OVERCOMING OBSTACLES TO SOCIAL INCLUSION

A submission by UnitingCare Community Options to the Inquiry into Social Inclusion and Victorians with a Disability.

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Introduction

UnitingCare Community Options provides a range of community-based services for older people, people with disabilities, those with a mental illness, their families and carers as well as other vulnerable and disadvantaged people living in Melbourne’s North, East and South. We are auspiced by the Uniting Church in Australia and belong to the wider UnitingCare Australia network, which consists of more than 400 organisations and provides over 25,000 residential and community care places.

As one of the leading agencies in the development and implementation of consumer directed care across aged care, disability and carers, we strongly believe in the importance of social inclusion in the life of an individual with a disability, and that social inclusion for Victorian with a disability can truly only be defined by individual Victorians with a disability. What social inclusion will look like and be acceptable to for one individual and their family will be unique to them and any discussion of social inclusion needs to start from a position of ‘what is an individual’s community and what is the individual’s expressed goals for them to feel a part of their community’. This needs to be our starting point, and we commend the Family and Community Development Committee for seeking this feedback from individuals with disabilities.

Whilst social inclusion is therefore a uniquely personal concept, there are some key foundations which help us move beyond mere participation and into inclusion:

- That inclusion is defined by the individual – *Don’t tell me I’m being included if this is not what I want to be included in or how I want it to happen.*

- Inclusion is often at its best when it involves inclusion within mainstream, generic services and community opportunities, not disability specific – *I want to play basketball, not wheelchair basketball.*

- Full inclusion requires a growth in the knowledge and understanding of the broader community – *I can only do so much to be included when people around me don’t know what I’m capable of or how I could readily be a part of these activities.*

- Social inclusion is best when designed as access for all, rather than access for people with disabilities – *It’s not just me who needs to feel included, but also older people, mothers, the unemployed, the homeless...*
While we have seen major progress over the past 20 years in improving accessibility and opportunities for people with disabilities to participate in the economic, social and civil dimensions of society, we are still battling against a perception that these are due to ‘accommodations’ for people with disabilities. The emerging issue over the next 20 years is to so entrench these ‘accommodations’ into all aspects of society that they become almost instinctive, and that as a consequence social inclusion becomes the norm, rather than a special effort only made by those who have the time, need, inclination or legal requirement to do so.

The following areas of discussion are not intended to be exhaustive, but have been identified through consultation with UCCO’s participants, our partnership workers (case managers), and our stakeholders as some of the key areas which contribute to social inclusion and exclusion, and which we believe need to be our priorities in addressing the social inclusion of Victorian with a disability.
Issues with transportation are often mentioned by our participants as a major barrier to being engaged in the broader community and the social inclusion that that brings.

Freedom of movement is a right under the Victorian Charter of Human Rights and Responsibilities, and is subsequently being limited by the lack of appropriate transport options for people with disabilities.

Social inclusion of people with disabilities and transport are related to two major factors:

1. Efficient, accessible transport is necessary to assist people with disabilities to be involved in mainstream activities, such as work, school, and recreation – as well as in regards to attendance and involvement in disability-focused activities and programs. This issue is therefore of considerable importance in considering the inclusion needs and expectations of people with disabilities, and society’s broader acceptance and understanding of people with disabilities’ involvement in all aspects of society.

2. Accessibility to transport itself assists in the facilitation of social network developments and connections amongst individuals – and thus social inclusion. By being able to access public transport, good levels of interaction between people promotes a sense of belonging and strengthens communities, which in turns builds capability and capacity in the community.

The diagram below depicts the mainstream thinking of how improved accessibility might lead to (for example) employment of a person with a disability, with the associated benefit of improved social inclusion. It also suggests an indirect path to social inclusion, by which improved accessibility leads to growth in social capital/community strengthening. In turn, the enhanced social networks thereby created may themselves assist the person to achieve employment and inclusion.¹

Accessible taxis in particular were highlighted by UCCO’s participants and partnership workers, with major difficulties encountered in securing a taxi booking during peak times. This meant that in many instances a participant would miss out on being able to attend their place of work, education or community program because of insufficient taxi operators. In addition, these have to be pre-planned significantly in advance, so any change of plans or spontaneous opportunities are unable to be accessed.

