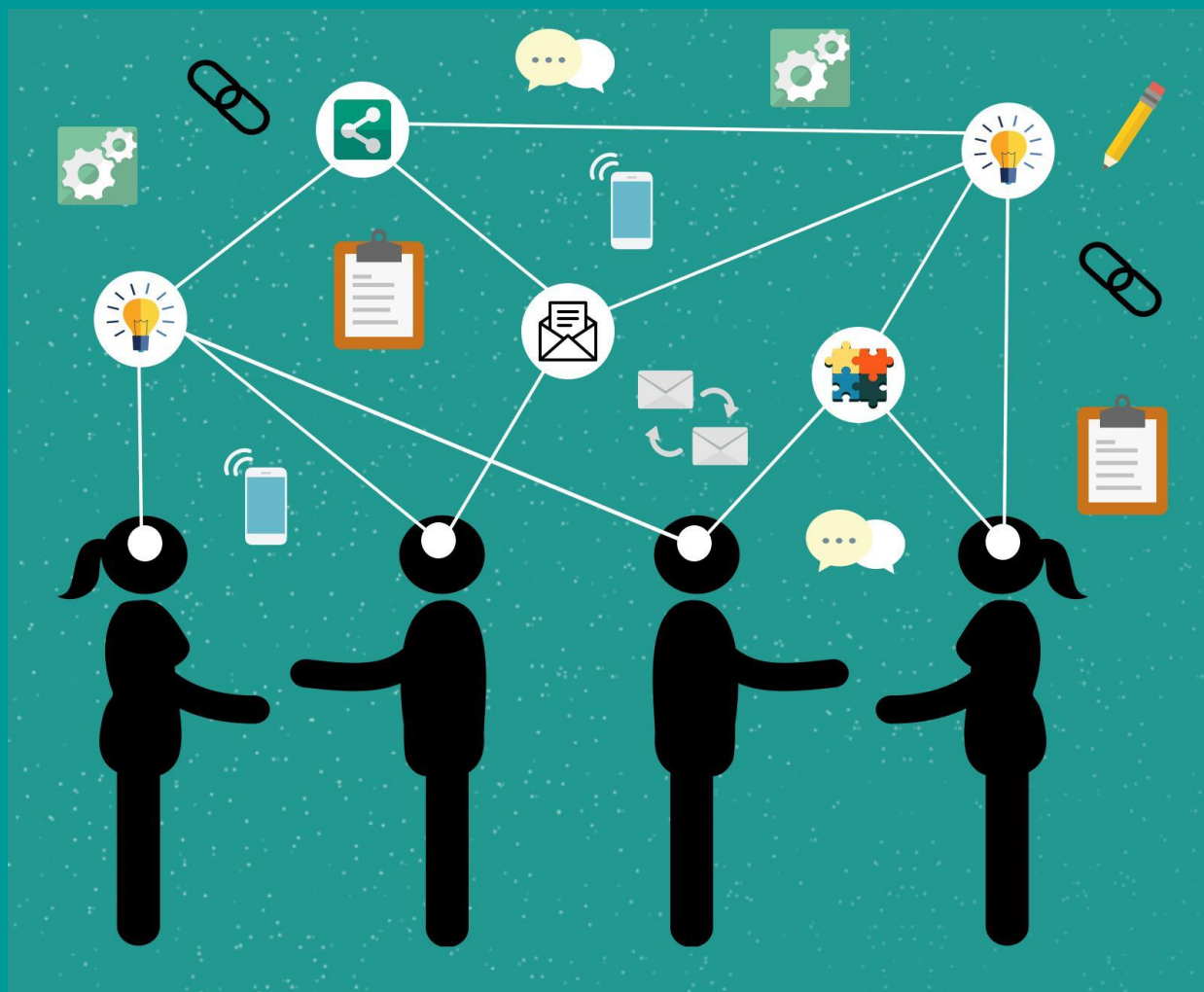# IMPROVING MENTAL HEALTH AND WELLBEING OF PEOPLE WITH INTELLECTUAL DISABILITY:

A RESEARCH TO ACTION DAY FOR PROFESSIONALS AND CARERS

UNSW SYDNEY

3DN DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

Research to Action Day

Contents

Background

Over 400,000 Australians have an intellectual disability. Compared to the general population, they experience poor health outcomes, including higher rates of physical and mental health conditions, and premature death from preventable causes. Conditions are frequently undiagnosed, undermanaged or inappropriately treated. A range of barriers prevent people with an intellectual disability from accessing healthcare. For example, stigma and exclusion, the person or their family and carer(s) not being aware of symptoms, and a lack of adequate training for health professionals.

