



# Roadmap to the Future

## Intellectual Disability Behaviour Support Program

Never Stand Still

Arts & Social Sciences



July 2016

## Foreword

**I am pleased to introduce you to the Intellectual Disability Behaviour Support (IDBS) Program and its Roadmap to the Future – a journey committed to improving and transforming the lives of people with cognitive disability.**

I strongly believe that embracing diversity in all its forms is fundamental to a strong and just society. To make real progress we need to find new ways of doing things – ways that involve, support, and inspire people in shaping their future.

This important program has been made possible by the generous support of the NSW Government who provided the core funding to establish the Chair IDBS in 2014. Since then the inaugural Chair, Associate Professor Leanne Dowse and her committed team of scholars have designed and commenced an innovative program of applied research, teaching, and engagement, focussed on building capacity to meet the challenge of complex support needs.

At UNSW we are dedicated to generating ideas and practical applications that make social change possible. We take pride in delivering significant and sustainable improvements for our partners and our communities.

This Roadmap sets out an ambitious and innovative plan to improve the way we understand and meet the needs of some of the most vulnerable in our community. It has the potential to improve and transform lives. I commend it to you.




**David Gonski AC**

Chancellor, UNSW Australia

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The President and Vice Chancellor of UNSW, Professor Ian Jacobs, initiated the 2025 Strategy in 2015 to take the university to a new position as a locally and globally engaged research intensive university ‘making a difference to people’s lives’. A pillar of the Strategy is progressing equity, diversity and inclusion. This, together with the depth of participatory research and scholarship by disability scholars at UNSW, makes it the natural home for the work of the IDBS program and its applied research and teaching. This document provides a roadmap for ongoing collaborative and inclusive research and program development building society’s capacity to support people with cognitive disability to flourish and live fulfilling lives.

It is an honour to Chair the dedicated IDBS Steering Committee and to support the IDBS team to fulfil the vision this Roadmap lays out.



**Professor Eileen Baldry**

Professor of Criminology and Academic Chair,  
UNSW Equity, Diversity and Inclusion Board

## ➤ Message from the Chair

The Intellectual Disability Behaviour Support (IDBS) Program was established in 2014 to build the capacity of those living and working with cognitive disability. Our work is focussed on providing meaningful and sustainable improvements to practice and policy for those with cognitive disability and complex support needs, their families, and supporters.

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Our team includes academic and professional staff with direct expertise in disability studies, inclusive research, delivery of disability services, social policy, knowledge translation, program evaluation, complex communication needs, learning, and teaching. We work collaboratively to engage all our stakeholders – including people with cognitive disability – in our programs of research, education, advice, and engagement streams.

The Program is located within the School of Social Sciences and is an integral part of the University of New South Wales' (UNSW) wider commitment to addressing the challenge of disability. We belong to a thriving multidisciplinary community of scholars uniquely positioned to deliver real social benefits.

My appointment as the first Chair IDBS – funded by the NSW Government – has enabled us to establish the IDBS Program and undertake critical foundational projects. Over our first two years of operation this core funding has also enabled us to successfully compete for additional grants and join larger multidisciplinary research projects.

We have demonstrated the need for our important cross cutting work. We know more now about what needs to be done. I am pleased to now present this Roadmap to our Future and set out the priorities we seek to address.



**Associate Professor Leanne Dowse**  
Chair IDBS

**“Throughout this document we use the term ‘cognitive disability’ to include many labels – including intellectual disability, borderline intellectual disability, acquired brain injury, and autism.”**

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## ➤ Our purpose

Our purpose is to **build the capacity** of society to support, include, and improve the lives of people with cognitive disability and complex support needs, their families, and supporters. We do this by working collaboratively and inclusively to generate knowledge, stimulate informed debate, and improve policy and practice.

## ➤ Our vision

We aspire to lead interdisciplinary scholarship and debate on cognitive disability and complex support needs in order to **improve and transform lives**. Our strong partnership with individuals, providers, and policy makers enables us to apply our knowledge and directly participate in the process of realising just outcomes for those living with disability.

Our commitment to this vision is further strengthened by UNSW's aspiration 'to be Australia's global university, improving and transforming lives through excellence in research, outstanding education, and a commitment to advancing a just society'.

