Alfred Child Youth Mental Health Service (CYMHS) Mental Health Intellectual Disability Initiative for Youth

- **What does the service do?**

The Mental Health Intellectual Disability Initiative for Youth (MHIDI-Y) is a specialist child and youth mental health service for children and young people (aged 12 – 25 years) with an intellectual disability and suspected mental health concern, experiencing challenges in emotional, behavioural and developmental wellbeing.

MHIDI-Y provides clinical mental health case management, assessment, treatment and consultation services, including a crisis response pathway.

As a Tier 3 service, MHIDI-Y specialises in the assessment and treatment of young people with a dual disability that affects their ability to engage in mainstream mental health services.

Young people have access to psychological therapies such as Cognitive Behavioural Therapy, Dialectic Behavioural Therapy and Family Therapy. Approaches are adapted to meet the cognitive, communicative and disability needs of the young person and family, for example:

- Adapted information, including family friendly, plain English, and strengths approach
- Mindful of lived experiences and impact of ID
- Use of alternative and augmentative communication such as visuals, signs, gestures, and communicative technologies
- Adapted verbal and written materials I.e. where abstract concepts are broken down into concrete ideas, learning is assisted through repetition of ideas, or use of associations to support comprehension

- **Is the service public/private?**

MHIDI-Y is a public area mental health service, part of Alfred Health Child Youth Mental Health Service (CYMHS), Neurodevelopment Stream.

- **What are the key roles in the team?**

The key functions of the MHIDI-Y team are to:

- Provide screening, assessment, intervention, treatment and consultation to improve mental health, physical health and wellbeing of young people.
- Engage with the young person using their preferred style of communication and tailor mental health treatment to meet the young person's intellectual capacity.
- Build capacity in care teams and provide practical assistance to improve behavioural concerns raised by families, schools, and other agencies.
- See young people and families in their homes, schools, work places or the community.

MHIDI-Y employs outcome measures for clinical and research purposes.

- **Is it a multidisciplinary team? How does it work**

MHIDI-Y is a multidisciplinary team. The team consists of:

- Consultant Psychiatrist
- Psychiatric Registrar
- Occupational Therapists
- Behavioural Intervention Specialist - Clinical Psychology
- Neuropsychologist
- Social Worker
- Specialist School Teacher – Avenues Education
- Speech Pathologist
- Family Peer Support Worker
- Psychiatric Nurse
- Peadiatric Registrar
- Evaluation and Research Development Officer

Each client is allocated a key worker who integrates interdisciplinary input and follows up the treatment plan goals. After intake, the first appointment usually involves a parent meeting to commence psychiatric assessment including completion of a developmental and medical history. Following this, a meeting is held with the young person to conduct a mental state examination. During assessment all clients are offered a physical health screen appointment with the Peadiatric Registrar (<18) or Registered Psychiatric Nurse (>18). Assessment of physical health is an important element in case formulation, particularly with those who have limited communication and behavioural disturbances.

At the end of the first 8 weeks, a psychiatric assessment report is complete by the psychiatric registrar, in collaboration with the Consultant Psychiatrist and key worker, with feedback from other disciplines involved. Short-term cases and consults may require only a letter back to the referrer, with a copy forwarded to the family, containing feedback and recommendations. Whilst a Comprehensive Assessment Pathway may require a more in-depth report.

Depending on the service pathway (Consultation, Short-Term or Comprehensive Assessment) a suite of adapted psychiatric and allied health assessments, tailored for people with intellectual disability, are administered and contribute to case formulation.

MHIDI-Y provides specialist consultation in the means of primary, secondary and tertiary consultation, to both external and internal agencies. All referrals for specialist consultation are directed through intake. Those not able to be managed through intake are triaged to the most appropriate team representative/s for follow-up.

MHIDI-Y provides opportunity for specialist workforce development, providing the only community based child and youth dual disability placement for allied health, medical and visiting professionals.

- **Why does it work for young people with intellectual disability and co-morbid neuro-developmental diagnoses, including autism?**

It is well documented mental health diagnoses present atypical in people with intellectual disability and co-occurring neuro-developmental diagnoses such as Autism (ASD), including:

- Communication challenges means a young person is often unable to express symptoms that clinicians look for when diagnosing a mental illness
- Behavioural and emotional challenges can be misinterpreted as a characteristic of intellectual disability or ASD, rather than being a symptom of mental illness. This is further complicated due to the unusual or infrequent presentation of symptoms in this population.

- Medical treatment of physical disorders or behavioural issues may mask mental health symptoms
- Medical histories may be inconsistent with missing or inaccurate information. This makes it difficult to determine whether a change in behaviour has occurred over time, making the process of psychiatric formulation a lot more complex.

For young people with an ID and ASD challenging behaviours can develop as learned ways of coping with situations found as difficult or can result from a mental health disorder. However challenging behaviour and mental health problems can exist at the same time. For example, a young person may display a long term challenging behaviour related to their ASD, I.e. repetitively checking items before leaving the home. This behaviour may remain whilst an additional behaviour indicative of a mental illness presents, for example, loss of interest in activities previously experienced as pleasurable (Depression). Alternatively, a long term challenging behaviour may remain but increase in intensity.

