

The empty nest is refilled

The joys and tribulations of raising grandchildren in Aotearoa

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Report written by Liz Gordon PhD, LLB, MRSNZ with the participation of members of the Grandparents Raising Grandchildren NZ Trust







The empty nest is refilled: The joys and tribulations of raising grandchildren in Aotearoa is the initial report of a study of grandparent and kin families in New Zealand.

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Liz Gordon September 2016

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Summary of findings

This report outlines the first cut of findings from a very large study into grandparents raising grandchildren in New Zealand.

The first section outlines results from questions that were included in the 2013 census. It counted 9543 families raising grandchildren, and published a significant amount of information about their ages, family formation, incomes and a range of other factors. Some unexpected findings were the income differentials between single grandparents carers and those with partners. The median income for the former group was around \$20,000 per annum, compared with around \$70,000 for couples. The implications of this for resources for the different family groups needs further analysis.

Around 1100 grandparents (12% of the population) commenced the survey in 2016, although only around three-quarters completed the 'marathon' quantitative and qualitative study. They were similar in age and family formation to the census data, but Māori were underrepresented (36%, compared to 43% of the overall population). The age distribution was from under 35 to over 85 years. There were 44 great grandparent families included in the study.

A literature review outlined the findings of international and New Zealand research into grandparents raising their grandchildren. Similar themes emerged from each context, including: the difficult and often catastrophic situations under which grandchildren come into grandparents' care; conflicts arising from these within the family and torn loyalties; falling incomes from reduced employment or other causes; housing issues; stress; and the needs of children who may come into care with a wide range of issues and disabilities.

Around half of participants in the study are in paid work, and a further 16% receive superannuation. The average income from employment was around \$40,000, although the range was from under \$10,000 to over \$100,000 per annum. Changes to employment include 141 people working fewer hours and 21 increasing hours or taking on extra jobs. Some had left employment on taking on the caring role then returned to work later.

Families often had other family members, or boarders or a range of other people living with them. Over half of all families in the study currently look after one grandchild, but others have from two to fifteen such children in their care. Our estimate is that on average a grandparent whanau will have 1.8 grandchildren living with them, making a total of around 17,000 such children in New Zealand (based on 2013 census figures).

Most participants note they struggle sometimes with the role, although some struggle daily while others are managing very well. Many note they love having the children and watching them grow. Many also comment that "this is not where I saw myself" at that particular point in life, and they had periods struggling with the role. Others comment on the parenting issues that arise from having troubled and disabled children in their care. Another group commented on the hard work that was entailed in looking after their

grandchildren. Finally, many participants noted that the role is stressful, tiring and financially and personally difficult.

Around one third of carers have no health problems, and the majority of the rest have minor problems. Problems include high blood pressure, heart disease, diabetes, joint pain and dysfunction (including hip and knee replacements) and depression and anxiety. A small number have multiple health problems or terminal diseases that make it difficult for them to bring up their grandchildren. Most reported their health has been unaffected, or has got a little worse, as a result of taking on care of children. Most lead a relatively healthy lifestyle, although 61% report having trouble sleeping. Around a third show moderate or severe mental distress on the Kessler 6 scale of mental wellbeing, which compares with 4.8 percent in the age-comparable population.

Income comes from the Unsupported Child Benefit, wages/salaries, National Superannuation and an adult benefit (in that order). Some receive tax credits and others have sources of income such as boarders, pensions and other income. Median family income after tax was around \$40-\$50,000. More than half report that their income has gone down some or a lot over the past five years. A variety of reasons are given for income changes.

The Unsupported Child Benefit (UCB) was by far the most common income received for the children, and 637 families received this for one or more children. Those receiving the UCB can also claim for a variety of child-related costs. Many turn to their local communities for help, including foodbanks and community grants, but families also use their retirement savings or borrow money to meet the children's costs. Over half have a Kiwisaver account, but half of these have less than \$10,000 in it. Some note other savings towards retirement while a quarter have no savings at all.

For those with inadequate housing to meet the needs of the children, housing was a particular problem. For those owning their own homes, the need to add on rooms, move or meet additional costs meant high costs. For those in rental accommodation, getting a house of adequate size and quality proved difficult. Some grandparents ended up sleeping on a couch in the lounge as there was inadequate space, and other forms of household crowding were evident. In total 178 families noted they needed a larger house. Others (121) stated they have significant problems with their current house: cold, damp, under-heated, needs decorating, inability to maintain property and many other problems. Another group of 110 noted their housing was unaffordable for them. Yet another group moved away from where they were living due to stress, safety concerns, a better situation for the children, climate and other factors. A small number had a statutory land charge placed on their property to secure eventual repayment of legal aid costs.

Grandparents are very grateful for the support they get though Work and Income. While some find the process painless, there were very widespread complaints about the processes within the agency. These included issues of interaction and of professionalism. There were also widespread difficulties reported in the processes to get the Unsupported Child Benefit. Once the UCB is provided, financial difficulties ease somewhat for most families, however, some people were unable to access the UCB for long periods.

Most grandparents are safe in their own homes, but 118 (14%) have been assaulted physically by grandchildren in their care. Far more (64%) have been verbally assaulted by the children's families. Most felt safe in their homes and many have a safety plan.

Grandparents sought help from many places for their and their children's medical and other needs. The local GP was the main source of health support. Some received counselling but many reported it was unavailable for them or too expensive. A number had to pay for special services for the children. Most spent little money on health costs, but some spent over a thousand dollars in 2015.

There is widespread criticism of the role of Child, Youth and Family (CYF). Most families have involvement with the agency in one or a number of ways. The main criticism is that support for the family is withdrawn when the immediate crisis is resolved, leaving grandparents with often very damaged children to look after and no support. A range of concerns are outlined by participants. Grandparents do receive support from family members, friends or community groups.

The participants in this study are raising 1763 children but answered questions for only 1324 of them. Most of the children are between 6 and 14 years of age. The caregivers are grandparents, great grandparents and other whanau. Many come to the grandparents from birth, although they may arrive at any age. The six main reasons cited for grandchildren coming to live with their grandparents are: drug addiction (579 or 43%); domestic violence (534 or 40%); family breakdown (527 or 39.8%); neglect (527 or 39.8%); parent unable to cope (507 or 38%) and alcohol abuse (336 or 25%). Many had multiple reasons. Other reasons included death of a parent, parent in prison, child abuse and health/ mental health issues.

CYF was involved with the children in many ways and, for most of the children, legal guardianship was sought through the family court.

Access by parents was sometimes regular and beneficial, but most often was relatively random and either neutral or harmful to the child. Most encouraged access but many are also very careful about not exposing the children to parental lifestyles.

The children are generally well but more than half have regular physical, emotional and behavioural problems. For around 15% of these the health issues occur most or all of the time. Mental health is better, although 71 children have significant mental ill-health. Common health problems include anxiety, a lack of confidence, skin problems, asthma, hyperactivity and difficulty sleeping. They tended to have multiple problems.

The participants gave schools a mostly positive rating, and many of the children were doing well. However, practices such as reduced hours for children with significant behavioural problems made it difficult for students to learn. Some had been suspended or excluded from school, some were being home-schooled and some were receiving external tutoring.

The study concludes by reiterating that this is a first cut report and that a number of further studies would further analyse the data.

About this study

The Grandparents Raising Grandchildren Trust New Zealand (GRG) was founded by Diane Vivian in 1999 and registered as a charitable trust in 2001. It is a charity that works to support carers across the country. The organisation has a deep understanding of the situation of these grandparent families, and is in a position to offer significant advice and support. On the website¹ it notes:

The grandparents take on the care of their grandchildren because they believe it is best for them to be brought up within the family. But they do this while enduring huge personal sacrifice, stress and ongoing challenges - financially, physically and emotionally. Many of the children have special needs and suffer from psychological damage. The grandparents who take on these traumatised children need considerable help and support.

Research has been an important part of the organisation's development. Two prior studies of members have been undertaken by Jill Worrall of Massey University, which considered many of the matters raised in this study (Worrall, 2005, 2009). The aim of research within the community sector is to examine and challenge the aims and assumptions underlying practice, identify themes for advocacy and service improvement and to improve practice. In the very diverse area of grandparents raising grandchildren, there is also the opportunity to consider the range of needs and experiences of the sector.

In 2015, GRG applied to the Lotteries Community Sector research fund for a grant to undertake a large-scale study of grandparents raising grandchildren in Aotearoa/ New Zealand. The study was to include both members of GRG and also other grandparents. While GRG had around 3500 families on its books, we knew from the 2013 census that there were around 9500 grandparent-led families across the country, and the aim was to reach as many as possible.

While the prior studies considered many themes that are also included in the current report, the new study has offered unparalleled opportunities to allow the participants to speak in their own words about the circumstances and experiences.

The purpose of this report is to inform policy and practice. The context is the upcoming abolition of Child, Youth and Family, which features significantly in this report, and the new Oranga Tamariki, a stand-alone Ministry. Also, the further context is the challenge to move towards a social investment approach, so that disadvantage experienced now can be overcome before it leads to disadvantage in the next generation. The concept of generational investment is very relevant to GRG, and the findings here will assist in identifying areas where additional support may impact on long term change.

The amount of data collected for this study is astounding. Participants threw their heart and souls into telling their stories. As an example, when participants were asked to describe in

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¹ http://www.grg.org.nz/Who+we+are.html

their own words how their grandchildren came into their care, between them they wrote 23,000 words of passion, despair and love.

This report, then, is a starting point – we have called it the 'first cut' report. It omits any stories about the Family Court experiences of the families, because these have been researched separately and a further report will be forthcoming. Reports and papers will cover at least the following topics:

- 1. Nga tamariki me nga tupuna. A report on the 36% of participants who are Māori.
- 2. The role of parental alcohol abuse in children coming into grandparent care.
- 3. A study of the 44 great grandparent families
- 4. The reasons for the children coming into grandparent care (qualitative study)
- 5. The health and wellbeing of the children
- 6. The role of income and housing in managing the taking on of grandchildren by grandparent families
- 7. Sole versus partnered families issues in bringing up grandchildren
- 8. The 'P' epidemic: family break-up, ongoing conflict and sick children

What follows then is the first instalment in a complex and fascinating account of grandparents who take on and bring up their grandchildren in Aotearoa today.

Previous research

In 2012, Jan Backhouse and Ann Graham carried out a study of grandparents raising grandchildren. They noted that New Zealand had, in the 2001 Census, reported 4000 children living with grandparents, compared with 10,000 in Australia. Since then, they reported, numbers appeared to have grown significantly, reflecting what they call a "new family type, the grandparent-headed family, largely attributed to changing social conditions over the past 25 years" (2012, p 306). They listed the factors in grandparents' care as follows:

The key issues underlying this worldwide shift in primary care arrangements are predominantly related to parental drug and alcohol abuse, incarceration, mental health problems, HIV/AIDS, child abuse and neglect, as well as the trend by welfare authorities towards placing children at risk into kinship care rather than foster care 2012, p. 307)

Other studies (Copen, 2006; Dolbin-McNab 2006) note large increases across the United States, with 2.5 million families and 4.5 million children affected (estimate in 2014 is 5.8 million children, Kresak et al p. 3). Increases are also noted in the British context (Glaser et al p. 2):

England and Wales, like the U.S., has experienced an increase in the prevalence of skipped-generation households – households consisting of grandparents and grandchildren but without the parents. This rose from 0.25% of adults aged 35 and over living in such households in 1981 to 0.42% in 2001. These households are likely to experience poverty and disadvantage. No other European country studied so far follows this pattern.

Williams (2011) also notes the increase in the number of grandparent led families, and discusses the reasons for this, which mirror other sources discussed here, with one difference: the authors discuss the role of grandparent carers associated with the deployment of troops to fight the 'war on terror'. This article focuses on policies and practices that do, or do not, support grandparent families. It notes that a range of support options are needed to ensure the families function effectively.

Smith and Beltran (2000 p. 9) note some of the factors that have caused the increase in grandparent carers:

Changes in family life, related social trends, and child welfare policies appear to account for some of the increase in grandparents raising grandchildren. Social forces that appear to have contributed to the incidence of grandparents caring for grandchildren include teen pregnancy, divorce, poverty, unemployment, the substance abuse epidemic with its ancillary HIV/AIDS epidemic, and the attendant orphaning of children due to parental incapacity and death. Coinciding with the substance abuse epidemic are high rates of incarceration, especially of women, related to harsher drug laws and mandatory sentencing. Incarceration rates of women increased six fold over the last decade (U.S. Department of Justice, 1997). The

U.S. Department of Justice (1994) found that when women were incarcerated, 50.6% of the children lived with grandparents while only 20.3% lived with their fathers or other relatives.

In calling for more policies and programmes for these families, Smith and Beltran (2000 p. 16) note:

Hubert Humphrey once suggested that a nation can be judged by how it cares for the very young and the very old. As the population ages during the next century and as the nation adjusts to a changing conception of the role of the old, considerable need and opportunity will emerge for advancing intergenerational approaches to programs and policies. Our response will be a testament of our national strength.

Bundy-Fazioli et al (2013 p. 447) observe that the nature of the transaction means that these children often come into grandparent care urgently and with little prior notice. Their study, using focus groups and interviews with 15 participants, found that the "abrupt change" caused a range of difficulties for the grandparents, including significant emotional distress. Difficulties came from concerns around the child's wellbeing, financial circumstances, housing issues and difficult family relationships.

Fitzpatrick and Reeve (2003) enrolled 499 grandparents into their large research study. Themes of coming into care, financial issues and lack of community support were highlighted, as well as issues about the justice system. The authors note:

Grandparents take on responsibility for their grandchildren with love, courage and determination that the children should have the best opportunities for healthy and happy lives. The Grandparents Raising Grandchildren Study has shown a failure of community support systems in regard to grandparents raising grandchildren. This failure has profound impacts on the lives of both grandparents and grandchildren – in the present and for the future (2003 p. 57).

Backhouse and Graham (2012) carried out qualitative interviews with 34 grandparents in Australia. They noted that the grandparents were often angry at being marginalised by the state, even though they were saving the system large amounts of money. While loving looking after their grandchildren, they felt under-valued and under-supported. The authors note:

This was particularly, and most frequently, evidenced by grandparents' comments in relation to 'saving the government money' by raising their grandchildren, yet not receiving adequate financial and social support to do this job. Grandparents believed they had always paid their taxes, but felt frustrated when they needed help, yet 'the government doesn't want to know you' and 'anything a grandparent wants they have to fight for it'. Many of the grandparents' narratives made reference to a belief that foster carers were 'appreciated' for the job they do; however, grandparent caregivers were 'expected' to do the same job without any recognition (Backhouse and Graham, 2012 pp. 312-313)

Grandparents as parents

Kropf and Kolomer (2004) note that the population of grandparents raising grandchildren is a "diverse" one. The diversity is of ethnicity, gender (with many women but also some men as primary caregivers) and age:

Therefore, a grandparent can be a thirty-five or ninety-year-old person. In addition, custodial grandparents may actually be the children's great-grandparent, as often these two roles are aggregated within the research (2004 p. 70).

The population is also geographically diverse, although other studies have demonstrated a tendency to cluster into poorer areas. Another area of diversity or difference is the needs of the children, with many having significant health problems or disabilities as they come into grandparent care:

The disability status of a grandchild is another situation that many grandparents face. Due to the high prevalence of addiction in the etiology of grandparent caregiving, it is not surprising that the children in these families may have medical conditions that are a result of prenatal alcohol or drug exposure (op cit p. 72).

The authors examine the social work implications of such diversity, noting that a variety of approaches might be examined through case study models (2004 p. 79).

Purcel et al (2014) echo the diversity theme in their recent study, noting the huge age range of grandparent families and stating that:

To date, however, there has been little recognition in the kinship care literature or in policy debate of the importance of age-related concerns for shaping grandparent carers' experiences and situations (2014 p. 468).

They suggest that this diversity requires a 'lifecourse' approach to research. This requires that, instead of researching a moment in time, there is a need to see the grandparent as carer role in the context of the "stages and trajectories" of their lives (2014 p. 469).

Another study (Sands and Goldberg-Glen, 2000) found that stresses were particularly apparent in younger grandmothers, grandchildren with psychological and physical problems and low family cohesion. They note that the findings strongly indicate the need for family services for grandparents raising grandchildren (2000 p. 104).

Various studies examined the approach to parenting taken by grandparents. Some grandparents felt they were able to repeat their successful parenting strategies from raising their own children, while others welcomed the greater wisdom and experience they had gained:

These grandmothers saw their increased wisdom as resulting from aging and believed their increased wisdom allowed them to avoid mistakes they made with

their children, parent with less trial and error, and follow their instincts (Dolbin-McNab 2006 p. 569).

Others again welcomed the opportunity to learn new approaches to parenting, in particular to compensate for poorer health and a lack of energy caused by aging. One effect of being older is a stronger commitment to the parenting role, whether or not they receive adequate financial support for it:

On the basis of the data available in this study, grandparents-as-parents are committed emotionally, financially and morally to the welfare of their grandchildren and will care for them regardless of whether or not they are financially or socially supported. This unconditional commitment to the grandparent-as-parent role means that grandparent caregivers are potentially vulnerable to ... marginalization (Backhouse and Graham 2012 p. 312).

A US study (Robinson and Wilks 2006) found that the increasing number of grandparent carers caused challenges for social systems and (in the particular case) the churches as support mechanisms. They note there is significant scope of support groups, education groups of parenting information in changing times and health support to reduce stress and anxiety.

Strom and Strom advocate grandparent education to assist them in adapting to the caregiver role. They believe that grandparents' success as parents is based on the successful completion of a range of tasks, such as:

Specifically, grandparent willingness to adopt the following goals are examined: modify aspirations to fit new conditions, cooperate with a parent who shares responsibility for childcare, monitor academic and social development of children, become familiar with family rights and social services, arrange relief from daily stress, and get to know grandchildren by spending time together. Caregivers who recognize the advantages of reaching these goals are motivated to take the steps needed to attain them (2011 p. 912).

They note that these requirements need to be taught explicitly, and grandparent families need to be supported to achieve these goals.

Vulnerable children

Many of the children coming into grandparent care are damaged by previous family "trauma, abuse or neglect" (Backhouse and Graham 2012 p. 307). Kresak et al follow others and list these vulnerabilities as "developmental, cognitive, neurological, behavioural, and/or emotional problems" (2014 p. 3), due to early life or prenatal experiences involving "drug/alcohol exposure, neglect/abuse, poor nutrition, lack of preventive medical/dental care, and inconsistent or dangerous living conditions" (2014 p. 4). These authors note that the developmental problems often lead to the children having significant disabilities, which affect health, education and social development and put particular burdens on the carers.

The disabilities noted by grandparents in this study included: ADD/ADHD, fetal alcohol syndrome, behaviour disorders, cerebral palsy and learning disabilities (Kresak et al, 2014 p. 7). This study found that grandparents of children without disabilities were likely to receive more social support than those with disabilities:

Caring for grandchildren with disabilities may be more demanding than caring for grandchildren without disabilities. Family and friends may not be able, or willing, to provide support for grandmothers raising grandchildren with disabilities, especially when the grandchildren exhibit challenging behaviours (Kresak et al p. 11).

Drug use, alcohol abuse and prison

There is emerging literature on children going into grandparent care with drug or alcohol problems. This social literature sits beside a clinical literature which documents the effects of substance abuse, which will not be reviewed here. Issues of drug and alcohol abuse are often dealt with together in the literature. Baldock (2007 p. 72) notes that the need for intervention for the children of addicted parents arises from 'chaotic' home environments, a lack of stable parental attachment and/or direct physiological damage arising from the substance abuse. A number of interventions are needed, she argues, including early intervention, counselling or family therapy, activities to enhance engagement in the community and affordable respite care.

Marx and Miller (2001) use a case study approach to understand the dynamics of families where a mother is a drug addict. These are complex relationships with high levels of conflict between generations, high levels of commitment by grandparents and often with extremely high costs:

The financial burdens have taken a toll on Laura and Mike. Retirement is a word they don't have in their vocabulary. While most of their cohorts are planning for retirement, they are deciding whether they need to sell their business and find something else to provide a more substantial income. The expenses incurred for the house for Karen and her first husband placed them about \$10,000 in the hole and the numerous attempts to help Karen get the drug abuse treatment she needed added another \$20,000. They will never recoup this money.

One study (Longoria 2010) reported on grandparents' use of alcohol and drugs and links to their emotional well-being. The study noted that while there were not strong links between the variables, the reluctance of researchers to examine this area, in terms of concerns about stigmatising the group (the so-called 'bad seed' theory), means that treatable matters are left alone, causing pain and suffering (Longoria 2010 p. 407).

Ben Raikes (2016) has examined the role of grandparents bringing up grandchildren because the children (in this case daughters) are in prison. He identified a significant lack of support for the role, and concludes with a broad recommendation:

It is clear from the literature and from our research that grandmothers caring for children of prisoners do so at considerable cost to their own quality of life and with very limited support. The care they provide is invaluable in terms of the number of children who, as a result, do not need to go into foster care or children's homes. However, there is an urgent need for agencies such as local social services departments to proactively support grandmothers in this situation, both in terms of financial and practical support, which in turn will promote a better quality of life for the grandmother, grandchild and the mother in prison (Raikes 2016 p. 9).

Economic need

Copen studied welfare reform and assistance to grandparent families in the United States. She notes (2006 p. 196) that: "Age, race, gender, social class, labour force participation, and difficult family circumstances intersect to create multiple points of disadvantage among grandparent caregivers." These points include poor housing, lack of food and access to health care. New policies for income support are criticised for providing inadequate support to grandparent families, by promoting a narrow definition of what a family is. Grandparents as parents are shut out from this, thus causing material harm to a needy population.

