The Medical needs for individuals with Developmental Disability across the lifespan, Globally and Locally

Context is all

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Acknowledgements

- People with Intellectual Disability & their families & supporters
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    - Chris Bain, Mike Kerr, Henny Lantman
- Funding
    - Qld Disability Service & Qld Health
    - NHMRC, ARC, GPEP, eHealth, AUS-Hi

LEARNING OBJECTIVES

- Recognize the medical needs of individuals with developmental disability
- Identify the gaps in medical care
- Assess how to act more effectively to overcome potential deficits in medical care
- Utilize provincial resources to promote a comprehensive continuum of care

Presenter Disclosure

- Nicholas Lennox
- Relationship with commercial interests:
  - Comprehensive Health Assessment Program (CHAP health check) commercialised by Uniquest – arm of The University of Queensland, Australia.
  - As the “inventor” I receive 1/3 of the royalties
  - I actively have NO relationship with Drug companies

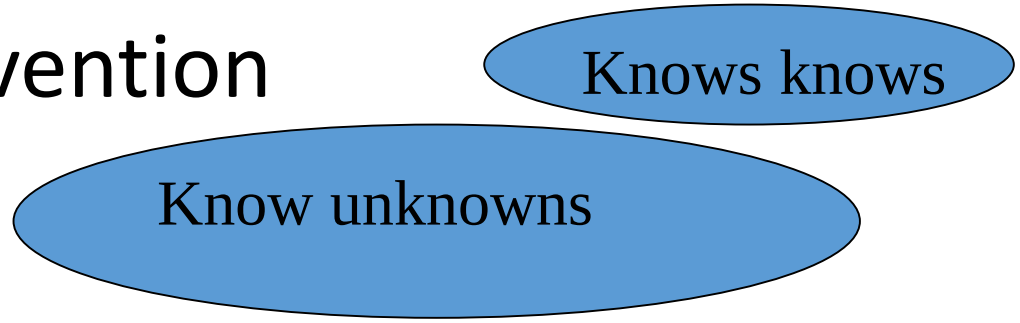
Managing Potential Bias

- Point the relationship out
- Present the evidence and limitations of the CHAP research

Recognize the medical needs of individuals with developmental disability

What do we know about health in adults with Developmental Disability?

- Mortality
- Morbidity
- Lifestyle
- Health promotion & disease prevention



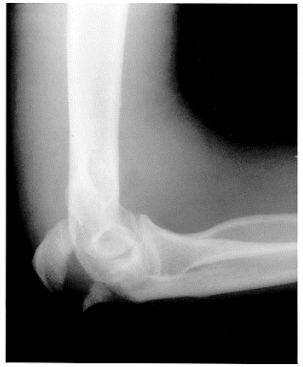
Unknown Unknowns

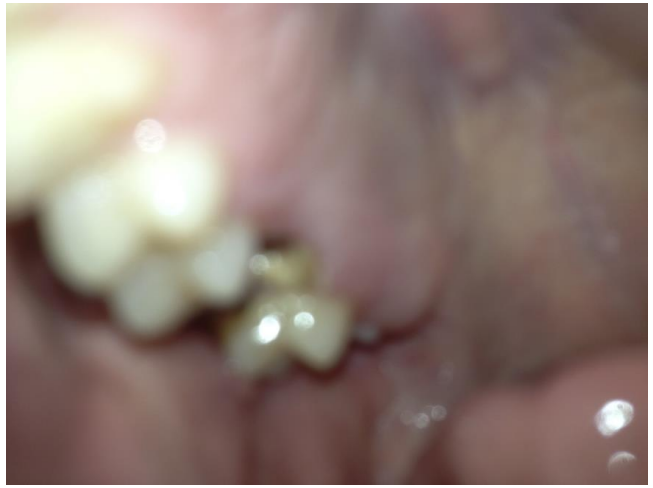
(the rest of the unknown universe/s)

What are the unmet medical needs?

“Known unknowns”

- **Physical Pain**
  - **dental**
  - **musculo-skeletal**
  - **gut**
- **Mental disorders**
  - **Depression, PTSD, Schizophrenia**
- **Psychological**
  - **environmental/learnt**
    - **abuse**





“Known unknowns”

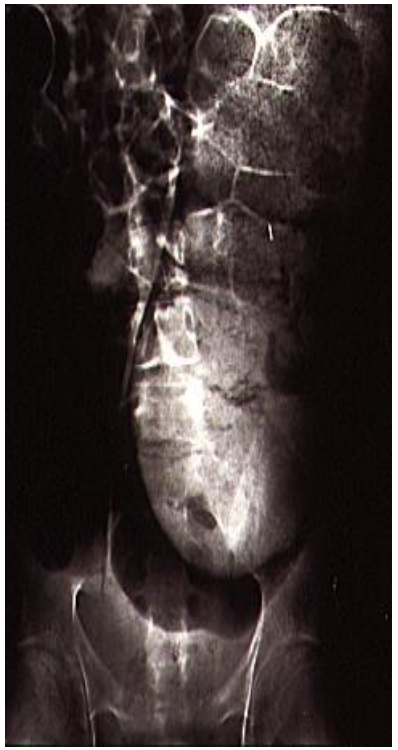
- **Medications**
  - **neuroleptics**
  - **anti-convulsants**
- **Epilepsy**
  - **under and over diagnosis**
  - **inadequate review & side effects**
- **Infections**

