

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

Results of an information
gathering exercise
undertaken in November
2015



**Te Pou o te
Whakaaro Nui**

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Language used in this report

The term 'people with autism' is used throughout *this report*. Its use is not intended to diminish the uniqueness of individuals but to maximise clarity for readers.

Disclaimer

While every effort has been made to represent the views of others with fidelity, the views expressed in this report are those of the author alone. Any errors of fact or interpretation are also the author's responsibility.

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Executive summary

This information gathering report describes the current learning and development activities that are in place across New Zealand for the workforce supporting children and adults with autism through funding from Disability Support Services (Ministry of Health).

Workforce analysis starts with understanding the workforce that is in place to support, and the context in which supports are provided. This report describes in broad terms the size and composition of the population affected by autism and the support services being used. Because of the limitations of New Zealand's data in this area, estimates are used in this report.

Prevalence

Autism was once thought to be an uncommon neurodevelopmental disorder. Recent studies have reported increased prevalence, and autism is now thought to occur in at least one per cent of children. This report suggests that at least 47,000 people in New Zealand are currently affected by autism. In contrast to previous views, the majority of these individuals are now believed to be without intellectual disability.

As a result of an eligibility clarification in 2014, a substantial portion of this population (estimated to be 33,000 people with autism and without intellectual disability) are now eligible for disability support. Most are children and adults described as having Asperger's Syndrome or other manifestations of autism on the full spectrum.

Services and supports

An analysis of disability support demographics by the Ministry of Health suggests that in 2013, 16 per cent of people allocated disability supports were those with autism and their families. The most common services are for children, and are accessed through the carer support subsidy. Several autism-specific services for children and young people were identified, but no autism-specific services for adults were identified. Historically, the services adults receive have been defined by concurrent disabilities, e.g. adults with intellectual disability in residential services.

People with autism and their families seek support and opportunities to manage their own lives to their potential and to participate as citizens in work, in the community and in their relationships. As new models of disability support emerge, the skills of the workforce will need to be increasingly diverse. Some important components of New Zealand's disability support services are already under review, such as Needs Assessment Service Co-ordination (NASC), and respite and residential services. This makes it difficult to be categorical about future workforce needs.

Throughout this project, contributors reiterated the critical importance of selecting staff with the right approach, and investing in activities to build on positive values within the workforce. They strongly suggested that skill development will supplement positive personal attributes; it will not substitute for them. There is an

opportunity to do more to support work-based learning so that knowledge and skills taught in values-based autism training are embedded into daily practice.

“..skill development will supplement positive personal attributes; it will not substitute for them.”

Access to learning and development for service provider organisations

Twenty service provider organisations responded to a survey, and provided good representation across the disability workforce. This survey identified the following findings.

- Autism is not peripheral to the disability workforce. Survey results estimate that 19-26 per cent of the disability workforce is engaged to some extent in support of people with autism.
- There was considerable uptake of training and development, though it was often outside a formal development plan.
- Home and community service providers supported very few clients with autism despite being the second most frequently allocated service (after carer support subsidy) to families and people with autism.
- Respondents described most training activities they accessed as basic. They identified a shortage of more advanced learning and development, and opportunities to build the skills of leaders and managers who are generally expected to coach and guide staff.
- Few mechanisms are in place to guide practice. Only the larger multi-regional services had internal capacity to provide any degree of workplace guidance and practice support specific to autism.
- Service organisations were uncertain about where to access assistance on workforce development related to autism. Few had a planned approach to building workforce capacity for autism support.

“Autism is not peripheral to the disability workforce.”

Providers of learning and development

Twenty learning and development providers completed a survey related to 49 different learning activities accessed by the disability workforce, families and the general public. This survey identified the following findings.

- Learning and development events were generally short and offered in workshop format to encourage participation.
- Only one provider delivered material on an online platform.
- Learning and development activities generally aimed to raise awareness and provide comprehensive basic skills on how to support individuals with autism.

- Skill domains were similar across learning activities, though providers often customised both content and skill-level targets for different audiences.
- There appeared to be relatively superficial attempts to measure training effectiveness, though a number of providers used at least one form of post-training follow-up.

There was inconsistent use of strategies to support the application of knowledge into practice.

Pressures and opportunities

Pressure on the existing workforce was identified in the project. The pressures relate to the following five key factors.

Increasing numbers of children and adults affected by autism seeking support from current or future services funded by Disability Support Services.

1. Increased diversity of people of the needs of those seeking support from a workforce with a more narrowly framed experience and skill-base (for working with people with autism and intellectual impairment).
2. Difficulty identifying learning and development opportunities for those in leadership, management, and practice guidance roles despite expectations that these individuals will demonstrate high skill.
3. Uncertainty about the models of support which will be funded in future, and therefore the competencies and skill-levels required for changing roles.
4. Mixed awareness across providers of workforce development frameworks and resources that would strengthen workplace learning and development and help services get the best outcomes from formal learning activities in daily practice.

Opportunities for strengthening the workforce were also identified through this project.

- **Diversifying the way learning and development is delivered.** There appears to be a foundation of introductory training activities. Training providers might be encouraged to diversify their modes of delivery to be more accessible to staff employed in small and individual employment situations (through IF), who often work part-time.
- **Support to design and implement organisational workforce development plans.** Services want to increase the skills and confidence of their workforce. It would, therefore, be helpful if they had guidance on how to design and implement workforce development plans.
- **Leadership development.** Leadership development could be more focussed on increasing skills and providing resources in coaching and supervision so that managers can be more active in embedding

skills and knowledge into practice in the workplace. Leadership development could be used to encourage the growth of the autism peer workforce to encourage their contribution in a range of roles.

- **Co-ordinated workforce development.** This project highlighted that sector-wide disability workforce development has already begun. Building on this foundation, there is more work to be done for the workforce supporting people with autism. In particular:
 - providing curriculum guidance and freely available information about where to access content-specific training support
 - resources and practice guidance that can be sourced by staff, managers and leaders for application across diverse roles and work settings, while also being relevant to the individual.
- **Autism awareness.** Current public awareness courses about autism would provide a foundation for all the workforce if more were available. Learning and development providers could then develop specific content and activities to increase the skill-level of the disability workforce.

This project has drawn attention to people with autism and those who care about them. Many people are aware of the scale of change that is needed, and are willing to assist people with autism and their families to achieve their potential. The disability workforce can contribute to this with supportive frameworks and guidance.

Limitations to this report

A number of limitations need to be considered in interpreting this report. The project was limited to describing the current situation for only part of the disability workforce. Some parts of the workforce were excluded as being beyond the sphere of influence of the Ministry of Health, or excluded because they were subject to other work initiatives or current review. Key omissions were the workforce engaged in NASC agencies, those in high and complex needs support for children with autism and adults referred through RIDCA, and the workforce engaged in disability information and advisory services.

In reality, many workforces overlap. People in disability support roles may not only work with people with autism. People with autism may not only access Ministry-funded Disability Support Services. In the course of this project, the lead met people who work exclusively with people with autism across diverse roles: in education facilitation, programme delivery, community outreach, and information and advisory services. Some were working in DSS-funded roles and others were not. The skills and capacity of those in roles not funded by DSS has not been assessed but they represent a rich resource, adding to the fabric of the ASD workforce.

The workforce development needs identified in this report were based on New Zealand data and research where this was available, though much had to be extracted from a general disability context to specifics related to people with autism. There was a paucity of New Zealand evidence available to inform this report, most particularly on the demographics of people with autism across New Zealand.

While the workforce survey was responded to by organisations that employ a substantial part of the disability workforce, only 20 organisations responded. It is likely that a number of smaller organisations did not respond. Their responses to learning and development needs may have differed from the responses received by larger organisations.

Limited sampling within consumer and family stakeholders has resulted in feedback that has been helpful but requires caution in regards to how representative it is of New Zealand's population, communities and the views held.

The development of this report included limited consultation with people with autism, families/whānau, or direct consultation with direct support workers supporting people with autism. The workforce commentaries largely come from employers and agency representatives, and the workforce with specialist skills in autism.

Consultation with key stakeholders regarding the report's recommendations was limited. There has been high interest in this project and enthusiasm for supporting its progression. Continued sector engagement would improve confidence in priorities for autism-specific development and training needs. Different methods of stakeholder engagement will be necessary to ensure full inclusion.

Future engagement with people with autism and their families would require a variety of engagement modes. This project benefitted from a variety of these approaches and much was learned about which modes work better than others, and communicating with people to ensure their lived experience is captured and contributes to workforce development.

Background

Disability Support Services (DSS) is a business unit of the Ministry of Health with responsibility for planning and funding disability support services. DSS has a commitment to meet the needs of people with Autism Spectrum Disorder (ASD) across New Zealand and build a workforce that supports positive health, social and educational outcomes for individuals with autism.

“The resources and tools that need to be developed should be based on evidence and developed in partnership with the sector.”

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

This work builds on a growing understanding shared by the Ministry of Health and Te Pou that workforce development, policy development and service development go hand-in-hand.

As a first step, Te Pou contracted the author of this report to undertake an information gathering exercise to investigate the current situation across New Zealand.

This report presents the results of this investigation.

Its purpose is to provide a foundation for planning the resources, tools and competencies that will support services and the wider disability sector to develop a workforce that is responsive to the needs of children and adults with autism.

Information was sought to describe the target population (people with autism and their families) supported by the disability workforce and the context in which they are being allocated or receiving support. Information was also gathered about the training that is currently available to the disability workforce supporting people with ASD, and the mechanisms used to embed the right knowledge, values and skills into the workforce's daily practice.

The information gathered was analysed and infused with the views of and feedback from families and people affected by autism about what would strengthen the disability workforce.

The New Zealand ASD Guideline (2008) (referred to in this report as The Guideline) provides an evidence-based guide to assist decision-making that improves the health, education and social outcomes for individuals with autism (Ministries of Health and Education, 2008). The needs of people affected by autism are often more than what can be met by disability support services alone and require joined up responses across health, education and disability services. In the workforce context, The Guideline recommended the development of a coordinated national plan for professional learning and development that would include standards and competencies for professional roles.

While the range of personnel involved across health, education and social services is extensive, this current project focuses on the workforce funded through DSS in the provision of services to people with autism and their families (for more information, refer to the section Limitations to this report). That said, the landscape in which the autism workforce operates is changing and reflects the continuing evolution of the wider disability service sector.

In recent years DSS has embarked on a change of strategic direction to provide more choice, direction and flexibility in how people with disabilities and their families receive support. This has been illustrated through initiatives such as Individualised Funding, and pilots of the New Model, Enabling Good Lives and Choices in Community Living. The workforce implications of these changes will require planning so that we can develop and retain the skills needed to support people to lead productive and valued lives.

All models of disability support, whether formally contracted services or new approaches, are premised on the principle of person-centred support. Increasingly this principle challenges existing frameworks that categorise who is eligible, and what can be provided within a service stream. These challenges should be welcomed as part of the continuing evolution of the disability and wider community support sector in which we all live.

Methodology

The project used a mixed-method approach and comprised five components.

1. A review of international and New Zealand literature relating to the nature and prevalence of autism, and related workforce training and development needs.
2. An online survey of New Zealand disability service providers, and home and community service providers regarding the learning and development of their workforce in ASD.
3. An online survey of New Zealand training providers regarding their provision of learning and development to this workforce that is specific to ASD.
4. Semi-structured interviews regarding past experiences with the disability workforce, with:
 - a. family members of individuals with autism
 - b. adults with autism.
5. Enquiries with key stakeholder agencies to understand the context of autism support and workforce development as follows:
 - a. Ministry of Health
 - b. Autism New Zealand
 - c. CareerForce
 - d. NZ Disability Support Network
 - e. Werry Centre
 - f. Te Pou o te Whakaaro Nui
 - g. Altogether Autism
 - h. NASCA.

Consumer and family reference network

A consumer and family reference network was formed to ensure consumer input and advice for the project manager on matters of complexity or uncertainty.

The project manager identified people willing to be members of the network comprising adults with autism and families. Membership was not intended to be representative, but to seek the contribution of people with

longstanding and broad knowledge. Project stakeholder groups such as Altogether Autism and Autism NZ recommended people that they considered should be part of the network, and the project manager invited their participation. Two network members were approached because of personal knowledge that they accessed disability support services. A total of seven people contributed to the network to various degrees.

