

National Mental Health and Disability Consultation Findings

During 2008, representatives of the Australian Social Inclusion Board met with several peak national bodies in the mental health and disability sector to discuss issues in the Board's key priority areas: jobless families with children, children at greatest risk of disadvantage and taking a locational approach.

This paper provides a summary of findings from these consultations, as well as summary findings from the *Telling it like it is report: Community consultations with Aboriginal people with disability and their associates throughout NSW, 2004/05*.

The organisations met with include:

- The Australian Federation of Disability Organisations;
- The National Ethnic Disability Alliance;
- The Mental Health Council of Australia;
- The Australian Mental Health Consumer Network;
- National Disability Services; and
- Carers Australia.

Summary of Findings

Human contact is vitally important

- Isolation and loneliness are more of a problem than income disadvantage.
- Isolation can be more acute in rural or remote areas (separation for individuals required to travel where there are less local services or jobs, lack of transport). Also impacts on carers.
- Housing and care models can contribute to the problem (e.g. scattered one-bed public housing apartments, poorly maintained housing stock, lack of culturally/disability appropriate housing design, lack of a 'customer service' or outreach approach by housing service providers).
- Alternative avenues for social connection are more important for those who can't work.
- Community or group meeting places can provide social connectedness, e.g. sports, recreation, and leisure clubs. It is not necessarily professional care that is needed.

Multiple, overlapping problems compound disadvantage

- Stigma and discrimination due to multiple disadvantage compounds disadvantage, e.g. a disability or mental health issue is an added layer for Aboriginal and Torres Strait Islander or other language or cultural groups who may already face exclusion (discrimination can be different within and outside the community as disability is viewed differently by Aboriginal and Torres Strait Islander peoples).
- Language and culture can create barriers to services – e.g. cultural sensitivities and differences; not knowing what support is available or being unable to communicate needs.
- Under-reporting of disabilities occurs in Aboriginal and Torres Strait Islander communities due to cultural reasons:
 - Some do not identify as having a disability to avoid the potential for further discrimination.
 - The prevalence of disability in Aboriginal communities means physical impairment or a psychiatric disability is not seen as an unusual occurrence.
 - There is a focus on physical or visible types of disability over mental illness.
- Some sub-groups of carers experiencing overlapping disadvantages are among the most disadvantaged in Australia (e.g. young carers in a sole parent family, and living in a remote area).

Jobless families

- Assist people with a disability, who can't work, to participate in community life.
- People with a disability may need extra help to go to work - individuals may need carer support to study, get a job or keep employment, and there are added costs of going to work, such as clothing and transport.
- Need for flexible employment arrangements for employees and employers.
- There are also added costs for employers – e.g. need to assist with physical mobility and access difficulties.
- Stigma and discrimination are perceived as barriers.
- Employers need to be educated (on employment potential of disabled people and their carers and of the need for/options for flexible arrangements).
- The earning capacity for carers of a child with a disability is much reduced. Their obligation is to care; they lose self-confidence in the workplace, or lose their working identity. Also, many carers in the workplace would be working below their capacity or qualifications. Many want to work but need job protection and flexible arrangements that take into consideration the long hours of care. The average time spent caring is above 40 hours per week.
- In Aboriginal communities in particular, the burden of care falls on family due to kinship responsibilities.

- Need for carers to be recognised as service providers, that their caring role be recognised as a job or labour – then other protections such as OH&S would apply.
- Need for sufficient paid carer's leave. Also for unpaid carer's leave, for use, as an example, by those carers who support someone in palliative care, to enable them to return to their current work environment. This reduces the stress on the carer and their family and there are short and long term benefits for the community.

Children at greatest risk of long-term disadvantage

- Disability, mental health or substance use issues in a family (parents or siblings) are a stressor that disadvantages children.
- Child needs support to care for parent – there may be barriers to their asking for help, such as fear of stigma, fear of removal from the family and fear of penalties for parents.
- Child may need support outside the family (advocate, neighbours, community networks), particularly if family environment is chaotic or unreliable.
- The stress of having a child with a disability can contribute to family breakdown or loss of employment due to caring responsibilities.
- Early support interventions put into place in the first 6-12 months will often mean better outcomes for carers and those they support.
- Education and the transition from education to employment is a significant issue for young carers and can lead to a reduction in long term earning capacity.
- Child of a parent with a disability or mental health issue can be disadvantaged through the impact on their school attendance and attainment, and schools can misidentify truancy when young carers' attendance is erratic.
- The [Children of Parents with Mental Illness](#) (COPMI) initiative provides online support.