Another view on the economic circumstances of grandparents raising grandchildren comes from Glaser et al, who argued that there was a tension between the role of grandparents, and especially grandmothers as carers and as participants in the labour market. In particular:

Given that grandmothers aged 50 to 69 who are not in paid work are the most likely to provide childcare, the plans of European governments to extend retirement ages and increase female labour force participation at older ages are likely to conflict with grandparents' role in providing childcare. This will have significant implications for labour market participation by younger mothers, and for pension acquisition and the financial security of mid-life women.

Purcal et al (2014 p. 469) note that a "recurring theme in the kinship care literature is financial disadvantage". The disadvantage comes from a number of sources: the need to give up or scale back work, the depletion of retirement savings to meet costs of care, accessing larger housing to meet the needs of the incoming children and compensating for the health and social needs of the children and/or the caregivers.

In 2015, Chan and Lent carried out an in-depth study of the financial situation of low-income grandparent carer families in Chicago and Trenton. Many different sources of financial stress were identified, including living costs (housing, food, clothing), need to cut back on employment, costs of legal proceedings and health, education and social costs of the children (especially addressing the effects of abuse and neglect).

Many find that the need to get good paid work to meet the children's needs occurs at the time of a diminishing labour market, especially for low-skilled workers. As a result, many

note that their costs exceed their incomes, leading to instability. While there are public programmes to assist, these are limited and are associated with severe restrictions. For example:

Other caregivers indicated that they felt unable to save because doing so would risk losing eligibility for a financial assistance program on which they depend. As one grandmother in Chicago said: "when you live in subsidised housing, it's hard to have anything extra, because any extra money you [have] will cause you to be penalized". Another grandmother in Trenton said, "when we are receiving Social Security income, you are limited to, I think it's \$2,000... They see you have a little money and they think, "oh you can afford things".

The report concludes with a range of policy options to meet the needs of grandparent carers.

The wellbeing of grandparents

There have been a number of studies that Dunne and Kettler (2007) examined on the psychological health of grandparents raising grandchildren in Australia. They found that grandparents raising grandchildren scored higher on a range of scales compared with a comparison group. Factors that contributed to grandparent stress included:

... a multiplicity of factors ... such as lack of financial support, conflict with birth parents and other family members, ongoing social, emotional and behavioural issues of their grandchildren, and coming to terms with the loss of their children to drugs (2007 p. 342).

Harnett et al (2014) found that grandparents reported greater stress in their role than foster carers, and scales of psychological distress echoed this. Issues include the needs of the children, the lack of community supports, health issues, family strain and a lack of financial resources. The report concludes that there is a need for support that addresses the needs of the grandparents as carers in specific contexts – a one size fits all approach does not work (2014 p. 419).

Minkler and Fuller-Thomson reported on a US national study of the health of grandparents raising grandchildren, compared with non-custodial grandparents. The results showed that custodial parents were significantly more likely to report limitations in the following areas:

...mobility inside the house, completing daily household tasks, climbing stairs, walking 6 blocks, doing heavy tasks, and working for pay (1999 p. 1383).

The differences continued in terms of ability to do daily household tasks or moving about inside the house. The self-reported health of caregiver grandparents was also worse.

A study by Kelley et al (2001) examined the effects of a multi-modal intervention on grandparents' stress. Stress factors included physical health, social isolation, family resources and legal issues:

The six-month intervention included home visits by registered nurses, social workers, and legal assistants; legal assistance from an attorney; and monthly support group meetings. All participants received the home visits; the majority also attended support group meetings (Kelley et al p. 39).

The results showed that the intervention reduced stress, had a medium effect on social support, provided a perception of increased resources to families and improved engagement with legal services. Mental health scores improved and feelings of insecurity decreased, especially because families "gained a sense of support and encouragement in knowing that there were others in similar situations as themselves".

Previous research in New Zealand

Compared to Australia, the USA and England in particular, there has been a dearth of research into the wellbeing and needs of grandparents raising grandchildren. The two reports that there have been (Worrall, 2005, 2009) were both sponsored by the organisation Grandparents Raising Grandchildren Trust (NZ) (known as GRG or GRG Trust in this report).

The situation in New Zealand mirrors, to a great extent, that of other countries. The common themes, discussed above, include financial loss, lack of recognition of the role, conflicts (familial, social and legal), despair over the situation of children, health issues for both grandchildren and caregivers, housing need and the role of state agencies.

Worrall's work was material in bringing a number of issues to the attention of policy makers, and especially the role of the Unsupported Child Benefit. The GRG Trust has worked tirelessly to ensure that this lifeline support is available to everyone who is eligible for it. Apart from that one (tremendous) change, while progress may have been made in a small number of areas, there is still little support for these families.

Methodology

This study was commissioned by the Grandparents Raising Grandchildren Trust (NZ) and was funded through the Lotteries Community Sector Research Fund. The study has the following aims:

- 1. To provide a current overview of the social and economic conditions facing grandparents² as the carers of grandchildren;
- 2. To investigate how economic factors relating to income, access to benefit support, other forms of carer support, allowances, general and special costs and other factors impact on the lives of grandparents raising grandchildren;
- 3. To assess the current situation of families on a range of social and health indicators, including mental health, and in dealing with service agencies;
- 4. To investigate a range of other questions such as access to education, transport issues, supervised access for the children and other issues that arise; and
- 5. To use the findings of the study to improve practice, advocate effectively on behalf of the organisation and implement a process of ongoing review of progress.

Application was made to the University of Canterbury Human Ethics Committee in February 16, and granted in March. An information sheet and consent form were developed for the project and approved, and these were sent to all participants and available on the website for online participants. An 0800 number was available for any queries, and quite a few participants phoned in with queries, or asked to conduct a phone interview.

The survey was a very large instrument, developed within the Qualtrics system hosted by the University of Canterbury. The survey was in three blocks: the caregiver, the children and the family and social issues. The middle block was to be filled out for one child at a time, and then 'looped' back by a question (Do you have any more grandchildren in your care? Yes/No) so that respondents could provide responses for second and subsequent children. The survey ran to 150 questions, plus the additional blocks of around 40 questions each for those with more than one child.

Another key characteristic of the survey was the large number of qualitative responses available to participants. In all, there were around 100 fields for people to fill in responses, which is highly unusual for this kind of large survey. However, the GRG Trust was very keen to give participants the opportunity to have their say. It has made data analysis a very long job!

² In this study, the term grandparents refers to a range of grandparents, great-grandparents and kin carers, and is a shorthand term for all of these.

What is interesting, though, is the extent to which caregivers were keen, very keen or extremely keen to have that say. While cumbersome in research terms, it has been the voices of participants that have provided the point of difference for this study compared to others, given the large number of respondents.

Administering the survey

The survey ran from mid-March to the end of May 2016. In order to maximise numbers, the goal was to encourage as many GRG members as possible to complete it online. The mechanism for this was to use an automated invite system through the Qualtrics software, which included reminders spaced over the period.

For those members without email addresses, telephone calls were made. Where possible, if participants indicated they had an email address, a link to the survey was sent. If not, appointments were made to carry out a telephone interview. There were very few refusals, but it was often difficult catching up with grandparents even after an appointment was made.

The phone interview process was highly engaging, largely because the constant requests for personal comments led to fascinating conversations between the researcher and the participant. As participants revealed their stories, some quite close bonds were developed.

We anticipated (from previous research findings) that Māori would be under-represented in the survey, and therefore focused the phone calls initially on areas of high Māori population – Northland, Bay of Plenty, Rotorua and the East Cape in particular. As time moved on, increasing numbers of people were ringing the research 0800 number asking for phone interviews, which meant there was little capacity left for targeted calling.

In addition to these processes, the GRG Trust, through its support groups, the helpline, the website and various events, urged its members to complete the survey.

A broader strategy was also used to attract participants, including those who were not members of GRG. Community networks and lines of communication were used through email newsletters, websites, word of mouth, libraries and other avenues. A media release also announced the survey. Around 13% of participants indicated they were not members.

All phone interviews were conducted by one of three people: Liz Gordon (research director), Natalie Wilson (experienced researcher) and Sheree McKenzie, a field worker for GRG Trust based in the Bay of Plenty.

Data collected

The data collection process was somewhat messy, with several people completing the survey (or parts of it) more than once, and many others simply unable to complete such a long and complex document. Some data cleaning has been carried out but, in general, incomplete responses were valid and have been maintained into the sample. During the

course of the survey, we lost around 25% of respondents through attrition (they stopped responding). By the final section, there were around 850 participants still responding. In addition, the sample indicated they had 1763 children living with them, but individual information was provided for only 1324.

Strategies to stop such attrition would have involved a shorter survey, fewer options for qualitative responses, answering questions about all children as one (instead of the survey 'loop') and asking questions in fewer domains. However, the survey team is very pleased with the quality of the completed responses, and considers the relatively high attrition rate as an acceptable side-effect of the detailed work. Given the large size of the survey, and the multiple routes to it, it is unlikely that the validity of the survey has been affected.

Data analysis

Three main approaches to data analysis were used to produce this report. The first was the built-in reporting and analysis system within the Qualtrics survey program. This was used primarily for the analysis of the quantitative results.

A range of data, including all the data for the child 'loops' was analysed through an Excel spreadsheet, for a variety of reasons. As well, all Tables and Figures were produced in Excel, to give the team more control over form and function.

Finally, the qualitative data has been analysed using the Nvivo analytics program. The process allows qualitative data to be arranged into multiple themes, which may include demographic, topical, categorical or related to timing, agencies or feelings. At present, for this first report, the goal was to make a wide selection of comments to give a flavour of the range of responses. In subsequent papers and when discussing specific issues, a thematic analysis will be presented.

The process of providing a more in-depth analysis of qualitative themes is called 'drill down', or sometimes a 360° scan. Such approaches are useful for linking to the policy process.

Reporting

The reporting schedule is discussed in the introduction. Essentially, this first cut report is to be followed by a series of in-depth papers on issues of interest and concern arising from the research. A range of topics are being considered for further work.

Who are the grandparents raising their grandchildren in Aotearoa?

For the first time in the 2013 census, a group known as 'grandparents in a parent role' was identified and data collected. This provided an opportunity to provide a national overview of who these grandparents were, where they lived and their demographic characteristics.

This chapter provides a summary of findings from the 2013 census relating to grandparents acting in a parenting role. On census night in 2013, 9,543 families reported they were raising grandchildren. Roughly two thirds of the families were a couple with children, (6,432) and one third were sole grandparent families (3,111). They tend to reside in the North Island, with a focus on Auckland, Waikato, Bay of Plenty, Wellington and Northland, as Table 1 shows.

Family type	Total grandparents in a parental role	Couple with child(ren)	One parent with child(ren)
<u>Area</u>			
Northland	759	483	276
Auckland	2571	1719	852
Waikato	1410	936	474
Bay of Plenty	921	612	312
Gisborne	282	171	111
Hawke's Bay	519	327	189
Taranaki	273	192	81
Manawatu-Wanganui	729	498	231
Wellington	780	546	237
Tasman	81	60	21
Nelson	78	54	24
Marlborough	75	57	18
West Coast	81	60	21
Canterbury	570	402	165
Otago	240	177	63
Southland	168	132	36
Total	9543	6432	3111

Table 1. Total grandparents in a parent role, by family status and region, 2013 census

Stated ethnicity of the census grandparents showed that 45% reported their main ethnicity as pākehā (European New Zealander), 42% as Māori and 13% as Pasifika. Māori, in particular, are more likely to be acting in a parent role to their grandchildren than other ethnicities, and historically, to an extent that has represented traditional custom, known as whāngai (Te Ara, ND). However, as less than five whānau (around 1%) referred to their grandchildren as whangai in this study, the reasons for being taken into grandparent care

are more reflective of a family breakdown than for traditional customary reasons. The distribution by ethnicity of the census data is shown in Figure 1 below:

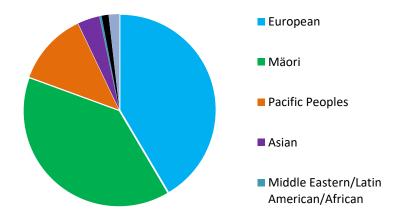


Figure 1. Total grandparents in a parent role by stated ethnicity, 2013 census.

While grandparents often tend to be viewed as elderly or retired persons, the age distribution of those bringing up their grandchildren is very wide, ranging from 34 or less up to more than 85 (some of the older families are great-grandparents). The median (and modal) age of grandparents raising their grandchildren is 55-59 in the census data.

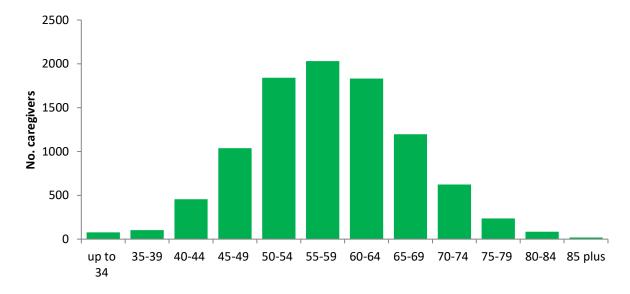


Figure 2. Age of caregivers by count, 2013 census.

Statistics New Zealand measures social deprivation on the basis of the small block (mesh block) in which people live. The index describes the least deprived decile (10 percent of households) as 'decile 1', and the most described as 'decile 10'.

Figure 3 graphs the number of grandparent households by deprivation decile. Several trends are revealed. The first is that grandparent families are spread across all deciles, demonstrating that grandparent families from all socio-economic backgrounds are bringing up their grandchildren. The second trend is that the more deprived the grandparents, the

more likely they are to be bringing up grandchildren (assuming that overall, grandparents are relatively evenly spaced across the deprivation deciles). The third trend is that over 40 percent of the grandparent families who are raising grandchildren are clustered into deprivation deciles 9 and 10, reflecting significant socio-economic deprivation within the population.

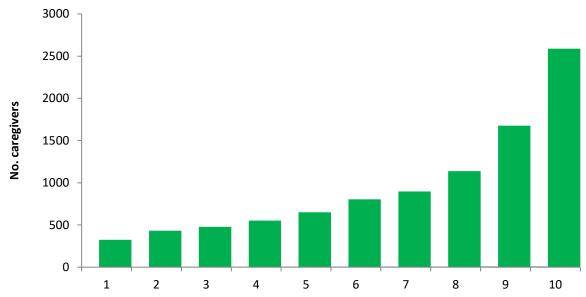


Figure 3. Count of grandparent families (with grandchildren) by deprivation decile, 2013 census.

Of the 9543 families included in the 2013 census, 4755 reported being in the paid workforce. Most of these (3612) reported they were paid employees, 288 were employers, 459 were self-employed and 129 were unpaid family workers, and the rest were not specified. The household income of grandparent families in the 2013 census is reported in Figure 4, showing a wide range of incomes across the spectrum, and a median income in the range \$60 - 70,000.

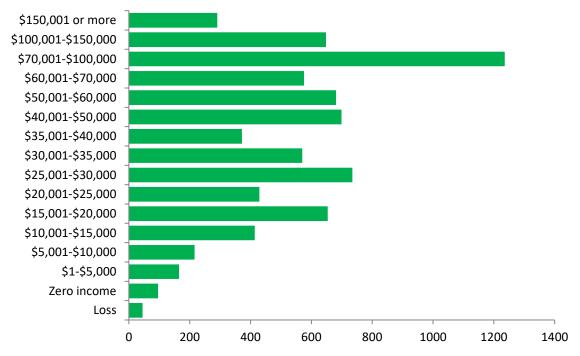


Figure 4. Reported household income of grandparent families, 2013 census.

Further analysis of income trends in Figure 5 shows a clear bi-modal income gap between sole grandparent families and those in a partnered relationship. The modal income for two-grandparent families is between \$70,000 and \$100,000, but for single-grandparent families is between \$15,000 and \$20,000. While both groups are distributed across the income range, the shape of the distributions differs significantly.

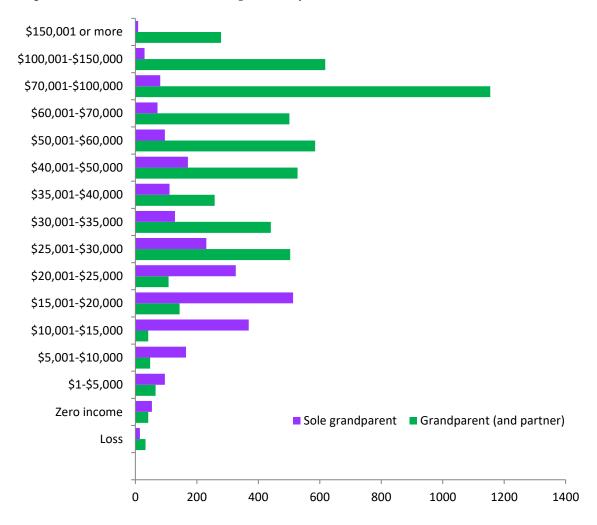


Figure 5. Number of grandparent families by income bracket and sole or partnered status, 2013 census.

Over half of the sole grandparent families report incomes of below \$25,000, compared to only around 10% of the grandparent/partner families. While census self-reporting of household income may be relatively inaccurate, it is still evident that there is a wide range of incomes within the grandparent group, and that sole grandparent families are likely to be significantly worse off than those with a partner.

The 2013 census also collected information on the sources of income for these families. In order to make an effective comparison between sole and partnered families, these have been converted to percentages. The results are shown in Figure 6 below.

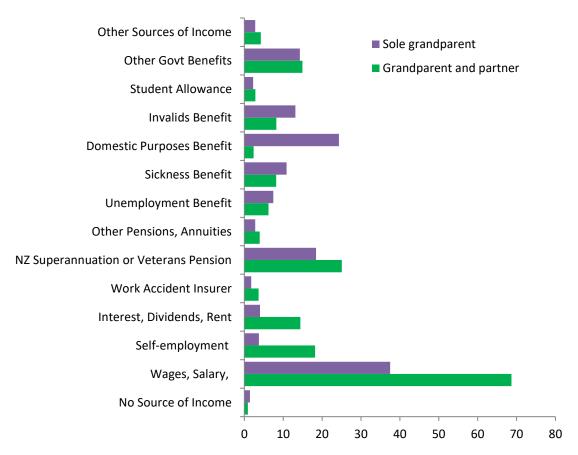


Figure 6. Sources of income, sole and partnered grandparents, with multiple options and reported as a percentage.

Figure 6 reveals that the main source of income for grandparent families in 2013 was wages and salaries, with around 70% of partnered families, and just under 40% of sole families, reporting income from that source. The second largest source of income for partnered families was NZ Superannuation, but for sole families it was the Domestic Purposes Benefit. For partnered families, the third and fourth sources of income were self-employment and income from interest or rent. For sole parent families, the third source was National Superannuation, and the fourth, fifth and sixth sources of income were various benefit payments.

There were also differences between sole and partnered families in terms of housing. Nearly half (49%) of partnered families owned their own home, with or without a mortgage. The comparative figure for sole grandparents was 27%. In contrast, 36% of partnered grandparents and 63% of sole grandparents were in rental accommodation. As well, 10% of partnered, and 5% of sole, grandparents were in a house owned by a family trust.

Grandparent families were asked the age of the youngest child living in the household. There were no significant differences between sole and partnered grandparent families in the age of the youngest child, and child ages were distributed across the whole age spectrum, and shown in Figure 7. Unfortunately, no figures are available for the total number of children in grandparent care from the census data.

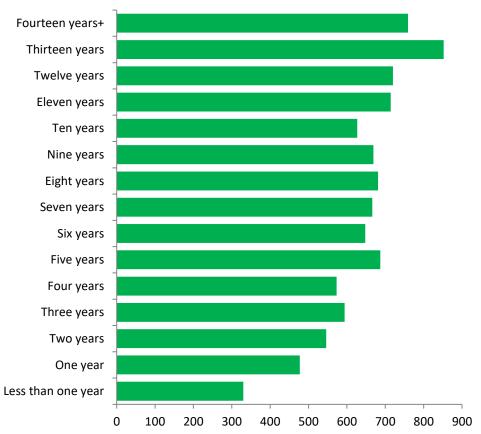


Figure 7. Age of youngest child living in grandparent-led families, 2013 census.

Summary

Data from the 2013 census demonstrates a very wide range of living circumstances of those grandparent or kin carers who are bringing up their grandchildren.

- There were 9543 such families in 2013.
- They tended to live in Northland, Auckland, Bay of Plenty and Waikato.
- They were 45% pakeha, 42% Māori and 13% Pasifika (multiple options allowed).
- The median and modal ages were 55-59, but there was a wide range from less than 35 to more than 85.
- The families were distributed across the income range but tended to be clustered in deprivation deciles 9 and 10 (most deprived).
- A wide range of family incomes were reported. A bi-modal distribution was noted for sole and partnered families, with large income differences between the two groups
- There were also large differences in sources of income between sole and partnered families. Partnered families were much more likely to be working and/or on NZ Superannuation, while sole grandparents, although most likely to be working, were also much more likely to be on a range of social security benefits.
- Partnered grandparents were much more likely than sole to own their own home, and much less likely to be paying rent.

About the survey participants

More than 1100 responses were received to the survey, which is around 12% of the total population of grandparent families raising children in Aotearoa. This was achieved through a combination of community-based recruitment and advertising using a wide range of sources, and included direct contact with the membership of GRG (NZ) Trust. The recruitment process is described above in the methodology. Non-members of GRG were also targeted, and 149 participants noted they were not members of the Trust.

