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Housing Needs for People with Disabilities in the Bay of Plenty and Lakes Region

A report prepared for the Project Steering Group on the Consultation Phase

Third Milestone Report

McKinlay Douglas Limited
and Etain Associates

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Contents

1 Introduction

Background to the report

This is the third of three milestone reports commissioned by the sponsors of a research project on the housing needs of people with disabilities in the Bay of Plenty and Lakes region. The report, prepared by the project team comprising McKinlay Douglas Ltd and Etain Associates, captures findings from a consultation process which forms a key part of the research.

The purpose of the project is to report on the current and future housing needs of people with disabilities in the region, with two objectives:

To improve understanding of housing need for people with disabilities and underpin future planning to meet that need
To identify practical responses that could be made at the regional level to meet unmet need.

The project has four components: a literature review and desktop data analysis (both completed); a stakeholder consultation phase (the subject of this report); and a final report presenting recommendations on options for future action.

The aim of the literature review was to provide context for the research, and to establish the beginnings of a conceptual framework for the final report. The desktop data analysis report presented detailed data on housing need in the region, gleaned from a wide variety of sources. A key finding from the desktop work was the significant gap that exists in the data available on the nexus between housing and disability in the Bay of Plenty and Lakes region. The report noted the Steering Group's wish for regionally-specific information and highlighted both the limited value of data drawn from national sources and the lack of data relevant to the Bay of Plenty and Lakes region.

About this report

This report rounds out the regional picture of housing need and disability found in the desktop work. It presents qualitative information drawn from the first-hand experiences of people with disabilities and their families. It reflects that at the core of the project is recognition of the overriding importance of housing for the quality of life of individuals living with disability, and that of their families.

The report also provides a voice in the research for people with disabilities in the region. In Part 3 we record in some detail the perspectives of the people who participated in the consultation process. Their views and experiences will inform the conclusions and recommendations put forward in our final report.

The report covers:

- People's experience with disability and housing, their circumstances and how their lives are affected
- Their views on disability and housing issues

- Their suggestions for what may be opportunities to improve housing outcomes for people with disabilities in the region, based on their experiences,

The scope of the consultation process

Fundamental to the project as a whole is the primary emphasis on a **social model of disability,** ie that people are 'disabled' by the inaccessibility of their built environment and society's attitudes rather than by their physical or other impairment. The consultation process was designed to continue the focus on the relationship between people with disabilities and their social and physical environment. We did, however, allow for the fact that there can be a point at which the issues associated with the disability itself become drivers in housing need. For some people, housing need is the result of a mix of the social and physical environment and the medical nature of their disability.

As with earlier stages in the research, we based the consultation phase on a **broad definition of disability**, including physical, psychiatric, intellectual, sensory and age-related disability, as well as sustained chronic conditions or frailty such as might create particular housing need.

The project is concerned mainly with **people with disabilities living in the community** – that is, people living independently (albeit with support) or with their families, rather than in residential care. It is not uncommon, however, for people with disabilities to be accommodated in places such as rest homes simply because of the lack of alternatives (most often a consequence of cost and availability), but whose preference would be to live in the community. Our consultation identified this as a significant issue.
The project covers a **wide geographic area**. The consultation process was designed to capture, as far as possible, the diversity of the Bay of Plenty and Lakes region. Part 2 describes the locations used for workshops and discussion groups.
One further, and critical, factor regarding the scope of the consultation phase was the relevance of **peoples' changing circumstances**, and the housing issues this raises. Particular cases covered in the consultations were children with disabilities growing up, changes in the lives of families where disability is present, changes in the severity or nature of a person's disability and ageing with disability.

The Structure of this Report

Part 2 sets out in detail the methodology used in the consultation phase.

Part 3 constitutes the main part of the report, with an overview of the themes that emerged from consultation and a detailed account of the views and experiences expressed by people who participated in the workshop and discussion groups, or contributed in other ways. It captures the lived experience of disability as it relates to housing.

Part 4 draws out some conclusions that we expect will lead into recommendations in final report.

2 THE METHODOLOGY

The project brief

As envisaged in the project brief, the aim of the consultation phase was, essentially, to obtain insights into, and information on, the experiences people with disabilities have with housing, within the Bay of Plenty/Lakes region, for the purpose of understanding the connections between disability and housing and the types of housing provision that would better meet peoples' needs.

The project specifications laid out a two-stage process involving stakeholders. The focus of the first stage was on disability-related community organisations. The second stage involved people with disabilities and their families, in direct dialogue.

Consultation was to be held in Tauranga, Whakatane, Rotorua and Taupo.

Participants were to be invited from stakeholder organisations including government agencies, health, housing and disability organisations, and support, advocacy and provider groups.

The second stage was to involve consultation with people with disabilities or their representatives, and family/whanau members.
In both stages there was to be consultation with Maori organisations and Maori people with disabilities.

Research ethics

The consultation methodology was governed by an ethics process which included registering the research with the Lakes District Health Board Research and Ethics Committee.

Important issues for the ethical robustness of the research were confidentiality for participants and appropriate communication.

Confidentiality was emphasised in both written communication and during workshop and Delphi group introductions. Participants were advised that:

- Their participation was voluntary and they could withdraw at any time
- Their names had been selected by organisations that support people with disabilities, and their families in the community.
- Their comments would be confidential and would be treated anonymously in reporting – participants would not be connected to specific comments and all reported information would avoid the possibility of individual participants being identified.
- Participation in Delphi groups would not affect a person's tenancy, rent or application for housing with Housing New Zealand
- That the information they provided would help create a better understanding of current and future housing need in the region

Other ethical procedures observed were that:

- Every effort was made to ensure that all communication was appropriate to the needs of participants. Participants could respond in writing rather than attend in person. A few invitees chose to do this.
- Consultation sessions were held in accessible buildings.
- The numbers taking part in Delphi groups were deliberately limited, to give participants maximum opportunity to contribute and in recognition of the needs of some types of disability.
- Organisations that passed invitations to potential participants in the 'Delphi' process (see following section below) were not been informed of the attendance or otherwise of those people.
- To manage raised expectations, participants were told that the ultimate purpose of the research was to produce actionable recommendations, but that decisions on future action lay with the key agencies on the Steering Group.

The consultation process

Focus

For both stages of consultation the focus was on the key objectives of the research: participants' views on current and future challenges; how different types and severity of disability are associated with housing needs; and factors in the demand for housing for people with disabilities currently and for the future.

Consultation with disability-related organisations

Provider and advocacy organisations were an integral part of the consultation process in two ways: first, their involvement in the workshop phase; and second; their role in acting as conduits for invitations for the second consultation phase, consultation directly with people with disabilities. They included field workers. Additional discussions were held with providers who were not able to attend the workshops.

We held six workshops across the region during March 2006, comprising one workshop in each of Tauranga, Whakatane, Rotorua and Taupo and workshops for Maori stakeholders in Rotorua and Tauranga. The Tauranga Maori workshop took the form of a presentation and discussion at a hui at Hungahungatoroa Marae, held under the umbrella of Te Whanau Poutirirangiora a Papa. Te Whanau Poutirirangiora a Papa encompasses Maori health provider organisations from the wider Bay of Plenty including the southern region.

Participants were recruited from a variety of sources, using a snowball approach that started with the Steering Group and, in parallel, contacts sourced from key informants in the housing and health and disability sectors. In Tauranga a project team member attended meetings of providers and field workers at SupportNet to explain the project and obtain permission to access email addresses in order to invite them to the workshops. We also conducted an Internet search for organisations in the region representing a diversity of disabilities. This process produced a list of 134 contacts all of whom were sent an invitation to a workshop in their area, mainly by email and by fax and post when requested. Total actual attendance was 62.

A diverse range of disability and housing organisations (and some individuals) attended, covering all categories of disability listed in the definition of disability used for the research.

The workshops were run in a structured fashion, based on a set of themes and questions sent in advance to those who had registered. These themes and questions were drawn from the two prior stages in the research: the literature review; and desktop data work. Participants were able to raise any further topics they wished to discuss at the workshops. Notes from each of the workshops were made, for use by the project team in writing reports. In accordance with the ethics process adopted for the research, the notes do not identify individual participants.

Appendix A contains a sample workshop invitation letter, the themes and topics circulated to participants in advance of the workshops and statistics on the number of organisations sent invitations and the number of participants at each workshop/hui.

Direct consultation with people with disabilities

For this phase we adopted a 'Delphi' method of inquiry. Small 'panels' of individuals (people with disabilities and/or their representatives and family/whanau members) were formed. We held two group sessions in Tauranga, two in Whakatane, two in Rotorua and one in Taupo.

The Delphi method was originally designed to gain the advantages of groups while overcoming their disadvantages. It uses panels most often consisting of experts who are capable of making informed comment and judgement on the views of others, in their field of expertise. We adapted this method for our research by placing individual people with disabilities and/or family members in the role of 'experts', and inviting them to attend discussion groups. The topics they were given to discuss were drawn from the workshops, which were in turn drawn from our literature review and desktop work. The advantages of this method of inquiry were two-fold: first, it produced rich data through which to understand the literature and data analysis; and second, it ensured that input from participants was connected to policy and provision while recognising individuals and family members as 'experts' in their own needs, desires and experiences.

