HEALTH PROGRAMME EVALUATION

Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial

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Background People with intellectual disability constitute ~2% of the population. They die prematurely, and often have a number of unrecognized or poorly managed medical conditions as well as inadequate health promotion and disease prevention.

Methods A cluster randomized controlled trial with matched pairs was carried out. The participants were adults with intellectual disability (n = 453 in 34 clusters). The intervention was a health assessment programme to enhance interactions between the adult with intellectual disability, their carer and their general practitioner (GP). It prompted the systematic gathering of a health history and, subsequently, access to a GP for a guided health review and development of a health action plan. It also provided information about the health of adults with intellectual disability. Follow-up was for 1 year post intervention, with outcomes extracted from GPs’ clinical records.

Results Increased health promotion, disease prevention and case-finding activity was found in the intervention group. Compared with the control group there was a 6.6-fold increase in detection of vision impairment (95% confidence interval 1.9–40); a 30-fold increase in hearing testing (4.0–230); an increase in immunization updates [tetanus/diphtheria a 9-fold increase (4.2–19)], and improvements in women’s health screening [Papanicolau smears were eight times more common (1.8–35)]. The intervention increased detection of new disease by 1.6 times (0.9–2.8).

Conclusions The Comprehensive Health Assessment Program (CHAP) produced a substantial increase in GPs’ attention to the health needs of adults with intellectual

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disability with concomitantly more disease detection. The presumption that these will yield longer-term health benefits, while suggestive, remains unexamined.

**Keywords** Intellectual disability, general practitioners, health assessment

### Introduction

Approximately 2% of all people live with intellectual disability. They die prematurely, and adults may have five or more unrecognized or poorly managed medical conditions of a diverse nature. Inadequate attention to disease prevention is also common, with, for example, cervical screening rates one quarter of that in the general population. Optimal response to these service deficiencies remains debatable.

One possible avenue is regular general health screening, despite its inappropriateness in the population at large. A reasonable analogy may be drawn with the elderly, who also have highly prevalent unrecognized health conditions, impaired communication, and cognition and recall difficulties. Meta-analyses of multidimensional geriatric health assessments have found benefit, so it is possible that adults with intellectual disability could also gain from a similar, albeit less complex, process.

Two uncontrolled studies have evaluated general practice-based health assessments in this population and a further small matched study has demonstrated benefits using a nurse-driven approach. All reported increased disease prevention, identification and treatment among over half their participants. A beneficial effect of the Cardiff Health Check on tetanus immunization was reported by Michael Kerr at the 10th World Congress of the International Association for the Scientific Study of Immunization, Helsinki, Finland, 1996.

We report here a more rigorous test of the concept—a randomized controlled trial (RCT) of the use of a health assessment, advocacy and education process, the Comprehensive Health Assessment Programme (CHAP), in general practice. We hypothesized that this would encourage beneficial patterns of general practice-driven activities, in particular increases in health promotion, disease prevention and case-finding activities, as well as appropriate management of these previously unmet health needs.

### Methods

#### Participants

Those eligible to participate were all 707 adults with intellectual disability who lived in the community in 24 h supported accommodation provided by the Endeavour Foundation, the main non-government service provider in Queensland, Australia. Dwellings had between 3 and 25 adults and residential staff.

We recruited participants through their residential staff and guardians; these were sent an information booklet and consent forms and were invited to an information session. Staff and guardians discussed the project with those in their care before consent was given formally by the adults themselves (via their guardian) and by their main residential carer and their general practitioner (GP) (Figure 1). The Behavioural and Social Sciences Ethical Review Committee of the University of Queensland approved the study.

We obtained baseline information from the Endeavour Foundation including demographic data, IQ, aetiology of disability and GP. Rates of clinical encounters for the year prior to the trial were extracted from GPs’ notes.

#### Assignment and masking

The units of randomization were natural clusters of participants interlinked via sharing a residence or a GP, so as to avoid participants in the control arm being exposed to the CHAP through such propinquity. Clusters were pair-matched on size, average age and proportion of adults with Down syndrome, and each pair randomized to intervention or control by a statistician (D.P.) using a computerized random number generator. Randomization was concealed, but the nature of the intervention precluded blinding of assignment.

