

## **Comprehensive Health Assessments During De-institutionalisation – An Observational Study**

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**Background** People with intellectual disability leaving institutions pass through a transition stage that makes them vulnerable to inadequate health care. They pass into community care under General Practitioners that are often untrained and inexperienced in their needs. Specifically designed health reviews may be of assistance to both them and their new GPs as they go through that phase.

**Method** This research aimed to investigate the effectiveness of a specially designed health review, the CHAP health review, in a group of adults as they transitioned out of the care of the last institution for people with intellectual disability in Tasmania. There were 25 residents reviewed by their GPs.

**Results** The CHAP reviews picked up a number of health conditions that possibly would not have been noted without it. Some of the findings were: a high number of abnormal BMIs (19 / 23), immunisations given (13 / 23), vision impairment reported (2 / 23), mental health issues recorded (4 / 23), and skin abnormalities described (17 / 23). There were 22 referrals made to other health professionals (Australian Hearing Service 4, dentists 3, optometrists 3, psychiatrists 2, neurologists 2, ophthalmologist 1, urologist 1, ultrasound 1, mammogram 1, family planning 1, physiotherapist 1, continence nurse 1 and respiratory physician 1). These were in addition to various requests for pathology.

**Conclusions** The CHAP health review was effective in detecting a number of health issues in the population of people with intellectual disability as they transitioned out of Institutional care into the general community.

## Background

The de-institutionalization of people with intellectual disability is still occurring in Australia. The people going through the process often have high support needs and very complex health needs. Onsite or visiting healthcare services, including medical services, are provided for them while they are still in institutions. Outside institutions, they go to their own General Practitioners (GPs).

The transition phase from institutional health care to community based GP care is a vulnerable time for this population. They may require more thorough support from their practitioners while this transition occurs<sup>1</sup>. However, the practitioners are often untrained and inexperienced with this specific population<sup>2-5</sup>. Therefore people with intellectual disability may be at higher risk.<sup>1</sup> They may still be at higher risk once they are past that transition stage and living in the community.

There are many barriers to high quality healthcare in community setting<sup>2</sup>. There is a lack of training in health care staff that may result in many unmet health needs in both institutional and community populations<sup>6-8</sup>. Abnormal health conditions are frequently present and are not recognised, or when recognised, are poorly managed<sup>9-12</sup>. There is also a lack of health screening/disease prevention activities for this population<sup>12-16</sup>.

One contributing cause of inferior health care for people with intellectual disability is inadequate record keeping<sup>17 18</sup>. There are often communication problems with the health practitioner and the person with disability, in both directions. There are also often changes of residences, so people do not have records and cannot give adequate histories to their new GPs<sup>19</sup>. This can result in lower levels of care.

In order to address these deficiencies, it would be of interest to determine whether specifically designed health care reviews could improve peoples' health during the transition stage from institutions to community care. These reviews would include the gathering of health histories. Two published observation studies have evaluated the usefulness of such a health assessment process<sup>12 20</sup>. Both were in community-based populations of people with intellectual disability.

These studies confirmed the benefits of health assessment through increased detection of deficits in healthcare. The deficits were primarily in health promotion and disease prevention activities, such as sensory screening, immunisations and cervical/breast screening. The studies also identified some previously unrecognised conditions, such as diabetes, cardiac arrhythmia and unrecorded cancers.

Through one of these studies, and building on the studies performed in Wales and New Zealand, we developed the Comprehensive Health Assessment Tool (CHAP) for use in this population<sup>12 21</sup>. The tool has subsequently been tested in four other studies (unpublished). These were two large randomised controlled trials and two cross sectional studies. The results of these studies are currently either under review or are in preparation for submission. The tool is currently being used by two state governments and by many non-government services across Australia and in the United Kingdom.

This study was carried out at the institution of Willow Court in Tasmania, Australia. Willow Court is of historical interest to Australians, because it was the first institution for people with intellectual disability in the country. It was built as an invalid depot and convict barracks in 1827. It was also the last institution for people with intellectual disability to be closed in Tasmania. It is now part of the Royal Derwent Hospital, a tertiary psychiatric hospital.

This paper shows the findings of the use of the CHAP tool at Willow Court as people transitioned out into the community. The clients' support staff and their new community-based general practitioner completed a CHAP assessment for each person as part of their deinstitutionalisation process. We present here the clinical findings from these assessments as recorded in the CHAP tool.

The aim of the study was to determine the effects of the CHAP health review used during the process of deinstitutionalisation of adults with intellectual disability and high support needs. We wanted to see if using the CHAP tool would result in a change in health care in this population. We specifically wanted to find out if appropriate health screening, disease prevention activities or improved detection and management of health problems resulted.

