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Belonging Matters' Submission to the Inquiry into the Social Inclusion of Victorians with a Disability, Parliament of Victoria Sept 2014

Introduction

Belonging Matters believes all people should have the opportunity to pursue a unique lifestyle that is personally meaningful, relevant and typically intertwined in the community. We are a small community based advisory service that builds capacity and knowledge predominantly with people with a disability and their families to enable them to have the opportunities typical of other citizens in the community. We are people-driven and value-driven.

The following is based on the experience of Belonging Matters over a 10 year period. The figures relate to 76 adults with disabilities of whom have requested personalised consultation from Belonging Matters.

a. **Define 'social inclusion' for Victorians with a disability;**

Social inclusion for Victorians with a disability can be summarised as typical, valued opportunities and pathways that are available to all citizens. This includes inclusive education, open employment, typical and inclusive recreational pursuits and civic roles, home tenancy/ownership, membership of community clubs, association and interest groups and access to typical places (rather than segregated, disability-specific places). It also includes participation, contribution and belonging and not simply presence.

Social inclusion enhances relationships with a range of people, including those with and without disabilities, and means that people are well known, part of their neighbourhood and valued. This can be assisted by a focus on sharing common interests (e.g. sport, music, art) rather than focusing on disability types or disadvantage as a point of connection. Joining community is then based on interest and not a label.

For service providers this means supporting people 'one person at a time' as unique individuals and holding a mindset of socially inclusive practice. Often this requires heightening expectations of what the person is capable of, and what the rest of the community is capable of. Good role models are useful for helping to raise individual and community expectations of what is possible. Aiming for the same standard and expectation as the majority of people is also important and fostering of valued roles. While social inclusion should be the aim, it cannot be manufactured but we can create a context for social inclusion to occur naturally by assisting with the inclusive pathways, thinking and support.

In order to understand what social inclusion is, it is also useful to consider what it is not. Social inclusion for Victorians with disabilities IS NOT being confined to disability-specific groups which exclude people from typical and ordinary opportunities. Similarly, social inclusion is not 'special' – it is not special groups or special programs, such as neighbourhood house groups, day programs, special

TAFE programs, 'disability discos,' or congregate social enterprise which exist in isolated enclaves. It is not 'parallel pathways' through life (e.g. special school, sheltered workshops, supported residential services).

This type of 'segregated' or 'congregated' support can increase marginalisation, exacerbate difference and create negative assumptions (e.g. that people 'need to be with own kind,' 'taken care of'). People with a disability are seen as "the other" or as different and an individual is always seen as part of a group. It is not simply about 'being in the neighbourhood' – a person needs to feel that they belong, have valued roles and contribute.

> **b. Identify the nature and scale of relative inclusion (exclusion) and participation of Victorians with a disability in the economic, social and civil dimensions of society;**

The scale of exclusion is enormous. There are many barriers to the social inclusion of Victorians with disabilities and they're not all about physical access. For example families are nearly always offered special programs and pathways for their family member with a disability. One family member, Meg, recently wrote about her daughter "As amazing as it may seem, in her 22 years Joscelyn has only ever been offered segregated, disability options" (Meg Sweeny, p4). This is unfortunately the experience of many of the individuals who come in contact with Belonging Matters. When first coming into contact with Belonging Matters' Personalised Consultation Services, 61 people were wanting to be more included in community life and activities e.g. work, study, recreation however 42 people were attending segregated settings e.g. ATSS day services, education or disability programs (Belonging Matters, 2014).

The predominant paradigm and mindset remains "special" pathways rather than ordinary, typical and inclusive pathways. As a result the investment continues to remain in "special" services and programs which segregate and separate rather than in *support* to pursue inclusive options.

There is a great lack of understanding about what community inclusion is. Largely the model for disability services in Victoria is overwhelmingly based on a congregate support/care, the medical model and a service oriented approach to meeting every human need. We have made little ground in moving towards a model of disability that emphasises social inclusion, contribution, rights, equality of opportunity and highlights exclusionary practice and attitudes as the barriers. The system also appears to be based on a welfare model that fosters pity and a sense of separateness and difference. Even by calling it a disability "sector" we make people with a disability separate and different.

