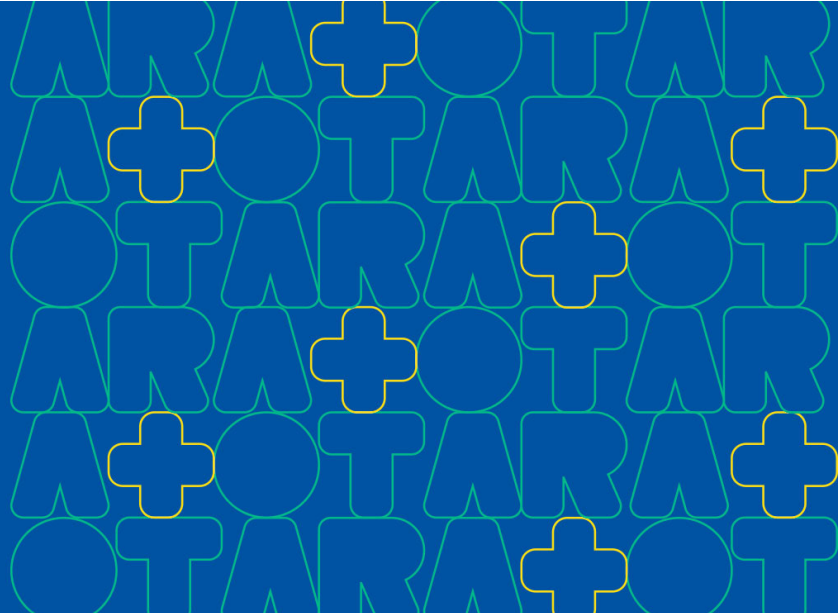




OTARA HEALTH  
CHARITABLE TRUST

# CHILD DISABILITY ALLOWANCE (CDA) Evaluation Report Launched

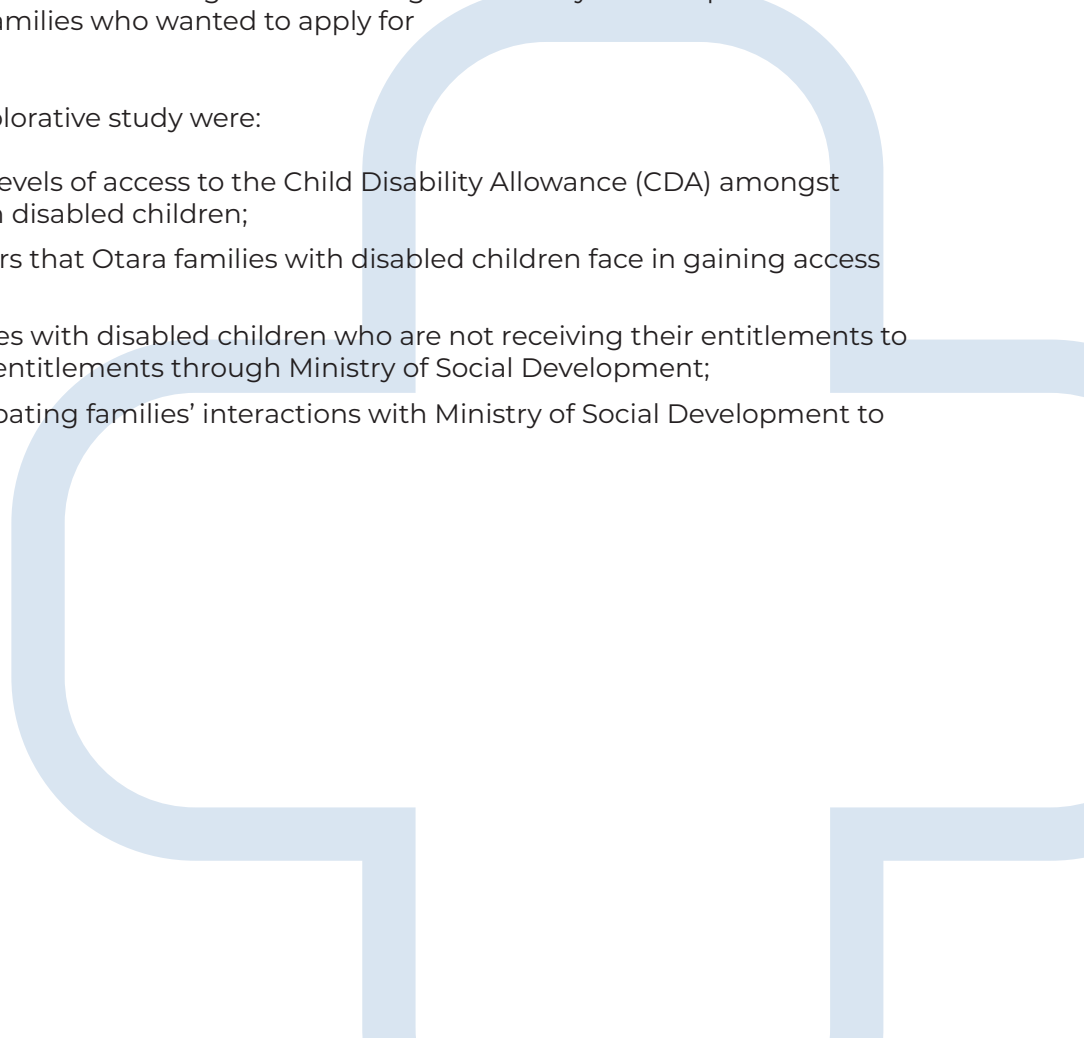


The purpose of the study is to examine the rate of CDA received amongst families in Otago. A previous report by Child Poverty Action Group 'It shouldn't be this hard: children, poverty and disability' (2015), found that the CDA is underpaid and difficult for families to access. The present exploratory study follows on from this and sets out to examine the current level of access to the CDA amongst families in Otago, and to identify ways of improving access.

Three separate organisations – Child Poverty Action Group, Disability Connect and Otago Health Charitable Trust, collaborated on this current study. A survey was developed which examined the extent to which health conditions and disabilities are prevalent amongst children in Otago. Families with children with disabilities or health conditions identified themselves to interviewers going door to door. The survey included questions to determine how many families are currently receiving the CDA and how many had previously applied but been declined. Information gathered through the survey made it possible for researchers to support families who wanted to apply for the CDA.

The objectives of the explorative study were:

1. To establish current levels of access to the Child Disability Allowance (CDA) amongst families in Otago with disabled children;
2. To identify any barriers that Otago families with disabled children face in gaining access to a CDA;
3. To assist Otago families with disabled children who are not receiving their entitlements to a CDA to gain these entitlements through Ministry of Social Development;
4. To document participating families' interactions with Ministry of Social Development to gain a CDA.





# Child disability and barriers to support

Uptake of the Child  
Disability Allowance  
in Otago

Jessica Suri and Alan Johnson  
Child Poverty Action Group  
November 2016

CHiLD  
POVERTY  
ACTION  
GROUP



# About Child Poverty Action Group

Child Poverty Action Group (CPAG) is an independent charity working to eliminate child poverty in New Zealand through research, education and advocacy. CPAG believes that New Zealand's high rate of child poverty is not the result of economic necessity, but is due to policy neglect and a flawed ideological emphasis on economic incentives. Through research, CPAG highlights the position of tens of thousands of New Zealand children, and promotes public policies that address the underlying causes of the poverty they live in.

If you would like to support CPAG's work, please visit our website: [www.cpag.org.nz](http://www.cpag.org.nz)

## Acknowledgments

Child Poverty Action Group acknowledges the generous contribution from the Think Tank Trust in supporting the research behind and the publication of this report. We also acknowledge as partners in this research Otago Health Charitable Trust and Disability Connect. CPAG would also like to thank Dr. Toni Ashton for her feedback on the draft and Dr. M. Claire Dale for editing the final report.

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### **Child disability and barriers to support**

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# Executive Summary

The Child Disability Allowance (CDA) is a non-income tested payment, paid to the carer of a child under 18 years with a serious disability or health condition in recognition of the extra care and attention required for that child. Research has shown that there is a relationship between disability including chronic health conditions, and poverty and that children with a disability are more likely to live in low-income households. A 2015 study by Child Poverty Action Group 'It shouldn't be this hard: children, poverty and disability' also highlighted that the CDA is underpaid and difficult to access for families in need.

This preliminary study set out to examine rates of disability and levels of access to the CDA in Otara – which is a low socioeconomic suburb. Considering the relationship between disability and low-income households, it was expected that Otara would have a higher proportion of children with a serious disability or chronic health condition. The objectives of the study were to establish current levels of access to the CDA, identify any barriers to receiving this allowance and assist families with children with a disability or chronic health condition not receiving the allowance to gain their entitlements through Work and Income, a section of the Ministry of Social Development (MSD). This was achieved through gathering both qualitative and quantitative data through door-to-door surveys within the Ferguson area of Otara. However the low response rate achieved, and lower than expected disability rate revealed means that this can be regarded as an exploratory study only.

A total of 112 children with disabilities or chronic health condition were identified from 1084/2215 households who answered door knocking (49% response rate). Of the 1084 households, 108 (10%) had at least one child with a disability or chronic health condition, and they had a structured interview. Of these, the majority reported a child with a serious chronic health condition (48.1% of respondents had a child with severe eczema and 20.4% with chronic asthma), and a minority reported a serious disability. Most of these families reported that they were struggling in terms of supporting their child and managing these conditions.

Only 7.6% of the 108 families were receiving the CDA. The majority of them had not previously applied for the CDA, with 82% of the respondents reporting that they were not aware of the allowance or that they could receive any assistance from Work and Income. There were also some respondents who had previously applied for the CDA but had been declined. These families' experiences showed that there were barriers which make the CDA difficult to access particularly in regard to the Work and Income application procedure. This included difficulties in understanding the application procedure itself, unpleasant interactions with Work and Income staff and difficulties in getting supporting documents for their application. Due to these barriers respondents were reluctant to re-apply for the CDA as many believed the effort was not worth the CDA payment.