This situation is exacerbated in regional areas, with a lower volume of accessible taxis combined with poorer public transport systems with reduced accessibility. This issue has also been observed in relation to education, with some participants with high needs unable to access the school bus in some areas. Even when children with disabilities are able to access a bus, we have seen experiences where a child can be on a bus for up to 4 hours due to poor scheduling and policies in terms of pick-up and drop-off. This can create a school day of 10 hours and a travel time with in unacceptable, especially for a child with a disability. These experiences discourage participation in school, worsen behaviour at school (due to tiredness and irritability) and reduce the time available for other opportunities for social inclusion.

A 2004 study undertaken in Northern Sydney echoes the experience of our own participants, with use of taxis restrained by expense, unreliability, not being willing to cater for short trips, and drivers being unwilling to provide assistance. This is compounded by other public transport options being fraught with barriers and a lack of assistance, or simply not going where they wanted to go.²

Transport services are part of a system – not just of transport services but also of other processes and pieces of infrastructure. UCCO’s participants, interviewees and survey participants in the mentioned study indicate that there is not enough coordination between different elements of the ‘system’, and there can be multiple difficulties with a number of the elements of the system for

some people. Unfortunately, getting these elements to work together is not easy, as each link involves different participants, including State and local government, government instrumentalities, service providers, owners and managers of infrastructure and related services and other individuals and organisations that may assist (formally or informally) along the way.

A positive step forward in terms of integrating the diverse transport systems and ensuring social inclusion of people with disabilities has been the cross-modal demand responsive transport system, recently planned for Western Sydney.

Under this system there will be one booking and scheduling point for all demand responsive bus services, including Community Transport and flexible public bus services. Passengers who require demand responsive or flexible transport will register with the system, indicating any special needs or preferences they may have. They then book services through one central point, either through the internet, by keying codes into a touch pad telephone or by calling a booking centre. The computerised system will allocate them to an appropriate service that matches their needs and, in turn, when all of the bookings have been completed, will schedule each service, optimising the route in the most efficient manner. The services may include flexible bus services or a community transport service. This will be the first example in Australia of this type of cross-modal approach to booking and scheduling services and will represent a major step forward in using modal mix to actively fit the demand patterns and personal needs of passengers.
Red Tape and Risk

While the introduction of strong quality and risk management systems aim to reduce the incidence of harm and have ensured that more participants receive safe, accredited services, they have also introduced significant limitations in terms of the provision of programs and services aimed at enhancing the social inclusion of people with disabilities.

This has been particularly prevalent in programs and activities which have relied on the use of volunteers. The difficulties in ensuring that an organisation’s use of volunteers does not put their quality accreditation at risk means that in many instances volunteers are not being sought, or the barriers to using volunteers are simply too onerous for an organisation and the individual volunteer to overcome. UCCO has seen this in relation to Circles of Support (a group of people who meet together on a regular basis to help somebody accomplish their personal goals in life), where the program has experience difficulties to operate more effectively due to the effort of getting and maintaining volunteers, due to the existing regulatory and quality requirements.

We have also observed similar situations around risk and regulation in a different aspect in relation to Local Council. One such example is of a transport operator (either operated or subcontracted by the Council) not being permitted to pick up participants from their local bus stop, citing risk-related rules and regulations as the reason for this. This clearly limited the social inclusion opportunities for the participant involved, as they were then unable to engage in their existing social, occupational and recreational activities.

Our partnership workers indicated that the increasing professionalisation of the sector is having the unintended consequence of stifling small, volunteer organisations who may provide valuable social inclusion services or activities for people with disabilities. Professionalism within disability services is to be celebrated and encouraged, but over-professionalisation runs the risk of reducing overall opportunities for social inclusion.