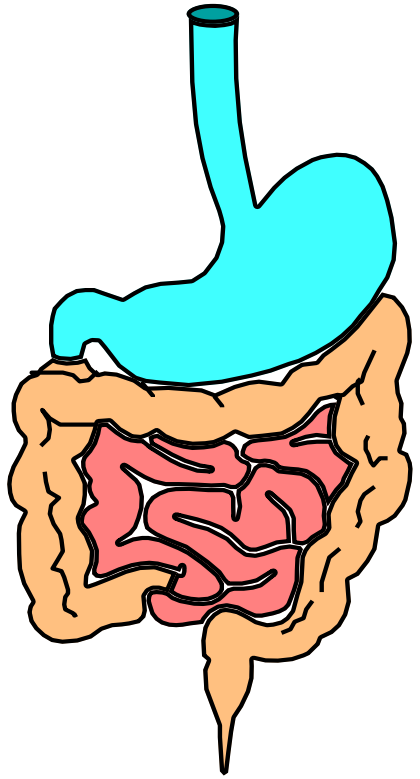
“Known unknowns”

- **Health promotion/prevention**
  - **immunisation, BP, breast, skin, PAP**
- **Lifestyle & nutritional problems**
  - **Obesity**
- **Osteoporosis & vitamin D**
- **Sensory impairment**

“Known unknowns”

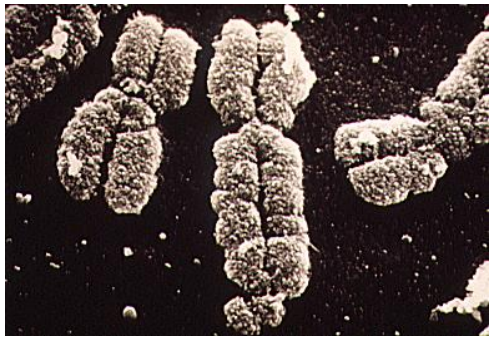
- **Gut problems**
  - **constipation**
  - **H.Pylori**
  - **gastro-oesophageal reflux disease**
- **Urogenital**
  - **Undescended testis**
  - **Hypogonadism**
- **Sexual and reproductive health**

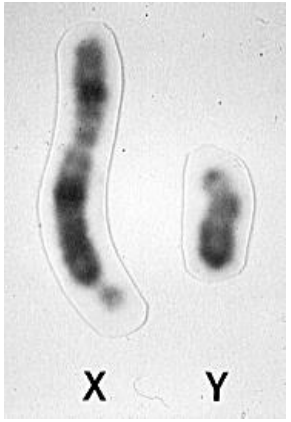


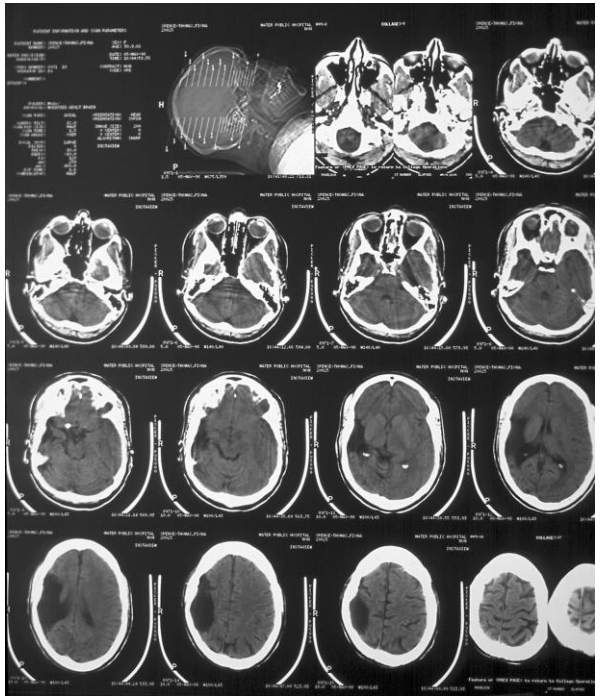


“Known unknowns”