Because of the differences in preferred communication styles, the network did not meet as a group. Contact was largely by direct and relayed email correspondence, phone or video linkage with the project manager. Two participants with autism sought face-to-face contact. In some instances, correspondence or comments were shared among network members at the discretion of the project manager (and with permission). Lessons from this project will be shared with Te Pou and Ministry of Health to improve future consultations.

Family interviews

Fourteen phone interviews with additional family members occurred using a semi-structured interview format conducted by a parent member of the reference network. A summary of responses is listed in Appendix A.

Feedback from the consumer reference network and from family interviews is incorporated into all parts of this report, such as their relevance to most sections of the report.

Results

People with autism and their families

What is Autism Spectrum Disorder (ASD)?

ASD is currently described as a complex neurodevelopmental disorder affecting people from childhood through adulthood. People affected by autism can experience a range of social, educational and developmental challenges largely related to two domains of adaptive functioning:

- social communication and social interaction
- restricted, repetitive patterns of behaviour, interests or activities.

Many experience challenging behaviour as a result. There is therefore enormous diversity in how the disorder presents across individuals. Categorisations are challenging to people affected by autism as well as those who care about them. There have been significant changes to how ASD has been categorised over the years since first described. The latest version of the diagnostic classification system DSM-5 (American Psychiatric Association, 2013) heralded more significant changes to the categorisation of the spectrum of disorders previously understood to be ASD (Broadstock, 2014). How this change will affect reported prevalence rates remains unclear, but will likely impact on the numbers of people seeking support from disability support systems, what they seek support for, and the skill of those required to provide that support.

There is still a lot to be understood about the spectrum of presentations and disorders now referred to generically as autism. In addition, there are widespread misunderstandings. A common misunderstanding also arises from the unevenness of skills often seen among people with autism, whereby some domains of life are so strong, yet others so weak. There can be a puzzling juxtaposition of ability and need. This unevenness is challenging for those who support people with autism as well as for purchasers and providers of services.

Here is an example.

- Difficulty initiating and organising a sequence of actions to replace a lost credit card, even though the person has an academic degree and career.
- *“... had detailed understanding of grammar and... was marking other students’ work in his final year at primary school. However, his personal expression and apparent written comprehension did not reach similar levels... (now as an adult) his social skills and ability to cope with stress and multi-tasking are not sufficient to allow participation in (workplace). [family member]*

Some misunderstandings relate to the wide-ranging terminology variously in and out of accepted use to describe variations on the autistic spectrum. This report acknowledges that different people and sections of society prefer some terms over others.

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. This report avoids the terms high and low functioning because of their potential to categorise autism along an intelligence continuum, and to play to stereotypes of savant skills. Such terms can mislead people to believe that only those with intellectual disabilities or other complexities require high and sustained support.

Debates over language and labels should not distract from the central importance of supports. The degree to which a person experiences disability is influenced, among other factors, by the social, educational and developmental supports available to them.

The term ‘people with autism’ is used throughout *this report*. Its use is not intended to diminish the uniqueness of individuals but to maximise clarity for the reader. It will refer to people with autism with and without intellectual disabilities. This is not to dismiss other co-morbidities known to exist (e.g. dyspraxia, ADHD). The terminology is applied as such because DSS-funded autism supports in New Zealand have previously been distinguished by the presence of other disabilities, usually intellectual disability.

Prevalence of autism

There remains no consistently agreed data source describing the prevalence of people with autism in the general population in New Zealand. Estimates of New Zealand’s prevalence comes from international prevalence data, which range between 0.6 and two per cent. In 2008, the Guideline suggested New Zealand adopts 1.16 per cent

as a prevalence estimate. Applying 2014¹ population numbers, estimates suggest at least 47,400 people in New Zealand are affected by autism.

For the several reasons that follow, this figure should still be considered conservative.

- International debate continues as to whether autism incidence is increasing or not.
- The Guideline encouraged improvements in diagnostic and assessment practices, perhaps resulting in more people being diagnosed at an earlier age.
- Six years after the Guideline's publication, the Ministry of Health clarified the criteria for eligibility to disability supports to include people with autism who do not have other disability support needs. Some with autism who are now eligible for support will be less familiar to DSS and its agencies, so may have under-recognised needs.

Age and gender of people with autism

“...many issues specific to adulthood remain poorly explored, and there are significant gaps in knowledge to inform service development and parallel workforce development.”

People of all ages are affected by autism. The implementation of the Guideline appears to have progressed actions for children, related to earlier assessment and diagnosis, and service developments for them and their parents. The emphasis on early education for families and interventions to promote childhood development has strong support.

However, many issues specific to adulthood remain poorly explored, and there are significant gaps in knowledge to inform service development and parallel workforce development relevant to adulthood and ageing. Issues for adults with autism have been cited as:

- 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
- establishment of long-term relationships and raising families
- interface with judicial and forensic systems
- physical health and self-management of this (Howlin, P et al, 2015).

Workforce needs for those working with children and their families may therefore be very different to those working with adults, not the least because of the changing dynamic within family groups over time.

It is reported that autism affects possibly four times more males than females (Guideline p. 30). Detailed commentary about the different experiences and societal responses to males and females is beyond this report's scope. However, these differences are likely to influence reported prevalence of autism among young females as

¹ http://www.stats.govt.nz/browse_for_stats/snapshots-of-nz/nz-in-profile-2015/population.aspx

diagnosis often occurs later, resulting in missed opportunities for intervention. Differences in communication styles or in earlier life experiences are also likely to influence how males and females interact with support staff.

Families (parents, whānau and aiga) and culture

For every person with autism, there is a family group of equal value and focus for the workforce providing support. For many people with autism, family members are critical sources of support and stability beyond childhood. For those significantly affected by autism and/or intellectual disability, families provide more than care. They are often required to interpret and advocate, and are significantly involved in their family member's life, e.g. arranging and providing transport, supplementing funds for activities that are not funded, and negotiating with agencies and government services.

Those employed in support roles require the right attitudes and skills to traverse changing family roles and relationships, manage tensions about privacy, and understand the development of identity across the lifespan.

The views of families are likely to be diverse and dynamic. They will reflect cultural values, life stages and families' experiences and expectations of formal and informal systems. Māori family perspectives were sought in a substantial report in 2004². A number of networks and parent support groups have arisen to acknowledge the desire for support from a safe and familiar cultural frame of reference e.g. Pacific Autism Support Group and the Chinese Families Autism Support Group. National and local organisations such as Autism NZ and the Children's Autism Foundation³ in Auckland provide sources and networks from which to draw family perspectives.

Autism with intellectual disability

“...it seems reasonable that NZ can expect the greatest increasing demand to be for those with no intellectual disability...”

Intellectual disability is reported as a common associated condition among people with autism. People with both autism and intellectual disability face significantly greater challenges in understanding and negotiating their world without sustained supports, and in being understood and supported well.

People with autism who have an intellectual disability have generally been supported by intellectual disability service networks, which have been funded through the Ministry of Health's DSS. It is likely the majority of those receiving DSS-funded support experienced both autism and intellectual disability (discussed in Service utilization by people with autism).

² Bevan-Brown, J. (2004). Māori Perspectives of Autistic Spectrum Disorder: A Report to the Ministry of Education. Massey University College of Education.

³ Children's Autism Foundation Stakeholders Plan (August 2015).

Frombonne (2003) estimated that as many as 70 per cent of people with autistic disorder⁴ had intellectual disability. This 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. The substantial Swedish youth cohort study (Idring, S; Lundberg, M; Sturm, H; Dalman, C; Gumpert, C; Rai, D; Lee, BK; Magnusson, C, 2015) reported prevalence of intellectual disability 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 prevalence of intellectual disability than previously accepted.

Applying overseas rates of intellectual disability prevalence among people with autism (from the upper figure of 29.4 per cent from Idring et al. to include adults), one might expect at least 14,000⁵ people in New Zealand to have autism with intellectual disability.

Though caution is warranted in taking such figures too literally, Idring et al's results suggest that for the purposes of projecting demand, it seems reasonable that New Zealand can expect the greatest increasing demand 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 (Baird, G; Simonoff, E; Pickles, A; Chandler, S; Loucas, T; Meldrum, D; Charman, T, 2006), they have been more pronounced for those with average or above-average IQ. Future service and workforce development should keep this projection data in mind.

People with autism and intellectual disability are exceptionally vulnerable to being misunderstood. In the main, the viewpoints of adults with autism are more likely to come from those without an intellectual disability. Consumer peers are in a strong natural position to give insights into the experiences of those less able to communicate. These voices can be added to the perspectives of families who have lifelong experiences and insights into their disabled family member. Similarly, families of adults can illuminate the meaning behind the communications that non-autistic people may struggle to understand.

“His staff sometimes don’t ‘get’ him. That’s where I and his brother can help.” [family member]

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. However, the revision of the DSM-5 enables different support levels to be recognised across the spectrum and be more aligned to adaptive functioning than diagnostic categories. These may prove more helpful in highlighting the unique differences in the attributes and needs people across the autism spectrum present (Broadstock, 2014).

⁴Frombonne (2003). The DSM-4 diagnostic category Autistic Disorder was distinct from Asperger's Syndrome, so those people currently deemed to have autism with no intellectual disability would largely have been excluded.

⁵Based on estimate of 47,400 national prevalence, 13,940 will likely have intellectual disability; 33,460 will not. Rounded numbers of 14,000 and 33,000 have been used.

Autism and mental health

“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 ASD.”

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 co-morbid mental health concerns both for those with and without intellectual disability (Matthews, 2015).

Emotional problems appear to be common for young people and adults with autism, and these become especially marked at times of transition. While transitions are commonly identified with childhood and adolescence (Ministries of Health and Education, 2008), transitions occur across the lifespan. Issues related to employment, relationships, parenting, loss and death pose significantly greater challenges for people with autism who may find adjustments to changes a challenge. When life transitions are poorly understood and inappropriately responded to, people with autism may suffer at the hands of others.

There is increasing evidence from research into the mental health needs of people with autism which indicates the requirement 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.

Prior to the eligibility clarification in 2014, many people with autism had only the mental health sector through which to seek support. In 2015, the Ministry of Health DSS, the Office of the Director of Mental Health and the Mental Health Service Improvement Group developed a 'Statement of Joint Agreement'. This sets out roles and responsibilities, client pathways and methods for resolution of disputes. The Joint Agreement helps each NASC and DHB Mental Health service to develop and operationalise their own local level agreement for how to work together. It is hoped this agreement will reduce confusions about the services available to support individuals.

This step towards closer collaboration may also enable better data collection and information about how people with autism interface with the mental health system. Referral and utilisation information was unavailable for this report, but would help with long-term planning for service and workforce development.

Services available to people with autism

“Many families and people with autism do seek additional supports, especially at times of transition or disruption to support arrangements.”

Ministry of Health DSS provides a range of supports for eligible people with disabilities through funding mechanisms such as subsidies (carer support and funded family care) and variations on direct payments, and

through contracts with providers for a range of services. The package of funded support services allocated to an individual is largely determined according to the person's needs as identified by NASC agencies.

Options include:

- home and community support
- community residential
- supported living
- respite
- equipment and modifications
- carer support
- behaviour support.

The Ministry also funds mechanisms to support disability services, notably:

- needs assessment and service coordination services (NASC)
- disability information and advisory services (DIAS), two of which are specific to Autistic Spectrum Disorders - Altogether Autism (nationwide) and Autism NZ (in Auckland)⁶.

In the past seven years, the support services provided to people with autism and their families have changed. Some of these changes have been generic to all people with disabilities. They are largely reflective of the continuing paradigm shift towards a social model which sets disability as the result of interaction between a person's impairment and their societal and interpersonal environment.

Significant changes generic to all people with disabilities.

- a) Individualised Funding (IF) opportunities have increased the choice and control that people with disabilities and/or their families have over how they receive support, so they are able to access and manage support through alternatives to contracted service providers.
- b) Alternative living options have expanded, for example supported living, reflecting a move from reliance on formal to less formal supports, and enhancing natural supports (Choice in Community Living, Enabling Good lives, New Model).
- c) Family funded care was introduced in 2014.

⁶ In addition to the many DSS-contracted DIAS providers, some community agencies provide information and advisory services through alternative funding sources.

