National Disability Data Asset

Australian Government
Department of Social Services

Australian Bureau of Statistics

AIHW

Disability led data and research to drive better lives for people with intellectual disability

Acknowledgement of Country

Recognition of self-advocates

We recognise self-advocates who have worked very hard over the years for equality and human rights for all.

CEO Inclusion Australia

Disclaimer:

The views I offer today are my own and do not represent the views of the Australian Government

National Disability Data Asset

Who is working on the data asset?

National Disability Data Asset

Australian Government
Department of Social Services

Australian Bureau of Statistics

AIHW

What will we talk about today?

National Disability Data Asset

Two main things

- Inclusive co-governance
- Data and data improvement

What will we talk about today?

Part 1: Inclusive co-governance

- The Charter
- What is co-governance
- Council and Co-chair role
- Advisory Panels

The Charter

Principles

Principles say how the data
asset should work.

Everyone has to
do what the Charter
says.

Rules

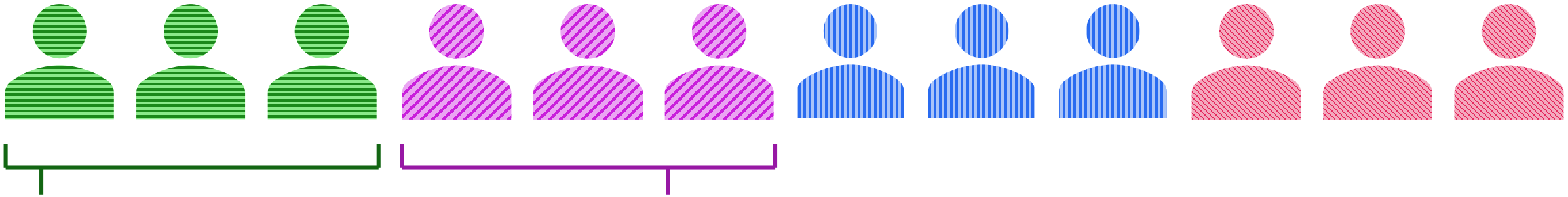
The rules tell
everyone what
can and **cannot**
happen with
the data asset

What is co-governance?

- The data asset is **co-governed** with people with disability and the wider disability community
- Co-governance means that governments and the wider disability community share responsibility and decision making for the National Disability Data Asset.

The Council

The Council is made up of:

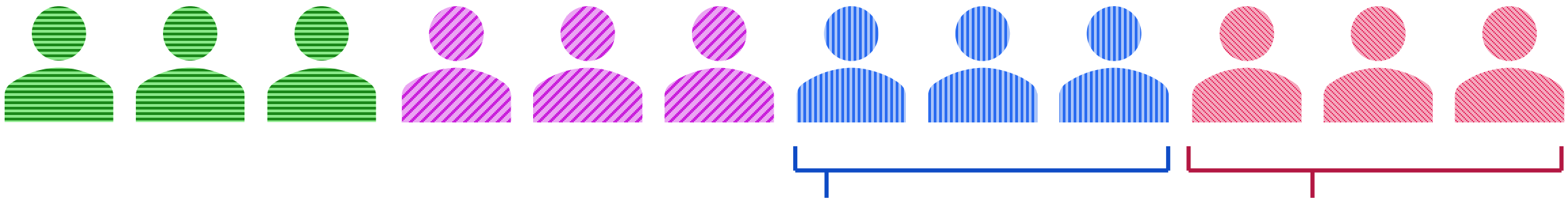


3
Australian Government representatives

3
state and territory government representatives

The Council

The Council is made up of:



3 disability community members

3 disability data experts

What does the data asset Council do?

- Makes sure the data asset is used in ways that help people with disability
- They tell disability ministers how to make the Data Asset better.

Advisory Panels

- The Council can set-up panels to share ideas on important topics
- Panels are groups of people who know a lot about something
- The panels include people with disability

Disability-informed Ethical Oversight Panel

The panel will

- Check projects that people want to use the Data Asset for
- Try to make sure those projects do not harm people with disability.

Panel Chair:
Dr Lisa Stafford

What will we talk about today?

National Disability Data Asset

Part 2 - Data

- What data about people with an intellectual disability is available?
- Development of ‘disability flags’

Why is data important?

National Disability Data Asset

Good data can

Help people advocate for laws, policies and services that work well

Good data can

Make sure the experiences of people with disability are at the centre of decision-making

‘There are refined insights into the lives of people with disability through data. The data tells our stories. It is our data’

National Disability Data Asset

Thank you!

Questions?