Mind Australia’s approach to working with people who have a dual disability.

Our approach to working with people who have an intellectual disability, acquired brain injury or autism spectrum disorder in addition to mental ill-health.
Foreword

We are pleased to present Mind’s approach to working with people who have a dual disability.

Mind is committed to being a preferred service provider for people with a dual disability, their families and carers through our commitment to individually tailored and specialised services.

This document aims to build organisational capacity and support all Mind staff to deliver best-practice approaches to working with people with a dual disability, their families and carers.

It can also be used to inform other community and health service organisations about the way we work.

Please take the time to read this document and develop a good understanding of our approach.

We would like to thank the Mind project team that worked on the development of this targeted practice approach.

Bronwyn Lawman
Executive Director Operations
Introduction

This document explains Mind’s approach and commitment to working with people who have a dual disability. Dual disability is a term used to describe the co-existence of mental ill-health and one or more of the following cognitive impairments or neurological conditions:

- an intellectual disability
- an acquired brain injury
- autism spectrum disorder

The term ‘dual disability’ is primarily used in the mental health sector. It is not commonly used or understood in the community or in human services generally despite its prevalence.

Dual diagnosis and dual disability are often confused and mean different things across Australia and throughout the world. At Mind we refer to dual diagnosis as the co-existence of mental ill-health and substance misuse.

About Mind

Mind Australia Limited (Mind) is a leading national community managed mental health service. We have been supporting people with mental health issues, their families and carers for over 40 years.

Our key purpose is to help people to gain better mental health and improve the quality of their lives. Everything we do is directed by the overall values of the organisation: client focus, making a difference, integrity, hope, creativity and innovation.

We support a diverse range of people including people from culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander peoples, lesbian, gay, bisexual, transsexual, intersex, queer or questioning (LGBTIQ) people, and their families and carers.

All people, regardless of who they are, where they come from, or their life experiences, will receive services tailored to their needs.

Mind has a strong commitment to supporting people to realise their human rights. This involves respecting and promoting the inherent dignity of the individual and working to ensure freedom from discrimination, abuse, neglect and exploitation.

We respect and value the lived experience of people with mental ill-health, their families and carers and understand this experience must inform service delivery. This is demonstrated through our employment of staff with a lived experience, our peer workforce, our National Consumer Reference Group, our National Family and Carer Reference Groups and the many opportunities we create for consumer feedback and consultation.

There are six core principles that guide our recovery oriented practice. These include:

- Supporting personal recovery and promoting wellbeing
- Taking a person centred approach to development of clients’ support plans
- Delivering services informed by evidence and consistent with a social model of health
- Building trusting relationships
- Ensuring our practice is sensitive to the needs of families and carers
- Working in partnership and collaborating with other services

Definition

At Mind we define dual disability as the co-existence of mental ill-health and one or more of the following cognitive impairments or neurological conditions:

- an intellectual disability
- an acquired brain injury
- autism spectrum disorder

Prevalence

Research tells us that people who have an intellectual disability, acquired brain injury or autism spectrum disorder are more likely to experience mental ill-health than the rest of the population. The research has shown:

- People with intellectual disabilities are at least 2 to 3 times more likely to experience mental ill-health than the rest of the population.
- At least 50% of adults with autism spectrum disorder will develop mental health issues at some time in their lives.
- People with an acquired brain injury have a greater risk post injury of developing depressive illness and schizophrenia than the general population.

About dual disability

Mind’s approach to recovery oriented practice

It is grounded in Mind’s approach to recovery oriented practice and aims to:

- build organisational capacity and support all Mind staff to deliver best-practice approaches to working with people with a dual disability, their families and carers
- provide information to other community and health service organisations.

Mind is committed to being a preferred service provider for people with a dual disability, their families and carers through our commitment to individually tailored and specialised services.

