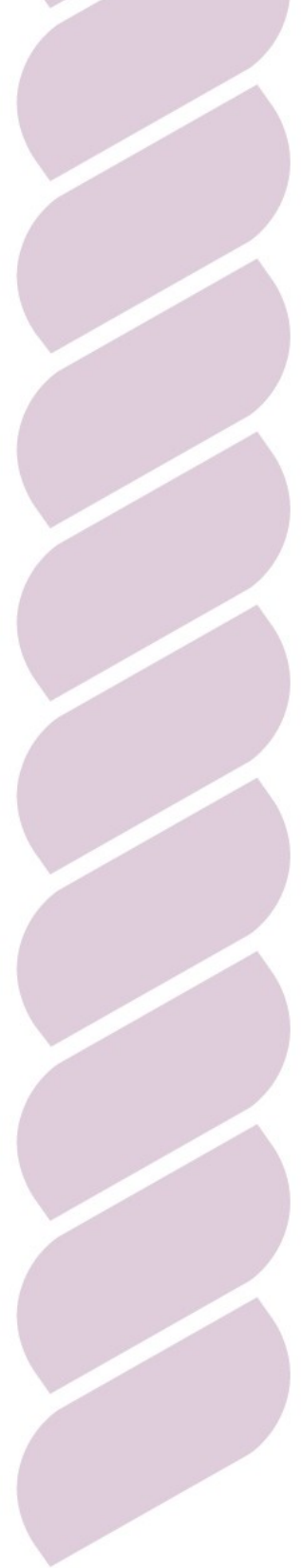


# Determining the workforce development needs of New Zealand's autism workforce

A summary



Te Pou o te  
Whakaaro Nui

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## Disclaimer

This summary report highlights the key points from *Determining the workforce development needs of New Zealand's autism workforce: Results of an information gathering exercise undertaken in November 2015* by Te Pou o te Whakaaro Nui. As a summary, it is a diluted voice of the original author and, ultimately, of those who live with autism, their families and support networks. More in-depth explanation and analysis can be found in the full report at [www.tepou.co.nz/resources](http://www.tepou.co.nz/resources).

## Background

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In 2015 the Ministry of Health commissioned Te Pou to investigate, evaluate and develop resources, tools and competencies to support the disability workforce to provide high quality, responsive services to people with Autism Spectrum Disorder (ASD). This followed a *Disability Workforce Action Plan 2013-2016* recommendation (Ministry of Health, 2013) to improve the skills of the regulated and non-regulated workforce in relation to autism support.

Te Pou contracted Sharon Brandford to author the report *Determining the workforce development needs of New Zealand's autism workforce: Results of an information gathering exercise undertaken in November 2015*, as a way of understanding the prevalence of autism, assessing what services are available and investigating the future pressures for the sector, and how the current workforce is equipped to meet those needs.

The range of professionals currently working with people with autism spans health, education and social services and includes government and non-government organisations. Community-based service providers include organisations who work under Ministry-funded contracts as well as those that are self-funded. This report, however, looks only at the workforce funded through Ministry of Health Disability Support Services (DSS) and does not fully explore the whole of the ASD landscape.

The information in this report was collected through consultation with a number of individuals, including people with autism, parents and other family members, through face-to-face conversations and phone interviews. An online survey of disability service organisations was conducted through the membership bases of NZDSN, Te Piringa Māori Disability Sector Network and NZ Home and Community Health Association, with responses coming largely from NZDSN membership. Fifteen organisations completed the survey and an additional five organisations were contacted by phone.

### Participating organisations

Collectively, respondents employed around 16,000 people across DSS contracts, representing a significant portion of the overall workforce, estimated to be between 19,000 – 22,000 people.<sup>1</sup> Respondents included:

- three large national or multi-regional disability service organisations
- ten smaller local providers
- three specialist disability service providers
- three large national home and community care organisations

- one small local provider.

Service contracts held by these organisations included community residential services, supported independent living, DSS-funded day support, home support, respite, EGL navigation/ Local Area Coordination/ Individualised Funding holder or host, behaviour support, carer support, parent education, RIDSAS, managing own IF (or on behalf of a family member) and ASD communication and behaviour service.