Participants were recruited by asking those who attended the workshops to pass on an invitation to people they know of with disabilities, and whom they thought would have the interest and ability to attend. This method ensured that privacy was preserved. The project team did not need to collate lists of names and addresses. Only the names and contact details of those who accepted the invitation was known by us.

On the basis of the number of invitations we suggested each workshop contact might pass on, we targeted a total of 144 -147 invitations. Total actual attendance was 41. Most people who attended had moderate to severe disability. Every effort was made to ensure that the main categories of disability were represented in the groups and that appropriate methods of communication were used.

The 2-hour sessions discussed and evaluated topics that emerged from the workshop in the same area as the Delphi group. These were circulated in advance. In this way individuals and families provided information from their own perspectives. The groups were also invited to add their own issues and ideas.

Appendix B contains a sample Delphi group invitation letter, the topics circulated to participants in advance of the sessions and statistics on the number of invitations targeted and the number of participants at each session.

Maori consultation

Consultation with Maori was a vital part of the process. As well as the two Maori workshops, a number of Maori organisations took the opportunity to attend the general workshops and provided a distinct cultural perspective. A number of Maori people also participated in the general direct consultation groups.

To create opportunities for Maori people with disabilities to participate in direct consultation specifically for Maori, the same process was used as for the general direct consultation groups. First, people attending the Maori workshop in Rotorua were asked to act as contacts for people with disabilities in their areas and were provided copies of the invitation to pass on. Second, following the Te Whanau Poutirirangiora a Papa hui, the Trust circulated the invitation to all of their providers asking them to forward it to Maori people with disabilities. The two direct consultation groups arranged for Maori people with disabilities attracted no participants.

The presence of Maori organisations and individuals at all the workshops, and at most of the general Delphi groups, meant that a Maori viewpoint was woven through the whole process. This revealed that nearly all the issues raised for people with disabilities in general were at least equally experienced by Maori. This outcome was reinforced in subsequent conversations with a significant Maori organisation. Issues specific to Maori that emerged at the general workshops and Delphi groups, and in Maori workshops, are recorded in Part 3 below.

General comments

Overall, the workshop and discussion groups together yielded a very satisfactory representation of the disability sector. Sessions that had light attendances were balanced by sessions with strong attendance.

The opportunity to participate appeared to be well received, and feedback to the project team from participants was entirely positive. At all the consultation sessions people were prepared to talk openly.

Some people were disappointed to be unable to attend on the scheduled dates, or found out about the workshops and discussion groups only after the event. We sent material to those who wished to have the opportunity to send written comments.

The process was time-intensive, highlighting the diverse nature of the disability sector even within a region, and the lack of what might be thought of as ready-made lists of organisations and people with an interest in the housing issues associated with disability. It was to some extent an uncharted field. A positive side benefit from undertaking the consultation was that a start has been made on the connections between housing and disability among those who directly participated, and among those who have been informed about the project and its objectives.

A further benefit was the compilation of lists of organisations and interested people that may be able to be used for any consultation the Steering Group wished to undertake subsequent to our final report.

Our assessment of the consultation process was that it was an effective means of meeting the aim of obtaining insights into, and rich qualitative information on, the experiences people with disabilities have with housing, within the Bay of Plenty/Lakes region.
One issue arising was the interest expressed by a number of those who participated in the consultation, in seeing reports that come out of the research. This is a matter for consideration by the Sponsor and Steering Groups. Advantages of making some form of report available publicly, and advising participants, include people's willingness to contribute to future research (avoiding the cynicism of the 'black hole') and the opportunity to engage a now-informed group of people in such policy development and implementation as may result from the project.

In designing the consultation process, we decided to hold separate discussions with the key government agencies as part of the policy development phase leading to the final report and recommendations, rather than including them in the workshops and Delphi groups. This allowed us to tap directly into their specialist expertise. The workshops and Delphi groups could thus focus on provider, advocacy and consumer perspectives (although two workshops were attended by Housing New Zealand Corporation personnel).

3 THE CONSULTATION: AN ACCOUNT AND FINDINGS

This section

This section deals with the outcomes of the consultation process.

Consultation was undertaken to gather qualitative information on housing need from disability-related community organisations and from disabled people and their families, to complement quantitative data presented in the project team's report on desktop data. The purpose was to provide a more complete picture of the nature and extent of housing need and experience for people with disabilities in the Bay of Plenty and Lakes Region.

In essence, the whole of this section is concerned with housing need in its various manifestations. We have structured it to highlight, first, some of the qualifying factors people identified with housing need. We then go on to record participants' views on, and experiences of, particular aspects of need:

- Housing supply
- Choice
- Support, care and housing
- Access to information
- Advocacy
- Factors impacting on individuals' access to adequate housing.

This is followed by a summary of issues identified during the consultation as relating particularly to Maori.

We conclude with suggestions put forward in the workshops and direct consultation groups on "ways forward".

We note that the themes and topics set for the consultations were, in the first instance, drawn from the literature review and desktop data analysis. Discussion at the workshops and direct consultation groups were not, however, confined to these.

The account that follows records, as closely as possible, the voice of the participants. We have not overlaid this with our own analysis, except to organise the material by theme. Nor have we attempted to 'correct' perceptions that may not be an accurate reflection of the factual situation.

Qualifying 'need'

As found in the course of work for the desk top data analysis, the current lack of consistent, readily accessible regionally-based statistics around disability meant that estimates were primarily made based on national data, and in some cases extrapolated from general population statistics. Such calculations gave only a very rough indication of the percentage of people with disability who would have housing needs in the Bay of Plenty and Lakes region.

Questions the desk top data could not address, but that were raised in the consultations, include:

- Are we (and others such as McDermott Miller[1]) correct to exclude people assumed to have mild disability, from calculating housing need for people with disabilities?
- At what point does chronic illness lead to a housing need?
- Is it really more a matter of income level compounded by disability, rather than disability alone, that gives rise to issues in housing for people with disabilities?

The workshops and direct consultation groups discussed these questions in terms of breadth of need, common needs and needs that vary according to individual circumstances.

Breadth of need

Participants represented a broad spectrum of disabilities. It was clear from their comments that **all** people (and their whanau/families) dealing with disability, regardless of income, type of disability, or assumed level of disability, experienced housing needs and issues at some point in time. A participant in one workshop commented that, when thinking about housing, “We need to *widen* the definition of disability.”

Participants in the direct consultation groups verified the breadth of need. For example, a participant who chose to respond in writing rather than attend a direct consultation group commented: “I disagree with this general assumption that all disabled are poor. Like any other group in our society there is a wide range of wealth and spending power within the disabled community.” There were participants in the direct consultation groups who owned their own homes and some who rented privately as well as those who relied on Housing New Zealand Corporation or other public providers.

Participants at both the workshops and the direct consultation groups provided examples from every type of disability, including frailty and chronic illness. Little distinction was made over degrees of disability other than perhaps for multiple disabilities where a high level of care, up to 24-hour care/supervision, was required. That is, any distinction made was in terms of the nature of need rather than whether there was a need at all – it seemed that **any** disability can have some impact on housing needs. As a direct consultation group participant said: “We can’t generalise. We need to find out what people’s needs and level of need is.”

There were some issues and needs that were common to all levels, types and circumstances (particularly incomes). Workshops and direct consultation groups suggested ‘universal’ features that should be “non-negotiable”. These were: ease of access; security of tenure; a secure environment; wider doors and hallways; adequate lighting with easily reached and used light switches; wet area bathrooms; and tap fixtures that are safe and easy to use.

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[1] Centre for Housing Research, Aotearoa New Zealand, *Housing choices for Disabled New Zealanders*. McDermott Miller, March 2005.

Variations in need

A strong point made was that the nature of individual needs vary across time and with the type and extent of disability, and family or individual resources. For example, participants at the workshops and the direct consultation groups spoke at some length (and, in the case of the direct consultation group participants, with some passion) about the needs of those families and individuals who needed the services of caregivers who came into the home. This leads to the need for extra parking and garaging, and “space for a caregiver to stay overnight.”

Participants in workshops and direct consultation groups also talked about changing needs over time. The majority of participants agreed that changing lives and lifestyles were an issue. They spoke of people whose disabilities changed over time (most physical disabilities do change with age) and as children grow up and parents age. One workshop identified “time in the life-cycle” as being one predictor of housing need: young people wanting to be independent; caregivers getting older and less able to provide care; and changing needs across time as a person with a disability grows and has changing needs.

Further variation in need relate to house design and modification. Features are mentioned above that are often thought of as ‘universal’ and necessary for people with disabilities. In fact, as we heard, wider doors and hallways may be a disadvantage for people with significant sight impairment, as might large bathrooms designed to take wheelchairs. People with hearing impairment need a “visual system” in terms of fire alarms and door bells, and electronic devices. A written response forwarded during the workshop phase noted that “these are not funded at all by the government. I come across deaf people leaving doors open so people can come into their houses”.

