

Evaluation of the Complex Carers Group Project.

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Executive Summary

The Complex Carers Group Project grew out of concerns expressed by families in Auckland caring for disabled children and young people with significant needs. The Wilson Home Trust initiated a project to set up a national body to represent these families. The Ministry of Health supported a proposal to develop a national body – the Complex Carers Group –

- to provide support and information for carers
- to provide expert advice to the Ministry of Health on relevant issues
- to act as a collective voice for the concerns of these carers

This original plan was adapted in the following ways:

- a research/mentoring role was added to the Project;
- a Pilot Project was undertaken in Waitakere City;
- ethical approval was sought and obtained for the Pilot from the Auckland Regional Ethics Committee;
- a process and outcome Evaluation Framework was established.

The Project Team involved a partnership among

- a provider, the Wilson Home Trust (Karen Forrester)
- a carer, who was the Complex Carers Group Coordinator (Jan Moss)
- the Ministry of Health (Karen McConnachie).

Anne Bray, from the Donald Beasley Institute, was the fourth member of the Project Team, and provided the research/mentor role.

These four contributions were all key elements in the Project's success.

Project Tasks

The Project Team:

- commissioned a literature review of research relating to carers;
- consulted with local agencies and key contacts in Waitakere;

- distributed 519 “Carer Packs” to 26 agencies;
- set up the Complex Carers Group for 48 carers who wished to join;
- analysed the detailed information from the 53 questionnaires returned by carers;
- undertook on-going process evaluation through regular reflection and meetings;
- commissioned an external evaluation, involving key informant interviews.

What has been learned from the Pilot Project?

Further developments for a National Complex Carers’ Network can now proceed on a firm basis, with the processes, ethical applications, questionnaire, and information analysis processes already prepared. Local consultation and minor adaptations to the ethical application and processes would still need to be undertaken.

Key elements to improve further developments have been identified from the internal and external evaluations undertaken in the Pilot Project.

The results from the Pilot Project have also demonstrated:

- the need to focus on carers of children and young people with high and complex needs, aged 0-25 years, rather than 0-65 years;
- a functional definition of high and complex needs, and of carers of this population, emerged from the questionnaire results.

The three initial goals for the national body have been achieved in the Pilot Project:

- a network of “complex carers” was successfully established in Waitakere city, including carers from all significant ethnic groups;
- support and information to these carers is now on-going, involving a range of issues, including some significant crisis situations;
- detailed information, both quantitative and qualitative, has been gathered and analysed for the Ministry of Health, on carers’ situations and needs;

- functional definitions of children and young people with high and complex needs, and of their carers, have been developed.

Information from carers

The 53 completed questionnaires provided detailed information on:

- the disabled person being cared for;
- the disabled person's care needs;
- the carers' needs;
- home support for carers;
- services and their coordination;
- carers' messages to the Ministry of Health.

Conclusions

The findings from the Pilot Project showed:

- serious shortcomings in the provision of needs assessment and coordination, in terms of:
 - inadequate assessment of carers' needs
 - the need for intensive service coordination
 - lack of crisis plans
 - the need for adequate resourcing, training, and flexibility in the operation of NASC agencies
- inadequate service provision, particularly in the areas of:
 - respite care
 - transition-to-adulthood services
 - alternative care including skilled caregivers

Areas for further policy development were also identified by the Project Team.

EVALUATION OF THE COMPLEX CARERS GROUP PROJECT

1. Introduction

This Evaluation Report provides a comprehensive account of the establishment of the Project, the process of its development, and its outcomes. An Evaluation Framework was developed early on in the Project to provide a structure for continuous evaluation (Appendix 1).

There is a separate document which provides a review of relevant research literature on carers of disabled people with high and complex needs. This review was undertaken as part of this Project.

As part of the Project, carers completed a questionnaire which provides detailed information on the disabled person they care for, their own needs, and their current access to services. The analysis of this information forms the final section of this Report.

A number of Appendices to this Report have been included as a separate attachment.

2. Description of the Project

2.1 Why was the Project set up?

The beginnings of the Project are firmly based in the realities of families caring for disabled children and young people. **The Project emerged from strong, “grassroots” concerns.**

The following key milestones were:

- “Just Surviving” Report, commissioned by the Health Funding Authority and Child, Youth and Family Service, December, 2000 was published; this Report explored the factors leading families to seek out-of-home care;
- The Wilson Home Trust identified the need for a national body to advocate on behalf of these families and contacted families to gauge support;
- Contact was made with the families who contributed to the “Just Surviving” Report, resulting in strong support for the proposal;

- Jan Moss, a former employee of the Wilson Home Trust and a carer, was approached to become the Coordinator of the proposed Complex Carers Group, and the Wilson Home Trust undertook to provide secretarial/establishment support;
- A Proposal was sent to the Carers Interest Group in the MOH, Disability Issues Directorate, accepted in 2002;
- The Project Team was established including: Jan Moss, carer of a person with complex needs; Karen Forrester, Wilson Home Trust; and Karen McConnachie, Ministry of Health. The vision of this Project team was:
 - to develop a national body to support carers providing an intensive level of care,
 - to provide expert advice to the MOH on relevant issues, and
 - to act as a collective voice for the concerns of these carers.

Thus, the initial vision of a national network for Carers of Disabled People with High and Complex Needs was borne. The key players were brought together: a service provider, a carer, and a funder.

2.2 How did the initial Project plan change and develop?

Over time, the initial plan developed in a number of significant ways. The key steps were:

- the addition of a “research/mentoring” role to the Project, to ensure that the Project would provide reliable data to inform policy and service development. Dr Anne Bray of the Donald Beasley Institute joined the Project Team to fulfil this role;
- notification of key agencies about the Project, and development of a Memorandum of Understanding with Carers NZ (who host the Complex Carers Group on their website);
- deciding to undertake a Pilot Project in Waitakere City to inform the national development, and setting up an Advisory Group of key stakeholders (see Appendix 2)
- holding a public meeting to inform all key stakeholders about the Project and to consult with them about processes to be followed;
- application for ethical approval for the Pilot Project to the Auckland Regional Ethics Committee (Appendix 3)

- developing an Evaluation Framework to ensure that a detailed process and outcome evaluation was undertaken.

2.3 What were the key elements contributing to these initial achievements?

Behind this summary of steps lies extensive work and involvement by all members of the Project Team. Reflections on this initial stage by the Team have identified the following key elements:

- advocacy, support, and advice from within the MOH, and ensuring the project's status as a Project, rather than a contract;
- the thorough project scoping and development of contractual requirements, plans, and monitoring, through advice and support from MOH;
- the inclusion of the research component at an early stage, to ensure that processes were ethical, the information gathered was sound, and the Project was evaluated;
- the three-way partnership among a provider (the Wilson Home Trust), a carer who was the Complex Care Group Coordinator, and the MOH;
- the knowledge, experiences, and shared values about families and disability among all four members of the Project Team.

