

How You Can Maximize the Healthcare Delivered to Individuals with Developmental Disability

Context is all

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Acknowledgements

- People with Intellectual Disability & their families & supporters
- QCIDD Team
- Colleagues & Mentors
 - Helen Beange, Jim Simpson
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 - Qld Disability Service & Qld Health
 - NHMRC, ARC, GPEP, eHealth, AUS-Hi



Learning objectives

1. Formulate proactive strategies to enhance healthcare received by individuals with developmental disability
2. Review evidence based actions to improve healthcare received by individuals with developmental disability
3. Identify how to ameliorate or overcome barriers



Outline of presentation

- Evidence to opinion
- Context is all
- Unmet health & wellbeing needs
- Barriers and enablers to high quality healthcare
- Building an approach to enable high quality healthcare
 - Specific Tools Interventions
 - Education
 - Basic strategies
- The Future



Presenter Disclosure

- Nicholas Lennox
- Relationship with commercial interests:
 - Comprehensive Health Assessment Program (CHAP health check) commercialised by Uniquist – 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

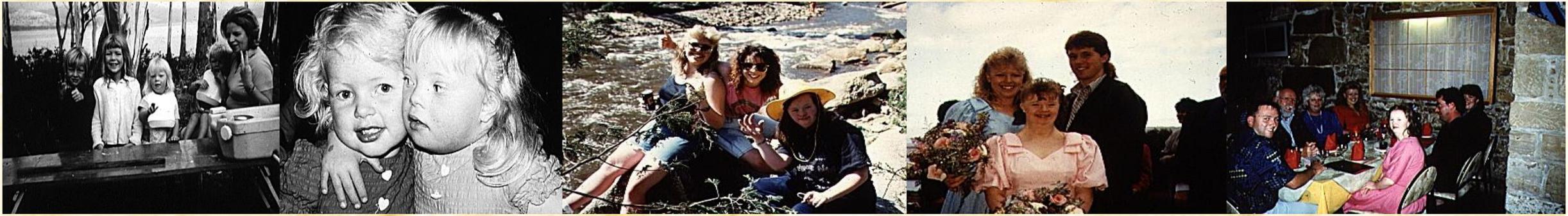


Managing Potential Bias

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



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Context is all
Two countries many similarities



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Australia

- Primary healthcare based system
 - Medicare + Private system – no capitation
- Area 7,692,024 km² (CA 9,984,670 km²)
- Population 25M (CA 37 Million)
 - 2.66 people/km² (CA 3.41/km²)
- GDP (PPP)/capita estimate 2018
 - \$44648.71 USD (\$44017.59 USD)



Primary healthcare based systems

- Decreasing mortality in disadvantaged populations
- Improved health outcomes; such as
 - infant mortality, heart disease and early detection of cancer, while simultaneously controlling the cost of the system.
- Higher ratios of primary care providers have healthier populations which mitigate the some of the negative effects of social disadvantage on health and delivers greater equity in healthcare
- Specialist systems lead to worse health outcomes

([Starfield, Shi et al. 2005](#), [Starfield 2012](#))