References:

1 "Many of our clients have experienced the negative and disabling impacts of persistent mental ill-health. They may have been incarcerated, homeless or had long periods of institutionalisation. They may have become alienated from friends and family. They may have experienced economic disadvantage, trauma, forced migration and limited educational opportunities. They may also have been stigmatised and devalued." (Mind Australia, 2016, Mind’s approach to recovery oriented practice, Mind, Australia)

2 Definitions for intellectual disability, autism spectrum disorder and acquired brain injury can be found in the glossary


5 Hage, M 2000, Submission to Review of Mental Health Services, Victorian Coalition AHI Service Providers
Our approach to working with people with a dual disability

Our vision for people with a dual disability, their families and carers is for them to enjoy equitable access to quality services that respond holistically to individual and family needs. Customers with a dual disability enjoy and experience the same positive life outcomes we strive to help all our customers to achieve. These are:*

- good health and wellbeing
- rewarding relationships
- connection, sharing and belonging
- participation in meaningful and enjoyable activities including education and employment
- making a contribution
- positive self-identity and self esteem
- choice and control
- liking where they live
- feeling safe and secure
- skills for community living
- solving practical problems

The National Disability Insurance Scheme (NDIS) is a major source of individualised funding for people with all disabilities including psychosocial disability. Mind is well positioned to offer quality specialised services to people with dual disability and complex needs as our services endeavour to ensure people with dual disabilities do not fall through the cracks.

Mind has over 20 years of experience in the delivery of specialised dual disability residential support services in Victoria. Our supported accommodation service in Sunshine began in 1998. Our second service was established in Werribee in 2014. We have also been providing community support to clients with dual disabilities and a range of complex needs in Northern Regional Victoria since 2009.

At Mind it is estimated that thirty percent of people using our services have a diagnosed or suspected dual disability. This was identified through our Dual Disability Capacity Building Project conducted for Mind between March 2016 and November 2017.²

In February 2016, Mind appointed its first Dual Disability Practice Advisor. The position was created to support the Mind workforce in developing their expertise and confidence to effectively meet the needs of people with a dual disability.

In 2017, Mind expanded services into Queensland and in 2018 established the Complex Care Support Team to meet the needs of Queenslanders with a dual disability and to build sector capacity for those with complex support needs and requiring specialised behaviour support services.

At Mind we understand that people with a cognitive impairment or neurological condition may have difficulties talking about their mental and emotional wellbeing. Whilst we listen carefully to what the person is saying, we also look to understand the individual’s needs and challenges by observing the things they do and the way they act (behaviour). We know that behaviour communicates an important message.

For people with a dual disability, mental ill-health can sometimes manifest in behaviours of concern⁶ that can be triggered by one or more of the following:

- Difficulties and distress expressing their feelings and needs, and understanding what is being communicated
- Frustration about their life, environment or support, or lack of support
- Undiagnosed health problems including physical pain or illness
- Seeking access to or avoiding people, environments or tangible items
- Life experiences such as social isolation and loneliness
- The person experiencing stigma, rejection and discrimination
- Traumatic events through their life.

Not all people with a dual disability will display behaviours of concern however we know that people with a dual disability may experience a range of challenges and barriers that may not be evident in people with mental ill-health, who do not also have an intellectual disability, acquired brain injury or autism spectrum disorder.

We also acknowledge that the differentiation of behaviour associated with mental ill-health and dual disability is not well understood and often results in higher levels of risk that are exacerbated when services do not meet the needs of individuals. It is another reason that dual disability requires a specialised approach and model of service.

Mind adopts a social model of disability and adheres to the United Nations Convention on the Rights of Persons with Disabilities⁴. Further to this is our recovery oriented practice approach which is the core approach to all service provision at Mind. It ensures our services are person centred and individualised. They are flexible and tailored to meet the person’s needs and choices.

An important component of recovery oriented practice is the provision of trauma informed care. Trauma informed care acknowledges the ongoing impact of trauma on people’s health, well-being and behaviour and ensures that the care provided is sensitive to trauma related issues. We take particular care not to exacerbate or trigger previous experiences of trauma. We are mindful that many people with mental ill-health have experienced trauma.

Staff, using a trauma informed approach work to:

- build trust
- promote safety
- promote hope and person centred recovery
- promote calm
- promote connectedness
- build self-esteem
- focus on the person’s strengths.

Our work with people with a dual disability also encompasses Person Centred Active Support and Positive Behaviour Support strategies and principles.

The figure on the next page brings together Mind’s practice approaches to provide a diagrammatic representation of Mind’s approach to working with people with a dual disability.

