

VIVIEN MAIDABORN

ACTION FOR INCLUSION



Vivien Maidaborn

Vivien Maidaborn has been the chief executive of CCS Disability Action, a community development organisation which supports disabled people, and works for their fuller inclusion within their families and communities. The organisation is one of New Zealand's largest community-based agencies, with an annual turnover of \$35 million, and employing over 800 staff in 16 branches throughout the country. During her time as CEO, Maidaborn led CCS Disability Action to establish an innovative social enterprise, Lifetime Design Ltd, which is working to change the design of New Zealand homes so that they can work well for people of every age, stage and ability.

Maidaborn has a background in social policy and social work, and has taken on a variety of management roles in the community and public sectors. These have included running the Wilson Home for Disabled children in Takapuna, being general manager for Disability Support and Community Health Services at Waitemata Health, and being chief executive of Relationship Services (New Zealand's largest counselling agency). She has also worked with Frankin Covey, a multinational company that consults in the field of business leadership and effectiveness.

Maidaborn was chief executive of CCS Disability Action from 2004-2011. She says she was attracted to the job because, even though it was a large and complex organisation, it had obviously not lost touch with the strong roots it had in communities. At the heart of the organisation are local committees who all want a say on where the organisation is going.

Maidaborn: "I really saw community democracy in action. There's real downsides to it, as it isn't efficient, and it isn't always 'on task'. But it is honest. It's real, and it is accountable. And in the end it is a very good indicator of the sort of healthy engaged citizenship and the val-



*Crippled Children Society
(above) Polio children at the Wilson
Home 1943
(right) children arriving at a CCS
special school*



ues that we need to grow around this work. This is civil society in action, and it is critical to the way we grow healthy communities, healthy families, and connected people.”

- CCS Disability Action started off in 1935 as the Crippled Children Society. It was a community response to the crippling disease polio (*paralytic poliomyelitis*) which affected hundreds of children at the time. A group of businessmen in Timaru thought the government was ignoring the effects of the polio epidemics, so they called upon the national Rotary service clubs to go door-knocking throughout the country and assess the situation for themselves. Over a three-year period Rotary members visited every home in New Zealand, and they found over 7,000 children with polio that government health services had been ignoring. So the Crippled Children Society was established, with a full network of local branches around the country.

The predominant thinking of the time was that the best thing for disabled people was to remove them from families and put them into institutional care. The Crippled Children Society attracted some significant philanthropy which enabled them to set up these institutions. Vocational choices for disabled people were also influenced by this same institutional thinking, and the society established many sheltered workshops and garden centres where disabled people were given activities to complete without being paid.

The last 30 years has seen the emergence of an international disability human rights movement which has forced a fundamental change to these attitudes. Disability rights

activists have argued that leaving disabled people to live in institutions, or just sending them to work every day at a local horticultural centre, was just not acceptable. The leadership at CCS became convinced that for disabled people to live healthy and whole lives, they needed to be a part of the families and communities they live in, rather than being secluded in special or separate environments.

The CCS Board made the decision to shift beyond managing a range of services that people came to and fitted into, and instead become a *community development* organisation. Maidaborn: “This means that CCS focuses on two main areas of work: The first is to be of support and build the leadership and confidence of disabled people so that they can get on with their lives. The second is to be a change agent in the wider society so that all the formal and informal structures of communities work in ways that make inclusion possible. In the first area, CCS works with about 6000 families. In the second area, we work with the whole of New Zealand.”

Once the decision to change their organisation was made, CCS gradually closed down all their residential homes, and their early childhood, vocational and work experience centres — all the services and activities that were keeping disabled people separated from their families, and from the rest of the community. These closures, and the inevitable controversies that come with this process of change, had already been going on for a decade before Maidaborn joined CCS as its chief executive.

When she came on board, however, what she found was that the organisation was on a much slower journey in terms of changing its own culture. Maidaborn says that it took over five years of investing in staff and recruiting them differently, so that (the now renamed) CCS Disability Action could get close to a consistent ability to ‘walk their talk’ on community development.

Maidaborn: “The fundamental shift from service provision to a community development response is counter-intuitive to the usual strategy of just going in and helping. CCS needed to more deeply transform the culture of service provision away from welfare-ism, problem management, and the victimisation of people with disabilities. This change in approach involves getting to know the disabled person and their family better, and being more responsive in finding out what they are interested in, and what they want.

“The challenge for a CCS Disability Action staff member is *not to go* into a family thinking “What’s a service that I can offer?”. The question instead becomes: “How do I get alongside this family? How do I help them identify their dreams and aspirations that include their disabled child or family member, and then figure out with them how to overcome any barriers to these dreams?”

