

NSW Health

Agency for Clinical Innovation

Intellectual Disability Clinical Network

Annual Forum

Prof Les White AM

Co-chair and NSW Chief Paediatrician

**Towards a Blueprint for Health Services
for People with Intellectual Disability**

SETTING THE SCENE

- The Work to Date
 - Today's Forum
- The NSW Health Blueprint of Services for People with Intellectual Disability (ID)

What is Intellectual Disability (ID)?

- Intellectual disability begins during the developmental period.
- The diagnosis is based on the severity of deficits in adaptive functioning determined by clinical assessment.
- Standardised intelligence testing is part of the person's assessment. (DSMV)

Health of People with Intellectual Disability

- Children, young people and adults with intellectual disability:
 - Have a range of additional health needs
 - Experience various impediments in accessing appropriate healthcare
 - Have poorer health outcomes
- Meeting such needs and removing impediments requires collaboration between agencies in and beyond Health services, as well as people with intellectual disability and their carers.

The Case for Change

- Additional health needs
- Poor health outcomes
- Challenges of access
- Scarcity of data
- Co-existence of ID/ MH/ Physical illness
- Consumers' and carers' expectations
- Workforce seeking support and guidance
- Alignment with National / State reforms

Drivers of Change in NSW as identified by the ID Health Network

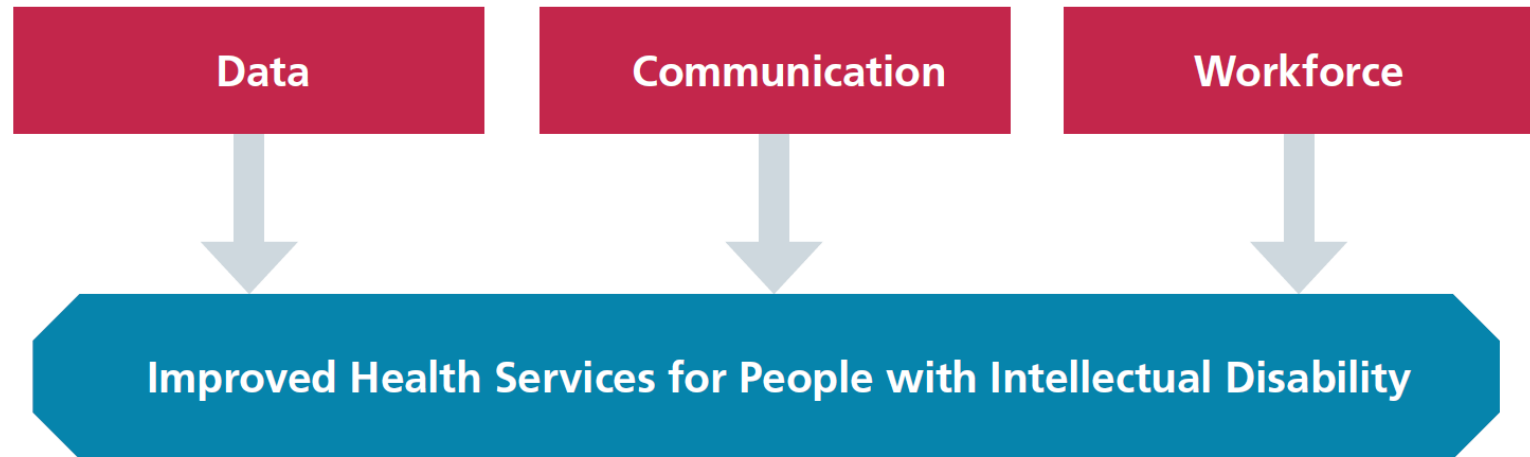


Diagram 1: The Identified Drivers of Change in NSW as identified by the IDHN.