2.4 How was the Pilot Project undertaken?

Following the receipt of ethical approval, the following key steps were undertaken:

- a literature review of research relating to carers of people with disabilities was undertaken by the Donald Beasley Institute (see next section for Executive Summary);
- all local agencies were re-contacted and asked to estimate the potential numbers of carers of disabled people with high and complex needs on their database;
- "Carer Packs" were prepared for distribution (Appendix 4)
- a total of 519 packs were sent to 26 agencies for distribution to carers;

- carers responded directly to the Coordinator, enclosing membership requests and completed questionnaires;
- detailed records were kept by the Coordinator of all personal interactions with carers throughout the Project;
- data from the questionnaires were entered on to an excel spreadsheet and summarized descriptively. These results are provided in Section 5 of this Report;
- the Project Team held meetings approximately every 6 weeks throughout the project to monitor progress, solve problems, and identify issues. Regular email and telephone contact was also maintained between meetings;
- the Project Team commissioned an external evaluation of the process through interviews with key stakeholders. Dr Berni Kelly of the Donald Beasley Institute undertook this evaluation (Appendix 5).

2.5 The Literature Review

The literature review, (“Families Caring for Members with High and Complex Needs: What does the research tell us?) is available as a full document. The Executive Summary is reproduced here.

Executive Summary

This literature review provides an overview of findings of recent research on informal or unpaid carers of children and adults with disabilities. These carers can be viewed by professionals or service providers as free resources, co-workers, or clients in their own right.

The background of carers

In this review, informal caring refers to a type and/or level of caring not typical for other people of that age. Carers are predominantly women and researchers have noted the social pressures on women to take on the carer role. Societal changes towards more community-based care for disabled people may have increased these expectations of women to provide care.

Carers of children and young adults are usually parents, although siblings sometimes take on the caring role when parents are no longer available. In contrast, carers of older disabled adults are more typically spouses or adult offspring. Thus, informal carers are almost always kin of the disabled child or adult. Non-kin typically perform paid, formal care tasks.

Carers are found in all adult ages but most commonly from 30-59 years, and come from every ethnic background. Carers may spend the majority of their lives in this role. Caring work may continue even after the disabled person has moved into residential services. Caring is usually a long-term responsibility.

What do carers do?

The intensity of care duties varies, but is frequently time-intensive and varies over time and circumstances. The intensity of caring may reduce over time for disabled children and young people, but may increase for older people with increasing levels of disability over time.

Carers perform many tasks, including often high levels of physical care and also instrumental tasks for the disabled person. These instrumental tasks are very varied and include many aspects of coordination, organisation, and transporting the person. Some work that carers do involves everyday tasks that are no different to what they would do for any other family member of that age. But many tasks are very unusual, such as performing medical procedures, or much more difficult and time-consuming, such as feeding a young child with significant disabilities.

Much of the research on carers has focussed on the physical demands of caring, whereas the other demands on carers may sometimes cause even more stress. Carers are also more likely to have to cope with emergency situations than other families. There is often little recognition that carers of people with high needs, particularly parents, are typically providing care for other dependent family members too.

The situation of carers

Carers typically have very little choice about providing care. This is not a “job”. They are kin and love the person they care for. Since the closure of institutions, carers may be in the position of having **no** choice about continuing to provide care into the future.

Informal carers both “care about” and “care for” the disabled person, in contrast to formal carers who undertake the tasks of caring but are not expected to care about the person, to the extent that kin do.

Research has commented on the ways in which caring can limit the rights and freedoms of the carer, with some writers identifying these limitations as types of “oppression”. Carers can experience these limitations directly from the person they are caring for, e.g. in the form of aggressive behaviour. Another form of limitation comes from the experiences that are often part of informal caring, such as financial worries, anxiety about the future, inability to leave the disabled person. These types of limitations affect the typical freedom over the direction of

one's life. Finally, carers experience "oppression" in the form of society and community attitudes towards disabled people, and sometimes from professionals and support services. Carers may be seen as unquestioned resources and feel forced into roles without consultation or agreement.

These experiences of carers are largely hidden from public view, and carers typically feel that the realities of their lives are not appreciated or understood by the rest of society.

The effects of caring

Carers have identified positive outcomes from their role, particularly satisfaction that their loved one is getting quality care that others are unlikely to provide. Support from family and friends contributes to carers' satisfaction. Both fathers and mothers have reported personal growth from their caring experiences.

There are also, however, personal costs often associated with caring.

Carers' lives are inevitably different to what they expected for themselves and their families. Caring is often continuing and exhausting, with no allowance possible for the carer being ill or unable to care. In addition to physical demands, caring may also bring extra emotional stresses. Some level of continuing sadness or grief may be a reality for carers.

Carers' relationships with others are inevitably affected to some degree. Family dynamics and relationships often change over time as other members grow and develop but the disabled person continues to need a high level of care. Siblings can be affected in various ways, and parents are often concerned about these perceived effects. Lack of support from other family members for the primary carer can be very stressful and isolating for the carer.

Restrictions on normal family activities can affect family life.

Research has found higher rates of separation and divorce among carers, with the primary source of support then often being unavailable. Greater involvement of both parents in care is more likely to lead to marital satisfaction.

Extended family members can be a source of practical and emotional support for some carers, but this is likely to depend on other family characteristics, (such as prior relationships, distance, age) rather than simply the presence of a disabled person in the family.

Many carers experience a smaller social network of friends than usual, due to the practical problems in making and maintaining friendships outside the family, particularly as their children get older.

Stress and coping

Families differ in how resilient they are in the face of stress. Research suggests that coping strategies which focus on solving problems are more helpful than emotion-focussed coping strategies. Mothers appear to be more likely to use positive coping strategies than fathers. However, family response to stress is a very complex area and carer needs therefore need appropriate assessment within their family context.

There are many sources of stress on carers, in addition to the ongoing caring tasks – such as continuing years of advocacy, financial pressures, managing family relationships, difficult behaviours in the disabled person.

Carers' health can be negatively affected by their caring role, and may decline as caring continues over many years. Carers may neglect their own health amid the demands of caring for others. Simply removing the demands of caring, may result in a return to good health. Sleep deprivation, heavy physical caring, and sometimes inflicted injuries are often reported by carers.

Carers are also at risk for poor mental health, with depression often reported, particularly when caring for a person with behaviour problems. The demands of caring often have negative effects on employment and financial status. Carers are less likely to be in paid work than non-carers. Combining paid work and caring can have positive or negative effects, when the strain of doing both is too great. When employment is not possible, there can be long-term effects on both the carer and the family.

The lack of appropriate after-school and school holiday care limits employment options for some carers. Changes are needed in the availability of such services and in work environments themselves, with more flexibility for carers.

