The Importance of Health to Social Inclusion

Submission to: Family and Community Development Committee Inquiry:

Social Inclusion and Victorians with a Disability.

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Executive Summary

- ❖ People with intellectual disabilities encounter **multiple barriers to social inclusion a**nd experience exclusion from mainstream facilities, services and community life. Barriers include physical, communication and cognitive access, learning and literacy difficulties, and the attitudes, assumptions and beliefs of community members, including health professionals

- ❖ **Health and social inclusion** are intimately related.
  - **On an individual level, optimising health and function** sets the foundation for participation. Conversely social inclusion and connection promote optimal mental health and resilience.

  - **On a community level, accepting and valuing diversity** promotes strong and inclusive communities. Inclusive attitudes facilitate understanding and access to health facilities and services for all community members.

- ❖ People with intellectual disabilities often experience a high rate of **chronic health problems** causing discomfort, pain and dysfunction. In order to optimise social inclusion, healthcare and health outcomes must be improved through a range of measures including:
  - Attention being drawn to the health needs of this group in the **education and training of health professionals**.
  - Attention being drawn to the health needs of this group in the education and **training of disability support workers and managers**.
  - Organisational policies, structures and processes that improve **access to healthcare** (e.g. rights training for health services managers and staff, communication skills training, priority access to services, appropriate Medicare Items)

- ❖ **Promoting and enabling positive interactions** between people with intellectual disability and the general public. Positive personal experiences are the most powerful influencer of individual attitudes. Such experiences reduce barriers created by ignorance, prejudice and misunderstanding and build opportunities for authentic social inclusion.

- ❖ **Social inclusion is dependent on** people with disabilities being provided in a timely way with the **access, aids and equipment** they require. These include communication and mobility aids, environmental control and emerging information technologies, access to supports for transport and adequate bathrooms, personal care supports and home modification. Provision of this equipment when and where it required enables people with disabilities to have the same opportunities for participation as other members of the community.

- ❖ **Health professionals** play an important role in supporting people with disabilities to achieve and maintain optimal health and function. Particular health disciplines with contributions to make include medical practitioners, occupational therapists, physiotherapists, speech pathologists, nurses, psychologists, dentists, optometrists, dietitians.

- ❖ **Disability Support Workers** have a central role in exploring opportunities for social inclusion and supporting people to both learn and practice the skills required. Appropriate and timely individual support is essential to ensure successful and positive experiences for both the person concerned and the general public.

<u>Health and Social Inclusion</u>

- ❖ **Health and wellbeing underpin social inclusion**. When people feel energetic and well they tend to become more outgoing and are more willing and able to reach out and embrace new experiences and opportunities. Conversely, when people are unwell or in pain, they tend to turn inwards, and withdraw from social contact.

- ❖ **Serious health, social and economic inequities exist for people with intellectual disabilities** (AIHW, 2003) compared to the rest of the population. People living with an intellectual disability have a shorter life expectancy (Gustavson, Umb-Carlsson, & Sonnander, 2005), and live with higher rates of illness and unmet health need (Balogh, Ouellette-Kuntz, Bourne, Lunsky, & Colantonio, 2008; Lennox et al., 2007).

- ❖ **Having access to optimal health care is an essential foundation for successful social inclusion.** People with disabilities are not fully included in healthcare services as significant barriers still exist to access appropriate health services. (Economics., 2008; Lennox et al., 2007; Mojtahedi et al., 2008; VicHealth, 2012). Adults living with an intellectual disability also encounter barriers to disease prevention and health promotion interventions. This then compounds the risk of preventable and secondary health conditions such as diabetes, pressure ulcers, pneumonia, depression and other mental health conditions (McDonald, Farnworth, & Hand, 2012).These health conditions interfere with the person's ability to participate in family and community life.

The Centre for Developmental Disability Health Victoria:

- ❖ The Centre for Developmental Disability Health Victoria (CDDHV) was established in 1992 through a **joint initiative** between the Department of Human Services, Monash University and the University of Melbourne. This initiative was a response to the identified poor health outcomes and unmet healthcare needs of adults with intellectual disability.

