

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

Context is all

Prof Nicholas Lennox

MBBS, BMedSc, DipObst, FRACGP, PhD, FASID,FIASSID.

[n.lennox@uq.edu.au](mailto:n.lennox@uq.edu.au)



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# Acknowledgements

- People with Intellectual Disability & their families & supporters
- QCIDD Team
- Colleagues & Mentors
  - Helen Beange, Jim Simpson
  - Chris Bain, Mike Kerr, Henny Lantman
- Funding
  - 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



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# 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 km<sup>2</sup> (CA 9,984,670 km<sup>2</sup>)
- Population 25M (CA 37 Million)
  - 2.66 people/km<sup>2</sup> (CA 3.41/km<sup>2</sup>)
- 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](#))

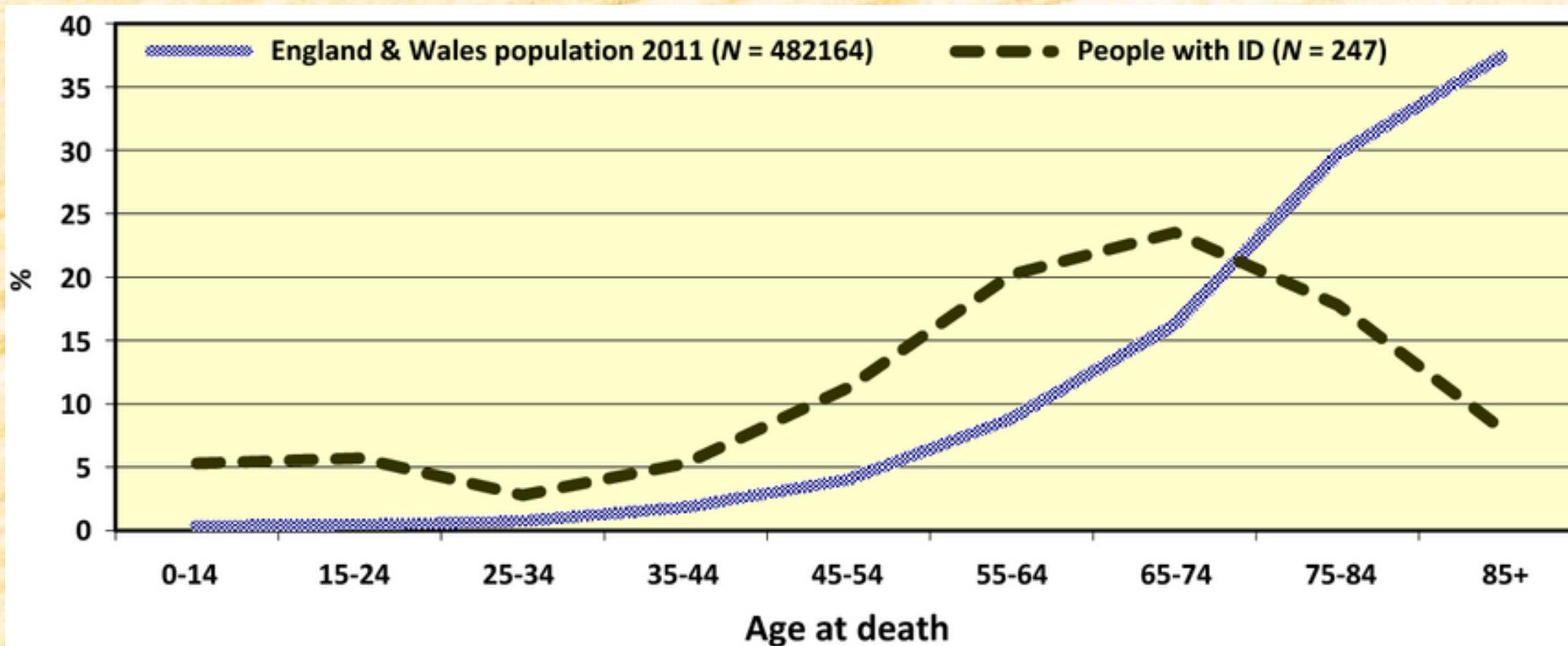