Overall comment

We can take from these aspects of need that at some point in time virtually all people affected by disability or a disabling level of chronic illness or frailty will experience a housing need that they may struggle to meet unaided. Where personal or family resources – especially income level – are low, the need will most likely require actual housing provision.

The issue of affordability was raised at most workshops and direct consultation groups. “Low income creates a dual problem.” Workshop participants seemed to feel that those with greater resources were less likely to have housing needs: “There’s plenty of support if you can afford to pay.”

The relatively small percentage of participants who could be described as ‘perhaps’ better resourced (wealthier) families and individuals, may mostly need information – although a shortage of suitably built or adapted housing does limit choice and options: “At the moment, if someone built a fully accessible house that suited me I would probably sell up and buy it.” This leads into the issue of the supply of suitable housing.

Supply

Shortages

The shortage of appropriate properties was strongly emphasised. This emerged from both the workshops and the direct consultation groups, and ran across all areas in the region (although there were some area-specific issues which tended to confirm the picture that emerged from the desk top analysis). The general lack of suitable housing related to both public and private stock and included numbers of houses, type and condition and affordability.

A typical comment was: “There is a great shortage of suitable housing. People are given options that don’t suit them at all, for example even having to move to another town.” “Systems are not keeping up with the housing market in terms of prices and where houses are being built, and also quality.”

Sub-regional factors

Some areas in the region had particular issues. In Taupo, participants at both workshop and direct consultation groups identified as constraints on supply high housing prices – rental and purchase - a tendency to build up for views creating access problems, and a significant gap in income to cost, as well as a lack of suitable “social housing”. These characteristics of the Taupo housing market for people with disabilities also emerged from the desk top analysis. In Rotorua a participant summed the situation up with the comment that: “Suitable housing is just not there to start with.” In Whakatane, the issue of the quality of existing homes was raised: “Lots of houses need basic improvements that are too expensive – things like sumps and water.” In Tauranga the picture that emerged also reinforced the desk top analysis: “[The problem is] a lack of suitable housing. It is partly affordability and partly access – closeness to shops, transport, services.” It was also: “Lack of affordable suitable land – people with disability often need level access”.

Even for those who appear to have adequate personal resources, the lack of suitable properties was an issue. “When you do own your own house there’s the issue of adapting it and not qualifying for any assistance. It’s very difficult to find something that really suits your needs.”

Rural housing

Issues related to rural districts were raised in the workshops and direct consultation groups in Tauranga, Rotorua and Whakatane. In general, comments indicated that the shortage of housing was most acute in rural areas and that rural housing was often substandard. Maori participants provided the greatest evidence of this and of its impact for them. In particular the plight of elderly Maori was mentioned: many elderly people are in substandard housing. “There is a problem for older Maori people who may have had a good house, but get sick and go to live on the marae where there may not be good conditions and where the accommodation doesn’t qualify as housing.”

Waiting times

The lack of a range of suitable properties was manifested in slow responses by agencies. This experience is illustrated in a comment by a direct consultation participant that reflected many such comments across all direct consultation groups: “The main agencies don’t always have a suitable property, and then you just go to the bottom of the list again.” And from another participant: “The HNZC waiting list for people with disabilities is dreadful. People wait two to three years to get into a house. They get as far as the list, told they are priority A, and then it is a waiting game for a suitable house.”

Participants at both the provider and client level expressed frustration at delays and lengthy waits. At one workshop a provider commented that: “People are fitted into what’s available, when what they need may be slightly different or even significantly different.” At the same workshop the comment was made that: “Delays in getting approvals can be too lengthy – and maybe too late!”

The lack of sufficient suitable housing, and the subsequent delays and frustrations, was itself seen as likely to contribute to need: “Inappropriate housing can lead to disabilities or exacerbate them by causing stress and mental health problems or faster physical deterioration.”

Slow response was identified as leading to a loss of opportunity to build up the stock of appropriate property. At three of the direct consultation groups, people spoke with considerable force of having attempted to sell properties they had modified, back to the major provider Housing New Zealand Corporation. In each case the process took so long that eventually the properties were sold on the open market. “I have given up [trying to get his house added to HNZC stock]. It’s a waste of time and takes too long.” This participant spoke strongly about the waste of a well kept and well modified house that has gone into open market stock and is currently occupied by a young family with no special needs. That this may be related to a lack of specific knowledge on the part of providers for whom specialist housing is not a core business, and lack of coordination between services and agencies, is addressed below, under factors impacting on individuals’ access to adequate housing.

Against these experiences, it is important to record the experience of an older couple who participated in a direct consultation groups. Following diagnosis of a brain condition leading to ongoing deterioration in mobility, “they [DHB and support services] got straight on to it. They did a thorough assessment, got the house altered and are there to be contacted whenever we need to. They have been wonderful”.

Choice

Flexibility and individual need

A major theme that emerged from all the consultation groups (provider workshops and direct consultation) was the lack of choice and flexibility in housing to meet the needs of people with disabilities. The general lack of suitable housing contributed to this but it was also related to the need for people to have their individual needs met. The following quote from one workshop sums up the general views expressed on this theme: “People are boxed into a disability ‘class’, usually their ‘primary’ disability. It doesn’t work like that!” In another workshop it was pointed out that limited housing stock and problems of affordability are both factors inhibiting choice.

Participants in the direct consultation groups stressed the importance of individual choice above most other factors. This was summed up by what an Occupational Therapist once told a client (consultation participant) “no-one knows more about you than you!”

Participants pointed out that people are prepared to take some risks for themselves, or make trade-offs, in order to achieve what is best for them. A case given was an older person who preferred to be put to bed at 8 pm by her in-home carer and remain “in her own space”, rather than live in a residential facility.

Participants identified a range of **general** requirements in housing. Repeatedly mentioned were: security (of tenure, and in terms of feeling and being in a safe environment); physical safety (for example, appropriately placed and designed electric fittings and switches, plumbing, ramps and non-skid paths and floors), single storey and level sites; wider halls and doorways; wet area bathrooms; easy-to-use taps and other features; adequate lighting; good parking; low maintenance (especially gardens); and space for care-givers to work and to sleep over if necessary.

Also identified were some specific requirements relevant to types of disability, including mental health, chronic illness and frailty. These were mentioned in several workshops and direct consultation groups where these disabilities were represented. It was noted, for example, that people with mental health issues require lower levels of stimulation and individual space – “not necessarily alone”, and “friendly landlords”. For those with sight impairments: “Most people aren’t totally blind. They need good lighting, non-shiny surfaces, different textures and possibly room for a guide dog.” Hearing impaired people need facilities to support communication equipment and possibly room for a hearing dog. For the elderly and chronically ill the requirement is for “warmth – easy heating – manageable size and affordable maintenance.” For people with mental health or intellectual disability there may be a need for sound-proofing, strengthened walls and removal of risks for children, such as places to climb.

Problems cited by participants in direct consultation groups included very specific requirements that were nevertheless quite critical for the person, and that seem not to be recognised. One participant with physical disability was provided with a shower head that was too heavy to handle, after asking for a light weight one. The participant’s feeling was that “they think I’m being difficult”.

In addition, there are individual needs or preferences that a social model of disability would suggest ought to be met, for example, a single bedroom unit may be inappropriate for a couple. There was “a lack of options for living alone on a low income”.

A participant in one direct consultation group proposed a model for conceptualising the variety of needs. Key elements of this model arose in most workshops and direct consultation groups. “There are three things that are needed in a home, companionship, security and convenience, and there are two groups, those who can afford to provide their own and those that cannot.” On each of these dimensions people will be situated at various places, for example some may enjoy and seek a clustered housing situation where companionship could be high, others may want somewhere for whanau/family to be around most of the time and still others may want a lower level of company and room to be alone. Similarly, security of tenure is important to everyone, but security in terms of feeling safe may vary from being happier in a gated and/or cluster housing to simply having an easily accessible telephone/emergency calling system. Convenience relates to everything from accessibility to wet area bathrooms, and will vary by type of disability. Similarly people’s circumstances will range from those who can afford all that they need, including modifications, through to those who have no means to provide any of their own housing needs in any form.

Flexibility and changing need

Lack of suitable housing also limited people’s choices as their needs changed. Solutions needed to be flexible to take account of people’s changing needs over time. The lack of variety and choice led to providers being unable to match clients to housing, and prevented individuals from sourcing housing that met their specific needs, at any given time. Maori providers, for example, pointed out that: “People with disabilities have to fit the criteria and accept what’s offered”. Participants in other workshops agreed, saying individualised service and assessment is crucial.

Discussions also covered the need for a sufficient variety of housing to relate to changing needs over the life of the individual and their whanau/family. At one direct consultation group it was explained that: “A person with a manual wheelchair can cope with a ramp and ordinary doorways and halls, but once they progress to an electric wheelchair they need wider access and a wet floor shower. But it is hard to get further modifications as things change." Similarly, at another workshop the issue of the changing needs of young families was discussed. Young families in rental housing "only get one chance for home modification, which is a real problem when they have to move for work or family or some other reason." In other workshops the ongoing changes needed for families was raised: "For families alterations need to be ongoing."