- Cause of developmental disability





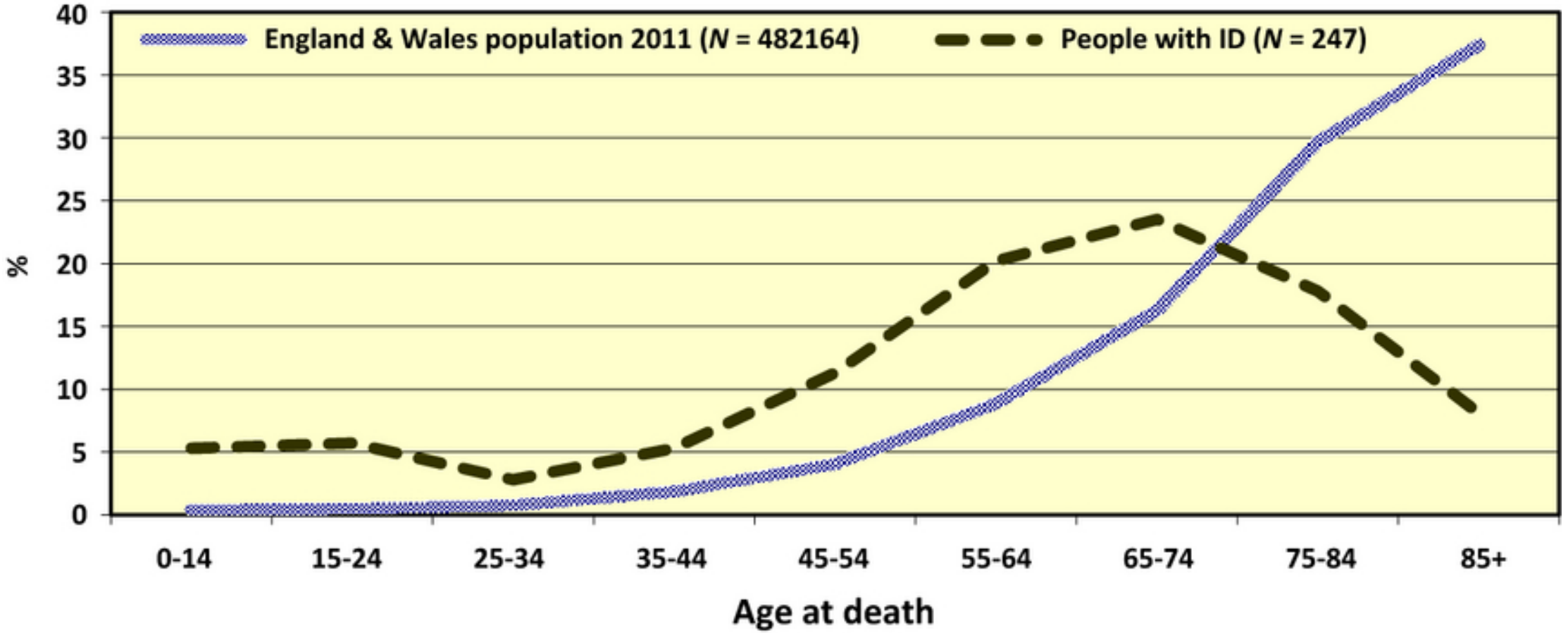


Aetiology of Intellectual & Developmental Disability

- > 750 +++++ known causes and increasing
- often divided pre, peri and post natal
  - Down Syndrome 1/1000 live births
  - Fragile X
    - 1/300- 500 carrier
    - 1 in 5,000-8,000 females
    - 1 in 2500 to 4000 males
  - Cerebral Palsy - 2 in 1000 live births
  - Autism Spectrum Disorder – 1 in 100

Are there changes in medical needs with age?

Age at death of people with intellectual disability compared with the population of England and Wales in 2011 (from Heslop et al. p.24).



Mortality of People with Intellectual Disabilities in England:
A Comparison of Data from Existing Sources

Mortality of People with Intellectual Disabilities in England: A Comparison of Data from Existing Sources, Volume: 28, Issue: 5, Pages: 414-422, First published: 09 August 2015, DOI: (10.1111/jar.12192)

Throughout aging

- Access to health care
- Independent living – dignity of risk & developmental principle
- Vulnerability to major mental disorders
- Vulnerability to abuse
- Ageing parents – grief and loss
- Loss focus on skill development & growth
- Isolation risk and narrow social range
- Epilepsy comorbidity

Young adults

- Emerging sexual expression and social context
- Changing and loss of relationships
  - Friends, siblings, parents, strangers and self
- Institutions – move from education to what?
- Access to health care
  - Transition to primary health care from Paediatric care
- Vulnerability to major mental disorders

Down Syndrome Disintegrative Disorder

- Jacobs *et.al* (2016) - "Down Syndrome Disintegrative Disorder", "New-onset Autistic Regression", "Catatonic Psychosis", "Acute Regression of Down Syndrome" or "Catatonia in Down Syndrome". Akahoshi *et. al.* (2012) use the broad term "Acute Neuropsychiatric Disorder".

- Small percentage of young adult patients who, despite often functioning well through adolescence, develop a rapid clinical deterioration

- An acute deterioration, significant decline in living skills, cognitive function, speech, development of abnormal sleeping patterns, depressed mood, anxiety, sometimes hallucinations and odd behaviour, repetitive behaviours and obsessional slowness, where it may take hours to complete activities that previously took minutes and may resemble catatonia (Jacobs *et.al.*, 2016, Dykens *et al.*, 2015).

Midlife adults

Key difference to early life

- Early aging in DS
- Medication long term side effect
- Loss focus on skill development & growth
- Risk of isolation
- Co morbidity of aging

Aging

- Dementia
- Increase sensory deficits
- Risk of poly pharmacy
- Medication long term side effects
- Increased risk non insulin dependent diabetes mellitus
- Loss focus on skill development & growth
- Aging associate morbidity