# Unmet health & wellbeing needs



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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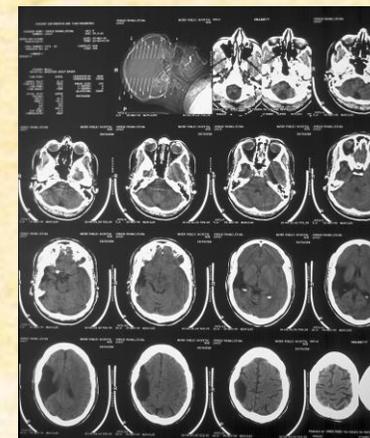
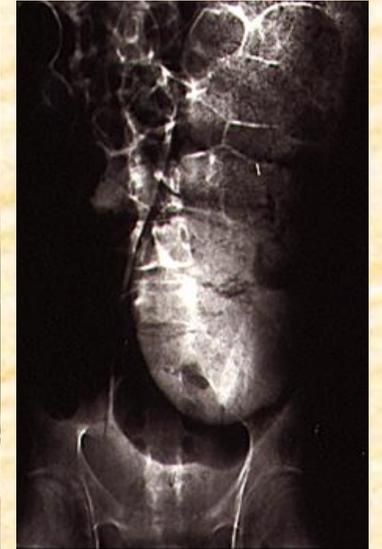
# Health status people with IDD

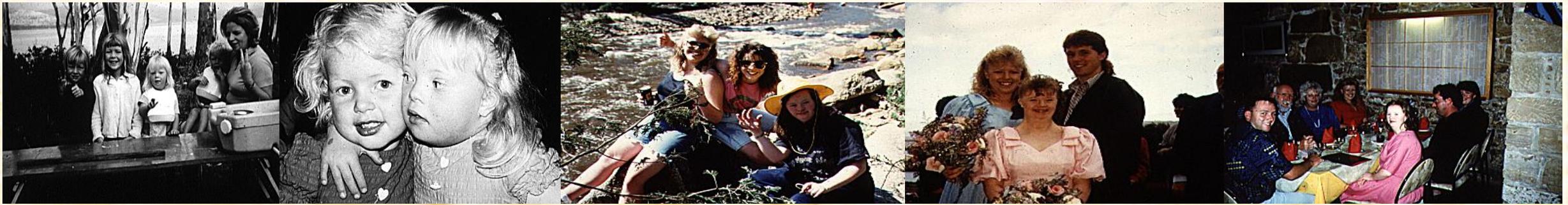
- Mortality
  - Earlier - mild ID (7 years) to severe (20 years)
- Morbidity
  - Unrecognised or poorly managed conditions
  - Lack health screening & health promotion
- Social context
  - Isolated, lack social engagement & relationships



# 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

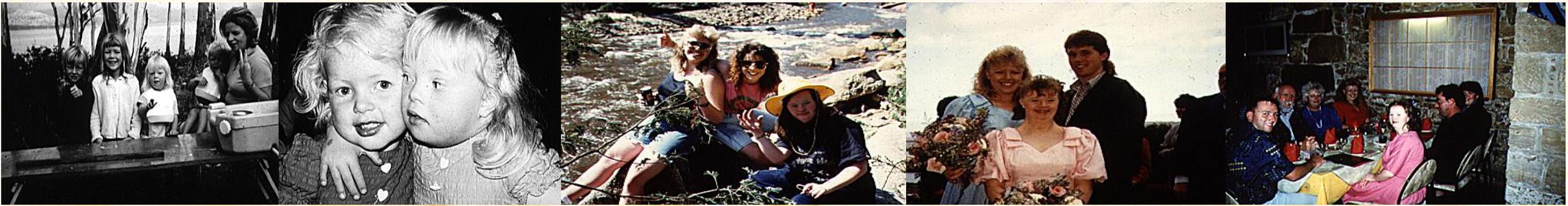
1. Attitudes & Values - general and individual
2. Empowerment of people with DD, families and paid of staff
3. Empowerment of health providers
4. Improve numbers of health practitioners with a focus on people with DD