Determination of whether a behavior of concern is new or long standing or increased in intensity is necessary in navigating diagnosis in dual disability, particularly for those who are non-verbal or of moderate to profound intellectual disability. Diagnostic overshadowing can result in young people being left untreated or incorrectly diagnosed. Symptoms can exacerbate and a cycle of distress often emerges where parents and schools are overwhelmed and feeling unable to cope. Intervening early to break this cycle is essential.

As highlighted above, for young people with ID and comorbid ASD, psychiatric assessment and management is complex. Problematic if left to the onus of mainstream clinical mental health services. It takes specialist experience, expertise, time and resources to adapt psychiatric multi-disciplinary services in regards to screening, assessment, treatment, intervention and specialist consultation approaches. A burden that historically has played out with harsh consequences for young people and families, creating barriers to service access, to and froing between disability and mental health services and resulting in a community of unmet need.

A case management and multidisciplinary wrap around approach has demonstrated consistently to be an effective and comprehensive strategy with this cohort. MHIDI-Y provides a unique and attractive service for young people and families with access to a one-stop-shop of multidisciplinary support. For example, along with case co-ordination from a key worker who provides continuity of care, a young person may access a number of other disciplines depending on their needs. This may include:

- A clinical psychologist to work with the young person and parents providing adapted psychological therapies such as cognitive behavioural therapy or positive behavioural support
- A speech pathologist to adapt mental health treatment in line with receptive and expressive communication skills
- An occupational therapist to support emotional regulation from a sensory grounding approach
- A family peer worker, to walk alongside the parents, sharing their lived experience and supporting parents manage the stress and grief associated with caring for a young person with complex needs.

- **Is there any evidence supporting the outcomes?**

The outcomes for the MHIDI-Y pilot indicate that such a service has immense benefits not only for the mental health of the young people with intellectual disability and their families but for other

services. We are seeing shorter mental health hospital stays, improved liaison with inpatient units, diminished Emergency Department attending and improved general health care for these patients - as well as a more supported Tier 2 system (paediatricians, for example). We strongly see the need for similar specialised outpatient services for this population to be extended to other area mental health services.

MHIDI-Y has observed the following demographics and case complexities,

- History of physical aggression
- Property damage
- Exposure to family violence
- Sexual behavioural Issues
- School refusal
- Schooling issues
- Communication issues (50 words or less, Non-verbal)
- History of youth offending
- Parenting challenges
- Substance use
- Deliberate self harm
- Carer burnout
- Frequent engagement with emergency services
- Psychiatric hospitalisation
- Psychiatric medication complications
- Unemployed or not in a meaningul Day Program or Vocational Activity (18+ years)

MHIDI-Y is seeing positive outcomes in the following areas:
For Parents/Families/Carers of a young person with a dual disability:

- Connection with services
- Management of stress associated with complex care-giving
- Parenting skills to manage behaviours of concern
- Relationship between the young person, family and/or friends
- Education regarding their young person's mental & physical health, psychiatric medications, hospital admissions and strategies to manage mental wellness
- Hope for their young person's future and their ability to have a meaningful and productive life

For external networks including schools/vocational/disability and other health & community services (police):

- Care team communication and co-ordination
- Understanding of mental health and strategies to manage wellness in young people with dual disabilities
- Crisis management and safety planning in mental health

For young people with a dual disability:

- Connection with services I.e. NDIS
- Behaviours of concern
- Ability to name and manage emotions
- Ability to manage daily life stressors and associated anxiety
- Education and strategies to manage mental and physical health
- Ability to communicate needs and wants
- Participation at school (18-)

- Participation at Day Program (18+)
- Community connection and integration

- **How many young people have co-morbid neuro-developmental diagnoses, including intellectual disability and Autism Spectrum Disorder?**

Although the service criteria is primarily for young people with an intellectual disability, 90 percent have a co-morbid diagnosis of ASD, with 81% male and 19% female population.

- **What are the current barriers to it being more effective?**

MHIDI-Y is a pilot program and resourced to provide service in the Alfred Health catchment to young people from 12 – 25 years. Often behaviours of concern become more problematic and unmanageable around age 12, as young people hit adolescence. However, children across the life span experience mental health issues despite whether or not they have an intellectual disability.

Continued and increased funding is required to expand MHIDI-Y across the age range and state-wide to ensure all young people with an Intellectual disability are afforded equitable access to mental health care that is adapted to meet their needs, no matter which location they reside.

Nationwide, there has been a lot of interest reflected by the large number of enquiries asking about the work of MHIDI-Y and service model. We discovered there is not a ready-made workforce when recruiting staff who have expertise in both youth mental health and intellectual disability. Largely most staff have required training to develop and consolidate skills in dual disability. MHIDI-Y is the only outpatient youth dual disability service that provides a crucial platform sector wide for workforce development. I.e. MHIDI-Y takes on allied health, medical and psychiatric student placements and is currently exploring opportunities to create a Nurse Practitioner role, in partnership with a youth psychiatric inpatient unit.

