

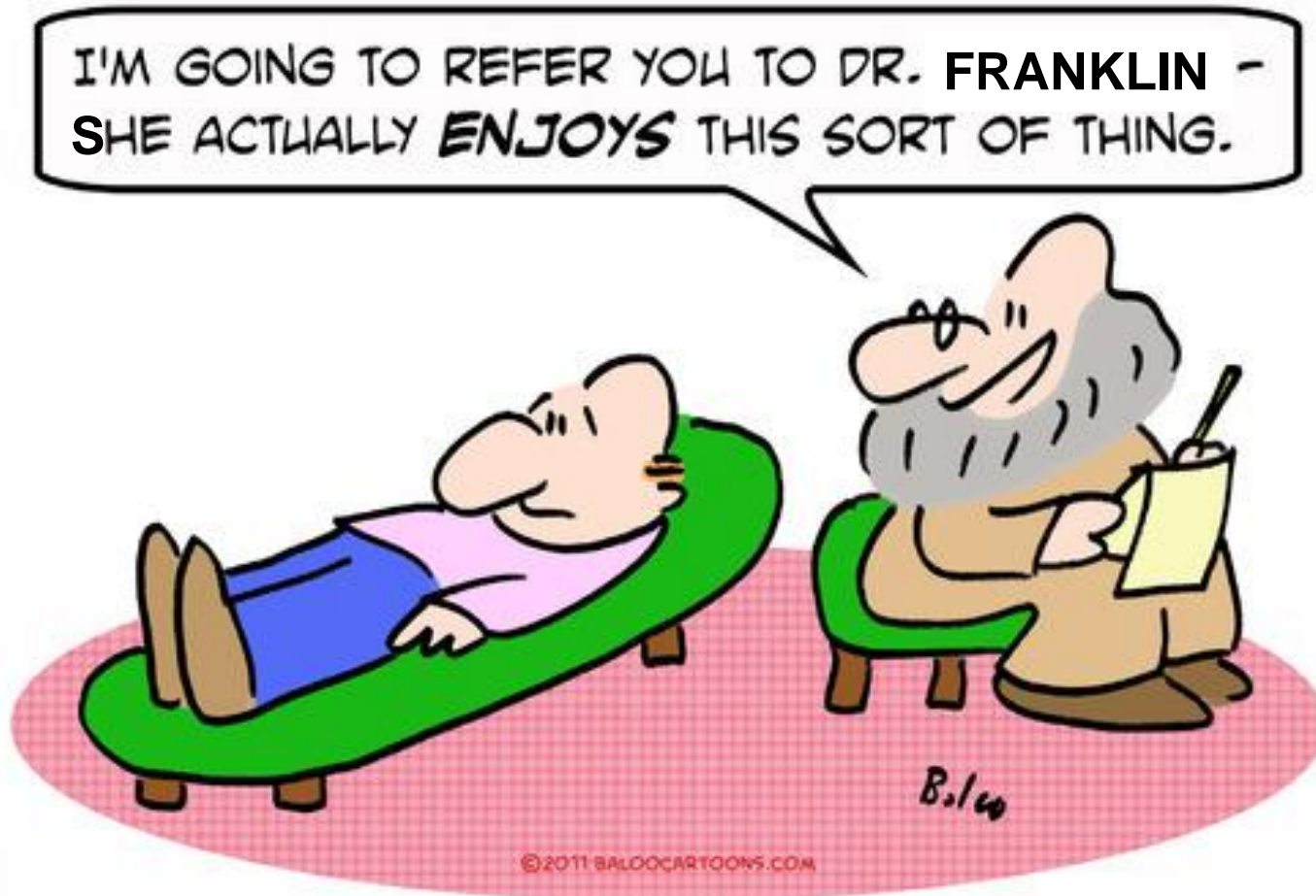
Mental Health in ID – A local perspective

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A warning



About Me



About Me



- Psychiatrist working with adults with ID / DD since 2004
- A/Director of the Mater ID & Autism Service
- Research work – Down Syndrome, Autism
- Education – teaching Psychiatry registrars, presentations to disability clinicians, support workers, families
- Committee Member of RANZCP Section of Psychiatry of Intellectual & Developmental Disability
- Secretary for AADDM (Australian Association of Developmental Disability Medicine)

Presentation Outline

What is mental health?

Problems

- Additional challenges for people with ID
- Challenging behaviour = communication
- Physical health in people with ID / DD
- Health service-related issues

Solutions

- Building resilience
- Tips for assessments
- Mater ID & Autism Service

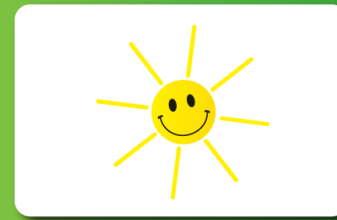


What is mental health?

A state of **well-being** in which every individual:

- realizes his or her own potential
- can cope with the normal stresses of life
- can work productively and fruitfully
- is able to make a contribution to her or his community

(NB: Health - a state of complete physical, mental and social well-being - not merely the absence of disease or infirmity)



Good
Mental
Health

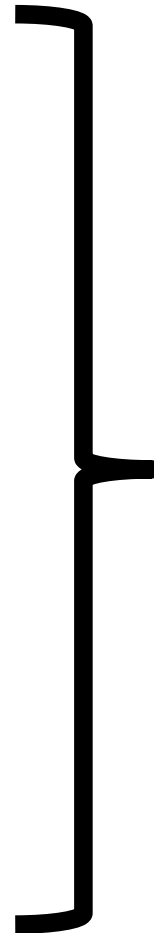
Problems we face

1. Additional challenges for people with ID
2. Challenging behaviour = communication
3. Physical health in people with ID / DD
4. Health service-related issues



1. Common experiences for people with an intellectual disability

Low socio-economic status (SES)
Limited social networks
Trauma and/or abuse
Significant life events
Sedentary lifestyle
Limited or no choice and control
Limited or no functional expressive communication
Stigmatisation and marginalisation



Cognitive functioning –
memory, processing,
executive functioning
Polypharmacy
Difficulties understanding
feelings/emotions

Affects:
Quality of Life
Mental Health
Health outcomes

Resilience



Resiliency factors = 'keeping mentally well'

Subthemes

- Importance of relationships with family and friends (n.b. participants included staff from home, day centre as 'friends')
- Keeping busy
- Autonomy and happiness.

