The Cost of Exclusion: Hardship and People with Intellectual Disability in New Zealand

Research report

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Cover Art:

Mark Burton
Windows and Reflections

Abstract, geometric and architectural.

Contents

Disclaimer

These results are not official statistics. They have been created for research purposes from the Integrated Data Infrastructure (IDI) which is carefully managed by Stats NZ. For more information about the IDI please visit https://www.stats.govt.nz/integrated-data/.

Access to the data used in this study was provided by Stats NZ under conditions designed to give effect to the security and confidentiality provisions of the Data and Statistics Act 2022. The results presented in this study are the work of the author, not Stats NZ or individual data suppliers.

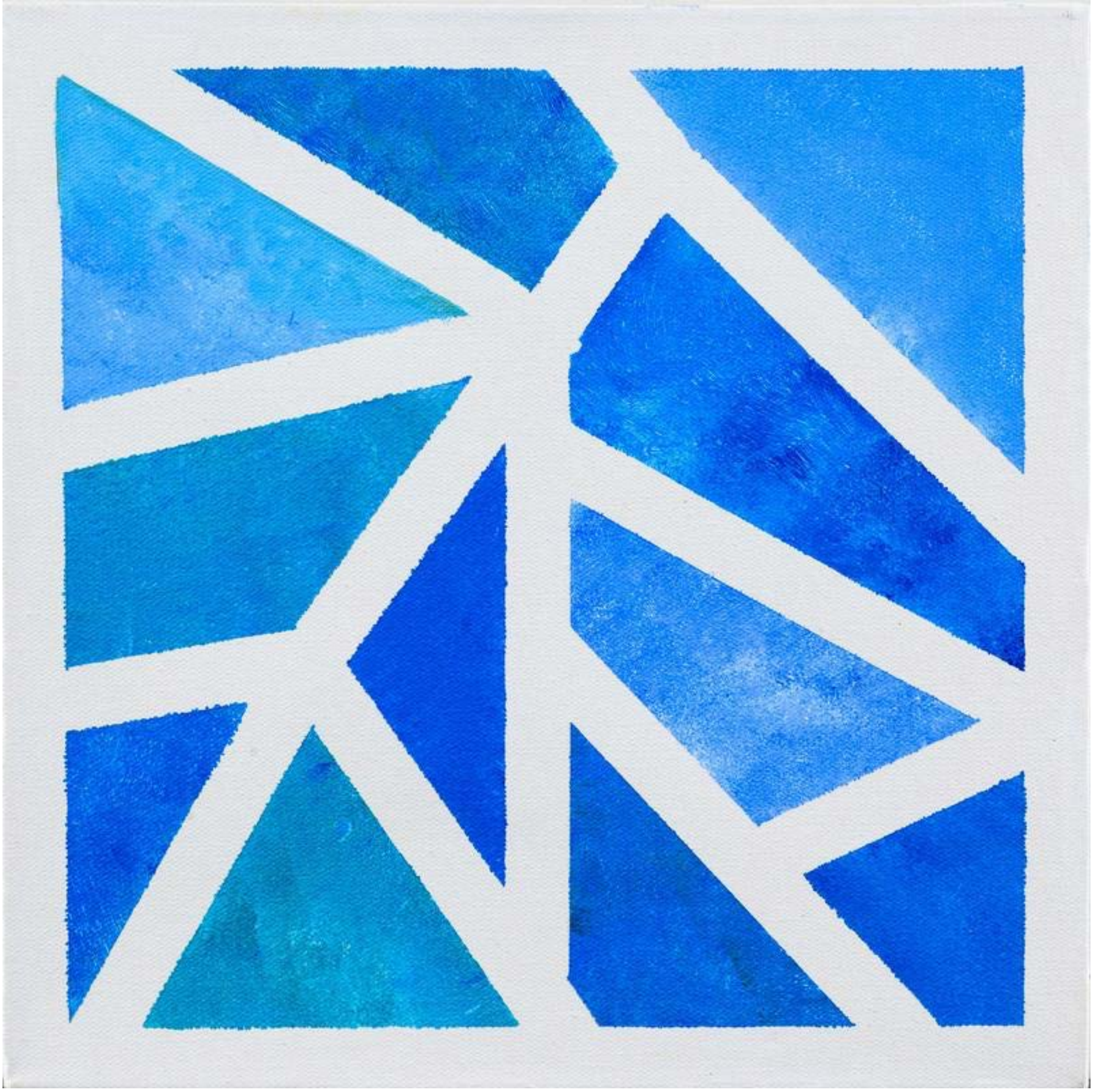
Acknowledgements

This report was commissioned and funded by IHC New Zealand. IHC advocates for the rights, inclusion and welfare of all people with intellectual disabilities and support them to live satisfying lives in the community.

The authors are extremely thankful to the people with intellectual disability and their families who participated in the qualitative interviews. We are grateful for their generosity with their time and the willingness to recount their experiences.

The authors are also thankful for the valuable input of Shara Turner, Tania Thomas, Dr Nicolina Newcombe and others from IHC New Zealand, Andrew Webber from the Social Investment Agency, the technical reviewers and Dr Henrietta Trip.

All the art in this report was created by intellectually disabled artists. The art was selected by the authors from over 500 entries into the IHC Art Awards in 2024. The authors were inspired by the complexity and diversity of the art created by the talented artists and thought it was critical to show what intellectually disabled people are capable of when they are well supported and included. The authors are very grateful to the artists for their contribution to the report.



Tara Hook - Triangle Blue
Blue triangle artwork with mixes of blue paint.

Foreword

Tēnā koutou katoa. He pūrongo tēnei e pā ana ki ngā take uaua e pā ana ki te rawakore o te hunga whaikaha ā-hinengaro.

Greetings to you all. This report addresses the pressing issues related to the poverty faced by people with intellectual disabilities.

2023's From Data to Dignity was a watershed moment for IHC. We produced a research report that few organisations worldwide could—one that provided robust, quantitative data on the realities faced by people with intellectual disability in Aotearoa New Zealand.

Successive governments have shown little interest in the wellbeing and empowerment of people with intellectual disability since 2003's To Have an Ordinary Life. The recommendations from that report were never significantly implemented, and today, too many intellectually disabled people still live in neglect.

From Data to Dignity was confronting for many within the intellectual disability sector. We have all worked tirelessly to improve outcomes, yet without political will, progress remains stagnant. One of the most alarming findings in From Data to Dignity was the extent of poverty experienced by people with intellectual disability, their families, and whānau—something that has largely escaped public attention.

In this report, we build on those findings by using the Integrated Data Infrastructure to capture the multifaceted nature of this poverty, alongside interviews that provide critical, lived-experience insights. The results are stark: people with intellectual disability in New Zealand are living in extreme hardship at double the rate of the general population. Many go without food and adequate clothing and rely on borrowing money from friends and family to cover basic expenses. Children with intellectual disability face not only financial deprivation but also profound social isolation—they are almost three times less likely to have friends over to play or share meals at home compared to their peers.

This poverty is not just a policy failure—it is a human rights violation. Under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), intellectually disabled people are recognised as economic rightsholders. They have the right to an adequate standard of living, social protection, and equal access to work and financial security. Yet, our findings show that these rights are being systematically denied.

This report is a call to action. It is time for the government to swiftly acknowledge the deep vulnerability of this group and take decisive, meaningful steps to address it.

Ka murua te pātea – The past is put aside

To move forward we must focus on the present and take immediate action toward a change.

Andrew Crisp
IHC Group Chief Executive

Executive summary

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) establishes clear economic rights for disabled people, including those with intellectual disabilities. These rights aim to ensure an adequate standard of living, social protection and freedom from economic discrimination.

Previous research commissioned by IHC, From Data to Dignity, has shown that New Zealanders with intellectual disability were much more likely than other New Zealanders to experience poor wellbeing outcomes in a range of areas of their lives, including being more likely to live in poor-quality housing in deprived areas, and to be living in low-income households. Recent poverty statistics highlight that child poverty in New Zealand is high compared to other developed nations. They also highlight that Māori, Pacific and disabled children are much more likely to be affected by poverty.

In this research, we use the same data that is used to provide national official poverty statistics to give a picture about how well people with intellectual disability and their families are doing relative to their non-intellectually disabled peers, providing a picture of what poverty and hardship look like for these families. We also conducted in-depth qualitative interviews with people with intellectual disability and their families to gain a deeper understanding of their experiences, what has worked for them and what could be improved.

Intellectual disability and poverty

People with an intellectual disability are more likely to experience material deprivation throughout their lives. Up to age 39, intellectually disabled people are twice as likely as the general population to be living in hardship, and between 40 and 64, they are three times as likely to be in hardship. Levels of severe hardship follow a similar pattern, with adults with intellectual disability disproportionately affected.[1] While hardship rates decline over the life course for the general population, this does not appear to be the case for people with intellectual disability, at least up to age 64.

People with intellectual disability are three times as likely to lack basic necessities. They are also much more likely to live in households unable to pay an unavoidable bill within a month without borrowing and to lack home contents insurance.

Although they were reported less frequently than other deprivations, people with intellectual disability were at least three times more likely than other New Zealanders to report not being able to afford to have a meal with meat or a vegetarian equivalent at least every second day, to not have two pairs of suitable shoes in good repair, to not have suitable clothes for special occasions, or to be unable to give presents to family and friends on special occasions. Results from the qualitative interviews in our study highlighted the same range of issues. Over half of participants indicated that they experienced these issues and that they were persistent and ongoing.

Families of children with intellectual disability face substantial financial barriers to social participation, such as being unable to afford school trips or other school events, or to have friends over to play and eat.

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[1] People are classified as being in hardship if their household reported six or more of seventeen hardship indicators. They are considered to be in severe hardship if they report nine or more hardship indicators.

Housing and household situation

Children with intellectual disability were much more likely than other New Zealanders to live in sole parent households, and to still live with their parents well into adulthood. As they aged into middle age, they were less likely than other New Zealanders to have their own children and were more likely than other New Zealanders to be living alone.

Families of people with intellectual disability in the qualitative interviews often relied on extended family for support, however caregiving put significant strain on relationships within and outside the family. Many parents reported that both they and their children were socially isolated, limiting the informal supports available to them.

Adults with intellectual disability were more likely than other adults to live in rental accommodation, in social housing, and in the most deprived areas of New Zealand, while intellectually disabled children were more likely than other children to have problems with dampness or mould and with keeping their house warm. Even participants in the qualitative interviews who were living in their own homes reported issues with housing quality, suitability or security.

Supports and services

Several formal financial and non-financial supports are available to all people with disability; despite this people with intellectual disability are more likely to be in hardship than other people of all ages, and they more frequently access emergency grants to meet their essential needs.

Participants in the qualitative interviews reported various barriers to accessing the supports and services they needed, including being unable to get diagnoses necessary to access funding, extensive paperwork, long waiting times, and costs that were ineligible for funding. Even when they could access supports, participants reported that they often only covered a fraction of the cost, leaving people to meet the shortfall themselves, or do without.

Employment

Adults with intellectual disability were much less likely than other adult New Zealanders to be working and were less likely to be in a household where people were working throughout their lives. Two of the seven intellectually disabled adults interviewed were unemployed and wanted to work, while a third person needed a job matched to their needs. Many caregivers in the qualitative interviews reported having to reduce their work hours or withdraw from employment altogether due to caregiving demands. These demands disproportionately fell on mothers, who were more likely to have their careers interrupted, with resulting financial vulnerability.

Social isolation

People with intellectual disability were considerably more likely than other New Zealanders to not have access to a vehicle, and to not have holidays away from home or overseas due to cost.

Children with intellectual disability were considerably more likely than their non-intellectually disabled peers to not have visits from friends due to cost, and parents often reported being unable to pay for school trips or other school events.

Patterns linked to hardship

The qualitative interviews highlighted several patterns that were associated with disparities in hardship levels. Families with dual incomes or stable financial backgrounds reported fewer hardship indicators, while single-income households and single parents, often with caregiving constraints, were more likely to be in hardship. While renters were especially vulnerable, facing instability and inadequate living conditions, homeowners were not uniformly shielded from hardship.

Families experiencing economic strain often faced parallel challenges in accessing education, healthcare, and social participation, exacerbating difficulties, in turn worsening developmental outcomes and increasing caregiving demands. Parents in the qualitative interviews nevertheless often reported trading off their own wellbeing for that of their children, prioritising their needs even at great personal cost. For example, delaying treatment for their own chronic health conditions due to the expense.

Delays or ineligibility for supports like the Ministry of Education’s Ongoing Resourcing Scheme for children with high learning support needs exacerbated hardships. Informal supports were also critically important in mitigating hardship. Families with supportive networks such as extended family or community groups experienced periods where strain, although severe, became more manageable.

Adults

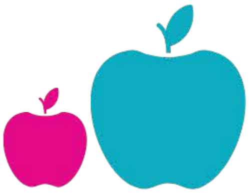
People with an intellectual disability are twice as likely to live in hardship or severe hardship compared to people who don't have an intellectual disability.

For most people, hardship decreases as they age, but the level of hardship experienced by people with an intellectual disability stays the same as they age.

Almost 1 in 5 people
with an intellectual disability live in hardship
compared to 1 in 13 people who do not
have an intellectual disability*

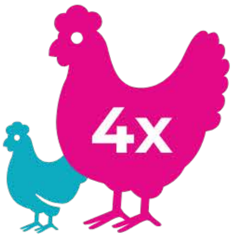
What does it mean for people with an intellectual disability to live in hardship?

Up to four times more likely to live in rental accommodation compared to the non-intellectually disabled population

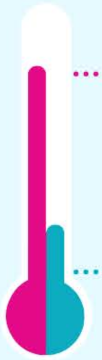


Almost three times more likely to cut back on fresh food due to cost compared to the non-intellectually disabled population

Over 42% of people with an intellectual disability couldn't pay an unexpected bill of $500 within a month without borrowing



Over four times more likely to not be able to eat meat at least every second day due to cost compared to the non-intellectually disabled population



13.5% of people with an intellectual disability put up with feeling cold because they can't afford to pay for heating

compared to 5.9% of the non-intellectually disabled population

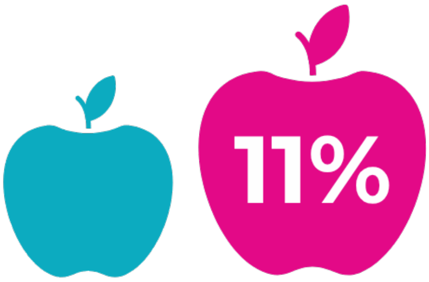
> ***"I found, finally, I'm starting to actually feel okay buying food regularly. I used to starve myself to save money."***
> **Lindell - adult with an intellectual disability**

*18.8% of people with an intellectual disability live in hardship compared to 7.8% of the non-intellectually disabled population.

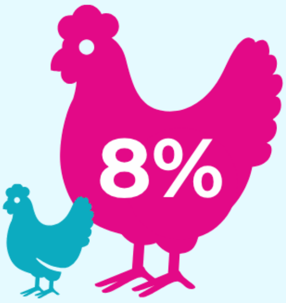
Children

Children with an intellectual disability are twice as likely to live in hardship compared to other children.

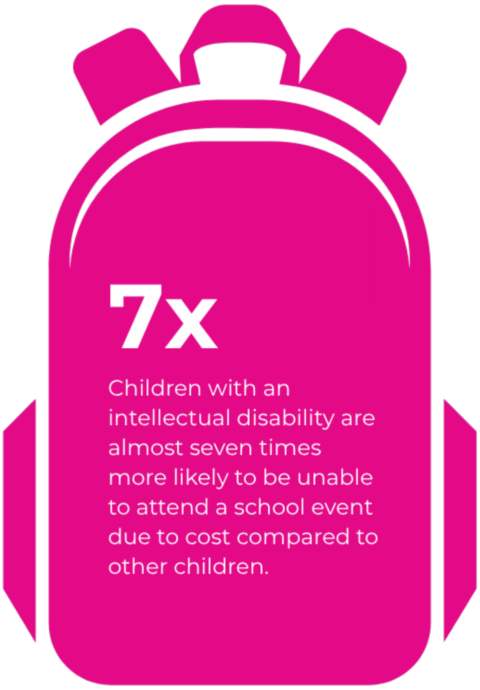
What does living in hardship look like for children with an intellectual disability?



Over 11% of children with an intellectual disability are not able to access fresh food due to cost compared to just under 5% of other children



Over 8% of children with an intellectual disability are not able to have a meal with meat in it every day due to cost compared to just over 3% of other children



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Children with an intellectual disability are almost seven times more likely to be unable to attend a school event due to cost compared to other children.

Over a quarter of children with an intellectual disability can't afford to have friends around to eat occasionally compared to just under 9% of other children

> ***"Getting funding feels like a full-time job...You have to prove, over and over, everything your child can't do, just to get the bare minimum."* Lani, mother of Meleia.**

1 Introduction

1.1 Background

This research explores the living situation and living standards of people with intellectual disability in Aotearoa New Zealand.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) establishes clear economic rights for disabled people, including those with intellectual disabilities. Previous research commissioned by IHC, From Data to Dignity (Beltran-Castillon & McLeod, 2023), showed that New Zealanders with intellectual disability were much more likely than other New Zealanders to be living in low-income households, to be living in more deprived areas, to report poor housing and to have worse health outcomes. The latest official statistics on child poverty published by Stats NZ show that disabled children and children in households where someone is disabled are more likely to experience material hardship than other children.[2]

In this research we use official data sources and measures of poverty to look at the living standards of people with intellectual disability in detail. We also look at people's living situation, the supports they receive, and the way these impact on their living standards and their likelihood of being in poverty. While other aspects of people's lives are also critically important to people's overall well-being, the focus of this report is on living standards, material well-being and poverty. That is, the way in which financial independence and supports enable people to live a comfortable life, with the material things they need. Other aspects of well-being are explored to the extent that they affect or are affected by people's material well-being.

Beyond the From Data to Dignity report noted above (Beltran-Castillon & McLeod, 2023), there is very little evidence about the living standards of people with intellectual disability in New Zealand. Recent research, however, shows that disabled children more broadly experience particularly high rates of poverty and material hardship (Wilson & McLeod, Forthcoming). The report shows that children living in households where there is a disabled person (either the child themselves or another person) account for over half of all children living in households experiencing material hardship, despite accounting for only three in ten children in total.

1.1.1 Economic rights of intellectually disabled people under the UNCRPD

The **United Nations Convention on the Rights of Persons with Disabilities (CRPD)** establishes clear economic rights for disabled people, including those with intellectual disabilities, through Article 28.[3] These rights aim to ensure an adequate standard of living, social protection, and freedom from economic discrimination.

These rights include the right to an adequate standard of living which consists of access to adequate food, clothing, and housing, as well as continuous improvement of the living conditions of people with an intellectual disability. State Parties that sign up to the CRPD are obligated to take proactive measures to promote and safeguard these rights, ensuring that intellectually disabled people are not disproportionately affected by poverty or inadequate living conditions.

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[2] https://www.stats.govt.nz/news/child-poverty-statistics-show-increase-in-material-hardship-for-the-year-ended-june-2023/

[3] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-28-adequate-standard-of-living-and-social-protection.html

Article 28 also enshrines the right to social protection without discrimination with specific obligations including ensuring that disabled people are including in poverty reduction initiatives and that the government recognise and provide financial assistance for any additional costs associated with disability.

The overriding intention of the CRPD is to uphold the inherent dignity of disabled people and guarantee them the ability to live on an equal basis with others.

1.1.2 From Data to Dignity

In December 2023, IHC published a comprehensive report on the wellbeing of intellectual disabled individuals in New Zealand, From Data to Dignity (Beltran-Castillon & McLeod, 2023). From Data to Dignity showed that outcomes for people with intellectual disability are different from those of the general population. Intellectually disabled people were shown on average to be disadvantaged across multiple domains of wellbeing compared to the non-intellectually disabled.

The report showed that there is a large household income disparity between intellectually disabled and non-intellectually disabled adults, especially in the older working-age population. While people in their 20s and 30s may be able to live with working parents who provide financial support, this may be less possible as they get older, exacerbating the differences in household income for the older working age.

With low employment rates and high benefit receipt, people with intellectual disability are generally reliant on government financial support. Consequently, the average total annual personal income of a person with intellectual disability does not vary significantly by gender or ethnic group.

Children with intellectual disability are more likely to live in low-income households, and overall, the average equivalised disposable household income is lower for children with intellectual disability than it is for children without intellectual disability.

1.1.3 Poverty research in Aotearoa

Since the early 2000s, in response to growing concerns regarding child poverty and the rise of income inequality, there has been a focus on the development of measures of poverty in New Zealand. These measures have been built based on international frameworks.

Recent poverty reporting highlight that child poverty in New Zealand is high compared to other developed nations (Perry, Child Poverty in New Zealand: Overview and Selected Findings, 2024). It also highlights that Māori, Pacific and disabled children are much more likely to be affected by poverty.[4]

Poverty can be measured using direct and indirect approaches. While indirect measures are based on income, direct approaches assess the current living conditions and therefore the effects of poverty. Non-income measures are important to study alongside income-based measures. The income, wealth, consumption, and material wellbeing framework used by the Ministry of Social Development (MSD) to report on the material wellbeing of New Zealand households (Perry, 2017) recognises that factors other than income can also affect material well-being.

International research typically defines income poverty in two ways: as absolute or relative poverty. While absolute poverty is measured against fixed standards, relative poverty measures whether people can meet their needs compared to others in their society. Relative poverty depends on the level of development of

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[4] https://www.stats.govt.nz/news/child-poverty-statistics-show-increase-in-material-hardship-for-the-year-ended-june-2023/

the country and asks whether everyone has the chance to enjoy the same living standards. In this sense high relative poverty is a form of social exclusion. In economically developed nations income poverty is now almost universally conceptualised in relative terms. New Zealand's official statistics follow this approach.

The Child Poverty Reduction Act introduced in 2018 to help achieve a significant and sustained reduction in child poverty in New Zealand, requires annual reporting on measures of child poverty. To support these reporting, Stats NZ expanded the existing Household Economic Survey (HES) to obtain good measures of child poverty since 2018/19. The official measures of child poverty are derived from HES data and use a mix of direct and indirect approaches to measure poverty. The direct measures focus on material hardship and use DEP-17, a well-established deprivation index developed by the Ministry of Social Development for New Zealand.

This study research approach draws on these previous developments to explore poverty in the context of intellectual disability. Details of the measures used in this study can be found on section 3 of this report.

1.2 Research approach

The research used a mixed methods approach. A quantitative analysis of linked survey and administrative data in Stats NZ's Integrated Data Infrastructure was complemented by a qualitative component of in-depth interviews with people with Intellectual Disability and their families. The quantitative analysis enabled us to describe the circumstances of people with intellectual disability, while the qualitative component provided important information about why people are in the situation they are in, how they got there, what helped them in their lives, and what could have helped them be in a better place.

1.2.1 A life-course approach

The research takes a life-course approach, recognising people's changing needs at different life stages and the cumulative impact of poor health over time. To the extent possible, we differentiate between people's characteristics and outcomes during childhood (up to 17 years), early adulthood (18 to 39 years), middle age (40 to 64 years), and older ages (65 and over)[5]. Because of the small samples involved we were unable to further break down our analysis by demographic characteristics such as gender and ethnicity, although further work is planned to look at intellectual disability from a Māori perspective.

1.2.2 Linked survey and administrative data

The Integrated Data Infrastructure (IDI) is a large population-level research database, managed by Stats NZ (Milne, et al., 2019). It contains linked individual-level data from several Stats NZ surveys alongside administrative data from a wide range of government agencies. The data is made available to researchers under strict conditions to ensure the security of the data and that people's privacy is protected. We combine data from the **Household Economic Survey (HES)**, which contains information about people's characteristics and the living standards of their families and households, with **administrative data**, which lets us identify an intellectually disabled population, the supports they receive, and aspects of their family situation.

The HES is the main source of data about poverty and material wellbeing in New Zealand and is the official government source for poverty

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[5] These life-course stages are typical of the general population, although there is evidence that in comparison people with some types of intellectual disability, for example those with Down syndrome, experience accelerated ageing (Horvath, et al., 2015).

measurement. We combine data from four HES years (2019/20, 2020/21, 2021/22 and 2022/23), providing a total sample of 138,318 people for whom we have material wellbeing data. While this is a large sample, we know that the number of people who are estimated to have intellectual disability is relatively small, at between 1 and 2 percent, depending on the source (Beltran-Castillon & McLeod, 2023), and that we can't identify all people with intellectual disability in the IDI.

The Household Economic Survey only surveys people living in private households. **This excludes people living in residential care or in supported living arrangements such as IHC Group's IDEA Services group homes**. We estimate that at least one in five people with intellectual disability overall, and two in five aged 65 and over live in residential care.[6] These people will be missing from our quantitative analysis, limiting the generalisability of the findings to some degree. Nevertheless, we were able to identify 789 people with Intellectual Disability living in responding HES households – around 0.6 percent of HES respondents in these years. No households were identified as having more than one person with intellectual disability.

People with intellectual disability are identified in the same way as in the From Data to Dignity report (Beltran-Castillon & McLeod, 2023). This uses administrative data sets from a range of government agencies in a range of settings, including data from hospital discharges, outpatient and emergency departments, mental health services, disability support services, income support, the Ministry of Education, and Oranga Tamariki.

Apart from being used to identify our study population of people with intellectual disability from the other HES respondents, we also use linked administrative data to identify the financial and other supports people receive from government. This includes benefits and supplementary payments paid by Work and Income, disability support services funded by the Ministry of Social Development.[7]

Because the results are not calculated from data on the whole population but are estimated from a sample of people, the estimates may differ from the true values. Therefore, results are presented as percentages **with confidence intervals which represent the level of uncertainty that arises through using data from a sample survey**. A 95% confidence interval means that we are 95% confident the true number lies within its bounds. We also present 'rate ratios' which compare the relative difference between the estimate for people with intellectual disability compared to people without intellectual disability. For example, a rate ratio of two would indicate that people with intellectual disability are twice as likely to experience that outcome. A series of tables are being published alongside this report. These contain the results graphed in the paper as well as some additional results.

1.2.3 In-depth interviews

Data for the qualitative component of the studies was collected through in-person semi-structured interviews lasting around two hours. Each interview included a standard questionnaire containing statistically derived material hardship indicators. Participants selected which general family and child-specific indicators were experienced during their parenting journey. They were also asked to confirm if such hardships had been persistent and ongoing or whether they had abated in recent years

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[6] This is estimated based on the number of people who either receive the Residential Support Subsidy or Residential Care Subsidy from Te Whatu Ora.

[7] Prior to the establishment of Whaikaha in 2022, disability support services were funded by the Ministry of Health, while these services became the responsibility of the Ministry of Social Development from late 2024.

We collaborated with IHC to develop selection criteria and relied on its communication networks to identify potential research participants. With respect to talking to parents, we sought to capture:

- Ethnic diversity, specifically including Māori and Pacific families,
- A range of child ages and intensity of support needs, and
- A spread of socio-economic circumstances and location types (as these determine access to support services).

Despite our best efforts to achieve a sample that represented the diversity of experiences, the cohort of parents we interviewed seemed to have a positive bias in favour of the materially better off, as most participants were homeowners. On the other hand, the degree of material hardship reported was high, despite initial concerns that our selection would not sufficiently capture the kind and level of hardship we were trying to understand. Relatedly, we found that most parents we spoke to were managing children with high or very high support needs. For these reasons, we were reassured that this qualitative study would offer important insights regarding financial and social hardship.

For the cohort of working-age adults with an intellectual disability we wanted to understand what their lives were like growing up, what their current living circumstances are, and their experiences of work preparation, job-seeking and employment. For five of the seven adults we interviewed, we could also speak with a parent or a sibling. We mostly achieved what we intended with the interviews of working-age participants in that they represented a relatively balanced distribution of gender, age ranges, and living circumstances. The overarching analytic framework for the qualitative component draws on the foundational principles of Enabling Good Lives[8] and A Good Start in Life[9], enriched by additional dimensions derived from observed needs in participant profiles and broader frameworks. It is designed to deeply analyse challenges, protective factors, and their impacts on families with children with intellectual disability, while integrating interdisciplinary perspectives and long-term policy goals and practice principles.

This report draws on results from the in-depth interviews to help explain what was found through the quantitative analysis, to fill gaps in areas where there is no quantitative survey or administrative data, and to give voice to people with intellectual disability and their families using direct quotes. All participants have been given pseudonyms to protect their privacy.

In addition, based on video or audio transcripts, we formulated a "profile" for each of the participants to convey their experience of living with intellectual disability or parenting one or more children with intellectual disabilities. Through compiling the profiles and survey responses, we were able to supplement each profile with a hardship summary table. These profiles can be found in Appendix 2 and 3 of this report.

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[8] https://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/

[9] https://www.hqsc.govt.nz/assets/Consumer-hub/Partners-in-Care/Publications-resources/Good-start-in-life-practice-guidance-Mar-2020.pdf

Ruhani Chauhan - Moodbrella - Youth Award Entrant.
Ruhani's emotional journey through moods and style.

2 Study population

2.1 Linked survey and administrative data

The demographic characteristics of the population with and without intellectual disability in each life stage and overall are given in **Table 1**, below. Results are weighted to reflect the New Zealand population between 2019 and 2023. Overall, the results reflect characteristics of the population identified through administrative data for the From Data to Dignity report (Beltran-Castillon & McLeod, 2023).

Table 1: Characteristics of people with and without intellectual disability in different life stages

Characteristic	Child (0-17)		Young adult (18-39)		Middle age (40-64)		Older adult (65+)		All ages	
	No ID (%)	ID (%)	No ID (%)	ID (%)	No ID (%)	ID (%)	No ID (%)	ID (%)	No ID (%)	ID (%)
Gender										
Female	48.5	47.1	50.2	39.2	52.4	44.6	53.0	39.3	51.0	42.7
Male	51.3	52.6	49.2	58.0	47.4	55.4	46.9	58.9	48.7	55.9
Other	0.2	S	0.6	S	0.2	S	S	S	0.3	S
Age group										
Under 5	26.5	S	S	S	S	S	S	S	6.0	S
5 to 9	28.3	15.7	S	S	S	S	S	S	6.4	3.9
10 to 14	28.9	50.4	S	S	S	S	S	S	6.6	12.7
15 to 24	16.2	27.0	28.7	41.2	S	S	S	S	12.4	23.9
25 to 34	S	S	48.9	45.1	S	S	S	S	14.8	18.7
35 to 44	S	S	22.5	13.9	19.7	19.2	S	S	13.0	11.2
45 to 54	S	S	S	S	41.3	43.3	S	S	13.1	12.2
55 to 64	S	S	S	S	39.0	37.5	S	S	12.3	10.6
65 and over	S	S	S	S	S	S	100.0	100.0	15.4	5.1
Ethnic group										
European	65.9	67.5	61.3	77.0	70.9	75.6	83.6	85.7	68.8	74.6
Māori	25.7	33.6	18.0	31.0	14.0	24.4	9.0	S	17.1	29.1
Pacific	13.0	10.9	9.3	8.6	6.1	S	3.2	S	8.2	7.9
Asian	17.9	12.4	22.6	S	14.7	S	6.7	S	16.6	8.0
MELAA	2.4	S	2.4	S	1.4	S	0.4	S	1.8	S
Other	1.3	S	0.8	S	1.5	S	1.6	S	1.3	S
Sample size	34,125	243	38,598	279	43,821	225	21,777	45	138,318	789
Weighted sample (000s)	1,144.9	6.9	1,525.0	11.3	1,595.6	7.7	779.1	1.4	5,044.6	27.2

Note: S represents cells which were suppressed due to small sample sizes for confidentiality and quality reasons.

