



## 2: Intellectual Disability in Medical Practice

Never Stand Still

Medicine

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# Intelligence/intellectual ability

- Refers to general capacity to engage in cognitive functions such as learning, reasoning, manipulating information, identifying patterns and relationships, problem solving, recall, planning etc
- Is complex and multifaceted
- Is assessed using one of several standardised tests for which the average population score (IQ) is 100

# What is Intellectual Disability? (intellectual developmental disorder)

- Impairments of general mental abilities that impact adaptive functioning. It affects how well an individual copes with everyday tasks.
- Disorder with onset in the developmental period
  - Deficits in intellectual functions (Below average intelligence, IQ of  $<70$ , ie  $<2$  SD below mean)
  - deficits in adaptive behaviours
  - onset before the age of 18



# Adaptive Behaviour or Adaptive Skills

- Refers to age-appropriate behaviours necessary for people to live independently and to function safely and appropriately in daily life
- “Skills of daily living”
- Is assessed using one of several standardised tests. Divided into:
  - **Conceptual skills**: language and literacy; money, time, and number concepts; and self-direction.
  - **Social skills**: interpersonal skills, social responsibility, self-esteem, gullibility, naïveté, social problem solving, ability to follow rules or obey laws and to avoid being victimized.
  - **Practical skills**: personal care, housekeeping, occupational skills, healthcare, travel & transportation, schedules/routines, safety, use of money, use of the telephone.

Reference: American Association on Intellectual and Developmental Disabilities (AAIDD)

[http://www.aidd.org/content\\_100.cfm?navID=21](http://www.aidd.org/content_100.cfm?navID=21)

# Relevance of ID

## Prevalence:

- Australian Population Prevalence of ID about 1.8%; range 0.4% – 3.0% (AIHW, 2003)  
<http://www.aihw.gov.au/publications/index.cfm/title/9671>
- About 400,000 Australians
- About 125,000,000 individuals world wide
  