The fundamental changes provoked by the disability human rights movement have also had a direct impact on the make-up of the CCS Disability Action board. Until recent decades, the board was made up largely of business and Rotary networks, and then parents of disabled people began to be elected more regularly. But now, for the first time, disabled people themselves make up the majority of the Board. In partnership with the parents, they provide a strong rights-based governance for the organisation.



Maidaborn: “These changes meant that it immediately became much harder to fall into a patronising or we-know-on-your-behalf kind of thinking. The fact that disabled people are now on the board or in key management positions at CCS Disability Action keeps the whole organisation incredibly conscious that its fundamental reason for being is to improve the lives of disabled people.”

- A third of the advocacy that CCS Disability Action does is in schools, recognising that education is a critical element in improving the lives of disabled people ... leading to the skills to find employment and other activities that suit their interests. CCS Disability Action works to ensure that disabled children can achieve the basic human right of being included in the school, and beyond this, to be fully included in recreation and sports, as well as in school trips and other learning activities.

Maidaborn: “Our experience of working in schools is that mostly don’t want disabled children, and they have so consistently done such a bad job in including them that parents are choosing to enrol their children in special schools so that their children get better attention. This is despite the myriad of research that reports that if you create separate environments from mainstream schools then the young people have a much harder time building the skills they need to get along with others, to have friendships, relationships and jobs.

“The goal here is more than just safe environments for kids to go to school in. Beyond the *learning* outcomes for disabled children, CCS wanted *social* outcomes as well ... and that means when they leave school they can move into work and/or other meaningful roles in the community. There is no doubt that there is a direct link between being in inclusive mainstream environments and achieving these wider social outcomes.”

Maidaborn concedes that parents are still split between those who want special schools for disabled children, and those who want inclusive education wherever the young person is. And she has tried to lead a conversation that goes beyond these polarities: “I wanted to avoid talking about whether special schools should exist or not, because that’s all we’ll talk about.



Vivien Maidaborn and John Stansfield in conversation at the NZSEF Retreat



Vivien Maidaborn presenting her social innovation workshop at the NZSEF Retreat

A more important question is: What would it take to do mainstreaming well? This is because, regardless of some great work being done by special schools, most disabled children will be going to their local school. We should have been asking: What would it take to ensure that the educational and social outcomes for all these children will be as good as they can be?

“When we asked those questions, we started to get a real conversation about what it will take to train teachers and resource them to run successful inclusive classrooms. We even started to get conversations that go beyond disability and talk about *all* the ways that classrooms are diverse, and *all* the ways that teachers need to be resourced and supported to succeed in them. If you are thinking about a school in Counties Manukau, for example, the teacher might be faced with 10-15 different ethnic groups, 4-5 different mother languages, and 2-3 different disability groupings. That teacher needs a whole lot more support than just knowing how to manage a wheelchair in their class.”

- CCS Disability Action has often had to reconsider their approach to government funding, because the agency has found that it cannot always depend on the government to provide its funding in the ways that disabled people need it to be delivered.

An example of this was when the government Accident Compensation Corporation (ACC) came up with a “Supported Independent Living” funding contract. This contract enabled a wide range of support to be provided for a disabled person to leave their parental home, or a residential setting, and live in a home of their own choice in the community. CCS Disability Action worked in partnership with ACC to draw up the specifications for this contract and, over a two-year period, had a very rapid growth of its services, involving around \$250,000 in income from that work.

But when, in 2010, ACC renewed their service specifications for this contract, they reduced the kind of support available to a short-term rehabilitation model. Maidaborn felt that these new specifications would lead to the disabled person becoming more isolated, less able to connect with their communities, and therefore less able to have a better life. CCS Disability Action decided not to apply for the contract, which meant that the branches that had geared themselves up to provide that service previously, now had to lay off staff.

Maidaborn: “Our board took the decision not to get caught in only providing the services just because this was what the government currently wanted to contract. They never would



CCS Disability Action Board 2010

just accept home aid contracts or residential care contracts without looking at the actual impact on the lives of disabled people, and seeing that the outcomes are aligned with their values. This was a very different way of approaching things compared to many other social service organisations.

“As a manager, some days I thought we were completely mad to hold this so strongly. And other days I just knew that *because* this principle was held so strongly, we got involved in other innovative initiatives. It’s not being “big” that matters. It was being what we said we would be.”

- In 2005, CCS Disability Action embarked on a prime example of this sort of innovation when it embarked on the creation of Lifetime Design and the establishment of the *Lifemark*.