Challenges for resiliency = 'mental illness'

Subthemes

- Abuse
- Long-term stress

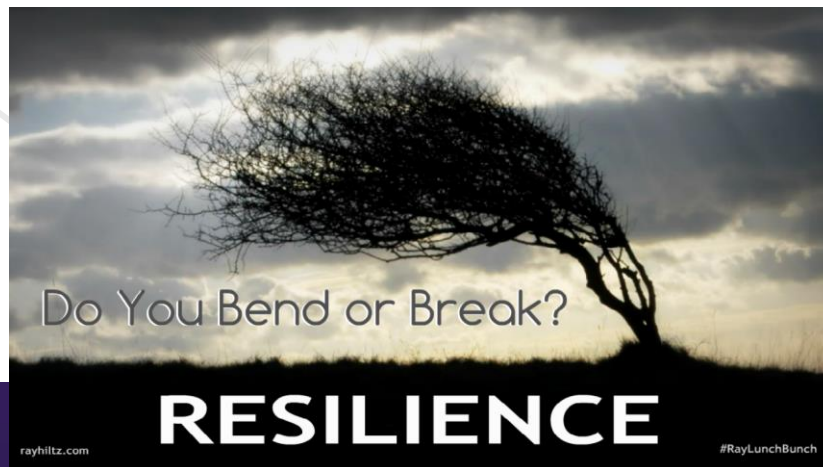
Conder et.al. (2015) Qualitative NZ study of 25 women with ID

Resilience

Conclusions

Many of the women demonstrated remarkable resiliency, despite setbacks and exposure to risks, **provided they were nested within a supportive context.**

Those women who experienced major mental illness shared evidence of **both higher risk factors** and **less support** available at crucial times.



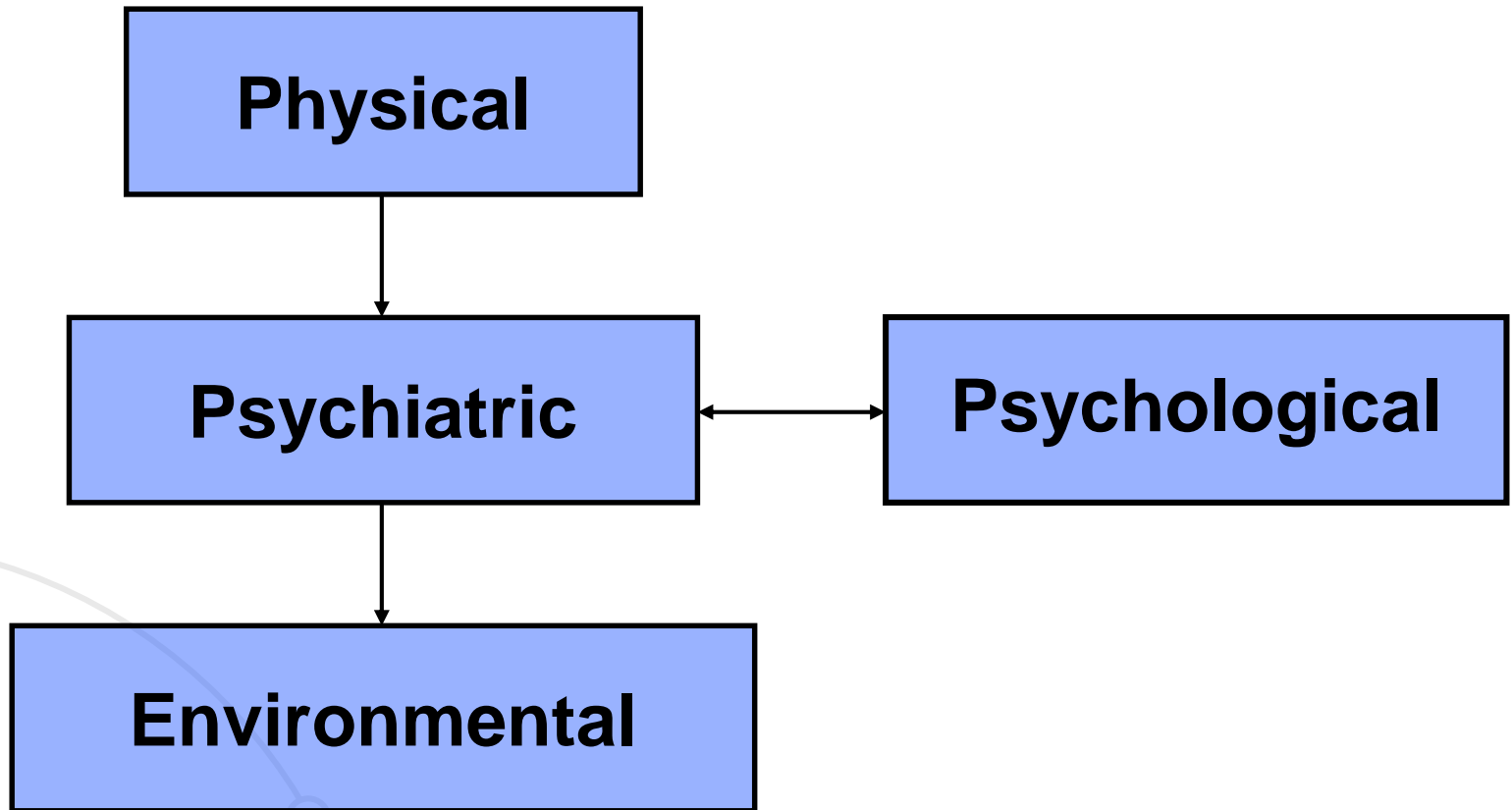
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2. Meaning communicated by behaviour



