<table>
<thead>
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<th>Category:</th>
<th>Therapeutic and Clinical Services</th>
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<tr>
<td>Entry Title:</td>
<td>The Mental Health and Intellectual Disability Initiative for Youth</td>
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<tr>
<td>Name of Applicant:</td>
<td>Richard Whitehead and Liza Hopkins</td>
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<tr>
<td>Organisation:</td>
<td>Alfred Health Child and Youth Mental Health Service</td>
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Additional Information about Entry

Within the current Australian healthcare landscape, individuals with intellectual disability (ID) and mental health difficulties and their families struggle to find appropriate services to assist them (Man, Kangas, Trollor & Sweller, 2018). The Mental Health and Intellectual Disability Initiative for Youth (MHIDI-Y) was created to address the gap in service provision and overcome the barriers that can limit individuals with ID receiving the mental health support they need. The MHIDI-Y was created based on the principles of co-design, involving service-user voices as a crucial aspect in the creation of the service. The result of the comprehensive co-design approach, combined with evidence-informed best practice, was the development of a service that was the first of its kind in Australia, combining a community based, youth-specific, multidisciplinary team that was person-centred, flexible, and supportive of the needs of families and young people. The service was particularly designed to specialise in the assessment and treatment of young people with a dual disability, who would otherwise not have their needs appropriately met in mainstream mental health services.

They key functions of the MHIDI-Y are to provide screening, assessment, treatment, and management to improve the mental health, physical health, and wellbeing of young people with an ID. A further function of the MHIDI-Y is to provide specialist consultation to other ancillary services needing specialist mental health support. To provide these functions, the MHIDI-Y team consists of: consultant psychiatrist, psychiatric registrar, occupational therapists, clinical psychologist, neuropsychologist, social workers, specialist school teachers, speech pathologist, family peer worker, psychiatric nurse, and a paediatric registrar. The team have been specifically trained in the dual disability of ID and mental illness and engage with young people using their preferred style of communication, so as to tailor mental health treatment to meet the young person’s intellectual capacity. Young people can participate in psychological therapies such as Cognitive Behavioural Therapy, Dialectic Behavioural Therapy and Family Therapy, and these therapies are adapted to meet the cognitive, communicative and disability needs of the young person and their family. In addition, MHIDI-Y provides advocacy and referral to other services to ensure the young person and their family are receiving comprehensive support across different areas of their life.

Although all families are different, the general treatment model involves each family being allocated a key worker who is the central point of contact for the family, and who integrates interdisciplinary input, and follows up the treatment plan goals. After a comprehensive multi-disciplinary assessment, a suite of adapted psychiatric and allied health assessments, tailored for people with ID are offered and contribute to case formulation. The MHIDI-Y works collaboratively with external care teams and provides specialist consultation to multiple services (including Tier 1 and 2), such as GPs, Paediatricians, Child Protection, NDIS and Disability Services. MHIDI-Y consultation aims to build dual disability capacity in care teams, helping them understand and separate symptoms of mental health from those of disability, and the interrelationship between the young person’s mental health condition, psycho-social and disability vulnerabilities.

A key aim of the MHIDI-Y is to provide innovative, person-centred and family focussed support where the young person behind the disability is ‘seen’. The MHIDI-Y program is the first program of its kind in Victoria that focuses specifically on supporting young people with co-occurring ID and mental illness, and uses a co-ordinated, multi-disciplinary, case management approach to treatment.
2.1 Evidence of a significant contribution to the field of mental health on a local, state or national level.

Research has shown that individuals with an intellectual disability (ID) have a higher prevalence of mental illness than the general population (Man et al., 2018; Platt, Keyes, McLaughlin, & Kaufman, 2019), with some studies suggesting the 64-65% of young people with an ID experience mental illness (Ludi et al., 2010; Platt et al. 2019). Young people with mental illness and ID also experience higher levels of aggression towards themselves and others than adults with ID (Weiss & Lunsky, 2010), and are at a greater risk of mental illness and suicidality (Young-Southward et al. 2017). Despite this, there is a lack of specifically designed services addressing the behavioural, biological, and mental health concerns of this group who can often fall through the gaps of traditional mental health services (Man & Kangas, 2019). One reason for this is the lack of a specialist skilled workforce to treat clients with ID and mental health issues (Donner et al. 2010; Weise, Cvejic, Eagleson & Trollor, 2020). There are also difficulties in distinguishing the characteristics of ID from those of mental health conditions due to masking effects, diagnostic overshadowing (Evans et al., 2012; Reppermund et al., 2017), and the atypical presentation of mental symptoms in those with ID.

