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## ‘Living well’? Children with disability need far greater income support in Aotearoa

Caitlin Neuwelt-Kearns, Sam Murray, Dr Jin Russell and Jane Lee

Child Poverty Action Group, September 2020

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## About Child Poverty Action Group

Child Poverty Action Group (Inc) (CPAG) is a non-profit group formed in 1994, made up of academics, activists, practitioners and supporters. CPAG has a strong education and research skills base which enables it to contribute to better informed social policy to support children in Aotearoa New Zealand, specifically children who live in poverty.

CPAG believes that the country's high rate of child poverty is not the result of economic necessity, but is due to policy neglect and a flawed ideological emphasis on economic incentives. Through research, CPAG highlights the position of tens of thousands of New Zealand children, and promotes public policies that address the underlying causes of the poverty they live in.

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## About the authors

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Jane Lee is a social worker and also teaches in the School of Health Sciences at Massey University. Jane has a Master of Social Work, and wrote her thesis on single-mother led families with disabled children in Aotearoa New Zealand. Jane lives in Orongamai with her child who is on the autism spectrum.

## List of abbreviations

CDA	Child Disability Allowance	NASC	Needs Assessment and Service Coordination
CPAG	Child Poverty Action Group	OSCAR	Out of School Care and Recreation
DA	Disability Allowance	SLP	Supported Living Payment
FFC	Funded Family Care	UK	United Kingdom
MoE	Ministry of Education	WEAG	Welfare Expert Advisory Group
MoH	Ministry of Health		
MSD	Ministry of Social Development		

## Executive summary

All children in Aotearoa have the right to have every opportunity to thrive. Through its ratification of the Convention on the Rights of the Child, New Zealand formally recognises that children with disability should enjoy “full and decent” lives, “in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community”.

Crucial to ensuring a good quality of life is income adequacy for all whānau. However, the welfare system has been chronically underfunded since the benefit cuts of the early 1990s, and income support mechanisms for people with disability are particularly inadequate. There is a strong relationship between poverty and disability in Aotearoa; disability brings its own expenses, and yet people with disability sometimes receive such meagre incomes that they would consign even people without disability to material hardship. The greatest burden of disability-related unmet need and hardship falls disproportionately on Māori, despite Te Tiriti obligations, and Pacific peoples.

Children with disability are doubly vulnerable to income inadequacy: both as children, and as people with disability. According to the 2013 New Zealand Disability Survey, parents of children with disability are 1.5 times more likely to report not having enough income than all parents (of both disabled and non-disabled children). There are various direct and indirect costs associated with raising a disabled child, including medical and therapy bills, and difficulty engaging in paid work.

However, this poverty-disability link is not inevitable.

Comparisons with other international contexts such as the United Kingdom demonstrate how more generous disability allowances can help to close this gap and ensure disabled children do not face compounding disadvantage. It is imperative that the state provides a robust and accessible system of income support in order to compensate for the costs associated with disability.

This report reviews mechanisms of income support administered by the Ministry of Social Development and the Ministry of Health, highlighting how allowances are far too low and difficult to access. Families and whānau must dedicate significant time and energy to receive what little financial support they are entitled to, creating a system that privileges those who have networks, disposable time and resources, and navigational knowledge of Pākehā systems. Given that Māori and Pacific peoples are disproportionately represented among those with disability, the status quo of an underfunded disability support system is worsening gross inequities in health and economic outcomes.

We are therefore calling for a review of the disability income support system in Aotearoa. Our recommendations centre on the need to make evidence-based decisions about income support mechanisms, with the goal of reducing socioeconomic deprivation among disabled children and among children who live in households with disabled adult/s .

Many of our 11 recommendations could – and should – be swiftly implemented, but they are not a silver bullet to eliminating poverty for disabled children. Given decades of

inadequate support, it will take an ongoing commitment among successive governments to improve the standard of living for these whānau. Such a commitment is vital to ensure children with disability are able to flourish free from poverty. These recommendations are an important place to start.

## Recommendations

- 1: Collect regular, quality data about children affected directly or indirectly by disabilities in Aotearoa. This includes data from outpatient healthcare settings, preschools and schools, and data on the socio-economic status of households with disabled children and/or disabled parents/caregivers. These data need to be reliably disaggregated by ethnicity, age, family composition, locality, and source of income support.
- 2: In line with Recommendation 25 of the Welfare Expert Advisory Group's 2019 report, establish a minimum income standard for the direct and indirect costs of raising a child with disability in New Zealand (with 5-year reviews), based on MSD evidence gathering including commissioning independent research and lived-experience focus groups.
- 3: Increase the base Child Disability Allowance and then set it at a variable rate according to severity of disability.
- 4: Stop prohibiting children from accessing the Child Disability Allowance if their caregivers receive Oranga Tamariki board payments for them.
- 5: Promote and increase access to the Child Disability Allowance via community networks to groups who underutilise it, such as Māori and Pacific people.
- 6: Increase the OSCAR subsidy rate for those children who receive the Child Disability Allowance, and widen its uptake to reach all eligible, especially Māori and Pacific people.
- 7: Set the Disability Allowance at an adequate fixed rate to remove administrative barriers to uptake, and have a higher rate for those with increased disability impairment. Consider renaming this supplementary assistance mechanism for clarity, to avoid confusion with the Child Disability Allowance.
- 8: Individualise all core benefits, including the Supported Living Payment, so that no full-time carer is made ineligible due to the working status of their partner.
- 9: Increase Supported Living Payment abatement thresholds to \$150 and \$250 per week in line with the Welfare Expert Advisory Group's 2019 recommendations.
- 10: Immediately replace the Carer Support subsidy with the 'I Choose' programme as was initially scheduled for 2019, thus enabling carers to manage their own respite through lump sum payments and choose a respite option that suits their own whānau circumstances, especially reaching Māori and Pacific families.
- 11: Investigate and remedy the ethnic disparities in the uptake of the Supported Living Payment for Carers and Funded Family Care.

