

Question 1: What's currently working well?

IHC recognises that there are some aspects of mental health and addiction services and supports that are working well. However, these are limited in number and they do not always work well for people with intellectual disabilities. There tends to be regional variation and lack of consistency across DHBs with pockets of good practice despite thinly stretched resources.

Co-ordination works well

IHC's consultation in preparing this submission suggests that whether coordination works well "depends on where you are." Examples were given of committed people with good relationships within communities (that often had been built up over many years) where local knowledge of people and their situations resulted in collaborations between disability support services, mental health services, GPs and other agencies such as Police that worked well for individuals with intellectual disabilities.

IHC is aware of another example of co-ordinated services working well involving maternal mental health care. This was a situation where a mother with mental health problems was caring for children in home including children with autism. The community mental health service worked well with disability support services and the NASC to coordinate supports for the mother and family.

Developing and working to best practice guidelines

Work by Spectrum Care with Auckland DHB pharmacists and other partners to review medications and develop transferrable guidelines for people in residential care is an initiative specifically aimed at addressing polypharmacy issues for people with intellectual disability. (J Garroick and A Prince. 2016 *Polypharmacy report prepared for Spectrum Care.*) This work provides a template for improving prescribing practices and reducing polypharmacy nationally.

Initiatives and supports that accommodate people with intellectual disability

The All Right campaign is delivered in a way that is accessible to many people with intellectual disability. IHC's Community Advocacy team has used the materials as the basis of wellbeing workshops.

Question 2 - What isn't working well at the moment?

People with intellectual disabilities are among the most disadvantaged and experience some of the poorest health and wellbeing outcomes of any population group in New Zealand (See IHC's response to question 5 for more detail). There is a lot that isn't working and many gaps across all aspects of the system for people with intellectual disability who often: face a lack of recognition of mental health problems; difficulty accessing services; responses that are not best practice; uncoordinated services; and are not counted or visible in quality assurance monitoring or Ministry of Health or DHB mental health reporting.

Starting with the person

There is a paucity of research about how people with intellectual disabilities and/or autism spectrum disorder (ASD) would like their mental health and treatment needs met. However, a recent New Zealand study (Matthews, M. *Autism and Comorbid*

Psychiatric Disorders: Assessment, Treatment, Service and Supports. A thesis submitted for the degree of Doctor of Philosophy at the University of Otago, New Zealand. June 2015) identified that participants didn't differentiate in their day to day lives between disability and mental health support. They expected support workers to have skills to assist with both. This is at odds with funding models which typically have separate funding streams for disability and mental health services.

Accessing mental health support

The first hurdle faced by people with intellectual disabilities is getting mental health problems recognised so they can access help when needed. Presenting problems are often dismissed as being 'behavioural' and due to the person's intellectual disability rather than indicative of an underlying mental health issue. This misattribution is referred to as diagnostic overshadowing.

Additional difficulties are experienced when there is a lack of understanding of intellectual disability and also of ASD. As examples, the heightened anxiety and/or sensory disorder and the level of distress experienced by many people with ASD are either not recognised or not sufficiently factored in to responses from services.

It can be difficult for people with intellectual disabilities and their families and disability support services to access help in times of crisis. Even if problems are recognised there is typically a high threshold of severity required in order for referrals to be accepted by mental health services. Waiting lists are usually long. Early and timely access is rarely achieved.

Access to counselling services isn't working well. It is difficult to find practitioners who understand and are able to work with people with intellectual disabilities. Being able to afford to pay for counselling or access funding support can also be a barrier. Counselling may be a longer process for people with intellectual disabilities and it is not easy (sometimes impossible) to get support over a longer timeframe. There is also often a misconception that people with intellectual disabilities can get counselling or specialist behaviour support services from their disability support provider if they have one.

While these issues occur across all life stages the transition from children's to adult services is a particular area of difficulty. Children and their families may have had support from paediatric services but despite often complex problems and co-morbidities as adults they are not deemed to be unwell or acute enough for adult mental health services.

The interface with services for older adults is another area where there can be gaps. Alongside problems in access and getting coordinated supports adults with intellectual disabilities can experience difficulties when age related problems are experienced at a younger age than the threshold for eligibility for older adult services.

Getting responsive and quality services and supports

Compounding the issues in recognition and access, services are siloed, under resourced and over stretched. Fragmented systems and funding models add to the barriers faced. The results are community based options are very limited as is support from mental

health services for people with intellectual disabilities, their families and disability support services staff.