Unfortunately, the lack of specialist targeted support has led to ineffective treatment practices including the overuse of antipsychotics to control aggressive behaviours (Edwards et al., 2007), a high level of polypharmacy among those with co-occurring ID and mental illness (Hobden et al., 2013), and a lack of agreed best practice guidelines specifically designed to treat those with ID (Man et al., 2018). A key focus of the MHIDI-Y was to address these barriers to treatment and provide comprehensive assessment and treatment for young people and their families/carers where they can receive individualised, specialist, biological, behavioural and mental health support.

As the first service of its kind in Victoria, MHIDI-Y has made a number of significant contributions in the field of mental health. As a tier 3 service, specialising in the assessment and treatment of very complex young people with both ID and co-morbid mental health concerns, MHIDI-Y offers care to some of the most vulnerable young people and most distressed families in the state. In addition, MHIDI-Y offers a specialist consultation service to other agencies needing advice and support when working with this complex and challenging cohort of young people. The significant, innovative features of the MHIDI-Y are: the specialist, highly trained workforce; the multidisciplinary assessment process; the coordinated multi-disciplinary suite of services; and the youth-specific psychiatric consultations focusing on the behaviour and mental health issues for young people with ID.

Specialist workforce

A major contribution of the MHIDI-Y is the development and training of the specialist team. There was no ready-made workforce in the field of dual disability when the program started. Consequently, there was considerable investment in the initial and ongoing research-informed training of staff to support the mental health of young people with ID and their families (see Man et al., 2018). The MHIDI-Y provides the only community-based, youth mental health service in Australia that offers specialist opportunities for trainees across the medical and allied health workforce. The MHIDI-Y team continue to evolve their practice in response to consumer feedback and assessment of service outcomes, and engage in ongoing training and development to ensure they are utilising research-informed best practice.

Comprehensive screening and assessment

One of the significant contributions that this program makes is in the intake and assessment phase of the program. This is due to the provision of a comprehensive and
supportive assessment process that is client-centred, and that seeks to understand the client from their own perspective. The initial assessment with the young person is adapted to optimise the young person’s capacity to engage, with consideration of the young person’s level of distress, mental health, and other behavioural risks. The purpose of an initial young person meeting is to get to know the young person, commence development of rapport and trust with the key worker, identify and engage with them using their preferred style of communication, and hear their concerns regarding their life and mental wellbeing. Having a specialist multidisciplinary team enables a comprehensive approach to the development of the young person’s recovery goals and provides a variety of perspectives and interventions to meet complex needs.

The assessment process involves a team with input from some or all of:

- Consultant Psychiatrist
- Psychiatric Registrar
- Occupational Therapist
- Behavioural Intervention Specialist - Clinical Psychologist
- Neuropsychologist
- Social Worker
- Specialist School Teacher – Co-location with Avenues Education
- Speech Pathologist
- Family Peer Worker
- Psychiatric Nurse
- Paediatric Registrar – through a partnership training program with Sandringham Paediatrics

Addressing diagnostic overshadowing/specialist youth-specific psychiatric consultations

To address the issue of diagnostic overshadowing, which is common in this cohort (Reppermund et al., 2017), the MHIDI-Y provides a rapid access pathway for clients for whom an opinion regarding pharmacological management is particularly sought. The clinic provides psychiatric assessment for the purposes of diagnostic clarification and treatment planning, with specific expertise in psychopharmacological management. Referrals are accepted from within the broader MHIDI-Y team or from external sources, including GPs, paediatricians, families, schools, or community agencies.

The MHIDI-Y’s specialist psychiatric service also plays a key role in focusing on issues of restrictive practice in addressing the possible overuse of medication in controlling behaviours in young people with ID (Edwards et al., 2007). The MHIDI-Y provides the best possible specialist advice regarding psychiatric medications and possible options regarding this, including potential side-effects and interactions between different medications.

