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Rebecca Christidis & Lucy Reynhout

National Centre
of Excellence in
**Intellectual
Disability Health**

Acknowledgement of Country

Project team

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Working group

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- **Associate Professor Mary-Ann O'Donovan** - *CEO Centre for Disability Studies*
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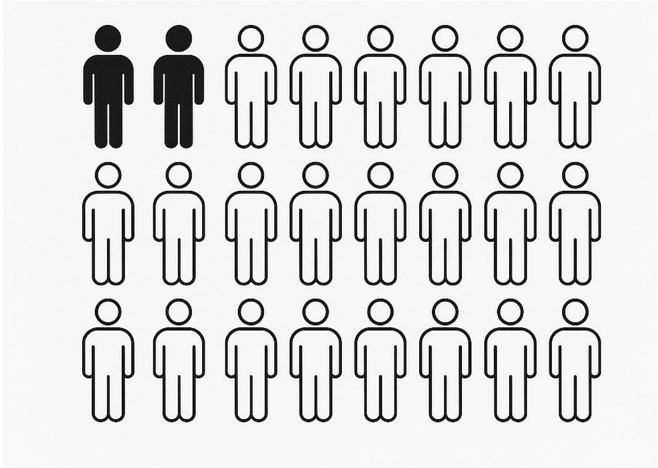
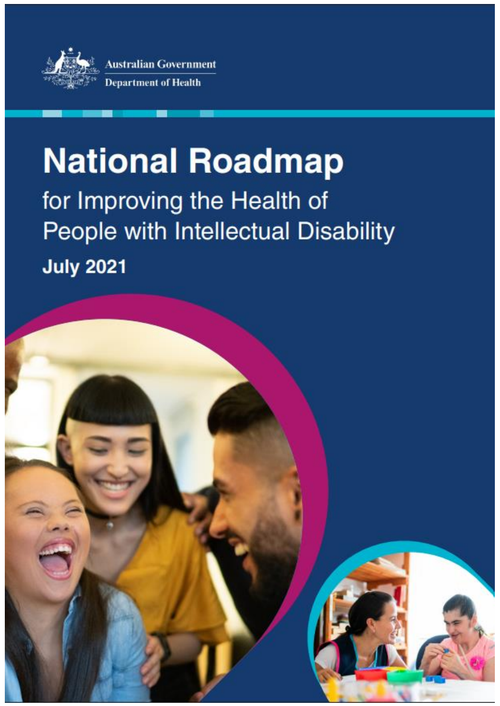
- **Dr Ellen Skladzien** - *Down Syndrome Australia*
- **Professor Helen Leonard** - *Associate Professor The Kids Research Institute*
- **Professor Jenny Downs** - *Head of Child Disability The Kids Research Institute*

Why this work matters



- **2%** of Australia's population have intellectual disability
- People with intellectual disability often experience poorer health and shorter life expectancy
- Health research critical in driving evidence-based policy and practice

Momentum for change



- National Roadmap[1], Disability Strategy (2021–2031)[2], and Royal Commission[3] highlight need for action
- Each framework calls for stronger data, research, and accountability
- The work examines whether funding aligns with these policy commitments

1. National Roadmap for Improving the Health of People with Intellectual Disability. Accessed at: https://www.health.gov.au/sites/default/files/documents/2021/08/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability.pdf
2. Australia's Disability Strategy 2021-2031. Accessed at: https://www.disabilitygateway.gov.au/sites/default/files/documents/2025-01/5831-dss3513-ads-strategy-2021.pdf
3. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Accessed at: Public hearing 4: Health care and services for people with cognitive disability | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Other research funding audits

- Research funding audits aim to identify **gaps in funding** and guide **where money should go**
- They check if research funding matches **health priorities** and **community needs**

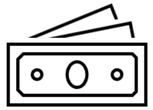
Examples of other audits:

- Cancer: mapped against national cancer priorities[1]
- Autism: compared funding with community priorities (Australia, UK, US) [2]
- Disability: checked funding patterns through published research[3]
- UK uses Health Research Classification System (HCRS) to compare[4]

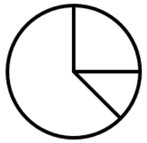
1. Cancer Australia. Cancer Research in Australia: an overview of funding to cancer research projects and research programs in Australia 2006 to 2011. Surry Hills, NSW: Cancer Australia; 2014.
2. Office of National Autism Coordination, National Institute of Mental Health, National Institutes of Health (on behalf of the Interagency Autism Coordinating Committee). 2019-2020 IACC Autism Research Portfolio Analysis Report. March 2024. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: https://iacc.hhs.gov/publications/portfolio-analysis/2020/
3. Smith-Merry, Darcy S, Dew A, Hemsley B, Imms C, O'Donovan MA. Et al. Who Funds Published Disability Research in Australia? Journal of Disability Policy Studies. 2024.
4. HRCS Online. Purpose of the HRCS 2025 [Available from: https://hrcsonline.net/getting-started/purpose-of-the-hrcs/.