## Introduction

All children have the right to have every opportunity to thrive. Through its ratification of the Convention on the Rights of the Child, Aotearoa New Zealand formally recognises that children with disability<sup>i</sup> should enjoy “full and decent” lives, “in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community”.<sup>1</sup> However, in spite of this formal commitment, children with disability face many obstacles to full engagement in society. Children with neurodiversity or physical, sensory or intellectual/learning impairments are widely disadvantaged by systemic barriers such as the design of houses and the environment, social exclusion and discrimination. Indeed, a range of factors impact on the wellbeing of disabled children; however, of these various challenges, financial circumstances are among the most crucial in determining the opportunities that children have to flourish both during childhood and later in life.<sup>2</sup>

Children with disability face compounding disadvantage in New Zealand on account of disproportionately living in poverty. While deinstitutionalisation has been advantageous in integrating disabled people into the community,<sup>3</sup> the trend towards care in community-based settings has increased demands on families and whānau without sufficiently increasing support.<sup>4</sup> According to the 2013 Disability Survey, parents of children with disability are 1.5 times more likely to report not having enough income than all parents (of both disabled and non-disabled children).<sup>2</sup> Many caregivers of disabled children require income support to compensate for limited participation in the formal workforce, and for the extra costs associated with raising a child with disability.<sup>4</sup> This need for compensation is particularly acute in single-parent households, in which disabled children are more likely to live than non-disabled children.<sup>5</sup> Early intervention can improve outcomes for disabled children, but poverty makes this much more difficult to achieve.<sup>6,7</sup> There are increased barriers for Māori and Pacific families which need to be remedied.

The correlation between disability and poverty is not inevitable. Appropriate and accessible income support can enable caregivers to provide a decent standard of living for their children, including meeting their disability-related needs.<sup>5</sup> Yet, in New Zealand, the system in its current form is failing these children and their whānau. While NZ may have good intentions – seeking to make this a ‘non-disabling’ country, as enshrined in the NZ Disability Strategy<sup>8</sup> – in practice, support for disabled children is neither comprehensive nor well-resourced and does not reach all eligible families. Fundamentally, payment rates are too low and do not accurately reflect the costs of raising a child with disability. Support is fragmented across different agencies, making the system difficult to navigate, with many people unaware of, and therefore unable to access, their entitlements.<sup>4</sup> Further, the administrative load associated with applying for some of these supports burdens caregivers who are often already juggling financial stresses with the particular care needs of their child.<sup>9</sup>

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<sup>i</sup> This report uses the terms ‘disabled children’ and ‘children with disability’ interchangeably. This decision reflects the varied opinions on terminology, as discussed in the Disability Strategy (2016). While some identify with the term ‘disabled people’ as a source of pride and identity, others prefer the term ‘people with disability’ as it centres the person, not the disability.

The 2020 Health and Disability System Review has been widely criticised among disability advocates, not least for the lack of representation of disabled people on its steering group or review panel.<sup>59</sup> However, despite not going far enough in proposing meaningful changes to the disability system, its agenda-setting is clear: “A focus on living well and preventing the exacerbation of disability should be a priority.”<sup>10</sup> Rather than wrestling with a disabling welfare system, families need adequate financial support in order to ensure their children are able to ‘live well’. In light of this objective, this report discusses the current state of the income support system for children with disability. Specifically, we focus on mechanisms administered by the Ministry of Health (MoH) and the Ministry of Social Development (MSD). In 2019, the Welfare Expert Advisory Group (WEAG) highlighted that the response of the welfare system for those living with disability, and those who are carers for people with disability, has been inadequate.<sup>11</sup> Consistent with WEAG’s conclusion, we highlight some of the shortfalls of the current system, presenting 11 recommendations that would go some way in improving the quality of life of many disabled children and their whānau.

In reviewing literature and providing policy recommendations, we seek to centre some of the first-hand experiences of caregivers affected by the current inadequacies of our income support system. To do so, we have drawn on insights gained through co-author Jane Lee’s 2019 research on experiences of single mothers raising disabled children in Aotearoa (see [Single-mother led families with disabled children in Aotearoa New Zealand<sup>12</sup>](#)). Quotes in this report are drawn from the stories of mothers interviewed as part of this project, and the names used are pseudonyms applied in the original research. These stories illustrate the significant barriers that the current system presents to achieving a good quality of life among families with disabled children.

Such a review is timely in the context of the current global pandemic. Those living with disability are at higher risk of contracting COVID-19 (due, for example, to contact with support workers), and are often more likely to experience serious complications if they do (due to underlying health conditions).<sup>13</sup> If face-to-face health or therapy services are suspended to avoid the spread of COVID-19, this can exacerbate disability, for example by leading to inability to perform daily activities. Further, without policy intervention, crises such as a pandemic exacerbate existing ethnic and socioeconomic inequalities, and past experiences of recessions have demonstrated that those who are already disadvantaged in the labour market – such as the caregivers of children with disability – are the most vulnerable to financial shocks.<sup>14</sup> Now more than ever, therefore, it is crucial that households with disabled family members receive adequate levels of support, in order to mitigate some of the worst impacts of this crisis.

