



Plunket



# Carers' Strategy Action Plan 2019-2023

Royal New Zealand Plunket Trust Submission on the *Carers' Strategy Action Plan 2019-2023*

Royal New Zealand Plunket Trust

## Introduction

Plunket is the largest provider of free support services for the development, health and wellbeing of children under five in New Zealand. We see more than 85% of newborns in New Zealand each year. Our submission is guided by our vision that in the first 1,000 days we can make the difference of a lifetime. Our vision is underpinned by three strategic goals:

**Healthy tamariki** – we make sure every child/tamariki has the opportunity to be as healthy and well as they can be.

**Confident whānau** – we build the confidence and knowledge of whānau and families across New Zealand.

**Connected Communities** – we make sure no family/whānau is left isolated, disconnected or unable to cope.

Plunket's submission in the *Carers' Strategy Action Plan 2019-2023*<sup>1</sup> focuses on caregivers who look after their children with special needs - these carers might be parents, grand-parents, siblings or the wider whānau.

As Plunket provides health checks and parenting support to families that have children aged 0-5, we see our role in supporting carers as threefold:

- Early referrals, which can facilitate early diagnosis and intervention, which supports the specific needs of that child. **(Healthy Tamariki)**
- Provision of relevant parenting information to these families and carers. **(Confident whānau)**
- Linking carers to relevant groups (e.g. parent support groups) and organizations (e.g. organizations that specialize in that impairment) thus providing carers the support they require. **(Connected Communities)**

## Executive Summary:

Plunket supports the development and the implementation of the Carer's Strategy 2019-2023 (the 'Strategy').

Almost half (49%) of children's disabilities are congenital (conditions that existed at birth). Plunket's role in supporting carers with special needs children are crucial especially as most of the carers we see are likely to be novice or first time carers.

1. Plunket supports actions that facilitate early diagnosis as this helps families receive financial assistance (*"if children are not diagnosed, nothing happens"*)<sup>2</sup>; and early intervention can improve the effectiveness of treatment for some types of disability<sup>3</sup>. Both early diagnosis and early intervention are closely linked to carers' perceived service needs<sup>4</sup>.

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<sup>1</sup> Carers' Strategy Action Plan 2019-2023. Ministry of Social Development, Wellington, New Zealand. June 2019.

<sup>2</sup> Child Poverty Action Group (2015). "It shouldn't be this hard": Children, Poverty, and Disability.

<sup>3</sup> An example would be children with autism spectrum, early intervention helps reduce symptoms severity and improve quality of life. Johnson C.P. & Myers, S.M. (2007). Identification and evaluation of children with autism spectrum disorders. *Paediatrics*, 120, 1183-1215.

<sup>4</sup> Llewellyn, G., McConnell, D., & Bye, R. (1998). Perception of Service needs by parents with intellectual disability, their significant others and their service workers. *Research in Developmental Disabilities*, 19, 245-260.

2. We think training opportunities should not only limited to carers, but also to primary health care professionals (such as Plunket nurses, GPs) in identifying early symptoms and providing support especially to novice carers.
3. Plunket believes the Carers' Strategy 2019-2023 should be strengthened to enable cultural responsiveness to include the unique needs of the CALD communities (Culturally and Linguistically Diverse)<sup>5</sup>.

## Children with Special Needs – Definition and Key Statistics

### Definition

Statistics New Zealand define disability as, “any self-perceived limitation in activity resulting from a long-term condition or health problem; lasting longer or expected to last longer than six months or more and not completely eliminated by assistive device”.

Generally speaking, disabilities are categorized into Sensory (such as vision, hearing); Physical (such as mobility, agility); Intellectual; Psychiatric/Psychological; Other. Disability can be congenital (born with), or caused by accidents or by ageing.

