positive or exceptional measures.

Role for the NDIS challenging the mainstream to respond

A powerful way of engaging the attention of mainstream services to the needs of people with intellectual disability is through government control of funding for mainstream services. The National Disability Strategy suggests for example that at a high level funding could be contingent on effectively addressing the needs of people with disabilities, through requirements to meet standards, indicators and targets of effectively doing so. The 2009 report of the National Health and Hospital Reform Commission for example suggested the aim of the health system was to ‘encourage and support everyone to achieve maximal health regardless of age or whether they have chronic illness or disability’. Funding
agreements at all levels of the system, may be one way of negotiating targets and making the health system more accountable for its actions in respect of people with intellectual disabilities.

While the Productivity Commission report (2011) recognised the importance of mainstream services for all people with disabilities, media attention, and advocacy work of the Every Australian Counts campaign has narrowed discussion to those people who will receive direct funding through the Scheme. This too has been the focus of Federal State negotiations and the bilateral agreements (Commonwealth of Australia, 2012) which have focussed on meeting needs through individualised funding rather than collectively through change in mainstream service systems. Finding a balance between the two, and identifying the necessary levers to resource and implement existing high level policies that mainstream services address the needs of people with disabilities is a critical task. The experience of the Nordic welfare states, exemplified in Tideman’s (2013) paper on Sweden clearly illustrated some of the difficulties of finding such a balance and that in Sweden entitlement to individualised support alone has been insufficient to achieve social and economic participation for people with intellectual disability. The increased identification of children in need of individualised disability related supports as a result of a trend towards expectations of higher standards and performance by mainstream education also illustrated the effect that changes in mainstream services have on the demand for disability services. Attention to the mainstream and finding a balance between individualised and collective responses to the needs of people with disability, is important not only in terms of the Schemes viability and the rights of people with intellectual disability, but also because to date much of the drive for change has relied on the initiative and resources of a dedicated disability system that is facing major reform that could reduce its capacity for this type of collective action.

Settling arrangements for the delivery of information, referral and service coordination for all people with disability which the legislation suggests will be through the Scheme is a major task. But both this and deciding where responsibility lies to fund collective services such as Advocacy and Self-Advocacy which play important roles in identifying shortfalls in mainstream services are steps that require significant government attention. So too does the allocation of resources to the elements of various State Disability Plans and the National Disability Strategy that set out strategies to increase the capacity of mainstream services, monitoring and evaluating progress are important steps too. Much work has gone into the aspirations of plans but relatively little into how these might be achieved and their implementation.

The National Disability Insurance Scheme Launch Transition Agency (the Agency) is in a position to play a number of key roles to drive change in mainstream services. The most direct of these is likely to be the Agency’s decision making about what are reasonable and necessary disability supports, and what should more appropriately be provided by other service systems. The Agency will have to grapple with issues such as whether needs ‘could possibly be met’ by other systems (if resources were available or services were adapted) or ‘should be met’ by other systems (but are not being met) or are ‘actually being met’ by other systems (but perhaps not uniformly across jurisdictions). An important consideration in order to maintain a national scheme will be consistency within and across jurisdiction, as inequity based on location was a fundamental failure of the system being replaced. The principles used to inform decisions about what is to be funded, and the consistent application of these will begin to set benchmark expectations of mainstream services across jurisdictions. Over time the normative effect of the Agency’s decisions and subsequent review processes will build a guide to what is reasonably expected of the mainstream for people with intellectual disability in Australia.

The Agency’s role in providing support with coordination and referral for people with disabilities to mainstream services will position it to identify shortfalls. For example, the role of its Local Area Co-ordinators will provide a wealth of first hand experiences of obstacles encountered by people with intellectual disabilities in accessing mainstream services. The Scheme will develop a depth of understanding about the interface between specific mainstream service systems and the needs of people with intellectual disability, which will enable it to facilitate more productive partnerships between sectors and perhaps leverage resources from mainstream or commercial sectors. The Agency’s experiences and data can also be used to draw public attention to poor performance or to support negotiations for change. The Agency will be able to use its Ministerial Council and access to government to ensure the responsiveness of mainstream services to people with disability remain high on public agendas.
Possibilities for the future
In its role in ‘raising community awareness of issues that affect the social and economic participation of people with disability and facilitate greater community inclusion’, (NDIS Bill, 2013) the potential also exists for the Agency to use its funds to seed and evaluate demonstration projects to pilot more effective strategies to address disability needs in the mainstream. Facilitating research that draws attention to the costs to the NDIS and the long term impact on the lives of people with disability of poor quality responses by mainstream services, such as the education or housing may also be used to stimulate change in these sectors. For example, if children with intellectual disability do not receive high quality educational experiences that develop intellectual as well as social skills, that fosters social connections and independence their long term costs of support are likely to much higher than might otherwise need to be; if young adults with intellectual disability are unable to separate from their parents and leave home due to a lack of housing the type of high cost financial and emotional needs current among of older carers and middle aged people with intellectual disability are likely to be replicated in future generations; or if young people do not access quality health care, health promotion or preventative services they will be more likely to experience chronic health conditions as they age. The principles of early intervention and the idea that an insurance approach will reduce lifelong costs as well as maximise potential of people with disabilities will be in danger of being compromised if sufficient attention is not given to the inter related performance of mainstream services and the National Disability Insurance Scheme. There are many possibilities at different levels for the NDIS to act as a catalyst for change in the mainstream and ensure a balance between responses arising from individualised funding and more collectively funded responses to people with intellectual disability. How this might be done requires concerted attention, and through innovative mechanisms, demonstration programs and rigorous evaluation, the compilation of an evidence base to inform action.

References


Dr Chris Fyffe is a consultant in disability with a longstanding commitment to working with people with intellectual disability. mcfyffe@grimwood.net.au

Professor Christine Bigby leads the Living with Disability research group in the Faculty of Allied Health at LaTrobe University. C.bigby@latrobe.edu.au
Specific Disability Services and the Mainstream – What do we mean?

Christine Bigby and Chris Fyffe

The report of the Productivity Commission on Disability Care and Support (2011) referred to some services or supports as ‘complementary’ to distinguish them from those that would be funded more specifically for people with disabilities. The PC report used the term complementary while other legislation and policy documents have used terms such as ‘mainstream’ or ‘services available to the general community’ to refer to services such as education, employment, health, and housing. The separation in this way of ‘mainstream’ from ‘specific disability’ services reinforces the significance of inclusion in mainstream services for people with disabilities. Since the era of normalisation in the 1970s inclusion more generally in mainstream life, and more specifically in mainstream services have been goals of disability policy. Pragmatically as the PC report points out, it is too costly for government to take responsibility for all the services and supports required by people with disabilities (and anyway in the past this has sometimes led to special and separate services that segregate people with disabilities). All people with a disability, including for the minority of people with disability who are eligible for the type of specific disability funding proposed by the National Disability Insurance Scheme will be reliant on mainstream services to meet some of their needs. This makes it important that mainstream services are accessible and responsive for all people with a disability. The PC stated;

Ultimately, there must be boundaries to the NDIS – it cannot take over responsibility for all services and supports that people with a disability use, or it would be too unwieldy and governments would be unlikely to implement it. The main complementary services are education, employment, health, housing, income support and public transport (p. 24).

The distinction between disability specific support funded by the NDIS and other mainstream services or support funded from other sources is found in section 34 of the NDIS draft legislation. This section indicates that ‘reasonable and necessary support’ will be funded by the NDIS, but support that is considered more appropriately provided by others as part of a ‘universal’ service obligation or required by disability discrimination law will not be funded.

Section 34 (f)

(f) the support is most appropriately funded or provided through the National Disability Insurance Scheme, and is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered:

(i) as part of a universal service obligation; or

(ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability;

The distinction between what is appropriately funded by special disability funding and what is available to people with a disability as part of the mainstream – as universal service obligation or required reasonable adjustment – is important to the viability of NDIS. If mainstream services are not accessible and responsive to all people including those with milder as well as more severe levels of disability there is likely to be pressure to expand the scope of services and supports to be funded by NDIS and thus the amount special disability funding.

The distinction between special disability and the mainstream is however, not as clear or unproblematic as the legislation might suggest, nor are the relative benefits of each, or the underlying task of ensuring the mainstream is accessible and responsive or pin pointing which part of government might be responsible for this task- special disability or the mainstream. By considering what is meant by the ‘mainstream’ particularly for people with intellectual disability, this paper discusses the implications of its differing interpretations and teases out some of the underlying implications that might flow from the NDIS relying on mainstream services to support people with intellectual disability and only providing reasonable and necessary supports which are not more appropriately funded or provided elsewhere in the social system. The issues include:

• Is inclusion in mainstream services always an ideal goal? – can inclusion in the mainstream lead to a second rate service being received or to separate and segregated services and experiences for people with intellectual disability?

• What is the difference between mainstream and specialist services – are service systems for other particular sub groups of the community
such as the aged care services or mental health services mainstream or specialist?

• Is inclusion in mainstream services possible for all people with disabilities – how should it be achieved, might one way of doing this be a specialist response as part of the mainstream and in this case who should fund it?

• Who is responsible for achieving and funding inclusion in mainstream services

• What is the relationship between mainstream services and specialist disability services?

• What if other systems should but don’t effectively include people with disabilities – What happens if there is a gap between what should and what does happen in terms of access to services mainstream services which are most appropriately delivered by other systems – who decides what is appropriate to expect?

Going back to disability theory

The inter relationship between special disability funded services and supports and mainstream service systems that the NDIS must grapple with are not new, and are very evident in disability theory. The differentiation between impairment and disability made by the social model of disability provides a useful way of thinking about special disability and mainstream services. Impairments stem from disease or body structures that cause difficulty in everyday functioning, and disability results from the complex interaction between people with impairment and discriminatory or ill adapted social processes. “It is not physical, cognitive or sensory impairments that cause disability, but rather the way in which societies fail to accommodate natural aspects of difference between people” (Priestley, 2003, p. 13). While impairment is a personal attribute, disability is the collective experience of people with impairments created by society. For example, as Magnus Tideman (2013) explains in his paper an underfunded and inflexible school system in Sweden that is experiencing problems in meeting the needs of students with diverse needs is labeling an increasing number of students as disabled. From this perspective, it is social arrangements, such as the way schools are funded and organized, that needs to change to reduce disability and maximize individual social inclusion. Change to the mainstream of society, to take account of people with impairments will need to occur to many different aspects; places (buildings or pavements); facilities and services (museums or hospitals); institutions (the banking or legal system); social processes (elections or dissemination of public information) and structures (government advisory groups). The more discriminatory these aspects of society are, the more disabled people with impairments will be and greater their need for specialist disability supports. In the social model, disability is a dynamic rather than static phenomena, change to the social and environmental arrangements will reduce the impact of impairment and thus the need or pressure to gain access to specialist disability services.

In NDIS terms the more accessible and responsive mainstream services are to people with disabilities, the less support they may require from the NDIS. However, the social model also acknowledges that as well as attention to increasing use of the mainstream, through removal of disabling barriers, some people with impairments will have a continuing need for individual support with the tasks of everyday living, planning, problem solving and self-management that they may not be able to carry out independently. Thus as Shakespeare (2006) suggests the individual experience of impairment, and knowledge about the nature of impairment is important, because if disability is only understood as the product of structural exclusion, then the number of disabled people no longer becomes relevant, nor knowledge about specific forms of impairment (p.32). It is also the case that knowledge of impairment specific needs and obstacles to participation are important in understanding and removing disabling barriers to make mainstream services accessible and responsive. There is thus a need for specialist knowledge about impairment and disability to inform both specialist and mainstream services.

Nevertheless, a social model analysis suggests there is potential for significant redundancy in disability specific services –and that inclusion in mainstream services is a preferable option as the vehicle to realize the aims of disability policy and inclusion in mainstream life. This position has been increasingly reflected in Australian disability policy and its preference for mainstream over disability services since the late 1980’s.

What does mainstream mean?

‘Being part of the mainstream’ of life

Being part of the mainstream means not being routinely segregated by being asked to live
away from, and being treated differently from, the general population as a consequence of membership of a group or a common diagnosis, such as intellectual disability.

‘Being part of the mainstream is something most of us take for granted. We go to work, look after our families, visit our GP, use transport, go to the swimming pool or cinema. Inclusion means enabling people with learning disabilities to do these ordinary things, make use of mainstream services and be fully included in the local community (Dept of Health, 2001, p.24)

Being part of the mainstream used in this way implies a pattern of life encompassing the same rights, opportunities and experiences as other citizens. It is the right to be in public places and attend public events; to participate in business and commercial life; to join community clubs, groups and activities; to be educated; to be as healthy and safe as possible; to have friends and close relationships; and to have a meaningful life. Being part of the mainstream is both a means to a goal and a goal in itself.

Mainstreaming

Since the shift from institutional to community based models of disability service, some parts of the disability sector have assumed that sooner or later they would work themselves out of a job by building sufficient capacity in the mainstream to enable all services to be responsive to the needs of people with intellectual disability. The argument has been that gradually the mainstream could acquire the commitment, expertise, resources and practice skills to include each person with intellectual disability without additional assistance from disability supports which inevitably single people out as being different. It was imagined, for instance, that the local pool or library would have support staff available with skills to support all people who want to use their services – be they people with intellectual disability, mental health problems or older people. Central to these ideas is the concept of mainstreaming found in United Nations disability policy which advocates that reliance should not be placed on ‘special arrangements’ for people with disabilities to be included in mainstream life and services (United Nations Economic and Social Council, 2007). Mainstreaming requires knowledge and actions attuned to the nature of the obstacles associated with all types of impairment, and the implications of these to be taken into account in legislation, policies and the day to day operation of services. Mainstreaming implies that inclusion of people with diverse needs becomes an integral part of the design of social systems, so they equally benefit people with disabilities, and not perpetuate unequal access. Examples might be:

- consideration of public transport accessibility would go beyond the physical access; design of new trams, trains or transport ticketing systems would include spoken instructions, visual signs, staff to help people navigate complex operations or directions, to take into account that not all people have literacy or numeracy skills.
- training of all professionals and public contact staff would include knowledge about different modes of communication and specific issues likely to arise relevant to people with intellectual disability.

The theory behind mainstreaming is similar that of universal access, which implies no ‘exceptional’ adjustments made on a one by one basis that draw particular attention to a person’s impairment should be necessary for the inclusion of people with intellectual disabilities. Mainstreaming represents a ‘whole of government’ approach to disability policy, where responsibility for inclusion lies with all arms of government rather than being the responsibility of disability services. Mainstreaming aims to build organizational capacity, which in the long run effectively embeds measures that promote inclusion, so they become the norm rather than add on demands made by those external to the organization.

What are mainstream services – Do they always lead to greater social inclusion?

In Victoria, driven by normalisation and the social model for people with intellectual disabilities, ideas about use of mainstream services were first foreshadowed in the Intellectually Disabled Persons’ Services Act (1986) which was the foundation of the ‘Ten Year Plan for the Redevelopment of Intellectual Disability Services’ (Neilson Associates, 1988). At its core was the redevelopment of Victoria’s large residential settings and the idea that people with intellectual disability should be supported ‘like other community members’ to be educated, to work, to be part of local communities’. The Plan challenged the status quo whereby there were services available in the wider community and separate and segregated services available to people with an intellectual disability. The plan proposed that
services ‘generally available to other members of
the community’ should also be available to people
with intellectual disability and to achieve this
community services might need to adjust in order
to respond to individual needs and circumstances.
The importance of services working together to
adjust and accommodate was also emphasised.
The goals of the second ten year plan, the
Victorian State Disability Plan 2002-2012 (DHS
2002) encompassed similar ideals that services
for the general community should be available to
people with intellectual disabilities. For example
goal three, leading the way, was summarized as:

to lead the development of a more inclusive
community for people with a disability by
developing more inclusive and accessible public
services and promoting nondiscriminatory
practices

Related to this, strategy five aimed to make public
services more accessible: so that people with a
disability, like all members of the community have
access to a range of services that support quality
of life-including education, public transport
and health services-and access to employment
opportunities as well as access to buildings and
other venues.
The draft State Disability Plan (2012) follows a
similar vein and makes several references to
mainstream services, each with a slightly different
degree of detail and examples:

‘By mainstream services we mean the services,
supports and resources that are available to
all members of the community such as health,
education, employment, justice and transport.
(p.5) ... government, private and community
sectors provide mainstream services, supports
and resources such as health services, transport
system, education and training, employment,
housing, parks and public spaces, shops
and recreation and leisure facilities. People
with a disability should be able to access the
mainstream services on an equal basis to all
other citizens (p 10). ... Like everyone else
people with disability use a wide range of
publicly available services and may engage
with a range of systems including health,
education, aged care and criminal justice
systems (p.19).

In broad terms then since the mid 1980s, there
seems to be little disagreement that mainstream
services should be accessible and responsive,
and are a key strategy to support the goal that
people with intellectual disability should be part
of the mainstream of life. As suggested in the
introduction this was also the position adopted
by the Productivity Commission (2011) which
referred to mainstream services as:

‘those that people generally use. They may
include government-funded services (education,
health care, public housing and transport, and
employment services) and services provided by
the private sector (a swimming pool, gym, the
theatre and holidays). People with disabilities
use these services like anyone else.’(chapter 5)

Policy tends to regard use of mainstream services
as preferable to specialist disability services and
to have a stronger chance of enhancing inclusion
and participation of people with disabilities in
community life. In contrast disability services
have tended to be seen as stigmatising with the
potential to isolate and segregate people with
intellectual disability.

Descriptions of mainstream services are however
vague and ill defined. Mainstream may refer to:
• publicly funded services that may be needed
by everyone such as health, education,
• publicly funded services that are only needed
at particular times by specific groups of the
population such as housing or employment
services for people who can’t afford to
purchase on the private market or who become
unemployed,
• publicly funded facilities such as leisure centres
which also have a strong user pays element,
• private for profit businesses such as gyms,
banks, theatres, shops; and
• public places such as parks

Irrespective of their actual nature mainstream
services generally seems to mean any service that
is not funded as a specific disability service, and
may include other targeted services for specific
population groups such as people with mental
health problems or older people, as well as more
universal services that are potentially available
to anyone in the population, such as preschools,
primary schools and libraries, should a person fit
the entry criteria or choose to use them.

Within a mainstream service system, such as
health care for instance there may also be specialist
services targeted at particular sub groups of
the population. For example, the mainstream
employment service system has specialist services
for job seekers with disabilities, the health system
has clinics for people with polio and in some
countries a specialism in developmental disability
medicine, there are memory clinics for older people with dementia or falls clinics and so on. Mainstream services encompass many different types of design and do not necessarily mean not specialist.

Policy statements are written at the level of principle and do little to articulate how mainstream services operate or if using a mainstream service will necessarily support a ‘life in the mainstream’ of the community. Somewhat simplistically services have been understood by their label and funding source, mainstream has tended to mean inclusive without a specific focus on disability funded by any source that is not earmarked as disability while, disability specific has tended to mean exclusionary or segregated and funded by a separate funding stream. This may not always be the case.

Examples from education in particular show that inclusion in a mainstream service system with mainstream funding may result in separate and segregated services for people with intellectual disability such as special schools. School education is funded and provided by Department of School Education. All children are educated by the department. This is arguably a mainstream response at a system level. However, within the school system, children with intellectual disabilities can be segregated. An inclusive curriculum where children learn alongside each other and the whole school is adapted to accommodate the individual needs of each student is not necessarily the way inclusion in the mainstream education system is enacted. Similarly, early intervention for young children is provided by Department of School Education. It is a targeted response for children with disabilities and developmental delay. There is no equivalent service/response for all children yet it occurs in a mainstream service system, and what is done to support children and families can be segregated or inclusive. Disability Open Employment Services are part of a mainstream employment system, funded by Department of Employment, Education and Workplace Relations (DEEWR). They are effectively a specialist service in the mainstream, but the mainstream imperatives have curtailed to an extent their capacity to respond to job seekers with intellectual disability and their clients have progressively shifted to people with less severe disabilities, and job placement rates have remained poor compared to other OECD countries (PC, 2011). Research and government enquiries have demonstrated the failure of mainstream health services, where no separate provisions are made for people with intellectual disability, to take into account the needs of people with intellectual disabilities, particularly around issues of communication, knowledge of specific issues and in the provision of ‘care’ services during periods of hospitalization (Alborz, et al., 2005; Backer, Chapman & Mitchell, 2009; Mencap, 2007). Inclusion in mainstream health services can result in poor quality services. In contrast, as previous Roundtable papers have demonstrated specialist disability support programs have the capacity to foster social relationships and facilitate inclusion for people with intellectual disability (Shanks & Young, 2010; Leighton & Hampson, 2010).

The simple idea that mainstream services will foster inclusive outcomes and special disability services are more likely to result in segregation or exclusion does not hold true. These points were illustrated by the architects of the first Victoria ten year plan in 1988. They referred to generic services as services in a specific field designed to be delivered to the whole of the community, such as public transport or health services but then showed that either mainstream/generic or disability services could deliver inclusionary or exclusionary outcomes. For example the report suggested that,

- segregated services were those ‘provided in an environment in which all participants have similar capabilities or backgrounds’. This term speaks to design of a service which could be delivered by either generic or special disability services. For example special schools are segregated but funded and delivered as part of mainstream education services.