Personal characteristics

Responses to individual questions varied significantly, with often 50-60 non-responders to various questions. There was also some non-completion of surveys. Response numbers to each question are included in all the data below.

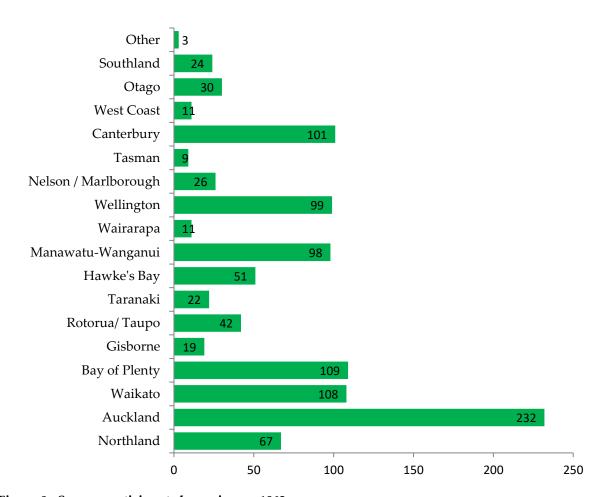


Figure 8. Survey participants by region, n=1062.

The distribution of responses by region is generally representative of where the grandparent families live, with a focus on the top half of the North Island, including the Waikato and Bay of Plenty. The three 'others' live in the Chatham Islands or Australia. Most participants (91% or 954) were female, and the rest male (108) (no participants stated they were trans or other gendered).

Multiple responses were available to those stating their ethnicities. Many noted multiple ethnicities, and especially Māori /pākehā. Three quarters of participants had a European heritage and a third have a Māori heritage, with significant overlap. Other ethnicities include non-NZ European, African, South American and a range of other ethnic backgrounds.

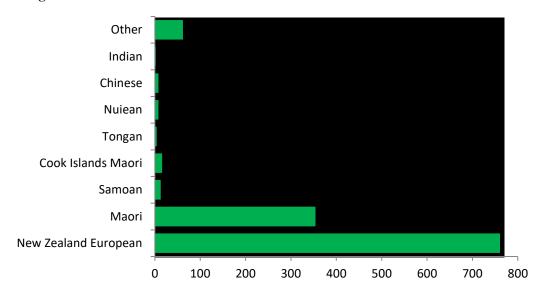


Figure 9. Stated ethnicity of participants, multiple responses allowed, n=1051.

The age distribution of participants almost exactly mirrors that of the census population of grandparents raising their grandchildren, with the mean, median and modal age group being 55-59, shown in Figure 10. Like the census, we interviewed grandparents younger than 35 and great-grandparents older than 85. A concern that the online survey would bias responses towards young families proved unwarranted.

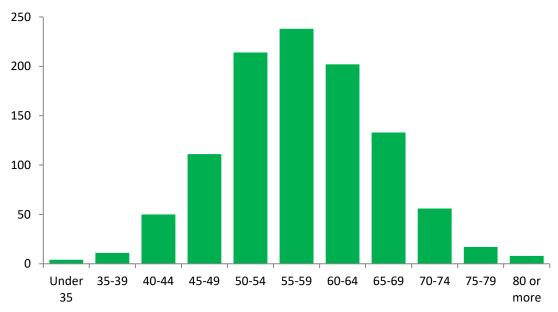


Figure 10. Age of participants on 1 January 2016. n= 1044

Sole and partnered families

In the 2013 census, approximately two thirds of families were partnered and one third sole grandparents. In this survey, sole grandparents are slightly over-represented, with 609 partnered participants and 450 sole grandparents. Most of those not with partners are divorced or separated, followed by widowed, never partnered and separated. A few 'others' noted they were engaged, 'on my own', and two were 'partly partnered', with a significant other living in a separate property.

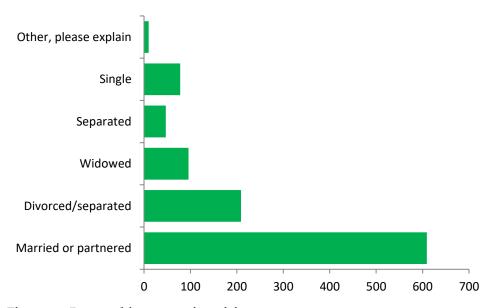


Figure 11. Partnership status of participants, n=1059

Of those on their own, 123 reported this has occurred since they became the carer for their grandchildren, while 317 noted they were alone before the grandchildren came to live with them.

A total of 606 participants noted they had partners. Male partners numbered 519 and female 87. Participants were not asked about sexuality but from responses it is clear that a small number of participants are in same-sex relationships.

NZ Europeans made up 70% of partner ethnicities, Maori were 25%, Pasifika 5% and other 8% (multiple responses available). Partner ages were in similar bands to participants, but the modal age of partners was 60-64 rather than 55-59. Partners were more likely than participants to be employed in the paid workforce (51%) and also more likely to be retired (19%). The modal income range of employed partners was \$60-80,000.

A number of partners were out of the workforce due to ongoing health issues (by count, 24), including heart disease, accident injury, COPD, cancer, stroke, muscular dystrophy and other disabilities. Some comments below:

He has been sick and unable to work for the past 12 or so years. Our mokos have significant issues where they need an adult at home 24/7. One is home-schooled

because of an intellectual disability and the other attends kura but is ADHD, behaviour disorder and possible bipolar.

My husband has been out of work because of his ongoing health issues. My whangai son was also having health issues. The stress of this meant I was unable to work full time for the past three years.

Other partners are not working in order to meet the needs of the children:

Full time is taken up with great grandson. Running him to school and back, running him to sports, scouts, swimming, other school as well as normal homework meals washing etc.

Income and employment

Participants were asked about their employment status.

Employment status	No. (%)	
Yes, I am employed	415 (40%)	
Yes, I am self-employed	80 (8%)	
No, I am not in paid work	380 (37%)	
No, I am retired	165 (16%)	
Total	1040	

Table 2. Stated employment status of participants, n=1040

Those who were employed were asked how many employers they had. Most (74%) had one employer, 14% were self-employed and 10% had two, three four or more employers. Thirty percent of the participants report working in the Health Care and Social Assistance industry, which probably explains the large number of multiple employment situations. Other significant employment categories were Education and Training (77 responses), Administration and Support Services (40 responses) and Retail Trade (38 responses).

Participants who were in the paid workforce were asked what their annual income was from all employment. There was a wide range of responses (from under \$10,000 to over \$100,000), with the modal response at \$30-40,000. The full range is shown in Figure 12.

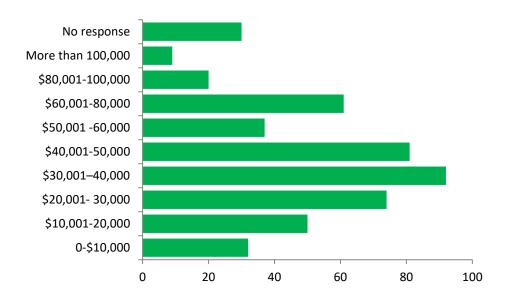


Figure 12. Annual income from employment, participants in paid work (n=486).

Participants were asked whether they had made any changes to their employment status as a result of caring for their grandchildren. Those answering 'yes' were 62% of the total (308 persons) and 189 said 'no'.

Changes made to employment	No.
Reduced hours of work	141
Changed type of work	67
Gave up work or retired	26
Increased hours of work	19
Took on an extra job	2
Other	52

Table 3. Nature of changes made to employment re caring for children. N= 307.

Many changes involved reducing hours, changing hours, fitting within the school day, working nights, moving to part-time work, working from home and similar strategies to ensure the care of the children. Some examples:

I changed hours around. Still 40 but start at 8.30 to get kids to school. Half hour lunch instead of one. After school care for one. Other is 14 so comes home.

I work from home after 3pm to care for the children

Asked for flexible hours, leave early some days work longer other days

A number of participants explained that they had left work for a period after first taking on care of the children, then returned later.

I gave up work, spent 2 1/2 yrs on benefit, have returned to work part time

I reduced my hours, then I stopped working, then I tried part time but I stopped again, now that they are both at school I have returned to work part time

Others made arrangements with their employers to meet the needs:

I informed my employer that my wife and I now had custody of my grandchild. If my wife is unable to take care of the child for any reason I may have to take time off.

Some noted the significant changes they needed to make:

Changed the whole pattern and lifestyle. Now had to take up all the responsibilities of a parent. We are great grandparents.

I did not take on a promotion

I stepped down from being a Principal

I had to give up work altogether because moko needed support

One woman describes her long journey to find a career path that fit with her responsibilities for three children with complex needs:

Yes, I had to make a career change which resulted in further studies. I worked in the IT industry in Australia, but realised that it would not be a viable option when raising a premature newborn, and two boys (2 yrs and 3 yrs). I obtained a Graduate Diploma in Arts (English) from Massey University (2011). I then graduated with a Graduate Diploma Secondary Teaching (2012) as I thought this would enable me to work while raising my grandchildren. I have found it difficult to find full-time teaching employment in [area]. The rules regarding registration are not in my favour as my provisional registration will expire in June. A requirement is that I should be in full-time employment for two years to obtain full registration with the Teacher's Council. I therefore decided to study towards a Diploma in Professional Counselling with NZIPC. I will finish the diploma in June, but this will not provide me with an opportunity to work in counselling. I still need to do Vocational Practice and comply with other requirements before I could be granted provisional registration with the New Zealand Institute of Counsellors. I have had the three children (complex needs) for six years and have studied while raising them.

Other members of the household

Participants were asked whether other adults lived with them, and 29% (304 families) stated that they did. Most of these (66%) had one other adult living with them, 75 (25%) had two and 28 (9%) had three or more. The relationship of these adults to the grandparents is outlined below in Figure 13, and reveals some complex family forms:

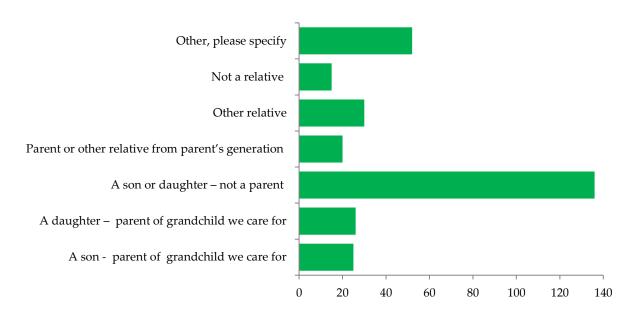


Figure 13. Relationship of other adults living in household to participants, n=304.

Others specified include a wide range of persons including grown up grandchildren, cousins and other relatives, step-children, ex-partners of own children (often parents of the grandchildren) and in-laws. A few examples:

Elderly boarder helps pay the mortgage (is 89)

Two daughters - one the mother, the other not

My disabled mother and my son (parent of the grandchild)

A 14-year-old granddaughter which I don't claim for because her father didn't want his wages affected. They have different fathers.

Our 34-year-old daughter (not parent of children) who has cancer.

Both daughters have recently come home after years of being away while we care for their children. This is not easy for us

3 adult transgender daughters

Granddaughter who we raised now 24 and has a baby and raises her younger brother

My own adult children (2), nephew, grandniece and son in law Mother, son, son's partner

It is evident that many of the participants have extremely complex caring relationships with extended family members.

Caring for the children

There were 968 grandparent families caring for 1763 children at the date of interview, and a further 83 families reported they currently have no children in their care. The number of children currently living with their grandparents is outlined below in Table 4.

Number of children	No. families	% families
1	485	51.54
2	260	27.63
3	115	12.22
4	43	4.57
5	22	2.34
6	4	0.43
7	4	0.43
8	3	0.32
9	3	0.32
10	0	0.00
11	0	0.00
12	0	0.00
13	1	0.11
14	0	0.00
15 or more	1	0.11

Table 4. Number of grandchildren/moko children in each participant family, n=941

Just over half of responding families that have children living with them are looking after one child currently. But it is important to note that some grandparent families in this survey have 2, 3, 4, 5, 6, 7, 8, 9, 13 and 15+ children currently living with them (at date of survey).

On average grandparent carers in this study look after 1.8 children. If this is applied to the population of all such carers in the 2013 census, at that time there were over 17,000 children in New Zealand being raised by their grandparents.

Coping and stress

Families were asked to rate how well they were struggling/ managing on a five-point scale, from 'I struggle daily' to 'I am managing very well'. In interview, a number commented on how difficult this question was to answer, as it varied from day to day, issue to issue. They were asked to give their best response. The results are recorded in Figure 14 below.

A couple of trends are evident. First, nearly as many participants stated they were 'struggling daily' as were 'managing very well'. Second, the modal response is 'I struggle sometimes' (one third of respondents), followed by 'I am managing' (over 200 respondents). Finally, all five categories were well-populated with responses.



Figure 14. Level of struggle among caregivers. N= 940

Study participants were keen to make comments to explain their responses. Comments fell into five major categories: love being a carer/ joy; this is not where I saw myself; parenting is different now/ the children have challenging needs; it is hard work; and it is stressful/ tiring/ financially difficult/ personally different. Many of the responses cover more than one of these themes. Some selected quoted illustrate these themes below.

Loving having the children

- I really enjoy caring for my whangai grandson
- I adore them and although it was a shock and a change of lifestyle for me we have adapted well and loving it
- It is a joy
- We love looking after our granddaughter, we don't know what else we would be doing
- For me an awesome time, sad for her mother missing out on her day to day growing up
- It was the best ever decision to make. She has been brought up as a daughter, rather than a grand-daughter and has called us Mum and Dad from the time she started speaking. She is a bright, intelligent young woman with a group of like-minded friends. I have loved every single second of her upbringing and will miss her terribly when she goes to university next year
- I wouldn't swap it for the world. It might be a hard road but to know my four grandchildren and three great grandchildren did not get separate living conditions has made it worthwhile. Being able to come into a whanau that they knew made the transition a lot less stressful on the children. To go to strangers after being taken off their parents I think is horrific and stressful to them.

This is not where I saw myself

- It is hard because you don't fit the "norm" neither with other parents nor grandparents.
- Life altering. Not where I saw myself. A solo mum in my 60s
- It is hard going back to the baby then 4-year-old stage again and your freedom is taken away
- I'm getting too old for temper tantrums. I'm dreading teenage years
- We mourn the fact that the plans we had have now been put on hold and struggle with the fact we cannot move away for work due to the father
- At first I really struggled with it, went through a period of resentment towards the situation and grief around my life plan being changed for the next 17 years. I have gotten my head around it now and feel a lot better.

Parenting issues

- causes stress particularly stealing from us and family trust issues cause lots of disappointments
- we are doing a good job because we know so much more now than when we did when we were younger and struggling with the difficulties of being young parents
- I wish I had been able to have more education on troubled kids
- As I have one who has major disabilities and another who has major behavioural problems I am not capable of giving each of them the attention they require
- It has been extremely hard on account of [child's] screaming outbursts which were daily.

Hard work

- It is bloody hard work, no support, no one listens, I will never do this again and always let people know that if I had the chance again I would never do it. It is the most THANKLESS part of my life I have ever had to deal with.
- It's hard work mentally and physically
- It is hard for Koro ... even though he looks after us ... he feels that he should be at his time of retirement and being out and about ... I work long hours and full time ... a lot of the time has been very stressful
- Dealing with behaviour problems is very difficult but with trust and talking they can be dealt with...teenagers are sometimes the pits to deal with at certain times
- Because she needs so much emotional support, I sometimes neglect the other members of my family.

Stressful, tiring, financially and personally difficult

- The losses to myself in the areas of lifestyle, financial and physical freedom as well as grief for my daughter are sometimes more than I can bear. It was much easier when he was little.
- I have given up my life to keep the children safe and looked after. I am always battling for help. I am now struggling financially.

- It is a HUGE commitment, especially as you age. Our terminal illnesses meant that for the past year, we could not get out and about with her anymore, we were constantly exhausted, and could see that the situation was really bad for her. Over the past year, we have worked really hard to try and explain to her that we were ill and that it would be so exciting for her to live with her little sister and grandparents. Each school holiday, she would go and stay, and absolutely love it. She was able to become a normal, happy child. Although we now live just around the corner from her, we do miss the everyday interaction with her terribly, but on Wednesday, she told me that she felt she had ALWAYS lived with grandma, and that we had ALWAYS just lived around the corner. We struggled financially and now have to rent a home, but to see her so happy and settled and doing well at school, is just such a huge relief to us both. It has been the best outcome for her.
- As much as we are absolutely committed to our grandchild and growing her up, it is not easy particularly because she has the added difficulty with her learning and socialisation with kids her age. I am 65 this year and hoped to begin our journey towards retirement. This has to be put on hold until we are financially able to reduce some of my hours. It is difficult to stay young in body and mind given the constancy of the situation. Our granddaughter is already beginning puberty and that for her brings another set of emotions and feelings. The cost of providing her with what she needs in life is also constant as she is a child who wears adult clothes and size 12 shoes. I am not suggesting for one minute that we would not do this however the feelings of unspoken hurt, anger and resentment towards her mother in particular is huge. She makes no contribution towards her daughter's care because she has continued to remain in an addictive life and says we should "get over it". I do worry about what happens for us in the future. Being emotionally and physically present for our grandchild is exhausting and neither my partner nor myself have any left for ourselves or each other.
- I get very tired with all the frequent trips to Drs and clinic appointments
- Not enough money ever [NB this is a representative comment of a large number of similar comments]
- It's just hard being a single older woman raising a teenage boy and having minimal finances.

As the extracts above show, grandparent carers meet complex situations with love and caring, difficulty, financial insecurity and worries about their own ability to cope. As well as the challenges caused by the difficulties that many of the children bring, there are concerns about their own health and mortality. These are considered in the next section.

Health and wellbeing of carers

Participants were asked whether they had any health problems that affected their lives. Most (74%) noted they had at least some problems, with 11% reporting quite a few or many problems, as outlined in Figure 15 below.

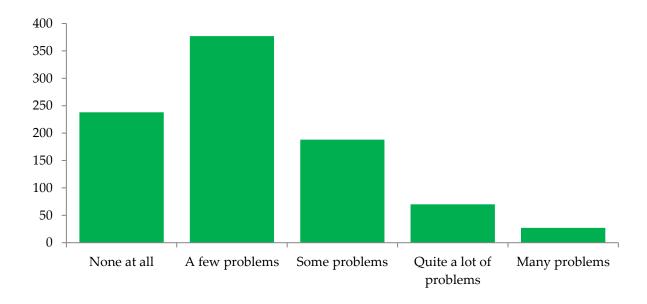


Figure 15. Health problems of carers as self-reported n=900

As can be seen in the word cloud on the next page, high blood pressure, heart problems, arthritis and diabetes are main problems.

- Heart ... diabetes ... high blood pressure ... age ... weight
- I have had high blood pressure since i got the boys

Quite a few participants report breathing difficulties, COPD or sleep apnoea, with one person currently in the terminal stages of lung disease (unspecified). An example:

• I was born with a breathing problem and have to use a CPAP machine. Diabetes/high blood pressure is all dealt with through my daily pills. Vertigo can sometimes put a spanner in the works.

Leg and foot problems, leg pain, bad knees, hip and knee replacements and pain from various forms of arthritis are common:

- I have a foot condition which at times makes it very painful to walk. It's mostly from being on my feet so much.
- At present am under an orthopaedic specialist for a damaged knee that was the result of a fall.
- I suffer chronic back pain & panic attacks. These are being treated with medication to help me cope



Figure 16. Word cloud of self-reported health problems (based on 614 responses).

Others report problems of depression and anxiety, post-traumatic stress disorder (PTSD), migraines, bi-polar problems and other mental health issues. These are sometimes the primary problem and for others accompany physical disorders.

A small number of participants have multiple ongoing problems that are particularly challenging for them in bringing up grandchildren:

- I am disabled as a result of a car accident in my early twenties involving domestic abuse. I have no function in my left arm and recently overuse issues in my right hand and arm
- Spinal fusion x2. Colostomy. The spirit is willing but the body is stuffed
- At present, twice weekly visits to the main hospital, an hour's drive away for followup appointments after eye surgery. Time consuming & costly
- Hip replacements, waiting for knee replacements, had to have bowel operation. High blood pressure, cholesterol and my own anxiety problems sometimes
- Heart, bowel cancer and breathing problems

Participants were asked whether their health had improved or got worse as a result of caring for their grandchildren. Around half felt their health had been unaffected, while 40% felt it had got worse and 10% felt it had improved, as noted in Figure 17 below.

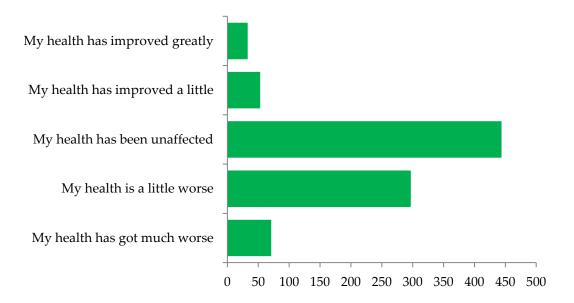


Figure 17. Health status as a result of looking after grandchildren n=898

Wellbeing

One driver of worsened health problems was likely to be stress. Participants were asked if they felt stressed, and 70% (629) felt they were under stress, while 30% (269) were not.

Participants were asked a series of true/false statements about their lifestyles.