For many families, therefore, financial hardship is an additional and on-going stress, with the extra costs of disability adding to this situation. Most sole-parent families have to survive on income support. Even when both partners work, family income is often still relatively low.

Support for carers

Many carers appear not to receive any formal help, or training in their role. They often lack knowledge about available services, due to a lack of clear responsibility for informing carers about available supports and services.

Even when services are available, access to them can be stressful and difficult, and a source of anxiety and frustration. Access can also be affected by the carer's socio-economic status or ethnicity.

Services provided are not always appropriate or accessible to all families. Carers often express concern about the lack of training in support workers, partly due to the typical low pay they receive.

Carers of people with high support needs do need respite from the demands of caring, but adequate respite is often unavailable, and is too often in response to a crisis, rather than regular and preventative.

Carers themselves can sometimes be reluctant to seek or access support, particularly older carers. There are many types of support that carers find helpful, including advice, inspiration, and support from other carers. Partners and other family members are the main support people, with other relatives and friends also important sources of support for many carers.

In terms of formal support, this is often **indirect**, as part of support aimed at the disabled person. For many carers, access to accurate and timely information is a major concern.

Support in the home can be a “mixed blessing”, mainly due to the lack of continuity and expertise in support workers.

Parents can also perceive a lack of respect, concern, and understanding from the professionals and workers who are supposed to arrange or provide support.

Many carers need practical support with everyday tasks, but this is often unsatisfactory even when available.

Respite care, a very important support service, is still not always available or is of poor quality, according to many carers. Respite should relieve the carer **and** provide a good experience for the disabled person.

Research has found more unmet needs among younger carers, but the reasons for this are unclear. However, this is of concern, as the general expectation in society is that support services have expanded and improved. This may be so for many families, but for carers of disabled people with high and complex needs, there is still some way to go.

Changes in circumstance can lead to some carers seeking alternative, out-of-home care for the disabled person. These changes can be in the carer e.g. aging, or in the disabled person e.g. getting bigger and harder to manage physically or emotionally. Changes in the family can also be a reason for seeking alternative care e.g. other relatives needing support.

A need for alternative care may sometimes be related to a lack of appropriate day services for a young adult. Decisions about seeking such care are typically the result of a long, agonising process for carers, both now and in the past when

institutional care was available. The majority of families do not want alternative care, and even when it is the chosen option, carers can remain stressed over its poor quality and lack of continuity, particularly in staff.

Policy changes away from institutional care are perceived as failing to provide viable alternatives for some people with high and complex needs. Some researchers see these policies as failing to consider unpaid carers' needs, particularly women who provide the vast majority of unpaid care.

Future service policy needs to improve both informal and formal sources of support. Family-centred models of support are promoted, rather than support focussed only on the needs of the disabled person. Support services need to be flexible and designed to meet the needs of individual families, whose needs also change over time. Flexible service models are in line with the social model of disability promoted in the New Zealand Disability Strategy.

The emphasis should be on planning services in partnership with families, with a focus on positive planning rather than responding to deficits or crises. Planning itself, however, must lead to actual services to meet the various needs of families. Professional support must be available to meet complex medical need, early intervention services, counselling, and ongoing, available professional advice and support. The alternative is a return to institutions which contain the necessary professional supports.

This review of the research literature has provided a picture of caring for disabled people with high and complex needs – a picture that will be familiar to most carers in New Zealand. There are consistent findings across countries and families that should not be ignored. While families want to care, they need better supports and services to do so. Many carers are under extreme stress. Carers need their own focus in policy and services, not simply as an indirect result of services for the disabled person. The education of professionals and support workers also needs urgent attention.

Without the necessary changes, strong calls are likely to emerge for a return to institutions or large, special facilities.

3. Evaluation of the Project's processes

3.1 What process aspects could be reduced in further developments?

All of the steps outlined were essential for the Pilot Project, but the time involved in some areas would not be needed to extend the Project to other areas. These areas include:

- scoping, specifications and contractual requirements would require less time, as models have now been developed;
- the ethics application would only require minor modifications to provide details of local personnel, consultations and processes;
- the information material and questionnaires are all prepared and would only need to have local information inserted;
- the spreadsheet that has been developed can be used for the questionnaire data entry and analysis;
- systems of networking and administration have been established.

3.2 What key elements would be needed in further developments?

From the Project Team's own reflections on the current Pilot Project and the external evaluation, the following key elements have been identified:

- limiting the Complex Carers Network to carers of disabled children and young people with high needs who are aged 0-25 years;
- a partnership approach involving, at a minimum, the National Coordinator, a paid local Coordinator (with first-hand experience of carer issues), and the Ministry of Health;
- clarifying the purpose of the Project with all key stakeholders at the beginning of the process;
- providing a definition of "complex carer" for the purposes of the Project, recognizing the importance of family context;
- consultation and involvement of Maori and Pasifica carers and agencies at an early stage;
- involvement of key agency representatives through an Advisory Group, throughout the Project;
- establishing positive relationships with key agency representatives;
- providing access to research, policy, and practice expertise;
- providing adequate time for providers to disseminate information to carers;

- considering alternative ways of accessing and communicating with some carers, including face-to-face group contact;
- setting up a process to identify the avenues through which each carer received the initial information e.g. coding each questionnaire;
- separating the membership/network part from the research/data collection part, to minimise the size of the initial information pack sent to carers and enable early personal contact with the Coordinator;
- providing summaries to key agencies throughout the process of the Project.

4. Evaluation of the Outcomes of the Project

The original aims of the Project were:

- **to establish a national network of carers of disabled children and/or adults with complex care needs;**
- **to provide support and information to these carers;**
- **to develop an avenue for carers to provide feedback and information about their needs to the Ministry of Health.**

A decision was made to undertake a Pilot Project first, in Waitakere City, in order to develop and evaluate the processes involved, and to provide a sound basis for the future development of the National Network. The first objective was therefore modified to: **the establishment of a network of “complex carers” in Waitakere City.**

As part of the Pilot Project, **an additional objective** was:

- **to develop a functional definition of “high and complex needs” as applied to carers.**

The achievement of each of these four objectives will be evaluated separately.

4.1 The establishment of a network of “complex carers” in Waitakere city

This objective has been satisfactorily achieved with regard to carers of 0-25 year olds. Contact with the Coordinator was made by 53 carers, 48 (91%) of whom became members of the Complex Carers Group. Of these 48 carers, 42 (87%)

chose to have their details included in the Carers Network Directory. This allows carers to make contact with others who may be in similar situations

As described in Section 5 these numbers represent 2.9% of the total number of caring households in Waitakere city, based on 2001 Census data.

These carers included 10 Maori (19%) and 5 Pacific Island carers (10%).