- High morbidity, mortality & unmet health needs

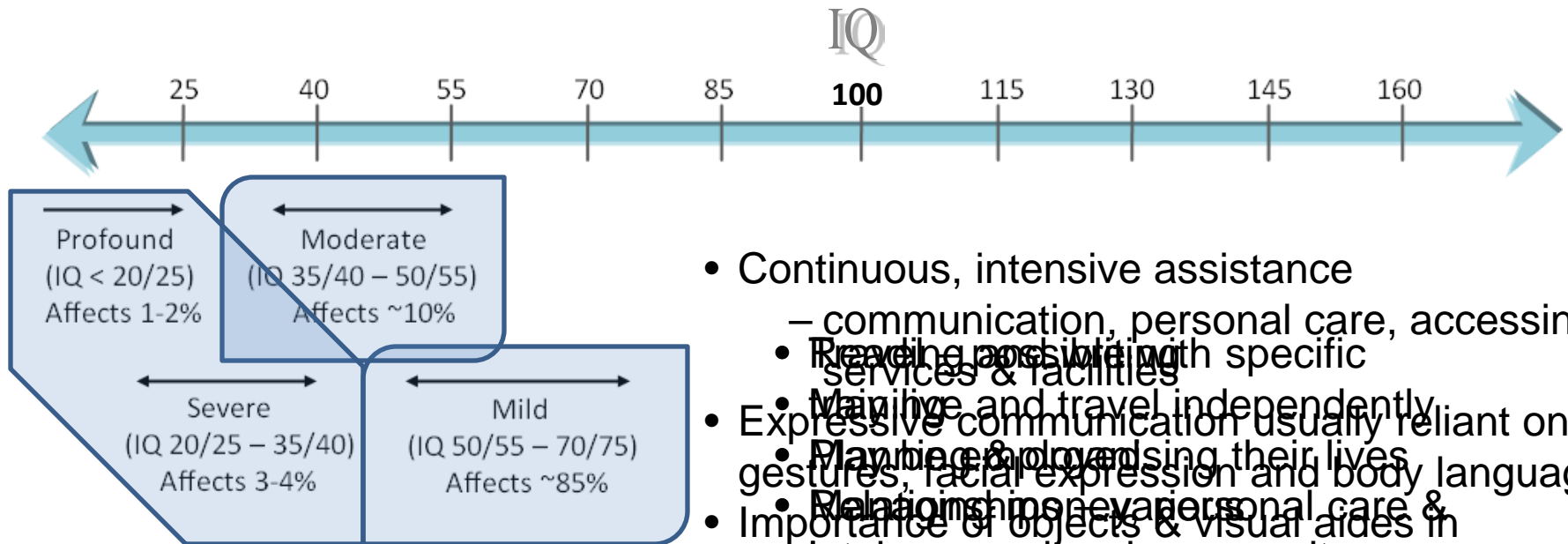
# Other Terminology

- Intellectual Disability
- Intellectual Developmental Disorder
- Intellectual Handicap
- Mental Retardation
- Learning Disability
- Developmental Disability
- Intellectual AND Developmental Disability
- **A Person With an Intellectual Disability**

# Some Causes of Intellectual Disability

Prenatal	Perinatal	Postnatal
<p>Chromosomal disorders</p> <p>Syndrome disorders</p> <p>Inborn errors of metabolism</p> <p>Developmental brain abnormalities</p> <p>Environmental factors eg maternal malnutrition; placental insufficiency; fetal alcohol syndrome; varicella infection; irradiation</p>	<p>Intrauterine: placental insufficiency; prematurity; obstetric trauma</p> <p>Neonatal: intracranial haemorrhage; respiratory distress; head trauma; kernicterus</p>	<p>Head injury</p> <p>Infections &amp; post-infectious</p> <p>Degenerative disorders</p> <p>Seizure disorders</p> <p>Toxic metabolic disorders eg lead poisoning</p> <p>Malnutrition</p> <p>Environmental deprivation</p>

# Classification



- Continuous, intensive assistance
  - communication, personal care, accessing services & facilities
  - ~~Reading possibilities with specific~~
  - ~~Main life and travel independently~~
- Expressive communication usually reliant on gestures, facial expression and body language
- ~~Planning & organising their lives~~
- ~~Relationships require personal care & intervention~~
- Importance of objects & visual aides in communication
- ~~Possible difficulty in relationships~~
- Importance of relationships – recognise and form close bonds with key people
- ~~substantial roles & responsibilities~~
- communication<sup>1</sup>

1. Centre for Developmental Disability Health Victoria 2008, *Factsheet: Working with people with intellectual disabilities in healthcare settings*; <http://www.cddh.monash.org/assets/documents/working-with-people-with-intellectual-disabilities-in-health-care.pdf>



# Historical Changes & Impacts

- Benefits of deinstitutionalisation
  - Social inclusion
  - Enhanced opportunities
- Other impacts of deinstitutionalisation
  - Historical separation of health and disability services
  - Erosion of expertise within health sector
  - Loss of educational and professional focus
- Subsequent service development
  - Enhanced behavioural support within disability services
  - Limited development of health services and policy

# How is disability conceptualised?

## Medical Model

- Focus = affliction, and provision of cure/ treatment, care and protection
- Disability viewed as deficiency or deviation from the norm: care directed towards changing the person, assimilating to the social norm
- Impairment itself causes the limitation