21% have an unhealthy diet 61% do not sleep too well 49% do not get regular exercise 41% do not get out much as a family 27% rely on prescription pills 4% drink too much alcohol 1% take other drugs

There is little self-report of alcohol or non-prescription drug use. One in five have an unhealthy diet and slightly more rely on prescription pills. Half do not get regular exercise. A high 61% report problems sleeping for a variety of reasons.

The Kessler 6 scale of psychological distress is a widely used measure of non-specific mental health issues. This measure is used in the NZ Health Survey for the whole population³. For

 $^{^3\ \}underline{\text{http://www.health.govt.nz/publication/annual-update-key-results-2014-15-new-zealand-health-}\\ \underline{\text{survey}}$

those aged 55-64, which is the median age for the grandparents group, those with a reading of 12+ on the Kessler scale constituted 4.8% of the population. The comparative figure for the grandparents group in this study was much higher at 33%, with 5.8% recording severe signs of psychological distress (Kessler 22+). The results for the three categories (scores 6-11, 12-19 and 20+) are shown in Figure 18 below:

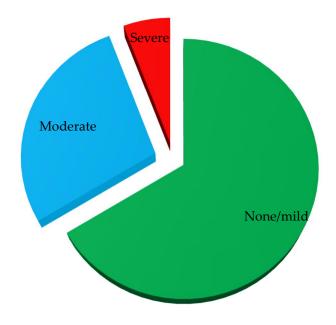


Figure 18. Proportion of participants in each of three score categories, Kessler 6, n=884.

Partner health and care-giving

Participants were asked whether their partners had any health problems. Some people without partners answered this question, and the responses are shown in Figure 19 below.

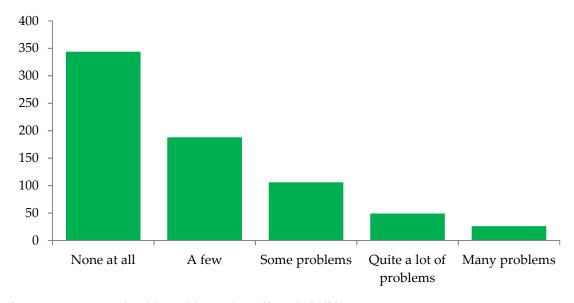


Figure 19. Partner's health problems that affect their life

Once again a word cloud has been generated to illustrate the health issues experienced by partners.



Figure 20. Word cloud illustrating partner's health problems n=344.

Participants reported many complex health problems affecting partners. Some examples:

- Asthma, hay fever, had cancerous tumour removed last year, sleep apnoea, eye sight deteriorating.
- Partially disabled previous head injuries from accident
- Lead poisoning
- There are car accident related problems from major injuries & there is ongoing pain & problems with back
- Major heart attack 2010, ongoing heart related issues, breast cancer, hip replacement, daily prescribed medication.
- Heart, high blood pressure, gout, diabetes, arthritis, sore hip, age
- Back problems, infections, heavy drinker, smoker

While many partners have health problems, only 46 participants reported that they were a caregiver for their partner.

Financial matters

Participants were asked to specify all their sources of income. The highest number recorded the Unsupported Child Benefit (UCB) which is not surprising, as this is the main government support for children who are not living with their parents and who are not in CYF foster care. Nevertheless, only 65% of the families (576/883) noted receiving the UCB (this is discussed further below). Income from wages and salaries was recorded by 531 (60%) of participants, with National Superannuation and adult benefit following behind.

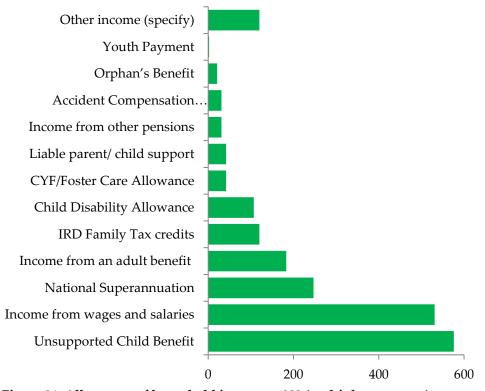


Figure 21. All sources of household income n=883 (multiple responses)

Other sources of income were given as self-employment, casual work, income from rents and trusts, farming income and a number of other sources. Some comments:

- We receive board from our sons as well as a small amount of cash from the rental left over from our home in Stokes Valley which we had to leave after 24 years as we were getting bullied and home invaded by [the grandchild's maternal family].
- IRD payment and child support go into a bank account plus father pays \$150 a fortnight into this account also for [the child]
- Income from my business which has been neglected due to me being depressed and distracted while I attempt to gain custody of both of our grandchildren.
- The unsupported child benefit didn't start until [the child] was at secondary school because there were problem getting it, not our problems but Work & Income

Other source of income includes various other benefits and pensions, ACC payment, accommodation allowance, student allowance and inheritance income.

Participants were asked to estimate their last year's household income, after tax but before costs such as housing. The self-reported results indicate household incomes across a wide range, from low incomes to high. There is a slight clustering around low incomes, which is in line with the bi-polar trend noted earlier in terms of individual incomes, and that many families are benefit-led. In total, 45% of households in the study had an income level of \$40,000 or below. Further work on analysing the income patterns shown here in a broader context will take placed in subsequent papers.

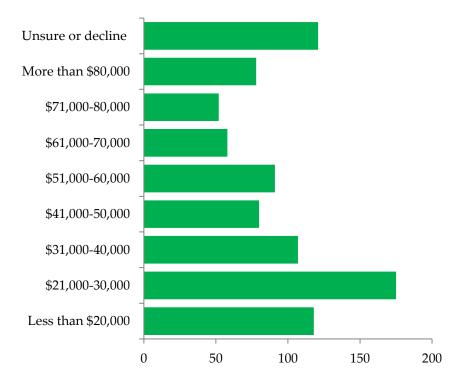


Figure 22. Household income after tax but before expenses n=880.

Participants were asked about their income compared to five years ago. More than half of all participants noted that their income had declined over the past five years, while 30% reported an increase. A high 38% considered their income had declined 'a lot'.

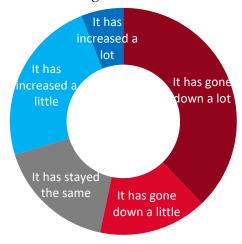


Figure 23. Change in incomes over five years n=880.

Main reasons for the reduction in income included changes in wages or salary (41%), the Unsupported Child Benefit (21%), partner's employment status (18%) or retirement (11%). Below are some examples of people's experiences. First, for those who were worse off:

- I used to work 2 hours per night seven nights a week on top of my 40 hours a week however since having my grandson I have given the night job up due to no childcare available
- We no longer get Unsupported Child Benefit as she has turned 18
- It is difficult for me to work within school hours
- Pension has not kept up with inflation, cost of food, clothing, school costs
- I was working 5 years ago then my granddaughter came into my care and I went on a benefit
- We have not taken up lucrative contracts as they would require us to spend time overseas and we believe our first responsibility is to our granddaughter.
- I am on a single benefit now as I am separated from my husband.
- I had to give up work because of a illness
- I only received unsupported child benefit in 2015
- Raising children again is expensive
- Interest rates gone down. Our savings have decreased because of the cost of supporting our grandchild

There were multiple reasons for falling income, including changing work hours, giving up work, family changes, loss of income from interest rates and loss of benefits. Some participants also noted that whether or not income had gone down, costs had risen hugely with the addition of the children.

Few participants talked about increased income from wages. The sources of additional income cited tended to be benefits and the result of family changes, or longer hours worked.

- I got back pay from WINZ as GRG helped to get the unsupported benefit for the children as WINZ refused to give it when applied for originally
- I had part time job for [employer] working weekends so my income supported us as well as the mother's input into rent etc. So when I went for custody after CYF came to see me when I shifted with children 5 years ago, this was the first time I received any money for children
- My mother came to live with us with her pension
- I have had to work longer hours e.g. nearly 60 hours a week

For those who have lost income over the past five years, often while costs are rising, there is significant financial strain:

- OMG stress and struggle
- Have no money spare each week, it's a struggle
- Unable to afford to do things with the boys outside of the home
- Pull our belts in

- Have to be more careful in our spending
- We had to purchase new furniture for her, clothes etc and pay large legal bills which have seriously drained our resources. We cannot deny her anything and go without ourselves in order to do that.

While most note that making ends meet is difficult, some are in worse circumstances, having to sacrifice basics to survive:

- Is stress on a daily basis over having enough money for necessities. I don't smoke or drink alcohol, we live a very frugal life with very few opportunities for anything for me and very few outings apart from what my remaining daughter or friends provide. Feel like I am always playing catch up with the power bill. No credit card, no hire purchase.
- Living on very low budget and minimal food only the bare necessities
- Struggle to feed and get grandson to school ie petrol
- We have grown more vegetables and fruit, and tried to live frugally.
- Could not afford to buy clothes for ourselves, and could not take her out to things she should be experiencing
- I don't really have a life outside of my boy as all I have goes on him or running round enabling parent time and times like now I have no money to do anything!
- Feel like we live on the poverty line.

For those who had gained additional income, the extra makes a lot of difference:

- The small increase has enabled us to meet the costs of raising our grandchild for now. Being able to pay off debts credit card, loans to financial firms to help with clothing, school fees, general household items, groceries, pocket money, birthday and Christmas presents
- Able to take more holidays & less of a worry about future status.
- It allowed us to spend extra on the repairs to our home after the earthquake.

A further question probed Figure 24: whether, taking into account changes to income and expenditure, participant households were better or worse off financially compared to when their grandchildren came to live with them. Most (64%) were worse off and about a quarter were just the same. Only 5% reported they were better off financially overall. However, the UCB took the pressure off many families, especially since a number of participants did not receive it straight away, so when it came it was very welcome:

- I was on a decent wage and had a full time job. Taking over the children took a huge slice of my financial plans and my credit card was maxed out in no time. GRG helped to give me some breathing space and they were able to get me on the unsupported benefit that they had previously declined and was also entitled to back pay so now debt free and we are so much better off and grateful to have GRG and all their support.
- Very hard to quantify. After my husband died it was not easy, but once the UCB was
 in place it became easier. We also now get a lump sum payment at the beginning of
 the school year and this is of tremendous help.

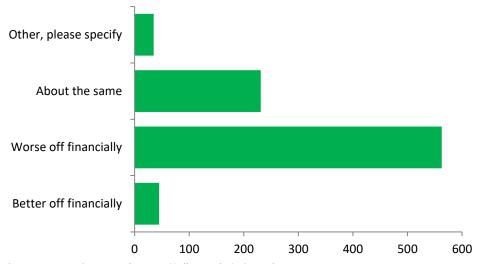


Figure 24. Estimate of overall financial situation. N=874

Additional costs noted included a bigger car, house extensions, moving to a better location, a bigger mortgage and costs associated with dealing with family difficulties:

- Our income is manageable while my husband keeps working, but we have sustained thousands in losses both from our foster child's destructive tantrums and from property stolen from us by the birth parents in the early days when we used to have them stay with us on visits to their daughter. Insurance refused to cover those losses
- Ours was a different situation, my wife was employed by our daughter and her husband, upon birth of our first grandchild my wife was appointed his caregiver. Our daughter committed fraud, she and her husband split, daughter had granddaughter to new partner in 2012. Our daughter their mother was imprisoned in 2014, the children are separated by the length of the North Island, we are in limbo.
- Legal fees have been our greatest costings as we don't get legal aid. We received nothing but the clothes on the child's back as the mother refused to provide for her daughter and hasn't since. Less income and we don't allow anyone to care for the child (attachment disorder) apart from her attending Day Care.

Other costs include education, food, sports, living expenses, holidays, school trips and various extras. Most families felt the UCB did not nearly cover the costs of raising a child.

- Five cannot live as cheaply as two! Children grow and need clothing, footwear, school expenses. Power costs more, internet access costs more. Benefit does not cover all this.
- Unsupported Child Benefit only covers half the cost of weekly day care costs. We have had to meet the balance and then all the expenses relating to clothing, etc that go with having a little one in the family.

Some appear to bear the whole cost while family members thrive. Here is one woman's story:

Before [child] came I was in a responsible position earning \$71000 a year and when he came I continued to work and initially he was here under CYFs so I received unsupported child benefit as well as clothing and gift allowance and \$300 more per month from liable parent. Once I became legal guardian I lost the allowances and when he started school after I was emotionally unwell and gave up full time work to be the person [child] came home to as he is a vulnerable young person. I relief teach in early childhood and supplemented my minimal benefit with this work.... Since 2013 I have relieved in primary school where [child] attends. Since the change in assessment of liable parent contributions I have lost almost the entire extra \$300 dollars I received from [child's] Dad each month. His income is substantial. He has also gained a more prestigious position ... with a salary increase. I have no medical insurance, house and contents insurance and am about to cancel my third party car insurance. When I was working I had all of these things including full car insurance. We live hand to mouth most weeks unless I have a day's work here and there. Struggle to find \$\$ to keep my hair tidy and as for trying to meet a new partner, nil opportunities for a number of reasons... I dread how it is going to be over the next few years as they get more expensive to clothe and feed and they need to be able to have a social life and activities with their friends. I am currently applying to go back to work but no success as yet.

Finally, a number of families lost two incomes as family relationships broke up over having the children:

• Well I had a partner and the two wages coming in but he left - he did not want the children so I had to make a choice him or the kids. Of course I chose the kids after 40 years of marriage.

Income received for the children

The most common income received for the children was the UCB, received by 637 recipients (but for more children than that). Other forms of income include the disability allowance (133), IRD tax credits (126), foster care allowance (61), liable parent contributions (51), orphan's benefit (21) and payments received within benefits. ACC payments were received for 17 families.

In addition, families got assistance with school year costs, extra care, funds from charities (especially Variety), help from within the family and the community. Funds were received for violin lessons, swimming coaching, various courses and tutoring, food and petrol grants and other forms of support.

A small number (67) reported not receiving any support at all. Some of these may well be eligible for the UCB or other help. Some have chosen not to apply for state support despite eligibility.

Other forms of support received from communities include koha from family and friends, getting in a boarder, credit cards, loans, food parcels, restructuring debt, selling assets and applying for grants:

- Had to use our retirement savings to get braces on her teeth &pay for her to go to Kip McGrath to help with her learning
- Loans, revolving mortgage, credit card, food parcels
- Credit cards maxed out, borrowed from my Kiwisaver, live in huge debt, friends give me food and clothes, have sold some of my stuff
- I have got a boarder in. Sold assets. Used all my savings.

Savings for retirement

Many participants noted that their financial plans for retirement had been disrupted by the unexpected arrival, and costs associated with, grandchildren. Table 5 records the type of savings reported, including that 264 (31%) of participants had no assets towards retirement.

Type of savings	No.
A kiwisaver account (balance less than \$10,000)	270
A kiwisaver account (balance more than \$10,000)	241
Ownership of properties (other than your home)	95
Investments in shares or other financial instruments	62
A work-related pension	46
Other savings towards retirement	105
I have no assets towards retirement	264

Table 5. Type of savings for retirement n=839.

In other parts of this study, grandparents have recorded various ways in which their savings and assets have been used up: for legal fees, having to move to a larger property, costs such as dentistry, other purchases and in general, outgoings being larger than income. Among a minority of participants, there is a view that a potentially comfortable retirement plan has been foregone in order to bring up their grandchildren.

Housing

While income is important for the quality of life for grandparent families, housing is as crucial. The difference between a family owning their own large home with space for the grandchildren to move in, and one renting a tiny property and with no home ownership, is huge. Home ownership, with or without mortgage, was reported by 63% of participants. Most of the rest rented privately, with around 10% renting a state or Council property.

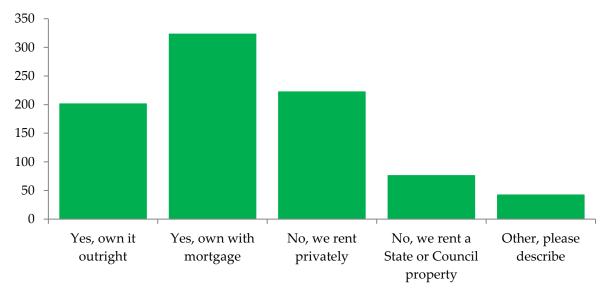


Figure 25. Housing status of participants n=869

Grandparents live in a wide range of circumstances. Some describe their 'other' situation as follows:

- We were first freehold in our first home in 1986. We then became freehold in this, our second home by 1998. We stupidly went guarantor for our daughter, our debt is now approximately \$50,000.
- The family home I was living in was trashed by the girl's parents, it is also currently part of a property settlement for my divorce which will finalised 2 years in June
- We live with my elderly father, this serves two purposes, I keep an eye on him and we have a roof over our heads. However, we do pay ALL the outgoings.
- We could not sustain our mortgage on one wage, sold our house and relocated to a more affordable area

A number of the families in this study were living in inadequate or difficult housing situations:

- It's owned by a family trust. I will be a beneficiary however won't be when I need it.
- The house is in whanau trust
- We used to own our own home
- We're homeless and have been on the waiting list since June 2014, so we're living with one of my daughters whom I care for her children.
- My ex partner signed the house over to me, I am very lucky in that regard
- Living in motor home
- I do not qualify for a state or council property as with the unsupported child benefit they tell me I get too much money??? I pay 300.00 per week rent.

Participants were asked what impact taking the grandchildren to live with them had had on their housing situation. Those in the best position both owned their own home and it was large enough for the additional children. For those or other reasons, 387 respondents (45%)

reported having no housing issues, and 55% reported a range of issues. Even those who are satisfied with their housing often found it a struggle to find good housing:

• It is really hard to find affordable warm accommodation especially when you have a young child with asthma. Luckily I have found a suitable place but we had to stay with friends while I sorted out the money for the bond.

Over the next few pages, the stories of participants who have particular housing issues are told in their own words.

Needing a larger house

The largest category of responses is those who needed a larger house (178 - 21%). Some have moved, others worked to extend their property and others still are waiting for larger accommodation.

- Once CYFs had found a safe place for the children they totally abandoned us. Technically we were soon overcrowded a boy and a girl of 10+ in the same bedroom is regarded as overcrowding. It didn't worry me at that stage, but would be inappropriate for teenagers, and the court order put them with me until 16. So I set about expanding the house. Didn't want to leave the district as I had them in good schools and wanted them to stay with their friends they had had enough upheaval
- I find being a grandparent I need more space, so does my grandson. This house is tiny, we feel house bound a lot as we spend a lot of time at home rather than out as money's tight
- I only had two of the grandchildren when we moved into this state house, now there are two more additions and also I have my other daughter (with anxiety issues) and her baby with me...we have applied for bigger housing with HNZ, but they said it would need to be a 5 bedroom, which there aren't any in the area...so we wait. Due to leaving work and being a caregiver, my finances went out of whack and I now have a bad credit rating, so private rental is not an option
- Had to increase the size of my house when I took on my granddaughter, but ran out
 of money to finish, so the house is not permitted and is falling apart at the seams. I
 only hope it stays standing until [child] leaves home and sees me through my
 lifetime
- Should be in a two bed instead paying for a five
- Housing in [provincial city] is so expensive! I cannot afford to live in a bigger house even though we need one. The house we are in is falling to bits and the landlord doesn't do anything to maintain it. Last year the fireplace fell apart and they wouldn't repair it. I had to buy gas and use electricity to heat the house which cost around \$50 extra a week. I am too scared to move, no-one wants single mothers in their homes, and the rent is huge.
- We require a large house due to our disabled grandson's equipment needs, it is very difficult to find a place that suits.

Current housing is inadequate

This was the second biggest category of concern (121, n=14%), with participants citing a wide range of problems with their current housing.

- Yes house is freezing in winter only one heat pump in lounge, no insulation, dreading winter and price of power to keep grandson warm. He now gets bronchitis like me in winter
- I am looking forward to having my own bedroom. I have been sharing with the grandchildren for too long. They are teenagers now and I share a room with my grandson. Is not really fair on either of us.
- The house is unhealthy, cold in winter even though it is insulated, mouldy and took 2 years to get fleas/cockroaches out of the property. Rooms are small with growing teenagers not really ideal, and the rents are too high to get anywhere decent.
- Rental housing is most appalling! Cold, mouldy and in poor condition. A WOF for rental housing is badly needed
- We haven't had the money to paint the house or maintain it & things really need to be sorted now, but not without money to buy what is needed or pay to have it done.
- My home is deteriorating as no money for maintenance
- Since [child] came to live the garden is a wilderness nightmare and I can't maintain it or a vege garden. I suffer from PTSD and depression so these things have been compounded by the fact I have to constantly supervise [child] and if I don't, like right now as I type this survey out, he IS getting into all kinds of mischief out of my sight. My depression gets in the way of any kind of regular maintenance plan around here. The house needs painting, and I've got zero motivation. No respite care, no time off.
- It can be very stressful caring for a child who has behavioural destructive problems which adds to financial pressure when having to repair property and worry about possible eviction due to behaviour issues.

Unaffordable housing

A proportion of the participants cannot easily afford the housing that they need (110, 13%)

- Went through a financial hardship with Housing New Zealand. Had to take out a loan or get evicted to catch up on arrears when our rent went up to 50% of our total earnings. They (HNZ) knew there was no way we could clear the debt so was eventually kicked out.
- I am now having to consider school zones again.
- I was renting an inner city apartment prior to becoming a caregiver. I have stayed where I am as I cannot afford to rent a 3 bedroom house/unit with a backyard. I do not own a car so need to live near work.
- Had to sell because no funds for renovations, couldn't get finance on mortgage because of husband's head injury
- We wish we could afford to buy our own home. We will have no home to live in when the children are gone.