The shortage of education opportunities and guidelines in this area contribute to the lack of skills, knowledge and confidence reported by the health and disability workforce when working with people with intellectual disability. To address these barriers 3DN have developed several new resources aimed at health and mental health professionals, disability workers and carers, which provide information and education on intellectual disability physical and mental health.

Aims

The aims of the Research to Action Day are:
- To launch:
    - The Intellectual Disability Mental Health Core Competency Framework: A Practical Toolkit for Mental Health Professionals
    - Cardiometabolic Health in People with an Intellectual Disability resources, including podcasts, and new Cardiometabolic health e-Learning modules
    - New ID mental health e-Learning Carers portal, mental health modules and disability professional modules
- To showcase:
    - Existing intellectual disability mental health modules and disability worker modules
    - The Guide
    - The Intellectual Disability Mental Health Core Competency Framework: A Manual for Mental Health Professionals
    - Existing Positive Cardiometabolic Health in People with an Intellectual Disability resources
- To raise awareness of the resources that are available to help people with intellectual disability receive quality physical and mental healthcare.
- To describe when and how the above resources can be utilised at different stages along the patient journey, and use discussion and practical activities to help professionals and carers become familiar with the resources so they can implement them successfully.

Timetable of the Day

Time	Topic	Speakers
9:00	**Registration**	
9:30	Welcome	Prof Julian Trollor
9:40	Welcome to Country	Bedegal People elder
9:50	Official launch	The Hon. Tanya Davies, MP
10:00	Overview of day and resources	Prof Julian Trollor
10:15	IDMH Toolkit and Manual; Mental Health e-Learning Modules	Prof Julian Trollor
10:30	Responsible psychotropic prescribing podcasts	Dr Bruce Chenoweth
10:45	Cardiometabolic resources	Mr Michael Sullivan
11:00	e-Learning modules for disability professionals	Mr Gordon Duff
11:15	e-Learning modules for carers	Ms Barbara Lewis
11:30	Resource wrap up and thanks	Prof Julian Trollor
11:40	Experience map introduction	Prof Julian Trollor
12:00	**Lunch**	
13:00	Workshop activity: Chelsea's story experience map	Prof Julian Trollor
13:45	Workshop activity: Familiarisation with resources and revisiting Chelsea's story using resources	Prof Julian Trollor
14:30	**Afternoon tea**	
15:00	Workshop activity: Group feedback on Chelsea's story	
15:45	Advocate perspective presentation	Mr Jim Simpson
15:55	Carer perspective presentation	Ms Maree MacDermid
16:05	Evaluation, closing and thanks	Prof Julian Trollor
16:15	**End**	

About 3DN

The Department of Developmental Disability Neuropsychiatry (3DN) is part of the School of Psychiatry within UNSW Medicine. We champion the right of people with intellectual or developmental disability to the same level of health and mental health care as the rest of the population. We promote a standard of excellence in clinical practice, research, workforce development, education and policy in the field of intellectual and developmental disability mental health.

Event Funding

Speakers

The Hon. Tanya Davies

The Hon. Tanya Davies is a member of the NSW Legislative Assembly. She is the Minister for Mental Health, Minister for Women and Minister for Ageing.

Prof Julian Trollor

Julian Trollor is Chair of Intellectual Disability Mental Health and Head of the Department of Developmental Disability Neuropsychiatry at UNSW Sydney, and a Clinical Academic within the South Eastern Sydney Local Health District. Julian provides a tertiary referral clinic for people with intellectual and developmental disorders and complex mental health needs, and in his university role he undertakes research, teaching and capacity building in intellectual disability health. His aspirations for the public mental health sector with regard to people with an intellectual disability is for mental health services and staff to be equipped to provide quality mental health services and supports for people with intellectual or developmental disabilities.