In light of these exploratory findings, recommendations made to improve accessibility to the CDA included:

- Increase promotion of the CDA to families and doctors, especially the eligibility criteria - by Ministry of Social Development and Ministry of Health.
- Simplify the application procedure for CDA.
- Better funding for culturally appropriate advocacy services by MoH and DHBs.

# Chapter 1: Introduction

## An overview of the Child Disability Allowance programme

The 2013 Disability Survey reported that 11% of children under 15 were disabled, compared to 24% of the New Zealand population. For children, learning difficulty was the most common impairment type: 6% of all children and 52% of disabled children had difficulty learning<sup>1</sup>.

The Child Disability Allowance (CDA) is a non-means tested tax-free payment paid to a parent or caregiver of a child under 18 years with a serious disability. The definition covers inherited and acquired disability, and includes chronic health conditions such as asthma, allergies and skin conditions<sup>2</sup>. The criteria for eligibility for a CDA payment are set out in section 39A of the Social Security Act 1964. These criteria are fairly stringent and generally apply to parents or caregivers of a child, who because of his/her disability:

- needs care relating to their bodily functions from another person or attention, or,
- requires supervision at a level which is substantially in excess of that required normally for a child of his/her age or
- requires supervision because of a danger to the child's safety.

The parent or caregiver completes the form. The medical certificate is a two-sided form to be completed by a registered doctor - this can be a General Practitioner (GP) or a specialist. The form is then taken by the parent/caregiver to Work and Income for processing, and a decision is made by Ministry of Social Development (MSD) staff.

The CDA is paid on a fortnightly basis to the parent or caregiver of the disabled child at a rate of \$46.49 per week.

Over the past decade there has been a significant variation in the way in which the CDA has been administered. This variability has occurred despite there having been no change in the Social Security Act 1964, under which the CDA programme is administered. These changes are illustrated in Figures 1 and 2 which respectively report the numbers of children receiving a CDA and the total budget for the programme since 2007.

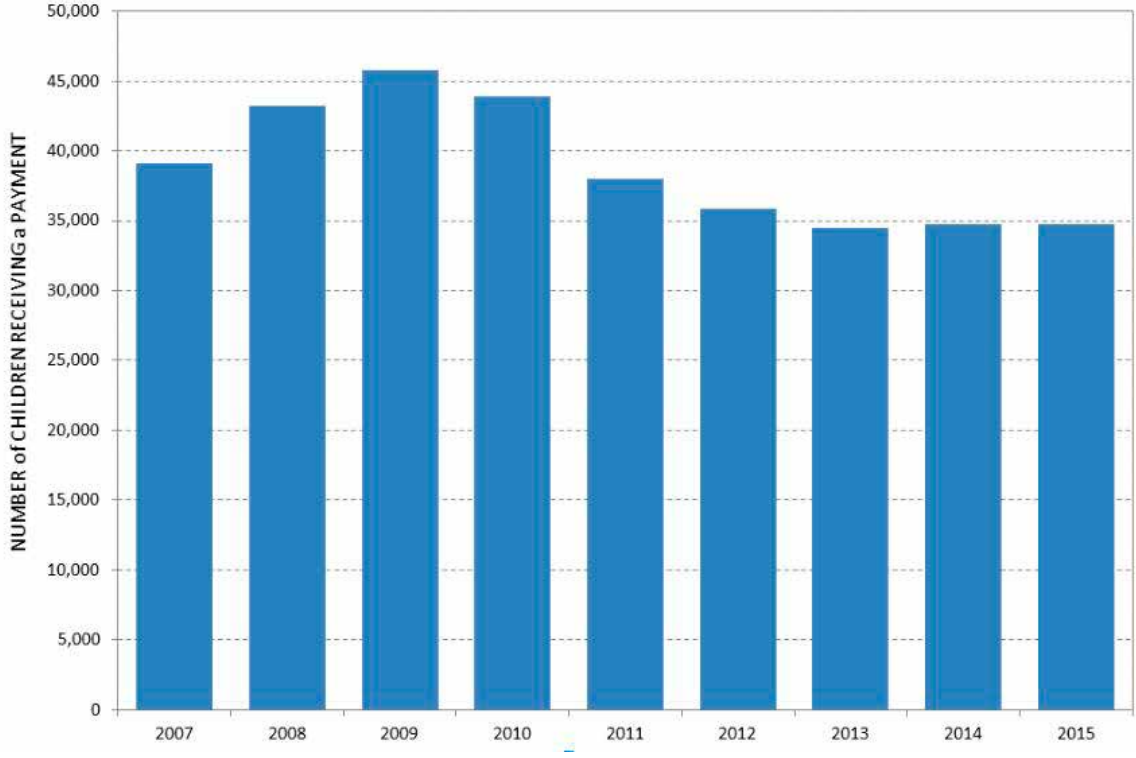
Figure 1 shows that the number of children in New Zealand (NZ) whose families received a CDA declined from over 45,767 in 2009 to around 35,000 since 2014 – a 32% decline. As expected against this drop in payments made, total spending on CDA also declined from a peak of over \$101 million in 2009/10 to an expected \$86 million in 2015/16. This is an inflation adjusted decline of almost 23%.

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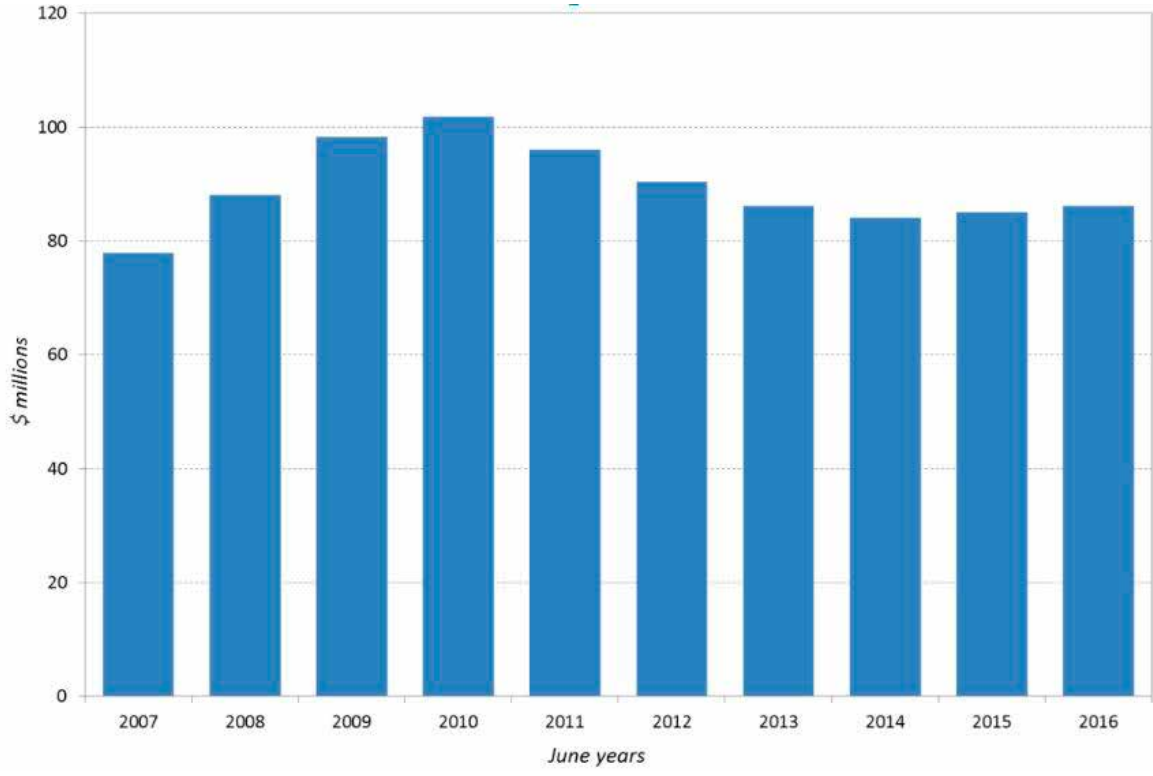
1 See 'Key Finding from the 2013 Disability Survey' at [http://www.stats.govt.nz/browse\\_for\\_stats/health/disabilities/other-versions-disability-survey-2013.aspx](http://www.stats.govt.nz/browse_for_stats/health/disabilities/other-versions-disability-survey-2013.aspx).

2 'Chronic' defines an illness or medical condition characterized by long duration or frequent recurrence.

**Figure 1. The numbers of children receiving a child disability allowance<sup>3</sup>**



**Figure 1. Spending on Child Disability Allowances – 2007 to 2016<sup>4</sup>**



3 Source: Ministry of Social Development's Statistical Reports for data from 2007 to 2012 and from 2012 from data obtained from MSD under the Official Information Act.  
 4 Source: New Zealand Treasury Budget papers – Estimates & Appropriations – Vote Social Development.

## 1.2 Outline of Otara research project

The purpose of this study is to examine the rate of CDA received amongst families in Otara. Otara is a South Auckland suburb with a population of around 32,000 people of whom 75% are of Pacific Island ethnicity and nearly one third are aged under 15 years old. A map outlining the boundaries of Otara is provided in Appendix 1.

A previous report by Child Poverty Action Group 'It shouldn't be this hard: children, poverty and disability' (2015), found that the CDA is underpaid and difficult for families to access. The present exploratory study follows on from this and sets out to examine the current level of access to the CDA amongst families in Otara, and to identify ways of improving access.

Three separate organisations - Child Poverty Action Group, Disability Connect and Otara Health Charitable Trust, collaborated on this current study. A survey (Appendix 3) was developed which examined the extent to which health conditions and disabilities are prevalent amongst children in Otara. Families with children with disabilities or health conditions identified themselves to interviewers going door to door. The survey included questions to determine how many families are currently receiving the CDA and how many had previously applied but been declined. Information gathered through the survey made it possible for researchers to support families who wanted to apply for the CDA.

The objectives of the explorative study were:

1. To establish current levels of access to the Child Disability Allowance (CDA) amongst families in Otara with disabled children;
2. To identify any barriers that Otara families with disabled children face in gaining access to a CDA;
3. To assist Otara families with disabled children who are not receiving their entitlements to a CDA to gain these entitlements through Ministry of Social Development;
4. To document participating families' interactions with Ministry of Social Development to gain a CDA.