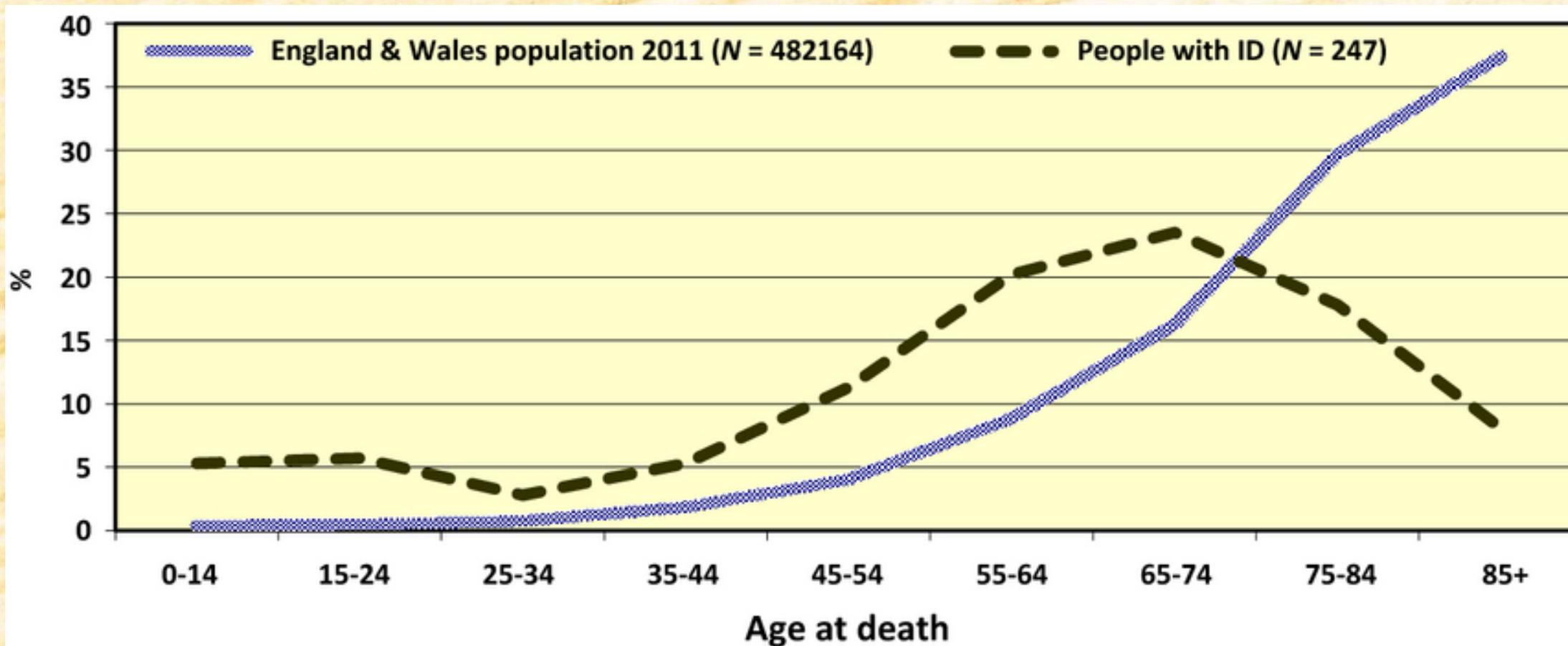




Unmet health & wellbeing needs



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



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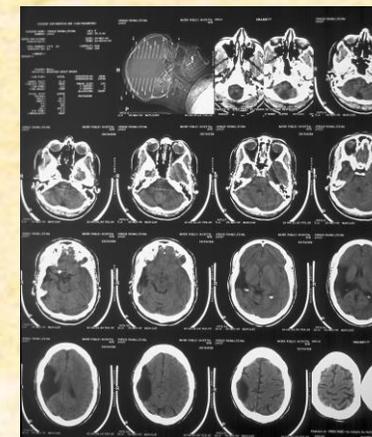
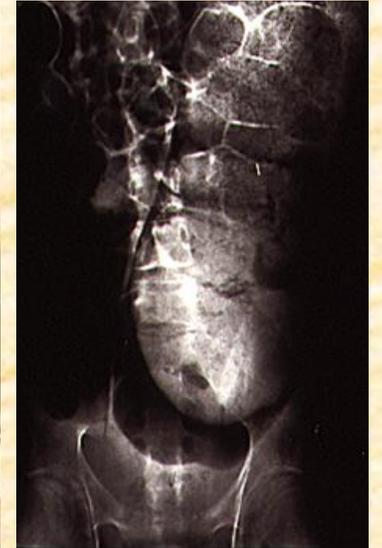
Health status people with IDD