## **Method**

The population in this study were the last residents of Willow Court and were known to have had high support needs. They were under the care of resident medical officers who were on-call 24 hours a day and who came from the adjacent psychiatric wards.

When this group of people were being moved from the institution into the community, the support staff and the clients' new GP in the community completed the CHAP health review process.

All 25 residents of the Willow Court Centre were included in the study. However two residents did not have the second part of the CHAP - the review by the GP. The reason for this was not recorded in the CHAP and remains unknown.

Of the 25 participants, 18 were males and 7 were females. The mean age was 45 years (SD 2 years) and the range in ages was from 23 years to 71 years.

The University of Queensland's Behavioural and Social Sciences Ethical Review Committee gave ethical approval for the project.

## **Intervention**

The intervention was the CHAP (Comprehensive Health Assessment Program). This was a one-off health review for people with intellectual disability. It had been developed and tested in previous work, with particular emphasis on its being attractive, credible and easy to use <sup>22</sup>. It is a 21-page, A4-size book divided into two main parts. There were no changes to the CHAP tool for this project.

The carer, who gathered the client's medical history, completed the first part of the book, and then took it to the doctor's surgery for the extended consultation with the client. In the second part of the book the GP was asked to review the client's history from the first part, perform a guided examination and complete a healthcare plan. A duplicate copy of the healthcare plan was given to the carer. Educational information for the GP with a list of commonly unrecognised or poorly managed conditions in this population was included. There was also a chart of syndrome specific co-morbidities.

Twenty-three people received the Chap examination from their community GPs. The Chap tools, including copies of the healthcare action plans, were returned to the researchers.

## **Outcomes**

Specific health outcome variables of interest to this project included:

- (1) vision/hearing screened, impairment detected and appropriate action taken
- (2) obesity identified, appropriate referrals advocated, weight loss accomplished
- (3) immunisation status investigated and updated
- (4) breast/paps/skin screening investigated and attended if appropriate
- (5) detection of health problems, which would most probably have remained undetected without the use of CHAP
- (6) medication usage described.

## **Statistical analysis**

All data from the completed Chap tool was de-identified, double entered, and cleaned using Access software. It was then transferred to SPSS software for statistical analysis. The simple frequencies of the measured outcomes of interest are shown here.

## Results

There were a number of striking findings and resultant actions from the 23 Chap reviews carried out, as Table 1 indicates. They covered a wide range of health matters, from health promotion activities to identification of previously unrecognised pathology.

**Table 1a:**

### WILLOW COURT ACTION PLAN RESULTS – COMPLETE

N=23

<b>ACTION</b>	<b>NUMBER (Total = 23)</b>
<b><u>Weights:</u></b> Weights recorded	22
<b><u>Findings:</u></b> Abnormal BMIs	19
Obese*	8
Overweight**	7
Underweight***	4
<b><u>Further Actions:</u></b> Diet	3
Obesity review	2
Weight monitor	1
Exercise and diet plan	1
Blood lipids test	1
<b><u>Immunisations:</u></b> Immune status reviewed	22
<b><u>Further actions:</u></b> Hep B vaccination	7
ADT vaccination	4
Hep A serology referral	3
Pneumococcus vaccination	1
Hep A vaccination	1
<b><u>Vision:</u></b> Vision tested	14
<b><u>Findings:</u></b> Unable to test vision	7
Vision impairment detected	2
<b><u>Further actions:</u></b> Optometrist referral	3
Check vision with spectacles	2
Ophthalmologist referral	1
<b><u>Hearing:</u></b> Hearing test done	14
<b><u>Findings:</u></b> No impairment found	10
Wax present in ears	7
<b><u>Further actions:</u></b> Aust Hearing service referral	4
Ear wax removal	4
<b><u>Mental health:</u></b> Review done	11

