

# Evaluation of the Implementation of Choice in Community Living

Phase one: 2013



**evaluate**research

informing social and economic change

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## **Executive summary**

This report is a summary of findings from the first 12 months of the Choice in Community Living (CiCL) demonstration project. The evaluation has aimed to help key stakeholders involved in its development and implementation by providing information about how activities are working and identifying issues for further consideration.

### **Background**

CiCL is a Ministry of Health-led demonstration project established in mid 2012. It aims to support people to live independently in their own home in a fiscally neutral way. People eligible for CiCL include those who are in residential care or have disability support needs similar to those living in residential care, who live with family/whānau or where their current living situation is unsustainable. People must also be eligible for disability support services funded by the Ministry of Health (the Ministry).

People access CiCL through the Taikura Needs Assessment Service Coordination (NASC), based in Auckland, or the DSL NASC, based in the Waikato. Once people have been assessed by the NASC as eligible, they are provided with information about the amount of funding they can access from the Ministry, and a list of support agencies in their area who can help them develop a person-centred plan and support their move into independent living.

### **Evaluation Findings**

The evaluation was conducted in June-July 2013 with staff from the support agencies, NASC and with 10 disabled people/whānau who have considered CiCL as an option. Nine disabled people and one whānau (representing the interests of their adult son) were interviewed. Four respondents are based in Auckland and six in the Waikato. The CiCL project manager was also interviewed. The evaluation findings are as follows.

#### **Promoting Choice in Community Living**

CiCL has been promoted by the NASCs and the eight support agencies in the demonstration project, through newsletters, pamphlets, face-to-face contact with people known to the organisations, a disability expo and community forums. The interviews with support agency staff and whānau suggest the face-to-face approach to promoting CiCL has worked best. It has helped to have stories from disabled people who had made the move as it gives others the confidence to think they can do it too.

Six months post implementation (July 2013) a total of 113 people had expressed an interest in CiCL. Twelve people (seven in Auckland and five in the Waikato) had been assisted to remain in their current home, or had moved from residential care into their own home.

#### **Readiness**

While some people are ready to move into their own home within a short time frame, others need time to think about, and assess, CiCL as an option. Fear of losing access to current supports was identified by three agencies as a barrier to families proceeding with CiCL. This fear is understandable given many disabled people and families have experienced cost-cutting measures to government-funded services. Other people have found out about CiCL at a point when they are in crisis mode. CiCL is unlikely to be an immediate solution, especially if a great deal of preparation work needs to be done.

## **Referrals and selecting a support agency**

Three agencies gave examples of disabled people they believe should not have been referred by the NASC. In both cases the agency staff did not believe the person was clinically or psychologically stable enough to sustain independent living. Part of their concern also relates to the level of funding available to support people with high needs. One agency respondent said the cost of supporting a particular person in the community would be much higher than if they stayed in a residential service, yet there is an expectation a person's funding package be cost-neutral. Data provided by the Ministry suggests some of the people with serious health conditions still want to move to CiCL.

People have been encouraged to shop around for a support agency that works best for them. They are given information about the level of funding available to them, so it is a case of selecting a support agency that can give them the best deal and with whom they feel comfortable working with. This approach appears to be working well for disabled people.

## **Working with disabled people**

Comments from six support agency respondents suggest CiCL does not represent a major shift in the way they currently work with disabled people. Some said their agencies have been through a significant "revamp" in recent years, supporting more people in residential services to live independently in their communities. CiCL has a fit with this shift in philosophy.

Some people require a great deal of support to successfully make the shift. Support staff described this intense period of planning as a different way of working for them. Typically agency staff are taking time to build a relationship with a person before they even start talking about developing a plan. The plan may include life goals, daily activities as well as practicalities such as support and education to enable the disabled person to negotiate bus routes, call a doctor, take medicine, pay the rent.

## **Support agency resources**

The time spent meeting with people and whānau, and then preparing potential support options, can be significant for support agents. One agency estimates they have spent 20 hours with two people referred by the NASC, who subsequently did not proceed with them as the support agency. Five other agencies, some working with current residents, commented the unpaid time they spent with a family investigating CiCL as an option was considerable. Currently agencies can claim up to \$2000<sup>1</sup> but only if they are a non-residential service. At least one agency has considered withdrawing from the initiative as they regard it as unviable.

## **Funding**

The NASC allocates a funding package<sup>2</sup> for each person moving to CiCL. This funding is paid to the provider, to be used to commission a range of different types of disability support for the person according to an agreed plan. Agencies have embraced this new transparent approach to funding; arguing it helps to know how much is available for an individual.

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<sup>1</sup> This amount is not deducted from a person's funding allocation but comes from separate pool for administering the Choice demonstration project.

<sup>2</sup> The guidelines on what funding can be used for are based on three criteria: 1) they are a disability support; 2) they contribute towards the achievement of outcomes that are identified in a person's individual support plan; and 3) they are within the scope of relevant Ministry policies and responsibilities.

## Access to housing

The opportunity for someone to live alone, particularly in Auckland, is limited because of the cost of rentals. For those reliant on a benefit for income, there may be little choice but to share with others. Through necessity some people are moving into a shared flatting arrangement. There is evidence this arrangement does not work well for some people.

Some initial transitions to CiCL have included people staying in their existing house. One person has moved to social housing owned by Accessible Properties, a company that manages a portfolio of houses for IHC.

## Summary of progress

It is too early to report any sustainable outcomes for people who have participated in CiCL. The main difference reported by people who are living independently is that they now have increased control over their lives. Below is a summary of progress against other key success indicators developed for the evaluation. Data supporting these assessments can be found in the report that follows.

	More work required	Mixed progress	Working well
Disabled people say support agencies are listening to them			
Disabled people have the support they need, when they need it			
People living independently say they are better off on balance than previously			
NASC providing good information about funding and assessment			
NASC able to test different tools and ways of doing things			
Guidelines consistent across NASCs			
People actively encouraged to explore CiCL; no evidence of gate-keeping			
NASC staff develop trusting relationships with disabled people & whānau			
NASC staff have good working relationships with support agencies			
Service agencies have a "can do" approach to working with disabled people			
Organisational practices in service agencies support a client-directed service			
Service agencies working together in the demonstration project			
Disabled people have adequate funding and resources to live independently			
Ministry encourages support agencies to work in dynamic, creative ways			
Seamless access across govt agencies to resources for people with disabilities			
Ministry policies/resources support those with high & complex needs to live independently			

## **Introduction**

This report describes and assesses the first 12 months of the Choice in Community Living (CiCL) demonstration project. The evaluation, conducted in mid 2013, aimed to help key stakeholders involved in its development and implementation by providing information about how activities are working and identifying issues for further consideration. A second phase of the evaluation will be conducted in mid 2014.

The Evaluate team members who worked on this evaluation include Mathea Roorda, Debbie Goodwin, Louise Were, Dr Martin Sullivan and Heather Nunns. The team sincerely thanks all participants for taking time to share their experiences of CiCL.

## **Background to Choice in Community Living**

Choice in Community Living (CiCL) is a Ministry of Health-led demonstration project established in mid 2012. The project is part of the New Model for Supporting Disabled People (CAB Min (10) 23/4 refers). CiCL aims to support people to live independently in their own home in a fiscally neutral way. People eligible for CiCL include those who are in residential care or have disability support needs similar to those living in residential care, who live with family/whānau or where their current living situation is unsustainable. People must also be eligible for disability support services funded by the Ministry of Health (the Ministry).

The demonstration project aims to support up to 150 people in Auckland and the Waikato over two years. The following support agencies have been contracted to support CiCL: CCS Disability Action Auckland and Waikato; Community Living Trust; Idea Services Ltd; Iris Ltd; Renaissance 2001 Ltd; Spectrum Care Trust and Te Roopu Taurima O Manukau Trust. Five of the support agencies have existing residential services.

People access CiCL through the Taikura Needs Assessment Service Coordination (NASC), based in Auckland, or the DSL NASC, based in the Waikato. Once people have been assessed by the NASC as eligible, they are provided with information about the amount of funding they can access from the Ministry, and a list of support agencies in their area who can help them develop a person-centred plan and support their move into independent living. Outcomes for a disabled person may include (but are not limited to):

- moving to independent living or remaining in their existing home
- family or carers receiving support so they can continue their caring roles
- developing skills and capabilities to support independent living
- more opportunities for relationships, community access and participation, inclusion in cultural activities
- being able to carry out family and whānau responsibilities.