This lack of high quality, timely, community based mental health support has extremely negative consequences for people's wellbeing and often leads to increasingly restrictive and sometimes abusive options being put in place. Individuals can end up in inpatient intellectual disability/mental health or forensic units that are more about containment than providing therapeutic and rehabilitative responses for people's mental health and wellbeing. Conversely it can be difficult for people to get specialist inpatient or residential care when they are in crisis or acutely unwell leaving individuals, families and/or disability support staff in distressing and sometimes dangerous situations.

Ashley Peacock's experience is a graphic case in point and example of the enormous amount of harm and 're-institutionalisation' that can be caused by faulty systems. Also illustrated by Mr Peacock's experiences are the difficulties in discharge from inpatient units, securing adequate funding for community living options and support, and getting collaborative working between DHB and community services. (Kirsty Johnston *Autistic man Ashley Peacock remains locked up a year on* New Zealand Herald 21 May 2018. https://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=12054812)

Further reported concerns included the loss of DHB funding for some community mental health vocational, day and recreational services (resulting in people having fewer supports and places to go and being more isolated with less social contact). Difficulties in finding and keeping work are also major issues.

Getting quality health services and reducing over medication

The lack of systemic action from government to address the disparities in access to healthcare and poor health outcomes experienced by people with intellectual disabilities is a national disgrace. Although improving health outcomes for people with intellectual disabilities is an action both in the Disability Action Plan and the NZ Health Strategy current work has stalled.

Too often physical health problems are missed or initial indications of problems are not adequately followed up. Added to these problems people with intellectual disabilities have a higher rate of polypharmacy than the general population. The overuse and overreliance of psychotropic drugs is of particular concern. Medication is too often used to manage people's 'behaviour', in many instances where there is no evidence that the drug used is either indicated or effective. A number of contributors to IHC's submission commented on poor consultancy input into the review of medications at hospital level and even poorer psychiatric input at community level.

Having a skilled workforce for quality supports

There is a lack of initial education and ongoing training for all health professionals in intellectual disability. While the supplementary mental health training in nursing is a step in the right direction, there is more to be done in nursing and for other health practitioners. In the UK there is a learning disability (UK term for people with intellectual disability) speciality in psychiatry that has had many benefits in clinical practice and research. New Zealand has no equivalent.

There are also issues around the current capacity of the disability support workforce and their training and support needs. Siloed training grants make it hard to get skills training across both the disability and mental health workforce inhibiting joint workforce development. Support staff employed by mental health services can't get free training in disability and vice versa for disability support services staff in mental health.

Agency and control

Having our personal agency recognised and control in our lives contributes significantly to our wellbeing. This is no different for people with intellectual disabilities. However, many are either denied the opportunity or do not have needed supports either in their daily lives or in their contacts with services. Outdated attitudes and practices in mental health and disability services about 'capacity' still exist despite being contrary to people's rights and inconsistent with New Zealand's obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Longstanding and persistent barriers to people with intellectual disability having autonomy, equal recognition before the law and access to justice include:

- Negative stigma that positions people with intellectual disability as not capable of decision-making, needing care and protection and even "less-than-human"
- A lack of timely, appropriate and specific support to individuals to help with decision-making
- Legislation that does not adequately recognise the ability of people with intellectual disability to make decisions with support
- The inability of the legal system, and the processes within it, to accommodate people with intellectual disabilities
- The absence of any pathways for adults with intellectual disabilities to seek protection or redress when they are mistreated.

(Office of Disability Issues. *Summary of progress on improving disabled people's exercise of legal capacity*. August 2017)

Currently processes for addressing concerns and complaints or challenging decisions in a timely manner are inadequate. There is also a lack of access to publically funded advocacy and limitations on what the Health and Disability Commission (HDC) is able to do. HDC can only investigate when services have been received so if lack of access to mental health services is the problem they are unable to be involved.

People with intellectual disability are not counted

People with intellectual disability in any setting in mental health (acute, forensic mental health, community etc) are not systematically counted or made visible in DHB reporting. Neither are people with intellectual disability included or identified in quality assurance mechanisms such as monitoring of seclusion. Where there is some information available this has to be extracted manually.

