Nga mihi ki a koutou. I am Ruth Gerzon of Inclusion Aotearoa. I one of only a few people with over two decades in the disability sector combined with considerable work in community development. More recently, for nearly four years, along with Lawrence Chok, I have been in a privileged position, supporting the Ministry of Health in their New Model work. As part of that work, I have been involved at the flaxroots in the Bay of Plenty Demonstration Project, seeing how the disability community and services are responding to changes introduced there.

Do note however that I am not talking on behalf of the Ministry of Health. This is purely my own take on possibilities. Our work for the Ministry finishes at the end of August when we handover Local Area Coordination to Imagine Better, who will take it forward in the long term.

During the work for the New Model, I have gained a new found respect for government agency staff and policy makers who battle for change from the inside. However my personal friendships and close working relationships with disabled people and their family/whanau give me a sense of urgency. I find change initiated by the government frustratingly slow. Six years on since the Select Committee report changes have yet to improve the lives of disabled people outside the demonstration projects.

Managers of disability services have, at times, asked me how they might strategically adapt to changes in the government direction. Some feel confused, some wait for clearer direction, or for the government to offer them flexible contracts. Yet, I believe there are already clear indications of changes ahead that can both add value to the lives of disabled people and their family/whanau, and enable services to thrive. No service need wait a moment longer for any government led initiative.

I want to share these ideas here today. We can be sure that flexible services that truly support choice and community connections will thrive in the changing environment.Today I will talk about the two key outcomes that services can work towards:

1. increased choice and diversity

2. improved connections to people’s communities of choice.

I am sure there is universal recognition in the disability sector of the importance of these.

But first let’s reflect on how well we are doing now. The outcome of flexible services would be:

*People supported by disability services lead rich and varied lives contributing to their communities of choice.*

never…………….rarely…………… sometimes…………….often……………….always

Is this true of services now? If you work in, or are supported by, a service, put aside your own experience and consider what you know of services in general. Then find a place on this continuum that reflects your view.

Personally I believe that, on the whole, services are not doing well and the statistics back this up. People with physical disability and high needs were the early users of Individualised Funding. Now, in the Bay many people with learning or intellectual disability, and, incidentally, Maori are embracing the Enhanced version of Individualised Funding. There is clear evidence that individualised funding is popular and its use is likely to grow, both in MoH and MSD funded supports.

As this shift increases, disability services need to ask why so many people are voting with their feet, choosing to leave them. How can services continue to attract people who now have the option to flexibly build supports that suit them?

I have personally supported two people to move from services to EIF and seen major positive changes in their lives. However I also know how difficult it is to manage the processes. For many people, support from services would be preferable, provided those services support them to live the lives they want.

Some people do lead good lives with the support of services but this often does not stem from good systems and policies. Rather it results from the dedication and advocacy of managers willing to bend the rules and go the extra mile. They succeed in spite of the service system rather than because of it. Other disabled people have a good life because of the dedication of support workers who go well beyond their job description. But this support can be capricious. It may bring hope and show possibility, only to have it all disappear when those staff leave. I have seen people begin to connect to their communities, their culture and their marae only to have these opportunities taken away.

We urgently need positive change for two reasons:

1. disabled people deserve to lead good lives like any other
2. only the best services will thrive in the coming decades

I am now going to turn to each of the two changes needed: around ‘choice’ and ‘community connections’ (or inclusion). These are often added to services’ value statements without an in depth examination of what they really mean and how to put them into practice. I want to challenge you to look deeply into these today.

I will begin by looking at the choice that enables diversity.

For over six years I have been haunted by a question put to me by a service manager at a presentation I gave on inclusion:

*My staff don’t like to be seen in public with the person they support. What can I do about that?*

What might that do this person’s self-esteem? If someone doesn’t like being seen in public with you, will they support you with respect and dignity in your own home? If you can’t be accepted at home, nowhere is safe.

I asked, ‘Why do staff dislike being seen in public with this man?’ and was told that he was a cross-dresser. I suggested the manager should recruit cross dressing support people and that Google might help him find a source. Maybe that happened, but my guess is that it did not.

It is at times like this we are challenged. Do we act with integrity to support people to live the lives they choose? When the going gets tough, and our own staff discriminate, do we stay true to our values and principles ?

This story also explains why I talk about communities not community. There are different communities where different values and behaviours are acceptable. There are church communities, sports communities, ethnic communities. In some I am comfortable and some I am not. Are we willing to go outside our own comfort zone, or employ others who fit into those communities, to support disabled people to connect there?

Even in much less challenging ways services may place restrictions around the interests they support disabled people to pursue. Now I am a cat person, but I recognise the value of dogs for inclusion. Cats don’t do inclusion, but dogs do. You only have to walk a cute and fluffy dog down the street and people (and other dogs) will approach you and talk to you (and your dog).

Nearly 30% of homes in our country have a resident dog, yet, in my experience, dog ownership among disabled people who live a life in services is closer to 1%. When I ask why, I am sometimes told it is against the rules in their accommodation. No excuse. Other people find landlords that allow dogs. Why can’t services help disabled people do the same?