- integrated services were those ‘provided in an environment shared by people with diverse capabilities and backgrounds’. This term speaks to design of a service which could be delivered by either generic or special disability services. For example, primary care or hospital services funded and delivered through the health service system would fit the definition of an integrated service delivered through the mainstream. A support worker funded by a specialist disability service who works with a community group leader and other members to plan how best to include a person with a disability in the group would also fit the definition of an integrated service but delivered by a specialist service in conjunction with a mainstream one.
supplementary services were services designed to meet the specific support needs of people with intellectually disability and their families which could not be met by generic service providers (Neilson Associates, 1988). They were not seen as alternative to generally available services, but as a supplement to those services, and could be delivered by either generic or disability specific services, and could foster either segregation and exclusion or inclusion. For example, the Access for All Abilities program is funded by the Department of Community Services with disability funding, administered through the Department of Sport and Recreation and delivered by local government and peak sporting organisations, it aims to support inclusion in mainstream sporting programs for people with disabilities (is this mainstream or specialist?): integration aides are funded and delivered by the Department of School Education and aim to support the inclusion of students with disabilities in schools alongside other students (is this mainstream or specialist?).

The point is that mainstream services may or may not be responsive to people with disabilities and may in including people with a disability provide segregated or poor quality services. The provision of responsive mainstream services that have inclusive outcomes may require considerable specialist knowledge. It may be useful to hold in mind this early way of thinking about services as segregated, integrated or supplementary as a more nuanced way of thinking about mainstream and specialist disability services.

Strategies to make the mainstream more responsive and accessible to people with intellectual disability

A mainstreaming approach demonstrates the ‘wide scope of contexts, actors and activities required to fully include persons with disabilities’ (United Nations Social and Economic Council, 2007, p. 3), and the patchwork of interdependent strategies needed. The challenge lies in identifying and convincing the broad array of organisational actors involved in any service system that inclusion is important, that it is congruent with their mission and will be beneficial to their agency. Strategies such as champions within organisations, ‘sticks’ in the form of penalties for non-compliance and ‘carrots’ in the form of funding or expertise to support efforts influence perceptions of what is important and win more than perfunctory support from agencies who may at first see inclusion as periphery to their mandate.

Anti-discrimination legislation has been a ‘stick’ used to push mainstream services towards being accessible and responsive to people with disabilities. This legislation makes unfavorable differential treatment of people with disabilities unlawful, and imposes penalties on individuals or organizations that transgress (Disability Discrimination Act, Cwth, 1992). Direct discrimination involves treating a person with a disability less favorably than people without disability in a similar situation. For example, not giving a lease on a house or not employing a person with a disability though they are equally qualified to a non-disabled person, for no other reason than their disability, is direct discrimination. Making this type of discrimination unlawful seeks equal opportunity or formal equality for people with disabilities. Indirect discrimination occurs where a “one size fits all” rule or situation unreasonably excludes or disadvantages a person with a disability in practice. For example, banking rules that require a person to be able to sign their name to open their own bank account, or the imposition of an extra fee for an easy dial feature on a telephone without which it cannot be used by a person without good fine motor skills are all forms of indirect discrimination. Prohibiting indirect discrimination aims to ensure social structures and process make ‘reasonable’ adjustments to take account of the needs of people with disabilities. Thereby conditions for equal outcomes, or substantive equality are created rather than just absence of certain discriminatory actions (Michailakis, 1997). The introduction of a Medicare item to reimburse GPs for annual health checks undertaken with people with intellectual disabilities is an example of removing indirect discrimination by ensuring the regulations take into account the particularly high and complex need of many people with intellectual disability (Pyne, 2007). The various forms of Companion Cards to give free entry to a support or personal care assistant to commercial and sporting events is another example of tackling indirect discrimination.

The Australian Human Rights and Equal Opportunity Commission oversees the effective implementation of anti-discrimination legislation and a variety of mechanisms which include: conciliation of complaints, community education, supporting the development of access standards and action plans, and conducting its own enquires.
and investigations into discriminatory actions. A number of community legal centres that specialise in disability discrimination have also been established to advise and support potential complainants, as well as to identify issues arising from the individual’s cases they deal with. Ten years after the legislation was enacted in Australia, the retiring Commissioner summed its achievements as:

- Thousands of disability discrimination complaints have been dealt with.
- Standards for accessible public transport have been adopted and already widely implemented.
- Telecommunications access has improved for deaf people and other people with disabilities.
- Negotiations on standards for improved access to buildings and education are in the final stages, and there are many practical instances of improved access in these areas.
- Captioning of television programs has increased, with further increases being negotiated.
- There has been widespread adoption by the banking and financial service industry of standards for disability access to ATMs, internet banking, EFTPOS and phone banking.
- Hundreds of service providers, particularly local governments and universities, have developed voluntary action plans for improved disability access. (Ozdowski, 2003)

The success of broad based legislation such as this depends on the resources available for implementation. A review of similar legislation, the Americans with Disabilities Act, 1990, suggested, for example, that it had not been effectively enforced and the community remained unaware of its provisions (The Arc, 1998). The mechanisms used to implement anti-discrimination legislation in Australia have been fairly dedifferentiated, and have failed to take into account the particular issues that affect people with intellectual disabilities. The majority of complaints have come from those with physical and sensory disabilities, whose peak organisations have championed the use of the legislation and for whom obstacles are more obvious. The bias inherent in a dedifferentiated approach was identified in the Productivity Commission’s (2004) report on the legislation, which found that people with intellectual or psychiatric disabilities ‘have not had the same clear benefits of people with physical and sensory disabilities’ (p. 38). The effectiveness of this legislation is also hamstrung by its limited powers and the limitation that only adjustment that are ‘reasonable and practical’ for the service or organisation can be enforced. It is for this reason that very long time frames are found in the Standards for Transport and Education that have been developed.

As well as the federal anti-discrimination legislation, state legislation has mandated the formulation of disability action plans as a means of embedding inclusive practices throughout government and community organisations. For example, section 38 of the Disability Act 2006, in Victoria, requires public sector bodies to prepare a disability action plan for the purpose of:

(a) reducing barriers to persons with a disability accessing goods, services and facilities;
(b) reducing barriers to persons with a disability obtaining and maintaining employment;
(c) promoting inclusion and participation in the community of persons with a disability; and
(d) achieving tangible changes in attitudes and practices which discriminate against persons with a disability.

An action plan may cover the broad range of activities, including governance, corporate management, information and communication, infrastructure, planning and development, services, economic development, human resources, and environmental management. The Human Rights and Equal Opportunity Commission (HEROC) (1998) suggested effective plans:

- demonstrate commitment to eliminating discrimination
- shows clear evidence of effective consultation with stakeholders
- has priorities which are appropriate and relevant
- provides continuing consultation, evaluation and review
- has clear timelines and implementation strategies and
- are in fact being implemented.

Disability actions plans can demonstrate that an organisation is moving towards compliance with anti-discrimination legislation, and may be used as a defence if complaints are made. More positively plans can reinforce the collective responsibility of all parts of an organisation inclusion and the idea of “no gaps”. In some local governments for instance, rather than being stand-alone disability action plans are integrated into council wide...
planning processes and linked for example to statutory public health plans. Disability action plans are generally dedifferentiated, and have been criticised for being too vague and generic, simply reproducing common stereotypes of people with disabilities as only using wheelchairs and failing to address the less visible disabilities of people with intellectual disabilities (Goggin & Newell, 2005). The success of action plans in fostering inclusion for people with intellectual disabilities is likely to lie in both their both the form and processes of development, but to date there has been very little evidence about either garnered from systematic research.

Who is responsible for making mainstream services accessible and responsive? What is the relationship between mainstream services and specialist disability services?

As some of the examples have illustrated, a mainstream service system might create its own specialist response to people with disability, and there are examples of this type of response having positive outcomes that foster wider participation in mainstream life (specialist liaison staff in mainstream hospital services in the UK see Brown et al., 2012 for instance), and those that simply lead to segregation (special schools as part of the mainstream education service). There are also examples of close working relationships between specialist disability funded services and mainstream services such as the work of Centre for Development Disability Health Victoria outlined in Jane Tracy’s (2013) paper. Either mainstream or disability specific services can take responsibility for making the mainstream responsive to people with disabilities or it can be done in collaboration.

Arguably specialist disability funding may be used to make mainstream services more responsive. For example, the NDIS legislation suggests that the scheme (using special disability funding) would facilitate referrals and use of mainstream services, and more generally facilitate greater inclusion of people with disabilities. The work of the Communication Resource Centre outlined in Solarsh, Johnson and West’s(2013) paper is an example of specialist disability funding and specific disability expertise being used to leverage change in mainstream services.

The role of disability services is evolving and new thinking identifies specialist disability responses as the bridge, partner or resource into the mainstream. Specialist does not have to mean segregated, and partnerships between specialist and mainstream supports are one strategy to achieve participation and inclusion for each person with a disability. There is a danger however, identified earlier, that demand may fall too heavily on inappropriately on the NDIS (i.e disability funding) and undermine its capacity to deliver on its mandate if the mainstream is not accessible and responsive. As suggested earlier, the success of the NDIS depends on the balance between mainstream and disability support. Inadequate access for people with disabilities to mainstream services may increase demand for and/or the cost of Tier 3 (individual transport provision in taxis for example).

For example, the PC report states. Access to generic services, such as health and housing, can affect demand for NDIS-funded services, and vice versa. It will be important for the scheme not to respond to problems or shortfalls in mainstream services by providing its own substitute services. To do so would weaken the incentives by governments to properly fund mainstream services for people with a disability, shifting the cost to another part of government (such as from a state government to the NDIS, or from one budget ‘silo’ to another). This ‘pass the parcel’ approach would undermine the sustainability of the scheme and the capacity of people with a disability to access mainstream services. If governments and departments thought that the NDIS would address both specialist and mainstream service needs, people with a disability may well be seen as a lesser priority for the generic services provided by government. (Chapter 5 PC report)

What the report did not consider is who should fund the necessary change in mainstream services, and will the NDIS be called upon to drive and fund that change in order to preserve the viability of the scheme.

What if other systems should provide but don’t – Who interprets and monitors access and responsiveness of mainstream services for people with intellectual disability

The NDIS legislation is remarkably clear that it will not fund the needs of people with disabilities that are more appropriately provided by other service systems – the mainstream. The question remains however, who and how are judgements to be made about what is available from other
systems. No doubt the regulations will provide a guide to decision making, which will have to grapple with issues such as does this mean; needs ‘can possibly be met’ by other systems (if resources were available or services were adapted) or ‘should be met’ by other systems (but are not necessarily being met) or are ‘actually being met’ by other systems or are demonstrably likely to be met (and this is consistent across all jurisdictions). The PC report (2011) for example alluded to inconsistencies across jurisdictions suggesting that what might be appropriately met by other systems might be a relative concept and situation specific. As French (2013) outlines the current federal anti-discrimination has little power to insist that the mainstream is accessible and responsive to people with disabilities if it is considered too onerous to do so or requires some form of exceptional treatment to take account of their disability related needs.

What will happen for people with intellectual disability who experience a gap between what should be provided by mainstream services and what actually occurs, will unfold as the NDIS is trailed in various sites. Perhaps another question to which little attention has been paid is what part of government will be responsible for a more robust way of monitoring, when the mainstream does respond to people with intellectual disability that it does so in a manner that delivers high quality supports or services that are not segregated, exclusionary or second rate.

The NDIS scheme and its administering authority are a potentially a very potent force to negotiate with mainstream services about appropriate boundaries between mainstream and disability services, and their respective responsibilities and potential partnerships in respect of people with intellectual disability. Hopefully it will pay attention to the quality of what mainstream services deliver to people with intellectual disability and ensure it reflects disability policies visions of social inclusion and life in the mainstream, as well as whether or not they are simply accessible. To ensure social inclusion, the focus of disability policy may need to go further than use of mainstream system but pay attention to what and how the mainstream responds to ensure mainstream experiences for people with disabilities are not exclusionary or second rate. Funding through NDIS or not does not guarantee life in the mainstream, unless attention is paid to what is the result for the person with a disability. There is likely to be a need for specialist disability knowledge within mainstream settings. It is difficult to understand why in every other domain of life we seek out specialists, trained people, experts, but in disability services it is often that case that support to people with intellectual disability is organized and delivered by people and systems with little training or specific knowledge about the nature of their impairment. This is a legacy of the past when too often the use of specialist knowledge was associated with an individualised or medical model of disability and such knowledge was used to disempower. It is time to move on and utilize specialist knowledge effectively to support the social inclusion and human rights of people with intellectual disability.

References


Dr Chris Fyffe is a consultant in disability with a longstanding commitment to working with people with intellectual disability. mcfyffe@grimwood.net.au

Professor Christine Bigby leads the Living with Disability research group in the Faculty of Allied Health at LaTrobe University. C.bigby@latrobe.edu.au
The Challenge of Including and Organizing Special Support in Mainstream Services – A Swedish Perspective

Magnus Tideman

In this paper I will first give an introduction to the welfare system in Sweden in respect to persons with intellectual disability. Secondly, I will explain the policy, laws, responsibility and the definition of intellectual disability, including the question of mainstream and special services/support. This is followed by a discussion about concepts of disability and about responsibility, collaboration, organisation and competence.

Swedish government and disability policy

At a national level, the Swedish people are represented by the Riksdag (the Parliament), which has legislative power. The Government governs the nation, implements the decisions of the Riksdag and proposes new laws or amendments to legislation.

Sweden is, on the regional level, divided into 21 counties. Each county has a county administrative board, which is the Government’s representative at the regional level. The county administrative board’s responsibilities include supervision of the municipalities’ traffic safety, environmental work and nature conservation, to name just a few. At county level there is also the county council, whose decision-makers are directly elected by the population of the county. By far the most important area of responsibility for the county council is health and medical services. Activities are financed primarily from taxation and to some extent from fees and government subsidies.

The cornerstone of the Swedish disability policy is the principle that every person is of equal value and has equal rights. General efforts to improve accessibility in the community are central to achieving the goals of inclusiveness and equality. Persons with disabilities may be in need of individual support from the community. The state, municipalities and county councils are jointly responsible for this aid, which is intended to ensure good health and economic and social security.

The Social Services Act (1982) applies to all citizens and will assure a good life with reasonable living conditions, but in the early 1990’s it was evaluated as not enough for persons with disabilities. In order to guarantee good living conditions for persons with disabilities, and to increase their levels of participation in society, a new law on rights in the area of disability came into force in Sweden in 1994, the Act Concerning Support and Service for Persons with Certain Functional Impairments. For persons with intellectual disabilities, this new law meant the right to certain defined individual measures, and the responsibility for support and service as well as for education was decentralised and passed over to the local municipalities, and that the dismantling of the institutions was to be complete. Actions such as housing with special services for adults, or daily activities for those who are inactive and not enrolled in education are regulated and municipalities have the main responsibility, in line with responsibility for people without disabilities. At the same time new legislation was introduced, societal development was dominated by economic problems for the public sector and the New Public Management (NPM)-inspired restructuring of the public sector with, among other things, increased levels of involvement from private enterprise within the areas of schooling, healthcare, disability care and care for the elderly.

Persons with intellectual disability – a growing group

The definition of intellectual disability is based on the administrative categorisation that is applicable in Sweden and for which society is responsible (Sonnander 1997). This means, apart from testing that indicates the existence of an IQ under 70, there is also the requirement for an investigated need for special support or education that cannot be met in another way, in order for a person to be categorised as intellectually disabled. This categorisation means that a large variation in intellectual ability exists within the group, and differences in the assessments performed exist at a local level. Traditionally the number of people with intellectual disability in total in Sweden has...
been approximately 0.45% of the total population. But the number of children and adolescents being categorised as intellectually disabled has increased significantly during the last 15 years (Tideman 2000, 2011). A large number of students in primary school have been categorised as such and have been moved over to the special form of schooling known as special programme (or “särskola” in Swedish). In the Swedish educational system, special programmes for children with intellectual disabilities constitute a form of instruction in their own right. Children that are deemed to be unable to complete mainstream primary school on account of their intellectual disabilities will, if deemed appropriate, be transferred to schooling in these special programmes. During the past 15 years, the number of children in such special programmes has more than doubled, a development that has meant an increase in the individual variation in abilities and learning conditions within the group. The reasons for the increased categorization can mainly be found in the increased theorisation in the primary school and coexistent inability in the primary schools to provide students with learning difficulties with adequate support due to reduced economic resources. We currently have limited knowledge about the categorisations’ effects in the longer term of the transition into adulthood on living conditions and how young adults experience these effects. The increase in the number of referrals to the special programmes for children with intellectual disabilities raises important questions regarding the effects of this increase on individuals as well as on society, both in short and long term.

Living conditions

During the past few decades, living conditions for persons with intellectual disabilities in the Nordic countries have undergone a number of changes, both legally as well as institutionally (see e.g. Tössbro et al, 2012). An objective shift within disability politics has occurred. The right to receive support in everyday life is now becoming a given priority, institutional care has been discarded and more active participation in society by this section of the population is being emphasised. The changes in Sweden from the beginning of the 1990s until today are characterised by a number of clear trends. Institutional living has been replaced by residential arrangements with staff service or the possibility for individuals to live in apartments of their own in ordinary residential areas. The level of variation in support and service depending on the city/town/area in which individuals live has increased, and private companies are becoming increasingly involved within the disability care sector. At the same time, there has been, as mentioned above, a significant increase in the number of people being categorised as intellectually disabled, as well as an increasing level of resistance among young adults against being viewed as passive care receivers.

Since the middle of the last decade, questions about living conditions for persons with disabilities have become the subject of increasing attention among politicians, authorities, user organisations and social science-oriented researchers. Concrete examples of the increased level of interest in such questions include the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the European Disability Strategy (European Commission, 2010). In 2010 the European strategy was launched with the express aims of raising public awareness of disability, removing obstacles to inclusion and capacity building in order to ensure people with disabilities gain control over their lives. Persons with intellectual disabilities represent a group that is of special interest when it comes to knowledge, both nationally and internationally, since it is a group of people with a long history of vulnerability and marginalisation. Today the living conditions for the group defined as persons with intellectual disabilities are considered to be status quo, almost the same as they were in the 1990s. This means that, apart from the increased standard of accommodation due to deinstitutionalization, no significant changes have occurred since that time to reduce the difference in living standards for persons with and without intellectual disabilities. At the same time the present development we know points to an increasing level of variation of support within the group itself, something that is linked to, among other things, an individual’s ability (or lack thereof) to negotiate on his/her own behalf. In line with the NPM this can be seen as an effect of the efforts to make a marketplace, where the well-informed and competent consumer is successful.

Power structures and discrimination

An important perspective when it comes to everyday life for adults with intellectual disabilities relates to the power structures that exist in society and the consequent risk of discrimination. Disability can be described as a social construct based on opinions of normality and deviation (Davis, 1995). Due to this, disability has long become a basis for discrimination in the form of
negative attitudes from the environment as well as the labour market, in both formal and informal social contexts. During the 1990s, legislation aimed at attempting to counteract discrimination against this group of people, was adopted. Many studies demonstrate, however, that disabled persons continue to be discriminated against in society and, in addition, are more socially isolated than other minority groups (Lindkvist, 2007). From this perspective one can see that there is an obvious power structure whereby disability can be viewed as a question of the distribution of resources rather than a given category (Söder & Grönvik, 2008).

Mainstream versus special services

In Sweden there has been a change in the disability debate from a focus on individual’s shortcomings to changing of the society/environments. The Nordic welfare policy has traditionally focused on basic economic security and compensating individual support. We are proud of the physical standard in the field of disability and the standard of individual special support but focus and attitudes has changed during last year. The special services have been looked at more and more as a part of a discriminating society. Some say that we, via economic safety for people with intellectual disability, have “bought us free” from the real challenge, to create a society where all people, including people with intellectual disability, have the same conditions and prerequisites as others. One major part of an accessible society for all is that mainstream services include support to people with special needs. In the following I will give some illustrations from a number of fields to try to show the situation in Sweden today.

Public transport

The possibilities for mobility are of great importance for people today. The labour market, shopping and the social relations often presumes an ability to use public transport. In Sweden that is the first choice for people with intellectual disability, but when impairment consequences are more extensive there is a mobility service to complement it. In order to make public transport more accessible, there are some simple things to do. One recent personal example from Melbourne can be used as an illustration: as a person who is in Australia for the first time and English is not the mother tongue, it is a challenge to use the public transport system. The information about which tram or bus goes where, is impossible when on the tram there is no information about which is the next stop. One way of making public transport services more accessible to people with intellectual disability (and to visitors) is to have accessible information, both verbally and with signs. In that respect the situation in Sweden is more advanced than in Melbourne. Nearly every stop has clear signs and verbal information and the metro, buses and trains provide verbal information ahead at each stop as well as legible signs which show the next stop and the next after that.

Education

In Sweden inclusive education has been a goal/vision for quite a number of years but we still have special programs for pupils with intellectual disability. The efforts during the last 20-30 years to make ordinary education more inclusive has lead to about 1/3 of all pupils with intellectual disability receiving their education today in the same classes as other non-disabled pupils. Two thirds are still in separate classes (although in the same school buildings as other pupils). We have had a long lasting debate about the advantages and disadvantages with inclusive and exclusive education. The new right-wing government has launched a policy which is friendlier to special solutions for pupils with disabilities. The research show that the variation is great among local authorities (who are responsible for education) which means that in some places nearly every child with intellectual disability is included in ordinary education and in some nearly none. This is an ideological question for politicians as well as for parents’ organisations and the arguments are in line with the well known history of special needs research analysis of inclusion/exclusion.