## Social Model

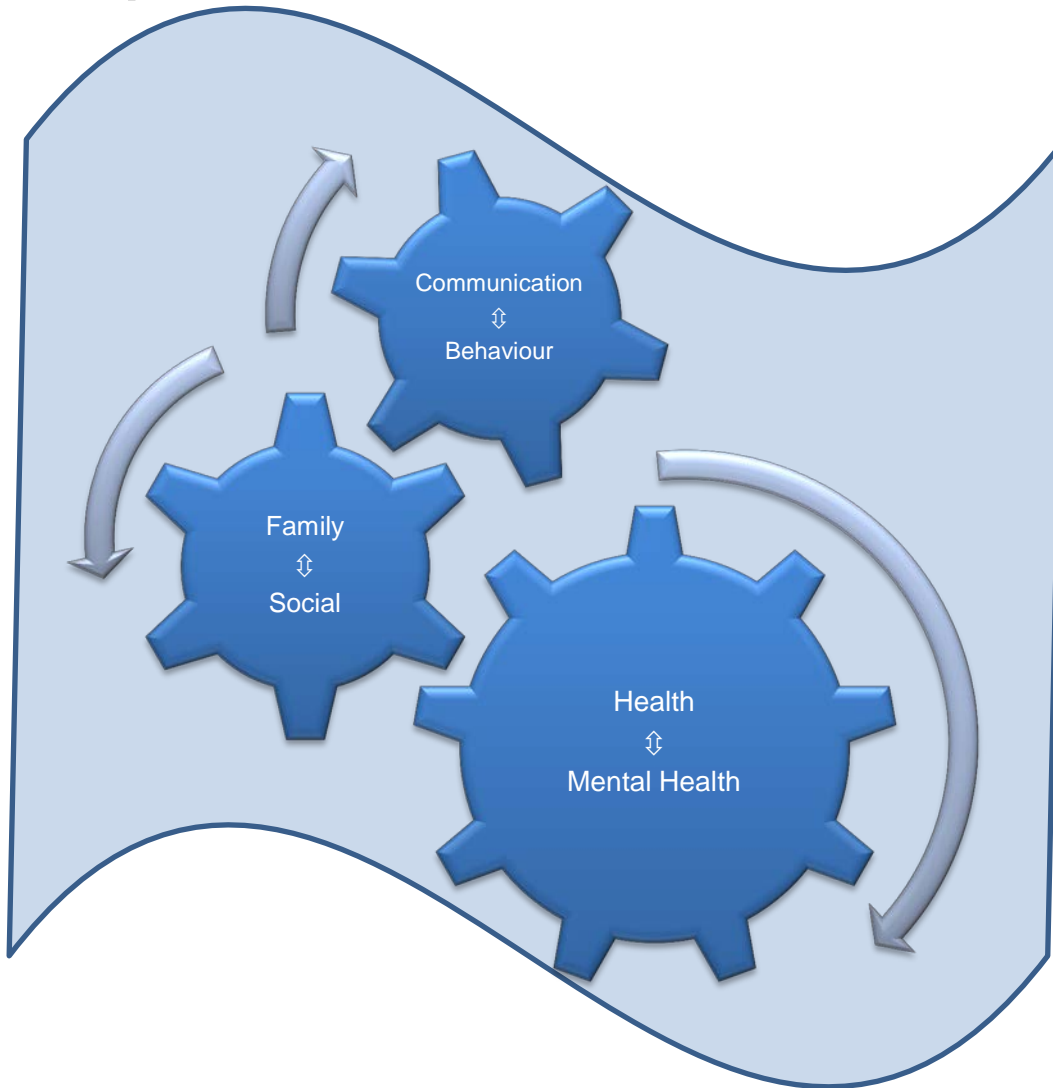
- Focus = acceptance of impairment as a positive dimension of human diversity
- The problem lies in the social norms that results in exclusion
- Experience of disability is located within the social environment, not the impairment itself

## Universalism

- Focus = respect for difference, widening the range of 'normal'
- Ability-Disability as a continuum, reflecting human diversity
- Boundary of 'disabled' vs 'non-disabled' drawn for social and political purposes, not based on scientific fact
- Impairment = an infinitely various but universal feature of the human condition

For review see Kayess & French 2008; Bickenback et al 1999

# Impact of Intellectual Disability



Diagnosis  
Lifespan perspective  
Transitions  
Lifetime caring role  
Multiple impacts