- Extensive legal fees have been necessary to protect myself and [child] throughout many challenges. This money would have been better spent paying off my mortgage.
- Housing issues are ongoing. Power, food and expenses are criminal as well. I don't know how some people survive.
- Remortgaged, can't afford extra maintenance
- The ongoing error with Housing NZ in having the correct rent day or week for my rent. At the moment I am paying for errors they said I was in arrears because when my benefit changed from weekly to fortnightly, I still owe a day or two in arrears because of it. I couldn't understand it so I gave in and WINZ is taking \$10 a fortnight for the arrears, which has made another hole in my pension.
- I need to do it up and cannot afford to.

Moving away

A number had to moved to another district for a variety of reasons (n=87)

- Due to the stress of everything that happened from when [child] was 14 months we needed to leave our home as previously stated. We could not sell our home in [town] as quickly as we needed to so after putting it on the market for sale we were advised by the property agent how we could remortgage, buy another home, and rent out our original home. Unfortunately, we had some issues with the first two lots of tenants not paying and damaging the house so now we have a property manager. Now everything is working out.
- We sold 2 homes in Auckland and moved to [town] for a school that better met the needs of Tom, and we are now freehold!
- We had to move provinces. The climate in this particular place did not suit [child]; it affected his. He was having ongoing respiratory problems. Even now we have to be careful about where we live; homes have to be insulated etc. From experience if the home isn't OK, [child's] health and my husband's take a dive. I have to take into consideration even the plants that may be in the gardens....
- We had to move away for awhile for safety reasons, we are now back home

Range of circumstances

Some had a range of factors that affected their housing situation:

- Rents are too dear. Facing homelessness because of this.
- We needed to be closer to better schools. We needed to have the opportunity to teach the children work ethic. We needed more space for three teenagers
- Because of the special needs child getting response from Housing NZ is terrible. I phone weekly but it is of no use.
- We have issues with intimidation from neighbour making unhealthy environment are trying to find new house in same area but rental rates are beyond our means.
- We are "Christchurch Refugees"
- We had to move away for awhile for safety reasons, we are now back home
- Yes issues with child's mother necessitating moves

A statutory charge on the house due to legal aid

- Had to sell my home in the very early years of being a grandparent caregiver and as
 there had been legal aid for a lawyer for the child it was against the house. I did not
 receive much back at all when the house was sold due to this lawyer's fees that had
 to be paid back on the sale of the house
- Legal aid is so unfair. The parent that kept me in family court for two years will never have to pay anything. I have a "registered interest" on mine

Other housing issues

A final group raised other housing factors that exacerbate their situation:

- We sold our larger house to move into our much smaller rental to cover possible legal costs when the father took action against us through the courts
- ACC has put in a lift and a disability bathroom, fencing and thicker glass in lower windows and recently a gate
- Current housing is not good for my and children's mental and physical health
- I am coping with situation. I did attempt to apply for a state house but don't fit the criteria because of partner's family owning house
- We will be fine for now and we have managed with larger whanau in the past not too bothered the whanau before them have pretty much wrecked the place so nothing to be precious about and we are lucky to have a roof over our heads
- It would be nice to have two bedrooms but that rent would outweigh the pluses of the private board now, so my bed is in the lounge

Financial support from Work and Income

There are a variety of circumstances under which grandparents raising their grandchildren may apply for financial support from Work and Income.

Grandparents raising their grandchildren are entitled to the Unsupported Child Benefit (UCB) under most circumstances, as long as the child/ren will remain for twelve months or more.

Grandparents may also leave work to look after their grandchildren, and receive full income support. Alternatively, they may already have been receiving income support.

Grandparents may be on National Superannuation, also administered by Work and income.

Finally, there are a range of additional supports that might be available to grandparents raising their grandchildren.

Participants were asked whether they had any experience seeking income support from Work and Income. Responses are recorded in Figure 26 below:

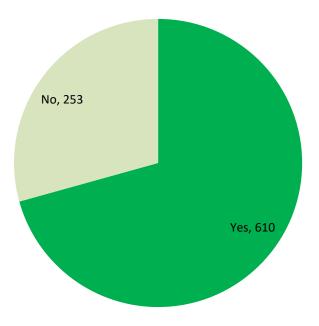


Figure 26. Number participants seeking income support through Work and Income (n=863)

Participants were asked to rate their experiences with Work and Income according to a number of criteria, which were developed to reflect past experience by members of Grandparents Raising Grandchildren (NZ) Trust. The results, set out below in Figure 27, show that grandparents had a range of experiences with Work and Income, ranging from "horrendous" to highly positive.

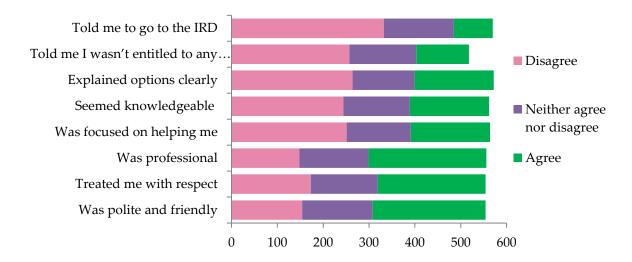


Figure 27. Agreement with a number of statements regarding Work and Income, n=572

A third or more of participants were positive about their experience with Work and Income, and those most happy had little to say about their experiences:

- Wonderful service
- My experience was faultless but have heard many other stories that were not
- Overall they are OK but it all depends who you see there
- Very friendly
- I do not have any issues. I have always been treated with respect.

Some have seen their experiences change over time, often after getting help from external agencies:

- Originally when I went to see Work and Income I was treated very badly. Then GRG
 helped me, we had a big meeting with the officials from WINZ and was able to
 obtain the Unsupported Child Benefit. Now WINZ bend over backwards for me and
 are very helpful
- When at first with the grandchildren it took a lot of time getting results but with the great grandchildren things moved a bit faster with the extra help from the Salvation Army
- I have almost knocked my local agency into shape but my experience supporting others on their WINZ journey have been of rude arrogant people without knowledge or kindness
- [Staff member] from GRG was knowledgeable and pretty much upskilled the WINZ lady which resulted in our getting the Unsupported Child Benefit. Prior to that we had been turned away which also included not been allowed any food grants or anything. We were given no financial assistance from anyone for months. WINZ would not help us in anyway and told us to sell our house.

Those who had ongoing concerns with Work and Income make up the biggest number of comments about this agency. This is not surprising, as those with no problems often have little to say. The comments can broadly be divided into two parts – those relating to the

treatment of the grandparents and those relating to the effectiveness of the organisation. There were, in total, over 400 comments about the experiences with Work and Income and most were negative. Other studies have also recorded negative experience of the agency⁴.

A number of comments have been summarised below. Under the heading 'poor treatment', which deals with the personal experiences and effects of dealing with Work and Income, there is a subheading relating to the treatment of people in relation to the requirement to look for work.

Poor treatment

- I was treated like dirt. The manager would not believe that there was a breakdown in the family. Even when I showed them court papers to prove the child was in my care they refused to give me a benefit. Eventually after a few months they agreed to give me my entitlement. I told them I was going to the newspapers to report them. They put me through hell. I'll never forget how they treated me!!
- I have to front up with a medical certificate every three months although my Doctor says I am unlikely to ever work again and has told them this. I asked for a loan to help move but was told at my age I couldn't afford it so borrowed privately. Have had very little helpful help from them.
- WINZ is the most horrendous agency to deal with. In fact, I have to take someone
 with me every time I go otherwise I become very sick. Takes me all my time not to
 heave in there, my experiences have been horrendous. I would prefer to go without
 than make an appointment with WINZ. It has affected my life hugely in a negative
 way.
- I absolutely detest going there for support. I wonder if they are paid by a system where they do not help those that request assistance.
- It has been horrible and degrading and they tried to not give me what I was entitled to.
- Too many to list. Such a humiliating and degrading experience.
- Very unpleasant it made me feel I should not be asking for help and financial support
- GRG told me to apply for benefit at [name of office] but they treated me with contempt, I laid a complaint and had to go to a different Work & Income
- Nearly drove me nuts. Beneficiary advocate helped me. My relationship had ended, I had a chronically ill child and no benefit as he was not my blood.
- They treat you as if you were scum.
- They do not give us what we are entitled to. If we don't know what we are entitled to they don't tell us. We have to take them through the review board process to get anywhere with them. Dealing with WINZ is a negative experience over all. They have sabotaged my life on more than this occasion and should be held accountable under failing to provide and crimes against humanity.
- They weren't interested in helping and seemed to go out of their way to not help

⁴ http://www.communityresearch.org.nz/research/access-to-justice-for-beneficiaries-a-community-law-response/

The requirement to look for work

The requirement for beneficiaries to look for work is embedded in the social security legislation. A number of participants outlined the problems they were having in meeting the work obligations, which often stemmed for their own circumstances and also the special needs of many of the children.

- I was my wife's carer and when she died I was told by W & I that I had lost my job and the only benefit I could get was job seekers. This would not pay my mortgage or support us. I contacted [child's] paediatrician who wrote a letter to W & I and all of sudden everything changed and a support program was worked out.
- I have very little to do with them. They want me to start looking for work but with my health I cannot see this happening plus I find looking after my grandson is a full time job in itself
- New obligations to work do not allow for flexibility

Organisational effectiveness

There were numerous complaints that Work and Income staff did not know about options available to grandparents, or failed to offer problem-solving options, or were uneven (i.e. it depended on who one talked to) or do not work in the best interests of the client. Below are listed a few of many complaints:

- They come across as helpful but they have had me on wrong benefit for 2 years. They are belittling. They are quick to take my money when I work but owe me money which I have been waiting months for.
- They do not offer or make available all of their services/benefits.
- Rude, you would think the money was coming out of their own pocket. They (the front line staff) do not understand so many entitlements
- It depends on who you see and what you are trying to get. Once tried to get help to get some dental work done, but was refused because my pension had gone in that day, so I had enough to pay the \$300+.
- They are not very knowledgeable about the UCB entitlements. I have had to help many people apply for this and it has been an absolute nightmare
- They do the best they can within their boundaries, but I have been told incorrect things in the past
- Last year I went off the benefit I was on because I took a limited tenure teaching position for a term. The rigmarole I have gone through to get benefit reinstated has been ridiculous but I have finally had the courage to apply and get the disability allowance for [child]. I believe there needs to be more flexibility and find the earning allowances being counted by gross amounts and paying secondary tax are ridiculous. I am counting down until I am 65 because my income will not affect my pension and I can then relieve as much as I like as long as I am still alive and able
- Stressful, exhausting and unprofessional

Getting the Unsupported Child Benefit

There were many complaints about the way the Unsupported Child Benefit is administered. Over time it has been a key role of GRG (NZ) Trust to ensure that all members understand the terms under which the UCB is available, as many people have wrongly been declined it. The UCB is a significant payment which can make a large difference to the family income – around \$10,000 p.a. per child for older children. The GRG Trust has also been involved in getting payment of arrears for families who were wrongly declined the payment for years. Some of the experiences of families in applying for the UCB are outlined here:

- They knew we were entitled to the unsupported child benefit & I had applied several times but were declined. I have been in tears because of not having enough money to live on & pay bills but that didn't seem to matter to them until I finally got a person who was willing to tell me my entitlements & got the ball rolling but this was 15 years later.
- When first got my grandchild W&I said I was only entitled to child support, it was someone else (from the public) who told us we were entitled to Unsupported Child Benefit, this was a few years later.
- When I applied for UCB I got together all my paper work and parenting court orders. I waited for a reply and got a phone call to say that I was not entitled to the benefit for the children. I had to write to Paula Bennett [Government Minister] so I could receive it. My case manager was so embarrassed that I had been turned down. The staff can be very rude and make you feel like you are bludging off them when it is government money and not their own.
- It took 8 weeks to get unsupported child approved. Phone calls to WINZ were not answered (16 in total). The WINZ manager when she finally returned a phone call said they needed more information which was really frustrating as I had supplied them with all the info they had asked for within a week of the initial interview. It took a social worker from Family Start to attend the [place] WINZ office before they would grant this benefit. Then they only granted it for 6 months. I have found it frustrating that I am not entitled to any child care subsidy, I do expect to pay for something towards child care but think that it is unfair that the entitlement is nothing as it is dependent on income.
- I was declined unsupported child for one child as the father is living with us, even though he had lost his job due to actions of the mother, and they refused to pay him solo parent support as I had custody.
- I have given up on Work and Income as I have been told that we earn "too much" and do not qualify for support⁵.

Participants were also asked a range of specific questions about the UCB, in order to probe their experiences of it, and these responses are contained in the next section of this report.

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⁵ The UCB is not a means tested benefit, so this person has been wrongly advised.

The Unsupported Child Benefit – a lifeline

As the UCB was designed precisely for circumstances where persons other then parents had the long term care of children, it is not surprising that the majority (69%) of participants received it. Reasons for not receiving it included: no eligible children at present, did not wish to receive it or had been declined it. It is likely that some families who were eligible for the benefit were unaware of the UCB, although this was not specifically stated in the survey.

Participants were asked to indicate which one or more of six indicators reflected their experience with applying for the UCB.

Of the 593 responses, only 102 participants noted that Work and Income told them to apply for the UCB on first contact. Some participants thought that staff appeared to have little knowledge of the UCB. Others noted (more cynically) that staff rarely offered up-front information about entitlements, so if an applicant did not know about a benefit, they would not get it. As well, 97 people noted they specifically were not told about the UCB when they first approached Work and Income.

The majority of the rest (343 participants) had received advice on the UCB from other agencies than Work and Income. The most commonly mentioned agency was the GRG (NZ) Trust:

- Everything I know I get from you (i.e. GRG) on Facebook
- CYF got me to contact Grandparents Raising Grandchildren and they both told me to apply

Other organisations included CYF, Family Start, Open Home Foundation, Paediatrician and legal advisor including Community Law Centres. Some found out through friends and other grandparents. Some took a while to find out they could apply:

• Learnt from GRG that we could apply. This was approx 3 years after [child] came into our care.

A variety of funding possibilities come attached to the UCB. There is now an establishment grant of \$350, which is automatic on being granted the UCB, but did not always exist. 207/595 (35%) received this grant. Most (545/595 or 92%) receive the school year start-up fund to help with school uniform and other costs. A smaller number (119/595 or 20%) have received the extraordinary care grant, but there is some dispute about the effectiveness of that fund:

- I was aware of the ECF but its criteria are impossible to meet. How do you know if the child is 'extraordinary'? As their extraordinariness appears, the fund has already closed
- I am currently applying for extraordinary care fund I only found out about this through GRG.

Others have used the fund for glasses, music lessons, other programmes, medical assessments and similar needs. Others also get the child disability allowance, childcare subsidy, money for OSCAR and other needs.

In total, 118 participants have never applied for the UCB and a further 98 were turned down for it. Of these, 40 were subject to the 12-month rule – as they could not prove they were likely to have the child for at least 12 months and the application was declined. Some remembered struggles around receiving the UCB, and some are ongoing:

- I was mortified as WINZ tried to get/arrange a family group conference with the children's mother. I had to go to a lawyer to get sorted. I already had the day to day care granted by the courts. WINZ told me that my parenting order meant nothing. Was a very stressful time.
- I sought advice from GRG and was granted after been turned away, our mokopuna will be in our care until we see physical evidence that parents have made changes and this will take years.
- As I was going through the courts to get custody of my grandson they told me I could not guarantee he would be with me as she was fighting it and therefore would not qualify so he could only be included in my benefit
- Form filling for Inland Revenue and WINZ is an on-going drama. They make our lives difficult, and really are a pain! Often they ask questions that we cannot easily answer, and recently they failed to process our update, so cut off the UCB with no notice. Hassle we really could do without!
- Took 3 years to receive UCB, after intervention from an advocate from budget services.
- We tried to apply, but were told to approach our daughter directly for payment which we did. She paid regularly for 7 months then stopped as she isn't working anymore.
- We met the criteria but were bullied into not applying with threats of financial dominance of holding off paying the benefit that I was on at the time, hence the court case with GRG and WINZ.
- I have just received my first payment after 3 years 10 months
- The guidelines are becoming so strict around UCB that a lot of grandparents give up instead of fighting for what they are entitled to.
- We were declined twice over the past ten years but the third time they agreed we
 were entitled after a meeting with myself and his mother. However, they have
 declined us the backdated payment that others have received. I have applied for a
 review. Why grant it then tell us we are not eligible for back pay when nothing has
 changed?

Even for those with good income, over time the lack of the UCB began to tell in the financial toll on families:

• I think we were unjustly treated and misunderstood. I was able to accept it at first because I had good income coming in, but as time went on we suffered financial hardship quite dramatically.

Others encountered significant financial hardship because the UCB was not granted.

In summary, the UCB is the main way in which the state can support grandparents who end up caring for their grandchildren because of a breakdown in the family. On the face of it, the criteria in section 29 of the Social Security Act 1964 for receiving the UCB appears relatively simple – i.e. because of a breakdown in the child's family, no parent is able to care for the child or to provide fully for the child's support and the caregiver is likely to be the principal caregiver of the child for at least 1 year from the date of their application for the UCB.

But the application of this benefit is far from simple, and a shocking proportion of participants are not told about the UCB, or are declined it, or find it very hard to get. A number reported that only when they take an advocate, or go armed with full information from GRG or another organisation, do they get through the barriers. Some thought that the problems were caused because of a lack of awareness by Work and Income staff of the UCB, and some thought that there was deliberate resistance. Whichever is true (or some variation of this), being granted the UCB was often a struggle for participants, even though the support is so necessary.

Grandchildren no longer living with their grandparents

Participants were asked whether they had any grandchildren who had lived with them but were no longer in their care. Of the 1035 responses, 284 responded 'yes' to this question. This high figure is partially because members of GRG (NZ) Trust who were no longer caring for grandchildren were encouraged to respond to the survey to 'tell their stories', and partly because grandparents may have a flow of resident children into and out of their homes, and so may be caring for some but not all of those originally taken in. Figure 28 records the destination of children leaving grandparent care:

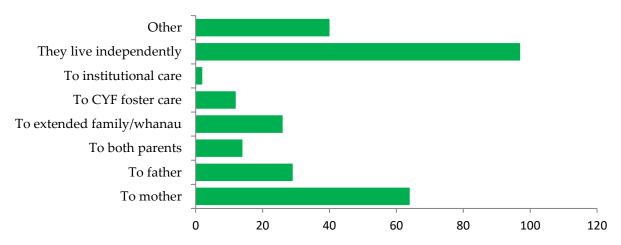


Figure 28. Destination of children leaving grandparent care (n=284 households)

To summarise, 34% went on to live independently, 37% went to one or both parents, 9% went to extended whanau and 5% went into CYF or institutional care. This appears to indicate that grandparents are remarkably effective in bringing up their children until they can leave home or return to their own parents. Around 15% of responses note other reasons, often demonstrating the complexity of the families in this study. In several cases the children went to other grandparents, or: "to her grandparents - we are her greatgrandparents", to the great grandmother from the grandmother, to friends or neighbours etc. Some example of stories below.

- Granddaughter is now living at our address with new boyfriend mother of the
 great granddaughter we are raising. They have a self contained living area under the
 house we are living in.
- Upon our daughter's imprisonment the eldest, our grandson went by court order to his father, the second and youngest grandchild, our granddaughter, lives with her father. He, to best of our knowledge, remains our daughter's partner.
- He was removed by the Police under 42 of the CYPF Act because of mental health concerns. I resisted calling the police for a very long time. Rang the police and they notified CYF and eventually they took him away and broke my heart.
- A is my step grandson, he was 3 when his mother became pregnant to my son. He stayed in my home on and off until he was 8 ½ when his mother asked me have day to day care of him with his 2 siblings already in my care. He was with us for 3 months and we had an application in court, when his father intervened, it became

ugly and his mother picked him up from my home. Prior to this he had lived with mother, his paternal grandparents (twice), his father in Australia (twice) and his maternal grandmother. Since then he has lived with his mother in a variety of boarding situations, usually with extended whanau but sometimes with strangers.

- One was killed coming home from school, another is now independent.
- One went to live independently, the other we asked to leave because of her attitude. We don't tolerate abusive behaviour and foul language etc. After several warnings, she had to move.
- My moko's older brother has stayed with me on and off many times. Three years ago his mother asked me to have day to day care of him too. He was with us 3 months but then she took him away again.

Grandparents were asked about why the grandchildren moved on, and whether it is working out well for them.

Grandparents were divided on whether they would have preferred the children who have left to have stayed in their care. 123 participants (44%) said they would have preferred it, while 157 (56%) said they would not have preferred it.

Keeping safe

The questionnaire included a series of questions around physical and verbal assaults on grandparents. This section was included because GRG (NZ) Trust had noticed in recent times increasing numbers of calls to their 0800 GRANDS helpline regarding violence.

Out of the 851 responses, 118 participants (14%) noted that they had been physically assaulted by a grandchild in their care, and that there was an intention to cause harm. Most of these (77%) believed the assault was due to a loss of conscious control by the grandchild. Participants were asked how often such assaults took place, and results are recorded in Figure 29 below:

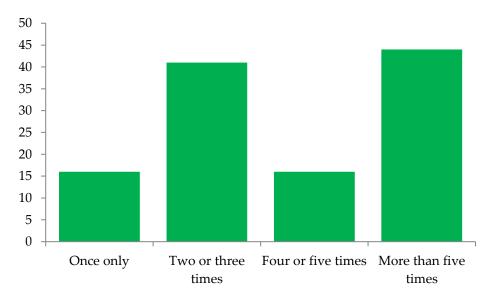


Figure 29. Number of times grandchildren had physically assaulted grandparents (n-117)

Participants were asked what they did when they were assaulted. Some "defended" themselves or restrained the child, others "consoled and comforted" (younger) child, some used punishment techniques such as removal of toys or "time out":

- He is 7. I sent him to his room and took his scooter off him
- He is 8 though can still pack a punch. Very strict rules about we are a no abuse family. He has responded well
- She is three! She was reprimanded and asked to apologise and reminded this is a noshouting no- hurting house.
- Need to calm him, restrain him, he can attack me, go for cover. CFYs came most recently. They are useless and don't know what to do with him. Go to all these meetings.
- I told him that wasn't nice and sent him to his room.