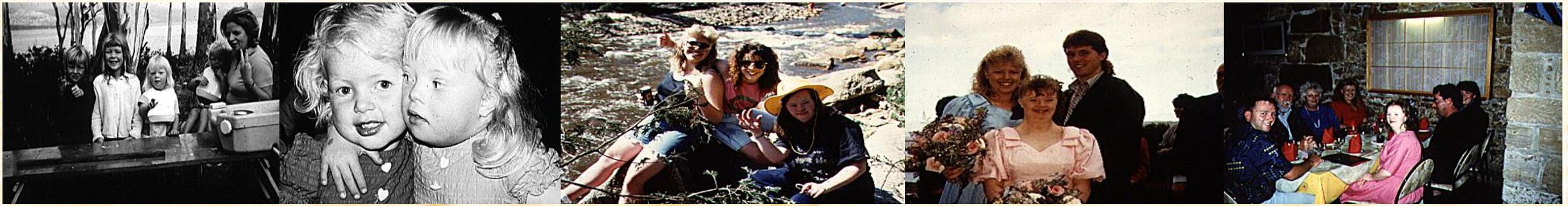
- Mortality
 - Earlier - mild ID (7 years) to severe (20 years)
- Morbidity
 - Unrecognised or poorly managed conditions
 - Lack health screening & health promotion
- Social context
 - Isolated, lack social engagement & relationships



Unmet health needs

- **Physical Pain**
- **Psychological Pain**
- **Mental disorders**
- **Medications**
- **Epilepsy**
- **Gut disorders**
- **Urogenital disorders**
- **Iatrogenic disease**
- **Sensory impairments**
- **Health Promotion & disease prevention**
- **Unknown cause of DD**





Barrier & enablers to high quality healthcare



People with DD, their families & supporters

- “Attitudes” & valuing
 - Respect & inclusion
- Autonomy, reasonable adjustments & support
- Communication & continuity
- Desire for connectedness & competence



Health care providers

- Communication & recall of information
 - Access to current & past health story
- Continuity over fragmentation
- Support
 - Education, specialist advice, access to other parts of healthcare system
- Time & Cost
- Attitudes of their colleagues & disability staff



Enablers

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



Possible strategies and interventions

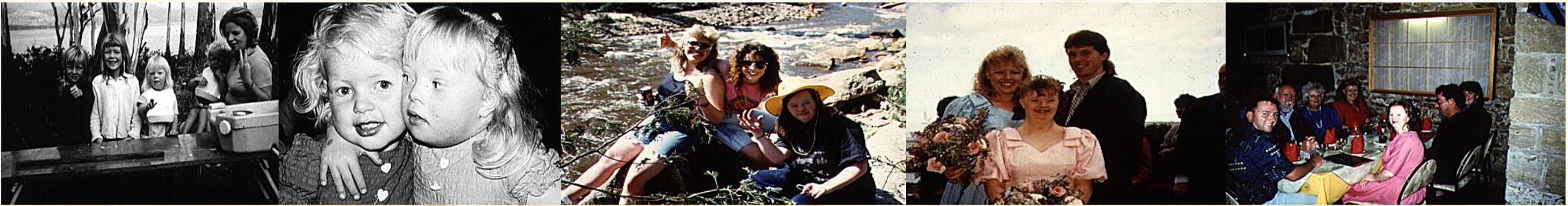
1. Attitudes & Values - general and individual
2. Empowerment of people with DD, families and paid of staff
3. Empowerment of health providers
4. Improve numbers of health practitioners with a focus on people with DD



Elements in consultation with health practitioner

1. Access
2. Communication – generally & health history
3. Knowledge - support
4. Enhanced advocacy
5. Follow up & continuity





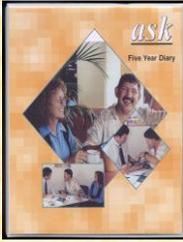
Building an approach to enable high quality healthcare



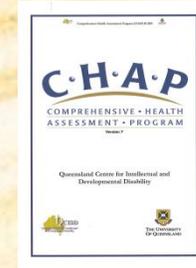
Build an approach

1. Health assessments as mechanism for change
2. Health diary or passport & other health advocacy tools
3. Build expertise through education and training – useful examples
e.g. Canadian Guidelines work
4. Embedding this evidence in practice





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.