Dementia in Down syndrome

Alzheimer type Dementia

Age specific rates N=201

40 - 49 Years - 9.4%

50 - 59 Years - 36.1%

60 -69 Years - 54.4%

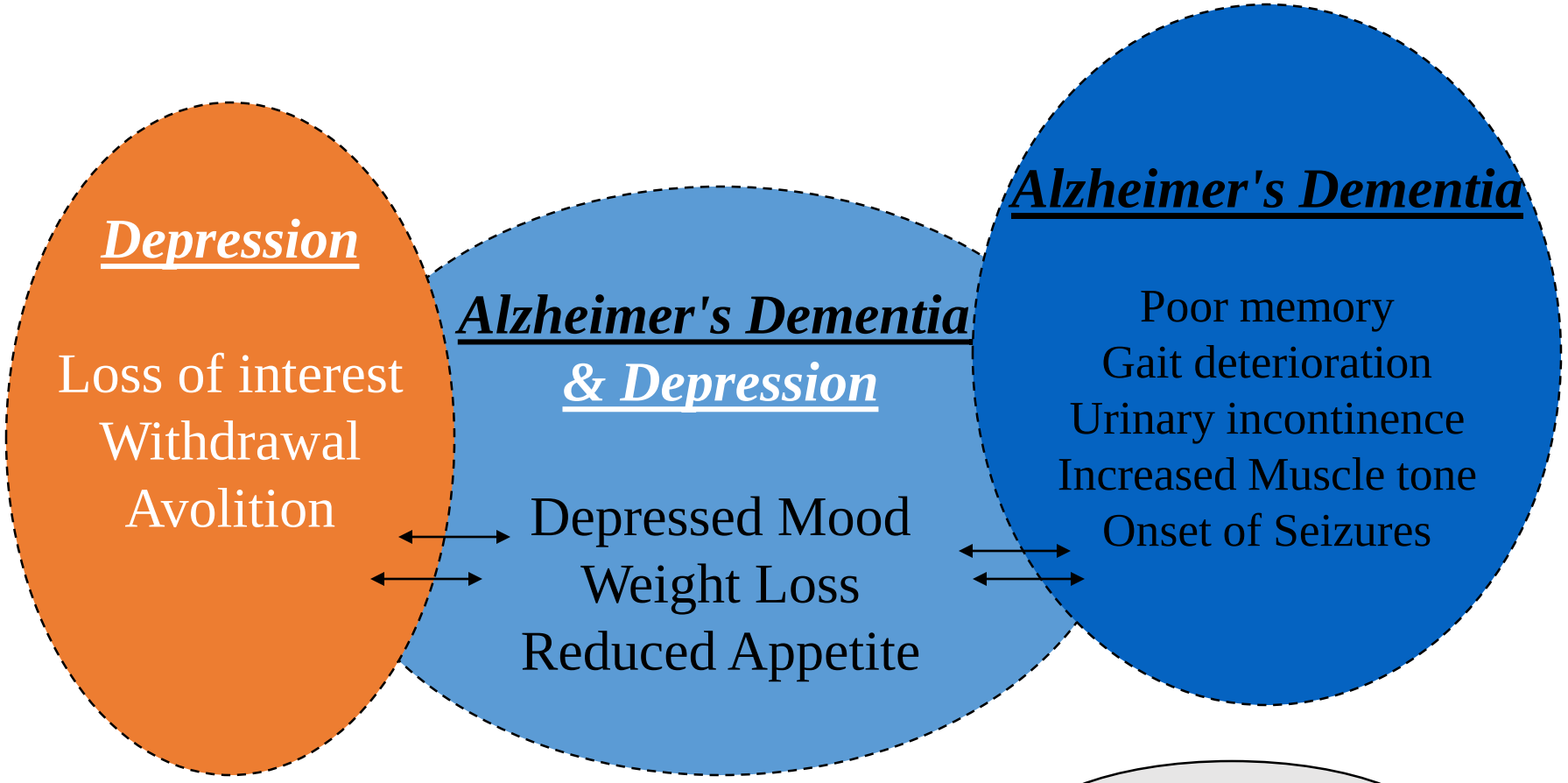
REF: Prasher VP. *Age-specific Prevalence, Thyroid Dysfunction and Depressive Symptomatology in adults with Down Syndrome and Dementia,* International Journal of Geriatric Psychiatry vol 10 25 -31, 1995.

Presentation

- Dyspraxia
  - Dyspraxia - partial loss of ability to perform coordinated acts.

  Skill loss
  - use of utensils, making bed & other domestic tasks
- Recall
  - response to complex requests
- Need detailed record of skills

Symptoms of Depression and Alzheimer's Dementia (AD)



Prasher VP. *Age-specific Prevalence, Thyroid Dysfunction and Depressive Symptomatology in adults with Down Syndrome and Dementia,* International Journal of Geriatric Psychiatry vol 10 25 -31, 1995.

Barriers & Enablers to high quality health care

People with DD, their families & supporters

- Respect & Inclusion
- Autonomy & level of support
- Communication
- “Attitudes” & valuing

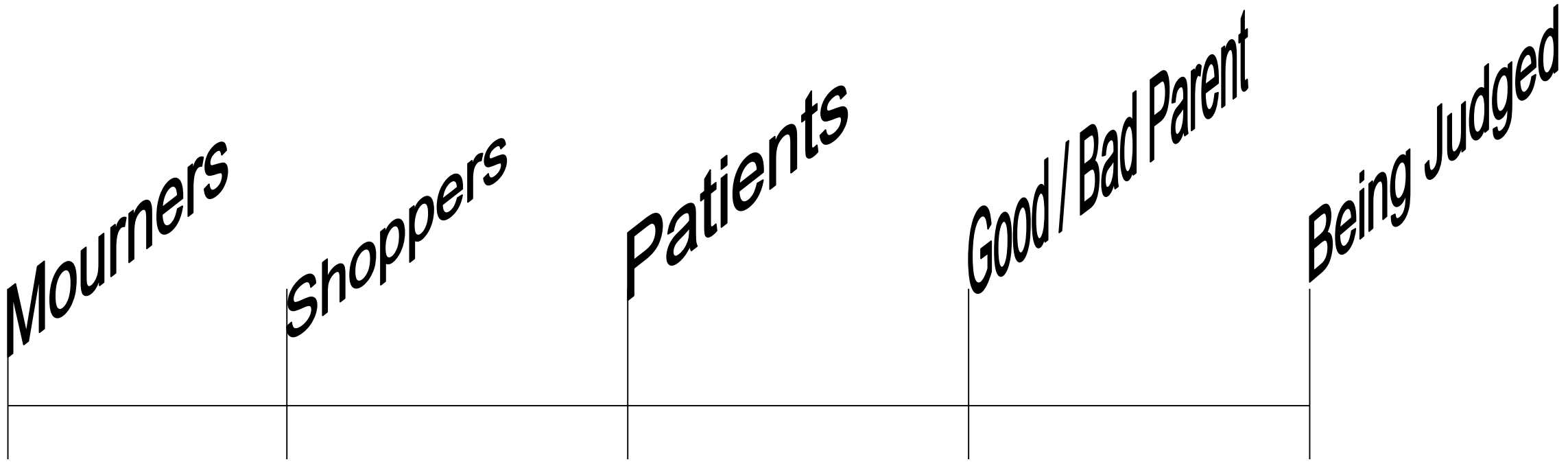
“It’s a funny thing about life; if you refuse to accept anything but the best, you often get it.”
Somerset Maugham