Dr Bruce Chenoweth
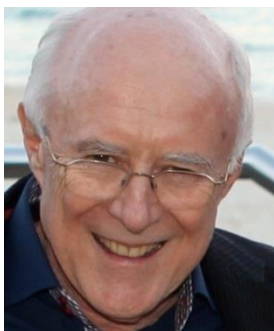
Bruce Chenoweth has had 17 years' experience as a Consultant Psychiatrist in Adolescent Mental Health, 7 years' experience in Early Psychosis Research and Treatment, and over 24 years in Intellectual Disability Mental Health (of which autistic spectrum disorders constituted a major component).

He was the Senior Developmental Psychiatrist at St George Hospital for 10 years with responsibility for a number of clinics for challenging behaviour. He has also been a VMO Psychiatrist for State NSW Aging, Disability and Home Care Services since 1992.

Bruce teaches Psychiatric trainees in the field of autism and intellectual disability. He has published in this field, and regularly presents papers to local, national and international conferences.

Bruce belongs to a number of academic bodies and societies relevant to intellectual disability and autism, including the RANZCP special interest group in intellectual disability, and is a member of several other groups including The Society for the Scientific Study of Behavioural Phenotypes.

He has been co-opted on to NSW state review and expert panels for the development of service delivery and management of complex cases, to the NSW Ombudsman's panel on 'abuse in care', and on to the Medicare Services Advisory Committee (Commonwealth) reviewing rebates for genetic testing.

Mr Michael Sullivan

Michael Sullivan is the chairperson for the NSW Council for Intellectual Disability. He joined NSW CID in 1997 and thrives on helping others with a disability.

Michael worked at the Teachers Federation for thirty years, retiring at the end of 2015. He is very excited to be able to devote much of his time now, to his advocacy work.

He credits the beginning of his life interest in helping others to his time at the Chatswood Social Club, where he held various positions including president. Working and being a member of Chatswood social club helped Michael to have the confidence to speak up and say what he thinks.

Michael feels that being a person with a disability himself has made him want to help other people who have a disability.

He has previously been on the National Disability Advisory Council in Canberra. Currently he is on the 'Partnership for Better Health Project Consumer Advisory Group' with UNSW, an NDIA reference group, and an NDS Community Participation Reference group. He was recently on a reference group for a new website about the NDIS targeted at people with psychosocial disability and is also the UNSW 3DN Ambassador for Healthy Ageing.

Michael enjoys being part of the team at CID. Speaking up for others with disability, and working in advocacy, with Honesty, Integrity and Dignity.

Mr Gordon Duff

General Manager – Sector Development and Research

Gordon Duff has more than 20 years' experience in human services and advocacy in a career spanning New Zealand, Canada, the UK and Australia, and across academia, government, non-government and business sectors. At NDS he leads work on Sector Development, Workforce Development and has led the establishment of the NDS Centre for Applied Disability

Research. He holds Honours degrees in Economics and Business Administration from New Zealand universities and a Masters in Social Policy from the London School of Economics.

Ms Barbara Lewis

Barbara has worked for over 13 years implementing the Carers program in Northern Sydney Local Health District.

She has contact with Carers every day walking many diverse journeys in caring for their family member.

Barbara's work has led her to be a part of the reforms that have taken place in recent years across the Community care sector. She is a strong advocate for considering Carers as partners in care across Health and the community care sector.

Mr Jim Simpson

Jim Simpson is a lawyer and advocate who has worked in the disability field for thirty years. He took a central role in establishing the Intellectual Disability Rights Service in Sydney. He is a senior member in the Guardianship Tribunal of NCAT, and does systemic advocacy work for NSW Council for Intellectual Disability. Jim is a member of the Intellectual Disability Reference Group of the National Disability Insurance Agency.