Comprehensive Health Assessment Program (CHAP) © 2009



C·H·A·P

COMPREHENSIVE • HEALTH
ASSESSMENT • PROGRAM

Version 7

Queensland Centre for Intellectual and
Developmental Disability

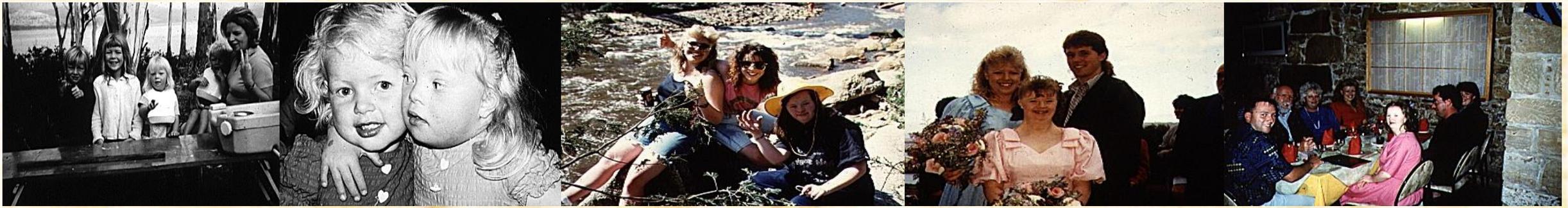


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Ref: Lennox N, Bain, C, Rey-
Conde, T, Purdie, D, Bush, R &
Pandeya, N. Effects of a
comprehensive health assessment
programme for Australian adults
with intellectual disability: a cluster
randomized trial. **International
Journal of Epidemiology**.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



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Results CHAP Health Check

Measure from GP notes

Methodology

Recruitment



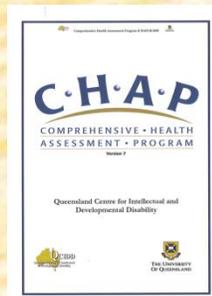
Baseline data



Cluster Randomisation

CHAP

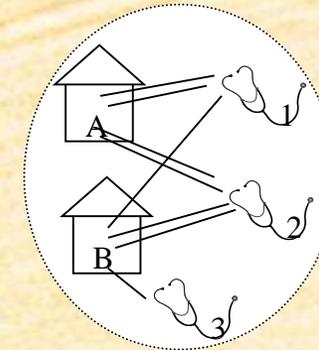
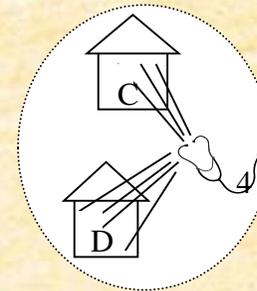
Usual Care



Follow for one year

505 (71%) adults with ID
118 (98%) residential staff
119 (91%) GPs

Baseline characteristics comparable



430 Adults with ID (95% of those recruited)



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Overall Findings

CHAP Health Check

- **Up to 30 times increase in health actions** across most outcomes we could measure

Hearing /vision testing 30x, Women's health screening, weight, Tetanus/diphtheria 9x, Hep. B given 2.4x, Breast examination 1.9x

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

- **Even more so as GP records underestimate**
 - the real level of CHAP - driven actions by 1.2-7.9 times more



Acceptability

- High recruitment and retention
 - Recruitment 71% people with ID & 91% their GPs

“[I] was missing things ... [that I am] now looking at more closely, more particularly”

“[the CHAP provides] reassurance that I’m doing the right things and [am] on track with the care of my patients; [it ensures I am] taking a more positive approach to picking up [or] recognising medical problems.



Lennox, N. G., et al. General practitioners' views on perceived and actual gains, benefits, and barriers associated with the implementation of an Australian health assessment for people with intellectual disability. JIDR (doi: 10.1111/j.1365-2788.2012.01586.x.)



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Weaknesses

- No evidence of long term effect
- No evidence it decreases mortality
- Cost – current literature cost neutral
- Presenter conflict of interest



Janet Robertson et al Reviews

Studies in UK, NZ and Australia

- Cardiff/Welsh health check, 21st Century health check & 17 others

“Health checks consistently led to detection of unmet health needs and targeted actions to address health needs. Health checks also had the potential to increase knowledge of the health needs of people with intellectual disabilities amongst health professionals and support staff, and to identify gaps in health services. Health checks are effective in identifying previously unrecognised health needs, including life threatening conditions.”