Health

The point of departure is that people with intellectual disability will use ordinary health services. Special medical doctors for special groups in primary care are no longer an option. If there is a health problem the individual will consult the general practitioner. This mainstream system is working well but when it comes to needing more special knowledge about certain impairments there will be a demand for expertise. Children's health services (CHS) can serve as an example. In Sweden all children and their parents are offered health services free of costs. CHS offers regular consultations with nurses and parent groups that discuss questions about bringing up children etc. This service is also for parents with children with
disabilities but when it comes to the needs of a special kind due to the child’s impairment or the need for meeting other parents with the same experiences of disability, the general/mainstream service often can’t fulfil this. Studies show (e.g. Broberg-Olsson 2006) that parents with children with disabilities need both the mainstream and the special services and that it is not likely that the children health services can manage that for all. The children’s habilitation, managed by county council as a part of health services, offers expert knowledge and support for both the child and the parents when it comes to very special circumstances (like rare diseases).

Housing
The process of dismantling the institutions in Sweden was completed at the beginning of the 21st century. Institutional living has largely been replaced by various forms of residential arrangements with staff support in ordinary residential areas. This has happened at the same time that market solutions have made themselves significant within the area of disability. During the first decade of the 21st century an increasing number of residential arrangements and daily activities have been outsourced to private contractors. To some extent this has led to increased freedom of choice for the individual, although the picture is still largely dominated by limited opportunities for participation, self-determination and making one’s own choices in everyday life. Persons with intellectual disabilities seldom receive real opportunities to choose their accommodation or workplace. Even if the residence’s physical design and size has changed and improved, the types of routines and traditions that existed in the institutions are to some extent still to be seen today, like the isolating effects in the form of special measures and activities for persons with intellectual disabilities.

Accessible information
With respect to the nature of intellectual disabilities the question of information accessibility is a major issue. We are living in an “information society” where written information is substantial. This is however a problem, as most information is not easy to access for people with intellectual and/or literacy disabilities. People in common need access to news, literature and societal information and some need it in Easy to read or other adapted shapes. It is fundamental – democracy requires accessible information. In Sweden four years ago a linguistic/language law was passed (SFS 2009:600) that states that it is the responsibility for authorities to use a simple and understandable language with respect to people with (and without) reading difficulties. This is in line with the definition of international Plain-language Association:

Plain language is communication designed to meet the needs of the intended audience, so people can understand information that is important to their lives.

Plain language is language that is understandable. What is clear, or what is plain to your intended audience, can only be decided by the audience. Most people expect a definition of plain language that describes writing of a certain style. Plain language is more a process -- it has been described as a means to an end.

This means that all correspondence with citizens should be in accessible ways. Notifications, forms and verbal communication (via telephone, meetings etc) should be adjusted to the receiver and when it is needed the authority should offer personal assistance. There are recommendations for written information (about easy to read language, disposition, designing and alternative format) but also for telephone calls, meetings and conferences, movies, television and video and of course for the Internet and e-services. There are in Sweden easy to read books, a weekly easy to read newspaper, understandable news radio program (each day) etc. At libraries in Sweden there are resources of easy to read books and at museums, the mass media and other public spaces efforts are made to make information more accessible, but especially authorities at large are still slowly proceeding when it comes to these type of questions.

Accessible information is on the agenda but also a discussion among researcher and people in practice about the problems with easy to read. Current research shows that when making the text simpler it can be too simple and nearly without meaning/sense. The users who can’t understand the context lose all interest when an easy to read text becomes too easy and without nuances. One good example of a recent publication is a easy to read version of the book “Zlatan – it’s me”. Zlatan Ibrahimovich is the most successful Swedish football player ever and his book became last year a bestseller. The easy to read version has succeeded in the ambition to tell his story in a shorter but not too simplistic way and it has been read by lots of people, both with and without disabilities. This shows an accessible way
of making mainstream literature responsive. But the lesson is that it requires competence to balance between a clear and understandable language and not making the text too vacuous.  

**Social work**

Even people with intellectual disabilities can of course “be hit” by social problems like addiction, homelessness, isolation and criminality. Treatment for social problems is in Sweden often based on verbal support. It means that people with intellectual disability are offered social problem support which may not basically improve their skills. In a report from the Swedish County Administrative Board (2005) it is apparent that the level of support provided to persons with disabilities varies, not only from county to county, but also from individual to individual within a county. The degree of variation is connected to an individual’s ability to claim his/her rights. It is also apparent from Szébehely’s study (2009) that women, persons with lower levels of education and persons born outside Sweden do not receive support from society to the same extent as men, well-educated persons and Swedish-born persons. The first-named groups are instead often dependent on support from relatives. It can be pointed out that a person with an intellectual disability may need to have contact with a large number of professional helpers who are specialists in different aspects of that person's needs, such as disability care, home modifications, assistance in finding employment, etc. This line of argument is particularly relevant if the person in question has a number of social problems. There are deficiencies in the collaboration between different authorities when it comes to persons with intellectual disabilities who are in need of measures from several different authorities, for example with double diagnoses or addiction problems (Swedish National Board of Health and Welfare 2005). Studies show that professional helpers are important to persons with intellectual disabilities, although there have also been incidents of personnel subjecting such persons to violence and abuse, for example at sheltered housing (Barron 2008). In the field of treatment for social problems for people with intellectual disability the mainstream services have to develop special support inside their framework. In Sweden we are just in the beginning of this process.  

**Self-advocacy**

The general development towards decentralisation and increased municipal freedom has opened up for freer forms of activity within disability care and has also created conditions for increased individual influence. New activities have appeared and developed whereby young adults with intellectual disabilities are able to meet regularly in order together to strengthen their control over their own lives and exert influence over the local community in the direction of increased participation and changing attitudes to intellectual disability. An increasing number of persons with intellectual disabilities do not accept the traditional role of the disabled that is associated with daily activities and other forms of societal support and service. They are choosing to position themselves either entirely or partly outside society’s welfare measures, and consequently new forms of fellowship are being developed. The growth of new forms of activity by and for persons with intellectual disabilities can be interpreted as those persons offering resistance to society’s traditional treatment and means of offering special support and service (Svensson & Tideman 2007).  

**Discussion and conclusions**

In summary, the development that has taken place for persons with intellectual disabilities in Sweden from the beginning of the 1990s until 2012 can be described, partly as a process from relative homogeneity to increased levels of variation in support and service as well as education, and thus even increased variation in living conditions, and partly as a process whereby shrinking normality has resulted in increased categorisation. As I see it, there is in Sweden at the same time reason to derive much satisfaction from, among other things, the fact that the process of dismantling the institutions has been completed, and that persons with intellectual disabilities are creating resistance against being treated as passive care receivers, outside the mainstream society.  

The development raises questions about accessible and responsive mainstream services as a way to counteract the variation in living conditions and services, and support for a more inclusive society and questions about concepts of disability and about responsibility, collaboration, competence and organisation.  

The relational disability concept (Söder, 1982) positions itself, as I see it, between the individual and society-based (social model) views of disability. The approach signifies an affirmation both of the fact that people can have individual impairments and that society can in various ways
Disability is seen as a relational phenomenon, where disability can occur in the meeting/at the meeting point between the individual and the environment. This means that the surrounding environment, not merely in its physical aspect but also in the shape of social relations and meetings, decides whether a person in a certain situation becomes disabled or not. The same person with impairment can become disabled when encountering a non-adapted environment/situation, while in another environment/situation no disability occurs. Disability is thus shifted from referring only to the individual or to the “qualities” of society, to referring to the relations between the individual and society. Both the individual and the social level are needed in order to understand disability and how it is construed. According to the relational approach, both individual and general efforts are important in order to minimise disability-inducing situations.

Using the relational approach to disability, the increase in special programmes for pupils with intellectual disability can be seen as the result of an encounter between individual shortcomings and the school’s failings. When the environment, in the shape of the school’s resources and approach, is not adapted to the backgrounds and prerequisites of all students, the school becomes an environment that creates disability for some pupils. Disability becomes a question of the relationship between individual factors, such as the pupil’s prospects and ability, and environmental factors. In addition to the potential of the individual pupil, factors such as the parents’ educational background also play a role. For example, the parents’ ability to look after the interests of their child and negotiate in order to gain access to support services is one factor. Other influencing factors include the local government’s financial commitment to the school, attitudes of the school management and teachers to children’s learning difficulties and how they should be dealt with, national demands for grading systems and theoretical knowledge, and so on. Disability can therefore be seen as a relational concept, where the relation between different factors can create disability. Since it is possible to influence this type of relation, it can be said that disability primarily is what society, through its actions, decides to call disability (cf. Bury, 1996). As I understand it the relational approach is possible to translate into the discussion about mainstream and special services. The key question is about the relation between them. Mainstream and special services are interconnected vessels. If mainstream works well the need for special services will be limited and vice versa.

In Sweden we have guiding principles about responsibility for disability accessibility where the basic principle is that the sector in society who is responsible for e.g. transports also has the responsibility for disability issues related to transports. This is a way off trying to do services more mainstream and there has been some success, but it also initiates the question of collaboration between sectors. The research about collaboration in the field of disability show results that indicate for example the presence of power conflicts (Danermark 2005). When it comes to different opinions about which kind of adaptation that will be required or the balance between mainstream and special support, appears the question of preferential right of interpretation. It often also comes to an argument about money. To make services accessible and responsive is seldom for free. In discussions about priority with limited resources, many years of experiences in Sweden shows that disability concerns vary with limited resources. The question of collaboration is not easy, besides power and money it is also about competence and attitudes.

From Swedish point of view one main problem for speeding up the implementation of mainstream services is the low level of staff education in disability care. Unlike other human service organisations there is no demand for staff to have post secondary education. Staff with none or low education are more likely to work in special services. They have concerns for their own jobs but also have an attitude that people with disabilities are served best via segregated social services. The special becomes security for both staff and service users. And the same goes for part of the disability movement. Many disability organisations in Sweden in their rhetoric advocate for a society for all and mainstream services. But when it comes to practical questions and implementation some of them promote special knowledge and special services. As a disabled person, or a parent so a disabled child, we want to meet the most skilled expert when there is need for health consultation or negotiations with the administrator of individual support. And, not to forget, there is among some parents a strong view that special services means security, which is their first priority.
The increased interest for universal design will probably mean that the physical environment and technical devices become more accessible and responsive to people with intellectual disability. The rapid development of inside information technology (like appropriate apps for smart phones and more accessible Internet) is promising from a disability perspective. But technique can’t replace the need for human assistance. The development is promising but raises two related problems, the first is, will intellectually disabled people get smart phones and iPads etc as technical aids? The second is to strengthen competence about these kinds of facilities amongst staff members (remembering the low level of education). In Sweden we have seen that ability improving technical aids for people with intellectual disabilities is present but not in use to some degree. What we see instead is that people, particularly with mild intellectual disabilities, use computers and smart phones without any special adjustment. Facebook and other social Medias are for instance very popular.

Even if the legislation is kept within bounds for different areas (like education, social services and public transport) making mainstream is mainly about how we organize. There is always a risk that special laws (like the Swedish Act Concerning Support and Service for Persons with Certain Functional Impairments) will lead to special services organized in separate ways. But it is possible, even with specific legislation, to organize the support inclusively, mainstream. We need then to make the difference between the administrative and the practical.

More accessible mainstream services will reduce the need for individual special support but never totally. The challenge is to make mainstream services accessible and at the same time manage to give those who need it, special support inside the mainstream area. This sounds quite easy but it is an issue. One perspective is that for some special support (e.g. alternative communication skills) you need special knowledge that is unlikely for everyone to have (like every bus driver or GP). When it comes to judgement, who decides where the limit for mainstream is and on what premise. The experiences from Sweden are as follows. We have in law and prescriptions a clear mainstream directed ambition. But when it comes to practice and implementation the level of ambition is decreasing. To explain that phenomena the research show how unstated economical aspects result in decisions that goes in a mainstream direction but just goes part way.

One example is the very mainstream rhetoric “From Patient to Citizen: A National Action Plan for Disability Policy” (1999). It contains a lot of very radical ambitions for creating a “society for all”, but in the implementation, when it came to the question of resources, the politicians decided to take some minor steps in that direction. They do it without saying that the goals in the plan were too ambitious and without any public debate. It is done in a kind of consensus silence. This shows how disability issues nearly always are non-political (Sandén & Tideman 1996) in that sense that they have low status in the political discussion and seldom cause different political standpoints. All political parties are eager to support people with disabilities but not to take the time or costs for doing the implementation in full. In addition many politicians share the view that special services are safer than mainstream and have problems to defend other solutions. A couple of years ago the left-wing government decided to close down special services for children with intellectual and physical disabilities but regretted it after a very small minority of parents and staff caused a mass media storm about letting vulnerable children down. Few politicians can cope with being accused of harming weak groups.

Special support efforts can brand and separate, but at the same time it is obvious that avoidance of special efforts can contribute to individuals not receiving the support they need and therefore risk even greater segregation (Söder, 1989). The most important question for the future is not whether there is a need for special support efforts for pupils with difficulties in school or for people with intellectual disability in the society, but on what grounds and in what manner special support should be handled in the mainstream schools and in the society of today and tomorrow.

From a Nordic perspective (Tossebro et al 2012) we can notice a need for revitalization of the ideological and political debate in the field of intellectual disability. There is a lack of strong stakeholders today if we compare it with 20 – 30 years ago. We need drivers for change. If we are able to develop mainstream services which includes special services it will be a way to tear down barriers for people with intellectual disability in the society. And it will mean that fewer with impairments will be disabled in their daily life and many with impairments will be disabled in fewer situations. In other words, steps towards a society for all, where the mainstream society is tolerant of people with different abilities.
References


Professor Magnus Tideman was a visiting Professor at La Trobe University during 2012/13, and is Professor of Disability Studies with focus on social work at Halmstad University, Sweden. Magnus.Tideman@hh.se
Vocational Services under a National Disability Insurance Scheme

Bryan Woodford

The original version of this Paper was prepared early in 2012 as a briefing document for the Victorian National Disability Insurance Scheme Implementation Taskforce and the officials who work with the Taskforce. Upon request, it was modified and used as part of the proceedings of the December 2012 La Trobe University Roundtable on Intellectual Disability Policy. Both versions preceded the publication of the outcomes of the Department of Education, Employment and Workplace Relations DES-ESS Tender, which is central to the Paper's discussion. This final version takes account of the results of the Tender, but, because the results were as projected, it is not materially different from the earlier versions.

Purpose

In the context of an imminent National Disability Insurance Scheme trial, this Paper seeks to identify concerns about whether workforce participation rates by people with a disability are likely to be raised under current policy settings. The raising of such rates will be a key statistic when the medium-to-long-term success of the implementation of the scheme is measured, both in terms of the impact on people's lives, and its viability and sustainability. Suggestions are made about how vocational and day services might relate more effectively and how this could be tested as part of a National Disability Insurance Scheme trial.

Importance of work for people with a disability under a National Disability Insurance Scheme

As noted in the now famous final line of the Productivity Commission Report Disability Care and Support Report (2011, p 976), “the Commission considers that the benefits of the NDIS would significantly exceed the additional costs of the scheme”. It had formed this view having reviewed the “collective evidence” and decided that, “ … there are strong prospects that the NDIS would substantially improve people's lives and improve efficiency” (Productivity Commission 2011, p. 953).

Improving lives brings about economic gains, as a sense of wellbeing increases motivation, enjoyment, participation, the drive to form relationships and even improve wellness. While some of these indirect benefits are not easily measured in economic terms (Productivity Commission 2011, p. 943), the direct benefits generally are. In the case of people with disabilities benefitting from a National Disability Insurance Scheme, these benefits would include the likelihood of reduced offending and fewer incarcerations; diminished frequency and duration of unnecessarily extended contacts with the health care system; and, through employment, increasing GDP, creating more purchasing power and thereby prosperity at the level of the individual, reducing the take up of the DSP, adding to the tax ‘take’ and lessening the burden on carers which would, in turn, improve their social and economic participation.

It is beyond the intention of this Paper to go into these diverse opportunities for economic benefits, save one, but it is important to note the Commissioners’ conclusion that “… the private welfare gains from additional resources provided by the NDIS to people with disabilities will be greater than the lost benefits to taxpayers” (Productivity Commission 2011, page 956). What this Paper will do is accept the Commissioners’ view that the gains are there to be had, but posit that in the area of disability employment, the gains may be at risk because of the way that disability employment support is structured.

The Productivity Commission commented at length about the importance of improving the workforce participation rate for people with disabilities. “A major objective should be for people with disabilities to obtain paid employment (or a voluntary job), even if they continue to receive partial income support from the Australian Government.”(Productivity Commission 2011, p. 271). However, as the Commissioners noted, “Australia has a relatively poor performance in employment of people with disabilities.” (Productivity Commission 2011, p.958).

This was illustrated by reference to Australia's low OECD ranking for employment outcomes for people with disabilities.

In raw terms, Australia had the 21st lowest employment rate of 29 countries for people with disabilities, well below countries like the United Kingdom and Canada. In fact, the situation is worse than this because it is important to correct for some of the factors that can bias measures of employment performance. Once these corrections are made, Australia was ranked 24th in terms of its performance, with the data suggesting that
Australia could improve its employment rate for people with a disability by more than 5 percentage points if it were to perform at the average of OECD countries. … The Commission estimates that less than 30 per cent of working age people eligible for funded support from the NDIS have any kind of employment, with part-time employment more common than full time employment. “Altogether, this suggests that the Australian Government should align … the participation goals of the NDIS … with contemporary disability policy” (Productivity Commission, 2011, p. 272-273).

It is the matter of alignment with which this paper is primarily concerned.

**How Employment Support Services are currently structured**

Employment support for people with disabilities is provided through three main approaches:

1. Work preparation and training services
2. Supported employment
3. Open employment

In terms of funding and administration, all these disability employment services lie within the jurisdiction of the Commonwealth Government. While the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) used to fund both open and supported service programs, policy responsibility for open employment transferred from FaHCSIA to the Department of Employment, Education and Workplace Relations (DEEWR) in October 2004. This policy transfer was presumably intended to position open employment services for jobseekers with a disability within generic labour market program arrangements and is arguably the point that:

“… marked the beginning of a gradual shift in administrative and funding arrangements, with disability employment moving closer to the administrative and funding model that regulates mainstream employment services, now known as Job Services Australia (JSA)” (Nevile & Lohmann 2011, p.11).

Funding for ADEs and work preparation and training services continue to be FaHCSIA responsibility. The purpose served by work preparation and training services is self-evident. The supports provided may be to school leavers; people in supported employment being readied for open employment; or, perhaps, people already in jobs who need refresher training, re-skilling or assistance to undertake new challenges. Work preparation and training commonly occurs in Australian Disability Enterprises (ADEs), (see below), but can also be undertaken through, for example, TAFE providers, Registered Training Organisations and supervised on-site work experience programs. Such training is usually unpaid.

Supported employment, a term that Australia uses differently from most other developed nations, is defined by the Commonwealth *Disability Services Act 1986* as:

Services to support the paid employment of persons with disabilities, being persons:

- (a) For whom competitive employment at or above the relevant award wage is unlikely; and
- (b) Who, because of their disabilities, need substantial ongoing support to obtain or retain paid employment.

Supported employment is provided through ADEs. These are “approximately 600 commercial businesses that provide real work opportunities for more than 20,000 people with disability across Australia” (FaHCSIA, Vision for Sustainable Supported Employment, 2011, p.10). ADEs seek to provide quality employment outcomes for people with a disability through their operation of profitable, sustainable businesses, but there is a tension in meeting these twin goals that excites considerable debate over the merits of ADE employment in comparison with open employment. (See, for example, the alternative Australian Federation of Disability Organisations Vision for funded employment support, presented as Appendix 5, Vision for Sustainable Supported Employment, 2011, p. 51).

Some jobseekers who wish to enter the open marketplace will spend time in an ADE, acquiring the skills they need to be successful with a competitive employer. It is also not uncommon for people in ADEs to want to trial open employment, although there are barriers that make this difficult. All this tends to mean that part of the ADE workforce moves through the system, while there is another substantial cohort which has no intention of moving from their ADE. Another reasonably large cohort of job seekers ‘churns’, meaning that they come into an ADE (perhaps more than one ADE, in succession), but do not remain in other than relatively short-term employment and generally do not move on to open employment.
Notwithstanding an inability to reference affirming data, it is not unreasonable to conjecture that many people with a disability who have or could acquire the skills to access the open employment market choose to remain in ADEs. To this extent, ADEs might have less of a ‘throughput’ than may be considered desirable in the context of contemporary policy aims. However, the main criticisms of ADEs are that they pay poor wages and that their service settings are segregated.

These issues notwithstanding, supported employment in Australia is recognised and endorsed across the Australian political spectrum, although there is also universal agreement that open employment is the premier service model. As such, competitive work in mainstream settings should be the clear aspiration of job seekers and Governments should be ensuring policy settings that promote and achieve this goal.

As noted above, open employment for people with disabilities is provided through DEEWR funded specialist disability employment assistance programs. Relatively recently, these have been streamlined, with the Disability Employment Services (DES) Program (introduced in March 2010) replacing the former Disability Employment Network (DEN) and Vocational Rehabilitation Services (VRS).