#### Intervention

The CHAP is a 21-page booklet developed to be attractive, credible and easy to use. The first part, completed by the carer, covered the medical history, and was brought to the doctor’s surgery. In the second part, the GP was asked to complete the CHAP assessment, which involved a review of the history, a targeted examination and assisting the carer to complete a health action plan. The CHAP tool also contained a list of commonly unrecognized or poorly managed conditions in this population and a chart of syndrome-specific comorbidity, to assist the GP and inform the carer. The comparison group received usual care only.

After the CHAP assessment, the carer retained a copy of the action sheet, and the CHAP tool was returned to the research team.

#### Follow-up and overall participant flow

The intervention period ran for 12 months from the date of the CHAP assessment by the GP. Control follow-up began on the median starting date of the corresponding intervention group cluster. There were no prospective stopping rules, nor any contact between researchers and participants during follow-up. Real-time monitoring was not possible as outcome data were collected only on completion of the project. Full details of participant flow are shown in Figure 1.

#### Data extraction and management

The data extraction tool was piloted on GPs’ notes before commencing data collection for the study. Information was extracted from GPs’ notes for 12 months either side of the intervention, except for hearing and vision testing and for immunizations, for which we searched back, respectively for 5 and 10 years prior to the intervention. Difficulties in reading the notes were resolved by receptionist or GP.
This process seems to have been reliable, with only 3% disagreement between different data collectors reviewing 16 sets of notes; no differences were relevant to ascertainment of any outcome.

All coding, data entry, cleaning and analysis of quantitative data were done blinded to intervention status. Data abstraction from the GP notes was in principle blinded as to exposure status (CHAP vs control), but this was compromised in 70% of the cases where GPs wrote in their notes that the CHAP had been performed. A comparative analysis between event (outcome) rates in this group and the remaining 30% was therefore performed to assess the potential for observer bias having distorted any apparent overall effect of the intervention.

We performed exit interviews with carers, GPs and some intervention-group adults with intellectual disability. Data from the CHAP tool itself were reviewed for purposes of validation and additional assessment of the process.

**Outcome measures**

We sought evidence of health promotion, disease prevention and case-finding activities and of appropriate interventions (as shown in Box 1) in both arms of the trial.

**Sample size**

We estimated the power of the study for primary outcomes where data on prevalence were available. For having an identified vision or hearing impairment this was 10%. With 450 subjects in 34 clusters, an average of 14 subjects in each (SD = 15), and assuming a pairwise odds ratio within clusters to be 1.5, the design effect for this study design was estimated to be around 2.0. This gave a power of ~80% to identify an increase in detection of vision or hearing impairment from 10% to 24%, at the 5% level of significance.

**Statistical analysis**

While data have been presented as overall proportions of individuals in each trial arm, statistical analysis has taken account of the clustering by using SUDAAN (Release 8.0, Research Triangle Institute, 2001), which offers robust variance methods to adjust confidence intervals (CI) and P-values by the relative amount of within- vs between-cluster correlation.
Percentages and risk ratios (with 95% CIs) were used to summarise and compare rates of health-related events in the two arms of the trial as randomized. Given the close baseline equivalence of the two arms, all analyses are unadjusted for individuals with intellectual disability.

Results

Of 707 eligible adults with intellectual disability we recruited 505 (71%), of whom 47 adults were omitted when 10 GPs refused to participate, and 1 died, leaving 458 who were randomized. Non-participants were very similar to those enrolled in their distributions by age, sex and IQ. There were 118 residential staff (98%) and 120 GPs (92%) (Figure 1) recruited between January and August 1999. From the participants 36 clusters were formed, pair-matched and each pair randomly assigned to intervention or control. One intervention group GP then withdrew and the corresponding control group cluster was combined with an existing control cluster which was similar in terms of age, sex, presence of Down syndrome and epilepsy. This left 34 clusters (17 pairs) with 234 intervention adults and 219 control adults of whom 430 participants (95% of those recruited) were successfully followed up at 1-year. The intervention took place between August 1999 and March 2000.

At baseline, there was a modest difference in the sex ratio between the groups, but age/IQ distributions, and the proportion with Down syndrome or a history of epilepsy were very similar (Table 1). This was also true for patterns of clinical activity prior to intervention (Table 1), indicating the effectiveness of randomization in balancing the makeup of the two groups. Comparisons of the follow-up outcomes are therefore unadjusted. GPs were mostly male (84% in both groups) and of similar mean age (49 and 48 years). Of the residential staff, 26% (intervention) and 36% (control) were male, with mean ages of 47 and 50 years.