Data Source: Household Economic Survey (2019/20 to 2022/23) linked to administrative data in the IDI.

People with intellectual disability are more likely to be male than female, particularly among adults, while very few children under the age of 5 are identified in the intellectual disability population, likely reflecting delays in diagnosis. Similarly, low numbers of 5- to 9-year-olds were identified, making up only an estimated 16 percent of children with intellectual disability. Adults with intellectual disability were more likely than the rest of the population to be Māori or European, while children with intellectual disability were more likely to be Māori.

The sample of people over the age of 64 with intellectual disability was very small, with only 45 respondents representing around 1,400 people in the population. This is likely to reflect the increasing number of people in residential care as they age, as well as the very low life expectancy of people with an intellectual disability, estimated to be around 65 years, more than 15 years less than people without intellectual disability (Beltran-Castillon & McLeod, 2023).

The estimated population of people with intellectual disability living in private dwellings was estimated to be around 27 thousand. This is in the ballpark of the 32 thousand people with intellectual disability not living in residential care estimated in the From Data to Dignity report. These results taken together provide some reassurance that, despite its small size, the sample from our study is broadly representative of the intellectually disabled population living in private dwellings in Aotearoa.

2.2 Qualitative sample

For the qualitative component of this research, we spoke to 12 caregivers and seven adults about the details of home life that involved raising one or more children with intellectual disability. When we discuss material conditions, development opportunities, or the lack of these for children with intellectual disability, we focus on the level of the family **household (13)**, even if this is relatively historic. In prioritising the household unit, we have been careful to include the distinctive experience and perspective of the adult with intellectual disability associated with each household.

We also needed to differentiate adults with intellectual disability living in other contexts and separated in time from direct experience of the family household milieu. These are the **individuals (4)** in supervised residences or supported flatting situations, where their lives have been substantially influenced by community-level conditions, often over decades.

Table 2 below shows the linkages and distinctions between the research participants we interviewed and characterised in this report – 12 caregivers and seven adults with intellectual disability. Each participant has been given a pseudonym and identifying details have been removed to protect their privacy. The various experiences and quotes detailed throughout this paper use the names below.

Table 2: Qualitative research participants and their children with intellectual disability

HOUSEHOLDS (13)			
Caregiver participants	**Children with ID at home**	**Adults with ID at home**	**Adults living elsewhere**
Sarah (mother)	**Ethan** (teenager)		
Hana (mother)	**Aria** (teenager)		
Riley (mother)	**Simon** (pre-teen)		
Helen (mother)	**Kyle** (teenager)		
Lola (mother)	**Josh** (pre-teen)		
Vicki (mother)	**Erica + Jamie** (pre-teens)		
Lani (mother)	**Meleia** (pre-teen)		
Louise (mother)		**Grace** (20s)	
David (father)		**Emma** (40s)	
N/A		**Lindell** (20s)	
Stephanie (mother)			**Mica** (30s)
Erin (mother)			**Chris** (50s)
Karun (sibling)			**Ajay** (60s)
			Robert (50s)
		ADULT PARTICIPANTS (7)	

Notes: Participants have been given a pseudonym to protect their privacy. Names in bold indicate interview participants.

2.2.1 Strengths and limitations

By combining data from multiple HES years, we construct a large database, which enables us to examine the outcomes of people with intellectual disability at different stages of their lives. Linking this to administrative data from government agencies allows us to connect people's experiences with the services they receive. Finally, the analysis of qualitative interviews provides a deeper understanding of people's lives, helps validate what we see in the quantitative analysis, and fills gaps in areas of people's lives we do not observe in the quantitative data.

As discussed earlier, the data and analysis that this report draws on is limited in several ways. With respect to the quantitative analysis, the survey population excludes people in supported living arrangements. This will particularly affect conclusions about the older (65 years and over) cohort, for whom we also have a very small sample, and consequently a high level of statistical uncertainty. The sample is also likely to be biased towards people who are still able to live independently.

The qualitative interview cohort primarily reflects the experiences of parents of children under the age of 18 (seven households). However, some families of adult children with intellectual disability and adults with intellectual disability were also interviewed (three family households and four adults living away from home). As a result, there is far more qualitative information to explain the circumstances of children and their caregivers than older people with intellectual disability (e.g., four over 40 and only one over 65).

In addition, recruitment for the interviews was through IHC connections, and as such interview participants are not representative of the intellectually disabled population more broadly. Having a connection to IHC may, for example, indicate someone being more informed of the services available to them and being more connected to those services.

3 Living standards

In this section we look at the living standards of people with intellectual disability relative to other New Zealanders. To do so we have selected 5 measures based on the poverty measures used in official statistics:

- Percentage of people living in hardship
- Percentage of people living in severe hardship
- Percentage of people living in households with less than 50% median equivalised disposable household income before housing costs
- Percentage of people living in households with less than 50% median equivalised disposable household income after housing costs for the base financial year (2017/18 is used as the base)
- Percentage of people reporting that their household does not have enough money to meet their everyday needs.

The first two hardship measures are derived using the Dep-17 scale, a key official measure of child poverty in New Zealand. Dep-17 is constructed from 17 questions (items) asked in the HES that focussed on different aspects of material hardship, with the final score calculated as the count of the deprivations experienced by a household. People living in households with a score of 6 or higher are considered as being in hardship, while those living in households with a score of 9 or higher are considered as being in severe hardship (Stats NZ, 2019).

The next two measures are indirect measures of poverty and are two of the standard income-based poverty measures used by Stats NZ. They measure household income relative to median income across all New Zealand households before and after housing costs.

Income is measured at the household level, as resources are assumed to be shared across the household. Disposable income is income after adjusting for tax and ACC levies, while equivalisation adjusts for household size and composition, so incomes can be compared in a meaningful way across households. This reflects the fact that larger households need more income than smaller households to achieve the same standard of living, that adults generally consume more resources than children, and that economies of scale apply as households get larger. For more information about these measures, see Stats NZ (2019).

The last measure is a direct measure of poverty that reports the response to a question about whether a household has enough money to meet their everyday needs.

These measures are reported at different ages across the life course, showing how living standards change with the life stage and how this pattern differs for people with and without intellectual disabilities.

As well the five measures stated above, for people with intellectual disability we report the responses to the 17 questions that form the Dep-17 index. These give detail of the households' experiences related to hardship. Finally, for children with intellectual disability we look at a set of 12 child-specific deprivation questions. These are items where there would be "a strong consensus that 'all children should have these and none go without'" (Perry, Child Poverty in New Zealand: Overview and Selected Findings, 2024).

3.1 Household hardship measures

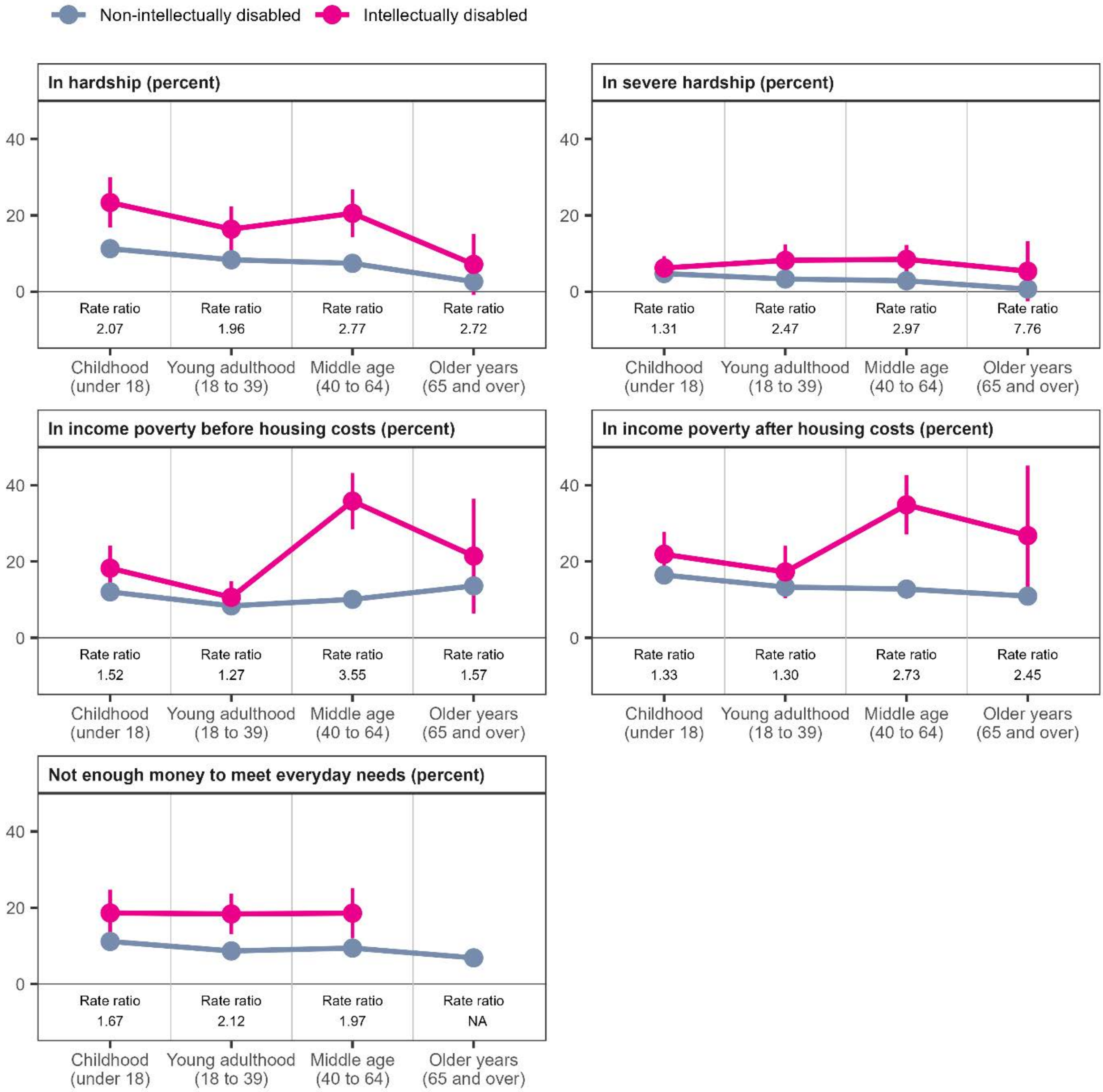
Figure 1 shows the five overarching poverty measures discussed above, across the life course, and whether a person has intellectual disability or not. For our main Dep-17 based hardship measures, we see that around one in five people with intellectual disability are living in hardship through to age 64. **This is around double the rate of hardship than people**

without intellectual disability up to age 39 and almost triple the rate at ages 40 to 64, as hardship rates continue to drop throughout the life course for people without intellectual disability.

While the differences in hardship rates at ages 65 and over between people with and without intellectual disability were much reduced relative to earlier years, the margins of error are very wide owing to the small sample. In addition, many people in this age range with intellectual disability are not observable in our data, as they are more likely to live in residential care. Finally, given the low life expectancy of people with intellectual disability, **we may see so-called 'survivor effects', where wealthier people are less vulnerable and are more likely to survive to old age.**

Severe hardship (9 or more Dep-17 indicators) shows a similar pattern to hardship, particularly through adulthood, although severe hardship among children with intellectual disability is only slightly more common than in children without intellectual disability. **Severe hardship rates are double those of people without intellectual disability in young adulthood, and triple in middle age.**

Figure 1: Hardship measures for people with and without intellectual disability across the life course



Note: Vertical bars indicate 95 percent confidence intervals around each estimate, showing where the true estimate may lie. Some points are suppressed due to small sample sizes for confidentiality and quality reasons.
Data Source: Household Economic Survey (2019/20 to 2022/23) linked to administrative data in the IDI.

Income poverty may be less reliable than more direct measures of poverty for people with disability. This is because while income may increase with disability-related payments, costs may increase commensurately, or to an even greater degree, leaving people worse off overall. These costs are not reflected in the income measures, which are only able to account for housing costs. Nevertheless, **people with intellectual disability are more likely to experience income poverty than people without intellectual disability across all life**

stages but especially in middle age, when they are more than two and a half more likely to experience it.

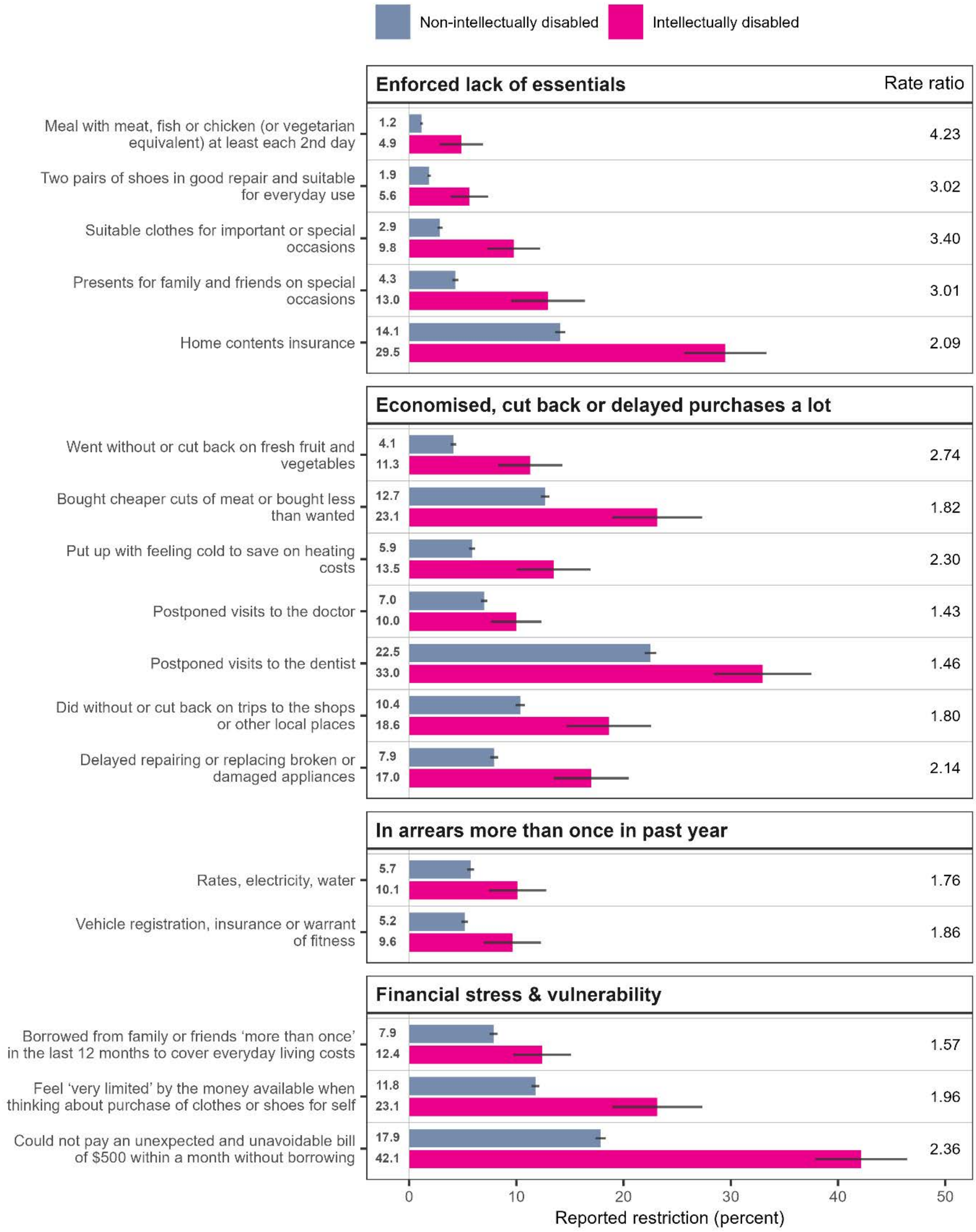
The number of people in households reporting not having enough money to meet their everyday needs is very similar to the number estimated to be in hardship, providing some reassurance of the validity of the hardship measure. As with the hardship measure, **people with intellectual disability are more likely to live in households with insufficient money to meet their needs throughout the life course.**

Figure 2 shows the Dep-17 deprivation items individually, allowing us to differentiate the areas of people's lives which seem to be particularly impactful for people with intellectual disability. Measures are shown for all people with intellectual disability, rather than separately for different life-course groups, as there are few differences in patterns between different groups. Where there are differences, they are discussed in the following text.

Consistently across all Dep-17 deprivation items, households that include people with intellectual disabilities are more likely to report hardship than households without people with intellectual disability in them. The largest differences were for households reporting that they would not be able to pay an unavoidable bill within a month without borrowing, a 24-percentage point difference (42 percent compared to 18 percent), while people with intellectual disability were 15 percentage points more likely to live in a household unable to afford home contents insurance (29 percent compared to 14 percent). Taken together, these highlight the financial vulnerability of people with intellectual disability and their households. Other large absolute differences of 10 percentage points or more were for households reporting feeling very limited when buying clothes or shoes, postponing trips to the dentist, or buying cheaper cuts or less meat than they wanted. **The smallest difference in both absolute and relative terms relates to postponing visits to the doctor, indicating reasonably good access to primary care overall.** This is consistent with the findings of From Data to Dignity (Beltran-Castillon & McLeod, 2023), where it was reported that the intellectually disabled population were high users of health services. However, despite the high use, on average, they had poorer outcomes than the non-intellectually disabled, including a much-shortened life expectancy.

Even in those items that are not reported by many people, the proportionate differences between people with and without intellectual disability could be very large, as shown in the rate ratios. **For example, people with intellectual disability were at least three times more likely than other New Zealanders to report not being able to afford to have a meal with meat or a vegetarian equivalent at least every second day, to have two pairs of suitable shoes in good repair, to have suitable clothes for special occasions**, or to be able to give presents to family and friends on special occasions. There is little evidence of differences in Dep-17 items across life stages for people with intellectual disability, however children are somewhat more likely to be in households reporting not having contents insurance and not being able to pay an unexpected and unavoidable bill.

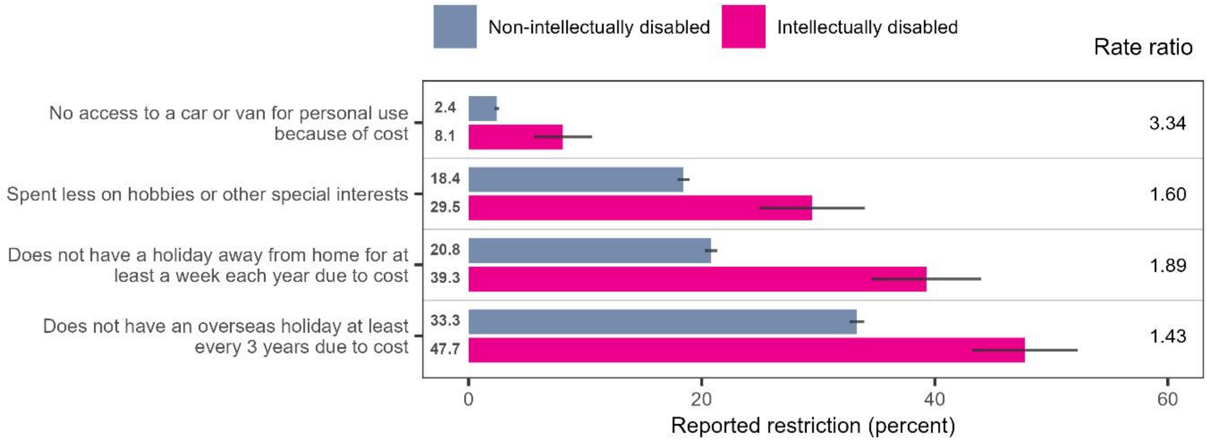
Figure 2: Dep 17 hardship indicators for people with and without intellectual disability



Note: Horizontal bars indicate 95 percent confidence intervals around each estimate, showing where the true estimate may lie.
Data Source: Household Economic Survey (2019/20 to 2022/23) linked to administrative data in the IDI

Finally, shown in **Figure 3**, we looked at a small number of hardship indicators related to people's travel, leisure and social connections. While the proportion of intellectually disabled people in households which did not have access to a car or van due to cost was low, at 8 percent, it was more than three times the rate of other New Zealanders. People with intellectual disability were also much more likely to report spending less than they would like on hobbies or other interest, half did not have overseas holidays every three years due to cost (compared to a third of other New Zealanders), and two in five reported being unable to afford an annual holiday away from home, compared to one in five people without intellectual disability.

Figure 3: Other hardship indicators for people with and without intellectual disability



Note: Horizontal bars indicate 95 percent confidence intervals around each estimate, showing where the true estimate may lie.
Data Source: Household Economic Survey (2019/20 to 2022/23) linked to administrative data in the IDI.

The qualitative analysis provided results that were consistent with this analysis. Parents reported going without things like presents for family and friends on special occasions or home contents insurance. They also postponed visits to the doctor or dentist, cut back on food, and continued to wear worn-out clothing. Nine parents reported financial stress indicators, such as borrowing from family or friends to cover basic living costs. At the same time, seven households experienced arrears on essential bills, such as utility payments or vehicle-related expenses. Over two-thirds of the parents with children under 18 (5 of 7) indicated that these limitations were persistent and ongoing, suggesting enduring financial vulnerabilities.

> *We did a loan through DTR. And that took a long time to pay off because those interest rates are horrendous. And that was to get my power reinstated.*
>
> *Sarah, mother of Ethan.*

Only one of the seven adults with intellectual disability that we interviewed (Lindell, mid 20s) had recent experience of severe and persistent material hardship. This finding is likely the result of positive bias in our selection process.

> *I found, finally, I'm starting to actually feel okay buying food regularly. I used to starve myself to save money or I used to undercut things...I really struggled there for a bit and my family wasn't that supportive.*
>
> *Lindell (mid-twenties).*

3.2 Child-specific hardship measures

Figure 4 shows difference between child-specific deprivation items for children with intellectual disability compared to children without intellectual disability. While all indicators were slightly higher for children with intellectual disability, some showed very little difference. In particular, people were only slightly more likely to report their child going without two sets of warm winter clothes, a waterproof coat for each child, or a separate bed for each child if that child was intellectually disabled.

As discussed later, the qualitative interview highlighted the extent to which parents would seek to cushion children from hardship, and this may have reduced these disparities. For example, Stephanie made considerable sacrifices to insulate her daughter Mica from experiencing material hardship. While Mica lives with some precarity, she has a generally comfortable and fulfilling life, while Stephanie still has to contend with some persistent deprivation (i.e. limited capacity to save and make provision for the future as an older working woman).

Larger differences were evident for parents reporting that they were unable to pay for school trips or other school events for their child (13 percent compared to 2 percent), or that their child was able to have friends around to play and eat from time to time (26 percent compared to 9 percent). This latter measure highlights the social isolation many parents reported in the in-depth interviews. Children faced challenges forming friendships, exacerbated by a lack of inclusive schooling and recreational opportunities. Simon, for example, avoided group activities at his high school due to overwhelming sensory stimuli and inadequate accommodations.

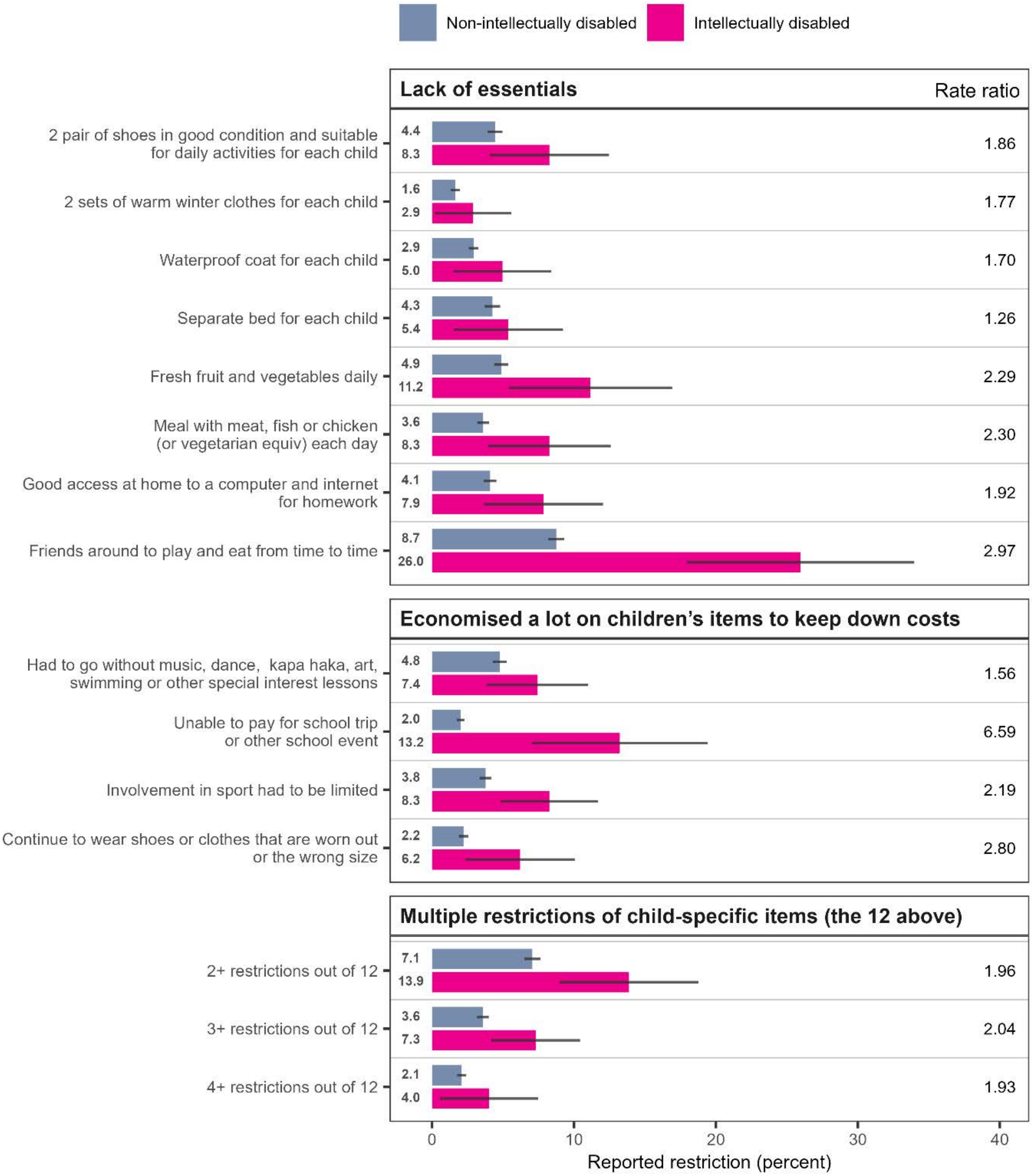
Parents in the interviews consistently reported trading off their own wellbeing for their children, prioritising the latter's essentials and activities even at great personal cost. For example, three mothers reported delaying medical attention for chronic conditions. None could afford privately funded surgery due to the costs and demands of looking after children with ID. This has resulted in declining physical and mental health – living in pain and becoming increasingly anxious about their ability to sustain looking after the children or working.

> *We always make things work, so I'm not going to economise a lot on children's items to keep down cost. Yeah, this happened to me [considering foregone essentials], but it never happened to the kids.*
>
> *Hana, mother of Aria.*

However, when resources are severely constrained, children's opportunities and basic needs remain unfulfilled. In eight out of 13 households, children lacked suitable clothing, raincoats, or digital technology and internet access for education. Nine of thirteen households reported economising on music lessons, sports, and other enrichment activities, limiting children's developmental opportunities.

> *We have to make choices between paying for a tutor to support Simon's learning – as that is the only way he has been able to learn as he is not provided with an adapted curriculum in school or the support he requires to learn – or paying for groceries, or Calie's school camp.*
>
> *Riley, mother of Simon and Calie.*

Figure 4: Child specific hardship indicators for children aged under 18 with and without intellectual disability across the life course



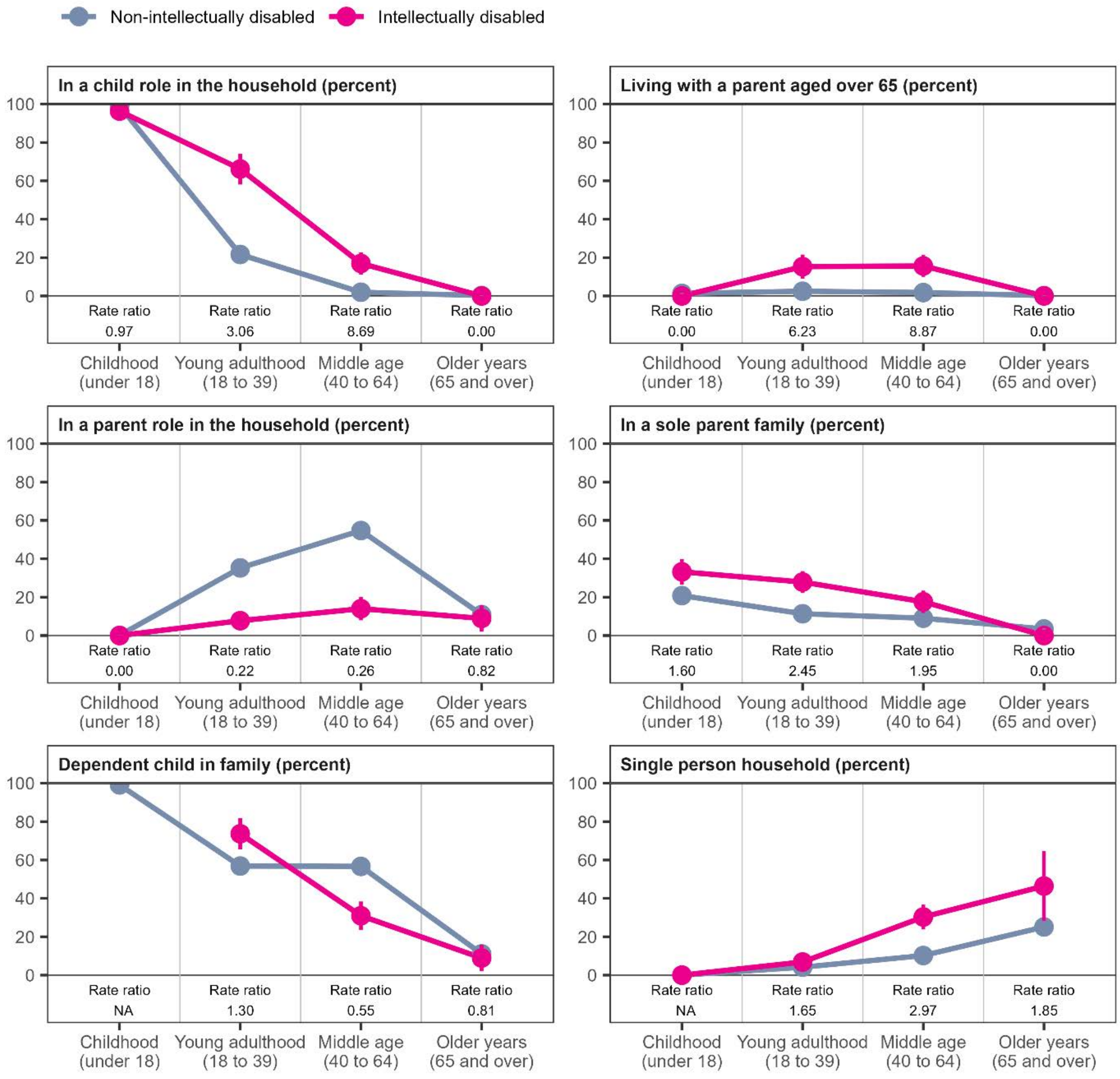
Note: Horizontal bars indicate 95 percent confidence intervals around each estimate, showing where the true estimate may lie.