For two decades, CCS Disability Action had been lobbying government to do something about the accessibility of residential housing. The problem of young disabled people not being able to leave home and start independent lives is predominantly influenced by the lack of accessible housing, which has meant that families have had to revert back to institutional solutions. CCS Disability Action were pretty good lobbyists, but they had never made any real progress on the question of government regulations affecting residential housing. When the Building Code was reviewed in the early 2000s, CCS Disability Action realised it wasn’t going to make much progress there either, and they had to concede that they had failed in their lobbying strategies.

Maidaborn: “When we finally named that our approach really wasn’t working —and it actually hadn’t been working for a very long time — we found it was very liberating. We decided to look at it as an opportunity. The blockage in our lobbying was an opportunity to take stock, do a review, stop struggling with the issue and create the space for something else to emerge. A manager in CCS went off to an international conference to see what was happening elsewhere. We got to see the beginnings of a wider global movement trying to get design principles adopted that would deliver ease of use for most people, no matter what their age or disability.

“Then someone else on the board made the throw-away comment that it was about time we gave up on the government and trusted the market. This was personally challenging to me, because at that time all my instincts were telling me you’ll never get social innovation out of the market. But it started me thinking: What would it look like if we rejected this polarity? What would it look like if we really combined the best of business entrepreneurship with the best of social innovation?”

These questions directly led to the creation of Lifetime Design Ltd — a business entity, owned by CCS Disability Action, which has the intention of creating more housing options for people across the ages and stages of life, and is able to make a return to CCS for further investment in creating accessible environments.

Maidaborn: “Lifetime Design is a business that operates as part of a consumer rights movement. My own background is in human rights movements, and I had never thought of using the market to drive a rights movement. But what I’ve learned with Lifetime Design is that consumers are also communities ... and that consumers can act as a community as easily as they can act as individual customers in a shop. We can see lots of social change happening here — with successful examples like Fair Trade, Certified Organics, and food labelling like the Heart Foundation tick. We have created the *Lifemark* to be an effective consumer trademark which is part of this overall movement.”

- Lifetime Design promotes a set of five key design principles. These include:
 - *Usability*. The designs are uncomplicated and can easily be used by people with differing abilities.
 - *Adaptability*. The designs can be simply adapted to meet changing needs over time.
 - *Accessibility*. The designs ensure that everyone can easily access the place or service.
 - *Inclusion*. The designs will work better for all ages, sizes, abilities and stages of life.
 - *Lifetime Value*. The designs are cost-effective, and can be readily adapted to meet the changing needs of future buyers.

The demand for housing that works better for all people is set to rise significantly over the next 30 years. Maidaborn points out that, by 2061, life expectancy will have increased by about six years and the 65+ age group is predicted to account for 27% of the population. Disability rates increase with age as people develop sensory impairments and mobility issues. But unfortunately, the design of most New Zealand houses does not yet take into account this dramatic shift in demographics, and currently around 45% of older people have a disability and live in homes that are not modified for their needs.

Homes that are awarded the *Lifemark* have over 30 design features which make the house accessible for everyone and easy to adapt as the needs of its residents change over time. These design features include a level entry, widened doors and well-lit passageways which give trouble-free access for wheelchairs, or older people using a walking aid, or for parents carrying children. The kitchen design ensures that there is enough space around

appliances and cupboards to move around easily, and that cooking and cleaning can be done in comfort, even when using a mobility device or wheelchair. Bedrooms also have plenty of space to manoeuvre. All living rooms have switches, power sockets and other controls at a handy height in order to avoid bending or reaching. The toilet is accessible for everyone and there's a bathroom on the entry level. The bathroom walls are strengthened to be ready to be fitted with future handrails, and there's enough space for a level entry shower that can also fit a shower seat.

Many of these Lifetime Design features are just good common sense ideas, and they are often subtle enough to pass un-noticed until they are needed. A great many of the features do not add a significant cost to the homes, especially if they are implemented at the time of construction. In fact, research has shown that retrofitting an existing house is considerably more expensive than building these features in right from the start.

A study by the Ministry of Social Development in 2009 clearly elaborates these savings. The *"Economic Effects of Utilising Lifemark at a National Level"* report found that the housing sector could save up to \$60 million a year by choosing the *Lifemark* design standards in all new housing. These savings would be made not just by private homeowners and housing developers — there would also be a significant savings benefit to taxpayers and the government. The Accident Compensation Corporation alone would save \$2 million a year if just 10% of those people disabled through an accident injury were living in a *Lifemark* home.