Much of Jim's work has been focused on issues facing people with disabilities in the justice and health systems. In recent years, he has done considerable policy development and advocacy in relation to the difficulties people with intellectual disability face in accessing mental health care.

Ms Maree MacDermid

Maree is the mother of two children, Joseph (10 years) and Finlay (8 years). Joseph has a severe intellectual disability after an aggressive brain cancer as a toddler. Prior to Joseph's diagnosis and treatment, Maree was a registered nurse and midwife but now works in horticulture, a different (and quieter) kind of nursery.

# Guide to Resources on Intellectual Disability Health and Mental Health

Intellectual Disability Mental Health Core Competency Framework: A Practical Toolkit for Mental Health Professionals

Who is it for?

Mental health professionals (including clinicians, managers and educators) from a range of professional backgrounds.

Aims

Designed as a companion document to the *IDMH Core Competency Framework Manual*, the Toolkit has been developed to provide applied guidance as to *how* mental health professionals in mainstream services can develop the core competencies outlined in the Framework Manual.
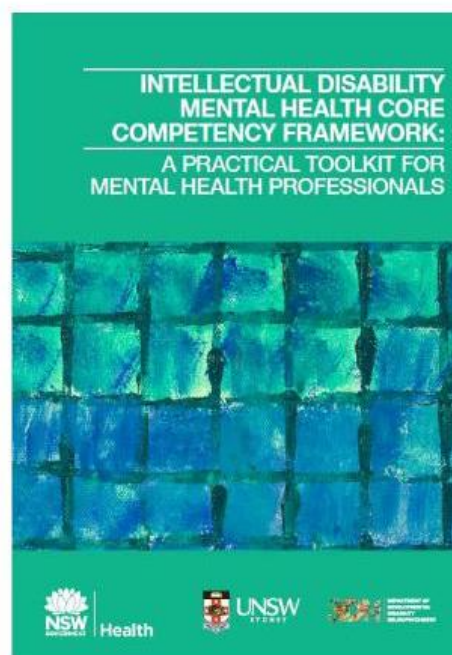
Contents

- The main section of the Toolkit covers considerations for each stage of the treatment pathway – i) Intake, ii) Engagement, iii) Assessment, iv) Treatment, and v) Transition.
- The Toolkit also contains:
    - a section with information for service managers
    - a summary of assessment tools that are suitable to use when assessing people with an intellectual disability (e.g. psychopathology, behaviour and emotion, and support needs)
    - links to resources including training and education opportunities, guides, reports and discussion papers, relevant policy documents, and resources that can be provided to people with an intellectual disability, their family and support networks.

Where to find it:

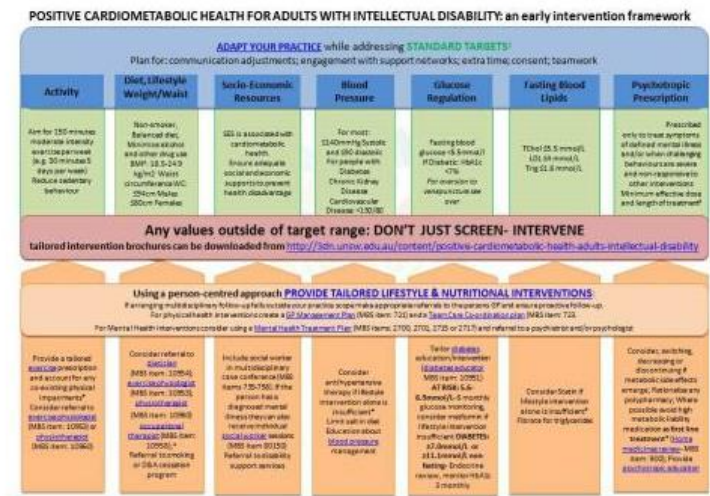https://3dn.unsw.edu.au/idmh-core-competency-framework

Positive Cardiometabolic Health for People with an Intellectual Disability

Who is it for?

Health and mental health professionals.

Aims

The early intervention framework aims to support health professionals to screen for cardiometabolic risk factors in people with an intellectual disability and provide targeted intervention strategies. The suite of resources also educates professionals, and empowers people with an intellectual disability and carers to ask their doctors to monitor cardiometabolic health.