Participants at direct consultation groups made the same point, that ongoing needs meant that changes are needed to the home over time, over and above any initial modifications.

A mismatch between housing and need relating to changes in the lives of older people was also highlighted. Older people can feel under pressure to maintain the family home, leading to under-occupancy. Workshop participants commented on the need for older people to have a step before rest homes "for people who need a protected or supported environment but [who are] not yet ready for just a room, and don't need rest home care – especially where the family lives elsewhere." Another factor for older people was the difficulty of adjusting to a new or advancing disability, for example, "adjustment to blindness can be more difficult for older people".

Choice and policy constraints

Lack of sufficient flexibility and choice was not merely a matter of lack of sufficient variety and the amount of housing stock, but was also identified as being caused by specific policies and the interpretation and application of these. This was raised at all workshops and most direct consultation groups. It was summed up by a participant at one workshop who commented that "transiency is common in the Eastern Bay of Plenty. The 'rules' don't take this into account. There are timelines on when a person can move house, and entitlements don't fit what people actually do or have to do."

Also affecting choice are policies and practices that involve housing people with mental health conditions in communities alongside older residents. In Taupo and Tauranga participants said this was a cause of considerable stress to older residents, sometimes causing them to sell up private homes and move away. This will be a particular problem for older people residing in neighbourhoods near hospitals, when the intent of the housing agency and field workers is to see people with mental health conditions placed near health services.

The relationship between policies, lack of appropriate housing, and need for flexibility and choice was illustrated by a participant at one workshop who said "The best thing that could happen is for services to intervene early and plan for future needs. Things are left too late and disability conditions are escalated. Often [assistance with housing] only happens when families are at burn-out point. Then it has to be done too fast, without scope to back-track when it doesn't work out and there's a need to go on a different path". Participants in the Maori consultation also identified an issue that is relevant across all sectors – that of compounding conditions, for example: "the best drugs for mental health conditions can cause obesity and result in physical disability. Or people with mental disabilities fall and become physically disabled. This is where you need universal homes that people can continue to live in with changing circumstances."

Support, Care and Housing

Relating housing and care

Both the workshops and the direct consultation groups emphasised that it is impossible to separate housing issues from those of support and care-giving. People who have specific housing needs due to frailty, chronic illness or disability almost always have greater need for other services and generally need some support to live independently. This in itself gives rise to a range of special housing needs. Many participants spoke about being unable to access all the support to which they were entitled, because of inadequacies in their present housing. “People often can’t access all their entitlement because their housing doesn’t allow it. If there’s no room for a care-giver, they can’t have that assistance even though they are entitled to it.” Or the situation of one participant at a direct consultation group: “Support Net is willing to give sleepover assistance, but the house is only three bedrooms and can’t support the full package.”

Inadequate housing also led to other problems in accessing support. “With only a small house [having care-givers in] means no privacy.” It raises issues of “personal space”, when an outsider must come into the home regularly. Direct consultation group participants talked about the importance of taking into account the whole home/family environment. This can be at the very practical level: “baseline need is two toilets, because when one is placed in a wet area bathroom it is not sufficiently available to the family”. Another example was extra sleeping space for a caregiver, and for a separate area for care-giving, so that the family can retain some privacy.

The issue of privacy, and feelings of having the home “invaded”, was exacerbated by poor pay rates for caregivers, leading to a high turnover of people coming into the home. Typical of comments made in direct consultation groups was a participant who said “The quality [of care] is not there these days. It’s hard to keep a good carer – they are so poorly paid and carry a big responsibility”.

This in turn indicates the extent to which having some separate facilities for caregivers in the house is important to the individual with disability and their family. Another direct consultation group participant summed it up as follows. “Your whole world turns upside down [getting a new carer]. Each one does things differently. The family has to get used to new ways.” Participants spoke of this happening continuously. “It’s like having another stranger in the house.”

Policies and practices

Participants identified policies and practices around housing that led to difficulties for families who wished to provide the care themselves.

The most often-mentioned issue was that where a family member takes the carer role, they are paid at a lower rate than external carers. Having a family member as carer can reduce the sense of invasion for the individual and their family and possible reduce some of the need to have separate facilities. The lower rate of recompense (in a market where full rate pay is still at the lowest end of the scale) is a disincentive and a double disadvantage. This double disadvantage also impacts on an individual’s ability to access appropriate affordable housing. Participants at the direct consultation groups pointed, for example, to experiences such as “if you are a single person you can’t have a two bedroomed flat, so there’s no room for a caregiver such as a family member to live with you”. The impact of “exclusionary” policies was illustrated by a comment made in consultation with Maori groups where a participant said “[there is] the problem of housing being provided just for the person with the disability. They get told ‘this is only for you, not a partner’. Yet relationships are the most stabilising thing in the lives of people with disabilities. People getting assistance when single are effectively being told they have to stay this way [ie single or alone]”.

There were other “traps” mentioned across the workshops and direct consultation groups that arose from policies. For example, older participants commented that although they were “ready” for pensioner housing, they were still too young (at 55) to access this option. This is an important issue given the point made during consultation that ageing for people with disabilities is less about chronological age and more about the progress of their disabling condition, or number of years in a wheelchair, and that inadequate housing can lead to more rapid deterioration for the person with a disability. Another policy-related issue concerned the situation where an individual with a disability is forced to sell their home (due to its unsuitability) but is then excluded from assistance on a means test. This issue was raised in two direct consultation groups.

Access to information

The importance of information

Access is more than the physical design features of a house that may allow people with disabilities to live confidently and comfortably in that place. An aspect of housing access emphasised in the consultation process as extremely important was the ability to access the necessary information and resources about housing and support. A picture quickly emerged across all the workshops and direct consultation groups of a field where there were numerous initiatives, agencies, policies and practices with so little connection that it was surprising that agencies achieved as much as they did. It was unrealistic to expect that front line staff in agencies and services, let alone people with disabilities and their families, would know all the possibilities, and how the policies and services fitted together. A comment from one workshop gave this perspective: “Access is also about access to the process – it’s about skills and knowledge. It’s access to appropriate support and advocacy.”

Information barriers

In workshops, representatives of providers and services expressed their frustration. “It can be a very bureaucratic process, five to six pieces of paper for one application.” “What is recommended for a person when they are assessed may not ‘fit’ what gets funded.” “Everyone focuses on who is the primary funder, no wonder there are such delays!” The complexities of individual need get lost in the plethora of services and entitlements. “People get categorised, usually by their ‘primary’ disability, but many people have multiple disability and may need [information about] a quite different facility for combinations of disability.”

A common complaint was that people are not told about all their entitlements or where to access particular assistance. “You have to find out for yourself.” One participant recognised the effect that lack of co-ordination had on front line staff in agencies. “People at the front-line in agencies don’t themselves know. … The big issue is lack of communication between agencies.”

Consequences

Lack of communication and co-ordination across agencies and services meant the standard of living for people with disabilities in the community could be impacted. As one family in a direct consultation group pointed out: “There needs to be a lot more information and communication between ‘the house’ and ‘the care’. The house needs to be updated as the person’s assessments are updated. This doesn’t happen, at least not easily.”

Participants also linked the lack of easily accessible information to loss of self determination and independence. A participant in a direct consultation group summed up what many people said in expressing this point. “We do not want to be told what to do. This comes from not knowing what to ask, so you don’t get the best answer. OTs might not suggest [options] and if you don’t ask, you don’t get! There aren’t many people who know what an OT can do for you. Who do you ask? There is no knowledge in the community about who does what – what is available.”

Information and co-ordination across agencies and services were also seen as necessary to allow proactivity in ensuring adequate housing provision. One participant observed that “no-one looks ahead, especially with aging. You get things a*fter* you need them. You’ll get a wet floor shower after you’ve fallen in the old shower!” This can lead to avoidable injury or deterioration of an individual’s condition and independence.

Advocacy

Lack of advocacy support

The importance of co-ordination and of easily obtained and understood information emerged clearly in the consultations as central to accessing appropriate housing, together with the support and care needed for the ‘bricks and mortar’ structure to make the difference intended. Discussion around the issue of information and co-ordination of agencies and services gave rise to discussion on advocacy. People’s experience of having little continuity of front line staff, being unable to self determine due to lack of information or knowledge of what to ask and having to wait until after a need arose before modifications or services were arranged, was evidence of the need for some form of advocacy for people with disabilities and their families in respect of housing and related services and support.

Both providers and clients in the workshops and direct consultation groups talked about the lack of, and need for, advocacy. Participants in the direct consultation groups had the same stories of an ongoing search and struggle to gain access to housing and services. They each had travelled the same path *alone* apparently unaware of, or unable to access, the accumulated experience and knowledge of others in similar circumstances. At one workshop a participant, who also had a disability, expressed this by saying “the lack of organised advocacy means that battles are often re-fought by each family and/or individual”. Frequently, even where people did know which agency or service to approach, difficulties were cited in making needs known or heard. A direct consultation group participant said that “you need someone to help you list and prioritise your needs. Often you’re upset and don’t know where to turn, and can’t always express your most urgent needs effectively”.