Hierarchy of Causes



3. Physical Health and ID / ASD



Health Issues Commonly Missed

- Physical Causes of Pain
 - dental pain
 - musculo-skeletal
 - gut
- Mental Illness: 30-40% prevalence
- Psychological
 - environmental
 - abuse
- Gastro-intestinal system
 - constipation
 - H.Pylori
 - Gastro-oesophageal reflux
- Urogenital
 - Undescended testis
 - Hypogonadism



Common Management Issues

- Medications - Neuroleptics
 - Anti-convulsants
- Epilepsy - Under- and over- diagnosis
 - Inadequate review
- Accidents, falls, burns
- Infections
- Health promotion - Immunisation, breast, skin, PAP smears
- Lifestyle and nutritional problems - Obesity
 - Diabetes
 - Osteoporosis and Vitamin D
- Vision / hearing impairment
- Poor oral health



4. Health service-related challenges



Challenge 1: Access to Mental Health Services

“Its not psychiatric, its behavioural”

“We don’t deal with disability, that’s Disability Services / NDIS”

“Not eligible for psychiatric follow-up”



Challenge 2: Finding Expertise



Challenge 3: Reliance on the private sector

Borderline /
Mild ID –
compliance,
attending

\$150+ gaps
Per consult



Comorbidities –
multiple
specialists need
to communicate

Severe ID – waiting
room challenges

Medicare (largely) only
rebates face-to-face with
patient

Solutions

1. Promoting mental health
2. Building resilience
3. Tips for obtaining a good assessment
4. Mater ID & Autism service
– clinic, research,
education, resources



1. Promoting mental health in ID



Maximize opportunity for mental health

- Positive environment
- Promote sense of identity – photos, life story, strengths, hobbies etc
- Regular exercise
- Improve autonomy – control over decisions and offer real choices
- Work towards goals: involved in community, work, social life
- Recognize and promote social bonds – friends, family and staff
- Stay physically healthy– see a (good) GP
- Avoid mental illness – if on medications, these should be reviewed regularly.

Lifestyle Factors

Good evidence

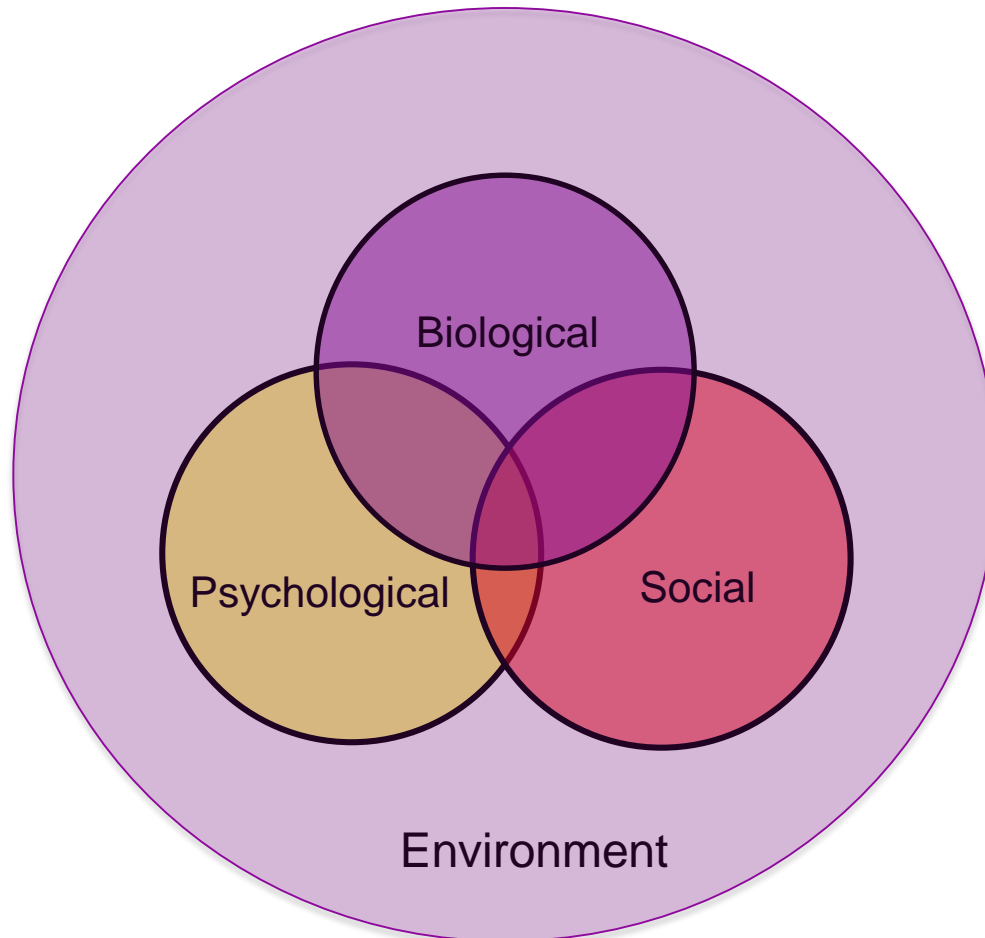
- Sleep
- Exercise
- Diet
- Social interaction

Developing evidence

- Environmental factors
- Relaxation / Meditation
- Pet therapy

**Food is the
most abused
anxiety drug.
Exercise
is the most
underutilized
antidepressant.**

2. Biopsychosocial Model in Context






Biological

Prevention and Building Resilience

- Early involvement and increasing involvement with GP: GP responsible for health screening and monitoring (use of CHAP tool)
- Advise GP re: routine (annual) monitoring for complications psychotropic medications
- Early identification of specialists to take over care
- Monitor for onset of major mental illness (as increased risk)



Psychological

Prevention and Building Resilience

- Cognitive behaviour therapy – for anger, aggression, depression, anxiety
- Developing self-esteem and identity – build skills and celebrate these
- Sex education – early, for both individual and parents (ignorance is not bliss!)