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² This project was led by Dr Erin Wilson, Associate Professor of Disability and Inclusion from the School of Health and Social Development (Faculty of Health), Deakin University. The prime purpose of the project was to identify the prevalence of clients with a dual disability and make recommendations on improving the capacity of Mind and its workforce to provide effective service delivery to people with a dual disability. (Wilson, E 2018, Dual disability capacity building project report: Dual Disability - A case for change, Burwood, Deakin University)

⁶ ‘Behaviour, that within a cultural context, is understood to be of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities, services and experiences’ (Emerson E and Einfield S L, 2011, Challenging Behaviour, 3rd Edition, Cambridge, UK).

⁴ The Convention on the Rights of Persons with Disabilities is an international human rights treaty of the United Nations intended to protect the rights and dignity of persons with disabilities. Parties to the Convention are required to promote, protect, and ensure the full enjoyment of human rights by persons with disabilities and ensure that they enjoy full equality under the law. [https://en.wikipedia.org/wiki/Convention_on_the_Rights_of_Persons_with_Disabilities]
Recovery oriented practice

Recovery is the foundation of mental health policies and practice nationally and internationally. It is an evidence-based, best practice approach to supporting people with mental ill-health.

A recovery oriented approach supports people to build and sustain lives that are purposeful to themselves. Only the individual can define what recovery means to them.

Personal recovery has been described as ‘reclaiming ... the right to a safe, dignified and personally meaningful and gratifying life in the community...’11 with or without symptoms of mental ill-health.

We emphasise those words because they illustrate a key difference between personal recovery and clinical recovery which is usually defined as a reduction of, or end to symptoms and a repairing (or regaining) of functioning. Whilst Mind supports people to access all clinical treatment interventions that are needed, our focus is on people’s individual strengths, values and preferences rather than on the presence or absence of the symptoms of mental ill-health.

When working with people with a dual disability, staff sometimes need to support individuals to explore their preferences, values, and what a good life means to them personally. Sometimes this can’t be explored through dialogue, but through getting to know the person and actively observing the environments, activities and relationships in which they function. Staff use person centred tools and trusting relationships to understand and honour what is important to the individual, and what is important for the individual and their safety and wellbeing.

We are aware that some people will always need a level of assistance to live active and meaningful lives, and through recovery oriented practice we support people to have as much control and choice in their lives as possible.

The creation of an individualised recovery plan is central to our practice. We work collaboratively with the person and their families and carers to identify individual goals and the support required to reach these goals. We also identify areas where the person may need specific support, or may need to acquire particular skills or knowledge and outline the responsibilities that both the staff member and individual commit to in working towards achievement of these.

Person Centred Active Support

Person Centred Active Support is “a way of working that enables everyone, no matter what their level of intellectual or physical disability, to make choices and participate in meaningful activities and social relationships”12.

Planning and providing the right level of support is an important component of enabling a person to have maximum engagement and participation in their own life activities at home and in the community. Staff work actively to assist a person to do as much as they can for themselves, whether it is a small part of a task or activity, or a whole task or activity. The goal of active support is to empower people to have more choice and control in their lives by helping them do things for themselves rather than having others do those things for them.

Another important goal of Person Centred Active Support is to support people to increase their independent living skills and personal capacity with the aim of reducing the support as the person’s abilities increase. With greater involvement and engagement in everyday tasks comes increased confidence, higher self-esteem and greater choice and control of one’s own life.
There are four essential elements to Person Centred Active Support.\(^{14}\)

1. **Seeing every moment as potential for engagement and participation:** everyday opportunities and all activities of daily living create opportunities for people to take part and engage. This requires looking at the many steps that make up every task and every social interaction, and involving the person in as many of these as possible.

2. **Encouraging the person to participate in all activities of their daily lives for short periods of time and often, if their ability to concentrate is impaired:** it is not always realistic to expect a person with a cognitive impairment to be fully engaged in one activity or task for the whole time and it is sometimes more realistic to support them in participating in part of an activity. The more often staff involve the person in activities, the more active and engaged the person can become. Staff need to pick the right time and the right moments to engage the person. Knowing the individual well helps with this.

3. **Maximising every opportunity to provide the person with choice and control:** even if it’s only about small things such as choosing a particular brand to buy, or which park to go for a walk in.

