Researchers discussing research activity and gaps

Health Managers/Clinicians talking about health services

Consumer/Carer interviews about their experience of the health system

Multi-agency team (including a Carer) examining discharge case studies

What people have told us

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Researchers discussing research activity and gaps
2 Clinical Nurse Consultants (one from health, one from ADHC),

2 Managers (one from health, one from ADHC), a mother whose daughter had recently been to hospital, 2 clinicians (one from regional and one from remote NSW) examined the discharge journeys from hospital and found .....(pg. 31)
Before discharge show the person with disability and their Carer what needs to be done at home, but also let them practice it before they leave hospital. Written information may need to be in easy English and have pictures.

Discharge planning and collaboration between agencies worked best when guided by policy.

Their discharge planning, expectations of support and date for discharge often suggested hospital staff thought supported accommodation employed nurses.
Each NSW Local Health District Chief Executive nominated a person / group of people to speak with about ID. **More than 80 conversations later...**

(pg. 23)
Most health managers and clinicians consulted, expressed a keen interest in knowing more about how to work with people with ID and their Carers to improve outcomes, reduce hospitalisation and make reasonable adjustments.

Do you have any suggestions for improving health services for people with intellectual disability and their Carers?
This work grew from a single conversation. **A Carer from regional NSW in a sub committee** spoke of her experience and ..... 

*(Real People, Real Lives pg. 70)*
“The introduction of a health summary card for people with complex needs would make an enormous difference for all of our lives.”

“What our issue is at any time may be really different to the main issue for professionals. No one asks us what our worries are.”

“She (LHD Carer Support Worker) has been an advocate for us so we can advocate for our son. She has also understood the complex needs of our whole family not just Daniel’s medical needs.”
Academics, Researchers and Clinicians told us about research in the area of ID:

What is happening, what isn’t happening and where it needs to happen.... (pg. 28)
Suitable sedation eg for dental examination

Effectiveness of CBT for people with ID

Older people with more severe ID

People with ID from culturally and linguistically diverse backgrounds

Modifying broader health campaigns

Effective communication strategies in hospital

Mealtime safety

Strategies to include people with ID in research (and not just research about ID)
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 Pieces of the Puzzle

- Surveys across LHDs
- Data Analysis
- Context Report & Toolkit
- Workshop
- Consumer & Carer Interviews
- Forum
- BLUEPRINT
The consultation, feedback and working in partnership continues through this process of shaping the Blueprint and beyond to implementation and evaluation.