Social

Prevention and Building Resilience

- Anticipation and expectation of change and loss: siblings, school environment, role change. e.g. social stories, photos, emotional support....helping the person define their own role and identity
- Family unit – support (unofficial vs official counselling), relationship counselling – before crisis point/s are reached; developing outside interests

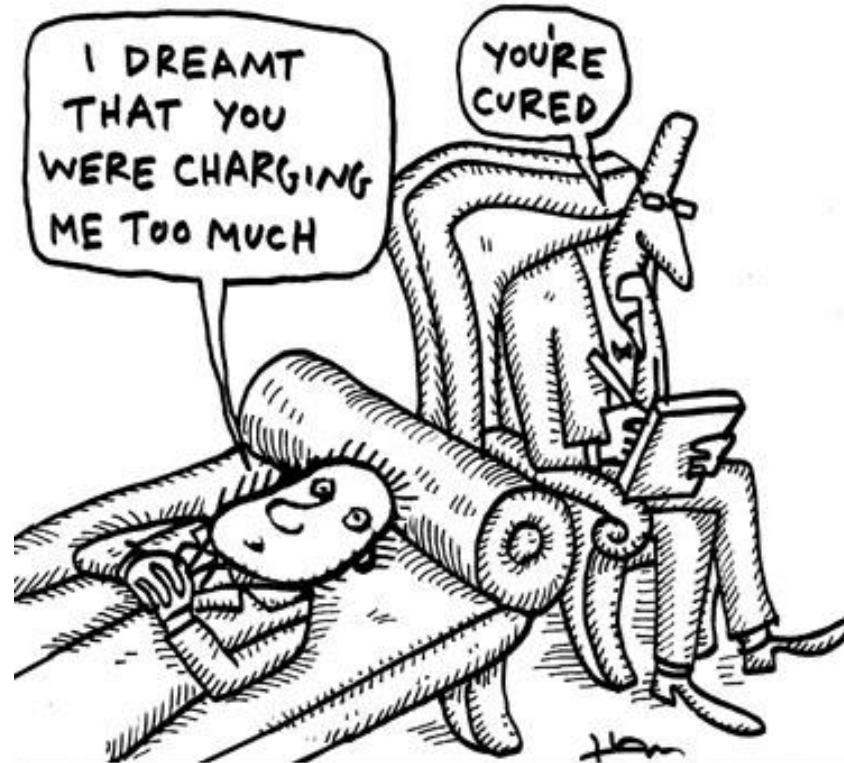


Environmental

Prevention and Building Resilience

- **Behaviour:** Earlier consideration of training parents and caregivers in principles of positive behavioural support
- **Speech Therapy:** Ongoing emphasis on improving communication and providing motivation to communicate (e.g. provide real choices)
- **Occupational Therapy:** Developing sensory interventions from childhood to adulthood
- **Disability Services (Social Needs):** Start early and clearly to define existing options and then work to improve options. This process can take years.

3. Obtaining a Good Assessment – Tips for Success



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Tips for Success - Preparation

(written for DS Clinicians, Service Managers)

Before the appointment

- Collect as much information as you can – not just medical.
- Meet with support staff to consider goals of the assessment and what questions will be asked
- Meet with the person, explain what will happen and why, ideally provide written information in pictures or an easy read version
- Book a long appointment, earlier in the day is usually better
- Consider who should attend (too many people is impractical)
- If you can't be there, send a letter with the information below:
- Compile a brief written summary of diagnoses, medication history (including side effects) and information on weight and sleep patterns

Tips for Success – On the Day

(Prepared for Disability clinicians, Service Managers)

At the appointment:

- Have a collaborative approach, demonstrate respect for the process and time pressures
- Model a person-centred approach (e.g. suggestions for how best to communicate with a person with impaired communication)
- Begin with presenting the information you have and ask your questions early (not as you walk out!)
- Use simple language to explain what you have observed.
- Don't be afraid to state what you think could be happening but be prepared to give reasons!

Tips for Success – Follow-up

- Continue to collect data to monitor response to treatment
- Make sure you and support staff understand possible side effects of treatment so you can monitor for these.
- Don't become too fixed with a specific diagnosis: psychiatric diagnoses can change over time, but the medications used, psychological approaches and behavioural support are often similar.
- Regardless of diagnosis, a positive environment and quality behavioural support are worth their weight in gold.



Extra Tips for dealing with Mental Health Services



- Avoid use of the term “behaviour”
- Focus more on neurovegetative function (sleep, appetite, enjoyment of pleasurable activities, attention and concentration)
- Try to give a longitudinal perspective – e.g. 2 years ago they were like this, now they are like this etc etc
- Consider using the PAS-ADD, be aware they likely won’t have any experience in using it (may need to point out the subscale scores)
- Consider taking the CHAP, which has some syndrome specific information, or other syndrome information

4. Mater ID & Autism Service



- Mission: to improve the health and well-being of adults (age ≥ 16) with intellectual or developmental disability through research, education and clinical practice.
- Formerly QCIDD – Qld Centre for Intellectual and Developmental Disability
- Opened 1997, jointly funded by Disability Services and Qld Health Mental Health Branch
- Now funded by Qld Health Mental Health Branch and Mater Health Services



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Clinical Service

- Psychiatric assessment & management (face to face and telehealth)
- Comprehensive health assessments
- Clinical staff
 - 3 part-time Psychiatrists (4 days total)
 - 1.5 full-time Psychiatry Registrars
 - 1 part-time GP (1 day)
 - 1 part-time (4 days) Clinical Nurse Coordinator
 - Planned: Psychologist



News

Mater Intellectual Disability and Autism Service unveiled

Friday 8 June 2018

Mater is proud to announce its new service: Mater Intellectual Disability and Autism Service. The service will continue to deliver the clinical services previously provided by the Queensland Centre for Intellectual and Developmental Disability (QCIDD).