## **Evaluation methods**

The evaluators conducted a workshop in May 2013 with staff from the two NASCs, eight support agencies, Ministry of Social Development and Ministry of Health. While the workshop included people with lived experience of disability, the perspectives of family/whānau of disabled people were missing from this forum.

A set of success indicators (Table 3) was developed for five partners in the initiative – disabled people, the NASCs, service agencies and the Ministry. These indicators informed the development of topic guides for qualitative interviews, conducted in June-July 2013 with staff from the support agencies, NASC and with 10 disabled people/whānau who have considered CiCL as an option. Nine disabled people and one whānau (representing the interests of their adult son) were interviewed. Four of these respondents are based in Auckland; six in the Waikato. The CiCL project manager was also interviewed.

A scan of international literature on barriers to (eligible) people transitioning to CiCL in Community Living-type initiatives; the difference CiCL-type initiatives make for disabled people, family, providers, other stakeholders; and unintended outcomes of CiCL-type initiatives.

## **Evaluation findings**

The evaluation findings begin by presenting the data on uptake of CiCL (Table 1 and Table 2), followed by a high level assessment of progress against a set of success indicators developed by key stakeholders (Table 3). The findings that support this assessment are then ordered in the following sections:

- Promoting Choice in Community Living
- Readiness
- Referrals
- Selecting a support agency
- Working with disabled people
- Collaboration with other providers
- Support agency resources
- Funding
- Access to housing
- Implications of CiCL for disabled people.

Unless otherwise mentioned, the term 'person' refers to a person with disability and 'whānau' refers to the person's family. Vignettes are used to illustrate the findings. Names of people, and some demographic details, have been changed to protect people's identities.

### **Uptake of Choice in Community Living**

As at end July 2013, six months post implementation, a total of 113 people had expressed an interest in CiCL (Figure 1). Of these, 68 (60%) were Auckland based; 43 (38%) were from the Waikato. The location of two other people is not known. Twelve people (seven in Auckland and five in the Waikato) had been assisted to remain in their current home, or had moved from residential care into their own home.

**Figure 1: Uptake of CiCL as at end July 2013**

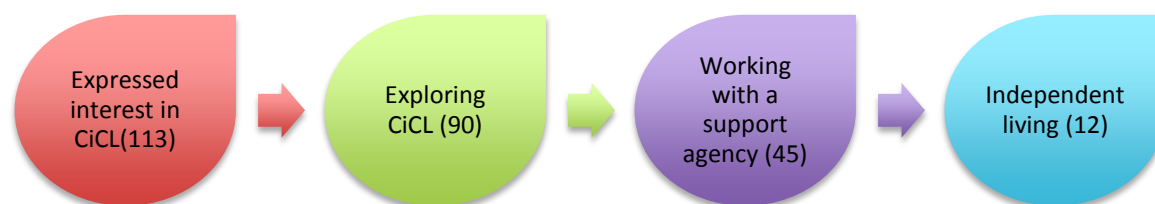


Table 1 identifies the location of the 45 disabled people who have worked, or are working, with an agency. Table 2 includes the ethnicity of disabled people working with a support agency.

**Table 1: People actively exploring CiCL with a support agency as at end July 2013**

Support agency	Auckland	Waikato
CCS Disability Action Auckland	4	0
CCS Disability Action Waikato	0	2
Community Living Trust	0	9
Idea Services Ltd	6	11
Iris Ltd	2	0
Renaissance 2001 Ltd	5	0
Spectrum Care Trust Board	2	1
Te Roopu Taurima O Manukau Trust	2	1
Total number of people actively exploring CiCL	21	24
Total number who have moved into independent housing	7	5

Source: Ministry of Health

**Table 2: Ethnicity of disabled people working with a support agency as at end July 2013**

Ethnicity	Auckland	Waikato
European	13	13
Māori	5	7
Asian	2	1
Pacifika	0	0
No ethnicity recorded	1	3
Total	21	24

Source: Ministry of Health



## Promoting Choice in Community Living

CiCL has been promoted by support agencies and the NASCs through newsletters, pamphlets, face-to-face contact with people known to the organisations, a disability expo and community forums. Some forums have been agency-specific; others have been joint agency events. Where possible, the CiCL project manager and NASC staff have also attended. Respondents reported that the forums have been attended by between 15 – 25 people, including a mix of disabled people, agency staff and people from the community. Of the 10 disabled people/whānau interviewed, five heard about CiCL when they attended a community forum; three from a NASC, and two from their existing support agency.

The interviews with support agency staff and whānau suggest the face-to-face approach to promoting CiCL has worked best. One person described receiving a pamphlet, however she did not understand what CiCL was trying to do. She said the NASC had provided additional information and also encouraged her to take her time thinking about whether this would work for her. Support agency staff commented it had also helped to have stories from disabled people who had made the move: “People start seeing role models and think about it for themselves”.

## Readiness

Some disabled people are clearly ready to move into their own home within a short time frame; others need time to think about, and assess, CiCL as an option. The following vignette demonstrates three people who were ready to make the move to CiCL immediately.

Georgina, Kataraina and Manu have lived in a residential home for many years. They say living independently “is something we’ve always wanted to do”. They attended one of the forums. From their perspective, they are ready and keen to make the shift straight away.

Barry is less ready. In his mid-40s, he doesn’t see himself as having a disability and he doesn’t trust disability services at all.

Barry’s parents provide him with significant support and say they “can’t carry on”. A NASC staff member has spent time with Barry over several weeks, getting to know him. CiCL may be a good option, but the time needs to be right for Barry.

Fear of losing access to current supports was identified by three agencies as a barrier to families proceeding with CiCL. It is also a barrier identified in the literature (Bowey et al, 2005). One respondent described a family whose adult son requires 24/7 support. The support agency gave the family several options about how funding could be used:

*They were quite excited, but there was a fear factor. At this stage they get respite every second week; they were scared about losing that.*

This fear, or suspicion, is understandable given many disabled people and families have experienced cost-cutting measures to government-funded services. CiCL also puts expectations on some families that they have not had before. A support agency respondent said one family’s response was:

*I don’t have to worry because (disabled family member) is in a residential service.*

Some people find out about CiCL at a point when they are in crisis mode. CiCL is unlikely to be an immediate solution, especially if a great deal of preparation work needs to be done. The following

vignette describes a whānau in this situation. While they rejected CiCL initially, it is an option they are now open to exploring.

Linda is a 'people person' who requires support with decision making and staying safe. She has lived for two years in a house with two others. Her family is concerned about the care she has received. They would like to remove her from the service, but have been told that if she leaves for longer than a week she will go to the bottom of the residential services list and have to wait for another opening. They were given a brochure about CiCL. Initially they "freaked out"; they had so many questions, and consequently didn't proceed. However, now they are less stressed they would like to find out more. They are still unclear about what CiCL involves.

One agency gave the example of a young woman "Debbie" who currently lives with a welfare guardian. Once Debbie turns 18 the guardian will not be eligible for support funding and Debbie has no choice but to leave. The support agency is concerned Debbie may not be ready: "[she] shouldn't be rushed". There is some pressure to find alternative housing for Debbie before she turns 18 in three months. Unfortunately Debbie was not interviewed. However, support agencies indicated her situation is not uncommon. There is currently no option for young people in Child, Youth and Family Services (CYFS) to be funded to stay in an existing supportive environment if that is their choice.

## Referrals

All referrals come via the NASC, who assess eligibility and determine the level of funding a person can access. With input from some of the support agencies, the NASC staff have developed a referral form for CiCL. Its purpose is to give the support agency a "start to developing a good life plan". At Taikura, the needs' assessment is conducted by a NASC staff member not involved with CiCL, thus separating the discussion about a person's aspirations from funding. The NASC coordinator at DSL conducts the assessment for Waikato people.

There is no evidence of gate keeping, that is, the NASCs actively discouraging people from considering CiCL as an option. On the contrary, some agency staff have suggested the NASCs be more selective about who is referred to CiCL. Three agencies gave examples of disabled people they believe should not have been referred by the NASC. In both cases the agency staff did not believe the person was clinically or psychologically stable enough to sustain independent living. Part of their concern also relates to the level of funding available to support people with high needs. One agency respondent said the cost of supporting a particular person in the community would be much higher than if they stayed in a residential service, yet there is an expectation a person's funding package be cost-neutral. Data provided by the Ministry suggests some of the people with serious health conditions still want to move to CiCL.