Consequences

The consequences of lack of advocacy were evident in discussions at the direct consultation groups where people spoke of giving up, being exhausted by the process or simply not being able to access the facilities and help they really needed.

One family participating in the direct consultation groups said that they had accessed all available support “for now!” They pointed out “we have had to learn to be very savvy and persistent”. This came at a cost. Several people in the direct consultation process spoke of this. “You get worn out with the fighting. The process can be so slow – it really taxes you.” Confirming this, a participant with a disability also alluded to a related issue that arose in many of the direct consultation groups – rapid changes in agency staff. “It uses up all the energy you have left after dealing with your disability. You just get in the ‘grid-lock’, then the staffer moves on and the next person may have different ideas, so you’re back to starting point again. And by the time you get through to a decision, your needs have changed, so you need something different yourself."

Factors impacting on individuals' access to adequate housing

A range of specific concerns emerged from the workshops and direct consultation groups. Some highlighted particular issues for specific groups and others more general issues. All were seen as seriously impacting on access to adequate housing that met individual needs and desires.

Anomalies

Commonly mentioned at all workshops and direct consultation groups was the different funding streams for people with chronic illness, congenital conditions and those under ACC. This was seen as creating inequalities in accessing suitable housing. In the words of some participants, "if you are going to be disabled, it is better to be disabled through accident than birth or sickness." As an example, it was suggested that some landlords favoured ACC-funded tenants because of their greater ability to pay rent from their income compensation. A small number of participants pointed to discriminatory practices in the private sector, such as insurance companies charging higher premiums for house and car insurance, for modified cars, and for people who may be deemed at high risk of damaging property. This is especially hard on people who already tend to be in the lower income bracket.

Respite Care

The issue of respite care was raised at most of the direct consultation groups. Where the person with the disability is cared for within the family home people struggled to gain adequate respite care, ether as a result of their housing or because of the loss of respite care facilities with the introduction of community care. As indicated earlier, to have a care-giver (for permanent or respite care) in the house requires adequate facilities. One participant at a direct consultation group was clearly overwhelmed and distressed by the process of attempting to get some respite care in the face of having none of the necessary house modifications. "We have been waiting on ACC for three years for a wheelchair. We rent a house that is too small with no room for a hoist, and we have to wait for a lump sum from ACC which *might* be enough for a deposit on a suitable house." The result was that the family could not access respite care in the home.

Even where appropriate housing is in place, accessing respite care may be a matter of having suitable facilities sufficiently near to the home. People spoke of needing to be near respite care facilities and needing some security and continuity of those facilities. In one direct consultation group a big issue was the closure of facilities, or funding changes that had reduced the quality or scope of the service. The parents of one special needs child said that "There is now no respite facility [nearby]. In the past [their child] would go to residential holiday programmes which were fabulous. Now we only get a break by paying a carer to come into our home while we go away." While this allowed care to be provided, it did not offer the benefits to the family and the child, of properly resourced and organised activities.

When school is over

A number of families indicated their worry about organising adequate current and future care, which included housing, once their son or daughter was no longer able to access special education. This was made even more difficult by the lack of respite care facilities.

The future was a major fear for many families who needed to consider meeting their and their child's needs for independence, while ensuring secure and appropriate housing. Some had considered providing a home unit built alongside the family home but did not know what the barriers would be to doing this, for example building regulations. One family spoke of their efforts to accommodate more than one disabled family member including a (now adult) child. "We wanted a property with a separate unit for ourselves and the family, and a specially modified house for the disabled members of the family." They have experienced considerable difficulty, and expected to have a long battle to achieve their goal.

Other families said they had searched long and hard for independent living arrangements for their mature children. "It took about four years to get to know about the existence and functions of many of the agencies that might help us. This included organisations such as CCS, IDEA, IHC, Home 2000, WINZ, Hohepa, Parent to Parent and various Trusts." In many cases participants in this situation spoke of having to accept housing that did not meet their ideal, and of efforts to create a more appropriate environment. A family that was unable to attend a direct consultation workshop was interviewed and spoke of wanting their child to continue to live within a rural community, and be able to undertake some farming or farming-related work.

The picture that emerged is that families whose child is due to exit special education face enormous difficulty in finding suitable independent living and/or respite care facilities. Their vision and desires for suitable housing and care are varied, as are those of every parent raising children, but the facilities and services available are not sufficiently varied, widely distributed or consistently available to meet their needs. Meeting these needs within their own resources is enormously difficult given the complexity of current services and policies.

Aging families and independence

A similar range of concerns was expressed by families who were looking to the future and asking where they could find suitable accommodation (with an appropriate level of care) for their sons and daughters as the parents aged.

There were participants in the direct consultation groups who were in residential care but would prefer to live independently. Generally they mentioned affordability as the main barrier, but families who attended direct consultation groups also said "there are not enough support people. Without the support, housing doesn't work."

This point was strongly endorsed by other participants. The 'solution' of a unit on parents' property was seen as less than satisfactory because it could just add to the problem of dependency, leaving no alternative when the parents can no longer sustain it. "Better to get them as independent as possible [for when we are no longer around]."

Security of tenure was an important consideration in getting adult children living in the community independently of their parents. Families taking part in direct consultation groups pointed out that people with intellectual disability, brain injury or mental health issues often take some time to get settled in a new environment. "It's not hard to find a place, but it takes a lot of settling down." In the private rental market this can become a problem when landlords may not welcome someone who can be a 'difficult' tenant. "It's hard to sustain renting because of the (adult child's] tendency to damage the property. We get it fixed, but we can't get a landlord reference, so we can't produce evidence of a track record."

Families taking part in direct consultation spoke about the frequency with which various mental health providers, such as Richmond Fellowship, changed or even closed operations in an area.

Finally, parents showed that they were generally willing to be flexible and wanted to ensure that their child was safe, secure but above all else happy – even when the accommodation did not match the parents' idea of suitability. "It is important that where they [son or daughter] end up living is their choice, even if it's not what we want – like living in a dark basement flat with the curtains pulled shut!"

Falling through the cracks

Some of the issues raised and discussed in workshops and direct consultation groups provided a view of those groups that were most likely to fall, or are falling, between the cracks, and in what ways this might be happening.

Being on a **low income** can mean falling through the cracks. "Low income creates a dual problem." Many participants gave examples of where and how they had been unable to access modifications or suitable housing due to lack of income. In general, people who talked of being on low income also appeared to be the least well informed at the consultations.

Those with **mental health** issues are especially likely to fall between the cracks. There were a number of comments indicating that private landlords tended to discriminate against people in this section of the community. In addition, as a workshop participant said, "They [people with mental health issues] don't have the confidence or skills to access services or housing for themselves." Letters written by participants in direct consultation groups, who had mental health issues, indicated several other crucial needs and factors that render them vulnerable. "People [who have mental health issues] need phone and other counselling and support services. They also need drop in centres for peer support." This indicates a need for housing for these people to be central. They also needed, however, to have some private space. These participants also wrote a lot about having very low incomes. "They [she and friends with mental health issues] are only surviving on $40 dollars to $20 dollars a week." "We help people out with food, I have friends that have starved and I have done that too." At the Rotorua workshop a provider spoke out about poor support for the homeless who include many with mental illness.

The elderly are also in danger of falling between the cracks. This was alluded to in the workshops and expressed by one participant as "older people's needs should be diagnosed earlier so suitable housing can be planned. It tends not to happen till the need is upon them. It is easy to see when a person is heading towards needing a change in their housing." In another workshop a participant commented that "there's a huge chasm for older people with mental health problems." But it was also acknowledged that often older people are reluctant to admit to needing help or to seek assistance.

Another group identified as likely to fall between the cracks were those with **chronic illness.** This was particularly so for people for whom the illness was recurring rather than continual, as with a seasonal or shorter term chronic condition. The difficultly was identified as a funding/policy mismatch. “There’s a significant gap for chronically ill people who may be in need for more than 6 months but less than three years.” As a participant in a workshop pointed out, “The disability has to be longer term, greater than 6 months. This doesn’t allow for conditions that are seasonal, for example asthma that affects people only in the summer months. They miss out on getting help they need.”

Finally, people in **rural areas** are also “at risk”. The desk top analysis revealed that in general a higher proportion of housing in the rural areas of the Bay of Plenty and Lakes Region was likely to be substandard. As one participant confirmed: “A lot of older houses in rural areas sit over water. Houses are damp and cold.” Substandard houses cannot be modified. In addition, families participating in direct consultation groups who came from rural areas spoke of the lack of services and facilities such as respite care or supported living in these areas. One participant suggested that “we need rural information clinics”. This participant also suggested that “affordable housing is too far out, people can only afford one trip to town a week to go to the shops, doctor etc”. Another participant said that “the private rental market is practically nil in rural areas and where it does exist it’s too expensive”.