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**"At the core of our organisation is a determination to deliver excellence built on an ethos of: academic freedom, facilitating open debate and the pursuit of ideas; creativity, being innovative and open to new ideas; and equality of opportunity for all regardless of background."**

*Professor Ian Jacobs, President and Vice-Chancellor, UNSW Australia  
UNSW 2025 Strategy*

## Our values

We share the overarching commitment of UNSW to place people at the centre of everything we do, respecting diversity, and providing opportunities to learn, research, and express views in a collaborative and respectful environment. This means that we actively seek out opportunities to include people with cognitive disability and complex support needs, their families, and supporters in all aspects of our work.

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Along with this overarching commitment to inclusion, our work, decisions and relationships are characterised by these core values:

### Excellence

Our work is academically rigorous. We strive for quality, innovation, initiative, and creativity.

### Respect

We respect diversity and difference. We place the person with disability at the centre of all we do.

### Partnership

We seek opportunities to partner with all stakeholders – including those with disability – in every aspect of our work.

### Justice

We are committed to achieving just outcomes for people with a disability, their families, and supporters.

### Integrity

We subject our work and decisions to rigorous review and the highest ethical and professional standards. We accurately represent the views and opinions of those with cognitive disability and complex support needs.

### Accountability

We engage openly, fairly, and transparently with all our stakeholders to responsibly understand and respond to their needs.

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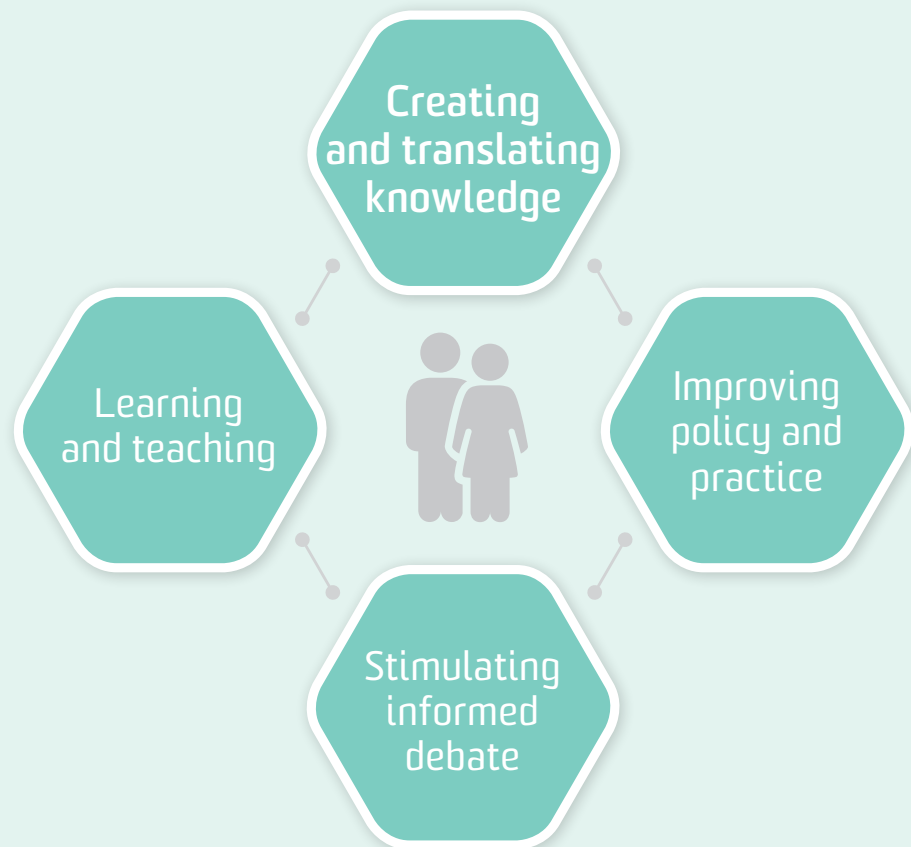
**“The United Nations Convention on the Rights of Persons with Disabilities, which Australia has signed and ratified, promotes, protects and ensures the ‘full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and promotes respect for their inherent dignity.’”**

*Article 1, United Nations Convention on the Rights of Persons with Disabilities*

## ➤ Our integrated approach

To realise sustainable improvements for people with cognitive disability, capacity must be strengthened at local, community, and system levels. Our program of work is designed to stimulate fundamental and systemic development informed by rigorous academic scholarship.