### Key Statistics

Data on children with disability are limited, however, some key findings from the *Supporting disabled people: 2013*<sup>6</sup> are:

- In 2013, 24 percent of the New Zealand population were identified as disabled
- Māori and Pacific people had higher-than-average disability rates, after adjusting for differences in ethnic population age profiles
- For children, learning difficulty was the most common impairment type. Six percent of children, 52 percent of disabled children, had difficulty learning
- The most common cause of disability for adults was disease or illness (42 percent). For children, the most common cause was a condition that existed at birth (49 percent)
- 12 percent of disabled children received extra help with personal care at least once a month because of their impairment
- For 10 percent of disabled children, their caregiver reported an unmet need for help around the house because of the child's impairment

Extra help needed in households with disabled children

- For children who received extra help with personal care, 82 percent received this help on a daily basis.
- For one-third (34 percent) of children who received extra help because of their impairment, some help was provided by an organisation (such as the district health board) or private business (such as a care service).

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<sup>5</sup> Brassart, E., et al., (2016). Strategies developed by service providers to enhance treatment engagement by immigrant parents raising a child with a disability. *Journal of Child Family Studies*, 26, 1230-1244.

<sup>6</sup> <https://www.stats.govt.nz/reports/supporting-disabled-people-2013>

- A similar proportion (35 percent) received some extra help from a person who did not live in the same house as them but was not associated with an organisation or private business.
- A small proportion of disabled children had caregivers who reported that they received help with domestic tasks because of the child's condition or health problem. Just 2 percent reported getting this type of support; however, 10 percent reported having an unmet need for such support.

## Carer's Strategy Action Plan

The following submission<sup>7</sup> is structured and based on the consultation document *Carers' Strategy Action Plan 2019-2023*<sup>8</sup>.

### Recognising

We support the following actions proposed in the consultation document:

- a. Make sure carers and their needs recognised.
- b. Make the work of carers more widely known and understood. Including through a national campaign or Carers Day.
- c. Find out more about different people who are carers and what they need. We don't know much about Maori, Pacific, younger and older carers.

Plunket supports the recognition of carers and their needs. However, we would like to draw specific attention to the carers in the CALD communities (Culturally And Linguistically Diverse) as their needs are unique and should be recognized in the Carers' Strategy. In addition to the possible language and cultural barriers, CALD carers might not be familiar with NZ health and social service systems<sup>9</sup>.

These can add considerable pressure to parents who try to navigate the system whilst at the same time being a carer for their disabled children<sup>5</sup>. As many of them are also migrants and former refugees, the support (such as respite) they receive from family members can be somewhat limited (as friends and family might still be overseas).

### Navigating

We support the following actions proposed in the consultation document:

- a. Make it easier for carers to find out about help available to them.
- b. Improve communication between people needing care, their carers and service providers.
- c. Learn about whanau-centered ways to help carers. Look at culturally appropriate approaches.
- d. Help carers to take breaks when needed. This includes looking at respite services across New Zealand.

Plunket supports improving communication between people needing care, their carers and service providers. For children 0-5, we also believe there needs to be greater co-ordination between early

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<sup>7</sup> We acknowledge the named strategy focuses on the needs of carers and not the person who needs special care. However, we also acknowledge their needs are sometimes inter-connected when navigating social, education and health systems.

<sup>8</sup> Carers' Strategy Action Plan 2019-2023. Ministry of Social Development, Wellington, New Zealand. June 2019.

<sup>9</sup> Ngai, M., Latimer, S., & Cheung, V. (2001). Final Report on healthcare needs of Asian Peoples. Waitemata DHB.

childhood providers, relevant agencies and the families. Service provision to this age group is limited and most assistance is only available when children go to school.

Related to this is also the need for diagnosis. In the *“It shouldn’t be this hard: Children, Poverty, Disability”* report<sup>10</sup>, it is noted that *‘if it (the disability) is not diagnosed, nothing happens’*. Parents shared their experiences of having difficulty of assessment and obtaining a diagnosis in some complex disabilities (mostly intellectual and learning disability). They felt uncertain of the help they can get as they need to provide evidence (assessment) to prove their children’s education and other needs. Plunket believes assessments should be more accessible for children who have disabilities that are complex, difficult to diagnose, and may in fact be under reported<sup>10</sup>.