Data Source: Household Economic Survey (2019/20 to 2022/23) linked to administrative data in the IDI.

4 Living situation

Living with family members can be an important source of informal support, while in turn caring responsibilities can also be a source of relationship stress. In this section we explore the ways in which the living situations of people with intellectual disability differ from those without, and how these change across the life course. **Figure 5** below presents a series of indicators of family and household structure for people with intellectual disability and compares these with people without intellectual disability at the same life stage (childhood, young adulthood, middle age and older ages).

Figure 5: Household and family characteristics of people with and without intellectual disability across the life course



Note: Vertical bars indicate 95 percent confidence intervals around each estimate, showing where the true estimate may lie. Some points are suppressed due to small sample sizes for confidentiality and quality reasons.

As we would expect, most children under the age of 18 are living in a "child role"[10] with a parent or caregiver, regardless of whether they have an intellectual disability. However, many people with intellectual disability stay with their parents as they age. Two-thirds (66 percent) of adults with intellectual disability were still in a child role at ages 18 to 39, compared to only 22 percent of people the same age without intellectual disability. Even at ages 40 to 64, 17 percent of people with intellectual disability were living with parents (without a partner or children). Almost one in six adults in each of these age groups was living in a child role with a parent aged 65 or over, a rate eight times higher than that of people without intellectual disability.

Adults with intellectual disability from middle age onwards were much more likely than adults without intellectual disability to live alone, with almost a third living alone at this age, three times more than people without intellectual disability.

Through childhood and into adulthood, people with intellectual disability were much more likely than other people to live in a sole parent family.

The qualitative interviews reinforced the prevalence of single-parent families, with four participants being primarily cared for by a sole parent. Five parents reported significant strain on their relationships due to caregiving demands, and three single parents cited caregiving as a barrier to forming or maintaining romantic relationships.

> *Because when we were together, I think it was really hard for us to take care of the kids...I think there was a lot of pressure...And when we split, it just felt like we had both had time to ourselves and the kids could also still be with their parents, although separately. [So, in a way, was it easier to parent separately?] Yeah.*
>
> *Hana, mother of Aria*

With one exception, participants indicated that their children's fathers were good people who couldn't cope with the fact and practical demands of having a child with disabilities. Most defaulted to being the breadwinner whose job was done after work. Mothers became de facto and full-time caregivers, including looking after their partners' needs and not expecting or getting any support from them. All were financially worse off after separation.

In many cases, parents interviewed were also reliant on grandparents for support, including providing caregiving, financial assistance (including regularly buying groceries), respite care and emotional support. Siblings also often provide essential emotional and practical support, but their involvement may come at a significant personal cost, including emotional strain, feelings of pressure and responsibility, and lack of attention towards their own needs, including social opportunities.

> *...I hate Christmas... I'd love to take the kids away. Like, it's horrible because we're stuck here. I've got the two boys, they've got each other. They've got no cousins to play with or anyone to show their toys to and muck around with. We don't have a family function to celebrate Christmas. It's just shit.*
>
> *Lola, mother of Josh and Steven.*

---

[10] Living in a child role means that a person does not have a partner or children and is living with one or more parents or caregivers.

Notably, we also found instances where grandparents were largely unavailable, even when living close by, or actively undermining of the parent, criticising their circumstances and parenting. The qualitative analysis highlighted the impact caregiving demands had on parents and other family members. **Box 1** describes this impact in the context of insufficient support.

Box 1: Impact of caregiving demands with insufficient support

Parents of children with intellectual disability who participated in the qualitative interviews noted the substantial ripple effects involving the whole family system.

Limiting parents' social lives –parents interviewed experienced significant isolation, driven by caregiving demands and the stigma associated with intellectual disability. Some struggled to maintain friendships citing exhaustion and lack of childcare options, others avoided social events due to the frequent illnesses and behavioural unpredictability of their children. Some cited the lack of understanding of their challenges among their friends.

> *If I get in trouble, for example, [recently] I was really unwell and had to go to A&E. My partner was away. I don't have anyone that I can call and say, "I'm going to be here till 03:00 a.m. [can you look after the children]."*
>
> *Riley, mother of Simon*

Constraining employment and career development –parents reduced work hours or left jobs due to caregiving. One parent stopped work to home school her daughter for a number of years due to concerns about lack of learning support and physical safety measures at intermediate and secondary schools. Families transitioning to single incomes faced intensified financial pressures and greater long-term precarity.

Emotional exhaustion and burnout - Feelings of being "emotionally drained" were consistently reported. Parents cited the relentless nature of caregiving without adequate respite or systemic support.

> *...the mental load for our family was just overwhelming most days. So I'd be checked out. If I didn't have anything on, I would be checked out numb on the couch, doing nothing, because it was just like, I have so much to do, but I don't have the mental space to do it.*
>
> *Lani, mother of Meleia*

Anxiety and depression - parents reported symptoms of clinical anxiety or depression, often stemming from a combination of sleep deprivation, chronic stress, isolation, and financial strain. Four parents disclosed experiencing suicidal thoughts during periods of extreme stress, often linked to sleeplessness, lack of support, and feelings of hopelessness. Ultimately it was the enduring concern and love for their children, and hopeful and touching moments, that have been keeping parents going, despite how bad they felt.

> *Even in moments when I felt like I couldn't go on, I couldn't imagine handing her over to a system that doesn't know her... Those moments [of hope and progress], even if they're rare, make me think it's all worth it.*
>
> *Stephanie, mother of Mica*

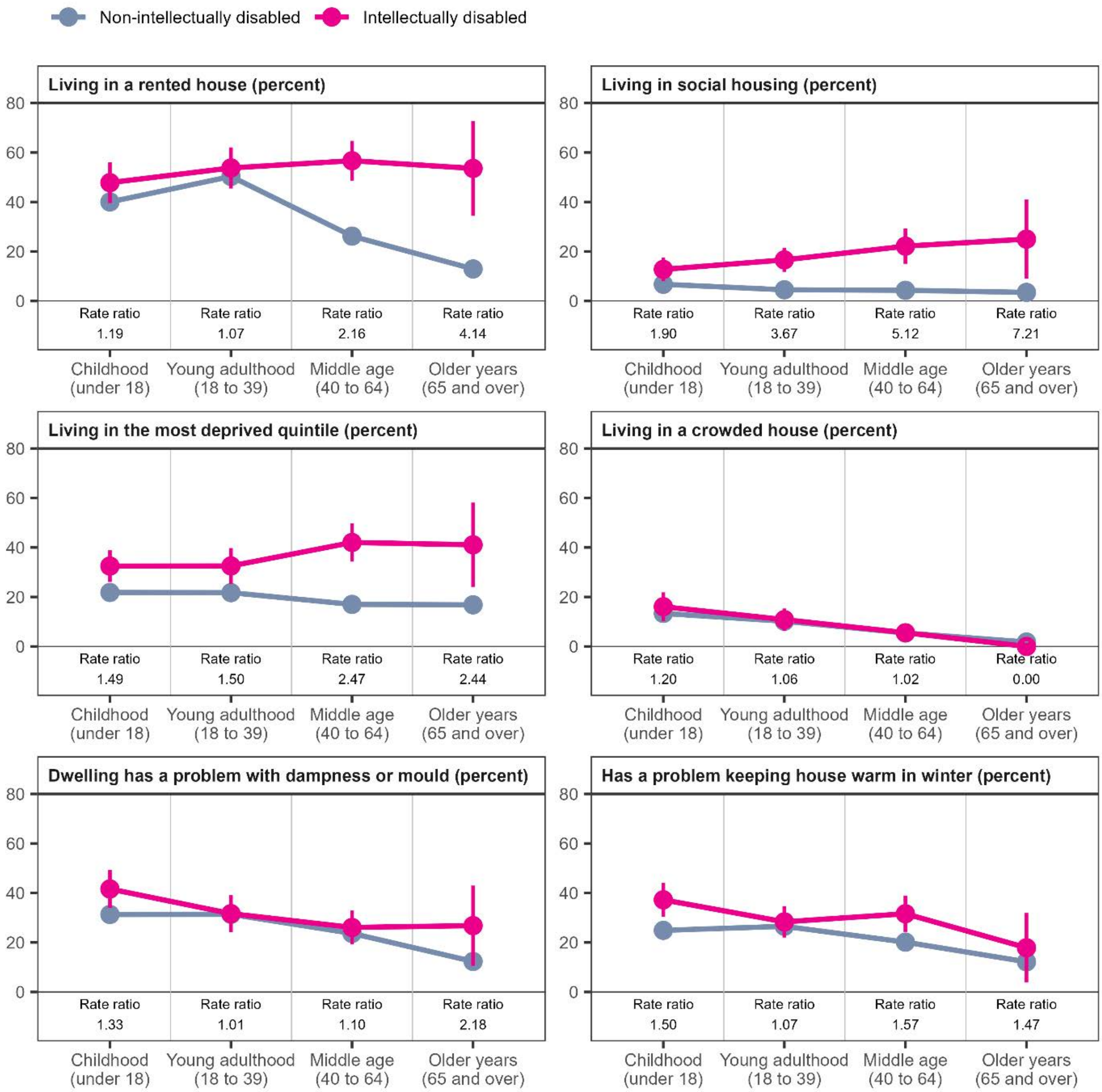
Chronic fatigue and sleep deprivation for the above parents came from fragmented or insufficient sleep. Reasons for this included nighttime caregiving demands, such as managing medical issues, calming anxiety, or ensuring the safety of their children who wandered or had behavioural outbursts.

Physical health deterioration –parents postponed addressing their own health needs due to caregiving priorities leading to worsening physical conditions.

4.1 Housing

Housing has the potential to provide a warm and safe environment for people, while home ownership has the potential to reduce expenses and provide financial security for the future. In **Figure 6** we look at the characteristics of people's housing across the life course. Around forty percent of children live in rental accommodation in New Zealand, with slightly higher rates among children with intellectual disability.

Figure 6: Housing characteristics of people with and without intellectual disability across the life course



Note: Vertical bars indicate 95 percent confidence intervals around each estimate, showing where the true estimate may lie. Some points are suppressed due to small sample sizes for confidentiality and quality reasons.

Rates of renting increase into young adulthood to around a half for both groups, while by middle age, fewer than a quarter of adults without intellectual disability live in rental accommodation. Over this period, rental rates continued to remain high for adults with intellectual disability however, with almost three in five living in rental accommodation at ages 40 to 64.

Home ownership did not automatically equate to material comfort or an ideal living situation among participants in the qualitative interviews. While six were homeowners, two indicated tenuous ownership, and both were experiencing enduring financial strain. Riley reported being unable to keep up with the mortgage payments unless something changes drastically. Lola, on the other hand, co-owns her house with her parents, with whom she has a very strained relationship, and doesn't earn enough to make ends meet.

> *… we're extremely lucky [having our own home]. We're only just holding onto the house, so we might have to sell this house again … At the moment, we're in the worst financial position we've ever been in… One income, high interest rates… every remaining piece of reserve that we had… Plus, you know, we dug ourselves into a huge hole [referring to the self-funded care for Simon].*
>
> *Riley, mother of Simon*

Housing insecurity was an issue for all five of the parents who have been on benefit in the qualitative study and continued to be an issue as they gained part-time work. Four of these parents lived in poor-quality rental accommodation – those with dependent children still at home – and one, whose adult children no longer live with her, has no stable accommodation at the time she was interviewed.

The quantitative analysis show that rates of social housing are similarly low for children with and without intellectual disability **(Figure 6)**, potentially highlighting problems in accessing social housing, however rates rise across the life course for people with intellectual disability (from an estimated 13 percent in childhood to over 22 percent in middle age and 25 percent in older age, albeit with a wide level of uncertainty). This contrasts with the experience of people without intellectual disability, who are progressively less likely to live in social housing as they age, decreasing from seven percent as children to three percent as older adults.

Two parents in the qualitative analysis found it difficult to access social housing. Stephanie eventually secured a flat for her daughter after years of trying. Attempts by Lani to secure better housing through private landlords and social housing programs have been unsuccessful despite her urgent need. Her current rental is a health hazard, but long waitlists and bureaucratic barriers have left her stuck. "They say I'm eligible, but that doesn't mean there's a house for me," she explains. Family size may be a prejudicial factor for large Pacific families like Lani's.

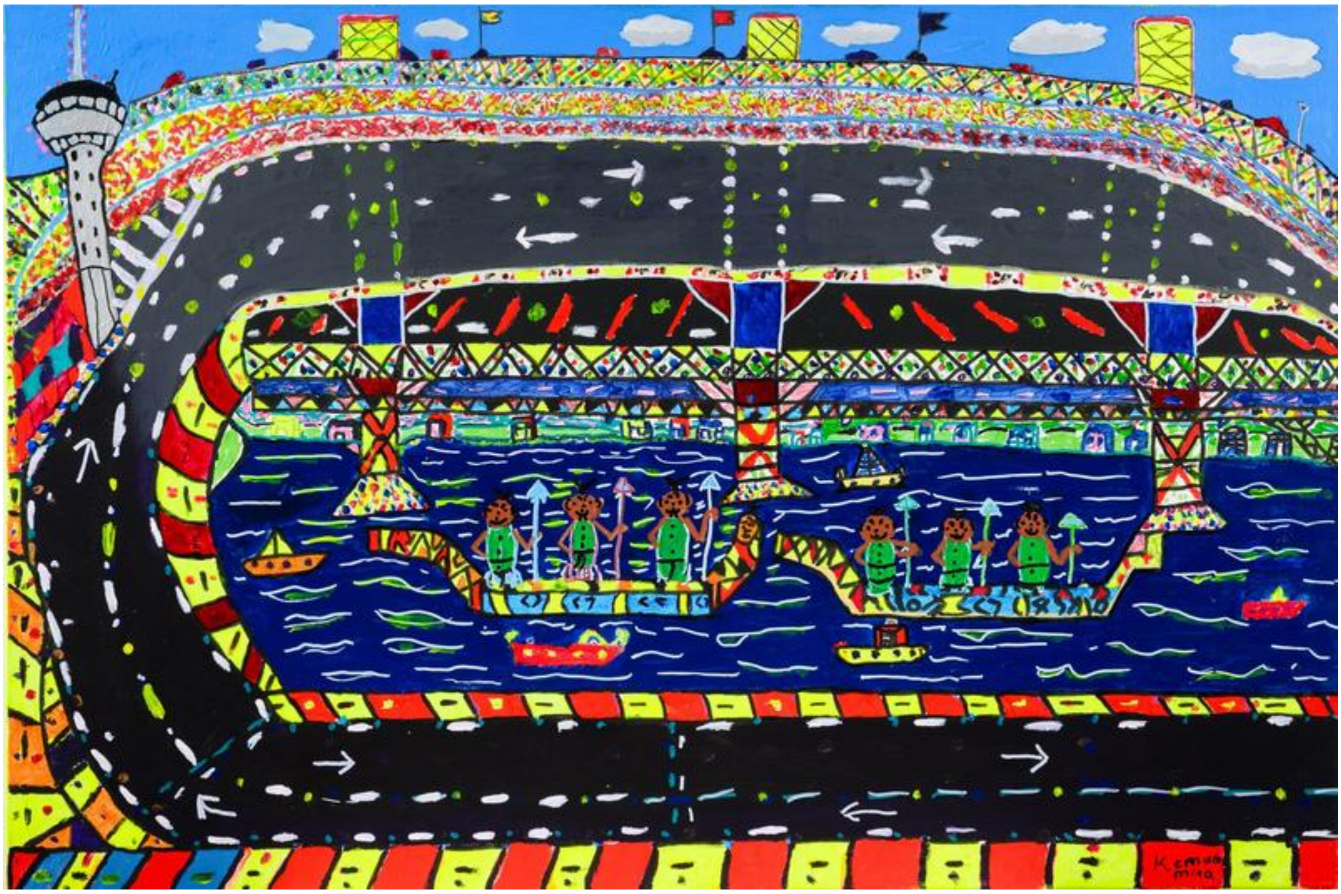
> *I've been stuck in this house for years – tried to move so many times, even applied for social housing, but nothing. With twins on the way, it's even harder to find something big enough for all of us. It feels like no one has options for families this size.*
>
> *Lani, mother of four, including Meleia, with twins on the way*

Consistent with increases in renting and accessing social housing, people with intellectual disability are also more likely to live in more deprived areas as they get older. Over 40 percent of adults with intellectual disability aged 40 or over lived in the 20 percent most deprived areas of the country, compared to less than 20 percent of adults the same age without intellectual disability.

In the quantitative analysis we looked at two measures of housing quality, whether the house had a problem with dampness or mould, and whether the house was difficult to keep warm in winter. Children with intellectual disability were more likely to live in both damp or mouldy homes, and in houses which were difficult to keep warm in winter, while people with intellectual disability in middle age were more likely to find it difficult to keep their house warm and older people with intellectual disability were more likely to be in a damp or mouldy home.

Eight of eleven parents in the qualitative study highlighted accommodation problems at some point, including dampness, mould, or inadequate heating during winter.

> *We do have black mould in the bedrooms, which is why we all sleep in one room.*
>
> *Riley, mother of Simon and Calie*



Kemara Mita - Auckland Harbour Bridge

Kemara delves into the rich narrative of waka voyages, weaving together the tales of exploration and discovery. Immersed in the backdrop of Auckland Harbour Bridge, Kemara brings this scene to life with vibrant hues and striking contrasts, capturing the essence of the journey in bold strokes and vivid colours.

5 Services and supports

In this section we look at the formal services and supports people receive from government, either through the benefit system, the disability support system, or from the Ministry of Education. These are summarised in Appendix 1. In addition to these core supports people may receive a range of other supports and services accessed privately of through community groups. The IDI allows us to look at the core supports that people receive, but it does not allow us to compare this with people's needs, the difficulties they may have accessing services, or the quality of those services once accessed. The qualitative component provides important information about these issues from the perspective of intellectually disabled people and their whānau.

5.1 Receipt of services and supports

Figure 7 shows how many people with intellectual disability receive disability-related payments from Work and Income, Special Needs Grants from Work and Income, or government-funded disability support services.

The data shows that up to age 65, people with intellectual disability were much more likely than other people to live in a household receiving an **income-tested benefit** such as Supported Living Payment (SLP). This ranged from almost 40 percent as children, up to over 80 percent for adults under the age of 65, most of whom received SLP, indicating that a doctor has assessed their condition as meeting the "permanent and severe" criteria[11]. Low rates of household benefit receipt among people aged 65 and over reflect universal eligibility for New Zealand Superannuation at that age.

As we would expect, the data shows that people with intellectual disability were more likely to live in households receiving a **disability allowance** throughout the life course. Rates were lower in childhood, at 20 percent, before increasing to almost a half at ages 18 to 39 and 60 percent at ages 40 to 64, before declining slightly at age 65 and over (with some uncertainty around the latter estimate due to small numbers in the sample). Many people do not receive the disability allowance however, despite having an intellectual disability diagnosis. As noted by Murray and Loveless (2021), the disability allowance application process requires people to identify relevant costs, provide evidence of those costs, and then get input and sign-off from a health practitioner. This may deter some from accessing or taking up the payment.

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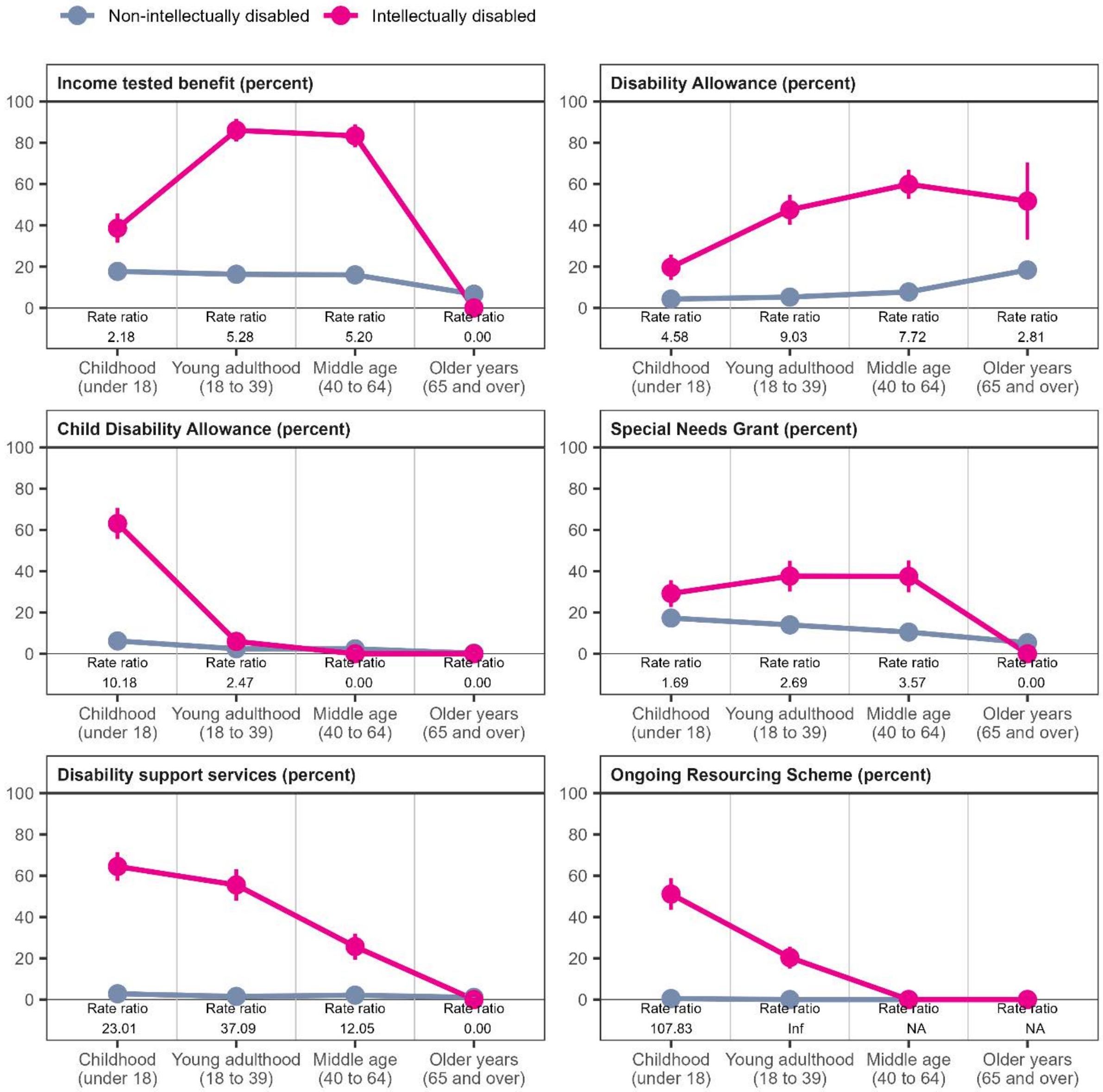
[11] Permanent is defined as "not likely to change in the next two years". Severe is defined as a person "not being able to regularly work for 15 hours or more per week in open employment".

Figure 7: Access to supports and services by households of people with and without intellectual disability across the life course



Note: Vertical bars indicate 95 percent confidence intervals around each estimate, showing where the true estimate may lie. Some points are suppressed due to small sample sizes for confidentiality and quality reasons. Disability support services data was only available up to September 2022. People who responded to HES after this date are excluded from the DSS estimates.
Data Source: Household Economic Survey (2019/20 to 2022/23) linked to administrative data in the IDI.

In terms of child specific financial supports, almost two-thirds of children with intellectual disability live in a household receiving **child disability allowance** (CDA). Low levels of awareness, or barriers to access, such as requirements for a doctor to assess the level of need, could be affecting the take-up of CDA among the families of intellectually disabled children. A Child Poverty Action Group study reported that a majority 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 (Neuwelt-Kearns, Murray, Russell, & Lee, 2020).

Access to **disability support services** was relatively high in childhood but declined across the life course. While almost two-thirds of children with intellectual disability accessed disability support services, this dropped to 55 percent in early adulthood (to age 39), and to a little over a quarter in middle age. This drop could indicate people with intellectual disabilities integrating into mainstream life as they age, however, it could also be due to the age profile of different types of intellectually disabled people and the information gap for people in residential care in this study. Services such as Carer Support, Individualised Funding, and Respite Services tend to have disproportionately younger clients, while Community Residential Support Services and Supported Living clients are more likely to be older. People receiving these latter services are likely to be missing from our sample as they may not be considered to be living in a 'private household'. Those still living in private households may have lower support needs on average.

When looking at the financial supports for the older age group, the data show very few people over the age of 65 receiving Disability Support Services. This is because, instead, they generally receive support through Te Whatu Ora – Health New Zealand. Due to the small number of over 65-year-olds in our study, we did not look at access to this funding.

In terms of emergency assistance, the data shows that, up until age 65, people with intellectual disability were much more likely than other New Zealanders to have received at least one **Special Needs Grant** (SNG) in the past year **(Figure 7)**. Almost 40 percent of adults under 65 with intellectual disability had had at least one SNG in the past year, while almost 30 percent of children with intellectual disability lived in a household which had received an SNG.

The data on educational support shows only half of children with intellectual disability were estimated to have received Ongoing Resourcing Scheme funding in the past year. While Ongoing Resourcing Scheme funding does not provide direct financial support to children and their families, it does provide access to essential services, therapies and other supports which parents otherwise may have to meet themselves.

The following three sections report on findings from the qualitative interviews that explore the adequacy of these supports and access barriers that people experience.

5.2 Adequacy of financial and educational supports

While income support payments do provide some additional financial support to people with intellectual disability, they may be insufficient to meet the full cost of disability, even if people receive their full entitlement. For example, based on the figures given above:

- a sole parent with an intellectually disabled child who is not working could receive up to an additional $10,149 per year from SLP, DA and CDA,
- parents who earn over the SLP and DA income threshold, may be able to receive CDA for their child at a rate of $3,080 per year,
- a single adult with intellectual disability who is not working could receive up to an additional $7,069 per year.

Although there is little New Zealand evidence around the additional income required for people with disability to achieve a similar standard of living to people without disability (i.e., the cost of disability), recent evidence using a 'standard of living' approach suggests this may be in the order of $21,000 for a sole parent with one child with a disability (Wilson, McLeod, &

Godfrey, 2025).[12] Earlier research used a 'budget standards' approach to estimate the cost of disability by impairment type and need. These costs ranged from $578 per week to $2,568 per week for an adult with an intellectual impairment with moderate and high needs respectively (Disability Resource Centre, 2010). Even the moderate needs scenario estimate is equivalent to an annual cost of more than forty thousand dollars per year in 2024 dollars.

Even taking the lowest of these estimates as a guide would indicate that current levels of financial assistance are insufficient to meet many people's needs, resulting in an increased likelihood of poverty and material hardship, **even relative to households reliant on benefit who do not have a disabled member.**

Even for those who do receive CDA or Disability Support Services, participants in the qualitative interviews reported that they often only cover a fraction of the costs associated with therapies, equipment, or education adaptations. For example, while Riley received CDA, this was insufficient to cover her son Simon's intensive care and therapy requirements. In addition, many essential costs, such as dental care, developmental assessments, medication, private therapies, and developmental programs, were excluded from funding eligibility, leaving some parents to self-fund these services.

Among participants in the qualitative interviews, families relying on benefits experienced the most severe material hardship, unable to afford essentials like heating, adequate food, or medical care. Six parents in our study relied on benefits and emergency grants during periods when caregiving demands limited their ability to work full-time. Borrowing from family or taking on debt was a common survival strategy, exacerbating long-term financial instability. Several participants reported that benefit rates were insufficient to meet their basic needs, resulting in the need for family support and emergency assistance from Work and Income.

For example, Sarah relied heavily on the Sole Parent Support benefit and occasional hardship grants to meet basic needs during periods when she could not work. Even with these supports, she lived in extreme material deprivation, borrowing from family and living in arrears for utilities like electricity and water, being unable to afford heating, regular medical care, home insurance, or new clothing. Sarah reported feeling humiliated by indifferent case managers when her applications for SNGs were declined, even for essential expenses like food or heating. Sarah described the ongoing financial strain as "profoundly stressful," adding to the emotional toll of caregiving.

Lola had been on benefits, as well as receiving supplementary assistance. As a single mother, Lola juggled part-time work with caregiving for her son Josh. Her income was supplemented by the benefit, which, together, were still insufficient to cover incontinence supplies and other disability-related expenses. She frequently applied for emergency grants to cover urgent bills but described the process as "humiliating" and burdensome. Consequently, Lola sold personal belongings to manage debt and described living in "constant financial anxiety."

Another participant, Riley, received a Child Disability Allowance and emergency assistance during later periods of unemployment. Riley's caregiving role prevented her from maintaining steady work, and she encountered numerous barriers to accessing support. Asset-based exclusions made her ineligible for some assistance, even though her income was insufficient. She frequently pleaded for hardship grants (i.e., SNGs) and had to rely on family support to cover basic needs like groceries.

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[12] Author's calculations, based on an estimated $20,000 household equivalised income, which corresponds to a household income of $26,000 per year for a one adult, one child household. Sole parent support is currently paid at a little under $26,000 per year. Estimated additional equivalised income required of $16,500 is equivalent to $21,450 in un-equivalised household income.