## Selecting a support agency

People have been encouraged to shop around for a support agency that will work best for them. They are given information about the level of funding available to them, so it is a case of selecting a support agency that can give them the best deal and with whom they feel comfortable working with. This approach appears to be working well for disabled people. For example, one person commented they chose a support agency because:

*they were communicating with me; the others weren't.*

In Auckland, a NASC staff member has provided a coordinating and support role at the selection stage. For example, a person reportedly selected a support agency based on a two-step process. They first met with two agencies. Of the two, their 'preferred' agency came back with a coordination

fee that left a significant dent in their allocated funding. The NASC encouraged the person to go back and negotiate a different package that would work for both parties.

The Auckland NASC offers to attend the initial meeting with the person/whānau and provider. She provides guidance about the questions the person might want to ask of support agencies, but at the meeting is not involved in the conversation. Disabled people have appreciated this support. The NASC respondent reflected that taking time to develop a relationship was a different way of working for her organisation: “Normally we’d be in there looking at needs, goals, and out again”.

### **Working with disabled people**

Comments from six support agency respondents suggest CiCL does not represent a major shift in the way they currently work with disabled people. Some said their agencies have been through a significant “revamp” in recent years, supporting more people in residential services to live independently in their communities. CiCL has a fit with this shift in philosophy. As two support agency respondents commented:

*We already work in a person-centred model. It’s about client choice in every aspect of their life.*

*[CiCL has] helped recognise the innovation that providers are doing anyway.*

This way of working was confirmed by one disabled person, who said the move to CiCL more accurately reflects the support she was already receiving. She said her paid support worker comes daily and also provides on-call support as required: “She does so much for me”. The planning process was very similar to her previous support plan. The main difference with CiCL is that it funding could now be used to support aspirational goals. This had previously not been possible. Support agency respondents also commented this was the major difference between CiCL and previous initiatives:

*The funding gives us the flexibility to be creative. It’s about ‘let’s see how’, rather than ‘sorry, we can’t. [It] opens up real choice and opportunities for people.*

Some people require a great deal of support to successfully make the shift. Support staff described this intense period of planning as a different way of working for them. Typically agency staff are taking time to build a relationship with a person “before we even talk about developing a lifestyle plan”. Once a plan is developed it is sent to the NASC for approval. The plan may include life goals, daily activities as well as practicalities such as support and education to enable the disabled person to negotiate bus routes, call a doctor, take medicine, pay the rent. Affordable and suitable accommodation must also be found, which some agency staff have found difficult:

*If you get it right from the beginning they [disabled people] should do well. We do not want to set them up to fail, or give false hope. There is a lot of pre-work (required for CiCL to be sustainable).*

Even with careful planning, unanticipated events can delay a move. One couple described being close to moving to their own home when one of the partners was made redundant. They had a support worker working “intensively” with them to help find another job and more affordable housing options.

Three agency respondents acknowledged a need to improve their staff training and to employ more highly skilled staff who can be flexible to an individual’s needs, providing an individualized, customized service:

*You need somebody who is really supportive and extends [a person's] skills, opposed to doing things for them.*

One agency said they had employed a disabled person to mentor staff and assist with training to “help develop our understanding and skill”. Access to quality support staff is an issue that was identified by some disabled people, after they had moved to CiCL. These included issues with support staff turning up unannounced, and not knowing how to provide the support a person needs.

### **Collaboration with other providers**

An expectation by the Ministry is that the support agencies share ideas and resources during the demonstration project. At the time the evaluation was conducted, meetings were being held once a month, bringing together agency staff, NASC, Ministry of Health, Ministry of Social Development and the CiCL Project Manager. Some support agency respondents said the meetings have been useful, well facilitated and have involved “open and transparent conversations”. However, others say the meetings have not been as useful as anticipated. One respondent commented “everyone is a bit protective...there is the potential for residential support services to lose clients to other providers”.

One respondent reported the Waikato support agencies have worked closely together as they have existing relationships as they collaborate on other projects.

### **Support agency resources**

The time spent meeting with people and whānau, and then preparing potential support options, can be significant (and costly) for support agents. One agency estimates they have spent 20 hours with two people referred by the NASC, who subsequently did not proceed with them as the support agency. Five other agencies, some working with current residents, commented the unpaid time they spent with a family investigating CiCL as an option was “considerable”. One agency described the “spade work” that was needed to put into place supports so a person could even consider living independently:

*At the moment we are doing the work needed to be done so they [person] are not set up to fail, even though the funding isn't there.*

Another staff respondent estimated they worked with a person for 40 – 50 hours to date:

*It's not an overnight process. Building relationships and working through the issues of moving to a house takes time.*

One agency respondent said they have been told they can recoup these costs from a person's funding package once it is in place. However, they do not believe there is enough funding in the person's package to cover their costs. Again, this raises a question about the adequacy of funding packages. Are there sufficient funds to support people with achieving more aspirational goals? Under resourcing of support for disabled people is a key barrier identified in overseas literature (e.g. National Disability Authority, 2010; Fyson et al, 2007).

Currently agencies can claim up to \$2000<sup>3</sup> but only if they are a non-residential service. At least one agency has considered withdrawing from the initiative as they regard it as “unviable”. At the same time they are concerned how this may reflect on their credibility with the Ministry.

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<sup>3</sup> This amount is not deducted from a person's funding allocation but comes from separate pool for administering the Choice demonstration project.

## Funding

The NASC allocates a funding package<sup>4</sup> for each person moving to CiCL. This funding is paid to the provider, to be used to commission a range of different types of disability support for the person according to an agreed plan. In theory funding allocated to a disabled person can be used more flexibly than in the past, to assist disabled people to participate in everyday activities. One person's goal is to reconnect with whānau and their Māoritanga. Another person's plan includes learning to drive and being more involved in music. Whether the person gets approval for funding to be used in this way has yet to be tested. It is unclear what proportion of a person's funding package is allocated to necessities, such as support and equipment, and what is available to make other goals a reality.

Agencies have embraced this new transparent approach to funding; arguing it helps to know how much is available for an individual:

*The funding gives us the flexibility to be creative. It's about 'let's see how' rather than 'sorry, we can't'.*

A respondent from one support agency described how two siblings, flatting together in a private rental, have arranged their funds. To make the dollars go further, they have pulled their funds into one package. They contract their own support staff; share nighttime support, but during the day have their own staff. The support agency's role includes management of the siblings' funds, ensuring invoices are paid on time and organising additional support if required. For this they charge a coordination fee.

A downside is that the siblings' rental property does not have an accessible shower. To speed up the moving process it was suggested some of their funding be used flexibly to have modifications done to the bathroom, and that they later be reimbursed. The respondent said they were told this option was not possible, raising a question about how flexible the funding is in practice. Another respondent described having to wait two months for a bed that would enable her to sleep with her husband. A third had spent months accessing equipment such as a commode. She has been told she cannot take them with her when she moves to her own home. Her frustration with the time it has taken to organise equipment was very evident in the interview. These findings raise a question about coordination between different funding pools, both within the Ministry and cross-agency, as well as between community agencies.

One agency commented on discrepancies between funding models in the two NASC areas. There is a perspective that people living in a group home in the Waikato can access less funding under the Transparent Pricing Model (TPM) than is the case in Auckland, where funding is based on levels of need (low, medium or high). Further investigation is required to clarify if this is the case, and if so, the implications for Waikato-based people.

Strong coordination between government agencies is critical in order to operationalize effective, flexible and well-coordinated supported living arrangements (Fisher et al, 2008). The findings from this evaluation indicate local Work and Income staff may need additional briefings about CiCL to ensure people get access to all their entitlements. One person commented they had visited Work and Income to explore financial options. She had to wait while staff contacted their head office for information. In another case, Work and Income was not forthcoming with the information they required

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<sup>4</sup> The guidelines on what funding can be used for are based on three criteria: 1) they are a disability support; 2) they contribute towards the achievement of outcomes that are identified in a person's individual support plan; and 3) they are within the scope of relevant Ministry policies and responsibilities.

around a re-establishment grant and the disability allowance. Coordination is also required between the Ministry and Housing New Zealand (discussed in the next section).

### Access to housing

Some initial transitions to CiCL have included people staying in their existing house. For example, three flat mates share a house owned by a disability provider. They have taken over the lease, the provider's signage has been removed and an old staff room has been turned into another living area. Another person interviewed co-owns a property with a disability provider<sup>5</sup> and has transitioned to CiCL without leaving her home. A fifth respondent moved into a Housing NZ (wheelchair accessible) property prior to transitioning to CiCL.