The newly-named service will continue supporting people with intellectual disability and/or autism and their families, through research, teaching and clinical activities. The state-wide service, which has a face-to-face clinic at Mater Young Adult Health Centre Brisbane and also a telehealth clinic for those in remote areas of Queensland, is one of only a few services of this kind in Australia.

The service is run by Psychiatrist and Senior Research Fellow at Mater Research Institute, Dr Catherine Franklin, and a multi-disciplinary team.

“People with intellectual disability and/or autism have complex and specialised health care needs but these are not well addressed in mainstream services, and they and their families struggle to find help,” Dr Franklin said.

“This represents a key aspect of Mater’s Mission, which is to provide services to those who are disadvantaged or in need and those who have limited access to mainstream services.”

Dr Franklin recently presented at The Royal Australian and New Zealand College of Psychiatrists Annual Congress in Auckland, advocating for increased clinical support for autistic adults.

“There is an urgent need for more training of psychiatrists on the diagnosis and management of Autism Spectrum Disorder and the mental illnesses that complicate the condition,” Dr Franklin said.

As a result, Mater Intellectual Disability and Autism Service will be expanding its clinical team and is looking forward to meeting the ever-increasing need for services in this important area.

[Services](#) » [Outpatient Clinics – for patients aged 16+](#) » [Referral Guidelines](#)

Mater Intellectual Disability and Autism Service – public patients

Purpose:

This page contains information for general practitioners on how to refer patients aged 16 years and over with a diagnosis of intellectual disability and /or developmental disability to Mater Intellectual Disability and Autism Service at Mater Hospital Brisbane

Service Availability:

Mater Intellectual and Disability and Autism Services (formerly QCIDD) is a state-wide service which aims to improve the health and wellbeing of adults with intellectual and neurodevelopmental disabilities through clinical practice, education and research. Our services are designed to assist current health practitioners and service providers by providing initial assessments and short-term interventions.

The patient, their family or carers can assist this referral by completing and returning the Pre-Appointment Questionnaire ([insert hyperlink](#)). Patients must be aged 16 and over, with a diagnosis of intellectual disability / or developmental disability

This service can provide

- Full health assessments
- Full mental health assessments
- Tele-health consults
- Telephone / email consultation

How to Refer:

If referral for care is indicated please list all of the [General Referral Information](#) and reason for request, and essential information as indicated below.

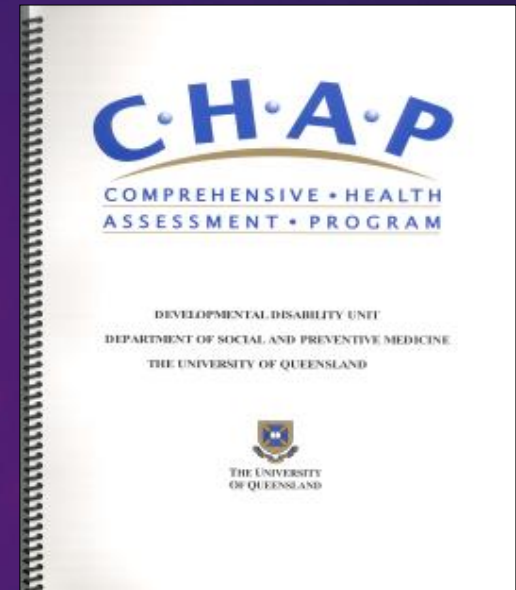
To refer, please fill in the [Mater Adult Referral Form](#), available to download and embed into most major Practice Management software applications.

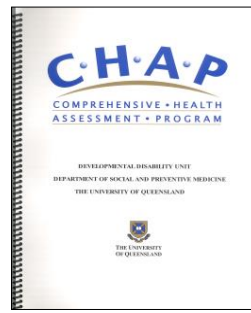
Referrals can be sent by:

Secure messaging	Medical Objects: HM4101000R8
	HealthLink EDI: materref
Fax	07 3163 8548

Research

- Acute Regression and Catatonia in Adolescents and Young Adults with Down Syndrome Study
- Down Syndrome Health Registry
- CHAP – Comprehensive Health Assessment Programme
- Living with Autism Cooperative Research Centre (CRC)
- Ask Project (Adolescent Health Intervention Study)
- Challinor Deinstitutionalisation Revisited
- HIP-Aus study - Prisoner Research
- SHAP – Students as Health Advocates Project
- Walk and Talk
- Healthy Living Study





CHAP

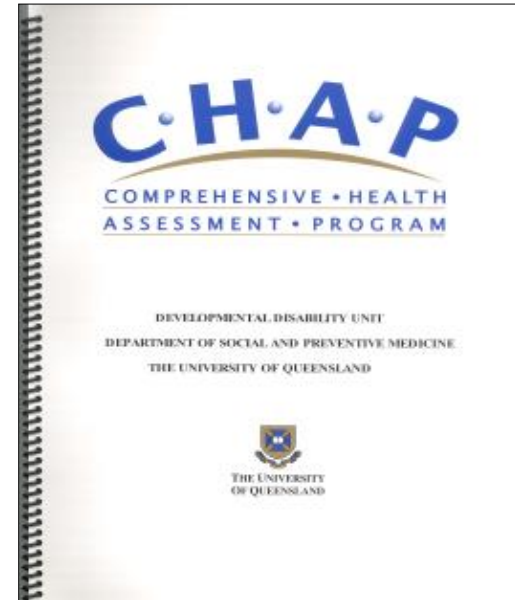
- Increased health promotion, disease prevention and case-finding activity was found in the intervention compared to control (n=453 cluster RCT)
- 6.6-fold increase in detection of vision impairment (CI 1.9–40) and 30-fold increase in hearing testing (CI 4.0–230)
- 9-fold increase tetanus/diphtheria immunisation (CI 4.2–19)
- 8- fold Papanicolau smears (CI 1.8–35)
- 1.6 times detection of new disease by (CI 0.9–2.8)
- Implemented by three state governments, many NGO and overseas
- 2007 Announcement of Medicare item for health assessments in people with intellectual disability