The United Nations Convention on the Rights of Persons with Disabilities states:

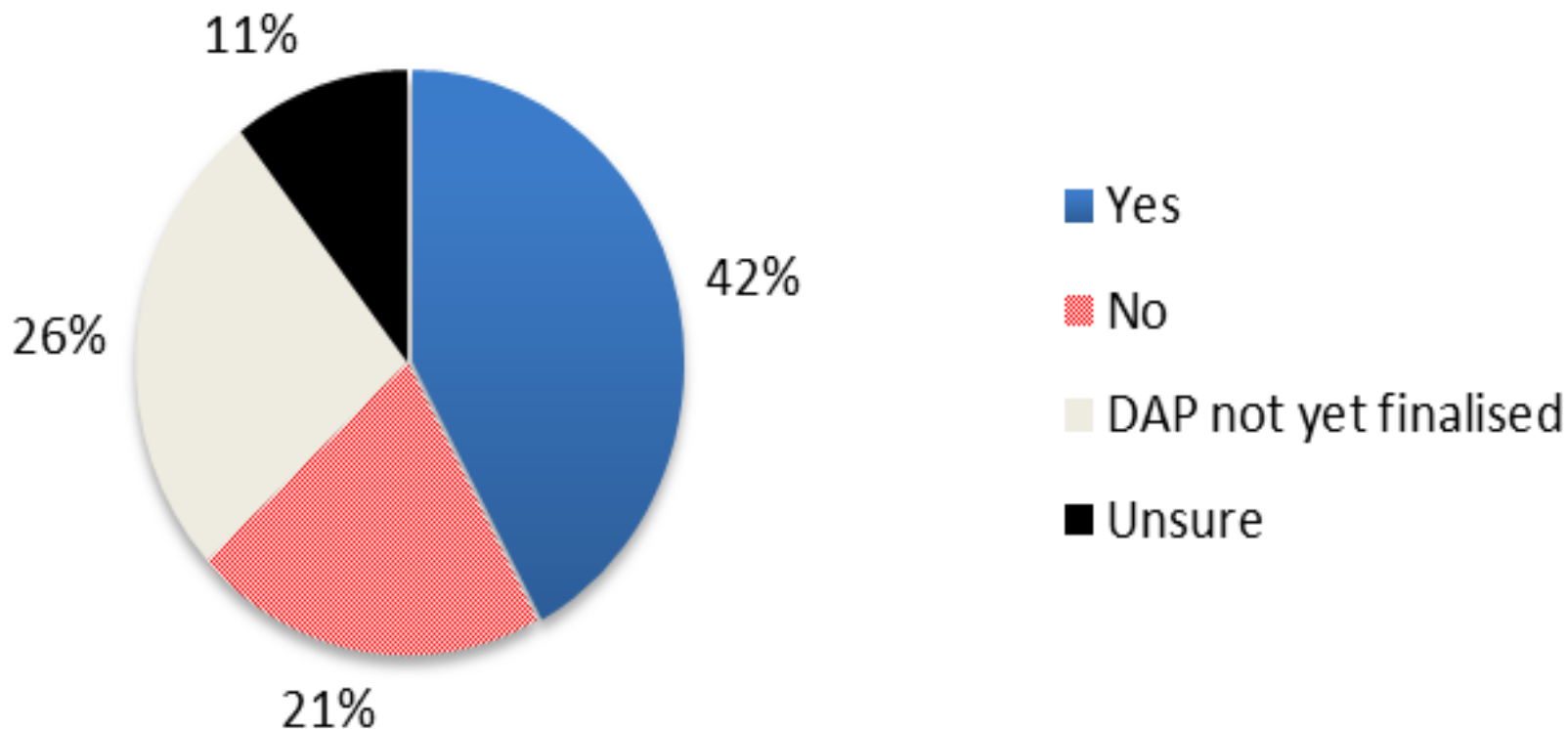
Persons with disabilities have the right to the highest attainable standard of health without discrimination on the basis of disability. They are to receive the same range, quality and standard of free or affordable health services as provided other persons, receive those health services needed because of their disabilities, and not to be discriminated against in the provision of health insurance (Article 25).