Riley's financial struggles caused her to delay medical care for herself (resulting in seriously worsening health) and her children, including essential therapies and equipment.

Several parents reported sudden reductions in respite care hours or funding, leaving them without essential relief. Riley, for example, lost flexibility in her Individualised Funding due to restrictive administrative requirements.

> *Whaikaha then reduced the flexibility by saying, now there's rules. Like you can't use [IF] to pay for supports on a school day when he's supposed to be at school because the Ministry of Education should be paying for that. Oh, yeah, right. But they don't obviously then pick up the tab... So that will mean practically for us that we won't be able to afford to pay for any of the activities that Simon currently does during school or after school. And we won't be able to afford to pay for any care or respite. And I won't be able to pay for my counselling or Calie's counselling unless we sell our house and move to a further out suburb.*
>
> *Riley, mother of Simon and Calie.*

In the qualitative interviews, parents consistently reported that educational supports for their children with disabilities either diminished over time or were inadequate to begin with. These exacerbated learning challenges and further burdened families. Issues could start as early as early childhood education

> *At two and a half he started going to a Montessori preschool [because of its small size and child-teacher ratio] for only 9 hours a week ...he stayed there for a year and a half, two years, say, but they hadn't raised any concerns apart from his behaviour. So every day I'd go to pick him up and they'd say, he smashed, smacked so and so ... And then a teacher that worked there rang me and said, you need to take him out of there. They're shutting him in a room on his own... so I removed him from there.*
>
> *Riley, mother of Simon and Calie*

Box 2 outlines issues faced by parents in maintaining access to educational supports.

Box 2: Diminishing or compromised educational support

Loss of teacher aide hours – In Jamie's case, Ongoing Resourcing Scheme funding was allocated in a large city, however, when the family moved to a provincial town the funding was temporarily discontinued and took many months to restore. More prevalent was the recurring issue of diluting teacher aide support. Parents reported that hours which were meant to be dedicated to their children were often redistributed to other students or across classrooms. This practice diminished the effectiveness of the support and left families feeling that their children's needs were deprioritised.

- Erica struggled to complete tasks and regulate her emotions without individualised support, leading to frequent disruptions and emotional setbacks. Carla had to repeatedly engage with the school to advocate for a fair allocation of teacher aide hours.
- Without adequate support, Simon faced significant challenges in adapting to the larger, more complex high school environment. Kelley noted that he often avoided school due to the overwhelming lack of tailored accommodations.
- Aria's progress slowed considerably, and Hana had to step in, often taking time off work to assist her daughter with school-related activities that should have been covered by a teacher aide.
- The lack of consistent support led to behavioural incidents and academic challenges, further isolating Ethan socially and academically. Sarah repeatedly raised concerns with the school administration but found little improvement.

Transition challenges - Erica's transition to intermediate school was marked by reduced support services, as the new school had fewer resources and less experience working with neurodiverse students. The gap in accommodations led to significant setbacks in her social and academic progress. Simon faced similar challenges during his transition to high school, where previously established accommodations were not carried over, leading to delays in appropriate supports.

Insufficiently trained teacher aides - While Erica eventually gained Ongoing Resourcing Scheme funding, her assigned teacher aide lacked adequate training to address her autism and intellectual disability. Carla often had to step in to educate teachers and aides on how to meet Erica's needs effectively. Ethan's school provided a teacher aide only after repeated advocacy from Sarah. However, the aide lacked experience working with children with autism spectrum disorder and foetal alcohol spectrum disorder.

Inconsistent or reduced accommodations - Simon's school initially offered accommodations for his sensory sensitivities and behavioural challenges, such as a quiet learning space. Over time, these supports dwindled, particularly as staff turnover led to a loss of institutional knowledge about his needs. Mica's school struggled to consistently provide the sensory accommodations she required, such as quiet spaces and predictable routines. As a result, Mica often became overwhelmed, leading to frequent disruptions and exclusions from the classroom.

Withdrawal of specialised programmes - Kyle was briefly enrolled in a specialised literacy program for children with intellectual disabilities. However, the program was discontinued due to funding cuts, leaving Helen to search for alternative resources at her own expense. Ethan was removed from a behavioural intervention program after just one term due to resource constraints. This left Sarah having to fund private interventions.

5.3 Impact of delayed diagnoses on accessing support

Few young children were identified in the administrative data as having intellectual disability, indicating that it may take some time for many children to be diagnosed. Mischaracterisation of children's intellectual disability and delays in diagnosis were reported as being an issue for several parents of children with intellectual disability who took part in the qualitative interviews. In many cases, delays in obtaining formal diagnoses resulted in delayed access to funding and significant institutional supports.

Ethan's delayed diagnoses, which took six years, meant he missed out on critical funding for specialised educational tools and therapies during his early schooling years. Consequently, Sarah faced significant financial strain, having to self-fund interventions while advocating for school accommodations, which remained inconsistent without formal diagnoses.

Erica's delayed diagnosis meant her early schooling lacked adequate accommodations, leading to frustration, social isolation, which contributed to significant delays in meeting developmental milestones. Delayed access to Ongoing Resourcing Scheme funding denied her the support of a teacher aide earlier throughout primary school. The family also had to self-fund interventions, such as speech therapy and cognitive behavioural therapy, straining their finances.

Kyle's developmental and physical challenges were identified early in infancy, with concerns about his motor skills and overall development noted by the age of 1 year. However, his intellectual disability was not formally diagnosed until he was 7 years old. Early evaluations focused on his physical delays without adequately addressing cognitive concerns. Consequently, the family didn't have Individualised Funding to cover early developmental therapies. Helen had to navigate multiple bureaucratic systems to eventually secure Kyle's supports and the family had to weather additional financial burdens.

> *So, he actually got [Ongoing Resourcing Scheme funding] based on more high health [needs, rather] than actual intellectual disability [Developmental Delay] … And it wasn't till, I think, he was about eight years old that Kyle came out with intellectual disability as a diagnosis [as a result of Helen hearing about and seeking a private assessment].*
>
> *Helen, mother of Kyle*

It took eight years for Simon to receive a formal diagnosis. Concerns about his development were first raised at the age of three, when he showed difficulties with communication, sensory sensitivities, and social interaction. However, Simon was not officially diagnosed until he was 11 years old.

In some cases, parents had to pay for diagnostic assessments themselves to secure formal recognition of their child's disability, which is a prerequisite for accessing government funding and educational resources. For example, Carla and Terry paid for private assessments for Erica and Jamie after public waitlists and lost medical records delayed their diagnoses. Similarly, Kelley self-funded Simon's developmental testing to confirm his intellectual disability after years of dismissed concerns, and Sarah funded specialist assessments for Ethan to formally diagnose his conditions, thereby enabling access to individualised education plans and specialist support.

These assessments have cost these families thousands of dollars, creating significant financial strain on families already struggling to manage.

5.4 Administrative complexity

Many families in the qualitative interviews reported facing extensive paperwork, administrative errors, and long wait times to secure or renew funding, further stressing already overwhelmed caregivers. Jamie initially benefited from Ongoing Resourcing Scheme funding for his autism diagnosis while living in a large urban centre. However, the family's move to a provincial town disrupted continuity of care, and crucial medical records were lost during the transition. Funding and educational supports were cut, requiring the family to start the diagnostic process again. Consequently, Jamie struggled with sensory sensitivities and behavioural self-regulation without adequate support, impacting his ability to engage in learning environments effectively.

> *Getting funding feels like a full-time job...You have to prove, over and over, everything your child can't do, just to get the bare minimum.*
>
> *Lani, mother of Meleia*

Aria's diagnosis of cerebral palsy and intellectual disability was complicated by inconsistent assessments and inadequate documentation of her learning needs. Initial reports focused on her physical disability while failing to fully account for her cognitive challenges. Repeated denials of Ongoing Resourcing Scheme funding applications required Hana and Tane to organise and pay for remedial tuition and therapy sessions themselves. Aria's school also struggled to accommodate her needs due to a lack of targeted resources, leading to slow academic progress and heightened family advocacy burdens.

Riley's efforts to secure an autism assessment for her son Simon were marked by repeated administrative obstacles and systemic failures. Despite clear signs of developmental and social difficulties from an early age, the process was delayed for years due to bureaucratic processes requiring frequent resubmission of identical paperwork to multiple agencies, long waitlists for publicly funded assessments, lack of communication between healthcare providers, educators, and disability services resulted in repeated misplacements of Simon's records.

Professionals initially downplayed Riley's concerns, attributing Simon's behaviours to parenting challenges rather than exploring underlying neurodiversity. The delays caused by these systemic barriers left Simon without critical early interventions, placing additional emotional and financial strain on Riley as she navigated an opaque and fragmented system and self-funded therapies.

Many families paid for therapies when public systems were unavailable, inadequate, or involved lengthy delays. For example:

- Carla and David funded speech therapy for their children when early interventions were delayed, enabling her to improve communication skills critical for their development.
- Helen self-funded OT sessions for Kyle to address his fine motor delays and adaptive skill development, as public resources were either unavailable or too limited.
- Sarah paid for private Applied Behaviour Analysis (ABA) sessions for Ethan to address social and emotional regulation challenges after his school's behavioural program was discontinued.
- Hana and Tane funded physiotherapy for Aria, as her school lacked the resources to provide consistent physical support for her cerebral palsy.

Most of the parents interviewed had to pay for multiple services and interventions they had reason to believe would be provided by the state. These cumulative burdens involved

- Financial strain: the costs of funding interventions forced families to economise on basic needs or take on debt.
- Missed opportunities: Without government support, families could not afford some

essential interventions, leading to developmental delays and compounding hardships for their children.

- Emotional toll: Parents expressed frustration with a system that required them to "prove" their children’s needs while navigating financial insecurity and the lack of accessible public resources.

> *I didn't even know about Individualised Funding, even though we had the assessment done when Grace was 10 or 11 [she is now in her early twenties]. They did offer us a behavioural specialist – an educational psychologist, who’d come over. So, we did do that. They offered us that when she was like 12, but it made no difference to her. Somehow, I found out about [IF] when Grace was 16. I think we got a new NASC worker who actually said to me a bit more of what she was entitled to.*
>
> *Louise, mother of Grace*

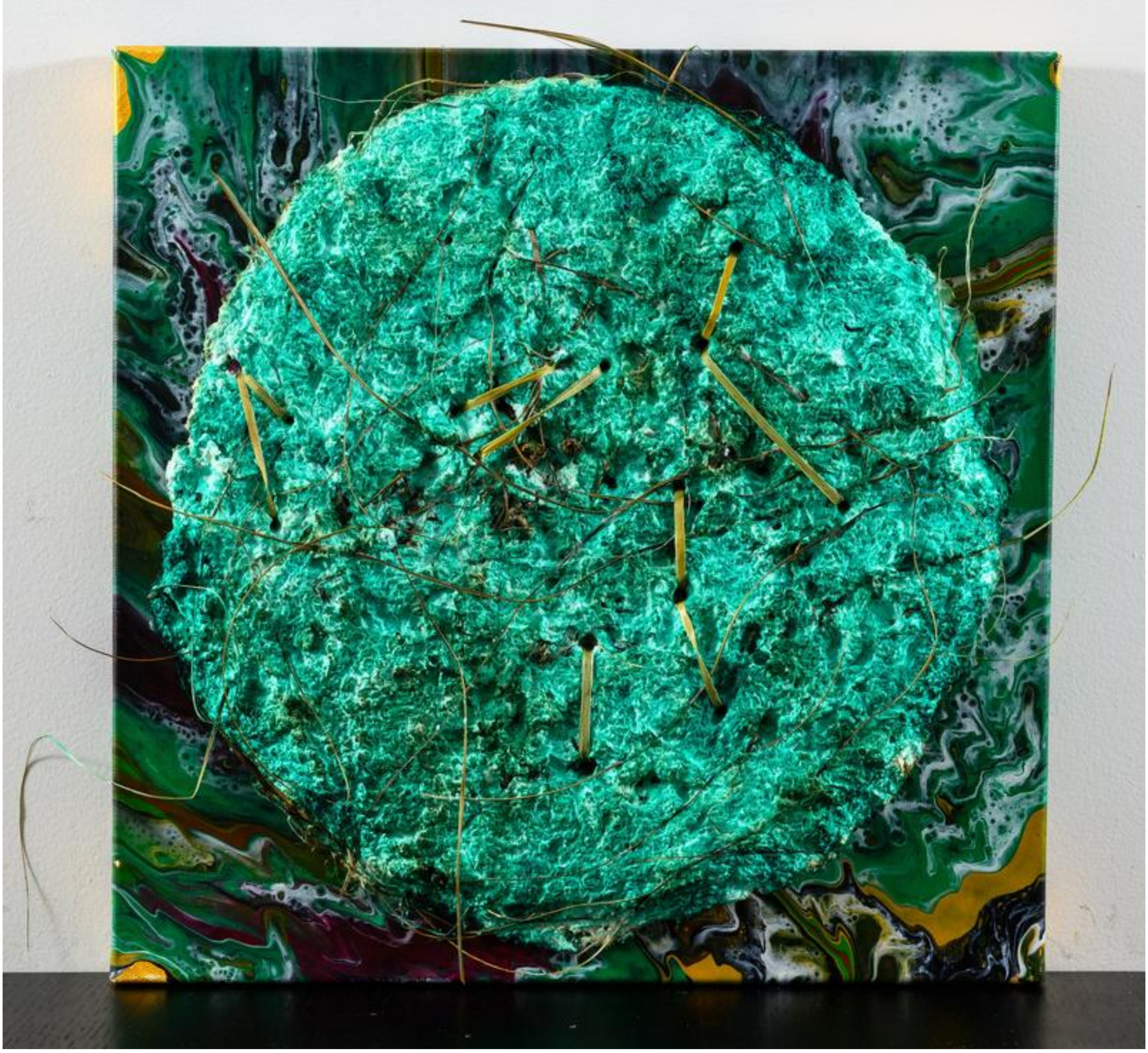
> *It's a compounding disadvantage if you are declined for one service... I went to the needs assessment coordination service. They said, do you have an autism diagnosis? I said, no, I've got an ADHD diagnosis for Simon. No. Okay. You're not eligible...then you try to get a needs assessment, but they say, no, you don’t have an autism diagnosis, so you can't get a needs assessment...So each time there's compounding disadvantage.*
>
> *Riley, mother of Simon*

> *Work and Income [provides] the Child Disability Allowance. And that has to be reviewed each time, even though [autism is] for life for those two, you have to keep continually going and getting medical certificates for them ... [Work and Income] question the doctors as well ... why would they do that in the first place? A medical practitioner who's got a degree, who's writing something, and the Ministry is questioning it?*
>
> *Vicki, mother of Erica and Jamie*

While parents understood the necessity of reviewing the capability and needs of their children, they had three particular concerns.

1. Retelling the same story to different professionals – the lack of continuity, relationship and shared understanding about children that are vulnerable and hugely precious to parents is exhausting and frustrating.
2. The deficit- rather than needs-focus. Parents talked about having to mentally and emotionally prepare themselves for intensive descriptions about all the things that their children couldn’t do that ‘normal’ children could.
3. The second-guessing of medical professionals by agency staff. This was seen as signalling a lack of respect at best and a generalised cynicism at worst.

> *...getting individualised funding was so hard... it runs on a deficit model – by what a kid can't do rather than who they are. So, I had to write down that comparison thing. I had to lock myself away to actually write it because I couldn't possibly write it by looking at Meleia. And so I had to outline exactly, basically, what my god-daughter can do and what Meleia can't do. And the supports are supposed to bridge the gap. I locked myself away for a month's worth of evenings to write that whole [20-page] document out.*
>
> *Lani, mother of Meleia.*



Uruamo Cook – Kakariki
Green, green everywhere.

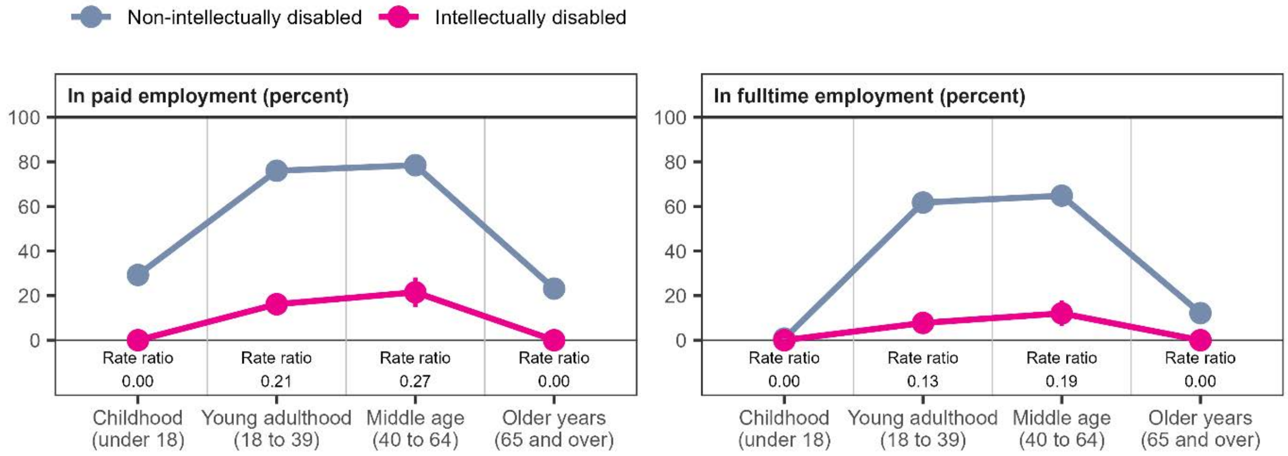
6 Employment

Employment is a critical avenue to financial security as well as social connections and general wellbeing. It is also correlated to economic hardship. This section shows the employment situation of people with intellectual disability and their families.

6.1 Employment of people with intellectual disability

Figure 8 shows indicators of employment for people with and without intellectual disability through their lives. Consistent with findings in the From Data to Dignity report (Beltran-Castillon & McLeod, 2023), we find that around one in five working-aged adults with intellectual disability were in some form of paid employment in the past year, while only around one in ten were in full-time work (8 percent of young adults, and 12 percent of middle aged adults). This compares to around three-quarters of other New Zealanders being in work at these ages, with almost two-thirds being in full-time work.

Figure 8: Personal employment for people with and without intellectual disability across the life course



Note: Vertical bars indicate 95 percent confidence intervals around each estimate, showing where the true estimate may lie. Some points are suppressed due to small sample sizes for confidentiality and quality reasons. Some points are suppressed due to small sample sizes for confidentiality and quality reasons.
Data Source: Household Economic Survey (2019/20 to 2022/23) linked to administrative data in the IDI.

The seven working-age participants in the qualitative study vary considerably in age and, therefore, life experience. The seven participants can be categorised in the following way:

1. Financially secure, socially engaged and in meaningful employment (three – two women in their thirties and one man in his fifties)
2. Financially secure, under-engaged and unemployed (two – both men, one in his fifties and the other in his sixties)
3. Looked after at home while preparing for work (one – a woman in her early twenties)

4. Financially precarious, stuck at home and doing unsuitable low-paid work (one – a woman in her mid-twenties).

Four of seven indicate degrees of marginalisation that fall short of the principles of Enabling Good Lives.

We identified that coming from a higher socioeconomic background is a big factor in the quality of social participation and life opportunities for adults with intellectual disability. Even with such advantages, two older people want to be more engaged in work or meaningful activity than they are. For adults with intellectual disability in the qualitative interviews, being able to work for a flexible employer and having an understanding manager were highly valued. For example, Robert's employer made various accommodations to enable him to do a range of tasks, including working as a checkout operator.

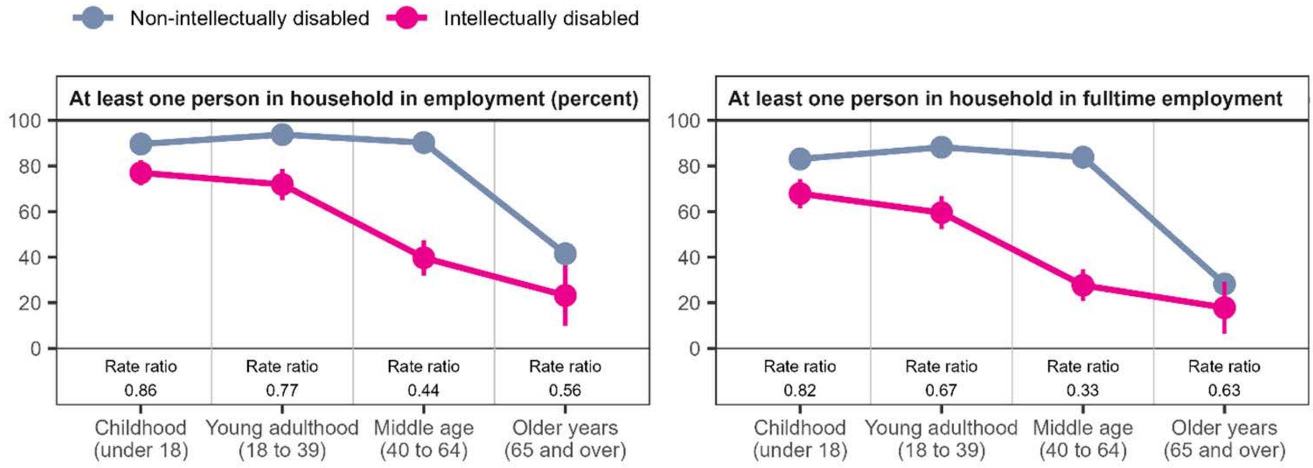
> *I told the supermarket manager that if I go to work on the checkout, I need help me with the money side of things. He said, "Okay. We will get someone to help you with that". They put a sign in the front of the checkout asking customers to be "patient for the guy learning how to operate the till, and let them know about my special needs too."*
>
> *Robert, paraphrased*

6.2 Employment of family and household members

Figure 9 shows indicators of employment for people with and without intellectual disability at a household level. At a household level, we see that fewer children with intellectual disability have at least one working person living with them (77 percent compared to 90 percent for those without intellectual disability), or at least one person living with them in fulltime work (68 percent compared to 83 percent).

The data also shows that as people with intellectual disability age into middle age, they are much more likely to be in a household where nobody works (60 percent) and where nobody works fulltime (72 percent). This is consistent with the lower employment rate of people with intellectual disabilities and the fact that at this age they are often either living by themselves or living with parents who themselves are no longer working.

Figure 9: Household employment for people with and without intellectual disability across the life course



Note: Vertical bars indicate 95 percent confidence intervals around each estimate, showing where the true estimate may lie. Some points are suppressed due to small sample sizes for confidentiality and quality reasons.
Some points are suppressed due to small sample sizes for confidentiality and quality reasons.
Data Source: Household Economic Survey (2019/20 to 2022/23) linked to administrative data in the IDI.

Seven of eleven caregivers in the qualitative study reported having to reduce their work hours or withdraw from the workforce altogether due to the demands of daily caregiving. For example, Helen could not work while managing the extensive number of medical appointments critical to her son's development. The relentless pace of appointments was akin to "a full-time job".

> *... probably for the first five years of their life ... probably longer [seven years, I realised] I'm never going to be able to go back to work. That's where I felt mentally ... because Kyle had so many appointments.*
>
> *Helen, mother of Kyle*

Riley also suffered burnout from the dual demands of caregiving and fulltime work.

> *I ended up working full-time for three years, which just about killed me...50 hours a week plus 15 to 20 hours advocating for Simon, payroll for carers, and dealing with OTs (occupational therapists) and everything else. It was like running a small business just for his care.*
>
> *Riley, mother of Simon*

Stephanie's part-time work as a retail assistant provided a modest and unpredictable income that barely covered essentials. Her hours were often reduced during caregiving emergencies, such as Mica's frequent medical appointments or hospitalisations.

Families frequently face job instability due to unanticipated caregiving emergencies, as seen in cases where sudden medical crises or school exclusions disrupt work schedules. This forced them into casualised, low-income and unpredictable forms of employment.

> *I mean, yesterday it was a struggle. I had to work yesterday. I had to take [Josh] to work with me knowing he was sick, you know. I was constantly back and forth every ten minutes, going out to the car because he didn't want to get out of the car, so the windows were down because it was hot. I parked the car outside so I could see him. He had his tablet and I was constantly having to stop every ten minutes, keep going back and forth, back and forth ... because I don't have any support. And it's hard even, you know, asking someone. If they've got kids, they do not want to look after a sick kid, do they? [Josh is often sick]*
>
> *Lola, mother of Josh*

In the qualitative interviews, caregiving responsibilities disproportionately fell on mothers, who were then more likely to experience career disruptions and financial vulnerability. Single mothers, in particular, bore an amplified burden, as highlighted in the cases of Sarah, Hana, Lola and Lani.

Dual-income households were rare in our qualitative participant study group. This was consistent with our quantitative analysis, which showed that only half of the children (48 percent) with intellectual disability lived in a household with two or more workers, and only a quarter (27 percent) lived in a household with two or more people working fulltime (compared to 61 percent and 39 percent for children without intellectual disability).

Box 3 examines some of the single income scenarios found in the qualitative interviews.

Box 3: Single income and caring

Families raising children with intellectual disabilities often face heightened financial precarity due to shifts from dual-income to single-income households. These transitions, often driven by caregiving demands, exacerbate economic vulnerability and restrict opportunities for long-term financial stability. Below, we examine three single-income scenarios.

In many cases, families operated as single-income households from the outset due to caregiving demands or limited opportunities for the non-primary caregiver to work. As a single mother, Sarah's income options were already constrained. Her inability to pursue consistent full-time employment, coupled with Ethan's ongoing support needs, left her reliant on benefits and occasional hardship grants. The financial strain intensified during periods when she volunteered or worked in a temping role that allowed for caregiving flexibility.

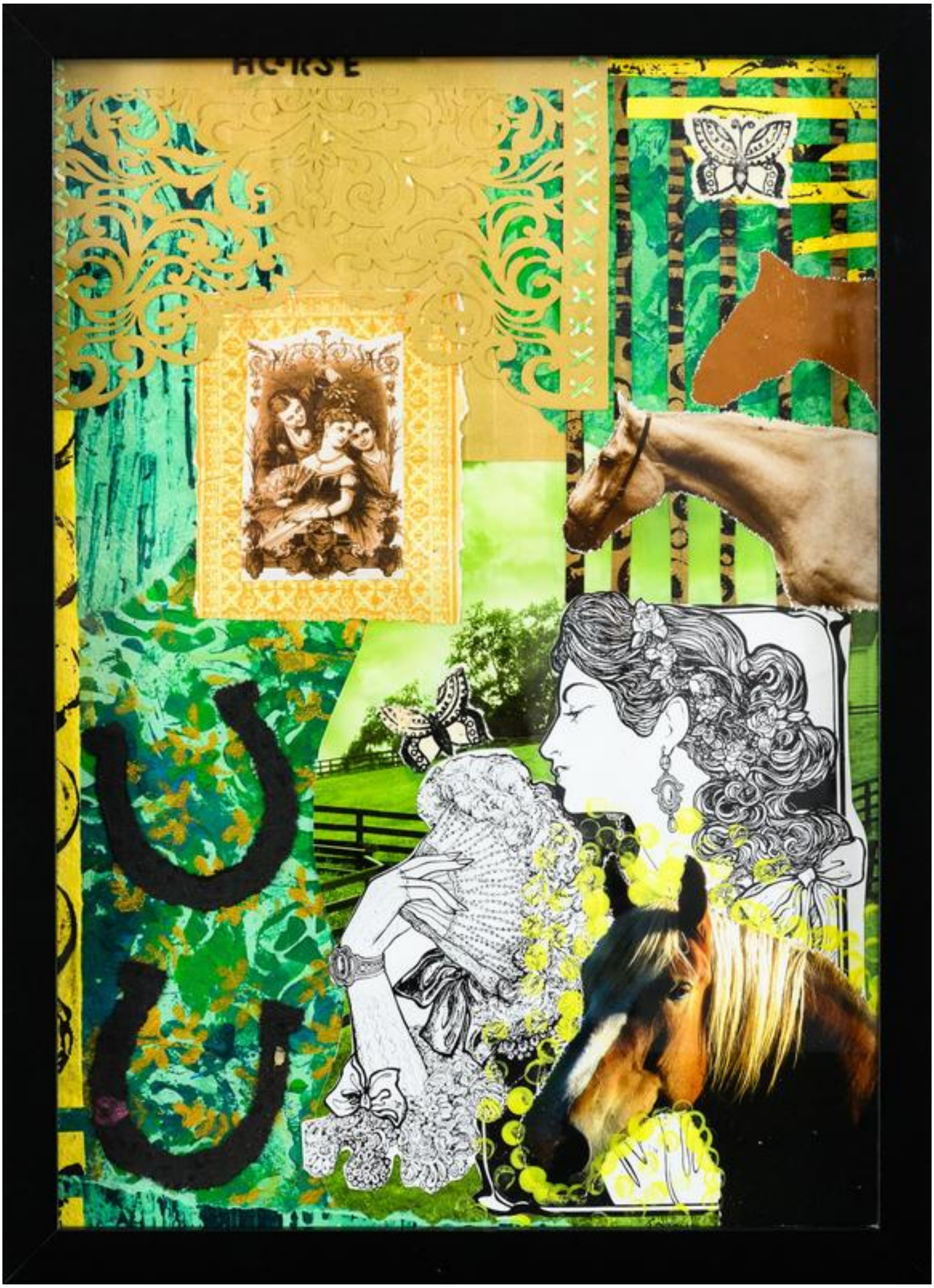
Helen's family operated on a single income for many years, as Liam's work flexibility enabled him to provide financial stability while Helen focused on caregiving. However, the strain of supporting three children, two with significant medical and/or intellectual needs, meant their single income was insufficient to cover therapies, household repairs, and educational supports.

Hana's household initially benefited from her part-time income and her ex-partner's s full-time work. However, as her daughter Aria's needs intensified, Hana reduced her working hours to focus on caregiving, leaving the family heavily reliant on one income. The couple then separated. These changed circumstances led to periods of financial strain, particularly when having to self-fund extracurricular and developmental programs for Aria due to insufficient systemic support. The latter was only possible through Hana gaining part-time work and re-partnering in recent years.

Riley and her partner Jared moved frequently due to Jared's job, and his income was the sole financial source due to their children's high support needs. When Jared was made redundant and could only find casualised low-paid work, Riley took a full-time job, which proved untenable alongside caregiving. This instability left them unable to save or invest in long-term financial security, and they experienced acute financial stress since Jared's COVID 19 precipitated lay-off.