# Elements in consultation with health practitioner

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





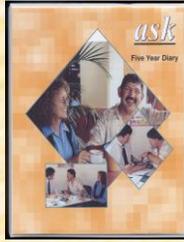
# Building an approach to enable high quality healthcare



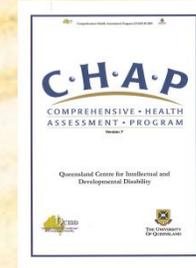
# Build an approach

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

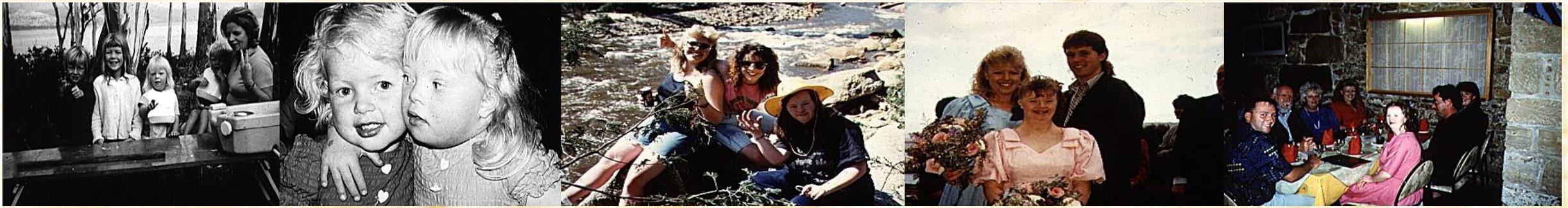


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Ref: Lennox N, Bain, C, Rey-  
Conde, T, Purdie, D, Bush, R &  
Pandeya, N. Effects of a  
comprehensive health assessment  
programme for Australian adults  
with intellectual disability: a cluster  
randomized trial. **International  
Journal of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



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# Results CHAP Health Check

Measure from GP notes

# Methodology

**Recruitment**



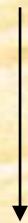
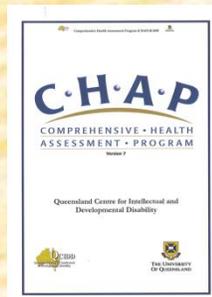
**Baseline data**



**Cluster Randomisation**

**CHAP**

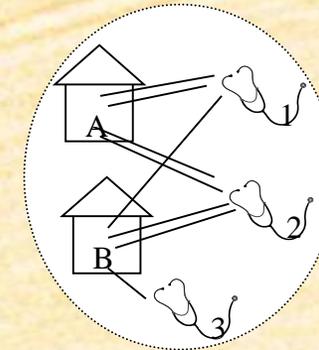
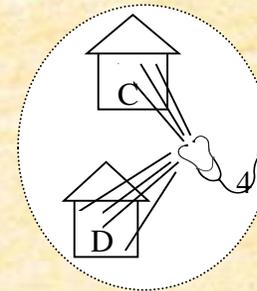
**Usual Care**



**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, 21<sup>st</sup> 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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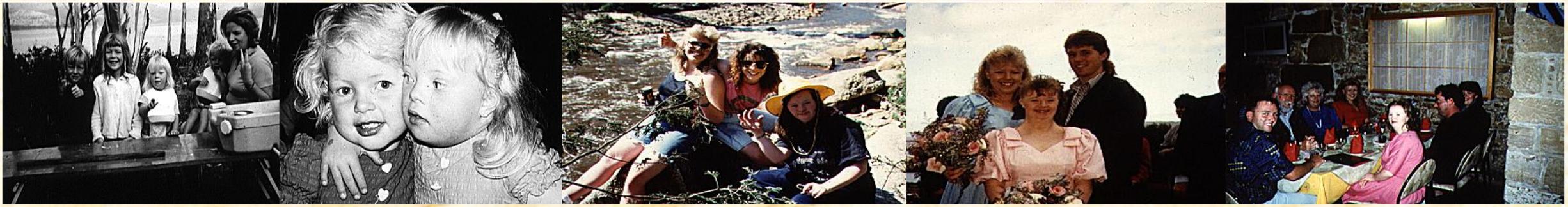
# Health Checks the rub

- 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.