A second group, mainly dealing with older children, took more serious steps, including calling the police, getting external help, getting medical help or sending the child away:

• Contacted police. Grandson now lives with his father

- Police called & police deal with her⁶
- Arrested and charged as 2 weeks over 17, had been to hospital night before and received strong pain killers that had effect, along with his life experience. Discharged without conviction.
- He went to anger buster program
- Have had his medication increased and done the Incredible Years parenting program to learn new techniques. [Child's] brain wiring is responsible for these outbursts, he is damaged and gets out of control, he's only a little guy right now but I can see all sorts of trouble ahead as he develops if I don't get some help and support
- I have got help through CYF, Open Home, police and other local agencies
- Gradually stopped after counselling, medication for ADHD. Happened for the first 3 years I had him on a regular basis (2-3 times a week)
- One child is currently going through youth court on assault charges. The older child now does not use violence and has not for some time

Some of the participants noted that the tendency towards violence in the children comes from their life experience plus often significant cognitive issues:

- He has been diagnosed as ADHD and on medication, we have also learnt skills to cope with outbursts.
- Held her until she calmed down and took her to Marinoto for therapy
- There is nothing that can be done for her outbursts
- [Child] does not understand he could hurt me, it is usually frustration. Spoke to [child's] psychologist about it and have a plan if I feel endangered, lock myself in my bedroom.

One particularly sad story involved a family with a boy whose anger and violence were endangering the life of his carer, his grandmother. Her story is mentioned in the section of this report on children no longer living with the grandparent. Over time she put up with significant violence and abuse from the young boy (aged 14 at the time he left). But eventually, scared for her life, she called the police and CYF on him and said she could no longer live with him. He was taken away and, she says, "broke her heart".

A smaller number (42/847) noted that they had been physically assaulted by a member of the child's whanau. Half of these were single assaults, which were dealt with by "kicking them out", "went to the police station", "told them to stop it or leave my house", "walked away" and various other tactics. Several people sought medical help. A few participants gave a more detailed account of what happened:

- It happened in [child's] bedroom. He was drunk, continued attacking me, grabbed me by the throat and tried to strangle me. I went limp. He realised that if I didn't want to fight, it wasn't terrifying for [child]. So he stopped.
- There had been a year of verbal abuse, texting, etc. This person had been to my home several times, I wouldn't let them in. My lawyer prepared a trespass order for me, I

⁶ There were more than 40 responses which mentioned ringing the police as the primary (or sometimes last) resort to child violence.

served it on my doorstep, that is when the assault (minor) happened but I called the police. That was ineffectual, they said the person now understood the situation. 1 hour later the texts started again, and emails. I applied for protection order. The judge added some extra conditions, which amazed me and they also made a huge difference to my feeling of safety in our home. It sent a message to other people. It meant that I could let the children bike up and down our safe quiet street, wander across the road to their friends without looking at every car that came down the street. It was a huge relief, and I finally started to relax and heal the trauma.

• Lived with it for 8 years and then left after building up the courage

Far more participants (539, or 64%) reported verbal abuse by the whanau of the children than physical. Figure 30 below reports the number of times participants were subject to verbal abuse.

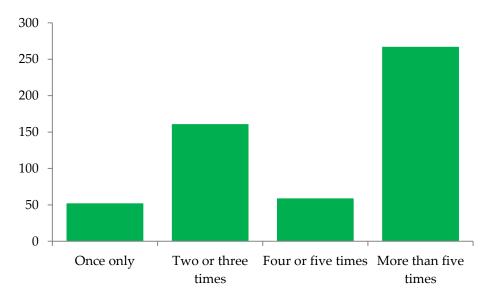


Figure 30. Number of times whanau had verbally assaulted grandparents (n-117)

Although different from the physical abuse, some of the confrontations experienced by participants were frightening and potentially dangerous. Grandparents were often able to walk away, hang up the phone, set boundaries, ignore or try not to respond and at times the police and CYF were involved. Some were quite pragmatic in dealing with the abuse:

- I just dealt with it because it was their guilt that caused the abuse that they hadn't financially helped with the child or made an effort to try to take care of them
- Nothing, it was a while ago and she was under great stress
- Learned to ignore it because our daughter had anger management problems
- Backed off, hung up, blocked them on Facebook
- I'll cut all contact from her for a time until she settles down. Or has no food then needs to come here to get it.
- Nothing ... not going to let anyone threaten me or my whanau ...
- Stood my ground with them. I will not be bullied
- Remained silent in my fear

Some participants documented serious or continual verbal assaults, that led to restraining orders, trespass orders, calling the police or getting help from other agencies.

- Threatened me with a contract from Black Power. Yelled and screamed verbal abuse and set me up when they shoplifted so that I was caught and not them.
- Hired a bodyguard due to death threats to children and ourselves. Told CYF/Mental Health/ Access Centre 'Care for Kid's.'
- Removed mokopuna and left straight away from situation and said "see you in court for access, get yourself a lawyer"
- Try to calm her. Called police a few times, but they refused to remove her from my property, and said their mandate was to arrest a male, and they would happily arrest and remove my son, although all the abuse was from her
- Discussed later after they calmed down. Twice had to call police who removed the mother.

Participants were asked whether children in their care had ever witnessed abuse from their parents/whanau to the grandparents. Nearly half (42%, or 355/846) had done so, with most of these (85%) witnessing the abuse more than once. Participants documented a range of reactions from the children to witnessing the abuse, including anger, upset, crying, becoming very quiet, "clingy, wetting/soiling, afraid in home", "nightmares", anxiety and asthma.

In some cases, the children told the abuser (often their parent) to "be quiet", or "after a few times it did become sort of norm and they carried on with what they were doing", or "I believe it affects them emotionally, however they appear to carry on with whatever they are doing". Some of the children become quite knowledgeable about mental health issues:

Their father is mental health and when he becomes unwell they know that he does and says things that are upsetting. Sometimes they cry and sometimes they tell me "Nan, dad is getting sick again".

Many of the children were very frightened, which they showed in different ways. It is also evident to a number of the participants that the children have suffered long term effects from viewing the abuse:

- Badly. Nightmares. Fearfulness. Needed a lot of physical cuddles and hugs and closeness for a couple of weeks afterwards. But I also think it contributes to our child's own lapses of control and judgement - it often seems like her mother all over again. Made me wonder how contact with such an example is very good in the long term.
- Emotionally upset and very clingy to me. He doesn't allow me out of his sight for long anymore as he finds it difficult to trust
- That (the day the child witnessed abuse) was the night my daughter assaulted me. We attending family counselling and I hope this helped them. I think they have grown to be better people.
- It has caused them psychological /anxiety problems
- He is torn in loyalties

- I think the oldest and youngest were affected and it has left an emotional scar
- He screamed, was upset. Showed signs of shutting down, very anxious and then shut down emotionally. Developed attachment issues

Safety at home

Participants were asked whether they felt unsafe in their home. The majority (516, or 61%) had never felt unsafe. A second group responded that they used to feel unsafe, but were safe now (189, or 22%). This left 17% who sometimes, often or always felt unsafe in their homes.

Around a third of participants (274 or 33%) had set up a safety plan for their home, and one fifth of these (52) had used it. Families had used a variety of strategies to stay safe. The most common safety strategy was to call the police, and 297 families (35%) had used this approach. Some (177, 21%) had a trespass order to protect them, while others (89, 11%) used a protection order.

Many participants used other strategies to ensure their safety. Some examples of approaches used are provided below. They also illustrate some of the problems that grandparent families face:

- Told the parents that my home was the children's safety place as their marriage breakdown got troublesome
- I filled out a family violence form at police station because I was getting texts from an ex -nasty texts for 6 months. I was the victim and the police made me fill this out and they warned him to stop then they blocked his phone after he didn't stop. He then went and got a Vodafone and carried on. This is what CYFs used against me to get my grandson.
- We set up a school safety plan after child abducted
- I kept my physical address secret from the children's mother for some time while I was unsure of the state of her mental health. She now knows where we live but I will not allow her to visit us here. Her contact with the children will always be away from my home. And that restriction also applies to one of the fathers.
- I have put a lock on my bedroom door
- I have fenced here and have barbed wire on the entrance gate, both to keep people out and keep [child] in as we live on the main highway. The gate is locked if we are home or not for the same reason. I'm lock conscious and have bought night vision security cameras as a backup but don't use them all the time. I also got given a dog to re-home but found having her bark when people stop at the gate a huge security aid so have not re-homed her. I would not have a dog if [child] wasn't here.
- We have moved to an address unknown to parents.

One person felt that safety planning had the potential to make things worse and, of course, many others noted they did not need a safety plan. However, in other comments it became clear that the safety of the grandchildren was a high priority for the participants:

- He knows we would do anything to protect him and keep him safe and although he sometimes thinks we are over protective he likes the fact that we care
- No we pretty much have it under control now
- The time we felt most unsafe was immediately after the court had awarded legal custody to us. As time went on things calmed down a lot.
- In the beginning I needed help in my trauma to protect my grandchildren but today we have grown together well with the support of my family unit, my siblings and my mother while she was still alive.

Some noted that time had passed and things had happened that made the family much safer:

- Eight years is a long time, issues in the first two years have been sorted
- It is good now the drug use has stopped and my son's father is inside
- Felt much safer with child's father in prison and when his other Nan died
- The price of safety is often very high, e.g. moving, changing phone numbers etc
- As we have had no contact from the mother for about 3 years we feel okay now.

Some were still wrestling with safety issues, however:

- If we grant access to her Mother, we have serious concerns about [child's] welfare due to her Mother's associates. We have a court order that states supervised access but her Mother has never been served the court paperwork and does not seem to understand this. How can we refuse a 12-year-old time with her mother?
- The mother of the children threatens to kill us, and police are unhelpful
- Parents are never allowed to be in our home
- It's the friends of the mother that are also a threat but of course I don't know them so it could be anywhere any time

Participants were asked to make any general comments they wished to about the safety of themselves and their grandchildren. The participants had quite a range of safety matters on their minds, and some extracts are provided below.

- The problem has not been so much the direct effect of the violence as the lies told to
 them to make it seem that the violence is justified and their consequent acceptance
 of violence as a means of dealing with people. Their own violence towards each
 other noticeably diminished while they were living with me.
- We haven't had verbal abuse, but we have had undermining from the mother, and one of the uncles.
- I question how access visits with parent/s benefit children when these very same people have abused them emotionally, physically and from the step father sexually
- My daughter will steal from me given a chance and my grandson has learned to as well.

Getting help

Many of the families in this study face significant hurdles in bringing up their grandchildren effectively and needed help for external agencies. The survey explored with them what help they received.

Medical and counselling services

All but 140 (17%) of participants had turned to a range of health-related services in seeking advice and support for the grandchildren in their care, or for their own needs in being a carer. The key services used are outlined in Figure 31 below:

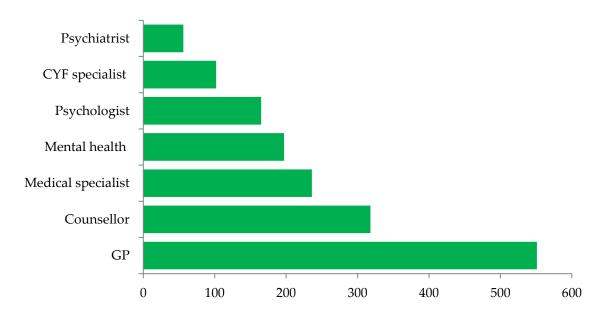


Figure 31. Medical and counselling support received (n= 838)

As well, 120 (14%) listed 'other' services they had attended to receive health support. Other services listed include iwi social services, Plunket, various local agencies, social workers in schools, community support groups, church, God and friends. A few comments illustrate some of the services accessed:

- Tried counselling but in the last 3-4 years not a month goes by without a major event happening...couldn't get over the last event before the next drama came so it was too much...learned breathing exercises
- We were referred by CYFS for these services as the mother was constantly fighting through the courts to regain custody of the kids. Joke really as the mother alone has cost this country thousands of dollars. She went on to have 7 kids in total all uplifted by CYFS
- I asked for grief counselling for my grandson as he has lived in our whanau home all his life, he has seen his great grandparents and mother pass away in his first 5 years. His great grandmother died six weeks before his mum. so the struggle was great for all

• After my grandson was born I started counselling under the sensitive claims ACC programme and was still getting this when the saga with my boy started so I learnt some stress management tips and how not to let my PTSD make the situation worse. I am good now but the stress was intense and I didn't know where to go so I just handled!

Participants were also asked what non-medical services they had accessed for help and support. The list was long and diverse, as shown in Figure 32:

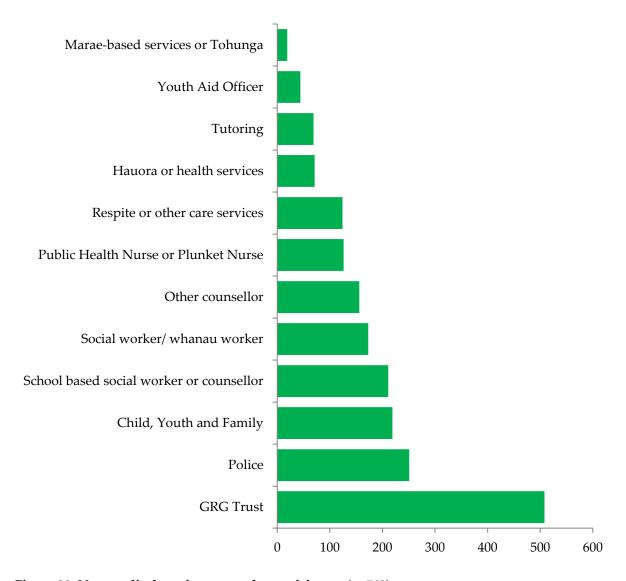


Figure 32. Non-medical services access by participants (n=762)

Participants listed 157 other sources of support including foster and community support agencies, charities and service providers, respite care, Māori Wardens, church and similar supports, tutors, education teachers, special education, legal support, various help lines, health camps, families and friends. Some (<20) noted the right supports were not available in their area:

• But there really is very little help available. Lots of talking but not a lot of the stuff that matters

Of those who sought this kind of support, most felt they had received the help they needed. However, many of these positive comments were qualified by statements that the support was only for a short period, or was not complete, or they had to "push" to get it, or "most times". Around 10% of these participants noted that they did not receive the help they sought. Participants cited cost as a barrier and a lack of the right kind of service.

The next request asked whether grandparents had to pay for *special services* for children in their care. Around 100 participants responded to this question, and 39 stated they did have to pay. Some listed what they had to pay for, these included

- Special shoes \$360
- Yes about \$15 per week extra for Counselling
- Counselling, psychiatric assessment
- Help with reading and writing.
- Mostly lessons: music, swimming, kapa haka, medical costs, etc
- Medical education therapy
- Specialist assessment related to her learning needs (SPELD)
- Petrol to and from appointments is my biggest pay out
- Extra learning at Kip McGrath & braces on her teeth
- Yes tutoring in maths anger management
- Pay for childcare (now \$380, was more) weekly
- Yes we went privately to a paediatrician that diagnosed high functioning autism and prescribed medication

Cost of support

Participants were asked how much it had cost to provide medical or other support needs of the grandchildren they cared for in 2015. In response, 366 people (44%) noted that they spent nil or less than \$100 on such services. A further 130 (16%) noted 'other' amounts, and their comments are summarised below. Of the rest,

172 families spent \$100-300 73 families spent \$301-500 42 families spent \$501-1000, and 54 families estimated they spent more than \$1000 in 2015.

Main costs noted were childcare:

- \$11,000 for childcare, June to Dec.
- For the last year I have paid \$100/week from UCB to my daughter in next city to look after our girl during the school week and she comes home weekends and school holidays. She wanted to do this because our daughter fosters two of our girl's

- siblings and she wanted to live more with them. In return some of them sometimes come back to us also for the weekend, so we are providing respite to each other.
- Plus I owe daycare around \$6,000 when my property gets settled.
- I paid for childcare to work approx \$41,000

The second large chunk of costs was for legal fees for those in the court system:

- If you count legal costs for guardianship and parenting order, about \$4,000.
- About \$15,000 for lawyers.
- Approximately \$5000 for lawyers and court costs

The third large amount was for extraordinary medical and dental expenses:

- [Child] goes to the Dr every month for medication, we cannot get this without a Dr visit so that's 40 mins drive each way. WINZ pay something toward this, his Dr and scripts are free again now but his tablets were costing me \$52+ a month until the law change
- Approximately \$20,000 for ear operations, educational assessments and counselling.

Finally, other costs were noted:

- We spent in excess of \$400,000 for his schooling and special needs from 2003 till 2012
- Ambulance and white cross
- It is more the cost of petrol and time for visits
- Over \$2000 between 2002 -2009

As noted in the section on finances, the grandparents interviewed for this study differ greatly from one family to the next in terms of their income and thus their ability to pay for additional costs. For some, medical bills in excess of \$100 per year are a financial strain, while others coped well paying out higher amounts. Some families are able to get financial support from agencies for their additional costs. When asked, 622 (74%) of participants noted they received no financial support to help with these costs. Some received support from whanau (8%), some from ACC (5%), some from CYF (4%) and some from charitable organisations or a local church (4%).

Other help received included:

- Extraordinary Care fund helps with counselling and we have medical insurance
- Ministry of Education covered \$5500 for special hearing aids and the orthodontist at [place] DHB has seen our granddaughter with braces and dental work free of charge
- We have free GP visits
- CYF told me that they would pay for my legal costs for the court cases, but I am still being sent an invoice from Legal Aid, so I am not sure what is happening there.
- Mileage allowance for over 100 kms
- Glasses
- GRG sometimes help with costs, like swimming lesson or tennis lessons

- I spoke to WINZ and they told me I would have to apply for a disability allowance for him.
- Sealords are going to sponsor swimming lessons in Term 3 of this year, this has been organised through Ngati Koata Iwi
- Yes \$4000 from the Extraordinary Care Fund
- At Christmas a man arrived from the Lions Club, and they gave me \$150 voucher

An Extraordinary Care Fund grant is available to meet special costs, and, as can be seen, a number of families have received it. Others, however, have been turned down, or receive only a small amount, or feel it is too much trouble to apply. There are also a range of other Work and Income supports that can be applied such as special benefit and disability allowances. A number of participants receive assistance from CYF.

Child, Youth and Family

The organisation Child, Youth and Family (CYF) is currently the lead agency in relation to the wellbeing of children in New Zealand. CYF alone has the statutory right to uplift children from parental care, and place them with others. In many cases CYF was never involved in the placement of the children into grandparent care. For 428 people who responded to this question (51% of respondents), CYF was never involved. For the rest, engagement with CYF ranged from a single contact through to long-term engagement relating to multiple matters. Figure 33 outlines how many participants were involved with CYF around various functions of the organisation:



Figure 33. Reasons for contact with Child, Youth and Family (n= 835)

The majority of the comments about CYF were negative. The most common stream was that CYF approached the grandparents to take the children, assisted (and sometimes funded) them to get custody through the courts, and then gave no further support:

- After the initial contact they were involved until we got custody then nothing
- CYFS could not wash their hands of us quickly enough. No support whatsoever once they had written the report that convinced the Family Court to allocate the children to my care. I asked for a FGC, but nothing was forthcoming.
- Since we got custody at the family court, we have had no contact with CYFs.
- I had a visit from CYF when I bought children to [provincial city] as violence with mother and former partner and police needed to know if the children were safe. CYFS told me to go to court and get custody, legal guardian etc as this had not been formally done as I was told could not do anything about her up there. Did this in the family court here uncontested. Mum was there. All of this happened in the first two years until I was awarded guardianship and custody through the Family Court. I liked having CYF involved as there was an outside authority to appeal to at times of conflict! It's a lonely job when CYF pulls out.

The main concern of this group was that the support from CYF was withdrawn (the agency thinking its work was complete, as a safe home had been found), but the problems of the children, for with the families needed support, continued.

A second set of comments were around family group conferences:

- Hui after hui...non productive and no minutes
- Three conferences. The third one was the final one. But it may start all over again because our daughter had a baby after losing three children by CYFS decision
- And it goes on... we never had a say, it seems the mother could click her fingers and we were summoned to court or to hui or to FGC tiresome and frustrating. Our whole lives put under a spotlight. Would we do this again?? NO NO NO
- We had meetings every six months. In some cases, I guess it all depended on who
 the social worker was at the time. They chop and change a lot they all have
 different ideas. Consistency would have helped a lot. [Child] had four social
 workers.

A number of families reported that they had been the subject of allegations of abuse to CYF. These allegations often came from the parents of the children, wanting to 'get back' at the grandparents for having the children. Such vexatious complaints were sometimes dealt with in ways that caused enormous stress in families:

CYFS never contacted us over the past six years since we got the children. I called the senior practitioner in 2012 to catch up and she told me that there was no concerns from CYFS regarding the grandchildren in our care. The parents were never interested in the children either. Their attendance at supervised visits in 2013/4 was

38%. All of a sudden we were bombarded in 2015 with police turning up at home. The mother had laid several complaints of child abuse against us and even went so far to drag extended family members in to lay complaints of abuse. A CYF Social Worker came to see me once. I was never contacted by CYF after that and had no visits from them either. The file was closed and the judge ordered the parents to stop harassing us as all claims by the parents were unfounded. CYFS never offered us any support in any way from the beginning.