Given these examples, can we really say that services support people to lead rich and varied lives? On reflection, would you change where you put yourself on that continuum? Take a moment to talk to the person next to you about your service or a service you know.

Disabled people are as diverse as the rest of us. Some live in poverty. Some are middle class. Some are blessed with families that provide strong support, high expectations and advocacy. Others are born into families with low expectations who keep them sheltered and separated from communities.

How can services support such diverse people to all lead good lives in their communities of choice? New government policies will ensure disabled people and their families/whanau have the power to decide how resources are used to shape their lives. Will they use these to buy services?

In the United Kingdom, where IF has been rolled out for longer, the term used is a ‘person centred approach’. In ‘personalisation’ funding is allocated to individuals and people work collaboratively with services on how their budget is used. Existing services are adapting their policies and systems and new small community based services are emerging. We can learn much from UK to ensure our services are ‘fit for purpose’ in the decades to come. There are some excellent resources, such as those produced by Helen Sanderson that help services develop strategic plans for the move towards person centred approaches.

Flexible services that maximise the control and choice they offer to disabled people will continue to thrive.

Now I will turn to the second change needed – services that truly support community connections bringing people from isolation to citizenship.

The importance of this is that it is through communities that we gain a sense of belonging and purpose. Communities are based on:

* **Interest** (sports, crafts)
* **Ethnicity** (Samoan, hapu)
* **Shared experiences** (gay, disability)
* **Action** (farmers, lobby groups, political, environmental)
* **Geographical** (neighbourhood)

Which ones are part of your life?

I try to avoid the term inclusion. I have seen servicesrespond to the calls for inclusion with visits to libraries, shops, beaches or hot pools. This I term ‘community tourism’. They are places tourists might go. Nothing is asked of you, apart from your money. True relationships in communities are built on contribution.

John McKnight[[1]](#footnote-1) observes that when our services step in, communities step back. Professionals take over the natural support we provide for one another, support that builds trust and community connections.

I saw this happen first in 1986. As a social worker my role was to ensure that disabled people were kept busy and out of sight of communities by day, attending a sheltered workshop, paid a token $ 15 a week.

One of the ‘trainees’ was a man called Kura Tawhi. Kura never liked coming to the workshop, but our policy said that people in residential homes had to spend their days there. Finally he got so angry that he struck out and was banned - just what he wanted.

He went down town with his guitar and began busking. After a few hours, he came into my office and emptied a container on my desk. He had made almost more than I had that morning.

For years Kura busked in Whakatane’s main street. People in our town enjoyed his warm personality and his songs.

When he died there was an article in the newspaper, followed by a letter to the editor saying:

***“I write this somewhat shaken. Kura is dead.***

***Who will catch my eye while I’m in town and give me a huge grin and ask a barrage of questions?***

***I ponder the power of a man with such simple wants to influence me so. He knew what cars I drove, my husband drove, where we worked, who our kids were and that music was important to my family. I don’t think he knew my name. When chatting to him, it never seemed to matter, we just sought each other out and shared laughs, for over a decade.***

***For me, my shopping will never be the same. I’ll miss you Kura.***

***Arohanui e hoa…..Jenny J”***

In spite of the service, which kept him segregated, Kura found himself a valued place in our community, and a way to earn good money.

I first came across McKnight’s ideas about 15 years ago when working alongside Hine Tihi, teaching disability studies courses at Waiariki Polytechnic in Rotorua. We talked about McKnight’s theory as we shared the drive from Rotorua to Te Teko. We had been involved in setting up the first kaupapa Maori residential house in Te Teko, close to two marae. A pioneering initiative. We had thought we were on the right track until we discussed McKnight and his views on the professionalisation of care. Before the house was set up, Hine told me, if a disabled person needed support in the whare kai, the whanau were there to help. With the service in place, with paid and trained staff, whanau pulled back, expecting the support workers to do this even on their days off. They were seen as the experts, the whanau were disempowered.

Working hard to bring people back from institutions, we had failed to anticipate the unintended consequence of setting up a service: that the service itself would become a barrier to natural community supports.

More than a decade later, we were both on the board of a day service focussed on supporting people in community options. Surely now we knew enough to get it right. Yet one day Hine told me how the transport that enabled her nephew to attend was no longer available. “What happened”, I asked.

“My husband took him fishing. He catches fish for the whanau. The fishermen laughed when he fell in the first time, and now he’s made friends with them all.” He found a way to contribute to his community. Once more, in spite of our good intentions, our service got in the way of true community, supplanting natural support.

Knowing this trap, how then can we ensure our services build, not weaken, communities? We need new tactics ensure communities grow stronger, and disabled people and their whanau can take their rightful place within them.

In the sector and in training we often talk of inclusion but rarely do we examine just how best to connect people into what can be discriminatory communities, safely and effectively so they can contribute and build relationships there. For this reason I supported People First to develop the DVD: Colours of Inclusion. This celebrates best practices throughout the country. I also developed and facilitate the Training for Inclusion course.