# CHAPTER 2: Analysis of payment rates of the Child Disability Allowance

The MSD has provided data on the payment of Child Disability Allowances by Work and Income Service Centres across NZ for the five year period through to 31 December 2015. These counts are snapshots of the payments made at the end of each year.

## 2.1 Disabled children and household incomes

Payment numbers by themselves say little about the need and the extent to which such need is being met. There is for instance no available data on the prevalence of child disability across New Zealand which might identify such a thing as a social gradient – that for example poorer communities have higher rates of disability amongst their child populations. There is however some local as well as international evidence that such a gradient exists although the documentation of such experience is sparse<sup>5</sup>.

A social gradient is however evident in hospital admissions for respiratory conditions that especially affect children who live in poverty. There have been ongoing increases in hospitalisations for severe asthma and other wheezy conditions, bronchiolitis (chronic lung damage) and lower respiratory tract infections, as well as many potentially avoidable hospital admissions for other poverty-related infectious diseases, such as serious skin infections, influenza, pneumonia and gastroenteritis<sup>6</sup>.

Anecdotally, the impact of having a child with a disability is thought to lead to breakdowns in relationships. If this is the case then there would be a higher incidence of single people bringing up children with disabilities and due to their single status they may be living in poorer socio-economic areas.

A claim that disabled children are more likely to live in poorer households is partially borne out by data from the 2013 Disability Survey which amongst other things has reported household income distribution of children with and without disability. This data is summarised in Table 1 below. This data shows that both a higher proportion of children living in poorer households have a reported disability and that a higher proportion of poorer households have disabled children. For example 27% of children living in households with an income less than \$15,000 per annum have a reported disability while just 16% of children living in a household with an income above \$70,000 did. From another angle 18% of children with a reported disability lived in households with a household income of less than \$30,000 while only 12% of children overall did.

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5 For example Craig et al. (2007) identify a definite social gradient in the incidence of such chronic childhood conditions as epilepsy and related conditions with poorer communities have twice the incidence of these (p.325). Shahtahmasebi et al. (2011) consider the UK experience of the relationship between childhood disability and family financial hardship and report that 'disabled children are significantly more likely to grow up in poverty than their non-disabled peers' (p.653).

6 Simpson J, Duncanson M, Oben G, Wicken A and P. M (2015). Child Poverty Monitor 2015 Technical Report. Dunedin, NZ Child & Youth Epidemiology Service, University of Otago.

Table 1: Household income distribution of children with disabilities – 2013<sup>7</sup>

Household income	Number of children with disabilities	Total number of children in such households	Proportion of these children with disabilities
Less than \$15,001	4,000	15,000	27%
\$15,001–\$30,000	10,000	32,000	31%
\$30,001–\$50,000	13,000	46,000	28%
\$50,001–\$70,000	13,000	68,000	19%
\$70,001+	38,000	236,000	16%
Total responding	79,000	397,000	20%
Total population	95,000	456,000	21%
Proportion under \$30K	18%	12%	
Proportion \$30-50K	16%	12%	
Proportion above \$50K	65%	77%	

It seems then that as well as children with disabilities being more likely to live in poorer households, they are more likely to live in poorer communities. This being the case we should expect to see a higher incidence of payment of child disability payments in poorer suburbs than in wealthier ones. The data on such payment distribution only partially supports this proposition.

## 2.1 Payment rates across Auckland suburbs

Table 2 below reports the average payment rate of CDAs for Auckland local board areas and for Otara and Papatoetoe as subdivisions of the Otara-Papatoetoe Board Area. These rates are estimates based on the reported number of CDAs by Work and Income service centres and the allocation of these payments across the local board areas around these centres<sup>8</sup>. The payment rates are averaged across three calendar years – 2013, 2014 and 2015. Details of the data behind these estimates are provided in Appendix 1.

<sup>7</sup> Statistics New Zealand – 2013 Disability Survey – Social and economic outcomes tables. Available at [http://www.stats.govt.nz/browse\\_for\\_stats/health/disabilities/disability-survey-2013-additional-tables.aspx](http://www.stats.govt.nz/browse_for_stats/health/disabilities/disability-survey-2013-additional-tables.aspx)

<sup>8</sup> Ministry of Social Development report payments of the main working age benefits both by Work and Income services centres and by territorial local authority (TLA) boundaries although the mapping of one to the other does not appear perfect. Included in the report by TLA boundaries are the 20 Auckland local board areas. Otara is defined as a subdivision of the Otara-Papatoetoe board area so is not reported separately for payment of benefits. Although there is a Work and Income service centre in the Otara Town Centre, it is likely that some Otara residents either visit the Work and Income service centres at Manukau, which is 1km west of the southern part of Otara, or at Hunters Corner in Papatoetoe - which 1km west of the northern part of Otara. CDA data provided on a customised basis by Ministry of Social Development for this study was reported on a service centre basis. This required the development of a matrix to allocate payments reported by service centres to local board areas and in Otara and Papatoetoe the subdivisions of this area. This matrix was developed using the observed relationships between service centres and local board areas for payments of the main working age benefits. The main assumption behind this approach was that individuals' patterns of visiting a convenient Work and Income service centre for accessing a main working age benefit would be the same as that for them accessing a child disability allowance. A secondary assumption here was that people would mainly visit either the service centre in their board area or one immediate adjacent to it. Although this allocation method is approximate the estimates of total numbers by board area offered in Table 2 are probably accurate by + or – 10%. In other words the Otara estimate of 259 CDA payments is possibly between 230 and 285 but most likely between 250 and 270. A variation of this extent will not change the conclusion offered here that the rate of CDA payment in Otara is close to the regional average rate for Auckland but well below the national average rate.

**Table 2: Payment rates per 1,000 children for Child Disability Allowances for Auckland Board areas – 2013 to 2015** (payments per 1000 resident children)

Local Board area	2015 population under 18	Average number of CDAs	Average payment rate per 1,000 children
Albert - Eden	22,600	525	23
Devonport - Takapuna	13,200	273	21
Franklin	18,200	468	26
Great Barrier/Waiheke	2,000	42	21
Henderson - Massey	31,500	903	30
Hibiscus and Bays	22,400	573	26
Howick	33,300	870	26
Kaipatiki	20,400	472	23
Mangere - Otahuhu	25,700	696	27
Manurewa	28,100	924	33
Maungakiekie - Tamaki	19,200	688	36
Orakei	19,300	168	9
Otara - Papatoetoe	25,100	636	25
Papakura	14,600	511	36
Puketapapa	13,400	312	24
Rodney	14,500	292	20
Upper Harbour	14,000	218	16
Waitakere Ranges	13,700	270	20
Waitemata	12,200	254	21
Whau	19,000	513	27
Auckland region	382,200	9,606	25
Otara	12,300	259	21
Papatoetoe	12,800	377	30

The average CDA payment rate for Otara appears to be close to the average rate for the Auckland region although it is significantly lower than other South Auckland suburbs such as Mangere-Otahuhu, Manurewa and Papakura. As perhaps can be expected wealthier suburbs such as Orakei and Devonport-Takapuna have lower than average payment rates although middle-income suburbs such as Albert-Eden have higher than average rates. Overall it appears as though South Auckland suburbs have a higher than average CDA payment rates although Otara-Papatoetoe appear to have a lower rate than surrounding suburbs.

## 2.3 Regional distribution of Child Disability Allowance (CDA) Payments

The relativity of Otara's CDA payment rate to that of the Auckland region should however be seen in the context of New Zealand-wide rates. Such a comparison is offered in Table 3 below. This table illustrates both the extent to which Auckland generally is underserved in the administration of CDAs and what CDA payment rates might be reasonable to expect if this administration was fairer or more even.

**Table 3: Payment rates per 1,000 children for Child Disability Allowances for New Zealand regions – 2013 to 2015 (payments per 1000 resident children)**

	2015 population under 18	Average number of CDAs	Average payment rate per 1,000 children	Median household income 2013*
Northland	42,800	1188	28	\$57,000
Auckland	382,200	9606	25	\$76,500
Waikato	112,400	2779	25	\$69,500
Bay of Plenty	72,200	2506	35	\$62,000
Taranaki	28,700	1225	43	\$65,500
Hawkes Bay-Gisborne	54,700	3130	57	\$62,000
Manawatu-Whanganui	57,400	3358	58	\$61,000
Wellington	113,900	3316	29	\$82,500
Marlborough-Nelson- West Coast	39,000	688	18	\$69,000
Canterbury	131,500	4185	32	\$78,000
Otago	46,300	1351	29	\$65,000
Southland	23,300	686	29	\$70,000
New Zealand total	1,104,400	34,644	31	\$68,600

\*See <https://figure.nz/chart/ve0JN1HqKe513bty-rFEfjnwobrwwDfa>.

Table 3 illustrates the wide variation in the rate of payment of CDA. With an average payment rate for New Zealand of 31 per 1,000 children, rates range regionally from a high rate of over 58 payments per 1,000 children to a low rate of less than 18 per 1000. It is difficult to understand how such a variance can be explained except by different attitudes and approaches to access to or administration of these payments. Certainly the differences in regional payment rates reported in Table 3 cannot entirely be explained by the level of variation in the incidence of child disability.

It is of course hard to determine what an optimum or equitable rate of payment is. The criteria for receipt of a CDA is a parent and doctor completing a form indicating why the child is eligible for a CDA, and then the MSD staff making a decision. The process is reliant on access to medical care, and different interpretations and judgements. It is usually the doctor who suggests the application to the parent, and different doctors may have different levels of knowledge about eligibility. When a reasonable application of these criteria and perhaps more effective promotion of the programme produces a payment rate of 58 payments per 1,000 children in one region, then it is difficult to see why such rates should not apply in other regions.

# CHAPTER 3: Research methodology

This explorative study used a cross sectional survey design to establish the current levels of access to the Child Disability Allowance amongst families in Otara. The Ferguson area of Otara was selected as a sample area. A total of 2,215 doors were knocked on by interviewers who were recruited locally and trained by staff of Otara Health. The interviewers were Samoan and Tongan and able to converse with respondents in these languages as required. Of these 2,215 doors, contact was made with 1,084 (49%) households. Of these 1,084 households a total of 108 households self-identified as having children with serious illnesses or disabilities, and agreed to participate in the study. This participation was by responding to the survey which was conducted on their doorstep by the interviewers.

