

My Lived ID — Newsletter



Hello, and welcome to the My Lived iD newsletter.

My Lived iD is a digital hub for people with intellectual disability, their families, carers, supports and health care professionals. It is an initiative of the Centre for Developmental Disability Health.

This newsletter contains news about My Lived iD, and news, resources and training opportunities about health and wellbeing for people with intellectual disability.

We hope you find it useful!



New National Standard on the use of psychotropic medicines

The Australian Commission on Safety and Quality in Health Care released a new national standard on 9 May 2024, Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care.

This standard provides guidance to clinicians, healthcare services and consumers on the safe and appropriate use of psychotropic medicines.

[Visit the Commission's website to view the standard.](#)

News and Resources



New My Health Matters cards

The Council for Intellectual Disability has developed an Easy Read folder called [My Health Matters](#).

The My Health Matters Folder aims to improve communication between people with Intellectual Disability and all health workers. This includes [My Health Cards](#), which are Easy Read conversation cards to assist people with intellectual disability to have conversations about their health.



Free resource for GPs to better support patients with disability

[Practice Connect](#) from PHN Western Victoria is a free PDF resource for medical practitioners to better support their patients with a disability.

Visit the [My Lived iD resources page](#) to download and save PHN templates, videos and resources.



Inclusive health care training

New e-learning modules about inclusive health care from The Council for Intellectual Disability are now live!

The [Just Include Me](#) modules are CPD-accredited and aim to shine a light on person-centred care. Learn more about resources, tools, and actions to promote inclusion for people with intellectual disability.

[Get started on the My Lived iD site now](#)



Australian Government Response to the Disability Royal Commission

The Disability Royal Commission's final report includes 222 recommendations aimed at all levels of government. The Australian Government Response includes responses to the 172 recommendations within the Australian Government's primary or shared responsibility. It does not include responses to the 50 recommendations within state and territory governments' primary responsibility.

[See the Commonwealth Government Response](#)



Down Syndrome Regression Disorder

Down Syndrome Regression Disorder (DSRD) is a rare and puzzling condition that affects some individuals with Down Syndrome. It involves a sudden and unexplained loss of skills they had previously mastered, like speaking, socializing, and taking care of themselves. Scientists aren't quite sure why it happens, but they suspect it might be due to a mix of genetic, brain-related, and environmental factors. Researchers are actively studying DSRD to find clues about its causes and to develop ways to help those affected. While there's still a lot to learn, the ongoing research is a hopeful step towards better understanding and managing this challenging disorder.

[Down Syndrome Regression Disorders \(DSRD\)](#)

[Regression & Down Syndrome](#)

[Updates on Down Syndrome Regression Disorder: What You Need to Know](#)



National Centre of Excellence in Disability Health Annual Conference 2024

The first annual conference of the National Centre of Excellence in Intellectual Disability Health is coming up online on 21 and 22 August.

Sessions will provide updates on what the Centre is working on and share important information about intellectual disability health. Presenters include academics, clinicians, advocates and people with lived experience of intellectual disability.

Recordings will be available after the conference.

Detailed conference information is covered in this [easy to read webpage](#).



New project to increase mental health access for people with a disability

Co-design of new system-based solutions to support people with disability is underway in the Geelong–Greater Queenscliff, Frankston–Mornington Peninsula and Benalla–Wangaratta–Mansfield regions.

The National Disability Services x VALID Mental Health Capability Uplift Project is a statewide, co-design project funded by the Department of Health Victoria. It aims to equip these three newly established Mental Health and Wellbeing Locals to provide accessible, appropriate, and responsive mental health supports for Victorians living with disability.

Each area has its own project working group comprised of people with lived experience of disability, disability providers and representatives from the Locals. The project is set to wrap up in 2025. For more information you can email mentalhealthvic@nds.org.au.

More information about the Mental Health and Wellbeing Locals is at [Mental Health and Wellbeing Locals - My Lived iD](#).

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