

A randomised controlled trial of two interventions to improve the health care of people with intellectual disability living in the community

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background

- ❑ Poorer health
- ❑ Poorer healthcare
- ❑ Shorter life-spans


Why?

- ❑ unrecognised or poorly managed disease
- ❑ inadequate health screening
- ❑ ineffective communication between medical practitioner and patient
- ❑ poor medical history taking
- ❑ service provider's poor knowledge of the person and their experiences of pain etc
- ❑ lack of training for general practitioners GPs
- ❑ GP lack of confidence in treating people with intellectual disability



evidence

Prior RCTs showed benefit from one-off primary-care-based health assessment: the Comprehensive Health Assessment Program (CHAP)




impetus

Can we increase the effect by extending the notion of health advocacy in the form of a long-term health record?
 We aimed to empower the person and their family with control of their health care.
 Health records (CHAP) can overcome the major barrier – communication



funding source

General Practice Evaluation Program
 Previous Centre trials had exceptional GP uptake and retention



development


Development of a health advocacy tool, the Ask health diary
 Wide consultation with people with intellectual disability, their families, carers, and associated professionals



interventions

Ask health diary

Comprehensive Health Assessment Program – CHAP



trial


- ❑ people with intellectual disability over 18 in community of South-East Queensland, Australia
- ❑ 2x2 factorial trial & between 2001 -2002
- ❑ cluster randomisation (participants by shared GP)
- ❑ Compare the *Ask health diary* (long-term) with the CHAP tool (one-off), & their joint synergy
- ❑ Effects on clinical activity 12 months post-intervention cf. 1 year pre-intervention (longer for immunizations)



statistical analysis

- ❑ 25 clusters in each arm of trial
- ❑ Post-intervention incidence rates unadjusted – 1 year cumulative incidences (10 years vaccination)
- ❑ Pre-intervention incidence of health event as covariates
- ❑ Multiplicative interaction on intervention arms

Stata v 9.2



recruitment

222 organisations contacted

63 refusals

34 Small NGOs
13 Government
6 Church groups
7 Large NGOs
3 Private hostels

111 expressed interest

49 Small NGOs
26 Government
15 Church groups
15 Large NGOs
6 Private hostels

Baseline

272 participants
(140 GPs)

48 participate

15 Small NGOs
13 Government
8 Large NGOs
9 Church groups
3 Private hostels

2735 enrolment packs sent



allocations

Control Only

77 participants
(35 GPs)

272 participants
(140 GPs)

Ask only


57 participants
(35 GPs)

CHAP only

61 participants
(35 GPs)


CHAP plus Ask

77 participants
(35 GPs)



baseline data

- ❑ Age, Sex, Level of impairment
- ❑ Education, Employment
- ❑ Residence
- ❑ Barthel level of independent living



baseline characteristics 1

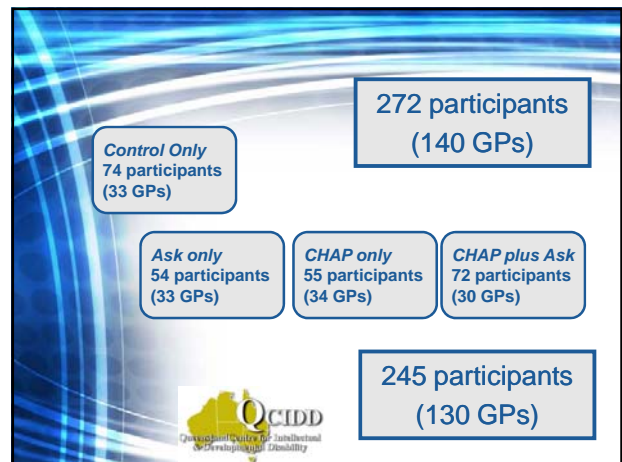
	Control	Ask only	CHAP only	CHAP plus Ask
Total number of participants	74	54	55	72
Number of clusters	33	33	35	30
Age (years) - mean (SD)	35 (11)	37 (13)	33 (11)	39 (14)
Years in residence - mean (SD)	15 (13)	14 (13)	14 (14)	11 (11)
Male Gender	52 (38)	59 (32)	61 (33)	60 (43)
Level of Intellectual Disability				
Mild/Moderate	56 (41)	46 (25)	46 (25)	28 (20)
Severe/Profound	19 (14)	28 (15)	22 (22)	33 (24)
Unknown	25 (18)	26 (14)	31 (17)	39 (28)
Down Syndrome	18 (13)	20 (11)	11 (6)	18 (13)