## 3.1 Participants

The participants in the study were parents or caregivers of children with a reported disability or long-term health condition. Participants were recruited via convenience sampling in the Ferguson area of Otara. Postcards with information about the study were distributed to every household in the area of interest, followed by door-knocking in the area a week later. Participants self-identified during the door-knocking, when asked whether they had a child with a long-term health condition or disability. Those who responded positively were then invited to participate in the study. Because the people of interest were children – parents or primary caregivers were required to give consent and complete the survey and thus were the respondents.

The 108 households participating in the survey represented 112 children. Their ages ranged from four months to 18 years old and they were identified as Samoan (31.6%), Cook Island (21.9%), Tongan (18.4%), Māori (9.6%), Niuean (4.4%), Fijian (0.9%) and mixed ethnicity (11.4%). Two participants (1.8%) did not report the ethnicity of their child.

## 3.2 Materials

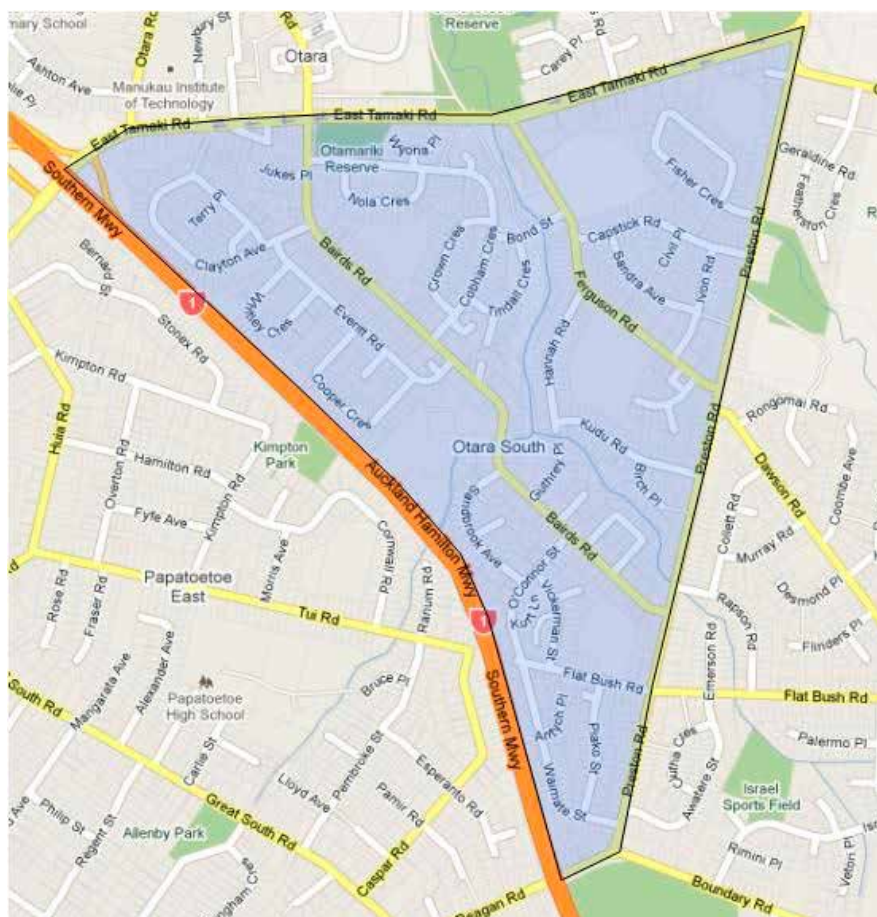
Respondents (parent or caregiver) completed a short survey (Appendix 3). Respondents were required to provide demographic information, information about the disability or health condition of the child, and the level of support received from government agencies and/or services and health providers.

Where it was apparent that a family was not receiving the CDA, a process of supporting them to apply for this was provided. A referral form was completed for participants to assist them in making contact with their doctor and getting in contact with Work and Income.

## 3.3 Approach

The research procedure included door to door surveys, which were completed initially in the Ferguson neighbourhood of Otara (see Appendix 2 for more information about Otara). Because the survey itself was carried out faster than anticipated, the study area was expanded to the streets on the other side of Preston Road in order to increase the size of the survey.

**Figure 3: Boundary of the Ferguson neighbourhood of Otago**



There were two parts to the study. Firstly, a questionnaire was completed to gather data about a) disabilities and health conditions experienced by children in Otago, and b) the level of access to the CDA. Secondly, families with children with a disability or long-term health condition who were not receiving the CDA were identified and referrals were made to their doctor to see whether they would be eligible to receive the allowance.

### 3.3.1 Survey procedure

The survey procedure included going door-to-door and speaking to residents about the study. Respondents were informed of the study and then asked whether they had any children with any chronic health problems or disabilities. If they did, then verbal consent was sought and privacy and confidentiality of the data was explained before continuing with the survey. Surveys were completed for all respondents who reported that their child experienced some chronic health condition or disability.

A copy of the survey form is attached as Appendix 3 of this report.

### 3.3.2 Referral procedure:

During the survey, respondents who reported that a child or children in their care experienced disabilities and/or health conditions were asked whether they received the CDA. For respondents who reported that they did not receive the CDA, researchers used their information provided while completing the survey to evaluate whether they might be eligible, and completed a referral form.

Referrals were offered to respondents if they reported more than one of the following:

- Their child had been experiencing a chronic health condition or disability for a period longer than six months;
- The respondent reported to be struggling financially, appeared to be struggling emotionally, and required (although the CDA does not require this, as it is non-means tested) external support to help care for their child;
- More than one child with a chronic health condition or disability.

Respondents were advised of the procedure for applying for the CDA with Work and Income as per the requirements on the Work and Income website and were asked if they would like a referral form to be completed for them to visit their GP to apply for the CDA. Respondents were also asked whether they required any support with transportation, any financial support for specialist visits or assessments, or assistance with their Work and Income application. Respondents were required to sign the referral form as consent for the researcher to contact their GP to advise that the respondent would be visiting in regard to the CDA.

A copy of the referral form is attached to this report as Appendix 4.

### 3.3.3 Follow up

After a referral was made, the GP clinic indicated on the referral form was contacted to advise that the respondent would be seeking a medical certificate in support of the CDA application.

A follow up call was also made to the respondent to confirm that their GP's practice had been contacted, and to confirm details on the referral form in case their circumstances had changed. The initial follow-up call was made to respondents within a week of the referral and then subsequent follow up calls were made as required. Support for transportation, financial assistance and support with completing the application was offered again during the follow up.

### 3.3.4 Analysis

The survey included a mixture of qualitative and quantitative data. There were some questions which required the respondents to describe or explain. For these questions, thematic data analysis was done to find common themes. SPSS was used for data analysis of quantitative data.

As the data was collected in interview format, to reflect respondents' experiences, the data were categorised after collection in order to make comparisons. This was completed for questions about the child's illness or disability, because many respondents could describe the condition but did not necessarily know or report the diagnosis. Data about why participants were not receiving the CDA was also categorised, as this information was provided to researchers through conversation. More information as to how data was categorised is provided in the results section.

# CHAPTER 4: Research results

During data collection, a total of 2,215 doors were knocked on, and contact was made with 1,084 (49%) households. This is approximately 15% of Otara households (Statistics New Zealand). From these 1,084 households, 112 surveys were completed by 108 households. A separate survey was completed for each identified child in each household. There were a total of 108 surveys included in the data analysis. Four surveys were omitted because the information collected was incomplete. Any respondents who had a child 18 years or older, and thus not eligible for the CDA, were excluded from the survey.

Of all respondents, 84% were the parent of the child in question (76.4% identified as the mother, 7.5% as the father of the child), 7.5% identified as a grandparent but also as a primary caregiver of the child, 2.8% were older siblings looking after the child whilst the parents were at work, and 5.7% were categorised as 'other' and included aunts or nannies who primarily looked after the child during the day. Given this wide diversity of respondents, it is possible that some who were not the parent or legal guardian of the child with disabilities were unaware of payments being made to support this child. This limitation relates only to the 16% of respondents who were not parents.

The results indicated that approximately 10% of households contacted had at least one child with a disability or long-term chronic health condition. Of the 108 surveys completed, eight (7.4%) respondents were receiving the CDA and 14.2% were receiving some benefit from Work and Income (type not identified). Most respondents not receiving the CDA were not aware of the CDA and its eligibility criteria, so had not applied for it.

## 4.1 Disability and illness

The survey required respondents to describe the disability or illness of their child. Due to the varied responses by participants, disabilities and illnesses were grouped into categories which included the following:

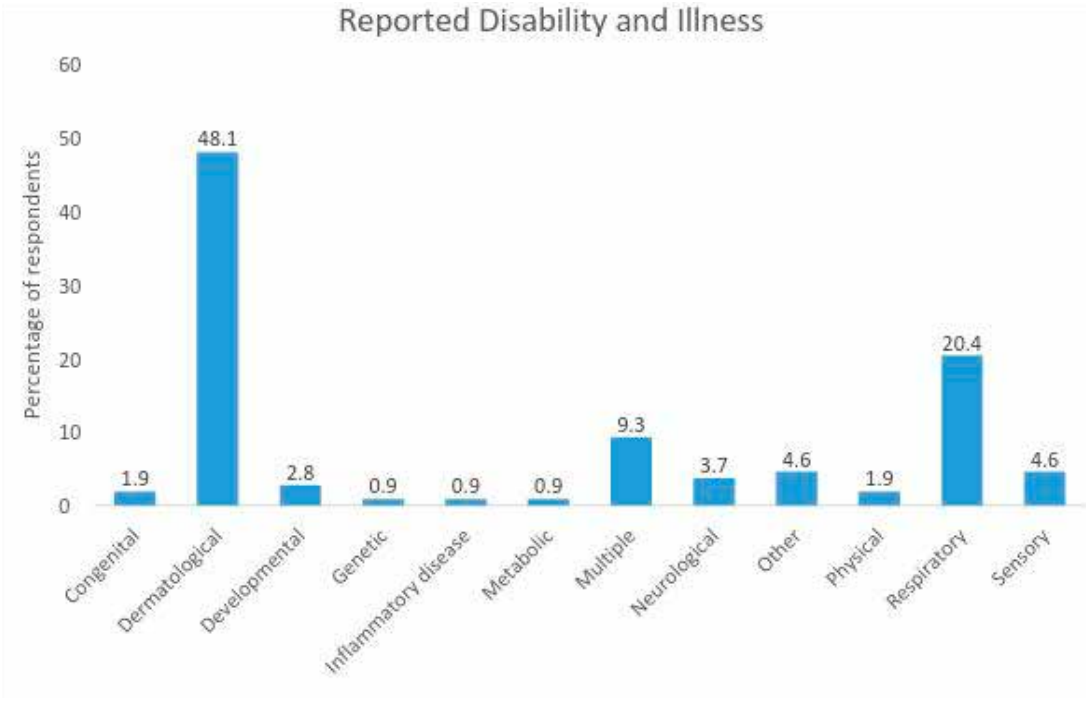
- 'Dermatological' which included chronic skin conditions such as eczema;
- 'Respiratory' which included bronchitis and asthma;
- 'Sensory' which included sight and hearing impairments;
- 'Neurological', which included epilepsy;
- 'Metabolic' which referred to chronic health conditions such as diabetes; and -
- 'Developmental' which included intellectual disability and Autism Spectrum Disorders.