Most health promotion and disease prevention outcomes in the CHAP arm were increased moderately to markedly (and were statistically significant) compared with control (Table 2). Effects on assessing sensory impairment were especially striking (e.g. a 30-fold increase in hearing tests), and 22 new cases of sensory loss were detected compared with one among controls. We can also see that among those receiving the CHAP, rates of testing increased substantially above their pre-CHAP values (Table 1), with 20-fold more testing of visual acuity and 10-fold more hearing tests (annualized).

Immunization rates were also influenced notably: tetanus/diphtheria boosters were given nine times more often in the intervention group and receipt of a hepatitis B booster or immunity testing occurred respectively, two and six times more often. Influenza immunization was uniformly high in both arms, as was blood pressure measurement, done in almost half the participants. Clinically significant excesses in activities related to weight and women’s health were also apparent in

<table>
<thead>
<tr>
<th>Characteristics of adults with intellectual disability</th>
<th>Intervention group % (n)</th>
<th>Control group % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>100 (234)</td>
<td>100 (219)</td>
</tr>
<tr>
<td>Male</td>
<td>60.3 (141)</td>
<td>51.1 (112)</td>
</tr>
<tr>
<td>Mean age (range)</td>
<td>38.2 (19–73)</td>
<td>39.2 (20–67)</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>24.4 (57)</td>
<td>26.5 (58)</td>
</tr>
<tr>
<td>Mild intellectual disability</td>
<td>38.5 (90)</td>
<td>36.1 (79)</td>
</tr>
<tr>
<td>Moderate intellectual disability</td>
<td>27.8 (65)</td>
<td>32.0 (70)</td>
</tr>
<tr>
<td>Severe/profound intellectual disability</td>
<td>23.9 (56)</td>
<td>22.8 (50)</td>
</tr>
<tr>
<td>Unknown intellectual disability</td>
<td>9.8 (23)</td>
<td>9.1 (20)</td>
</tr>
</tbody>
</table>

Clinical records of adults with intellectual disability (from GP notes)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Intervention group % (n)</th>
<th>Control group % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy history (any)</td>
<td>14.5 (34)</td>
<td>19.6 (43)</td>
</tr>
<tr>
<td>Vision test (previous 5 years)</td>
<td>5.1 (12)</td>
<td>4.1 (9)</td>
</tr>
<tr>
<td>Hearing test (previous 5 years)</td>
<td>6.4 (15)</td>
<td>2.7 (6)</td>
</tr>
<tr>
<td>Tetanus/diphtheria booster (previous 10 years)</td>
<td>37.6 (88)</td>
<td>45.2 (99)</td>
</tr>
<tr>
<td>Hepatitis B booster (previous 10 years)</td>
<td>33.3 (78)</td>
<td>32.4 (71)</td>
</tr>
<tr>
<td>Hepatitis B serology (previous 10 years)</td>
<td>28.6 (67)</td>
<td>15.5 (34)</td>
</tr>
<tr>
<td>Weight recorded</td>
<td>4.7 (11)</td>
<td>5.5 (12)</td>
</tr>
<tr>
<td>Cholesterol tested</td>
<td>7.3 (17)</td>
<td>4.1 (9)</td>
</tr>
<tr>
<td>Thyroid test</td>
<td>21.4 (50)</td>
<td>14.2 (31)</td>
</tr>
<tr>
<td>Papanicolaou smear</td>
<td>12.9 (12)</td>
<td>7.5 (8)</td>
</tr>
<tr>
<td>Mammogram</td>
<td>4.3 (4)</td>
<td>9.4 (10)</td>
</tr>
<tr>
<td>Average number of consultations (range)</td>
<td>4.8 (0–20)</td>
<td>4.6 (0–34)</td>
</tr>
</tbody>
</table>

* From Endeavour Foundation unless otherwise stated.
* Occurrence in previous year unless otherwise stated.
* Women only (intervention n = 93, control n = 107).
the CHAP arm (Table 2), with Papanicolau smears almost eight times more common. However, absolute frequencies were still fairly low, and the rate of cervical screening in the CHAP arm was actually little changed, so the excess over control rate may be artefactual.

Effects on detection of new diseases (Table 3), were less marked. Overall, 24 new conditions of some import were diagnosed by GPs using the CHAP compared with 14 among the comparators, a 60% excess ($P = 0.07$). Most notable clinically were four cases of reflux disease in the intervention group compared with one, and the two cases of epilepsy and one case of diabetes, all found in the intervention group. There was no difference in hospitalizations, and GP consultation rates were unaltered beyond the intervention visit. No adverse effects from the CHAP were found.