baseline characteristics 2

Current Residence	Control	Ask only	CHAP only	CHAP plus Ask
Private home	63 (46)	54 (29)	59 (32)	47 (34)
Shared house/not family/ hostel	30 (22)	39 (21)	31 (18)	36 (26)
Other	7 (5)	7 (4)	9 (5)	17 (12)

pre-intervention

	Control	Ask only	CHAP only	CHAP plus Ask
Thyroid Review	11 (8)	11 (6)	4 (2)	6 (4)
Epilepsy Review	11 (8)	15 (8)	15 (8)	4 (3)
Tetanus/diphtheria ^b	34 (25)	24 (13)	40 (22)	43 (31)
Influenza ^b	32 (24)	37 (20)	31 (17)	40 (29)
Hepatitis A ^b	5 (4)	7 (4)	11 (6)	10 (7)
Pneumococcus ^b	9 (7)	4 (2)	7 (4)	25 (18)
Hepatitis B ^b	23 (17)	15 (8)	16 (9)	19 (14)
Papanicalou smear ^c	11 (4)	9 (2)	0 (0)	3 (1)
Mammogram ^c	17 (6)	5 (1)	9 (2)	14 (4)
Breast Examination ^c	19 (7)	18 (4)	9 (2)	17 (5)
Hearing Test	4 (3)	4 (2)	2 (1)	13 (9)
Vision Test	11 (8)	9 (5)	4 (2)	19 (14)
BP Check	35 (26)	33 (18)	24 (13)	40 (29)
Weight Measurement	22 (16)	22 (12)	17 (15)	31 (22)



post-intervention data

Evidence from GP records of:

- health promotion / disease prevention
- new diagnosis / actions

- Medicare data on consultation patterns
- Parent Stress
- Experience of the tools

effects

Odds Ratio (95% confidence intervals)

Outcome Measure	Ask only	CHAP only	CHAP plus Ask
Hepatitis A Vaccination	0.7 (0.1-5.7)	6.1 (1.6-23.4)	3.8 (0.9-17.2)
Epilepsy Review	3.6 (0.7-18.9)	1.8 (0.3-12.1)	2.9 (0.5-15.2)
Hearing test	2.1 (0.5-9.2)	7.8 (2.4-26.2)	5.8 (1.7-19.7)
Vision Test	2.6 (0.7-10.2)	4.1 (1.1-15.0)	7.5 (2.0-27.6)
Weight measurement	1.7 (0.6-4.6)	4.1 (1.1-15.0)	7.5 (2.0-27.6)
Constipation investigation	6.0 (0.5-67.4)	2.9 (0.2-37.4)	2.1 (0.2-21.7)
New disease detected	1.3 (0.2-10.6)	1.3 (0.2-10.4)	1.0 (0.1-6.9)

little or no effect

Across the arms, little or no effect in:

- ▣ thyroid review
- ▣ osteoporosis investigation
- ▣ psychiatric visits
- ▣ challenging behaviour visits
- ▣ vaccinations for tetanus, hepatitis b or influenza
- ▣ pap smears
- ▣ breast examination
- ▣ blood pressure check
- ▣ weight management
- ▣ skin examination



problems

- ▣ Recruitment – reduced power
- ▣ Range of residential settings
- ▣ Range of organisation types
- ▣ Clusters slight imbalance



successes


94% retention rate of participants

Clear outcomes in some health measures



significance

- The **CHAP** successful in detecting unmet health conditions - **widened applicability**
- The **Ask diary** - some effect but not over the short term - implies **long term potential**
- **Further RCT**



recommendation

Introduce both tools earlier in the people's lives



Thank you! Your questions...