- So if this is all just pragmatic "common sense", why hadn't it been done already? Maidaborn points out that, until the establishment of Lifetime Design, there had been no organisation brave enough to take on the complexity of working with all the different groups and sectors that need to work together in order to make it happen.

"The reason nobody else has taken on this challenge is because mostly, as a human species, we tend to think in our own silos. The disability sector has got their own space and services, and until the activism of recent decades they never really saw themselves as a human rights movement. Aged care and older people's movements have also got their space. Grey Power, for example, hasn't really been connected to other community agencies, even though it has developed huge lobbying powers in itself. Injury prevention groups have tended to work in an ACC-funded environment which hasn't been a political environment. And the 'Green Building' movement has done a lot of incredible work on the concept of sustainable building, but the notion of the sustainability of the people living in these building has been largely missing.

"Meanwhile there's also a huge boundary between all these social movements and the marketplace. And that leaves out all the construction industry, the finance industry, and the whole design industry of architects and engineers. Nobody has been connecting them ... so that has left the territory totally wide open for innovation and initiative."

As Maidaborn and CCS Disability Action picked up this challenge, they brought together representatives from a wide cross section of interests including the construction industry, developers, architects and housing designers, community groups, consumers, manufacturers, suppliers and the government. The immediate common response was: "Yes, we have been talking about the need for this for years — let's make it happen!"

Confidence in the initiative has grown quickly as companies across the country have embraced the Lifetime Design philosophy, and taken advantage of the research and experience provided by Lifetime Design staff. Summerset Retirement Villages became the first retirement village operator in New Zealand to sign up to the programme, and in 2009 they finished the construction of a new *Lifemark* approved retirement village in Manukau City (opened by Prime Minister John Key).

By 2010, over \$50 million of new housing development was underway throughout New Zealand with designs that had already been approved by *Lifemark*. And further government support for the Lifetime Design initiative has come with the passing of Budget provisions of \$1.5 million over three years to help promote the *Lifemark* standards. Maidaborn says that this support will enable Lifetime Design to further activate the consumer movement that can drive business change:



“Business has needed to take notice of this movement not just because of consumer demand, but because of a much deeper layer of social understanding that has fundamentally changed. Responding to this understanding is something that adds value to any business model.”

- Maidaborn reflects that an early personal breakthrough in developing the Lifetime Design concept came at a Social Entrepreneur Fellowship retreat. It happened during a frustrating period when Maidaborn found she was getting far too bogged down in the details of trying to understand and manage the building industry.

“I was taking the business too far into the housing industry and trying to sort out issues of compliance education, and registration. But then I realised I was not valuing enough the huge competencies and experience that was available in my own organisation. The core competency that CCS Disability Action was taking into this business was the knowledge and experience around adaptability, accessibility and usability. We were also providing a competence in networking that crosses many different sectors. And we were good at local networking and accessing government agency and political networks.

“I just wasn’t valuing these things enough. I was stuck on trying to build a business in housing — when I needed to think wider than just the housing. Instead of saying: ‘How am I going to get builders to do this?’ I realised I had to change the question to: ‘How do we build a social movement of New Zealanders who say I want to buy a product or house and live in an environment that meets this criteria?’ I immediately realised that CCS Disability Action and Lifetime Design knows a lot about how to answer that question. So I went home from the fellowship retreat and re-wrote the business plan so that we focused on our core strengths.”

Lifetime Design’s vision is that, by 2015, a third of all new homes in New Zealand will be built to the *Lifemark* standard. This might seem ambitious enough, but Maidaborn also points out that the principles of the Lifetime Design – accessibility, adaptability and usability etc – are just as applicable to areas beyond the housing industry. The Lifemark has the potential to be a consumer mark in many other areas from urban design and housing subdivisions, to the design of furniture, household fixtures and fittings, tools, and transport. A goal here for

Robin Allison,
Vivien Maidaborn,
Brian Donnelly and
Campbell Roberts at
the Housing Issues
Social Innovation
Dialogue



Lifetime Design is to create the first New Zealand register of products that has usability in mind, and to encourage product manufacturers to have their product endorsed with the *Lifemark*.

Maidaborn: “One of the motivations with the Lifetime Design initiative was to create independent income streams for CCS Disability Action that will enable the organisation to continue to fund our social change programmes. This will be done through commercialising the expertise and intellectual capital through a range of products and services including brands, tools and trademarks. It’s been quite a shift for many people to get their heads around the notion of CCS Disability Action setting up a company to do this. And that’s despite the fact that government departments and philanthropic trusts are constantly warning us about being dependent on them for resources. But for some people the idea of community organisations going to the marketplace and generating wealth and using it responsibly is not at all familiar, or even comfortable.”