## Defining disability in the New Zealand context

The United Nations Convention on the Rights of Persons with Disabilities broadly defines disability as impairments that may hinder people’s full and effective participation in society on an equal basis with others.<sup>5</sup> A wide variety of conditions are grouped under the term, whether these are short-term or permanent, present at birth or developing later in life. In 2013, according to the NZ Disability Survey, one in four New Zealanders had a disability, including physical, mental, intellectual and sensory impairments.<sup>15</sup>



Despite these official classifications, the term ‘disability’ is disputed. There are many words used to identify disability, reflecting the diverse experiences, histories and opinions among those classified as ‘disabled’ and those working within the sector.<sup>8</sup> The term ‘disability’ has been contentious among some Māori as it is a word that can be traced back to European colonial understandings of ‘abnormality’, terminology that was mobilised to justify the subordination of indigenous peoples.<sup>16</sup> Colonisation led to a loss of Māori understandings of disability; advocates in the Māori disability sector are seeking to reclaim what it is to be Māori and disabled, under the rubric “whānau hauā”, “a uniquely Indigenous Māori perspective on disability that is holistic and based on spiritual, collective and relational values”.<sup>17</sup>

In the context of diverse opinions on terminology and understandings of what it is to be ‘disabled’, the unifying factor among people with disability is the barriers they face in navigating day-to-day life. As expressed in the 2016-2026 NZ Disability Strategy, which was developed in consultation with, and written from the perspective of, disabled people,

“Disability is something that happens when people with impairments face barriers in society; it is society that disables us, not our impairments, this is the thing all disabled people have in common.”<sup>8</sup>

This view of society as disabling (the social model of disability) rather than the individual as disabled (the medical model of disability) has informed approaches to policy and service provision in NZ. Enshrined in the 2001 Disability Strategy, this approach is important as it shifts the onus of responsibility for ensuring accessibility to society itself, rather than to individuals with impairments.<sup>18</sup>

The effects of disability are not felt evenly across the population. Māori experience disability at a higher rate than any other ethnic group in New Zealand, with an age-adjusted disability rate of 32 percent compared to 24 percent for non-Māori.<sup>17</sup> Māori are also more likely to have unmet disability needs; among the disabled population, Māori adults aged 15-64 were roughly 9 percent more likely to have an unmet need to see a health professional than their non-Māori counterparts.<sup>16</sup> Disabled people face a range of barriers to accessing support – some of which are discussed in this report – and such barriers are only heightened for Māori, who disproportionately face challenges such as discrimination within the health system and socioeconomic disadvantage.<sup>17</sup>

Pacific people are similarly overrepresented among the disabled population in Aotearoa. In the 2013 Disability Survey, after adjustments for differences in ethnic population age profiles, Pacific people had higher-than-average disability rates, albeit lower than Māori.<sup>15</sup> After adjustments for differences in age profiles, the rate of disability among Pacific people was 26 percent, compared to 24 percent for NZ/European. Despite having higher rates of chronic disease and premature disability, Pacific populations are less likely than their non-Pacific peers to access disability-related entitlements such as the Child Disability Allowance.<sup>19</sup> Such disparities in health outcomes, coupled with lower uptake of disability supports, mean that the current system is exacerbating socioeconomic inequities for Māori and Pacific peoples.

## Disability and poverty

As highlighted in the 2020 Health and Disability System Review, disabled children are more likely to live in low-income households in NZ.<sup>10</sup> This relationship between poverty and disability is complex. Being born into a socioeconomically disadvantaged family increases the likelihood that a given child will develop chronic conditions.<sup>20</sup> Pākehā children are, on average, socioeconomically advantaged compared to their Māori and Pacific counterparts,<sup>21</sup> and as such, have a decreased likelihood of developing chronic conditions from a young age.

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*“I had some savings but that just went. I should have sat down and figured out how many thousands I’ve spent [on unsubsidised therapy for my son].”*

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– Ruth

Conversely, having a disabled child can itself lead to financial hardship due to the ongoing expenses over and above those normally associated with raising a child. Without a high and sustained income, medical, transport and private care costs can put significant strain on the resources of a family.<sup>3</sup> In some cases, such supports may simply be beyond reach.

This financial strain is even more severe in single-parent households, in which children with disability are more likely to live than non-disabled children. In 2013, 30 percent of children with disability lived in one-parent households, compared with 17 percent of non-disabled children.<sup>5</sup> The pressure of meeting the needs of a disabled child without adequate support can often result in the breakdown of parental relationships.<sup>22</sup> Inadequate support (including financial support) can contribute to relationship breakdown, which can lead to further poverty – thus forming a vicious cycle in the context of child disability.

Beyond the direct costs of having a disabled child, there are opportunity costs associated with not being able to work, exacerbated by the inadequacy of benefit levels. Many households with disabled children are reliant on income support from a main benefit; in the month ending June 2018, MSD data shows that 11,800 of 37,000 children receiving the Child Disability Allowance (CDA) (or 32 percent) lived in households supported by a main benefit other than a Veteran’s Pension or NZ Superannuation.<sup>23</sup> In other words, while not all children with disability will be receiving the CDA, one third of those children who are receiving the CDA live in benefit-dependent households. Given WEAG found that households supported by a main benefit often have insufficient income for basic needs,<sup>11</sup> caregivers of children with disability who are unable to engage in paid work are thus locked into inadequate incomes.

Given the Government’s own emphasis on child poverty elimination, and in light of the relationship between disability and poverty,<sup>24</sup> addressing disability-related inequality must be a priority. It is not just those who are themselves disabled who are affected, the whole whānau is impacted by stretched resources.<sup>17</sup> While in NZ, we do not have reliable data on family composition and disability, CCS Disability Action use the United Kingdom (UK) as a comparable case study, where in 2017/18, 31 percent of children lived in a family where at least one member was a disabled person.<sup>2</sup> Beyond the implications for children with

disability, therefore, disability-related inequality has consequences for their siblings, parents, and wider whānau.