All responding organisations provided support to people with autism to varying degrees. Twelve out of 20 stated that people with autism comprised 30 – 50 per cent of their client group. Specialist organisations provided services to an even larger proportion of people with autism. One organisation, Explore, indicated that more than 50 per cent of its behaviour support clients have autism and IDEA Community Specialist Services reported that all of its clients have ASD. Both indicated they support individuals with and without an intellectual disability. The home and community care organisations indicated they work with people across all age ranges, including those without an intellectual disability, but support “very few” people with autism.

### Learning and development providers

A total of 25 learning and development providers were identified as part of this project, of which 20 returned surveys. However, there is no verification that this represents all learning activities available to the workforce.

Autism learning and development providers include not-for-profit trusts, commercial businesses, individual consultancy services, District Health Boards and NZQA Private Training Establishments. Less than half of those that responded provided training to one geographic region, four provided training across three or four regions and seven delivered to the whole country. In total, these providers delivered 111 learning events over the previous year.

Training providers reported delivering content that is widely agreed to be of value. Most deliver short courses of less than four hours, which is a format believed to enhance access, though only one provider utilised an online format. Activities were generally offered in a generic way but many providers indicated capacity to tailor training to specific individuals and support networks. Few activities were targeted to developing advanced skills, few had been developed with specific cultural contexts in mind and fewer than half were deemed suitable for people supporting those with autism and no accompanying intellectual disability.

For the full methodology, please refer to full report at [www.tepou.co.nz/resources](http://www.tepou.co.nz/resources).

## Current workforce development opportunities for the autism workforce

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### Training and development

Sixty-two percent of the responding organisations reported that information about autism was included in the usual orientation processes for new staff. The depth of this information varied considerably but generally included some basic information for staff if they were supporting a person with autism, often sourced from the

person or their family/ whānau in the context of developing the person's support plan. They also indicated they may request additional information from Autism NZ or a knowledgeable person within their organisation.

All but one of the disability organisations had provided at least one learning and development activity over the past 12 months and most provided several opportunities. Development activities varied widely in type, length, frequency, purpose and cost. Some larger organisations also accessed specialists from within their own organisations. No home and community care organisations reported providing courses, workshops, conferences or non-managerial supervision related to autism. These organisations provided their workforce with basic information only.

Respondents from disability organisations provided information about specified skill levels for their staff. Essential skills, which are fundamental for all staff, were reported as most likely to be taught through courses and workshops. Some employees at this level may have also had access to some form of non-managerial supervision, but this resource was not reported as being widely available. At the capable skill level, for more experienced staff working in direct support roles, courses, workshops or conferences provided these individuals with professional development opportunities. Also, these staff were more likely than new employees to have access to non-managerial supervision. Specialist staff at the enhanced level took part in all forms of activity offered (courses, workshops, conferences, clinical and/or peer supervision) although workshops were seen as the most appropriate for developing specific skills to more advanced levels; the majority of organisations also offered non-managerial supervision to these staff members. Responses indicated that the majority of organisations offered clinical or peer supervision for managers and leaders as the main source of development, however for these individuals, courses were seldom attended, workshops weren't accessed at all and conferences were attended infrequently.

Disability organisation respondents were asked to comment on the desirability of specific skill domains. More than half of the responding organisations identified that the following areas of autism knowledge were needed for all employees:

- understanding the general characteristics of autism
- general tips and guidance
- creating structure and routine
- communication strategies
- social support strategies
- managing challenging behaviour
- knowing where to seek further assistance.

They also identified the need for staff at Capable, Enhanced and Leader/ Manager level to be competent in all domains including those already mentioned but also:

- causes and diagnosis of ASD
- sensory strategies
- managing anxiety
- supporting people with their mental health
- practical day-to-day support
- relating knowledge to individual situations and goal/ service planning.

These domains were largely similar to those identified as desirable from families and people with autism as well. Families specifically expressed the relevance of community integration skills, reflecting a somewhat greater focus on the community as a work setting, and social and community integration as desired goals. People with autism and their families also noted the importance of understanding sensory issues and strategies.