- **Opportunities to improve service offering?**

In relation to the complexity of needs seen in the young people in the MHIDI-Y program, the service is focused on achieving the following goals:

- Continue work rolling out a review of service practices in line with the Intellectual Disability Mental Health Core Competency Framework, as referenced through the work of the University of New South Wales and NSW Government.
- All of team training in behaviour management including development of behaviour support plans and functional needs analysis to assist the young person, families and schools identify the reason for the behaviour and establish more adaptive behavioural responses.
- All of team training/skilling up in intellectual disability, ASD and communication processes. Including alternative and augmentative communication approaches such as use of key word sign, pictures, and communication aps etc.
- Adaptation of mental health psychological therapies such as Cognitive Behavioural Therapy, psycho-education, relapse prevention, recovery and safety planning
- Ongoing staff training in assessment and intervention in dual disability across a multidisciplinary team
- Continued partnership development with key service networks including sexual health services, NDIS, schools, police/corrections and juvenile justice services, Child First, Child Protection, Schools (mainstream and special schools).

- **How is funding received? Is this funding ongoing or once-off?**

MHIDI-Y is a 4-year pilot program, funded by the Department of Health and Human Services, Mental Health Branch. Alfred Health, Child Youth Mental Health Service (CYMHS) won the tender to roll out the MHIDI service with Youth (12 – 25 years) and Monash Health with the Adults (16 – 64 years). MHIDI-Y commenced in July 2016 and comes to the end of the pilot on the 30th June 2020. Alfred CYMHS is hopeful funding for MHIDI-Y will continue and extended to a state-wide initiative.

In the establishment of the MHIDI-Y tender and service design, Alfred CYMHS conducted three co-design forums that involved input from young people, families and relevant service partners with lived experience in mental health and intellectual disability.

In addition to co-design principles, the Alfred CYMHS MHIDI-Y service model incorporates elements of:

- Family centred practice, from a resiliency model
- Crisis management from a trauma informed approach
- Multi-disciplinary expertise, bringing together best practice with in disability and mental health
- Empowered decision making (recovery model)
- Systemic practice, building capacity and connection between the young person, families, care teams, services and communities

Future recommendations for the child and youth mental health sector

Reflecting on our experiences the following recommendations are proposed to address current service gaps. We hope that these may provide insight into the future direction of resources that would better support young people with a dual disability, their families/carers and the systems of care around them.

1. There is a missing step up, step down residential options such as a Prevention and Recovery Care (PARC) service specific for young people with a dual disability aged 12 – 18 years. There is a current service gap in meeting the psychiatric inpatient needs of this age range, especially for those with more moderate to profound intellectual disability who don't transition easily into existing hospital inpatient care settings. A PARC setting providing either short or medium term stay options is urgently needed. Such a unit could be designed with the needs of this group foremost so that the environment is more conducive to consistent care team response, assessment and management of challenging behaviours, more comprehensive opportunity for multidisciplinary and psychiatric review.

2. There are times when an urgent psychiatric inpatient stay is needed. Current psychiatric inpatient wards are not designed to support the special and complex needs of young people aged 13 – 18 years with a dual disability. Additionally, the risks are too high to mix this group with the mainstream during a psychiatric crisis. Recently one new model of care for young children have been explored with the establishment of the Oasis Unit. This new initiative will provide a vital new response for young children under 12 but unfortunately for those aged 13 – 18 years the only other option remains mainstream inpatient settings. There is an urgent need for more responsive inpatient options such as access to special beds/pods for 13 – 18 year olds in current inpatient settings for a longer length of stay in order to conduct effective psychiatric reviews. These pods or units could be attached to existing youth units and develop specialised treating teams with competence in dual disability.

3. From our experiences with families of a young person with a dual disability more and more consistent respite options are needed. In particular, more overnight options. Most families with a child with complex needs will require respite to manage the burden of care associated. So far our case experience has been that consistent and effective respite appears to be one of the strongest protective factors for managing stress, and sustaining family relationships and tenure in the family home. Respite also provides a necessary space so that parents can bond and care for other siblings. Other siblings can feel neglected due to the disparity in care time dedicated to looking after the other sibling with a dual disability. These issues often compound to the detriment of family functioning and lead to further mental health issues in other family members.

4. Due to the complex nature of care and cumulative stress associated with caring for a child with a dual disability some parents are unable to care for their child until adulthood. The decision for families to relinquish a child into care is typically traumatic. In some instances, parents are able to find alternative placement for their children through the Department of Human Services, however for many the only course open to them is to relinquish through crisis and child protection intervention and solutions. This further adds to the trauma of relinquishment because of stigma associated with child protection. Alternative placement options are urgently needed for some children who are unable to stay in the family home. The state disability system has historically managed many of these young people and there is a lack of clarity going forward as to how these young people will be served through the NDIS system.