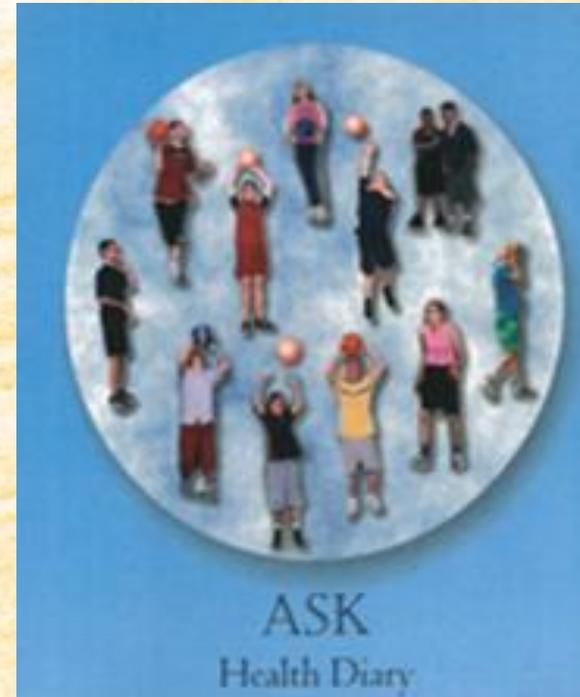
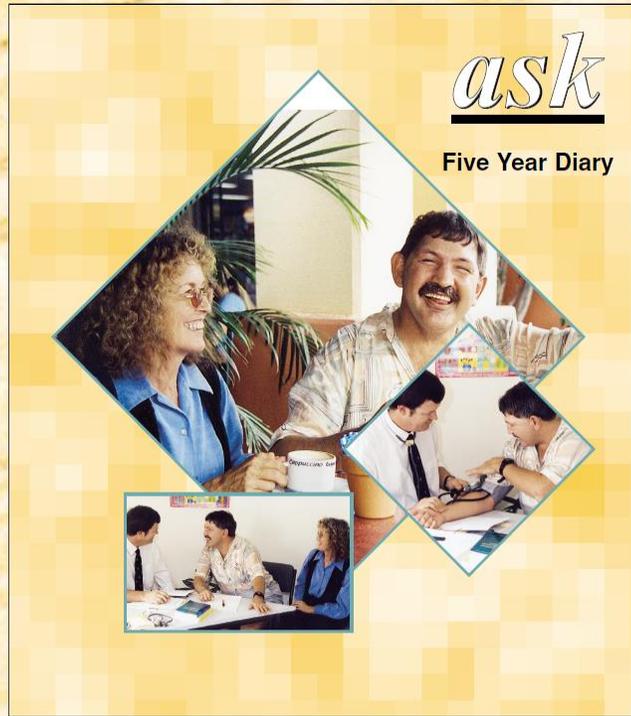
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