

# **Transformation, Inclusion and Citizenship**

# A Sector Briefing from NZDSN The New Zealand Disability Support Network

# August 2016



Leading and influencing change that supports inclusive lives

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# **ABOUT US**



Leading and influencing change that supports inclusive lives for disabled people

NZDSN is a national network of over 160 organisations that provide support services to disabled people, mainly through contracts with government. We are governed by an elected Board from the wider membership and employ a full time Chief Executive with a small staff team mostly based in Wellington.

Our focus is leading and influencing change that supports inclusive lives for disabled people. We provide a strong voice and policy advice to government on behalf of our members and facilitate innovation and quality with providers.

The NZDSN Sector briefing is an annual report to the sector in which we outline:

- issues and concerns that are significantly impacting service providers and the lives of disabled people,
- recommendations to government for addressing these matters, and
- NZDSN's own commitments to support change.

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# **EXECUTIVE SUMMARY**

The Enabling Good Lives Initiative (EGL) signals the possibility of a transformation whereby disabled people and families/whanau have the choice and control to imagine and direct for themselves what the good life entails. It also means that funding will increasingly come to service providers, not directly from government, but through individuals and families and the choices they make in relation to their use of services.

As this transformation unfolds it will be essential that appropriate policy and structural changes are made so that all sector participants – individuals, families/whanau and providers are able to engage with and participate in a transformed disability service system with confidence. Investment is needed to grow this confidence – individuals and families/whanau need information and navigation support, and providers need to learn how to adapt and respond in a different funding and service provision environment.

# Transformation as an ongoing work in progress

To an extent, transforming the disability service system will always be a work in progress and needs to be linked to the broader transformations we would want to see in our society and communities. We do not operate in a benign policy environment and as a result we need to grow our ability to distinguish between policies and legislation that have genuinely *transformative potential* and those that will simply maintain the status quo for disabled people – into pre-determined services and into society as it currently is.

Our understanding of inclusion and the implementation of Enabling Good Lives needs to speak to those broader social and economic changes we would like to see - ones that move us beyond assimilation to address matters of inequality, direct access to the mainstream as well as the citizenship and human rights of disabled people.

Momentum for transformation that is authentic and sustainable is essential if we are to avoid what has been described as a state of "cruel optimism"<sup>1</sup>. Cruel optimism describes the idea that policy rhetoric is forever promising disabled people a "good life" that remains tantalisingly out of reach because of a bedrock of government austerity when it comes to the actual investment and policy changes needed. As a result there is an ongoing gap between the rhetoric and a reality that continues to lock in financial insecurity, poor access to housing, transport, employment and limited opportunities to exercise choice and control in the use of funded supports. This is the reality of assimilation – disabled people always having to fit into service systems and communities that are not designed, organised or resourced in their interests.

There are two dimensions of transformation we need to be addressing. One is the initial platform of policy, structural and administrative changes needed to create the opportunity and possibility for disabled people and families to have real choice and control. The second is the ongoing investment and support needed to ensure that everyone can participate with confidence in the new environment.

<sup>&</sup>lt;sup>1</sup> Renswick-Cole,K and Goodley, D (2015) Disability, Austerity and Cruel Optimism in Big Society: Resistance and the "Disability Commons." In Canadian Journal of Disability Studies 4.2 pp 166

# There are two dimensions of transformation we need to be addressing

One is the initial platform of policy, structural and administrative changes needed to create the opportunity and possibility for disabled people and families to have real choice and control. The second is the ongoing investment and support needed to ensure that everyone can participate with confidence in the new environment.

Confidence will take time to develop. Although there will be early adopters we can anticipate a gradual uptake over a number of years as people warm to the idea of more self-directed approaches. Providers need to be ready sooner rather than later and it is important that support is available to assist with the many aspects of transitioning to person directed approaches to decision making and funding.

### The need for bolder and more coherent approaches to change

The current structures and policy settings of Government don't easily facilitate and inspire the innovation demanded by the EGL principles. Being bolder about both the scale and scope of demonstrations will enable a much better sense of the impact, costs and benefits along with the supports that participants will need.

Service providers have longstanding and ongoing issues with the levels of Government funding along with the fragmented commissioning and purchasing arrangements associated with contracting. However our expectations for change have to be a lot more sophisticated than simply "more funding".

The solution to these issues lies ultimately in arguing for a transformed system where disabled people and families are able to access flexible, personalised budgets from nationally pooled funding – *and at a level that fosters pricing arrangements that encourages providers to respond with certainty, confidence and innovation.* 

This year's Sector Briefing emphasises the need for transformative change that can truly support the agenda for inclusion and citizenship – an agenda that the sector is committed to pursuing. Again, it is our intention that the NZDSN Sector Briefing will highlight the most pressing concerns, promote sector wide dialogue and lead us closer to solutions that enable providers and government to better support the aspirations and lives of disabled people and their families/whanau.