[REF: Research in Developmental Disabilities](#)

The impact of health checks for people with intellectual disabilities:
An updated systematic review of evidence, Janet Robertson, Chris Hatton,
Eric Emerson, Susannah Baines

[Volume 35, Issue 10](https://doi.org/10.1016/j.ridd.2014.06.007), October 2014, Pages 2450-2462 <https://doi.org/10.1016/j.ridd.2014.06.007>



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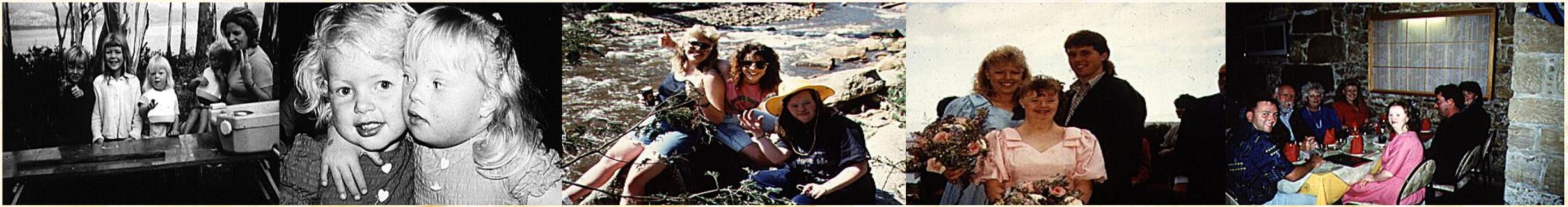
Health Checks the rub

- Can you implement it in Canada?
 - Shahin Shooshtari et al JARID 2017
 - What we did in Australia – Luck & timing
- If yes, then which one?**
 - No studies comparing health checks
 - Develop your own versions for Canadian situation?
 - E.g. Netherlands - Esther de Bakker

Ref: Shooshtari S, Temple B, Waldman C, Abraham S, Ouellette-Kuntz H, Lennox N. Stakeholders' Perspectives towards the Use of the Comprehensive Health Assessment Program (CHAP) for Adults with Intellectual Disabilities in Manitoba. Journal of Applied Research in Intellectual Disabilities 2017;30(4):672-83.