# Communication

Giving information

Receiving Information

## Social Communication

The underlying purpose of communicating

Knowing how to communicate with different audiences

Non-verbal communication, eg. eye contact

Getting the "gist"

## Verbal communication

### Expressive Language

- Complexity of sentences
- Vocabulary
- Speech impairment

### Receptive Language

- Multiple instructions
- Idioms and humour
- Literal language
- Processing speed
- Concepts and abstract thinking

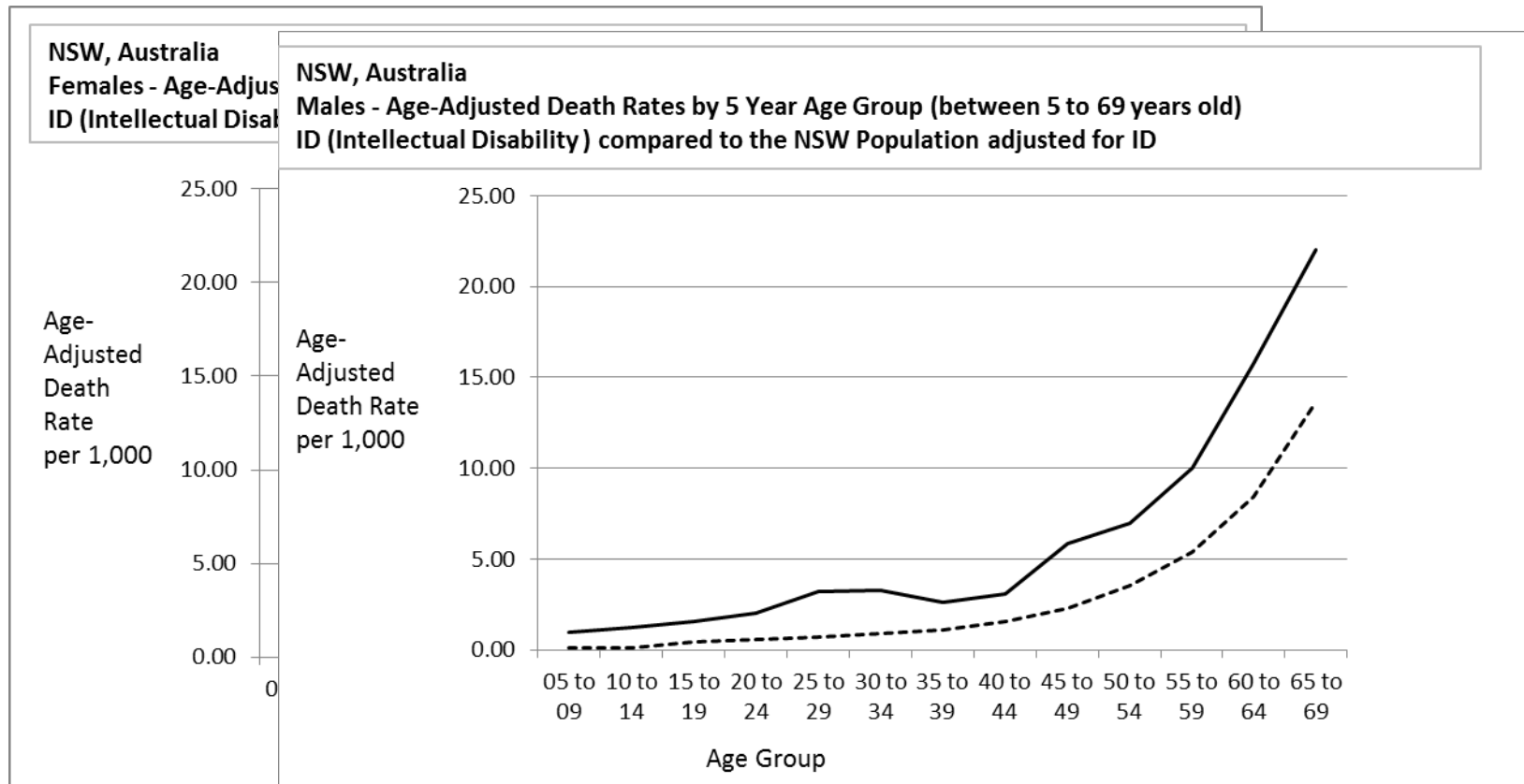
Adapted from presentation by Annette Elias during the workshop series *Mental Disorders in Intellectual Disability*