Dr Garth Bennie Chief Executive NZDSN Wendy Becker Chairperson NZDSN

August 2016

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# THE YEAR IN REVIEW

Since the release of our first Sector Briefing in early July 2015 there have been a number of developments. The extent to which these can be directly attributable to the impact of the briefing are, of course, arguable. We are however confident that the 2015 NZDSN Sector briefing has contributed in part and it has certainly led to a more informed sector and some lively debates about the issues being raised. In particular:

- It was heartening to see Government initiate a process for a negotiated settlement to the issue of equal pay and other workforce related issues, and that NZDSN has been able to represent the DSS funded employers at the negotiating table
- We have travelled some distance from what was originally put forward with regard to proposed changes to MSD employment and community participation contracts, although some concerns remain
- Our Provider Development programme is now in full swing with very consistent positive feedback and over 800 participants in the year to June 2016
- We have published the New Zealand Disability Support Workforce Survey Report which provides up-to-date data and highlights longstanding workforce challenges
- There have been regular meetings and dialogue with the Minister for Disability Issues and the Associate Minister for DSS services. We also

have ongoing dialogue with relevant officials in the Ministries of Health, Social Development and Education

- NZDSN contributes representatives to 20 Government working parties and reference groups
- We are partnering with the Donald Beasley Institute in the development of a national research project looking at the wider Health and Economic benefits of employment
- NZDSN is leading a project to develop sector wide practice guidelines for employment support services
- We are involved in a nationwide project in partnership with the National EGL Leadership Group to enhance engagement, understanding and implementation of Enabling Good Lives principles by providers
- NZDSN has contributed significantly to the emergence of the Disability Caucus and its role to promote political leadership and commitment to sector transformation



# **ENABLING GOOD LIVES AND SYSTEM TRANSFORMATION**

The notion of "first principles" are critical as a point of reference to guide major change initiatives. The Enabling Good Lives principles<sup>2</sup> are a remarkably good start as a "touch stone" that we (as a whole sector) can use to guide decisions about policy and system changes and to evaluate their implementation. There is a developing momentum about the need for transformation, spurred on by expectation generated through the EGL demonstrations and other "new model" initiatives.

Sector transformation means turning the vision that the principles of Enabling Good Lives offers into solutions for implementation so that:

- Disabled people and families can engage in self-directed planning informed by knowledge about a personalised budget
- Disabled people and families are able to determine for themselves the balance between the use of specialist support services and resources applied to direct access to the community
- > There is an approach to "pooled" government funding that has no exceptions
- There is a sustainable funding system, a mechanism for keeping it this way and that enables disabled people and families to decide on what investments in a good life need to be made and when
- There is investment so that all participants in a transformed system (disabled people, families and providers) can participate with confidence.

disAbility Caucus Introductory document (unpublished)

# Some observations

- It is imperative that momentum for change is not diminished or lost due to the potential for wavering enthusiasm on the part of Government and a lack of cross government leadership and coordination.
- There is a need for a broad and cohesive sector wide approach that drives the thinking and actions needed to transform the disability service system in line with Enabling Good Lives principles. The emergence of the disAbility Caucus is a key development in this regard, one that NZDSN has been a key contributor to.

The disAbility Caucus is a non-aligned, self-funded group of national networks and leaders from across the disability sector (including disabled people, families and providers) that have come together to drive sector transformation that is informed by

<sup>&</sup>lt;sup>2</sup> See Appendix 1

Enabling Good Lives principles<sup>3</sup>. The disAbility Caucus has been developed in a way that enables it to complement, work alongside and add value to the work of groups like the Enabling Good Lives National Leadership Group and Disabled People's Organisations (DPOs).