One other person has moved to social housing owned by Accessible Properties (AP) Ltd<sup>6</sup>:

Lenore attended a public forum about CiCL after hearing about the initiative via a NASC staff member. She phoned several support agencies before selecting one she felt could work for her. A three-bedroom Accessible Properties house became available almost immediately, so Lenore and the agency had to work quickly to develop an initial plan and, in particular, a budget. Lenore needs support twice during the night. Lenore has engaged a family member to live rent free in exchange for providing night support. She splits the \$320 rent with a flat mate who also has a disability.

Lenore's experience raises a question about the level of control people have about who they live with. AP accommodation is targeted at people with disabilities. The evaluators were told there is an expectation these houses be occupied by disabled people. While Lenore commented she was happy to share a house with another disabled person, others may want more say in selecting flat mates.

Housing New Zealand is another social housing option, with some accessible properties in their stock. However, as Jim's vignette illustrates, it can be difficult for people to access a Housing NZ property if they are currently in stable housing.

Jim lives in a two bedroom flat owned by a disability support agency. For a long time he's wanted to move to his own one-bedroom place, preferably something with a nice outlook. He has lived with others in the past and is adamant he now wants to live alone. He's found a few places in his price range (\$250 max) but it's challenging to find a place that is wheelchair accessible. He is also on Housing NZ's books, but the support agency is not sure if he is high on their priority list as his current accommodation is stable, if not ideal. Jim has networks in the disability sector so has been actively searching on his own. He also meets a support agency staff member for 'café meetings'; they hook up a laptop and search potential priorities together. The support agency estimates they have spent 80 hours with Jim, planning and searching for a new home.

Another family had been successful in securing a Housing NZ property for their son. Their success has been attributed to proactive advocacy; they enlisted a Member of Parliament (MP) to provide support and also provided "significant" documentation. This example further illustrates the skills required of support staff. If a disabled person or family are not able to actively advocate on their own, support agency staff need to negotiate the Housing NZ, Work and Income and other bureaucracies on their behalf.

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<sup>5</sup> The co-ownership was an existing arrangement, prior to the person moving to Choice.

<sup>6</sup> Accessible Housing manage a portfolio of 1100 IHC properties throughout New Zealand, of which 80 percent are houses.

The lack of affordable, quality private rental housing in New Zealand is well documented (CRESA, 2007; IHC, 2009). Auckland support agency respondents commented the opportunity for someone to live alone in an Auckland rental is limited because of the cost of rentals. For those reliant on a benefit for income, there may be little choice but to share with others. One person said she had been told by Work and Income that she would not be able to afford to live independently. Through necessity she had moved into a shared flatting arrangement. The arrangement was not working well and she commented her health was suffering as a result of friction with her flat mate.

### **Implications of Choice in Community Living for disabled people**

It is still early days for people who have moved to CiCL, and too early to report any sustainable outcomes. Appendix 1 includes findings about implications of CiCL-type initiatives as reported in overseas literature. The findings in this section are based on interviews with six people who have moved to CiCL (one other was about to transition). The main positive difference reported by people was increased control over their lives. One person reported a less positive experience.

#### ***Positive differences: increased control***

For five people, shifting to CiCL has meant a subtle change as they have been able to stay in an existing home, and have existing supports around them. However, a key difference is that they now have more control over their support arrangements. Some said they had been involved in interviewing support workers. The following vignette describes a positive initial outcome for one woman:

Deirdre got married in late 2012 and moved into her husband's flat, a wheelchair accessible property owned by Housing NZ. In 2013 she moved to CiCL. After being supported 24/7 for a number of years, Deirdre now needs support only in the mornings and evenings. She has a more active and independent life; going to town, shopping, to the movies, visiting the library, and having coffee with family and friends. Before CiCL, she was expected to attend a vocational service four out of five days. She did not like this arrangement, primarily because she could not choose the staff that worked with her. Under CiCL, she has advertised, interviewed and selected her own staff. Her key requirement is staff who are "not too bossy". Deirdre is now reconnecting with her ethnic community, attending cooking classes and is planning to do a computer course.

Likewise, two other disabled respondents report positive changes since they moved to CiCL. The biggest outcome is a "sense of freedom". Kataraina reports she now has the confidence to catch a bus and train by herself. Georgina said she could choose where she goes and how she spends her time, so if she doesn't want to go to the vocational service, she doesn't. She enjoys being at home, answering the phone and dealing with daily activities: "It's better here. I'm happy". These findings are similar to those reported in overseas initiatives similar to CiCL (McGlaughlin et al, 2004; Fyson et al, 2007; Tichá et al, 2012; Stainton et al, 2011).

#### ***Negative difference***

One person who has moved to a flat (Simone) reported a less positive experience with CiCL. The parents of her flat mate, who live in another house on the property, own the flat. Simone had been in the flat for four weeks but found her flat mate "uptight and bossy". She found the flat to be cold. She was not allowed to bring her cat with her: "My cat is No. 1 – even better than my phone". Simone feels "lost and upset" and wanted to move. She said her support agency had suggested she write her own rules to share with her flat mate. However, Simone says: "There is no point, as I have to repeat myself all the time".

## Discussion

The purpose of this evaluation was to help key stakeholders involved in its development and implementation by providing information about how activities are working and identifying issues for further consideration. The evaluation findings are based on a small number of interviews with disabled people/whānau, as well as support agency, the CiCL Program Manager and key NASC staff participating in the demonstration project.

Despite the size of the evaluation, some clear themes have emerged. The NASC staff have been a critical source of support for disabled people/whānau exploring CiCL as an option. They have also developed good relationships with most of the providers, which has helped to ensure a seamless transition for disabled people. Most support agencies are also providing good support to people exploring CiCL and are committed to making this initiative work. As a result, a small number of people have successfully shifted to more independent living situations and are enjoying an increased level of control over their lives.

At the time the evaluation was conducted, most of those interviewed had stayed in their existing accommodation, rather than move to a new home. The findings indicate it can take time for disabled people, and their whānau, to ascertain their level of need required to move to independent living and to decide if CiCL is a good option. The evaluation was not able to engage with sufficient numbers of people who have considered CiCL and made a decision not to proceed. However, the data did identify a number of barriers that may be contributing to the lower than anticipated uptake. These will be explored in phase two of the evaluation.



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## Appendix 1: Choice In Community living literature review

This is a small-scale review of literature on Choice in Community Living-type initiatives, limited to the UK, US, Australia, Canada and New Zealand. The review focuses on the following questions:

What are the barriers to (eligible) people transitioning to Choice in Community Living (Choice) -type initiatives?

What difference do CiCL-type initiatives make for disabled people, family, providers, other stakeholders?

What (if any) unintended outcomes of CiCL-type initiatives are reported in the literature?

The review focuses on research-based literature describing what is involved in a disabled person and their family considering and in some cases, undertaking a move from a residential or family home to independent living, and the outcomes of such a move for the disabled person, their family, support providers and other stakeholders.<sup>7</sup>

In respect of housing arrangements, the review focuses on literature that describes individual and shared tenancies (in which a disabled person chooses to live with another person or people), or homes owned by the disabled person. Only initiatives where there is a separation between the landlord and the support provider are included in the review. Arrangements where people are unable to choose where and with whom they live (e.g. clustered or group tenancies, village or intentional communities, some types of dispersed housing) are excluded from the review. There were a number of studies describing independent living arrangements where it was not clear whether this separation existed. Such studies were not included in the review.

### **Limitations**

Attempts were made to ensure coverage across the five countries of interest. Given the small-scale nature of this review, this approach precluded in-depth examination of key themes. For example, the CiCL demonstration project involves self-directed support and supported decision making/person-centred planning. There are substantive literatures on both of these topics, which are broader than housing-related initiatives such as CiCL.

It is not possible to identify the extent to which initiatives examined in the literature are similar to CiCL in respect of self-directed funding for a disabled person, or the funding of support providers. Similarly, it was not possible to ascertain the extent to which providers described in the literature have a similar role to the providers in the CiCL demonstration project. The absence of these and other contextual and structural factors in the literature (such as level of support funding and accommodation subsidies) make interpretation of the research findings problematic. It is suggested that such contextual and structural factors may be significant contributors to the success (or lack of success) of CiCL-type arrangements. The role of contextual and structural factors is endorsed in research done by Noonan-Walsh, Emerson, Lobb, Hatton, Bradley, Schlock & Moseley (2010). This is discussed further below.

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<sup>7</sup> The majority of the papers in this review are from peer-reviewed academic journals. Some papers were sourced from the internet and do not fit this category. The majority of these papers are from national or state disability organisations.