Contents

- Positive Cardiometabolic Health for People with an Intellectual Disability: an early intervention framework
- Postcards for people with an intellectual disability and carers to take to the doctor. The front side provides information on cardiometabolic health for people with an intellectual disability or carers; the back side informs the doctor about the Early Intervention Framework.
- Free online resources for clinicians, people with an intellectual disability and carers.
- e-Learning modules for health professionals on Cardiometabolic Health in People with an Intellectual Disability. These modules will enhance professional knowledge and skills in the assessment and treatment of cardiometabolic ill health in people with an intellectual disability.

Where to find it:

- Early Intervention Framework, postcards and online resources: https://3dn.unsw.edu.au/positive-cardiometabolic-health-ID
- e-Learning modules: http://www.idhealtheducation.edu.au/

Responsible Psychotropic Prescribing to People with an Intellectual Disability Podcasts

Who is it for?

Medical and mental health professionals.

Aims

To educate professionals on safe and effective prescribing practices for the treatment of mental health disorders in people with an intellectual disability.

Contents

- Podcast Series 1. Responsible psychotropic prescribing to adults with an intellectual disability
- Podcast Series 2. Responsible psychotropic prescribing to children and adolescents with an intellectual disability.

Where to find it:

https://3dn.unsw.edu.au/content/responsible-psychotropic-prescribing-people-intellectual-disability-podcasts

e-Learning for Mental Health Professionals

Who is it for?

Mental Health Professionals.

Aims

The modules aim to equip the mental health workforce in responding to the needs of people with intellectual disability and mental illness.

Contents

About Intellectual Disability

- Module 1 – Introduction to Intellectual Disability
- Module 2 – Living with an Intellectual Disability
- Module 3 – Intellectual Disability – Changing Perspectives

Fundamental Skills in IDMH

- Module 4 – Communication: the Basics
- Module 5 – Improving your Communication
- Module 6 – Equality in Mental Health Care – A Guide for Clinicians
- Module 7 – Consent, Decision-making & Privacy – A Guide for Clinicians

Clinical Foundations in IDMH

- Module 8 – Mental Disorders in Intellectual Disability
- Module 9 – Assessment of Mental Disorders in Intellectual Disability
- Module 10 – Management of Mental Disorders in Intellectual Disability

Specialist Topics in IDMH

- Module 11 – Challenging Behaviour I – Introduction
- Module 12 – Challenging Behaviour II – Assessment
- Module 13 – Challenging Behaviour III – Management
- Module 14 – Emergency Mental Health Care 1: Understanding Intellectual Disability in the Emergency Department
- Module 15 – Emergency Mental Health Care 2: Journey Through the Emergency Department

Where to find it:
http://www.idhealtheducation.edu.au/

e-Learning for Disability Professionals

Who is it for?

Disability Professionals.

Aims

The modules aim to further equip the
disability workforce in responding to the
needs of people with intellectual disability
and mental illness.

DISABILITY PROFESSIONALS

Contents

IDMH Introduction

- Module 1 – Why is it Important to know about Mental Health?
- Module 2 – Introduction to Mental Health
- Module 3 – Mental Illness in Intellectual Disability

IDMH Practical Skills

- Module 4 – A Person-Centred Approach
- Module 5 – Recognising Common Mental Illness
- Module 6 – How to Support a Person with a Possible Mental Illness and Intellectual Disability
- Module 7 – Supporting Behaviours of Concern

IDMH Advanced Topics

- Module 8 – Enhancing Interagency Working with Health Professionals
- Module 9 – Treatments and Supports for Mental Illness
- Module 10 – How to Support a Person in a Mental Health Crisis
- Module 11 – Supporting Carers, Colleagues and Self-Care