# Impact of ID – Behaviour

- Higher rates of behavioural problems
- Relationship to communication difficulties
  - Behavioural change can be:
    - A communication of needs
    - A response to environmental and situational factors
    - A manifestation of a medical/psychiatric condition
    - Reinforced by learning
- Behavioural phenotypes
- “Challenging behaviour”

# Impact of ID – Health

- Lower life expectancy<sup>1</sup>



# Impact of ID – Health

- Higher morbidity<sup>2,3</sup>
- Lower rate of detection and treatment<sup>2,3</sup>

1. Bittles et al. 2002; 2. Lennox & Kerr 1997; 3. Beange, McElduff & Baker, 1995

# Health Challenges – Physical Health

- Dental disease (7x)
- Vision impairment & eye disorders (7-20x)
- Hearing impairment
- Thyroid problems
- Epilepsy
- GERD
- Osteoporosis
- Hospitalisation (2x)
- Serious injury (2x)
- Mobility problems
- Multiple chronic complex disorders
- Polypharmacy
- Lifestyle related
  - Overweight & obesity
  - Constipation
  - ↓ Physical fitness



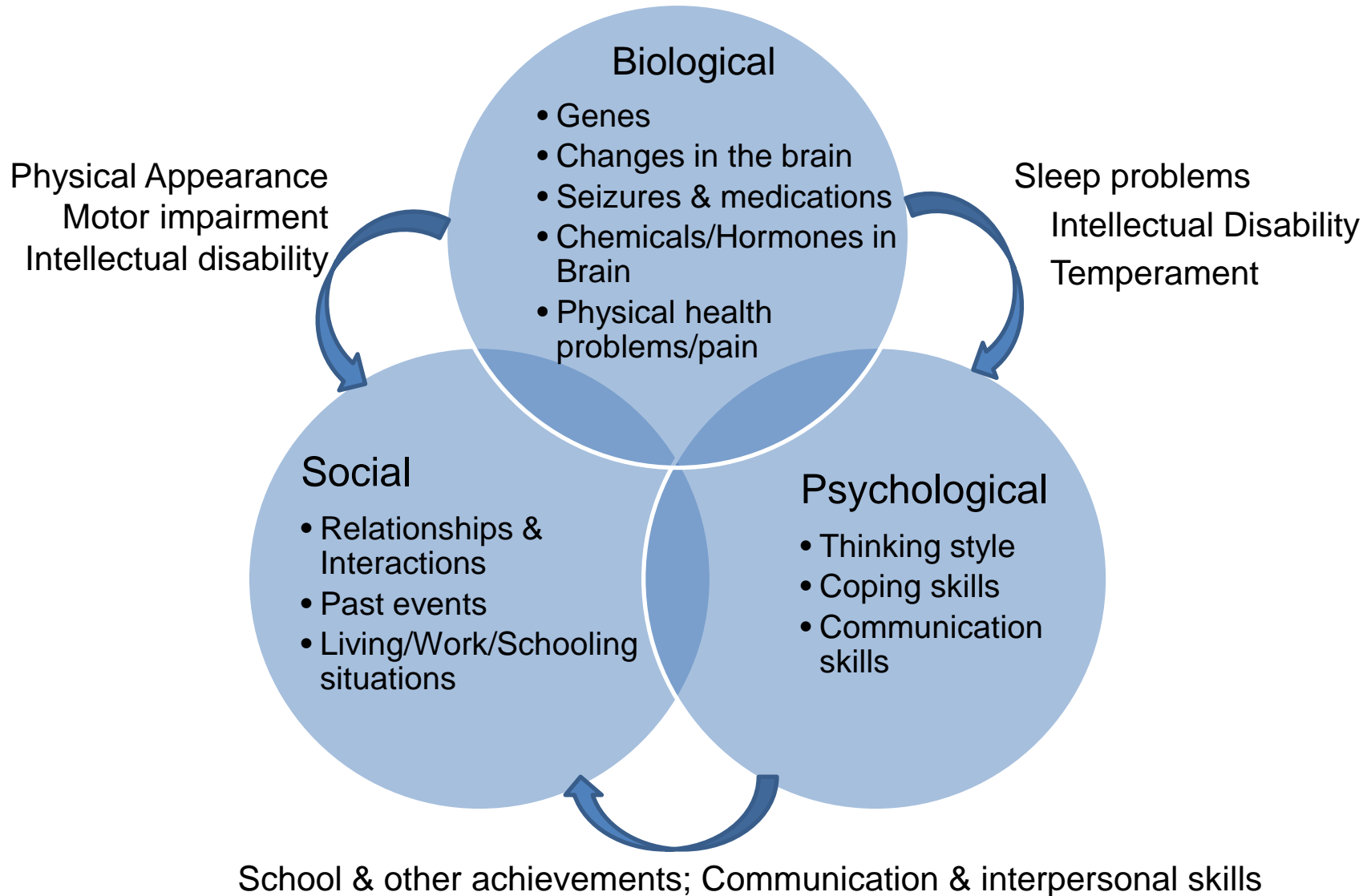


# Health Challenges– Mental Health

- People with ID experience:
  - the full range of mental disorders seen in adults without ID
  - higher rates of mental disorder ( $\sim 40\%^1$  v  $\sim 20\%^2$  )
  - increased prevalence of mental disorder with increasing disability<sup>1</sup>