Training/education

Speaking of agencies, one participant at a direct consultation group made the point that “it’s as if disabled people live in another dimension from theirs. Our reality and theirs’ bear no resemblance. They are so far apart from us. I don’t know how they get trained!” Other participants agreed strongly with this, a view shared by other direct consultation groups. There was some understanding that this may be unsurprising, given that dealing with special needs and in particular people with disabilities and their families, is not a core function of some agencies.

Participants at both workshops and direct consultation groups agreed that more effective training and education is needed for those who must deal with the needs of people with disabilities in respect of housing and related services.

The private sector was also seen as needing to be educated. Participants commented on the apparent reluctance of private landlords and property developers to accommodate the needs of people with disabilities. Comments included “private landlords are resistant to disability features for short term tenants”; “the private sector is resistant to making alterations or developing accessible housing”; and “developers are reluctant to add basic features such as rounded corners.” Another participant did point out that “some landlords seem happy enough to modify if it’s paid for”.

As a result of these experiences participants at one workshop concluded that education is needed so that landlords and developers know about the needs and benefits of making housing accessible and suitable for people with disabilities. This idea also emerged from discussions in other workshops.

Privacy

The issue of privacy was raised in both workshops and direct consultation groups. One aspect raised was private landlords who discriminate against people with mental health issues, and in some cases people with intellectual disabilities. Participants said that landlords acted as “gate-keepers” in accessing rental accommodation and asked questions of prospective tenants that would not be asked of the general population.

The “system” (of housing and services) can also be intrusive. Participants talked about the way in which policies for provision of housing and support mean that very personal questions are asked when an individual moves and requires help or further modifications. “We [in this case Maori] are a transient community. When a person moves, the agencies often ask people with disabilities quite private questions about why. It should be all about housing need, not the person’s reasons for moving – which will usually be out of necessity.”

Support workers can also breach privacy simply by how they go about their work. One participant said that “the community worker comes to [my house to] administer medication and walks up the drive with clipboard and medical bag!” The issue of privacy seems to relate to that of education and training. In one area of the region participants in the direct consultation group commented that in their area “it seems that once you seek help everyone knows all about you”. There were six participants at this meeting and they were all able to give examples.

What gets in the way

Participants identified a number of factors they felt contributed to their experiences in accessing appropriate housing. Those that arose across the majority of groups were (in no particular order):

- Deterioration of infrastructure for housing people with disabilities from mid 1980s at a time when the need became more acute. A participant who put this view explained that “infrastructure means services, providers and physical housing”. At another workshop a participant stated that “the move from the mid-eighties to leave residential facilities has created a greater need for housing in the community than can currently be met from the type and number of houses in the region. This is common to all sectors of disability.”

- The lack of advocacy. This, as highlighted above, was seen as “especially true for those in the mental health system” but was confirmed by participants from all disability sectors.

- Policy issues. These included the existence of different funding streams (as discussed above) that lead to inequalities, but also confusion. A participant at a direct consultation group pointed out that “these [different policies across sectors and agencies] limit peoples’ choices”. Another policy issue was the general rule that modifications can usually be done only once. A participant pointed out that this impacts on individual choice and the ability to improve one’s situation.

- Funding issues. In general, participants suggested that the focus of funding was wrong, “Funding is going to the service offered under current policies – not going to *people.”* This was seen as leading to competition among funders.

- Agencies tending to work in isolation of each other. A workshop participant saw this as “a lack of a ‘big picture’ approach”. A related issue was lack of communication across agencies and the absence of reliable information about both numbers in need and existing available properties. At one workshop it was suggested that “a data-base of available, suitable housing – rental and owned, private and public – should be developed”. This was echoed at other workshops and direct consultation groups.

Issues affecting Maori people with disabilities

As noted in Part 2 above, the presence of Maori organisations and individuals at all the workshops, and at most of the general Delphi groups, meant that a Maori viewpoint was woven through the whole process. Maori participation revealed that nearly all the issues raised for people with disabilities in general were at least equally experienced by Maori – although often compounded by social and economic circumstances. They included: affordability; the shortage of suitable housing, especially in rural areas, and lack of choice; and lack of knowledge on where to go for assistance (an issue that goes back to advocacy). That these factors were highly relevant to Maori was reinforced in subsequent conversations with a significant Maori organisation.

While the connection between housing, disability and care and support in the home emerged throughout the consultation, for Maori it had a particular acuteness because of the role whanau play. Two examples were given. One was where the level of care required could not be provided close to the person's hapu, necessitating a move to accommodation in a more distant centre. The distress caused by the severing of the whanau link adds a big burden to the person with disability and their whanau members. The other example, one that is not uncommon, is overcrowding caused by accommodating a whanau member in the house to take on the care role. Mention was made of kaumatua living, unapproved, with whanau in a Housing New Zealand Corporation home to be cared for and because "there isn't anywhere else to go".

The plight of older Maori people who, because of chronic illness or frailty, have to move from their own homes to live closer to, or with, whanau is highlighted above. This may mean moving from relatively comfortable housing to an overcrowded home not suited to accommodating an older person.

Housing that has been built in the past for older Maori people (kaumatua flats) no longer meet society's expectations – and is often not modified for accessibility. Modification is gradually occurring, but for the mean time there are older Maori people who are not appropriately accommodated. One person, in commenting on the inadequacy of some kaumatua housing, observed that "our kaumatua these days are not as strong as kaumatua used to be – they haven't had such physical lives as they did in the past. So they need their modifications."

Maori participants commented frequently on the waiting times for getting home modifications approved. "It takes ages to get things done through the DHB."

One aspect that came through from Maori more strongly than from people with disabilities generally was the importance of good housing for preventing a disability becoming worse or accelerating. This reflected the incidence for Maori of such problems as overcrowding, damp and cold housing and poor access to bathrooms, combined with the incidence of chronic illnesses.

Ways forward

Workshops and direct consultation groups were asked to focus on 'solutions' to the experiences and issues they identified. There was wide agreement across all groups and workshops on possible actions to improve the current situation. Within these broad ideas there were a number of initiatives suggested. The most commonly suggested actions are outlined below.

A "one stop shop"

Every group and workshop discussed ways to centralise information and make it more readily available. This ranged from the simple request that "agencies work more closely to achieve a common goal" to a major development at national level: "how about a service like Health-Line for health and disability – including housing. It could be national and have all the information on agencies, where to access specific requirement, what entitlements you have including what information the individual needs to collect and how to present this. There could be a local advocacy service that helps with the specifics then, after you have checked it out with the Help-Line".

The need to provide some sort of advocacy service was raised at every workshop and group. It tended to be linked to the centralising or provision of a simpler system, as the quote above illustrates. Advocacy was seen as being needed to assist individuals and families in negotiating around the "system" and also within the "system". It was suggested also as a way to ensure a better service from the private sector. "An advocacy group needs to be formed to act between landlords, tenants and the housing and disability agencies – similar to tenancy services." But also: "there's a real need for someone who knows the system and who can go with a client [to the agency or service provider] if necessary to convey their needs to the agency or landlord concerned".

Universal housing

Workshops and direct consultation groups agreed that the concept of universal housing was admirable. There were some concerns that it was not practical ("property developers wouldn't want to invest in that for such a small group"), or that it will not have an immediate impact ("universal housing is a great idea but it will only be new housing and most people with disabilities can't afford to buy a new house").

Other participants were more optimistic and felt that we should start somewhere. In one workshop a participant put this in context saying "it should be mandatory to build to the needs of the coming growth in older people with disability".

Discussion of universal design, and the perceived reluctance of private landlords to modify houses, led to consideration of mandatory regulations for at least universal/life-long housing as compared with incentives for private developers and landlords. All workshops and groups discussing this agreed that while it would be possible and perhaps ideal to legislate for basic features, incentives and education would be more effective. Some of the points that were made included:

- Factors that could be used to entice developers. "It can be cheaper to build a ramp than stairs, or a wet area shower than a standard cubical. I cannot emphasise enough the benefits the wider community would receive from universally accessible buildings."

- Having show homes with universal features. This would help create a demand in the wider community, and allow developers to see what was needed and how it could be done.

- The suggestion that feng shui principles in housing design were very compatible with housing for people with disabilities, with the concept of flow and functions - for example rounded corners. "Feng shui has been successfully sold to the mainstream architects as highly desirable – why not incorporate the principles in housing for people with disabilities? It would cover many of the needs of people with disabilities."

Establishing a data base

The suggestion of a data base of suitable properties, raised at workshops, was quickly endorsed by participants at the direct consultation groups. It was envisaged that the data base would include all accessible housing in an area. "Properties would need to be inspected before going onto the data base and it could include an indication of features." This idea was extended in some workshops to include the real estate industry: "real estate agencies putting some indication on their adverts to show where a property has specific features such as wet area and ramps".

Ongoing information on need

There was a feeling, expressed at most workshops and endorsed by the direct consultation groups, that a more accurate picture of current and ongoing housing needs for people with disabilities was required. "We need to know exactly how many [people with disabilities there are in the region], and what they need, to provide for them properly." Ideas included the suggestion of a full survey of the needs of affected people and families, regularly updated, to produce specific and reliable information for each area within the region, and that there was a need to "build better [information] capacity within HNZC".