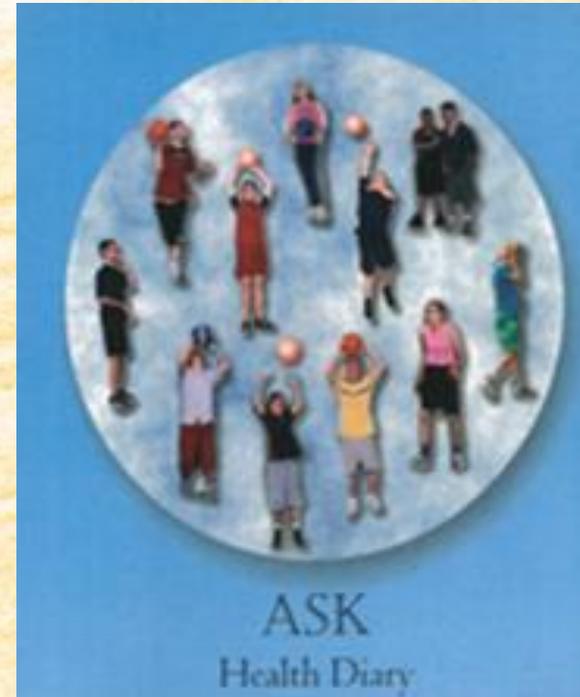
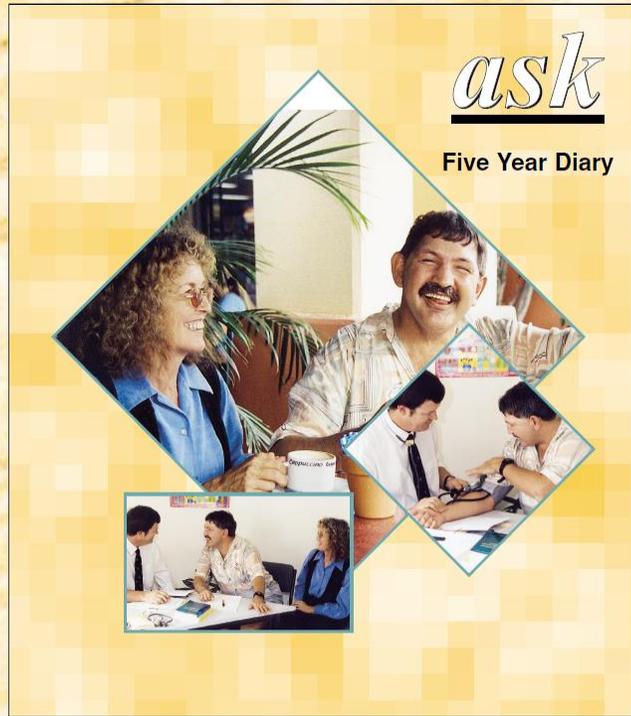
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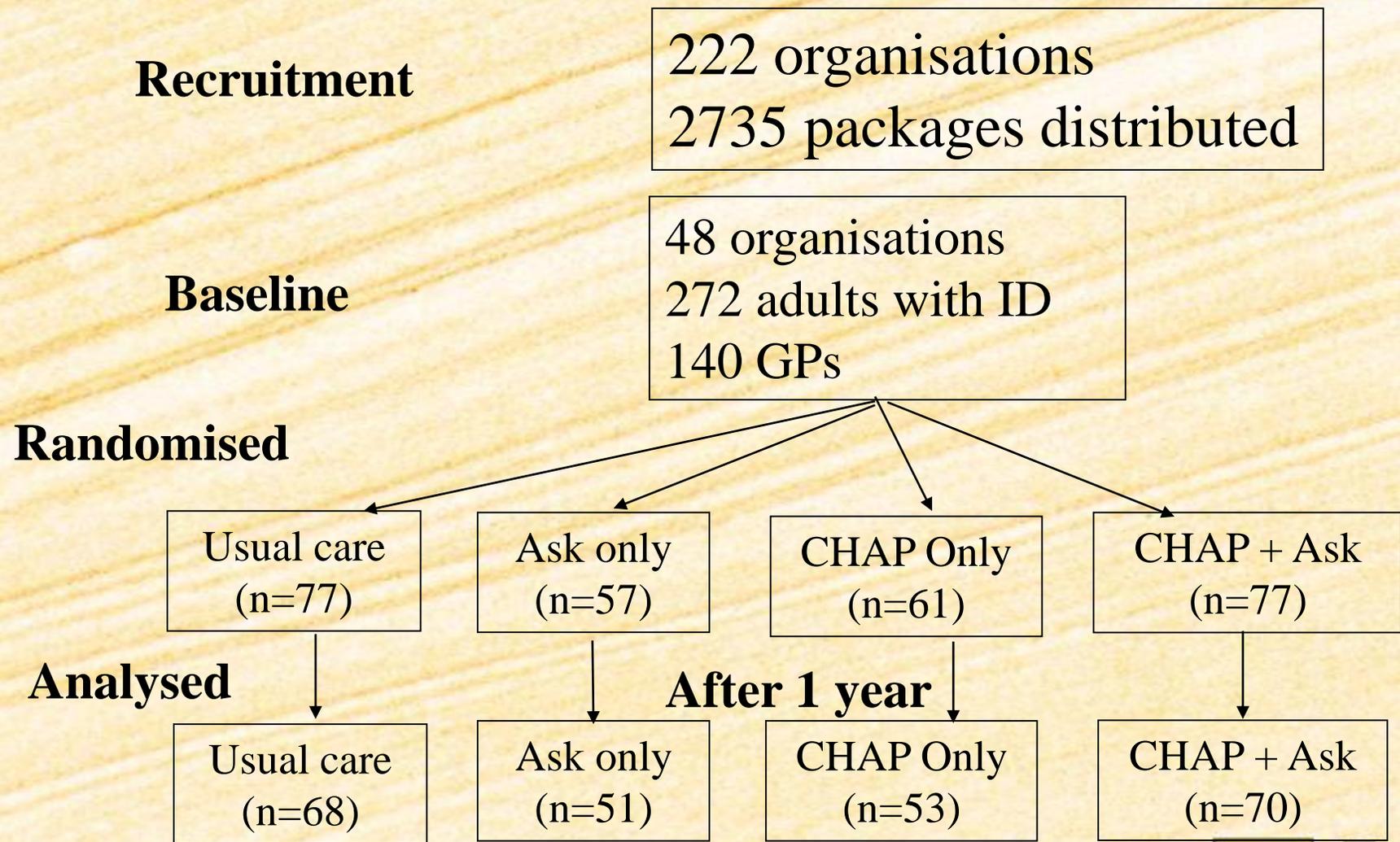
Health advocacy diary or health passport