> *How could I get a job to fit in with my commitments – impossible. No holiday programmes will accept them – there's only one now. Even then, the kids don't want to go.*
> *Riley, mother of Simon*

Initially a dual-income family, Vicki and Terry restructured their roles to prioritise caregiving for Erica and Jamie. Terry became the primary caregiver due to his natural aptitude for creating structure and responding to the children's sensory needs. This meant Vicki became sole income earner, leveraging her employer's flexibility to balance work and advocacy. Her salary had to cover the costs of daily living, therapeutic interventions, dietary supplements, and specialised educational tools, leaving little room for unexpected expenses. For example, to ensure the family's financial stability, Vicki has had to wait for surgery in the public system to remedy ongoing chronic pain. Paying for a private operation is inconceivable.



Joanne Stutt - Hold Your Horses
I made my artwork from handmade paper that I printed on using stencils, stamps, ink and paint. I collected pictures of horses and interesting things and an old envelope. I used all these things to make a collage all about horses. My vision was to create an art piece on my love for horses running free on green grass.

7 Interaction between living situation, supports and living standards

The qualitative interviews gave critical insights into the complex relationship between people's living situations, access to and quality of supports and services, and their resulting material living standards in the context of intellectual disability.

7.1 Patterns explaining disparities in hardship levels

Several patterns were evident in the qualitative data. In particular, families with dual incomes or stable financial backgrounds experienced fewer hardship indicators, while single-income households, often with caregiving constraints, were more likely to have substantial hardship.

While renters were especially vulnerable, facing instability and inadequate living conditions, homeowners were not uniformly shielded from hardship. Families with tenuous ownership due to high mortgages or inadequate housing conditions reported substantial material stress.

Access to effective services and financial support may reduce material deprivation. This is hard to determine in a small qualitative study. Such funding and support often arrived late, i.e., at times of increased developmental challenges for children, reduced school support and increased care demands associated with larger households. However, delays or ineligibility for supports like Ongoing Resourcing Scheme consolidated hardship.

Informal supports were critically important in making hardship more manageable at times. Families with supportive networks such as extended family or community groups experienced periods of respite from pervasive strain. For example, in Sarah's case, practical support from her parents ensured she and her son had food and some periods of respite. Recently Ethan has been staying with his grandparents during weekends, which has enabled Sarah to have some time for self-care, which was scarce previously – being able to go to the gym, see friends, read, and have some quiet moments to herself. This development has improved the quality of Sarah's life and mitigated the extreme stress she has experienced over many years as a single working mother looking after a child with an ID.

7.2 Associations between child-specific and family-level hardship indicators

The range of child-specific hardship indicators across families ranged from a lack of necessities such as warm clothing or shoes to reduced participation in enriching activities such as sports or arts. This variability closely aligned with the broader material challenges faced by the family unit.

Families reporting extensive child-specific hardship (e.g., missing meals, limited access to education resources, or exclusion from activities) often simultaneously experienced severe parent-level deprivation. Parents economise on food and postpone essential healthcare for themselves, leaving limited resources for their children. Housing inadequacies (e.g., dampness, lack of heating) directly impacted the children's physical well-being and school readiness. Financial stress, characterised by borrowing for everyday costs and frequent arrears on utility bills, constrained parents' ability to meet children's specific needs. School-related deprivation, such as being unable to afford field trips or educational technology, was a common consequence of limited family resources.

Families with fewer child-specific indicators of hardship were typically more financially stable. Dual-income households or families supported by extended networks reported fewer instances of economising on children's needs. These families were often homeowners or renters in more stable situations, reducing exposure to accommodation-related hardships that affect children's day-to-day experiences.

In families where parents reported significant personal deprivation (e.g., worn-out clothing, postponed medical care), child-specific indicators were often moderated. Parents prioritised children's essentials, such as school-related expenses or warm clothing, despite severe financial constraints. However, in households with extreme financial stress, children also experienced significant deprivation, such as missing extracurricular activities or adequate nutrition.

In families experiencing delayed or denied systemic supports (e.g. Ongoing Resourcing Scheme ineligibility), child-specific hardship indicators were exacerbated. Without access to funded teacher aides or adaptive educational resources, parents faced increased costs that restricted their ability to address other family needs.

Hardship in families with high levels of deprivation for both parents and children shows the interconnectedness of these experiences. Addressing family-wide systemic barriers (e.g., housing, financial support) is critical to reducing child-specific deprivation. Families with targeted support, such as individualised funding or community programs, reported narrower hardship ranges, even in challenging financial situations.

Box 4 highlights some key patterns of marginalisation of children with intellectual disability identified in the qualitative interviews.

Box 4: Marginalisation of children with intellectual disability

The interviews highlighted patterns of marginalisation of intellectually disabled children:

- **Interconnected challenges across domains** – Families experiencing economic strain often face parallel challenges in accessing education, healthcare, and social participation. These create feedback loops that exacerbate difficulties, which in turn worsens developmental outcomes and increases caregiving demands.
- **Adaptive capacity vs. systemic failures** – Families with greater social capital were better able to avoid marginalisation and consequently had a relatively low 'parenting load'. While social capital can mitigate some challenges, it cannot replace equitable systemic supports, which remain critical to reducing parenting load and marginalisation.
- **Escalating and cumulative vulnerabilities** – Delays or failures in addressing a single challenge often triggered ripple effects across multiple domains, including child development, family financial stability, and caregiver well-being. This accumulation of challenges created 'compounding adversity', often leading to a state where it feels impossible to function properly.
- **Structural dependence on advocacy** – Systems relied on families' social capital, knowledge and ability to advocate to compensate for service gaps, creating inequitable outcomes. This reliance exacerbates inequities and leads to caregiver burnout, creating a reinforcing cycle of disadvantage.

Impacts were observed to be disproportionately high in certain circumstances:

- **Single-income households** – Single-parent families or those where one caregiver had to exit the workforce faced compounded financial strain, reduced access to respite care, and limited participation in community activities.
- **Families with high support needs** – Children requiring extensive support placed exceptional demands on caregivers. The high costs of interventions, combined with limited systemic flexibility, exacerbated these families' challenges, often leading to severe burnout and financial instability.
- **Provincial and geographically isolated families** – Families in less-resourced localities faced significant barriers to accessing specialised therapies, inclusive education, and community support.
- **Families facing cumulative adversity** – Families experiencing overlapping disadvantages were particularly vulnerable.

While marginalisation was lower in other circumstances:

- **Dual-Income or financially secure households** – Families with stable dual incomes or substantial financial resources were better positioned to self-fund therapies and interventions. This financial security reduced the cumulative impact of systemic inadequacies and improved access to developmental opportunities.
- **Early diagnoses and coordinated interventions** – Families who secured early diagnoses for their children reported better developmental outcomes and reduced stress. This is particularly the case for an early diagnosis of intellectual disability as well as co-existing physical conditions. These families often benefitted from systemic coordination, demonstrating the importance of early, sustained support.
- **Stable housing and robust support networks** – Families with secure housing and access to community or extended family support experienced less strain compared to those in precarious or overcrowded living situations.

Tasmyn Grindlay - My Happy Place
Waterfall and nature in the style of Bob Ross.

8 Conclusions

This study highlights the fact that people with intellectual disability are more likely to experience hardship than other people throughout their life. It describes the way this manifests in multiple areas from social and family relationships to housing, physical and mental health, education and leisure activities.

People with intellectual disabilities are often reliant on parental caregiving well into adulthood, while older adults with intellectual disability are more likely than other New Zealanders to end up living alone, often in deprived areas. Home ownership is rare for people with intellectual disabilities or their families, but even when they do own their own home, this doesn't guarantee financial security. Many people with intellectual disability live in homes which are damp, mouldy and cold.

Few adults with intellectual disability are supported to engage in paid employment, while parents of children with intellectual disability are often forced to reduce their employment to care for their loved ones, further compromising their ability to financially support the family.

While there are many services and supports available to people with intellectual disability, and disability more broadly, they are often difficult to access, with tight eligibility criteria, delayed diagnoses, waiting lists, and inflexible services all contributing to people not being able to access the help they need. This means that people are often forced to purchase disability-related products and services out of their own pocket, often at great expense. Even if people can access the full range of supports to which they might be entitled, there is strong evidence that this is insufficient to stave off material hardship and poverty. Many people with intellectual disability of all ages rely on emergency grants or loans from family and friends to make ends meet.

People with intellectual disability and their households are more likely than other people to live in material hardship, being forced to reduce or buy cheaper products, to postpone medical appointments, and to risk further financial insecurity by not owning contents insurance. They often report having insufficient money to meet their everyday needs, and that they would be unable to meet an unexpected bill without going into debt.

Many people with intellectual disability and their families are forced to forego both the necessities and small 'luxuries' that other people take for granted, including holidays, hobbies, time to relax, and social connection. Due to insufficient or delayed formal supports and services, many are heavily reliant on informal supports from extended family, and where these supports are unavailable, people are often forced into extremely financially vulnerable positions. Children are somewhat cushioned from the direct impacts of hardship by their parents however some are so financially stretched that these impacts are unavoidable.

In addition to financial stress, lack of appropriate supports results in social isolation, constrained employment, fatigue, emotional exhaustion and poor mental health, even leading to suicidal thoughts. Stress associated with caregiving responsibilities often puts strain on relationships within and outside the immediate family.

Gary Buchanan - Christchurch Cathedral - Scholarship Award Entrant - The White Room
A painting of Christchurch Cathedral.

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Glen Griffith - King of Hearts
My version of a painting I saw.

Appendix 1 Services and supports identified in the IDI

Disability-related benefits

This section outlines the formal supports accessed by people with intellectual disability and their households. Various types of financial support are available to people with disability in New Zealand. These include income-tested benefits such as Supported Living Payment, as well as government-funded disability support services (Kia Piki Ake - Welfare Expert Advisory Group, 2019). In addition, there are two main supplementary payments, administered by Work and Income, to support adults and children with disability.

- **Supported Living Payment** – Supported living payment (SLP) is an income-tested benefit available to people who are both permanently and severely[13] restricted in their capacity to work because of ill health or disability. People can also receive SLP if they are caring full-time for someone who would otherwise need to receive hospital or residential-level care. The rate of payment for SLP reduces (abates) as a family's income increases.[14] A sole parent with 1 child would currently become completely ineligible for SLP if they earned over $52,011 per year before tax. SLP is paid at a higher rate than other main benefits, with a sole parent with one child on SLP receiving $57.34 more each week than a sole parent with one child on a Sole Parent Support benefit ($552.14, compared to $494.80).[15]
- **Disability Allowance** – Disability allowance (DA) is a weekly payment for people (including children) who have regular ongoing costs because of a disability. While people do not have to be on benefit to receive DA, it is income tested, with a sole parent with 1 child becoming ineligible if they earn over $47,930 per year before tax. DA is a non-taxable payment, currently set at a maximum of $78.60 per week.[16]
- **Child Disability Allowance** – Child disability allowance (CDA) is a payment made to the main carer of a child or young person with a serious disability, recognising the extra care required for that child. CDA is not income-tested, is non-taxable, and is currently paid at a rate of $59.23 per week.[17]

Disability support services

As of late 2024 disability support service funding is managed by the Ministry of Social Development, after being managed by the Ministry of Health, and more recently Whaikaha. In order to access this funding, a needs assessment is undertaken by a Needs Assessment and Service Coordination (NASC) provider to determine eligibility and support needs. The NASC provider then makes referrals to service providers who may provide a range of services, including home and community support services, which help with household management and personal care, and respite services to give carers a break.[18] The most common services, as at 2020 when the data was

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[13] Severely is defined as a person 'not being able to regularly work for 15 hours or more per week in open employment'.

[14] https://www.workandincome.govt.nz/products/a-z-benefits/supported-living-payment.html. Retrieved 28 November 2024.

[15] https://www.workandincome.govt.nz/map/deskfile/main-benefits-cut-out-points/sole-parent-support-cut-out-points-current.html. Retrieved 28 November 2024.
https://www.workandincome.govt.nz/map/deskfile/main-benefits-cut-out-points/supported-living-payment-cut-out-points-current.html Retrieved 28 November 2024.

[16] https://www.workandincome.govt.nz/products/a-z-benefits/disability-allowance.html. Retrieved 28 November 2024.

[17] https://www.workandincome.govt.nz/products/a-z-benefits/child-disability-allowance.html. Retrieved 28 November 2024.

[18] https://www.disabilitysupport.govt.nz/disabled-people/assessment-and-funding.

most recently published, were Carer Support, Home and community support services, Individualised funding, Community residential support services, Supported living, and Respite services (Ministry of Health, 2022).

- **Carer support** is allocated to a disabled person to enable their full-time, unpaid carer to take time out for themselves and support them to continue in their caring role. The subsidy provides a contribution towards the costs of accessing a support person to care and support a disabled person during this time.
- **Home and community support services** (HCSS) support people to live at home. These services include household management and personal care, and support for people to access the community.
- **Individualised funding** allows people to directly purchase their own HCSS and respite services. It gives people more choice, control and flexibility in terms of how they are supported.
- **Community residential support services** provide people with support for up to 24 hours a day in a home-like setting in the community. This support may include help with activities such as shopping, cooking, household chores, personal care and getting out in the community.
- **Supported living** services help people to live independently. They provide support with social connection and facilitating activities such as accessing community facilities, shopping and cooking, and interacting with agencies.
- **Respite services** provide short-term breaks for the carers of a disabled person. The services include facility-based and home-based respite.

Ongoing Resourcing Scheme

The Ongoing Resourcing Scheme is funded by the Ministry of Education and provides specialist support for students with the highest levels of support needs. Ongoing Resourcing Scheme funding can provide services and supports including specialists such as therapists, psychologists and learning support advisors, additional teacher time for a teacher to provide specialist teaching support, a contribution for a teacher aide to assist with the student's learning support, and a consumables grants for buying small items to support the student's needs.

Emergency assistance

Special Needs Grants (SNGs) are one-off payments which people may be able to access to help meet an essential or emergency need they couldn’t otherwise pay. As such, they are a strong indicator of financial hardship. They are income-tested and are only available to people who have few assets. Some SNGs are recoverable, meaning they need to be repaid to Work and Income.

Appendix 2 Profiling parents' experiences

Riley – combatting "hidden challenges" to get her children the help they need

The household and immediate family support

Riley is the primary caregiver for her two pre-teen children, Simon and Calie, who both have special needs. She lives with her partner, Jared, and their children in a suburban home in a major city. Simon has ASD, ADHD, sensory sensitivities, and a combination of disabilities that render him functionally intellectually disabled. Calie has sensory sensitivities, ADHD and a learning disability. Riley's aging parents, who live nearby, provide occasional support, but their health limits their involvement. Jared's job requires frequent travel, leaving Riley to manage the household and caregiving responsibilities on her own. Financial strain and health hazards, such as black mould in their home, have made their living situation untenable, forcing the family to sleep together in a single room.

Introducing Simon and Calie

Riley describes Simon as bright, creative, and kind-hearted, with a love for the outdoors and a talent for spatial activities like building with Lego. However, he struggles with extreme sensory sensitivities, sleep challenges, and difficulty understanding language, which result in social and behavioural difficulties, including screaming episodes and aggression. These challenges have strained relationships with neighbours, escalating to death threats that forced the family to avoid their garden and relocate multiple times. This repeated upheaval has added stress and expense, profoundly impacting the children, who often experience extreme reactions to changes in their living environment. Additionally, the challenges have resulted in the denial of appropriate educational and support services.

Calie is vibrant, empathetic, and socially intuitive, with close friendships among neurodiverse peers. However, she struggles with attention, anxiety, sleep difficulties, and sensory sensitivities, often using earmuffs for regulation. Calie's coordination and physical development are significantly delayed compared to her peers, and she has difficulty acquiring physical skills. Her needs, overshadowed by Simon's challenges, concern Riley, who believes Calie would benefit from counselling and tailored interventions to address her anxiety.

Early years and initial challenges

When Simon was born, Riley and Jared lived in a rural area with limited access to specialised healthcare. Simon had feeding issues and early sensory sensitivities, but his broader developmental needs went unrecognised. Diagnosed with "failure to thrive," the family received minimal support, leaving Riley isolated and unsure of how to help him. After relocating to a regional centre, Simon's needs intensified, but Riley still lacked adequate healthcare or community support. A Plunket nurse validated Riley's concerns, but no structured follow-up occurred. At a Montessori school, Simon's behavioural issues led to him being isolated in a separate room without Riley's consent, and an ultimatum about his behaviour forced a move to a rural kindergarten. These experiences further isolated both mother and child.

Diagnosis and initial support attempts

Around age four, Simon was diagnosed with ADHD by a private paediatrician, whom the family consulted out of desperation, following a year-long wait for an appointment through the public system. However, attempts to manage his symptoms with medications like Ritalin resulted in severe side effects. Riley sought help from public paediatric services, the Ministry of Education's Early Intervention Service, the Open Home Foundation, and CAMHS but received minimal, fragmented support, with no coordinated overview or assessment of Simon's needs. Riley was completely socially isolated due to Simon's challenging behaviour. Despite advocacy, Simon's significant challenges did not meet the criteria for Ongoing Resourcing Scheme funding, leaving Riley to negotiate term-by-term teacher-aide support so Simon could attend school part-time. The lack of a coordinated approach by the Ministry of Education, lack of Ongoing Resourcing Scheme funding and piecemeal support added to their difficulties and impacted their home life and relationships. Having to keep Simon home from school and manage the significant dysregulation resulting from inadequate in-school support also affected the family's finances. Due to the short-term nature of the funding provided for teacher-aide support, it was not possible to adequately train someone to work with Simon. By the time a support worker had figured out how to best assist him, they would leave and be replaced by someone new. This fleeting and inconsistent support significantly disadvantaged Simon and impacted his learning.

Simon's "deceptive competence" often led to underestimating his needs and denying critical resources. Some High and Complex Needs funding was eventually secured, but its effectiveness was undermined by the deployment of multiple part-time aides instead of a consistent support person. Informal resources like Parent to Parent and the IHC library offered helpful information, and Riley found value in an introductory course on anxiety provided by IHC Idea Services. Riley attended regular support groups run by Parent to Parent. While good in themselves, support groups often intensified her emotional stress due to the shared weight of others' similar struggles and the fact that many of the parents spoke of suicide attempts by their young children.

Main and most effective sources of support

Privately funded activities, individualised funding, and occupational therapy (OT) provided some of the most stabilising support for Simon. Individualised funding from Whaikaha has been vital to the family's survival. It has allowed Riley to access respite care and therapeutic services, though recent policy changes introduced restrictive administrative requirements, meaning that some supports cannot be funded. An occupational therapist proved transformative, teaching Riley about sensory processing and techniques like deep pressure and vestibular exercises that helped Simon self-regulate and significantly improved his ability to cope with his sensory environment. However, the high cost of private support remains a constant challenge.

Financial strain and attempts to secure income

Riley's previous career as a consultant once provided financial security, but full-time caregiving forced her to stop working. Jared's sporadic, low-wage employment and frequent relocations for work caused further instability, with the family moving seven times in five years. High mortgage rates, Jared's COVID-related job loss, and eight years of self-funding Simon's support before his diagnosis and needs assessment left them on the brink of financial collapse. Though Jared recently regained employment, their financial position remains precarious.

Riley’s attempts to secure financial assistance were met with repeated barriers. Initially ineligible for the Jobseeker benefit, Riley only qualified for a $96-per-fortnight Child Disability Allowance after Simon’s autism diagnosis, leaving her to cover significant therapy and caregiving costs. Additionally, her efforts to secure a small bank loan were denied. Family assistance, like occasional grocery purchases by her father, has provided temporary relief but is unsustainable in the long term. When Riley took a demanding 50-hour-per-week job, the additional 15-20 hours managing Simon-related caregiving tasks and administration led to burnout, forcing her to leave the position.

Looking to the future

The focus on Simon’s needs has left little attention for Calie’s challenges, and Riley worries about her delayed development and anxiety. Riley fears for Simon’s stability if her health declines. She anticipates a breakup with Jared, which would make her the sole caregiver and would likely force her to sell their home to afford Simon’s care. With aging parents requiring more support, Riley feels overwhelmed by the cumulative emotional, financial, and health-related stresses of caregiving, leaving her desperate for systemic changes to better support families like hers.

For Riley, the most significant difference would be an intervention system that identifies ongoing needs and allocates funding accordingly to support children's development throughout their schooling. This would eliminate the need to prove she is more needy—or her children more disabled—than everyone else.

Experience of material hardship – Becoming increasingly prevalent

Enforced lack of essentials **(6/7)**	· meal with meat, fish or chicken (or vegetarian equivalent) at least each 2nd day · two pairs of shoes in good repair and suitable for everyday use · suitable clothes for important or special occasions · presents for family and friends on special occasions · home contents insurance · a good bed
Economised, cut back, or delayed **(9/9)**	· went without or cut back on fresh fruit and vegetables · bought cheaper cuts of meat or bought less than wanted · put up with feeling cold to save on heating costs · postponed visits to the doctor · postponed visits to the dentist · did without or cut back on trips to the shops or other local places · delayed repairing or replacing broken or damaged appliances · continue wearing clothing that is worn out · spend less on hobbies or other special interests than you would like
In arrears more than once in any given year (1/2)	· Vehicle registration, insurance or warrant of fitness. [Insurance was cancelled years ago due to high cost]
Financial stress and vulnerability (4/4)	· borrowed from family or friends 'more than once' in the last 12 months to cover everyday living costs · feel 'very limited' by the money available when considering buying clothes or shoes for self · could not pay an unexpected and unavoidable bill of $500 within a month without borrowing · feel limited about buying a $300 item they would really like to have
Accommodation problems (2/2)	· dampness or mould · heating and/or keeping warm in winter. [Avoid running heating system due to cost]
Child-specific lack of essentials (3/8)	· 2 pairs of shoes in good condition and suitable for daily activities for each child · meal with meat, fish or chicken (or vegetarian equiv) each day · friends around to play and eat from time to time (because of the cost)
Child-specific economising to cut down costs (4/4)	· had to go without music, dance, kapa haka, art, swimming or other special interest lessons · unable to pay for a school trip or other school event? [Upcoming problem] · involvement in sport had to be limited · continue to wear shoes or clothes that are worn out or the wrong size

Lani: Personal growth and supportive parenting despite profound adversity

The household and immediate family

Lani is a single mother of Pacific and European descent who lives with her four children – two older boys and two younger girls – and has twins on the way. They live in a damp, overcrowded and dilapidated rented house on a busy main road in a large urban centre. The walls are streaked with mould, and the cold intensifies during the winter months when heating becomes a luxury Lani can't afford. While the house is a source of stress, it is also the only place she has to call home.

Introducing Meleia, Talia, Noah and Leo

Meleia, the older daughter, is a bright and inquisitive pre-teen and loves sensory activities like trampolining and playdough. While her autism and developmental delays mean she sometimes struggles with emotional regulation, her curiosity and love of routine bring a sense of rhythm to the household. Pre-schooler Talia is energetic and curious, though her fearless nature requires Lani to be constantly alert. Lani also has to be additionally vigilant to keep Talia safe from Meleia. Talia has recently gained the same diagnosis as Meleia.

The two boys are in their mid-to-late teens. Noah, the younger one, has a sharp sense of humour and a strong sense of loyalty. However, he finds school challenging due to his dyslexia (which has not yet been formally confirmed). Leo, the older boy, is creative and intelligent, with a keen interest in exploring new ideas. His ADHD-like traits and disengagement from school have left him uncertain about his future.

While the household is sometimes chaotic, the siblings are close-knit and supportive of one another and their mum.

Lani receives minimal occasional support from her family members. Her mother died before Lani's two daughters were born, a profound loss. Her brother sometimes helps by lending money or covering essential costs, like groceries, during particularly tight financial periods. However, his ability to assist is limited, and these contributions are sporadic rather than sustained. Lani's relationship with her father is complicated and distant. Emotional support is rare, and Lani often feels isolated as she tries to manage all her responsibilities.

Parental stress, breakup and parenting alone

Lani's journey as a mother became uniquely challenging when her third child, Meleia, began missing developmental milestones as a toddler. Over time, sensory sensitivities and communication delays led to a diagnosis of autism and developmental delays. While this offered some clarity, it also marked the beginning of a relentless battle for resources and support. At least the formal diagnosis enabled a successful application for individualised funding – paying for therapies and some respite care – and Ongoing Resourcing Scheme funding, enabling access to specialised schooling.

Lani and the children's father, Shane, broke up when Talia was three. This was a period of intense caregiving demands as Lani was still navigating the early stages of Meleia's autism diagnosis and concentrating on securing appropriate help. The strain of these challenges, combined with differing parenting styles and Shane's difficulty adapting to the realities of raising a child with intellectual disabilities, ultimately led to the end of their relationship.

The breakup further entrenched Lani's isolation, even though she found it easier to parent alone. Now, she navigates the dual roles of caregiver and household provider without the partnership she had once hoped for.

Her older children, Leo and Noah, have not had the same level of attention or resources. This came into sharp focus for Lani after the separation. She discovered that both boys needed glasses, and Noah required hearing aids. Leo has since disengaged from school entirely, leaving Lani worried about his future. Noah's undiagnosed dyslexia and hearing issues have made education a source of frustration and shame.

The youngest, Talia, presents a different set of challenges. Adventurous and inquisitive, she needs constant supervision, particularly in their unsafe living environment. Without a fenced yard or space to play, Lani spends much of her time chasing after her daughter while balancing the demands of her other children.

Formal supports – Partial and hard-fought-for

Community organisations like Parent to Parent and IHC offered information, emotional support and occasional guidance, which were highly valued. Aside from these community resources, Lani's support network is patchy and unreliable. Her ex-partner, Shane, spends weekends with the children every other week, but his involvement is largely superficial. A care provider delivers respite services when funding allows, and caregivers are not consistently available, leaving Lani with few places to turn when crises arise.

Lani navigates the complexities of individualised funding through an IF provider to ensure Meleia receives therapies and caregiver support. Yet even these victories are hard-won. For Lani, applying for funding is akin to a full-time job, requiring her to repeatedly prove her children's limitations to receive assistance that still falls short of addressing their needs. She is frustrated and exhausted by how many times she has had to plead for extra help, and it never seems to be enough.

Attempts to secure better housing through social housing programs have been unsuccessful despite her urgent need. Her current rental is a health hazard, but long waitlists and bureaucratic barriers have left her feeling stuck. Lani has been told she is eligible but holds no hope of gaining suitable social housing for her large family.

On the upside, the support gained from early intervention teachers, Ongoing Resourcing Scheme funding and Meleia's learning environment – a special stream within a primary school – has meant Meleia is developing and content at school. Even so, she has only recently received glasses after a lengthy delay due to the referral process and waitlist for assistance in the public system.

Persistent financial strain

Financial hardship defines Lani's daily reality. Her separation from the children's father had significant financial and caregiving implications. Shane's involvement with the children became limited to alternate weekends and holidays, leaving Lani as the primary caregiver. This shift not only increased Lani's physical and emotional workload but also deepened her financial stress. Shane provides no substantial financial support.

Unable to work due to her caregiving responsibilities, she relies on government benefits and individualised funding, which barely cover essentials. She sometimes resorts to borrowing money from family, although, as previously stated, this financial support is minimal. She also uses buy-now-pay-later services like Afterpay and cuts corners wherever possible. Despite these measures, Lani has ticked every material hardship indicator for herself and her children, including skipping medical appointments, economising on food, and living in arrears on utility bills.

Her efforts to secure loans have been met with rejection, and interactions with the Ministry of Social Development (MSD) have left her frustrated and demoralised.

A house that isn’t a home

The family’s living situation compounds their challenges as the house is ill-suited to their needs. During the COVID-19 lockdowns, the lack of space became unbearable as Lani struggled to meet the diverse demands of her children without any external support.

The twins’ arrival will add even more pressure. Lani worries about where they will sleep and how she will manage with her already stretched resources.

Looking to the future – capabilities, worries and potential developments

Amid the challenges, Lani finds strength in small victories. Watching Meleia flourish in her special learning unit or seeing Talia light up during a trampoline game brings her moments of joy. She feels better equipped to manage the challenges ahead than she has in the past. Her growing understanding of mental load and stress management, combined with practical strategies learned through occupational therapy and peer networks, has strengthened her ability to create stability at home and advocate effectively for her children. By establishing routines, securing individualised funding, and prioritising self-care (she is no longer taking antidepressants), Lani has built a foundation that allows her to be more present and adaptable.

In the short term, having a suitable house for her family would make the biggest difference in their lives – a home that is right-sized, healthy, and safe. Lani wants to advocate for systemic change. She envisages a future where families like hers don’t have to fight so hard to have their basic needs met.

Experience of material hardship – persistent and ongoing

Enforced lack of essentials **(7/7)**	meal with meat, fish or chicken (or vegetarian equivalent) at least each 2nd day two pairs of shoes in good repair and suitable for everyday use suitable clothes for important or special occasions presents for family and friends on special occasions home contents insurance a good bed a holiday away from home for at least a week every year
Economised, cut back, or delayed **(9/9)**	went without or cut back on fresh fruit and vegetables bought cheaper cuts of meat or bought less than wanted put up with feeling cold to save on heating costs postponed visits to the doctor postponed visits to the dentist did without or cut back on trips to the shops or other local places delayed repairing or replacing broken or damaged appliances continue wearing clothing that was worn out spend less on hobbies or other special interests than you would like
In arrears more than once in any given year (2/2)	rates, electricity, water vehicle registration, insurance or warrant of fitness
Financial stress and vulnerability (4/4)	borrowed from family or friends 'more than once' in the last 12 months to cover everyday living costs feel 'very limited' by the money available when considering buying clothes or shoes for self could not pay an unexpected and unavoidable bill of $500 within a month without borrowing feel limited about buying a $300 item they would really like to have
Accommodation problems (2/2)	dampness or mould heating and/or keeping warm in winter
Child-specific lack of essentials (8/8)	2 pairs of shoes in good condition and suitable for daily activities for each child 2 sets of warm winter clothes for each child waterproof coat for each child (because of the cost) separate bed for each child fresh fruit and vegetables daily meal with meat, fish or chicken (or vegetarian equivalent) each day good access at home to a computer and internet for homework friends around to play and eat from time to time (because of the cost).
Child-specific economising to cut down costs (4/4)	had to go without music, dance, kapa haka, art, swimming or other special interest lessons unable to pay for school trip or other school event involvement in sport had to be limited continue to wear shoes or clothes that are worn out or the wrong size.

Lola: Championing the development of her pre-teen

The household and immediate family

Lola is a single mother raising her two sons, Josh and Steven, in a modest home she co-owns with her parents in a provincial town. She works part-time in customer service and retail roles.

Lola's parents provide financial support and have a close relationship with Lola's oldest son, Steven. However, Lola's relationship with her parents is strained, arising primarily from her mother's judgmental attitudes that leave Lola feeling unsupported. This criticism extends to how she handles Steven's ADHD and Josh's disabilities, further exacerbating her feelings of isolation and undermining her confidence as a caregiver.