Multi-disciplinary approach to treatment

Something identified as lacking in previous service provision for dual disability clients is a co-ordinated multidisciplinary approach to treatment (Man & Kangas, 2020). This is a key focus of the MHIDI-Y, and after the assessment process, a suite of adapted psychiatric and allied health assessments, tailored for people with ID, can be accessed. A key worker is allocated at intake and co-ordinates all the services involved with the young person and their families to ensure everyone is talking to each other and is collaborating on what is best for the young person and their family.
A typical client of the MHIDI-Y program may require multiple disciplines such as: a psychiatric consultant to monitor medication, a speech pathologist to address communication impairments, a behavioural specialist to provide positive behaviour support, a family peer worker to work with the parents, and an occupational therapist to optimise mental health and overall functioning. These disciplines may all be working together seeing the young person and their family and providing specialist consultation to the young person’s external care team. This multidisciplinary model, although unique at the time of the beginning of MHIDI-Y, has since been supported in recent research (Man & Kangas, 2020) identifying a coordinated multi-disciplinary model as best-practice when working with dual disability clients. This finding was also echoed in qualitative interviews with parents using the service:

To have a team that all come together and see them as a whole person, but each with their own little specialities, is amazing. That is exactly, as a special needs family, is what you hope for. Everyone on the same team, all working together, all chatting to each other. Really, that is what you hope for.

2.2 Evidence of innovation and/or recognised best practice.

The MHIDI-Y was the first program of its kind in Victoria and was established on the basis of emerging evidence for best practice in meeting the mental health needs of young people with ID and their families. To ensure the MHIDI-Y remains up to date with best practice guidelines and the latest research, as well as supporting the work of the MHIDI-Y from a systemic perspective, the MHIDI-Y Reference Group was established. The reference group provides a forum to support development, implementation, and evaluation of an integrated systemic service response to young people (12-25 years) with dual disability and their families. To ensure multiple perspectives and areas of expertise, membership of the MHIDI-Y Reference Group includes organisations such as DHHS disability, DHHS child protection, Victorian Chief Psychiatrist, Department of Education, NDIA, Forensic Service representative, Principle Practitioner Disability, VDDS Consultant, MHIDI Adult Consultant, lived experience parent of a young person with ID, Paediatric representative, the Centre for Developmental Disability & Health representative, and a representative from an adolescent psychiatric inpatient unit.

At a meeting of state-wide disability services at the Victorian Dual Disability Service, the MHIDI-Y’s reference group model was highlighted as a trail blazing model that could be extended to benefit the cohesion of state-wide intellectual disability services.

Although there is a dearth of research literature into the most efficacious evidence- and practice-informed best practice when working with dual disability clients, two recent studies highlighted what constitutes best practice for a dual disability service (Man & Kangas, 2020; Whittle et al., 2018). The findings of these studies identified the need for a holistic approach to treatment involving a system and assessment approaches that were flexible and could be adapted to suit the needs of the individual. This is a key feature of the MHIDI-Y where all services are tailored to the individual and their specific needs:

They basically adapt to the preferences (of the parent) and that really works well and when I've had to contact them, they've been available like on email. So, it's worked really well and, in a sense, that they're adapting to how life works for every individual. [Parent]

Psychoeducation was also identified a necessary component to best practice, providing parents/carers with training and education to assist them to provide support and identify potential risk factors in their young people. This is also a key factor of the MHIDI-Y, with much of the treatment focusing on educating the carers on how to best understand and communicate with the young person. This is highlighted in a parent’s description of the impact of the program on their interaction with their son:
...the way we approached him changed... I think a lot of the work has been done with us as parents... I think yes, we’ve taken strategies and we’ve taken really good ways of doing things. Like I said, I changed my style and it helped a lot... His behaviour improved; we were able to cope better.

Research (e.g., Man & Kangas 2020) also identifies the need for a specialized workforce with relevant clinical experience that engages in ongoing professional development and consults relevant research to ensure they are working towards an evidence-based best practice. As mentioned above this was a key aspect of the development phase of the MHIDI-Y with considerable resources going into training and development of the workforce that was specifically trained in the assessment and treatment of young people with dual disability and who can provide expert consultation to other professionals needing support in this area.