Our integrated program encompasses **knowledge creation and translation**, **learning and teaching**, **improving policy and practice**, and **stimulating informed debate**. Our collaborative and inclusive approach ensures that people with disability, their families, and supporters remain at the core of all we do.

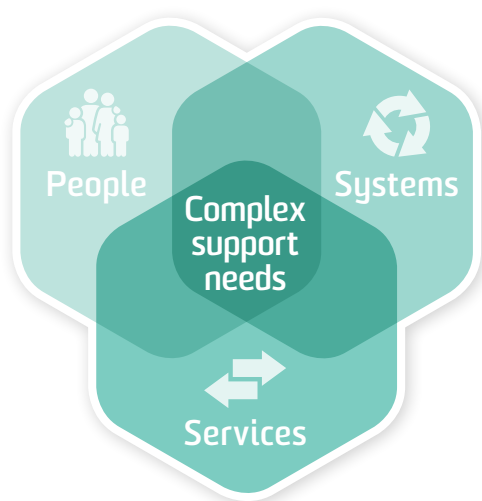


“UNSW is home to a multi-disciplinary community of over 100 scholars committed to working with people with disability to explore new ways to benefit from their increasing participation and contribution in the community.”

*Disability@UNSW Survey 2015*

## ➤ Our challenge

We take an ecological approach that accounts for an individual's characteristics, circumstances, and experiences as well as the full context of their social support systems at every stage of life. Our focus is on improving and transforming the lives of the most vulnerable; the people with needs that current systems fail to meet.



**“Complex support needs emerge across the ‘fault lines’ between our services and systems. Real support has to match real need”**

*Gordon Duff*

*National Disability Services*

People with cognitive disability are a large and diverse group. Almost three in every 100 people have a cognitive impairment. These people have a wide variety of capabilities, attitudes, and life experiences. Their disability may or may not be diagnosed or given a label. Often they will experience cognitive disability together with other physical, psychosocial or sensory impairments. Their disability will impact the lives of their families and supporters in profound and life changing ways.

It is widely recognised that people with cognitive disability are frequently socially disconnected and experience poor access to social support, education, employment, housing, health care, and justice. People with cognitive disability are disproportionately represented in our prisons, are more likely to experience violence and abuse, and to be subjected to physical or chemical restraint and intrusive medical interventions. Those who are parents are at higher risk of having their children removed. Some are exposed to high risks of homelessness and have harmful levels of substance use. These experiences are intensified for Indigenous people with cognitive impairment and those from culturally and linguistically diverse backgrounds. These difficult life experiences interact with cognitive disability to produce complex support needs.

Due to the nature of cognitive disability, needs for support are not easy to communicate or recognise. People with cognitive disability and complex support needs can be the most challenging to support. Individuals may have deep needs in a few areas as well as broader needs across many areas. Current systems struggle to cope with the challenge of complex needs – and particularly with needs that evolve in different ways across a lifetime. People with complex support needs are particularly vulnerable to marginalisation and disadvantage. ‘Complexity’ of need is a product of individual life situations together with the failure of support structures. Where needs in multiple domains remain unmet, intense social disadvantage and exclusion can be the result.

## Our supporters

The core funding for the Chair IDBS reinforces our independence as advocates for sustainable social change.

The NSW Department of Family and Community Services, Ageing Disability and Home Care generously provided the core funding to establish the Chair IDBS. This funding – which provides us with \$500,000 annually for four years – has enabled us to appoint the Chair and other key staff, create foundational materials, engage with practitioners and commence primary research. To sustain our program into the future it will be necessary to secure further core funding.

Support for our applied research increasingly comes from competitive grants and commissioned projects. Our research is widely recognised for its intellectual excellence as well as its practical impact. As our program becomes more established we expect the proportion of our income from competitive grants and commissioned projects to grow.

UNSW provides us with a range of in-kind support including facilities, administrative and financial services.



This funding provides the essential income to enable foundational research, development of teaching programs, and engagement with policy makers, providers and people with cognitive disabilities, their families and supporters. The Chair is currently funded by the NSW Government.



This funding provides the resources for specific targeted research. We continue to be successful in winning highly competitive Australian Research Council and National Health and Medical Research Council grants.