The original age group envisaged for the network was 0-65 years. However, even though a broad range of agencies was used to contact carers in the Pilot Project, only 3 carers of disabled people over 25 years of age replied. Only 1 carer mentioned ACC as a key person or agency. It appears that carers of younger people saw the Network as more relevant to them than did carers of adults, who may be better served by Carers NZ, and are also more likely to receive services through ACC. For example, adults with head injuries would constitute a significant proportion of adults with high and complex needs, whose carers would normally obtain support through ACC. Also, many adults with high and complex needs would currently be in fulltime, residential services, for example, those provided by IHC and Spectrum Care.

We recommend that the proposed National Complex Carers Network focus on carers of children and young people (0-25 years) with high and complex needs.

4.2 To provide support and information to carers

Contact has been made with all carers, by telephone, mail, email, or face-to-face. Information and support has been provided as requested. In some circumstances, carers have been referred to another more appropriate source for advice or information. Many of the carers stated that they were grateful for the opportunity to have someone who had a real understanding of the issues they faced, to discuss their situation with.

Many of the queries have been around the following issues:

- problems with NASC agencies and processes;
- support workers;
- respite care;
- young adults with high and complex needs and their future.

It became apparent from the study and subsequent discussions, that many of the carers felt totally unsupported and were at a loss to know whom they could turn to for the support they needed.

In some cases, in which carers were clearly undergoing crises, significant advocacy and support has had to be provided, in partnership with Carers NZ.

As a result of this support and advocacy, a working party has now been established in Auckland by Carol Searle, Deputy Director General of Health, Disability Services Directorate, to clarify a process for NASC agencies so that appropriate support can be provided for families who are caring for a person with high and complex needs. The Coordinator was invited to participate in this working party, which is still meeting regularly.

Participation in this pilot study provided a timely opportunity for some desperate families to receive support to achieve positive outcomes. Carers have continued to make contact with the Coordinator for advice and support. This has mostly involved carers who are feeling helpless about finding some satisfactory resolution to the issues they have. To date this year, five carers have requested help to resolve significant difficulties they are having. It is apparent that there is a real need for clear, user-friendly, **accurate** information to be provided for carers, either written, or other suitable format, especially around the role of the NASC agency and their responsibilities to carers. Ongoing support for this group is imperative and already the advantages of the “collective voice” are obvious.

4.3 To develop an avenue for carers to provide feedback and information about their needs to the Ministry of Health.

This objective has been achieved in two ways:

- through the completion of a detailed questionnaire by each of the 53 carers (the findings from these questionnaires are provided in full in Section 5 of this Report); this information provides a sound basis for policy and service development for the MOH. Extending this information gathering throughout the country would be extremely valuable, and could also be used to monitor progress in services for these carers;
- through the identification of critical carer situations which have the potential for serious risks for the carer and/or the child/young person and/or harmful media exposure (discussed also under 4.2).

This second type of feedback was not originally envisaged as part of the project outcomes, but has been essential in this locality. This situation may not occur in other localities in which the Complex Carers Group becomes established in the future. It is important to note, however, that the partnership approach in this

Project involving a senior MOH staff member has ensured that these crises can be attended to in a timely and professional way.

4.4 To develop a functional definition of “high and complex needs” as applied to carers.

The term “high and complex needs” is used and defined in different ways within and among different government departments. In the context of this Project, the term is used primarily to refer to the needs of the disabled person being cared for. However, the implication is that the carer(s) of that person will also have high support needs **as a carer**. As a carer, there will also be other contextual factors that affect carer stress and burden, for example the number of other dependent persons for whom the carer is responsible (83% in this Project). These contextual factors must be considered when assessing the **level** of support needed for carers of disabled people with “high and complex needs”.

The need for a specific focus on carer needs has been recognised in the recent “Best Practice Evidence-based Guideline on Assessment Processes for Older People” (Ministry of Health, ACC, and New Zealand Guidelines Group, 2003). This publication states:

Carers have particular needs resulting from their carer role, and supporting those needs results in improved outcomes for both the carer and the care recipient, including a reduction in abuse in caregiving situations.

Carer needs assessment should be integrated with any programme of assessment of older people (p. 23).

Similar guidelines could also apply to carers of disabled children and young people, particularly those with high and complex needs.

From the information provided by carers in this Project, the disabled child or young person being cared for typically had

- a severe level of disability (87%)
- multiple disabilities, with the most common being communication (83%), intellectual (74%), and physical (64%)
- recognition of High and Very High Needs, under the ORRS Scheme for educational resources (83%).

A functional definition of a child/young person with high and complex needs, which reflects this reality, is as follows:

A functional definition of “high and complex needs”

“High and complex needs in a child/young person with disabilities includes:

- a severe level of disability in at least one area of functioning **and** effects on at least **three** areas of functioning OR
- a moderate level of disability in at least one area of functioning **and** effects on at least **four** areas of functioning.

The areas of functioning are:

- physical
- intellectual
- visual
- hearing
- communication
- continence
- behaviour
- neurological (including epilepsy)
- ongoing health needs

A functional definition of a “complex carer” (for the purpose of the Complex Carers Project) is:

- **an unpaid carer who has primary responsibility for the care of a child/young person, aged 0-25 years, who has high and complex needs (as defined).**

In terms of meeting carers’ needs, needs assessment agencies must also consider the individual carer’s family situation, including such factors as:

- number and ages of other dependents
- carer’s own health status
- age of carer
- availability of support from other family and extended family members
- financial needs
- suitability and quality of housing
- intersectoral stressors e.g. how well educational needs are being met

This definition could be adapted to define unpaid carers of adults with high and complex needs, by simply changing the age criterion.

The next section contains the findings from the Carers' Questionnaire. These findings, along with the review of literature, provide strong evidence of the need for improved support for carers of children and young people with high and complex needs. Part of this support must lie in better services for these children and young people.

5. The information from carers' questionnaires

Completed questionnaires were returned by 53 carers. Of these 53 carers, 48 became members of the Complex Carers Network and 42 chose to have their details included in the Carers Network Directory. One disabled adult being cared for has since died. Three of the carers were caring for two disabled children.

5.1 The disabled person being cared for

The age range of the people being cared for was six months to 42 years. The majority (70%) were school-aged children (Table 1). Sixty-six percent were males and 34% were females.

Table 1: Ages of disabled people receiving care

Age in years	N	%
0-4	5	9
5-16	37	70
17-25	8	15
26+	3	6
Total	53	100

From the 2001 Census data on Waitakere city, 4% or 1,849 households reported caring for an ill or disabled person in their own household. The households identified here as caring for a person with high and complex needs therefore constitute 2.9% of the total number of caring households.

Given the assumption that this is a relatively small group covering primarily children and young people, the results should be reasonably robust for children and young people with high and complex needs in Waitakere City. The small number of results from carers of adults suggests that different methods for contacting these carers may be needed. However, it should be noted that Waitakere City is a young city with 39% of its population under the age of 24 years (as at 2001 Census).