It is not inevitable that being disabled, or having a disabled child in your care, means living in poverty; although for many in New Zealand, this is currently the case. In the UK, for example, households with disabled children are not at greater risk of income poverty. While we cannot directly compare statistics across international contexts, disability-related allowances are paid at a significantly higher rate in the UK, pointing to the importance of adequate income support in breaking the poverty/disability link. In 2018, the median payment rate for children from disability-related allowances in the UK was almost three times that in NZ.<sup>5</sup> It is therefore imperative that we review how well our welfare system is serving whānau with disabled children. As Sam Murray of CCS Disability Action puts it, “the link between poverty and disability can, and should, be broken.”<sup>5</sup>

### Making the disabled child visible

There is very limited data available on the prevalence of disability in Aotearoa. The disability status questions in the 2018 Census are not designed to give us estimates on the number of disabled people. The best source of data on prevalence, disabled children, and the ethnicity of disabled people in NZ comes from the 2013 Disability Survey, with the next scheduled update in 2023. However based on data from Statistics NZ and the 2018 Census, CCS Disability Action estimates that there were about 1.2 million disabled people in 2018.<sup>2</sup>

Data on experiences of disability among children in Aotearoa is similarly slim. CCS Disability Action estimates that in 2018, there were 143,000 children and young people with disability under 20 years old.<sup>2</sup> According to the 2013 Disability Survey, the most common disabilities among children and young people in NZ are related to impaired learning, speaking and developmental delay.<sup>15</sup> While these statistics indicate that almost 12 percent of all children and young people under 20 are directly affected by disability, the number of children indirectly affected is even greater if we consider those who are raised by parents with disabilities. Their numbers are more difficult to estimate.

The recent Health and Disability System Review identified the need for greater visibility of disability at a system level in order to address inequities, stating that it is a ‘high priority’ to improve data collection and the sharing of disability data across government agencies.<sup>10</sup> Indeed as many advocates have long highlighted, a lack of data collection and reporting often renders people with disability invisible in the debate and design of policy.<sup>3</sup> Without quality data, it is difficult to lobby for better services, and it is easier for successive governments to overlook the impacts of policy on children with disability and their whānau.

For instance, children with disability have barely been mentioned in major welfare reforms implemented since 2010, despite these policies having significant implications for this group.<sup>3</sup> From 2010 parents receiving a main benefit have been required to attend job-preparation courses and make themselves available for part-time work when their youngest child turns six, or full-time work when their youngest child turns 14.<sup>17</sup> During debate over these reforms, disabled people – and disabled children in particular, along with all families with high needs or in complex situations – were largely invisible; these work obligations

carry no specific exemptions for caregivers of children with disability or in complex situations, putting immense pressure on those juggling onerous caregiving needs.<sup>3</sup>

Of particular relevance to this project, a lack of data makes it difficult to analyse access to, and efficacy of, existing measures of income support among households with disabled family members. In their 2019 review, WEAG drew attention to a lack of data on children with disability in the welfare system, and take-up rates for disability-related benefits.<sup>25</sup> For example, in some instances MSD only collects data about the caregiver of the child on behalf of whom a disability-related allowance is being administered, rendering invisible the disabled child themselves. Recognising the impact that disability has on the whole whānau, data must be collected about children both directly and indirectly affected by disability in Aotearoa. WEAG among others – such as the Office for the Children’s Commissioner’s 2012 Expert Advisory Group<sup>26</sup> – have thus called for more accurate data collection on child disability in Aotearoa.

**Recommendation 1: Collect regular, quality data about children affected directly or indirectly by disabilities in Aotearoa. This includes data from outpatient healthcare settings, preschools and schools, and data on the socio-economic status of households with disabled children and/or disabled parents. These data need to be reliably disaggregated by ethnicity, age, family composition, locality, and source of income support.**

## Disability and income support in Aotearoa

The relationship between having a disabled child, disproportionate relationship breakdown and socioeconomic disadvantage means that it is crucial that caregivers of children with disability are adequately supported in order to ensure the best possible quality of life for their children. Despite the proven link between disability and poverty, however, current income support measures for children with disability in NZ remain inadequate. While the UN Committee on the Rights of Persons with Disabilities highlights the importance of financial

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*“The case manager [at Work and Income] was trying to tell me that normal single mums live on \$256 per week ... not even rent is less than \$250 a week.”*

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– Lara

support for carers in compensating for limited access to the labour market,<sup>5</sup> parents of disabled children in Aotearoa frequently report having to rely on supplementary forms of assistance in order to make ends meet, such as foodbanks, churches and/or support from family.<sup>3</sup> Seeking these takes extra energy and time, and may involve demeaning processes.

In seeking state-based financial assistance, households with a disabled family member must engage with multiple government agencies. Reviews of the disability support system in NZ – including the recent Health and Disability System Review<sup>10</sup> **Error! Bookmark not defined.** – have found that the system is complex and time-consuming to navigate, and not user-centred.<sup>4</sup> At present, children with disability receive support primarily from Ministry of Education (MoE), MoH and MSD. MoE is responsible for funding various learning-related services for disabled children. MoH provides support through Disability Support Services, particularly Respite

Services and Carer Support; though from June 2020, the parents of children with disability can potentially receive Funded Family Care (FFC) payments, which are direct payments to family caregivers to care for those with high support needs.<sup>27</sup> MSD administers financial support for children with disability and their families, either through direct support or the payment of service providers.

This report focuses on key mechanisms of income support administered by MSD and MoH that specifically assist families with disabled children. It first discusses the CDA and the Disability Allowance (DA), two supplementary support mechanisms administered by MSD, followed by a discussion of the Supported Living Payment (SLP) for carers. It then explores two key forms of support administered by MoH, namely Carer Support and FFC. At present, many of these mechanisms are inadequate and difficult to access, compounding the challenges of having a disabled child, such as high levels of carer stress.<sup>3</sup> In reviewing these payments, we therefore highlight the urgent need for reform of this system to ensure it reflects the true costs, both direct and indirect, of raising a disabled child.

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*“Should I have to start taking medication [for my anxiety] because there is a lack of resources, because there is a lack of support?” – Lara*

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## Ministry of Social Development

### The Child Disability Allowance

The CDA is a fortnightly fixed payment available to caregivers of children with a serious disability in “recognition of the extra care needed” for a disabled child.<sup>28</sup> It is currently set at \$49.26 per week. In order to be eligible, a child must be assessed as needing ‘frequent attention from another person in connection with bodily functions which is required as a consequence of the disability’, ‘attention and supervision substantially in excess of that normally required by a child or young person’, or ‘regular supervision from another person to avoid substantial danger to themselves or others’.<sup>29</sup> This assessment is made first by a registered doctor, and then by Work and Income, with the ultimate decision made by MSD staff who may not have the requisite training, expertise or cultural competency.