CYF had the ability to pay for court proceedings for grandparents to get custody, and in many cases did so. In other cases, however, the families did not get this help:

- Agreed to pay the \$12,000 legal costs initially incurred towards parenting orders but have set us adrift since.
- CYF was supposed to be there during her childhood but weren't. CYF sent us to family court, it cost \$17,000. We had a lot of issues but we couldn't afford to go back to court. It was a huge battle the whole time, a psychological battle with the other grandparents who said the court order was incorrect, but the mother and father were fine with her being with us.

Some people were very keen to outline their experiences with CYF. The following story comes from a grandparent who found that support from the agency often came with a cost:

I want to tell you about the CYFs debacle. We used to get a clothing allowance four times a year for clothing and medical expenses. Now we get the same amount, \$2000, but we have to go into a shop or service, get a quotation, take it to CYFs and leave it with them, get it approved and then go back to purchase the items. It is very time-consuming. One young shop assistant commented: "you people make so much extra work". My grandchild heard that and was very embarrassed and refused to go back in there. Why are they doing this? Well, we asked them that and they said, one grandparent used the money to register her car. And I thought, well doesn't that grandparent drive her grandkids around everywhere? Why shouldn't she use it to register the car?

Aside from issues of quality and consistency relating to service from CYF, there are major unanswered questions from grandparents about what help and assistance they could get from the agency. CYF has a responsibility to provide support to families who are fostering children through the agency, but once custody or parenting orders have been awarded, as noted above, CYF workers and supports disappear, to be replaced by the UCB in most cases. However, where specialist support is required, CYF sometimes offers support (e.g. sexual abuse counselling), but it is not clear what the criteria are. One person suggested that CYF

could channel extra funding for family needs through 'Grandparents Raising Grandchildren.'

By taking on guardianship, parenting or custody of their grandchildren, these families save the state many millions of dollars each year. However, the way CYF has operated has not always helped grandparent families, many of whom are highly critical of the agency. The announcement that CYF will be replaced in 2017 by Oranga Tamariki will undoubtedly be met with cautious optimism by grandparent families.

Community, friends and whanau

Grandparents raising grandchildren get support from a range of organisations. Not surprisingly, most participants in this survey (around 71%) list GRG (NZ) Trust as a form of support, followed by friends (57%), whanau (50%) and other agencies (12%). Results are outlined in Figure 34 below:

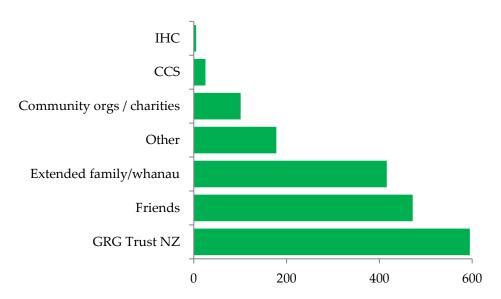


Figure 34. Community based supports used by participants (N=833)

Other supports comes from a very wide range of agencies, including Barnardos, the Variety Club, Birthright, Foster Kids, Whirinaki, Open Home, Life to Max, Big Brother, Big Sister, Supporting Families in Mental Health, Salvation Army, Antara, Jigsaw, various iwi trusts and organisations, Gateway, Epilepsy NZ, Fostering Kids, Shine, Youthtown, Home Builders, Abuse Prevention, STOP, Family Start, many churches, neighbours, other family members (including, for example, great-grandparents being used for respite) and many other agencies.

Some are quite isolated and only have support such as: "GRG online on the Facebook page", "your (GRG) newsletters offer some handy tips". Some commented that they did not need external support, but "if need be we will seek the appropriate assistance". Overall, however,

the wide range of agencies demonstrates that grandparent families do access help to assist the grandchildren in their care, including general and specialist agencies, whanau and friends.

Many participants in this study have recounted significant disputes with the parents of the grandchildren in their care. The study sought information on the overall support offered by whanau to grandparent families, and asked whether extended families had been supportive:

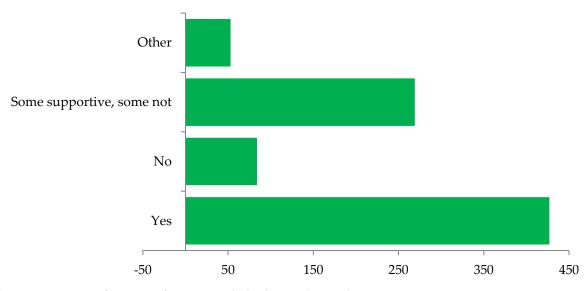


Figure 35. Extent of support from extended whanau (n= 833)

A number of the grandparent families received direct support and assistance from their whanau, but in a limited way – the occasional night of respite care from children, the other grandparents or others was mentioned. No participant wrote about more substantial family relationships, although these clearly exist. Some go out of their way to ensure the whanau knows what is happening with the grandchildren:

Both sides of the family are supportive. I've kept them in the loop. I haven't held back, they know exactly what is going on

Some found their whanau supportive but this did not mean they were able to assist on a practical basis with the role of bringing up the children:

- All overseas but have had moral support from them
- I have had emotional support only. no one is in a position to offer respite care
- I had some support from them initially but we don't see any of them at all now
- While the family remains supportive, the issues of distance, travel and the need to work continue to generate considerable impediment
- Family are all busy with their own families
- The ex-husband, grandfather of the children, was initially supportive, but quickly tired of the role! My son was simply wonderful! Could not have done it without him.

For some, family dynamics and individual views rule out support from whanau:

- We have lost my son, his wife and my daughter, they have completely turned on us because we are supporting my wife's daughter. They should be proud of us. We would like their kids if they needed it but luckily they don't need it like these ones do. We love them but we are very disappointed in them
- Supportive but also judgemental...hard to understand for many
- My ex-husband does everything he can to aggravate the issues between me and [child's] mother
- Some people behave strangely when in stressful situations.

Often the whanau relationships are complex and the support limited. The following extract demonstrates this:

My eldest daughter is the most helpful. She will spend time with the kids when we visit or she comes here. The same with her husband, but they will not offer to take the children off our hands for a bit so we can spend time by ourselves. My parents do not want to know about the children or their mother as they are ashamed of the situation and how it came about. Other extended family members couldn't care less.

Around a third of respondents reported feeling estranged from their whanau (282/833).

Respite care

The government-sponsored KidzaCool programme is offered around the country for five days at various times of the year. Children living with biological or adoptive parents are not eligible, so it is very much targeted to grandparent and foster care families. The programme is advertised in GRG (NZ)'s newsletters and on their website.

Despite this, only 39% (321/832) of participants stated they were aware of the programme, and only 94 families (11%) have used it. Of those who have used it, most (71%) thought it was long enough, and most (86%) thought it was beneficial for the children.

One participant noted:

They have now cut them down to only twice per year, used to be three times. They are too small and therefore can only take a small number of children. They do not cater for special needs children. They are not long enough and yes, from what I have heard they are beneficial and much needed.

Those who provided a written response about any camps they had used were divided between those who had found and used camps, those who had not found an appropriate camp and those who do not need or want this kind of respite care. Sometimes just a day programme during the holidays can provide adequate respite:

The school holiday programme has been invaluable. It's given me the best respite and been super beneficial for the kids.

A variety of programmes were mentioned as beneficial, including Matakokiri, the YMCA, Christian camps, school camps and a range of day programmes.

The children

According to Figure 15 above, 1763 children currently live with the grandparent families in this study. The goal of the study was to capture detailed information on each of the children, and therefore a bank of questions was asked, which looped back second, third and subsequent times to capture information about each child. Given that the survey was very long even without these multiple responses, it is not surprising that many of the participants took up the survey's invitation to complete only as many loops as they wished. In fact, most complete only one or two, with some completing three or four. One hardy participant completed six. In total, individual information was provided for 1324 children. The data provides a rich repository of information about the situation and wellbeing of these children. Not all cells were complete for all children, which explains differences in the number count.

The age breakdown of the children is outlined in Table 6 below:

Age in years	Number
Less than 1	54
2-5	281
6-10	501
11-14	319
15-18	145
18+	24
Total	1324

Table 6. Number of children by age of child (n=1324)

The gender of the grandchildren was 644 females and 683 males. A summary of the relationship of the carers to the children is provided in Table 7. The category 'Grandparent' also includes Great-Aunt, Great-Uncle and Step-Grandparent.

Relationship	Number	
Aunt or Uncle		27
Grandparent		1235
Great grandparent		44
None		18
Total		1324

Table 7. Relationship of carers to children (n=1324).

Participants were asked how long each child had been living with them and responses are laid out in Figure 36 below. The modal number of years was 3-4 years, followed closely by 6-8 years, but the sample represented the full range of living years.

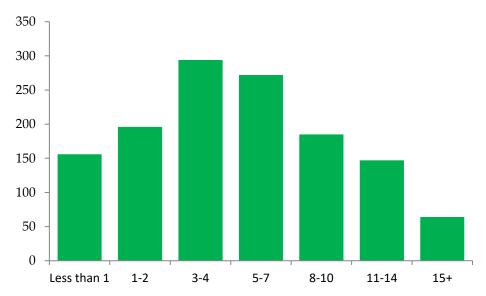


Figure 36. Number of years children have lived with grandparent carer (n=1314)

There were 10 blank responses to this question. Participants were also asked with whom the child had been living prior to coming into the grandparents' care, and responses are outlined in Figure 37 below.

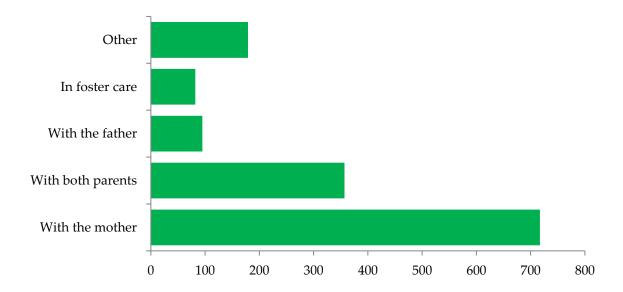


Figure 37. Prior placement of children (n=1327)

By far the majority of 'other' comments noted that the child had come into care from birth (or close to it). As one participant cutely answered: "in Mother's tummy". Below are a variety of comments from those who have had the child since birth:

- My moko and I have lived together since his birth, with his parents it has only been the past four years that I have had sole care of my moko.
- I have had her from birth. I got her from the hospital at 4 days of age
- He has lived with me since birth, the first year his mother was unreliable so I sought legal advice and applied to the family court for guardianship.

- With me but mother came and went
- Barnardos Home two days after birth and came to me at two weeks.
- She was in Holly House
- Prem baby born 22 weeks and is now 6 weeks old. Waiting for release of my mokopuna sometime this week.

Other scenarios were explained by participants, involving a range of often complex triggers for grandparent care:

- Mother was killed in a motor accident. Nobody wanted him
- Was with adoptive parents but mother wanted back, father (our son) intervened and was granted day to day order of said child.
- Was with great grandmother
- Child Youth and Family had placed [child] with the paternal Grandmother
- Other Grandmother also until [child] was 14 months had guardianship
- She has lived with us from birth, as the granddaughter we raised was only 16 when she had her
- Mother died, father is useless

Participants were asked to list all of the factors that led to the child being in grandparent care. This involved choosing from a long list of reasons, and also the ability to add 'other' reasons. The top six reasons, all cited by over 300 participants, are outlined in Figure 38.

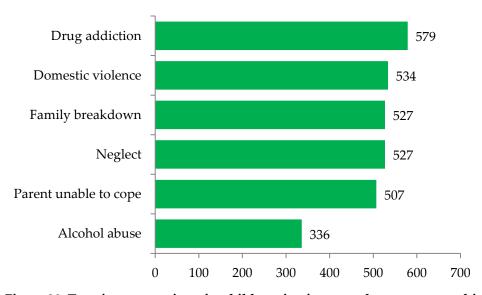


Figure 38. Top six reasons given for child coming into grandparent care, multiple reasons allowed.

Many of the 'top' reasons are cited together much of the time, and tell a difficult story of drug use and abuse, cycles of violence, break-up of the family, increasing neglect of the children's needs, a feeling that the custodial parent is unable to cope and related alcohol abuse. Not all, or course, cite all these reasons, and the stories often differ from whanau to whanau.

The rest of the chosen indicators range from a high level of parental illness, down to a small number of physical, mental and intellectual disabilities of the child that led to them being put into the care of grandparents. Other smaller issues include parental imprisonment, abandonment and the youth of the parent. In total, 69 parent caregivers died leading to the children being placed into grandparent care.

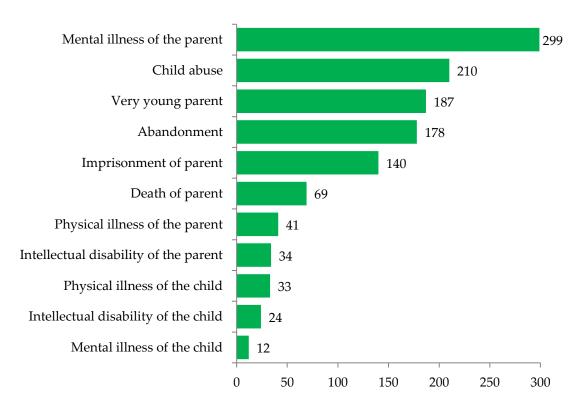


Figure 39. Other reasons given for children coming into grandparent care, multiple responses allowed.

As well, 145 participants noted other reasons, including CYF orders, gambling addiction and bad influences such as gangs, violence, sexual abuse (in one case by a brother) and children left alone. Some of the outlier 'other' responses were that the mother suffered from Munchhausen's by Proxy, a mental illness that involves exaggerating or, in some instances, causing a child's illness in order to get attention; the death of both mother and father, the murder of the father, the murder of the mother, suicide and suicide attempts and a child not "fitting in" to a blended family.

Participants were given the opportunity to tell the story in their own words of how and why the child/ren came into their care. They wrote well over 20,000 words between them, and these stories will form a separate paper at a later date.

Child, Youth and Family involvement with the child

As noted above, CYF has a number of different roles in relation to the children in care, and the participants were very keen to give their views about the agency. In this section, the role of CYF in facilitating the move into grandparent care is examined. While there was no involvement with CYF in relation to 374 children, for many others, CYF played multiple

roles around the shift into grandparent care. The different roles played by CYF, and their frequency, are listed in Table 8, from the most common to the least common.

Type of action	No. children
Child Youth and Family made an assessment/investigation	499
and had concerns about this child's welfare	
Child Youth and Family asked me to get parenting/custody	498
orders from the Family Court for this child	
A Family Group Conference was held	380
No involvement with Child, Youth and Family	374
A Family Whanau meeting with Child Youth and Family was	335
held	
Child Youth and family asked me to take on the care of the	331
child	
Child Youth and Family got court orders and placed the child	201
in my care	
I have this child in my care through the Home for Life	88
programme	

Table 8. Various roles played by Child Youth and Family around grandparent care.

As well as those listed roles, participants were keen to have their say about the role of CYF. Comments ranged from families who were "very pleased" with the role of CYF, to those who believe the agency's intervention was anything from incompetent to disastrous. There is little doubt that some unevenness exists in the agency's response to families. It is also clear that the space in which the agency works is highly contested and not easy.

One area that was revealed in the research was that in some cases CYF would pay the whole cost of the Family Court process for caregivers, while others were left to cover their own costs, with disastrous results:

[Child's] Father and I went to CYFs for advice. I expected them to take this family under their wing and perhaps give [child] to me for a period of time whilst they worked with the family but they sent me straight off to the family court which is costing me a fortune as I own a property whilst both parents are on the dole and have had to pay nothing.

A number of participants made brief comments that CYF was attentive, helpful, communicated well and did good work. Those who had become 'Home For Life' carers were, in general, pretty happy with the support they received in this programme.

For others, the process was far from smooth, and CYF did not always work effectively with grandparent families. We will provide three examples of accounts written by the participants:

The family group conference didn't achieve much, it was Family Works support that got us through. They were brilliant. The lady there was absolutely disgusted with CYF. CYF never followed up on anything they said they would do. Only visited us ONCE and that was 2 days before the final orders. The lady was no sooner here than she got a phone call and said she had to go!

Child Youth and Family allowed the children to be returned to their mother. They kept my mokos under a family agreement for a year and there was a breakdown in the family. I then put a complaint regarding my concerns and then my mokos were placed 12 times with other people who were not kin. I then applied for my caregiver papers and was approved after one year. My mokos live with me full time. CYF has a lot to answer for.

The child was removed from the mother's care when we reported concerns that the mother was verbally abusing him and only returned following a FG Conference. The FGC was a disaster. Nobody knew what was going on and nobody had time to think through the consequences. Throughout CYF were adamant that the child should go with the father's family and totally ignored the gang environment, suspected drugs and physical violence environment into which he would be placed. He returned from one visit to his father and there were obvious signs of physical abuse which was confirmed by a G.P. This was ignored by both the Police and CYF because the report had not been carried out by a child paediatrician.

Legal status of the caregiver

Most caregivers have sought formal agreements or court orders in caring for their grandchildren. There have been several drivers of this. The most-cited reason is a search for security and stability in the relationship. With many of the parents involved in drug-taking, family violence, and a wide range of other problems (as noted above), clear rights and responsibilities are important to the carers. As well, in many cases CYF encourages carers to get family court orders to formalise the relationship. This can sometimes be a prerequisite for forms of financial support.

In this study, 823 of the children have carers that were awarded a custody order (before July 2005) or a parenting order after that date. In most cases (535) parents agreed with or did not oppose the order, but in a minority of cases there were ongoing disputes around the court orders.

In the case of 133 of the children, there are no legal orders, but likely to be parental agreement to the caring arrangement. Most of these families (119) have a written agreement in place that governs matters such as caring arrangements and visitation rights. Essentially, where there is no dispute over caring, there is little need for a legal order unless CYF becomes involved. The law does not require parenting orders or written agreements as to care to be eligible for the UCB.

Eighty-five children's carers were currently still in legal dispute, and 29 stated they did not know the current legal status. In some cases, a range of factors have held up the completion of legal processes, so that while the child is in the care of the grandparents, this remains a voluntary or contested situation until the court orders are complete.

We were supposed to go through mediation, but my daughter has not yet done the parenting program we were both supposed to do. I have done my bit, but have been waiting on her, which my lawyer had advised me to do. Mediation is on hold, but my daughter has since voluntarily given him to me & I am currently taking on the responsibility of caring for him on a full day to day basis (for now anyway)

Other points were made by 194 participants.

Several noted that children in their care were now 18 or older but still dependent because of severe disabilities. One person noted:

- I was the legal guardian until he turned 18 and now I have to go back to court to get the rights to meet his needs.
- She is no longer a child but is diagnosed on Autistic Spectrum

Others have apparently just continued caring for the young adult.

Some continue caring for their grandchildren even when agreements have expired or are changed, often involving quite complex relationships:

- I have a letter from [child's] previous caregiver, who had legal day to day care at the time. She wrote a letter stating that she was placing [child] into my care and would keep in touch for the next 6 months. After that, she left the area and does not check up on how things are going.
- His father has legal day to day parenting order and his mother has no contact unless
 it is agreed to by us (which I do as its important for our boy, it's spasmodic but better
 than nothing as she lives four hours away from us and isn't quite all there mentally).
 As his father is in prison the child continues to live with us. CYFS may be involved
 later when his father is out and wanting contact.
- Court Order shares the responsibility between the aunty and father. Child is supposed to stay with aunty and has every second weekend with father. Holidays are shared equally. However, because of aunty's work commitments is unable to cope so he has ended up with us.

Joint parenting orders, and situations where the carers are not legal custodians, are not unusual:

- I am a joint guardian with the father. I have sole custody.
- I have additional guardianship and day to day care
- Other grandmother has custody also however never sees her

- My older daughter has shared legal guardianship and has started shared care the
 past year and we now share week about care of him. I chose this option but shared
 was his wish as has had me as main carer all his life
- Great grandparents have parenting and guardian orders ...still waiting for CYF to transfer orders to grandparents (4 months later)
- I think it is that CYFs have legal guardianship of the children
- The father has custody, we care for the child

CYF can gain or transfer permanent or interim custody under sections 101 and 102 of the Care of Children Act, through the courts, and many people noted that their children were under 101 or 102 orders. CYF also encourages some grandparent carers to provide a 'Home for Life', which offers custodial stability and state support.

The caregivers of 597 children consider the current legal situation to be stable and long-term. Some are concerned about what will happen in the future, once orders expire (some when the child reaches 16). Some 'think' the arrangement is stable, but:

- I think so, however the parents are currently going through the courts for full custody.
- I think so, however the parents are currently going through the courts for return of all their children to their care.

Some have strong concerns – expressed strongly!:

- It's crap drug addicted parents should not be guardians
- No I don't think our status is stable or long term
- No, this is my third time in family court for this child, I doubt it will be the last
- When the children are feeling safe and are stable the courts allow parents to have them again and mess them up all over again. I personally think the law is an ass

While around half of the children are in very stable situations, then, a range of issues face the carers of the other half, maintaining their anxiety about the future care of the children.

The Family Court processes experienced by the families, while touched on here, are being examined in two further studies in 2016 and 2017.

Access

Participants were asked how often the child had access to their mother. Responses are outlined in Figure 40 below.

