Providing Health Services for People with Intellectual Disability in New Zealand

Case studies of programmes and tools
# Contents

**Introduction**  
1

**Health assessments track patient care**  
2  
   The CHAP screening tool  
   IDEA Services health assessment  
   Other checks  
2

**Better health through better information**  
5

**Healthier living in daily life**  
7

**Nursing roles bridge patient care**  
9

**Empowering people with intellectual disability to stay healthy**  
11  
   ‘My Health, My Choice, My Responsibility’  
   Healthy Athletes programme extended  
   Pushing health education further  
11

Providing Health Services for People with Intellectual Disabilities: Case Studies of programmes and tools used in New Zealand
Introduction

On the back of a broad look at successful health interventions and tools for people with intellectual disabilities, the Ministry of Health focused on some in depth case studies of health interventions and tools currently being used in New Zealand for people with intellectual disabilities. These five case studies, undertaken in early 2012, are not necessarily the full extent of what is under way in New Zealand. The Ministry hopes that the case studies, along with the literature review, will help the sector on ways to improve the policy, planning and service delivery decisions of district health boards, primary care providers and other health providers for people with intellectual disabilities.

The Ministry would like to acknowledge and thank everyone who contributed to the case studies.
Health assessments track patient care

A number of health assessment tools are being used in New Zealand to check and screen the health of people with intellectual disabilities. The three tools outlined below have points in common and are all intended to ensure better health outcomes for patients.

The CHAP screening tool

The Comprehensive Health Assessment Programme (CHAP) captures key information about a patient and includes a thorough clinical analysis to help doctors identify health and screening gaps in a patient’s history. It is being used by a number of doctors around New Zealand to screen patients with intellectual disabilities, including those in Waikato and Counties Manukau District Health Boards (DHBs).

Professor Nick Lennox, who developed the CHAP at the University of Queensland, says the tool documents a person’s health history in a systematic way, and therefore illuminates any health care or screening gaps. ‘People with an intellectual disability often “lose their health story”. This tool gathers it and keeps it safe,’ says Professor Lennox, who has also worked as a general practitioner (GP) in New Zealand.

The first section of the CHAP assessment is a patient questionnaire, which is designed to be completed with the assistance of a support person. It includes detailed observations on breathing, coughing, stomach and bowel systems, hearing and eyesight, along with questions on immunisation, screening and general health. The second section, which is generally completed by a GP but can be completed by a practice nurse, begins by outlining commonly neglected areas of health in people with intellectual disabilities, and includes blood tests to check for diseases such as hepatitis.

Once a full physical examination has been completed, a health action plan is drawn up by the GP in collaboration with the patient and their support person. This plan covers areas for further assessment and any screening gaps identified in the patient questionnaire.

Two randomised controlled trials of the CHAP’s use in Australia have shown significant increases in immunisation and patient screening procedures, including an eight-fold increase in Pap smears and a two-fold increase in breast checks, Professor Lennox says. There has also been a 30-fold increase in hearing tests and a four-fold increase in vision testing. Tetanus immunisation increased nine-fold following assessment.

Spectrum Care, a support provider for people with intellectual disabilities, introduced the tool for people accessing its residential services two years ago. Judy Garriock, General Manager Business Development & Marketing, says they chose the CHAP tool because it was developed by a GP specifically for GPs. Professor Lennox’s New Zealand experience was also a factor, along with the fact that it is widely used throughout Australia. Professor Lennox is working on the continuing development of the tool, Ms Garriock says.
Spectrum Care is currently undertaking a review of the tool to help inform its future use, with roll-out planned through the rest of the organisation. Ms Garriock says the CHAP screening process appears to be working well, but ideally it would be part of a national electronic database so that the health history it captures can be accessed by health professionals. Spectrum Care is in discussion with Professor Lennox about developing an electronic version of the tool in New Zealand, Ms Garriock says.

Hamilton GP Dr Chris Nihotte has carried out CHAP assessments for Spectrum Care, involving around 15 people with intellectual disabilities. He says it is a very thorough assessment that establishes exactly what tests and screens a person with intellectual disabilities has undergone. ‘Certainly, as an initial warrant of fitness for everyone [with an intellectual disability] I thought it was a very successful tool. When it’s all written down in black and white with little tick boxes you can’t miss stuff.’