Those with multiple health issues and disabilities were grouped into 'multiple' and the respondents who were not yet given a diagnosis by their doctor due to a complex health problem were categorised under 'other'.

The most common illnesses reported were dermatological and respiratory illnesses which were chronic (Figure 4). 9.3% of children also suffered from more than one long-term chronic illness or disability, which in most cases was eczema and a respiratory illness (asthma or bronchitis or both).



**Figure 4: Frequency of each disability and illness**



Respondents were asked three questions about the level of care and support their child required. The questions included whether their child required additional care and support on a daily basis – more than what would be required for a child without illness or disability of the same age; whether their child requires supervision most of the time; and whether the child requires support with feeding and washing. Overall, while 72.6% of respondents reported that their child lived okay as a part of their family so they were coping, 75.9% reported that their child required additional care and support, 37% required supervision most of the time and 19.4% required support with feeding and washing.

**Table 4: Percentage of all respondents reporting children needing extra support**

	Requires additional care and support	Requires supervision most of the time	Support with feeding and washing
Yes	75.90%	37%	19.40%
No	21.30%	60.20%	76.90%
No response	2.80%	2.80%	3.7

The majority of children suffering from a disability or chronic health condition required extra care, which was evident across all of the disability and illness categories (Table 2).

Table 5: Number of children that require additional care and support from a caregiver by illness category

Illness	Requires additional care and support	
	Yes	No
Congenital	1	2
Dermatological	38	11
Developmental	3	0
Genetic	1	0
Inflammatory	0	1
Metabolic	1	0
Multiple	8	2
Neurological	4	0
Physical	2	0
Respiratory	5	0
Sensory	14	8
Other conditions	5	0
Condition unreported		3
Total	82	26

## 4.2 Cost of disability and illness

Respondents mainly spoke about the extra time they are required to spend to care for their child.

Children who experienced dermatological and respiratory conditions often required an adult to help with the application of medication (which were creams with eczema) or support with taking an inhaler. The need for this support was greater for younger children. There were many respondents who also spoke about having to take time off work or other duties if their child needed to go to the doctor or was hospitalised. In our sample, there were many children with respiratory conditions who were frequently hospitalised. Caregivers would be required to take time off work to care for their sick child, which would result in a loss of income.

Along with extra time spent, many respondents spoke about the additional costs of medication. A few parents and caregivers whose children had chronic eczema spoke about the subsidised medications prescribed by their doctor not being sufficient in managing their child's condition, which prompted them to purchase non-subsided creams that cost more.

Another common cost mentioned by respondents was money spent on heating during the winter in an attempt to avoid deterioration in the health condition. Many of the respondents in the sample were living in a Housing New Zealand (HNZ) house which could get "cold, damp and mouldy" during the winter, exacerbating asthma and bronchitis.

## 4.3 Financial support

As a part of this study we were interested in how many families are receiving the CDA. Of the 108 respondents, only eight respondents reported receiving the CDA, whereas 15 respondents had previously applied for the allowance (Table 6). None of the children in our sample group with physical and sensory disabilities were receiving the child disability allowance (Table 7).

Table 6: Percentage of survey participants receiving benefits

	Receiving CDA	Applied for CDA	Other Work and Income Support
Yes	7.60%	14.70%	14.20%
No	94.40%	85.30%	85.80%

Table 7: Number of Children receiving the CDA by illness category

Illness	Receiving Child Disability Allowance	
	Yes	No
Congenital	0	2
Dermatological	0	50
Developmental	2	1
Genetic	1	0
Inflammatory	0	1
Metabolic	0	1
Multiple	1	9
Neurological	1	3
Physical	0	2
Respiratory	2	19
Sensory	0	5
Other conditions	1	4
Condition unreported		3
Total	8	100

For those who reported receiving the CDA, the weekly amount ranged between \$42 and \$46, which was paid to the respondent fortnightly. There were 15 respondents who said that they received financial support from Work and Income. Payments from Work and Income ranged from \$217 to \$320 per week. This support was independent of the child's needs and was presumably paid because the respondent met the eligibility criteria for a working-age income support benefit.

## 4.4 School and ECE support

In New Zealand there is funding, services and support available for children with disabilities and special needs to be able to attend mainstream schools. The results indicate that amongst the respondents with children attending a school or Early Childhood Education (ECE) provider, most reported that they did not receive any additional support from the school or ECE their child attended (Table 8). In our sample only 10.2 per cent of school-aged children were reported to receive additional support through their school and only 4.3 per cent received support at an ECE.

Table 8: Proportion of children receiving support at School or ECE

	Attending a School or ECE		Not attending a school or ECE	
	Receiving support	No support	Receiving support	No support
Younger than 5 years	4.30%	78.70%	21.30%	78.70%
5 – 17 years old	10.20%	8.20%	81.60%	91.80%

In the study group, there was only one child that was reported to be attending Mt Richmond Special School, with the remaining children in local mainstream schools. In the surveys, 23 respondents did not disclose which school their child attended.

The child attending Mt Richmond Special School was reported to be receiving a wide range of support that included special education and physiotherapy, arranged by the school. Amongst the mainstream schools, Chapel Downs Primary School was reported by respondents to provide special education for learning disabilities.

## 4.5 Other support

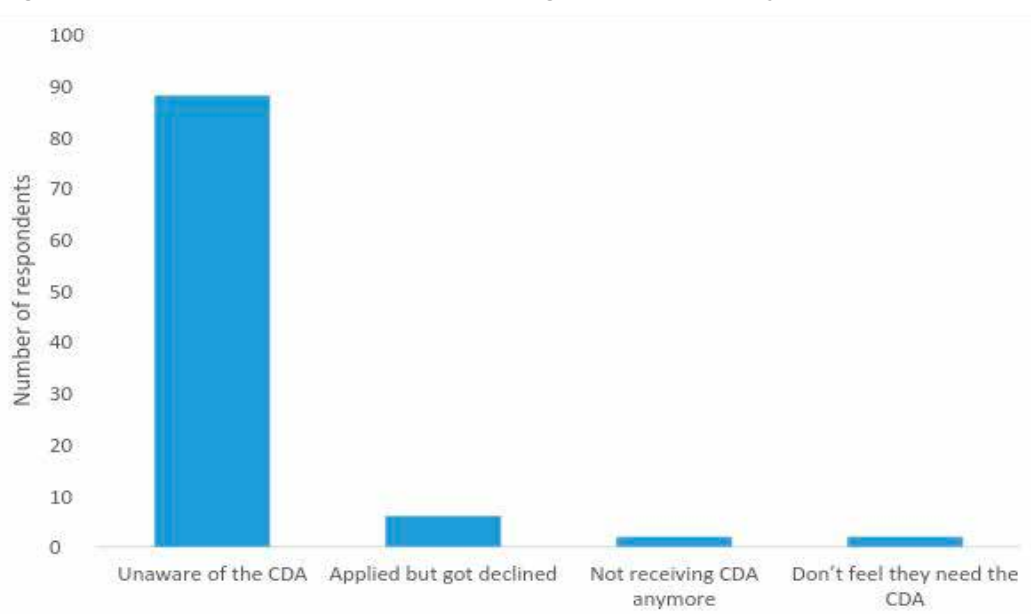
Along with financial support and support received for their child through schools and ECEs, respondents were asked about any support they were receiving through external agencies or groups. There were 17.3% of respondents who reported receiving support from outside agencies. The agencies and professionals that were mentioned included public health nurses, community support workers, general practitioners, social workers, Taikura Trust, Early Child Intervention Teams, speech therapists and teacher aides.

Taikura Trust was reported to provide a half-day or care for children to give families a break and was also reported to provide advocacy for families. Organisations including Family Start, Otara Health Charitable Trust and Child Youth and Family were also mentioned by some respondents in being involved with advocating for families to get them the support required. The majority of respondents however, relied on emotional and social support from family to help care for their child.

## 4.6 Barriers to support

The main barrier to receiving the CDA appeared to be a lack of awareness. In the group that was surveyed, 88 respondents said they had not applied for the allowance as they were not aware of it, six respondents had previously applied for the allowance but were declined, two had been receiving it previously but were told they did not qualify anymore and two respondents felt that their child's condition did not require the CDA. No clear response to this question was received from 14 respondents.

**Figure 5. Respondents' reasons for not receiving the Child Disability Allowance**



While over half of the study group had not previously sought any support from Work and Income, among those that had tried to get support 11% of respondents spoke about having problems. The Work and Income application procedure was also identified as a barrier to getting the CDA. Respondents who were aware of the CDA, stated difficulty in understanding what documentation they needed to provide the Work and Income office in order to lodge an application. Those that had previously tried to get the allowance recounted having to make multiple trips to Work and Income to provide information.