Entered into force : May 2008

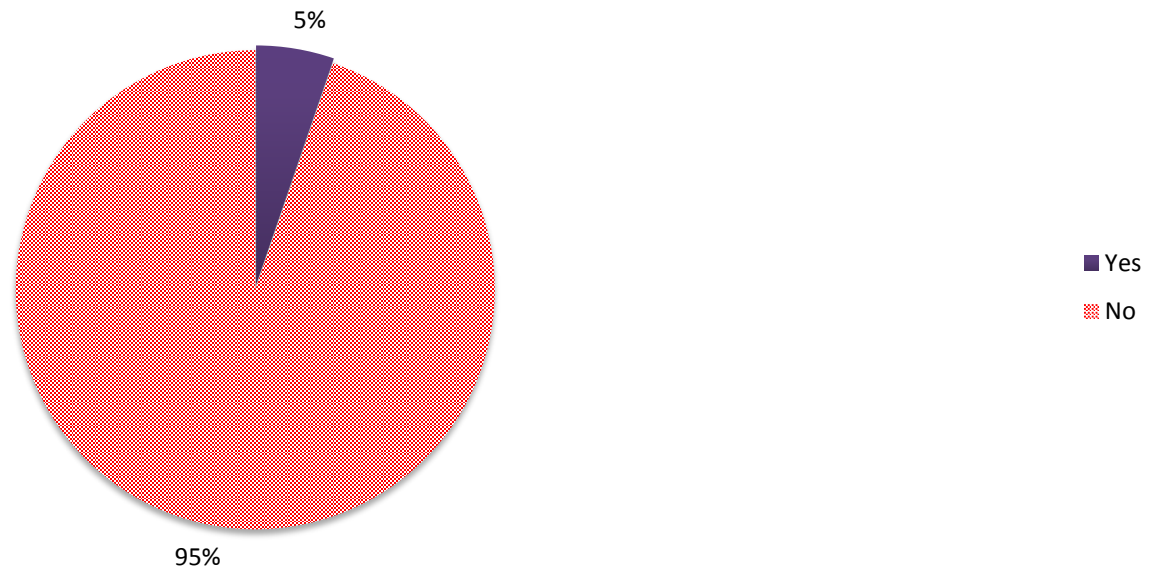
Ratified by Australia: July 2008

State Wide survey by ID Health Network (2013/14)

Does your LHD Disability Action Plan (DAP) include support for people with ID?