- d) Behaviour support services were contracted to one national provider in 2014.

Changes that are autism-specific.

- a) Development and ongoing maintenance of the NZ ASD Guidelines (the Living Guideline group is funded by the Ministry of Health).
- b) Agreed assessment and diagnostic processes (with an investment in post-clinical training to a range of health professionals involved in assessment).
- c) Establishment of an ASD-specific disability information and advisory contract held by Altogether Autism.
- d) Greater access to a range of parent education programmes for families of pre-schoolers, school-aged children and young adults.
- e) ASD coordination services within some district health boards for families of children.

Not all families of children have a need for formal services. Instead, they seek funding mechanisms that enable them to identify and strengthen natural supports. Similarly, not all adults seek or need contracted services. They may have learned how to maximise their skills and capacity to minimise the potential disruptive effects of autism on their lives; indeed, they may see their autistic qualities as assets and positive markers of their identity. However, many families and people with autism do seek additional supports, especially at times of transition or disruption to support arrangements.

Service utilisation by people with autism

Workforce planning needs to 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 data from 2013 about disabled people who were allocated Ministry of Health-funded Disability Support Services through NASC agencies (as distinct from services used). This data contributes to a picture of the work settings in which people are employed.

Referred to here as the Demographic Report, it has significant limitations for the purposes of describing current and future service demand related to autism support, because the data:

- relates to a period before eligibility to DSS funding for people with autism and no other eligible disability support needs
- excludes some DSS-funded services accessed by people with autism and their families; specifically excluded but allocated were child development and coordination, parent education programmes and intervention services such as behaviour support and ASD Communication and Behaviour services.

The Demographic Report describes DSS services allocated to people with autism.

- 4,898 people diagnosed with autism were allocated services.
- The majority were children aged under 15 (65 per cent), with four times as many boys as girls.
- Based on population estimates at the time, only 10.3 per cent of those with autism were allocated DSS-funded services.
- The most commonly allocated resource was the Carer Support subsidy, followed by Home and Community Support. Combined these two comprise 85 per cent of the services allocated.

Carer Support is a subsidy which reimburses some of the costs of hiring a support person so that a full-time carer can take a break from caring for a disabled person. 67 per cent of people with autism were allocated this subsidy, largely for children and young people.

Home and Community Support services help a person live at home. Staff provide assistance with both household management and personal care through a range of providers contracted by the Ministry of Health. Eighteen per cent of clients with autism were allocated these services.

Formal structured services such as community residential services, supported living and respite made up only 14 per cent of the services allocated to people with autism.

While the Demographics Report sourced data through referrals to NASC agencies, a number of DSS-funded autism-specific services are accessed through different referral pathways, e.g. self, pediatricians and DHB ASD coordinators. These were not included in the Demographics Report. They represent positive initiatives from the Ministry to improve the volume and range of service responses, and need to be included in the picture of service utilisation.

It has not been possible to determine the extent to which users of these services are additional to those clients of funded-DSS included in the Demographic Report. They are reported in different ways. Future inclusion in the same data set would help form a clearer picture of service allocation and uptake. The available data from some of the autism-specific services is provided below (Table 1).

Table 1: Autism-specific services

| Service type | Reported volumes for people with autism per annum | Covering time period | Data source |
|--|---|------------------------|------------------------|
| Parent education: <ul style="list-style-type: none"> • ASD Plus⁷ • Growing up with Autism⁸ | 430 | 12 months 2014-2015 | IHC Annual Report 2015 |

⁷ Most referrals related to children and young people with autism and no intellectual disability.

⁸ Other agencies such as Autism NZ, Children Autism Foundation also provide parent education as well which are resourced through private fees and charitable donations.

| | | | |
|--|----------------------|------------------------------------|---|
| ASD Communication and Behaviour Service ⁹ | 703 | 12 months 2014-2015 | IHC Annual Report 2015; IDEA Specialist Service (Autism NZ Conference 2014) |
| ASD Coordinator Service (DHB) ¹⁰ | 973 (average) | 2,918 across 36 months | Evaluation report ASD Coordination MoH 2015 |
| Behaviour Support Services ¹¹ | 1,138 (extrapolated) | 569 for six months (Jan-June 2015) | Explore (personal communication) |

Trends in allocation and utilisation

“...increased referrals related to young people ... patterns of service allocation and utilisation for adults has yet to become clear.”

There appears to be an increase in diagnosis and referral rates for services, with NASC agencies reporting an increase in referrals from people with autism. The Demographic Report confirmed that 22.5 per cent of new clients referred to NASC in the preceding nine months of 2013 were affected by autism. Health Partners’ analysis of autism-related referrals¹² suggests a particular dominance of new referrals for children aged 5-14.

This pattern of increased referrals related to young people has also been seen among agencies not funded by the Ministry of Health, for example Child Autism Foundation in Auckland provided twice as much outreach service in the past 12 months as the year before. The autism-specific services listed in Table 1 also reported considerable waitlists. This suggests demand beyond what is contracted (i.e. unmet need).

Given recent changes to eligibility, trends in service allocation and utilisation for adults are yet to become clear. In regards to this project, feedback from adults with autism suggests rates may not reflect real demand while the current service options are not designed to meet their need.

Survey of the disability support workforce and the use of learning and development

An online survey of NZDSN, Te Pieringa Māori Disability Sector Network and NZ Home and Community Health Association members was undertaken. Responses came largely from NZDSN’s membership. Fifteen

⁹ This service is for children up to age 18. It is not a behaviour support service; it is designed to provide short-term earlier intervention for families. All those referred have autism, most with no intellectual disability.

¹⁰ These services have had variable development over three years of contracting, so past volumes may not predict future volumes.

¹¹ January-June 2015, as reported by Explore through personal communication. Thirty-eight per cent of referrals for behaviour support services involved people with autism.

¹² Unpublished report, data presented to ASID Conference September 2015.

organisations completed the survey, but were not adequately representative of the wider sector. Five additional organisations were contacted and interviewed by phone. Their responses were then included in the analysis.

As a result, responses were received from 20 organisations; five providing supplementary information through phone interviews (listed in Appendix B). While this may not seem a substantial response rate, collectively these respondents employ around 16,000 people across their DSS contracts. This represents a significant portion of the workforce, estimated to be between 19,000 - 22,000 people (Ministry of Health, 2013). The respondents provided good coverage of the disability and home and community care sectors, and are representative of the size and types of organisations that make up these sectors.

They included:

- three (3) large national or multi-region disability service organisations
- ten (10) smaller local area disability service organisations
- three (3) specialist disability service providers¹³
- three (3) large national home and community care organisations
- one (1) small local area home and community care organisation.

These organisations deliver services through a range of DSS contracts. Several providers deliver on multiple contracted services (Table 2), but they provided information about workforce involvement with people with autism in aggregated form across multiple service contracts.

Table 2: DSS service contracts held by workforce survey respondents

| Contract type | # | % |
|---|----|------|
| Community Residential services | 10 | 52.6 |
| Supported Independent Living | 7 | 36.8 |
| DSS-funded day support | 6 | 31.6 |
| Home Support | 4 | 21.1 |
| Respite | 4 | 21.1 |
| EGL Navigation, Local Area Co-ordination or Individualised Funding Fund Holder/Host | 4 | 21.1 |
| Behaviour Support | 3 | 15.8 |
| Carer Support | 2 | 10.5 |
| Parent Education | 2 | 10.5 |

¹³ Explore Behaviour Support Services, IDEA Community Specialist Services, Enabling Good Lives navigator team.

| | | |
|---|---|-----|
| RIDSAS | 1 | 5.3 |
| Manage own Individualised Funding (or on behalf of a family member) | 1 | 5.3 |
| ASD Communication and Behaviour Service | 1 | 5.3 |

Clients

All responding organisations provided services to people with autism to different degrees and across all ages. Of those that provided disability support services, 12 stated that people with autism comprised at least 30-50 per cent of their client group.

Specialist organisations provide services to an even larger proportion of people with autism. Explore indicated that more than 50 per cent of its Behaviour Support clients have autism and are across the age range. IDEA Community Specialist Services indicated that all its clients have ASD, and are usually children and young people.

Of the organisations surveyed, few supported people with ASD with no intellectual disability (20 per cent). The service supporting people with autism exclusively did so for those both with and without intellectual disability, as did the provider of behaviour supports.

The home and community care organisations indicated that they support “very few” people with autism, and that those clients vary in age from children to 65-year-old adults, and may or may not have an intellectual disability. This aligns with the Demographics Report (people with autism comprised only six per cent of total clients allocated home and community support services).

Learning and development accessed by providers of services to people with autism

Respondents indicated high satisfaction with the learning and development activities accessed. They indicated accessing a range of activity types (course, workshop, conference, supervision etc), and a number indicated internal strategies to supplement this, e.g. with mentoring or seeking internal expertise for advice.

Orientation

Disability providers reported significantly more autism-specific content at orientation of new staff, compared with home and community support providers. This is likely due to the difference in reported presence of people with autism in disability and home and community care services. Sixty-two percent (62%) of the responding disability organisations reported providing information on autism in their usual orientation process for new staff.

The depth of this information varied considerably. It would generally include 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 indicated that new staff may request additional brief information (e.g. one-page factsheets) from Autism NZ, or a knowledgeable person within the organisation.

None of the responding home and community care organisations reported including autism information in the orientation of new staff. It should be noted their workforce is significant, and engages with widely diverse client populations, of which people with autism appear to be a very small proportion¹⁴.

Courses, workshops, conferences and supervision

Respondents indicated what courses, workshops, conferences and supervision opportunities (clinical or peer) were provided to their staff that was specific to autism in the previous 12 months.

All but one of the disability organisations had provided at least one development activity over the past 12 months¹⁵. Most provided several opportunities. Development activities varied widely in type, length, regularity, reason for provision and cost. Some larger organisations also accessed specialists from within their own organisations.

None of the responding home and community care organisations reported providing courses, workshops or conferences, or non-managerial supervision related to autism. Basic information, such as that described above at orientation level among disability providers, was the full extent available.

Targeting the development activity for the audience

“...low utilisation of supervision as a workforce support tool.”

Service providers indicated some degree of difference in the types of learning and development activities for staff depending on their level of skill required and roles. See Table 3.

Table 3: Activity type accessed by different staff groups

| | Essential - new staff | Capable - staff with experience | Enhanced - specialist staff | Leaders - managers |
|----------------------|----------------------------------|--|--|-------------------------------|
| Courses | 100% | 66% | 66% | 13% |
| Workshops | 63% | 75% | 75% | 0% |
| Conferences | 0% | 46% | 33% | 33% |
| Clinical supervision | 14% | 25% | 50% | 57% |
| Peer supervision | 23% | 23% | 53% | 53% |

¹⁴ The subsequent survey of Learning and Development providers reported providing training to a home and community organisation that did not reply to the survey. Variation is likely.

Essential skill level (applicable to all new staff).

- Courses were the most likely activity provided, though they may also attend workshops.
- Staff required to demonstrate Essential skill level may have access to some form of non-managerial supervision.

Capable skill level (staff with experience).

- Courses, workshops or conferences were provided as appropriate.
- This group was more likely to have increased access to non-managerial supervision.

Enhanced skill level (specialist staff such as behaviour support workers, nurses and senior leadership teams).

- Specialist staff take part in all forms of development activity. Workshops were seen as appropriate by 75 per cent of respondents (possibly because they offer a more in-depth look at topics of interest).
- Non-managerial supervision was offered by more than half the organisations.
- Specialist service providers offered very specific workshops for their staff, to develop skills to a more advanced level than available from general programmes.

Leaders skill level (team leaders and managers).

- Courses are seen as less suited to this group, though they sometimes attend them.
- Workshops (which could be surmised to have a hands-on/practical focus) are rarely attended by this group.
- More than 50 per cent of the organisations surveyed said they provide non-managerial supervision for staff in leadership roles.
- Conferences are seen as having some applicability.

Responses indicate low utilisation of supervision as a workforce support tool. Even for those in specialist or leadership roles, availability was no greater than 57 per cent.

When looking at the skill levels and domains needed for those in leadership roles, service providers showed strong agreement that staff in leadership roles and the management of others were expected to have the matching breadth and depth of skills to those of their staff. However, their rates of participation in courses and workshops was very low. The survey did not identify if managers already had these skills from prior learning. It is possible that providers do not tailor the development to achieve the desired outcomes; rather, they take advantage of opportunities as they arise in an ad-hoc manner.