The CDA is not means-tested and is paid irrespective of income, assets, or costs. However, families are ineligible for the CDA if they are also receiving board payments from Oranga Tamariki for that child.<sup>28</sup> This anomaly in the eligibility criteria overlooks the fact that disability and Oranga Tamariki care commonly co-exist and must be supported through separate funding streams; there are extra costs associated with raising a child with disability irrespective of how they came to be in that caregiver’s care. This exception is therefore discriminatory and unfairly disadvantages disabled children who are also in care.

The ambiguous goal of the CDA – to ‘recognise’ the care and attention a disabled child requires – perhaps in part explains its lack of success as an income support mechanism. As the CDA does not explicitly set out to address disability-related poverty, MSD does not collect data on the level of socioeconomic deprivation among families with disabled children, nor does it evaluate the sufficiency of the CDA rate in preventing families from

falling into poverty due to disability-related costs. The current CDA rate can be traced back to the original rate set in October 1978 as \$8 per week.<sup>30</sup> Since then the original rate has simply been inflation adjusted, albeit slightly imperfectly; it should be \$50.77 (rather than \$49.26) if fully inflation adjusted.<sup>31</sup> There has been no attempt to update the rate to reflect modern circumstances beyond inflation adjustment. Instead, we rely on a decision in 1978 being appropriate for today. Unsurprisingly, the CDA rate is inadequate and does not reflect the costs associated with having a disabled child, such as accessing occupational, speech language or behavioural therapy for children with disability where this is not readily available in the public health system.

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*“It would also be nice if organisations talked to each other and I think that even when you first get your diagnosis, you got an information pack that said ‘these are the services’. I know so many people who don’t know about things like the Child Disability Allowance and things like that.”* – Vera

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The baseline CDA rate must therefore be increased, and should be paid at variable rates according to the degree of burden of disability. In 2019, WEAG recommended that the level of income support provided by the CDA be increased, and that three rates of payment be introduced to reflect differing degrees of need (low, medium and high).<sup>4</sup> In the UK, for instance, the Disability Living Allowance for children is paid at a variable rate, reflecting a recognition of the diversity of ability and consequent financial demand among children with disability. Lifting the base rate and enabling variation in rate of payment as is done in the UK would therefore better

reflect the financial realities of raising a disabled child.<sup>5</sup>

Uptake of the CDA is relatively low among families with disabled children, in part reflecting the lack of easily accessible information about disability supports. The 2020 Health and

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*“You’re never told what you are entitled to, you have to try and figure it out yourself. Basically, I thumb a ride through Facebook and ask other parents what they got and how they got it.”* – Lara

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Disability System Review highlighted the lack of centralised information for disabled people, with many – in particular, Māori and Pacific – struggling to access information about their entitlements.<sup>10</sup> Lack of awareness is a key barrier to access; a 2016 CPAG Ōtara-based study found that 82 percent of participants who had children with a disability or chronic health condition were unfamiliar with the CDA and/or unaware that they could receive assistance from Work and Income at all.<sup>9</sup> As at 30 June 2019, there were 38,427 children whose

parents were receiving the CDA,<sup>32</sup> only roughly 25 percent of the total number of children with disability according to CCS Disability Action’s estimates.<sup>2</sup> Efforts must therefore be directed to ensuring information is more readily available about entitlements, both to ensure eligible families are aware of what they can access, and also to minimise the burden among caregivers of having to seek information from various dispersed sources.

**Recommendation 2:** In line with Recommendation 25 of the Welfare Expert Advisory Group’s 2019 report, establish a minimum income standard for the direct and indirect costs of raising a child with disability in New Zealand (with 5-year reviews), based on MSD evidence gathering including commissioning independent research and lived experience focus groups.

**Recommendation 3:** Increase the base Child Disability Allowance and then set it at a variable rate according to severity of disability.

**Recommendation 4:** Stop prohibiting children from accessing the Child Disability Allowance if their caregivers receive Oranga Tamariki board payments for them.

**Recommendation 5:** Promote and increase access to the Child Disability Allowance via community networks to groups who underutilise it, such as Māori and Pacific people.

#### *CDA and the OSCAR subsidy*

The Out of School Care and Recreation (OSCAR) subsidy is a payment administered by Work and Income designed to help families with the costs of before and after school care, and school holiday programmes. This payment is designed to support low- and middle-income families with the cost of childcare in order to enable caregivers to work or study.<sup>33</sup> The amount of money a family can receive depends on family size, household income and how many hours per week a child goes to childcare. For most children, the OSCAR subsidy cuts out at age 14, but a child receiving the CDA can receive OSCAR funding until age 18.<sup>33</sup>

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*“I would be keen to do some part time work, probably teacher aiding, something to give back. But I need to find something that will fit in around my son, that’s my biggest challenge.” – Vera*

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Many parents of disabled children, including those quoted in this report, express a desire to work to enhance their sense of purpose and independence, yet face significant challenges in accessing affordable childcare. While the OSCAR system acknowledges the higher caring needs for disabled children through enabling subsidised care up to age 18, it provides a flat rate for all children, which does not factor in the extra support needed on a day-to-day basis by many children with disability. For children with disability who need extra assistance in a childcare setting, finding an OSCAR provider that will take a child for the base rate may be extremely difficult. This may mean that parents of children with disability either must pay for childcare out of their own pockets, or care for their children themselves. The unemployment rate for primary carers of children with disability is high compared to carers of non-disabled children – an unemployment rate of 17 percent as reported in the 2013 Disability Survey<sup>15</sup> – and 30 percent of disabled children

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*“You can’t put these kids into after-school or before-school care, so there is no real allowance for that extra cost that goes on parents who are trying to pay for a nanny. That is one of the biggest barriers, as to why a lot of single mums wouldn’t go out and work.” – Lucy*

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lived in one-parent households in 2013.<sup>15</sup> Ensuring that these parents are able to access subsidised childcare is crucial to improving employment outcomes.