Introducing Josh and Steven

Lola describes her preteen, Josh, as a loving, empathetic, and bright child who thrives in structured environments and has successfully formed friendships at school. The family dynamic is significantly shaped by Josh's intellectual and physical disabilities, which stem from a severe stroke at birth that caused hemiplegia and developmental challenges.

Steven, in his early teens, often struggles with jealousy due to the attention his brother receives. Although he is supportive of Josh at times, Steven's ADHD makes it difficult for him to manage his emotions and focus. This creates tensions within the household and requires additional attention from Lola. Steven's disengagement from education and tendency to get into trouble further compound Lola's concerns about his emotional development and his relationship with Josh.

Early years and medical crisis

Josh's birth was marked by severe complications, including seizures and a life-threatening stroke that damaged two-thirds of his brain. The family was immediately thrust into a whirlwind of medical interventions. Lola faced isolation during Josh's neonatal intensive care stay in a major city, while she was left unsupported in a provincial centre nearby. The lack of coordinated care between hospitals exacerbated her stress.

Despite early interventions like occupational therapy (OT) from an exceptionally responsive practitioner, Lola found the healthcare system fragmented and unresponsive. Limited physiotherapy and ill-fitted orthotics left Josh struggling with mobility. Frequent changes in therapists disrupted his speech therapy, further hindering his development. Lola describes herself as "the voice" for Josh, advocating for essential support like suppositories, which were not readily offered despite their necessity. Josh could not tolerate any oral medication.

This constant advocacy took an emotional toll on Lola, who describes the frustration of repeatedly fighting for services that should have been automatically provided. The uncoordinated nature of the healthcare system added to her burden, leaving her feeling drained.

Adjusting to schooling and care systems

A notable early success was Josh's time with an in-home childcare provider who offered a nurturing and structured setting. This experience helped Josh adjust to new social settings and built his confidence, underscoring the importance of tailored care. This care arrangement also incorporated a range of therapies Josh required. However, these positive experiences were rare, and Lola frequently encountered systemic barriers that hindered Josh's progress.

Josh’s transition into school was difficult, as he struggled with new environments and routines. While some teachers were remarkably inclusive, Lola found the educational system unable to cater to Josh’s needs. The school’s communication about and implementation of Josh’s Individualised Education Plan was inconsistent and unhelpful. Furthermore, Josh was denied teacher aide support because he was not considered “severe enough” once he was toilet trained. Lola felt forced to fight for every resource, often without success.

Financial and emotional strain

Lola and the children’s father separated several years after Josh was born. The mounting stress and the uneven distribution of caregiving responsibilities created insurmountable differences. The situation deepened Lola’s financial difficulty and increased her caregiving burden.

Lola’s caregiving responsibilities prevented her from working full-time, leaving the family financially vulnerable. She juggles a part-time merchandising job while managing Josh’s care and school needs. The Supported Living Payment supplements Lola’s income, and she also receives Individualised Funding for Josh and a minimum level of child support. However, this income is insufficient to cover some essential costs like Josh’s incontinence supplies, which amount to $70–80 per week. Debt and financial stress are constant challenges, forcing Lola to sell personal belongings to pay bills.

Lola’s mental health has suffered significantly. She has experienced panic attacks, depression, and chronic fatigue, compounded by her inability to access affordable counselling or consistent mental health support. Lola often feels isolated, emotionally depleted, and overwhelmed by the relentless demands of caregiving and financial strain.

Advocacy and support

Despite these challenges, Lola has remained a fierce advocate for Josh, navigating complex systems to secure what limited resources she can. The family has benefited from Individualised Funding, which has paid for equipment like a trampoline and a tablet, which provide sensory and recreational support for Josh. Several teachers who normalised classroom activities for Josh helped him develop socially and academically.

Steven occasionally plays a supportive role, helping Josh through medical procedures by modelling calmness and cooperation. These moments highlight the strength and adaptability within the family. However, these instances are often overshadowed by the tensions created by Steven’s struggles with jealousy.

Impact on health, work, and wellbeing

Lola’s health and wellbeing have been dramatically affected by the lack of systemic and familial support. Caregiving demands leave her physically exhausted and emotionally depleted. Financial constraints further limit her ability to access needed counselling, healthcare and basic necessities, perpetuating a cycle of stress and deprivation.

The implications extend to Steven, whose feelings of neglect and jealousy toward Josh concern Lola. She worries about the long-term effects on Steven’s emotional development and his relationship with Josh.

Josh’s future remains a pressing concern. Lola fears systemic inadequacies will prevent him from achieving independence, leaving her deeply anxious about his educational and social prospects as he grows older. Responsive schooling and trustworthy and consistent caregiver support would substantially improve the family’s quality of life. These developments would enable Lola to work more consistently and have some time and energy for self-care.

Experience of material hardship – persistent and ongoing

Enforced lack of essentials **(3/7)**	· presents for family and friends on special occasions · home contents insurance · a holiday away from home for at least a week every year
Economised, cut back, or delayed **(8/9)**	· went without or cut back on fresh fruit and vegetables · bought cheaper cuts of meat or bought less than wanted · postponed visits to the doctor · postponed visits to the dentist · did without or cut back on trips to the shops or other local places · delayed repairing or replacing broken or damaged appliances · continue wearing clothing that was worn out · spend less on hobbies or other special interests than you would like
In arrears more than once in any given year (1/2)	· rates, electricity, water [always]
Financial stress and vulnerability (4/4)	· borrowed from family or friends 'more than once' in the last 12 months to cover everyday living costs · feel 'very limited' by the money available when considering purchase of clothes or shoes for self · could not pay an unexpected and unavoidable bill of $500 within a month without borrowing. · feel limited about buying a $300 item they would really like to have.
Accommodation problems (0/2)	
Child-specific lack of essentials (0/8)	
Child-specific economising to cut down costs (2/4)	· had to go without music, dance, kapa haka, art, swimming or other special interest lessons · involvement in sport had to be limited

Vicki: Actively shaping safe and creative environments for her children

The household and immediate family

Vicki and Terry's life in a provincial town revolves around the needs of their two pre-teen children, daughter Erica and son Jamie. Both children are on the autism spectrum, with Erica also having an intellectual disability. Despite the heavy weight of caregiving and systemic failures, the family has crafted a life full of creativity, love, optimism and determination, built around navigating the daily challenges of caregiving, advocacy, and financial pressure.

Introducing Erica and Jamie

Erica is caring and determined. She loves crafting and playing netball, with a strong desire to prove her capabilities to herself and those around her. She faces significant challenges with cognitive retention and communication, often struggling to make herself understood outside of their home, but she never lets these hold her back.

Jamie is bright, energetic, and passionate about music and extinct animals. When he was a toddler, a paediatrician told the family that Jamie would never speak, yet his creativity and subsequent verbal development defied this prediction. Nonetheless, he continues to navigate sensory sensitivities and struggles with self-regulation.

A pragmatic caregiving solution

For Vicki and Terry, parenting is not just a role but a relentless commitment to securing the support and services their children need while balancing financial and caregiving responsibilities to reflect their respective strengths and limitations.

Early in their parenting journey, Vicki and Terry made a pragmatic decision to organise their lives to maximise stability for their children. Terry, who is autistic and has experienced challenges with traditional employment, became the primary caregiver. His natural patience, aptitude for creating structure and deep understanding of and ability to respond to the children's sensory and emotional needs make him the ideal parent to provide consistent, day-to-day support. Terry takes on responsibilities such as helping Jamie cope with his night terrors, attending to his toileting needs, managing Erica's physiotherapy, engaging with the children's education plans, and maintaining the household routine. His commitment has been a cornerstone of the family's stability.

Vicki, on the other hand, took on the role of the family's sole income earner. Her professional position, while demanding, offers a level of security and flexibility that has been critical in sustaining their household. Her employer, aware of her family's caregiving responsibilities, allows her to work from home when necessary and accommodates her need to balance her professional and parental duties. This understanding has been a lifeline, enabling Vicki to advocate for her children's needs during school hours or attend urgent meetings with service providers without jeopardising her job.

Though this arrangement mitigates some challenges, it also has its difficulties. Vicki shoulders the dual burden of advocacy and work, and her salary must stretch to cover all household expenses, specialised educational tools, Jamie's dietary supplements, and Erica's therapeutic shoes.

Early struggles – diagnosis and relocation

The family's journey began in their home city, where Erica and Jamie received their initial diagnoses. Erica was diagnosed with autism and an intellectual disability at age four, while Jamie was diagnosed at age two. Erica's intellectual disability was often mischaracterised as a behavioural issue, delaying access to critical interventions. For years, Vicki and Terry were denied Ongoing Resourcing Scheme funding for Erica, leaving them to fight for recognition of the challenges she faced. Early interventions for Jamie were promising. He initially benefited from ORS funding, which gave him access to the support he needed to start his developmental journey.

In 2020, the family decided to leave the city and move to a provincial town. While providing a quieter environment for the family, the move severed ties to established support networks and resulted in the loss of Jaime's essential medical and educational records. Starting over in a new place meant navigating unfamiliar systems and service providers, and local schools lacked the expertise to support children with autism and intellectual disabilities.

Systemic challenges and hard-won progress

As systemic barriers emerged, Vicki's role as the family's primary advocate became essential. Teacher aides assigned to both children were underfunded and lacked sufficient training to address their unique needs, leaving them vulnerable in the classroom. Jamie, who often struggled with sensory overloads, faced isolation and exclusion at school. The family had to provide additional support at their own expense, further straining their finances.

Vicki often found herself having to fill the gaps – creating profiles of her children's attributes and needs for educators, providing resources, and explaining conditions that should have been understood. She spent hours each week navigating bureaucracies, attending Individualised Education Plan (IEP) meetings, and making phone calls to ensure her children weren't overlooked. Her relentless advocacy eventually paid off. In 2023, after eight years of rejection, Erica was finally granted Ongoing Resourcing Scheme funding, opening the door to more tailored educational support.

This victory, while significant, underscored the emotional toll of navigating a system that often places the burden of proof on families. Specialised resources and educational materials for both children have pushed the family's budget to its limits, and the financial strain leaves little room for unexpected costs. Vicki and Terry often defer their medical care to prioritise their children. Vicki, for example, who has been in chronic pain for years, has postponed a necessary surgery because they simply can't afford it.

Support systems that made a difference and glimpses of hope

Despite systemic barriers, a few key individuals and services have made a difference. A family-whānau liaison worker from IHC has been a key ally and steadfast advocate, offering emotional support and helping the family navigate resources. A Ministry of Education adviser intervened and worked with Vicki to improve Jamie's school's responsiveness to his needs. They ensured Jamie could get to a toilet in a timely way and was unable to leave the school grounds unattended because he's "a runner". Community organisations, like CCS Disability Action, provided some connections to resources, though inconsistently. Vicki has also benefited from her involvement with the local access and inclusion network, which provided a platform to advocate for broader systemic improvements. Most importantly, Erica's hard-won Ongoing

Resourcing Scheme funding has proved invaluable.

At home, Vicki and Terry nurture their children's growth through creative outlets, and the family celebrates small victories. The moments of connection, accomplishment and jubilation, such as Erica's pride in her crafting projects and Jamie's joy in composing music, make the challenges worthwhile.

Looking ahead – hopes and concerns

As their children grow, Vicki and Terry's hopes and concerns evolve. Erica dreams of becoming a counsellor to help others with disabilities, while Jamie's creativity points to a future filled with potential. However, Vicki and Terry worry about how their children will fare as they transition into adulthood. Without seamless systems to support education, employment, and daily living, the burden of advocacy and care may continue to rest heavily on their shoulders. The family's financial vulnerability exacerbates these concerns as Vicki anticipates working beyond retirement to ensure the children's long-term care.

Despite these burdens, Vicki and Terry remain unwavering in their commitment to their children's well-being. Vicki envisions an integrated system where education, health, and social services work seamlessly together, communicating and collaborating to support families like hers. She wants no other family to have to fight as hard as hers to secure a viable and fulfilling life.

Experience of material hardship – some are persistent and ongoing

Enforced lack of essentials (3/7)	· meal with meat, fish or chicken (or vegetarian equivalent) at least each 2nd day · presents for family and friends on special occasions · a holiday away from home for at least a week every year
Economised, cut back, or delayed (7/9)	· bought cheaper cuts of meat or bought less than wanted · postponed visits to the doctor · postponed visits to the dentist · did without or cut back on trips to the shops or other local places · delayed repairing or replacing broken or damaged appliances · continue wearing clothing that was worn out · spend less on hobbies or other special interests than you would like
In arrears more than once in any given year (0/2)	
Financial stress and vulnerability (3/4)	· borrowed from family or friends 'more than once' in the last 12 months to cover everyday living costs · feel 'very limited' by the money available when thinking about purchase of clothes or shoes for self · could not pay an unexpected and unavoidable bill of $500 within a month without borrowing.
Accommodation problems (1/2)	· heating and/or keeping warm in winter [Put off buying curtains – run heat pump on high]
Child-specific lack of essentials (2/8)	· waterproof coat for each child (because of the cost) · fresh fruit and vegetables daily
Child-specific economising to cut down costs (1/4)	· continue to wear shoes or clothes that are worn out or the wrong size.

Afterword

There have been recent positive developments for Erica, as the parents were anxious about her transition to high school. The Ministry of Education support person who has been supporting the family recommended visiting a nearby college. To Vicki and Terry's amazement, the college has all the facilities to cater to Erica and Jamie's needs. Furthermore, due to Ongoing Resourcing Scheme funding, both children can attend college until the age of 21 if need be. The staff and facilities were impressive, and there seemed to be many classes that would suit both children. While finances and the children's long-term future remain worrying, Vicki is comforted that the children are likely to feel safe and secure and thrive during their secondary school years.

Sarah: Determined that her son will have a fulfilling adult life

Household and immediate family

Sarah is a single mother raising her only son, Ethan, now in his late teens. Ethan has been diagnosed with ADHD (Attention-Deficit/Hyperactivity Disorder), Autism, and Foetal Alcohol Syndrome Disorder (FASD). They live in long-term rental accommodation in poor condition in a major city, with issues including dampness, mould, and insufficient heating. Despite this, Sarah wants to buy the flat to ensure long-term housing stability. The household consists of just the two of them. However, Sarah and Ethan have regular contact with Sarah's mother and stepfather, who live nearby and are their primary sources of emotional and practical support.

Introducing Ethan

Ethan is "loving and engaging" when not under pressure or being asked to do things, but is also "defiant and resistant" when he feels pressured. He is highly empathetic toward animals and enjoys hands-on activities, especially working with his grandfather on projects like fixing engines. However, his intellectual disabilities make it difficult for him to maintain focus, regulate his emotions, or manage social relationships. Ethan often becomes defiant, especially when pressured in school or home environments, which has created significant challenges for Sarah throughout his life.

Initial diagnosis and implications

Ethan was formally diagnosed with ADHD, autism, and FASD in 2009 when he was about two years old. This early diagnosis had two main implications. Firstly, it enabled timely intervention from the Ministry of Education to support Ethan's learning and engagement in school settings. Secondly, it brought the realisation that Ethan would most likely require lifelong support, starting with intensive educational and behavioural interventions. Sarah realised that raising a child with such complex needs would be emotionally and financially demanding, and she soon found herself having to engage with multiple roles and services to secure the support that Ethan needed.

Foundational support from family

Between the ages of one and five, Ethan was primarily cared for by Sarah's mother and stepfather, enabling Sarah to focus on addressing her challenges. During this period, Sarah undertook drug and alcohol counselling, parenting courses, anger management, and work training. This foundational support from her family was crucial, as it allowed Sarah the space to stabilise her life, prepare for her role as Ethan's primary caregiver, and become more independent by securing her own place.

Profound challenges – parenting and financial stress

Sarah's journey as Ethan's primary caregiver has been rife with challenges. In his early years, Ethan struggled with severe behavioural issues, and Sarah was forced to manage his defiance, emotional dysregulation, and difficulty with transitions, particularly within the school system. The constant demands of caregiving left Sarah feeling emotionally exhausted and isolated.

Compounding these challenges was Sarah's financial hardship. For many years, she relied on the Domestic Purposes Benefit (DPB) and the Accommodation Supplement from WINZ, as well as occasional hardship grants. Despite this, Sarah and Ethan experienced profound material deprivation, unable to afford basics such as proper heating, regular doctor or dental visits, home insurance, or new clothing. Sarah's mother bought their groceries during this time. However, Sarah still needed to borrow from family and living in arrears for utilities became a regular occurrence, adding to the stress of managing Ethan's care. Sarah also experienced humiliating indifference from case managers when her grant applications to WINZ were declined.

Sarah continued to experience substantial deprivation as she volunteered for a charity organisation for around three years while she sought permanent paid work. However, volunteering also provided several benefits. Sarah got good-quality second-hand clothes that would have been unaffordable otherwise. Also, through connections made there, she got a temporary job that led to a full-time position six months later.

Main and most effective sources of support

Amidst these difficulties, Sarah found some relief through key sources of support. One of the most significant came from the Ministry of Education (MoE), which coordinated early assessments and funding for Ethan's schooling. An MoE adviser helped secure essential wrap-around support involving teacher aides, a Special Education Needs Coordinator (SENCO) and Resource Teacher Learning and Behaviour (RTLB), individual education and behavioural plans, and ultimately, a placement in a special residential school in 2018. This school provided Ethan with an environment tailored to his needs, where he thrived academically and socially, forming meaningful friendships with teachers and peers. This was a pivotal moment in his development.

In addition, Sarah's mother and stepfather continued to provide essential respite care, allowing Sarah to work and focus on her own mental and physical health. By 2015, Sarah had secured full-time employment, significantly alleviating some of the financial burden, although the effects of prolonged material deprivation still linger.

Ongoing risks and uncertainties

While Sarah's financial situation has improved, substantial uncertainties remain, particularly regarding Ethan's future. Now a teenager, Ethan faces social integration and schooling challenges, having struggled to adjust after leaving the special residential school and returning to mainstream education. His defiance in school and lack of meaningful friendships raise concerns about his ability to transition into adulthood, find employment, or live independently.

Moreover, the support systems Sarah once relied on have begun to wane. CAMHS and Autism New Zealand were unwilling or unable to provide consistent mental health or behavioural support. The school's reduction in teacher aide availability and a general lack of follow-up from these services have left Sarah questioning where to turn next as Ethan transitions into adulthood.

Financial uncertainty also remains a pressing concern. Despite her stable income, Sarah cannot secure a mortgage to buy their home, and any unexpected expenses – such as large bills – continue to strain the household.

Looking to the future – reasons for optimism

Despite these uncertainties, several positive factors give Sarah and Ethan reasons to be hopeful. Despite the persistent effects of long-term material hardship, Sarah's full-time employment (and a promotion) has provided financial stability. Ethan has also greatly benefited from his involvement in an after-school and holiday programme, where he has built a strong relationship with the manager and engaged in volunteer work. This has boosted his confidence, social skills, and sense of responsibility.

Sarah has also become more skilled at managing Ethan's behaviour. She sets firm boundaries, giving herself time to decompress after work, which has helped maintain her mental health. Additionally, her mother and stepfather continue to offer emotional and practical support, providing respite care on weekends, which has proven invaluable. While Sarah's father and stepmother live further away, Ethan stays with them on their rural property during school holidays. Sarah now has the time to do things for herself, such as regularly going to the gym, reading and enjoying their numerous household pets.

Ethan is considering enrolling in a hospitality course at a local polytechnic. Sarah expressed optimism about this opportunity, emphasising the importance of keeping Ethan motivated and engaged in the course. She recognises that this structured vocational pathway could give Ethan a sense of purpose and direction while developing practical skills. Potential challenges include Ethan's struggles with structured environments and staying focused.

Access to supported living and employment, along with the persistent support and advocacy of his mother and grandparents, are likely critical to Ethan's experience of a good life on his terms.

Experience of material hardship – some are persistent and ongoing

Enforced lack of essentials (4/7)	• suitable clothes for important or special occasions • presents for family and friends on special occasions • home contents insurance • a holiday away from home for at least a week every year
Economised, cut back, or delayed (5/9)	• put up with feeling cold to save on heating costs • postponed visits to the doctor • postponed visits to the dentist • did without or cut back on trips to the shops or other local places • continue wearing clothing that was worn out
In arrears more than once in any given year (2/2)	• rates, electricity, water • vehicle registration, insurance or warrant of fitness
Financial stress and vulnerability (4/4)	• borrowed from family or friends 'more than once' in the last 12 months to cover everyday living costs • feel 'very limited' by the money available when considering purchasing clothes or shoes for yourself • could not pay an unexpected and unavoidable bill of $500 within a month without borrowing. • feeling limited about buying a $300 item they would you would really like to have
Accommodation problems (2/2)	• dampness or mould • heating and/or keeping warm in winter
Child-specific lack of essentials (1/8)	• good access at home to a computer and internet for homework
Child-specific economising to cut down costs (1/4)	• unable to pay for school trip or other school event

Hana – Enabling her teenage daughter's learning and development

Household and immediate family

The household comprises Hana, who is also pregnant, her partner Tane, their teenage daughter Aria, and their younger son Manu. Aria, who has cerebral palsy and an intellectual disability that was diagnosed at age eight. Manu is a typical teenager with no diagnosed disabilities. The family lives in their own home in a large city suburb. Hana is Aria's primary caregiver, managing the household while working part-time.

Introducing Aria

Aria, a bright and shy teenager, enjoys art and has a playful nature, especially at home. She is eager to engage in creative expression. However, her disability significantly impacts her communication and social integration. Outside of home, Aria becomes withdrawn and struggles to communicate, often feeling isolated, especially in school settings. Her developmental challenges require ongoing educational and therapeutic support.

Early life, medical diagnosis and interventions

Early in Aria's life, developmental delays became apparent, including asymmetric crawling and limited use of one hand. Medical assessments between six months and eleven months old confirmed cerebral palsy and later MRI scans revealed the cause being a stroke affecting areas of the brain tied to language and development. Early intervention with physiotherapy and occupational therapy improved Aria's motor skills and development, but this marked the beginning of Hana's journey in navigating specialised support systems to meet her daughter's needs.

Hana initially felt overwhelmed and isolated by Aria's diagnosis. Perceived negative judgments from close family members, who misunderstood Aria's condition, compounded her sense of confusion. At the time, Hana did not have the knowledge or words to explain Aria's condition to others, as she herself was still learning. The family's living situation was also unstable, as they shared rental accommodation with various family members who came and went. This lack of stability made it even harder for Hana to provide the consistent support she wanted for Aria and Manu.

"Grey area" diagnosis and systemic barriers to Aria's learning and development

At age eight, a psychological assessment confirmed that Aria has an intellectual disability. This assessment, which came about unexpectedly as part of a physical remediation package, led to Aria being placed in a "grey area" that disqualified her from Ongoing Resourcing Scheme funding—funding that would have typically provided individual school support, tailored education, and access to specialists. Hana was unaware that this assessment would disqualify Aria from Ongoing Resourcing Scheme funding, leaving her to manage Aria's learning and development largely unsupported.

Compounding this challenge, Hana and Aria's father struggled with their relationship. Hana felt relegated to a full-time caregiver role, with little room for her own needs and aspirations. As tensions built, their relationship ended in separation. While the co-parenting arrangement eventually brought some relief, it also caused substantial emotional and financial strain. Hana had to rely on a Domestic Purposes Benefit while working part-time and casual jobs and often had little parenting support. She also had to navigate the emotional needs of the children during the separation.

Aria's attendance at Te Kura Māori became a central focus of Hana's advocacy efforts. While the kura connected Aria to her cultural roots and language, it did not formally recognise her intellectual disability. Without in-school advocacy or individual learning accommodations, Aria struggled to participate in activities such as kapa haka, leaving her feeling isolated and unconfident, especially as she fell behind academically. This lack of tailored support was in stark contrast to Aria's early childhood education, where activities were adapted to her needs, and the environment was nurturing and supportive.

Hana regrets not having the knowledge or confidence to advocate for additional support services during these primary school years. Her unheeded concerns about Aria's development deepened her sense of isolation and made it increasingly difficult to address Aria's unmet learning needs.

Experience of material hardship

For many years, Hana's family faced substantial material hardship. They often had to economise on household basics, fall behind on bills, and endure financial stress and vulnerability. There were times when they couldn't afford essential items like warm clothing or recreational opportunities for the children. Despite these challenges, Hana always found ways to make do, even if it meant making sacrifices on her own needs.

For example, during the colder months, Hana had to choose between heating the house and buying necessities. The family's accommodation often had dampness and mould, further exacerbating their challenges, particularly in winter.

Mid-childhood challenges and covid-19

The years leading up to and during the COVID-19 pandemic were especially difficult for Hana and Aria. Regular therapy sessions, critical to Aria's progress, were severely disrupted, setting back her physical and cognitive development. With minimal external support, Hana continued her primary caregiving role, but the strain increased as options for Aria's education remained limited.

Without access to Ongoing Resourcing Scheme funding and no suitable school alternatives, Hana felt stuck. She didn't want to disrupt the positive aspects of Aria's schooling but also couldn't ignore her daughter's growing academic challenges.

New stability through re-partnering and work

During this challenging period, Hana took the opportunity to return to university. With the support of her new partner, Tane, who helped care for her children, Hana was able to focus on her studies. Over time, she secured part-time professional work, and after retraining, found a permanent job that brought both fulfilment and financial stability.

These new developments marked a major turning point. Hana and Tane were able to buy their first home, and the family's financial situation began to improve significantly. With more stability, Hana could focus on advocating for Aria and creating a better future for her children.

Recent developments in education and additional learning support

A few years ago, a friend encouraged Hana to reach out to the Halberg Foundation. There, an enthusiastic instructor introduced Aria to rock climbing and involved both siblings in surfing activities. These experiences boosted Aria's confidence and provided a sense of achievement, helping her feel more capable and connected. However, these activities were cut short when the instructor left the country.

In response to Aria's struggles in school, Hana enrolled her children in Kumon at her own expense. This after-school program provides structured repetition and self-paced learning in literacy and numeracy. For Aria, Kumon has been a source of achievement and progress, though the program requires her perseverance and regular motivational support from Hana. While still in the early stages, it's proving to be a vital tool in rebuilding Aria's confidence.

Recently, Hana initiated discussions with Aria's kura about implementing more individualised learning strategies. While the school staff have shown a willingness to explore alternatives, the lack of formal Ongoing Resourcing Scheme support means the prospects for meaningful change remain uncertain. Still, this dialogue has made Hana hopeful for a more responsive approach to Aria's education.

Looking to the future – consolidating gains and aspirations for Aria

Re-partnering with Tane and securing a stable job have brought financial stability and emotional relief to Hana's family. The connection to Māori culture through the kura, as well as their involvement with the local marae, has been a key source of strength for Aria's identity and sense of belonging. Additionally, Hana has a supportive network of good whānau, friends and cousins, who provide essential emotional support and relief.

Despite the progress, Hana's primary goal remains to improve Aria's school experience, boost her confidence, and create pathways for her meaningful participation in society as she approaches adulthood. While it's a daunting challenge, Hana remains committed to advocating for the right resources, as she believes that each step toward supporting Aria's learning is a victory for their future.

Experience of material hardship – abated in recent years

In recent years, Hana's financial situation has improved, but the family still faces occasional hardships. These include economising on basic household needs in favour of prioritising spending for the children's essentials, such as clothing and activities that support their development.

Enforced lack of essentials (3/7)	• presents for family and friends on special occasions • home contents insurance [only just got this] • a holiday away from home for at least a week every year
Economised, cut-back, or delayed (7/9)	• bought cheaper cuts of meat or bought less than wanted • put up with feeling cold to save on heating costs • postponed visits to the doctor • postponed visits to the dentist • did without or cut back on trips to the shops or other local places • delayed repairing or replacing broken or damaged appliances • spend less on hobbies or other special interests than you would like
In arrears more than once in any given year (2/2)	• rates, electricity, water • vehicle registration, insurance or warrant of fitness.
Financial stress and vulnerability (4/4)	• borrowed from family or friends 'more than once' in the last 12 months to cover everyday living costs • feel 'very limited' by the money available when thinking about purchasing clothes or shoes for yourself • could not pay an unexpected and unavoidable bill of $500 within a month without borrowing. • feel limited about buying a $300 item they would really like to have.
Accommodation problems (2/2)	• dampness or mould • heating and/or keeping warm in winter.
Child-specific lack of essentials (1/8)	• 2 sets of warm winter clothes for each child
Child-specific economising to cut down costs (1/4)	• had to go without music, dance, kapa haka, art, swimming or other special interest lessons.

Helen: Seeing that her fragile premature baby has a rich teenage life

Household and immediate family

Helen and Tim are raising three children in a large urban centre. Kyle and Lucas are twin boys in their mid-teens, and Mia is their preteen daughter. Kyle has intellectual and physical disabilities, and Lucas also has a relatively manageable cerebral palsy condition. Helen works part-time as an education support worker, bringing her accumulated expertise into her parenting role. For his part, Tim, as a business owner, works flexibly at times to be more available for his children. Their three-bedroom home is increasingly inadequate for the family's needs. Kyle and Mia sharing a room limits privacy, while the lack of quiet zones and additional space for therapeutic equipment or study further compounds the challenges. For Helen and Tim, the crowded living situation also restricts their ability to decompress and focus on their own mental health and relationship.

Initially, Helen struggled with family members who misunderstood Kyle's needs, which required her to educate them on how to interact with him. Over time, some family and friends became critical supporters, offering emotional and occasional practical assistance.

Introducing Kyle, Lucas and Mia – caring and supportive siblings

Kyle, the twin we are focusing on, has a great sense of humour and a passion for football. Kyle wants to be a professional football referee. He and his father, Tim, share a mutual love of sport. Kyle is intellectually younger than his age, which impacts his social interactions and learning experiences. However, Helen has observed him progressively coming out of his shell, naturally adopting leadership roles when playing football with peers and bonding with teammates over music.

Lucas, Kyle's twin, does not have the same level of visible need as his brother. Growing up alongside Kyle, he has experienced the dynamics of having a sibling with complex medical and developmental needs.

The youngest, Mia, has developed a close relationship with her brother Kyle. She often steps in as a watchful companion when her parents are unavailable. Mia has her unique challenges as an anxious preteen who finds it stressful to be away from her mum and struggles at school. Her understanding of Kyle's needs and willingness to watch over him reflect a caring role within the family.

Early challenges – diagnosis, initial interventions

Kyle and Lucas were born prematurely, with both boys facing early medical challenges that led to extended hospital stays. Kyle experienced additional hospitalisations as a baby due to issues related to developmental delay and motor impairments. Initially oxygen-dependent, he was diagnosed with hemiplegia when he was around three years old. His hemiplegia affects one leg, requiring physical therapy and specially modified footwear. A local trust provided speech-language, physiotherapy and music therapy and assisted with feeding and toileting when Kyle started kindergarten. It wasn't until Kyle was about eight years old that he was diagnosed with an intellectual disability – an assessment that his parents had to organise and pay for privately.