Interaction with Work and Income staff was also identified as another barrier, as there were many respondents who had unpleasant experiences at the Work and Income office when seeking help.

One respondent spoke about having all the required documents and certificates but said she was declined for the CDA as the doctor's certificate she had obtained from Wanganui when her child first got sick was too old. After making multiple trips to try and get the allowance she decided that it was not worth the payment and would just make do without the extra support. Many other respondents had similar experiences with trying to get the allowance; some recalled leaving Work and Income in tears as they were frustrated by having to re-explain their situation every time. These respondents had also decided to give up trying to get support.

When made aware of the CDA, most respondents were reluctant to apply for the allowance even though it would help them financially. One of the reasons included having to get a medical certificate from their GP. Many respondents reported long waiting times at their GP. One respondent spoke about waiting to see the doctor for two hours the last time her child was sick, furthermore she could not afford to take a day off work to get the documentation required for the application. A few respondents mentioned getting a medical certificate from their doctor as a barrier to seeking support. As well as long waiting times, some respondents said that the doctor did not feel their child's condition was as serious as the parent and caregiver felt it was. This contributed to a reluctance to apply for the CDA.

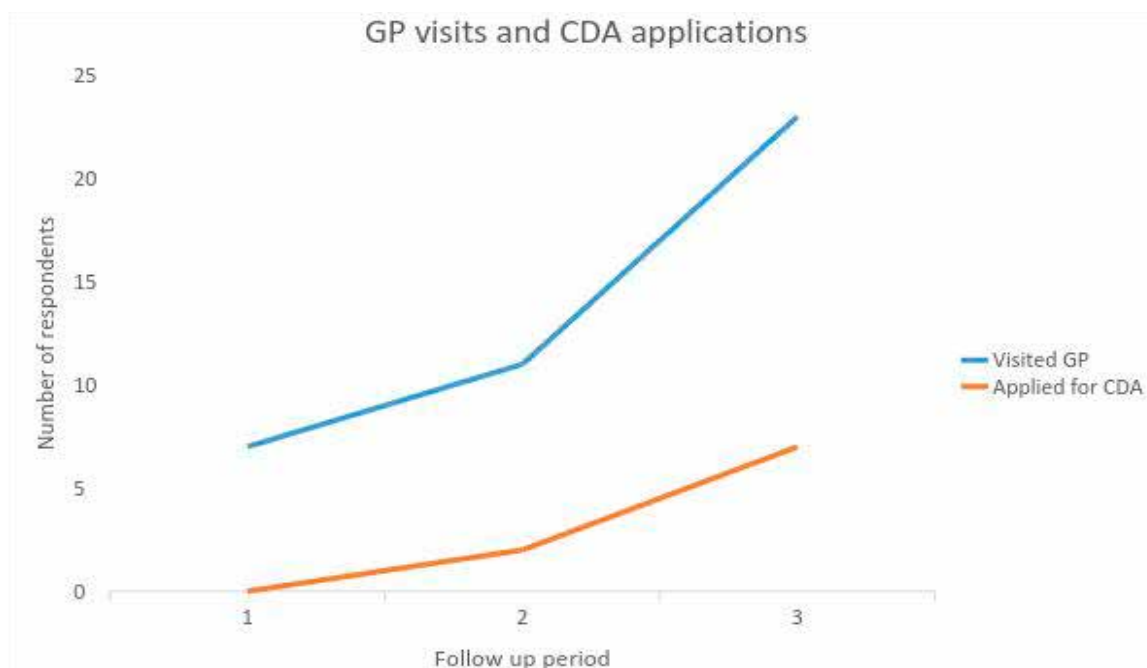
## 4.7 Advocacy

Part of the study included promoting access to the CDA among the participants who were not receiving it and might possibly be eligible. This included both providing information about the CDA and eligibility criteria, as well as offering support to respondents who wished to apply for the allowance.

A total of 54 referrals were accepted by the respondents and eight respondents declined, when offered to be referred to their doctor to apply for the CDA. Respondents were offered additional support, which included transport support to their GP or any specialist appointments, payment of any charges for specialist visits or assessments and assistance with their Work and Income application. Respondents were also asked if they required any additional support. GP clinics or doctors that were listed by respondents were contacted and were informed about the study and that their patients may be visiting in relation to the CDA application.

There were three follow up calls made to each respondent who had been referred to see how they were progressing with their application, and if they required any further support. The first follow up occurred about a week following the referral, the second a week later, and the third occurred a month from the initial referral date.

**Figure 6. Number of respondents who visited their GP and applied for the CDA following the survey**



Of the 54 referrals that were made, there was no uptake of any transportation costs. For all respondents, contact was made with their GP or clinic by the research team prior to their visit. A total of nine respondents were unable to be contacted on the phone number provided, as these numbers had been disconnected.

At the first follow up phone call, five respondents had changed their mind and decided that they did not want to apply for the CDA and that they were getting along fine without it, and seven had already visited their doctor. One respondent had been referred on to a specialist and was awaiting an appointment at the Super Clinic.

At the second follow up, there were an additional four respondents who had visited their GP and another two who had applied for the CDA. By the third follow-up, there were a total of 23 respondents who had visited their doctor in regard to the CDA and seven that had completed a relevant Work and Income application.

The respondents who had not visited their GP or applied for the CDA mentioned barriers that prevented them from doing so. Two barriers were mentioned frequently. The first was that the children were away visiting family – as this study took place in the school holidays. The second was that parents were unable to take time off work to take their children to the GP. One of the parents mentioned the waiting times at the GP to be a major barrier, as they sometimes had to wait up to two hours to see a doctor. Therefore, she said she would wait until her child was unwell again to visit the doctor and apply for the CDA.

By the third follow up period, 15 respondents had also changed their mind about applying for the CDA. These respondents said that since the visit by the researchers, they no longer felt that their child required the CDA as the condition was now manageable and did not feel it was worth going through the process as it can be quite time consuming.

# CHAPTER 5: Discussion

The present study aimed to identify the current level of access to the CDA amongst families in a low-income area, for whom the CDA could make a difference in the financial resources to care for their child. There is increased likelihood of children with disabilities living in low-income households as identified in the 2013 Disability Survey with 15% of children living in households with an income under \$30,000 a year having a disability, compared to 10% of children with a disability in all households (Statistics New Zealand, 2014). The Disability Survey also identified the most common form of disability being 'physical', however in the sample interviews taken for this research, a high proportion of physical disabilities were not reported, but rather of chronic long term diseases, such as asthma or eczema.

The results from this study have found unexpectedly low numbers of families in Otago receiving the CDA. Of the 108 surveys completed, it was found that only 7.6% of respondents who reported having a child with a long term health condition or disability were receiving the CDA. The majority of the respondents of the survey were not aware of the CDA or the eligibility criteria. The results of the survey highlighted a number of key issues that are prevalent for families with children who may be suffering from long-term chronic condition or disability. These included mainly the extra expenses associated with illness and disability, the time spent on caring for their child, taking time off work, and also the exacerbation of their child's health condition due to poor housing conditions.

## 5.1 Health conditions and disability

The findings from this study indicate that there are a large number of children experiencing chronic 'dermatological' and 'respiratory' conditions. Over half of the respondents reported that their child suffered from chronic eczema (48.1%) or chronic asthma (20.4%). Although lay people may not consider such disorders as disabilities, the CDA criteria do, when the symptoms and care required are of sufficient magnitude (see examples on the website). The CDA criteria thus recognise the extra care and attention required to look after a child with serious long-term health conditions.

On the Work and Income website, it is stated that "the child or young person must need constant care and attention, over and above the ordinary care and attention required by a child or young person of the same age" and need that care for a period of 12 months or more in order to qualify for the CDA. This includes: frequent care and attention from another person in connection to their bodily functions, attention and supervision substantially in excess of that normally required by a child of the same age and gender, or regular supervision from another person to avoid substantial danger to themselves or others. The assessment of whether or not the child meets the criteria is completed by a registered doctor who is involved in the ongoing medical care of the child.

Many survey respondents reported struggling with their child's health condition. The survey results found that while only 19.4% of respondents reported that their child required extra support in regard to feeding and washing, 75.9% of respondents felt that their child required additional care and support on a daily basis.

Caring for a child with chronic eczema can be time consuming, expensive, and cause loss of sleep. As it is recognised to have the greatest financial and social costs of any chronic medical condition (AS Kemp Atopic Eczema – Its social and financial costs. J Paediatrics and Child Health 1999; 39:

229-231), it would be appropriate for parents of children with more severe eczema to receive the CDA. Many of the caregivers in this study spoke about the additional costs of skin care, particularly expensive non-subsided creams and the time taken for caregivers to apply the creams, and the other treatments and routines required. (The Eczema Clinical Network, 2014). Chronic, poorly-controlled asthma may require a lot of parental support, treatment and supervision, and may be triggered by environmental factors, many of which may not be able to be controlled by the parent or caregiver (Asthma Foundation NZ).

Work and Income website gives guidance on the severity of disability for the CDA with regard to medical conditions, for example:

#### *Asthma*

*Jane is a 12-year-old girl with severe asthma who needs reliever inhalers administered two to four times a day, is too unwell to attend school several times each month, cannot play sport and has sudden asthma attacks requiring emergency hospital care four to six times per year. Jane's illness creates significant family disruption.*

- *Jane is likely to qualify for the Child Disability Allowance.*
- *Suggested review period – two years.*

#### *Skin conditions*

*James is a six-year-old boy who has atopic eczema to his trunk and limbs. He requires daily dressings to affected areas and takes regular anti-histamine medication. He requires short courses of oral steroids when the eczema flares up. His skin condition means he is distracted and has difficulty getting to sleep. He is limited in his outdoor activities because of his dressings and constant irritation from his skin condition.*

- *James is likely to qualify for the Child Disability Allowance.*
- *Suggested review period – 2 years.*

## 5.2 Awareness and active promotion

In order to qualify for and receive the CDA, parents are required to apply for the allowance and gather the required documents including a doctor's certificate which confirms that the child is experiencing a disability or chronic health disorder. However, one of the key findings from this study was that most of the respondents were not aware of the CDA. Out of the 108 surveys completed, 82% of the respondents said that they did not apply for financial assistance as they did not know about the CDA. These respondents had not been told about the allowance by their GP, despite having visited their family doctors' multiple times for the persistent health condition of their child.