Education

- Psychiatry registrars
- Medical students
- Disability Services professionals
- Support workers
- GP / PHN / MH PHN groups



Resources



Education – AbleX MOOC

The screenshot shows the edX website interface. At the top, there is a navigation bar with the edX logo, links for 'Courses', 'How It Works', 'Schools & Partners', and 'About'. A search bar contains the text 'I want to learn about...'. To the right are 'Sign In' and 'Register' buttons. The main content area features the University of Queensland Australia logo and a large banner for 'Intellectual Disability Healthcare'. The banner text reads: 'Understand barriers and enablers faced by people with intellectual disability and their families and recognise best healthcare practice.' Below this is a 'Start the Series' button. A play button icon is visible on the right side of the banner.

Courses in this XSeries Program

The courses in this XSeries can be taken individually and in any order, but it is best to take the ABLE101x Through my Eyes course first.



Through my Eyes – Intellectual Disability Healthcare around the World
Learn, from personal stories, the daily life and challenges faced by those with intellectual disabilities.
[Learn more](#)

Self-Paced

Enroll Now

I would like to receive email from University of Queensland and learn about its other programs.



Well and Able- Improving the Physical Health of People with Intellectual Disability
Learn how to help those with intellectual disability achieve better health.
[Learn more](#)

Self-Paced

Enroll Now

I would like to receive email from University of Queensland and learn about its other programs.



Able-Minded- Mental Health and People with Intellectual Disability
Gain an understanding of mental health issues and ethical decision-making for people with intellectual disability.
[Learn more](#)