<p><b><u>Findings:</u></b> Disorder recorded</p> <p><b><u>Further actions:</u></b> Psychiatrist referral Change medication Monitor Behaviour intervention</p>	<p>4</p> <p>2</p> <p>2</p> <p>1</p> <p>1</p>
<p><b><u>Neurology:</u></b> <b><u>Further actions:</u></b> Epilepsy review Neurologist referral Anticonvulsant review</p>	<p>3</p> <p>2</p> <p>1</p>
<p><b><u>Medications:</u></b> <b><u>Further actions:</u></b> Medication review Medication decrease Medication begin</p>	<p>4</p> <p>3</p> <p>3</p>
<p><b><u>Skin:</u></b> Skin review done</p> <p><b><u>Findings:</u></b> Skin abnormalities described</p> <p><b><u>Further actions:</u></b> Topical antibiotics Observe skin condition Other actions Emollient begun Nail scraping m/c/s Cryotherapy</p>	<p>20</p> <p>17</p> <p>3</p> <p>2</p> <p>2</p> <p>1</p> <p>1</p> <p>1</p>
<p><b><u>Renal:</u></b> Blood pressure recorded</p> <p><b><u>Findings:</u></b> Systolic BP &gt;140mmHg</p> <p><b><u>Further actions:</u></b> Continence nurse referral Urology clinic referral Renal tract US referral Haematuria monitor Fluid balance monitor Urine m/c/s</p>	<p>23</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p>
<p><b><u>Reproductive:</u></b> <b><u>Findings:</u></b> Testes examined (n of males=16) Breast examination (n of females=7) Unable to do pap smear reasons noted Pap smear examination done Undescended testes described</p> <p><b><u>Further actions:</u></b> Ultrasound referral Mammogram referral Family planning consultation</p>	<p>8</p> <p>5</p> <p>4</p> <p>2</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p>



<u><b>Endocrine:</b></u> <u>Findings:</u> Endocrine review general 21 Thyroid review 1 Diabetes review 1 Anaemia review 1 Polycystic Ovarian syndrome described 1 <u>Further actions:</u> Blood sugar test 2 X-Ray abdomen 1	
<u><b>Gastrointestinal:</b></u> Review done 22 <u>Findings:</u> Inguinal hernia reviewed 1 <u>Further actions:</u> Constipation review 2 Commence treatment 1	
<u><b>Respiratory:</b></u> Review done 22 <u>Further actions:</u> Respiratory physician referral 1	
<u><b>Musculoskeletal:</b></u> Review done 20 <u>Findings:</u> Joint pain described 1 Gait problem described 1 <u>Further actions:</u> Physiotherapist referral 1 Weight control plan 1 Check feet 1	
<u><b>General:</b></u> <u>Further actions:</u> Dentist referral 3 Haemochromatosis investigation 1	
<b>Referrals total</b>	<b>22</b>

\*Obese =BMI >30

\*\*Overweight = BMI 25-30

\*\*\* Underweight = BMI <20

From the sensory screening performed by the GP a number of significant findings were made. Vision impairment was found in two people. It was not possible to test the vision on 14 people. The reasons were unable to test (5), poor comprehension (3), blindness (3), uncertain of the reason (2) and no cooperation (1). Four people were referred to the Australian Hearing Service for hearing testing. We do not have access to the reports to determine the results of those investigations.

In the health promotion activities, the weights of nearly all participants were recorded. One person could not be weighed. Of those whose weights were recorded, atypical weight was common, and covered a wide range (39kG – 115kG). The BMIs ranged from 13 to 43 (Normal Range 20 – 25). The distribution of the BMIs was skewed towards being overweight.

Immune status was reviewed in nearly all participants and a high proportion of people had vaccinations at the time of the health review. The highest number was in Hep B vaccinations.

In the reproductive health area, two pap smears were completed on the 7 females in the group. The reasons for not doing pap smears were “not indicated” (2), “not sexually active” (1), and “refused / distressed” (1). Breast examinations were carried out on five of the women. The potentially most important finding was of an undescended testicle in one male.

Skin problems were described in a high number of participants – 14 of the 20 who had skin reviews. The most common issue was excoriation (3), then ulcerations (2), tinea (2), dermatitis (2), and there were 6 other types of skin complaints. One person had three different types of skin complaints. Eight skin treatments were carried out.

Eleven people had mental health reviews and some mental health disorders were recorded. The GPs recorded obsessive-compulsive disorder (1), hallucinations (1) and self-mutilation (1). It is not known if these were new diagnoses.

There were changes in medications in 10 people as a result of the Chap health review. This was nearly half of the participants in the project.

From the medications data taken there was a range of 0-8 medications per person at the time of the health review. The average was 4.3 medications per person. Only one person took no prescription medication. 21/25 people were taking multiple medications and 3 people were taking 1 drug.

The highest number of people taking specific types of drugs was for the alimentary tract (19 people) and for the nervous system (18 people). People also took drugs in decreasing order of frequency, for various other body systems. These were the genitourinary, respiratory, cardiovascular, musculoskeletal, blood, hormonal and sensory systems.