To address the limitation of social inclusion due to issues of risk and safety, we need to take a graded approach to the management of risk and quality. The costs and benefits of taking a rigorous approach to volunteers and small, locally-based community services need to be examined to ascertain whether a more ‘hands-off’ approach, with minimal safeguards, would allow for greater building of community capacity, and provide more low-cost, locally based, creative opportunities for social inclusion for people with disabilities. This would also assist larger organisations who utilise volunteers in their attempts to recruit and maintain their volunteer-base, and enable them to provide opportunities for inclusion without unduly limiting or burdening their volunteer staff.
Society has come a long way in terms of their understanding and acceptance of people with disabilities. While there is still significant room for improvement, it is reasonable to state that for many people with disabilities, most communities have taken significant steps to ensure that they are accepted, included and provided with the same opportunities as all members of the community.

However, we are still aware of a particular imbalance in regards to how society sees and understands ‘disability’. While society is growing more familiar with disabilities, this tends to mainly relate to people with ‘classic’ disabilities – which usually fit into the physical category (eg. Physical disabilities, vision impairment, etc.)

When it comes to disabilities such as autism and intellectual disability, we detect a significant reduction in terms of the understanding and acceptance of these within society. People with these disabilities and their carers have cited significant experiences where they do not receive the same level of understanding extended to those who, for example, may be in a wheelchair or using obvious disability aids. Invisible disabilities such as these tend to polarise public opinion much more, with many regarding them as simply behavioural issues which should not be extended the same level of tolerance or inclusiveness as physical disabilities. We are observing this across all aspects of society, including employment, education, and broader social inclusion in recreational activities.

An approach to social inclusion of people with disabilities based on Universal Design is important in addressing both visible and invisible disabilities, as well as making significant strides towards a more comprehensive and in-depth approach to social inclusion. Based on the concept of universal access, designing education, employment, infrastructure and community building activities so that all levels and forms of disability can be accommodated for without the obvious need for modification or adjustment means that people with disabilities are not restricted from involvement, and furthermore, not seen as requiring special treatment to be involved in their communities. The current initiatives taking place in regards to education session in Mental Health are a positive example of how we can lift community awareness and knowledge around disability issues, and consequently improve the effectiveness of social inclusion opportunities.
Related to the issue of public understanding of people with disabilities – especially in relation to non-physical disabilities – is that of sufficient work being done within schools to ensure that people with disabilities are not only included, but that their social inclusion is seen to be a norm – both by staff and students. In many aspects, we require a focus on a return to basics around building understanding around diversity and disability for educators, parents and children, leading towards intergenerational and societal changes to improve overall social inclusion.

Autism again makes a significant appearance here – with the Autism coach for teaching staff program not being sufficiently prioritised. Not only does this mean that children with autism are not being sufficiently supported by their teachers – it also has flow on effects in that their unmanaged behaviour in class results in them becoming socially isolated amongst their peers, and not invited to be involved in the sorts of social activities with other kids take for granted (eg. Able to join in games, invited to parties, etc). This also has additional flow-on effects for the parents or carers of children this disabilities, as they are often blamed for not sufficiently managing their children’s behaviour.

Our staff also report the negative impact that the current school ratings programs are having on children with disabilities. With the need to protect a school’s public academic rating, children with disabilities have been encouraged not to attend school during NAPLAN testing. This may have been put to the child and family as out of a need to protect them from the distress of the test, but this in itself is a form of social exclusion regardless of the intentions for the decision. This either needs a revisiting of the testing and ranking regime currently in place, or more likely a more nuanced approach to the interpretation of results data, so that people with disabilities can be more readily accounted for within the results.

We have also received reports that even when children with disabilities are able to take part in NAPLAN testing the adjustments available are insufficient to fully accommodate for their disability, as compared to the VCE system (which was positively reported as having strong consideration and flexibility for people with disabilities.)

As mentioned previously, the approach of Universal Design for Learning (UDL) can make significant steps in overcoming the barriers to participation of people with disabilities, and send positive messages about the inclusion that we expect for all levels of ability in society. Using the principles of UDL can provide students with disabilities easier access to course materials, thus reducing the amount of time needed to make the material accessible.
Universal Design for Learning.

There are nine primary principles for implementing UDI: equitable use, flexibility in use, simple and intuitive, perceptible information, tolerance for error, low physical effort, size and space for approach and use, a community of learners, and instructional climate.