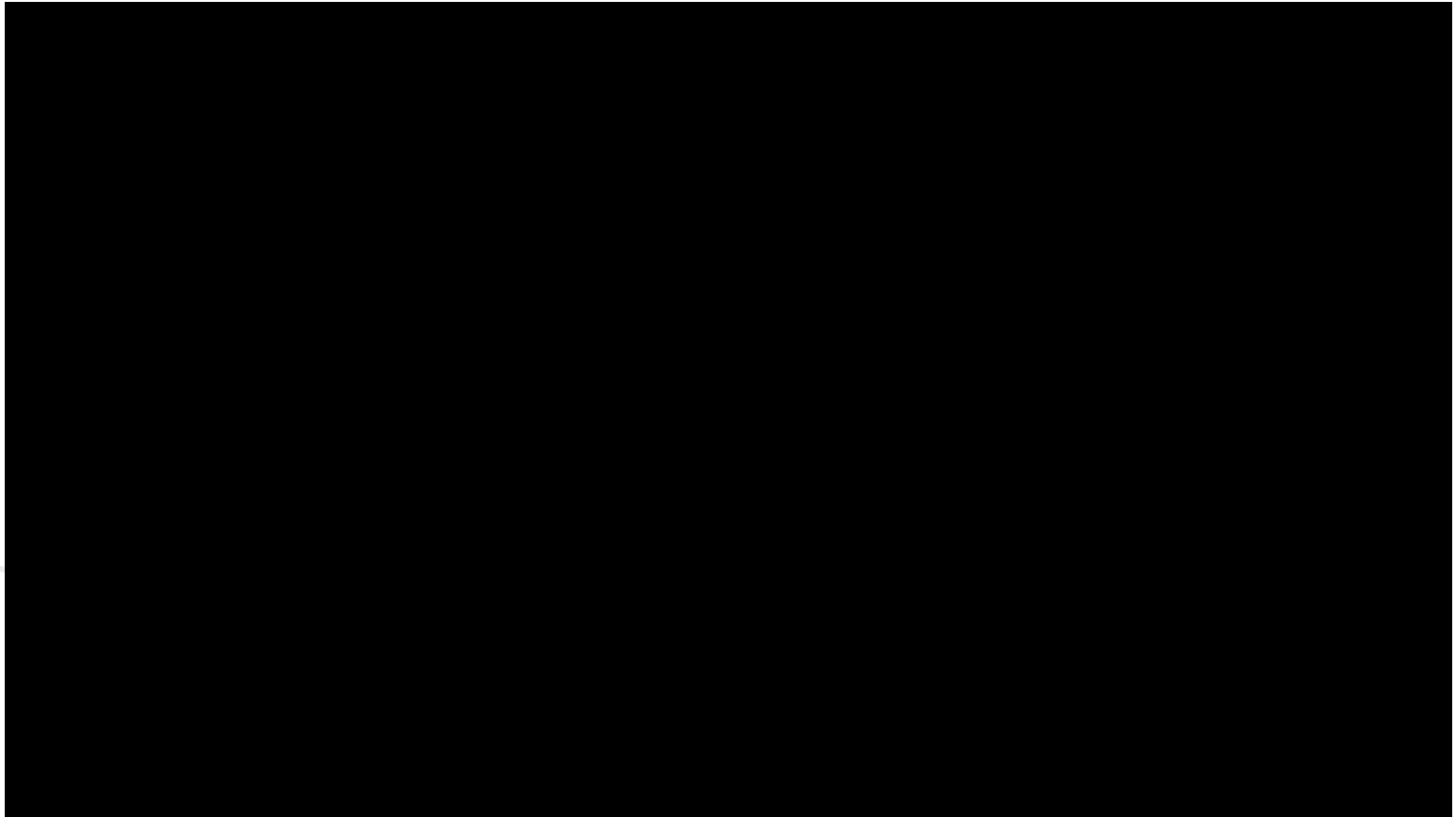
Self-Paced

Enroll Now

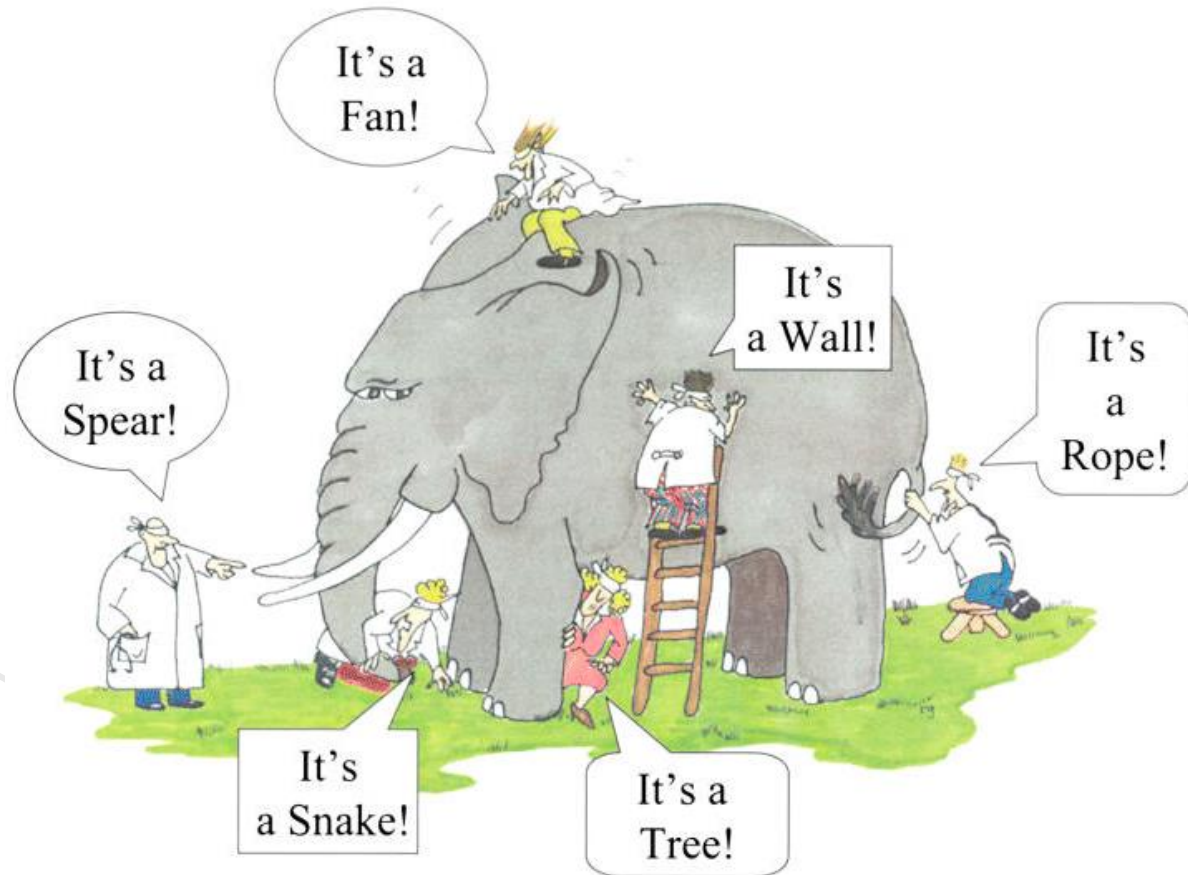
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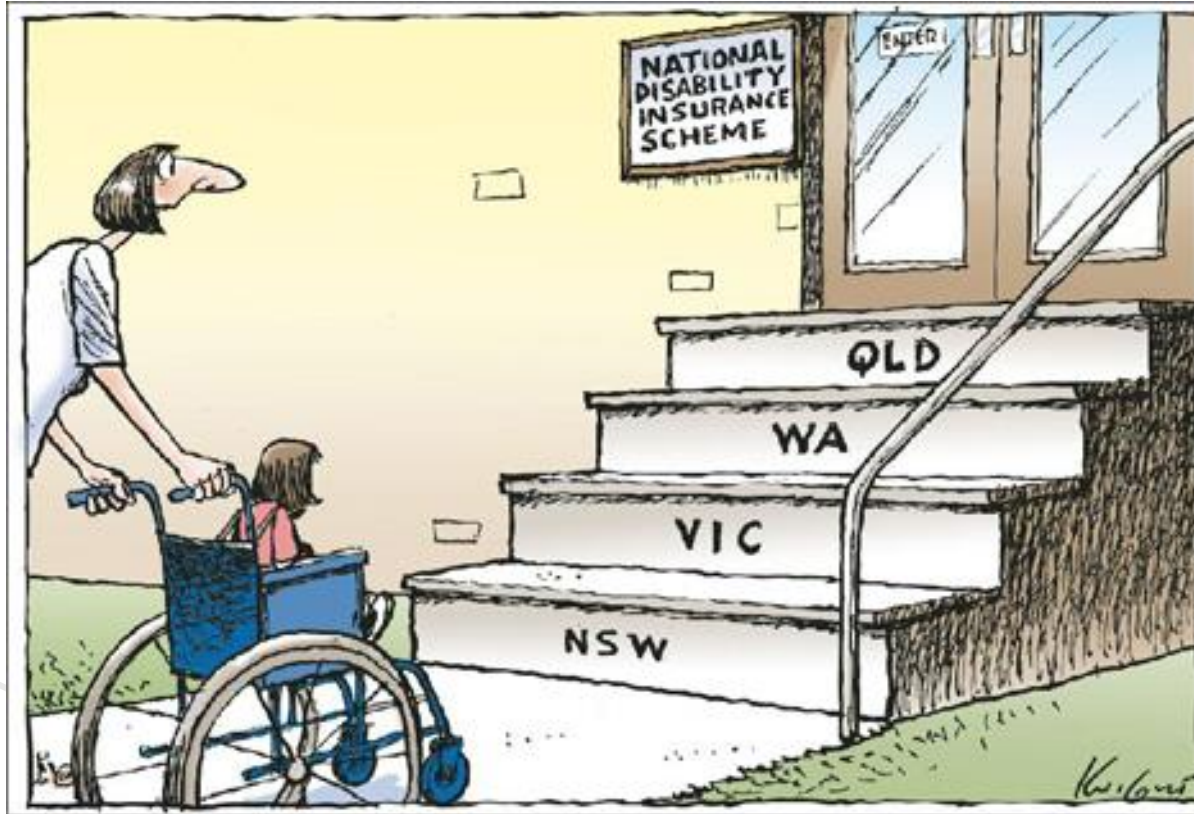
Able X Series – edX MOOC



See the Big Picture



NDIS





WHO'S IN YOUR
LIFEBOAT?