DES is made up of two streams:

(a) Disability Management Services (DES-DMS) for job seekers with disability, injury or health condition who require the assistance of a disability employment service but are not expected to need long term support in the workplace; and

(b) Disability Employment Support Services (DES-ESS) for jobseekers with permanent disability and with an assessed need for more long-term, regular support in the workplace. (The Senate Education, Employment and Workplaces Relations References Committee, 2.2, 2011)

The same Senate Report states that there are more than 146,000 workers with a disability receiving DES supports. It also notes that whereas access to ADEs is capped, DES programs are fully uncapped (The Senate Education, Employment and Workplaces Relations References Committee, 2.1 and 2.2, 2011).

When developing its National Disability Insurance Scheme model, the Productivity Commission considered the services which should fall within the purview of the NDIA and those which should be externally located. In its Draft Report (February 2011), the Productivity Commission recommended that whereas supported employment and job readiness training should be part of the National Disability Insurance Scheme, open employment should remain where it is, i.e. positioned as a generic labour market program. A number of submissions advocated for all disability employment support to be located within the National Disability Insurance Scheme, but this was not supported by the Commissioners in the Final Report:

The Department of Education, Employment and Workplace Relations provides open employment services through Job Services Australia. This covers disability employment services (which are uncapped and include specific supports for people with disabilities) and generic employment services (which offer standard employment assistance to job searchers regardless of disability). The number of people with disabilities covered by Job Services Australia would be much greater than those eligible for NDIS-funded supports. Given that, and the significant benefits from having a single coherent system for open employment services, these services should lie outside the NDIS.

The Commission considers that employment services should remain a mainstream concern. However, a clear exception would be ‘job readiness’ programs (targeted support) currently provided by the disability services sector. These intensive post-school programs last around two years, and help people in the transition to the workforce. Another clear exception would be supported employment” (Productivity Commission 2011, p. 240).

It is in the division of the various disability employment support programs between the National Disability Insurance Agency and DEEWR that the potential alignment problems reside.

Problems with the current approach and the potential impact of this on the National Disability Insurance Scheme

As noted above, the Disability Care and Support Report discussed at length the need to assist more people with disability into employment and calculated that if this is done in sufficient numbers, the economic impact will be dramatic.
However, many from this target group will be people with permanent and significant disabilities, whose workplace support needs will similarly be long term and, probably, intensive. The provision of intensive and/or long term supports is inimical to the DEEWR model, which aims for ‘efficiency’, conceived as maximum job-seeker through-put based on least-possible, short term interventions.

Not only does the DEEWR model not encourage the sort of support regime that works best for people with permanent and significant disabilities, but the Department’s administration has arguably been on a track that will likely lead to a smaller number of specialised services that are positioned to meet the needs of this population. DES providers are star rated. In a well flagged and organised move, DEEWR determined that other than the higher rated DES-ESS services should go out to tender in 2012 and despite not inconsiderable opposition, this is what happened. Several commentators, including the author in the earlier iterations of this Paper, conjectured that, apart from an unnecessary and potentially damaging disruption to jobseekers’ efforts, the tender’s result would likely be a smaller number of larger providers in the marketplace. This conclusion was based on the reality that this has been the trend in the last several years. The same commentators also cited the data, which suggest that providers of services which are not specialists in working with people with significant barriers to employment – including jobseekers with a disability – do not achieve strong outcomes with this group (Disability Employment Australia 2012, p.3). They noted that since the large providers of services (the ones projected as most likely to win the tenders) are not specialists in working with people with disabilities and look for volume throughput rather than long term client resourcing, a diminished focus on jobseekers with a disability could be expected in the future and, therefore, fewer of those jobseekers successfully accessing open employment opportunities under this model. Such outcomes, they said, would be stridently discordant with the directions of the Productivity Commission, which saw a significant rise in employment participation on the part of people with disabilities as vital.

The results of the tender were substantially as predicted – and feared – and were captured in a pithy, confidential e-mail comment from a senior peak body Manager to the author:

The tender is a disaster. Specialists cut by 50%, traditional providers savaged, business redirected to high volume, large traditional JSA type providers (personal communication). By late 2012, when the tender outcomes were published, several of the most widely respected specialist DES services had lost business and, in some cases, a lot of business. In fairness, it should be noted that DEEWR would have been developing its tender strategies while the National Disability Insurance Scheme was still an insignificant speck on the radar screen, but it is nevertheless a here-and-now consequence that the whole-of-life needs of Tier 3-eligible jobseekers are to be the responsibility of a funding agency that appears to place the highest value on providers that move jobseekers through the system as rapidly and with the least number of interventions as possible.

This emerging misalignment and its potential to blunt the vocational policy goal ambitions of the Productivity Commission will likely be exacerbated by additional considerations:

1. **Poor interface between the different employment programs and day services**

   There is not a seamless interface between open and supported employment programs, because one is the responsibility of DEEWR and the other of FaHCSIA. The programs are administered differently and because one program is capped and the other is not, it can be hard for jobseekers to move between open and supported employment without feeling that they are taking a substantial risk. Similarly, because so-called ‘dual funding’ (i.e. funding provided by both DEEWR and FaHCSIA at the same time) is proscribed, it is even harder for a person to ‘have a foot in each camp’. Needless to say, the relationship between the federally funded employment services and state and territory funded day services is similarly complicated, with limited client movements resulting. This all works against the interests of job seekers with a disability. The situation is compounded by employment disincentives which exist within current income support arrangements (albeit that these have been relaxed recently), all of which serves to unnerve job seekers and create uncertainty for service support agencies.

2. **Inappropriate and insensitive ‘Red tape’ requirements**

   Disability Employment Australia holds the view that DEEWR has imposed an administrative approach for DES providers...
that is characterised by excessive red tape and attempts “… to impose top down, narrow performance requirements on a system that is complex” (Disability Employment Australia 2012, p.3). It certainly appears to be the case that DEEWR’s approach is not sensitively attuned to the National Disability Agreement’s stated goal of building economic and social inclusion for people with a disability, and (as also noted above) focuses instead on what seems to be generic labour market program administrative processes. In particular, the DEEWR DES approach is not specifically aligned with the United Nations Convention on the Rights of Persons with a Disability, which requires that signatory states adopt all appropriate “… administrative and other measures for the implementation of the rights recognised in the present convention”. (Article 4.1 (a), cited by Disability Employment Australia 2012, p.5). Disability Employment Australia moreover suggests that program outcomes are insufficiently broad for the specialised disability employment sector and that the program is not client directed. (Disability Employment Australia 2012, pp 3 – 4; and Nevile & Lohmann 2011, p.31 et seq). This last point is very directly at odds with the person-centred model that is proposed for the National Disability Insurance Scheme.

3. Possible unintended migration of jobseekers with a disability to supported employment

If the future of DES services is uncertain in the current environment, this is similarly the case with ADEs. In February 2012, the Department of Families, Housing, Community Services and Indigenous Affairs Advisory Group’s Report Vision for Sustainable Supported Employment was released. The Report addressed the major issues faced by ADEs and made a number of recommendations, but as has been noted above, a single vision was not supported across the entire sector, with the Australian Federation of Disability Organisations dissenting from the majority and presenting its own alternative. This Paper does not seek to align with any party over the issues which divide them, but merely acknowledges that the future pathway for ADEs will be neither straight nor easy. While some larger, mainly metropolitan based ADEs are successful in operating sound businesses that provide employment outcomes that their workers seem to value, many others are marginal, including enterprises that are rurally/regionally based. This has implications for the market choices that will be available to jobseekers with a disability, once a National Disability Insurance Scheme is operating.

One of the key issues facing these enterprises is that they lack volume and certainty in the sort of work they need – that is, work that is profitable and, at the same time, is the sort of work that a majority of their supported employees can successfully undertake. ADEs overall have tended to have an image problem and this has impacted on the willingness of some mainstream Australian businesses to deal with them, other than at the margin. All this means that much more needs to be done by ADEs to ensure their future viability, sustainability, and ability to generate excellent employment outcomes for their supported workers.

Against this backdrop, there is the prospect that an open employment sector that is not functioning optimally could significantly impact ADEs. If, as has been argued, the future scenario is that fewer jobseekers with a significant disability will be placed by DEEWR-funded agencies, then those same jobseekers may seek to migrate to the supported employment sector. However, because there is already a dearth of suitable and profitable work for ADEs in many places (which, accordingly, makes these very fragile enterprises), it will be highly problematic if such an exodus occurs. This is beside the issue that it is clearly unacceptable for jobseekers with a disability who could work in open employment not to be supported to do so.

Alternative approaches to offering employment support under a National Disability Insurance Scheme

Perhaps controversially, it is proposed that an underlying operating assumption for the National Disability Insurance Scheme should be that all persons with a disability who can work would ordinarily be expected to do so. This is normative in Australia today and is consistent with the principle of mutual obligation. While such a requirement is not a pre-condition for other areas of policy development, the introduction of the National Disability Insurance Scheme is a watershed moment and so is a good time for
clearly establishing the ground rules that will apply in the future.

At the moment, day services, supported employment and open employment all operate as silos, with poor interfaces being the consequence. While there is superficial goal congruence around building economic and social inclusion for people with a disability, there appears to have been limited success in terms of harmonising the programs. This Paper posits that what is required to move people from welfare to work, with optimum efficiency, is for all day activities to be conceived, structured and administered as a service continuum. Accepting that the path from school to work will be different for individuals, it should nonetheless be barrier-free, and give jobseekers maximum flexibility to ‘mix and match’ from amongst vocational training activities, ADE placements, workplace trials and open employment over their working careers. As noted, the barriers to free movement along such a continuum are currently formidable.

For this approach to work well, it would seem practical that all employment services for those who are Tier 3-eligible should fall under the aegis of the National Disability Insurance Agency and not just supported employment and job training and readiness programs. This would, of course, require a reconsideration of funding arrangements, since such an approach would imply that the cost of the purchase of open employment Tier 3 jobseekers’ supports would be a National Disability Insurance Agency – rather than a DEEWR – responsibility.

JSA agencies with disability employment capability would continue to be funded by and accountable to DEEWR in respect of all non-Tier 3 clients; however, they would also be there ‘for hire’ by Tier 3 clients wishing to enter the job market. For these clients, the agencies would be operating on a de facto ‘private’ basis, with the job seeker paying for and directing the activity. If the National Disability Insurance Agency laid down procedures and accreditation requirements that would have to be met in order to be eligible to offer services to Tier 3 jobseekers, it would be for individual agencies to decide if they wished to operate in that part of the market, however, the key point is that for Tier 3 clients, there would be no need for the provider agency to conform to DEEWR’s operating regulations.

A third suggestion is that open employment support services for Tier 3 clients should be open to ADEs to operate, along with any other outlets approved by the National Disability Insurance Agency. As indicated above, labour market programs for other than Tier 3 jobseekers would remain with DEEWR and it would be up to ADEs to decide if they wished to try and enter that particular market. To do so would require them to win business operating rights under DEEWR’s stringent tender processes, but winning such a right would not be a pre-condition of supporting Tier 3 jobseekers wanting a job in a mainstream employment setting.

The corollary of this is that ADEs should not be permitted to operate open employment services for Tier 3 jobseekers without being able to satisfy any testing requirements specified by the National Disability Insurance Agency.

The advantages of the approaches suggested above are that:

1. Since all employment services and non-vocational day services for Tier 3 clients would be person-centred and funded by the National Disability Insurance Agency, improved outcomes from aligned service goals could be anticipated.

2. A seamless service continuum for Tier 3 clients would be created that would maximise opportunities for participants to access a range of work and work-related activities. For example, a person could have an ADE job for two days a week, while attending a TAFE college on another day to acquire new workplace skills, and working in (or trialling) an open employment setting for the rest of the week. People transitioning from school or into retirement could be given specialised supports from within the one, National Disability Insurance Agency-controlled system.

3. Maintaining key repositories of expertise (which might otherwise be in jeopardy under DEEWR) around securing long term open employment for job seekers with significant disabilities would be more assured.

4. By creating a flexible interface between the different service functions, ADEs would be encouraged to facilitate the movement of more people through their services and into open employment. This should serve to limit instances of ‘client-capture’ by agencies that hold on to productive workers to enhance their profitability.
Recommended principles to guide the further development of employment supports under a National Disability Insurance Scheme

1. That all Governments’ policies and their implementation should be directed towards ensuring that people with disabilities have the same right and opportunity to work as all other Australians.

2. That people with disabilities should have free and full access to the individualised supports they need to find, secure and maintain employment.

3. That all disability employment support services for Tier 3 workforce participants and jobseekers should fall within the administrative and funding purview of the National Disability Insurance Agency.

4. That in order to bring about innovation and service efficiency, all vocational and non-vocational day support services should operate in a competitive environment, with unencumbered entry to the market for accredited providers.

5. That all day activities should be structured as a service continuum, which is barrier-free and easily navigated.

6. That while all forms of employment and all activities designed to secure that employment are valued, people with a disability will be channelled towards open employment to the greatest possible extent.

7. That the normal expectation of persons with a disability will be that they will work, if they are able to do so.

Summary

1. One of the most important messages of the Disability Care and Support Report is that the National Disability Insurance Scheme has the capacity to generate substantial economic benefits. Many things will contribute to the achievement of these benefits, but one of the key factors will be the – vicarious – capacity of the National Disability Insurance Agency to increase the employment participation rates of people with disabilities.

2. The Productivity Commission recommended that open employment for people with disabilities should remain a DEEWR responsibility, but the current DEEWR emphasis on short term, high volume interventions is inconsistent with an insurance based model that recognises the value of individualised, intensive, long-term supports that foster long term efficiencies. At the same time, the DEEWR approach appears to work for other jobseeker cohorts.

3. Accordingly, individualised, intensive, long-term supports would be best provided by agencies that are part of a service continuum regulated and monitored by the National Disability Insurance Agency.

4. The approach suggested above could be trialled in the Barwon region commencing 1 July 2013 and be compared with results from the Hunter region, where the current operating modus operandi could continue to apply.

Postscript

Discussion arising out of one of the earlier iterations of this Paper resulted in the author being invited to join a Disability Employment Australia Taskforce. This Taskforce has been formed with the broad remit of looking at how employment goals will be addressed through the National Disability Insurance Scheme, but it has more particularly considered how the forthcoming National Disability Insurance Scheme trials might be used to test alternative approaches to achieving strong employment outcomes for Tier 3 jobseekers.

An edited Disability Employment Australia Member Update dated 28 November 2012 reads as follows:

The Taskforce has identified a number of tensions between the way that DES-ESS works and the principles that will apply to the new NDIS scheme. Perhaps the most important of these is that while DES-ESS provision is driven by the contract and KPIs, the NDIS will be driven by consumers. ... Some have advocated for all employment assistance for NDIS Tier 3 clients to be provided through the NDIS. There are some compelling arguments in favour of this view. It would provide greater consumer control, overcome service ‘silos’ and promote a ‘whole of life’ approach. On the other hand this approach could pose risks to aspects of service delivery that require longer term certainty – like investment in professional development and long-term employer strategies. ... Disability Employment Australia is proposing a trial of consumer directed employment services in one or more of the launch sites from July 2013
… The trial would include the opportunity for approximately 50 Tier 3 NDIS clients to access employment assistance through the NDIS instead of DES for one year. These people should be drawn from people not currently participating in DES including some people who may have an assessed work capacity of less than 8 hours and others who may be eligible for, but not participating in, DES. In addition,

- The trial should be conducted with the involvement of local DES and ADE providers who volunteer to participate;
- These providers would work with the NDIA locally to develop assistance packages and would participate in evaluation of the trial;
- Consumer advocates should be involved in development and education process for the trial;
- Participants in the trial would be excluded from performance ratings or market share;
- A national steering group be established for the trial.

The trial evaluation process would include:

- Comparison of outcomes with similar cohort in mainstream services (includes employment / participation outcomes and consumer views of value/quality of assistance);
- Comparison of costs and benefits for stakeholders;
- Feedback from providers / LACs and other stakeholders; and
- Recommendations in relation to future adjustments that may be needed to DES and/or the NDIS.

A trial would help us better understand whether employment and the role of the NDIS, for whom, how and when. It would also help us learn about what a model of consumer directed service might look like if it stayed in the NDIS.

References


Bryan Woodford is Chair of the Victorian NDIS Implementation Taskforce.
There is an urgent imperative to improve the healthcare provided to people with intellectual and associated developmental disabilities. People with intellectual disability have unique and significant health vulnerabilities throughout their lives (IASSID, 2002; Scheepers, 2010; Tracy, 2011b). There are specialized services supporting them through childhood, but when they reach adulthood the current expectation is that their health needs can be met by mainstream health services. The complex health and social issues experienced by people with intellectual disabilities contribute to the significant health inequalities of this group. These inequalities are underpinned and compounded by social and economic disadvantage (Emerson & Baines, 2010; VicHealth, 2012) and are manifest in the increased morbidity and rates of premature death among people with intellectual and associated developmental disabilities (Lennox & Taylor 2008; VicHealth, 2012).

In the drive towards inclusion, the need for a focus on the unique health needs of people with intellectual disabilities has been undervalued. Many members of our community have particular health needs including children; indigenous Australians; older Australians; people with mental illness and people with intellectual and associated developmental disabilities. Services focusing on the distinctive needs of people within these populations have enabled the development and maintenance of experience and expertise in their healthcare which has, in turn, supported and informed the practice of mainstream practitioners. The importance and benefits of this approach with respect to people with intellectual disabilities have been well documented (IASSID,2002; Lennox et al., 2007, Lennox et al., 2010). The comprehensive and timely provision of care and appropriate interventions has minimised the restrictive and isolating effects of illness, discomfort and sensory impairment and has improved the provision of disease prevention and health promotion interventions (Lennox et al., 2010). In this context the provision of specialist services and resources has supported mainstream providers and promoted health and wellbeing thus enhancing the individual’s interest in and capacity for inclusion and participation in community life.

This paper argues the case for a network of services with specialist expertise and experience in working with people with disabilities collaborating with and complementing existing specialist and mainstream health services (that is, those services not specifically set up to meet the needs of people with disabilities) to provide high quality health services for people with intellectual and associated developmental disabilities. Together these specialist and mainstream services would form a healthcare service system able to meet the diverse needs of the Victorian community.

Background

People with intellectual disabilities receive most of their healthcare from the same services accessed by the rest of the Australian population: mainstream health services. Human Rights discourse, national and state legislative instruments designed to address discrimination and the National Disability Strategy have highlighted the need for equity in access to and provision of community based services, including healthcare (United Nations, 2010; VicHealth, 2012). More recently discussions around the National Disability Insurance Scheme have lead to an increased awareness of the imperative to acknowledge and address the needs of this currently disadvantaged community group.

The Centre for Developmental Disability Health Victoria (CDDHV) is an academic unit within the Faculty of Medicine Nursing and Health Sciences at Monash University, Victoria. The Centre was established in 1998 to further develop the capacity of mainstream services to meet the needs of people with developmental disabilities through a range of educational, clinical and research activities. Over the last few years, the social and political drivers outlined above have lead to an increasing number of requests to the CDDHV by health professional course conveners, Community Health Services, Medicare Locals and Private Health providers, among others, for education and training, clinical services, and collaboration in research projects all aimed at improving the health and healthcare of people with intellectual and associated developmental disabilities.
Current issues
People with intellectual and associated developmental disabilities have cognitive and communication difficulties that may impair their ability to speak and advocate for themselves in a healthcare context. In this situation their healthcare depends heavily on effective communication and partnership between themselves, their Disability Support Workers (who have had little or no training in health) and their medical practitioners (who have had little or no training in disability). Gaps in knowledge and understanding between disability and health professionals contribute to the poor health outcomes currently experienced by people with disabilities (Tracy 2010, McDonald, Farnsworth & Hand, 2012).

Likewise, people with disabilities living independently or with family members rely on their medical practitioner to communicate and collaborate effectively with them, and to provide the proactive care needed to achieve and maintain optimal health. Many medical practitioners have had little or no specific training in working with people with cognitive and communication impairments and feel they lack the knowledge and skills they need to do so effectively.

A parallel universe?
Some health professionals working in mainstream services believe a ‘parallel universe’ of services specifically set up to meet the needs of people with disabilities exists. Staff at the CDDHV are frequently asked to provide details of how health professionals can refer people to these services. Of course, there is no such parallel universe, but rather there are a range of public and private health services intended to meet the needs of all Victorians. People with intellectual and other developmental disabilities have the same rights to access and care from those services.

The belief – or even hope – by some health professionals that there is a ‘parallel universe’ of health services in large part reflects their lack of familiarity and confidence in this area of practice. This in turn relates to the lack of content in relation to the health issues of adults with disabilities in their health professional training.

It takes many years for health professionals to complete their training and emerge as independent practitioners. The inclusion of a focus on the healthcare of people with intellectual and associated developmental disabilities is relatively recent in Victoria, and is still patchy and inconsistent between Universities and courses. Unlike other areas of need there is very little opportunity for early career professionals to develop familiarity or competence within a supported clinical setting focusing on the health needs of this population. Consequently most health professionals, including medical practitioners, in current practice, particularly those in senior positions, have had little or no training in this area.

