

Developing a mental health service website for people with intellectual disability- Results report

Background

This research project conducted in 2021 aimed to look at what supports people with intellectual disability and their support networks require at each stage of a person with intellectual disability's mental health journey. A person's mental health journey includes times of good mental wellbeing, to first seeking help for mental health concerns, to recovery. The aim of this research study was to assist us to develop a mental health service pathway website. This Tool will link people with intellectual disability and mental health professionals to the resources that they need to support a journey through mental health services and to promote good mental health.

What the research study involved

Using interviews we consulted with 19 people with an intellectual disability and 22 support network members (carers, family members and paid support workers) around mental health and physical health support needs to inform the development of the website contents.

What we found

Good mental wellbeing

Participants provided their thoughts on what helps them or the person they support to have good mental wellbeing. People said these things in particular help them to have good mental wellbeing:

- exercise and sport
- relaxation and meditation
- friendships and doing activities with friends
- meaningful relationships
- having a sense of purpose
- choice
- adequate support
- being a self-advocate.

These ideas have helped to inform information and advice to include on the website.

Experiences with accessing supports for health concerns

Participants told us that they generally receive good support from their GP. It appeared most GPs have knowledge of appropriate supports for mental health, but some are not familiar with available community activities and groups that could help to support a person with intellectual disability's mental health. Feedback was more varied for allied health professionals such as psychologists. Many reported that allied health professionals did not have adequate knowledge of intellectual disability health issues and did not know how best to support them.

Helpful attributes of health professionals reported included having good rapport and good knowledge of health supports in the person's district. Unhelpful attributes included professionals asking people to repeat information for multiple assessments, a lack of knowledge around intellectual disability health, and not asking the individual how they were finding their medication e.g. side effects.

These results helped to inform groups (e.g. allied health professionals) we should provide specific information to on the website.

Supports that are required across a mental health journey

Participants identified that more supports and information are required for:

- support with trauma
- housing
- people in contact with the criminal justice system
- relationships and sexual health
- planning for old age.

We asked people what advice they felt was needed to help people navigate the mental health system. Advice required included:

- where people can find an advocate
- how people can advocate for themselves when navigating the mental health system e.g. calling mental health services if they do not hear back
- list of service types/service directory
- importance of peer support for finding services e.g. networking with other parents or carers.

Participants suggested including advice in the following areas for mental health professionals:

- that people with intellectual disability require support to get to appointments
- more information and supports should be provided around preparing for older age
- check if bullying may be the cause of behaviour change
- the importance of disability support staff visiting and ensuring a person has someone to talk to if they are in hospital for their mental health
- that regular appointments are needed to 'check-in' with a person to prevent hospitalisations and to prepare families for what to do if a person's mental health gets worse.
- that more follow-up support is required after discharge from hospital; people require home visits, a support worker/case manager and information as to what to do if their mental health gets worse.

We have included advice in the above areas for people with intellectual disability, their support networks, and professionals on the website.

How we have used the results

We have used the results from these consultations, along with survey data from mental health professionals to make the *Intellectual Disability Mental Health Connect* website. This website is being trialled in two NSW Local Health Districts before being made available to the public in early 2023. Tailored information is provided to people with intellectual disability (plain English and Easy Read), support networks, and professionals to help navigate the mental health system and support people with intellectual disability to receive quality mental health care.

For more information

If you would like further information about this study or the results, please contact Claire Eagleson, Project Officer at c.eagleson@unsw.edu.au or 02 9065 9516.