The ethnicity of those being cared for varied, with higher proportions of Maori among those responding than in the Census data (Table 2). This may reflect the different age distribution between Maori and NZ European.

Table 2: Ethnicity of disabled people receiving care

Ethnicity	N	%	Census %
NZ European	33	62	72
Maori	10	19	13
Pacific Island	5	10	14
Asian	3	5	11
European	2	4	Not reported
	53	100	100

The types of disabilities among those cared for demonstrated the overwhelming presence of multiple disabilities, and severe disabilities (Tables 3 and 4).

Table 3: Types of disabilities among those cared for

Types of disability	N *	%
Physical disability	34	64
Intellectual disability	39	74
Visual impairment	16	30
Hearing impairment	11	21
Communication	44	83
Incontinence	26	49
Difficult behaviour	31	58
Epilepsy	24	45
Neurological disorder	25	47
Ongoing health condition	23	43

* The numbers do not sum to 53, as carers ticked all those disabilities that applied.

Table 4: Severity of disability of person cared for

Severity	N	%
Severe	46	87
Mild/moderate	6	11
Unknown	1	2

The cause of the person's disability was unknown in 43% of the group, whereas 30% of causes were identified as occurring prenatally (Table 5).

Table 5: Cause of person's disability

Cause	N	%
Prenatal	16	30
During birth	4	8
Injury after birth	1	2
Illness after birth	3	6
Inherited condition	4	7
Other	2	4
Unknown	23	43
	53	100

The majority of carers had other dependents (83%), ranging in age from seven months to 72 years. The number of other dependents ranged from one to seven.

5.2 The disabled person's care needs

The amount of supervision required for the disabled person was very high for 94% of these carers (Table 6).

Table 6: Level of supervision required

Supervision needs	N	%
Constant/continual	42	79
Most of the time	8	15
Regular checking on	1	2
Only at certain times	2	4
	53	100

Daily care was normally provided by only one or two people (85%). (Table 7).

Table 7: Number of daily carers

No. of carers	N	%
One	21	40
Two	24	45
Three	7	11
More than three	2	4
	53	100

When the disabled person needed to go outside the home, the majority of carers managed by themselves (73%) (Table 8), although this may well change as these children and young people get older.

Table 8: Carers needed to go outside the home

No. of carers	N	%
One	38	73
Two	14	27
	52	100

Ninety percent of those being cared for lived at home most or all of the time (Table 9).

Table 9: Disabled person's living situation

Location	N	%
At home all the time	33	62
At home some of the time	15	28
In residential service some of the time	3	6
In residential service all of the time *	2	4
	53	100

* This finding illustrates the fact that caring and carer stress does not automatically cease even when the disabled person is in residential care.

A small majority of carers were satisfied with their out-of-home care (58%) but 9% had major concerns (Table 10).

Table 10: Satisfaction with out-of-home care (including at school)

Level of satisfaction	N	%
Very satisfied	15	31
Satisfied most of the time	13	27
Concerned about some aspects	16	33
Very dissatisfied/major concerns	4	9
	48	100

The expressed concerns of carers about out-of-home care were varied and included:

- concern about the lack of adequately trained staff and high staff turnover (7 comments);
- other family members' lack of confidence with medical procedures;
- lack of stimulation;
- negative effects on or dislike of respite by the disabled person;
- not being able to take the person to organized activities;
- lack of respite care to meet family's needs e.g. at weekends; lack of consistency; lack of prompt service;
- concern about males providing intimate care.

Three carers made positive comments about the care provided for their child at school.

Almost half of all carers (47%) felt that the equipment needs of the disabled person were not adequately met, with 68% of those using equipment needing multiple pieces. (Table 11).

Table 11: Equipment needed by disabled person

Type of Equipment	N *	%
None	19	36
Crutches	6	11
Manual wheelchair	17	32
Electric wheelchair	3	6
Positioning device	9	17
Special feeding equipment	6	11
Communication aid	14	26
Lifting equipment	7	13
Special furniture	15	28
Bathing and showering equipment	6	11
Special buggy	2	4
Standing frame	3	6

* These numbers add to more than 53, as many of the 34 people needed multiple types of equipment.

Carers commented on the following issues related to equipment:

- problems transporting equipment between settings;

- the excessive time taken to access needed equipment or alterations to equipment;
- low income limiting the provision of practical communication aids such as communication books with photographs;
- lack of proactive, responsive and coordinated service;
- need for greater flexibility in equipment provided to meet individual needs;
- long waiting periods for house alterations;
- help with computer software and training;
- size of child and need for modified equipment.

Most disabled people being cared for received some services or undertook activities outside the home, with 42% receiving multiple services (Table 12). It is concerning that some adults were apparently not accessing day or vocational services.

Table 12: Services/activities outside the home

Services/activities	N *	%
Respite care	26	49
Early childhood education	6	11
School	36	68
Special recreation (e.g. Riding for the Disabled)	7	13
Adult day service	1	2
Adult vocational service	2	4
None	6	11

* These figures add to more than 53, as many people accessed more than one service or activity.

Most carers (83%) were satisfied with the quality of these services or activities, with only two being very dissatisfied. Of the children still at school, 83% had been verified as having High or Very High Needs, under the ORRS Scheme.

5.3 The carers' needs

All of the carers who responded lived in West Auckland, with 12 living in a rural or small town. Ten of the 50 carers who responded to the question on respite had never had an overnight break from the person they cared for (Table 13).

Table 13: Respite from Caring

Amount of respite	N	%
Never had overnight break	10	20
At least one night per week	9	18
A few days occasionally	4	8
One to two weeks per month	0	0
28 days' respite per year	13	26
More than 28 days per year	14	28
	50	100

Respite care provisions are sometimes used by carers for care during the day, rather than overnight care. Forty-three carers responded to a question about how respite care is paid for. (Table 14). Only 32% of respite care was provided directly by a disability support service.

Table 14: Payment of respite care costs

Payment	N *	%
Unpaid	8	19
ACC	3	7
Family/friends paid by carer	2	5
Family/friends paid by MOH	26	60
Non-relative, paid by carer	0	0
Non-relative paid by MOH	6	14
Paid organisation e.g. IHC	14	32

* Three carers used multiple options – the total number of carers replying to this question was 43

Most carers (65%) chose respite care provided by family or friends. However, of the 43 carers who responded, 74% said they did **not** receive an adequate amount of respite at present. One quarter of carers had experienced asking for respite and having their request denied.

Carers appeared to prefer having a greater allocation of respite care days per year (45%) which they could then use (Table 15).