- With several of the Social Entrepreneur Fellowship members working on housing-related issues, the retreats have enabled Maidaborn to look at this issue from different perspectives, and explore what the entrepreneurs could offer to each other’s projects.

Maidaborn: “I have come to realise in the fellowship that there is so much that I didn’t know, even in the sector that I have worked in for 30 years. I’ve come to more deeply appreciate the value of meeting with a group of people — Maori, Pacific and Pakeha — with enough quality time so that you get beyond politeness and into really generative conversations ... which also add real value to each others thinking and work.

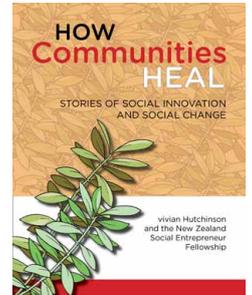
“One of our retreats was solely dedicated to housing issues, and we used the ‘U-process’ of social innovation dialogue, where the conversation went to a place that we couldn’t have put on the agenda ... as it had to emerge. It meant we had to get outside of all the particular interest areas in housing that we were bringing to the meeting, and think about the whole overall picture and get a sense of what’s missing and what we would do to strategise around that.

“This type of dialogue goes to the heart of how social entrepreneurs learn and think outside their own boxes. And it has had a very practical effect: new houses have now

been built, and there are people living in them. But it is important to recognise that it was the relationships established in the fellowship environment that forced us to consider these different possibilities.”

Notes and Links

- This article by Vivian Hutchinson is part of the [HOW COMMUNITIES HEAL project](#) — stories of social innovation and social change featuring members of the New Zealand Social Entrepreneur Fellowship. It is available online at tinyurl.com/hchmaidaborn
- In 2011, Vivien Maidaborn left her job as CEO of CCS Disability Action to establish a consultancy supporting individuals and organisations to realise their social innovation dreams. Vivien Maidaborn can be contacted at vivmaidaborn@gmail.com
- *The CCS Disability Action can be contacted at* CCS Disability Action Head Office, PO Box 6349, Marion Square, Wellington 6141, or through their website at www.disabilityaction.org.nz
- *the crippling disease Paralytic Poliomyelitis...* was virtually eliminated by a mass vaccination campaign in 1962, but it wasn't until 2000 that New Zealand was officially declared Polio free.
- *“Including All for a Better Future”* interview with Viv Maidaborn in the *Dominion Post* 30 January 2008
- *special education ...* comments from radio interview with Viv Maidaborn on the 2010 government review of the special education sector National Radio *“Nine to Noon”* 19 March 2010
- *Lifetime Design* is part of an international movement that has been around for three decades (in a variety of forms) in the Britain, Europe and the US. A range of terms are used for the same principles, including “Inclusive Design” and “Universal Design”.
- *The Lifemark* website is at www.lifemark.co.nz
- *“The Economic Effects of Utilising Lifemark at a National Level”* (November 2009) report prepared by the Ministry of Social Development (lead author and principal analyst Geoff Rashbrooke)
- *The costs of Lifemark standards ...* Research commissioned by the Joseph Roundtree Foundation in the UK has shown that incorporating Lifemark design standards in buildings is inexpensive. This research by chartered quantity surveyors shows that the costs of incorporating the standards would be between 0.5% and 1% of building costs. See *“Costing Lifetime Homes”* by Kim Sangster (Joseph Roundtree Foundation 1977). The MSD report in 2009 (Rashbrooke) estimated that the average extra costs to a conventional New Zealand home would be something in the order of \$2,000.
- *“Let's Make houses that say welcome”* by David Russell in *New Zealand Herald* 28 December 2009 available at tinyurl.com/27fspl2
- *David Russell on the Lifemark* www.youtube.com/watch?v=kIKT5ZFrBmk
- *New Zealand Government Budget 2010 announcement* of support for Lifetime Design see tinyurl.com/2798ths
- Viv Maidaborn profile in *Her Business Magazine* July 2010, showcasing New Zealand's leading entrepreneurial women, is available at tinyurl.com/2aeonst
- *Viv Maidaborn comments* taken from workshop presentations at the NZ Social Entrepreneur Fellowship Retreats at Long Bay 2007 - 2009, and at the NZSEF Social Innovation Dialogue on



Housing Issues June 2008. Also catch-up interviews with Vivian Hutchinson 26 June 2008, and interview for the HOW COMMUNITIES HEAL project 21 May 2010.

- More articles in this series, and further information on the HOW COMMUNITIES HEAL project can be found at www.nzsef.org.nz/howcommunitiesheal
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