Where to find it:
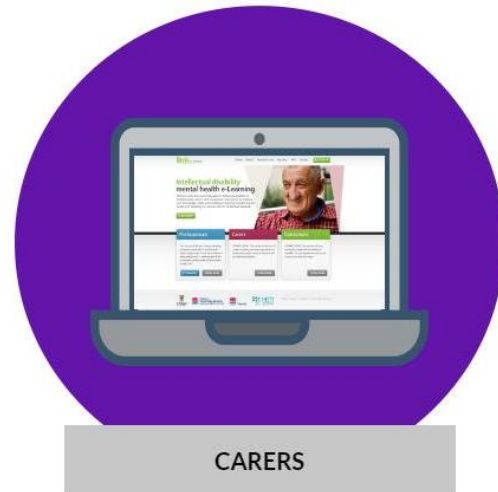
http://www.idhealtheducation.edu.au/

e-Learning for Carers

Who is it for?

Carers.

Aims

The modules aim to equip carers in recognising and responding to the mental health needs of people with intellectual disability.

CARERS

Contents

Foundations

- Module 1 – About Intellectual Disability
- Module 2 – About Mental Health

Mental Health and Illness

- Module 3 – Mental Health and Intellectual Disability
- Module 4 – Detecting changes in Mental Health and Wellbeing

Specific Mental Illnesses

- Module 5 – Signs and Symptoms of Mood Disorders
- Module 6 – Signs and Symptoms of Anxiety Disorders
- Module 7 – Signs and Symptoms of Schizophrenia and Other Psychotic Disorders
- Module 8 – Signs and Symptoms of Dementia
- A downloadable 'wellbeing record'. This document will support carers to keep a record of the person's wellbeing.

Where to find it:

http://www.idhealtheducation.edu.au/
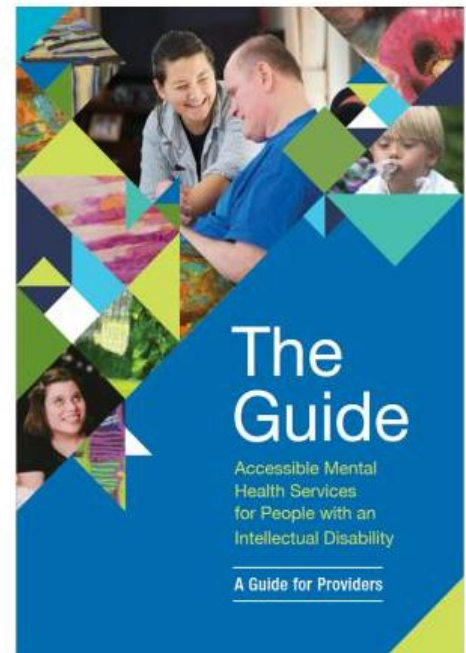
The Guide

Who is it for?

Mental health professionals and organisations that provide mental health services.

Aims

To assist health services in providing equitable access, a skilled workforce and appropriate treatment to people with an intellectual disability and a mental disorder.

Contents

- Principles that should guide service delivery
- Practical strategies for inclusive and accessible services
- Implications for the service system

Where to find it:

https://3dn.unsw.edu.au/the-guide

Hard copies of The Guide are available for purchase for $15 (including GST) per copy, which covers the cost of printing. To order and purchase hard copies of The Guide, contact Rachel Roth rachel.roth@unsw.edu.au.

Intellectual Disability Mental Health Core Competency Framework: A Manual for Mental Health Professionals

Who is it for?

Mental health professionals (including clinicians, managers and educators) from a range of professional backgrounds.

Aims

- To describe the core attributes required of the mental health workforce to deliver quality services to people with an intellectual disability.
- To inform readers of reasonable adjustments to clinical practice that should be made when working with people with an intellectual disability.

Contents

- Background information on intellectual disability and mental health

- The core competency framework that describes the specific knowledge, skills and attitudes (arranged over 11 domains) that mental health professionals require to provide quality mental health services to people with an intellectual disability.