Although limited in scope, these early interventions were essential for Kyle's development. Helen's having to continuously self-advocate added to her stress during this critical adjustment period.

Deepening financial and emotional strain – emerging trauma and depression

In the early years, managing the intensive needs of her twins, including a constant round of medical appointments, took all of Helen's time. Helen was diagnosed with PTSD, and the associated depression was compounded when she realised she would not be able to return to work in the foreseeable future. Instead, she felt increasingly overwhelmed and socially isolated and experienced growing financial stress and hardship.

Helen sought help from her GP, who made a referral to maternal mental health services. While affording some initial relief, the support was limited, leaving Helen feeling like she was facing these insurmountable challenges alone. Over time, Helen turned to alcohol as a way to cope with the emotional and physical demands of her daily life. This reliance on alcohol eventually affected her family relationships, prompting an ultimatum from Tim to stop drinking. Recognising the need for change, and with the encouragement of her father and husband, Helen committed to sobriety. This decision was a turning point in her personal and family life, ultimately strengthening her relationship with Tim and deepening her resolve as a parent.

Financial pressures have remained significant for the family. Tim's full-time income and Helen's eventual part-time work have had to stretch to cover medical expenses, specialised education resources, and the ongoing home adaptations. While individualised funding helped offset some costs, the complexity of applying for financial assistance, like the Supported Living Payment, poses additional barriers. Financial constraints have forced the family to prioritise, often delaying non-essential expenses such as dental visits and home repairs and staying in a home that is too small for their family.

Schooling – support and gaps

Kyle's educational journey has been marked by enabling support and notable gaps. In primary school, he received partial teacher-aide assistance funded by Ongoing Resourcing Scheme. However, when he entered intermediate school, the absence of structured support became apparent. He encountered social challenges, struggling to navigate social cues and frequently misinterpreting peer interactions, sometimes leading to his involvement in risky situations.

Kyle's transition to high school brought him into a supportive special needs class that provided a safe environment to develop and learn at his own pace. In addition to catering to Kyle's academic needs, the class ensured his social inclusion and, by extension, his psychological and emotional wellbeing at school.

Effective supports and systemic challenges

Helen's experience highlights several essential supports that contributed to Kyle's development and her family's ability to endure and thrive. In the early days, Tim's supportive employer offered him flexibility, enabling him to attend Kyle's medical appointments and help manage the twins' intensive care needs. Early intervention therapies, including speech-language, physiotherapy, and music therapy, helped Kyle reach key milestones, such as taking his first steps and building a foundation for his growth.

Supportive educators and healthcare providers were also pivotal. Kyle's long-term paediatrician ensured continuity of care, profoundly understanding his medical and developmental history, which reduced the burden on his parents to constantly explain his needs. Educators, particularly in his high school's special needs class, created a nurturing and inclusive environment where Kyle has demonstrated leadership qualities. More recently, Individualised Funding allowed for tailored skill-building activities, like preparing meals with a family member, fostering Kyle's independence and preparing him for greater autonomy in adulthood.

Nevertheless, Helen experienced persistent gaps in what should have been routine service provision. Delayed in-home assistance, inconsistent school support during intermediate years, and complex administrative processes for financial aid underscore systemic barriers that added to Helen's stress. She had to continuously advocate for herself and her children.

Planning for the future

Looking to the future, Helen and Tim's primary concerns include gaining the financial means to support Kyle's long-term needs and moving to a larger home to better accommodate their family. They are also focused on preparing Kyle for semi-independent living, balancing his aspirations with the reality of his ongoing support needs. The next step is engaging Kyle in voluntary work for the family business to give him a sense of responsibility and accomplishment, enabled by close supervision and encouragement.

Experience of material hardship – abated in recent years

Enforced lack of essentials (3/7)	· two pairs of shoes in good repair and suitable for everyday use · suitable clothes for important or special occasions · a good bed
Economised, cut back, or delayed (5/9)	· put up with feeling cold to save on heating costs · postponed visits to the dentist · delayed repairing or replacing broken or damaged appliances · continue wearing clothing that was worn out · spend less on hobbies or other special interests than you would like
In arrears more than once in any given year (0/2)	
Financial stress and vulnerability (2/4)	· feel 'very limited' by the money available when considering purchasing clothes or shoes for self · feel limited about buying a $300 item they would really like to have.
Accommodation problems (1/2)	· heating and/or keeping warm in winter.
Child-specific lack of essentials (2/8)	· 2 pairs of shoes in good condition and suitable for daily activities for each child · good access at home to a computer and internet for homework.
Child-specific economising to cut down costs (2/4)	· involvement in sport had to be limited · continue to wear shoes or clothes that are worn out or the wrong size.

Stephanie: Creating the conditions for a good life for her daughter, Mica

The household and immediate family

Stephanie is staying temporarily in the modest home of her adult daughter Mica, who has a global developmental delay, Bell Palsy and sensory sensitivities. Stephanie has spent much of her life navigating the challenges of raising two children with substantially different needs.

Early losses and enduring gaps in family connection have shaped Stephanie's experience of family support. The death of her parents while she was still young resulted in increasingly limited contact with her many siblings and wider family, leaving her without the strong familial network many rely on. Over the years, only her brother and his wife offered occasional practical help, but this support was infrequent and did little to alleviate the pressures of caregiving.

This lack of support stood in stark and often painful contrast to the warmth and care she experienced, albeit briefly, from her second husband's Pacific family, who welcomed her and her children with openness and generosity. The disparity highlighted Stephanie's enduring isolation within her own family, compounding the challenges of raising Mica and managing her household mainly on her own.

Introducing Mica and Amelia

Mica is a vibrant, socially curious and confident single woman in her mid-thirties with a mischievous sense of humour. She thrives in structured environments and enjoys social interactions when they are not too overwhelming. Mica's cognitive limitations – getting information muddled or getting distracted – have made independence challenging, requiring ongoing support in areas such as employment and daily living.

Amelia, Stephanie's younger daughter, is now in her early twenties. She is independent, thoughtful, and deeply aware of the unique challenges her family has faced. Growing up alongside Mica, who is also much older, has shaped her sense of responsibility and empathy. Amelia, who is flatting on her own, occasionally visits Stephanie and Mica, offering support and maintaining a close, loving connection with her family.

Early years and key interventions

Mica's developmental delays, marked by speech difficulties and motor delays, became apparent early. While briefly living in Australia, Mica attended a special preschool that provided invaluable early interventions, such as speech and occupational therapy. These services offered a promising start, equipping Mica with foundational skills. Upon returning to New Zealand, Mica continued her education at an inclusive primary school that embraced her and managed her needs. After-school and holiday programs provided Mica with therapeutic benefits while allowing Stephanie to work full-time for a short period.

Employment, relationship and financial strain

The caregiving demands of raising Mica have dictated Stephanie's career trajectory. With limited external support, Stephanie often worked part-time or in roles that allowed for flexibility but offered little financial security. Her financial challenges intensified following her separation from Mica's father, who provided minimal caregiving or financial support. A subsequent relationship, which led to the birth of her second daughter, was also strained by the imbalance of responsibilities and economic pressures.

Over the years, housing instability compounded Stephanie's difficulties. Repeated moves and the inability to secure affordable, permanent housing placed additional strain on the family. These disruptions affected Stephanie's financial security as she struggled to meet rising rental costs. They also created emotional challenges for Mica, who relied on a stable environment to thrive. The constant need to relocate made it difficult for Stephanie to establish consistent routines or long-term plans.

Support systems: gains and gaps

Stephanie sought various supports to meet Mica's evolving needs. A pilot community programme and a support service organisation provided structured environments where Mica thrived socially and emotionally. However, these successes were also tempered by systemic failures. Periods of high staff turnover and insufficiently trained personnel in adult support services undermined the quality of these programs, leaving Stephanie as the default caregiver during critical gaps in care.

Employment preparation services initially seemed promising, helping Mica secure short-term jobs. However, the lack of ongoing support and accommodations meant these placements were unsustainable. Similarly, attempts to negotiate Individualised Funding approvals were met with bureaucratic hurdles, further complicating Mica's transition to adulthood. The inconsistency of adult support services left Stephanie sceptical about the system's ability to address her family's long-term needs.

Material hardship and its impacts

Stephanie's caregiving role has profoundly impacted her financial and material circumstances. Frequent economising became the norm—skimping on heating, postponing medical care, and relying on outdated or insufficient appliances. Mica's needs often took precedence, with Stephanie directing scarce resources toward ensuring her daughter's well-being. This trade-off left Stephanie facing unmet personal needs, including delayed medical and dental care, contributing to physical and emotional exhaustion.

Advocacy and community engagement

Over the last few years, Stephanie has started working for a local trust. This organisation provided a nurturing group residential environment for Mica, which Mica outgrew after 18 months – it became increasingly taxing getting to courses and activities using public transport. Stephanie then arranged for the trust to provide Mica with a stable community support team. These support workers were known and trusted and have become whānau to Stepanie and Mica. After many years of effort, Stephanie recently negotiated a long-term social housing placement for Mica. Mica now lives independently in her very own flat, enabled by dedicated support from her care team. Previously, Mica had various short-term periods flatting over the span of 12 years while mostly living with Stepanie.

Looking to the future – consolidating recent gains

Despite many hurdles, Mica recently secured permanent part-time employment with an NGO. The organisation is committed to accommodating people with intellectual disabilities, and Mica is further aided by supplementary practical support from Stephanie and the care team. Even at five hours per week, having paid work has been a transformative development for Mica and Stepanie. However, money is still tight, as Mica has to save for the shoes she needs, for example.

Stephanie is now focused on further developing Mica's and her own independence. Stephanie needs greater flexibility to pursue more lucrative work – wherever that may be –, to save for the future (as she looks to her 60s) and to extend herself personally and professionally. However, she can only do this if Mica sustainably increases her hours of work and earning capacity and maintains her independent living situation. Stephanie worries that Amelia, Mica's much younger sister, may feel compelled to take on Mica's care, which might be something she is not prepared for. The family has arrived at a state of flux, where recent positive developments and a sense of hopefulness are balanced against substantial uncertainties, especially reliable employment and sufficient income.

Experience of material hardship – some are persistent and ongoing

Enforced lack of essentials **(6/7)**	· two pairs of shoes in good repair and suitable for everyday use · suitable clothes for important or special occasions · presents for family and friends on special occasions · home contents insurance · a good bed · a holiday away from home for at least a week every year
Economised, cut back, or delayed **(8/9)**	· went without or cut back on fresh fruit and vegetables · bought cheaper cuts of meat or bought less than wanted · put up with feeling cold to save on heating costs · postponed visits to the dentist · did without or cut back on trips to the shops or other local places · delayed repairing or replacing broken or damaged appliances · continue wearing clothing that was worn out · spend less on hobbies or other special interests than you would like
In arrears more than once in the past year (2/2)	· rates, electricity, water · vehicle registration, insurance or warrant of fitness
Financial stress and vulnerability (4/4)	· borrowed from family or friends 'more than once' in the last 12 months to cover everyday living costs · feel 'very limited' by the money available when thinking about purchase of clothes or shoes for self · could not pay an unexpected and unavoidable bill of $500 within a month without borrowing. · feel limited about buying a $300 item they would really like to have.
Accommodation problems (2/2)	· dampness or mould · heating and/or keeping warm in winter
Child-specific lack of essentials (2/8)	· good access at home to a computer and internet for homework · friends around to play and eat from time to time (because of the cost)
Child-specific economising to cut down costs (1/4)	· had to go without music, dance, kapa haka, art, swimming or other special interest lessons

Louise: Guiding Grace into safe and meaningful social participation

The household and immediate family

Louise lives in a major urban centre with her husband Reece and their four children: Grace (early twenties), Chloé (pre-teen), Noah, and Alexis (early to late teens). Grace, the eldest, has an intellectual disability caused by Foetal Alcohol Syndrome Disorder (FASD) and a traumatic brain injury. Alex and Noah are adopted siblings who also face challenges stemming from early trauma, while Chloé, the couple's biological daughter, acts as a stabilising presence in the household. Louise juggles part-time work with caregiving, while Reece works full-time, leaving much of the daily management of their children's needs to Louise.

Broader family support has been limited despite adoptive grandparents overseas providing occasional financial and emotional contributions. Judgmental or ambivalent attitudes from extended family have compounded Louise's isolation, underscoring her reliance on formal systems and informal networks for help.

Introducing Grace and her siblings

Grace's intellectual disability profoundly impacts her daily life. She requires significant supervision due to her challenges with basic life skills and safety awareness, which means she cannot be left alone. Despite these limitations, Grace exhibits exceptional memory recall and thrives in structured environments, such as volunteering at a charity and attending programs at a local trust that provides vocational services for people with disabilities. These opportunities provide her with a sense of purpose and social engagement.

Grace's siblings experience their own struggles and play varying roles in the family dynamic. Chloé, despite her young age, is empathetic and supportive, often acting as a stabilising presence in the home. In contrast, Noah, who has a recent ADHD diagnosis, exhibits behavioural challenges that frequently disrupt household harmony, including constantly bullying or putting Grace down. Alexis provides occasional emotional support to Grace, occasionally keeping her company, but can also treat Grace poorly. Alexis has left school and wants to live independently but is not yet motivated to find employment. The siblings' relationships reflect complex family dynamics, and Louise worries about them all.

Grace's early diagnosis and transition to New Zealand

Grace's intellectual disability was diagnosed by age three when the family lived overseas. Comprehensive neuropsychological assessments linked her to therapies such as speech and occupational support. These interventions and individualised learning helped Grace build foundational skills and adapt to her cognitive and behavioural challenges. However, navigating an insurance-driven health system brought its own stresses.

Upon returning to New Zealand, Louise faced a fragmented and slower system. Her GP initially dismissed Grace's challenges as minor, delaying referrals for further assessments. Long public waitlists and inadequate guidance from paediatric services left Louise feeling unsupported. It wasn't until Grace was eight that she was finally assessed in New Zealand, and a definitive diagnosis of intellectual disability and FASD was secured.

The struggles of primary school

Grace’s primary school years were marked by frequent bullying and inadequate support. Despite evident developmental delays, teacher-aide assistance through the Ongoing Resourcing Scheme was denied until after her diagnosis. Louise’s persistent advocacy for educational accommodations was met with slow responses, forcing her to shoulder much of the coordination of responses herself. These years saw a decline in Grace’s confidence and social engagement, further isolating her from her peers.

Transition to homeschooling and relocation

When Grace was 10, Louise started homeschooling her, initially as a temporary solution to address bullying and the lack of in-school support. However, the absence of viable educational alternatives extended this arrangement until Grace reached working age. Homeschooling demanded Louise’s full attention, leaving her unable to pursue paid work.

Midway through this period, the family relocated from one city to another for financial reasons and better opportunities. They had a cohesive homeschooling network that provided Grace with structured group activities and social engagement. The move disrupted these connections, leaving Louise to formulate and manage Grace’s education entirely on her own. This upheaval also took an emotional toll on the family, with Grace struggling to adjust to a new environment and her siblings reacting negatively to the loss of familiar social networks.

During Grace’s teenage years, Louise secured Individualized Funding (IF), which allowed her to hire neighbours as part-time caregivers and purchase adaptive equipment for Grace. While IF brought some flexibility, navigating the system through NASC was frustrating. Differing levels of availability and cooperation among caseworkers and unclear guidance often delayed access to much-needed services.

A transformative year: social participation and independence

Over the past year, Grace’s life has significantly transformed. She began attending a trust that provides vocational services, where she participates in fitness training, group outings, and life-skills workshops. Initially apprehensive about this new institutional setting, Grace has flourished, forming meaningful friendships and gaining a sense of belonging. Her increased social engagement has improved her confidence and reduced her reactivity at home. Her growing closeness with her youngest sister, Chloé, has further eased tensions in the family, particularly in her relationship with Louise.

In the last year, Grace started volunteering at a local charity shop, performing tasks like sorting and pricing items. She thrives in this supportive environment, enjoying the camaraderie of colleagues who understand her needs. This experience has given her a sense of accomplishment and sparked aspirations for future employment.

These changes have brought considerable relief to Louise. With IF funding covering part-time caregiving, she has returned to flexible part-time work, alleviating financial pressures and providing a much-needed reprieve from full-time parenting. This change also enables Louise to more closely attend to the needs of her other children and her own health. While the family has not endured substantial material hardship, the siblings have missed out on beneficial activities due to cost. Recent financial pressures have included having to find $5,500 to pay for a private neuropsychological assessment for Noah.

Lingering challenges and hopes for the future

Despite recent progress, significant challenges remain. Grace is on a waitlist for supported living accommodation, but the timeline and suitability of such arrangements are unclear. Due to Grace's trusting nature, Louise worries about her safety and vulnerability to exploitation in work and social settings. For these reasons, Louise has been awarded power of attorney over Grace granted welfare guardianship over Grace. Within the family, Noah and Alexis's needs and behaviours weigh heavily on Louise as she tries to fortify sibling relationships and well-being.

Looking forward, Louise envisions a future where Grace can access subsidised employment in a supervised environment that builds her independence and self-worth. Expanding programs that teach practical social skills and safety awareness would further enhance Grace's confidence and independence. Consistent respite care and having more streamlined access to helpful services remain critical to alleviating Louise's chronic fatigue and emotional burden. While uncertainties about Grace's long-term care persist, Louise finds strength in the progress Grace has made, both socially and personally, over the past year.

Experience of material hardship

Child-specific economising to cut down costs (1/4)	· had to go without music, dance, kapa haka, art, swimming or other special interest lessons.

Erin: Orchestrating long-term wrap-around support for her son Chris

The household and immediate family

Erin and her husband, Peter, have raised three children who are now adults. Their oldest son, Chris, now in his early fifties, has an intellectual disability and epilepsy. Chris and his two younger sisters, now in their thirties, have all gone on to pursue independent lives. Despite geographic distances, the family remains close-knit.

Erin's business allowed her to care for Chris after school while earning a steady income, and Peter's consistent earnings and entrepreneurial ventures provided additional stability. Together, they co-founded a successful manufacturing company. These ventures ensured sufficient financial security and flexibility to meet their children's needs. Their long-time family home remains a haven where challenges are managed, and milestones are celebrated.

Introducing Chris

Chris is a cheerful, affectionate man with a strong sense of justice and a deep love for routine and structure. His intellectual disability and epilepsy were diagnosed in early childhood. His speech is limited resulting in others often underestimating his level of understanding, yet Chris recognises two languages and has a strong memory.

Concerns about Chris's development emerged early, with delays in walking and speech prompting his family to seek expert guidance. While the family was living overseas, Chris attended a specialised kindergarten that provided movement therapy and speech interventions, setting the foundation for his developmental progress. These early interventions, along with a nurturing and inclusive family dynamic, helped Chris develop critical motor and communication skills.

Persistent advocacy and learning to responsive practices within mainstream schools

The family's move to New Zealand in the early 1980s marked a pivotal chapter in Chris's journey, with continuing opportunities for his education and development. This transition was defined by proactive advocacy, effective use of services, and a collaborative effort between institutions, professionals, and the family. These enablers not only supported Chris's growth but also established a foundation for his independence and inclusion in the community.

In the early stages of their lives in New Zealand, Erin and Peter used respite care (equivalent to one month per year), which provided short-term relief from caregiving responsibilities. This support was particularly valuable as they navigated the challenges of settling into a new country without extended family nearby.

New Zealand's education system gave Chris access to integrated special education classes within mainstream schools. Chris had access to a psychologist, and teacher aides supported him in navigating classroom tasks and developing essential life skills. Specialist teachers and resource teachers for learning and behaviour (RTLBs) addressed his unique needs, ensuring consistent support. His progress was further enhanced by regular access to speech therapy, which improved his communication (including speaking English], occupational therapy to strengthen fine motor skills and adaptive abilities, and physiotherapy to improve mobility and overall health.

Erin played a pivotal role in orchestrating this tailored educational pathway. Recognising that a standard approach to special education would not suit Chris, she actively collaborated with the Ministry of Education (MoE), specialists, and school administrators to create a consistent, needs-focused experience. Her advocacy ensured continuity across primary, intermediate, and high school, maintaining stability vital for Chris's social and emotional development. She pushed for small, specialised classes within mainstream schools, combining individualised instruction with opportunities for social inclusion, and secured consistent teacher-aide support and specialised training for staff.

Erin also emphasised integrating therapeutic interventions into daily routines and advocated for Chris's participation in mainstream school activities. This holistic approach helped Chris master key life skills, form enduring friendships, and develop the confidence to transition into adulthood. One of Erin's most impactful efforts was ensuring a small, stable cohort of children, including Chris, together throughout their schooling. This intentional grouping allowed the children to form enduring friendships and fostered a sense of community and belonging. The group provided a stable peer environment substantially contributing to their confidence and emotional well-being.

Fostering Chris' independence

One of the most significant enablers of Chris's development was Erin's emphasis on fostering his independence. With her consistent guidance and encouragement, he learned to navigate public transport and made his way to school, the library, and local shops on his own. Furthermore, these travelling experiences expanded his social engagement and confidence, as he talked happily with bus drivers, passengers, shopkeepers and passersby.

Additionally, Chris participated in various preparatory programs and courses designed to help him gain employment, providing a mix of structured training and practical experience. Chris had opportunities to work in manufacturing and hospitality, where he learned basic vocational skills under supervision. While these experiences offered a sense of accomplishment and helped Chris develop a routine, policy changes resulted in program closures that disrupted his progress. Since then, Chris has only had episodic, part-time work.

Parental strain and Chris' move to supported independent living

At 22, Chris moved into a supervised group residence then managed by the IHC. The decision was based on balancing Chris's changing needs with broader family dynamics, including raising two small children. Erin also recognised that a structured environment could foster Chris' independence while allowing the family to focus on the intensive caregiving needs of her youngest children. She realised that while the move provided family stability, it also limited Chris's autonomy – a trade-off she needed to make. Erin's support for Chris didn't waver though, as she was instrumental in securing the funding and purchase of several of the supervised residences that Chris lived in, ensuring stability for the housemates.

Chris became quickly and increasingly frustrated at imposed limitations and support failures. His outbursts and behavioural challenges required intensified supervision, further constraining social and employment opportunities.

Looking to the future – concerns and ongoing parental commitment

Erin remains deeply involved in Chris' life, seeking to comprehensively address gaps in IHC's Idea Services support and to enrich his days with structured activities that align with his strengths and interests. She regularly visits him, maintaining his emotional connection to the family and organises activities like art workshops, gym sessions, and swimming. He also visits the family home every Sunday. Financially, she supports extracurricular programs, transportation, and personal needs not covered by Idea Services. Looking to the future, Erin and Peter also established a trust fund decades ago to ensure Chris' long-term financial security and wellbeing.

Erin also continues to seek employment opportunities for Chris as she has done for the duration of Chris' time living in IHC/Idea Services residences. She tees up jobs and advocates with Idea Services to liaise with prospective employers and provide work-specific support so that these placements can succeed.

Erin's overall judgment about Chris' life in the Idea Services managed residential setting is pragmatic rather than an ideal solution. She remains concerned about limitations in the quality and consistency of care. Chris' opportunities for meaningful activities and social engagement are often insufficiently supported, and his autonomy is curtailed in ways that lead to frustration and reactive behaviours. Despite these shortcomings, Erin believes the current arrangement is the best available option, given the family's circumstances. Her continued involvement and advocacy ensure that Chris' needs are met as comprehensively as possible within the constraints of the current care system.

Erin's family has not experienced material hardship

David: forging the conditions for Emma's self-directed and richly interdependent life

Early foundations and developmental support

David and Claire are the parents of three daughters: Emma, Samantha, and Alice. Their eldest, Emma, was diagnosed with Down syndrome and from an early age, she struggled with developmental delays and communication difficulties. Emma's fine motor skills were limited, causing her to struggle with tasks requiring dexterity. With a background in primary education, Claire integrated learning tools into her daughter's daily life, drawing on her teaching expertise to create daily routines and learning activities to support Emma's development in language, motor skills, and social interaction, building her confidence and independence.

Motivated by Emma's needs, David made a career shift from working in the arts to social and community work. Recognising the impact that community and systemic support had on families like his, David became involved in local disability advocacy. His work with various organisations not only brought needed resources to their family but also allowed him to contribute to policy improvements, which enhanced community resources for others facing similar challenges. David's advocacy role extended into forming parent-led groups, establishing monthly meetings where families and practitioners could share resources, and securing community support that has remained part of Emma's life.

Building a supportive community network

David and Claire understood the importance of community early on as a means of growing Emma's sense of confidence and belonging. They realised that without such support, Emma could be disadvantaged by living on the fringe of the major city. Consequently, David and Claire created a local support network, starting with their neighbours. These networks then expanded to include all the schools that Emma attended and have been maintained through her adulthood.

Soon after, David founded a family-practitioner group that met monthly and David and Claire built a "village" around Emma, composed of friends, mentors, and fellow advocates. These relationships, including friendships from kindergarten and school, have provided enduring support through Emma's transitions in school, work, and life.

Their advocacy also brought systemic changes in local education, with schools adopting inclusive policies that enabled Emma to learn and socialise with her peers. This took some time and considerable effort. Claire's role as an educator was instrumental in facilitating these changes, with her involvement in local schools bridging Emma's needs with status-quo educational policies and practices. These efforts ensured that Emma could experience a continuous, inclusive education, which proved foundational to her development.

Creative expression and personal development

The arts have been essential in Emma's personal growth. David and Claire saw creative expression as a therapeutic outlet for Emma, enabling her to explore her emotions and connect with others. They involved her in activities including dance, theatre, and storytelling, which allowed her to articulate her experiences and form connections within her community.

David's work with a disability theatre group and a graphic publication project has been particularly influential. Emma has been exploring acting and performance through the theatre group in a supportive, inclusive environment for decades. She has gained confidence and learned to navigate social interactions. The graphic project focused on representing people with intellectual disabilities through narrative, allowing Emma to share her story in a relatable format, helping others understand her capabilities and experiences. Meanwhile, dance offered Emma a physical and emotional outlet, with her regular classes providing structured yet expressive sessions where she could connect with peers and enjoy movement-based collaboration and performance.

The role and impact of personal assistants

Personal assistants (PAs) are integral to Emma's care system, providing support tailored to her unique needs. David and Claire have carefully selected and trained Emma's PAs, emphasising skills, values alignment and emotional compatibility with Emma. The relationship between Emma and her PAs is founded on mutual respect and understanding, with the assistants providing companionable and practical support. This supportive relationship makes Emma feel empowered rather than dependent, encouraging her to make decisions and assert her preferences.

Overcoming systemic barriers

Navigating systemic barriers has been a constant challenge for David and Claire. Early on, they encountered limitations in accessing specialised services, particularly speech and language therapy. Limited local resources led them to seek intensive support abroad, including a family-centred language program in Australia that proved transformative for Emma's communication skills. Although this experience highlighted the gaps in local support, it motivated David to continue advocating for improvements in disability resources in New Zealand.

Funding structures also presented challenges, particularly rigid models that limited flexibility in organising suitable support services. Dissatisfied with initial fundholding organisations, David sought alternatives that allowed him and Claire to manage Emma's care directly. By working closely with a different Individualised Funding provider, they have gained greater control over Emma's care decisions, allowing them to focus on her needs rather than conforming to institutional limitations. This funding model, coupled with their oversight of personal assistants, have given Emma a rare level of autonomy within traditional care systems.

Assistive technology and interactive learning tools

Assistive technology has played a key role in Emma's development. During Emma's early years, David and Claire introduced devices and programs to support her communication, literacy, and motor skills. One of her first tools, the Apple II GS computer, equipped with game software that promoted expressive language, helped Emma to interact with language in a fun, meaningful way. Later, a MacBook with language software that offered auditory feedback and grammar support improved her written communication, while interactive games further enhanced her language skills. An assessment through TalkLink also resulted in access to specialised devices tailored to Emma's needs. More recently, an iPad and iPhone have become essential, offering accessible tools for communication and planning in her daily life.

Securing secure and fulfilling work

Despite an early experience of workplace exclusion due to a change of management, Emma has been in stable part-time employment for the past seventeen years. Her family's connections facilitated job opportunities, providing Emma with structured work in school settings. Voluntary roles soon became paid positions. The work tasks are well-matched to her capabilities, and she is embedded in a supportive school community. Due to Emma's struggle with changes in routine, she has occasional difficulty meeting the expectations at her workplace, "pushing back" when her capacity for flexibility has reached its limit. Her colleagues understand this and provide calming guidance and practical support as needed. They have become enduring firm friends.

Flexible housing for a sustainable future

Recognising the need for a stable yet adaptable living arrangement, David and Claire structured their housing setup to accommodate Emma's evolving needs. The family lives in a dual-property arrangement, with David, Claire and Emma in one home and their middle daughter, Alice, and her family in an adjacent, accessible home. This arrangement offers Emma, now in her early forties, the independence of her own space while providing immediate access to family support. Alice and her husband will gradually assume a more substantial caregiving role for Emma, a plan that David and Claire established to ensure continuity for Emma as they age. Their home had been designed with accessibility in mind, featuring modifications like wide corridors and lowered handles to support Emma's mobility.

Securing a healthy, interdependent future for Emma

David and Claire's parenting journey has involved careful planning, community-building, and advocacy, including driving for flexible Individualised Funding and establishing avenues for creative expression and intergenerational care. Anticipating that Emma will experience premature cognitive and physical decline, they have made every possible provision to ensure Emma's future wellbeing.

David's family has not experienced material hardship

Rebekah Were – Hibiscus - Scholarship Award Entrant - Grey Street Studio
Rebekah particularly enjoys capturing the natural world of animals and flowers in her paintings.

Appendix 3 Profiling the experiences of adults with Intellectual Disabilities

Lindell: Learning to back herself despite all obstacles

Lindell and her family

Lindell is a mid-20-year-old woman living in a major city. She has a casual part-time job and enjoys art, caring for animals, and online gaming. She also manages multiple conditions, such as ADHD, autism, and dyspraxia.

She grew up in a complex family environment with her mother, father, and two younger sisters. Her father, often absent due to work or physical separation within the household, lives in an outbuilding, while her mother has taken over the lounge as a bedroom. Lindell's relationship with her mother has been fraught, marked by denial of Lindell's learning challenges and a lack of emotional and financial support. Substance reliance, particularly alcohol, has also been a recurring theme in her family dynamics.

Lindell is the eldest sibling, and her experiences have starkly contrasted with those of her sisters. She describes a sense of neglect and a lack of recognition for her struggles, compounded by her mother's insistence on maintaining appearances of normalcy. Lindell felt she was scapegoated in the family and suffered regular put-downs. These experiences added to her sense of inadequacy and alienation.

Lindell's household experienced extreme material hardship throughout her childhood. These included enforced lack of essentials, economising on basic items, being in arrears for ongoing essential services, borrowing and feeling stressed about covering everyday costs and living in accommodation with mould or dampness and insufficient heating. The children were equally affected by these deprivations.