Developing a focus on the healthcare of adults with intellectual disability in Victoria
As deinstitutionalization occurred in the 1980s and 90s and people with disabilities took their rightful place in their communities, they increasingly sought access to local health services. In the late 1980s the then Victorian Department of Community Services responded to the knowledge that the lack of training of medical practitioners in the care of adults with intellectual disabilities was impacting negatively on the healthcare they provided. In 1992 the predecessors of the Centre for Developmental Disability Health, the Intellectual Disability Units at Monash and Melbourne Universities, were established through an initiative of the Department of Community Services and the two University Departments of General Practice. The intention was to build the capacity within Victoria’s medical workforce to address the needs of people with intellectual disabilities.

Staff at these Units advocated for the inclusion of educational sessions, for both medical students and doctors in practice, in providing healthcare to adults with intellectual disabilities. In 1998 the Units amalgamated to become the Centre for Developmental Disability Health Victoria (CDDHV) and the resulting combined experience and critical mass facilitated the further development of this work. Since then CDDHV staff have worked to improve the health and healthcare of people with intellectual and associated developmental disability through a range of educational, research, clinical and advocacy initiatives.

The CDDHV has contributed to the training and education of medical students, and provided targeted professional development opportunities, seminars, conferences and articles within professional journals for doctors in practice. Gradually the CDDHV’s impact has increased and most new Victorian medical graduates now have...
the opportunity to develop an understanding of the healthcare needs of people with intellectual disabilities during their course. The work they do in this area develops their appreciation of the diversity of the community in which they will work and the responsibility they have to meet the needs of all community members to the best of their ability.

Historically the Centre was established to influence the training and practice of medical practitioners. Subsequently the importance of supporting a focus on the healthcare of people with intellectual disabilities more broadly was recognised as being essential to the Centre's aims. The CDDHV therefore now plays in active role in the provision of both teaching sessions and educational resources to the curricula of other health professionals including occupational therapists, physiotherapists, paramedics, nurses, dietitians, oral health therapists and dentists.

The Centre has the unusual position of being within the Faculty of Medicine Nursing and Health Sciences at Monash University, while also being closely associated with the Faculty of Medicine Dentistry and Health Sciences at the University of Melbourne. This enables contribution to the training of undergraduate health professional students, including medical students, in disability health issues across both universities.

There has been vigorous discussion over the years as to whether the Centre's primary focus should be on health professional students or practitioners. Teaching undergraduates has the advantage of being able to influence large numbers of students as they progress through their course. These students are our future health professionals and the intention is that they will enter their field of practice with a competence and confidence in working with people with intellectual and developmental disabilities that translates into better healthcare and health outcomes. The disadvantage of working with undergraduates is that there is a prolonged lag time between teaching and practice and limited opportunity to follow this up with direct clinical experience and supervision during their early careers.

On the other hand, professional development sessions for medical and other health practitioners have the advantage of a potentially immediate impact on practice, but numbers attending professional development sessions tend to be small as people with intellectual disabilities comprise only a small proportion of the practice population of most health professionals. The debate continues, but in practice work in both domains continues.

Disability professionals

Just as the CDDHV has contributed to the training and education of health professionals about disability, so it has offered opportunities to disability professionals to understand more about the health issues of the people with whom they work. The Centre has offered both broad based and general training (e.g. communication, health promotion and disease prevention, aids and equipment, understanding behaviour), and targeted sessions focusing on an area of immediate relevance and concern (e.g. epilepsy, dementia). Training and educational sessions have been provided to particular staff groups, seminars have been run as part of the Centre's educational activities calendar and presentations and workshops have been offered within Disability Support Worker conferences.

Improving medical care: there is still much to be done

The health inequalities currently experienced by people with intellectual disabilities demonstrate there is still much improvement in healthcare provision still needed (Vic Health 2012). Further work to develop the confidence and competence of health professionals to work with people with disabilities is required.

Familiarity and attitudes

Medical practitioners have the same range of community experiences and attitudes as the rest of the population. Many have had little opportunity to know someone with an intellectual disability personally, and feel uncertain about how best to communicate and work with someone with a cognitive impairment. The direct participation by people with disabilities in the training and education of health professional provides opportunities for students to have positive personal experiences: a powerful way to develop more positive attitudes (Iacono and Tracy 2008). If members of the community have such a positive experience through their childhood and adolescent years, they are more likely to recognize the commonalities between all people and recognise people with disabilities as equal members of their community. This is one of the reasons inclusion of children with disabilities in mainstream schools is so very important for the long term changes in community attitudes (Graves and Tracy 1998).

Education and training

The education and training of medical practitioners in Victoria is still far from ideal. At Monash
University, a comprehensive vertically integrated curriculum in Developmental Disability Health has been provided to all medical students since 2002. At Melbourne University, a few specific teaching sessions in this area exist within the curriculum, but this falls short of a cohesive and comprehensive vertically integrated learning pathway within curriculum. Deakin University medical school purchased learning and teaching resources from the CDDHV, but the ways in which these have been used is unclear.

Some University curriculum coordinators have argued that the proportion of people with intellectual disabilities within the population is so small that time focusing on the needs of this group cannot be justified. Those committed to education in this area believe that targeted and specific teaching in this area is warranted in the light of the serious health outcome inequalities evident in this disadvantaged population. Moreover, one in five Australians have a disability impairing their daily functioning (VicHealth 2012) and building student competence in working with people with disabilities enhances their ability to work with those with a disability arising from any cause. In addition, through attending to the needs of people with intellectual and associated developmental disabilities, students build the attitudes, understanding, skills and knowledge essential to provide high quality healthcare to other vulnerable community members who have chronic and complex health and social needs; cognitive and/or communication impairments from any cause; and those who required advocacy as a part of healthcare provision.

**Registrar training programs**

After graduation, medical practitioners enter training programs in their chosen area of practice. Until recently there have been few requirements for registrars in training to develop specific competencies in the care of people with intellectual and associated developmental disabilities.

General Practitioners play a central role in the healthcare of people with intellectual disability (Vanney Levy & Hayes 2009, Tracy 2011a). The 2011 Curriculum for the Royal Australian College of General Practitioners now includes a comprehensive set of competencies for medical registrars training to become General Practitioners. CDDHV staff were involved in the advocacy for this change, and for the writing of the RACGP supportive documentation. (Royal Australian College of General Practitioners 2011).

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) has a Special Interest Group in Intellectual and Developmental Disabilities that has, just this year, been successful in ensuring the competencies for registrars training to be psychiatrists must now include competencies in working with people with intellectual and developmental disabilities in the RANZCP 2012 (competency-based) Fellowship Program. Staff at the CDDHV have been instrumental in the advocacy for this initiative.

**Systemic barriers**

There are systemic barriers to medical practitioners providing optimal care to people with intellectual disabilities. The first is the way General Practices are organised and remunerated. In the Australian system there is an emphasis on and reward for throughput, with 87% of General Practitioner consultations lasting 13 minutes or less (Britt Valenti & Miller, 2002).

The time-tiered Medicare payments for General Practice discriminate against patients who require longer consultations. People with intellectual disabilities, attending with or without a support person, require longer consultations to enable their active participation; the time pressure on both the patient and doctor can undermine effective communication in this context. Factors such as complex health and social problems, administrative issues, cognitive and communication difficulties and behaviours of concern can contribute to the extra time it takes to adequately assess and work with people with intellectual disabilities. Further compounding this at times is the need to work with the organizations and individuals supporting the person with a disability. The resulting time pressure on both the patient and doctor can mean at times consultations focus on the acute presenting problem with less attention paid to important chronic health problems and disease prevention and health promotion activities.

The addition of the Health Assessment for People with Intellectual Disabilities to the suite of Health Assessments for Australians (Australian Government Department of Health and Ageing, 2013) known to have multiple and complex health and social issues was a constructive step in addressing the issues of consultation time and the need to monitor for the health vulnerabilities of people with developmental disabilities. This has been further enhanced with the requirement of state funded accommodation services to arrange for yearly medical checks often using...
the Comprehensive Health Assessment Profile (CHAP) (Victorian Government Department of Human Services 2012). These health checks help identify the major health issues for people with developmental disability and ensure that basic parameters such as blood pressure, weight, immunization status, hearing, vision and medication side effects are monitored. There is still, however, a need for better integrated health management plans initiated through and coordinated by the General Practitioner. While there has been financial support for this within the Enhanced Primary Care initiatives as with other areas of chronic health care there has been limited take up by General Practitioners. Further work is required in this regard, both in building the awareness of health professionals in relation to the presentation and management of health issues experienced by people with disabilities and in enhancing their understanding of the roles and responsibilities of disability support workers and services.

**Professional support**

The structure of professional support and expertise contributes to the difficulties experienced by medical practitioners in providing healthcare for people with intellectual disabilities. For children with disabilities, paediatricians take the lead role in providing and coordinating healthcare and access to other appropriate social and community services. They are supported by a well developed infrastructure that enables access to a range of allied health services and, at times, to multi-disciplinary teams. For adults, however, there is no specialist in intellectual or developmental health and so the provision and coordination of care is the responsibility of General Practitioners (Tracy 2011). General Practitioners seeing people with intellectual disabilities currently do not have a network of medical (both physical and mental health) services to which to refer when the complexity of care is beyond their perceived level of expertise. There is also limited availability of allied health professionals with expertise working with people with intellectual and associated disability.

**Specialist services**

In most areas of medical practice there is an expected foundational level of knowledge for General Practitioners. When the patient’s condition requires an expertise beyond this the General Practitioner is able to refer to a ‘specialist’ to access specialized knowledge and skills. This is not yet the case in Australia for the specialty area of Developmental Medicine.

An analogy is working with older Australians. All General Practitioners expect to see older Australians in their practice and have the basic skills and knowledge to provide appropriate care for those who have a straightforward medical issue. There are some particular health risks, and consequent healthcare needs, in this population and most General Practitioners will continue to build their knowledge and skills throughout their working life to ensure their care continues to develop and is up to date in relation to the known issues and risks of this particular population group (e.g. a greater likelihood of multiple medical issues, poly-pharmacy and slower healing). When the General Practitioner feels that the presenting issues are beyond her/his experience and expertise, s/he seeks to refer to a specialist – a Geriatrician in this example. This is entirely appropriate when the issues are beyond the scope of the generalist. The availability of referral to this secondary, and in some cases tertiary, level of specialization ensures the patient receives the best care; the generalist medical practitioner feels supported in his/her role and continues to develop knowledge and skills through their patients.

In Australia we do not (yet) have recognised accredited specialists in Intellectual or Developmental Medicine in the same ways it is in some other parts of the world including the UK and the Netherlands (Evenhuis & Penning, 2009).

**Healthcare for people with intellectual and developmental disability**

At an individual level, good healthcare relies of the effective collaboration between the person with the disability, those who support them in their daily life, and their healthcare provider(s): each is a vital member of the healthcare team (Figure 1). An example of the ways members of this collaborative team can work together is given below (Figure 2).

**Figure 1: The healthcare team**

![Healthcare team diagram](image-url)
The healthcare of people with intellectual disability may be compromised at each step for a variety of reasons. Building the skills of all those involved improves ultimate health outcomes achieved. Throughout the process of presentation, assessment, management and review the active participation, including decision making, of the person concerned should be facilitated to the greatest extent possible.

**Figure 2 The Health Care Cycle in People with Developmental Disability**

1. **Person becomes unwell.** People with intellectual and associated developmental disabilities may not appreciate the significance of symptoms and/or may have difficulty expressing their experience or symptoms of illness. **Intervention:** Building the health literacy and advocacy skills of people with disabilities would assist in people being willing and able to bring their symptoms to the notice of those supporting them.

2. **Identification of symptoms.** A Disability Support Worker (DSW), family member or friend may notice a difference in the person’s health or behaviour which alerts them to the possibility of illness and the need for medical assessment. **Intervention:** Training of DSW and other relevant people in health issues and the way in which these may present may lead to more timely detection of symptoms and assessment being sought from an appropriate health professional. An understanding of the healthcare system enables the DSW to access the appropriate health service in a timely manner. The recognition of the expertise of the person concerned in their experience of their health issue is paramount. Every effort should be made to enable the person to speak for themselves and contribute to the assessment process. Likewise the knowledge and experience of family members and DSWs who know the person well must be respected and valued.

3. **Appropriate and timely assessment:** Staffing issues, transport, communication and cognitive barriers, administrative issues, attitudes of health service staff and the knowledge of primary healthcare providers may all result in barriers to the person seeing the appropriate health professional in a timely manner. **Intervention:** Regular health checks and the education and training of both support staff and health professionals in the presentation of common conditions, and the conditions to which particular people with disabilities may be vulnerable can increase the likelihood of timely referral. Health services also need training and auditing to ensure their service is accessible to and supportive of people with cognitive, communication, social and behavioural differences.

4. **Comprehensive assessment** will help identify current health issues. Such assessment requires review of conditions that occur commonly in the general population but may present differently in people with developmental disabilities as well as knowledge of the health conditions that are more common in people with particular disabilities. **Intervention:** The education and training of health professionals in Developmental Disability Health can increase the likelihood of accurate assessments. Respecting the contribution of the person concerned to the discussion of the issues of concern, and the ways in which the assessment is carried out is an essential aspect of professional care.

5. **Development of management plan:** People with intellectual and associated developmental disabilities often have chronic and complex health and social issues. A management plan is a comprehensive plan for addressing these issues and may involve collaboration between the person concerned, family (where appropriate), support staff, the referring health professional and various other health and community service providers as appropriate. This may involve referral to a specialist provider with expertise in Developmental Disability Health. **Intervention:** The education and training of health professionals in Developmental Disability Health...
Health can increase the likelihood of accurate assessment. Access to specialist expertise is helpful when people have complex presenting issues and/or when the reason for the presenting issue is unclear. It is essential that the person concerned plays an active role as possible in decision making with respect to healthcare choices, the development and implementation of the management plan and the people supporting the person through all phases of the plan.

6. Implementation of management plan. People with intellectual and associated developmental disabilities often need support in implementing their management plan. Good communication and collaboration in relation to the contents of the plan and the people responsible for each step is crucial to accurate implementation.

**Intervention:** Training and education of health professionals in the use of a management plan, and the importance of communicating that plan clearly to others involved is essential. Likewise education of Disability Support Workers is required in appreciating the importance of communicating the plan clearly to their team, following the plan and informing the doctor of difficulties or adverse outcomes.

7. Review. Unexpected obstacles to implementing the plan may arise, or the plan may be implemented but the desired health benefits may not eventuate. Review by the health professional is essential to ensure the assessment was accurate, the management plan appropriate, the expected health outcomes were achieved and that appropriate disease prevention and health promotion interventions have been provided.

**Intervention:** Training and education of support workers in health, and health professionals in disability is required to ensure the importance of review is fully understood.

---

The role of specialists in providing support to mainstream: Centre for Developmental Disability Health Victoria as an exemplar

The lack of accredited specialists in intellectual or developmental medicine in Australia means that mainstream health services have relied on the sparse network of specialist Centre's throughout the country to support them in their care of people with developmental disabilities. In Victoria it has been the role of the CDDHV to further build the skills and knowledge of medical practitioners to enable them to better work with people with intellectual and associated developmental disabilities. The CDDHV also provides a secondary and tertiary referral service for the assessment of physical and/or mental health issues to support General Practitioners in the care of their patients.

Areas of activity include:

**Student teaching**

The Centre was established to specifically contribute to the development of the medical workforce. The importance of the healthcare team has become an area of increased focus in medical education and the Centre seeks both to contribute to the training and education of medical and other health professionals (including physiotherapy, paramedic, OT, Dietitians, OT, dental students and oral health therapists, and takes every opportunity to promote and encourage Interprofessional Education and Practice.

**Support for medical practitioners**

The development of a health system that supports the complex and at times unique physical and mental health requirements of people with intellectual and associated disabilities needs to consider how change occurs across the profession. The CDDHV has made considerable inroads into the undergraduate training programs and has had some success within the training programs of general practitioners and psychiatrists. It has achieved this through the work of professionals with a special interest in developmental disability. As in all fields of medicine change occurs through research and through opinion leaders placing research into practice. The clinicians use specialized skills and knowledge to support primary health care professionals and specialists caring for people with intellectual and associated developmental disabilities and as such is integrated into mainstream services.

Through its placement within the School of Primary Health Care at Monash University the CDDHV has been a regular contributor to the General Practitioner professional development programs run by the school. These have included contribution to seminars and conferences and to the development of online courses in collaboration with the RACGP. These programs have been well received by the General Practitioners that participate but it has been a struggle to get more than a committed few to attend.

Medical practitioners working with people with intellectual and developmental disabilities in the community are invited and encouraged to:
• Ring CDDHV clinicians for advice with respect to the healthcare of their patients
• Refer their patients to the CDDHV clinics for assessment and management recommendations. Comprehensive reports designed to share expertise are provided.
• Attend appointments when their patients are assessed.
• Attend professional development opportunities in Intellectual and Developmental Disability Health organised through their Divisions of General Practice – and soon through Medicare Locals.

Support for allied health professionals
The CDDHV has developed and run professional development modules in relation to the health and healthcare of people with developmental and intellectual disabilities for health practitioners working in Community Health Services. Multidisciplinary clinics though the CDDHV clinical service in Notting Hill clinic and this service will expand to some regional areas in 2013. Local providers will be invited to partner with CDDHV clinicians in the assessment of people with complex needs, and to identify local sources of ongoing support and care.

Teaching and learning resources for all health professionals in disability
The CDDHV has developed a number of teaching and learning resources for medical and other health professionals working with people with developmental and intellectual disabilities. These include:
• Health and Disability: Partnerships in Action – a multimedia inter-professional teaching and learning resource in disability health
• Supporting Women: Guides for General Practitioners and Carers about supporting women with intellectual disabilities to manage their menstruation.
• Down Syndrome and Alzheimer’s Dementia
• Accessing Mental Health Services for People with Intellectual Disabilities
• Healthcare Scenarios in Developmental Disability Medicine – a CD ROM based around medical consultations with people with developmental disabilities
These and other resources are available on the Centres website (http://www.cddh.monash.org/products-resources/books.html).

Research
Research into the health and healthcare related issues for people with disabilities designed to increase the knowledge and understanding of the needs of this group. A recent project highlighted the need for improved knowledge of people with ID and their caregivers of available services; tools and other supports to assist people with ID access services; improved knowledge of healthcare providers in relation to the needs of people with ID; increased awareness of healthcare providers of the services offered by other healthcare providers; and affirmative policies to improve the appropriateness and accessibility of services for people with ID. (McDonald, R., Farnworth, L., Hand, M. 2012).

Policy and advocacy
All aspects of the Centre’s work involve advocacy for the right of people with intellectual and associated developmental disabilities to have ready access to the high quality healthcare they need to optimise their health and well-being. Partnerships and collaborations enable a sharing of knowledge and expertise and are also central to the Centre’s work. CDDHV staff have worked with national, state and local government and non-government organisations; with the health and disability sectors; and with academic institutions and clinical service providers. The Centre has been able to provide both contribution and leadership in the development of policy and resources in relation to the health and wellbeing of people with disabilities, and the design and implementation of curriculum for health professional students and practitioners.

A vision for the future
The CDDHV is one of a sparse and incomplete network of services across Australia focusing on improving the health and healthcare of people with intellectual and associated developmental disabilities. There is an imperative to further develop this network to better understand and address the healthcare issues of people with disabilities and the training and education needs of medical and other health practitioners.
A national network of disability health organisations could support and resource health professionals across the nation to provide high quality care to people with intellectual and developmental disabilities. At a state level a ‘hub and spoke’ model could be established so people with disabilities and their health professionals
had local access to specialist expertise and support wherever they live. Educational, clinical and research activities could also be designed and provided based on this model. Local clinical units could work with and support local services, building relationships, confidence and competence in management and care while providing the convenience of local healthcare provision.

Enabling a group of health professionals to focus on the unique needs of any group within the community enables the development and maintenance of expertise and peer support.

Examples in other areas of health include services focusing on the needs of people of a particular age group: paediatrics, adolescent medicine, geriatrics; or gender: women's health, men's health; or engaged in particular activities: aviation medicine, sports medicine. It is especially important to develop such a focus on groups identified as experiencing health disadvantage and inequality such as indigenous Australians, refugees, and people with intellectual disabilities. Together these specialist services form a suite of responses to the many and varied needs of the population. Developmental disability health is but one thread within the tapestry of services designed to support our rich and diverse community.

References:


Dr Jane Tracy is the Education Director, for the Centre for Developmental Disability Health, Monash University. jane.tracy@monash.edu

Housing People with Intellectual Disability under the National Disability Insurance Scheme

Ilan Wiesel

The aim of this paper is to review the treatment of housing issues in the Productivity Commission’s (PC) proposal for a National Disability Insurance Scheme (NDIS), with a focus on the implications for people with intellectual disability. The Australian Government has already committed $1 billion in its 2012-13 budget to support the first stage of the NDIS, which is expected to commence mid-2013 in a limited number of selected regions across Australia. At this stage, however, it is still unclear to what extent the full range of the PC’s recommendations will be adopted and implemented.

The paper provides a brief overview of the PC’s NDIS proposal in general, and then, more specifically, an outline of the housing issues it addresses. The PC makes a distinction between provision of specialist housing, which will be funded under the NDIS (Tier 3), and access to mainstream housing which the NDIS will not fund but will assist people with a disability to access through referrals (Tier 2). These two aspects of the PC’s proposal are discussed in separate sections.