While there is potential in new initiatives for getting better data this is not realised for people with intellectual disabilities. One new initiative is the PRIMHD data base which enables the tracking of service activity and outcomes for individuals. Another is the Office of the Director of Mental Health annual reports, which have improved the transparency on the use of the Mental Health Compulsory Assessment and Treatment Act. However, people with intellectual disabilities are not identifiable in reported data. As examples the PRIMAD can't identify Intellectual Disability Compulsory Care and Rehabilitation (IDCC&R Act) care recipient seclusion data and the Director of Mental Health annual report doesn't identify people with intellectual disabilities.

Question 3: What could be done better?

There are a number of areas where things could be done better or differently in order to promote wellbeing and to improve mental health support and services for people with intellectual disabilities and their families. To be successful these need to be part of a holistic approach that

- starts with the person and not the diagnosis or funding stream
- invests in communities and provides more resourcing for early and more timely intervention and ongoing support.
- ensures service delivery is better connected across government agencies
- makes changes to commissioning and funding practices in order to break down silos and enable integrated ways of working.
- is sustainable over the longer term (underpinned by a cross party agreement).

In addition to the above steps that will benefit all New Zealanders IHC makes the following recommendations:

- Include people with intellectual disabilities and their families in all initiatives aimed at reducing inequities, improving education and employment outcomes and addressing the social determinants of poor health – poverty, financial stress, not having warm, dry and affordable housing, not being able to get a job, being discriminated against, being bullied, experiencing abuse and violence.
- Afford people with intellectual disabilities the same opportunities to access public health and mental health campaigns to enhance wellbeing and reduce abuse and violence and resource accommodations so that a range of accessible formats are available.

For better mental health services and supports

- Have easy to find information for people with intellectual disabilities, families and others in support roles to help in knowing what to look for so mental health issues are identified early.
- Draw on consumer feedback to make improvements to current services and to develop more flexible models of support that enable better coordination and more effective use of resources.
- Create more therapeutic and rehabilitative inpatient environments and community services, including through best practice guidelines and adequate resourcing. There are resources that can be drawn from such as NZ Autism Spectrum Disorder Guidelines and overseas reports and research on mental health support for people with intellectual disabilities. Reference should also be

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made to the principles and ways of working under community development approaches and Whānau Ora .

- More frontline staff and bed capacity so there are timely responses when individuals and families need help.
- Reduce polypharmacy and misuse of psychotropic medications by developing standard medication protocols to ensure prescribing and review practices are consistent with pharmacy/use of medicines. These processes should involve clinical pharmacists.
- Ensure all mental health professionals have initial training and ongoing professional development in understanding and working with people living with intellectual disabilities and with autism. This should include the recognition that mental health conditions may present differently in these population groups.
- Provide support and training for disability support staff in mental health that, amongst other things, promotes understanding that challenging behaviour may be a person communicating their distress.
- Implement the recommendations of Improving Health Outcomes Reference Group under the Disability Action Plan. This should not wait until the outcomes of the Mental Health and Addictions Inquiry or the recently announced health review.
- Count and make visible people with intellectual disabilities in all Ministry of Health and DHB data and quality assurance monitoring.

To promote and protect human rights

- Raise awareness about the human rights of people with intellectual disability, especially amongst mental health service providers, including rights to have supports and safeguards for decision making. Resources are available from IHC and Auckland Disability Law to support good practice and supported decision-making.
- Provide people with intellectual disabilities with the support and communication assistance they need to participate meaningfully in decision-making and the services they access.
- Review existing law, such as the Intellectual Disability (Compulsory Care and rehabilitation) Act 2003 and the Protection of Personal and Property Rights act 1988, to ensure consistency with New Zealand's international human rights obligations.
- Develop a legal framework based on supported decision-making rather than substitute decision-making. (The Irish model is a good example. See *Essential Principles: Irish Legal Capacity Law*, available here; <https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Legal-Capacity-Essential-Principles.pdf>)
- Establish pathways and publically funded independent advocacy for adults with intellectual disabilities to seek protection or redress when they are mistreated. This may include improvements or extensions to Office of the Health and Disability Commissioner.

Question 4: From your point of view, what sort of society would be best for the mental health of all our people?

The sort of society that would be best for the mental health of all our people is one that is inclusive and respects the human rights of all people, including people with intellectual disability; a society that enables us all to live lives of dignity and purpose. Tolerance, equity, inclusion, responsiveness, support and empowerment are among the values that would underpin such a society.