- A self-assessment tool for professionals to determine which core competencies they already meet, and which they will work towards

- A detailed list of resources that support professional development in intellectual disability mental health.
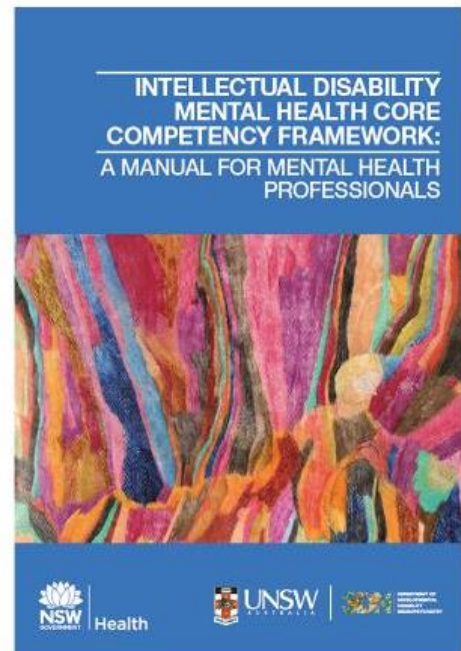
Where to find it:
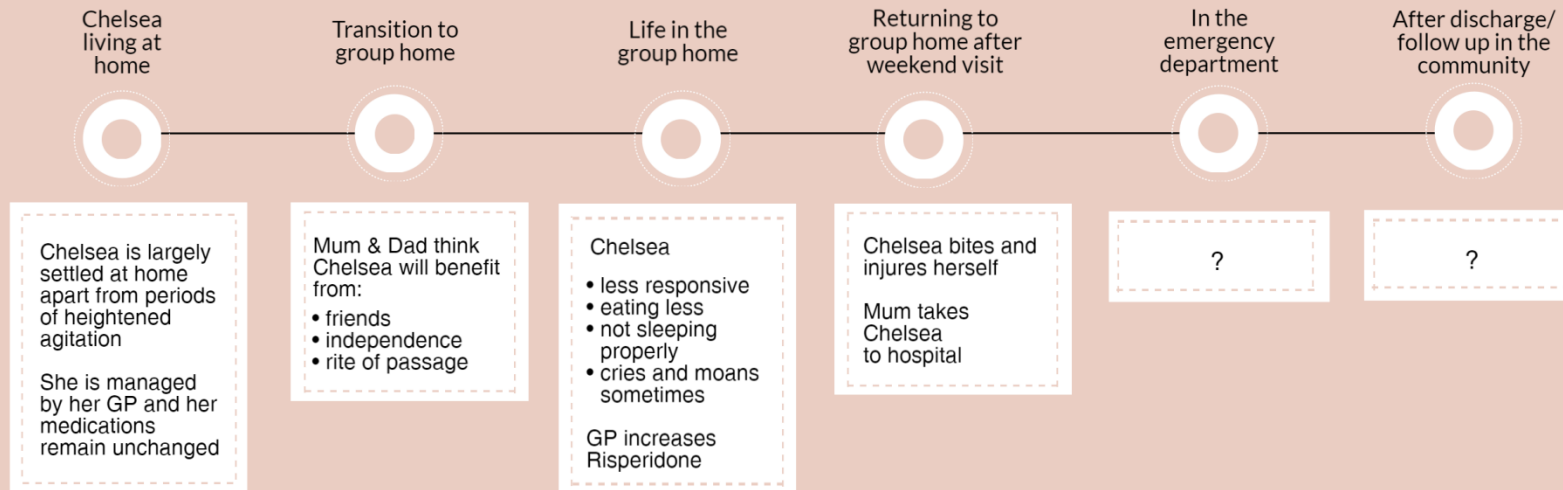
https://3dn.unsw.edu.au/idmh-core-competency-framework

Workshop Activity Resources

Workshop Activity: Chelsea's Story

- Chelsea is a 42 year old single woman, living with her parents
- She attends a day program 5 days/week
- She enjoys gym, craft and excursions
- She excels at art, and several of her art works have been included in local exhibitions

- Chelsea has Down syndrome and an associated moderate-severe intellectual disability and autism
- She is largely non-verbal but able to effectively communicate her needs through signing with her mum and people who know her well
- She has had past periods of self-injury and agitation, and has been on regular risperidone and PRN diazepam since 7 years of age

Chelsea living at home	Transition to group home	Life in the group home	Returning to group home after weekend visit	In the emergency department	After discharge/ follow up in the community

Chelsea is largely settled at home apart from periods of heightened agitation

She is managed by her GP and her medications remain unchanged

Mum & Dad think Chelsea will benefit from:
- friends
- independence
- rite of passage

Chelsea
- less responsive
- eating less
- not sleeping properly
- cries and moans sometimes

GP increases Risperidone

Chelsea bites and injures herself

Mum takes Chelsea to hospital

?