An overview of the Productivity Commission’s NDIS proposal

The cost of the NDIS is estimated at approximately $13.5 billion per annum, an increase of about $6.5 billion over current government expenditure on disability services. The basic structure of the NDIS comprises three tiers:

Tier 1 is seen by the PC as an insurance cover for all the Australian population. In addition to insurance, the NDIS will proactively fund programs to minimise the impact of disability and to increase opportunities for social participation of people with a disability.

Tier 2 targets all people with a disability (4 million) and their primary carers (800,000) providing information about and referrals to mainstream services, as well as promoting community engagement. The NDIS will not directly fund, nor provide substitutes to, existing mainstream services.

Tier 3 targets people with a significant and ongoing disability (410,000), to fund a full range of long-term disability ‘specialist’ supports.

The NDIS provides ‘full coverage’ of people with intellectual disability, who are grouped under the criteria of ‘significantly reduced functioning in self-management’ (PC, 2011, p. 62). The PC does not question the fact that people with intellectual disability have significant and ongoing support needs (PC, 2011, p. 172), which implies that they should have access to services at all three tiers, to varying degrees depending on individual assessments of need.

Housing responses

The PC report recognises lack of access to suitable, stable and affordable housing as a major issue for people with a disability. It also recognises that the housing needs of people with a disability are diverse, and therefore require a range of strategies and solutions, as detailed in Table 1 below:

Table 1: NDIS responses to diverse housing needs

<table>
<thead>
<tr>
<th>Affected individuals</th>
<th>Range of possible NDIS supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>People seeking independent living arrangements</td>
<td>Referral to mainstream housing options</td>
</tr>
<tr>
<td>People with physical or sensory disabilities</td>
<td>Home modifications</td>
</tr>
<tr>
<td>People who require specialist disability accommodation</td>
<td>NDIS-funded specialist housing (supported accommodation)</td>
</tr>
<tr>
<td>Homeless people</td>
<td>Outreach services</td>
</tr>
</tbody>
</table>

Source: PC, 2011, p. 229

The PC makes a distinction between specialist supported accommodation services (which will be funded under the NDIS) and referrals to mainstream services (which will not be funded under the NDIS). Both strategies are elaborated below.

Referral to mainstream housing assistance programs

Most people with intellectual disability will be assessed as not being in need of specialist housing. For this group the NDIS would not provide direct housing assistance, but will offer ‘referrals’ into mainstream housing services, including social and affordable housing, rental subsidies and private housing. Home modification grants provided under the NDIS would also make mainstream housing more suitable for people with a physical disability. While acknowledging that
there is a major shortfall in mainstream housing which is suitable and affordable for people with a disability, the NDIS will not respond to these problems by providing its own substitute services:

‘To do so would weaken the incentives by governments to properly fund mainstream services for people with a disability, shifting the cost to another part of government (such as from a state government to the NDIS, or from one budget ‘silo’ to another). This ‘pass the parcel’ approach would undermine the sustainability of the scheme and the capacity of people with a disability to access mainstream services. If governments and departments thought that the NDIS would address both specialist and mainstream service needs, people with a disability may well be seen as a lesser priority for the generic services provided by government’. (PC, 2011, p. 237)

Nevertheless, the PC considers that the National Disability Insurance Agency (NDIA) should monitor the availability and quality of mainstream services to people with a disability and produce annual reports.

**Private rental**

People with intellectual disability whose main source of income is the disability support pension, will not be able to afford housing in the private market without substantial financial assistance. Currently, the Australian Government’s Commonwealth Rent Assistance (CRA) scheme provides direct subsidies for low-income households renting privately. Around one in five (220,000) recipients of CRA also receive the disability support pension (PC, 2011, p. 241). However, the CRA subsidy on its own does not meet acceptable affordability benchmarks. Housing is generally considered affordable if it costs less than 30 per cent of a household’s income. Under this definition, a person with an intellectual disability whose income includes a disability support pension and the maximum CRA payment (a total income of $416.5 per week) can only afford to rent at less than $125 per week. This may only be sufficient for very low-cost boarding type or shared accommodation with shared bathroom and kitchen facilities in a low cost location. The PC’s proposal that people with a disability should be able to ‘cash out’ their rental share in supported accommodation may help close the affordability gap by providing an additional source of subsidy for private rental. However, this additional subsidy will only be available (if at all) to a small group of people who are assessed as being in need of specialist housing.

**Social housing**

Another mainstream housing option for people with intellectual disability is social housing – comprising of public housing managed by state governments and community housing managed by not-for-profit organisations. Social housing provides affordable, long-term accommodation. Rents are typically designed not to exceed 25-30 percent of a household’s income, and social housing offers much greater security of tenure for residents compared to private rental. Public housing allocations are increasingly targeted at special needs households — including those with a household member with disability (Table 2).

At 30 June 2008, 31 per cent of public housing households contained a household member with disability (SCRGSP, 2010).

**Table 2: Proportions of new public housing tenancies allocated to households with special needs, 2006-07 and 2008-09 (percentages)**

<table>
<thead>
<tr>
<th>State</th>
<th>2006-07</th>
<th>2008-09</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>52.3</td>
<td>63.4</td>
</tr>
<tr>
<td>VIC</td>
<td>54.5</td>
<td>63.5</td>
</tr>
<tr>
<td>QLD</td>
<td>64.6</td>
<td>70.3</td>
</tr>
<tr>
<td>WA</td>
<td>64.6</td>
<td>59.5</td>
</tr>
<tr>
<td>SA</td>
<td>65.8</td>
<td>70.7</td>
</tr>
<tr>
<td>Tas</td>
<td>63.9</td>
<td>65.9</td>
</tr>
<tr>
<td>ACT</td>
<td>48.5</td>
<td>51.8</td>
</tr>
<tr>
<td>NT</td>
<td>66</td>
<td>64.6</td>
</tr>
<tr>
<td>Total</td>
<td>57.8</td>
<td>64.8</td>
</tr>
</tbody>
</table>

Source: AIHW, 2008a, 2008b, 2010a, 2010b; Wiesel et al., 2012, p. 9

Social housing accounts for less than 5 percent of all dwellings in Australia, and is considered a highly residualised system, reserved for those in greatest need. After long decades of disinvestment and declining supply of social housing, the last few years have seen some growth in new supply delivered under the 2009 Social Housing Initiative (SHI) of the Nation Building Economic Stimulus Plan. In Victoria, the SHI has provided funding for the construction of approximately 4,500 new social housing dwellings (DHS, 2010). Despite this one-off boost, there is still a severe shortfall in availability of social housing and the waiting lists are extremely long (PC, 2011, p. 242). In allocation of social housing units, priority is given to those who are at immediate risk of homelessness, and people with intellectual disability living with their families who are not in crisis situation may wait years until offered a social housing tenancy. This may undermine the PC’s aspiration to facilitate the transition of young adults into
independent living in line with community norms (PC, 2011, p. 260).

Applying for social housing can be a difficult process, involving extensive paperwork requirements and an understanding of a highly complex and fragmented administrative system with multiple providers (Wiesel et al., 2012, pp. 47-54). Furthermore, social housing providers will require strong evidence that an applicant with an intellectual disability receives sufficient support to live independently. State governments across Australia have been working to simplify and streamline the process of applying for social housing for all applicants, by developing integrated waiting lists (where a single application covers a wide range of social housing providers). In Victoria, the implementation of an integrated waiting list has been delayed (Wiesel et al., 2012). More specifically for people with a disability, the PC proposes establishing referral services to ease access to mainstream services such as social housing, including a centralised electronic database of service providers. The PC proposes that the NDIA will seek memorandum of understanding (MOU) with the relevant mainstream service sectors, to specify the process for making referrals between specialist disability and mainstream services.

In some cases such MOUs could include ‘nomination rights’ whereby housing units are reserved for clients of a disability support service (Hulse & Burke, 2005). However, to secure such nominations, disability support organisations will be expected to make some contribution to the capital costs of new housing projects, typically in the form of cash or land. It is unlikely that the NDIS will provide disability service providers with the funds necessary to obtain nomination rights, since this can be seen as indirectly funding a mainstream service – unless the nomination rights are used for housing individuals eligible for specialist housing, as discussed in a separate section below.

The PC notes that the location of available social housing often does not meet the specific requirements of individuals with a disability, for example close to their families, support services and social networks. The PC recommends experimenting with innovative measures such as allowing people with a disability to ‘cash out’ their social housing rebate as a subsidy for private accommodation, which is more suitable for their needs (PC, 2011, pp. 241-2). It is unclear whether such a subsidy, if offered, would be sufficient for individuals to afford private rental in central locations. Furthermore, there is a risk that trading ‘bricks and mortar’ with funding packages for individuals will gradually erode publicly funded housing assistance.

Affordable housing
An emerging model of housing in Australia – which is not explicitly discussed in the PC report – is the provision of ‘affordable housing’: rental accommodation provided by not-for-profit organisations, to accommodate low and moderate income households at a discounted rental rate. The National Rental Affordability Scheme (NRAS) has been the primary vehicle for growth in affordable housing supply. Since 2008 close to 10,000 new dwellings across Australia have been provided with NRAS subsidy, and an additional 30,000 NRAS incentives have already been reserved for future development. A provider receives approximately $10,000 per year, for a period of ten years, in cash or tax-credits, for each NRAS approved and occupied newly-built dwelling (Australian Government, 2012).

The discounted rent in affordable housing schemes increases the range of opportunities for people with intellectual disability to access high quality, well-located rental housing for independent or supported living (particularly in the cases where disability service providers have nomination rights, as discussed above). However, only a relatively small proportion of new affordable housing units will be offered at rents which are affordable for people with intellectual disability whose main source of income is the Disability Support Pension.

Some affordable housing units are leased for a fixed discounted market rent (e.g. 74 percent of market rent), regardless of the residents’ income. In high value locations, households whose primary source of income is the disability pension may not be able to afford such rent despite the discount and the CRA subsidy. Other affordable housing projects accommodate a mix of households with low and moderate income, with variable rates (e.g. moderate-income households pay 74 percent of market-rate, whereas low-income households, in the same project, pay 30 percent of their income). In such projects, a certain proportion of the units will be affordable for people with an intellectual disability whose primary source of income is the disability pension.

Some community housing providers emphasise provision of housing for people with disabilities
as one of their primary missions. In Victoria, Housing Choices Australia has committed to allocate 25 percent of all of its housing to people with a disability. In 2011, the organisation reported that it has surpassed this target and delivered more than 35 percent of its housing to people with a disability (HCA, 2011, p. 5).

The Australian Government has not yet committed to the expansion of NRAS beyond 2012, and strong advocacy is required to ensure that the scheme receives cross-party political support, and to encourage community housing providers to set appropriate targets for inclusion of people with an intellectual disability in affordable housing.

**Home modification grants**

Existing private rental and social housing stock in Australia is by and large unsuitable for people with mobility restrictions and sensory disabilities, and does not meet minimal accessibility standards. For people with intellectual disability who also have a physical disability, access to private rental or social housing may therefore require modifications to the structure, layout or fittings of a home. The NDIS will provide home modifications grants for people living in all types of tenures (social housing, private rental and owner occupation). A continuing problem is that in private rental, landlords often refuse to allow such adjustments – even if funded by others – and are not legally required to do so (Disability Council of NSW 2005, p.15; Tenants Union of Victoria 2008, p.24).

**Homelessness outreach services**

The PC (2011, p. 233) recognises homelessness among people with mild intellectual disability and mental illness as a key issue, and calls for a strategy which involves both specialist and mainstream support. The PC notes the important role of existing mainstream outreach services, which connect homeless people to appropriate housing and support services. At the same time, the PC recognises that the NDIS should also fund specialist homeless outreach services for people with a disability, in collaboration with mainstream services in the not-for-profit sector and government.

In the current national policy context, people with intellectual disability who are recognised as homeless, or at risk of homelessness, may receive priority access into social housing. The Australian Government’s 2008 Homelessness White Paper (FaHCSIA, 2008) assigns a greater role for social housing in securing stable long-term accommodation for people who are homeless or at risk of homelessness, as one of the key strategies to halve homelessness by 2020.

**More flexible funding options for specialist accommodation**

For a ‘smaller group’ (PC, 2011, p. 229) of people with a disability, the PC considers specialist accommodation (or ‘supported accommodation’) the most appropriate response to address both housing and support needs. The report acknowledges that supported accommodation is currently in short supply. It is hoped that the NDIS will offer greater flow of funding into the system, and will therefore help address the existing shortfall in supported accommodation for people with intellectual disability.

On top of supply shortfalls, the PC notes structural problems in the existing system of shared supported accommodation, particularly the ‘inability of the current systems to take account of individual preferences’ (PC, 2011, p. 230) which results in highly constrained choices for people with a disability in need. For example, in the traditional model of shared supported accommodation, the provision of supports is tied to a particular residence, restricting the choices people with a disability have. To address this problem, the PC recommends ‘unbundling’ housing and support to allow people to choose to live in a dwelling owned by one provider and to receive support from another, making possible a wider range of living arrangements. For example, people could pool their funds with others to form a group home. The PC also recommends that individuals assessed as needing supported accommodation should have the option to ‘cash out’ their share of the rent (priced at the market rate, not the subsidised rate), for an equivalent subsidy for private rental. In a later stage of implementation, the PC expects that these funds would also be available for home purchase.

So far, in Victoria, individualised support packages were provided in small amounts allowing some individuals with low support needs to move out of their family home or shared supported accommodation. Typically, their place in shared supported accommodation was taken by a person with higher support needs, often without adequate changes to staffing and resourcing (Bigby & Fyffe, 2007). At the same time, people with higher support needs were typically unable to move out of shared supported accommodation or their family home, because individualised support packages have been too small.
Several disability service providers in Victoria have initiated the development of innovative projects to accommodate people with intellectual disability with low support needs and individual support packages. This has allowed such organisations to deliver individual support packages more efficiently, and to provide their clients affordable accommodation which was not available in the private rental market. One problematic aspect of such developments has been the clustering together of units for people with intellectual disability, arguably in contrast to the philosophy of community inclusion. Another problem has been the exclusion of people with higher support needs who did not have their own individualised support packages.

In contrast, if the PCs recommendations are fully implemented, under the NDIS it is possible that individuals with higher support needs would be able to ‘cash out’ their funding for supported housing as a means to purchase mainstream housing (private rental or affordable housing) and support. It is also possible that disability service providers will be able to experiment with new models of supported accommodation for people with higher support needs, funded as innovative specialist accommodation. NRAS will be another potential source of mainstream subsidy for such developments. NRAS may not be available for isolated initiatives by individual providers, yet a partnership comprising a number of disability service providers together with mainstream community housing providers could potentially put together an NRAS bid to fund a bundle of geographically dispersed projects, including both housing for people with intellectual disability and mainstream affordable housing.

An indication of the type of innovative housing models which may emerge under the NDIS has been provided by the Commonwealth Government’s Supported Accommodation Innovations Fund (SAIF), which committed capital funding for up to 150 new supported accommodation or respite units across Australia. SAIF funds are explicitly targeted at projects for adults with severe or profound disability including, but not exclusive to, intellectual disability. Several of these projects have been developed through partnership between disability service providers and mainstream community housing providers such as Housing Choices Australia, Yarra Community Housing and Haven. One of the most notable approved projects is the Cairo development in Southbank, a tower of 220 apartments, of which 10 are supported accommodation units. This development offers people with profound disabilities the opportunity to live in a highly desirable central location.

The funding rules for SAIF do not specify restrictions on clustering of units, apart from a general comment that the scheme will not fund projects “deemed to be institutional” (FaHCSIA, 2011, p. 6). An overview of eight approved projects in Victoria (table 3 – on page 52) shows that six of these include the clustering together of 5-10 units for people with a disability. This highlights the need for clearer guidelines in policy and in funding rules about the uppermost limit for number of housing units for people with intellectual disability which are allowed to be clustered together.

The shift away from block-funding to largely consumer-driven funding will require significant restructuring to the business and operation models of support providers. A key challenge will be to develop structures which provide some level of residential stability in housing models based on the pooling together of individual funds. For example, the NDIA would need to consider how to address situations where one resident chooses to move on and pull out their share of the pooled funds. Another key challenge acknowledged by the PC (2011, p. 376-7) is the provision of supported accommodation facilities in remote communities, particularly smaller ones, where block funding will be crucial to ensure the viability of purpose built and staffed residential and respite facilities.

Conclusions

The PC’s proposal for the NDIS, if fully adopted, would hopefully see a substantial increase in funding available for disability services, and consequently a significant step forward in addressing the shortfall in supported accommodation for people with intellectual disability who are assessed as being in need for specialist housing. The PC’s recommendation to offer more flexible, consumer-driven forms of funding to promote innovations in the provision of shared supported accommodation may also potentially open up opportunities for individuals to achieve a greater level of self-determination and potentially improved outcomes in getting the housing and support that best fits their own preferences and needs. This approach can be seen as advancing recent initiatives in Victoria to individualise provision of support. However, unlike current programs which offer relatively small individualised support packages to people...
with low support needs, under the NDIS – as envisioned by the PC – such opportunities may also be available to people with higher levels of support need. This is a welcome advancement, but will require significant restructuring to existing services. Furthermore, there is a risk that many ‘innovative models’ will be based on the clustering together of a large number of housing units for people with intellectual disability. While encouraging innovation, the NDIS must also include clearer guidelines about what constitutes unacceptable concentration of housing units for people with intellectual disability.

At the same time, the PC emphasises the central role of mainstream housing in providing accommodation for most people with disabilities who do not require specialist accommodation. This includes private rental, social housing and affordable housing – although the latter is not explicitly mentioned in the report. The NDIS will not provide direct funding for mainstream housing, but will assist individuals to access it by providing referrals. However, because of severe shortfalls in supply of mainstream housing which is affordable to low-income people, mainstream housing opportunities for people with intellectual

Table 3: SAIF funded projects in Victoria

<table>
<thead>
<tr>
<th>Provider</th>
<th>Project title</th>
<th>Location</th>
<th>SAIF funding</th>
<th>State operating funds over four years</th>
<th>Housing</th>
<th>Target group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life Without Barriers</td>
<td>Active Whittlesea, New Beginnings</td>
<td>Whittlesea</td>
<td>$1,041,060</td>
<td>$3,176,000</td>
<td>6 one-bedroom townhouses</td>
<td>5 people with intellectual disability, autism and challenging behaviours</td>
</tr>
<tr>
<td>Marillac Ltd</td>
<td>Heidelberg Key Ring</td>
<td>Heidelberg/Watsonia</td>
<td>$1,612,220</td>
<td>$400,000</td>
<td>7 apartments</td>
<td>5 singles or couples with a disability</td>
</tr>
<tr>
<td>EACH Housing Limited</td>
<td>Independent Living</td>
<td>Venus Bay</td>
<td>$710,690</td>
<td></td>
<td>2 co-located apartments</td>
<td>2 individuals with a disability</td>
</tr>
<tr>
<td>SCOPE</td>
<td>Cairo</td>
<td>Southbank</td>
<td>$4,100,000</td>
<td>$2,880,000</td>
<td>10 one bedroom apartments for people with disability within a tower of 220 apartments</td>
<td>10 people with a disability</td>
</tr>
<tr>
<td>Gateways Support Services</td>
<td>Gateways and HCA Innovative Housing Model, Greater Geelong</td>
<td>Geelong</td>
<td>$2,064,971</td>
<td>$2,460,000</td>
<td>7 units</td>
<td>7 people with severe or profound disability and high or complex needs</td>
</tr>
<tr>
<td>Noweyung Ltd</td>
<td>Supporting Pathways for Disability Accommodation in Bairnsdale</td>
<td>Bairnsdale</td>
<td>$1,556,740</td>
<td>$1,120,000</td>
<td>Shared and independent living arrangement</td>
<td>7 individuals with severe or profound disability</td>
</tr>
<tr>
<td>Yooralla</td>
<td>Lardner Road Mixed Purpose Unit Development</td>
<td>Frankston</td>
<td>$1,939,000</td>
<td>$1,880,000</td>
<td>A mix of 2 and 3 bedroom units (in a complex with student accommodation)</td>
<td>6 people with profound disability</td>
</tr>
<tr>
<td>MIND Australia</td>
<td>Dual Disability, Housing and Support</td>
<td>Wyndham/Brimbank</td>
<td>$1,930,631</td>
<td>$2,452,000</td>
<td>No information available</td>
<td>5 people with disability and mental illness</td>
</tr>
</tbody>
</table>

Source: Victorian Government, 2012
disability will remain extremely limited and referrals will be far from sufficient to ensure placements. This may undermine, for example, the PC’s aspiration that young adults with an intellectual disability should be able to move out of their family home to independent living in line with community norms. People with intellectual disability, their families, support providers and advocates will need to continue and struggle to increase the supply of affordable mainstream housing, and to ensure a sufficient proportion of placement are allocated to people with intellectual disability.

References


Dr Ilan Weisel is a Research Associate in the City Futures Research Centre at the University of New South Wales. i.vizel@unsw.edu.au
The Concept of Reasonable Adjustment in Commonwealth Disability Discrimination Law and its Implications for Equality for Persons with Intellectual Impairment

Phillip French

Introduction

The purpose of this paper is to explore, generally, the effectiveness of the DDA since its enactment in protecting persons with intellectual disability from discrimination on the basis of their disability and in promoting and facilitating the participation of persons with intellectual disability in public life. More specifically, the paper will interrogate the concept of 'reasonable adjustment' in Commonwealth disability discrimination legislation and its implications for the attainment of equality for persons with intellectual impairment.