All staff from national/multi-region agencies were likely to attend some form of autism-specific course during their first year at work, additional to basic orientation information. However, the position was much less clear for smaller disability organisations. Although some expected staff to attend an autism-specific course of some sort, the majority reported they would provide this only if related to the support of a particular individual.

Cost was cited by 73 per cent of respondents as a barrier to accessing learning activities. As a result, many were sourcing autism-based learning and development only when individual client needs made it essential. Other barriers to accessing training included a lack of suitable options and the location of activities, both of which may also have a cost component, and the length of activity.

Smaller organisations were likely to contract in a training provider or access courses that were open to a wider audience, which was less specific to the needs of an individual. They also accessed courses less routinely, usually for a team supporting a particular individual. All national/ multi-region disability organisations routinely provided learning and development activities using internal facilitators. Given the size of their combined workforce (approximately 8,500) and their high involvement with people with autism (between 30-60 per cent of clients), this represents a high activity level worthy of more detailed enquiry than the current project permitted.

There was agreement among disability organisations about where there are gaps related to more advanced learning opportunities, particularly around topics such as the cognitive aspects of ASD, life stages and common changes, supporting people to understand their own diagnosis, how funding works for families and practitioner interventions. Training and development for supporting adults without an intellectual disability was also identified as a need because organisations stated they could not readily access this type of professional development. In fact, the three providers who specifically stated they supported this client group had accessed no such training. Organisations reported that they were also seeking practical and in-depth training for experienced staff that can be followed through into the workplace, particularly around the practical aspects of behaviour management, social skill development and helping people to develop their communication skills.

## **Volume demand**

From 2014, an additional estimated 33,000 people may have become eligible for disability supports as a result of the clarification that a person with autism does not require concurrent disability in order to access funded support. Using the Ministry of Health's Demographic Report (2015), it is estimated that, previous to this clarification, approximately 10 per cent of people with autism were allocated disability supports<sup>ii</sup>. This data suggests lower delivery rates in the past than one might expect in the future, which is likely then to put pressure on the existing workforce to grow to meet demand. Estimates based on responses to the workforce survey indicate that 18.6 - 26.4 per cent of the current workforce work with people with autism.<sup>iii</sup>

There remains no consistently agreed data source describing the prevalence of autism in the general population in New Zealand. Estimates of prevalence come from international data, which ranges between 0.6 and two per cent. In 2008 the NZ Autism Spectrum Disorder Guideline suggested New Zealand adopts 1.16 per cent as a prevalence estimate. When 2014<sup>iv</sup> population estimates are applied, this suggests at least 47,400 people in New Zealand are affected by autism. This figure should be considered conservative as there is still debate about whether the incidence of autism is increasing and the health sector is responding to earlier recommendations regarding improved diagnostic and assessment practices. In addition, recently revised Ministry of Health criteria clarifying that people with autism do not need to have comorbid disability in order to access funded disability support services means that this population, having been previously restricted from the sector, will likely have under-recognised needs.

Intellectual disability is reported as a common associated condition among people with autism. These individuals have generally been supported by intellectual disability service networks, which have been funded through contracts with Ministry of Health DSS. Previous estimates stated that as many as 70 per cent of people with autistic disorder<sup>v</sup> have intellectual disability. This proportion has been commonly used to estimate the prevalence of intellectual disability among people with autism. However, more recent studies suggest this over-estimates prevalence in the context of current diagnostic categorisations. Recent research<sup>vi</sup> reports that the prevalence of intellectual disability is between 17.4 per cent (for children aged 0-5) and 29.4 per cent (for young people aged 18-27). This is a significantly lower reported rate of intellectual disability than previously accepted. When applied, one might expect at least 14,000<sup>vii</sup> people in New Zealand to have autism and intellectual disability.