4. **Providing graded assistance to ensure success:** staff support the person to learn new skills by breaking tasks down and helping the person learn the task one step at a time. For example, the person may be able to peel carrots on their own, but may need guidance to use a knife safely and shown how to cut the carrots in the easiest way.

Graded assistance includes the following:\(^ {15}\)

- **Asking - ASK** (or SUGGEST or TELL) is a verbal prompt which lets someone know that it’s time to do something or that something needs to be done.

- **Instructing - INSTRUCT** is a series of verbal prompts which tells the person what to do next. It is like an instruction but works better when the person does not easily understand words. Briefly miming an act can provide a lot of information for the person to follow. PROMPT can be combined with INSTRUCT.

- **Prompting - PROMPT** is a clear gesture or sign to tell the person what to do one step at a time. It helps to guide a person through the activity.

- **Guiding - GUIDE** is giving the person direct physical assistance to do something. The type of physical support and how long the support worker does it for can vary according to the person’s need for support. Guidance may be given only at the beginning of a step to get the person going (like a prompt), or it may be given throughout the step. GUIDE can be combined with PROMPT or INSTRUCT and can follow SHOW.

Two examples illustrate Person Centred Active Support in action:

**Example 1**

Stacey asks the Mind support worker to phone her mother for her. She wants to say hello. Stacey hands her own phone to the support worker who suggests to Stacey she makes the call herself. Stacey says she doesn’t know her mother’s phone number and doesn’t know how to make the call.

The support worker locates her mother’s phone number and instructs Stacey on how to save and recall the number in her phone. She firstly demonstrates to Stacey how to make the call, secondly, does it with Stacey giving very clear instructions and thirdly, prompts Stacey to make the call herself.

Stacey’s mum answers the phone and Stacey hands the phone over to the support worker to talk. The support worker encourages Stacey to talk on the phone herself and gives her some words to help her start the conversation: “How about you say ‘Hello mum, it’s Stacey. I called to see how you are’ “.

Hesitantly, Stacey starts the conversation and they end up having a great chat.

Stacey finishes the call feeling very proud for making the call herself and starting the conversation independently.

Over time Stacey is able to call her mother independently with a small amount of prompting and instruction from the support worker.

**Example 2**

When the support worker arrives at Ali’s house, he hands her his washing and asks her to do it for him. He has just moved into the house and has never washed his own clothes. The support worker suggests he learns to do it for himself and encourages him to engage in the task. At the start he isn’t very interested but she really encourages him to stay with him whilst she loads the clothes into the washing machine and turns the machine on. When the washing is finished she suggests to Ali they take the washing to the clothes line together. The support worker loads the washing into the washing basket. She then encourages Ali to carry the washing basket to the line and she hangs the washing out with Ali next to her.

Over time the support worker assists Ali to do more of this task for himself. It was difficult for him to identify the right buttons on the machine to push and to actually push them. The support worker takes pictures of the correct buttons and places them on the wall right next to the machine in sequence. She also places his hand (with permission) over Ali’s hand and guides his hand as he presses the buttons. He then gets the idea of how hard to press the button and eventually starts to do these things for himself.

He is really happy that he can now do most of the task for himself, although he still occasionally needs reminding to hang the washing out once the machine finishes.

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14 See 10 and 11

Positive Behaviour Support (PBS) is an evidence based approach to decreasing behaviours of concern and improving the person's quality of life. PBS planning devises the best way to work with a person who has behaviours of concern.

PBS has two main aims:

• To improve the quality of life for the person and those around them.
• To decrease behaviours of concern.

PBS does much more than focusing on the problem behaviour. It is underpinned by acknowledging that all behaviour holds a purpose. Ensuring an evidenced based understanding of this and implementing tailored support strategies allows the person to have a quality life and be an active member of their community.

PBS planning is the first step in the creation of a behaviour support plan. Planning involves:

4. Implementing the plan

• Making environmental changes
• Supporting the person to achieve long and short-term goals and increasing opportunities for access to a variety of activities.
• Teaching functionally equivalent replacement behaviours such as coping skills and effective communication
• Implementing short-term change strategies to promote rapid change in behaviour
• Implementing immediate response strategies, including de-escalation, to maintain the safety of the person and all others
• Supporting staff to ensure effective support that is consistent and predictable

5. Reviewing and evaluating

• Determining if the behaviour support plan is effective
• Evidence based outcomes
• Reviewing the process, its impact and outcomes
• May result in reviewing assessment or planning stages
• May result in a better quality of life for the person and those around them and reduced behaviours of concern. The plan may no longer be needed or may be modified as the individual's behaviour changes.

