



CPAG 2023 Policy Brief on disability support

Stop driving disabled children into poverty

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VISION

All tamariki will grow up surrounded by loving, thriving whānau within supportive communities where there are resources, opportunities and systems to enable them to live self-determined lives and futures.

CPAG acknowledges that tamariki Māori and whānau have unique rights as tangata whenua, affirmed within He Whakaputanga and Te Tiriti o Waitangi. The significant inequities in well-being outcomes and child poverty for tamariki Māori are the result of ongoing colonisation, systemic racism and neglect. Reducing child poverty in Aotearoa requires our country to address the inequitable distribution of power and resources that prevents Māori from flourishing.

ISSUES — THE CURRENT REALITY

The state discriminates disproportionately against disabled people, including children, and locks them into poverty.

Over one in five disabled children are burdened with material hardship (poverty), and nearly one in ten experience severe hardship. These rates are much higher than for non-disabled children (Figure 1) – pointing to systemic discrimination – and this inequity has increased rapidly since the beginning of the COVID-19 pandemic.¹

Figure 1: NZ Rates of Children Living in Material Hardship, by Disability Status, June 2022 (StatsNZ)



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This hardship is not experienced equally across groups. Tamariki Māori have inequitably high reported disability rates.² Moreover, it is likely that the rates of disability for both tamariki Māori and Pacific children are higher than is reported.³

BARRIERS REQUIRING POLICY ACTIONS: INADEQUATE AND INACCESSIBLE SUPPORT OVER THE LIFE COURSE

Currently the state meets only limited disability costs, leaving whānau of disabled children to attempt to meet most of the additional costs associated with their child's disability by themselves.

These costs range from needed equipment, medicines, travel for healthcare appointments, education, expenses related to dietary needs and physical therapies to taking unpaid leave from employment to provide needed care and support. Via these additional costs, the state is placing financial strain on whānau. Even where state-funded support is available, it is inadequate, difficult to access and the experience of trying to access it is often experienced as actively hostile.

The establishment of Whaikaha Ministry of Disabled People (Whaikaha) is welcome and offers hope for much-needed simplification of support and better accessibility. However, the Ministry will make very little difference unless resourcing for the entire disability sector is increased by an order of magnitude, given the ongoing and woeful systemic neglect of disabled people and their rights.

“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.” – Parent of a disabled child⁴

1. Inadequate financial support

Targeted financial supports for disabled children are inadequate. The [Disability Allowance](#) (up to \$75.10 per week, criteria includes supplying receipts and being on low income; level depends on income and disability needs) and [Child Disability Allowance](#) (a separate payment) must be accessed via Work and Income but no one agency is responsible or accountable for families receiving them.

They are administratively burdensome to apply for,⁵ and do not cover the additional costs borne by whānau.

The [National Travel Assistance Scheme](#) can only be accessed post-travel and the reimbursement amount (28c/km) does not accurately reflect travel costs. There have been repeated calls for increases in these allowances because of their inadequacy.⁶

[Carer support](#) provides reimbursement for some of the costs (often inadequate) of using a support person to care and support a disabled person, but access is inconsistent and varies hugely between localities.⁷

Education-related funding for disabled children is reliant on a successful Ongoing Resource Scheme (ORS) application, yet 1 in 3 ORS applications are routinely denied by the Ministry of Education, leaving children, teachers and parents struggling.⁸

The Out of School Care and Recreation (OSCAR) subsidy rate is not higher for children with disabilities, and therefore is inadequate to meet their care needs, limiting the capacity of parents of disabled children to accept paid work.⁹

2. Inaccessible support

Child disability-related support is fragmented across multiple agencies and services (education, health, social development, disability), making the full range of support needed for disabled children extraordinarily hard to reach, and family location can be an additional barrier.

Each part of the system is difficult to navigate and requires knowledge of specific services as well as agency-specific documentation and assessment. There is no cohesive mechanism for ensuring that whānau are aware of and can access their entitlements.¹⁰

Whānau Māori face discrimination and racism; experience the medicalised process of needs assessment as culturally inappropriate; and are faced with some health professionals whose expressed view of disability as a deficit is at odds with the whānau view drawn from te ao Māori.¹¹

Lack of support to navigate these systems exacerbates all existing inequities. For example, while the Child Disability Allowance is not means-tested, MSD admits that it is “not overtly promoted to families with disabled children”.¹²

In 2016, CPAG found that the system had not disclosed the existence of the Child Disability Allowance to over 80% of families with disabled children in Ōtara (a low-income Auckland suburb with a high Pacific population).¹³ Carer Support funding comes from Whaikaha, yet claims have to go to Manatū Hauora (Ministry of Health); each locality administers this differently.