In addition to the Man and Kangas (2020) study, a recent study (Weise et al., 2020) was conducted into what the ideal intellectual disability mental health (IDMH) service would look like to families and carers. They found that the ideal IDMH service should provide both face-to-face clinical contact with individuals needing support, as well as providing advice and consultation to other mental health and disability services in order to enhance the system of care. This is also a major aspect of the MHIDI-Y, who provide specialist consultation and collaboration to multiple services to help them understand and separate symptoms of mental health from those of disability.

2.3 Evidence of participation of mental health consumers, in the planning, implementation and evaluation as relevant.

The design of the MHIDI-Y was based on the philosophy of co-design, which involved service users as crucial voices in establishing the guiding principles of the service. Recent research has shown the co-design process to be innovative and effective in mental health settings (Cooper et al., 2016). Co-design utilises the expertise of staff and service-users in a genuine and reciprocal relationship to create a better level of healthcare service experience. As dual disability clients and their parents/carers often feel that current service provision does not meet their needs (Weiss & Lunsky, 2010; Man & Kangas, 2020), the voices of young people with dual disability and their families was integral in the development of the MHIDI-Y.

The result of the co-design forums was the establishment of a number of aims of the MHIDI-Y, including:

1. Access to a flexible system
2. A service that was responsive to families in a welcoming and non-judgemental way with a range of family-based interventions including family peer workers
3. Innovative and best practice treatment models
4. Build on existing services with key partners
5. Intensive behavioural assessment and intervention
6. To make sure the young person “behind” the disability was seen

These were the guiding principles in the design of the MHIDI-Y, and provided the basis for ongoing workforce development and the service provision model of the MHIDI-Y. The MHIDI-Y continues to adapt to the voices of service-users in its continual development and evolution. For example, based on feedback from the parents and young people, the initial meeting was adapted to suit the needs of clients. For those with moderate to severe ID, flexible options were provided such as an initial parent meeting without the young person present, followed by a separate meeting involving the young person. This provided parents the space to talk openly about their concerns without exposing the young person to these difficult conversations.
The MHIDI-Y has also ensured service-user’s voices are integral in the evaluation process. In addition to quantitative measures used, a large part of the research involved lengthy interviews with parents/carers of young people attending the MHIDI-Y to ask for their feedback, and suggestions they have on improving the service. This is an important aspect of the service evaluation as it ensures service-users continue to be heard and are factored into the ongoing service development and adaptation.

2.4 Evidence of Partnerships and Linkages (collaboration for continuity between organisations).

Integral to the ongoing service provision of the MHIDI-Y are the many partnerships and linkages that provide collaborations to benefit the MHIDI-Y clients and the MHIDI-Y team. A major source of collaboration and linkages is the MHIDI-Y reference group described above. Discussion and collaboration at reference group meetings has been extremely beneficial for identifying systemic barriers and opportunities for service collaboration, understanding the extent and nature of unmet need and areas for advocacy for service development, as well as helping to identify key priorities for the MHIDI-Y.

Some further key partners with the MHIDI-Y are:

Education Department

MHIDI-Y has established a strong partnership with Avenues Education, a Victorian Education Department school providing specialist support to young people with mental health concerns. Avenues Education employs teachers with dual disability expertise and provide in-kind support which enables teachers to contribute to the assessment and management of young people with dual disability who encounter difficulty engaging or participating in schools. Input is provided in relation to curriculum content, the learning environment, and strategies to maximise participation or explore alternative education experiences that may be more suitable. MHIDI-Y has also been working hard with the special schools in our catchment providing outreach through clinical meetings, secondary consultations, input into behavioural management, and support plans and staff education sessions when requested. MHIDI-Y has liaised with every special school within the catchment over the first two years, developing trust and strong relationships.

Victoria Police

To help to assist the management of complex risks in the community associated with young people with a dual disability, the MHIDI-Y has a collaborative relationship with police to develop systems around flagging young people with special needs who have potential for offending. This includes providing consultation to police on how to best respond to incidents, assist in de-escalation, and prevent high-risk problematic behaviours. In situations where police are frequently involved, the regional Police Youth Resource Officer has engaged with the MHIDI-Y in taking a preventative approach by developing integrated crisis response plans. These plans are developed with the young person and family to ensure meaningful strategies to manage potential risks are identified and enacted.