Often there is an assumption that it is more expensive to provide individualised support to enable social inclusion however, many families when redirecting their vision and efforts with encouragement have been able to create inclusive pathways for their son/daughter with the same amount of money that was available, for example in the day program. This is usually because people are able to draw on a range of supports that over time naturally occur in communities e.g. in a workplace, club or

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association. In nurturing belonging, asking others to come forward and engaging our communities we can foster less reliance on paid supports.

c. Understand the impact of Victorian government services and initiatives aimed at improving inclusion and participation;

Exclusion occurs in community, economic and political dimensions because many people do not hold typical or high expectations of people with disabilities. Nor are providers clear on what social inclusion means. Unfortunately, this may include a number of existing initiatives that are aimed at improving inclusion.

In terms of education, the majority of people with intellectual disability that come into contact with Belonging Matters have been through the special school system. When young people with disabilities leave school, they don't get career advice - instead, they receive a booklet with a list of disability service providers and programs. Continually people with disabilities are limited to perpetual skills training/ 'getting ready for work' which is often group-based and irrelevant to an individual's ambitions or needs. Advice from services is given on what services are available and is not based on the person's aspirations or typical options and inclusive pathways (including questions such as, 'what career would you like to pursue?').

There are many people with an intellectual disability that Belonging Matters comes into contact with who are unemployed. Only 4 people or 5% of people assisted through our Consultation Services were currently working at the initial point of contact but 29 people said they wanted to find work! Disability Employment Services, for example, often fail to get people with significant disabilities work that is not in a sheltered arrangement. Or the only type of "work" offered to people with a disability is in welfare types of environments e.g. people with disability volunteering in opportunity shops, soup kitchens, nursing homes etc. What is often offered are pre- employment programs/training, with no real assistance to find and secure work. The disability services then become an end in and of themselves, rather than being a means to living a more fulfilling life based in the community. Customised employment initiatives which identify people's strengths, interests and abilities and work over a period of time to secure and support open employment for people with intellectual disability are rare in Victoria. We have found that it is usually families who have recognised the multiple benefits of open employment and persist of their own accord and push the boundaries to secure paid employment for their son/daughter. There are also disincentives which effect work e.g. few job coach hours available for people who take longer to learn a job; loss or threat to pensions

Many of the parents and individuals with a disability that Belonging Matters comes into contact with, don't even know they have an Individualised Service Package (ISP). Although intended to create greater choice, control and inclusion, people/families are often uninformed that they can actually direct their package. We still witness instances in which a service receives the ISP, writes the plan for the person to fit their program, all without the person's or family's knowledge.

This over-reliance on services in the current environment of segregated programs means that services are seen as the only adequate way to meet need, which then becomes the life defining role for the person. This can have the inadvertent result of breaking connections and 'deskilling' the community. Social inclusion is not just positive for people with a disability but it's also positive for our community. It's the great promoter of diversity and acceptance.

Services may appear to support the goal of inclusion or use the slogans of inclusion but this is often not followed through in practice. An example of this is some local Government initiatives that were built to promote social inclusion but conversely advertise and promote special groups, such as 'Disco for the disabled,' 'Riding for the Disabled,' 'Bowling for the Disabled,' 'Art for the Disabled,' 'Music for the Disabled etc.' Once again these groups prevent the possible connection people with a disability could have with non-disabled peers. Instead of joining a local art group and providing the support for the person to join and share their common interest with other art lovers, a person with a disability will be referred to the art group for disabled people.

Similarly, when people want to move out of home there are few "accommodation" options available. Often what is deemed innovative is a re badging of congregate care e.g. 'cluster housing' which continues to inadvertently separate people from the broader community. Of the people involved with Belonging Matters' Consultation Services, 23 people wantted to move out and live in the community. With education, capacity building and personalised advice, 17 people have moved into their *own* home in the local community and are supported by a range of flexible creative supports (including living with non-disabled flatmates).

   d. **Identify examples of good practice on inclusion and participation driven by local government and the community sector;**

Good examples of a life fully embedded in local community, often emerge from people and families who have been provided with capacity building to expand their vision, create a mindset of social inclusion and have assistance to implement life plans themselves. However, this can be tiring as there is such little support and investment in authentic inclusion. Anecdotally, Belonging Matters has also seen it emerge that where children have been included in mainstream school and typical expectations are held by their families, it is more likely that socially inclusive pathways are pursued post school and "special" options are rejected. The Belonging Matters website has a number of examples of positive and effective social inclusion. As does the Belonging Matters periodical "Thinking About…"