It will be argued that while it is not the only limiting factor, the concept of reasonable adjustment as it has existed, and indeed as it continues to exist in disability discrimination law in Australia, is a feature of a formal equality paradigm that is incapable of securing genuine equality for persons with intellectual disability. In this respect, although the Commonwealth's proposed new equality law attempts to articulate a substantial equality paradigm, it carries forward vestiges of the existing formal equality paradigm that are likely to continue to make realisation of equality rights difficult for persons with disability generally, and very difficult indeed for persons with intellectual disability in particular.

Equality rights and persons with intellectual impairment

There can be little argument that the DDA has largely failed to impact on the life circumstances of persons with intellectual disability in Australia, perhaps with the limited exception of the area of education. Certainly, the prospects of employment of persons with intellectual disability in the mainstream workforce have not improved since 1992, and in fact, have deteriorated. Improvements in access to premises, and the 'protection' available against discrimination in the area of accommodation, have not in any identifiable way improved the quality of accommodation available to persons with intellectual disability or protected them from segregation and institutionalisation.

Nor has the DDA had any identifiable impact in addressing other major rights issues for persons with intellectual disability; for example, the high rate of incarceration of persons with intellectual disability in the criminal justice system; non-therapeutic sterilisation of girls and women with intellectual disability; a migration law which prevents persons with disability from obtaining Australian citizenship. Nor has it in any way assisting in addressing the crisis in unmet demand for specialist disability services, which has and continues to impact on persons with intellectual disability to an even greater extent than it does for other persons with disability.

Even in the area of education, the impact of the DDA has been mixed to say the least. While access to mainstream school education for children with intellectual disability may have improved in some respects, no one could doubt that there remain very significant problems and challenges. Many children with disability, particularly those with behaviours of concern, are likely to be excluded from education for substantial periods of time. Bullying of children with disability within the school system is a gravely serious problem.

Leaving those issues aside, many children with disability, in particular those with intellectual disability, are not provided with the curriculum adaptations and individualised tutorial support they require to reach their academic and social potential.

In fact, it is difficult to identify any leading case, indeed any case, where the DDA has resulted in substantial positive change for an individual with intellectual disability, still less for persons with intellectual disability as a class. There simply aren't any.

On the other hand, there have been a number of DDA cases now that have very significantly limited the equality rights of persons with intellectual disability in Australia. No doubt some commentators would say these cases have simply clarified the law rather than limited what the law previously provided. Perhaps that is correct in jurisprudential analysis. However, from a social perspective these cases have slammed shut doors to equal participation that persons with intellectual disability and their associates genuinely believed the DDA originally intended to open.
Consequently, we are obliged to confront the uncomfortable reality that the DDA has not only failed to advance the equality rights of persons with intellectual disability to any significant extent. It has also been used as a vehicle to strip persons with intellectual disability of equality rights.

The formal equality paradigm of the DDA

In international law the right to equality and non-discrimination is a civil and political right that is immediately realisable. Its modern ‘statutory’ origin (or recognition) is in Article 2 of the Universal Declaration of Human Rights. In the post-war era this obligation was first made legally binding on State Parties of the International Covenant on Civil and Political Rights in in Article 2(1) of that Covenant. In international law equality rights under the ICCPR may be limited in specific circumstances for objectively defensible reasons.

It was against this international law backdrop that the DDA was enacted. The DDA purports to give effect, at least in part, to Australia's international obligation to prevent discrimination on the ground of disability. “Disability” as a protected characteristic is broadly defined in the DDA, at the impairment level, to include: ‘a total or partial loss of mental functions’ or ‘a malfunction of a part of the person's body,’ or ‘a disorder or malfunction that results in the person learning differently from a person without the disorder of malfunction’ or a ‘disorder, illness or disease that affects a person’s thought processes, perception of reality, emotions or judgement or that results in disturbed behaviour.’ “Disability” that is otherwise covered by this definition includes behaviour that is a symptom or manifestation of the disability. Persons with any type of cognitive impairment, including persons with cognitive impairment, are consequently protected from discrimination on the basis of their disability where the DDA otherwise applies.

However, inconsistently with Australia’s international obligations the DDA only prohibit discrimination on the basis of disability in specified areas of public life, not with respect to all areas of public life. These areas of life include: access to premises; education; employment and some related areas; goods, services and facilities; accommodation; clubs and associations; and, the administration of Commonwealth laws and programs.

The DDA makes both “direct” and “indirect” discrimination unlawful.

Direct discrimination occurs when the discriminator treats the aggrieved person less favourably on the basis of his or her disability than the discriminator would treat another person in circumstances that are not materially different. The legal test for direct discrimination thus involves a comparison between the circumstances of the person with disability and another person who does not have that persons with disability (the comparator test).

Indirect discrimination occurs when the discriminator imposes a requirement or condition on the aggrieved person that the aggrieved person is unable to comply with because of the aggrieved person's disability, in circumstances where that requirement or condition disadvantages persons with the aggrieved person's disability, and where that requirement or condition is not reasonable.

Conduct is not unlawful discrimination if it falls within an exception or there is a defence available. In political/legal theory these are (or are based on) the objectively defensible reasons why differential conduct on the basis of disability is permissible. For example, migration and social security laws and their administration are excepted from the DDA. ‘Special measures’ (that is, those that purportedly seek to benefit a class of persons) are also exempt from the prohibition on discrimination. Conduct will also not be unlawful is avoiding the discrimination would constitute an unjustifiable hardship for the discriminator.

Although the text of the ICCPR itself is silent on the question, the interpretation and application of that text by the Human Rights Committee has made it clear that the standard of equality mandated in the ICCPR is substantial rather than merely formal equality. Consequently, positive action is expected of State Parties to advance the interests of disadvantaged groups.

In spite of this, the DDA was originally drafted within a formal equality paradigm which sought to achieve equality between disabled and non-disabled persons by treating them the same and ignoring disability as an irrelevant characteristic.

Within this paradigm the objective was, and remains, to ‘eliminate, as far as possible, discrimination against persons on the ground of disability’ and ‘to ensure, as far as practicable, that persons with disability have the same rights to equality before the law as the rest of the community.’ (emphasis added)
The heuristics through which the formal equality analysis is transacted are the comparator test in direct discrimination, the reasonableness test in indirect discrimination and the unjustifiable hardship test. Interpreted and applied, as they are, in light of the objects of the DDA, these tests have permitted the Courts to run wagon-trains over the equality rights of persons with disability generally, and persons with intellectual disability specifically.

The formal equality paradigm is not neutral or benign – it privileges the status quo as paradigmatically normative and thereby entrenches, and may even exacerbate, the pre-existing disadvantage of the putatively protected class.

In this respect, with very few exceptions, the Australian Courts have repeatedly refused to interpret and apply the DDA in a manner that would advance the status of a person with disability (whether as an individual or as a class) relative to a non-disabled person (or class of persons). Adopting a social model analysis, they have refused to interfere with the social relations of disability.

**Purvis v State of New South Wales – a case study**

The nadir of this approach was reached in 2003 in the High Court of Australia’s decision in *Purvis v State of New South Wales*. This was a school education case. Daniel Hogan lived with intellectual disability that was the result of a brain injury acquired in infancy. He sometimes became frustrated and angry at school and in these situations caused harm to others (biting, kicking, hitting and pushing other students and teachers). The school failed to put in place a positive behaviour support plan. Daniel was ultimately expelled for his behaviour.

Daniel’s father, Alex Purvis, complained that Daniel had been discriminated against on the basis of his disability because the school had failed to make adjustments (including the provision of positive behaviour support) that Daniel required due to his disability. For technical reasons, the case was run as a direct discrimination case and Daniel’s comparator was thus a central issue. Alex succeeded at first instance before a hearing Commissioner of the Australian Human Rights Commission. However, the decision was appealed and Alex lost the appeal before the Federal Court, and then on his appeals lost before the Full Federal Court and the High Court.

In its decision the High Court said that at least with respect to direct discrimination the DDA did not, according to its terms, require reasonable adjustments to be made to accommodate a person’s disability – it required persons with disability to be treated equally with others. In this case, the Court found that Daniel was treated no differently to any other child – who did not have Daniel’s disability – who engaged in behaviours of concern. Any other child who engaged in the behaviour Daniel did would also have been expelled. In this respect, the real reason or true basis for the conduct of the school was not Daniel’s disability, it was his behaviour.

**Limitations of the formal equality paradigm for persons with intellectual disability**

The limitations of the formal equality paradigm in achieving equality for any person with disability will be obvious. Perhaps more than any other protected characteristic, persons with disability only have the potential to attain equality with others if their disability is recognised – rather than disregarded – and positive action is taken to accommodate any needs that arise from that disability.

However, the equal treatment paradigm is especially disastrous for those persons with disability – including persons with intellectual disability – who least resemble – in the sense of being most disbursed or distant from – the normative fulcrum on which this paradigm rests. This theoretically normative person is plainly not a disabled person, and he or she does not exist in a world in which diversity is, a priori, normative.

The attainment of equality for the disabled person requires them to be capable of assimilation to the theoretical norm without challenging the underlying structure of the putative norm. Any claim beyond this means, alternatively or additionally, that the person’s circumstances are materially different (in direct discrimination), their claim is not reasonable (in indirect discrimination), and an unjustifiable hardship on the duty bearer from which by operation of law they must be relieved. Consequently, they must remain an outsider to the norm.

To argue the point somewhat differently, persons with intellectual disability are in many respects excluded from public life, a priori. For example, they may be excluded from mainstream employment and obliged to accept supported employment. There can be no sensible comparison...
made between conditions of employment in mainstream employment and those that apply in supported employment because the circumstances of the employment are materially different. Consequently, from the point of view of law, one cannot say the conditions of employment in supported employment are less favourable than those in mainstream employment – you cannot compare an apple with an orange.

Similarly, with respect to accommodation, persons with intellectual disability may be excluded from mainstream accommodation because they require support in order to live in and be a part of the community. As a consequence they may be obliged or compelled to live in a variety of non-normative contexts, such as group homes, specialist boarding houses and residential institutions. Disability discrimination law does not permit a comparison to be made between the living conditions of persons who do not have intellectual disability (or indeed those who do) who live in mainstream accommodation options and those who live in segregated options. Consequently, the disability discrimination act has nothing to say about the substandard conditions in which many persons with intellectual disability are compelled or obliged to live.

In fact, with respect to direct discrimination the circumstances of persons with intellectual disability will rarely not be materially different from persons who do not have intellectual disability. They will typically be subjected to environments and conduct which other persons do not have to endure. They are a priori, outsiders, to disbursed or distant from the normative fulcrum on which discrimination law turns.

**August 2009 amendments to the DDA and the proposed new Commonwealth human rights and anti-discrimination law**

In partial response to the High Court’s decision in *Purvis* the Australian Government amended the DDA, effective from 5 August 2009, to provide that there is an obligation on duty bearers to make reasonable adjustments to accommodate a person’s disability. The failure to provide such adjustments may amount to discrimination on the basis of disability. These amendments take a step towards a substantial equality. There is not yet any significant case-law that considers the impact of these amendments.

These amendments have been carried forward into the Australian Government’s Bill for a new Commonwealth equality law. The Bill would also make some other significant changes relevant to this discussion. The objects of the Bill plainly seek to better position Australia’s anti-discrimination laws as substantial equality laws. For example, one object of the Bill is to ‘promote recognition and respect within the community for the principle of equality (both formal and substantive equality.)’ Another object of the Bill is to recognise that achieving substantive equality may require the taking of special measures or the making of reasonable adjustments. Perhaps most significantly of all, the first object of the Bill is to eliminate discrimination … consistently with Australia’s [international human rights obligations].’

In this respect, the weasel words of the DDA ‘as far as possible’ and ‘as far as practicable’ would be abandoned. The test for discrimination, including what constitutes an unjustifiable hardship, would need to be reconsidered in light of these newly positioned objects.

The tests for direct and indirect discrimination have also been changed in the draft Bill. With respect to direct discrimination conduct will now be unlawful, relevantly, if the discriminator treats a person with disability unfavourably because of the disability. This new formulation of the test appears to be designed to eliminate the comparator test and to focus on the consequences, or potential consequences of the conduct for the individual. With respect to indirect discrimination, the reasonableness test has been removed from the definition.

With respect to both direct and indirect discrimination, under the Bill, differential conduct would not be unlawful if it were justifiable. Conduct will be justifiable if the conduct in question was engaged in in good faith, for the purpose of achieving a particular aim, and that aim is legitimate, if a reasonable person would have considered that engaging in that conduct would achieve that aim, and the conduct is a proportionate means of achieving that aim.

With respect to discrimination on the ground of disability, the Bill provides that conduct will not be justifiable if a reasonable adjustment could have been made. A person is viewed as being capable of making a reasonable adjustment if the person could have made the adjustment without an unjustifiable hardship being caused to the person. The unjustifiable hardship test would remain as it is under the DDA now. It requires all relevant matters to be taken into account including the nature of any benefit or detriment likely to accrue to, or to be suffered by, any person concerned; the
effect of any disability of any person concerned; the financial circumstances of the first person, and the estimated amount of expenditure that the first person would have to incur in order to make the adjustment; the availability of financial and other assistance to the first person.

It should also be noted that the draft Bill is articulated so as to, in part, implement Australia’s international human rights obligations, including those that are incorporated into the Convention on the Rights of Persons with Disabilities. There is no doubt that these proposed reforms, if enacted, will have some positive impact in terms of improving the effectiveness of Commonwealth anti-discrimination legislation in eliminating discrimination on the ground of disability. The question for this symposium must remain, however, if these reforms will ensure that disability discrimination law penetrates to the lived experience of persons with intellectual disability. In this respect it is difficult to be optimistic.

Although the test for direct discrimination would change under the proposed Bill to focus the inquiry on whether the impugned conduct has resulted in the aggrieved person being treated unfavourably, simpliciter (as opposed to less favourably than another person without that person’s disability in circumstances that are not materially different), it is difficult not to see a latent comparator test, and the formal equality paradigm, still present in the reformulation.

How does one determine if a person has been treated unfavourably unless one compares the alleged unfavourable treatment with normative or expected conduct? Would Purvis have had a different outcome if the test was one of unfavourable conduct as opposed to less favourable conduct. It is not immediately clear that this would have been the case. What Daniel required of the school was positive action to accommodate his disability, including structured assistance to eliminate anti-social and develop pro-social behaviour. In this sense, he required more favourable treatment rather than equal treatment. Can it be said he was treated unfavourably because he was not treated more favourably?

Of course this is where the concept of reasonable adjustment comes in. It is certainly arguable that the obligation to make reasonable adjustments to accommodate disability, especially when viewed through the lens of a substantial equality standard, is bolstered under the proposed Bill. However, as a matter of law reasonable adjustments are not special measures. Special measures – or positive measures – are specific initiatives designed to advance equality rights for a protected class. They represent differential treatment of a favourable kind that as a matter of law do not constitute prohibited (or unlawful) discrimination.

The current DDA and the proposed new Commonwealth equality law contemplate special measures as distinct from reasonable adjustments. Neither the current DDA nor the proposed new equality law would require a duty bearer to institute a special measure to achieve equality for persons with disability whether as individuals or as a class. The critical issue is therefore where a reasonable adjustment ends and a special measure begins? The most obvious answer is of course at the point of unjustifiable hardship, but that answer is not complete. Part of the answer must also lie in the real character of the benefit sought. Will an Australian Court be prepared to say, whether under the current DDA or the proposed new equality law, that the support Daniel required was merely an adjustment to the education program and related services provided by his school required to ensure that he is not treated less favourably, or unfavourably, respectively. Or would they view the support he required as special measure that cannot be required of the school under anti-discrimination, however desirable such support may be? Unfortunately, I view that question as open to the Court.

**Conclusion**

Commonwealth disability discrimination law has essentially failed to penetrate to the equality rights of persons with intellectual disability. It has failed to benefit persons with intellectual disability, and in key respects has made things worse. This law has been subject to as yet untested reform, and more substantial reforms are now proposed. However, it is not clear that the DDA as it is now, or the new equality Bill, if enacted, will make a significant difference to the circumstances of persons with intellectual disability, although they may well improve the effectiveness of disability discrimination law more generally.

A principal reason for this is that Australian disability discrimination law was created within a formal equality paradigm from which it is yet to escape, even under the proposed new equality law. Formal equality disregards rather than recognises and embraces difference. It assumes that persons with protected characteristics can be assimilated in public life on an equal basis with
others provided their differences are ignored. That cannot work for people with intellectual disability. There are ontological realities that must be confronted and dealt with. Extending the same treatment to persons with intellectual disability as others will rarely result in that person obtaining the same benefit.

For disability discrimination law to have the prospect of benefiting persons with intellectual disability their disability must be recognised and accommodated. In many circumstances this will require significant efforts – or positive measures – aimed at achieving substantial equality.

The obligation to make reasonable adjustments is unlikely to have significant impact on achieving equality for persons with intellectual disability, though it certainly has better prospects of doing so for other disability groups.

If Daniel is to be assured of obtaining the support he needs to participate in education with equal benefit to others his educators must be reposed with an explicit obligation to provide him with the more favourable treatment he needs to succeed.

Dr Phillip French is Director of the Australian Centre for Disability Law.
Communication Access: A Journey Towards Inclusion for People with Intellectual Disability

Barbara Solarsh, Hilary Johnson & Denise West

Effective communication enables people to fully participate in the community. People with disabilities who use additional methods of communication other than speech during interactions have identified elements in the environment that facilitate effective communication when interacting with strangers (Collier, Blackstone & Taylor, 2012). These elements may equally apply to people with intellectual disabilities who have communication difficulties, when accessing mainstream services in their communities.

Inclusion and participation for people with disabilities in all aspects of life is a human right in many countries (United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). Inclusion can be facilitated through applying the fundamental principals of universal access to create a barrier-free society. The concept of universal access has evolved from a focus on the physical or built environment in the 1960’s to a much more comprehensive concept. Access is required within the identified life domains of education, employment, business and organisations (United Nations, 2006), as well as health care, local government and justice (World Health Organisation, 2011). Creating universal access includes the physical environment, signage and way finding, accessible transportation, access to written information, access to communications technologies and most recently, access to people or communication access.

Communication access has been defined as “having the means, supports and opportunities to communicate effectively, meaningfully accurately and authentically in order to get equal uncompromised access to goods and services” (Collier et al., 2012, p. 3). In order for people with communication difficulties and intellectual disability to access mainstream services, all types of access may need to be addressed, as responding selectively may mitigate against full inclusion and participation. The universal approach to access, pioneered by be accessible in New Zealand (www.beaccessible.org.nz) promotes multiple levels of community involvement through a range of strategies at an individual, community and systemic level. Nevertheless, their approach to facilitating communication access focuses on people with physical and sensory impairments rather than people with cognitive difficulties. Communication access is an integral part of community inclusion and relies, in Victoria, Australia on community capacity building approaches funded through the Department of Human Services as part of the therapy program. This funding source may be under threat in the event of a National Disability Insurance Scheme (NDIS). In this paper we will focus on the issues around communication access and the barriers and facilitators related to accessing mainstream services for people with intellectual disability.

One of the steps towards creating universal access is having disability and human rights legislation. Disability legislation in Australia (Disability Discrimination Act, 1992), Canada (Accessibility for Ontarians with Disabilities Act (AODA), 2005), the USA (Americans with Disability Act 1990), and the United Kingdom (Equality Act, 2010) has established the necessity of providing barrier-free environments thus reinforcing the importance of universal access. Universal access and universal design has focussed primarily on implementing standards that assist in reducing physical barriers in the built environment. An early example of universal design was the development of pavement cut outs, a strategy that not only assists people with physical disabilities but improves the everyday movements of people with trolleys or prams or pushers (Goldsmith, 1997). The principles of universal design have also been extended into communication technologies with features to assist adaptations for people with vision and physical impairment being built routinely in all devices (Clement & Shade, 1996).

Architects have taken a lead role in promoting universal access and supported the development of the first disability access symbol, adopted by the World Congress of Rehabilitation International in 1969. In Australia, the Australian Institute of Architects professional body has taken responsibility for driving policy and promoting government legislation around issues of accessibility. They state, “Architects should, in co-operation with the broader community, work toward the elimination of barriers to equitable access with the built environment” (Australian Institute of Architects, 2008). However, making
society more accessible requires changes not only in the physical environment but also in the social aspects of community engagement, areas that are infrequently specified in discrimination legislation (Johnson, West, Solarsh & Bloomberg, 2010). The CRPD state the necessity for providing people with the communication supports they need to participate in community life (United Nations, 2006) and the AODA refer to the need for accessible formats and communication supports that “may include, but are not limited to, captioning, alternative and augmentative communication supports, plain language, sign language and other supports that facilitate effective communications” (Accessibility for Ontarians with Disabilities Act, 2005).

The Ministry of Community and Social Services (MCSS) Ontario, Canada, is in the early stages of implementing a broad approach to promoting access to the private sector, government and non-government services by 2025. The MCSS define accessibility as “giving people of all abilities opportunities to participate in everyday life”. Unlike most other universal approaches to accessibility the MCSS include customer services as one of five components to full accessibility, a component that focuses on a person-centred approach to interactions in order to meet individualised needs.