He has also found it to be a good tool for understanding some of the day-to-day health issues his patients experience, such as any bowel functioning issues, through the information provided by support staff, which can often be overlooked. ‘It’s really because they look after [the person with intellectual disability] all the time – I’m only seeing the [patients] for specific health issues so don’t always get the big picture.’

**IDEA Services health assessment**

Intellectual Disability Empowerment in Action (IDEA) Services, IHC’s service delivery arm for supporting people with intellectual disabilities, have developed their own health assessment tool, which is based on the Cardiff Health Assessment, developed in the UK for people with intellectual disabilities. IDEA Services strongly encourage their clients to take up the annual health check, which research has shown to be a reliable way of picking up health issues a person with intellectual disability may not be able to convey themselves, says Wendy Rhodes, General Manager, Quality & Special Projects.

The comprehensive screening tool includes a syndrome-specific checklist for complications associated with conditions such as Down syndrome, Prader-Willi and Fragile X, as well as a range of other health- and support-related checklists. These include the patient’s immunisation record, reproductive health, gastro-intestinal and cardiovascular condition, along with mobility, vision and communication abilities and mental health. A one-page health checklist is completed before the screening by support workers, or family, in conjunction with the person. It includes any reports of pain, issues with mobility, digestion or breathing, and the condition of ears, eyes, teeth, mouth, feet and legs, along with the patient’s vaccination status.

Papanui Medical Centre GP Robyn Hay cares for around 20 IDEA Services clients, all of whom she assesses annually using the IDEA tool. A practice nurse assists with the first part, including recording height, weight and blood pressure and taking a urine sample, before Dr Hay completes the assessment, including the physical examination. Dr Hay says screening is not always straightforward and can depend on the person’s level of intellectual disability, including how they are feeling that day.

The more invasive screening elements can include breast examination, Pap smear or prostate examination. Some clients, particularly autistic patients or those sensitive to touch, will sometimes refuse a procedure; for example, an abdomen compression as part of a physical examination. However, on the next occasion this may be acceptable to them, and so Dr Hay often carries out the assessment over more than one appointment.
She believes there is often a cost to the GP practice carrying out the health assessment because of the time involved, which the client is responsible for paying. IDEA Services do reimburse the cost for patients in their residential services, including those in foster care and contract board, but the annual check is voluntary and not all of the residential service population elect to have it. Dr Hay says that, while she already has a good grasp of her patient’s health and screening needs, the annual health checks do provide a good safety net, particularly if there is no regular contact between a patient and their GP.

**Other checks**

Health care checks have also recently been incorporated into the work of Palmerston North Hospital’s intellectual disabilities nursing specialist, Dina Cole. As part of a Master of Nursing degree she operated a nurse-led clinic using the CHAP health assessment tool, before going on to develop her own assessment programme called My Yearly Health Check. Ms Cole liked the thorough, clinical analysis provided by the CHAP assessment but wanted to add pictures and simple questions, which she felt would help engage a person with intellectual disability in the information-gathering process.

The nearly 30-page booklet is divided into two parts. The first part is accompanied by visual aids and includes a health history, specific questions relating to male and female health, along with hearing, oral and immunisation screening. The second part, the clinical assessment, concludes with an action plan which identifies any health issues and the steps to be taken. ‘You’ve got to empower the person with the intellectual disability – they’ve got the ability to learn about their own health care,’ Ms Cole says.
Better health through better information

The word ‘passport’ is associated with essential documentation, and that is how Dr Pauline Boyles wants the new Health Passport to be seen. The bright purple Health Passport contains essential disability support information a person with disability wishes to share, which can be used by health professionals with whom they come into contact. The unique feature of this record is that it is ‘patient owned’ and is held by them at all times. The Health Passport is intended for patients with a wide range of disabilities, including patients with intellectual disabilities.