  - psychopathology that varies with level of disability<sup>1</sup>

1. Cooper et al., 2007; 2. Slade et al., 2009

# Things that affect mental health



# Health Challenges – eg Down Syndrome<sup>1</sup>

- Visual impairment, cataracts
- Hearing impairment
- Hypothyroidism
- Epilepsy
- Congenital heart defects (40-50%)
- Atlantoaxial instability
- Skin disorders, alopecia, eczema
- Depression
- Alzheimer's disease
- Sleep apnoea
- Increased susceptibility to infections
- Coeliac disease
- Blood dyscrasias
- Childhood leukaemia

1. Lennox & Eastgate, 2004. Adapted with permission from Nick Lennox



# Health Challenges – eg Tuberosous Sclerosis<sup>1</sup>

- Retinal tumours
- Sleep problems
- Epilepsy
- Cerebral astrocytomas
- Rhabdomyomas
  - Eye
  - Bone
  - Liver
- Hypertension
- Kidney & lung hamartomas
- Polycystic kidneys
- Dental abnormalities
- Skin lesions
- Autism Spectrum disorders
- ADHD
- Anxiety Disorders

1. Lennox & Eastgate, 2004. Adapted with permission from Nick Lennox

# Health Challenges – eg Fragile X Syndrome<sup>1</sup>

- Visual impairment
- Hearing impairment
  - Recurrent ear infections
- Epilepsy
- Aortic dilation, Mitral Valve prolapse
- Connective tissue dysplasia
- Scoliosis
- Congenital hip dislocation
- Hernias
- Autism Spectrum disorders
- Anxiety Disorders
- Attention Deficit/Hyperactivity