There was limited evidence of recorder bias due to mention of the CHAP in GPs notes: of the 12 common or important factors assessed, substantial differences were seen for four, but even for them the rates seen among those without mention of the CHAP in their notes remained substantially above control rates (except for hepatitis B booster); and none were statistically significantly different (Table 4).

There is also strong evidence from the completed CHAP booklets that the GP notes taken on their own underestimated the real level of CHAP-driven activity. For example, based on the CHAP booklet data vision and hearing assessments were seen to have been performed in 68.7 and 83.4% of adults respectively, three to six times the rates recorded in the GP notes (on which our effect estimates are based).

Exit interviews found 24 of 48 GPs considered the health of their patients had improved as a result of the CHAP, as did 14 of 35 carers; the remainder were unsure or thought the adult’s health was already optimal. GPs (63%) and carers (80%) identified personal gains through provision of better care and/or increased knowledge.

Discussion
These results show that a primary care-based health review in this population substantially lessens deficits in healthcare among adults with intellectual disability through encouraging a wide spectrum of appropriate clinical interventions to promote health, prevent disease and make new diagnoses. Prime realizations included many-fold increases in the identification of hearing and vision impairment, attention to immunization status, identification and management of obesity, more thorough implementation of women’s health screening and moderately elevated detection of new diseases. Of course, many of these changes are only intermediary steps in the pathway to clinically significant benefit, so we are unable to

| Table 2 | Rates of detection sensory deficits and of health promotion and disease prevention actions in the intervention and control arms of the CHAP trial, with risk ratios and confidence intervals |
| --- | --- | --- |
| Outcome measures | Intervention group % (n) | Control group % (n) | Risk ratio (95% CI) |
| Sensory systems | 100 (234) | 100 (219) | 3.8 (1.1–7.6) |
| Vision (test of visual acuity)$^a$ | 20.9 (49) | 5.5 (12) | 3.8 (1.1–7.6) |
| Visual impairment detected | 3.0 (7) | 0.5 (1) | 6.6 (1.1–40) |
| Acuity corrected by glasses | 1.3 (3) | 0 | $\infty$ |
| Otoscopic examination | 39.3 (92) | 22.8 (50) | 1.7 (1.2–2.5) |
| Hearing test$^b$ | 13.7 (32) | 0.5 (1) | 30.0 (4.0–230) |
| Hearing loss identified | 6.4 (15) | 0 | $\infty$ |
| Immunizations | 24.8 (58) | 2.7 (6) | 9.1 (4.2–19) |
| Tetanus/diphtheria booster given | 16.2 (38) | 6.9 (15) | 2.4 (0.6–8.7) |
| Hepatitis B booster given | 27.8 (65) | 4.1 (9) | 6.8 (3.2–14) |
| Tetanus/diphtheria booster given | 59.8 (140) | 56.2 (123) | 1.1 (0.8–1.4) |
| Blood pressure and weight | 50 (117) | 45.2 (99) | 1.1 (0.8–1.5) |
| Blood pressure checked | 42.7 (100) | 16.4 (36) | 2.6 (1.7–3.9) |
| Obesity identified | 7.3 (17) | 1.8 (4) | 4.0 (1.4–12) |
| Management plan established$^c$ | 41.2 (7) | 25.0 (1) | 1.7 (0.2–14.3) |
| Raised cholesterol | 7.7 (18) | 3.2 (7) | 2.4 (1.0–6.0) |
| Women’s health | 16.1 (13) | 2.0 (2) | 7.9 (1.8–35) |
| Papanicolau smear performed$^d$ | 16.5 (15) | 8.8 (9) | 1.9 (0.7–4.8) |
| Breast examination by GP$^d$ | 14.6 (13) | 4.1 (4) | 3.5 (1.1–12) |

$^a$ Performed by the GP, optometrist or ophthalmologist.
$^b$ Performed by the GP, audiologist or ENT surgeon.
$^c$ denominator number of obese noted.
$^d$ Where clinically indicated and according to national guidelines.
say with assurance that adults with intellectual disability will have achieved markedly better health because of this programme. However, the overall trend to improved healthcare suggests likely real benefit given to their substantial unmet health needs, lack of viable alternative strategies, and the support of a large proportion of carers and GPs.