The initiative is being led by New Zealand’s Health and Disability Commissioner (HDC) and is based on a similar passport developed in the United Kingdom, with modifications to fit New Zealand standards and practices. Following a successful pilot at Capital & Coast and Hutt Valley DHBs in 2011, the Health Passport is now also established at Waitemata and Waikato DHBs. The HDC is now working with other interested DHBs to implement the initiative in hospitals throughout New Zealand, including Northland, Auckland, Whanganui and South Canterbury.

The Health Passport was introduced in response to concerns from some families about the level of understanding among health professionals regarding the complex health and support needs that people with disabilities have. This can be particularly evident during a hospital stay, when a patient has contact with a variety of health professionals.

Dr Boyles, who is Senior Disability Advisor at Capital & Coast DHB, believes the Health Passport can make a real difference to the outcomes for patients with a range of impairments. ‘It’s about giving a disabled person a voice, it’s about empowerment,’ says Dr Boyles, who is also project liaison for the Health Passport’s Wellington pilot, run in conjunction with Hutt Valley DHB.

Included in the Health Passport is space for the user to record essential information about anything they feel is important to their overall needs. This may include a record of relevant health conditions (eg, ‘I have epilepsy and my seizures may last up to three minutes’), communication needs, allergies, mobility needs (eg, ‘Lie me on my left side’), family contacts, and information about who can speak on their behalf.

Such information is vital in an emergency, particularly when an ambulance officer or an emergency doctor may not be able to communicate with the patient, Dr Boyles says. ‘Also, users can record information that may ideally go into hospital handovers within the nursing care plan, but because nurses and wards are often too busy, [the information] often gets missed.’

Patients who have filled in the Health Passport template have reported that it has provided a conversation point for discussion with family members, Dr Boyles says. This is particularly so with regard to those issues that people often shy away from, such as discussing the significance of a health condition for the family, or what happens if a family member is unable to voice their wishes. ‘Busy health professionals will often just focus on a person’s illness, rather than what helps [people] with impairments stay well on a daily basis. This and the fact of having to communicate vital information repeatedly to every new doctor, nurse or carer can be frustrating and exhausting,’ Dr Boyles says.
There is also scope for personal insights in the Health Passport, such as understanding how a person exhibits stress or anxiety and what staff members need to do to ensure an anxious person can be relaxed. ‘One of the hospital staff reported that the passport particularly helped them understand how to provide quality care for those with serious head injuries. This was achieved by families using the record to give nurses and doctors a real sense of the essence of their partner, son or daughter,’ Dr Boyles says.

So far more than 1000 health and disability professionals around Wellington and the Hutt Valley have been trained in the Health Passport’s use. Training sessions range from short briefings included in staff meetings, to a three-hour practical training session with nurse educators and other health staff. A key to the Health Passport’s success will be having health professionals – in the community and in hospitals – families and service providers get behind it and encourage and support it, Dr Boyles says.

For example, there may be some alterations to the format to make sure it as user friendly as possible for both patients and staff, says HDC Education Manager Dr Elizabeth Finn. ‘[W]e recognise that district heath boards work differently, so we expect to work with each DHB individually to advise and assist with its introduction,’ Dr Finn says.
Healthier living in daily life

Working alongside people with intellectual disabilities in their homes until their service is no longer needed is how Explore likes to operate. ‘We see a referral as an invitation to come in and work alongside people and their support networks in a trans-disciplinary way, to holistically consider all the aspects of a person’s life that may impact on their health and wellbeing,’ Explore National Manager Joan Cowan says.

Explore is a Ministry of Health-funded agency, established after the deinstitutionalisation of residents in 2006 from Levin’s Kimberley Centre, which provided residential and educational services for people with intellectual disabilities. Families of former residents who had intellectual disabilities expressed concerns that their family member would no longer have adequate access to medical and specialist support in the community.

The Explore team includes disciplines such as speech–language therapists, specialist nurses, occupational therapists, behaviour support specialists and psychologists. Explore’s work includes assisting with health issues that commonly affect people with intellectual disabilities, such as managing swallowing and feeding problems, and epilepsy. More recently, the role of Explore’s nurse consultant has broadened to include healthy living in the community, with a focus on healthy nutrition, increased activity, and participation in home life and the wider community.