It seems reasonable that New Zealand can expect the greatest demand increase to be for those with no intellectual disability and that past service utilisation data will significantly underestimate future demand. Although increases in the identified prevalence of autism have been noted at all levels of intellectual ability<sup>viii</sup>, they have been more pronounced for those with average to above average IQ. However, distinguishing between people with autism on the basis of intellectual functioning will likely become less relevant over time as a result of the removal of intellectual functioning for eligibility purposes; the diagnostic criteria in the DSM-5 revision enables the recognition of different support needs across the spectrum, more aligned to adaptive functioning.

## Service development

Disability Support Services within the Ministry of Health provides a range of services for eligible people through a number of funding schemes. The package of disability support is largely determined according to an individual's support needs as identified by Needs Assessment and Service Coordination services (NASC). These include home and community support, community residential, supported living, respite, equipment and modification, carer support and behaviour support. The Ministry also funds mechanisms to support disability services such as the NASC and Disability Information and Advisory Services (DIAS), two of which are autism specific. Altogether Autism provides this service nationwide and Autism NZ provides it in Auckland.

In the past seven years, support services for people with autism and their families have changed. Some have been generic to all people with disabilities such as the introduction of Individualised Funding (IF), greater enhancement of natural supports through initiatives like Choice in Community Living, Enabling Good Lives



and New Model, the expansion of alternative living options such as supported living, the introduction of family funded care in 2014 and the move to a national provider of behaviour support services in 2014. Other changes have been ASD specific such as the ongoing maintenance of the New Zealand ASD Guidelines, agreed assessment and diagnostic processes with an investment in post-clinical training to a range of health professionals, the establishment of an ASD-specific disability information and advisory contract, greater access to a range of parent education programmes for families of pre-schoolers, school-aged children and young adults and ASD Coordination services within some DHBs for families of children.

Workforce planning should be informed by current and future service use, since this indicates the work settings of those engaged in the workforce. The Ministry of Health Demographic Report (2015) provides 2013 data about disabled people for whom NASC agencies allocated funded Disability Support Services (as distinct from services used). The Report contributes to a picture of the work settings in which people are employed. However, it has significant limitations for the purposes of describing current and future service demand related to autism support. This is because the data relates to a period before ASD eligibility was clarified to those with autism and no other eligible disability support needs, and also excludes some DSS-funded services accessed by people with autism and their families, including child development and coordination, parent education programmes and intervention services such as behaviour support and ASD communication and behaviour services.

There are significant knowledge gaps for informing parallel service and workforce development relevant to adulthood and aging. However, a number of issues have been identified including tools for assessment and diagnosis in adulthood, co-occurrence of mental health problems in adulthood, the nature of employment support and civic participation, transitions in education, home life and relationship domains, establishing long-term relationships and raising families, interface with judicial and forensic systems and self-management of physical health.<sup>ix</sup>

The training and development needs of those working with children and their families may therefore be very different to those who work in support of adults, not the least because of the changing dynamic within family groups over time.

There is an increasing body of evidence about the significant mental health needs of some people with autism. Recent New Zealand research about mental health disorder prevalence among people with autism confirms high rates of non-diagnosed comorbid mental health concerns both for those with and without intellectual disability.<sup>x</sup> Emotional problems appear to be common for young people and adults alike and these become especially marked at times of transition. There is a need for greater collaboration across workforce and service sectors and better access pathways to mental health services. There remains an urgent need for greater awareness among mental health professionals, disability NASC and community providers of the mental health support and treatment needs of those with autism.

## **Attitudes and values of the workforce**

People with autism vary in their opinions about describing themselves as people with disabilities. Some believe the term reflects the disabling process described by the social model of disability and therefore welcome the term. Others reject it for its potential to devalue and deny their unique identity. Similar debate occurs regarding



the use of terms such as high and low functioning, which can potentially categorise autism along an intelligence continuum and encourage the stereotype of savant skills. These terms can also mislead people to believe that only those with intellectual disabilities require high and sustained support, when in fact intelligence may have little impact on the adaptive functioning of an individual. These debates over language should not distract from the central importance of supports. The degree to which a person experiences disability is influenced in large part by the social, educational and developmental supports available to them.