We undertake a range of specific commissioned projects and consultancy services for a range of clients including state and federal government agencies and non-government entities including peak bodies and service providers.

*Source of current funds June 2016*



# ➤ The road so far

Since our commencement in 2014, IDBS has delivered research, teaching, and social engagement aimed at building capacity to better understand, and respond to, the support needs of those with cognitive disability. Our efforts have been directed to three main areas: **living**, **working**, and **responding**.

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## Living

This stream of work is directed towards enhancing the understanding of disability as a lived experience for **people** with a cognitive disability, their families, and supporters. This work is informed by our original research and directed by our knowledge translation strategy.

We connect with students globally through our innovative online and open access learning and teaching activities.

**Thinking through and working with Disability: People, Policy and Practice**

» Tertiary course on disability available to all UNSW undergraduates

**Massive Open Online Courses Disability and a Good Life**

» 5,000 students  
» Global reach

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## Resource Kits

» Complex support needs planning and implementation  
» Evidence based practice advice for case managers and service co-ordinators

## Project RE-PIN

» Evaluating drug and alcohol rehabilitation for people with cognitive impairment

## Working

We provide evidence based resources and guidance for professional practitioners working with those with complex support needs. We use findings from our person-centred exploration of complex support needs and **service** systems to improve behaviour support, decision-making, service planning, and implementation of safe and sustainable supports.

This work stream applies research to build the capacity needed for the more intensive, co-ordinated, and longer term support required to meet complex needs.

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## Responding

Our third stream of work is focused on the **systems** of response to cognitive disability and complex support needs. We aim to understand and communicate the experience of those with cognitive disability as they interact with systems of social care, justice, health, education, and housing. Our research has opened up the space for scholars and practitioners to understand more fully what is required for meaningful inclusion for people with complex support needs.

Since 2014 we have undertaken a series of original research projects on the impact of social systems on people with cognitive disability across the life course.



The demand for our work means that we are consulted by practitioners and policy makers to help with evidence based improvements to services and systems. We work with many advisory councils and reference groups on matters of central concern to those with cognitive disability and complex support needs, their families, and supporters including behaviour support, transition to new service models, supported decision-making, violence and abuse, access to justice, and implementation of the National Disability Insurance Scheme.

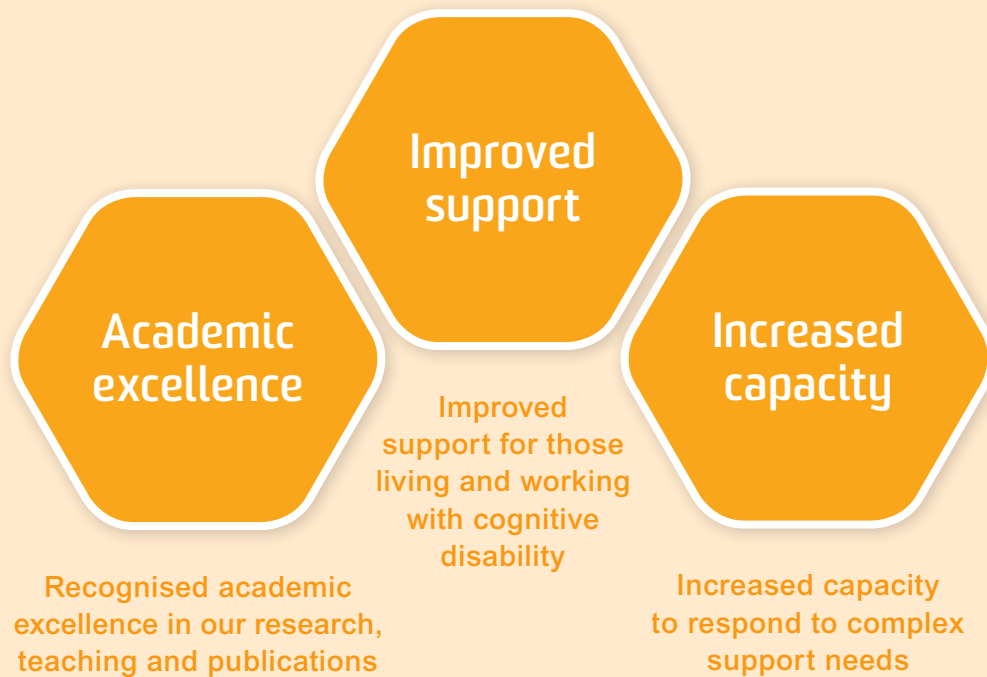
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**"I encourage everyone to think about how they can act inclusively so people with disability have the opportunity to live life their way."**