An emphasis on the importance of social interaction is of relevance to the inclusion of people with intellectual disability as they are group of people who experience a range of communication difficulties and are often marginalised in their access to services. Although there is little published research about the experiences of people with intellectual disability in mainstream services in general, there is a growing body of literature that describes the difficulties people with intellectual disability face in accessing health services (Gilbert, Wilkinson & Crudgington, 2008; O’Regan & Drummond, 2008; Ward, Nichols & Freedman, 2010). Consequently staff training packages have been developed to improve access but with few positive outcomes reported. Although reasons for this are unclear, staff training delivered by professionals rather than training involving positive contact with people with a disability, may have a lesser impact (Gilbert & Ward, 2008). Ward et al (2010) studied the quality of health care received by people with an intellectual disability through analysing qualitative data from ten focus groups and interviews with 18 self advocates, 41 parents/guardians, 57 community support professionals and 26 health professionals regarding. Self-advocates reported a lack of direct communication from health providers and parents/guardians reported the absence of augmented communication supports for those with little or no speech. As these findings apply to communicative interactions from health providers, who are likely to have some understanding of the needs of people with communication difficulties through their undergraduate training, it is unlikely that interactions with community members will be more positive than in health settings. The findings from the health literature suggest that communication difficulties are likely to be a daily experience for people with intellectual disability when interacting in the general community.

Communication and people with intellectual disability

Access has largely focused on people with physical and sensory disabilities rather than those with intellectual and communication disabilities. Perhaps this is unsurprising as people with physical disability are the largest group of people with a disability in the population and many are effective self advocates. Almost 60% of people with intellectual disability have severe communication limitations (AIHW, 2008) and even people with less severe communication impairments will still face communication barriers related to interaction, relationships, self advocacy, choice and decision making. They are limited in their ability to achieve participation in four key mainstream areas identified by the Australian Government’s Social Inclusion framework, that include

1. learning through education and training,
2. participating in paid or voluntary work,
3. being included in leisure activities in their local community and engaged with others;
4. being able to speak up and influence decisions that affect them. (Australian Government, 2012) Improving communication access for each of these areas will improve inclusion and engagement that will be reflected in real relationships and genuine interactions but these will require additional external supports. While these supports may be in the form of direct support to the individual, much can be achieved by improving the communication environment in which friendships and interactions take place. With a significant number of people with an intellectual disability having communication difficulties, communication as an access issue in its own right must be addressed.
Communication access – a new concept and a new symbol

From 2008-2010, Scope’s Communication Resource Centre, led a project to identify a symbol for communication access through a state-wide consultative process that followed the Australian Standard AS 2342-1992. This standard provides a framework for the development, testing and implementation of information and safety symbols and symbolic signs. Over 1,700 people from 16 different stakeholder groups in Victoria responded to 10 possible symbols. People with communication disabilities (including people with intellectual disability) were able to make their selection using a set of custom made Talking Mats®, a strategy to support choice making for people who cannot speak (Murphy & Cameron 2008). The symbol selected became the new symbol for Communication Access.

Application for endorsement of the symbol was made to Rehabilitation International (RI) to give recognition to the symbol for communication access and what it represents, as separate from and additional to, the symbol for physical access introduced by RI 43 years ago, in 1969. Information about the symbol, process of development, application and standards behind the symbol were presented by a member of the Communication Access Advisory Group who has a communication disability, and one of the authors, at the 22nd Rehabilitation International World Congress (2012) in South Korea. Presentations were also made to the RI International Committee on Technology and Access (ICTA). The symbol has been recommended as an international symbol pending the final decision of the Rehabilitation International Board.

Identifying communication barriers

Once the symbol was selected in 2010, staff from the Communication Resource Centre (experienced speech pathologists and people with a communication disability) embarked on developing a communication access symbol awareness strategy. Thirteen forums took place across Victoria for over 700 relevant stakeholders including service providers and people with disabilities. Each forum varied in size and included a session on communication access delivered by a person using a voice output aid and concluding with group discussions sessions. A total of 50 small discussion groups were held as part of the forums and data collected in response to two main questions. The questions were (1) why do you think people with communication disabilities have negative experiences in the community? and (2) what do you think could be done to address this? Written data was collated from the groups and grouped into six themes (see Table 1). Fear of people with disabilities and lack of understanding about people with communication disabilities were the most highly ranked themes. Responses to the second question for strategies to address negative experiences were grouped into six categories with public education being ranked the highest (see Table 2).

Table 1: Themes identified as to why people who have communication difficulties have negative experiences

<table>
<thead>
<tr>
<th>Theme</th>
<th>% of groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of people with disabilities</td>
<td>70%</td>
</tr>
<tr>
<td>Lack of understanding about disability and people with communication disabilities</td>
<td>70%</td>
</tr>
<tr>
<td>Impatience when interacting with people with communication disability</td>
<td>65%</td>
</tr>
<tr>
<td>Lack of public education about disability</td>
<td>60%</td>
</tr>
<tr>
<td>Lack of personal experience in interacting with people with communication disability</td>
<td>53%</td>
</tr>
<tr>
<td>People are unable to understand the message</td>
<td>48%</td>
</tr>
</tbody>
</table>

Individual feedback forms were also collected from participants who attended the forums and when summarised contained seven key strategies for creating communication access. These included (a) listening to people, (b) educating the public, (c) recognising communication as a human right, (d) spreading the message of communication access, (e) taking individual responsibility for communication access; (f) making resources available and g) advocating for people to use their chosen method of communication.

The communication barriers identified during this process were similar to the two types identified by Collier, Blackstone and Taylor (2012) in respect of people with complex communication...
needs who had cerebral palsy or acquired and progressive disabilities. The first related to interpersonal interactions with communication partners and included issues such as, allowing insufficient time for people to get their message across, talking to the person's companion rather than the individual, talking about the person in their presence and judging their abilities based on their difficulties with speech. The other type referred to context specific barriers that are found in different settings such as education, healthcare, justice, employment, leisure and emergency services. Thus interpersonal barriers need to be addressed according to the specific context and unlike physical access; elements contributing to communication access may need to be modified according to their level of importance in the different contexts.

Table 2: Ideas to redress the negative experiences of people who have communication difficulties

<table>
<thead>
<tr>
<th>Theme</th>
<th>% of groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public education</td>
<td>98%</td>
</tr>
<tr>
<td>Having some communication resources such as picture based menus, would make a difference</td>
<td>50%</td>
</tr>
<tr>
<td>More publicity in the form of radio and TV adverts</td>
<td>50%</td>
</tr>
<tr>
<td>People with communication disabilities need support to advocate for themselves</td>
<td>48%</td>
</tr>
<tr>
<td>People with communication disabilities need to be more present in communities to break down barriers</td>
<td>48%</td>
</tr>
<tr>
<td>Communication partners needed more skills</td>
<td>48%</td>
</tr>
</tbody>
</table>

*Developing communication assessment checklists*

In order to ensure that people with communication disability played a central role in developing standards for communication access and contributing to the development of the Communication Access Checklist, four forums consisting of 6-8 people with communication disabilities were held. The information from these forums combined with that of the public forums was used to formalise a process for services and businesses to become communication accessible. In addition, a set of minimum standards for awarding the symbol was developed. The standards require that the communication partner, the service or organisation, take some responsibility for effective communication. By following communication access standards, a service states it is prepared to communicate effectively with anyone who wishes to use that service.

Five categories of potential barriers that broadly cover issues with communication access in all settings formed the basis for the Communication Access checklist. The checklist was piloted by people with communication disabilities and is currently being used to assess services, businesses and organisations who wish to be awarded with the communication access symbol. The five categories of questions include (1) ten questions about staff related to interpersonal communication; (2) three questions about the display and the clarity and ease of information provided about products and services; (3) five questions about the place or service and how the environmental supports could improve communication and contact with the place; (4) five questions about signage and (5) two questions about dealing with money and payment. In addition there are three questions related to staff training, the frequency of people with communication difficulties using the service and whether the person could successfully get their message across.

From these 30 questions, 12 are essential pre-requisites (minimum standards) for a service to be awarded the symbol. Five relate to interpersonal communication, one relates to display and information about products, two relate to the place or service, two relate to signage, one relates to money matters and one as to whether the communication assessor was able to get his or her message across. These criteria closely resemble the findings from the research by Collier et al. (2012) in which they asked people with complex communication needs what changes should be made for them to be able to communicate effectively in their communities. In Collier et al.'s research, aspects related to interpersonal communication were rated the highest in order of importance in ensuring communication is successful by people with disabilities. The other highly rated aspects referred to the place and having a quiet area, contacting the place by means other than the telephone, using information written in plain English, having a website that is easy to navigate and having a communication assistant to help take notes, hold written information in a place where the person can read it, or supporting the person to sign documents.
The communication assessment process

The process for undertaking communication access assessments has evolved over time and it is not identical for all services or places as contexts vary in their demands and needs. An integral part of the communication assessment is to ensure that a person with a communication disability, who has undergone training to become a communication access assessor, conducts the assessment. There are several factors that need to be understood prior to the assessment process including knowledge of the nature of the service/industry, understanding the key contact points for customers, the motivation for requesting an assessment and developing some sense of the current level of communication access in the place/service. An initial meeting/discussion with the customer is critical to determine how the assessment is to be conducted, ensure assessors have appropriate queries to make and to identify the number of points of assessment.

With large organisations and complex services there is also the option of a mystery customer visit prior to the actual assessment. Here one of the communication access assessors will interact with staff at the place/service and provide feedback to the service on their experience. This process clarifies the points of access that need to be assessed and how communication/interaction occurs. For example, staff at a leisure centre, were unsure of the number of service points that needed assessing. A mystery shopper ascertained four points where communication was necessary. These points were the main reception area, the café, the swimming pool area and the gymnasium. It is also necessary to understand the nature and volume of face to face enquiries, telephone enquiries and email/online enquiries. After interactions at the initial site visit of the previously mentioned leisure centre, both face to face interactions at the four areas identified as well as telephone enquiries were deemed critical points of interaction. To assess the service’s performance in relation to telephone enquiries, the communication access assessors were required to make telephone calls using the National Relay Service as well as telephoning in person using either their speech generating device or using speech.

While the Communication Access Checklist aims to assess baseline generic communication access and identify minimum standards of communication accessible places/services, extensive work needs to be undertaken to address situation specific communication barriers. For example complex and or life threatening situations require varied visual supports and additional time and person supports. In the healthcare setting, the issue of enabling people with intellectual disability to give consent about their health and wellbeing requires plain or Easy English documentation as well as positive interpersonal interaction. In the justice system, the issue of accepting third party evidence or evidence given through communication aids and/or assistance from others requires specific skills, careful documentation and planning. Addressing these communication access issues requires partnership, consultation and commitment to action by the sectors and authorising bodies. While some of the barriers apply to the availability of professional services, attitude to people with disability is evident as a barrier in all environments. This was clearly indicated in the most common reasons for people having negative communication experiences.

Reducing communication barriers

Becoming communication accessible may be a long term process. The assessment constitutes negotiations that involve people with communication disabilities that in itself sensitises staff to the needs of people with communication difficulties. Over the past few years a growing number of communication assessors have been trained with differences in age, disability and communication skills in order to cater for the varying needs of the industries requesting communication access. The position of communication assessor is one of paid employment and confers rights and responsibilities as with any other employee. All of the assessors (even though most are literate or semi literate) require considerable time support in preparation for the assessments, discussing the results of the assessment and preparing reports. However this also results in growing confidence and activism among the people with a disability and a commitment to work in partnership with other professionals and community services to move communication access forward.

The need for staff training is usually identified during the communication access process and this may take different forms depending on the service involved. The value of staff interacting with the communication assessor has been repeatedly expressed by services as a motivating factor to improve communication access for all community members. The notion of treating people with disabilities with dignity and respect...
and that of addressing them directly rather the person accompanying them, has historically always been a part of disability awareness training and recognised as good practice (Ward, Nichols & Freedman, 2010). However these good practice notions have become essential practices when interacting with people who have difficulties understanding speech or using speech effectively to get their message across. Thus communication access could be considered part of universal design in that having a range of communication practices not only assists people with a communication disability but others, such as people from cultural and linguistic diverse backgrounds and tourists with limited English, who could be identified as having communication difficulties. Reducing communication barriers for people with intellectual disabilities means considering the issue of universal design within our environments and including those practices that have a similar social impact to the physical impact of implementing pavement cut outs.

What are the models we can use to make mainstream services accessible and responsive?

At present, a comprehensive model of communication access is yet to be formulated. Designing a model or framework needs to take into consideration three interconnecting building blocks. These are (a) considering each specific domain and the individual sub-domains that require communication access; (b) an operational model for creating generic communication access at an individual service or grassroots level as well as at a comprehensive organisational approach; and (c) a comprehensive access or universal sector model of access of which communication access is one aspect.

1. **Domains and sub-domains.** Creating generic communication access within communities and creating access within professional services require different levels or types of access. Generic access within hospitality, retail and leisure environments is adequate for those settings and achievable with relatively little effort and expense. However, additional levels of communication access involving professionals are required in other settings such as the justice system (Australian Human Rights Commission (n.d.) and healthcare. For example in accessing a health care setting such as a general practitioner, access would be needed to the surgery, the consultation and to making a health decision. Creating an accessible environment in a surgery waiting room is one level of access. The receptionist creates a welcoming environment, treats the person with dignity and respect and supports the person to complete relevant forms. The way the doctor communicates with a person with intellectual disability during the consultation is another level. In addition to the doctor communicating directly with the individual, s/he may need extra time, resources to help the person understand their condition and the skills or extra resources to explain a procedure at the right level of complexity for the individual. If a serious decision needs to be made about a medical procedure with potential risks, the information must be understood in order for informed consent to take place, this is yet another level of access that needs resourcing and may require the support of a consultant speech pathologist.

The domain and sub-domain model could identify services where generic access is sufficient, as opposed to environments where a professional speech pathology or a skilled communication partner needs to engage in a detailed, ethical and authentic communication process with a person with communication difficulties. Communication access could be considered across five separate domains, (1) social and retail, (2) services, (3) professional, (4) critical life issues, (5) life decision making.

The outcomes for communication access for the first two domains, the social and retail domain consisting of cafes and restaurants, arts and culture, sport and leisure, and the services domain including transport, council services, and government services would be similar. The communication access symbol could be awarded at specific points of access. That is, there would be a creation of awareness about communication, individuals are treated with dignity and respect, successful communication is achieved in a welcoming environment, the person is listened to and people are responsive to the way the person communicates.

The expectations for communication outcomes in three other domains, the professional domain (community based allied health services, community based/outpatient medical and dental services, education, disability equipment/technology vendors, banking); the critical life issues domain involving the legal system, justice system, and complaints and the life decision making domain including the health sector, transitioning between sectors, accommodation and individualised life planning would need
additional support beyond generic communication access. Although the communication access symbol could be awarded at a specific point of access e.g. reception, additional speech pathology intervention or specifically trained communication assistant services may be needed if a decision making process is involved. Currently funding for these services is not available in Australia.

2. Operationalising Communication Access. The second building block of the model is one of operationalising communication access at a generic level at an individual service or comprehensive organisational level. The individual service level has been developed within the Communication Access Network (CAN) (Communication Access Network (n.d.). CAN is a hub and spoke model of service provision across 13 Regional Communication Services in Victoria that employs speech pathologists specialising in augmentative and alternative communication. The hub of CAN is Scope’s Communication Resource Centre (CRC) which has led the development of the communication access initiative. Communication access is part of the strategic goals for the whole CAN Network.

The CRC, in its leadership role, has developed training resources and processes for the employment and training of communication access assessors who deliver awareness raising sessions and carry out the communication access assessments. In the development phase of the communication access initiative, all communication access assessors have been based in Melbourne. In accordance with key values of CAN which aim at empowerment and leadership of people with communication disabilities across Victoria, this model is expanding to include all regional areas. For example, in the Southern Loddon Mallee area, the Regional Communication Service speech pathologist has trained a local team of Communication Access Assessors. If a request for a communication access assessment comes from Southern Loddon Mallee, it is the Regional Communication Service speech pathologist who will work with local communication access assessors to complete checklists and award the symbol. This becomes an unfolding hub and spoke model for creating communication access.

This model of creating communication accessible places is a bottom-up approach in which a high quality, labour intensive approach is adopted to creating communication access. In Victoria, Australia, the infrastructure provided by a government funded initiative such as CAN has made this possible. The CAN network is well placed to invest time and resources in refining procedures and standards for achieving communication access. However, an additional top-down model for the roll-out of communication access at an organisational or corporate level is needed. In this model the organisation adopts communication access as a service standard and takes responsibility for ensuring its staff and services apply these standards. Such a model makes the national and universal roll-out of communication possible.

3. Universal sector model. The third building block starts from the perspective of access to a particular life area or domain. It considers all aspects of access relevant to that sector forming a Disability Action Plan, including communication access. For example when considering transport, the physical access issue is obvious. But access also involves the ability to read timetables, accessing information on the internet, accessing platforms and vehicles, and communicating with staff. Both physical social and information barriers will need to be addressed.

What evidence is there that communication access works?

Communication access assessments were initiated in Victoria at the start of 2012. There are ten places that have been awarded with the Communication access symbol, and appear on the Scope directory of Communication Accessible Places (http://www.scopevic.org.au/index.php/site/whatweoffer/communicationresourcecentre/communicationaccess/businesses). One of these businesses is Café Escape. Informal reporting has indicated that this café is benefiting economically since becoming communication accessible and being awarded the symbol. Another business was enthusiastic about the increase in customers, many of whom were people with communication disabilities. There are an additional 8 services and organisations that are developing communication access in anticipation of being awarded the symbol early in 2013, and a further 50 places registered to start the communication access process.

What have we learned?

Follow up enquiries with places and services working towards communication access have indicated that they are investing in becoming communication accessible for a number of reasons. These include: 1) A response to complaints. A number of large organisations are addressing the
concept of communication access within a broad context aiming to improve communication to all customers, including those with a communication difficulty. This will meet the communication needs of the wider community, for example people who do not speak English. 2) Compliance. Organisations are realising they need to meet the objectives stated on their Disability Action Plans. 3) Risk-aversion strategy. Organisations are considering ways to avoid formal complaints/ and or claims of discrimination. 4) Good communication is Good Business! It makes good business sense to promote their business as communication accessible and improve their customer base. 5) Disability services being driven by consumer choice and individual packages in the future. Services that have been developed/funded specifically to provide services to people with disabilities are a significant group investing in being awarded the status of communication access. Some are making changes to become communication accessible driven from a strong human rights framework, while other service providers see the economic future of disability services to be driven by consumer choice and the purchase of individual packages. 6) Personal experience of a disability may drive the organisation to seek becoming communication accessible. The business has a personal connection with someone who has a communication disability either as an employee or a family member. 7) Organisation culture. One banking organisation, that has a clear community involvement culture, a commitment to building better communities and assisting community members who are disadvantaged, was one of the first organisations to contact the CRC to look at how they could be communication accessible.

Whose responsibility is communication access?

Community access is everyone’s responsibility. The Commonwealth Government state on their website that their vision of social inclusion includes the desire “to build relationships and address isolation by supporting people who may be unable to help themselves” (Australian Government n.d.). However, the interaction of resource limitations, opportunities and individual capabilities (AIHW, 2009) continue to impact on the social inclusion of adults with intellectual disabilities. There are clear indicators that improving communication access does not only benefit people with communication disabilities but also people with communication difficulties such as those who are not fluent English speakers. Although architects see themselves as the drivers for legislative changing regarding building standards, the gains made towards physical access would not have happened without the activism of people with a disability. The physical access symbol was adopted in 1969, countries have had discrimination legislation for over 20 years, yet much of the world is still not physically accessible.

Although speech pathologists consider themselves to be experts in communication and Speech Pathology Australia have endorsed the symbol, improving communication access is only just beginning. The people who are most affected by a communication disability are already disadvantaged by the lack of a voice and need supporters to advocate on their behalf. Access to social media is limited as it often relies on good physical access and high level literacy skills.

Communication access may be provided through improved social skills and attitudes as a result of interacting with people with a disability; providing communication aids, clear signage and information that is easy to read. All of these strategies are part of a broad movement to ensure people with communication disabilities have opportunities to engage in community activities, get their needs met and live a full life.

The NDIS, being introduced in Australia to improve access to funding for people with disabilities, has made no clear statement about funding community capacity building as part of their suite of services, and a clear economic argument needs to be made to ensure people with communication disabilities get the support they need.

Questions that remain to be addressed

1. How do we further facilitate the engagement of people with intellectual disabilities in leading and participating in the concept of communication access?

2. How do we develop an evidence base that evaluates the outcomes of communication accessible services both from a business perspective and customer perspective?

3. How do we present an economic argument for communication access? We need to be able to present this to the tourism and aged care industry as valuing adding to their industry. The accessible tourism industry is valued at $4.8 billion.

4. Most places/services want to be awarded the status of communication access however is our approach the best and is it sustainable?
References


Dr Barbara Solarsh is a Senior Speech Pathologist with Scope bsolarsh@bendigohealth.org.au

Dr Hilary Johnson is a Research Fellow with the Living with Disability Group at La Trobe University and a co-manager of the Communication Resource Centre, Scope H.Johnson@latrobe.edu.au

Denise West is the co-manager of the Communication Resource Centre, Scope dwest.crc@scopevic.org.au
MAKING MAINSTREAM SERVICES ACCESSIBLE AND RESPONSIVE TO PEOPLE WITH INTELLECTUAL DISABILITY: WHAT IS THE EQUIVALENT OF LIFTS AND LABRADORs?