What parents want from healthcare

- Someone who knows about the health issues for their adult
- Co ordination between healthcare specialists & with disability support systems
- Enabled & powerful health advocate who can challenge medical opinion
- Better access & understanding at all levels of the health system
- Family medicine & mental health professionals improved & supported

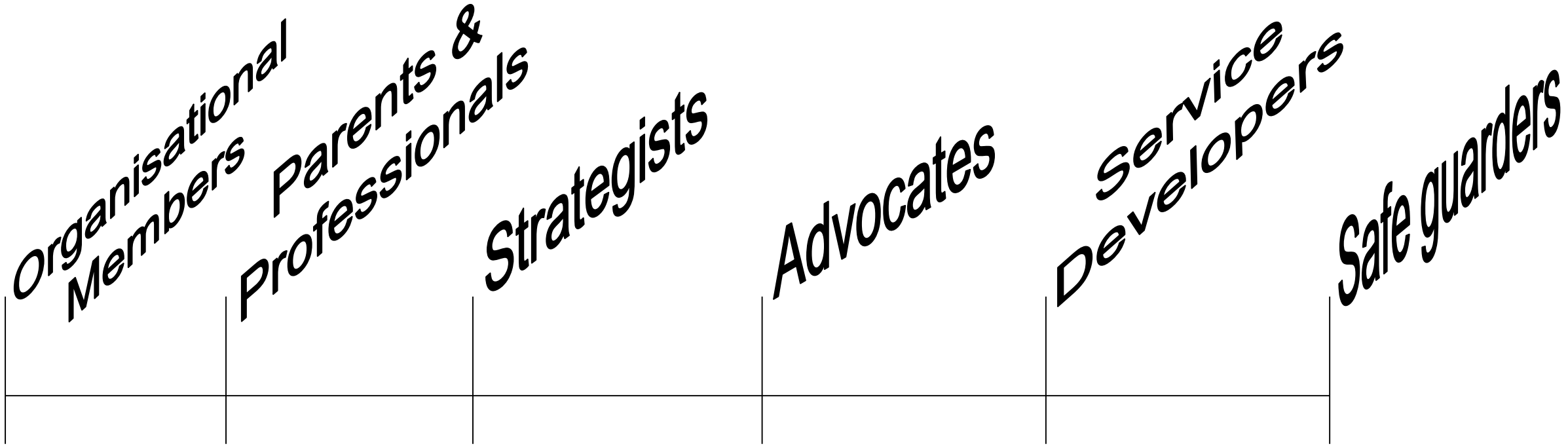
Parent to Parent
The Role Continuum – part one

- During this period <u>parents are often seen as part of the problem</u>



Parent to Parent
The Role Continuum – part two

- During this period <u>parents are often seen as part of the solution to the problem</u>



What do Psychiatrists & GPs think?

- Considerable stress
  - Structural reasons & others
- Untrained
- “Hard to do it” “difficult patients”
  - Poor history
  - Flux of staff
- Psychiatrist feel they (& the system) fail this group
- Aware they need to do extra but competition with other groups
- Time and remuneration

Ref Jess G, Torr J, Cooper, SA, Lennox N, Edwards N, Galea J, O’Brien G. Specialist versus generic models of psychiatry training and service provision for people with intellectual disabilities. Journal of Applied Research in Intellectual Disability. March 2008;21(2):183-193

Health Care Barriers

- Access
- Communication & recall of information
  - Access to current & past health story
- Fragmentation c.f. continuity
- Support
  - Education, specialist advice, access to other parts of healthcare system
- Time, Cost & Attitudes

Health Care Enablers

- Improve access
- Health story available & accessible
- More time
- Continuity of care not fragmentation
- Diminish barrier to other parts of healthcare system
- Support & education

Minimise barriers

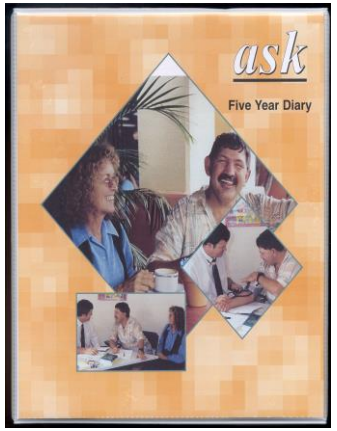
- Macro
  - Enhance valuing & attitudes
  - Autonomy and empowerment
  - Health & disability policy
- Meso
  - Service development and training
  - Knowledge – health generally and the persons health specifically
  - Tools to empower families, supporters and individuals with DD
- Individual
  - Maximise communication
  - “The M factor”
  - “Reasonable adjustments”