Method

Audit aims



- How much funding went to intellectual disability health research (2019–2024)



- What types of health issues were studied

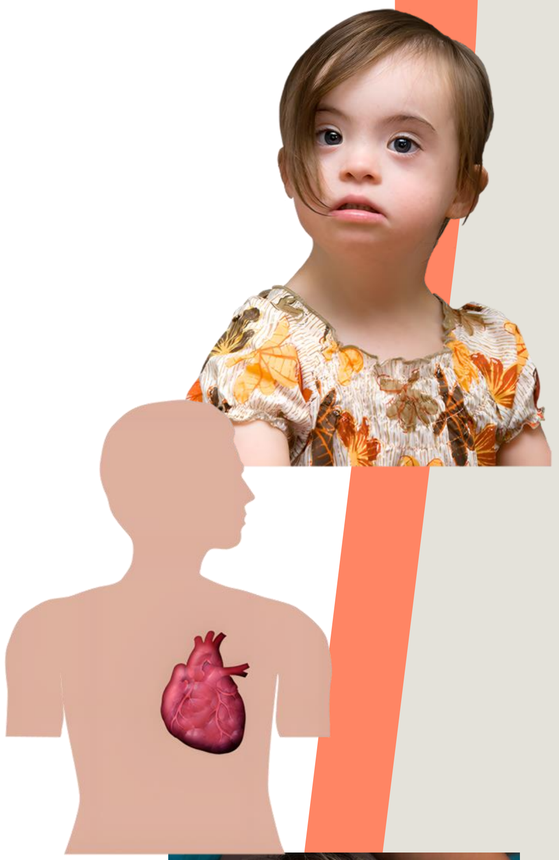
- What kinds of research were funded

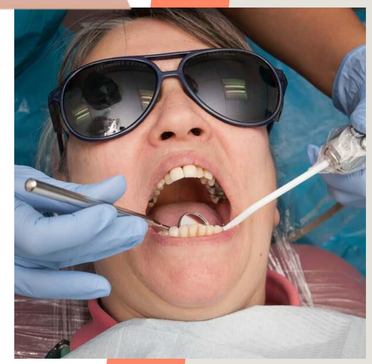
Method

- Data sourced from **Dimensions** database and desktop search
- **Inclusion criteria**: projects addressing both intellectual disability AND health
- Health Research Classification System (HRCS) to map health categories and research activity types

Health categories

- Blood
- Cancer and tumours
- **Congenital disorders**
- **Heart and blood vessel health**
- Ear health
- Eye health
- Infection
- Inflammation and immune system
- Injuries and accidents
- Mental health
- Metabolic and endocrine
- Musculoskeletal
- Neurological
- **Oral and digestive health**
- Kidney and urinary health
- Reproductive health and childbirth
- Respiratory health
- Skin
- Stroke
- General health and wellbeing
- Unclear causes and conditions





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Research activities **

- Basic research
- Causes of diseases
- **Preventing illness and staying healthy**
- Finding and diagnosing illness
- Making new treatments and medicines
- Testing treatments in real life
- Managing illness and health problems
- **Research on health and support services**
- **Consumer health care experiences****

HRCS Online. Research activities. [Available from]: https://hrcsonline.net/research-activities/