A specific provider issue

Discussion with some providers not able to attend workshops highlighted further issues that may be pertinent to policy analysis and proposals in the final report.

One of these was a lack of coordination between the funding policies of the various government agencies, an issue that may affect people's access to housing and the overall cost of provision. If our inference is correct, it would appear that the effect could be to put a focus on minimising agency costs as compared with overall costs to the government. This suggests potential for considering the best utilisation of existing funding for housing related to disability in achieving the best outcomes for people with disabilities.

Summary remarks

The consultation process was structured in such a way as to explore, with stakeholders (providers, advocates, people with disabilities and families/whanau), issues identified in the earlier research – the literature review and the desktop data analysis.

The findings, described in detail above, confirm the validity and relevance of those issues at the regional level. Consultation across the region, with people working across the sector and with people across different disabilities, produced strong parallels between the picture presented in existing research and statistics and what are experienced as, and perceived to be, housing needs for people with disabilities.

In addition, and of vital importance to future planning to improve access to housing for people with disabilities in the region, is the depth of qualitative insight gained from the consultation process, capturing as it did the lived experience of people with disabilities. Planning for, and making decisions on, the provision of housing for people with disabilities needs to be done with an understanding of the patterns of disability, the living situations of people with disabilities and the impact housing can have on both on their health and their quality of life.

The overriding emphasis throughout the consultation process was that providing a varied range of housing options, and allowing for flexibility to meet different and changing needs and circumstances, was ultimately the key to meeting the housing needs of people with disabilities. All discussions emphasised individual choice and simplification of access to housing and support.

Consultation also highlighted the extent to which people saw current housing availability failing to match actual need. Included in this were the lack of a meaningful private sector presence in housing provision, a shortage of suitable public housing and delays in matching people with the housing they needed.

That said, the consultation also presented a picture showing the Bay of Plenty and Lakes Region as having a rich resource among providers, support people, families and people with disabilities who, with appropriate direction, encouragement and infrastructure, could guide the region to provision of high quality housing to meet the needs of families and people with disabilities in their areas.

Part 4 below draws together key questions to address in the final phase of the research project, which is to analyse policy implications and present recommendations.

4 CONCLUSIONS

A primary objective for the research project is to recommend effective action to ensure movement towards more adequately meeting the housing needs of people with disabilities and their families in the region.

The consultation process revealed a complex layering of connections between housing and disability, some to do with individual experience and some related to how the system functions. For the purpose of future planning and identifying possible future responses, these can be distilled into the following sets:

- Affordability as a major and continuing barrier to people with disabilities accessing suitable housing.
- The supply of suitable housing, for both rent and purchase, and in particular differentiated housing supply to match the pattern of need for people with disabilities.
- The varying needs of people with disabilities in different situations, with different disabilities and with life-time changes. Choice is a major consideration, whether limited by:
    - availability of suitable and affordable housing
    - the connection between housing and care and support
    - location
    - the time involved in accessing suitable housing (including further needs that arise from life-time changes)
    - community acceptance.
- The relationship between different policies and funding streams, and coordination between government agencies in respect of both policy and practice.
- The structure of incentives for funding agencies in terms of utilising available funding in the interests of meeting housing need for people with disabilities.
- The availability and provision of information. This includes:
    - how people find out about their entitlements and options
    - access to precedent (how people can learn from the experience of others and avoid ‘inventing their own wheels’)
    - advocacy (essentially, managing access to information)
    - information on housing available in the private market (an efficient mechanism for identifying appropriate properties and landlords)

  - information for private sector providers (landlords, developers and real estate agents) on the potential benefits from meeting the needs of people with disabilities.

- The intersection of housing and care and support for people with disability who live in private households.

- The ‘compounding effect’ of disability for Maori in relation to housing, in particular the intersection of deprivation, housing and disability, poor housing in rural areas and the effort of maintaining whanau care and support.

- Barriers perceived or experienced in housing regulation and the potential that lies in universal housing design.

These issues will be taken up in the final phase of the project, as principal themes for policy development and potential recommendations.

APPENDIX A

Workshop consultation

This appendix contains material relating to the consultation workshops held with disability and housing provider and advocacy organisations in Taupo, Rotorua, Whakatane and Tauranga. It includes:

- A sample copy of the workshop invitation letter (Rotorua)
- Statistics:
  - number of organisations/people sent invitations
  - number of participants
- Themes and topics circulated to participants in advance of the workshops.

Sample copy of workshop invitation letter

8 March 2006

HOUSING NEED FOR PEOPLE WITH DISABILITIES IN THE WIDER BAY OF PLENTY: A WORKSHOP INVITATION	
Date	**1 – 3 pm Tuesday, 14 March 2006**
Venue	**“The Board Room" Rotorua Hospital site (map to be provided)**
RSVP	**By Wednesday 8 March to: Adrienne von Tunzelmann, adrienne@mdl.co.nz; tel 07 5794217 or 021725293**

A research project is underway in the Bay of Plenty/Lakes region to build a picture of the current and future housing needs of people with disabilities in the region. It is a collaborative project between Housing New Zealand Corporation (leading the project), the Bay of Plenty and Lakes DHBs and the Tauranga Community Housing Trust, all of whom have a shared interest in the results.

This is the first time work of this kind has been undertaken, with a special focus on disability and housing need. The aim is to gain a better understanding of housing need and the distinct and changing housing needs of people with disabilities. It will be used for future planning and decision-making, to help meet these needs effectively within our region - not simply research for research’s sake!

The priority given to this work reflects the importance of improving access to appropriate, affordable, secure and sustainable housing for people with disabilities in the Bay of Plenty and Lakes community, and the considerable impact unsuitable housing can have on the lives of people with disabilities and their families.

We are using a wide definition of ‘disability’ to include physical, psychiatric, intellectual, sensory and age-related disability, and people with sustained chronic conditions or frailty such as leads to special housing need.

Stakeholder input - from provider organisations, advocacy groups and people with disabilities and their families – is a central part of the project. The first phase of consultation is workshops for providers (including field workers) and advocates. Consultation with people with disabilities and their families will follow.

In the first phase, workshops will be held in Tauranga, Whakatane, Rotorua and Taupo. They are being facilitated by the project team at Tauranga-based policy advisers McKinlay Douglas Ltd. We have teamed with Dr Janett Levien, a Napier-based social researcher, to carry out the project.

We hope a representative of your organisation will be able to come. We are especially keen to talk with front-line people who see, first hand, the issues people with disabilities have in relation to their housing. Once we have heard back, we will be sending participants some background material which will give you a feel for the issues that have emerged in the work so far, and an agenda.

The workshops are an opportunity for us to hear your experience with housing and disability, and for you to add your insights to dealing with current and future housing needs for people with disabilities in the region.

If you have any queries, please feel free to contact me (contact detail above). Or you can phone Peter McKinlay, (07) 579 4217.
We warmly look forward to hearing from you.

Yours sincerely

Adrienne

Adrienne von Tunzelmann
(for Project Team)

Material circulated in advance to registered workshop participants

To: Workshop Participants
Housing and Disability Project

This note tells you a bit about the consultation workshop on Housing and Disability in the Bay of Plenty and Lakes Region.

A list of suggested topics for discussion is outlined.

About the workshops

We have so far conducted a literature review and desk top data analysis around the issue of housing and disability, with as much focus on the region as possible. As is often the case, this work has raised many questions which can best be answered by tapping into the experience and insights of local people in the field. This is the purpose of the workshops.

Attached is a set of key issues that have arisen from the initial phase of work, for you to read and think about before the workshop. The floor is also open to other issues you may wish to raise.

As a volunteer participant in the workshop, your input is extremely valuable and will be respected. Confidentiality, including matters relating to people with disabilities and clients of service providers, will be carefully preserved. Participants names will not included in any reporting without your express agreement, and we will ensure that no other identifying aspects are reported.

We have a special request to make at the workshop. As well as consulting with provider and advocacy groups, we will be talking with people with disabilities themselves. We hope the workshop might help us identify people who could be invited to take part in this phase of the research.
The aim of the project is to provide a greater understanding of the housing needs of people with disabilities in the region and to help the organisations supporting the work - Housing New Zealand Corporation, the Lakes and Bay of Plenty DHBs, the Tauranga Community Housing Trust and the Taupo and Tauranga local councils - better plan for the future. We look forward to seeing you, and hearing your views, at the workshop.

Adrienne von Tunzelmann and Janett Levien
Project Team and Workshop Facilitators

TOPICS FOR DISCUSSION AT THE CONSULTATION WORKSHOP

Theme 1: A discussion about housing need

1 The interplay between disability and other factors in accessing suitable housing for people with disabilities.

For example, is it mainly disability that impedes access and choice in respect of housing? In accessing suitable housing, how important are issues associated with disability, compared with general socio-economic factors such as low income? How do you recognise this?

2 The needs of people with disabilities in different situations and with different disabilities.

How does the level of disability, or the type of disability, affect housing needs - in terms of both degrees of housing need and the nature of housing need?