Explore’s clients tend to have high health and support needs. Recognising this, Explore takes a holistic approach to assessment with the initial comprehensive core assessment, which looks at physical and mental wellbeing, and social and environmental goals. An initial referral to Explore could be for a faulty footplate on a wheelchair, but once the person is assessed it could be found they have other concerns that need to be looked at. ‘You can’t look at a person in isolation. [For example] it’s highly likely if they’re presenting with concerning behaviours this could be due to a health problem,’ Ms Cowan says.

Once a core assessment has been completed, an individual plan is developed. This includes all identified concerns and subsequent agreed goals to manage these concerns. The plan may also include additional referrals for support from other disciplines within Explore. ‘It’s often only when a full assessment is carried out and you’re able to “join the dots” that the bigger health picture becomes clearer,’ says Ms Verena Lyons, an Explore specialist nurse. Explore assigns a lead specialist worker to each client to coordinate the support they provide in the least intrusive manner possible.

The Explore specialist workers ensure ongoing support, monitoring and review of the goals in the individual plan in conjunction with the person, their family and whānau, and their support team. This includes providing, mentoring and delivering any intellectual disabilities training. ‘You need to establish strong relationships with people’s support networks who have developed a good understanding of the people they support and how they communicate,’ says Ms Cowan.

Ms Lyons says that managing one concern will often enable improvements in other aspects of a person’s life. For example, Explore received a referral to assist a client to transition from a large physical disability service to a smaller community home. The client was often vocal and unsettled for large parts of the day, particularly at meal times, and had limited speech.
Following the core assessment process, recording charts were implemented to establish possible patterns and causes of behaviour. As a result it was identified that the client was not happy with being fed pureed food. A referral to an Explore speech–language therapist was made to assess whether food could be finely cut up instead of pureed. A swallowing study was completed, and it was established that key changes could be made to the types and consistency of food the client was able to eat. Alongside this, the Explore occupational therapist arranged for suitable utensils and techniques to promote the client’s independence when eating.

These changes have had a positive impact, with the client becoming increasingly active in all aspects of her life and with few times of unsettled behaviour. She appears happy and positive, and her enjoyment and engagement levels have significantly increased.

Ms Lyons also sees her role as acting as an advocate for clients. She keeps up to date with relevant medications and liaises with GPs about the most suitable treatment options for issues such as emergency seizure management. ‘Each person is an individual with different needs, so each situation will call for a unique solution,’ she says.
Nursing roles bridge patient care

Intellectual disabilities nursing specialist Dina Cole works on the frontline of health care at Palmerston North Hospital. Her busy role includes being a key liaison between people with intellectual disabilities, their families, support workers and the hospital’s nurses, clinicians and other staff. Her position came about in 2006 after the deinstitutionalisation of residents from Levin’s Kimberley Centre, which provided residential and educational services for people with intellectual disabilities.

Ms Cole, who worked as a specialist nurse (intellectual disability) in British hospitals, knew that many of the former residents were settling in the local community and foresaw the need for the role in the Manawatu. Ms Cole believes her job provides an essential bridge, helping provide better care for patients with intellectual disabilities.

A typical day starts with a visit around the wards to any patients with intellectual disability in the hospital, checking in on them, assessing their current needs and chatting with staff about treatment plans and how their stay is progressing.

Key to the role’s success has been acting as a liaison person on the ward and sharing knowledge with a range of hospital staff, including nurses, clinicians and registrars. Ms Cole points out that there is little training for student doctors or nurses in the care or health needs of people with intellectual disabilities. ‘We’ve developed a mutual respect through the sharing of skills and knowledge. I make it clear that I’m not there to police or observe work. It’s purely because I have the expert knowledge on the patient’s specific health needs related to their [intellectual disability],’ says Ms Cole.

Putting care systems in place has also been essential. Patients with intellectual disabilities whom she has worked with carry a small pink version of a ‘health passport’\(^1\) to any hospital or health checks, which records the essential information about their care. The colour theme is continued in the patient’s documentation, with a discrete pink stripe through the top corner of their notes to signal they have an intellectual disability and that a specific care plan is in place for them.