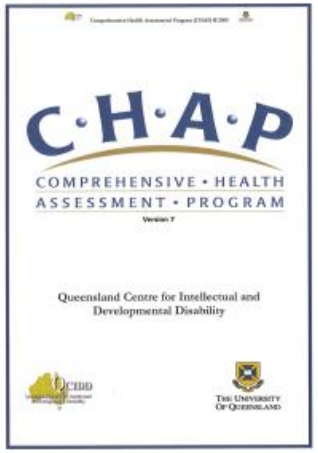
Tools to Enable Health Checks to Education

Tools

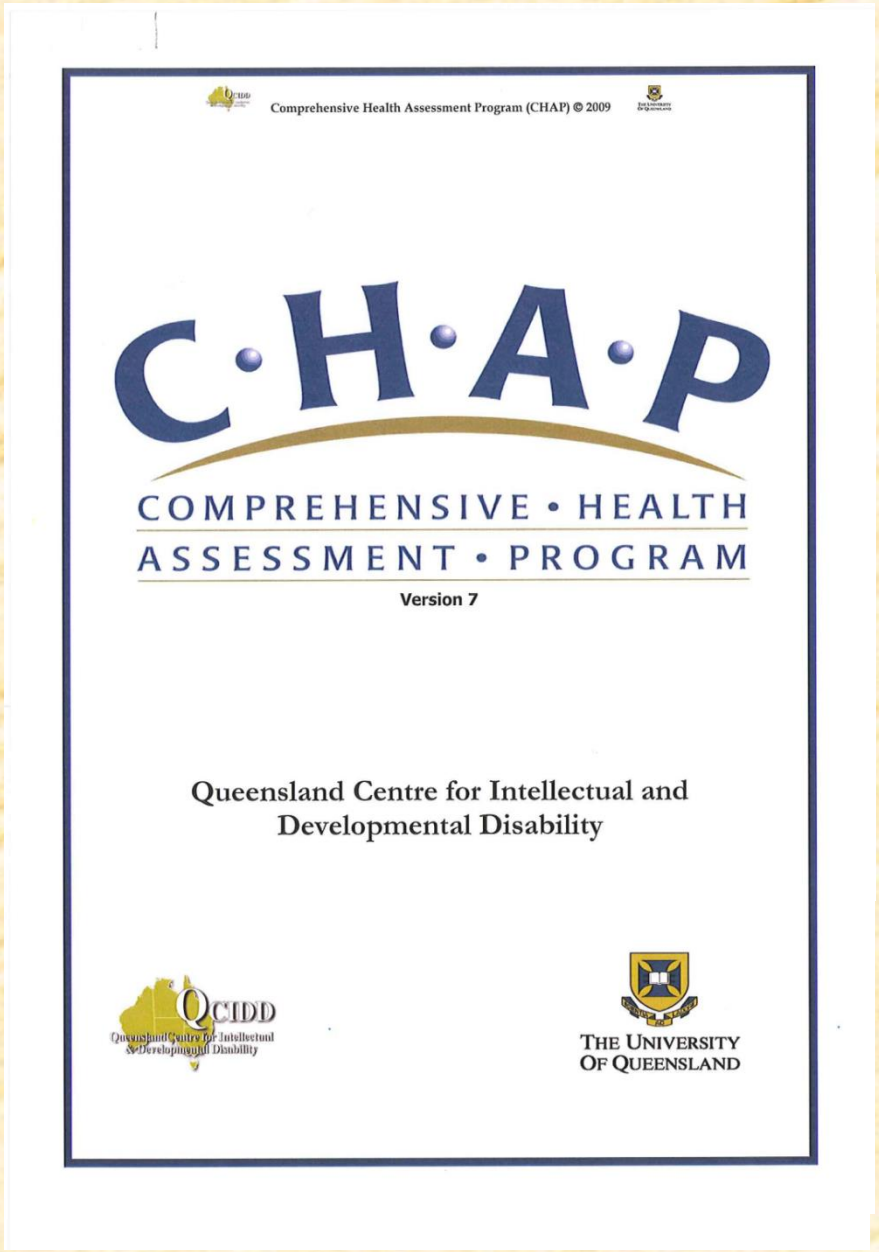
- Guidelines http://ddprimarycare.surreyplace.ca/guidelines/
- CFP http://www.cfp.ca/content/64/4/254
- Health passports and diaries https://www.porticonetwork.ca/web/hcardd/healthcareresources/people-with-developmental-disabilities-and-caregivers
- Health assessments
  - Comprehensive Health Assessment Program (CHAP) health review
  - The RCT and qualitative evidence, issues around implementation
  - UK Health checks http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/health-check-toolkit.aspx
- Mental health tools – PAS-ADD & DBC

Research program





- Survey of GPs & Psychiatrists
- RCTs
  - 1999/2003 - CHAP health check - adults
  - 2000/2005 - A&H - Ask diary & CHAP - adults
  - 2003/2004 - Risperidone trial - adults
  - 2006/2010 - Ask diary & CHAP - adolescents
  - 2007/2012 - RCT Passport to health – ex-prisoners
- Key areas – health checks, health promotion, perceptions & education of providers.