### **Descriptions and standards**

A range of terms is used in the literature to describe CiCL-type initiatives, such as supported living, dispersed housing, consumer-directed services, independent living environments, and community living.<sup>8</sup> Regardless of the term used, the arrangements share the same principles, namely, separation of support provision from accommodation provision, with an individual having full legal status as a tenant or home owner with the rights and responsibilities conferred by such status. For example, the National Disability Authority in Ireland uses the International Association for the Scientific Study of Intellectual Disability (IASSID) definition of community living:

Community living is defined as comprising the same range of accommodation available to the general population, in the same locations where the general population reside, offering people with disabilities choice over where and with whom they live and providing the necessary supports for community participation (2010, p.5).

Significant effort appears to have happened in the UK to define supported living. This may be due to the requirement for services to change from residential care homes into supported living services (Strong & Hall, 2011). For example, the UK Association for Supported Living that works with people with learning disabilities identifies the specific features of CiCL-type initiatives (2004, cited in Fyson, Tarleton and Ward, 2007) as shown in Table A.

**Table A: Features of supported living, UK Association for Supported Living, 2008**

The tenant should have a choice in where they live
The tenant should have a choice about with whom they live
The tenant should have been offered a range of options for their living arrangements
There should be clear separation between the provider of support and the provider of accommodation
The tenant should have a tenancy agreement
There should be no contract between the provider of support and the provider of the property
The tenancy agreement should make no mention of support provision
The tenant should have real choice in who provides their support
The tenant should decide who enters their home
There should not be an office for use by support staff in the property

Options (formerly known as “Paradigm”) is a UK organisation, has produced nine standards for supported living arrangements as listed in Table B. These add extra dimensions to those listed in Table A.

**Table B: Reach standards for supported living**

I choose who I live with
I choose where I live
I choose who supports me
I choose how I am supported
I choose what happens in my own home
I have my own home

<sup>8</sup> It is acknowledged that these terms may have different meanings in different countries. For example, “dispersed housing” can refer to both a small group home owned by a service-providing agency, and an arrangement where a person owns or rents their own home in the community (Mansell & Beadle-Brown, 2009).

I make friendships and relationships with people on my terms

I am supported to be safe and healthy on my terms

I have the same rights and responsibilities as other citizens

The National Development Team for Inclusion, a UK agency working with people with learning disabilities, has developed “The Real Tenancy Test” (2010) which focuses on the tenancy status of the person. Eleven questions underpin the descriptors listed below.

1. A tenancy agreement is in place
2. The tenant has control over where they live
3. The tenant has control over who they live with
4. The tenant has control over who supports them and how they are supported
5. The tenant has control over what happens in their home.

Two Australian research projects of supported living arrangements have produced quality frameworks. The first is a framework for personalised residential supports for adults with developmental disabilities living in independent arrangements, developed by the Centre for Research into Disability and Society at Curtin University in Australia (Cocks and Boaden, 2010). The research was based on case studies of six people with a primary intellectual disability with high to low support needs living in independent living arrangements.

The second research project was undertaken by the Disabilities Study and Research Institute of the University of New South Wales (2008). The project reviewed existing national and international approaches to 24-hour supported living in independent settings. The findings were used to develop a framework for assessing the effectiveness of 24-hour supported living approaches.<sup>9</sup> The framework was then applied to six case studies of supported living initiatives in South and Western Australia.

### ***Quality of life outcomes***

Comparison of the quality of life (QOL) outcomes of disabled people living in different types of supported living arrangements (e.g. independent living, cluster housing, group housing) appears to be the subject of some dispute in the literature. Authors describing a particular supported living arrangement may make claims (explicit or assumed) about the merits of a particular approach based on the QOL outcomes for disabled people from the arrangement (for example, a summary of QOL outcomes reported for people living in CiCL-type arrangements is provided below).

A review conducted by Noonan-Walsh, Emerson, Lobb, Hatton, Bradley, Schlock & Moseley (2010) of research on QOL outcomes for disabled people from different types of supported accommodation challenges such claims. The review examined 86 articles reporting 67 studies to identify the association between the type or characteristics of living circumstances, and the QOL outcomes for people with an intellectual disability. The authors identified variations in quality within any particular approach to providing supported accommodation, leading them to conclude that the basic model of care appears to be less important than other factors. Such factors may include - income and poverty (of the disabled person), organisational culture (of providers), and neighbourhood and community characteristics. The authors note that these factors have been absent from the variables examined in previous research projects.

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<sup>9</sup> The 24-hour support was in the form of a package of formal and informal support, on-call support and more support at times of greater need.

## **Summary of literature**

The literature is presented in two parts. Part one summarises the key findings about the three questions: (i) barriers to transitioning to CiCL-type arrangements (ii) the difference such arrangements make for disabled people and others, and (iii) unintended outcomes. Part two provides information about the research referred to in this paper - purpose of the research, research method, and the disability described.

### **Part one**

#### **Barriers**

This section is divided into the following sections – structural barriers, barriers for disabled people, barriers for and by families, barriers for and by providers, other barriers.

#### **Structural**

Private rentals:

Affordability of the New Zealand private rental market (IHC, 2009).

The quality and accessibility of suitable private rental accommodation in New Zealand (CRESA, 2007).

People with disabilities may find it more difficult to obtain rental accommodation than other people, even after factors such as income are allowed for (McDermott Millar, 2005)

Of utmost importance in any housing arrangement is the availability, flexibility and diversity of affordable and purpose appropriate housing options (Fisher et al, 2008).

Social housing:

Lack of choice about where to live due to a general lack of social housing in the UK (Hogg, 2005).

Limited availability of social housing in the UK that met particular needs such as level access. Available houses were in undesirable neighbourhoods (Fyson et al, 2007).

With increasing demand for social housing the eligibility criteria for accessing social housing in Australia has become more focused on higher need clients, which may be preventing people who are in need (but not in crisis) from gaining social housing (AHURI, 2002).<sup>10</sup>

Low incomes:

Choice limited by lack of income i.e. receiving benefits. The few research participants who did have jobs were in voluntary or low-paid work (Fyson et al, 2007).

Most people with intellectual disabilities do not have the financial resources to purchase their own home. Even the upfront costs of a tenancy may be problematic (National Disability Authority, 2010).

Under-resourcing of supports: An examination of independent living supports in Ireland noted that although there were comprehensive support packages in place, supports for independent living were under-resourced (National Disability Authority, 2010).

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<sup>10</sup> The 2011 changes to Housing New Zealand Corporation's Social Allocation System give priority to applicants who are deemed to be less able to sustain accommodation in the private rental market.

A paradigm shift: Shared or supportive living is not a model. It is an approach to assisting individuals with disabilities that enables them to receive the support they need and to live in a home they want. It involves a culture and values shift for providers, communities and policy makers (NYSACRA, 2009).

Other structural barriers: The provision of supported living services in Idaho was limited by the nature of the person's impairment (e.g. people with significant behavioural challenges were less likely to be able to attract supported living services) and where the person lived (i.e. geography) (O'Shea et al, 2002).

### ***The disabled person***

Anxiety about family's reaction/impact on family:

Older people feel they need to remain at home to care for elderly parents (Shaw et al, 2011).

Concern about how their families will feel if they leave home (McGlaughlin et al, 2004).

People do not verbalise their wishes to avoid conflict with family members (Bowey et al, 2005).

Personal concerns:

Feel powerless because they feel they have little choice, and decisions are made by professionals or family members (McGlaughlin et al, 2004).

Lack confidence about how they will cope living independently (McGlaughlin et al, 2004).

Concerns about personal safety in the community (Shaw et al, 2011).

Nature of transition: Slow, purposeful transition which builds on gains made, rather than quick, crisis-driven moves into services is seen as crucial for people with disability to develop confidence and security in their new living arrangements (Fisher et al, 2008).

### ***Family***

Concerns:

Anxiety about "letting go", feelings of guilt (Bowey et al, 2005).

Parents' perceptions that their adult child lacks the required functional skills to live independently (Shaw et al, 2011).

Concerns about personal safety in the community (Shaw et al, 2011).

Concern about the availability and quality of supports (Bowey et al, 2005).

Concern about the possibility of social isolation (Shaw et al, 2011).

While wanting the family member to be involved in decisions, the family is concerned that s/he may not always understand the consequences of decisions (Bowey et al, 2005).

The size of the transition from living in a family home to living independently is huge. Families suggest opportunities be made available for the person to 'try out' independent living before making a decision (Shaw et al, 2011; Bowey et al, 2005).

### ***Providers***

Support quality is mediated by support staff, whereby the staff can be either be facilitators of inclusive living, or gatekeepers from inclusive living (Fisher et al, 2008).