Excellent services now use strengths based practice to increase contribution in communities. Disabled people have abilities, not just disabilities. Outstanding models of services, such as supported employment and micro business, help disabled people become active and contributing members of their communities. One person at a time, this increases contribution. But we can do much more. Community building initiatives can strengthen communities and speed up real change for everyone. I learnt this from a passionate American advocate for inclusion, and colleague of McKnight, Mike Green, a parent of a disabled young woman. Mike Green[[2]](#footnote-2), is adamant that we can’t wait for inclusion to happen one person at a time. Mike Green focusses on initiatives that heal communities for everyone.

Traditionally services have focussed on disability and when I go to community network meetings I rarely see people from the disability sector. The forces at work in communities and ways partnerships can benefit everyone are not well understood in our sector. Inspired by Mike Green, I developed a new workshop to fill this gap (A Community Building Approach for Disability Services).

Communities weakened considerably in the 70’s and 80’s but there are now encouraging signs that they are growing stronger again. New environmental movements, book clubs, support groups, neighbourhood support and community gardens are developing. Most promising are the ways the internet now connect people in their local communities through timebanks, Meetups and Neighbourly[[3]](#footnote-3).

In the Bay of Plenty, in their role as community connectors,

Inclusion Aotearoa’s team of Local Area Coordinators have been joining local networks and build partnerships so they can successfully support disabled people to contribute to their communities. However, if all disabled people are to take a role as full citizens in their communities of choice, this work needs to be embraced by services too.

A good example of how services can work with communities to benefit everyone is the work of Pou Whakaaro. From 2004 to 2010, when I was chair of their board, we developed strategies to ensure our service built community. Pou Whakaaro has now made a significant start to this journey. Some of you may have been to their presentation on micro business in the last session.

We began with a Timebank for the whole community. Timebanks are based on reciprocity, on giving and taking. They work a bit like TradeMe. People list the things they can do and then are matched with people who need that kind of help. From that beginning, Pou Whakaaro , is now leading the way in organising community based education for all citizens, and investigating options for setting up a community centre for all people in that town.

Such community building initiatives are still uncommon in disability services. Yet to make real change possible we need to take the essential first step to lift our eyes beyond the disability sector to the many options and possible partnerships in our communities.

In the decade ahead, services that anticipate and adapt to change will thrive, and more importantly, enhance the lives of disabled people. This journey will be as ground breaking, important and life enhancing as the deinstitutionalisation promised to be all those decades ago.

Disabled people and their families/whanau have been waiting long enough. The government is slowly making changes. Their direction is clear. Services can now accelerate changes that will benefit everyone, by truly supporting choice and community connections.

**Appendix**

**Forces at work in changing communities: a brief overview**

A generation ago when we dreamt of bringing people out of institutions to full citizenship in supportive communities, we underestimated new barriers arising from social changes well beyond our sector. During the 1970’s and 1980’s professional care had gradually replaced the support people gave one another. This happened in elder care and child care as much as well as in the disability sector. Lawn mowing, shopping, lifts to hospital, sports coaching – all the things we did for one another, the work of communities that we term ‘natural supports’ in the disability field - were gradually replaced by paid services.

Why did this happen? There are two different theories, both with something important to tell us.

In his analysis of the rise and fall of communities, Robert Putnam[[4]](#footnote-4) points to many factors in their weakening over the past few decades. The introduction of TV, the rise of the suburbs and commuting time, increased individualism and commercialism, and the number of women working: all these factors played a part.

Can this trend, one that inhibits ‘natural support’ be reversed?

Looking at the history of communities over a long time frame points to a possible answer. Just over 100 years ago, in the early 20th century, communities were weak, crime and alcoholism high. From the ferment this caused, new community building initiatives arose: the Red Cross, Scouts and Guides, Plunket, service clubs, Maori Women’s Welfare League, and Country Women’s Institutes and sports groups. Though these trust was built and communities once more became connected.

A century later, many of these organisations struggle to find members, as once again suicide, mental illness and alcoholism rise. Yet again new community building initiatives are arising from the change. New environmental movements, book clubs, support groups, neighbourhood support, community gardens are developing. New and initiatives such as timebanks, meetups and neighbourly use the internet to connect people in communities of place. An innovative national organisation, Inspiring Communities, supports community builders by spreading new ideas.

**Our services as a problem**

Putnam gives some reasons behind the weakening of communities, but a more worrying analysis comes from John McKnight[[5]](#footnote-5). He observes that when services step in communities step back. Professionals take over the natural support we provide for one another, support that builds trust and community connections.

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1. McKnight, J (1996) The Careless Society: Community and its Counterfeits [↑](#footnote-ref-1)
2. www.mike-green.org [↑](#footnote-ref-2)
3. [www.neighbourly.co.nz](http://www.neighbourly.co.nz), [www.timebank.org.nz](http://www.timebank.org.nz), www.meetup.com/cities/nz [↑](#footnote-ref-3)
4. Putnam, Robert (2000) Bowling Alone: The Collapse and Revival of American Community [↑](#footnote-ref-4)
5. McKnight, J (1996) The Careless Society: Community and its Counterfeits [↑](#footnote-ref-5)