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e. **Assess how the *Disability Act 2006* has impacted on the social inclusion of people with a disability with respect to Victorian government services; and**

The Disability Act sets out good principles for realising justice and inclusion for people with disabilities. However, difficulties remain with implementation and practice. Individuals, families and services do not necessarily know how to move beyond the slogans of social inclusion and make them a lived reality. It is impossible to have a fully included life if we keep perpetuating special schooling, special programs and special services that keep people apart. We keep perpetuating the assumption that the only way people can gain support is through segregation or congregation rather than adding support to typical and inclusive pathways. Furthermore, as outlined in the answer to Question C, almost all of the disability services funding is tied up in congregate care. There is little focus on social inclusion initiatives that are personalised, non-group-based, and which seek genuine social inclusion. For example, Belonging Matters is funded $160,000 per year for whole of state of Victoria to deliver education and capacity building about social inclusion.

f. **Recommend ways to increase social inclusion, including the roles of and collaboration between local, state and federal governments, the community sector, individuals with a disability and their carers.**

Social inclusion for Victorians with disabilities should be an expectation from birth – as it is for all children. The principle for ensuring social inclusion should be, "Do the ordinary and add support – Don't do 'special' to get support." Another important maxim for realising social inclusion is "one person at a time." Given the uniqueness of each person's needs and aspirations it's impossible to assume that all needs can be met through the same means (often an underpinning of group-based congregated care and support).

When Belonging Matters assists a person, we view them as a unique individual, ascertain their interests, desires, gifts, aspirations and needs. We then discover how these can be pursued and supported in the community - utilising specialised support only if it can't be found in the community. For example, if a person has an interest in exercise and also has Cerebral Palsy, they might need specialised advice in regard to exercise. But the exercise can happen at the local gym, at the time the person's aged peers might exercise, as part of the *regular* gym classes and with a "specialist fitness" trainer if necessary. However there is more to inclusion than this. It could be possible that the "specialist trainer" teach the other trainers at the gym, the person could join other classes at the gym and could even explore other roles at the gym e.g. work roles. The person could also be encouraged to foster relationships with other members as they get to know them. This way the person is known as an individual (not as a group), gets the specialised support if necessary but also becomes socially included. Such an approach means joining existing realms of community activity, not creating new, disability-specific programming. What often happens is that a special class for people with a disability will be started at the gym as the prevailing mindset is separate and special.

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Crucial to our work is building a relationship with the person and their family over time. This enables trust and a deep knowledge about the person and their family. Social inclusion is careful, deliberate and thoughtful work – it doesn't happen in a few visits or by dropping people at community activities. To build genuine inclusion and belonging, as with all people it takes time and a skill around how to connect people and build relationship.

To enable this to occur we need to create a mindset of socially inclusive practice through building the capacity of individuals, families and services rather than merely educating people about what "special services" are available. This might include providing inspiration and training about ways to seek and foster social inclusion (and not simply through disability services), skilling up support workers, creating a community of practice in regard to social inclusion and fostering leadership in authentic inclusive practice. We can see the impact of capacity building has through the efforts of Belonging Matters' Inspiration and Education Program and Consultation Services. Of the 42 people attending segregated settings (e.g. an ATSS day programs, education or disability programs) before contact with Belonging Matters' Consultation Services, 35 people are now included in typical community activities, education or organisations. This is also because we hold an unambiguous commitment to the principle of social inclusion

Investment can also be directed to a work practice that is focused on inclusion first—on connecting individuals to existing, non-disability specific community groups, workplaces and pursuits. This requires that workers hold typical expectations of what people with disabilities could be doing in life (e.g. pursuing a career, being in mainstream education opportunities [with support if need be), and so on). This requires that Victoria moves beyond the era of 'special programs' as it did with institutions. Instead, the State, if it wishes to foster social inclusion, must support and nurture typical experiences, opportunities and relationships from birth. The government can assist by promoting good role models for social inclusion, and pointing to individuals and families who are experiencing genuine social inclusion. Another way of describing the above is to take a community development approach, where the role of services is to build and foster relationships between a range of citizens. While the choice model is important, it is paramount that people with disabilities are given the same choices as other citizens should expect.

Sweeny, M (2103). 'I'll skip on the special and have the ordinary and usual thanks,' *Thinking About What it Means to Be Authentically Included in Society. Thinking About* issue 17 Nov 2013. Belonging Matters: Melbourne

Belonging Matters (2014). Statistical Data

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