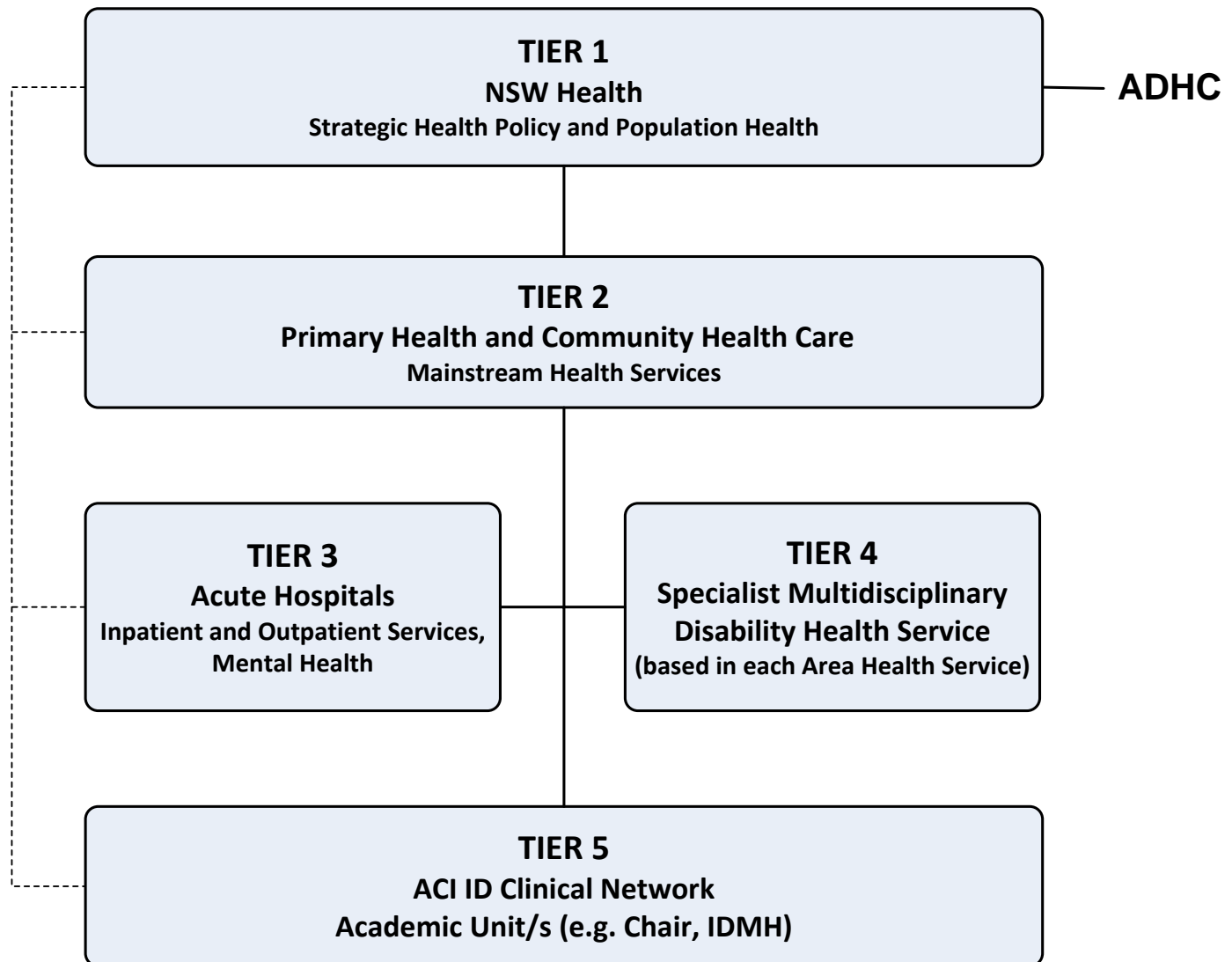


Are supports / adjustments routinely available for people with intellectual disability in your LHD to facilitate access to health services?



Service Framework to improve the health care of people with intellectual disability (Pub. 2012)

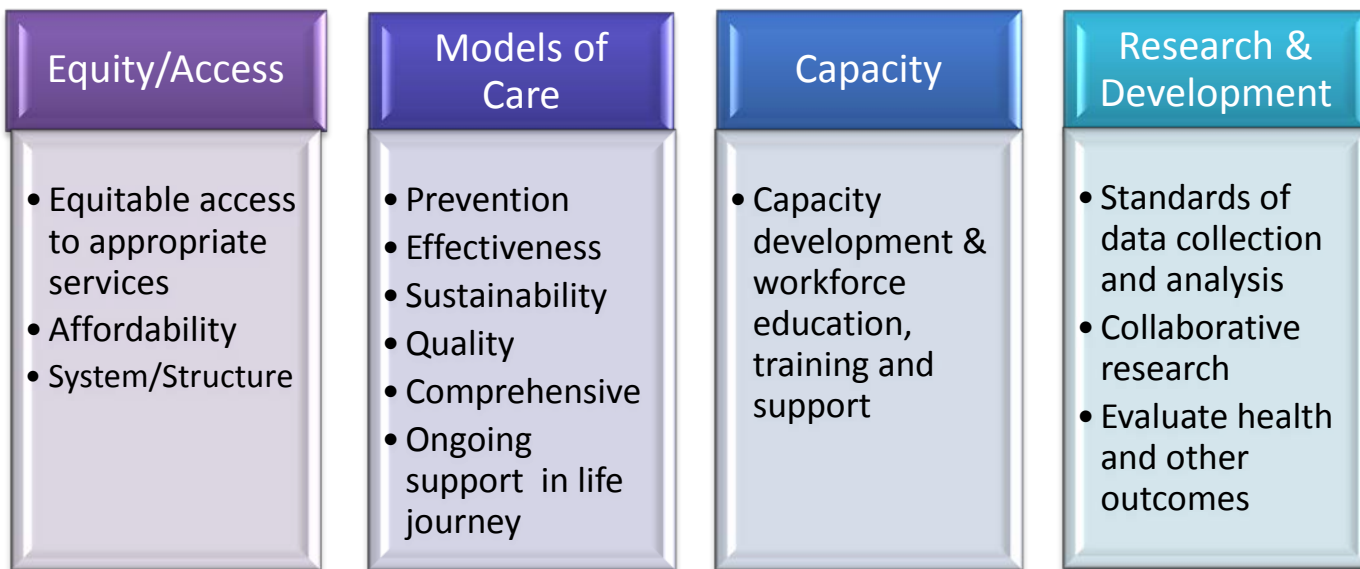
NSW Health Service Framework for People with ID and their Carers