3 Predictors of housing need.

What factors do you see are most likely to lead to a need for help with suitable housing for people with disabilities? Are there compounding factors, such as income, age, gender or ethnicity? How do these interact to indicate a likely future need for suitable housing?

Theme 2: The issues around the actual provision of housing

1 In your experience, how do people with disabilities and their families provide for their own housing needs when living independently in the community? For example, what, if any, modifications or special requirements are needed to allow independent living, and how do these get provided?

2 What is the capacity of service providers and agencies in the region to significantly assist people with disabilities to fulfil their housing needs?

3 What do you see as barriers in the built housing environment, and in building and planning regulations such as building by-laws and codes, and zoning?

4 Would more use of ‘universal housing design’ (houses designed to meet the needs of all people throughout life) help in housing for people with disabilities? Is it a practical solution? What should it include?

Theme 3: What the situation should be - now and in the future

1 What do you see as the main solutions to meet housing needs for people with disabilities?

2 Who is best placed to work on these solutions, and in what ways? For example, government, local councils, district health boards and community providers. Are there solutions that could work effectively by agencies working jointly?

3 What, if anything, might be needed for the private sector to better contribute to assisting people with disabilities with their housing needs?

OTHER THEMES AND QUESTIONS THE WORKSHOP COULD DISCUSS?

Workshop invitations sent and participation, by location

TAUPO	
Number of invitations sent	25
Number of participants (incl 2 District Council staff)	6
ROTORUA	
Number of invitations sent	12
Number of participants (one also provided written comment)	6
MAORI WORKSHOP, ROTORUA	
Number of invitations sent	16
Number of participants	4
WHAKATANE	
Number of invitations sent	34
Number of participants	12
TAURANGA	
Number of invitations sent	47
Number of participants	21
Number of additional written responses	1
MAORI WORKSHOP, TAURANGA (Te Whanau Poutirirangiora a Papa hui)	
Number of invitations: presentation was at the invitation of the Trust	0
Number of participants	12
Total number of invitations sent	134
Total number of participants	62

APPENDIX B

Direct consultation with people with disabilities

This appendix contains material relating to the direct consultation groups for people with disabilities in Taupo, Rotorua, Whakatane and Tauranga. It includes:

- A sample copy of the invitation letter (Rotorua)
- Statistics:
    - Invitations sent
    - number of participants
- Themes and topics circulated to participants in advance of the direct consultation groups.

Sample copy of workshop invitation letter

31 March 2006

AN INVITATION TO CONTRIBUTE RESEARCH PROJECT INTO HOUSING NEED FOR PEOPLE WITH DISABILITIES IN THE WIDER BAY OF PLENTY	
Date	**Wednesday 19 April Choice of times: 9.30 am – 11.30 am or 12 noon – 2 pm**
Venue	**Lakes DHB (room to be advised)**
RSVP by: RSVP to:	**Tuesday 11 April Janett Levien Email: janett.l@clear.net.nz Tel/fax: 06 836 6362; mobile 027 6990413**

The Invitation
A research project is underway in the Bay of Plenty/Lakes region to build a picture of the current and future housing needs of people with disabilities in the region.

The research is a collaborative project between Housing New Zealand Corporation (leading the project), the Bay of Plenty and Lakes DHBs and the Tauranga Community Housing Trust, all of which have a shared interest in the results. McKinlay Douglas Ltd, an independent Tauranga-based policy consultancy, has been contracted to conduct the research.

We are seeking input from people with disabilities and their families. We would like to invite you to one of several group meetings (details at the head of this letter) to provide your views on the issues as you see them. The meetings are an opportunity to tell us your experience with housing and disability, and for you to add your insights to dealing with current and future housing needs for people with disabilities in the region.
If you would like to attend, we will send you a summary of issues and ideas that have arisen so far. The summary includes comments from workshops held during initial consultation with support services (including field workers) and advocates. At the meeting you will be able to add your viewpoint.

You are welcome to have a representative to attend on your behalf, if you wish.

About the project

This is the first time work of this kind has been undertaken, with a special focus on disability and housing need **in the Bay of Plenty**. The aim is to gain a better understanding of housing need and the distinct and changing housing needs of people with disabilities. It will be used for future planning and decision-making, to help meet these needs effectively within our region. The priority given to this work reflects the importance of improving access to appropriate, affordable, secure and sustainable housing for people with disabilities in the Bay of Plenty and Lakes community, and the considerable impact unsuitable housing can have on the lives of people with disabilities and their families.

We are using a wide definition of ‘disability’ to include physical, psychiatric, intellectual, sensory and age-related disability, and people with sustained chronic conditions or frailty such as leads to special housing need.

Confidentiality

Your confidentiality is assured. This invitation has been forwarded to you by an individual or organisation with which you are currently associated. We do not have your name or contact details.

If you agree to take part in the group meeting, any information you provide, and your views, will remain confidential. Nothing that identifies you individually will be included in the research reports.

If you decide to attend, please provide your name, phone number and email address (if applicable) with your reply. We need this information so we can keep in contact with you.

If you have any questions, please contact Janett Levien (contact details are above).
We warmly look forward to hearing from you.

Yours sincerely

Adrienne von Tunzelmann
(for Project Team)

Material circulated in advance to registered workshop participants

11 April 2006

RESEARCH PROJECT INTO HOUSING NEEDS FOR PEOPLE WITH DISABILITIES IN THE BAY OF PLENTY
Rotorua Discussion Group

Thank you for agreeing to take part in a discussion group on housing and disability. This note confirms your attendance:

Date: Wednesday 19 April 2006
Time: 9.30 am – 11.30 am
Venue: Lakes DHB: Mental Health Clinical Training Room, Mental Health Service Building

To help you, we have enclosed a summary of some of the ideas from an earlier workshop in your area. You may like to review these before you come.

At the workshop, we would like you to tell us your views about these ideas. We will also ask for your own ideas and experiences with housing.

It is important that your privacy and confidentiality is protected. There will be no record of your details kept after the meeting and we will ensure that your identity cannot be connected directly with anything that you say or contribute in the meeting. The information we present in our report will not identify any individuals who have taken part.

The venue is well signposted from the main entrance to the hospital, off Arawa Street. There is a car park below the building. If you need mobility access, your vehicle may be driven to the door up the main ramp, but will need to be parked below. **A map of the hospital is attached**, showing the Mental Health Services building on the bottom right.

We look forward to meeting you and to hearing your views. Please call us if you have any questions. Our contact details are below.

Janett Levien (Project Team)

CONTACT DETAILS:
Email: janett.l@clear.net.nz
Tel: 06 836 6362
Mobile 027 6990413
Fax: 06 836 7372

SUMMARY OF IDEAS FROM ROTORUA WORKSHOPS ON DISABILITY AND HOUSING

When we asked the Rotorua workshop participants what they felt the situation should be now, and in the future, in housing for people with disabilities. They made the following points. What do you think?

1 Types of housing for people with disabilities:

Cluster housing is not suitable, as it creates ghettos. The exception may be housing for the elderly, in some circumstances.
Family needs must be considered. Ongoing modifications to the home as circumstances change, and the right to move when necessary, are important.
Practical needs include space for people to stay overnight (sometimes a garage is converted for overnighters) and parking/garaging for the person's own vehicle and a carer's vehicle.
Minor modifications can make a big difference, but can be hard to get, for example, blinds and non-slip treads on steps and pathways.
People with chronic conditions who may need housing assistance for more than six months but less than 3 years are "falling between the cracks".

2 Housing design:

Universal home design (houses designed for anyone to live in) is an excellent concept BUT new homes are generally unaffordable, so it would take a long while to have an impact.
Start now with building codes that require all new dwellings to have universal design features.
Incentives will work better than regulation – provide incentives for landlords and those renovating houses to incorporate facilities for people with disabilities, for example, tax breaks on materials for wet area bathrooms, and rate rebates for modifications to make a dwelling accessible.

3 Providing enough houses for people with disabilities:

The sums need to be done to find out what the actual housing need in the Rotorua area is, then build to that need.

You will have ideas of your own about how we might go about making things more like we feel they should be. The meeting will be an opportunity to share these.

Direct consultation invitations sent and participation, by location

The “invitations sent” figures comprise the number of invitations potentially passed on to people with disabilities by people attending the consultation workshops, so are indicative only. Invitations were sent out through workshop participants rather than directly from the project team. Workshop participants who agreed to pass invitations on through their networks were given a suggested number to pass on, based on the number they offered at the workshop. Some may have sent fewer, some more.

TAUPO	
Potential number of invitations passed on by workshop participants	16
Number of participants	5
Number of additional written responses	2
ROTORUA	
Potential number of invitations passed on by workshop participants	19 - 22
Number of participants	8
Number of additional written responses	1
MAORI DIRECT CONSULTATION, ROTORUA	
Potential number of invitations passed on by workshop participants	11
Number of participants	0
WHAKATANE	
Potential number of invitations passed on by workshop participants	31
Number of participants	7
TAURANGA	
Potential number of invitations passed on by workshop participants	67
Number of participants (four also provided written comment)	18
Total indicative number of invitations passed on by workshop participants	144 -147
Total number of participants	41