Uptake of the OSCAR subsidy among families receiving the CDA is poor. In the June 2019 quarter, only 5.5 percent of the total number of children receiving the CDA were also receiving an OSCAR subsidy.<sup>34</sup> This is concerning given that disabled children are overrepresented in low income households in New Zealand. In order to increase uptake of the OSCAR subsidy among families with disabled children and improve employment outcomes for carers, there needs to be a higher subsidy rate for children receiving the CDA. The costs of doing so are likely to be at least somewhat offset by increased workforce participation among carers, and consequently lowered spending on benefits. While there are inevitably carers for whom work is not appropriate, this change would help to enable those who do wish to work but currently cannot afford to do so.

**Recommendation #6: Increase the OSCAR subsidy rate for those children who receive the Child Disability Allowance, and widen its uptake to reach all eligible, especially Māori and Pacific people.**

#### The Disability Allowance

The DA is a weekly payment for people who have ongoing costs due to a disability, such as medical bills or transport. A disability must be likely to last at least 6 months in order for an individual to be eligible.<sup>35</sup> Caregivers can apply on behalf of their dependent children, and if eligible, families can receive both the DA and the CDA for the same child. Unlike the CDA, the DA is means-tested, and households must be below the annually-indexed income limits in order to be eligible (see Table 1 for current thresholds). Above these thresholds, individuals lose eligibility altogether; in other words there is an immediate 100 percent abatement.<sup>36</sup>

**Table 1: Income thresholds for Disability Allowance. Source: MSD<sup>35</sup>**

Your situation	Weekly income limits before tax
Single 16-17 years	\$549.57
Single 18+ years	\$676.61
Married, civil union or de facto couple (with or without children)	\$1,006.82
Sole parent 1 child	\$766.47
Sole parent 2+ children	\$807.54

The rate of payment for the DA is calculated on an individual basis based on verification of costs. MSD require receipts for expenses, meaning that often families are required to pay the costs themselves upfront, and then claim expenses back. Many recipients report that the DA is inadequate to meet their disability-related costs.<sup>9</sup> While the maximum weekly payout is \$65.36, very few children receive this maximum amount. For instance, as at June 2018, the median rate of DA payment for children 17 and under was \$15.50.<sup>32</sup> Similar to their recommendations for the CDA, WEAG recommended that the DA be increased with



the introduction of three rates (low, medium and high) related to the degree of burden of disability or care needed.<sup>4</sup>

At present, uptake of the DA is not as high as it could be.<sup>9</sup> While a disabled child may technically be eligible for both allowances, in practice, few children do receive both. As at June 2019, only 8 percent of those children receiving the CDA were also receiving the DA.<sup>32</sup>

### **Box 1: The Disability Allowance and mental health counselling support**

An individual who is not eligible for funded counselling under the ACC sensitive claims process, or via a specialist mental health service, may be eligible to claim the Disability Allowance for counselling costs so long as they do not exceed income thresholds.<sup>56</sup> The application process requires the affected individual to attend a Work and Income office with the appropriate paperwork, which includes a signature from their specialist doctor or general practitioner. This initial application is capped at 10 sessions, meaning that in order to access further sessions, they must re-apply through Work and Income. Given widely documented experiences of stigmatisation, excessive wait times and difficulty advocating for entitlements when attending Work and Income offices,<sup>37 38</sup> this process potentially poses particularly high barriers for people attempting to access funding for support for mental distress.

As is the case with all Disability Allowance entitlements, people must pay counselling expenses themselves and claim back costs. Beyond the administrative burden of this process, this assumes that people can afford to pay service fees upfront, creating a financial barrier for those who do not have the disposable income. Further, the maximum amount one can claim per week through the Disability Allowance (\$65.36 at the time of publishing) means that many must top up this allocation with co-payment in order to afford sessions and to pay for any travel required. This renders counselling simply unaffordable for some.

Uptake of the Disability Allowance for counselling costs is decreasing over time. According to an Official Information Act request, the number of costs claimed for counselling decreased by 30 percent between the end of the September 2013 financial quarter and the June 2018 quarter.<sup>58</sup> This decrease in uptake is concerning given increasing mental distress among children and young people in New Zealand; for example, the Ministry of Health reports that while in 2012, five percent of 15-24 year-olds reported psychological distress, in 2017 this figure was almost 12 percent.<sup>57</sup> There is a correlation between socioeconomic deprivation and poor mental health outcomes, reinforcing the need for adequate income support to ensure cost is not a barrier to accessing counselling. The recently published Youth19 survey results demonstrated that high school students in deprived areas are more likely to experience mental distress.<sup>3939</sup> The Disability Allowance must therefore be made more accessible, with rates of payment reflecting the true costs of disability treatment such as counselling, so that all children and young people – not just those who are well-resourced – are able to get the support they need.

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*“I wasn’t getting any Disability Allowance, it was really hard. They needed some reports from the doctors that my grandson goes to. So I went through all that channel, and when I got it, they had to back-pay me for two years.” – Rose*

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Various barriers to uptake of the DA have been identified. These include the high administrative burden, and distrust and reluctance to engage with MSD.<sup>4</sup> The laborious process of reclaiming expenses is a common barrier to accessing the allowance, as it requires more time than people can afford and may be especially difficult where English is a second language. The fact that the DA is not a fixed payment means that caregivers must negotiate the bureaucracy of Work and Income and medical providers on an ongoing

basis in order to access their entitlements.<sup>3</sup> See Box 1 for an example of how this bureaucracy can present significant difficulties for people in claiming back disability-related costs.