National Disability Insurance Scheme (NDIS)

With the introduction of the National Disability Insurance Scheme (NDIS), a growing focus of the MHIDI-Y is to address the challenges that arise with the change in funding model for young people with a dual disability and their families/carers. To address these issues the MHIDI-Y team have embarked on the following:
• Involvement of the NDIS as a key partner to the MHIDI-Y Reference Group, providing a forum to address system matters that arise from NDIS access.
• Partnerships developed with the local area co-ordinator of Brotherhood of St Lawrence and Youth Disability Advocacy Service (YDAS) to deliver training to case managers who support young people and families through their NDIS application and review processes.

**Inpatient Units (IPUs) at the Alfred Hospital**

MHIDI-Y has played a role in minimising bed blockages and supporting a reduction in inpatient hospital stays including length of hospital stays for young people with a dual disability. Hospital inpatient stays are very difficult for young people with dual disability. The change in environment, routine, and proximity to family or carers causes anxiety and distress. The presence of this contextual anxiety can impede the diagnostic process and make it more difficult to determine cause and effect relationships especially when medications are being changed or trialled. There are also risks associated with inpatient unit stays including the vulnerability of exploitation amidst the general population. This can include risk of being sexually, emotionally or financially exploited.

To assist in minimizing the risks and providing the best support for young people with dual disability, and for hospitals seeing them, the MHIDI-Y team have advocated for ‘treatment in the home’ type models of care and when required shorter hospital stays. Partnership strategies that have assisted reduce length of stay include:

• Consultation to treating teams to assist review processes including medication rationalisation, diagnostic interpretation, and behavioural management support.
• Advocate for use of usual carers and disability support workers to support hospital staff in behavioural management,
• Facilitating liaison between hospital and community care teams to assist discharge transitions

**Respite Services**

For families with a young person with a dual disability, respite provides a much-needed break from the extreme burden of care associated with having a child with special needs. We have found that when respite service placements breakdown, this places greater strain on families who are barely managing. Respite placements can breakdown because of the complexities of managing behavioural issues in young people with dual disability and a lack of suitably trained care staff. To address this issue, MHIDI-Y have established partnerships with residential respite services providing consultation to support the staff better manage the young person’s behaviour and wellbeing. These partnerships provide positive payoffs in sustaining the respite placement, which in turn supports family functioning which may in turn improve the young person’s mental wellbeing.

**Disability Services**

MHIDI-Y has worked with a number of young people who are currently linked with Disability Services, including disability vocational services and disability support workers in the young person’s home. MHIDI-Y involve all parties of the care team to enhance communication and information sharing that positively supports the goals of the young person and their families/carers. The MHIDI-Y provides support to disability services by providing consultation to enhance knowledge and skills of disability support staff managing mental health and behavioural concerns in young people with an intellectual disability.
**Child Protection**

In cases where Child Protection involvement has been needed, the MHIDI-Y has worked closely with families and child protection workers to support the best interests of the child. These cases can be tricky to navigate particularly where competing interests of different family members exist, or where family members with full guardianship rights disapprove of the course of treatment. MHIDI-Y have worked carefully with Child Protection case managers to navigate these issues and advocate for the best interests of the child. Successful relationships with child protection and families have resulted in secure out of home accommodation placements and supported steps towards parent and child reunification.

**Paediatricians and other Medical Providers**

Many young people involved with the MHIDI-Y have complex medical needs, often overlooked because they might dislike change, or have difficulty tolerating blood tests and other procedures such as dental examination. MHIDI-Y has worked closely with our partner paediatricians and GPs. We see a clear role in supporting these practitioners, who often see the young person over many years. MHIDI-Y provides more in-depth monitoring for medication side effects and behavioural analysis than can be achieved in busy private practices. This assists greatly with medication rationalisation, ensuring the young person receives the most appropriate support for their physical health as well as mental wellbeing.

**2.5 Verification and evaluation of the program's effectiveness**

To establish the MHIDI-Y’s efficacy in reaching its aims to provide behavioural, medical and social support to young people with ID and mental health concerns and their families, the MHIDI-Y team included a post-doctoral research officer. The research officer undertook a comprehensive program evaluation at the end of the MHIDI-Y’s first four-year pilot.