The first principle, ‘equitable use,’ refers to the need for the design of any instructional materials to be accessible to students with diverse needs. Post-secondary instructors should ask: Can the information be easily obtained, and utilized by the student? The second principle, ‘flexibility in use,’ should entail a straightforward instructional approach with a variety of methods that allow for different types of learners. “Simple and intuitive” instruction ensures that instructors design instruction in a straightforward way in which nothing is implied or ambiguous. “Perceptible information” requires the instructor to respect and respond to the different learning styles and abilities of their students by taking into account their diverse needs. Principle five allows for ‘tolerance for error,’ in which students are offered consistent feedback and the provision of additional opportunities for demonstrating growth. Principles six and seven, ‘low physical effort’ and ‘size and space for approach and use’ address such issues as: mobility, physical exertion, efficiency and communication limitations. The development and maintenance of a “community of learners” is described in principle eight. Within this principle, consideration needs to be given to the provision of opportunities for productive communication between students, as well as between instructors and students. The final principle, ‘instructional climate,’ refers to the building of an environment that respects diversity and is designed to be inclusive.3

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3 Csoli, Bennett & Gallagher, Ready or Not, Here They Come: Inclusion of Invisible Disabilities in Post-Secondary Education. Teaching and Learning (2009) 5(1), 53-62
Employment

Australia is among the bottom end of OECD countries in terms of generating employment for people with disabilities. The UN Convention on the Rights of Persons with Disabilities clearly outlines that people with disabilities have the same economic rights as those without impairments and should be able to live a life free from discrimination. Further, the National Disability Strategy prioritises the jobs and economic security for people with disability. However, in practice Australia is failing dismally to live up to these expectations.

Countries that have been able to generate meaningful jobs for people with disabilities generally have made use of incentives policies (subsidising employers to take on people with disabilities etc. and emphasising the responsibility of people with disabilities). There are numerous economic articles that demonstrate that providing such incentives does increase the social inclusion of people with disabilities and generate positive return on social investment.

Employment for people with disabilities often is seen as a double-edged sword. In one respect, there are great challenges posed for people with disabilities in obtaining sufficient support from Centrelink in regards to the Disability Support Pension. We have recently seen significant changes in regards to people with disabilities being sent back to Newstart and required to look for work, even when this is detrimental to their health and long-term outcomes. This often has the consequence of pushing people with disabilities further into poverty and alienating them from their communities, and detrimentally impacting upon their mental health – which then further compounds the impact of their disability and reduces their chances for meaningful social inclusion.

However, we also have the contrasting situation, where Centrelink staff when faced with a person with a disability who is seeking employment, will in many cases immediately refer them directly to a disability related enterprise (eg. Waverley Industries), rather than seeing them as a person seeking mainstream employment and provide them with the necessary resources, supports and opportunities to seek mainstream employment.

The employment system needs to work from a perspective where we prioritise employment through mainstream services in the first instance. This is what, in most cases, people with disabilities seeking employment are after, and is what most fully supports the notion of social inclusion. Only if and when these opportunities become too challenging should secondary disability-focused supports be brought into scope.
Health status is closely linked with an individual’s social inclusion. The most accommodative and proactive measures to engage people with disabilities in community activities achieve little if an individual’s health is such that they are unable to fully partake in or benefit from these opportunities.

According to publications tabled by the Australian Institute of Health and Welfare, around 600,000 Australians (around 3% of the population) have an intellectual disability and around 60% of people with intellectual disabilities have severe communication limitations (Australian Institute of Health and Welfare, 2008). Overall, people with an intellectual disability have poorer health outcomes, experience a higher prevalence of significant medical and mental health conditions (Australian Institute of Health and Welfare, 2010, Krahn and Drum, 2007), and as a consequence experience a lower level of social inclusion due to the constraints of their health.

While the gap in life expectancy, particularly for people with mild to moderate Intellectual Disabilities (ID), has narrowed considerably over the last decades, the burden of age-related chronic illness has increased dramatically in this population (Australian Institute of Health and Welfare, 2008, Perkins and Moran, 2010). Policy makers have targeted the gap in health outcomes experienced by people with intellectual disabilities. However people with IDs still face greater difficulties obtaining health services than the general population (Australian Institute of Health and Welfare, 2010, Perkins and Moran, 2010), and health conditions are often un- or mis-diagnosed and/or poorly managed (Australian Institute of Health and Welfare, 2008). Furthermore, the coverage of health promotion and preventive care programs targeting older adults with lifelong disabilities specifically has remained poor (Perkins and Moran, 2010).