?

Workshop Activity: Experience map – Chelsea's journey (group work) instructions

Step 2.

- Plot everyone's experience
- Use colours to plot the different experiences:

Chelsea: **RED**	Chelsea's mum: **BLACK**	Disability professionals: **GREEN**	Health & mental health professionals: **BLUE**

- Plot one person at a time
    - How well are that person's needs being met at each point? How positive or negative is the experience for them?
    - There's no right or wrong answer, try to arrive at a general consensus
- Remember: the purpose of the experience map is to visually show
    - How a person's experience changed over time
    - Differences between two people's experience of the same event

Experience map – Jared's journey to see Pirates of the Caribbean
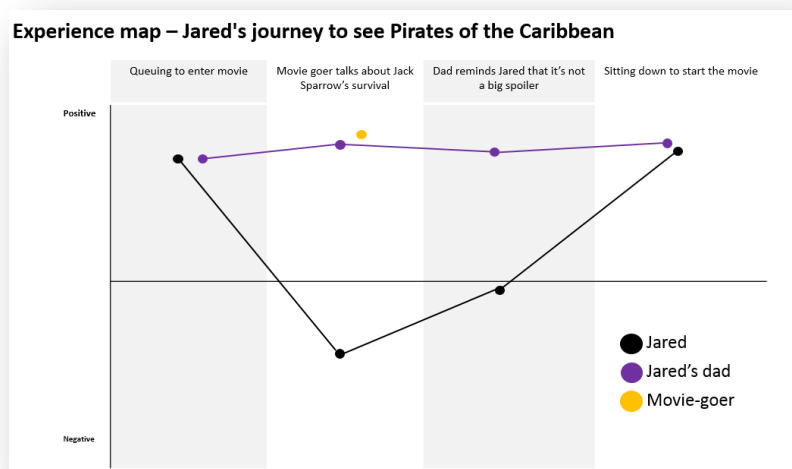
Workshop Activity: Experience map – Resources (group work) instructions

Step 3.

1. Each table split into three groups
   o Each group takes one third of the journey
   o Which resources would be used? How would these resources make a difference to everyone's experience?

2. Feedback findings to rest of your group

Experience map – Chelsea's journey

Chelsea living at home	Transition to group home	Life in group home	Returning to group home after weekend visit	In the emergency department	After discharge/follow up in the community
Very positive ... Group A add resources for this section ... Very negative		Group B add resources for this section		Group C add resources for this section	

QUICK RESOURCE SUMMARY: WHICH RESOURCES ARE FOR WHOM?				
	People with intellectual disability	**Carers**	**Disability professionals**	**Health & mental health professionals**
The Guide				✔
Core competency manual				✔
Core competency toolkit				✔
Cardiometabolic health	✔			✔
Responsible prescribing				✔
E-learning		✔	✔	✔

19

Thank you

Thank you to everyone who attended the Research to Action Day, and to those who registered for the waitlist but were unable to attend.

Thank you to all of the presenters and supporters today including the Bedegal People elder, The Hon. Tanya Davies, Dr Bruce Chenoweth, Mr Michael Sullivan, Ms Nicole Lee, Mr Gordon Duff, Ms Barbara Lewis, Mr Jim Simpson and Ms Maree MacDermid.

Thank you also to all the volunteers who helped today, including Eleanor Hall, Mashaal Hamayun and 3DN staff.

Finally, thank you again to the Mental Health Branch, NSW Health; and the Department of Ageing, Disability and Home Care, Family and Community Services NSW, for providing the funding that enabled us to host Improving Mental Health and Wellbeing for People with Intellectual Disability: A Research to Action Day for Professionals and Carers.