Skills domains in autism learning and development activities

Respondents were asked to comment on the desirability of specific skill domains. These are summarised in Table 4.

For new employees, five skill domains were sought by more than half the respondents.

- Knowledge of general characteristics of ASD, and general tips and guidance.
- Communication strategies.
- Creating structure and routine.
- Support for/managing challenging behaviour.
- Knowing where to seek further assistance/information.
- For staff in roles requiring more experience (capable skill level), all topics were rated as being necessary by at least 57 per cent of respondents. This added the following skill domains to the five listed above.
- Social skills.
- Sensory strategies.
- Supporting people with their mental health.
- Practical day-to-day support.
- Goal and service planning.

For staff employed in roles requiring enhanced skills (specialists such as speech language therapists, behaviour support workers, family educators and nurses), 50 per cent of respondents thought that competency in all topics was necessary.

Staff in leadership roles were more likely to be expected to have the full range of skills. It was more common that managers and leaders were expected to have skills in service/goal planning, mental health, individual support strategies and sourcing additional assistance, than for staff in other roles.

Table 4: Competencies needed by different staff groups

| Topics | Essential | Capable | Enhanced | Leaders - managers |
|--|-----------|---------|----------|--------------------|
| Understanding general characteristics of ASD | 64% | 64% | 50% | 79% |
| Causes of ASD | 30% | 57% | 50% | 57% |

| | | | | |
|---|-----|-----|-----|-----|
| Diagnosis of ASD | 30% | 57% | 50% | 64% |
| General tips and guidance | 64% | 64% | 50% | 79% |
| Creating structure and routine | 50% | 57% | 50% | 64% |
| Communication strategies | 64% | 64% | 50% | 71% |
| Sensory strategies | 30% | 64% | 50% | 64% |
| Social support strategies | 50% | 64% | 50% | 64% |
| Support for/managing anxiety | 42% | 64% | 50% | 64% |
| Support for/managing challenging behaviour | 50% | 64% | 50% | 64% |
| Supporting people with their mental health | 30% | 64% | 50% | 71% |
| Practical day-to-day support | 42% | 64% | 50% | 64% |
| Where to seek further assistance or information | 64% | 64% | 50% | 71% |
| Specific individual situations | 30% | 64% | 50% | 64% |
| Goal/service planning | 30% | 64% | 50% | 71% |

At this point, it is worth noting that these skill domains were largely similar to those identified as desirable from families and people with autism as well.

Some minor differences were noted. Service providers, families and people with autism emphasised the importance of staff knowing how to interact and communicate effectively with a person, though this was expressed slightly differently across each group. 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. Indeed, some adults identified this as their most critical support need. People with autism and families also noted the importance of understanding sensory issues and strategies, perhaps more so than the service providing organisations.

Costs

Costs reported here pertain only to fees for attendance at a training activity. The additional costs of paying staff to cover those attending development activities have been previously raised as a financial barrier to accessing opportunities, but were not able to be included within the scale of this project.

Respondents believed the costs associated with development activities were “reasonable”¹⁶, although course fees varied considerably. Despite this, 73 per cent of respondents cited cost as a barrier to accessing learning activities, resulting in many only able to source autism-based learning and development when individual client need makes it essential. All organisations prioritised who attended workshops and conferences. The majority of short workshops cost \$100 to \$200 per person. Conferences were reported to be upwards of \$500, with additional travel and accommodation costs.

All responding national/multi-region disability organisations routinely provided learning and development activities using internal facilitators. Internally provided activities did not incur a direct fee, and were reported as being of “no cost”. Clearly, however, there is a cost borne by the provider. Given the size of the combined workforce in these organisations (approximately 8,500) and their high involvement with people with autism (between 30-60 per cent of clients), the significant investment in learning and development from internal sources warrants more detailed enquiry.

Smaller organisations were likely to contract a training provider or access courses that were open to the public. Only one organisation reported “sharing” a learning activity with another organisation. Smaller organisations reported accessing courses less routinely, usually for a team supporting a particular individual. Because of costs, smaller organisations needed to carefully prioritise who attends. Most one-two-day courses cost from \$200 to \$300 per person.

Volumes of attendance

Staff working for the four community and home care organisations that responded were unlikely to have attended any form of learning and development activity related to autism (none reported).

The 16 responding disability service organisations listed the various learning and development activities they have accessed over the previous year. Three organisations (large multi-region providers) sourced activities internally, the remainder contracted them from external agencies. Based on information provided by these organisations about the proportion of clients with autism that they support, it is estimated that 19-26 per cent of the disability workforce is engaged to some extent in support of people with autism (3,000-4,200 staff)¹⁷. While

¹⁶ Reasonable does not necessarily equate to affordable when seen in the context of limited budgets and the need to prioritise the most important content areas for staff.

¹⁷ Some staff may have attended multiple activities. High staff turnover requires this estimate to be treated with caution. Estimated using data in Appendix B.

not likely to cover all attendances¹⁸, this provides an estimate of the volume of learning and development related to autism that is provided by disability service organisations to their staff.

All staff from national/multi-region agencies were likely to attend some form of autism-specific training 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 related to the support of a particular individual. They were likely to contract this in or send staff to a course open to a wider audience (and therefore less specific to the needs of an individual).

Reasons for seeking learning and development activities

Organisations indicated the main triggers for arranging learning or development activities. The most commonly reported reason was an individual's support needs. The second most common reason was internally generated organisational requirements (including a formal organisational or staff development strategy). By contrast, external compliance-related triggers were less commonly reported (e.g. professional registration requirements, contract funder requirements).

Barriers to accessing learning and development

All organisations identified some barriers to accessing learning and development activities. The most commonly identified barriers were:

- cost (73 per cent) – smaller providers indicated that this leaves them in a position where they can only provide autism-related activities in response to individual need, rather than to build capacity
- lack of suitable options (which may also relate to cost) (53 per cent)
- location of the activity – usually in larger centres, which again adds cost (46 per cent)
- length of the activity (46 per cent).

Content gaps

Survey respondents reported wide variations on perceived gaps in the content of autism-specific learning and development. There was greater agreement among service provider organisations on the following gaps.

- a) Seeking more advanced learning and development opportunities. Particular topics that would be desirable included:
 - cognitive aspects of ASD

¹⁸ Some training records were difficult to access for this purpose. Some organisations provided more activities than fields available in the survey.

- life stages and common changes
 - supporting people to understand their own diagnosis
 - how funding works for families.
 - Practitioner interventions
- b) Seeking training and development in support of adults with autism without an intellectual disability. These may be available, but providers reported they were difficult to find or access. Indeed, the three providers who specifically stated they supported this client group, had accessed no such training.
- c) Seeking practical and in-depth training for more experienced staff that can be followed through into the workplace to get better traction, particularly on the following skill domains:
- practical aspects of behaviour management
 - social skills development
 - helping people to develop their communication skills.

It is possible that some of the reported content gaps are actually addressed in the autism activities on offer. The perception that content was “missing” may reflect a lack of confidence in work-based follow-up to embed practical strategies and to address support in more complex situations.

Workforce planning

Respondents were asked whether their organisation had an articulated ASD development pathway, and whether they felt there was enough information available about what a workforce development pathway might include.

Sixty-eight per cent of respondents said their organisation did not have an articulated ASD development pathway, while 25 per cent did (seven per cent were unsure). Those with a development pathway suggested it was partial, with gaps at the more advanced end of the learning continuum.

“Like many, we struggle to recruit quality support workers – which makes it difficult to provide an articulated pathway. We are trying our best with current resources... staff turnover remains near 30%.”

Respondents were evenly divided about the adequacy of information available to help them develop a pathway. Comments from respondents included the following:

“There’s a lack of cohesive information. I’m sure what we need is out there but there’s no one place to go and try to find it.”

“There’s no pathway for advanced level skills. It’s really ad hoc.”

If the lack of advanced level training is removed from the equation, it seems likely there is sufficient information, and sufficient courses available, on which to base the foundations for a pathway for skill development. However, there appears to be less information to guide organisations in the continued development of their staff – half of the respondents reported adopting ad-hoc approaches as they became aware of opportunities.

Summary of the service provider survey

Twenty large and small disability providers and home and community service providers completed a survey. Between 19 and 26 percent of the workforce represented through this survey are engaged in support of people with autism. Home and community service providers reported low engagement with people with autism and their families, and low activity regarding autism learning and development. The results were largely descriptive therefore of the disability service providers who responded.

Disability service providers reported significant uptake of autism-specific learning and development, although this was often outside a formal agency or service development plan for its workforce. While providers identified a range of learning and development approaches including conference attendance and supervision, they seldom adopted a planned approach to prioritising resources and opportunity. Most training sought was described as fulfilling basic requirements for largely inexperienced staff. The results indicate a shortage of learning and development opportunities to build the skills of leaders and managers who are generally expected to coach and guide staff.

Barriers cited most often related to cost of learning programmes and a lack of options, especially for learning opportunities beyond the general/essential skills level.

Few had accessible means to support and strengthen practice after learning events, the exception being larger multi-regional providers who could provide workplace guidance. Service providers were uncertain about how to get support to build greater workforce capacity for autism support.

Survey of learning and development providers

A stocktake was undertaken of autism-specific learning activities available to the workforce within New Zealand. A list of 25 learning and development providers was compiled from the Te Pou Disability Training Directory, Altogether Autism Services Register, web searches and word of mouth. These providers were invited to contribute to the survey. The survey was also promoted on the Te Pou website.

Activities targeted at parents, teachers and health clinicians were excluded from the survey unless they were also offered to the disability support workforce. Also excluded from the stocktake were e-learning programmes on autism that are based off-shore¹⁹.

¹⁹ Several New Zealand disability support service providers currently access such programmes, e.g. Open Future Learning.

Also excluded were courses not specifically related to autism, e.g. positive behaviour support and MAPS²⁰ planning. The development of a learning and development framework would need to recognise the complementary skills and opportunities available through this rich tapestry of training.

A total of 20 training providers completed the survey. Uncompleted survey responses (four) appear to have come from respondents who recognised they did not provide activities to this particular workforce, and their data was removed from the analysis.

This project was not able to verify that the survey results represent all learning and activities available to the workforce. Several enquiries came after the survey closed. However, it is estimated to be a fair representation.

The majority of those who responded (13) are charitable or not-for profit trusts. Four operate as either a commercial business or as an individual consultancy service. Two are district health boards. Three are registered as NZQA private training establishments for part or all their involvement with regard to autism learning and development.

Eight (40 per cent) of the training providers delivered training only in one region. Four provided training across three to four regions. Seven (35 per cent) delivered programmes across the whole country. The survey identified that all regions have access to opportunities from at least one training provider.

Learning and development activities delivered

Survey respondents delivered 49 distinct learning activities. Activities were often delivered more than once per year, with five providers delivering particular activities more than 10 times each year. From this survey, it can be estimated that at least 111 learning events were provided by these agencies over the previous year.

Most activities usually had between six and 25 participants at each event (82 per cent), though group sizes of six to 15 were most common. Six events were delivered to large audiences (40 plus), though these were best described as presentations from visiting guest speakers.

Table 5 summarises the learning activities in terms of format, skill level, person-specificity, duration and cost. Survey respondents provided this information on the basis of confidentiality. Information therefore has been aggregated to respect this.