School years and challenges

Lindell's school years were marked by significant struggles. She recalls noticing a growing gap between herself and her peers around the age of ten, both socially and academically. Her mother's denial of her learning difficulties meant that Lindell received little support from her family or school, leaving her to cope in silence. She describes herself during this time as shy, quiet, and repressed, often feeling overwhelmed, confused, and unable to advocate for her needs. Lindell's experience at school, along with her alienation at home, led to substantial periods of depression and pervasive anxiety.

While most teachers were dismissive of her needs, one male teacher in high school stood out for his ability to adapt his teaching style, helping Lindell grasp complex concepts in math and art. Despite these small victories, her school experience was essentially isolating, and she completed school in 2014 with limited preparation for the challenges of adulthood. A delayed diagnosis of ADHD, autism, and dyspraxia in her early twenties retroactively explained many of these difficulties, providing her with much-needed clarity.

Beginning to make headway despite mental and physical health challenges

After leaving school, Lindell undertook a tertiary course. While she completed her studies, the daily commute to the city centre proved exhausting, and financial pressures, including her mother's use of her student loan for household expenses, added to her challenges. By 2018, Lindell had begun seeking employment, eventually securing a part-time role in food preparation through a personal connection she made through a study group. This transition marked her entry into the workforce, providing her practical experience and a sense of accomplishment; she now trains new workers.

Before obtaining a job, Lindell also sought professional help for her mental health and developmental challenges. In 2018, she financed, from savings, a private psychological assessment at the cost of $2,500, which resulted in her diagnoses of ADHD, autism, and dyspraxia. These diagnoses were pivotal, enabling her to access ADHD medication and develop targeted coping strategies. However, systemic supports such as WINZ offered limited help, as their generic job-seeker courses failed to address her specific needs as an autistic individual and offered inconsistent case management. Lindell also tried to reach out to various community organisations before she was officially diagnosed. However, she found this disheartening as she frequently didn't get a response or found the information provided not useful.

Current living and financial circumstances, health and social support

Lindell currently lives with her parents and one of her sisters, a situation that continues to be a source of tension. Her mother's denial of Lindell's disabilities and insistence on Lindell paying for her own food and board exacerbates financial strain. Lindell works part-time in a minimum-wage institutional role that, while providing stability, is stressful due to its noisy environment. She modestly supplements her income through pet-sitting, a quieter and more flexible job that aligns with her preferences. Despite her tertiary qualifications, Lindell has struggled to find employment that fully utilises her skills or accommodates her sensory needs. A contributing barrier to suitable employment is not being able to drive and finding public transport anxiety-provoking, especially after being assaulted at a train station.

Socially, Lindell has limited connections, but her long-term relationship with Ryder, a man who lives overseas and whom she met online, has been a cornerstone of her support system. Ryder provides emotional reassurance and practical advice, helping Lindell navigate financial challenges and establish boundaries with her family. Lindell can also confide in her manager about the tensions at home with her family. Often, she feels there is no one else she can turn to, when feeling confused, overwhelmed or distressed. She is comforted by the company of pets.

Despite her apparent ability to make do with very little, financial independence remains a significant hurdle. Lindell has made progress in reducing her student loan debt and managing her expenses. However, the casual nature of her employment, including extended periods when paid work is unavailable, the lack of sick leave, having to fund her own assessment and having little systemic support, leaves her in a precarious position. Although now able to afford sufficient food – Lindell used to starve herself – material deprivation remains an ongoing issue, for example, affording the special shoes she needs. Lindell has only recently obtained a credit card with a modest limit. For some years, her attempts to secure credit were declined due to her mother's history of credit defaults.

Looking to the future: challenges and aspirations

Lindell's sense of a positive future involves overcoming ongoing challenges and maintaining her aspirations for personal development. Financial stability remains a priority, as does finding employment that better suits her sensory needs and long-term goals. She is actively seeking opportunities that align with her interests in art and design or animal welfare while continuing to manage her needs as best she can in her current workplace.

Socially, Lindell hopes to strengthen her connections and find communities that understand and accommodate her disabilities. Her relationship with Ryder provides a strong foundation, offering her encouragement and a vision of a healthier, more autonomous future. Lindell struggles to reach out for help – not knowing what to ask for and doubting that she is deserving despite Ryder's encouragement.

Lindell believes her life could significantly improve with tailored employment support and stable, independent housing. Opportunities to connect with inclusive social networks and advocacy support would also help her navigate and address financial, social, and professional challenges more confidently. Feeling she has reliably available, capable, and caring people on her side would make a big difference.

Experience of material hardship – persistent and ongoing

Lindell responded to this questionnaire as a young adult with intellectual disability living at home, covering general household questions along with the child-specific measures.

Enforced lack of essentials (7/7)	· meal with meat, fish or chicken (or vegetarian equivalent) at least each 2nd day · two pairs of shoes in good repair and suitable for everyday use · suitable clothes for important or special occasions · presents for family and friends on special occasions · home contents insurance · a good bed · a holiday away from home for at least a week every year.
Economised, cut back, or delayed **(9/9)**	· went without or cut back on fresh fruit and vegetables · bought cheaper cuts of meat or bought less than wanted · put up with feeling cold to save on heating costs · postponed visits to the doctor · postponed visits to the dentist · did without or cut back on trips to the shops or other local places · delayed repairing or replacing broken or damaged appliances · continue wearing clothing that was worn out · spend less on hobbies or other special interests than you would like.
In arrears more than once in any given year (2/2)	· rates, electricity, water · vehicle registration, insurance or warrant of fitness.
Financial stress and vulnerability (4/4)	· borrowed from family or friends 'more than once' in the last 12 months to cover everyday living costs · feel 'very limited' by the money available when considering purchasing clothes or shoes for self · could not pay an unexpected and unavoidable bill of $500 within a month without borrowing. · feel limited about buying a $300 item they would really like to have.
Accommodation problems (2/2)	· dampness or mould · heating and/or keeping warm in winter.
Child-specific lack of essentials (8/8)	· 2 pairs of shoes in good condition and suitable for daily activities for each child · 2 sets of warm winter clothes for each child · waterproof coat for each child (because of the cost) · separate bed for each child · fresh fruit and vegetables daily · meal with meat, fish or chicken (or vegetarian equivalent) each day · good access at home to a computer and internet for homework · friends around to play and eat from time to time (because of the cost).
Child-specific economising to cut down costs (4/4)	· had to go without music, dance, kapa haka, art, swimming or other special interest lessons · unable to pay for school trip or other school event · involvement in sport had to be limited · continue to wear shoes or clothes that are worn out or the wrong size.

Mica: Enjoying a full life – work, family, friendship, spirituality, and sport

Mica is a warm, sociable woman in her 30s who thrives on meaningful connections and structured routines. She has a broad range of interests and is supported by her family and a network of professionals who help her navigate daily life and work. Mica experiences intellectual and physical challenges, including difficulties processing information, Bell's palsy, and health issues. These require support but do not overshadow her capacity for independence and her enthusiasm for life.

Living and financial circumstances

Mica lives in her own accessible flat in a large city, which is affordable due to her eligibility for social housing. Her ability to live a fulfilling and independent life is underpinned by a well-coordinated network of family, professional support workers, and community connections. A significant part of Mica's journey centred on living in a supported group residence. During this time, Mica benefited from a structured and supportive environment that helped her adapt to living outside her family home while laying the foundation for her strong support system today.

Mica's financial stability comes from a combination of modest but steady part-time income and Individualised Funding overseen by her mother, Stephanie. These arrangements allow her to manage her basic needs without significant financial strain. Careful budgeting with her mother and support team enables Mica to engage in hobbies and participate in social outings. However, her financial situation leaves little room for unexpected expenses or more ambitious personal goals.

Current support network

Mica's mother, Stephanie is the cornerstone of her support network, providing emotional guidance and advocacy. Living with Mica or nearby, Stephanie is a steady presence, ensuring Mica always has someone to rely on for practical assistance or advice. Mica's current support team consists of three central people who help her manage her daily routines, finances and employment responsibilities. They continue to develop her independent living skills and assist with breaking tasks into manageable steps, ensuring Mica remains organised and confident. A trust manager oversees the broader coordination of her support network, while volunteers provide additional social and practical assistance. Mica's involvement with a local spiritual centre adds another dimension to her support system. The centre is a significant source of social and emotional connection, where Mica enjoys the company of friends she has known since childhood. These relationships contribute to her sense of belonging and emotional well-being.

Experience of school and preparation to enter the workforce

Mica's schooling combined mainstream education with tailored support to address her intellectual disability. During her primary years, she received focused help with reading and writing from dedicated teachers, fostering her confidence and enthusiasm for learning. Her high school experience blended mainstream classes with a specialised learning support centre, overseen by a coordinator who ensured her needs were met across all aspects of her education. Additional literacy programs provided further support, helping to address specific gaps and equip her with foundational skills.

While her school experience laid some groundwork, post-secondary training programs further contributed to Mica’s transition to the workforce. These gave her essential life and workplace skills and provided work placements and volunteering opportunities. Despite such preparations, no paid work was forthcoming. It took some years and good luck – meeting a well-connected individual at an event – that eventually led to a permanent paid position.

Experience of working life

Mica works part-time in a communications role for an NGO, a position that aligns with her people-focused nature and desire to make a difference. She commutes to work and to her various activities using public transport. Mica benefits from workplace accommodations, such as clearly defined tasks, consistent routines, and hands-on demonstrations. Her support team ensures she remains organised and confident in her work.

Mica’s work history demonstrates her adaptability and growth. Her previous jobs include childcare, customer service, and cleaning and reception duties. Mica values the independence that comes with earning her own income and enjoys the social interaction her job provides. She takes pride in her role. The sense of purpose she gains from contributing to an organisation that aligns with her values adds to her fulfilment. For Mica, work is not just about tasks but also about building connections and feeling competent and valued.

While Mica finds much to enjoy in her work, she faces challenges common to individuals with intellectual disabilities. Tasks that require complex processing can be overwhelming unless broken into smaller, more manageable steps. Changes to her routine can be difficult for her to navigate, and she relies on her support team to help her adapt to unexpected developments. Ensuring that her workplace remains inclusive and responsive to her needs is crucial to her continued success. Mica is content in her current role but remains open to new opportunities that align with her strengths and interests.

Mica continues to volunteer, thereby making a social contribution, being part of a team and growing her confidence. Through volunteering in a public-facing role, Mica demonstrated impressive practical skills and initiative that led to having sole responsibility for particular jobs.

Challenges – what has made things difficult

Mica faces several interconnected challenges that affect her daily life, work, and long-term aspirations. Systemic barriers, such as limited inclusive employment opportunities and societal stigma toward individuals with intellectual disabilities, restrict her access to diverse roles and full workplace inclusion. While her part-time job provides stability, reliance on disability funding and limited opportunities for increased hours or promotion are potential vulnerabilities. Mica still has to manage money very carefully with the help of her support team to get by; there is no buffer for costly and unexpected expenses.

On top of Bell's palsy, Mica faces other health challenges, such as thyroid issues, iron deficiencies, and complications from past foot operations, including infections. These conditions require ongoing monitoring and emphasise the importance of consistent and reliable accommodations.

Looking to the future and what makes life meaningful

In addition to having secure and rewarding work, Mica leads a rich and fulfilling life centred on her interests and community connections. She enjoys baking, dancing, and singing, as well as participating in Special Olympics sports and swimming. Mica draws strength from her family, friendships, and involvement with her spiritual centre, all of which provide her with emotional support and a sense of belonging.

Expanded work hours and income in a reliable job will be crucial for Mica's future financial security.

Mica has no current experience of material hardship

Growing up, Mica's family experienced significant deprivation, which Mica has avoided through a combination of her mother's efforts and state funding.

Grace – Growing confidence and aspirations

Now in her early 20s, Grace is like many young women her age – she enjoys basketball, listening to music and going on group outings. Grace is also embracing a period of growth and newfound independence. Diagnosed with Foetal Alcohol Syndrome Disorder (FASD) and a traumatic brain injury in early childhood, she faces lifelong challenges in cognitive development, social understanding, and safety awareness. Yet, recent experiences have brought her a sense of belonging, purpose, and optimism for the future.

Life skills and social engagement

Grace's days are filled with meaningful activities that foster her personal development and social connections. She attends a vocational support programme twice a week, where she participates in fitness sessions, first aid training, and life-skills workshops. The programme has been instrumental in helping Grace build confidence and cultivate friendships. These relationships have had a transformative impact on her, replacing years of isolation with feelings of inclusion and acceptance.

Volunteering at a local charity shop once a week adds further structure and fulfilment to Grace's life. Her tasks include sorting and pricing items, tidying the store, and assisting customers. Grace takes pride in her work and enjoys the support and camaraderie of her colleagues, who encourage her growth. This experience gives her a sense of accomplishment and strengthens her aspirations for future voluntary work or paid employment.

Living and financial circumstances

Grace lives in a safe, comfortable home with her parents and three younger siblings. She has her own bedroom, a private space that allows her to unwind and feel secure. Her parents, Louise and Reece, manage finances on her behalf (having power of attorney), ensuring she can access to everything she needs without experiencing material hardship. Grace enjoys the normal variety of food and suitable clothing and subsidised safe transport to the activities she values. This stability is crucial in enabling her to focus on her personal growth and participation in community programs and opportunities.

Family and community support

While sibling relationships have had their challenges, Grace's growing closeness with her youngest sister, Chloé, has been a source of joy and stability. Chloé often joins Grace in activities like basketball at a nearby school, where Grace feels safe, supported and encouraged by one or both sisters. Grace also enjoys the company of an empathetic cousin her age.

Informal support, such as neighbours employed through Individualized Funding (IF), has also played a critical role in Grace's care. This network enables her to engage in activities independently while ensuring her safety. Additionally, regular church attendance provides a social and spiritual outlet. Louise's advocacy and active facilitation have been pivotal in securing these supports and ensuring Grace can access environments where she can thrive.

Challenges and aspirations for the future

Grace's progress reflects the principles of Enabling Good Lives, emphasising her right to meaningful participation, tailored support, and social inclusion. However, her journey is not without challenges. Her trusting nature makes her vulnerable to exploitation, requiring careful supervision in work and social settings. While she is on a waitlist for supported living accommodations, the timeline and details of this next step remain uncertain.

Looking ahead, Grace dreams of finding permanent, paid work in an environment that values her abilities and provides ongoing support. She aspires to continue building her independence through living arrangements that offer safety, a degree of autonomy, and further opportunities to contribute meaningfully to her community. For Grace, a thriving future depends on the continued alignment of responsive support systems, inclusive programs, and her family's unwavering advocacy.

Grace has not experienced material hardship

Robert: Enjoying a rich life with good support

Robert and his family

Robert is an independent, single man in his mid-fifties who lives in a large city. He lives alone in stable rental accommodation and has continuously worked since leaving school. His early years were marked by the profound loss of his parents in a tragic accident when Robert was in his early teens. His older sisters stepped into caregiver roles, and he lived with one of them for some years before moving into a flat of his own. His sisters gave him stability and all the necessities during his formative years.

Though these family relationships remain significant, physical distance and life circumstances mean contact with his siblings is less frequent. Robert values their occasional financial support, which helps him participate in family events and activities.

School years and major change

At the end of primary school, the headmaster recommended that Robert transition to a special class at a local high school – he has Down Syndrome. Initially, his parents were uncertain about this suggestion, but they ultimately agreed, and it turned out to be a pivotal decision for Robert's development. The special class provided him with tailored learning experiences and confidence-building opportunities. The school also introduced Robert to structured responsibilities, including managing small tasks like answering phones and playground monitoring, which laid the groundwork for his future work ethic.

Employment, interests, and community participation

Robert has a driver's license and a car, which he uses to get around the city in conjunction with public transport.

Robert's work history spans forty years and reflects his adaptability and commitment. Most of this time involved cleaning for a local church. He secured this permanent part-time role by responding to a notice board ad. The job offered variety, routine and a supportive work environment. Other roles included supermarket work, waste collection and driving for a family-run business. These roles often featured accommodations that respected his unique needs, allowing him to thrive. For example, the supermarket manager was particularly invested in Robert's capability and job satisfaction.

Robert recently established a garden maintenance business, leveraging skills and knowledge gained from an IHC Landskills programme. Running his business gives him independence and pride in his achievements, though the physical demands sometimes challenge his health, mainly due to recurring back pain from past injuries.

Current living and financial circumstances, health, and social support

Robert actively participates in the local IHC branch committee and has long volunteered for a community group. He also supports church events, showcasing his commitment to community service.

Robert lives independently in a rental property he found on Trade Me. He receives a Supported Living Payment (SLP) to help cover his expenses. Tom, a long-standing support worker, visits twice weekly to assist with practical tasks like cooking and administrative errands, including dealing with the IRD. Robert loves Tom; he appreciates Tom's laid-back manner, friendship and practical support, which helps Robert maintain his independence.

Financial challenges are an ongoing worry for Robert. Rising living costs, particularly for essentials like petrol and food, strain his limited income. These constraints have occasionally prevented him from fully participating in family activities involving travelling to other centres, deepening feelings of isolation. Despite these limitations, Robert's essential daily needs are met, and sometimes, his sisters fund his travel. Health issues, particularly back pain, also impact Robert's capacity to work, but he remains optimistic about improving his physical condition through tailored support.

Despite these challenges, Robert has a strong sense of community and connection. He volunteers for local organisations and uses his computer skills to network, maintain social connections, and promote his business. Social media platforms allow him to engage with clients and community members, expanding his reach and fostering meaningful interactions.

Robert also enjoys watching movies and has an extensive DVD collection. He follows sports, particularly watching soccer and rugby when they are on. Though he does not play, attending or watching games provides him with entertainment and a sense of connection to broader community events. Robert has regular contact with friends through following sports and his church and volunteering activities.

Looking to the future

Looking ahead, Robert aspires to expand his business and envisions a future where he can employ others to help manage the workload. He sees growth opportunities but acknowledges the need for additional financial resources and tools to achieve his goals. Robert looks forward to interacting with his growing group of clients. He also hopes to deepen family connections through frequent visits and opportunities to participate in shared activities.

Robert has few unmet needs but could use additional help managing his pain and business development resources to consolidate his new livelihood. This assistance would contribute to his ongoing independence and lively community engagement.

Robert has not experienced material hardship

Ajay: Cared for but waiting for more to do and look forward to

Ajay and his family

Ajay, a man in his late sixties of Indian descent, lives with cerebral palsy and an intellectual disability compounded by a brain injury he sustained early in life. He lives in supervised residential accommodation with four other housemates. As his condition affects his mobility and communication, Ajay often uses a walking frame to navigate his environment.

He grew up in a family of four siblings in a large city. His parents, immigrants with limited English, worked hard to provide for their children, with his mother taking on the primary caregiving role for Ajay. The family faced significant challenges, including stigma within the Indian community toward disabilities, which added to Ajay's mother's stress and likely contributed to her mental health struggles. Despite these difficulties, Ajay's parents emphasised his inclusion in family life and community activities, and he was well provided with life's essentials.

When his parents passed away in the 1980s, Ajay was in his 20s, and his brother Karun and sister-in-law, Dakshata assumed his care. For many years, Ajay lived in their household with their children and extended family. Dakshata was actively involved in Ajay's daily care, ensuring he was well-supported and included in family life, a consistent duty of care that she and Karun have maintained to the present day.

This arrangement provided Ajay with a supportive environment where he thrived in the company of loved ones. The family worked to maintain his social engagement, encouraging independence while balancing his care needs. This period underscores the strength of family bonds and the enduring commitment to providing Ajay with stability and opportunities.

However, this living situation had to change when Ajay's mobility became increasingly limited, intensifying his care needs.

School years and transition to work

Ajay's formal education occurred at a special IHC-run school that focused on developing life skills and routines rather than academic achievement. This environment prepared Ajay for the next phase of his life by fostering social engagement and introducing structured activities. Ajay transitioned seamlessly into work at an IHC sheltered workshop, which became a cornerstone of his adult life. The workshops provided him with routine, meaningful tasks like packing and assembly and opportunities for social interaction with diverse peers and staff.

These early work experiences were pivotal in giving Ajay a sense of purpose and community. Ajay engaged in a variety of tasks and social environments through the workshops' partnerships with businesses, which kept him engaged and motivated. In these early times, Ajay was semi-independent – he could use public transport and make himself well enough understood. He needed consistent and adaptable, not constant care. His family supported his involvement by coordinating transportation, or the IHC provided this as Ajay lost mobility, ensuring he had access to these opportunities.

Employment, living situation, and interests – early to middle years

Ajay's entire working life occurred within an IHC sheltered workshop context – spanning about twenty years – performing tasks that matched his abilities. His responsibilities included putting letters in envelopes, wrapping confectionery and assisting with general and routine office tasks. He received a nominal wage supplemented by government benefits.

Ajay also received significant support to sustain his employment in the workshop, including adaptive task assignments and close supervision. Family members and caregivers helped him understand instructions and manage tasks, ensuring he could perform his duties to the best of his ability.

During this period, Ajay's living situation shifted. His growing mobility challenges prompted his move to a supervised IHC group home (later run by IHC's Idea Services) and paid for Ajay's Individualised Funding. While this transition was difficult, it provided him with the specialised support required to meet his changing needs.

Following the closure of the workshops in the mid-2000s, Ajay became permanently unemployed. Efforts to identify similar opportunities were hindered by limited support service resources and a lack of alternative placements. Caregivers have explored volunteer and community-based roles, but inconsistent support and funding constraints have prevented long-term solutions. Instead, Ajay participated in day programs with a focus on art-based activities. He found fulfilment in creating and occasionally selling his artwork, which provided a sense of accomplishment and recognition. However, recent changes at the day base, including staffing adjustments, have reduced opportunities for him to participate in art, leading to a decline in his interest and the feasibility of this activity.

Current living and financial circumstances, health, and social support

Ajay has lived in IHC group homes for over 30 years, with familiar housemates and caregivers moving with him between residences, providing comfort and continuity. His basic needs are met. Individualised Funding covers accommodation, personal care, and medical support. Additional financial support from a trust fund established by his late father, managed by Karun and a lawyer, allows Ajay to enjoy discretionary activities like annual holidays in New Zealand and occasionally abroad, which are highlights of his year.

Although Ajay's mobility has declined, requiring him to use a wheelchair for longer distances, he still participates in structured activities like weekly bowling outings, which provide physical activity, social connection, and enjoyment. Periodic trips to the local IHC Day Base give Ajay the highly anticipated chance to spend time with his special friend Priti, as they don't see each other outside of that setting. Ajay thrives on routine and finds satisfaction in helping with small household tasks. However, he is increasingly reluctant to go on outings without his housemates, preferring familiar social settings.

Ajay remains closely connected to his family, who play a vital role in his sense of belonging. Karun and Dakshata visit regularly, facilitating Ajay's involvement in cultural and family events such as Diwali, weddings, and dinners, ensuring his comfort and inclusion. These gatherings bring Ajay joy and maintain his familial bonds. His sister, Amita, also maintains occasional contact, while Karun's and Amita's children and extended family include him in multigenerational events, enriching his sense of community.

Caregivers at Ajay's group home provide essential daily support, including personal care and coordination of social outings. However, staffing and resource limitations restrict the frequency and scope of these activities, particularly group-based ones. Combined support from family and caregivers ensures Ajay stays socially engaged despite these challenges.

Looking to the future - aspirations and challenges

While Ajay's material needs and family connections are well-supported, his greatest aspiration is access to activities that bring routine, purpose, and enjoyment to his daily life, reminiscent of his experiences at the sheltered workshop. Ajay often expresses quiet frustration about “waiting” for opportunities. This is particularly salient, as Karun notes, as Ajay cannot concentrate on TV or puzzles and cannot read and write. Addressing this would significantly enhance his well-being and sense of fulfilment.

Ajay has not experienced material hardship

Chris: Waiting for a job or more occupying things to do

Chris and his family

Chris, now in his mid-50s, lives in a large city in a supervised group residence run by IHC Idea Services. Friendly and sociable, Chris thrives in environments where structure and routine allow him to participate meaningfully. His deep interest in fairness, work, and community reflects an outlook shaped by his family and his experiences of society.

Chris moved to New Zealand with his parents, Erin and Peter, when he was of primary school age. His intellectual disability and epilepsy have always required tailored support, which Erin ensured through her tireless advocacy. Chris grew up alongside two younger sisters who remain close despite living in different regions. The family's strong bonds and proactive planning have provided Chris with stability and opportunities throughout his life.

Experience of school and work

Chris's school years were pivotal in fostering his development. Through his parents' persistent advocacy, he participated in integrated special education classes, which provided a stable environment for learning and social engagement. Access to therapies, including speech, occupational, and physiotherapy, enhanced his communication skills, motor skills, and overall confidence. Erin's efforts ensured that Chris, alongside a small peer group, received consistent support across primary, intermediate, and high school, forming lifelong friendships and achieving key developmental milestones.

Upon finishing school, Chris entered supported employment programs designed for individuals with intellectual disabilities. These programs introduced him to structured work environments, and with the guidance of job coaches, Chris gained valuable experience.

Chris's work history has been characterised by part-time and intermittent jobs, often in task-oriented or manual work that aligns with his strengths. Over the years, he has had various positions that involve arranging retail stock, assisting at a community centre, and undertaking small-scale production tasks. These very part-time, short-term or irregular jobs reflect systemic problems providing sustaining supported employment opportunities. The gaps between roles have been frustrating for Chris, as he thrives on routine and the sense of accomplishment that comes with being part of a team effort and completing tasks.

Over decades, Chris's mother has been instrumental in setting up job opportunities and coordinating with Idea Services to follow through. Such work placements have required the presence of a support worker to help Chris navigate tasks, manage social interactions – Chris can become frustrated easily – and maintain focus. These support workers are critical in enabling Chris to succeed in the workplace by providing guidance and facilitating communication with employers and coworkers.

Current living, financial, and social circumstances

Chris's current living arrangement in a supervised IHC residence provides essential support, including assistance with daily routines and emotional well-being. His primary income is Individualised Funding, which covers housing costs, utilities, and basic needs. With the help of caregivers and family, Chris manages a small discretionary budget, using it for social outings and personal items. Financial contributions from his parents supplement this budget, ensuring he does not experience material hardship or lack social opportunities.

For Chris, a good life revolves around routine, social connections, and engaging activities that bring him joy and a sense of inclusion. For a short period, many years ago, Chris attended a nearby IHC Day Base that offered opportunities for arts and crafts, recreation, and socialising. However, Chris was made unwelcome there – he was not allowed to join in with other visitors when he attended and was ultimately excluded because of his behaviour. Chris gets frustrated and angry when others do things that don't make sense to him.

On the other hand, Chris values the camaraderie of his housemates – they understand each other – and he looks forward to outings with them. He has a long-standing supportive relationship with several support workers who have known him for decades.

While a support worker must accompany Chris most of the time, he enjoys taking short walks around the neighbourhood and to his parent's place. These walks give him a sense of independence and allow him to explore his surroundings. Chris' weekly visits to his family home additionally provide a sense of belonging and continuity.

Social outings to cafes allow Chris to relax, enjoy good food, and interact with others. Organised group activities – including those involving residents from other IHC Idea Services homes – foster social connection and variety in his life. He has found fulfilment in creative pursuits like painting, although the residence is not set up for it. Chris loves cooking cakes, walking, taking the bus, listening to music and dancing.

Looking to the future: aspirations and challenges

Chris wants consistent and occupying employment, with clear structure and a team-oriented environment where he can contribute, feel valued and get paid. This would give him more meaningful, structured daily routines. His dream job is working in a chocolate factory, a setting he believes would combine structured tasks with his interest in hands-on work and his enjoyment of good food. However, systemic barriers – such as the lack of supported employment coordinators, reduced funding for job placements, the loss of a volunteer coordinator and his supervision requirements – have made it difficult for him to feel fulfilled.

Chris has not experienced material hardship

Chris' parents have made provisions for his long-term financial needs and care.

Emma: A full life of work, creative pursuits, friends and family

With a flair for performance and a dramatic stage name, Emma has been active in dance and theatre for several decades. Due to her Down syndrome, Emma struggled with developing both her communication and fine motor skills. To aid their daughter's progress, David and Claire established routines and systems to enhance her development, providing access to therapies, increasingly responsive schooling, and avenues for creative expression. Emma's creative pursuits are core components of her weekly routine, contributing significantly to her sense of identity and self-worth. These activities maintain her social engagement, personal development, and self-advocacy in the case of her theatre group.

Work and creative routines

Another core aspect of Emma's identity comes from her role in a school library, where she has had a four-day-per-week job for most of her working life. Having once been a student at the same school, her long-standing dedication to her job maintains a profound sense of connection to the place and its community. Her work has two aspects – teaching assistant, which entails supporting teachers with organisation and daily tasks, and library assistant, which sees her maintain the library's operations. She loves her job. Emma finds great satisfaction in helping students return their books and assisting with a programme that teaches children how to grow and cook their own food. The library provides a supportive environment, and the wider school offers a community she belongs to. Her job also provides her with routine and structure, which underpin her happiness at work. She works at the library Monday through Thursday, leaving Friday for theatre, Saturday for dance, leaving Sunday as her day off.

Social life

Emma maintains a vibrant and active social life. She is surrounded by a strong network of supportive colleagues, family members, and friends she has made through her work and creative pursuits. Emma has built close bonds with colleagues who provide professional support and emotional encouragement at her workplace, making her feel valued and socially connected. Emma's dance group and theatre company expand her social circles, allowing her to meet new people and maintain long-standing meaningful relationships. Some are friends from childhood. Emma thrives in these environments, where her participation maintains her confidence and self-determination. She also benefits from personal assistants (PAs) carefully selected by her parents to foster a peer-like relationship with her. A PA plays a dual role, providing practical help with her daily and creative activities while also acting as a companion that encourages and enables Emma's independence, for example, going shopping or travelling to meet up with friends.

Family and home

Family plays an essential and active role in Emma's life, providing emotional and practical support. Her mother and brother-in-law are instrumental in ensuring Emma can maintain her work and creative commitments by assisting with transportation to and from the school where she works. Emma takes great pride in her family members, particularly her siblings, in leadership roles within education. This reflects a family culture that values education and social contribution.

At home, Emma lives in a comfortable, family-oriented environment that provides stability and a sense of belonging. On Sundays, Emma spends time at home relaxing, sleeping in, and enjoying her family's company, including her young niece and nephew. These close relationships substantially result from the home environment Emma's parents designed to support intergenerational living. Two houses are accessible by one driveway, with Emma and her parents in one and her sister and her family in the other. The configuration provides her with future security: when her parents eventually age out of their caregiver roles, Emma's sister and brother-in-law will be able to take over.

Emma has not experienced material hardship

Emma's parents have diligently planned and made provisions for her long-term financial needs and care.