Families and people with autism involved in this project suggested they do not necessarily ascribe the same value to specific qualifications that employing organisations do. A common response was that the attitudes and values of the individual, along with their ability to relate to the person they are supporting, were more important than a formal qualification. Families interviewed stated they wanted staff to be able to facilitate participation in ordinary community spaces and to facilitate connections between the person and others. Those employed in support roles require the right attitudes and skills not just to work with an individual, but also to traverse changing family roles and relationships, manage tensions about privacy and understand the development of identity across the lifespan.

### **Workforce development framework**

The vast majority of organisations consulted for this report did not have an articulated ASD development pathway. For those that did, many identified that it was incomplete, particularly in relation to the advanced end of the continuum. Limited resources, high turnover, a lack of cohesive and centrally located information and non-existent pathways for advanced level skills were all identified as contributors to this. The absence of a workforce development framework was illustrated in several different ways through the project.

There appears to be little information to guide organisations in the continued development of their staff. Half of the respondents reported taking ad-hoc approaches to the opportunities they became aware of.

Levels of funding and pay rates for those employed in this sector were identified as critical to improving skills and retention. Pay rates were described as commensurate with essential entry level skills, but service models and consumer expectations were for staff with skills at capable and experienced levels.

Service providers, families and people with autism commented on difficulty getting information about learning and development options and resources, including guidance on what competencies they should be seeking for the various roles people fill. Overseas models, such as the website Skills for Care UK, illustrate what might meet this sector need.<sup>xi</sup> The range of current programmes most directed at general awareness could well form a solid foundation for specific and advanced skill-building.

Almost everyone consulted identified the importance of content about person-centred planning. Many staff in community disability organisations receive guidance about understanding behaviour through activities based on positive behaviour support or applied behaviour analysis. Learning related to this range of topics is not particular to the support of people with autism, but likely to be highly relevant.

It is well established that training alone will have little effect on staff performance. What is also needed is organisational action to support the retention and use of skills and knowledge acquired in instructional programmes.<sup>xii</sup> Organisations could take a more systematic approach to workforce development by defining performance, ensuring that staff are aware of what they need to know and do, monitoring performance to determine competencies and skill deficits, instruction using formal and informal methods to build staff competency and providing feedback to reinforce knowledge and practice or make corrections. This needs to be embedded in the workplace and in the learning programme matched to the roles people fulfil. For example, the workforce survey identified that providers wanted leaders to have all skill domains but didn't tend to send them to workshops with practical based teaching.

The findings described here suggest there is value in supporting organisations with a framework for the development of the workforce across diverse settings. It must support the rapidly changing face of autism support, and will need to include those parts of the workforce currently receiving less attention such as staff providing carer support, home and community support services, and staff in leadership, coordination, managerial and specialist roles. The services most used by people with autism are carer support and home and community services. Therefore, people employed in these roles require the knowledge and skills to support people with autism. In addition to the supports more commonly accessed, families would also prefer more skilled personnel in direct support roles and in specialist practice support and advisory roles, such as ASD communication and behaviour service for adolescents.

Service provider organisations identified two primary triggers to seek learning and development related to autism. The first is related to the individual's needs, promoting the model of person-specific or team-based learning, which is desirable. The other trigger is related to internal organisational requirements, such as development strategies. This indicates the value of supporting providers to develop workforce plans to encourage greater uptake of instructional programmes tailored to people in different roles. These workforce plans would also support the application of training into work settings and would help service providers to be better informed about their specific learning and development needs.

The service provider survey indicated that larger organisations often deliver substantial learning activities internally. Further feedback suggests internal delivery is also being considered by smaller providers to minimise costs from external provision. It seems that it would be more efficient to make the existing programmes more affordable. Any resources allocated for internal delivery could then be focussed on embedding the learning into practice through performance monitoring and coaching, and implementing necessary service changes as a result of better knowledge.

A number of agencies contribute to the development of the health and disability workforce, but it is not clear how autism support has figured in their planning. Specific to the needs of people with autism, there appears to be differential uptake of some service approaches as individuals seem to be in favour of funding models such as IF whereby there is greater choice and control on how resources are spent.