Locational approaches

- Where there is less access to services in rural or remote areas, more support is needed e.g. transport to services or outreach (separation from family, social isolation, lack of jobs). The UK introduced transport reforms to make transport systems more socially inclusive.
- Access to supporting aids and equipment for people with a disability is more difficult or non-existent in remote and rural areas and can be compounded for Aboriginal and Torres Strait Islander people with a disability in remote communities.
- Data shows increased numbers with mental illness in rural and remote areas – this is then reflected in a rise in the number of carers. Policy and program reviews should also consider the role of carers through stressful times – e.g. drought.

Resourcing models could shape accountability for outcomes

- The government funding model for non-government organisations doesn't support a holistic approach - based on provision of units of a specific service, not outcomes for the client. Build accountability through measures of outcomes for individuals.
- Provide recurrent funding to non-government organisations on a longer term basis, e.g. a three-four year cycle.
- People in the community need long term projects. Instead of running more pilot projects, use existing models of good projects.

Resources need to be sufficient and flexible

- People with a disability experience a diverse range of circumstances. Services must be flexible to respond appropriately for each individual, and deliver a level of control to the individual, e.g. allocate carer payments through a service provider of choice.
- People with a disability who work can still suffer the impacts of income poverty, due to low wages and high costs (e.g. travel, medical and equipment costs). In Australia, people living with a disability can compete in the open market for a job, or eligible people can be employed under the Supported Wage System.
- Support payments models should look at the interaction between wages and payments tiers to better support a decision by disabled people to work.
- Needs and situation is individual – criteria for funding or support must respond.
- Funding to organisations needs to be flexible to cover gaps or individual situation.
- Carers are in short supply. Need for carers to be recognised as service providers, that their caring role be recognised as a job or labour, with appropriate resources.
- Physical accessibility (public and private e.g. transport, building standards) is still a concern across the board.
- While technology will not be the answer for all, it has tremendous potential as an enabler – social connection, information, support network.
- There is a need for more significant resources to resolve issues. for those with multiple disadvantage (e.g. with a culture, language barrier and living in a remote area).

Outcomes measurement

- Indicators or measures should be based on outcomes for individuals, rather than units of service, to build accountability on the provider.
- Need more specific data breakdowns for indicators to be most useful.
- More research on the health status of Aboriginal and Torres Strait Islander people with a disability is needed.
- Impacts on carers should be considered across all relevant policies. For example, the Pharmaceuticals Benefits Scheme, Employment and Pension and Tax Reviews etc.

Services need to be relevant, flexible, affordable and reliable to respond to individual's needs and empower clients.

- Individuals with complex needs currently encounter complex service systems, which the individual has to navigate. Could redesign and/or provide for advocates or client contacts.
- Services are siloed - coordination across multiple services is needed.
- Need a better balance between acute and primary services – this requires cooperation and trust between organisations.
- Services can encourage dependency – should foster independence, autonomy and control over own life and capacity building (participation in decision making, domestic activities, enterprise etc).
- Services can contribute to stigma, e.g. by unintentionally identifying clients by doing home visits in identified vehicles, or reinforcing perceptions of the mentally ill as dangerous by sending police rather than ambulance to respond to episodes.
- Focus on early intervention processes, so that initial interactions with the system lead to positive outcomes. For example, increased funding for primary services including home care so that interactions with the police are not the first point of contact for people with a mental illness.
- Support service delivery by locally owned, managed and staffed providers, in particular for Aboriginal and Torres Strait Islander communities.
- Service providers, including advocacy services and agencies, should be culturally competent and disability aware and take an outreach approach. Services should be culturally appropriate.

Community education is still needed, including the following messages

- All people have the same basic needs and aspirations, including those living with a mental illness or a disability – to have a secure and stable home, meaningful activity and relationship with other.
- People living with a disability or mental health issue are a part of the community, so general/universal services should be available to all, including those living with a disability or mental health issue – this is not an 'extra'.
- Disabilities and mental illness present extra challenges to things most people take for granted, and a combination of these and/or differences in language or culture affects compounds these challenges and makes accessing services even more difficult.
- Need to raise the profile of carers in the community to assist self-identification, identification by service providers and schools, and build appreciation of the value of the work performed by carers.