Lack of strategic planning which acts as a barrier to agencies working together in a holistic manner (Jordan, 2012).

## **Other**

Lack of information about options for independent living (Bowey et al, 2005; Jordan, 2012; McGlaughlin et al, 2004; NYSACRA, 2009).

Strong coordination between government and non government housing and support agencies is critical in order to operationalise effective, flexible and well coordinated supported living arrangements (Fisher et al, 2008).

Lack of expectations and aspirations (Jordan, 2012).

## **Implications of CiCL-type approaches**

### ***Positive differences for the disabled person***

#### Increased control over life

When compared with small-group homes, participants in supported-living schemes experienced greater choice overall, greater choice over with whom and where they lived, and had a greater number of community-based activities (Emerson et al, 2005).

The opportunity to have their own home was highly valued by disabled people: "I'm my own boss" (McGlaughlin et al, 2004).

People living in a supported living tenancy had a greater degree of choice and control within the home (for example, being able to choose what to watch on television, what to wear) than other residential arrangements (Fyson et al, 2007).

One of the most potent symbols of the difference between residential care and a supported living tenancy for some people was the fact that they held the key to their own front door (Fyson et al, 2007).

Controlling for the same covariates, people with mild and moderate intellectual and developmental disabilities (IDD) had more control over *everyday choices* when living in their own homes, whereas people with severe and profound IDD had more control when living in agency homes of three or fewer people i.e. who decided the daily schedule, how the person spent their free time, who chooses what to buy with spending money (Tichá et al, 2012).

Controlling for the same covariates, individuals with all levels of intellectual and developmental disabilities living in their own homes had significantly more *support-related choices* than those living in other residential arrangements i.e. choice of who to live with, where to live, who helped them at home (Tichá et al, 2012).

People in supported living arrangements had more choice and control in hiring and managing staff than people living in group homes and family model homes (Stainton et al, 2011).

#### Improved quality of life

More privacy/time alone than in group living arrangements (Fyson et al, 2007).

People living in independent arrangements showed more independence (i.e. required less assistance) in performing domestic and safety tasks compared with those in group homes (Kim et al, 2012).

People living in independent arrangements had more participation in community activities compared with those in group homes (Kim et al, 2012).

Support: Compared to people living in group living arrangements, people living in independent arrangements received more individualised support (Fyson et al, 2007).

### ***No difference/ negative difference for disabled person***

Access to, availability and amount of support:

Individual tenancies (a single person or couple) with floating support (i.e. staff providing support for a specified number of hours per week to help with specific tasks) were associated with lower levels of support and the potential for greater independence, but also loneliness. Paid support staff were frequently the main, or only, source of social contact for tenants living alone. Part of the reason for this is that local 'Supporting People' guidelines typically preclude money being used to provide social activities (Fyson et al, 2007).

Compared to people living in group and family homes, people living in an independent home or apartment had:

- poorer access to supports and service delivery and crisis support
- lower satisfaction levels with residential supports and perception of positive outcomes of services and support
- fewer community connections and received less assistance in making connections (Stainton et al, 2011).

While people living in supported-living schemes had a greater number of community-based activities than people in small-group homes, they had fewer hours and days per week of scheduled activity (Emerson et al, 2005).

Some people felt their daily life was constrained by when their support was available (one individual stated it interfered with her 'having a life') (Allen et al, 2002).

Safety and other risks:

When compared with small-group homes, participants in supported living arrangements were more likely to have had their home vandalized and were considered at greater risk of exploitation from people in the local community (Emerson et al, 2005).

While the majority of tenants said that they felt safe within their own homes, they were concerned with the potential danger posed to them by other people, rather than any danger they might cause to themselves. Examples of members of the public abusing the trust and friendship of people with learning disabilities were not uncommon. Stories of bullying and harassment from neighbours and passers-by were recounted even more frequently. As a consequence of such incidents, many tenants described feeling unsafe when they left the house, particularly in the evenings (Fyson et al, 2007).

There was no difference in perceptions of safety of people living in dispersed housing compared to those living in cluster/campus housing (Mansell, J. & Beadle-Brown J. 2009)

Increased freedom brings increased community-life risk. Such risk must be attended to with as much planning as opportunities for social relationships, community participation and integrated employment (Lakin & Stancliffe, 2005).

Awareness of rights as a tenant: While people were aware of their responsibilities as tenants, they were less aware of their rights as tenants (Fyson et al, 2007).

Quality of life/satisfaction:

There were no statistically significant differences in the rated satisfaction of participants or their relatives in supported living schemes, small group homes, or large group homes (Emerson et al, 2005).



There was no difference in the following measures for people living in dispersed housing<sup>11</sup> compared to those living in cluster/campus housing:

- quality of life outcomes (social inclusion, interpersonal relations, material well-being, emotional well-being, physical wellbeing)
- relationships with members of the wider community (Mansell, J. & Beadle-Brown, J. 2009).

Residence size - quality of life association is not supported: The international research literature shows a mixed picture about the reported association between structural characteristics of community living residence such as size, and quality of life outcomes. Increased choice and more frequent community activity may be a consequence of the service model rather than size or other structural characteristics of community living (Felce and Emerson, 2005).

### ***Support providers***

Provider “buy-in” and role interpretation:

The lives and lifestyles of individual service users varied according to the extent to which support provider had taken on board the principles and practice of enabling tenants with learning disabilities to exercise choice, independence and control (Fyson et al, 2007).

Staff from the same support provider and working with the same client group interpreted their role and priorities differently in respect of care tasks and social inclusions tasks. The findings suggest (1) the pervading service culture is one of ‘care’ with a high level of shared meaning as to what this entails (2) explicit directions and guidance from service leaders and managers to support staff about their role is required (3) specification of and training in the new social inclusion function is required to create shared meaning (McConkey & Collins, 2010).

Priority given by provider to social inclusion activities: Support staff working with people with an intellectual disability in three service settings (supporting living, shared residential or group homes, day care centres) rated more care tasks as having higher priority than they did the social inclusion tasks. However staff working in supported living settings rated more social inclusion tasks as having higher priority than did staff from the other two service settings (McConkey & Collins, 2010).

### **Unintended outcomes**

#### ***The disabled person***

Managing finances: Money was usually regarded by tenants as one of the aspects of living independently that was most difficult to handle. The transition from residential care was financially difficult for some people, in particular coming to terms with having ‘more’ money, but not being able to spend this as they pleased (Fyson et al, 2007).

Availability and flexibility of supports:

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<sup>11</sup> The “dispersed” group included people living as tenants in their own home, and people living in a property owned by a service-providing organisation. The paper did not differentiate the results of these two types of dispersed housing.

It was not always possible for every person to receive their support at the times they wished. Inevitably, when providers were responsible for delivering support to a number of tenants each of whom lived alone, demand for support peaked at certain times of day. For example, many tenants needed support to prepare an evening meal, so demand for support was high between 5pm and 7pm (Fyson et al, 2007).

It was not easy to change support hours at short notice. Support provider organisations did their best to be as flexible as possible, and all offered an out-of-hours on-call service for emergencies, but most required at least 24 hours' notice in order to change staff hours. For the more able and independent tenants who did not require daily support this was less of a problem, but it did limit the ability of many less able tenants to act spontaneously (Fyson et al, 2007).

### ***Support providers***

Need for change to existing services:

Support providers that have previously provided support in group residential settings must modify their provision of services.

- Staff who had previously worked in residential care often described finding their new role more challenging than their old one. In particular, it was difficult for some to learn how to stand back and, sometimes let tenants learn from their own mistakes (Fyson et al, 2007).
- Potentially higher costs per hour of support, because of the need to allow for staff travel time (Fyson et al, 2007).

Requires more flexible and responsive support services.

- A person's support needs will change as the individual does. This requires that agencies providing supported living services organise themselves in ways that are flexible and responsive to changing needs. Support staff must be willing to wear many hats and play different roles at different times. For example, a staff member may help an individual learn how to travel independently to a site where they will begin to work as a volunteer (the role of a teacher) and later that day provide the individual with assistance in showering (the role of personal assistant) (NYSACRA, 2009).

Role boundaries: More individualised care arrangements in the setting of the disabled person's own home bring new challenges to the traditional role boundaries which operate in group residential settings. Defining what is an appropriate boundary is likely to be different in comparison to past ways of working, especially when the person is employing their own staff via self-directed initiatives (Parkes & Jukes, 2008).