The evaluation of the MHIDI-Y utilised a mixed methods approach to data collection and analysis. First, quantitative outcome measures were assessed at intake and again at completion of the episode of care with the MHIDI-Y. The well-validated measure of the Health of the Nations Outcome Scale (HoNOS) was used to assess any changes in client outcomes over the course of treatment. Results provided support for the efficacy of the program and show that young people who participate in the program showed overall improvements (see Table 1). Specifically, young people showed a significant improvement in their behavioural issues, such as violence directed at the self or others, and a significant improvement in social functioning, such as the quality of their peer and familial relationships. Clients’ level of impairment (e.g., scholastic ability) also reduced, although these reductions were not significant. Client’s symptoms (e.g., hallucinations) were also shown to remain stable. These findings were very promising given the complex nature of the cohort and the many issues of case complexity (see Appendix E).
Table 1.

HoNOS scores at admit and Discharge

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<tr>
<th>Measure</th>
<th>Admit Mean (SD)</th>
<th>Discharge Mean (SD)</th>
<th>Mean Difference</th>
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<tr>
<td>Total HoNOS</td>
<td>19.30 (7.48)</td>
<td>15.57 (5.04)</td>
<td>3.74*</td>
</tr>
<tr>
<td>HoNOS behaviour</td>
<td>4.74 (3.24)</td>
<td>2.96 (2.31)</td>
<td>1.78**</td>
</tr>
<tr>
<td>HoNOS Impairment</td>
<td>3.22 (1.47)</td>
<td>2.96 (1.67)</td>
<td>.261</td>
</tr>
<tr>
<td>HoNOS Symptoms</td>
<td>2.00 (2.15)</td>
<td>2.04 (2.01)</td>
<td>.043</td>
</tr>
<tr>
<td>HoNOS Social</td>
<td>9.35 (3.90)</td>
<td>7.61 (3.13)</td>
<td>1.74*</td>
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Note:** = p <.01, * = p <.05

In addition, qualitative interviews were conducted with the parents of young people using the service. In total, 10 interviews were conducted either in person or over the telephone. Interviews took between 30 and 65 minutes. Transcripts of interviews results in more than 40,000 words of data for analysis. A thematic analysis was conducted on the data according to four main areas of: experiences before beginning the MHIDI-Y; experiences of the MHIDI-Y; impact of the MHIDI-Y; and general feedback and areas for improvement. The results of qualitative study provided comprehensive feedback about parents/carers experiences of the program. Most of the feedback was positive with interviewees feeling supported by the program and reporting that the program had a positive impact on their own mental health, their ability to manage stressful situations, and their child’s mental health and behavioural issues. All parents/carers interviewed stated they would recommend the program to other families and saw it as an improvement on the services they had accessed in the past:

*I think this program should be rolled out everywhere, I really do. I think there is a lot of benefits for families, for schools that have these kids… I just think they are doing an amazing job. I'm thankful, really thankful. We feel lucky.*

Parents reported that the program had had a positive impact on the young person and the family in general. This was often discussed in the strategies that the parents themselves had developed for learning how to best communicate with their child and to assist them in difficult times:

*We went from a period of quite high anxiety in our household, him being quite aggressive in his behaviour to a period where actually regained some normality and control and it de-escalated the situation… the way we approached him changed… I think a lot of the work has been done with us as parents… I think yes, we have taken strategies and we've taken really good ways of doing things. Like I said, I changed my style and it helped a lot… His behaviour improved; we were able to cope better.*

Parents/carers described that they felt supported by the team and that they valued having a multi-disciplinary approach that was co-ordinated and personalised:

*We felt that there was a support network around us, we were more confident to face into it as well because we were at a point where we were just struggling to get through the day.*
Just the holistic family support that you get. You can’t get that from anywhere. There is no other program, in our area, from talking to other parents, that’s available.