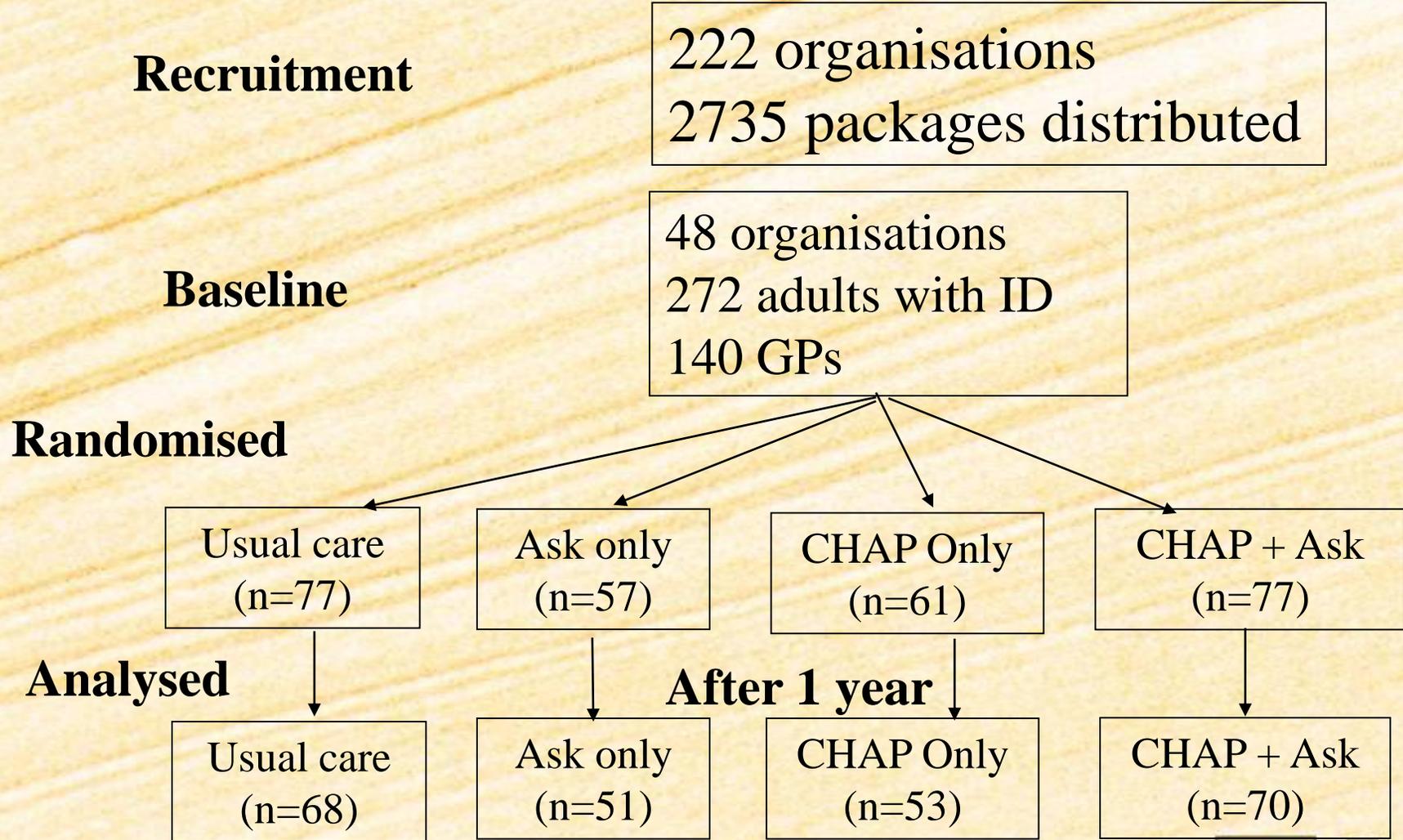
# Health advocacy diary or health passport