### ***Structural issues***

Quality assurance of community-based arrangements: Traditional quality assurance systems have not been expanded and/or been sufficiently well redesigned to meet the rapid growth and dispersal of community residential settings (Lakin & Stancliffe, 2005).

Support workforce issues: The problems of workforce recruitment, training and retention have largely been left up to the individual agencies that employ staff working in community settings. Workforce issues include low wages, high job demands and poor understanding and preparation for the work role (Lakin & Stancliffe, 2005).



## Part 2: Information about research projects

Details about the research projects on which the information in part one is based is provided below. Papers referred to in part one that are not based on research are not included below.

References (in alphabetical order by author)	Disability	Location	Research / publication purpose	Research design
Assessing the barriers to achieving genuine housing choice for adults with a learning disability: the views of family carers and professionals  Bowey, L., McGlaughlin, A. & Saul, C. 2005	Learning disabilities	UK	The study explores barriers to providing genuine housing choices for people with learning disabilities.	Five focus groups with family carers (2), care and housing professionals (3)  Literature review.
A quality framework for personalised residential supports for adults with developmental disabilities  Cocks, E., & Boaden, R. 2010	Developmental disabilities	Australia	To examine the nature, purposes and outcomes of residential supports that are developed around the needs and preferences of individual adults with developmental disabilities.	The research consisted of a literature review, case studies of six individuals who were supported in independent living arrangements, a survey of experts from four stakeholder groups (parents, service providers, authorities and policy-makers), and a focus group of 10 adults with developmental disabilities who were living in independent housing.
Housing and Disability:  Future Proofing New Zealand's	Physical disability	New Zealand	The research focuses on:  The current housing experiences of physically disabled people, both	Focus groups involving 39 people were undertaken in the North and South Islands. Also an individual survey (121

<p>Housing Stock for an Inclusive Society</p> <p>CRESA, Public Policy &amp; Research, Auckland Disability Resource Centre. 2007</p>			<p>young and old;</p> <p>The capacity of the housing market to respond to the rising demand for 'lifetime homes'; and</p> <p>The opportunities to establish a housing stock that is future-proofed for those affected by challenges to their mobility and agility through moderate to severe physical disability and ageing.</p>	<p>people) and parent survey (31 people).</p> <p>Surveys of 125 agencies in the community housing sector and 81 real estate agents in New Zealand's five main centres.</p> <p>Literature review.</p>
<p>Costs and outcomes of Community Residential Supports in England</p> <p>Emerson, E., Robertson, J., Hatton, C. Knapp, M., Noonan Walsh, P. &amp; Hallam, A. 2005</p>	<p>Intellectual disabilities</p>	<p>UK</p>	<p>To measure the costs and outcomes of different types of residential supports - village communities, residential campuses, dispersed housing schemes, including supported living arrangements.</p>	<p>A cross-sectional design. Information was collected from a target sample of 540 adults with intellectual disabilities living in village communities, residential campuses, dispersed housing schemes, including supported living arrangements. Information was collected by a combination of mailed questionnaires and follow up interviews with a member of the participant's support team, interviews with service recipients, and a mailed questionnaire sent to the relatives of service recipients.</p>
<p>Community living: costs, outcomes and economies of scale. Findings from U.K research</p>	<p>Intellectual disabilities</p>	<p>UK</p>	<p>To review UK research to identify the relationship between size, resource input (cost), staff-to-resident ratios and outcome</p>	<p>Review of research</p>

Felce, D. & Emerson, E. 2005				
Effectiveness of supported living in relation to shared accommodation  Fisher, K., Parker, S., Purcal, C., Thaler, O., Abelson, P., Pickering, E. Robinson, S., & Griffiths, M. 2008	Intellectual, physical, sensory disabilities	Australia	To build on existing knowledge, and increase understanding about accommodation services and housing for people with disabilities.	An overview of existing national and international approaches to 24-hour supported living, including examples of innovative practice.  A detailed analysis of six case studies of innovative Australian approaches to supported accommodation, followed by an application of the assessment framework to the six case studies.
Support for living? The impact of the Supporting People programme on housing and support for adults with learning disabilities  Fyson, R., Tarlton, B., & Ward, L. 2007	Learning disabilities	UK	To examine how local Supporting People teams were interpreting the national guidelines in relation to the provision of housing-related support and to explore the impact that this was having on adults with learning disabilities	The research took place in four geographically and socially diverse administering authorities.  Interviews with 31 people with learning disabilities living in a range of differently-configured supported living services; 11 support staff managers and commissioners, and members of Supporting People teams. Analysis of Supporting People strategies.
A National Study of Community Living: Impact of type of residence and hours of in-home support  Kim, R. K., & Dymond, S. K. 2012	Severe developmental disabilities	US	To investigate the frequency of community participation and level of assistance needed to perform domestic and safety skills for individuals with severe disabilities who live successfully in the community either in small group homes or supported apartments.	280 residential specialists (case managers, staff, support providers, group home managers) who support people in small group homes and supported apartments.
Expenditure and Outcomes: directions	Intellectual	Internatio	Not applicable	Not applicable

in financing, policy and research  Lakin, K. C. & Stancliffe, R. J. 2005	disabilities	nal	Identifies policy and research implications of findings from the preceding chapters of the book: "Costs and outcomes of community services for people with intellectual disabilities" (2005). Stancliffe, R.J. & Lakin, K.C.	
Dispersed or clustered housing for adults with intellectual disability: A systematic review  Mansell, J. & Beadle-Brown, J. 2009	Intellectual disabilities	International	Literature review to evaluate research on the quality and costs of dispersed community-based housing when compared to clustered housing.	Reviewed 19 research papers relating to 10 studies done in UK, Ireland, Netherlands and Australia
The role of support staff in promoting the social inclusion of persons with an intellectual disability  McConkey, R. & Collins. S. 2010	Intellectual disabilities	Northern Ireland	To identify the contribution of support staff in facilitating social inclusion of people with intellectual disabilities.	A written questionnaire was completed by 245 staff working for services in Northern Ireland providing day or residential support to people with intellectual disabilities.
Housing Choices for Disabled New Zealanders.  McDermott Miller. 2005	Not specified	New Zealand	To identify housing research projects that address key issues identified as impacting on housing choices for disabled New Zealanders.	Face-to-face interviews and questionnaires with stakeholders; a Delphi Panel with selected experts.

Enabling adults with learning disabilities to articulate their housing needs  McGlauglin, A., Gorfin, L., & Saul, C. 2004	Learning disabilities	UK	This study is about involving adults with learning disabilities by asking them to articulate their own needs in relation to housing.	The sample comprised 72 people with learning disabilities living either with their families or in residential care, and four were living independently. People were interviewed individually based on a housing needs questionnaire.
Models of Residential Provision for People with Disabilities  National Disability Authority. 2010	Intellectual, physical and sensory disability	Ireland	To outline a variety of residential supports that are currently available for people with disabilities and to highlight those options that provide optimal quality supports for residents.	Not applicable
Creating Innovative, Individualized Living Options For Persons with Developmental Disabilities  New York State Association of Community and Residential Agencies. 2009	Developmental disabilities	US	To explore the development of creative approaches to housing options for individuals with developmental disabilities.	A symposium to share good practice; seven regional forums across New York State; an electronic survey of interested individuals (people with disabilities, family providers); a review of literature
Noonan Walsh, P., Emerson, E., Lobb, C., Hatton, C., Bradley, V., Schlock, R. L.	Intellectual disabilities	International	To review evidence related to quality of life models of supported accommodation for adults with	A review of research published between 1995 and 2005 in English-language reviewed academic journals. A total of 86 articles reporting the



& Moseley, C. 2010			intellectual disabilities identified in English-speaking nation deinstitutionalised and post deinstitutionalised studies	results of 67 studies were analysed.
Professional boundaries in a person-centred paradigm  Parkes, N. & Jukes, M. 2008	Learning disability	UK	A discussion paper drawing on other research.	Not applicable
The housing and support needs of people with an intellectual disability into older age  Shaw, K., Cartwright, C., & Craig, J. 2011	Intellectual disability	Australia	The aim of this study was to explore the views of people with intellectual disability and their family members who care for them regarding preferred models of housing and support for people with an intellectual disability who are ageing.	Focus groups and individuals interviews were conducted with 15 people with intellectual disabilities who work in supported employment (aged 19 to 55 years, with a mean age of 46 years) and 10 family members who care for adults with intellectual disabilities
Comparison of community residential supports on measures of information and planning; access to and delivery of supports; choice and control; community connections; satisfaction; and overall perceptions of outcomes	Intellectual disability	Canada	To compare outcomes across four types of community residential settings: group homes, family model homes, independent home or apartment and family home.	A large scale survey (n=852) of family members and support staff of adults with intellectual disabilities receiving community living services, comparing outcomes across four types of residential settings: group homes, family model homes, independent home or apartment, and