Table 15: How much more respite is needed

Allocation	N	%
More respite each week	6	14
More respite each month	7	16
More days per year	20	45
School holidays	2	5
9.00-3.00 p.m. for over 21's	1	2
Residential care	2	5

In family emergencies when urgent care was needed, 42% of carers reported that none had been available when they needed it. For 18 families, this situation had been experienced more than once, for one family it had occurred eight times during the year.

Carers reported a number of issues related to respite care provision, including:

- the lack of appropriate after school and holiday care;
- finding qualified/trained staff and keeping them;
- the need for respite crisis care during the weekend;
- the need for respite care to meet unexpected commitments e.g. funerals, other sick children;
- the difficulties in accommodating an extra adult (support worker) in the family setting.

Almost half of all carers (43%) had seriously considered full-time out-of-home placement for the disabled person they cared for. The most common reasons likely to push the carer into seeking such care were the increasing age and physical care needs of the disabled person, and personal illness or injury to the carer. Most carers who responded noted a variety of situations that are “pushing” them into this decision, including:

- a decrease in respite currently provided;
- continuing lack of sleep;
- increasing age and ill health;
- a desire for a more normal adult life for the disabled person;

- the need for more expert and structured care for the disabled person;
- lack of suitable respite carers (many responses);
- nowhere to leave disabled person for more than a weekend, impinging more on other children, e.g. holidays away;
- the safety needs of the child;
- lack of enough respite care for adults.

Other carers noted general issues around the provision of respite and out-of-home care, including:

- the disabled person's need to be with peers, not just parent(s);
- the low pay (for support workers) leading them to pay more and receive fewer support days;
- the need for help during the night, especially when the carer or disabled person is sick;
- the disabled person's unhappiness and stress from lack of continuity in carers;
- having to go away to have a break, as respite care provided in the disabled person's own home;
- siblings having to care in emergencies.

Carers do not "demand the earth". As one carer said, "I need someone to come in for half a day each week so I can have a break and get groceries etc."

A few carers had positive comments on respite care services, particularly when the disabled person clearly enjoyed this experience.

5.4 Other home support for carers

The majority of carers (62%) did not receive any regular help with practical tasks (Table 16).

Table 16: Regular help with home tasks

Help received	N	%
None	33	62
Unpaid	1	2
Paid by self	1	2
Paid by MOH	18	34
	53	100

A similar picture emerged with regard to help for the disabled person in the home setting. Only 31 of those cared for (58%) received any regular support in the home (Table 17).

Table 17: Help for the disabled person at home

Type of support	N *	%
No support	22	42
Attendant care	12	23
Behavioural support	8	15
Communication	4	7
Support in daily activities	14	26
Help with medical or nursing needs	2	4
Other: supervision of child	3	6
once a week to access activities	2	4

* Some people received more than one type of support.

Carers were asked about any concerns they had about the quality of any in-home support they received. Among the 38 replies to this question, 11 carers (23%) noted no concerns, although they often added “at this stage”. The remaining 27 carers had multiple concerns in a number of areas (Table 18).

Table 18: Carers’ concerns about the quality of in-home support

Concerns	N*	%
No support	11	29
Inadequate training	15	39
Unreliable or variable	16	42
Poor quality of support for disabled person	10	26
Poor relationships of worker with other family members	3	8
Too many changes of support person	16	42
Other	16	42
* Most carers identified more than one concern.		

There is no crisis plan in place for 83% of these families, even though all of them know that they need one. Of the nine carers who did have a crisis plan, seven responded to detailed questions about the plan (Table 19). Only three of these crisis plans were written down. Only one had funding attached.

The lack of a written crisis plan for 94% of these families is of the utmost concern, and urgently needs attention, as its lack places severe stress on families and could precipitate serious situations, placing the disabled person and carer(s) at serious risk of harm.

Table 19: Content of crisis plans

What is included	N *
It is written	3
It names the specific people who will “take over” when needed	3
It has agreed funding to go with it	1
It can come into force at short notice	4
It contains a list of the person’s medication and/or health needs	2
It contains critical information about the person’s behavioural needs	2
It contains critical information about the person’s communication	2

5.5 Services and their coordination

Carers identified various other types of help that would make their caring task easier (Table 20).

Table 20: Other types of help requested

Type of help	N *	%
Information about what help is available	38	72
Support and understanding from other carers in a similar position	19	36
Counselling/a listening ear	18	34
Gardening and/or home maintenance	25	47
Help with my other children	16	30
Training in special areas relevant to caring for that person	** 23	43

* Most respondents ticked more than one type of help.

** Some carers noted the particular need for specialist trainers in the management of behaviours associated with autism.

The first three identified areas of support reinforce the potential value to carers of the Complex Carers Network. The other practical areas highlight the need to respond flexibly to carers’ needs, in terms of the support that will make

the most difference for that particular carer and family. The request for special training also highlights the need for targeted training for particular carers, in contrast to generic training in the carer role.

Other types of useful help nominated by carers included:

- financial help;
- two sets of equipment – one for home and one for school;
- help with cleaning;
- a list of caregivers for respite days;
- caring, knowledgeable support that continues;
- extra tuition for a child in a mainstream school;
- one person who can refer you to the relevant person;
- management of own funding;
- physiotherapy at home;
- accessible programmes for carers, particularly in terms of time available, to meet the needs of carers of children, and single parents;
- information on social activities e.g. in school holidays; after leaving school;
- training in safe ways to deal with aggression;
- meeting serious housing needs.

Carers were asked who they saw as the key person or agency whom they contacted to obtain or coordinate services. While NASC was the most common agency noted (85%), 29 carers identified multiple agencies (Table 21).

Table 21: Key person or agency nominated by carers

Person/agency	N *	%
ACC	1	2
NASC	45	85
IHC	8	15
CCS	8	15
Child Development Service	5	9
General Practitioner	13	24
Paediatrician	10	19
School	18	34
Nursing service	1	1
Mental health services	3	6
CYFS	0	0
Spectrum Care	4	7
Other	7	13

* These numbers add to more than 53, as 29 carers nominated more than one key contact.

With NASC identified as a key agency by most carers, the quality of service provided is clearly a key issue needing attention. Two other significant contacts for families are General Practitioners (24%) and schools (34%), highlighting the intersectoral nature of support for carers and people with high and complex needs.

5.6 Carers messages to the Ministry of Health

What do carers want to say to the Ministry of Health? Thirty-seven of the 53 carers provided further comments. These are included here to meet the objective of providing **direct** feedback from carers.

Caring for two special needs children prevents me from seeking employment. Yet the “job” is full time. There is no money for a holiday, seeing family, parents in Europe. No retirement savings plan is possible. It feels like punishment. Why should I be a beneficiary for the rest of my life? I am in constant back pain, and need physiotherapy that I pay for myself.

I feel that all children are different and should not have a price value against their name. The needs should be met so that the child will get the best attention/service it needs instead of having to suffer.