Information about the CDA and its eligibility criteria is readily available on the Internet via the Work and Income website. While we did not collect information regarding how many of the respondents have access to the Internet in their household, census data shows that in the Otago-Papatoetoe area, only 65.6% of household have Internet access (Statistics New Zealand, 2013). No data is available for the survey area of this study, however Ferguson is an area of high deprivation (10 on the deprivation index), so it could be expected that there would be less people with access to the Internet than the percentage for the Otago-Papatoetoe Local Board area. This may explain why so many families were unaware of the CDA.



The results show that only 7.8% of children with a disability or long-term chronic health condition in Otara are receiving the CDA and that 82% of parents and caregivers were not aware of the allowance. This highlights the need for greater promotion of the allowance and demonstrates that the information provided on the Work and Income website is not reaching the population with the most need, therefore information about the CDA should be more accessible for low-income families. The results also indicate a lack of responsiveness or acknowledgment of children with disabilities by healthcare professionals, as families are not being made aware of the CDA, even when children are visiting the doctor frequently for the same health condition.

## 5.3 Accessibility

Another major barrier mentioned by respondents was the difficulty in understanding and completing the application form for the CDA. Amongst respondents who had previously sought support from Work and Income relating to their child's health, 11% reported having problems getting support. This was mainly due to difficulty in understanding what was required of them when filling out the application, frustration associated with having to make multiple trips to Work and Income offices regarding their application, and previous negative experiences with Work and Income staff.

Respondents who were aware of the allowance reported their reluctance to apply for it despite being offered support by the researchers. The main reason provided was the process being time consuming. Parents and caregivers felt that the amount received through the CDA was not worth taking time off work to take their child to the doctor and then having to make a Work and Income appointment. Many respondents also did not have favourable opinions of Work and Income processes, especially those who had been declined for support in the past.

This reports given above emphasise the application process as a barrier to seeking out the allowance. The present process involves either visiting Work and Income to complete an application or applying for it online. The online process requires creating an account and providing a lot of information which includes income details from the last 52 weeks, any other ways the individual is earning money, details about expenses (including childcare and medical costs), IRD number, bank account details and contact information. Applicants who are not born in New Zealand are also asked to provide details about when they left their country of birth, when they arrived to New Zealand and the date they were granted citizenship (Ministry of Social Development). Gathering information is not only time consuming, but some of the families that did not have access to the Internet in their homes would have to make time to access the Internet from a library or other facility.

Another issue with the application procedure reported by respondents was the difficulty in understanding what was required for the application. This would cause applicants to be sent to obtain the missing information and then would return to Work and Income to a new staff member and have to start the process all over again. Many respondents had negative experiences with Work and Income staff in the past and were therefore reluctant to apply for the CDA even though they might be eligible.

The current application process is a major barrier especially for working parents or caregivers who would be required to take time off work to gather the information required, obtain a medical certificate and apply for the allowance. Changes need to be made to the application process in order improve the accessibility to the CDA.

## 5.4 Housing

As could perhaps be expected, one of the findings from this study was the concerns of families about their housing conditions and the contribution of these to their children's health. Poor housing conditions, particularly damp housing, is related to children's development of respiratory conditions and symptoms such as wheezing, headaches, sore throats and runny nose (Platt et al., 1989). This relationship was evident amongst the participants in our study as there were many respondents who claimed they lived in poor housing conditions and had children experiencing respiratory health problems.

There are no statistics available to show how many Otago families are residing in poor quality housing, however Statistics New Zealand (2012) has data which shows that 57% of Māori and 55% of Pacific peoples in rental properties report housing-related problems. As the Otago population is predominantly Māori and Pasifika, this provides a good indication of how many Otago families are living in substandard housing.

Further, it has been found that low-income families are spending a higher proportion of their household income on heating their home (Howden-Chapman et al., 2012), which would leave less money for other necessities, thus driving families further into poverty. One parent who participated in the study reported spending up to \$200 per week in the winter to heat her Housing New Zealand home in order to prevent her daughter from being hospitalised, which left little money for necessities such as food and nappies for her baby. While this family was receiving the CDA, they were still struggling to cope with the expenses related to their child's illness.

## 5.5 Advocacy Services

There were few respondents (17.8%) who spoke about receiving additional support from outside organisations or agencies (other than Work and Income). One of the main forms of support received was advocacy for the family to ensure they received the help they were entitled to. Organisations such as Taikura Trust, Family Start, Otago Health Charitable Trust and Child Youth and Family were mentioned as organisations which had helped families to receive the CDA. One respondent also mentioned that their GP at Otago Family and Christian Health Centre had been a strong advocate for them to get the CDA for their child. Other than Taikura Trust, the organisations mentioned by respondents are not organisations that specialise in disability advocacy.

Having advocacy services that are well equipped to provide information and support to families can be beneficial. The results from this study indicate that there is a need for better advocacy for families and doctors not only to raise awareness about disability related entitlements but also to support families in applying for benefits such as the CDA. This could be achieved by providing existing community organisations with funding so they are better able to support families that require information and support for applying for benefits.

## 5.6 Recommendations

The results from this explorative study indicate that there are gaps within the system preventing families in need from accessing the CDA. The following recommendations have been made by giving consideration to the experiences of parents and caregivers that participated in this study.

### **5. Extending the criteria for qualification of the CDA**

There are a number of families that the study identified that might not qualify for the CDA, however they are struggling with the cost of their children's health conditions. This was particularly evident for those with children who have recurring respiratory conditions or eczema which can be variable in its severity over a 12-month period. Even though these conditions are not deemed to be serious consistently over 12 months, they still require parents and caregivers to spend time and money over and above the amount that would be spent on a child of a similar age without the condition. Therefore, it is recommended, that the criteria for the qualification of the CDA be extended to children that may experience health conditions that vary in severity, especially conditions that can be triggered by environmental factors which may be out of the control of parents and caregivers. In addition we recommend that those parents be supported to apply for the Disability allowance where they do not qualify for the CDA.

### **6. Greater promotion of the CDA**

The high proportion of respondents in this study that were unaware of the CDA highlighted the need of increasing awareness of CDA. At present the main avenue of information about benefits is through the Work and Income website, but in low-socioeconomic areas such as Otara, not everyone has access to the Internet. It is thus recommended that information should be readily available through Primary Health Organisations (PHOs), through factsheets available at reception in GP clinics and verbalised to parents and caregivers of children diagnosed with a disability or chronic health condition by either their GP or nurse. There may also be instances in which disabilities may be first identified through schools or in ECE in which case, schools and ECE providers should also have information about entitlements readily available for parents and caregivers.

### **7. Changes to the application procedure of the CDA**

The process of applying for the CDA was mentioned as barrier by some parents and caregivers. There were two key findings in relation to the application process, firstly that some respondents found difficulty in understanding what was required as a part of the application and secondly, many working parents and caregivers were unable to take time off work to gather the required documentation and visit Work and Income in regard to the application. Therefore, many respondents felt that it was not worth applying for the allowance, even though it could help ease their financial burden.

One of the recommendations that could help to improve the accessibility of the CDA would be for families to be offered the CDA at the time of diagnosis of their child's disability or health condition as opposed to having to go through the application process. All documentation could be provided to the doctor who would then forward the information to Work and Income who would then approve the application. This integration between Work and Income and PHOs would make the process far more efficient and easier for working parents as they would only be required to visit their doctor.

## **8. Support for extra expenses**

The study identified that parents and caregivers of children experiencing a disability or chronic condition often have extra financial burdens on them which are cannot be covered by the \$46.49 per week. There were a number of families that were living in poor housing conditions which exacerbates their child's illness. These families have extra heating costs which intensifies their financial burden. Consideration should be given to families in such situations with access to the (confusingly similarly named) means-tested Disability Allowance<sup>9</sup> being an obvious option.

There are two further recommendations that can be made with regard to families living in Housing New Zealand homes that are uninsulated: They should be referred to the Auckland Wide Housing Initiative (AWHI) to ensure they are fast-tracked to improving the insulation of their home. There may also be some homes in which insulation cannot be improved, so heating costs for these families should be subsidised so that they are able to keep their home warm and dry for their children.

## **9. Better funding for advocacy services**

In this study, some respondents mentioned receiving help from organisations that advocated for their family to receive the CDA. Families can be overwhelmed with the management of their child's disability or chronic health condition, therefore having advocates to provide information and assist with getting entitlements such as the CDA can be beneficial. Many of the organisations that were involved with advocating for the respondents in this study were not organisations that specialise in disability advocacy. It is recommended that funding should be available to community organisations that, so they have the capacity to provide specialist disability advocacy to those who need it.

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<sup>9</sup> Information available at <http://www.workandincome.govt.nz/products/a-z-benefits/disability-allowance.html>

# CHAPTER 6: Limitations and future directions

This study aimed to identify the extent to which the CDA is being accessed amongst families in need in Otara, as well as the many barriers in place for those who have been unable to access the allowance. However the survey component gained only a modest response rate of 50%, and a lower than expected rate of disability reported. The results showed that the majority of families, with a child or young person in their care who experiences either a chronic health condition or disability, were unaware of the CDA that would provide them with some regular financial support.

While this study was able to highlight many important issues in regard to access, there were some limitations which provide opportunities for further research. Firstly, it was found that the numbers of children with physical and intellectual disabilities in the sample were much lower than expected. During the data collection, there were three people who confirmed that they had a child with a disability but did not consent to participate in the survey. Therefore, we were unable to determine what type of disability or health condition their child had and whether or not these families were receiving the allowance. This study also relied on self-reported data which most likely has some bias toward under-reporting.

The lower number of physical and intellectual disabilities found for this study may be partly due to the fact that a large number of households were unable to be contacted when the researchers went door-to-door to complete the surveys. The study took place in the school holiday period, and there were many houses where there was no-one home. There were also some households that had a dog on the premises, so the researchers were unable to knock on the door. Researchers were only able to make contact with approximately 50% of the houses in the study area. It is likely that there were children or young people with physical and intellectual disabilities within the study area but who were missed out as a result. This limited coverage cannot explain this discrepancy entirely however.