Greater understanding of and respect for human rights would help to ensure people with intellectual disability are able to participate fully and effectively in society on an equal basis with others.

Central to the mental health of people with intellectual disability is building a society that recognises and respects the right of people with intellectual disability to be the authors of their own life stories and ensures that effective safeguards are in place to prevent abuse.

All people with intellectual disabilities, including those with significant impairments, can exercise self-determination with supports. This is shown by research and enshrined in international human rights law.

Family and having good support

For all of us having good supports, especially to help us through challenging times, is critical to our mental wellbeing. A society that values and fosters strong, supportive families for all, throughout the life-course, would be good for mental health.

Education

Access to education can be major positive factor in mental health. IHC strongly believes that an inclusive education system is an essential component of good mental health for everyone. Currently many children and young people with intellectual disability are excluded from the education system, either formally or informally. Being excluded, not going through school with your peer group and not having the same opportunities for learning and participating in school life can result in trauma as well as a compromised education. (Starr, K and Janah, N. Challenging the Barriers: *Ensuring access to education for children with special educational needs*. YouthLaw. September 2016)

Work

Having a job is often fundamental to our wellbeing, providing a sense of purpose and enabling us to contribute to our communities. Earning an income makes a difference to how we live and therefore our wellbeing. People with intellectual disabilities tell us they want jobs but have difficulty finding paid work. People with intellectual disabilities must be included, and not left behind, in New Zealand's employment strategies.

Question 5: Is there anything else you want the Inquiry to know?

Across the lifespan people with intellectual disabilities are over represented in the social determinants associated with poor health including inequality, poverty, exposure to abuse, social isolation, discrimination, employment and education.

IHC asks that the Inquiry take into account the particular rights, needs and circumstances of people with intellectual disability of all ages when addressing the factors that can lead to poor mental health and when considering improvements to the mental health system.

IHC notes research by the Child Poverty Action Group that finds an accepted relationship between poverty experienced in childhood and a greater likelihood of mental health problems through the life span. (Gibson, K et al, *Child poverty and mental health: a literature review*. Child Poverty Action Group and The New Zealand Psychological Society. May 2017). A disproportionate number of children and young people with disability live in poverty. They are also more likely to live in low income families and in one parent households. (Disability Survey 2013). Children and young people with disability are also over-represented in abuse and neglect statistics and in the youth justice system.

We also draw the Inquiry's attention to the following:

- Males with intellectual disabilities have an average life expectancy of more than 18 years below that of all New Zealand males and females with intellectual disabilities have an average life expectancy that is almost 23 years below that for all New Zealand females.
- People with intellectual disabilities have higher rates of potentially preventable causes such as those from respiratory disease which occurs at twice the rate of that in the general population.
- People with intellectual disabilities are more vulnerable to mental health conditions than the general population with around 30% of people with intellectual disabilities having a mental health condition if behaviour disorders are included and 20% if behaviour disorders are excluded.
- 50% of people accessing MoH disability support services live in deciles 4 and 5 of the New Zealand deprivation index, the two most deprived decile ratings.
- Māori and Pacific peoples have higher than average disability rates after adjusting for differences in ethnic population groups.

Transformation of the disability support system.

Currently work is underway to transform the disability support system and implement the principles of Enabling Good Lives (<http://www.enablinggoodlives.co.nz/>). This 'new design' aims to increase choice and control for people with disabilities and their families, and provide more individualised, flexible and better integrated services and supports. The Objectives of the Enabling Good Lives Approach might be a useful resource for the Inquiry. They are available here:

<http://www.enablinggoodlives.co.nz/about-egl/egl-approach/objectives/>

About IHC

IHC was founded in 1949 by a group of parents who wanted their children with intellectual disabilities to participate in and have equal access to services in their communities. The IHC of today strives for these same rights, advocating for the welfare

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and inclusion of over 80,000 people with intellectual disabilities and their families and whānau in New Zealand.

IHC's service arm IDEA is New Zealand's largest provider of residential, supported living and vocational services for people with intellectual disabilities providing support for around 4,500 people. IHC's wholly owned subsidiary Accessible Properties is a registered community housing provider, is a charitable organisation and manages one of New Zealand's largest non-government social housing portfolios. IHC's charitable arm includes an extensive advocacy programme, a one to one volunteer programme and the country's largest specialist intellectual disability library. Nationally we work with many disability, community and government organisations and contribute internationally through our membership of Inclusion International.