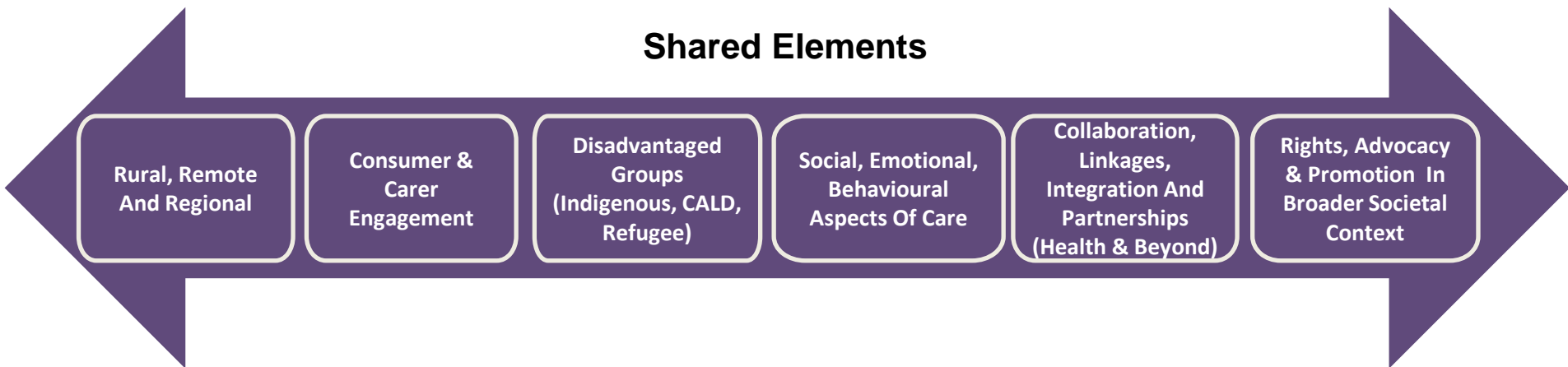
Activity Matrix of Intellectual Disability Network

Domains of Activity

To Progress and Promote:



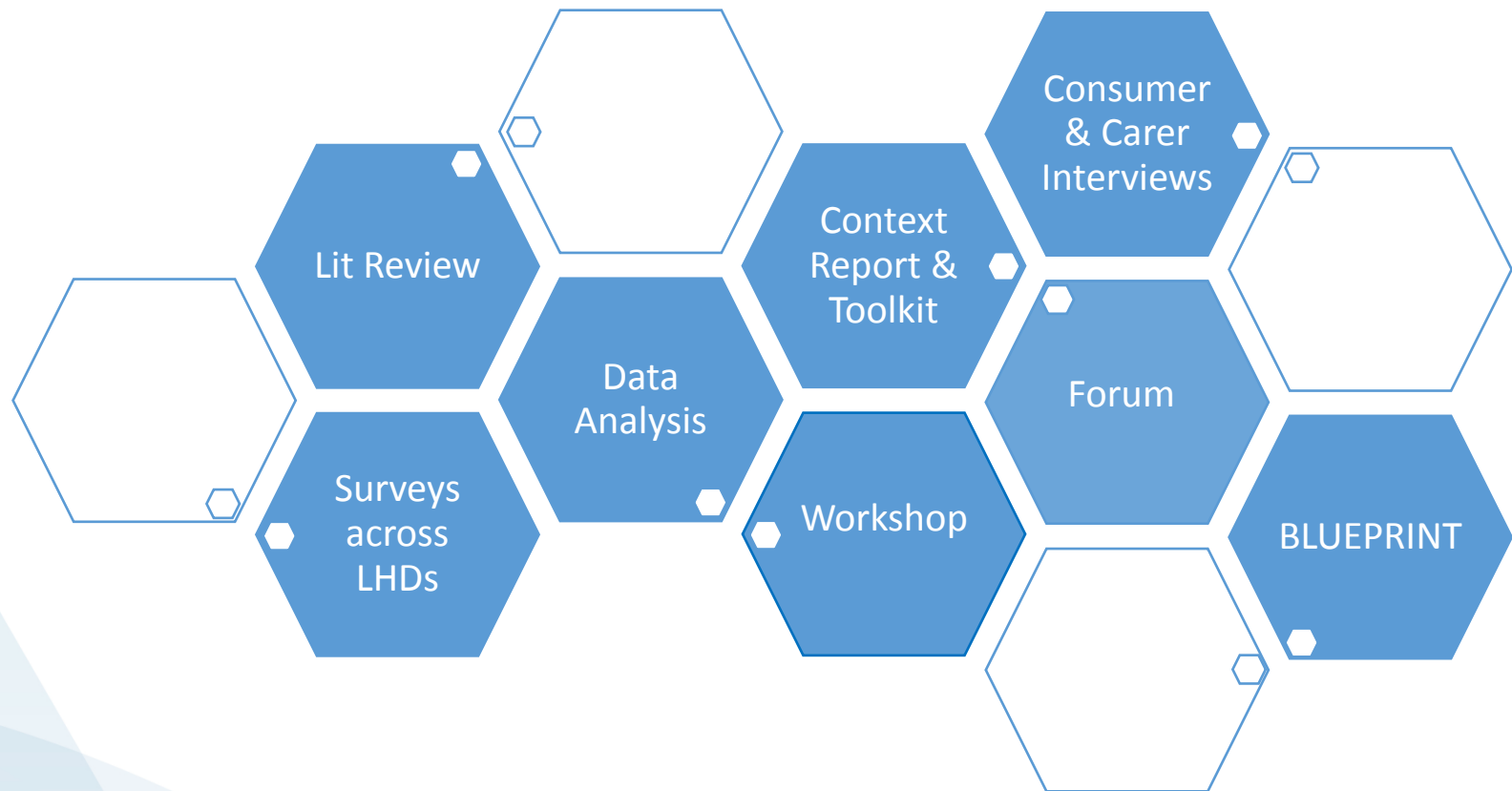
Shared Elements



The 3 ID Health Team “Pilots”

- Northern Sydney ID Health Team (NSIDHT) NSLHD – based in Cremorne
- Metro-Regional Intellectual Disability Network (MRID.net) SESLHD – based in Kogarah
- Specialist Disability Health Team (SDHT) CHW – based in Fairfield
- Other specialist services and hubs of expertise across NSW

The Pieces of the Puzzle



Context Report and Toolkit

A compilation to date of the work undertaken by the Network's membership.

The 16 sections align with key themes

Links with toolkit and other relevant documents

Collaboration within NSW
and other agencies and Carers

Component of Resources package

The Literature Review

The Social Policy Research Centre (UNSW), conducted a literature review of current models of health service delivery for people with intellectual disability for the period 2011-2015.