She also works closely with theatre staff and will assist in surgery preparation and procedures for patients with intellectual disabilities. This can include home visits to the patient beforehand to explain what happens in hospital and follow-up care. Communication is the key to successful treatment, Ms Cole says. Talking to patients with intellectual disability in a clear, step-by-step way, explaining what will happen, helps take the fear out of the situation. This is where staff training plays an important role, she says.

Ms Cole runs several training programmes, including a day-long course on the nature and causation of intellectual disabilities, and specialist courses on autism and Down syndrome. She has also facilitated basic visual communication and sign language courses through the organisation Voice Thru Your Hands. Voice Thru Your Hands have taught a programme to the region’s 43 dental assistants, many of whom treat patients with intellectual disability.

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\(^1\) Note that this is different to the Health Passport that is currently being rolled out in DHBs, overseen by the Health and Disability Commissioner.
Resources, including simple illustrated cards, can also be used by staff to help with communication. ‘We talk about the different levels of intellectual disability. There’s not just one level – it graduates from mild through to profound. You’ve got to adjust simplicity of language.’

Ms Cole’s close links with families and whānau who have members with an intellectual disability often mean she is also contacted in an emergency situation. This means that, where appropriate, she can alert hospital staff to establish a care plan in advance of the patient’s arrival. ‘While the aim of community integration is that people with an intellectual disability are treated the same, some won’t be able to cope with waiting at an emergency department,’ Ms Cole says. ‘If I’m working, I can go in and help get things set up so they are in and out as quickly as possible.’

Ms Cole would like to develop her role to that of a nurse practitioner. This would mean she could more effectively and independently carry out health assessments and health promotion work without needing a doctor to confirm a diagnosis.
Empowering people with intellectual disability to stay healthy

Health promotion programmes in New Zealand are improving the health outcomes of people with an intellectual disability, while empowering them to take responsibility for their own wellbeing.

‘My Health, My Choice, My Responsibility’

IDEA Services, a support provider for people with intellectual disability, introduced a successful health and wellbeing education programme in 2009 after examining ways to further enhance self-management of health by their clients.

My Health, My Choice, My Responsibility, developed by the Westchester Institute for Human Development in the United States, was initially trialled with two groups of young adults with intellectual disabilities: one group in a school setting, the other in an IDEA Services vocational setting.

The programme comprises eight educational sessions: ‘Take charge of your health’, ‘Develop a health plan’, ‘Be a health self-advocate’, ‘Get moving’, ‘Eat right’, ‘Be healthy at home’, ‘Feel good about yourself’, and ‘Stay on track’. Each session takes approximately two hours, and participants learn course material through discussion, activities, visual aids and developing goals as they learn. For example, the ‘Eat right’ session discusses different types of food and asks, What is healthy food? Picture cards are used to play a game to aid learning, and there is an option to cook a healthy meal at the end.

IDEA Services made some content changes to the sessions to make them easier to use and more New Zealand-specific. This included altering documentation, such as the medical form and My Health Plan, which lists goals developed during the seminar.

An evaluation by IDEA Services of the My Health, My Choice, My Responsibility trial found that those who took part were ‘highly motivated’ to learn more about their health and consistently expressed a desire for more personal responsibility as a result. Feedback indicated that both the self-advocacy and educational component were highly valued.

It has subsequently been used in around 15 different locations serviced by IDEA, says Wendy Rhodes, General Manager, Quality & Special Projects, with positive results. ‘If we’re going to meet the needs of younger intellectually disabled people then this will be one area that we need to invest in more.’

The majority of participants recognised the importance of being ‘health wise’ and indicated that they had ‘learned something’ from attending the programme. This included a young man who only attended the ‘Eat right’ session and subsequently made positive changes to his diet, which were attributed to this session.
Ms Rhodes says the programme is more accessible to younger people who have a moderate or mild intellectual disability, and because the programme is resource intensive to teach, IDEA tend to focus it on younger clients. In its evaluation, IDEA state that while the basic programme design has value for people who have a more severe learning impairment, the programme’s content and delivery would need more extensive modification from an occupational therapist and/or speech–language therapist for someone with greater support needs.