Another of the other key themes from the interviews with the benefit parents/carers found in having the dual disability expertise of the team, who could provide advice and management around medication:

I think one of the features that has helped a lot is there’s been sort of a really detailed and focused piece of work around what medication (she) was taking, and the way we should increase or decrease dosages. I think that’s been a huge part of the success

A number of the parents/carers also made valuable suggestions for improvement. Specifically, a theme arose where parents/carers outlined the need for greater clarity about what the program entailed before intake, and greater clarity in relation to the length of time they could remain in the service. The MHIDI-Y views this feedback as crucial in its ongoing service provision and adaptation, and changes have been made regarding providing greater clarity to external referrers and to provide specific service pathways (e.g., short-term or long-term treatment or consultation) depending on client needs.

Recognition

In addition to the positive feedback received from service users, the contribution of the program in supporting young people with dual disability has been recognised by the Victorian Disability Awards where the MHIDI-Y was a finalist in the category of ‘promoting health and well-being for people with disabilities.’

Further, a detailed study documenting the design, implementation and evaluation of the MHIDI-Y was submitted and is currently under review in the Journal of Mental Health Research in Intellectual Disability. This research article makes a unique contribution to the research literature by providing the first investigation of the experiences and impact of a youth-specific dual disability service in Australia. Adding to the evidence and knowledge base by publishing in this journal not only provides peer-reviewed support for the MHIDI-Y but provides a blueprint for service implementation and effective treatment for young people with dual disability that can be followed by other services in the country or abroad.

Conclusion

The MHIDI-Y is the first youth-focused dual disability service in Victoria, and provides comprehensive assessment, treatment, and secondary consultation for young people with mental illness and ID, and their families/carers. The MHIDI-Y utilises an innovative multi-disciplinary specialist team to provide a co-ordinated and adapted approach to assessment and treatment that is flexible and addresses the individual needs and level of functioning for some of the most vulnerable young people and most distressed families in the state. The results of the program evaluation provide support for the efficacy of the program and provide evidence that this unique program addresses some of the common service and system failures found in the research literature. The findings also suggest that future services designed to treat dual disability clients may look to a specialist case management multi-disciplinary team as an effective model for clients.
Bibliography


Referees – (support letters available if requested)

1. Kerrie Hancox – MHIDI-Y Reference group member

Former Role
Principal Practice Leader
Integrated Health Care Team
Office of Professional Practice Community Services Operations Division
Dept. of Health and Human Services, Victoria.

Current Role
Director of Behaviour Support for Tasmania and Victoria
NDIS Commission

2. Dr Jane Tracy - Medical Practitioner, Disability Health

30 years of experience working with Victorians with intellectual disability; working in clinical, educational, and research roles.
I started having mental health issues when I turned 15 in year 9 at school, I struggled I was referred to CYMHS for my social problems, I saw an occupational therapist and I was put into a girls group, I struggled anyway bullied at school and bullied in this group I made to the end although, I stopped going after a while, when I was 22 or 23 I was had been through trauma so much it started to ruin my life, I went from happy and bubbly to always sad and suicidal person after 12 weeks of specialist counselling and suicidal thoughts because of the trauma I was referred to headspace, I was a broken and scared young person at headspace I didn’t really stick with anyone there, so one day I get a phone call and get told about this new program starting at CYMHS, Headspace referred me I was like the first client to get into the program I saw a great psychiatrist for 6 months she saved me from really just wanting to end it all I was encouraged to fight I was diagnosed with generalized anxiety disorder and PTSD then after 6 moths I saw another psychiatrist for 6 moths and the program was growing and I started to see the best psychologist she had been through the best of times and the worst of times with me she taught me a lot and helped move past my tears I cried a lot and I still feel embarrassed to have anxiety attacks in front of people, she helped me want to change and I would have weekly appointments and this psychologist she was also my case manager so I could call her anytime to get help outside my appointments them I reached the age 25 and was still at CYMHS at 26 I am in the transition and monitoring stages, this program is for anyone aged 12 – 25 and they have emotional difficulties of a learning disability to all youngsters out there never give up because you’re not alone and CYMHS really helped me and they can help you to I’m now going into adult mental health system and I still struggle I never gave up parents of these youngsters talk to your child’s therapists they will help you understand your child better I’m studying to be youth worker because I want to help youth just like I was helped when I was a youth thank you Alfred CYMHS and thank to all the people involved in my treatment for getting me to this point and your support is ongoing this my journey and its only just the start and I’m really happy it stated with CYMHS.
Appendix B – MHIDI-Y snapshot; a Mother’s story

The following is a mother’s personal story of her son’s journey while in the MHIDI-Y service. Her son is 13-years-old son, has Autism, intellectual disability, anxiety, and depression.