# The Ask Diary



# Advocacy & Health Study - Ask diary & CHAP health check



**ask**

**A**dvocacy

**S**kills

**K**it

Advocacy is speaking up  
for YOURSELF & others.

At the doctor's,  
Speak up for Yourself.

*ask ask*



## SECTION 1

# All About Me



# CONTENTS

## Section 1 - All About Me

This is ME	12
The best way I communicate	14
This is what helps me talk to and understand you	16
Places I have lived	18
What I like	20
What I don't like	20
What I am good at & things I find difficult	22
What I do during the week	24
Important people in my life	26
Where to send doctors' letters about me	28
My support person (family)	30
My support person (paid or unpaid workers)	32
My statutory health attorney	34
My GP	36
My specialist doctor	38
My dentist	40
My therapists	42
My allied health carer	44
My complementary health carer	46
Bus routes to clinics & Trains to clinics	48
Taxi numbers & Maps to find clinics	50



## SECTION 2

# Health Advocacy Tips



# CONTENTS

## Section 2 - Health Advocacy Tips

Tips for the advocate	52
Tips for the patient	54
Before I visit the doctor	56
Patient Notes	58
What to take to the doctors	60
At the clinic	62
The doctor might ask	64
After the doctor visit	66
What to take with you when you leave	68
The doctor might refer me to the hospital	70
Female body pictures	71,72
Male body pictures	73,74
Medical words	76
Ideas	78
Notes	
Menstruation Diary	82
Bowel Diary	84
Bladder Diary	86
Epilepsy Diary	88
Pain Diary	90
Emotion Diary	92
Behaviour Diary	94



# SECTION 3

## For the Doctor



# CONTENTS

## Section 3 - For the doctor

<b>FOR THE DOCTOR</b>	
Why health problems?	96
Tips for the clinic staff	98
Tips for the doctor	100
Enhanced primary care	102
Syndrome Checklists	104
Autism Spectrum Disorders	106
Angelman Syndrome	107
Cerebral Palsy	108
Down Syndrome	109
Fragile X	110
Neurofibromatosis	111
Noonan	112
Phenylketonuria	113
Prader-Willi	114
Rett	115
Tuberous Sclerosis	116
Williams	117

## Section 4 - Medical Records

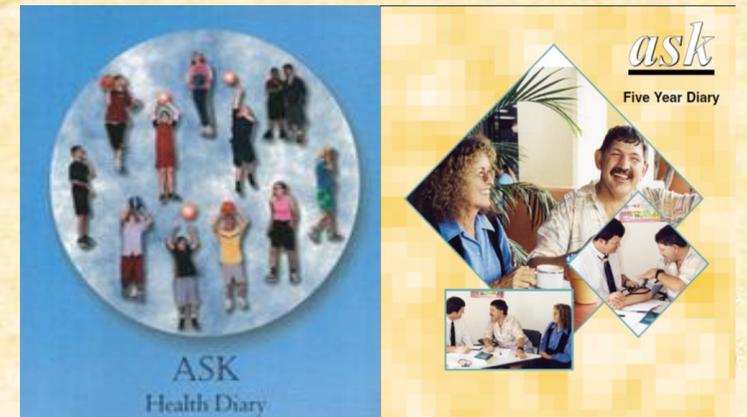
<b>MEDICAL RECORDS</b>	118
Commonly missed problems	120
Cause of disability	122
Diagnosis & operations history	124
Medications history	125
Immunisation history	126
Allergy history	127
Family history	127
Consultation record	128



# 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.<sup>13</sup>

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.<sup>13,14</sup>

Strongly Recommended

RECOMMENDATION STRENGTH

TYPES OF KNOWLEDGE

BACKGROUND

# People with a Disability and Caregivers

## Health Passports and Communication Tools

### Today's Health Care Visit

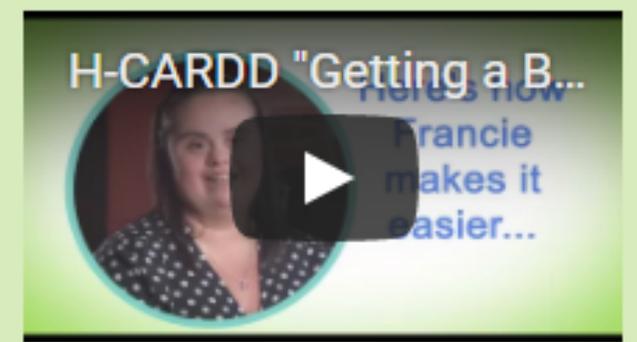


The **Today's Health Care Visit** is a worksheet you can use to write information down before a health care visit. Click on the picture to print the worksheet.

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](http://www.hcardd.ca)



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](http://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](http://www.hcardd.ca)





# Education

The evidence?



# Empowering Education



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



[WWW.QCIDD.COM.AU](http://WWW.QCIDD.COM.AU)



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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	1 1	1 2	1 3	1 4	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
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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?