Healthy Athletes programme extended

Intellectual disabilities clinical nurse specialist Dina Cole is adapting and expanding the Healthy Athletes screening programme for Special Olympics athletes to the general population of New Zealanders with intellectual disability.

The Healthy Athletes programme monitors the health of Special Olympics participants through a series of screenings, which it calls Fit Feet (podiatry check), Healthy Hearing (audiology checks), MedFest (sports physical exam), Opening Eyes (vision), FUNfitness (physical therapy), Health Promotion (better health and wellbeing) and Special Smiles (dentistry).

Launched in 1997, Healthy Athletes also educates participants on healthy lifestyle choices and identifies problems that may need additional follow-up. Since its inception the health of thousands of athletes, who have disabilities across the spectrum, has been improved.

Ms Cole, in her role as Clinical Director Health Promotion with Special Olympics New Zealand, organised a Healthy Athletes event in Dunedin in August 2011 in the lead-up to the 2011 National Winter Games. More than 200 athletes were checked for blood pressure, bone health, height, weight and BMI. ‘We had a lot [of people] who were overweight and also had issues with blood pressure. A number of these were referred on to a GP.’ Ms Cole says that it is not uncommon to diagnose up to five conditions in competitors during a screening session.

The athletes were also educated through visual displays. This included healthy food stands displaying good dietary choices, including portion sizes. Participants were encouraged to try a new fruit or vegetable to widen their food choices. There was also a display illustrating just how much sugar a can of fizzy drink contains, and a smoke-free display illustrating the build-up of tar over time caused by smoking.

Ms Cole says a number of participants returned with carers the next day to share their learning. Its success provided a basis for future events that will be held around the country for the general population of people with an intellectual disability. At this event the Healthy Athletes screening programme will be provided, along with sports and games in an adjacent hall, to draw people to the event while spreading the healthy living message.

Volunteer nurses, doctors and dieticians will carry out event screenings, which provide an opportunity to upskill them in providing health care for people with intellectual disabilities. A three-hour training session before the event will be held to educate and inform the volunteers.

‘The fact they spend the weekend with people with intellectual disabilities coming through [the programme] – it provides them with a total immersion experience. I have no hesitation in saying, I’m sure I’ll get volunteers,’ Ms Cole says.
In the longer term Ms Cole would like to develop Special Olympics health coaches: people with intellectual disabilities educating and delivering the Healthy Athletes programme alongside health professionals. ‘That’s my dream – to have people with [intellectual disability] educating their peers.’

**Pushing health education further**

As a result of Ms Cole’s Special Olympics involvement, she has also identified a gap in health promotion material. In response, she is developing a programme to deliver health promotion material to an intellectually disabled audience. ‘With the Healthy Athletes events you’re just capturing the ones that are already engaging with healthy living, but there are many more out in the community whose need is probably greater.’

The programme, which she is completing as part of her Master in Nursing, is still being finalised, but consists of an initial 16 leaflets in plain language with pictorial aids, which together act as an educational series. Topics covered include blood pressure, temperature, asthma, diabetes, cardiovascular, healthy bones, and the risks of smoking and sun exposure. Each topic is accompanied by a PowerPoint presentation and is aimed at an audience with mild to moderate intellectual disability.

‘All the leaflets are part of a health promotional resource, but they are also stand-alone resources that you can use to explain health matters on an as-needed basis,’ Ms Cole says. The aim is that they are utilised in any health or educational environment.

Ms Cole believes there is a large gap in the area because health promotion, such as Sunsmart messaging, is not usually targeted at an intellectually disabled audience. Professor Nicholas Lennox, Director of the Queensland Centre for Intellectual and Developmental Disability, agrees that more needs to be done in health promotion for people with intellectual disability. He cites obesity as an example. ‘It is a huge issue for much of the population [of people with intellectual disability], but there is currently very little information on this issue targeted at such an audience – essential if the issue is to be tackled,’ he says.

Professor Lennox is involved in wider discussions with colleagues about a centralised system, perhaps via a website, whereby health educational material such as fact sheets that have been developed for an intellectually disabled audience can be shared.