It is not helpful being assessed and allocated time and days over and over again when there are no people out there that can or will do the job. What we need is recognised training for supported living, supported jobs

and recreative activities. Recognised career paths and opportunities with the pay packets to match for people that are willing and able to do this. What we do not need: Students whose priorities change when the next term roster appears or people with degrees who study you to get their degree and will move on the moment there is a better paying job, or people who are great for the job, but who have to have two-three jobs to make a living.

Years of unaided help, of bumbling around in the health system, I just want them to know they don't even know she exists. Our kids need individual care not a number.

We feel it is very important that the caring of an individual with complex needs has to be consistent, and that the lines of communication are always open between parents and caregivers. Communication is very important, because it outlines any difficulties that can arise and gives parents the opportunity to give support and help when such times arise.

Grandparents raising grandchildren have their own issues way over and above caring for a child with a disability. What I need is a babysitter and someone to help around the house with lawns/gardening/changing taps, washers etc. I am full of arthritis.

Yes, when a parent asks for support that their needs are listened to, we have to continue our lives, not make us feel guilty for asking for resources – coordination of services e.g. between MOH and MOE etc.

We desperately need a respite centre in West Auckland, similar to the Wilson Home on the North Shore.

Information on what support is available is sometimes hard to get if you don't know how to get it. I have been very lucky in that I have learnt over the last 12 years to assert myself and gain the support I need. I think there is a major shortage of in-home carers. I now work 9.00 – 3.00 Monday to Friday and would like to have help with housework.

There needs to be more trained professionals running and being involved in all aspects of complex care. To get good quality caregivers there needs to be more complex training and the remuneration needs to be higher to attract a higher quality of carer.

I have a plethora of names and numbers of people who have contacted me re my son which are absolutely useless. When you ring one the person has left or the department has closed/moved or the service is now

dealt with by some other organisation. Now I don't contact anybody about anything but wait till I am contacted which is probably why we have not had a review or needs assessment for at least two and a half years. It is easier to plod along on our own, making do, than it is to find out who to contact about what.

I have suffered from three bouts of depression, medication makes me ineffective as an advocate for my children's health and disability needs, the continual need to push for services and follow up on promises - leaves no room for poor health and a break from single parenting. The personal toll is huge but the rewards are gratifying.

There are huge gaps in services and NASC agencies are hard to get hold of and only seem helpful in crisis. It would be nice to feel supported before things got to that point.

I find it very frustrating dealing with - to recruit and train support workers. The pay is poor, the training is inadequate and ongoing support/training is non-existent. If I could self manage the funds, I could recruit and train more suitable people and pay them more, and I could do it quickly. (Service provider) have never recruited a permanent worker for me, and someone I recruited filled out their application form and police check form in August, and completed the orientation and was ready to work by 25 August. It's now October and still waiting for (Service provider) to get her on the payroll so she can start work with my son. I am desperate for help but cannot afford to pay someone out of my own pocket. My son is now ready to go into regular respite care and we are waiting for a place to become available. Auckland needs a lot more respite care facilities for children with complex needs. I have found it very frustrating also dealing with (NASC agency) because it is so hard to get hold of anyone and calls are not returned on the same day, if at all. I have had several changes of needs assessors, but am not advised when these changes occur. When I do manage to get hold of someone they are very helpful but a lot of misunderstandings occur...

We are a family in crisis and whilst it is difficult to admit you are at breaking point and can no longer care for your son - you are put on hold. We are screaming for help and as a mother I am losing control of my own wellbeing and now require medication to keep the family together.

1. Preventative measures take too long to get. 2. Don't feel like she is getting all she needs. 3. To get services/things for her it is such a

"stressful" process, in having to keep on asking, keep contacting agencies, keep on fighting for her needs, it's no wonder people give up and the disabled miss out. We have such a busy time caring for them already, with added stress to tip us over!!

Please – more respite need for our children. I am willing to look after my girl – but need regular respite especially for our older adults 18 years and over. This is crucial!!!

1. I would like a survey done on the health conditions of the carers. Most of the Mums I know suffer chronic health/or back conditions that have resulted from persistent stress for years. It is not just our mental health that takes a pounding. 2. The reliance on a title (diagnosis) to access therapy and services. My son had exactly the same problems and needs the day before and the day after diagnosis - however the title was a green card to access - sadly at 18 he was too old then and his lack of access to Speech, Physiotherapy etc. when he was younger has further decreased his quality of life as an adult. 3. Why is there nothing between a Paediatrician and a Geriatrician? Or a disability liaison person at the General Hospitals for information and support within the system? 4. We don't 'fit' or belong anywhere. Even the major disability organisations primarily deal with one type, and you can't get your needs met at one organisation. And the current disability climate of total rejection of the medical model/issues for social, really worries me.

Share care with dad – three nights dad, 4 nights mum. I would just like to comment that in general I don't like dealing with MOH or MOE; I've mostly found them unhelpful and lacking in understanding of the realities and difficulties in having a child with disabilities. I've usually come away from a phone call with the Ministry feeling that because I'm a parent and not an 'expert' i.e. a social worker or other person employed by an agency of some kind, that they're not very interested and don't take me seriously at all. Caring for my son is both very challenging at times and always extremely rewarding and a blessing to me. The amount of bureaucracy paperwork and time involved in getting the support we need is draining and basically hard work. I often feel for people who perhaps are less supported/articulate/proficient in English and wonder how they manage to access the support systems they need??

It's a big ask!! Never in my wildest dreams could I have ever imagined what my life has been, with this perfect little man with Autism!! Every aspect of his little life seems a struggle and for his sibling and his dad

and I!! He has brought incredible joy into my life and also incredible frustration, sadness, anger, inability-understanding, non-judgmentalness. I'm a better person because of my son! Thank you for **your** understanding and your efforts in this field. May my life-style be eased, even if just slightly, because of your concern - my thanks to you.

More financial help needed to afford "Nappies" and just to be able to take them on outings. An extra \$100 per week would ease the burden a little. These children have a heart and they matter to us. They should be treated with the utmost respect and get #1 care.

Because our daughter's condition is rare and the prognosis unknown not enough is known in the medical or wider community about her condition. Her size (small) makes accessing equipment a problem and her fragility poses a problem in keeping her 'safe' without limiting her having a 'normal' lifestyle.

The amount of extra money needed to adapt your home and the cost in repairs if you don't have someone to help. Outside of house needs maintaining but unable to watch kids because they are into everything.

Making your home a safe environment for ASD kids is expensive as you have to plan everything but be willing to change depending on the child's behaviour and their lack of social development. Two of everything, ASD kids development is slower and they can't always cope around others. Exercise equipment to lower stress levels. Safe space that can handle it. Calm. Water, with full supervision, spa pool. Adapting your home to give extra space to be able to separate children for everyone to have a break Fencing to keep safe.