Table 5: Aggregated details of learning and development activities

| | | # | % |
|---------------|-----------------|----|------|
| Format | Workshop | 27 | 55.1 |
| | Seminar/lecture | 8 | 16.3 |
| | Online | 1 | 2.0 |
| | Customised mix | 11 | 22.4 |

²⁰ Making Action Plans

| | | | |
|----------------------------------|----------------------------------|----|------|
| | Did not know/state | 2 | 4.1 |
| Skill level ²¹ | Awareness | 20 | 40.8 |
| | Application of skills | 17 | 34.7 |
| | Advanced | 11 | 22.4 |
| | Leadership | 0 | 0 |
| | Did not know/state | 1 | 2.0 |
| Specificity to individual | Always specific to individual | 14 | 28.6 |
| | Sometimes specific to individual | 15 | 30.6 |
| | Not specific to individual | 19 | 38.8 |
| | Did not know/state | 1 | 2.0 |
| Duration | 1-4 hours | 28 | 57.1 |
| | 5-8 hours | 11 | 22.4 |
| | 9-12 hours | 3 | 6.1 |
| | 13-16 hours | 2 | 4.1 |
| | More than 16 hours | 3 | 6.1 |
| | Did not know/state | 2 | 8.1 |
| Cost to participant | Less than \$100 | 25 | 51.0 |
| | \$101-200 | 12 | 24.5 |
| | \$201-400 | 3 | 6.1 |
| | \$401-600 | 1 | 2.0 |
| | More than \$600 | 2 | 4.1 |
| | Did not know/state | 6 | 12.2 |
| | | | |

Format of learning and development

Workshop style was the most common format for delivery, and aligns with that sought by service provider organisations. A quarter of all programmes described were delivered on a customised basis, with content and skill level being the main features that were customised according to the audience. Only one was offered in an online learning platform.

Skill level sought for participants

Most of the activities (75.5 per cent) were identified by the providers as suitable for building awareness and basic application of skills. Only 22.4 per cent were targeted to develop advanced or leadership skills.

²¹ See appendix B. Used simplified descriptions of “Let’s get real: Disability” skill descriptions as most providers unlikely to be familiar with these as yet.

Person-specificity

There was an even response to whether the identified activities were delivered in a person-specific way. Though this person-specificity is a key criterion of the quality of learning activities, more than half (59.2 per cent) were either always or sometimes delivered in this way (Bevan-Brown, J; Bourke, R; Butler, P; Carroll-Lind, J; Kearney, A; Mentis, M, 2011). The needs of an individual was the most common reason reported for seeking a learning and development programme for staff (see Table 5).

Nearly 40 per cent of the learning activities reported were of a general nature, and not particular to a known person. This may be reasonable given the high proportion described as general awareness raising.

Relevance to workforce across different settings

Learning and development providers believed their activities were highly relevant to the wide range of roles in the disability workforce and across work settings. This included community residential services, supported living, carer support, home-based support, behaviour support, respite, community work and New Model options.

They believed it was very important that support workers, team leaders and managers, and specialists attended (95 per cent, 83 per cent, 71 per cent respectively). Regarded as important, though less so, was the attendance of people with autism and family (42 per cent), and people in governance roles (24 per cent).

Families involved with Individualised Funding reported a greater awareness of the learning and development activities their staff had participated in than those families and people who used formal services. They also expected high levels of involvement of themselves in training.

Service providers placed less importance on team leader/manager attendance than the learning and development providers, favouring conference attendance, possibly for the broader exposure conferences offer and the relative value for leaders who work across diverse settings.

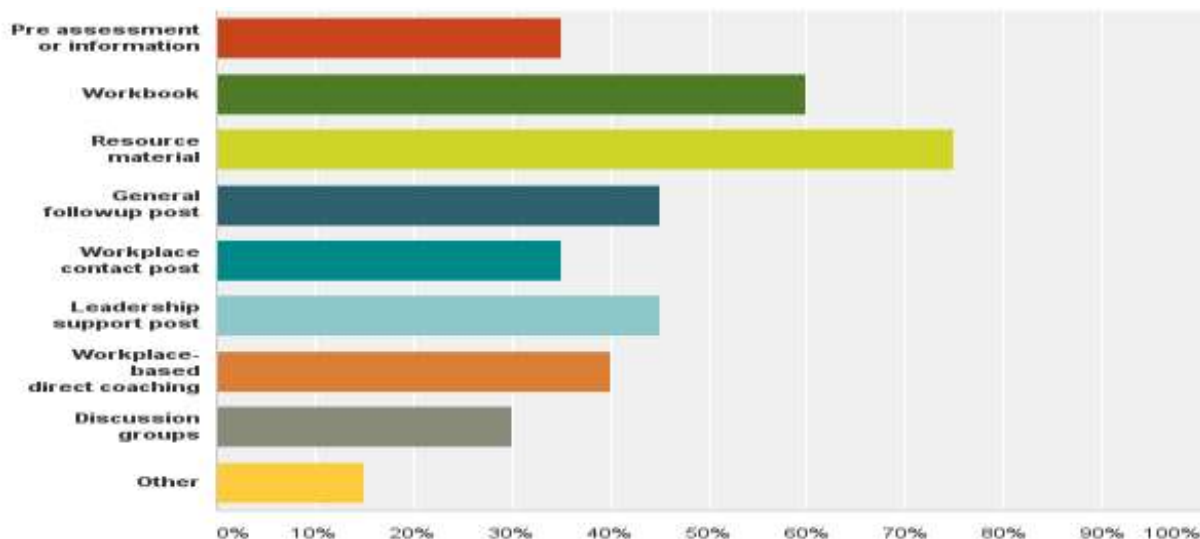
Learning activities therefore were provided often for a wide audience in a range of settings. This is contrary to the recommended merits of courses being tailored to the audience (Bevan-Brown et al, 2011). There was frequent customisation of both the content and skill level targeted in approximately a quarter of the learning activities on offer. This suggests a willingness to accommodate the needs of specific workforce groups. It also suggests an opportunity for more workplace learning adaptations post-training that would support the application of learning.

Strategies to support learning and development

The providers surveyed used a range of mechanisms to support learning activities. This is illustrated in Figure 1. Specific resources for participants such as workbooks or other resource material were commonly provided. Seven providers (35 per cent) used strategies prior to training such as pre-assessment or preparatory information sharing.

Almost half provided post-training support. This occurred through workplace contact including phone, direct support to team leaders and managers, or direct coaching on-site. No learning and development providers (or indeed disability service organisations) reported using homework or study groups to support participants' learning experiences.

Figure 1: Reported strategies to support learning and development



Duration and cost

The length of each activity and cost are listed in Table 5. Most activities offered were of short duration, being less than eight hours. More than half (59.6 per cent) were between one and four hours. This accords with recommendations from Te Pou's 2011 report on ways to reduce barriers to access. (Te Pou o Te Whakaaro Nui, 2011)

Participant costs were generally low, with more than half being below \$100. The three activities that cost more than \$400 per participant were also the longest and delivered by commercial businesses. Six respondents did not disclose price, though this number may include several whose websites indicate they are free (funded through charitable donations). More than half of the responding providers were charitable trusts or not-for-profits, so cost comparison across providers with different business structures is not possible on the basis of the information provided.

Activity content

Learning and development providers described the content covered in each activity. This is summarised below in Figure 2. It reveals a high degree of common ground on skill domains covered, and close alignment with what service providers and families sought.

Seven skill domains were present in more than 85 per cent of activities reported by the providers.

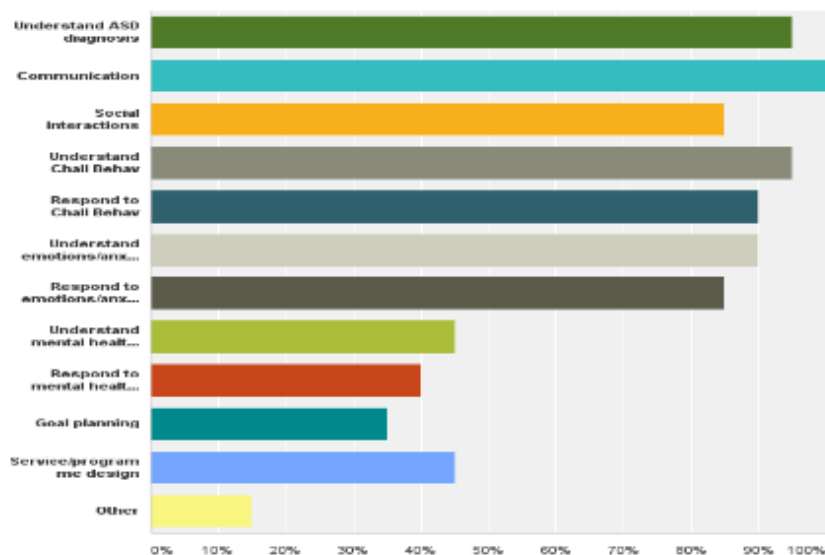
- Understand ASD diagnosis

- Communicate with person with ASD
- Social and community interaction
- Understand challenging behaviour
- Respond to challenging behaviour
- Understand emotions and anxiety
- Respond to emotions and anxiety

The following skill domains were covered in 15-45 per cent of activities.

- Understand mental health issues
- Respond to mental health issues
- Goal planning
- Service/programme design
- Other (included skills for friendship and play, environmental adaptations and self-management).

Figure 2: Reported skill domains in learning activity



Response to diversity of people with autism

“Even fewer had tailored their activity to Māori, Pasifika or other cultural groups.”

Most learning and development providers stated their events were suitable for the workforce supporting either adults or children. See Table 6. Less than half (42.1 per cent) indicated training had been tailored for participants

working with people with autism and no intellectual disability. Learning activities were indicated as more likely to be suited to those supporting people also with intellectual disability.

Even fewer had tailored their activity to Māori, Pasifika or other cultural groups. One provider, however, had developed an autism learning resource expressly within a Pasifika cultural framework. While not specifically asked in the survey, a number indicated they tailored their delivery when participants spoke another language or were from diverse cultures.

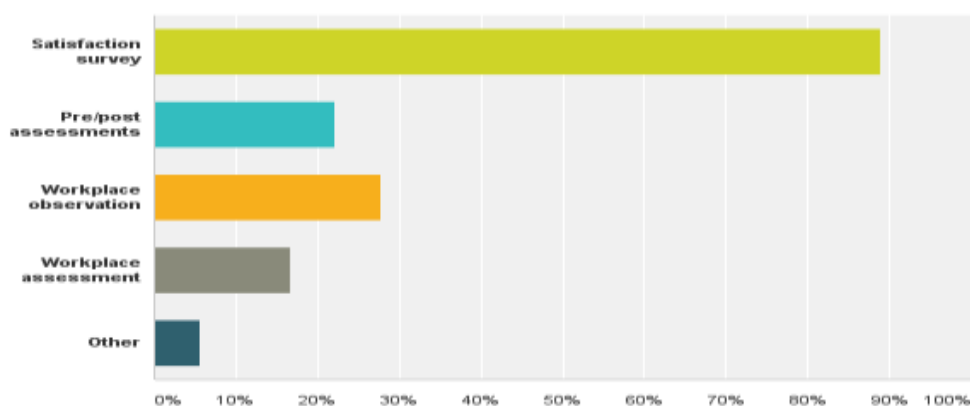
Table 6: Percentage of activities reported suitable for diversity of autism population

| | | |
|-------------------------------------|-------|----|
| Children and young persons | 78.9% | 15 |
| Adults | 78.9% | 15 |
| Presence of intellectual disability | 68.4% | 13 |
| No intellectual disability | 42.1% | 8 |
| Māori | 26.3% | 5 |
| Pasifika | 31.6% | 6 |
| Asian | 21.1% | 4 |
| Other | 10.5% | 2 |
| Total Respondents: 19 | | |

Quality assurance

This project did not evaluate the quality or effectiveness of learning and development activities. It asked what providers did to check effectiveness of their work. Almost all used satisfaction surveys to gather feedback. Some used multiple methods. Objective measures such as pre- and post-assessments, workplace observation and assessment, and evaluation for a qualification were less common.

Figure 3: Reported quality assurance methods



Development and review of learning activity

Learning and development providers identified three document resources as most relevant to the development and review of the activities they offered. These were (most to least) the:

- New Zealand ASD Guidelines
- New Zealand Disability Strategy
- UN Convention on the Rights of Persons with Disabilities.

Other reference sources were of some relevance, though less so. These were (most to least) the:

- NZQA Framework (and qualifications revisions)
- Ministry of Health Workforce Action Plan 2013-2016
- DSS initiatives (New Model, IF, EGL)
- Māori Perspectives on ASD (Bevan-Brown, 2004), and other published research about autism and adult learning (not specified).

Learning and development providers also drew from sets of people when designing or reviewing their material, such as:

- subject matter experts (including experiences of presenters/facilitators)
- people with autism
- families of people with autism.

One provider noted the value of diversity within its reference group.