- While the recent emphasis has been on the Enabling Good Lives demonstration projects, there is now an urgent need to engage the rest of the country with the EGL principles and their implementation.
- There is a myriad of government project and evaluation activity currently occurring under the auspices of the EGL agenda. Quite how all this will inform and lead to a coherent road map for sector transformation is unclear. This lack of clarity is unhelpful and reflects dispersed and uncoordinated leadership on the part of Government. An added dimension to this activity that could make a useful contribution would be an evaluation of how well government is incorporating the principles of EGL into its policy and planning!
- The voice of, and leadership from disabled people needs to be supported with far better levels of resourcing for DPOs so that participation in policy development and system design is without barriers.
- There needs to be some consensus and a decision on a model of independent facilitation that provides the navigation support and "front end" for accessing the disability service system, but without adding an expensive layer of bureaucracy. We hope that the current review of NASC and DIAS leads to some decisions in this regard.
- There appears to be little recognition of the investment required to implement the kind of transformation envisaged by the EGL principles. Instead we are regularly reminded about the need for "fiscal neutrality", and observe that government's investment approach seems steeped in an overriding concern for spending austerity and control when it comes to disability support.
- Observations by government agencies that there is "already enough funding in the system" and related calls for "efficient use of existing funding" mask the reality that we simply do not know what the ongoing cost of a transformed system might be. This is why demonstration on a much larger scale is needed – to fully understand the impacts and costs on disabled people, families/whanau and providers – and that is not predicated on very low support worker wages.
- Ultimately, we need a transformed system where disabled people and families are able to access flexible, personalised budgets from a nationally ring fenced pool of funding and at a level that fosters pricing arrangements that encourages providers to respond with certainty, confidence and innovation.

# **Recommendations to Government**

• **Contribute to the disAability Caucus** on the development of a coherent road map for sector transformation as outlined in its "key messages"<sup>4</sup>

<sup>&</sup>lt;sup>3</sup> See Appendix 2

<sup>&</sup>lt;sup>4</sup> See Appendix 2

- **Establish a single point of leadership** for the implementation of system transformation, with oversight by a budget holding Minister
- **Implement** a large scale demonstration of a transformed disability system (covering one or even two NASC jurisdictions) where everyone has access to a personalised budget and where a consistent independent facilitation model is followed.
- **Invest appropriately in DPOs** to support the level of participation required in codesign approaches to policy and system design.

# NZDSN's commitment

- **NZDSN endorses** the key messages from the disAbility Caucus and commits as a key participant in the work of this newly established group
- **Partner with the EGL National Leadership** group on a national "roadshow" that engages providers in the EGL principles and their implementation
- **Explore** the idea of a provider accreditation process based on practice guidelines drawn from the Enabling Good Lives principles.

# **WORKFORCE DEVELOPMENT**

The report on the workforce survey conducted in partnership with Te Pou o Te Whakaaro Nui provides comprehensive updated data on the disability sector workforce<sup>5</sup>. The survey results remind us that longstanding issues remain as significant workforce challenges: low wages - the average hourly rate for support workers is a paltry \$17.04; a predominately female workforce (75%); an aging workforce – a third will be over 65yrs in ten years' time; high staff turnover; and low representation by Maori and Pasifika in leadership roles. There is also very low (7%) representation by disabled people in the disability support workforce (acknowledging that there may be a degree of under reporting).

# Some observations

- We are encouraged by the fact that we are party to the equal pay negotiations which are a potential step change in terms of fair remuneration and the possibility of disability support work being viewed as a viable career option. However we are concerned that a settlement fully reflect the "on costs" that providers would incur from any wage increase. Providers are not in a position to absorb these costs.
- Quality and innovative services rests to a significant extent on the availability of a well-trained and supported workforce that can access appropriate qualifications. This access will need to take account of a workforce where part time work and casualisation is a growing trend, along with the direct employment of support workers by disabled people and families/whanau.
- The sector is experiencing "market failure" in terms of the lack of parity between support worker rates in the NGO sector compared with DHB rates. This market failure is the direct result of a legacy of downward pricing pressure from government resulting in sustained pay inequity and disparity. Questions remain about whether

<sup>&</sup>lt;sup>5</sup> Te Pou o te Whakaaro Nui & NZDSN (New Zealand Disability Support Network). (2016). *The New Zealand disability support workforce: 2015 survey of NZDSN member organisations.* Auckland: Te Pou o te Whakaaro Nui.

government is prepared to front with the resourcing that is really needed to address these issues in a substantive way.