The development of behaviour support strategies will vary depending on the severity, complexity and risk factors associated with the behaviour of concern. In developing strategies and support plans, the person, their family or carers, supporters and other key stakeholders are consulted and included wherever possible.
Where restrictive practices are required to support a person who presents with actual harm or significant risk of harm to self or others, Mind implements relevant state legislative requirements such as seeking approval to use restrictions, developing specialised behaviour support plans, monitoring and recording the use of restrictions, always ensuring the least restrictive approach is used and ensuring staff have the relevant skills and training to implement supports. Any restrictive practice must adhere to Mind’s least restrictive practices policy and procedure.\(^{18}\)

Mind has a specialised Complex Care Support Team that assists in Positive Behaviour Support for people with a dual disability and complex support needs.

Two examples will further illustrate Positive Behaviour Support in action:

**Example 1**

James recently moved into a shared group home. He was very quiet and quite anxious. He was hitting out at other residents and support workers on a regular basis. He was strong and sometimes he would really hurt others. The staff team worked together to understand what was happening for James. They learnt the fact he had never lived away from his family before, he attended a community program during the day where this was not happening, and he had stopped engaging in a number of regular evening activities because of the geographical move. Through exploring the past and present for James, the staff came to realise it takes a long time for James to trust people. He was assaulted a few years ago by a stranger in the street. They also found out that he used signs and gestures at the community program to communicate some simple things. The staff also took careful notice of the settings and triggers for James’ lashing out. They realised it was usually when people came within a certain distance of James and were speaking loudly.

Through talking with his family, community program staff and finding out what they could about the things that had happened for and to James they determined that he could possibly be bored, or anxious and afraid of the new people he was meeting.

The staff tried a few strategies. They made sure they kept a reasonable distance from James when communicating with him and used a very gentle and reassuring tone. They asked other residents to do the same. They worked to help him engage in regular evening activities similar to those he had previously done. They also supported James to place his hand up in a stop sign if he wanted a person to move back from him.

These strategies worked over time and the hitting out reduced dramatically and eventually stopped. James was much happier and started enjoying all the extra activities he was doing, and got to know the staff and co-residents. He began to trust the people around him.

**Example 2**

Soula is a young woman with Fragile X syndrome and chronic and debilitating mental ill-health. She lives with her mother. She is a very tall and large woman. Soula was lashing out at her mother on a daily basis. This resulted in regular injuries to her mother. Soula was also prone to grabbing anything she could and throwing it at windows. There had been many broken windows.

Soula’s support worker met with Soula’s clinical mental health support team and spoke with her mother at length. Soula was unable to express her feelings and thoughts to the support worker, although the support worker spent time with Soula trying to develop an understanding of what was happening for her. It became clear that many things had been tried, but nothing had really worked. Things were getting more difficult because Soula had developed much greater strength now she was an adult.

Because of Soula’s complex needs a Positive Behaviour Support specialist practitioner was engaged to undertake a full functional assessment. In consultation with others the specialist was able to develop some positive behaviour support strategies and help mum, Soula and the support workers to put them in place. The specialist worked holistically on other aspects of Soula’s life that were creating boredom and frustration.

Over time these strategies assisted in reducing Soula’s behaviour of concern and improving her quality of life. Soula seemed much happier, was able to go out more and participate in community activities more, and mum was then able to have a bit of respite and did not feel afraid of being hurt anymore.

\(^{18}\) Mind Australia, 2017, Mind’s Least Restrictive Practices Policy & Least Restrictive Practice Procedure
Mind offers a wide range of services to people with a dual disability, their families and carers. We are welcoming of and committed to including people with dual disabilities in all our services. Mind also offers specialised support through targeted services that are delivered by staff with extensive experience and expertise in working with people with a dual disability. Many of these services are offered through the NDIS and can also be purchased on a fee-for-service basis or through an alternative individual support package such as through the Traffic Accident Commission or National Injury Insurance Scheme.