Summary of the training provider survey

The stocktake of available learning activities reveals the existence of a network of providers offering numerous autism-specific learning and development opportunities. They report delivering content that is widely agreed to be of value. Most deliver short courses which is a format believed to enhance access, though there was minimal use of e-learning strategies, which would further enhance access to a dispersed and part-time workforce, and reduce costs of participation. Activities were generally offered in a generic way but many providers indicated capacity to tailor to specific individuals and support networks. Few activities were targeted for the development of advanced skills. Few had been developed with specific cultural contexts in mind. Fewer than half were deemed suitable for people supporting those with autism and no accompanying intellectual disability. This aligns with feedback from service providers about the scarcity of such learning and development activities.

This survey did not ask whether family members or people with autism were facilitators on learning and development events, though it is reported that a number of facilitators are parents. Most, however, involved people with lived experience of autism in course development or review in consultative roles.

Disability workforce sector

Disability workforce

It is estimated that between 19,000-22,000 people are employed in the disability support workforce. The size and composition of this workforce have been extensively described elsewhere (NZ Disability Support Network & PSA, 2012).

The disability support workforce includes a range of occupational groups undertaking many roles. Though it largely comprises people in direct support roles who are part of the “unregulated workforce”²². It also includes professionally qualified people from the regulated workforce. For the purposes of this project, the latter is equally important when looking at the services currently provided to people with autism, and considering the future demand for more skilled support.

The workforce of interest for this project includes the following staff and service groups.

- a) Staff employed through service contracts with organisations to provide home and community support, carer support, respite, community residential, supported living, behaviour support and specific day support as agreed.
- b) Staff employed through funding mechanisms such as a carer support subsidy and Individualised Funding (self-managed).
- c) Autism-specific support services contracted to providers by the Ministry of Health: DIAS, parent education (ASD Plus, tips for autism, Growing Up With Autism), ASD Communication and Behaviour services and ASD Developmental Coordination.

The workforce of interest for this project *excludes* the following staff and service groups

- a) Disability workforce not funded by the Ministry of Health. A number of agencies provide intervention and therapeutic services²³ which are resourced through private fees and charitable donations. The composition of this workforce is unknown and beyond this project’s scope. However, these services are often staffed by people with significant specialist knowledge and clinical qualifications. Therefore, they include people who would be an asset to the workforce of central focus to this project.

²² Regulated workforce is that workforce subject to regulation under the Health Practitioners Competence Assurance Act 2003. The unregulated workforce refers to those employed who are not subject to the Act.

²³ This workforce includes facilitators of training and parent education programmes, field workers providing information and advisory services, and therapists providing intervention within families and to individuals with autism through a range of evidence-based models, e.g. ABA, Stepping Stones.

- b) Unpaid carers have also been excluded from this project’s consideration of workforce development. They make an enormous contribution to the workforce but in unknown volumes specific to this topic. Given the Ministry of Health’s strategic direction to strengthen and draw from natural and informal supports, there is considerable scope for their inclusion in future work (Grimmond, D, 2014).
- c) NASC personnel, whose professional development is being considered through another work stream.
- d) The mental health/IDCCR/forensic workforce.

Frameworks for workforce development

- a) Te Pou o te Whakaaro Nui

Te Pou is the national centre of evidence based workforce development for the mental health, addiction and disability sectors in New Zealand. Since 2010, Te Pou has been contracted to support workforce development in the disability sector, additional to its long standing involvement in workforce development in the mental health and addiction sectors.

Te Pou has developed an over-arching framework called “*Let’s get real: Disability*” to describe the essential knowledge, skills, values and attitudes in delivery of quality services that meet the needs of disabled people and their carers, family and whanau. It was adapted from the mental health sector. In 2014, Te Pou published the framework describing values and attitudes in common across the disability sector, seven “Real Skills”²⁴ and broad competencies related to each. Supportive resources to aid implementation were published in 2015²⁵. Te Pou is currently rolling out training workshops to embed this framework into organisations. The framework presents opportunities for the workforce that is involved with people with autism.

- b) Careerforce

“...how can providers afford training for staff when wage is low meaning they have a high turnover of staff?” [person with autism]

Careerforce is the industry training organisation (ITO) for the non-regulated workforce which includes direct support workers involved in the disability sector, as well as those in mental health and health. Careerforce refers to this broad sector as the “kaiawhina” workforce, and it includes social service and mental health support workers.

Careerforce acknowledges the disability, community and mental health sectors are changing, but the disability workforce is still largely characterised as “being fragmented and centred mainly on the source of the funding

²⁴ The seven Real Skills are: Working with disabled people, Working with Māori, Working with families and whānau, Working with communities, Challenging stigma and discrimination, and promoting value, Upholding law, policy and practice, and Maintaining professional and personal development

²⁵ Guide for Managers and Leaders, Human resources tool, Workforce planning tool, and Service planning tool.

and provider needs rather than the needs of the person requiring the support and the skills required of the people delivering it.” (Careerforce, 2015)

For this project, many parents and people with autism noted the impact for them of a workforce that is generally poorly paid. For those employed, their passion and dedication often assume greater importance in determining their longevity in the role, despite low wages (NZ Disability Support Network & PSA, 2012).

“...how can providers afford training for staff when wage is low meaning they have a high turnover of staff?” [person with autism]

Components of Careerforce’s recent Action Plan describe steps to develop a vocational career pathway. It suggests there is a qualifications framework and pathway to enter the sector, and progress towards leadership roles and entering the regulated workforce (Careerforce, July 2015). Careerforce is increasingly offering assistance to enable workplaces to customise specific content modules and competency levels required for organisations to develop a workforce development plan.

c) New Zealand Disability Support Network (NZDSN)

NZDSN is a peak body representing more than 150 disability support organisations across New Zealand. It has been active in describing the issues it believes have constrained the development of quality supports for people with disabilities across New Zealand. At various times it has worked with unions, government funders and workforce agencies to contribute to achieving sustainable workforce development. Its workforce surveys have contributed to a better description of the issues particular to workforce.

NZDSN has partnered with Te Pou to encourage the implementation of the “*Let’s get real: Disability*” framework and tools within disability service organisations, and is currently identifying “champions” across its membership for this work stream.

NZDSN is also currently embarking on a provider development programme which has the potential to build stronger autism capacity within organisations. This includes:

- a leadership mentoring programme
- developing “communities of practice” (networks developed around common topics to share knowledge and experience).

Qualifications

A qualification is a recognition of learning outcomes, and in many instances a key mechanism to move to roles that are better paid. The achievement of a qualification is also generally believed to be a powerful way to develop and maintain skills and knowledge.

Careerforce has contributed to a substantial review of health, disability and social service qualifications as part of the NZQA Targeted Review of Qualifications. The review is expected to result in a suite of qualifications to

deliver safe and quality services to clients in the future. This is welcomed, especially if the level of minimum qualification also rises. Several people contributing to this project noted the low minimum qualification for the disability sector (level 2 and 3 Certificates on the NZQA framework, compared with the level 4 Diploma for mental health support workers). Level 4 qualifications require demonstrated learning and application, which has previously been recommended for this diverse workforce (HeathRose Ltd, 2009).

There has been a positive improvement in uptake for qualifications within the disability sector, though it is reported as still being less than that within the aged, social and mental health sector workforces. Future demands will raise the expectations of skills commensurate with changing roles and functions fulfilled by staff. It is likely that qualifications and career pathways will comprise part of the solution, although with the strong trend towards person-specific recruitment under new funding models, some will place less value on prior qualifications as a marker of workforce quality.

“The right person is most important. A qualification is no guarantee of this.” [family member]

Assistance to access learning and development

“There is significant potential to increase the contribution of adults with autism as participants in the disability workforce.”

Disability workforce grants are available to help cover the costs of employees taking part in leadership and skills development activities. In 2014, 5,699 people accessed the disability workforce development grants administered by Te Pou.

In 2013, the Ministry agreed to target autism to respond to recommended action from its Workforce Action Plan. As a result, Te Pou funded eight organisations in 2014 for specific training in autism, which involved 125 participants and total funding of \$31,471. By the time the grant pool was fully allocated in 2015, 144 participants from eight organisations had been supported to attend autism courses at an average cost of \$230 per attendance.

Leadership grants are also provided as part of a wider commitment to enhance the voice and influence of people with disabilities in the sector and in wider society.

Specific allocations to people with autism from the consumer grant pool is uncertain, though there is significant potential for this, now that eligibility criteria do not exclude the majority of people with autism.

Te Pou has information and resources to help the mental health and addiction sector develop and grow the peer workforce in a sustainable and measured way. This is in response to recognition that the peer workforce can effectively contribute to support of service users and whānau. There is significant potential to increase the contribution of adults with autism as participants in the disability workforce in diverse roles, drawing on the experience of peer workforce development elsewhere (Davidson, Bellamy, Kimberly, & Miller, 2012).

Information about workforce development and learning and development

Te Pou established a disability training directory in 2010. It is accessed from the Te Pou website, and has basic search functionality. It currently holds 114 entries on a range of disability topics and learning activities. Many are relevant to the support of people with autism, for example training about person-centred planning, or training for inclusion. However, only four entries are autism-specific or indicate their relevance to autism support using the current search functions.

Altogether Autism is an autism-specific disability information and advisory service. It has a service directory on its website. Search functionality is very limited (to geographical location). For this project, manual searching was required of its many entries to identify those who provided learning and development.

Both directories are passively managed, so contain entries that have not been updated or removed by the providers listed. This project identified 25 training providers. It received survey responses from 20, representing a total of approximately 49 courses. This suggests the potential value of promoting and actively managing a single directory with improved functionality for providers and families enquiring about learning opportunities.

Training for related workforces

a) Health workforce

Health Workforce NZ (HWNZ) provides national leadership as it works with stakeholders involved in the development of the health and disability workforces. It is part of the National Health Board. The roles and functions of HWNZ appear to overlap with those of Te Pou, Careerforce and Werry Centre. While its scope is broad and includes the disability workforce, the current work programme reflects a focus on health professionals. Families and people with autism frequently commented for this project on the importance of health professionals' knowledge and attitudes towards autism, in particular the mental health workforce.

“He told me I couldn’t be autistic because I had good eye contact.” [person with autism, speaking of a psychiatrist]

“Our experiences with those professionals was excellent ... The most outstanding features (apart from their obvious confidence) was their ability to engage with him and us about the problems and encourage us through a very difficult period.” [family member, speaking of mental health professionals]

The Werry Centre is a national centre for research, teaching and workforce development for infants, children and adolescent mental health. Since 2014, the Werry Centre has provided ASD Health Specialists' Training to assist psychiatrists, paediatricians, psychologists and lead clinicians to increase their autism-related expertise, confidence and wider sector knowledge. To date, this has had a focus on assessment and diagnosis in children and young persons. The Centre also has a role in promoting the learning activities of relevance to those engaged with children with autism, e.g. tips for autism.

Some DHB lead clinicians identified uncertainty about where they could access awareness and advanced learning and training for their nursing and clinical workforce, suggesting that HWNZ or the Werry Centre may have a role in supporting the health workforce to demonstrate the minimum standards related to disability and autism awareness.

b) Education workforce

Professional development of the education workforce is beyond the scope of this project. However, development of the disability workforce needs to ensure consistency in the attitudes and specific skills demonstrated in education settings, given the overlap of these sectors in the developmental years for a young person with autism. There is also considerable movement of direct support staff and specialist professionals across the education and disability sectors.

The Ministry of Education supports a number of professional development opportunities for the education sector regarding autism, some of which are listed here.

- ‘Tips for autism’ is an education focussed programme for teams (teachers and families) who support students aged 5-12 with autism (co-funded with Ministry of Health).
- A postgraduate Diploma in Specialist Teaching: ASD is offered by Massey University.
- Social Communication, Emotional Regulation and Transactional Supports (SCERTS) Model is a framework for use in the home and early childhood education settings regarding preschool aged children with autism.

Discussion

Theme 1: Volume demand

From 2014, an additional estimated 33,000 people may have become eligible for disability supports as a result of clarification that a person with autism was not required to have support needs as a result of a concurrent disability. Previous to this clarification, approximately 10 per cent of eligible people with autism were allocated disability supports²⁶, using the Ministry’s Demographic Report (2015). Both these estimates suggest lower delivery rates in the past than one might expect in the future. This is likely then to put pressure on the existing workforce to grow to meet demand.