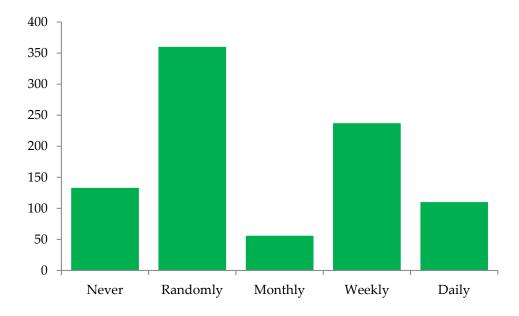


Figure 40. Frequency of visits with mother, excluding 'other' response (n=896)

The most common response was 'randomly', indicating that for many children, a good pattern of visitation was not continuing. As well, 388 participants responded to other arrangement. Many of these document visits more frequent than weekly:

- This has been every Wednesday 3 hours every Saturday 10 til 5 and every second Saturday overnight
- We have an arrangement whereby the child sees her mum at least twice weekly and stays overnight with her once each month. Extra visits take place when and if my daughter asks me for them and it is a suitable time often.

Some parents sometimes have difficulty making regular good visits:

- More regularly when she is in town, but she keeps leaving...runs out town chasing druggie boys, we are left to pick up the pieces
- When he was a baby. But I was always there. Was always late and stoned... so in the end I told her no more. She has made no effort to see him since.
- When she is drunk or drugged out of her mind she uses electronic media to contact him in the middle of the night and abuse my name and telling him to toughen up and go back to "The Bros"
- Originally it was daily for the mother but not the father. I allowed her to stay with the parents one weekend when she was three and she witnessed her father hitting the mother and then he raped her in front of the two girls.
- Could hear from mother two three days in a row then not for a month or more

Social media and the internet has provided a (mostly welcome) new way of keeping in touch:

- She is on Facebook now. Contact with siblings all the time, contact with mother on FB is alright, but never let her stay with mother, been there done that
- The mother can only see her in court approved supervised place and she has not arranged this in 3 years

Sometimes grandparent carers have to travel with the children to gain visitation. A number comment that they have to drive from one town to another, and some a considerable distance, to ensure that the child sees their mother. Some have to go to prison:

- Sometimes she phones him from prison and occasionally we take him to visit. He has not seen her since mid-December because twice when I have arranged to take him he has decided he didn't want to go
- While in prison court ordered every weekend. On this second term of imprisonment we take [child] when we can

Participants noted 46 times that a child's mother was deceased, including as a result of murder and suicide. As the deceased parent is often the child of the grandparent, there is often significant pain associated with those deaths:

• [child] had very limited contact with her mother due to her ongoing personal problems. However, in the last year she was making great effort to be a part of her daughter's life & spent a wonderful week & a half with my granddaughter & seemed very positive about seeing her more often. Sadly not long after that holiday together she took her own life due to other personal problems:-(

Sometimes there are no visits, as a result of choices by the children or the mother:

- The boys are old enough now to choose, and they choose not to have any contact. They got sick of having visits and not have her turn up or being hours late.
- He use to have contact but every time she contacted or seen him his behaviour would go downhill everyone noticed it "SAFE, School, Me" He was asked he wanted to see her and his answer was (No its alright Nana, I not want to see her) things have become better since he doesn't have to see her he knows he can have contact with her if he wants but he wishes not to
- She has not heard from her Mother since she was 11 years old and told her Mother to stop lying all the time and step up and be a Mother and stop letting her down all the time. She refuses to talk to her Mother because her Mother kept calling her a liar.
- The mother stopped her visits to the child when he was two years old
- Should be Thursday every week but she never turns up
- Mother is welcome to have contact and was but seems to have disappeared and not heard of for two years now. Hard to explain to a child. Needs to be a part of her life or not.

Participants were asked whether the visits with the mother were beneficial or harmful to the child. Responses are summarised in Figure 41:

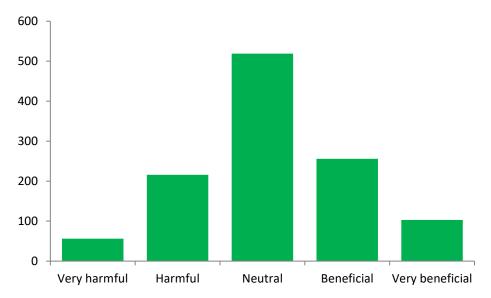


Figure 41. Effect of the visits with the mother on the children (n= 1150)

In addition, 178 responses were not recorded, as the child did not see the mother. The graph skews slightly towards the beneficial end – more grandparents felt the visits were beneficial than not. The largest group in terms of response was neutral – that maternal visits made no difference to the child.

Participants were then asked how often the child had contact with the father.

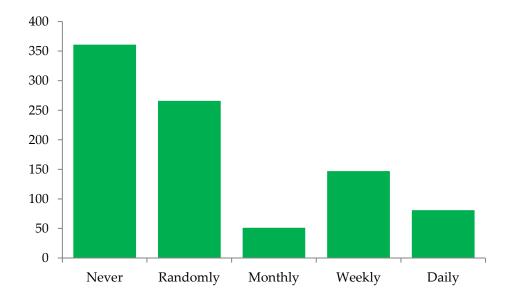


Figure 42. Frequency of visits with father, excluding 'other' response (n=895)

Fathers were much more likely than mothers to never see their children. In other comments (374), participants noted a high imprisonment rate (20 currently in prison) and that 32

fathers were deceased. The 'other' comments had few positive stories about visiting with the children.

A similar pattern to mothers is revealed when participants were asked what effect the father visiting had on the child. Around 20% were concerned that the visits were harmful or very harmful, while most were considered neutral, beneficial or very beneficial.

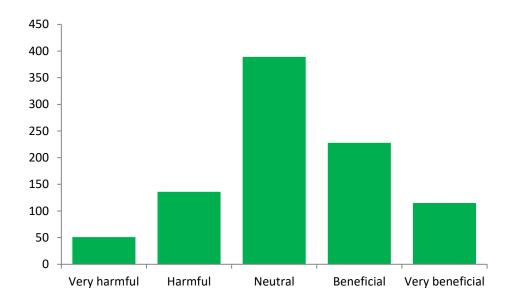


Figure 43. Effect of the visits with the father on the children (n= 919)

In many cases, when deciding on guardianship or custody, the family court also rules on how often the parents should have access to the children. In other cases, the guardian is able to make such decisions themselves. In this study, 482 (36%) of the children had access set by court order. This group was asked whether the terms of the contact order was beneficial to the children. Many (30%) thought it was beneficial, most thought it was neutral (40%) and many thought it was harmful (30%).

Comments about access generated around 1200 responses, and ranged from hair-raising stories of overnight visits to very beneficial access. Five comments, spanning the spectrum, are outlined below, and this data will be analysed separately in a later paper:

- The fortnightly contact is difficult. The father is not really working and makes no real effort to go training or upskilling. There is that gang environment and guns and hero worshipping. The house is small so the boy has to sleep on the couch and he does not have a room or a place on his own. Cousin showing the boy a gun is not good. The boy has stated on a number of times that the father has punched him. We have him settled and stable then when he comes back from his father it can take at least two days to get him focused and back on the right track again and not talking about cousin ***** and his gun.
- I agree with contact, set up right it should be beneficial for children. However the court leaves supervision to caregivers or family and friends. The do not understand the issues, and what is required of a supervisor. The biggest harm from contact visits

is the verbal, emotional and psychological abuse. e.g. getting the child to lie (even about things like not using a car seat that is legally required), constantly questioning the children and undermining my caregiving (telling her that I am mentally unwell). This would be disruptive for any child but with a child who has suffered abuse in her earliest years, it is constantly re-traumatising her twice a week, first with contact with mum and then with contact with dad.

- The relationship he has with his mum is really good and healthy. Don't know where the father is at all
- Saddened by the fact that in the 8 years I've had her, open access has always been available to her father (my son) but he disregards it and I feel it in my heart for my granddaughter what she must be feeling for such a distant father
- Contact is at my discretion. At the moment I have no concerns. My moke stays with his mother for weekends once a month. He has contact with his siblings which is good for him and his big brother
- She is on good terms with her birth father and step father
- The father fills them with hope then lets them down by not keeping his promises
- It is good that they are seeing their mother again they used to worry about her when they didn't know where she was.

The health of the children

Participants were asked to estimate how often the children suffered from physical, mental, emotional and behavioural problems on a five point Likert-type scale. The responses (raw numbers) are outlined in Table 9 below:

	Physical	Mental	Emotional	Behavioural
Never	445	944	376	417
Sometimes	729	203	588	540
About half the time	53	52	166	150
Most of the time	26	37	90	102
All of the time	17	34	50	61
Total	1270	1270	1270	1270

Table 9. Frequency of health problems (n=1270)

The least frequent health problems were mental illness, with less than 10% of the children having such problems half the time or more (mean score 1.43 out of a possible 5). Physical health problems (1.77) were next least prevalent. Both behavioural and emotional problems scored an average of 2.1, with around 20-25% having such problems half or more of the time.

Participants were then asked to indicate any problems the child has, from a list drawn up of common health and behavioural problems of vulnerable children. While 277 children have none of the problems, most had one or more.

The results are outline in Figure 44 below. The most common problem was anxiety, followed by a lack of confidence, skin problems, asthma, hyperactivity and difficulty sleeping.

Lesser problems (often occurring in conjunctions with others) were damaging property, bedwetting, soiling, unusually quiet, stealing, self-harm, sexually inappropriate behaviours and running away.

Of those children who had a problem, on average they each had 2.6 problems.

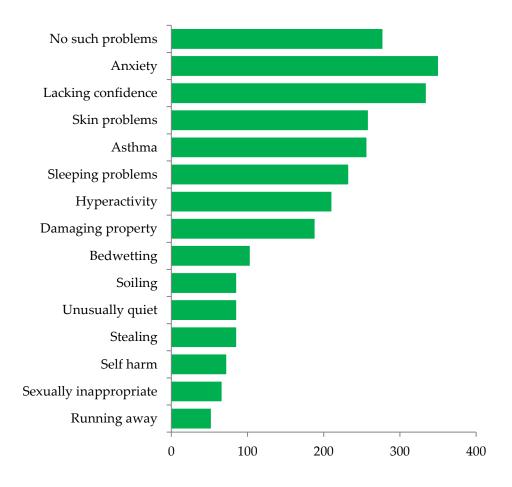


Figure 44. No. of children having specified health or behaviour problems (n=1270)

Participants were asked whether they had sought help for these problems. Most (767/1267 or 60%) had done so. Of those, 397 stated they were happy with the help received. Others felt they should wait until the child is a bit older, or are waiting for treatment, or are relatively happy at the moment. Of those who were not happy, there were issues from access to services, to quality of service, a tendency to 'talk down' to the grandparents and a range of other problems. Some stories below:

- No, very unhappy. Our GP has been our rock. He is absolutely appalled at the lack of help. He referred her to child mental health 2 years ago. The parents do not support the referral. This part of the reason we are in court (for over a year now). Child mental health will not assess her until we have a court order for permanent care. Meantime she has been self-harming for 2 years.
- I have been very unhappy in the help. The length of time it takes, the quality a lot of trainees and experimenting, right back through MOE and mental health services
- The school knew she was suicidal and arranged counselling without telling me until afterwards. Maybe they thought I might not cope with it. They were trying to keep her stable and I had a lot going on
- He has Noonan syndrome and cerebral palsy (two different things). In wheelchair during the day and needs help at night. At the moment I pay one of my granddaughters to come up and help. I am waiting for new needs assessment. A 74

- year old woman left alone to look after young man with severe disabilities. They offered to come in at 3.30 and put him to bed 'no way'. He is in [name] Home 3 Thursdays a month and one weekend. My granddaughter showers him.
- This has become more prevalent as she has got into her teens. We are dealing with suicidal and self harming issues at present. We are seeing [MH service] but would like more assistance from a psychological perspective rather than strategies on how to cope!
- It was so hard to find help I asked and asked and cried and cried at the little help there was for me and my Grandson it wasn't until it spilt over at school after one of his Mother's visits that I was contacted about his behaviour and then I was offered support from SAFE I put him in it and it was one of the best things Now in his sessions he brought up about what his Mum had done to him and his counsellor said when he finished that he needed to get support through a counsellor to help him with what his Mum had done to him There are no children counsellors up here in the Far North It's been 6 months and I still can't find one or his Doctor, not one that deals with children anyway
- No. He is now under [disability provider]. They have done nothing. They never turned up on the initial appt date. I have trouble getting through to the social worker. He doesn't answer calls. He said over a week ago, he would send forms for respite care. The forms haven't arrived yet. 3 other people have told me, you have to keep phoning to get any service. A big disappointment.

Around half the sample state they still need help with the health issues. Help needed includes access to services, someone to talk with, a proper diagnosis, support group, access to free services in the community. Please, a number of them said, help us.

Psychological issues

Participants were asked whether the children had any diagnosed psychological problems. Compared to the previous sections, the numbers were relatively small, perhaps supporting the caregivers' complaints that they could not get effective access to services. Of the 1162 responses, 481 children, or 41%, had diagnosed problems. Of those with diagnosed problems, there were on average 1.63 diagnoses per child (481 children shared 786 diagnoses).

The most common diagnoses were Attachment disorder (113), Anxiety disorder (110), ADHD (106), violent or aggressive behaviour (92) and post-traumatic stress disorder (PTSD) (74).

Others were Destructive behaviour (67), Dyslexia (38), Autism (36), Asperger's Syndrome (32), Dyspraxia (20) and misuse of drugs or alcohol (16).

The incidence of diagnosed psychological problems is outlined in Figure 45 below:

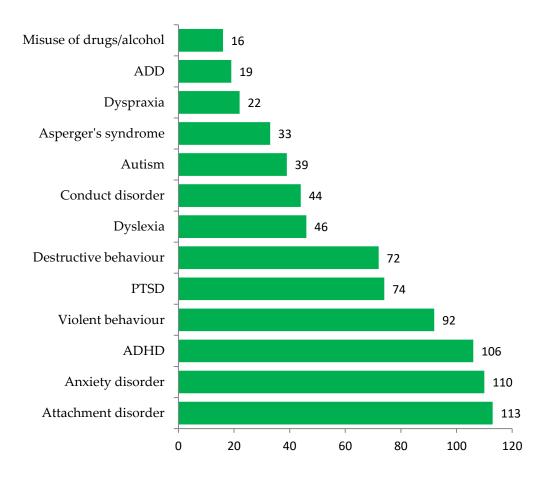


Figure 45. Incidence of diagnosed psychological problems (no. children =481)

Many (216) other comments were received on this question. Others noted many different diagnoses, some with significant psychological implications. Of these, a diagnosis of fetal alcohol syndrome (FASD) was the most common (10 or more), and oppositional defiance disorder (ODD) was relatively common. Some noted a range of factors: "FASD, Separation disorder, ODD, Genetic disorder".

A number of people noted they did not have a diagnosis, but: "None diagnosed but she sure ticks a lot of boxes for symptoms of some of these", "no diagnosis yet", "We have had three court ordered Psych reports and each time they arrived at different conclusions and all three have been wrong. Not just my opinion" and "She displays behaviour that fits under several of the above conditions but she has not had a formal diagnosis".

Most children had no reported intellectual disability, but nevertheless the incidence of intellectual difficulties is higher than the overall community (estimate of 5% in community, 12% of this sample). Around 9% of the population (115 children) reported minor intellectual issues. Many of these stem from other health or development issues, including development delay, deafness, learning problems and the FASD noted above.

Around 5% of the child population in the study (70 children) have an intellectual disability that 'somewhat' affects their lives. These include missing chromosomes, Cerebral Palsy, FASD (more severe) and a very wide range of other diagnoses, for example:

- Cohen's syndrome
- This child attends Special Education. Plays football for Sunshine Football Club.
- Bipolar affects her badly some days but we have good days too.
- He is in a motorised wheelchair 95% of the time if he walks around too much he falls and at 38kgs he can be rather heavy for a old lady to lift. I do have a hoist but until we are given a transfer by Housing NZ the lift and the wheelchair are not compatible to this home. Housing promised 2 years ago but nothing is happening.
- Eye problem hearing and speech
- No memory retention
- Down Syndrome
- He has Sotos Syndrome, in his early years affected his intellectual quite bad, but is border line now, they called it an impairment
- Spina Bifida, Hydrocephalus VP Shunt, Arnold Chiari malformation 2
- Very slow learner, doesn't retain what he has been taught, as result of head injury. Two instructions at a time is the most he copes with.

Finally, 20 children, which is about 1.5% of the child population, are reported to have an intellectual disability which severely affects their life.

- IQ 72, severe global developmental delays, physical delays, social phobia, school phobia (bullied and embarrassed that she can't do the same work as the other children) at 8.5 her levels are still below new entrant. ADD
- Shaken baby syndrome
- [child] is unable to attend school due to his brain injuries that is over ridden by his
 previous home life and inadequate care from the WDHB when admitted when run
 over.
- ADHD, PTSD, Sexual abuse, Delayed Global Development, Dyslexia, Opposition Defiance Disorder
- Cerebral palsy

This section has reviewed the many and multiple health issues that affect the children in the study.

Education

Participants were asked what kind of early childhood education or schooling the child was receiving, and responses are summarised in Table 10 below:

Type of education	No.
Early Childhood (ECE)	188
School	903
Home School	8
Other	125

Table 10. Type of education by provider, children (n=1224)

Twelve of the others noted that the child attended Te Kohanga Reo or Kura Kaupapa Māori . Several children had been suspended or excluded from school, and others have left school young. One girl is at a Teen Parent school. Two are at a special school and many have special needs funding or receive special education. Others attend out of school classes for literacy, music, karate and other learning.

A number of children are said to be on 'reduced hours' (usually because the school states it cannot deal with the child's needs in the classroom):

- 3 hours schooling a day, due to lack of focus and anger
- 3 hours school per day
- Shortened hours has RTLB to help

A number of children are in transition or tertiary courses, doing their NCEA, doing degree studies, studying for diplomas or NCEA on the tertiary framework.

	Support to learn and achieve	Support for healthy development	Support for grandparent carers	Protects child
Strongly disagree	53	47	42	30
Disagree	82	80	55	23
Neither agree nor disagree	159	191	163	327
Agree	510	542	502	469
Strongly agree	449	393	491	404
Total	1253	1253	1253	1253

Table 11. Ranking of schools attended by children on a range of characteristics.

Many of the grandparents expressed their great happiness with the education that the children are receiving:

• We are so lucky to be at a school which cares about the children they educate. Amazing school.

• She is doing extremely well at school, academically and sport plays netball and is full of confidence.

However, many of the children were facing difficulties at school. Some are only at school a few hours per day (a relatively common arrangement that does not follow the Education Act), or are home schooled because they do not fit in at school. Some stories:

- Most teachers were very understanding and supportive. However in Year 5 the
 teacher had no understanding of the difficulties we were experiencing and banned
 her from going to camp with her class, because of her behaviour. The school
 supported his decision but two other teachers who knew her well were anxious for
 her to go and they would support her. but she missed out on camp that year.
- 3 years high health fund, then changed schools and denied funding so no toileting help at school
- He has had teachers who couldn't cope with his family placement issues (mood outbursts) when he was struggling. Once the school was spoken to by me, he is now with a mature teacher and absolutely thriving.
- He was excluded from school
- Private school for her special needs
- I have been teaching my moko Te Reo and would very much like this to continue, however today I was told that I should maybe just stick to English since I do not speak fluent Te Reo, and that I would be confusing him at school by speaking Te Reo at school, but yes they do not have that at his school, they do have a kapa haka group, but nothing for the younger students.
- I have cut down on the food bill to pay for Kip McGrath for help with Maths and Grammar.
- We are putting in a lot of resources into [child's] education

Most reports of the children's schooling are reasonably positive, although a minority have ongoing difficulties with schooling, and can pay the price for this in home-schooling arrangements, private schools, tutoring, short hours or additional support. For a small minority, schooling is a constant struggle, while for many others it is going very well. The question here is whether the problems arise with the children in the previous chapter who have known health or psychological problems, and thus need the most additional support.

Conclusion and next steps

This 'first cut' report is concluded, but there is far more work to be done with the data collected in this study. As noted in the introduction, a range of drill-down issues have been identified for further study and these will be released over the next few months. An additional study on the Family Court experiences of the families will also be released before the end of the year.

The participants in this study are socially and economically diverse and at different ages and stages of their lives. They are united in having, in parenting terms, skipped a generation (or two). The outcomes for them depend on a range of internal and external factors, including family resources, quality of housing, their health, single or partnered families, the relationship with the children (including reasons for the grandchildren coming into care), issues in custody, treatment by state agencies and, finally, the needs of the children.

What should be clear is that the families deserve our support. They provide not only the necessities for their grandchildren, but also something that cannot be bought or contracted by the state: family love. This shines through in many of the words used by the grandparents to describe their relationship with their grandchildren. Without these grandparents, most of them women, the state would be stuck with the costs and the often negative outcomes of non-kin foster care.

Bless the grandparents doing this crucial labour of love!

* * * * *

fveryone needs to have access both to grandparents and grandchildren in order to be a full human being. ~ Margaret Mead

If I had known how wonderful it would be to have grandchildren, I'd have had them first. \tilde{f} fois W_{yse}

What children need most are the essentials that grandparents provide in abundance. They give unconditional love, kindness, patience, humour, comfort, lessons in life. And, most importantly, cookies. ~ Rudy Giuliani

Perfect love sometimes does not come until the first grandchild. ~ Welsh Proverb

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