Our services include:
1. consultation, information and advice
2. recreation, leisure and support groups
3. counselling and coaching
4. in home and community support
5. supported independent living – long term, short term, respite residential services
6. sub-acute residential services
7. group learning
8. family and carer support
9. specialised behavioural intervention assessment and support
10. Positive Behaviour Support planning and training for practitioners
11. support coordination (assistance to coordinate support packages)
12. clinical and therapeutic services

We assess each request for service on an individual basis to determine our capacity to meet the person’s needs.

Mind’s workforce capability framework sets out the key attributes, knowledge and skills required of its entire workforce. We place emphasis on these capabilities for our staff working directly with people with dual disability.

Figure 3: Mind workforce capabilities (personal attributes, relationships and results stream)
Mind staff focus on holistic support and ensure they pay attention to the disability, physical health and the psychological and emotional support needs of the person. They seek to understand issues or problems the individual may be experiencing through this lens using a biopsychosocial\(^{21}\) approach.

Our staff:

- Communicate effectively and spend time to explore the person’s preferred communication style. They adapt the way they provide information and receive information to meet the individual’s needs. We can provide information in Easy English.
- Practice Person Centred Active Support. They support the active engagement and participation of the person in all activities, and are skilled at building independent living skills.
- Use Positive Behaviour Support strategies to assist individuals that demonstrate behaviours of concern.
- Seek information to understand each person’s unique support needs and understand that it is essential to establish a deep understanding of an individual and their circumstances.
- Include others that are involved in the person’s life to ensure everyone that cares about the person is collaborating and helping to obtain the best possible outcomes for the person.
- Support decision making by the individual and are strong advocates of human rights.
- Identify and implement reasonable adjustments necessary to protect the individual’s rights. For example, they may allow more time than usual for a meeting with someone if that person needs longer to comprehend information and express themselves.
- Protect the rights of people who are in particularly vulnerable situations. For example, they ensure a client being interviewed by police has an independent third party present or formal guardian where relevant.
- Know about the range of services (mental health, clinical and community) and community resources that are available to assist a person and their families and carers, or where to find this information.
- Acknowledge and are sensitive to the barriers and challenges experienced by people with a dual disability, their families and carers.
- Understand that people with disabilities are more likely than the rest of the population to have experienced trauma, abuse and neglect\(^{23}\). They provide trauma informed practice.

We have a dual disability Practice Advisor and Complex Care Support Team as well as full staffing teams with extensive experience in dual disability service delivery and working with people with complex needs, their families and carers. These staff support best practice at Mind and also provide a consulting and advisory service to our staff, families, carers and other government and non-government agencies.

Mind will create more opportunities to honour and learn from the lived experience of people with a dual disability and their families and carers, ensuring we are providing services and support in the most effective and supportive way possible.

We are committed to continually developing and evaluating our work with people with a dual disability, their families and carers.

We do this by:

- keeping abreast of contemporary research, service developments and national and international innovations and examples of best practice
- learning from the practice experience of our staff
- learning from our clients, their families and carers about their experiences, and the outcomes they achieve with our support.

We have in place and are continuing to develop a range of training programs to ensure an increasing number of our staff have the skills and knowledge required to work with people with a dual disability.

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\(^{21}\) The biopsychosocial approach systematically considers biological, psychological, and social factors and their complex interactions in understanding health, illness, and health care delivery.

\(^{22}\) This needs to happen with the consent of, and in consultation with the person.

Intellectual disability

A person is identified as having an intellectual disability if:

- they have a below average intelligence quotient (IQ) level of 70 or less (this relates to general capacity to engage in cognitive functions such as learning, reasoning, identifying patterns and relationships, solving problems, information processing, recall and planning)
- they experience challenges in adaptive functioning (undertaking daily and practical tasks in life such as caring for themselves, housework, banking, cooking and shopping)
- the disability occurs before the age of 18.

Approximately three percent of the Australian population has an identified intellectual disability. Eighty-five percent of those have only a mild intellectual disability. Most people with a mild intellectual disability can live independent lives in the community with a small amount of support from families, friends or paid support workers.

Only 1 to 2% of people with an intellectual disability will have a profound intellectual disability. A profound intellectual disability refers generally to someone with an IQ lower than 25. This could result in the person being unable to walk or talk. They may also have other disabilities. People with profound intellectual disabilities have very high support needs and will require assistance in every area of daily living.

