



What GPs need to know about intellectual disability

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Acknowledgements

Fragile X Association of Australia

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Terminology

The term developmental disabilities will be used to mean intellectual disabilities and autism

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Who?

- Definition
- How many Australians?
 - Over 300,000
- Where do they live?
 - In the community... mainly







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Diagnosis in children with possible developmental delays

Low threshold for referral

If parents are concerned about developmental delay, **referral recommended**

The Blue Book gives milestones, and Parent Evaluation of Developmental Status (PEDS).

These are general guides to how the child is developing, but neither is accurate enough to definitively exclude developmental problems

If parents say school is concerned, ask school to provide report

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Where to refer

Private paediatrician

Follow Medicare Local Pathway if available

Early Childhood Centre

Community Health Centre

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Preparation for referral

- Health information about child
- Health, wellbeing information about family
- Can obtain allied health assessments if delays suspected, e.g. speech, physio, hearing assessments
- Relevant pathology, e.g. thyroid function
- Add GP developmental assessments, eg Ages and Stages Questionnaire if you are experienced with them

Is it autism?

- Lack of interpersonal empathy
- Disturbances in communication
- Narrow constricted interests, intolerance of change, sensory idiosyncracies

However, there are many subtleties and variations, and diagnosis is for experts
The critical action for the GP is to recognise concern about developmental deviance and arrange assessment.

**Developmental disabilities are not just childhood problems
People with developmental disabilities need lifelong health care**

Some aspects of health care

Physical Pain

- Dental
- Musculo-skeletal
- Gut
- Infections



Epilepsy

- Under and over diagnosis
- Inadequate review and side effects



Health promotion/prevention

- Immunisation, BP, breast, skin, PAP

Lifestyle and nutritional problems

- Obesity

Osteoporosis and vitamin D

Sensory impairment



Gut problems

- Constipation
- H.Pylori
- Gastro-oesophageal reflux disease

Urogenital

- Undescended testis
- Hypogonadism



Mental Health and Behavioural Problems

Key point: Behaviour problems are not caused by ID per se, they are caused by comorbid factors which need to be understood.

These factors may be biological, psychological and/or social.

For example

- Comorbid mental disorders
 - depression, PTSD, schizophrenia
- Psychological
 - environmental/learnt
 - Abuse and PTSD



Mental Health and Behavioural Problems

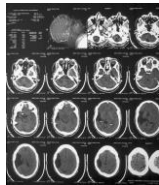
Management

Resist the pressure to prescribe ever-increasing doses of major tranquilisers for behaviour problems

Instead seek referral to psychologist or mental health service for assessment

SSRI's can be useful for reducing obsessions in autism

Cause of intellectual disability



750+ known causes

Often divided pre, peri and post natal

- Down Syndrome 1 in 660 live births
- Fragile X
 - 1/300 – 500 carrier
 - 1 in 5,000 – 8,000 females
 - 1 in 2500 – 4000 males
- Cerebral Palsy – 2 in 1000 live births
- Autism Spectrum Disorder – about 1%



Key message about cause

Don't accept that there is no known cause for your patient's intellectual disability unless there has been an assessment by a geneticist in the last few years

Genetic technologies are improving rapidly, e.g. genome-wide assessment scans
Knowing the cause can help with understanding brain dysfunction, prognosis and treatment

Autism – Has the prevalence increased?

No good evidence of a real increase in incidence, but recognition and labeling has increased greatly

Largely as a way of getting services, e.g. through Helping Children with Autism Package

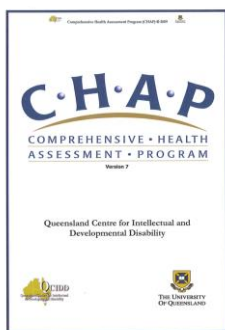
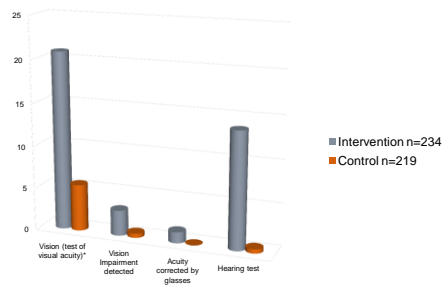
What we knew about physical health in the 1990s

5.4 conditions per person – half unrecognised or poorly managed
 – 1995 North Shore of Sydney

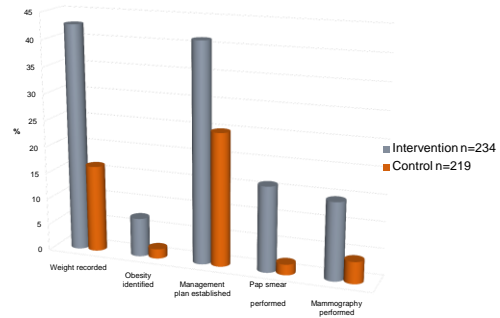
Similar findings in day services and institutions in UK



CHAP EF outcome measures



CHAP RCT outcome measures



Further CHAP outcomes

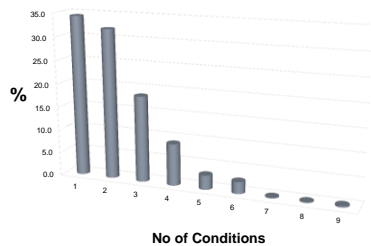
Tetanus/diphtheria 9 ×

Hep. B given 2.4 ×

Breast examination 1.9 ×

24 new diagnoses (c.f. 4 in control) RR 1.6 × (0.9 to 2.8)
 – GORD, Diabetes M, epilepsy

Number of physical conditions per person



Working with disability services

Demand that service providers provide accurate information with an experienced support person so GPs can make reasonable judgments

Written reports, not just hearsay by whichever carer comes along to GP

Direct the service providers to interact with their general practice in a way that works for the general practice and the patient

Consent

In NSW, Guardianship Act applies for persons over 16 years old

- First, determine if the person can give informed consent to any assessment or treatment
- If not, the consent of the Person Responsible under the Act must be obtained

Consent – Some fundamentals

Generally - health provider must obtain consent to provide health care

- Patients need information on the risks, side effects, benefits and alternatives to treatment
- Patients must be able to receive, comprehend, retain and recall relevant information
- Evaluate benefits and risks in terms of personal values
- Select an option and give cogent reasons for the choice
- Communicate that choice to others
- Persevere with that choice, at least until the decision is acted upon
- Adults with capacity have the right to refuse health care

Capacity is...

Decision specific

Domain specific

Time specific

"Person Responsible" under the Guardianship Act

A person declared by the Guardianship Tribunal to be a person with authority to make decisions about health matters for an adult who does not have capacity to make their own decisions.

Who can be a Person Responsible?

Person's **spouse/partner** (close and abiding relationship) or family can be assumed to be the Person Responsible if the Guardianship Tribunal hasn't ruled otherwise

Person's close friend

Not a paid carer

The Office of the Public Guardian

The Public Guardian is the Person Responsible if there is no family or friend who can fill that role

Contact:

http://www.publicguardian.justice.nsw.gov.au/Pages/publicguardian/pg_contactus.aspx

Some health care can be carried out for adults with impaired capacity without consent

Mandatory reporting

Life sustaining measures in acute emergency

A case study



Questions?

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