

## Case study 5: New tool helps NGO get better GP services for disabled people

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*With initial support from a DHB, a non-profit disability support provider has introduced an annual evidence-based health assessment tool from Australia into New Zealand general practices.*

Due to growing concerns about poor health outcomes and relatively high mortality rates for the people with disabilities accessing its residential services, **Spectrum Care** commenced a journey in 2009 to change things for the better.

Spectrum Care is an independent charitable trust providing services for children, young people and adults with disabilities and their families. Services include 24-hour support for around 400 people living in residential homes throughout the Auckland and Waikato regions, and respite care in these regions and the Bay of Plenty. Spectrum Care also offers specialised home support, behaviour support and work and activity services in the greater Auckland region.

The journey began with Spectrum Care reviewing its health tools, processes and support systems to identify gaps between health outcomes for people with disabilities and the general population. This review identified that many of the poor outcomes were linked to breakdowns in primary health supports through:

- unrecognised or poorly-managed health conditions and diseases
- inadequate or non-existent health screening
- ineffective communication between the individual, their family/whānau, support workers and GPs.

“There’s a huge amount of research on disability and ageing, but very little information on how to address the identified issues,” says Judy Garriock, General Manager – Business Development and Marketing at Spectrum Care.

Through its research, Spectrum discovered the Comprehensive Health Assessment Programme (CHAP), which is an evidence-based health assessment tool for GPs. The CHAP was developed in 1999 by Professor Nick Lennox – an Australian GP with New Zealand experience. Professor Lennox is the Director of the **Queensland Centre for Intellectual and Developmental Disability**, which is part of the School of Medicine at the University of Queensland. The CHAP is funded by Medicare and used by GPs throughout Australia, and is currently being introduced in the United Kingdom.

In 2010, Spectrum introduced the CHAP as the health assessment component of a joint pilot with **Counties Manukau District Health Board (CMDHB)**. The pilot programme aimed to improve the health outcomes for ageing people with intellectual disabilities, who were aged over 50 and living in two Spectrum residential homes in South Auckland.

The partnership with CMDHB came about due to fortuitous timing on two fronts – Spectrum Care chief executive Chris Harris happened to meet CMDHB Aged Care General Manager Jenny Coles at a function, shortly after a similarly-focused CMDHB Adult Rehabilitation and Health of Older People (ARHOP) project had been completed at a local aged care facility.

CMDHB immediately saw the value of the pilot and positioned itself to support it. Dr Shankar Sankaren, the Clinical Head and consultant geriatrician for Community Geriatric Services – ARHOP, became actively involved in the pilot service design and research.

During the pilot, GPs completed health assessments using the CHAP to provide an in-depth health baseline. Many of the people accessing Spectrum Care residential services have higher and more complex needs (e.g. significant intellectual and physical disabilities with communication challenges), so support workers played an important part in these interactions with the GPs.

For Spectrum Care staff, the pilot challenged historical behaviours in the choice of peoples' GPs. Staff have begun to realise that the closest GP may not be the most appropriate and will now help people select a GP who has empathy and interest in supporting them.

To improve the support workers understanding of ageing and age-related conditions, an age-training programme was developed. The training increases support worker understanding rather than changing them into clinical caregivers.

"It's about changing our awareness and attitude, so our support workers feel empowered to challenge and engage GPs where necessary," explains Judy.

"Everyone has a voice, even if they can't communicate. Everyone has the right to be offered the same treatments and screenings as the general population, and to decide if they want to have them. Many significantly disabled people have never been offered breast screening or prostate exams because many GPs are unsure how to raise the topic or gain consent."

As part of the pilot, increased interaction was facilitated between the general practice and CMDHB clinicians, Spectrum Care staff and the people they support. The geriatrician from CMDHB was involved with medication reviews, age-related discussions and mentoring with the GPs.

Interviews with the GPs and support staff were completed in March and September 2011.

Feedback about the CHAP indicated that while some GPs were "very into it", others were more reluctant – perceiving the longer in-depth assessments and completion of paperwork as "not a valuable use of their time" – even though, in some cases, Spectrum Care booked a double appointment to ensure adequate time.

Much of the historical health information was unknown by the GPs and unable to be entered on the forms, so Spectrum Care is now exploring ways to summarise this for inclusion in future CHAPs.

Both staff and GPs were desperate for a digital version of the tool, which has been picked up by the Australian developer. Spectrum Care is assisting with advice on an electronic format.

"Going forward, it will be important to be able to connect in with the DHB and PHO IT systems," says Judy.

"A web platform for sharing health information between providers, PHOs and DHBs will help with real-time information sharing and records retrieval for new health providers."

Spectrum Care has now begun to roll-out the CHAP to residential services organisation-wide, commencing in the Waikato region.

Others in the disability sector, such as the New Zealand Disability Support Network, IHC, IRIS and Hawksbury Community Living Trust are watching progress to see what outcomes result, and Spectrum Care is keeping them informed through regular networking.

In Waikato, Spectrum Care has entered into a partnership with **Waikato DHB** to contract 0.3 of a Clinical Nurse Specialist (CNS), who has been crucial in improving the interface between staff and GPs and practice nurses. So far, Spectrum Care has been unable to partner with Auckland DHBs to contract CNS services, but is continuing the CHAP rollout regardless.

The different financial circumstances and priorities of different district health boards is a challenge for many non-profit providers – especially those whose services cover more than one DHB area. Even when multiple DHBs are able to support an initiative, the repetitive negotiation and contracting processes can be a major drain on an NGO's time and resources.

“When you're getting great feedback or support from one funder about a proven tool or service that works, it can be incredibly frustrating when you can't offer it to all your people because of DHB differences in attitudes and priorities. The inequity of 'healthcare by postcode' is huge and processes need to be streamlined or be given direction from the Ministry when health disparities result from DHB and PHO indifference to disability conditions,” says Spectrum Care chief executive, Chris Harris.

Spectrum Care is keen to connect with one or two PHOs to help identify GPs with an interest in improving health outcomes for people with disabilities.

“It's important that we don't inundate a few keen GPs with too many high-needs patients, but it would be good to find some who have an interest and who might support and encourage their peers to spread the load,” says Judy.

“We're exploring ways of identifying GPs with an interest in disability, but the endorsement of the CHAP by the Ministry of Health is vital to support constructive engagement with the GPs. Ideally, we'd like the CHAP recognised as the national health assessment tool for all people with disabilities”.

**More information:** [www.spectrumcare.org.nz](http://www.spectrumcare.org.nz)

This is one of the 15 case studies profiled in *How NGOs Make a Difference to Health Care in the Community* – a 96-page report from the Health and Disability NGO Working Group, Jan 2012.

The case studies cover acute nursing services, health information services, virtual practices, youth one-stop-shops, mental health networks, community development approaches, cardiac rehab, Whānau Ora and Asiasiga models of care, and more – from North to South.

See [www.ngo.health.govt.nz](http://www.ngo.health.govt.nz) for more of the report.