Mind Australia, 2016, Practice factsheet: Intellectual disability

Acquired brain injury

An acquired brain injury refers to any damage to the brain that occurs after birth. That damage can be caused by an accident or trauma, by a stroke, by a brain infection, by alcohol or other drug abuse or by diseases of the brain like Parkinson’s disease.

Brain injury is common. According to the Australian Bureau of Statistics, over 700,000 Australians have a brain injury, with daily ‘activity limitations’ and ‘participation restrictions’. Three in every four of these people are aged 65 or under. As many as two out of every three acquired their brain injury before the age of 25. Three-quarters of people with a brain injury are men.

It can impact on:

- cognitive or thinking skills
- communication or speech
- physical and sensory functions
- emotions and behaviours.


Autism spectrum disorder

Autism spectrum disorder is a lifelong neurodevelopmental condition which can impact on:

- social communication and social interaction
- behaviour, interests and activities.

The word ‘spectrum’ describes the range of difficulties that people on the autism spectrum may experience and the degree to which they may be affected. Some people may be able to live relatively normal lives, while others may have accompanying learning challenges and require continued specialist support.

The main areas of difficulty are in social communication, social interaction and restricted or repetitive behaviours and interests.

People on the autism spectrum may also have:

- unusual sensory interests such as sniffing objects or staring intently at moving objects
- sensory sensitivities including avoiding everyday sounds and textures such as hair dryers, vacuum cleaners and sand
- intellectual impairment or learning difficulties.

An estimated one in 100 people has autism; that’s almost 230,000 Australians. Autism affects almost four times as many boys than girls.

https://www.autismspectrum.org.au/content/what-autism
In 2013, Dr Maria Tomasic, a Senior Consultant Psychiatrist at Disability Health in South Australia received funding through the Churchill Fellowship trust to visit a range of services for people with mental health issues and an intellectual disability in England, the Netherlands and Canada. At that time Dr Tomasic wrote:

‘People who have both an Intellectual Disability and a mental disorder are a particularly vulnerable group in the community who often fall through the gaps between mental health services and disability services and there is an enormous unmet need for appropriate mental health care. They are often unable to advocate for their own needs, suffer socioeconomic disadvantage and alienation within the broader community. They suffer higher rates of mental disorder than the general population and yet there are few specialised services for them.’

‘With the lack of appropriate services the burden of care too often falls onto family and carers who then risk high rates of emotional distress, family disruption and even physical harm and a reduced ability to care. This is not a satisfactory situation. Developing effective services and improving collaboration between disability and mental health services will have a positive impact on improving the lives of these people and their families and increase their ability for social inclusion.’

This statement, whilst only pertaining to people with mental ill-health and an intellectual disability, was equally true for people who had autism spectrum disorder and acquired brain injuries.

Since 2013 some significant progress has been made towards improving clinical and community support.

May 2013 A first National Roundtable on the Mental Health of People with Intellectual Disability was held in Canberra organised by the NSW Council of Intellectual Disability in partnership with the Department of Developmental Disability Neuropsychiatry University of NSW (3DN), Australian Association of Developmental Disability Medicine and the Queensland Centre for Intellectual & Developmental Disability (QCIDD), with the funding and support from Department of Health and Ageing. The meeting included a focused consultation with 95 recognised leaders in mental health and intellectual disability from consumer and advocacy representatives, health, mental health, disability, education and non-government organisations to develop ‘a guide for providers’ on ‘accessible mental health services for people with intellectual disability’.

2014 The Guide: Accessible Mental Health Services for People with an Intellectual Disability – A guide for Providers was written by the 3DN, University of NSW.

2016 The Intellectual Disability Mental Health Core Competency Framework: A Manual for Mental Health Professionals was written by the 3DN, University of NSW.

2017 The Intellectual Disability Mental Health Core Competency Framework: A Practical toolkit for mental health professionals was written by the 3DN, University of NSW.

2018 Second national roundtable event held in March. More than 100 leading mental health and disability experts including Mind met to discuss action needed to improve the mental health of people with intellectual disability.

There have also been a small number of specialist services established across Australia and a core capability framework for working with people with a dual disability developed by Western Australia Council of Social Services.

Appendix 1: Past to present

References

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