The numbers of drugs taken were much higher for the nervous system (59) than for the alimentary tract (25). The nervous system-affecting drugs were mainly anti-psychotics (in 16 people) and anti-epileptics (in 9 people). Seven people were taking both anti-psychotics and anti-epileptics.

The most common number of anti-psychotics taken per day was 2 (8 people), then 1 (6 people). One person took three anti-psychotics per day, and one person took four. Only one of these people had psychiatric diagnosis recorded in the carers or GP completed parts of the file and all had severe challenging behaviour, based on the descriptions of the behaviour.

Nine people took drugs from the antiepileptic drug group - five people took one antiepileptic drug per day and four people took two antiepileptic drugs per day. All nine people were known to have had seizures in the last year.

The most common type of drug taken for the alimentary system was laxatives, being taken by 11 people and then GORD medication by 9 people.

Taken as a whole, the biggest effect of the Chap review was the total of 89 actions recommended for the 23 participants who had Chaps done. There was an average of 3.9 actions per person with a range from zero actions (one person) to nine actions (one person). There were 21 referrals generated as a result of the Chap, approximately one per person. 10 of these were to medical specialists excluding Pathology.

## **CONCLUSION:**

We found the CHAP procedure prompted appropriate healthcare activities in the study sample. Vision testing, obesity identification, vaccinations carried out, pap smears completed, skin examinations done and new disease detection were all strong outcomes from the reviews. As well, there was an increase in health-screening and disease-prevention activities. These results support what has been found in previous studies<sup>22-23</sup>.

It is well known from other studies that sensory impairments are often unrecognised in both the institutional and community setting<sup>24-28</sup>. The results of this study support this.

It is difficult to determine from our data whether the weight control measure were initiated as a result of the Chap review, or were continuations of measures already in place. In either case, with 19 of the participants being of abnormal weight, the case is well established for the need to address this issue.

One perhaps surprising result is the high number of Hepatitis B vaccinations that were necessary. Institutions often have used a vaccination regime for Hepatitis B, as this population are at great risk of this disease. National guidelines have

pointed to a need for immunisation against Hep B for many years. In spite of this the participants in this study seem to have previously not been vaccinated.

The high rate of multiple medication use could be directly related to the high rate of support needs and challenging behaviour in the people in this study. This could also be true for the high use of antipsychotics. These rates are greater than those previously quoted for people with intellectual disability (M Ryan, personal communication).

In conclusion, there was increased detection of important health problems as a result of the CHAP review even in this small population. The management of these problems should have improved after the review, but we have no data to determine this. These results confirm those from another study looking at health in the transition stage from institutions – Hep B vaccinations needed, gastrointestinal problems, epilepsy reviews needed<sup>1</sup>. We also consider our findings are consistent with the known unmet health needs of this population.

This study group is a small population who are not typical of all people with intellectual disability, however it reinforces that the CHAP is useful in people who are in the process of deinstitutionalisation and have high support needs. Three other studies using this particular tool in community living populations have been completed from this centre and demonstrate similar benefit. These studies found the same healthcare deficits - confirming the tool's reliability. The other studies used more rigorous methodologies, were large and had more representative populations of people with intellectual disability. These results lead to the conclusion that people with intellectual disability with a wide range of support needs and living in a variety of setting can benefit from the tool's use.

The hypothesis that significant numbers of GPs would not agree to do comprehensive health assessments in this population was disproved in this study. A similar hypothesis was proposed in relation to carers. It was assumed that they too, because of time constraints, would not do the first section of the health review. In fact, carers did do it. These two outcomes, GP and carer support, even without the clinical results obtained, were remarkable.

This study allows the community-based GPs an opportunity to perform a complete review as a baseline to ongoing care. It almost certainly has benefits in building a relationship between the person with the disability and their new GP.

This study illustrates why a health review should be used during the deinstitutionalisation process. It results in improvements in the healthcare of the person with intellectual disability.

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### **References**

1. Tyler CV, Jr., Bourguet C. Primary care of adults with mental retardation. *Journal of Family Practice* 1997;44(5):487-94.
2. Lennox N, Diggins, J., & Ugoni, A. The General Practice Care of People with an Intellectual Disability: Barriers and Solutions. *Journal of Intellectual Disability Research* 1997;4(5):380-390.
3. Lennox N, Chaplin R. The psychiatric care of people with intellectual disabilities: the perceptions of trainee psychiatrists and psychiatric medical officers. *The Australian and New Zealand Journal of Psychiatry* 1995;29:632-637.
4. Lennox N, Chaplin R. The psychiatric care of people with intellectual disabilities: the perceptions of consultant psychiatrists in Victoria. *The Australian and New Zealand Journal of Psychiatry* 1996;30(6):774-780.
5. Cook A, Lennox N. General practice registrars' care of people with intellectual disabilities. *Journal of Intellectual and Developmental Disability* 2000;25(1):69-77.
6. *Management Guidelines People with Intellectual and Developmental Disability*. 1 ed. Melbourne: Therapeutic Guidelines, 2000.