Key Findings:

- Nine models of health service delivery. They stressed the need for interagency collaboration.
- The importance of integration of expertise from specialist services within mainstream services

Faculty of Psychiatry of Intellectual Disability (RCP UK)

Community-based services for people with ID / MH
Recommendations:

1. Person-centered; service spectrum; skilled staff
2. Interdisciplinary / inter-agency; pathways
3. Outcome-focus; support at / near home
4. Research and evaluation
5. In-patient ID / MH facilities
6. Service configuration of networks and community teams
7. Workforce development

Guiding Principles for the Delivery of Health Services for People with ID, as developed by the NSW ACI IDHN

- 1. People with ID should have the same access to and quality and range of health services as other people.**
- 2. People with ID are individuals, and part of their family, community and culture. Health services should recognise these parts of their identity.**
- 3. Health care services should be delivered in a person and family centred way, based on a human rights framework.**
- 4. Early diagnosis and intervention is necessary to ensure optimal outcomes.**
- 5. The additional determinants of poorer health outcomes for people with ID should be recognised.**
- 6. Health services for people with ID should be integrated across primary, secondary and specialised care and delivered in the local community whenever possible by appropriately trained staff.**
- 7. Specialised health services have a role in improving health outcomes for people with ID and complex, chronic health needs.**
- 8. Other government and non-government agencies (e.g. schools, supported accommodation services) may play an active role in maintaining the health or treating an acute illness for a person with ID.**
- 9. Health policy and models of care for people with ID should be evidence-based.**
- 10. Data should be collected and used to inform ongoing health service development.**

Guiding Principles

Underpin the work of the Network

■ For example :

Principle 6: Health care services for people with intellectual disability should be **integrated** across primary, secondary and specialised care and delivered in the **local community** whenever possible, **by appropriately trained staff**.

Measuring meaningful outcomes is the starting point for value-based health care reform

5 reasons why outcome measurement is essential:

- 1 Outcomes define the **goal of the organization** and its accountability to patients
- 2 Outcomes inform the **composition** of integrated care teams
- 3 Outcomes highlight **value-enhancing cost reduction**
- 4 Outcomes motivate clinicians to collaborate and **improve together**
- 5 Outcomes enable payment to shift **from volume to results**

what matters most

Patient Outcomes and the
Transformation of Health Care

Faculty of Psychiatry of Intellectual Disability (RCP UK)

ID Outcomes Framework Domains:

1. Prevent premature death
2. Enhance QoL and determinants of health
3. Keep out of hospital; recover from episodes
4. Positive experience of healthcare
5. Safeguard vulnerable adults

Consultation around the Context Report and Toolkit and ultimately the Blueprint

The Solution Design Workshop (June 2015):

- 60 people - representatives from NSW Local Health Districts with the Network's Executive Group and the Carers from the subcommittees.
- The Executive Group has broad representation.
- Discussion groups based on the 7 main topics

The Topics

- Workforce and Education
- Mental Health
- Hospitalisation
- Specialist Services
- Data & Research
- Integrated Care : Connectivity within the NSW Health Service
- Integrated Care : NSW Health Service and the NGO sector and Primary Care

Consultation around the Context Report and Toolkit and ultimately the Blueprint

The Annual Forum(today)

- Broader audience
- Identifying gaps under the 7 main headings from the Solution Design Workshop and assisting with prioritisation.

The NSW Health Blueprint of Services for People with ID

We are seeking your guidance to help us shape the Blueprint. Key elements to consider:

- Standards for the delivery of health services for people with ID
- A model of integrated health services delivery for people with ID across NSW
- Responsive interface / relationships beyond NSW Health
- Monitoring the outcomes of health service delivery
- Workforce support; development

For participants today

The summarised input from the Solution Design Workshop

- Two topics on each table according to allocated tables.
- Every table has mental health as one of it's topics and one other.
- Each table has a group facilitator to assist the discussion about issue prioritisation and keep the group to time.
- The topics are also on the walls if you would like to add additional comments to other topics.

At your table please consider...

- What is your burning issue under the table's topics?
- Has it been covered in the list? If not please add it with some explanation.
- Identify your top three priorities under the topic lists on your table by putting a dot next to it. (It assumes your burning issue will be one of the three)

QUESTIONS