A mother’s story:

For us, parenthood is a gift. It is mostly, joyful with moments of heartache. Parenting a teenage boy with multiple diagnoses differs somewhat. It can be endless heartache, big to small. Then, peppered with moments of joy.

We live for our family; for family unity. My boy will always belong to our family and be called, "son" & "brother".

However, his life will be enriched if he chooses to be physically and emotionally present some of the time, surrounded by the few that truly care. Given the choice and opportunity, would a person prefer to stay alone in a world of pain?

Our son was indeed very sick. His mental health declined considerably in his 12th year and we crashed along with him. He suffered in all aspects of his daily life across all settings be it home, school, or respite facilities. We didn’t know how to help him feel settled and happy. We could not manage his behaviours. We were more and more isolated as a family from the outside world and within our home, sometimes taking refuge in separate zones like strangers in a hotel.

Family unity was in crisis. Caregivers in other settings felt the strain & struggled to cope.

Initially, at CYMHS there was much discussion. It became apparent he required urgent medical intervention.

Behaviour Support Intervention followed when he began to respond to medications.

Throughout, his caregivers, family, school teachers and respite workers have needed the knowledge, the strategies, the support, the confidence and the motivation to persist.

Very slowly, our son is improving as is his management of challenging behaviours. He continues to learn, little by little. We have good and bad moments, good and bad days.

Overall, more regular, joyful moments which we celebrate! Less heartache.

His peoples have a renewed sense of purpose and hope in helping him to succeed across the environments. There is greater collaboration between all parties.

So, it is not only our son who is changing for the better. We are changing as well.

CYMHS is helping our son find happiness. Consequently, we feel happier.

His family are remaining strong and united. He is learning to be a part of it and part of his school and respite families, too.

Together, CYMHS and all his families form a wonderful Team.

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PREPARING TO VISIT THE CLINIC

My morning at CYMHS

- On Wednesday at 10am I will visit CYMHS
- My Support Worker will drive me there
- I can bring a snack and a drink with me
- I can bring an activity or a game with me

When I arrive I will wait in the waiting room with my support worker and family

I will meet Rebecca and Rachel
ARRIVING AT THE CLINIC

Communication Board

- I have an appointment
- I need help
- Where can I get a drink of water?
- Where is the toilet?
- What is your family name?
- What time is your appointment?
- Who are you here to see?
- Take a seat and I will call your clinician
- I don't know
- I don't understand
- Can you write it down?
- I need help to calm down
ENVIRONMENT CONSIDERATIONS
POP-UP SENSORY ROOM
Appendix E – Issues of case complexity for current clients in the MHIDI-Y

**Behavioural contributors to case complexity**

**External contributors to case complexity**
Appendix F – Quotes from parents attending the MHIDI-Y

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<tr>
<th>Parents’ Experiences of the MHIDI-Y</th>
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<tr>
<td>“To have someone, to know that we’ve got people in our corner, yeah. It’s really impacted our family in a positive way.”</td>
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<tr>
<td>“There is one person who you should contact to co-ordinate everything, and who checks in on you. So, I think that’s been really well handled. It’s very different to anything else I’ve done before.”</td>
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<td>“I thought it was a great process. I thought they were engaging and I think they were great with my son and I can’t ask more than that.”</td>
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<td>“Our general feeling was one of a degree of reassurance. We felt like there was a focused approach to management of the issues that we were dealing with, by people that knew what they were talking about”</td>
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<td>“That one central point. That’s really effective and it’s efficient. I actually found that really … it kinda takes a load off.”</td>
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<td>“From my perspective, it’s great to have a team of people who are understanding the situation... I think it just gives you some comfort that you have specialists who will come up with some great ideas... to guide you and advise you on ways to manage some of the behaviours and situations that we have to deal with.”</td>
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<td>“(I was) very much made to feel like, I’m part of the team and an expert on my son... The expert. And so my views were very much valued and taken into account.”</td>
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