Beyond this burden of claiming expenses through the DA process, there is also evidence of confusion over the eligibility of disabled children for the DA among health practitioners and families alike due to its inconsistencies with the CDA. Given the naming, there is sometimes an assumption that the DA is for disabled adults only, as the CDA is for children with disability only.<sup>5</sup> Moreover, as the DA is means-tested, unlike the CDA, Wynd reports that doctors sometimes overlook this form of assistance as it requires consideration of the families’ circumstances, not just the child’s disability.<sup>3</sup>

There is also evidence of ethnic inequality in access to the DA. For the last decade, Pākehā have received higher median and average payment rates from the DA than Māori and Pacific people. Between the March 2010 quarter and the March 2020 quarter, for working age disabled people, Pākehā median payment rate were 1.4 and 1.6 times higher than for Māori and 2.1 and 2.4 times higher than for Pacific Peoples.<sup>40</sup> This is likely to be linked to the complex application process which relies on people having good access to primary care to begin with. Māori and Pacific people are more likely to experience barriers in accessing general practice clinics, including transport and cost, but also experiences of discrimination.<sup>41, 42</sup> The best way to eliminate the current inequality is to base DA eligibility on having a disability, set it at an adequate fixed rate, increasing for increasing disability impairment and remove the current requirements around the verification of costs.

**Table 2: People receiving the Disability Allowance aged 18 to 65. Source MSD<sup>32</sup>**

	Māori	Pākehā	Pacific	Other	Unspecified
<b>Average weekly rate</b>	\$19.42	\$22.79	\$14.68	\$19.56	\$18.99
<b>Median weekly rate</b>	\$9.95	\$13.68	\$6.25	\$9.80	\$9.60
<b>Number of Disability Allowances</b>	25,066	52,577	5,355	16,599	2,802

**Recommendation #7: Set the Disability Allowance at an adequate fixed rate to remove administrative barriers to uptake, and have a higher rate for those with increased disability impairment. Consider renaming this supplementary assistance mechanism for clarity to avoid confusion with the Child Disability Allowance.**

#### Supported Living Payment

The SLP is a core benefit available for disabled adults, but also for caregivers of those with disabilities. In order to be eligible as an SLP carer, individuals must be caring full-time for someone that would otherwise need hospital or residential-level care who is not their partner.<sup>43</sup> SLP carers make up 10 percent of all SLP recipients.<sup>4</sup> Not all of these will be carers of dependent children, but as MSD only collects demographic information about the carer and not the person being cared for, we cannot know the number of people receiving the SLP on behalf of a child with disability.

The SLP is means-tested, with carers subject to the gross income cut-out points in Table 2, beyond which they are not eligible. These are joint-income tests, meaning that carers with a working partner would be unlikely to qualify even if they are caring full-time for a severely disabled child.<sup>4</sup> SLP payment rates are also abated according to the thresholds outlined in Table 3. The Welfare Expert Advisory Group concluded that these thresholds were too low, recommending that they be increased to \$150 and \$250 per week respectively rather than the current \$115 and \$215 thresholds.<sup>11</sup>

**Table 3: 2020 Gross weekly income cut-out points for Supported Living Payment.**

Source: MSD<sup>44</sup>

Category	Net weekly benefit	Gross income cut-out point	
		Per week	Per year
Single, 16 - 17 years	\$253.31	\$535.00	\$27,769.00
Single, 18+ years	\$307.14	\$611.00	\$31,768.00
Married, civil union or de facto couple (without children)	\$495.22	\$880.00	\$45,740.00
Married, civil union or de facto couple (with children)	\$522.08	\$918.00	\$47,735.00
Married, civil union or de facto couple, with non-qualified partner (with children) or Married, civil union or de facto couple, with partner on New Zealand Superannuation or Veterans Pension (with children)	\$274.46	\$957.00	\$49,729.00
Sole parent	\$422.50	\$776.00	\$40,338.00

**Table 4: Abatement thresholds for Supported Living Payment. Source: MSD<sup>45</sup>**

Income	Abatement rate
Up to \$115 per week	Unabated
Between \$115 and \$215 per week	Benefit reduced by 30 cents for each \$1.00 of income
Income over \$215 per week	Benefit reduced by 70 cents for each \$1.00 of income

**Recommendation 8: Individualise all core benefits, including the Supported Living Payment, so that no full-time carer is made ineligible due to the working status of their partner.**

**Recommendation 9: Increase Supported Living Payment abatement thresholds to \$150 and \$250 per week in line with the Welfare Expert Advisory Group’s 2019 recommendations.**

## Ministry of Health

### Carer Support

Carer Support is a subsidy provided by MoH that funds respite for full-time carers. It reimburses partial costs of a paid support worker to give those carers who usually provide more than 4 hours per day unpaid care a break.<sup>46</sup> Carers are expected to have to pay a ‘top-

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*“In terms of carer support, the amount that you get paid is not enough to cover a professional person, and I couldn’t top it up. There’s no way I could top it up.” – Vera*

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up’ for the service.<sup>47</sup> The subsidy itself is inadequate for hiring a support worker to provide respite; the Carer Support subsidy currently pays around \$76 per day (which can be anywhere between 8 to 24 hours of care), a rate unchanged in 22 years.<sup>48</sup> Many private carers ask for \$20 to \$25 per hour, meaning many low-income carers are unlikely to afford the financial contribution necessary to access this subsidy.