We also agree looking at ‘culturally appropriate approaches’ for carers would be valuable, but this needs to extend to service providers. As the population diversifies, it is also critical for agencies and organizations to be culturally responsive.

### Supporting

We support the following actions proposed in the consultation document:

- a. Make information more helpful for carers. For example make it available in different languages.
- b. Update A Guide for Carers so that there is more information to help carers in different circumstances.
- c. Make it easier for older carers to stay connected so that they can get the support they need.
- d. Respond to the Mental Health and Addiction Inquiry recommendations for families and whanau carers of people requiring mental health and additions support.
- e. Find ways of making the financial supports for carers easier to access.
- f. Look at ways of improving financial support for carers.

In addition to making information available in different languages, we believe there should be more support to organizations that run parent groups (or parent’s network) that cater to specific population groups.

Availability and accessibility to Maori, Pacific and Ethnic support groups for parents who have disabled children are very limited. Access to peer support groups is valuable in terms of sharing experiences and increase engagement with health services<sup>11</sup>.

Whilst making information more helpful and specific to carers can be beneficial, studies<sup>12</sup> show parents require more ‘professional’ knowledge in managing their children’s conditions. In this study, parents rated *“wanting help with child’s development”* most (63%), followed by *“the need of finding activities for their children”* (60%) and *“needing respite”* (53%). The same study also found the greatest gap in service (from parent’s perspective) is to help with vocational skills (e.g. exploring work options), accessing resource and friendships<sup>13</sup>.

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<sup>10</sup> Child Poverty Action Group (2015). *“It shouldn’t be this hard”*: Children, Poverty, and Disability.

<sup>11</sup> Glasper, A., & Evans, K. (2014). Improving services for disabled children and their families. *British Journal of Nursing*, 23 (11), 600-601.

<sup>12</sup> Esine, S., & Yurtsever, S., (2007). Difficulties experienced by families with disabled children. *Journal for Specialists in Paediatric Nursing*, 12(4), 238-252.

<sup>13</sup> Llewellyn et.al., (1998). Perception of service needs by parents with intellectual disability, their significant others and their service workers. *Research in Developmental Disabilities*, 19 (3), 245-260.

## Balancing

We support the following actions proposed in the consultation document:

- a. Launch CareWise, a Carers Alliance initiative to promote flexible working arrangements.
- b. Develop carers' skills and learning through training and education.

Plunket supports the promotion of flexible working arrangements for families who care for children with special needs. Barriers to childcare for working parents (with children who have a disability) can be attitudinal, material, and physical. Many parents also find formal child-care is rare and almost non-existent, they rely on informal child-care such as family to provide instrumental care and respite<sup>14</sup>.

We recognise that there is a need to develop carers' skills through learning and training. However, we believe there needs to be specific training for primary health care professionals on identification of some types of disability. It has been found some disabilities, such as autism can benefit from early intervention to reduce symptom severity and improve quality of life<sup>15</sup>. This in turn can also reduce carer distress. As early intervention proves to be valuable, we believe upskilling Well Child practitioners on some of the early signs would be beneficial<sup>16</sup>.

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<sup>14</sup> Kagan C., et. al., (1999). Enabled or disabled? Working parents of disabled children and the provision of child-care. *Journal of Community and Applied Social Psychology*, 9(5), 369-381.

<sup>15</sup> Daniels, A.M. & Mandell, D.S. (2013). Children's compliance with American Academy of Paediatrics' Well-Child care visits guidelines and the early detection of Autism. *Journal of Autism Developmental Disorder*, 43, 2844-854.

<sup>16</sup> <https://www.tvnz.co.nz/one-news/new-zealand/new-zealand-first-sees-post-natal-nurses-trained-diagnose-autism>