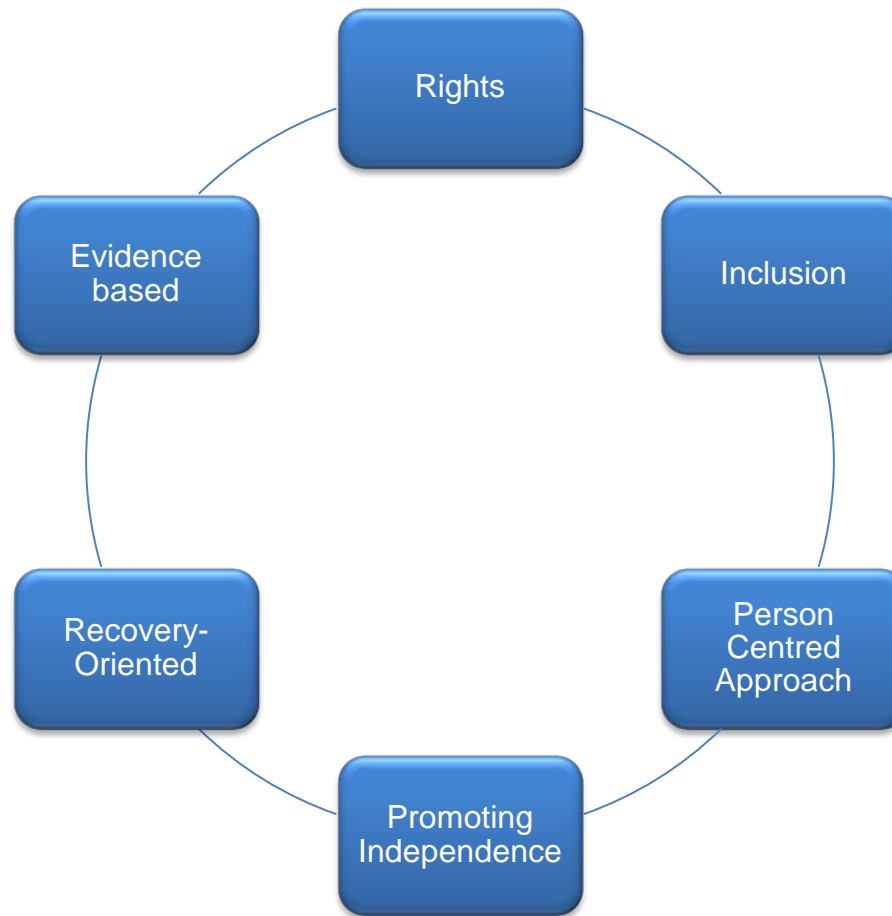
1. Lennox & Eastgate, 2004. Adapted with permission from Nick Lennox



# Why are People with an ID at Higher Risk of Ill Health?

- Multiple barriers to health care:
  - Less likely to express health concern or seek help
  - Reduced insight and awareness
  - Reduced supports and self advocacy
  - Communication
  - Lack of awareness of carers
- Atypical presentations
  - Signs of health condition or mental disorder are confused with a feature of ID or a behavioural problem
- Limited specialised services for people with ID
- Limited skills in general medical workforce
- Limited access to prevention, early intervention strategies
- ID specific health needs

# Guiding Principles for all Practitioners



# Principles Guiding Approach to Health Services

- UN Convention on the Rights of Persons with Disabilities
  - Adopted by the UN on 13 December 2006
  - Australia: signed 30 March 2007; ratified 17 July 2008
- Equity of access to (mental) health care
- Article 25:
  - the same range, quality & standard of free or affordable (mental) health care
  - (mental) health services needed specifically because of the disability
  - services to prevent secondary disabilities
  - services as close as possible to own community, including rural areas
  - (mental) health professionals who:
    - provide the same of quality (mental) health care, including on the basis of free and informed consent
    - raise awareness of human rights, dignity, autonomy and needs of persons with disabilities
    - provide training and promulgation of ethical standards for public and private (mental) health care
  - a system which:
    - prohibits discrimination in provision of insurance
    - prevents discriminatory denial of (mental) health care, services, foods/fluids