Another possibility could be that physical and intellectual disabilities were not disclosed to the researchers during the survey. It was suggested by the fieldworkers, that it was likely that there would be Pasifika families that would not disclose having a child with a disability as it may be seen as shameful. Both of the fieldworkers were Pasifika and spoke about their cultural attitudes towards disability, so felt that respondents would be less likely to disclose their child's disability or health condition and would also be less likely to seek help in regard to it. The data gathered through the survey could not show cultural attitudes towards disability – as this was not the focus of the study. Furthermore, there is currently no literature to suggest this relationship between culture and disability.

The shortcomings of relying on self-reported data for this study were not only related to disclosure but also to correctly identifying a disability or health problem. Some of the parents and caregivers were not entirely sure what their child's health condition was called. Parents and caregivers were asked to describe the disability or health condition, which was then categorised into the most appropriate category during data analysis. Through self-reported data, it was also difficult for the researchers determine whether the families would definitely be eligible for the CDA.

A comparison of the survey results with the estimates of the number of CDAs likely to be paid to families in Otara show another anomaly which is difficult to explain. These estimates (see Table 2) suggest that between 250 and 270 CDA payments are being made on behalf of Otara children.

This survey reached in excess of 1,000 households which represents approximately 15% of Otara households. On this basis we could expect that 35 to 40 of the respondent households were receiving a CDA payment on behalf of child in their household. Yet as reported above, only eight households with children with disabilities reported receiving a CDA. This anomaly perhaps provides an insight into the extent of non-reporting of serious or significant degrees of disability amongst children in Otara.

Findings and observations made from this study provide opportunities for future research to explore, particularly in regard cultural perceptions of disability that are associated with access to health benefits such as the CDA. It could be important to understand perceptions of disability in different cultures and whether these can be associated with barriers to accessing care. Such findings could have major implications for children and young people living with disability or chronic health conditions.

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# APPENIDIX 1

Child Disability Allowance payments by Auckland local board areas - 2011 to 2015

YE December	2011	2012	2013	2014	2015	Change 2011-15
Albert - Eden	526	542	517	540	519	-1.20%
Devonport - Takapuna	306	289	266	283	269	-12.20%
Franklin	475	455	429	474	500	5.20%
Great Barrier/Waiheke	51	45	40	44	41	-19.60%
Henderson - Massey	1006	958	903	901	906	-10.00%
Hibiscus and Bays	670	628	595	577	548	-18.30%
Howick	971	899	877	887	844	-13.00%
Kaipatiki	538	501	460	474	481	-10.70%
Mangere - Otahuhu	772	728	710	711	666	-13.70%
Manurewa	1081	1011	934	921	916	-15.30%
Maungakiekie - Tamaki	1025	840	766	654	646	-36.90%
Orakei	240	159	151	179	173	-28.20%
Otara - Papatoetoe	658	627	610	645	654	-0.70%
Papakura	642	575	513	517	503	-21.70%
Puketapapa	302	293	298	309	328	8.60%
Rodney	341	308	289	297	290	-15.10%
Upper Harbour	231	234	225	222	206	-10.80%
Waitakere Ranges	297	289	272	270	268	-10.00%
Waitemata	313	280	265	252	244	-22.10%
Whau	591	536	516	512	512	-13.40%
<b>Total Auckland Boards</b>	<b>11,036</b>	<b>10,197</b>	<b>9,636</b>	<b>9,670</b>	<b>9,511</b>	<b>-13.80%</b>



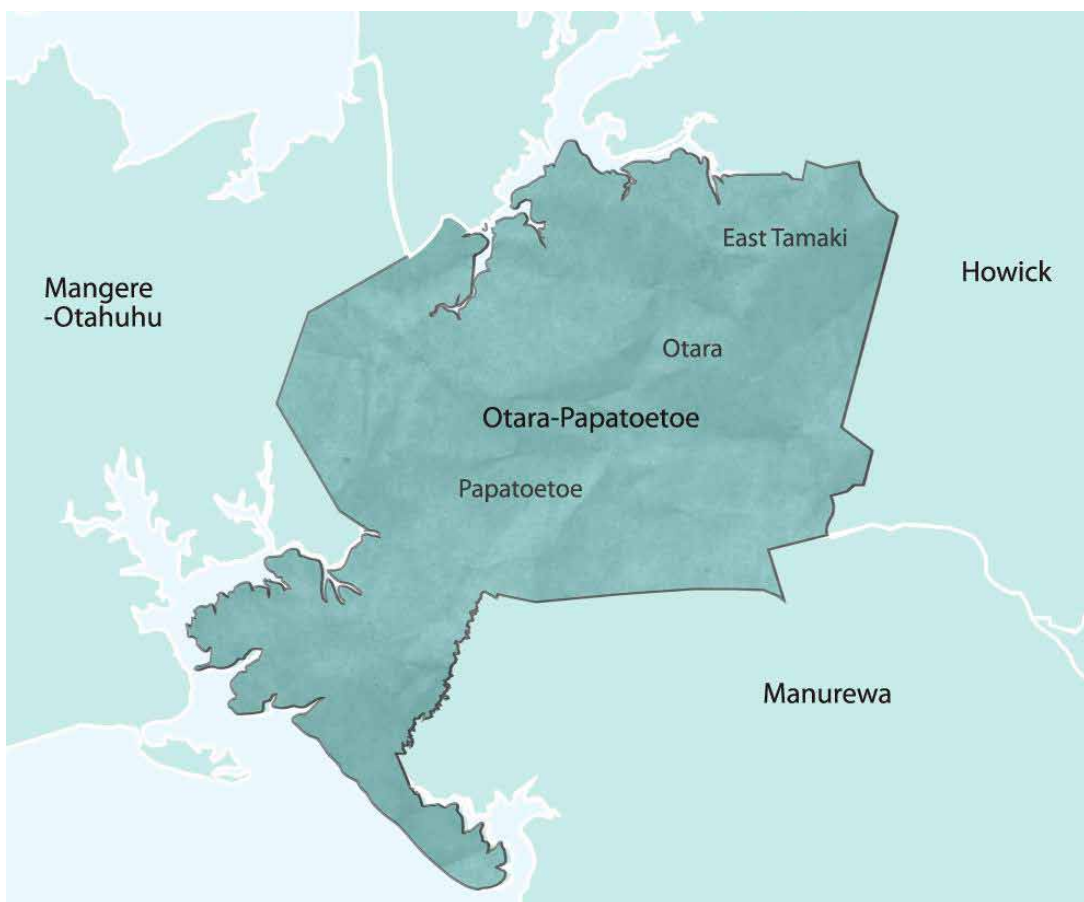
# APPENIDIX 2

## A profile of Otara

Otara is a suburb in South Auckland which is known to have a large number of state houses. It is located 18 kilometres south from Auckland CBD. Otara is generally considered to be one of the poorer suburbs in Auckland, which is often linked to poverty and crime. Otara has the second lowest median income in the Auckland region, at \$25,9000 (NZ Census data) and is rated a 10 (most deprived) on the index of socio-economic deprivation.

Whilst ethnically diverse, Otara has a predominantly Pacifica population, followed by Māori. The majority of Otara residents do not own their own home, with greater than 60 per cent of the population living in a rented home.

**Figure 3: Otara's boundaries**



# APPENDIX 3

Survey form

INTERVIEWER'S NAME ..... DATE

SURVEY FORM NUMBER ..... - *please record this on the street sheet as well*

Has the respondent been advised of privacy issues and have they given their informed consent to take part in this interview? (Y/N)	
--	--

RESPONDENT'S FIRST NAME

RESPONDENT'S HOME ADDRESS

RELATIONSHIP OF RESPONDENT TO CHILD

Child's first name	
Child's age	
Child's gender	
Child's ethnicity(ies)	
Child's school or ECE (record name if attending)	

**Nature of child's disability** (*record respondent's description*)


**Cause of child's disability** (*record respondent's description*)


--

**Level of care required** *(record respondent's description)*


If possible tick one of the following boxes to describe the level of care this child requires

Child lives OK as just one of the family

.....

Child needs some additional care and supervision every day

.....

Child needs someone looking after them most of the time

.....

Child requires someone to feed and wash them

.....

**Support provided outside agencies** *(record respondent's description)*


Then ask the following specific questions if these have not already been answered

Do you receive financial support from Work & Income to help meet the costs of looking after your child? (Y/N)

If yes – how much per week is this payment?

.....

Do you receive a Child Disability Allowance from Work & Income to help meet the costs of looking after your child ?(Y/N/Don't know)

If yes – how much per week is this payment?

.....

If no – has the family every applied for the Child Disability Allowance? (Y/N)

**Support from outside agencies - continued**

Does the family or child receive support from the school or ECE (if they attend these) and if so what sort of support (*record respondent's description*)


Has the family ever had problems getting support from public agencies like Work and Income, schools and ECE's and if so what sort of problems (*record respondent's description*)


<b>Other matters or concerns the respondent raised or wished to discuss</b> <i>(record respondent's comments)</i>

Was a referral considered appropriate? (Y/N)

Was a referral and related support offered to the respondent? (Y/N)

Did the respondent accept the referral and sign off the referral form (Y/N)

# APPENDIX 4

## Referral form

### REFERRAL FORM

INTERVIEWER'S NAME ..... DATE .....

RESPONDENT'S NAME .....

RESPONDENT'S HOME ADDRESS .....

RESPONDENT'S PHONE NUMBER .....

RELATIONSHIP OF RESPONDENT TO CHILD .....

DOCTOR'S NAME .....

REASON FOR REFERRAL .....

ASSISTANCE REQUIRED	TICK IF REQUIRED
Advice that person is visiting their GP	
Taxi transport to GP	
Payment of any charges for specialist visits or assessments	
Taxi transport to any specialist appointments	
Assistance with their application to Work and Income	
Other support required	

Approval is given to advise our family doctor that we will be soon visiting him or her to seek help with our child's needs

.....  
NAME

.....  
SIGNATURE

### FOOTNOTES



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