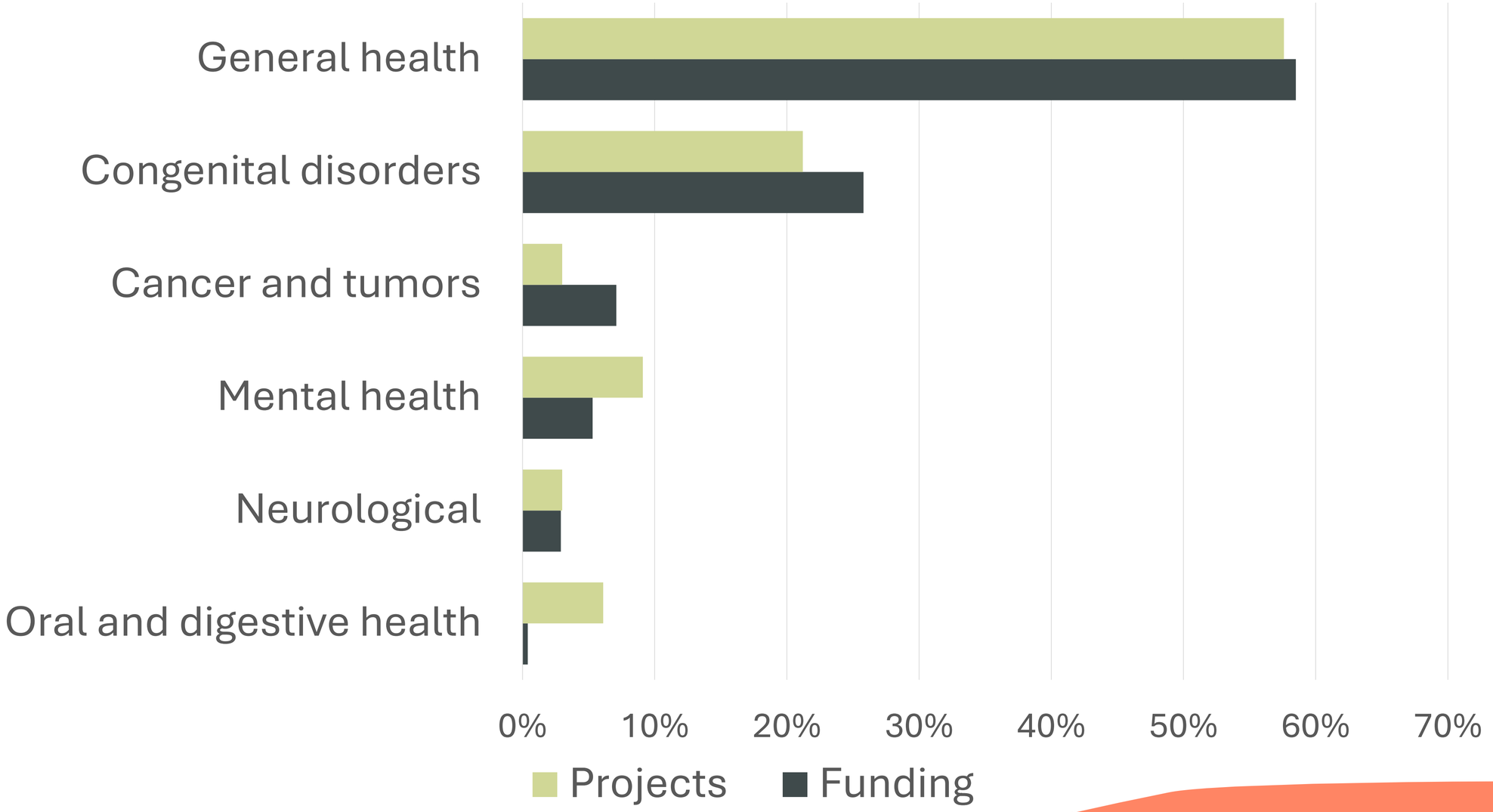
Working together

Results

What we found

- 33 projects funded between 2019 and 2024 (total AU$ 20.3 million)
- NHMRC ≈ 70%, MRFF ≈ 27% of total
- 2021 NHMRC Targeted Call for Research