<p>Stainton, T., Brown, J., Crawford, C., Hole, R., &amp; Charles, G. 2011</p>				<p>family home</p>
<p>Correlates of everyday choice and support-related choice for 8,892 randomly sampled adults with intellectual and developmental disabilities in 19 states</p> <p>Tichá, R. Lakin, C., Larson, S., Stancliffe, R.J. Taub, S., Engler, J., Bershadsky, J., &amp; Moseley, C. 2012</p>	<p>Intellectual and developmental disabilities</p>	<p>US</p>	<p>To examine the effect of residence size and residence type on everyday choice and support-related choice of 2008-2009 participants in the National Core Indicators survey, controlling for other predictors of choice.</p>	<p>Analysis of results from the 2008-2009 participants in the National Core Indicators survey examining (1) the everyday choices made by 8,892 adults with intellectual and developmental disabilities (IDD), and (2) support-related choices made by 6,179 people with IDD receiving services from 19 state developmental disabilities agencies</p>

## **Appendix 2: Evaluation methods**

The purpose of this evaluation was to support the development and implementation of CiCL by providing information to key stakeholders about how activities are working and identifying issues for further consideration.

The evaluation approach has included semi-structured face to face and telephone interviews with 10 disabled people and whānau, 21 staff from the eight support agencies contracted to deliver CiCL, two NASC staff, the CiCL program Manager, and a literature scan.

### **Workshop to develop success indicators**

A workshop was held in May 2013 with staff from the two NASCs, eight support agencies, Ministry of Social Development and Ministry of Health. Participants developed a set of success indicators for key partners in CiCL (disabled people, support agencies, NASC and the Ministry). The evaluators then sought input on the draft success indicators from the Choice in Community Living Local Working Group at a face-to-face meeting. A key limitation of the success indicators is that there was limited input from family/whānau stakeholders.

### **Qualitative interviews**

The success indicators informed the development of topic guides for qualitative interviews with key stakeholders. The interviews were conducted by three experienced evaluators, two of whom are Māori and one Pākehā. All disabled people were sent a letter providing information about the evaluation and inviting them to participate in an interview. The interviews were conducted in June and July 2013. At the interview, respondents were again briefed about the evaluation and asked to sign a consent form if they agreed to participate. Interviews were conducted at a venue selected by respondents, and at a time that suited them.

Interviews with the CiCL programme manager, support agency and NASC staff were conducted in person by telephone or Skype.

All interviews were coded using Nvivo, a qualitative data analysis package. All members of the research team read each of the interviews and participated in a high-level analysis discussion, to identify and discuss key themes. In-depth analysis was then conducted by two team members and the draft findings reviewed by team members for quality assurance.

### **Literature scan**

The review of literature on Choice in Community Living-type initiatives was limited to the UK, US, Australia, Canada and New Zealand. The review focused on the following questions:

- What are the barriers to (eligible) people transitioning to Choice in Community Living (CiCL) - type initiatives?
- What difference do CiCL-type initiatives make for disabled people, family, providers, other stakeholders?
- What (if any) unintended outcomes of CiCL-type initiatives are reported in the literature?

Attempts were made to ensure coverage across the five countries of interest. Given the small-scale nature of this review, this approach precluded in-depth examination of key themes. For example, the CiCL demonstration project involves self-directed support and supported decision making/person-centred planning. There are substantive literatures on both of these topics, which are broader than housing-related initiatives such as CiCL.

It was not possible to identify the extent to which initiatives examined in the literature are similar to CiCL in respect of self-directed funding for a disabled person, or the funding of support providers. Similarly, it was not possible to ascertain the extent to which providers described in the literature have a similar role to the providers in the CiCL demonstration project. The absence of these and other contextual and structural factors in the literature (such as level of support funding and accommodation subsidies) made interpretation of the research findings problematic.

## Appendix 3: Topic guides

### Topic guide for disabled people who are not yet living independently

1. Tell me about where you live now.
2. What do you like about your life now? Why is that important for you?
3. What would you like to change about your life? Why is that important for you?
4. How did you find out about Choice in Community Living/name of support agency?
5. Tell me your story about working with (X).
6. Have you been asked to write a plan about your goals?
  - How useful has this plan been for you?
  - Have you been given a copy of the plan? Can I have a look at it?
  - Tell me the story about how the plan was developed? Who had the ideas? Do you feel x listened to your ideas?
7. Who is helping you to achieve your goal/s?
  - ask about X – how have they helped? What do you like/not like about how they help you?
  - Who else is helping you achieve your goal?
8. (If appropriate) what are the barriers that are stopping you from moving into your own home?
9. If you want to complain about something, who can you talk to?
10. Is there anything else you would like to tell me?

### Topic guide for people who are living independently

1. Tell me about where you live now.
  - Who lives in this house?
2. Tell me about where you used to live.
3. What do you like about your life now?
4. Who helped you to achieve this goal?
  - ask about service agency – how have they helped? What do you like/not like about their help?
  - Who else/what else has helped?
5. What has got harder?
6. If you want to complain about something, who can you talk to?
7. How did you find out about Choice in Community Living?
8. Have you got a copy of the plan (X) developed with you to set out your goals?
  - a. How useful has this plan been for you?
  - b. Do you have a copy I can look at? Or: Is it OK if I look at your plan?
  - c. Tell me the story about how the plan was developed? Who had the ideas? Do you feel (X) listened to your ideas?
9. Is there anything else you would like to tell me?

## Topic guide for CiCL support agencies

1. Background to implementing CiCL in your organisation:
  - When did you start providing CiCL as an option?
  - How do people find out about CiCL? What active marketing, if any, are they doing?
  - Who else are you working with? E.g. NASC, other community organisations? What works well/not so well in working with these groups?
2. How many disabled people have you been working with as part of CiCL?
3. Take me through how you work with disabled people/whanau as part of CiCL?
  - How is this different / the same as the way you've worked with people in the past?
4. As part of the planning process, what safeguards do you build in to protect the person should things fall over/start to go awry?
5. What are the challenges you have encountered when exploring transitioning to a new home with disabled people?
  - What solutions have you been able to identify? What's made these solutions possible? Any 'creative' solutions that you've not been able to do before?
  - For those who CiCL is not going to work, what are the barriers?
6. What changes may be required to address some of the challenges you're encountering?
7. What changes to your organisation have you had to make as a result of CiCL?
8. How useful are the monthly meetings you have with the Ministry & NASC, for reflecting on what's going well/not so well with CiCL?
9. What's working well, not so well with the NASC, from your perspective? (ask for evidence, examples)
10. For those who have moved into their own accommodation, what type of housing are they moving to?
  - What's made it viable for these people to move into their own homes?
  - How sustainable do you think these arrangements are?
11. Any unintended outcomes occurring as a result of CiCL?
12. One of the aims of CiCL is for the Ministry to pass on the maximum amount of flexibility it can, via the new purchasing guidelines. To what extent do you think these new purchasing guidelines are working well/not so well for disabled people?

## Topic guide for NASC staff

1. How are you working with disabled people/whanau as part of CiCL?
  - How do people find out about CiCL?
  - What's the role of the NASC in relation to CiCL?
  - What is different to/ the same as the way the NASC has worked with people in the past?
  - What 'person-centred' tools are you using to facilitate planning?
  - What has been the outcome so far of the different way you're working with people?
  - How is the NASC utilizing CiCL to be responsive to Māori and Pacific Island disabled people?
  - What community resources are you linking Maori disabled/whanau to? Other ethnicities?
2. How many disabled people have been offered CiCL?
3. What are the challenges you have encountered with the people you've worked with, in transitioning to their own home?
  - What solutions have you been able to identify? What's made these solutions possible? Any 'creative' solutions that have not been possible before?
4. What structural/other changes may be required to address some of the challenges disabled people/whanau are encountering?
5. What's working well, not so well with the CiCL providers, from your perspective?
6. What changes to the NASC way of working have you had to make as a result of CiCL?
7. For those who have moved into their own accommodation, what type of housing are they moving to?
8. Any unintended outcomes occurring as a result of CiCL?
9. One of the aims of CiCL is for the Ministry to pass on the maximum amount of flexibility it can, via the new purchasing guidelines. To what extent is are the new purchasing guidelines working well/not so well for disabled people?