3. Life course barriers

Disabled youth are half as likely to be supported by the educational system to attain formal qualifications before leaving school, and four times as likely to be “NEET” – that is, to Not be in Employment, Education or Training.¹⁴ This lack of educational support has implications for the life course of the disabled young person – disabled people are more likely than non-disabled people to live in poverty throughout their lives.



RECOMMENDED POLICY ACTIONS

1: Increase financial support for disabled children to adequate levels

Substantially increase financial supports for disabled children to fully cover the extra everyday living costs associated with having a disability. That is, **immediately increase**

- The **Child Disability Allowance** to restore its original (1978) value, fully indexed annually. In 2022, this would have lifted it from \$52.76 to ~\$82 per week.
- The **Disability Allowance** to an adequate fixed rate (\$72.10 retrospectively, fully indexed from when this amount was set), not requiring receipts, to all eligible people, and ensure it is fully indexed annually.
- The **National Travel Assistance Scheme (NTAS)** from 28c/km to 83c/km (the current IRD self-employed guideline), and index it to the IRD rate in future.
- **Ongoing Resource Scheme (ORS)** funding to cover adequately all children who are disabled, and extend this scheme to all disabled children in early childhood care and education (ECCE).
- the **Out of School Care and Recreation (OSCAR)** subsidy rate for those children also receiving the Child Disability Allowance.

Mandate Whaikaha to commission independent research and focus groups to establish actual disability costs. Review this every 2 years.

Ensure all families have liveable incomes (see relevant CPAG 2023 Policy Briefs at www.cpag.org.nz/policybriefs).

2. Ensure all whānau receive timely and adequate disability-related support appropriately tailored to them and their child. Simplify the mechanisms and improve accountability for identifying, finding and accessing supports for disability and for reducing inequities

- Establish one disability centre within each relevant Ministry: Education, Social Development, Health, each reporting to Whaikaha. Resource Whaikaha to create an effective integrated data system supporting families with disabled children so that data on education, housing, health, and financial assistance are all together, to see what's missing, and what might be needed in future.
- Resource and mandate Whaikaha to be responsible for coordination for each whānau and family who needs it, including navigators to help families through diagnosis, needs assessment, and securing funding.
- Resource and mandate Whaikaha to collect data and report annually on progress towards equity of uptake of tailored supports, by ethnicity, location and socioeconomic disadvantage.
- Whaikaha and Te Whautu Ora to ensure needs assessment services are joined up across the country and use the same systems for assessing and allocating funding in each locality.

- Resource and mandate Whaikaha to ensure all families get the Child Disability Allowance for their disabled children – via actively promoting it, prioritising appropriate targeted promotion for equity groups, and monitoring and reporting its provision.
- Resource all disability support programmes (e.g. Respite, Carer Support, Enabling Good Lives) adequately and ensure equity of access throughout the country.
- Whaikaha and Te Whatu Ora to engage in commissioning processes that privilege disabled people and disabled-led organisations.

3. Improve professional expertise and support

- Mandate specialised training in disability needs for all professionals who have face-to-face interactions with families of disabled children, such as teachers in ECCE, schools, care-givers (including in after-school care), GPs and other community health professionals, social workers, Work and Income staff, etc. Ensure all are well informed about disability supports, and have a clear process for assisting families.
- Establish clear and easy-to-access feedback procedures for families with disabilities to give feedback and complaints about their treatment – without retribution.

IMPACTS AND INDICATORS

If implemented, these actions would be steps towards moving Aotearoa to be a nation where all children and families flourish free from poverty.

- Disabled children will be no more likely to experience material hardship than other children. Indicator: StatsNZ child poverty statistics.
- Disabled children will have better life outcomes on average than they do currently. Indicators: StatsNZ Disability Surveys and NEET statistics.

