Commonwealth Funding and Administration of Mental Health Services in Australia
Response to Inquiry
5th August 2011

By email: community.affairs.sen@aph.gov.au

About Ability Options

Ability Options was founded in 1976 as a union between the Rotary Club of Guildford and the NSW Health Commission and provides support services to people with a disability. During the mid-70's a courageous group of people including parents, brothers, sisters, advocates got together and made the decision to enable their family members to leave long term institutional care at Rydalmere Psychiatric Hospital and move into housing in the community. All of these people had a **primary intellectual disability**. The organisation continues to provide supports to people with a primary intellectual disability and mental health needs, a situation we term as a person who has a dual diagnosis.

There are currently 440 people supported by Ability Options through the National Disability Agreement and state based funding (NSW). Up to 89% of people have a primary intellectual disability diagnosis with support needs that range from low to very high. There are a high percentage of people with secondary disabilities such as mental health.

Within the Federally funded Disability Employment Service the percentage of people with identified psychiatric disability is currently 36%. This figure does not account for secondary diagnosis.

This submission is focusing on:

- The adequacy of mental health funding and services for disadvantaged groups including:
    - Culturally and linguistically diverse communities
    - Indigenous communities and;
    - People with disability

In our experience there are significant gaps in mental health services to meet the needs of people with disability who also have a secondary diagnosis of mental health ailments.

Ability Options currently supports more than 3000 people and their families across NSW through the following programs:

- open employment
- supported employment
- supported living
- case management
- self managed supports

- post school and day program options
- community access, development and training
- housing options and asset maintenance

The **aims** of the organisation include:

- To promote the independence, worth and dignity of people with disability.
- To provide a range of supported living options for people with disability.
- To promote employment opportunities and conduct work and other training for people with disability.
- To provide counselling and any other assistance to people with disability to encourage their participation in their community.
- To liaise with other community agencies to improve existing services offered to people with disability.
- To encourage and promote citizen and self advocacy for people with disability.

The **mission** of the organisation is to:

- To provide people with disabilities better opportunities that will enable them to enhance their lifestyles and achieve their goals.

We welcome the opportunity to make a contribution to this Inquiry and have included some comments below.

Ability Options supports the position of the National and NSW Councils for Intellectual Disability and the Australian Association of Developmental Disability and their paper: 'The Place of People with Intellectual Disability in Mental Health Reform (19/7/2011). The key proposition is that:

> "*People who have both an intellectual and mental illness need to be included from the start in health reforms. They currently have poor access to appropriate mental health services."…..*require *"funding by particular specialised intellectual disability mental health psychiatrists and nurses who can act as consultancy, training and research adjunct to mainstream mental health services"*.

In our experience, people with a primary intellectual disability and secondary mental illness have difficulties accessing appropriate supports. The same is also true of people with a primary mental health diagnosis and secondary intellectual disability.

Broadly speaking, the disability and healthy sector operate on a primary 'diagnosis' basis. This means that a person with an intellectual disability who additionally has a significant mental health diagnosis will be excluded from accessing community based mental health supports, and vice versa.

The number of people with an intellectual disability with a mental health diagnosis is much higher than in the general population. Current percentages are that 30-50% of minors and 30-40% of adults with an intellectual disability fall within this dual diagnosis of having a mental health issue as well. [1]

[1] Information received from Jim Simpson (NSW Council for Intellectual Disability) by Garth Benneyworth (Ability Options), 5 August 2011

A case study:

Jane is a young woman who has just finished school. She has lots of abilities and has chosen the Transition to Work program in NSW, because she has been assessed as being eligible for this 'program' and open employment and she is thinking about her future and some support to help her to achieve her goal. Mum and Dad are very supportive and work full time but are flexible to be around for Jane.

Jane and her family choose a provider to assist with her goals around employment. It soon becomes clear that Jane has significant mental health issues that require the input of disability and mental health services working together. Jane spends a lot of time in psychiatric care. She is lucky that she has a committed disability service provider around her work objectives - through her transition to work program. They provide support as flexibly as possible to meet Jane's needs. Her parents are in despair because they cannot manage Jane's self injurious behaviours. Applications are made for additional disability supports, and she is deemed to be too high functioning and not eligible for disability supports. Meanwhile, she continues to access emergency mental health services.

This is one of a number of examples of experiences by people with disability and their families who may have a secondary mental health diagnosis and secondary intellectual disability or vice versa.

People with intellectual disability have high rates of mental disorders. For people with communication limitations, atypical profiles and mental health presentations there continues to be a lack expertise to provide appropriate intervention.

In our experience, people with intellectual disability and mental health will experience poor access to appropriate health services and receipt of inadequate standards of care, particularly psychiatric disorders in people with intellectual disability, which are often misdiagnosed and inappropriately treated.

Ability Options currently provides some specialist supports to people with intellectual disability and mental health conditions. The organisation has a number of examples of people who have been diagnosed or inappropriately treated. One such person is Mary (not her real name).