*NSW Minister for Disability Services, John Ajaka  
International Day of People with Disability, 2015*

## > The road ahead

The IDBS program aims to deliver outcomes in three strategic areas:



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Each area represents a major outcome of our integrated program of work and is integral to achieving our vision of leadership in transforming the lives of people with complex support needs, their families, and supporters. To be included in our work program, projects must demonstrate clear links to one or more of these outcomes.

The framework for linking these outcome areas with our integrated research, teaching and engagement program is presented in the following Strategic Map.

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In this early phase of our development, **our overall objective is to deepen our understanding of complex support needs and increase our engagement with decision and policy makers.**

We will continue to build on our existing research program to improve our understanding of the impacts of core systems of social support on those living with and alongside cognitive disability. We will use this work to extend our engagement through our research, teaching, and advocacy.

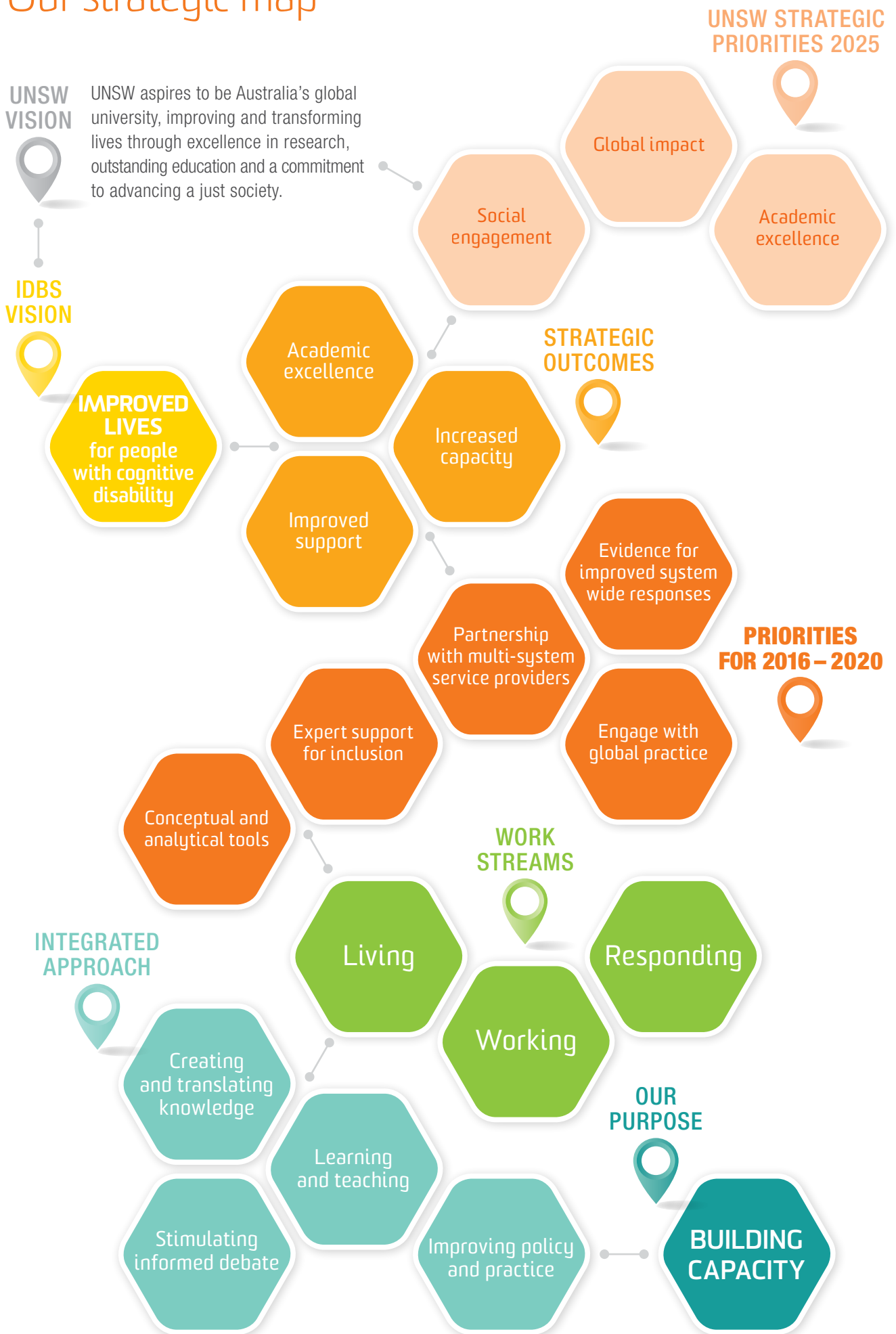
## ➤ Our specific priorities for 2016–2020 are to:

-  Undertake **scholarship** to create the **conceptual and analytical tools** necessary to build effective shared understanding of complex support needs across the networks, services, and systems providing support to those with cognitive disability. In doing this, we will promote direct engagement of those with cognitive disability and complex support needs in our work.
-  Establish IDBS as a recognised source of **expert** practical advice **on the inclusion** of people with cognitive disability and complex support needs.
-  Create opportunities for strategic **partnership with multi-system service providers** to deepen our understanding of system-wide impacts of **practice** on those with cognitive disability, and participate in developing effective and sustainable systems of support.
-  Extend our research into systems of governance including the National Disability Insurance Scheme to provide information and **evidence to support effective and sustainable policy responses** to complex support needs.
-  **Engage with global practice** relating to cognitive disability and complex support needs, and explore the potential for collaboration and international partnership under the UNSW PLuS Alliance.

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To ensure these priorities are fully integrated into our work streams, annual research, teaching, and engagement activity plans are also developed. These plans set out the links between specific program activities and priorities – and enable us to monitor our progress towards our strategic outcomes of academic excellence, improved support, and increased capacity.

# Our strategic map



# Our leadership and governance

## Leadership

Associate Professor Leanne Dowse was appointed the inaugural Chair of the IDBS Program in May 2014, as part of the NSW Government's commitment to improving services for people with cognitive disability. The Chair's role is to expand the body of knowledge and increase capacity to support people with cognitive disability with complex support needs.

Leanne is well known as a scholar, practitioner, supporter, and ally in the area of cognitive disability and complex support needs. As well as teaching social policy, social research methods, disability studies, human behaviour, and criminology, Leanne continues to lead major research projects and is chief investigator on many Australian Research Council, NHMRC, and Federal and NSW government funded grants.

## Steering Committee

Our Steering Committee is chaired by UNSW's Professor Eileen Baldry, an esteemed researcher internationally recognised for her prolific research on the criminal justice system and mental health and cognitive disability. Members of the Committee are drawn from across the disability sector and provide guidance and insight into our strategic choices and plans.

### The current members of our Steering Committee are:

Professor Eileen Baldry (Chair)	School of Social Sciences, UNSW
Associate Professor Leanne Dowse	School of Social Sciences, UNSW
Meredith Coote	NSW Department of Family and Community Services
John Della Bosca	Every Australian Counts
Gordon Duff	National Disability Services
Damian Griffis	First People's Disability Network Australia
Professor Kelley Johnson	Social Policy Research Centre, UNSW
Angela Koelink	NSW Department of Family & Community Services
Nicholas O'Neil	Law School, UNSW
Therese Sands	People with Disability Australia
Jim Simpson	NSW Council for Intellectual Disability
Phillip Snoyman	NSW Department of Justice
Professor Julian Trollor	School of Psychiatry, UNSW

## Research independence and confidentiality

IDBS undertakes independent research for public dissemination. While we actively seek to engage stakeholders in contributing to our general work agenda – including research, teaching, advice, and engagement – our priorities are determined by our Chair, in consultation with funders and the Steering Committee.

Our research activities are subject to review by the various UNSW Research Ethics committees. Where we have access to confidential and sensitive information, we work with our research partners to ensure concerns about disclosure and privacy are respected. All our publications are subject to peer review.

## Implementation and reporting

The IDBS Program is located in the School of Social Sciences within the Faculty of Arts and Social Sciences at UNSW. We are accountable to the School for the quality of our research and teaching, and actively participate in this vibrant community of scholars. The School provides facilities, and administrative and professional support, for our staff and students.