7. Beange HL, N; Parmenter, T. Health targets for people with an intellectual disability. *Journal of Intellectual & Developmental Disability* 1999;24(4):283-297.
8. Cathels B, Reddihough D. The health care of young adults with cerebral palsy. *The Medical Journal of Australia* 1993;159(October 4):444-446.
9. Beange H, McElduff A, Baker W. Medical disorders of adults with mental retardation: A population study. *American Journal of Mental Retardation* 1995;99(6):595-604.
10. Wilson D, Haire A. Health care screening for people with mental handicap living in the community. *British Medical Journal* 1990;301:1379-1381.
11. Howells G. Are the medical needs of mentally handicapped adults being met? *Journal of the Royal College of General Practitioners* 1986;36:449-453.
12. Webb O, Rogers L. Health screening for people with intellectual disability: the New Zealand experience. *Journal of Intellectual Disability Research* 1999;43(6):497-503.
13. Bond L, Keer M, Dunstan F, Thapar A. Attitudes of general practitioners towards health care for people with intellectual disability and the factors underlying these attitudes. *Journal of Intellectual Disability Research* 1997;41(October/ Part 5):391-400.
14. Kerr M, Dunstan F, Thapar A. Attitudes of general practitioners to people with a learning disability. *British Journal of General Practice* 1996;46:92-94.
15. Lennox NG, Rey-Conde T, Bain C, Purdie DM, Bush R. The evidence for better health from health assessments: A large clustered randomised controlled trial. *Journal of Intellectual Disability Research* 2004;48(4-5):342.
16. Lennox N, Cook, A., & Diggins, J. Caring for adults with intellectual disabilities. *Modern Medicine* 1997;CME 3:79-87.
17. Djuretic T, Laing-Morton T, Guy M, Gill M. Cervical screening with women with learning disability. Letter: Concerted effort is needed to ensure these women use preventive services. *BMJ* 1999;318(20 February):536.
18. Martin BA. Primary care of adults with mental retardation living in the community. *Am Fam Physician* 1997;56(2):485-94.
19. Ziviani J, Lennox N, Allison H, Lyons M, Mar CD. Meeting in the middle: Improving communication in primary health care consultations with people with an intellectual disability. *Journal of Intellectual and Developmental Disabilities* 2004;29(3):211-225.
20. Lennox N, Green M, Diggins J, Ugoni A. Audit and comprehensive health assessment programme in the primary healthcare of adults with intellectual disability: a pilot study. *Journal of Intellectual Disability Research* 2001;45(3):226-232.
21. A randomised controlled trial of general practice based yearly health checks for people with a learning disability. 10th World Congress of the International Association for the Scientific Study of Intellectual Disabilities; 1996; Helsinki.
22. Lennox N, Green, M., Diggins, J., & Ugoni, A. Audit and comprehensive health assessment programme in the primary healthcare of adults with intellectual disability: a pilot study. *Journal of Intellectual Disability Research* 2001;45(3):226-232.
23. Webb S, Dowell A, Heywood P. Survey of general practice audit in Leeds. *British Medical Journal* 1991;302:390-2.
24. Evenhuis H. Medical aspects of ageing in a population with intellectual disability: II. Hearing impairment. *Journal of Intellectual Disability Research* 1995;39(1):27-33.
25. Evenhuis H. Medical aspects of ageing in a population with intellectual disability: I. Visual impairment. *Journal of Intellectual Disability Research* 1995;39(1):19-25.
26. Kerr AM. Medical concerns in people with severe learning difficulties: report on a vision week and symposium at the Royal College of Physicians and Surgeons of Glasgow, Scotland, 8-12 March 1993. *J Intellect Disabil Res* 1994;38(Pt 1):85-95.
27. Kerr AM, McCulloch D, Oliver K, McLean B, Coleman E, Law T, et al. Medical needs of people with intellectual disability require regular reassessment, and the provision of client- and carer-held reports. *J Intellect Disabil Res* 2003;47(2):134-145.
28. Wilson D, Haire A. Health Care Screening for People with a Mental Handicap Living in the Community. *British Medical Journal* 1990;301:1379-1381.