The Carer Support subsidy is widely acknowledged as being dysfunctional and is overdue for an overhaul. MoH was set to roll out a replacement programme, ‘I Choose’, also known as a ‘flexible respite budget’, in 2019.<sup>49</sup> This scheme would give families more control over how money is used by paying out lump sums once or twice a year. It would reduce administrative burden, and enable more flexibility in the types of respite taken.<sup>48</sup> Indeed the 2020 Health and Disability Review reiterated the need to give people more freedom to manage their own support, pointing to the importance of such a reform.<sup>10</sup>

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*“Who are you going to find for \$76 [for an eight-hour care period]?” – Lara*

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However, the implementation of I Choose was stalled following concerns over funding. Creating a more user-friendly system meant that more carers would take up the scheme, thus costing more; while the Carer Support system was allocated \$45 million a year, it only ever paid out \$35 million due to the barriers faced by carers to finding and using respite.<sup>49</sup> As such, MoH has put the

scheme ‘on hold’ indefinitely, sidelining the wellbeing of carers, particularly those on low incomes.<sup>48</sup>

**Recommendation 10: Immediately replace the Carer Support subsidy with the ‘I Choose’ programme as was initially scheduled for 2019, thus enabling carers to manage their own respite through lump sum payments and choose a respite option that suits their own whānau circumstances, especially reaching Māori and Pacific families.**

### Funded Family Care

FFC provides funding for some disabled people to employ family members over 16 to provide them with care and support.<sup>4</sup> Since June 2020, eligibility has extended to family members caring for children with disability.<sup>50, 51</sup> A child must have 'high' or 'very high' support needs in order to be eligible for this payment, and as such only a smaller subset of children with disability in Aotearoa would be potentially eligible. Eligibility is assessed by Needs Assessment and Services Coordination (NASC) services, which are organisations contracted by MoH.<sup>4</sup> A family funded carer can be a parent or other family member 16 or older that lives with the eligible child, and a disabled child may have more than one family funded carer fulfilling their FFC hours. Previously, individuals eligible for a funded family carer had to be 18 years or older and the eligibility change may reduce poverty amongst whānau with disabled children who have high and very high support needs, but it is too early to tell.<sup>52</sup>

Within the changes to FFC implemented in 2020, pay rates have also been lifted from the current minimum wage to new rates of between \$20.50 and \$25.50 per hour, depending on a carer's qualifications.<sup>52</sup> These new rates close the gap between family carers and those employed by formal providers. A funded family carer is generally paid for up to 40 hours per week, however in some cases exceptions will be granted by a NASC.<sup>47</sup>

This boost to pay rates for funded family carers is significant, and recognises the hard work of many caregivers that has previously gone under-recognised. However following these changes, there is now a sizeable gap between the SLP and FFC payments. SLP is an income support payment and is generally much lower than what a carer could receive through a FFC wage.<sup>4</sup> As at 14 April 2020, the gross weekly rate for a sole parent carer receiving the SLP is \$489.50,<sup>53</sup> whereas the same carer could receive anywhere between \$820 and \$1,020 in gross wages for a 40 hour week under FFC.

This gap is of concern and in urgent need of investigation due to the ethnic disparities in uptake between the two income support mechanisms. Māori are significantly overrepresented among SLP carers, and underrepresented among FFC recipients. In 2018, European/Other made up 61 percent of FFC recipients, while Māori were 18 percent.<sup>54</sup> By contrast, as at 30 June 2019, only 42 percent of SLP carers identified as European/Other, while Māori were 38 percent of SLP carers.<sup>34</sup> This difference in uptake must be investigated in order to prevent the exacerbation of ethnic inequalities for carers over time. In general, now that FFC has been opened up and pay rates improved, MSD needs to review the situation of SLP carers to reduce inequality between the two.

**Recommendation 11: Investigate and remedy the ethnic disparities in the uptake of the Supported Living Payment for Carers and the more generous Funded Family Care.**

## The way forward

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*“Quality of life is definitely me having a social life and something that is for me, as well as my job. Also being able to provide for my kids.”* – Lucy

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While Aotearoa is well-intentioned in seeking to become a non-disabling society, we are far from realising the vision of the Disability Strategy.<sup>8</sup> Many disabled children continue to live in poverty, and Māori and Pacific whānau and families are bearing the brunt of the burden without accessing support. Raising a disabled child is financially demanding, with extra costs such as medical and therapy bills and transport putting a strain on family resources. Further, the practical demands of raising a child with disability often make it more difficult to maintain full-time employment,

and in many cases can lead to relationship breakdown. All these factors undermine the quality of life for disabled children and their carers.

The link between poverty and disability is not inexorable, as countries such as the UK demonstrate; however, a robust system of income support for carers is needed to overcome this cycle. Rates of payment from subsidies administered by MSD and MoH are inadequate and do not accurately reflect the direct and indirect costs of raising a child with disability. At present, a lack of data collection on the socioeconomic status of households with disabled children means that these costs are not known, and therefore not accounted for, within the current system of income support. In order to bolster the disability support system, therefore, the government must commit to gathering evidence on the experiences of people raising a disabled child, in order to ensure allowance rates are evidence-based and not arbitrarily set.

Moreover, income support mechanisms for families with disabled children must be made easier to access. At present, various administrative barriers make eligibility difficult to decipher, and payments laborious to apply for. The design of the current system means that support is most accessible to families with disposable time and resources to navigate the system and advocate for their entitlements. Assistance is therefore not being provided to those who need it most, exacerbating inequities particularly for Māori and Pacific whānau. It is time to change this discriminatory situation.

In the 2019 Child and Youth Wellbeing Strategy, Rt Hon Jacinda Ardern stated that “Ensuring we love, care and nurture all our children and young people throughout their lives is the most important task we have.”<sup>55</sup> Disabled children cannot be left out of this equation, and indeed their wellbeing must be prioritised, consistent with the current Coalition Government’s own focus on child poverty reduction. This report has highlighted the urgent need for up-to-date data on affected children and whānau; and reconsideration of income support mechanisms and how they serve families with children with disability. The adoption of our 11 recommendations for reform would reflect significant progress in breaking the disability-poverty cycle, ensuring all disabled children are provided with opportunities to ‘live well’ in Aotearoa.

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