The Ask Diary



Advocacy & Health Study - Ask diary & CHAP health check



ask

Advocacy

Skills

Kit

Advocacy is speaking up
for YOURSELF & others.

At the doctor's,
Speak up for Yourself.

ask ask



SECTION 1

All About Me



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SECTION 3

For the Doctor



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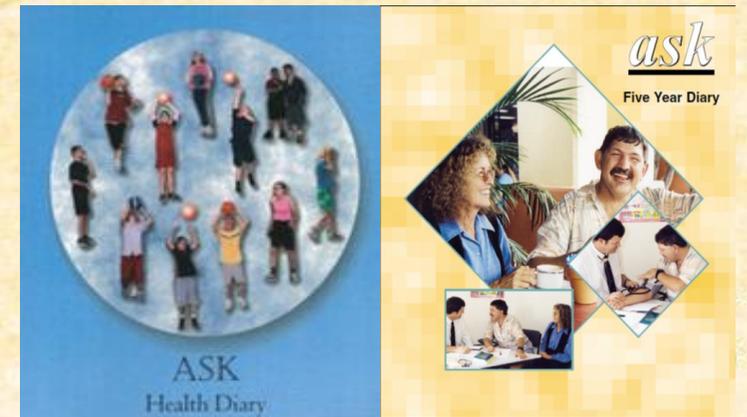
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Benefit of Ask diary?

- Appears very useful to some people
 - some evidence lead to more discussion about health problems, increase health related knowledge & awareness of personal health issues
- NO quantitative data of benefit we could find
- Some loved it!
- Improved self advocacy

Lennox N, Bain C, Rey-Conde T, Taylor M, Boyle FM, Purdie DM, et al. Cluster randomized-controlled trial of interventions to improve health for adults with intellectual disability who live in private dwellings. *Journal of Applied Research in Intellectual Disabilities*. 2010;23(4):303-11.



Meanwhile in Ontario



<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**

Primary Care Guidelines

[About Primary Care Guidelines](#)

Approaches to Care

A Person-centred Approach to Care

[Effective Communication](#)
[Capacity for Decision Making](#)
[Families and Other Caregivers](#)
[Interprofessional Health Care Teams](#)
[Health Assessments](#)
[The Cause of IDD](#)
[Cognitive Ability and Adaptive Functioning](#)
[Pain and Distress](#)
[Polypharmacy and Long-term Use of Certain Medications](#)
[Abuse, Exploitation and Neglect](#)
[Life Transitions](#)