# Approaches to Diagnosis (I)

- Presentation (general health and mental health)
  - may be more complex or atypical – requiring careful enquiry
  - the importance of investigating behaviour
- Adults with mild ID and/or reasonable verbal skills: ***similar presentation to adults without ID***
- Adults with moderate-severe ID, ID & autism, or limited verbal skills: ***↑ changes in behaviour, including disturbed or regressed behaviour***

# Approaches to Diagnosis (II)

- Principles of Dx same as for non-ID
  - however due to ambiguities extra care is required
- Adapting communication
  - Rapport, respect and involving the individual
  - Seeking information from a variety of sources
- Longer consultations may be necessary
  - Medicare schedules
- Hierarchy of causes
  - ↓ Medical
  - ↓ Psychiatric
  - ↓ Behavioural

# Approaches to treatment in people with ID

- Management of physical and mental illness in people with an intellectual disability should mirror that of the general population.
- Depends on severity/treatment context.
- Biopsychosocial approach:
  - Psychological and behavioural interventions
  - Pharmacological interventions
  - Social support

# Approaches to Treatment II

- Principles of prescribing and Tx generally the same (applies to medical and mental disorders)

## HOWEVER

- Possible atypical response to medication
- Higher risk of polypharmacy
- May require active monitoring of side-effects
- May require support to manage compliance
  - Involving carers
  - Simplifying instructions and interventions
  - Etc – depends on individual circumstance



**PREPARING:** Take the time to prepare for working with a person with an intellectual disability by finding out about their strengths, and the support they may require to actively participate



**REFLECTING:** Reflect on how your personal beliefs, and emotional reactions towards people with a disability might influence your clinical practice



**ADJUSTING COMMUNICATION:** Determine the person's preferred communication style, and appropriately adapt your communication style to meet their needs.



**LEARNING & INTEGRATING** knowledge into practice: Learn about Intellectual Disability Mental Health and use your new knowledge to improve practice

## MAKING SERVICES ACCESSIBLE TO PEOPLE WITH AN INTELLECTUAL DISABILITY



Engaging **SUPPORT**

**NETWORKS:** Identify the person's support network, and when appropriate to do so, work with them at all stages of service delivery.



**SEEKING SUPPORT:** Identify and actively seek support from specialist intellectual disability mental health professionals, when required



Facilitating **SUPPORTED**

**DECISION-MAKING:** Facilitate supported decision and give priority to the persons expressed wishes, as far as possible



Making information **ACCESSIBLE:** Provide information to the person with an intellectual disability, their family, and support networks in accessible formats, at all stages of the clinical process, acknowledging that the format may be different for different



Knowing what **SKILL SETS** are available: Be aware of the different skills and approaches available in the mental health and disability sectors, and use this knowledge to facilitate collaborative work



**COLLABORATING** across agencies: Work with partner organisations to deliver a seamless service to people with an intellectual disability, their families, and support networks.

# ID Services & Resources

- Cut across service systems and sectors (government, non-government)
- Early developmental assessments and interventions
- Disability specific supports
- Educational supports
- Social supports
- Housing and accommodation supports
- Administrative, decision making and legal supports
- Physical and mental health supports
- Support for self advocacy

# Conclusions

- The implications of having an intellectual disability result from the complex interaction of social, family, interpersonal and intrapersonal factors and are shaped by the socio-cultural environment
- People with intellectual disability experience significantly poorer health and mental-health relative to non-ID peers
  - higher morbidity and mortality
  - lower rates of detection and treatment
- Providing appropriate medical care to a person with an intellectual disability means
  - adjusting communication and consultation time as required
  - being aware, open, sensitive and vigilant

# Acknowledgements/Declarations

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- Australian Government Department of Health and Ageing
- Australian Research Council (ARC)
- National Health and Medical Research Council (NHMRC)
- NSW Institute of Psychiatry
- Autism CRC