- ❖ The Centre strives to **improve the health and healthcare of adults with disabilities** in Victoria through research, educational and clinical activities.

- ❖ **Research activities** have included projects focusing on health and healthcare and strategies to address health inequities. Most of the Centre's work focuses on identifying barriers to healthcare, and exploring ways of effectively addressing those barriers. Specific issues include unmet health needs in people with intellectual disability, depression and social inclusion, dementia in people with Down syndrome, behaviours of concern, communication and behaviour, pathways of care. There have also been projects around the outcomes and effectiveness of educational interventions aimed at better preparing health professionals for their work with people with disabilities.

- ❖ **Educational activities** have been aimed at both medical and other health professional students and practitioners and disability support workers. Improving the healthcare provided to people with disabilities improves health and wellbeing. Barriers to provision of healthcare are the attitudes, skills and knowledge of healthcare professionals. An essential component of Medical Education in Victoria is the inclusion of people with disabilities in the teaching of health professional students. (Tracy & Iacono 2008)

- ❖ **Clinics** have been run by general practitioners, psychiatrists, occupational therapists, health and human relations counsellors, physiotherapists, speech pathologists and by multidisciplinary teams.

CDDHV and social inclusion

- ❖ The CDDHV has worked **to support people with intellectual and associated developmental disabilities to participate** in their family and community life. The barriers and enablers of social inclusion, particularly as they relate to health, are integral to our research, teaching and clinical work.

- ❖ The CDDHV recognises that **people with disabilities are the experts** on their own health, experience and life goals, and that their direct contribution to health professional education is therefore essential. This contribution both builds student knowledge and skills, and promotes the development of positive professional attitudes.

- ❖ **People with disabilities are part of the CDDHV teaching team**. Information has been provided through a number of channels , and people expressing an interest are employed as tutors and presenters within the CDDHV teaching program for medical students. The evaluation of the sessions by both medical students and tutors with disabilities is overwhelmingly positive. This model has been extended into other health professional teaching and training delivery in the Department of Occupational Therapy at Monash University..

- ❖ A major focus of the Centre's work is **developing capacity** in mainstream health services to better meet the needs of people with disabilities.

- ❖ **Collaboration:** The CDDHV has a long history of working collaboratively with people with disabilities and their families and support staff, community services, disability service organisations and State government services. These collaborative partnerships are integral to the Centre's research and educational activities. People with intellectual disability face many barriers in successfully gaining employment, with the minority doing so. Work is crucial for many aspects of social and emotional health including feelings of empowerment, social inclusiveness and belonging and a sense of accomplishment. Providing people with disabilities opportunities to be employed as tutors for medical students builds their skills, confidence and curriculum vitae.

- ❖ **Research into social inclusion:** Specific attention has been paid to the interplay of health and social inclusion in a number of CDDHV research projects. A recent example is a project, funded by Department of Human Services that explored the relationship between social inclusion and depression for people in Disability Accommodation Services.

- ❖ **Professional Development sessions** offered by the CDDHV included a 2013 Study Day on 'Disability, Health and Social Inclusion'. Presenters included world-renowned social inclusion researcher Professor Roy McConkey, author of the McConkey Scale of Social Inclusion. Other contributors to the day included disability self-advocates, representatives of the Summer Foundation, Department of Human Services, National Disability Insurance Scheme, Monash University and parents and practitioners.

CDDHV research into social Inclusion for people with Intellectual disabilities

In a recent (2013) CDDHV study on social inclusion, a large majority of people with intellectual disability had low levels of social inclusion.

❖ **Over half of the participants had no contact with friends**; 35.3% of participants reported no known friends outside the home while 16.2% had friends but had no contact with them. Only 22% of the people surveyed had at least monthly contact with any friends (McDonald, Forster, et al., 2012).

❖ **Only half (41.2%) of participants were reported to have frequent contact with their family,** while 48.1% were reported to have occasional contact. In 8.9% of those surveyed it was reported that they had no relatives or no contact with family. This is particularly concerning where the person has no other friends or networks as family can provide a social group to which people feel connected, and a 'bridge' to the broader community.