The promotion of health and wellbeing of people with disabilities and their carers should be systematically explored and implemented both within a primary health as well as within a community care setting.
Holistic Service Provision

The social inclusion of people with disabilities can only be guaranteed by a complex, and carefully balanced interaction of multiple areas. As has been described throughout this report, sectors such as transport, employment, and education all play a part in assuring social inclusion, and the failure of a single aspect in any one of these can have flow on affect to all other areas. For example, the offer of an ideal, inclusive place of employment to a person with a disability is of no benefit if their education has not equipped them sufficiently for that job, or if there simply isn’t a means of transport to get there.

Similarly, the disability service sector itself is complicated and multi-faceted, which creates challenges towards the full social inclusion of our participants. Multiple entry points and fractured services create confusion and subsequent barriers to access. This is compounded by the gatekeeping practices of some agencies or sectors, with the need to repeat their story and complete numerous screening tools or eligibility criteria mean that many participants retreat from engaging in the service and consequently remove themselves further from society, even when those services are supposed to be designed for them.

The lack of some services to take a holistic approach, long-term approach which looks beyond their own service offerings also restricts social inclusion. Our workers cited experience with participants who were quickly directed towards disability specific activities and projects, instead of the agency working towards general inclusion in society. A classic example is of a child with a disability being immediately channelled towards a disability sports program, rather than working with mainstream sports clubs and providers to see what can be achieved for people with disabilities within their own programs.

This is also experienced longitudinally with programs which cease after a certain age (eg. Provision of supportive autism funding, which ends at the age of 7), which does not adequately support participants (especially in relation to key transition periods – eg. Between school stages) to build their capacity for current and future social inclusion. The issue of inadequate funding is also a major barrier to social inclusion – as when a care package is limited, funding will be directed in the first instance to personal care. As a consequence, finding funds to help people access the community often falls upon families to fund directly, fundraise for, or seek philanthropic support regarding.

The NDIS has the potential to provide a more holistic approach, but this needs to be clearly articulated in the NDIS design, with a focus on long-term, flexible planning, which prioritises social inclusion of people with disabilities and creates progressive plans towards building an individual capacity to engage in mainstream activities where possible. This needs to be reflected with activities undertaken by the NDIS itself or related agencies focused on building broader community capacity.
and overcoming the ongoing prejudicial or risk-averse preconceptions of educators, employers and other enablers across the community. With the move to a more individualised approach to funding and service provision, we need to ensure that advocacy and community capacity building are supported as critical factors in a participants long-term social inclusion.
In conclusion

The impacts of social inclusion on our participants are readily expressed to and observed by our partnership workers. As we see participants missing out on the opportunities which are readily accessed by the rest of the community we observe the increased disconnection from society, the diminished mental health, the increased pressure on existing family members and friends to care and provide social engagement (and become socially isolated themselves), and the development of isolated, excluded behaviours which become further entrenched along the life course.

But additionally, this level of exclusion also means that society and local communities miss out on the opportunities presented to them by people with disabilities. The strengths, contributions, perspectives and skills of people with disabilities are too invaluable not to seek in all aspects of society, from local clubs and events, to employment and civic engagement. It is therefore in the interests of all people, regardless of their level of disability, to strive to continually be more inclusive in our practices, policies and systems.

The most important aspect which has echoed through this paper to support this is in addressing social inclusion holistically. Inclusion of people with disabilities is complex, and it only takes one factor to fall down for all other efforts at inclusion to be wasted. Therefore, we need to undertake this work with an eye to all factors and, most importantly, ensure that people with disabilities themselves are a part of the process to highlight and work through the barriers to social inclusion which they will be most aware of.

Inclusion as a mainstream organisational, business and community practice has come a long way in the past 20 years. We have no doubt that we will see ongoing improvements of a similar magnitude in the years to come, and look forward to playing our part alongside people with disabilities, their families, communities and governments, to identify those barriers, get ourselves over or through them together, and continue to work towards an inclusive, stronger, and richer society.