Results - Health categories



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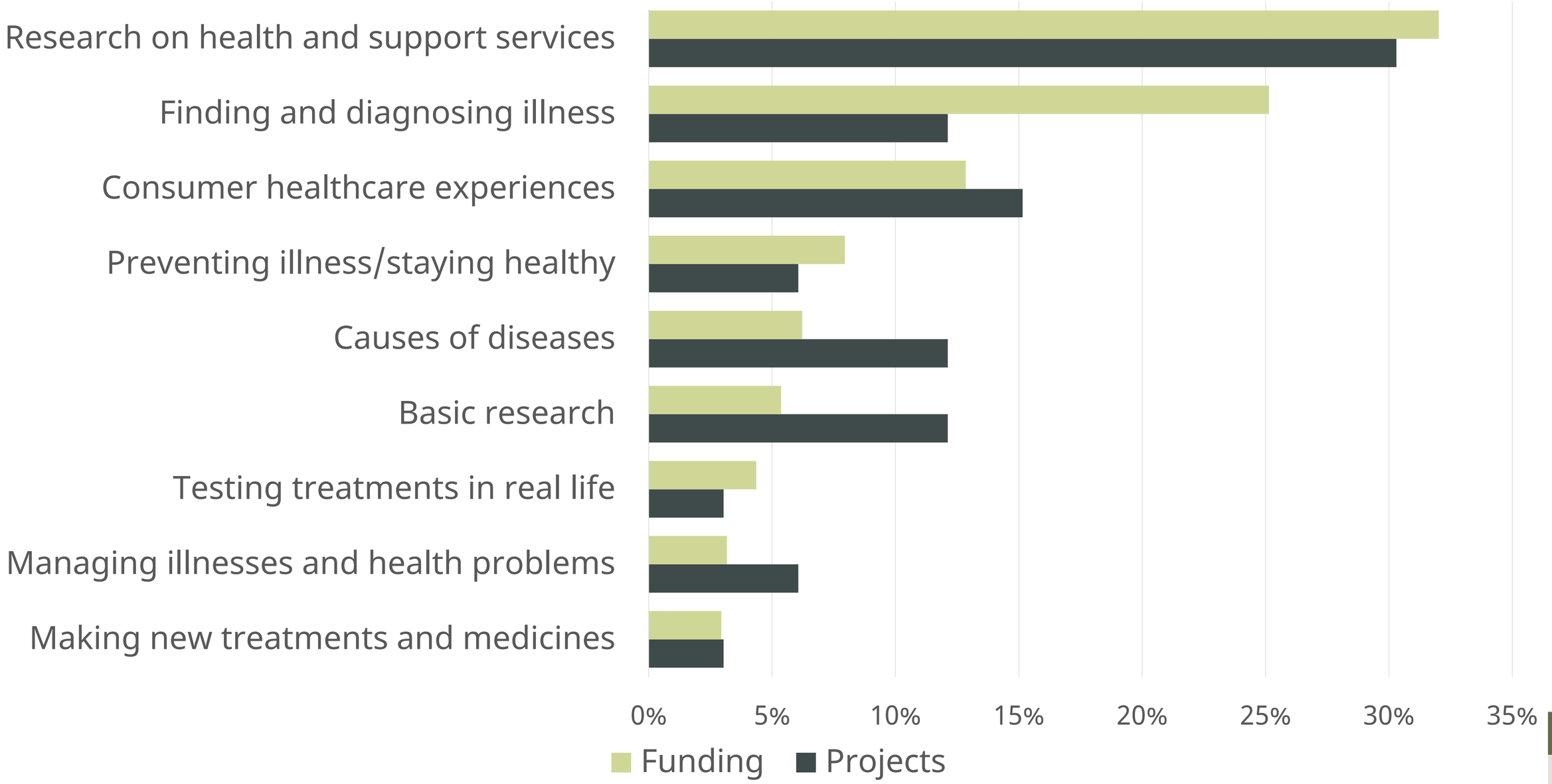
Research on health and support services
Finding and diagnosing illness
Consumer healthcare experiences
Preventing illness/staying healthy
Causes of diseases
Basic research
Testing treatments in real life
Managing illnesses and health problems
Making new treatments and medicines
0%
5%
10%
15%
20%
25%
30%
35%
Funding
Projects

What does this mean

- There isn’t enough funding for intellectual disability health research given the need.
- The one-off Targeted Calls for Research are an important chance for funding in intellectual disability health research.
- New research should:
    - Be about the areas where there are gaps
    - Say when it is focused on people with intellectual disability

Other work in the research landscape

The Centre is doing lots of important work in intellectual disability health research including:

- Co designing and setting national research priorities
- Building research skills and capacity
- Creating a strategy to make research culturally safe for people with intellectual disability
- Delivering inclusive research training

Scan here for more information about the Centre's research

National Centre of Excellence in **Intellectual Disability Health**

Thank you!

CDS Centre for Disability Studies | cid Council for Intellectual Disability | Down Syndrome Australia | First Peoples Disability Network | Queensland Centre of Excellence in Autism & Intellectual Disability Health | QDN Queenslanders with Disability Network | The KIDS Research Institute Australia | The University of Melbourne | UNSW Sydney

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