Ref: Lennox N, Bain, C, Rey-Conde, T, Purdie, D, Bush, R & Pandeya, N. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. **International Journal of Epidemiology.** February 2007;36(1):139-146

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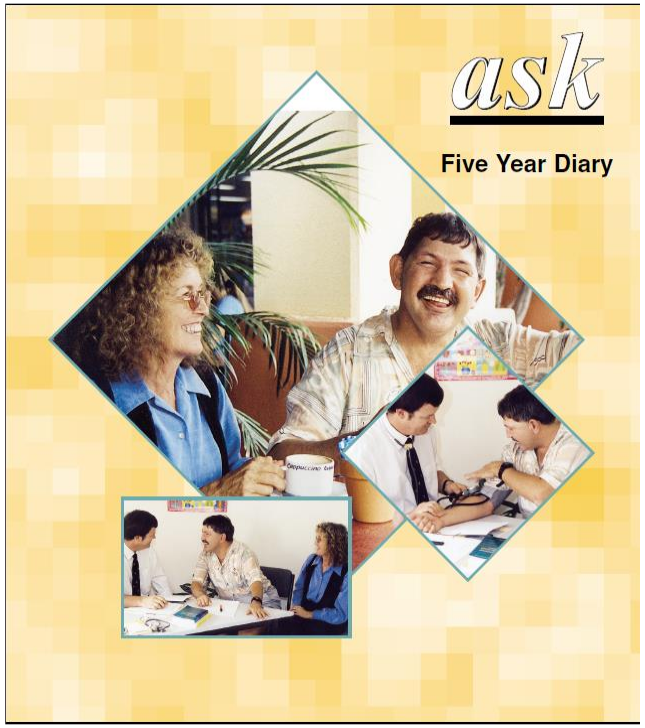
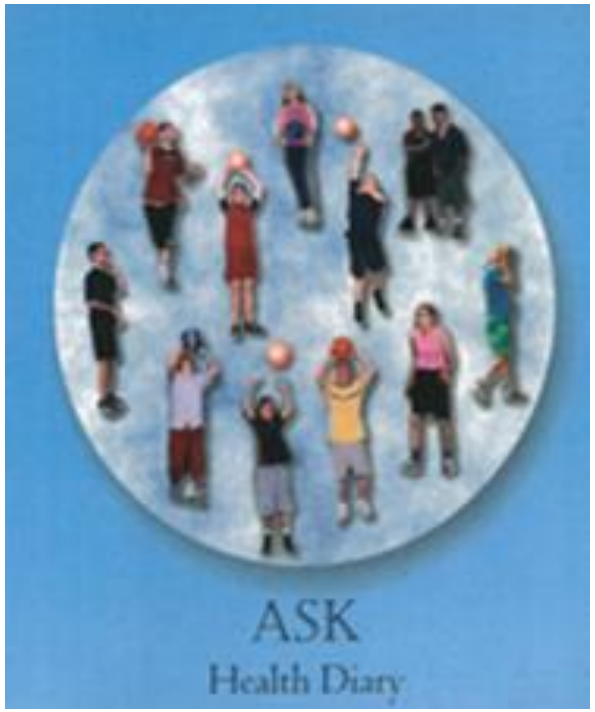
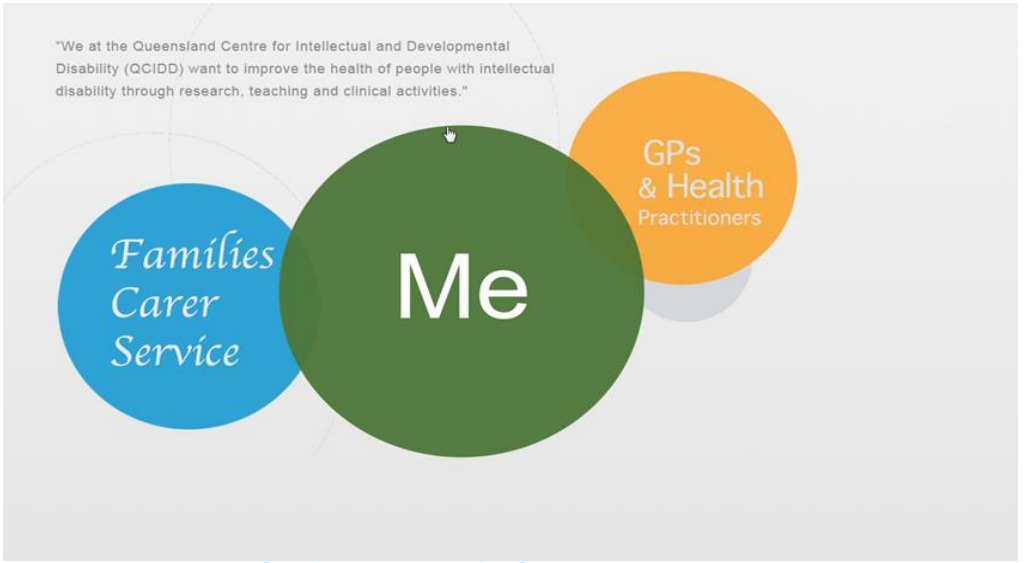
The Ask Diary





Empowering Education



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Research Article | Practice

Primary care of adults with intellectual and developmental disabilities

2018 Canadian consensus guidelines

William F. Sullivan, Heidi Diepstra, John Heng, Shara Ally, Elspeth Bradley, Ian Casson, Brian Hennen, Maureen Kelly, Marika Korossy, Karen McNeil, Dara Abells, Khush Amaria, Kerry Boyd, Meg Gemmill, Elizabeth Grier, Natalie Kennie-Kaulbach, Mackenzie Ketchell, Jessica Ladouceur, Amanda Lepp, Yona Lunsky, Shirley McMillan, Ullanda Niel, Samantha Sacks, Sarah Shea, Katherine Stringer, Kyle Sue and Sandra Witherbee

Canadian Family Physician April 2018, 64 (4) 254-279;

Abstract

Objective To update the 2011 Canadian guidelines for primary care of adults with intellectual and developmental disabilities (IDD).