The Ministry of Health and disability workforce bodies agree that improving qualification levels across this workforce is an important strand in workforce development. Careerforce could lead much of the work for those

not currently qualified. HWNZ and Werry Centre could focus on ensuring qualified professionals are well-informed about autism and, therefore, add value to the sector. It is critical that qualifications address the skills sought by employers and those receiving support from the workforce. Qualifications must also be regularly refreshed to ensure they remain relevant as children and adults with autism become more involved.

Bevan-Brown (2011) identified a number of quality criteria and broad indicators for the evaluation of *Tips for Autism*, a parent learning programme specific to autism. These included team-focussed, needs-based, knowledge-based and instructionally-based approaches. This research provides a sound basis for the evaluation of current and future autism-specific learning programmes.<sup>xiii</sup>

## Conclusion

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Significant potential pressure on the existing workforce has been identified in this project.

There will likely be a considerable upsurge in people with autism of all ages seeking support from current or future services funded by DSS.

The current workforce, experienced in working with people with an intellectual disability and autism, will be challenged by the greater diversity of needs of people across the spectrum, and learning and development appropriate to this will be required.

It is currently difficult sourcing advanced learning and development opportunities for leaders and managers who are required to support staff to embed learning into daily practice. There remains uncertainty about the models of support which will be funded in the future and, thus, the competencies and skill levels required for changing roles. There is also the absence of a workforce development framework that extends value and resource to workplace support and a relatively low awareness among service providers of where to get assistance to implement learning and development within their workplaces.

There are also a number of emerging initiatives which might be harnessed to support workforce development.

There is a reliance on instruction as a strategy and this could be maximised through formal organisational practices based on reflection, collaboration and the application of learning.

Te Pou's resource *Let's get real: Disability*, a skills framework for staff in the disability sector, provides an opportunity to assist organisations to design services for diverse support needs along with accompanying workforce development. Additionally, Careerforce can support providers to develop a learning programme that can sit within the agency's workforce development framework. Training providers can best support development through tailored training, with material customised to the role and the team context.

Documenting an agreed curriculum would help employers identify what learning product best suits the different roles people fill and the individual needs of people with autism. There is also a significant opportunity to invest in developing managers and leaders and to include people with autism and families more generally in consultation about workforce development, particularly in the content and delivery of programmes.

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<sup>i</sup> Ministry of Health 2013.

<sup>ii</sup> Based on reported total of 4,898 allocated DSS services and New Zealand's total number of people with autism being estimated at 47,400.

<sup>iii</sup> Calculated: Extracted from responses as to an individual organisation's reported workforce total, and reported percentage of clients with autism. Assuming reported client proportions with autism will result in similar proportions of workforce working with them. As most providers have a workforce that works across a range of consumer groups, it is only possible to estimate. Providers were generally not able to distinguish an ASD workforce from their total workforce.

<sup>iv</sup> [http://www.stats.govt.nz/browse\\_for\\_stats/snapshots-of-nz/nz-in-profile-2015/population.aspx](http://www.stats.govt.nz/browse_for_stats/snapshots-of-nz/nz-in-profile-2015/population.aspx)

<sup>v</sup> Frombonne 2003. The DSM 4 diagnostic category Autistic disorder applied was distinct from Asperger syndrome, so those people currently deemed to have autism with no intellectual disability would largely have been excluded.

<sup>vi</sup> Idring et al., 2015

<sup>vii</sup> Based on estimate of 47,400 national prevalence, 13,940 will likely have an intellectual disability; 33,460 will not. Rounded numbers of 14,000 and 33,000 have been used.

<sup>viii</sup> Baird et al., 2006.

<sup>ix</sup> Howlin et al., 2015

<sup>x</sup> Matthews, 2015

<sup>xi</sup> <http://www.skillsforcare.org.uk/Document-library/Skills/Autism/autism-awareness-learning-resources.pdf>

<sup>xii</sup> HeathRose Ltd, 2009

<sup>xiii</sup> Bevan-Brown et al., 2011, pp.13-15

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