Mary (37 yrs.) has an intellectual disability and lives in a specialist group home for people with dual diagnosis. As a teenager, Mary demonstrated challenging behaviour such as aggression and absconding. Her family found this very difficult to cope with and over a period of years approached a number of medical professionals which resulted in Mary being admitted to hospital for long stays.

Mary's behaviour was ascribed to her disability, yet her family identified that her prescribed antipsychotic medication actually worsened her behaviour. Mary lived in a number of group homes as her family were unable to have her living at home. Mary experienced several breakdowns. A few years ago, Mary's family took her to a psychiatrist who diagnosed Borderline Personality Disorder, general anxiety and changed her medication.

With this diagnosis, Mary's support staff sought advice from an experienced clinician to develop a personal support plan for her to manage her mental health. At her request, Mary

was provided with counselling and, with her management plan in place, family relationships and behaviours significantly improved. Currently, Mary participates and engages in community based activities, which she previously found difficult to do.

Our experience is that the system currently treats the symptom, not the cause. At worst a stand-off can occur between mental health and disability services, which results in limited access to any support services. People living with a dual diagnosis of intellectual disability and mental health ailments and their families are significantly impacted on as they often are more likely to slip through the gaps between the health and disability systems.

For example, people with dual diagnosis often end up in situations that negatively exacerbate their personal circumstances while impacting financially both on the individual and society. For example, minor issues, such as dental problems can escalate into cyclical substance abuse, homelessness and criminality. Medical interventions are known to over prescribe, resulting in the person seeking alternative self-medication options, thus creating a dysfunctional cycle, in turn triggered by cyclical substance abuse. This occurs despite the efforts of well-intentioned people in the community who, lacking the skills and resources, cannot achieve long term beneficial outcomes. Additionally, ageing compounds the situation, due to hard living, homelessness, advanced ageing, loss of brain function and frailty.

Yet, alternatives do exist for people with dual diagnosis. We motivate for a service system where mental health and disability services work together to provide an integrated and holistic response to a person's needs. Assessment and treatment would both treat and understand the persons' life journey, based on a 'whole of person' centred approach.

Our priorities for action in mental health reform are:

1) Specific government funding for a network of specialist intellectual disability mental health psychiatrists, nurses, psychologists and other professionals. These professionals would act as a consultancy, training and research adjunct to mainstream mental health services and include clinical services in local areas and education centres of excellence linked to universities. [2]

2) Enhanced joint planning by disability services and mental health services including development of a mandated shared case coordination capacity where intellectual disability and mental disorder co-exist. The psychologists, social workers and other professionals in disability services have a key role in working with mental health professionals to ensure a holistic response to mental disorders. [3]

3) Mandated training in intellectual disability mental health to minimum standards for front-line and other professional staff in disability services and mental health services. [4]

We motivate that funding of specialist intellectual disability mental health professionals is vital to the success of the joint planning and training of mental health and disability staff. Action on the above priorities would result in: [5]

[2] Ability Options share the same view point as that articulated by The National and NSW Councils for Intellectual Disability and the Australian Association of Developmental Disability as published by these organisations , see: 'The Place of People with Intellectual Disability in Mental Health Reform (19/7/2011), p. 4
[3] *Ibid*
[4] *Ibid*

- Improved access to mental health care for people with intellectual disability,
- Improved mental health treatment and holistic support of people with intellectual disability and a mental disorder,
- Improved health and quality of life for people with intellectual disability and a mental disorder, and
- More appropriate use of psychotropic medication with people with intellectual disability. [6]

National action is required to address the mental health of people with intellectual disability, in particular the funding of specialist intellectual disability mental health psychiatrists and nurses. In our experience, this is the standout gap in the health and disability professionals needed for intellectual disability mental health.

The Australian government has already made a commitment to outcomes in line with the National Disability Strategy. Better integration of mental health and disability supports will assist people to achieve the highest possible health and well being outcomes possible.

We also await the government's response (in November) to the Productivity Commission report into the *Long Term Care and Support Needs for People with a Disability.* The Draft report sought additional feedback around the inclusion of people with a mental health diagnosis as part of a National Disability Insurance Scheme (NDIS). The hope in outcome of the government's deliberations is the capacity of people with disability and dual diagnosis to be able to have their care needs met over their lifetime and to be able to access the services or supports to meet their needs.

Most importantly, in our view, is that the NDIS seeks to establish a better integration of services and supports and the provision of capacity so that issues are addressed in a holistic manner. Such a system, balanced against an integrated approach to the treatment of people living with dual diagnosis is what is required to deliver appropriate supports to people vulnerable in a system which the Productivity Commission has identified is currently underfunded, fragmented and inefficient.

We look forward to the outcomes of the Inquiry to provide integrated services for people with intellectual disability across the state based health and housing portfolios.

Yours sincerely,

Matt Donnelly

Chief Executive Officer

Ability Options Limited

---

[5] Ability Options share the same view point as that articulated by The National and NSW Councils for Intellectual Disability and the Australian Association of Developmental Disability as published by these organisations , see: 'The Place of People with Intellectual Disability in Mental Health Reform (19/7/2011), p. 4

[6] *Ibid*