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

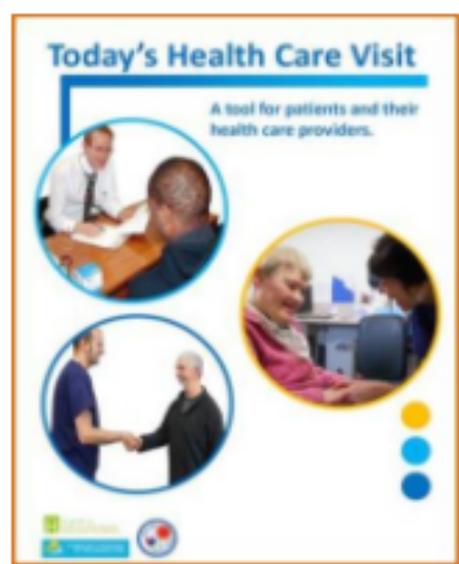
TYPES OF KNOWLEDGE

BACKGROUND

People with a Disability and Caregivers

Health Passports and Communication Tools

Today's Health Care Visit

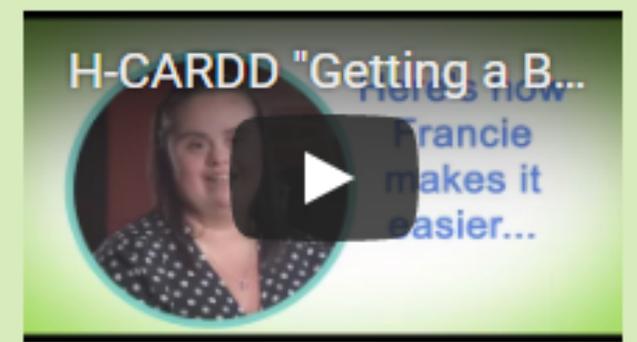


The **Today's Health Care Visit** is a worksheet you can use to write information down before a health care visit. Click on the picture to print the worksheet.

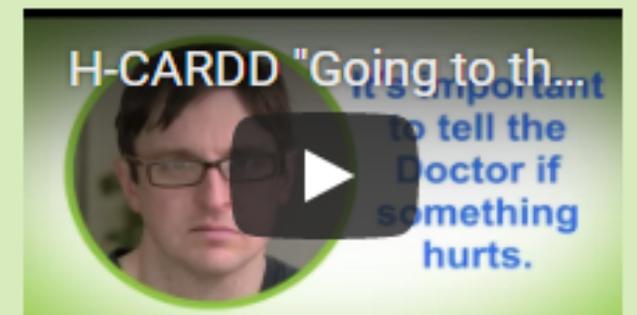
Having trouble reading the Today's Health Care Visit pamphlet? Try the **Large Print** version instead!

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.





Health Care Access Research
and Developmental Disabilities



Implementing Health Checks for Adults
with Developmental Disabilities:

A Toolkit for Primary Care Providers

www.hcardd.ca
2016



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

www.hcardd.ca
2016





Education

The evidence?



Empowering Education



- ✓ [Able X Series - Massive Open Online Course](#)
- ✓ Edx or UQx



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Other basic strategies to make healthcare more responsive



What I tell Doctors

“History enhancement”

Think proactively & look around corners

Health screening/care planning

Personal health records

Give yourself a chance

Do a diagnostic formulation ... Please

Review Review Review

Reciprocal KTBH

“Over” investigate

? Limit numbers



Build relationships with your Family Dr (or any other health professional)

- Build relationships
 - negotiate how you do it
 - continuity crucial
 - understand and don't bypass
- Understand each others problems & uncertainty
- Provide education, accurate & accessible information
- Don't split



Seizure chart Name: _____ Year: _____

Seizure type

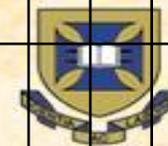
A B

C D

Insert A, B, C or D for each seizure

Seizure
chart

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Jan																															
Feb																															
Mar																															
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Example of strategies, useful chart &
Questions to ask Drs
see online version of presentation



Possible future strategies

- eHealth Records
- Algorithms in delivery of healthcare
- National health status data
 - Serial health measures
- Process & integration of care
 - E.g. Implementation health checks & measurable outcomes of education
- Individual & systemic advocacy



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Conclusion

- This is “rocket science”
 - Complex
 - Multidimensional
- The “Solutions”
 - Include advocacy, education, implementation of proven interventions, ongoing challenging the sea of devaluing & negative attitudes



The
End?

Thank you & Questions?