The randomization procedure worked well in practice despite the relatively small numbers of clusters, and follow-up was virtually complete; thus, confounding and selection bias are unlikely to have affected the findings. Chance is of course a possible explanation for some specific findings, but the consistent positive pattern of strong associations is quite unlikely to be random.

Although we aimed to blind data collection, 70% of CHAP reviews were noted in GP consultation records making it possible those abstractors scrutinized these more closely. The systemized training and structured abstraction process, and good inter-rater reliability should have limited the scope for imbalance. Furthermore, reasonably comparable patterns were seen whether or not the review was noted, and many effects were too large to reasonably ascribe to information bias.
The limited prior observations are also wholly congruent. Further, additional clinical data from the CHAP booklet suggests an even stronger effect.

To whom do these findings apply? Certainly to those living in supported care: we achieved unusually high representation of the source population in the study (65% compared with <10% in most randomized trials\textsuperscript{13}), and even more striking levels of recruitment of GPs and carers. The results may be less applicable to adults with intellectual disability living in different circumstances, e.g. private residential or institutional settings. However the institutionalized, with yet higher unmet health needs, could benefit even more from comprehensive reviews.\textsuperscript{14,15} We have examined use of the CHAP in such a population and found outcomes similar to those described here.\textsuperscript{16}

We believe the success of the CHAP process came through alleviating barriers to healthcare.\textsuperscript{17} We designed it to compensate for difficulties with recall, communication and transfer of information experienced by adults with intellectual disability, their carers and their GPs. These difficulties often require interpretation of non-verbal communication, such as behaviour, and proxy communication by carers to GPs. The CHAP also facilitates the organization of this process and stimulates contact with the GP who is then prompted to address known potential unmet health needs. In addition, it educated GPs and carers about core health issues for this population and did so where most applicable, in the consultation or the carer’s workplace.\textsuperscript{17–19}

High staff turnover is characteristic of disability services, and in this study only 65 of the original 118 residential care staff could be contacted at its conclusion. One effect of the turnover is a loss of the adult’s health history. It seems likely that the CHAP process can assist in the transfer of information over time and in education of residential staff. Together with continuing barriers to good healthcare and unmet health needs, this suggests that the process should be repeated regularly. The disability services that have implemented it plan to use it yearly, largely because this fits organizational needs, this suggests that the process should be repeated more from comprehensive reviews.\textsuperscript{14,15} We have examined use of the CHAP in such a population and found outcomes similar to those described here.\textsuperscript{16}

To explore other ways to further enhance the healthcare of adults with intellectual disability we have developed a more complex health advocacy, education and record-keeping tool and are currently completing an RCT of its use in combination with the CHAP.\textsuperscript{22} This approach seeks to further enhance communication and knowledge retention and transfer especially in the long term. There is some support for this approach from a pilot study among older US adults with intellectual disability.\textsuperscript{23}

This is the first published RCT of such an intervention among adults with intellectual disability; ideally further trials will test and extend our findings. Longer term studies with larger samples will be needed to demonstrate with surety that the anticipated reductions in morbidity and premature mortality do actually occur. Also, an enhanced focus on qualitative benefits for all concerned in the clinical interaction will be highly desirable.

**Contributors**

The trial was conceived/initiated by N Lennox, who, with C Bain, R Bush and D Purdie and M Green, designed the study and obtained the funding. G Parsons, N Lennox and D Rice performed the recruitment of participants and N Lennox, T Rey-Conde, M Green, D Rice, C Bain, R Bush and D Purdie designed the tools. The implementation of the trial was performed by T Rey-Conde and D Rice, and overseen by the trial Steering Committee of N Lennox, C Bain, R Bush and D Purdie. Interviews and data extraction were performed by T Rey-Conde, S Faint, J Brown, T Barnes and C Phillips. Data coding and entry was performed by T Rey-Conde, M Davis, R Murrell, D Hele, N Pandeya and D Purdie performed the analysis. All contributors have confirmed their agreement to this acknowledgement. The article was drafted by N Lennox and crucially revised by all authors. N Lennox is the guarantor.

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**Conflict of interest:** The University of Queensland owns the Comprehensive Health Assessment Programme (CHAP) and receives a licensing fee from organisations that use the CHAP. One third of this licensing fee is paid to N.L.

**KEY MESSAGES**

- The study is the first RCT of a health assessment in adults with intellectual disability performed by their general practitioner.
- It found increased health promotion/disease prevention activities and a trend to increased case finding.
- The health assessment process was acceptable to those involved.
References