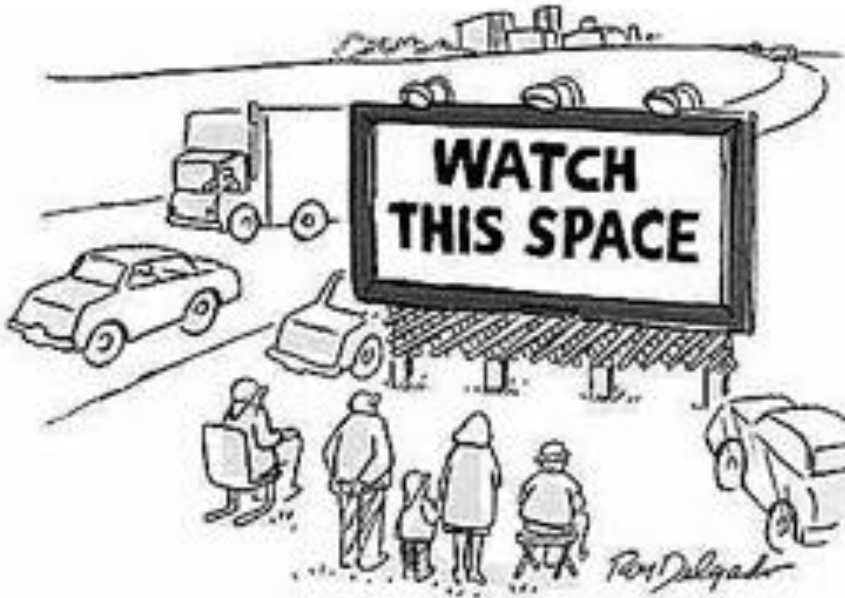
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Thank you

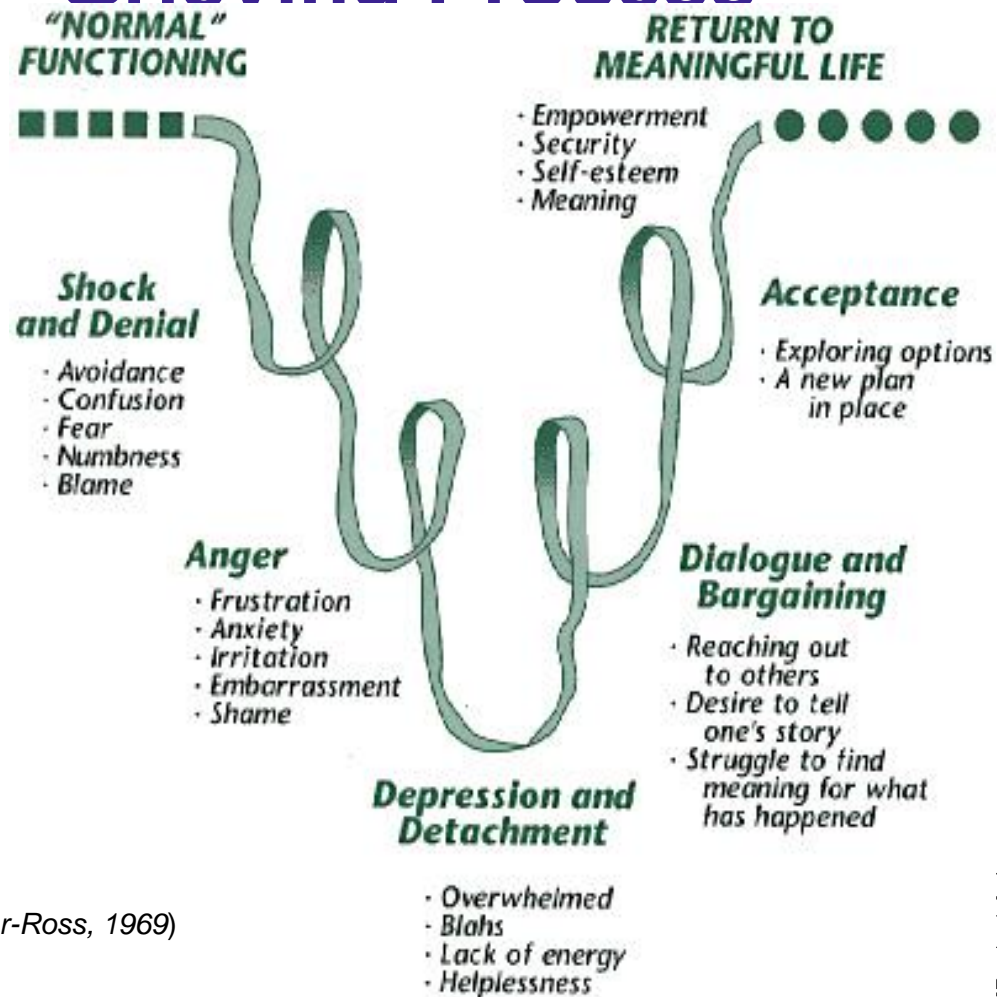
Dr Cathy Franklin

Email: midas@mater.org.au



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The “Normal” Grieving Process



After Kubler-Ross, 1969)