Stopping the impoverishment of disabled children, whānau and families is an essential step towards:

- The Crown addressing te Tiriti o Waitangi obligations
- New Zealand meeting its obligations under the UN Convention on the Rights of Persons with Disabilities
- New Zealand meeting its targets for UN Sustainable Development Goal 1: “End Poverty in All Its Forms Everywhere”; Goal 2: “End Hunger”; and Goal 10: “Reduce inequality”.¹⁵
- The national vision “that New Zealand be the best place in the world for children and young people”.¹⁶

References

- ¹ See StatsNZ (2023), [Measuring child poverty: Concepts and definitions \(second edition\)](#) for explanations of the differences between material hardship and income poverty.
- ² StatsNZ (2014). [Disability Survey: 2013](#) (The next survey is due to be held in 2023.)
- ³ For example, there are barriers to Pacific families accessing the Child Disability Allowance (CPAG, 2016), so a count of CDA recipients will under-indicate the number of Pacific children eligible.
- ⁴ Lee, J. (2019). [Single-mother led families with disabled children in Aotearoa New Zealand](#). Massey University Masters thesis (social work), quoted in Neuwelt-Kearns et al. (2020).
- ⁵ For example, there is evidence to suggest that the Child Disability Allowance is particularly inaccessible for Pacific and Asian families, assuming the rate of serious disability among children is the same for all ethnicities, and that MSD and StatsNZ data uses the same ethnicity definition. Supporting the indication of inequity, geographically Auckland is underrepresented in CDA take-up (where the majority of Pacific and of Asian families live), accounting for only 25% of CDA take-up but for 34.6% of all children in NZ (with and without disability). See MSD (2022b), [23/11/2022 - Request for information regarding the Child Disability Allowance \[DATA\]](#) (Excel 13.16KB); total child population numbers from StatsNZ (2023) [Child Poverty Statistics: Year Ended June 2022. Table 1.03](#).
- ⁶ See for example: Neuwelt-Kearns et al. (2020); Wynd, D. (2014), '[It shouldn't be this hard': children, poverty and disability](#)' CPAG; Murray S. (2018), [Breaking the link between disability and child and whanau poverty](#). Policy Quarterly, vol 14:4; Welfare Expert Advisory Group (2019), background paper [Current state: the welfare system and people with health conditions or disabilities](#); Welfare Expert Advisory Group (2019), [Whakamana Tāngata](#) Recommendation 40.
- ⁷ Synergia (2022). [The state of caring in Aotearoa: A report for Carers NZ and the Carers Alliance](#), August 2022.
- ⁸ McCulloch, G. (2022). '[It's a broken system': More than a third of disabled children funding applications denied](#)'. Stuff, 3 December 2022.
- ⁹ Neuwelt-Kearns, C., Murray, S., Russell, J., Lee, J. (2020). [Living well'? Children with disability need far greater income support in Aotearoa](#). CPAG, NZ.
- ¹⁰ Neuwelt-Kearns, C., Murray, S., Russell, J., Lee, J. (2020). [Living well'? Children with disability need far greater income support in Aotearoa](#). CPAG, NZ.
- ¹¹ Ingham, T. R., Jones, B., Perry, M., King, P. T., Baker, G., Hickey, H., ... & Nikora, L. W. (2022). [The Multidimensional Impacts of Inequities for Tāngata Whaikaha Māori \(Indigenous Māori with Lived Experience of Disability\) in Aotearoa, New Zealand](#). *International Journal of Environmental Research and Public Health*, 19(20), 13558.
- ¹² MSD (2022a). [23/11/2022 - Request for information regarding the Child Disability Allowance](#) (PDF 1.45MB).
- ¹³ Suri, J., & Johnson, A. (2016). [Barriers to Support: uptake of the child disability allowance in Otago](#). CPAG, NZ.
- ¹⁴ Statistics NZ (2017), "[Forty-two percent of disabled youth not earning or learning](#)".
- ¹⁵ United National Sustainable Development Goals. [sdgs.un.org/goals](#) Relevant targets for Goal 10 include "10.2 By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability..." and "10.3 Ensure equal opportunity and reduce inequalities of outcomes...".
- ¹⁶ NZ Government (2019). [Child and Youth Wellbeing Strategy](#).