This project has also estimated the proportion of the current disability workforce already working with people with ASD. The estimation is based on responses to the workforce survey about the proportion of clients with autism and the size of the workforce. This showed that between 2,986 and 4,214 staff out of 16,000 work with

²⁶ Based on a reported total of 4,898 allocated DSS services, and New Zealand’s total number of people with autism being estimated at 47,400.

people with autism (18.6 per cent-26.4 per cent)²⁷. The Demographic Report indicated that 16 per cent of all those allocated disability support services in 2013 had a primary or secondary diagnosis of autism. Within the limitations of this estimation method, the estimate that up to a quarter of the disability workforce is supporting people with autism provides a strong basis for the inclusion of ASD-specific competencies across all formal learning programmes and qualifications for community support workers supporting people with disabilities, and stronger still for personnel in roles of service leadership. Careerforce programmes for staff seeking level 4 and 5 qualifications may need to keep this high presence of autism in mind.

The surveys conducted for this project indicated that significant volumes of learning and development are provided to the disability workforce. They were not however able to quantify what proportion of the workforce received autism learning and development. Without much more detailed enquiry with employers, estimations from the current picture would be distorted by the high turnover rates common across the sector. Further enquiry with learning and development providers would also be required to break down the mixed attendance at events by family, workforce and the wider public.

Workforce pressure will be felt because of:

- increased volumes of adults and children possibly eligible for disability support
- the move toward more flexible and community-based supports which will require different skill sets demonstrated from the current workforce
- the challenge of embedding new knowledge into daily practice for people employed in increasingly diverse roles and work settings.

Theme 2: Service development

This project has identified that a range of services are currently being used by people with autism but current data focuses on the resources allocated rather than the support accessed. Future workforce planning would benefit from common data collection based on service use. This would recognise that different referral pathways are available to people with autism and their families accessing support, and changing preferences regarding service options. This data is not readily available at present.

What is known is that, of the services used, there appear to be different workforce issues.

- a) Large volumes of less structured service utilisation through carer support, home and community support, and IF. These supports are provided by a large and often part-time workforce which is not easily identifiable, and is being asked to work more flexibly.

²⁷ Calculated: Extracted from responses as to individual organisation's reported workforce total, and reported per cent of clients with autism. Assuming reported client proportions with autism will result in similar proportions of workforce working with them. As most providers' workforce work 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 pool.

- b) Emerging services with a focus on parent education, coordination and short-term intervention to maximise functioning. These supports often require staff with experience of complex situations and applied skills that can be demonstrated, and greater contribution from the regulated workforce.

It is important to note that current service responses focus largely on those people with autism who also have an intellectual disability. Models are evolving and changing, and reflect societal expectations of inclusion and adherence to human rights commitments. Service expectations are shifting towards the provision of support and skills to manage one's own life as a citizen in society with its opportunities and its obligations.

Many contributors were encouraged by the introduction of different service models for children and families with autism. Nevertheless, several family and consumer contributors described recent experiences of what were described as “clayton's opportunities”.

“He told me we can get x and y, but that's not what we need. Really, do we have to be reduced to begging?” [parent of adult with autism]

Commonly reported gaps.

1. Respite for children and adults through a variety of approaches.
2. Transition service options for those stepping towards more independent living.
3. Support for community integration for those living at home.
4. Parent training and intervention programmes being more consistently funded.
5. Information and advisory services directed to people with autism and their families about what their entitlements are, and where to get support and workforce information.

Further engagement with people with autism and with families will be required to consider these gaps more fully. People with autism and families interviewed for this project signalled they seek diverse support across the life span. Service models will need to enable flexibility of delivery according to the diverse needs of individuals. Current prescriptions about what can be delivered within service models will limit their usefulness to both children and adults.

As indicated earlier, it is difficult to develop an accurate picture of where people work now or in the near future because of the lack of comprehensive data. It is pleasing to see this has been identified in the Ministry of Health's Workforce Action Plan as needing attention.

Theme 3: Attitudes and values of the workforce

“Positive attitudes and values are seldom taught. They can be illustrated in training, and modelled in practice.”

Families consistently emphasised the importance of staff having “the right view of disability”. They commented on the long-term effect of staff attitudes on their child’s motivation and self-esteem. Several preferred to recruit staff whose experience was not in disability work (where previous experience may have entrenched attitudes), but rather in whatever interest the person has to support their full participation in ordinary community settings. This might be photography or renaissance architecture.

“In order to be part of the community it works better to have support people who are part of the ordinary community and whose thinking has not been tainted by services.” [family member]

“...had the most success with people who have shown that they understand the problem, have a warm and natural engagement with the problems experienced by ASD sufferers and their families. In this environment, problems are identified and solutions found.” [family member]

People with autism expressed the importance of recruiting people with specific attitudes and values.

“Always respectful. Being straight with me not precious, adult to adult, and definitely not judgemental - that’s respectful.” [person with autism]

“Sense of humour very important. I need this to calm down and get back on track.” [person with autism]

“Sensible, a good manager ... allowed to make choices... punctual, organised, pleasant, friendly, and kind.” [person with autism]

The qualities and attitudes noted by families are closely aligned to those on which many learning activities should be based, and match those in workforce development frameworks such as *Let’s get real: Disability* (see Appendix B).

Positive attitudes and values can be instilled in training, and modelled in practice. The changing service landscape will require a selection of tools and strategies for bringing new people into the workforce, and for selecting people from the existing workforce who can successfully adjust to different service models and work settings. As previously highlighted, the current and future demand for support is likely to increase, and workforce planning will need to harness as much skill and commitment from the current workforce as possible.

Learning activities that target attitudes and values were not specifically explored. Some families interviewed advocated Social Role Valorisation and similar programmes to provide a strong values base from which specific skills can be developed.

Attitudes and values of the workforce must remain the foundation for all workforce development. In practice however, having sound attitudes or positive values is seldom enough. Equally important is the work of nurturing those values into appropriate expression in the workplace through experience and guidance. With inattention however, positive attitudes and values can decay. It is, therefore, vital that workforce development includes activities that refresh values and attitudes, and provide guidance for staff on negotiating daily complexities. An example described relates to the importance of staff being flexible, yet still able to maintain routines important to the person or their employing organisation.

Theme 4: Workforce development framework

Workforce development specific to people with autism will have to occur within the context of development for the social and disability workforce. This project has identified a number of agencies contributing to the development of the health and disability workforce, but it is not clear how autism support has figured in their planning. The changing configuration and focus of disability services and autism-specific services introduces new roles and skill sets. Specific to the needs of people with autism, there appears to be differential uptake of some service approaches in favour of:

- funding models such as IF whereby there is greater choice and control on how resources are spent
- more skilled personnel in direct support roles and in specialist practice support and advisory roles, e.g. ASD communication and behaviour services for adolescents.

A framework that is relevant to the workforce is required. It must support the rapidly changing face of autism support and include parts of the workforce which are currently receiving less attention, including staff:

- providing carer support and in home and community support services
- in leadership, coordination and managerial roles
- in specialist roles.

Services most used by people with autism are those engaged in carer support, and home and community services. Though the size and composition of this workforce cannot be accurately identified, people employed in these roles still require the knowledge and skills for supporting people with autism.

Service providers, families and people with autism commented on having 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. For example, smaller providers accessed training when prompted by an individual's needs, but often sent staff to open public courses which may not provide the person-specific content that is more meaningful. Service providers said they would welcome guidance on what courses exist and for whom. The Skills for Care UK website provides an international example of what could be created in the New Zealand context to meet this sector's need.²⁸ The range of current programmes directed at general awareness could well form a solid foundation for specific and advanced skill-building.

Te Pou's report on the disability workforce (Te Pou o Te Whakaaro Nui, 2011) identified the three key barriers to accessing training were funding, staff release and the inability to offer incentives. Throughout this project, levels of funding and pay rates for staff were identified as critical for improving skill levels and retention rates. Pay rates were described as commensurate with essential entry level skills, but service models and consumers' expectations were for experienced staff with capable level skills.

²⁸ <http://www.skillsforcare.org.uk/Document-library/Skills/Autism/autism-awareness-learning-resources.pdf>

Developing a curriculum

Autism-specific learning and development sits in the wider context of disability learning and development. The focus of this project on autism-specific workforce development means that other learning and development activity was not directly considered. A number of families placed greater value on learning and development related to community building, than specifically on autism. Such content might be sourced from beyond the disability sector.

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

Service provider organisations identified two primary triggers for seeking learning and development related to autism. The first relates to an individual's needs. This creates the opportunity to provide a person-specific or team-based format, which is desirable. The second trigger was internal organisational requirements, such as development strategies. This indicates the value of supporting service providers to develop workforce plans, which encourage greater uptake of instructional programmes tailored to the different roles people hold, and increases the likelihood of an infrastructure that supports the application of learning into the work setting. When service providers can develop workforce plans that are based on service need, they can also inform learning and development providers about what is required and what works for the workforce; e.g. short online courses that part-time staff can participate in.

Parallel work is needed to distinguish between the skills and attributes desirable across the diverse roles needed in the autism workforce so that we can:

- encourage strategies that promote the application of, and reflection on, learned skills into the workplace, e.g. teams completing a post-training self-assessment of what they need to change in their daily work to implement their training
- build networks of workforce support (e.g. virtual NASC)
- supplement knowledge, skills and attitudes for the changing shape of services in which people will be working, e.g. awareness of judicial processes if someone requires legal assistance.

Workplace learning and development

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 (HeathRose Ltd, 2009). This project has illuminated the opportunity to support organisations and employing bodies to take a more systematic approach to workforce development, and broaden our thinking beyond training courses.

Staff learning and development within organisations is best promoted by:

- defining performance – what people need to know and do
- monitoring – to determine what staff actually know and do
- instructing – using formal and informal methods to build staff capacity and competency
- providing feedback – to reinforce knowledge and practice, and correct these
- evaluating effectiveness – in the real context evaluating the impact on the nature of the supports provided (Nankervis & Matthews, 2006).

This needs to be embedded in the workplace and in learning programmes matched to the roles people fulfil. For example, the workforce survey identified that providers wanted their leaders to have all skill domains, but they didn't send them to workshops with practical-based teaching where they would learn the skills.

Qualifications

The Ministry of Health and disability workforce bodies agree that improved qualification levels across this workforce is an important strand in workforce development. Families and people with autism involved in this project suggested they do not necessarily ascribe the same value to specific qualifications.

“...rather than qualifications, people who work with people make good staff.”

[family member]

Tools and resources (including autism unit standards) exist to support those people seeking the achievement of a recognised qualification.

However, the qualifications must address the skills sought by employers and by those receiving support from the workforce. Families interviewed stated they wanted staff to be able to facilitate participation in ordinary community spaces, and facilitate connections between the person and others. Qualifications must be regularly refreshed to ensure they remain relevant as children and adults with autism become more involved.

Quality assurance

Providers of learning and development said they design their courses from a solid evidence-base, including that related to adult education. However, employers (including families) currently have few objective measures or programme evaluations to determine the quality of learning and development programmes which are on offer. Bevan-Brown et al. (2011)²⁹ identified a number of quality criteria and broad indicators for the evaluation of ‘tips for autism’, an autism-specific parent learning programme. These include:

- team-focussed
- needs-based
- knowledge-based

²⁹ J. Bevan-Brown, R et al. (2011). pp13-15.

- instructionally-based.

They provide a sound basis for the evaluation of current and future autism-specific learning programmes.

Peer workforce development

This project has identified a potential opportunity for families and consumers to contribute to the strengthening and expansion of the autism-related workforce. Peer workforce is the term used to describe an occupational group whose members all have lived experience of autism. They can fulfil diverse roles such as consumer advisers, peer educators, peer advocates, peer researchers, peer supervisors, peer consultants and consumer auditors. Considering their inclusion in future workforce planning aligns with the Government's commitment to closer collaboration with consumers. Existing resources from the mental health and addiction sector could be used as the basis for building peer contributions to the disability workforce in relation to autism support³⁰.

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

Conclusion: pressures and opportunities

There appears to be relatively broad access to and uptake of learning and development activities that provide a basic awareness and overview of autism. Many of the surveyed training providers deliver such learning activities, which have similar competencies and content. Making this training more widely accessible would do much to improve foundation knowledge across the workforce and wider community. Targeted work might then focus on gaps such as more advanced training on specific skill domains, and on resources for managers and team leaders to support the implementation of skills in the workplace.