❖ **The literature emphasises the critical role of support staff in enabling (or creating barriers to) social inclusion** (Abbott & McConkey, 2006; Black, et al., 2010; Hartley, et al., 2008; McConkey & Collins, 2010a, 2010b; McConkey, Walsh-Gallagher, et al., 2005). Staff in supported accommodation settings have consistently been shown to give greater priority to care tasks rather than to social inclusion tasks (McConkey & Collins, 2010a).

❖ The CDDHV study demonstrated that **support workers had difficulty enacting social inclusion**. There was confusion about what social inclusion was with some defining it as relating to people while other related it to places. The literature supports social inclusion being intimately related to an individual's social needs and goals (Gannon & Nolan, 2007; McConkey & Collins, 2010c). Identifying that determining an individual's needs and goals and supporting them to address these is core business of disability staff is therefore an important way forward for DSW training and practice in social inclusion.

CDDHV recommendation for ways to increase social inclusion

1. *Improve the health and wellbeing of people with disabilities.*

Health and wellbeing underpin social inclusion. Serious health, social and economic inequities exist for people with intellectual disabilities. Having access to optimal health care is an essential foundation for successful social inclusion.

Improving health and healthcare requires a multifaceted approach:

a. **Addressing social and financial inequities** that relate to the social determinants of health
b. **Ensuring equitable access** to mainstream health services through policy and organisational change
c. **Educating health professionals**
    i. In the implications of disability for health, and the implications of health for disability.
    ii. In the barriers to healthcare encountered by people with disabilities and strategies to address these barriers.
    iii. In the knowledge and skills required to provide high quality care to people with disabilities
    iv. On the responsibilities of service providers to make reasonable adjustments required for equitable access to health services by people with disabilities

2. *Training of support staff in social inclusion*

The role of support staff is critical in enabling social inclusion for people with disabilities (Abbott & McConkey, 2006; Black, McConkey, Roberts, & Ferguson, 2010; Hartley & Birgenheir, 2008; McConkey & Collins, 2010; McConkey, Walsh-Gallagher, & Sinclair, 2005).

Disability Support Workers need specific training on the importance and practice of social inclusion, as staff tend to prioritise household and personal are tasks above social inclusion activities. The emphasis needs to be on a relationship-centred (rather than place centred) perspective of social inclusion. Training should be developed and/or delivered by skilled professionals who appreciate the significance of social participation, fulfilment of social roles and engagement in meaningful activities. Such training needs to include opportunities for staff to identify and explore strategies to overcome, barriers to social inclusion.

Access to health professionals to support disability staff. A number of health professionals – including occupational therapists, psychologists and social workers – have a role in supporting people with disabilities to set and work towards personal

goals. Unfortunately there can be financial, transport, knowledge and attitudinal barriers to professionals being involved.

3. *Person Centred Practice and Priorities*

Person centred practice is key for authentic social inclusion. Individual assessment of the social needs and opportunities available to each person is required in order to establish clear goals within Person Centred Plans. Person Centred Active Support (PCAS) is the foundation of current disability service provision, and outcomes of this support for most people should include increased social participation and inclusion. Further research into how best to support people in ways that facilitate social inclusion is required.

4. *The Use of Assessment Tools and Goal Setting to Measure and Promote Social Inclusion*

The use of assessment tools to reliably measure social inclusion is required to ensure progress towards goals is monitored. Social inclusion and participation are central components of Person Centred Active Support. Appropriate tools must available and be easy to use for those supporting someone with an intellectual disability. Research based on the information gathered through the use of these tools would enable the identification of priorities for the individual, any barriers to social inclusion, and interventions that would enable specific goals around social inclusion to be met.

The types of assessment tools that might be useful include role checklists, Quality of Life Measures, Friendship atom, Community Integration scales, the Housing Toolkit (Winkler, Sloan, Seabrook, Anderson, & Callaway, 2013), and interest checklists. These would identify the roles and relationships that the person desires.

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