Less waiting times for claims to be paid. Easier access to services. More funds available for funding for software for computers and for computers themselves. Making the entire system easier to use.

I am concerned about my son's quality of life. I am tired of being the recipient of "band aid care" because of the lack of resources available and don't see why his quality of life and the rest of his family's should be at stake. And my health has been affected by the endless frustration of asking the 'systems' for 'help' and being let down time and time again. This false hope is very damaging to the soul.

Due to my daughter who is Autistic having her hips pinned because of a fracture, I was put in a horrible situation when the hospital tried to send her home with me. She needed a wheelchair and help with showering. I had ACC and (NASC agency) not wanting to pay for caregivers saying it was the other agency's job.

Families such as ours need ongoing, reliable and qualified people, working alongside of our disabled members. We need help to support our disabled members become as independent as they can be, in a positive and compassionate environment. There needs to be more training in understanding disabled people, made readily available to the public.

Some carers identified serious problems with services from their NASC agency, and one with ACC.

Whanau's dealings with (NASC agency) are ongoing. Whanau has unresolved issues over very poor communication from (NASC agency), who do not respond to faxes, or very slowly. They have not responded to a letter of complaint at all. Needs assessment completed July 03 contains statements of our dissatisfaction but the final copy promised 6 weeks after that date has not been received... Who reviews the (NASC agency's) performance? Very tiring and sad, all these matters we are dealing with, made worse when support agency has to be chased up again and again or as the husband said of dealing with the (NASC Agency) "Too hard, Give up". There has been no ROBUST service coordination for this family since SES.

Copious notes on file. Main points are as follows: When Needs Assessments have taken place families shouldn't have to be involved to the degree that we have become the Service Coordinators ourselves and active advocates. We are battle weary. Lack of understanding early on by Starship and health professionals re: communication problems with family e.g. no fax no's provided for confirming appointments because mother is deaf. Approaches made to social worker - organised and supported by the whanau. Health and Disability Code - We note also that the family have been failed under (3) Dignity and Independence (4) Proper Standards (5) Communication (8) Support but lack the energy to start another complaints process. 1. Needs Assessor and Service Coordinator need to be the same person. 2. Service appropriate to needs - information gathering - decision making in their own time. 3 Assistance with form filling. 4. A service which is reliable, accessible, timely and with good communication is needed. 5. A Service in which the support person will

advocate where necessary. 6. A support person who will summarise discussions and options in simple English.

Finally, one carer simply said, “**A Magic Wand, please**”, expressing the desperation and frustration of so many of these carers.

6. Conclusions

This Pilot Project to establish a network for carers of people with high and complex needs has provided strong evidence of a small group of families in our society under severe stress. The findings about the stresses and joys involved in caring are also supported by a review of research literature.

The Pilot Project’s information came primarily from parents of children and young people with multiple disabilities, often complicated by chronic health conditions and/or difficult behaviours. As these children grow into adults, their needs will not diminish, but are likely to add to the demands on carers.

The findings from this Project strongly support the need for immediate and urgent action in two main areas.

6.1 Needs Assessment and Service Coordination

There are serious shortcomings in the provision of needs assessment and service coordination in this region.

6.1.1 Assessment of needs must be focussed on the carer and their family context, as well as on the needs of the disabled person. The needs of children and young people are interdependent with the needs of their primary carers, their parents. In the area of assessment of older people, the need for separate assessment of the carer’s needs is now well-established (Ministry of Health and NZ Guidelines Group, 2003). Similarly, “best practice” evidence in services for young disabled children and their families strongly supports family-focussed intervention and services.

6.1.2 Secondly, these families need prompt, intensive, coordination, which is clearly not occurring. This intensive service coordination needs also to provide intersectoral coordination. Families in this Pilot Project often identified stressors from the lack of intersectoral coordination, and the enormous burden they shouldered in trying to take on this role themselves. Further work is required to understand what intensive service caseload coordination should include, in terms of appropriate expertise, specialisation, and practice, for this small population of families with high and complex needs.

6.1.3 Thirdly, there is an extremely urgent need for all families to have a written, crisis plan which includes clear responsibilities and attached funding. Previous best practice guidelines prepared for the Ministry of Health by the Donald Beasley Institute identified this as absolutely essential for people with high and complex needs (Ministry of Health, 1998, “Best Practice Guidelines for People with Intellectual Disabilities with Challenging Behaviours, unpublished).

6.1.4 If NASC agencies are to provide an appropriate service to these families, they must be resourced and trained adequately, and provided with the flexibility to meet the needs of individual families, not merely to allocate predetermined packages of services.

6.2 Inadequate service provision

6.2.1 Current services are clearly inadequate to meet the needs of these families. Even when families are “allocated” respite care, often there is no appropriate respite care service for families to use. Support workers are seldom adequately trained, often cannot cope, and change frequently. There appears to be an unwillingness locally to develop a facility-based respite care service, and yet this could address some of the inadequacies of the current situation, in terms of adequate staff training, continuity, and regular respite for carers. While shared care with another family may be seen as a preferred option philosophically, the reality is that for most of these children and young people with high and complex needs, other families are not able and/or not willing to provide this type of care on a regular and on-going basis.

6.2.2 The other significant service gap is in the area of transition to adulthood for young people with high and complex needs. Young people should be expected to be moving towards care outside of the family, as a natural move towards adulthood, not as a response to family crisis. At the same time, carers acknowledge their own aging and health needs and the growing physical and other demands from the young disabled person. Transition services need to be developed to include **all** the young person’s needs – educational, vocational, living, recreation, and daily activities. Once again, **an intersectoral approach is urgently needed.**

6.2.3 For most families, more adequate and accessible services would prevent their need for fulltime, out-of-home care in the foreseeable future. However, **a few families, due to their own complex circumstances, need the option of alternative care for their family member. This need**

should not be framed as a “care and protection” issue, with all the negative outcomes that this brings, including disruption to the extremely important relationship between the parent(s) and the child/young person. There appears to be a “culture of blame” towards some carers who express their desperation for appropriate support, and this is detrimental to meeting the needs of the family and the disabled child/young person.

6.3 Areas for further policy development

During the Pilot Project, it became apparent to the Project Team that there are a number of broader issues affecting carers of disabled people with high and complex needs that need policy attention.

These areas are identified below (in no particular order of priority):

- an examination of the need for carer legislation;
- urgent attention to the needs of young people leaving school;
- clarification of the policy and regulations around s139 and s141 of the Children Young Persons and their Families Act, and its use for children with high and complex needs;
- how the perspectives of disabled people with limited means of communication can be obtained to inform policy, service development, and service monitoring;
- clarification of policy and service development on out-of-home care for children and adults with high and complex needs;
- the need for policy, guidelines, and training for NASC agencies in the assessment of **carers’** needs.