Alongside this developmental work, it would also be helpful to have a repository of information about workforce opportunities in one place so that families, staff teams and allied workforces can easily access and find information about learning opportunities, funding assistance and post-programme resources.

Pressures

Significant potential pressure on the existing workforce has been identified in this project, related to five key factors.

³⁰ <http://www.tepou.co.nz/resources/competencies-for-the-mental-health-and-addiction-service-user-consumer-and-peer-workforce/536>.

1. Increasing numbers of children and adults affected by autism who may seek support from current or future services funded by Disability Support Services.
2. The experience of the current disability workforce in working with people with autism and intellectual impairment will be challenged by the greater diversity of need presented by people across the autism spectrum, and the expectations of direct participation in training and development from consumers.
3. Difficulty identifying advanced learning and development opportunities for the workforce required to demonstrate greater competency or lead and manage others.
4. Uncertainty about the models of support which will be funded in the future, and thus the competencies and skill levels required for changing roles.
5. The absence of a workforce development framework that extends value and resources to workplace supports so that instruction and skill acquisition are embedded into daily practice; and the relatively low awareness of service providers about where to get assistance with implementing learning and development within their workplace.

Opportunities

This project identified a number of emerging initiatives which might be harnessed to support development of the workforce supporting people with autism. These opportunities are listed here.

1. Support organisations and employers to develop the workforce

This project has identified a reliance on instructional responses in the absence of other workforce development strategies where skill and confidence can be more assured, e.g. recruitment and selection, mentoring and coaching and readily accessible practice guidance.

Investing in workforce training and development could be maximised if workplace strategies existed to support learning. This could be localised, for example a parent and support worker discussing what to try differently after attending a learning event. It could also be more formalised organisationally by providers developing workforce development strategies.

Let's get real: Disability is a framework that assists disability organisations to approach workforce development in a more strategic, deliberate and coordinated fashion. The aim is to design services which are appropriate for the diverse support needs of people affected by autism.

Careerforce also can support service providers to develop an autism-specific learning programme that sits within the organisation's workforce development framework. Building awareness of the learning opportunities and providing easy access to them would be helpful.

2. Tailored learning for the workforce

Where and how people work in support of children and adults with autism is rapidly changing. Learning and development providers need to be able to customise their material to the role and team context.

Employers and employees would benefit from guidance on the wider curriculum in which autism-specific training or development might sit. Documenting an agreed curriculum would help employers identify what learning products best suit the different roles people fill. Careerforce developments are underway to tailor learning material from the suite of resources and unit standards available, at least one of which is autism-specific.

3. Investment in the development of managers and leaders

There is an opportunity to invest in a peer workforce so that adults with autism can contribute in a range of ways to strengthening the community and disability sectors.

This will involve people with autism and families more generally in consultations about workforce development, particularly in regards to the content and delivery of programmes. Te Pou could consider investing in leadership development for adults with autism to foster this.

Encouraging practice guidance networks such as the “virtual” NASC trial would strengthen the quality of leadership, coordination and management. Currently there are a number of skilled practitioners and professionals with extensive knowledge about how to build knowledge and capacity. This could be a resource that is supported to contribute more to workforce development. NZDSN’s leadership development programme and “communities of practice” networks offer opportunities to demonstrate practice guidance that could be more accessible across all provider networks, whether they are small trusts or self-managed support arrangements.

Appendices

Appendix A: Family interviews: summary of responses

Methodology

Semi-structured phone interviews were conducted by a parent. Questions for the interview were developed by the interviewer and project lead. The interview guide contained both multi-choice rating options and open questions. Care was taken to ascertain workforce skill preferences before exposing the families to an extensive 'wish list' of skills to rate.

Individuals were identified by snowballing method (a non-probability sampling technique where existing study subjects recruit future subjects from among their acquaintances), and word-of-mouth, with a focus on identifying a mix of ages, geographic spread and formal and informal supports.

Family sample

Fourteen family members were interviewed; most were of European ethnicity, with three being of Asian or Pasifika (including Samoan) nationality. Efforts were made to recruit a diverse group but access to families of people under 18-years using formal services proved difficult within the constraints of the recruitment approach. No Māori families were interviewed³¹.

The ages of people with ASD ranged from eight to 58. They came from across New Zealand. Two families lived rurally, two in provincial towns and the others in major urban areas.

Families used either formal services to deliver supports or self-managed using Individualised Funding (IF). DSS supports accessed included personal cares, household management, respite, carer support, day service, residential service, supported independent living and behaviour management.

The presence of intellectual disability was spread evenly across those who use formal services and those using IF, but families using formal services generally described their family member as lower functioning on the spectrum than those using IF. Those using formal services were more likely to be non-verbal.

Families' knowledge of training staff had accessed

Families using formal services had no knowledge of the training their staff had accessed. By contrast, those using IF all knew what training their staff had undertaken. A number of families using formal services said they would like to know about the training.

Family role in ASD staff training

Nearly all families thought they should play a significant role in the orientation of new staff for their family

³¹ Maori families were willing however the sampling methodology favoured a spread according to age of family member over ethnicity.

member but in other areas of staff training (beyond orientation), those using IF felt the family should have a greater role than those using formal services.

Attitudes and values

Every family interviewed expressed that it was very important to them that their ASD workforce hold the following attitudes and values:

- values the person with ASD and others with a disability
- believes that people with ASD can live an ordinary life – with supports
- able to work appropriately and sensitively within the culture and spirituality of our family
- works respectfully with family and person with ASD
- acknowledges the family as the natural authority.

Workforce knowledge of ASD, ID, prior experience

Families generally thought knowledge of ASD was important, particularly an understanding of the range of abilities and the uniqueness of individuals on the spectrum. An understanding of intellectual disability was important for those whose family member has an intellectual disability. Prior experience working in the area of ASD was seen as less important, particularly for those using IF. A number of families stated they never employ staff with prior experience working in the disability field and prefer to find suitable people “off the street” in order to avoid a disability mindset, low expectations and not seeing the disabled person as an individual. “Bear in mind that not everyone wants to employ people with ‘disability mindset’. In order to be part of the community it works better to have support people who are part of the ordinary community and whose thinking has not been tainted by services.”

Qualifications

In terms of particular qualifications for the ASD workforce, three families desired a qualification and these were limited to a tiered qualification in ASD, first aid, and relevant NZQA Level 4 qualifications. “The right person is most important. A qualification is no guarantee of this” was a typical comment.

Current skills of ASD workforce

We asked families to comment on the skills they observed and valued. In general families tended to report personal qualities rather than specific learned skills in their current ASD workforce (refer to the qualities heading). A few had staff with skills in first aid, an understanding of ASD, or in managing challenging behaviours. One had staff skilled in teaching coping strategies to the child and another had organisational skills. A few families reported the value of recruiting staff skilled in whatever interest the person has in order to support the person to participate fully in ordinary community settings.

Desired skills currently lacking in the ASD workforce

All families wanted staff to have the skills or training to help the person with ASD manage emotions.

Most families could indicate desired skills they thought were lacking in their ASD workforce. These included knowledge, understanding of, and skills to apply the following: ASD, Applied Behaviour Analysis, Social Role Valourisation, first aid, behaviour management, communication strategies, how to read anxiety and behaviour, sensory skills, community integration and social skills.

Where the family member experiences seizures, families wanted staff to have an understanding of medical issues including the treatment of seizures.

Several families using IF were unaware of the funding available for staff (and family) training through Te Pou.

Current or desired personal qualities in staff

Families overall favoured specific qualities in their support staff as follows: maturity, reliability, confidence, courage, commitment, honesty, empathy, common sense and valuing the person. Understanding and anticipating the needs of the person were seen as vital for staff working with people who are non-verbal.

Staff and community skills

All families wanted staff with the skills to help their family member participate in ordinary community spaces. Most wanted staff to be able to facilitate the connection between the person and others. One comment was that, “the focus early on was ASD and ABA and we were blinkered to community participation but now skills in that area are paramount to ensuring the good life for our child”.

Staff and communication skills

All families wanted their ASD workforce to be skilled in communicating appropriately with the person with ASD. Most wanted the workforce to be skilled in using suitable communication strategies.

Advocacy and access to government services

Skills in advocacy were important for most families. The ability to support access to other government services was more important for families using formal services.

Comments on staff pay

A number of families made comments to the effect that the whole sector is underpaid and that staff have not been adequately rewarded for what is, or should be, skilled work. Improving pay rates was seen as important in the development of a skilled ASD workforce.

‘Big picture of training’

One comment referred to the current random dispersal of information about training opportunities, and suggested a “one stop shop” listing all training available throughout the country. Several families suggested an employment portal so families could find skilled staff.

Many families voluntarily commented on how pleased they were that ASD workforce development is being addressed although several families of people over 18-years-old saw ASD-specific skills as less important now than they were when the person was younger.

General comments about the ASD workforce

- Rather than qualifications, people who work with people make good staff – e.g. students in teaching, social work, psychology, health sciences, physiotherapy.
- Listen to the family – the family knows the person best.
- In services – recognition of the family beyond ticking boxes.
- Right view of disability.
- No prior experience in ASD or disability.
- Attitudes and values are key.
- Arrive on time every time.
- Staff need support too and supervision in the way counsellors have supervision.
- Need openness between staff and family.
- Family want to be involved but this is hard as parents age.
- Staff must talk to the person with ASD, not about him or her.
- Staff who understand and believe in the vision we have for our son.
- Able to listen and observe and reflect.

Comparison of values and attitudes between family interviews and *Let’s get real: Disability*

| | |
|--|--|
| Families and people with autism consulted for this project | Maturity, reliability, confidence, courage, commitment, honesty, empathy, common sense, humour, valuing the person. Understanding and anticipating the needs of the person. |
|--|--|

| | |
|---------------------------------------|---|
| <i>Let's get real: Disability</i> | Compassionate, caring, sensitive and understanding. Enabling, encouraging, accepting and supportive. Genuine, warm, friendly, fun. Honest, fair, sincere, trustworthy. Non-judgmental, non-discriminatory, uncritical. Open-minded, culturally aware, self-aware, creative, positive risk-taker. Optimistic, positive, enthusiastic, inspiring. Patient, tolerant, flexible, accommodating. Professional, accountable, reliable, responsible. Resilient, emotionally strong, able to bounce back in face of challenges. Understanding, perceptive, considerate, and responsive. |
|---------------------------------------|---|

Appendix B: Service organisations contributing to workforce survey

| Organisation | Reported numbers of employees (DSS services only) | Proportion of people with ASD who access the organisation |
|--|---|---|
| National or Multi-Region Disability Service Providers | | |
| NZCare Disability | 2,000 | 30-50% |
| IDEA Services | 5,500 | 30-50% |
| Spectrum Care Trust | 1,000 | 50%+ |
| Local Area Disability Service Providers | | |
| SILC | 147 | 50%+ |
| Emerge Aotearoa | 140 | No data |
| Community Connections | 101 | Up to 30% |
| Te Roopu Taurima | 400 | No data |
| Enrich+ | 63 | 30-50% |
| Hohepa Hawke's Bay | 400 | 50%+ |
| Supported Lifestyle Hauraki Trust | 60 | Up to 30% |
| Nelson Marlborough DHB | 320 | Very few |
| CCT | 220 | Up to 30% |
| Hawksbury Trust | No data | No data |
| Specialist Disability Service Providers | | |
| Explore | 150 | 50%+ |
| IDEA Community Specialist Services | 33 | 100% |
| Enabling Good Lives (Navigators) | 7 | Up to 30% |
| Home and Community Care Service Providers | | |
| Lifewise Homecare | 180 | Very few |
| Access Home Health | 1,000 | Very few |
| Enliven (Northern region) | 500 | Very few |
| Healthcare NZ | 1,600 | Very few |
| TOTAL WORKFORCE NUMBERS | 14,180 | |

Skill level descriptors used in the workforce survey

Essential: all new staff regardless of their role or level.

Capable: staff with experience, including support workers, team leaders and managers who can demonstrate both essential and capable skill levels.

Enhanced: specialist staff such as behaviour support workers, nurses, senior leadership teams whose work involves complex skills and knowledge.

Leaders: team leaders and managers.

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