Methods Family physicians and other health professionals experienced in the care of people with IDD reviewed and synthesized recent empirical, ecosystem, expert, and experiential knowledge. A system was developed to grade the strength of recommendations.

Recommendations Adults with IDD are a heterogeneous group of patients and have health

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Canadian Family Physician
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http://ddprimarycare.surreyplace.ca/guidelines/

The 2018 Canadian consensus guidelines on primary care for adults with Intellectual and Developmental Disabilities outline standards of care to support clinical decision making. These guidelines are developed by family physicians, nurses, psychiatrists and other experts who are experienced in the care of people with IDD.

About Guidelines

This page is at http://ddprimarycare.surreyplace.ca/guidelines/

Approaches to Care Guidelines

Physical Health Guidelines

Mental Health Guidelines

A Person-centred Approach to Care

ENGAGE PATIENTS AND CAREGIVERS

Engage patients and their caregivers to find effective ways of collaborating.[13]

Strongly Recommended

RECOMMENDATION STRENGTH | TYPES OF KNOWLEDGE | BACKGROUND

IDENTIFY A SUPPORT PERSON

Identify with them someone who knows the patient well who will attend health care appointments, help to coordinate care and monitor ongoing health and social needs.[13,14]

Strongly Recommended

RECOMMENDATION STRENGTH | TYPES OF KNOWLEDGE | BACKGROUND

Behaviours that Challenge (BTC)

USE A SYSTEMATIC DIAGNOSTIC FORMULATION

Develop a diagnostic formulation (eg, HELP) that considers causes sequentially and systematically, such as the following[50]:

Health: Assess for possible physical health problems, (see Physical Health guidelines for head-to-toe sequence of common medical concerns), pain, and adverse and other side effects of medications.

Environment: Facilitate "enabling environments" that meet these unique developmental needs and can diminish or eliminate behaviours that challenge (BTC). Work with an interprofessional team and caregivers to address problematic environmental circumstances (see A Person-centered Approach to Care, Effective Communication, Psychosocial Context and Mental Well-being).[73] Ascertain whether existing supports match needs (see Cognitive Ability and Adaptive Functioning).[258]

Plan for a functional behavioural assessment by a behavioural therapist or psychologist.

Life experiences: Screen for distressing life experiences that might be contributing to BTC (see Life Transitions).[72, 252, 259, 260]

Psychiatric conditions: Having attended to the above, consider psychiatric conditions (eg, adjustment difficulties, mood and anxiety concerns). Refer as needed for assessment to an interprofessional mental health team (see Interprofessional Health Care Teams).[48, 72, 252, 261, 262]

Strongly Recommended

RECOMMENDATION STRENGTH | TYPES OF KNOWLEDGE | BACKGROUND

HCARDD
Health Care Access Research and Developmental Disabilities

https://www.porticonetwork.ca/web/hcardd/healthcareresources/people-with-developmental-disabilities-and-caregivers

People with a Disability and Caregivers

Health Passports and Communication Tools

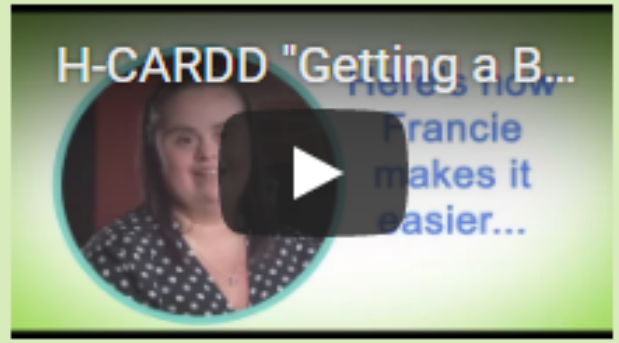
Today's Health Care Visit

The **Today's Health Care Visit** is a worksheet you can use to write information down before a health care visit. Click on the picture to print the worksheet.

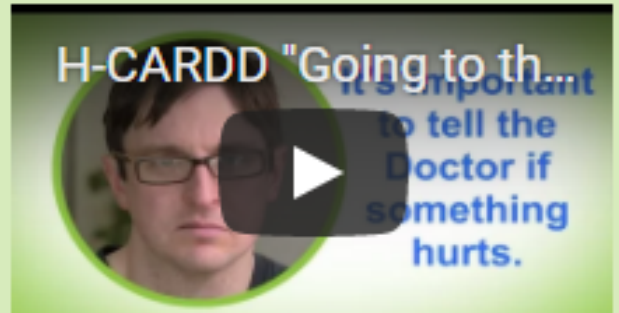
Having trouble reading the Today's Health Care Visit pamphlet? Try the **Large Print** version instead!

About Me

Watch a Video



Getting a blood test. In this video Francie gives some great tips how you can make it easier to get a blood test done.



HCARDD

Health Care Access Research and Developmental Disabilities

Implementing Health Checks for Adults with Developmental Disabilities:

A Toolkit for Primary Care Providers

To download a copy of the Primary Health Care Toolkit and the Companion Guide or to learn more about the Primary Health Care intervention, please visit the Health Care Resources section at

www.hcardd.ca

Caring for your adult patients with Developmental Disabilities (DD):

Tools for Completing a DD Health Check

A companion guide

Conclusion

Conclusion

- Solutions to high quality health & mental care emerging albeit too slowly
- Education available and developing
- Canadian specific approach showing real promise

Thank you

Questions?