The Chair, IDBS oversees the development and implementation of program activities. Regular progress reports are provided to funders and the School of Social Sciences. An annual report of our activities is made available on our website. In addition to our internal program and grant management processes, we are subject to regular internal and external audits co-ordinated through the School and UNSW.

## *Disability@UNSW*

The Chair, IDBS is co-convenor of *Disability@UNSW* – a collaboration of over 100 academics and Higher Degree Research (HDR) students from faculties across UNSW whose work involves enhancing the lives of people with disability through applied research, teaching, and engagement with policy and practice. *Disability@UNSW* aims to consolidate these efforts via regular networking forums, development of disability-inclusive research and teaching practices, and assistance in developing knowledge translation plans.

## Behaviour support

Behaviour support includes appropriate ways to assist a person to communicate, make choices, and otherwise participate in the community. Behaviour support is used to address the severity of challenging behaviours in order to increase a person's quality of life. Challenging behaviour includes actions of such an intensity, frequency or duration that they threaten the quality of life and/or physical safety of the person or others, and is likely to lead to restrictive, aversive or exclusionary practices.

## Cognitive disability

The term cognitive disability encompasses a variety of diagnostic labels including intellectual disability, borderline intellectual disability, acquired brain injury, and autism. Generally, having a cognitive disability means that a person will have difficulty with things such as self-management, decision-making, and communication.

## Complex communication needs

Communication involves the exchange of information and meanings between two or more people. People with complex communication needs may have communication problems associated with a wide range of physical, sensory, cognitive, and environmental causes which restrict or limit the person's ability to participate independently in society.

## Complex support needs

Complex support needs are the interplay of cognitive, developmental, psychosocial, physical impairment and/or health conditions combined with adverse environmental factors, for example, behavioural risks, substance misuse, criminal justice contact, insecure housing, cultural or intergenerational disadvantage or a history of violence, trauma, and abuse. Typically, complex support needs have both breadth and depth in the sense that they span multiple domains and/or involve high levels of need in one or more areas.

## Inclusion

Inclusion is about making sure everybody has the same opportunities to participate in every aspect of life to the best of their abilities and desires. Inclusion involves more than simply encouraging people; it requires making sure that adequate policies and practices are in effect in a community or organisation.

## Inclusive research

Inclusive research relates to the active participation of people with disability, their families, and supporters throughout the research process. Inclusive research aims for researchers and people with disability to collaborate in setting a research agenda, conducting research tasks, and jointly disseminating research outcomes to further the interests of people with disability.

## Intellectual disability

Intellectual disability is a condition involving impairment of general mental abilities that is first apparent during the developmental period (usually before the age of 18), and impacts significantly on the person's adaptive functioning. Diagnosis is usually based on standardised assessment of deficits in adaptive functioning, intellectual abilities or both. The severity of intellectual disability can usually be described as mild, moderate, severe or profound.



## Knowledge translation

Knowledge Translation is the exchange, synthesis, and ethically-sound application of knowledge – within a complex system of interactions among researchers and users – to accelerate the capture of the benefits of research for all.

## Massive Open Online Courses (MOOCs)

A Massive Open Online Course is free, and aimed at unlimited participation and open access via the internet.

## Mental health conditions

Mental health conditions are clinically diagnosed conditions that include significant disturbance of mood or thought, and which can affect behaviour and cause distress for the person or those around them. Mental health conditions may impact the person's cognitive, emotional, and social abilities.

## National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is an Australian-wide insurance-based scheme established on 1 July 2013 to provide individualised support to people a permanent and significant disability. The NDIS supports people with intellectual, physical, sensory and psychosocial disabilities.

## Psychosocial disability

Psychosocial disability describes the disability experienced by some people living with a mental health condition. This can include reduced physical, social, and emotional wellbeing.

## Supported decision-making

Supported decision-making upholds the equal rights of people with disability to make decisions about issues affecting their lives. Some people with disability will need support to make, communicate and participate in these decisions. In providing support for decision-making, the will, preferences and rights of the person with disability must direct the decisions made, and legal frameworks must safeguard the person against abuse and undue influence in the decision-making process.

## Contact details

For more information on the IDBS Program visit:  
[www.arts.unsw.edu.au/idbs](http://www.arts.unsw.edu.au/idbs)

### For further information contact:

#### **Associate Professor Leanne Dowse**

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