- The days should be long gone when the disability sector is competing with entry level jobs in supermarkets for direct service staff to undertake skilled and complex social service roles, however this is still the reality.
- NZDSN is encouraged by the development of the new Health and Wellbeing level 4 apprenticeship qualification and the new level 5 Diploma; we look forward to the increasing emphasis on pastoral care and efforts to ensure consistency across different provider settings.
- NZDSN has implemented a Provider Development Programme designed to bring practitioners and leaders into contact with the latest best practice and innovations in services. Over 800 people have participated in this programme in the year to June 30 2016.
- While there has been an acceleration of uptake in level 3 qualifications (from 24% to 41% between 2012 and 2015) it is a level 4 qualification that better reflects the actual work being done, and its growing complexity especially in the context of facilitating community. The level 4 apprenticeship needs to be established as the new benchmark qualification. However uptake may ultimately prove challenging if there is not a marked shift in wages that enables the qualification to be recognised with an appropriate level of remuneration.
- There is now a glaring absence of a degree level programme that brings together an academic focus on the theoretical, policy, research and leadership dimensions of disability support work. This focus is needed to provide the academic rigour and material that can inform and support certificate and diploma level qualifications. It is also a necessary development in terms of workforce leadership pathways.
- There is an urgent need for the sector to lead by example and substantially improve the proportion of its workforce that live with disability – not just in support worker roles, but also in leadership positions. We are in danger of perpetuating the very myths that we challenge other employers about for not hiring disabled employees.
- There will be increasing numbers of people directly employed by disabled people or families and we need to ensure that this emerging workforce has the same access to training and qualifications.
- The new Health and Safety legislation has highlighted the need for providers to
  ensure that good workplace practice prevails. There are particular risks the workforce
  may encounter in the varied contexts involved in disability support work. Some of
  these are well known, for example around supporting individuals with challenging and
  complex needs, but the emergence of new service paradigms creates a variety of
  new circumstances to consider an itinerating workforce with less direct access to
  immediate supervision and collegial support, and working in a variety of community
  settings, including people's own homes. Providers need to ensure that their due
  diligence obligations are met under the new legislation, and that the resources,
  policies and procedures are in place to manage identified risks.
- With pricing and funding at their current levels many providers feel increasingly exposed in the environment created by the new Health and Safety legislation.

Government has adopted a "hands off" approach – simply requiring in contracts that providers comply with relevant legislation. This approach does not acknowledge the benefits of an approach where risk should be shared by funder and provider, especially where pricing and funding is undermining the very quality outcomes that Government is seeking.

# **Recommendations to Government**

- **Recognise** and resolve the serious investment needed to address long-standing issues around low wages and their impact on related workforce issues such as retention, and recognition of qualifications including the new level 4 apprenticeship.
- **Recognise** that the development of quality and innovative services rests upon an appropriately trained and qualified workforce that is paid accordingly.
- **Recognise** the need to engage with the sector in a shared leadership role to address issues and concerns related to the new Health and Safety legislation.

# NZDSN's commitment

- **Continue** to participate in good faith with the current equal pay negotiations, highlighting the need to recognise that a settlement must include the ability of providers to meet the on-costs of wage increases.
- **Continue** to work with Careerforce to support the development, implementation and uptake of the new level 4 and 5 qualifications.
- Contribute to initiatives that lead to the development of degree level qualifications.
- **Continue** with the development and expansion of the NZDSN Provider Development programme, including leadership mentoring and communities of practice opportunities.
- **Ensure** Maori and Pasifika engagement with proposed leadership mentoring programmes.
- **Develop** an "action plan" with providers that aims to lift the proportion of the workforce living with disability.
- Initiate a project to develop a sector "Health and Safety Code of practice" that sets out a framework to guide providers in meeting their due diligence obligations. Continue to provide development opportunities to ensure all providers are fully aware of their due diligence obligations.

# LIVING OPTIONS

It is clear that we are on the cusp of another wave of deinstitutionalisation. There is a strident call for more personalised, person directed approaches where disabled people have real choice and control about where and with whom they live, along with what support arrangements should be in place. It is increasingly recognised that the established default "group home" model of residential support has in many ways created "micro institutions." Providers are keen to develop more person-centred options and are highly engaged with recent initiatives such as Choices in Community Living, Flexible Disability Supports and Supported Living contract extensions for residential providers.

# It is clear that we are on the cusp of another wave of deinstitutionalisation

There is a strident call for more personalised, person directed approaches where disabled people have real choice and control about where and with whom they live, along with what support arrangements should be in place.

Observations that supported living is not for everyone and that there will always be a place for "traditional residential services" alarmingly echo the same arguments that were mounted in defence of large institutions a generation ago. We also hear the same fiscal arguments being mounted that supported living and other personalised approaches will reign in the mounting costs of more traditional residential services. The fact that these residential services operate in a sector plagued with pricing irregularities and operate in an environment based on very low wages should serve as a warning about the validity of such arguments. The idea that we can achieve this paradigm shift with a "fiscally neutral impact" is absurd. There is no doubt that supported living may be a less expensive option for some, but it may very well be more expensive for others. There has been no systematic benchmarking of what the real costs of providing services are (whether residential or supported living) so we actually have no idea of what the ongoing costs of transformed services might be.

The availability of accessible and affordable housing may yet present the most significant barrier to disabled people achieving the "good life" even if long standing funding issues are addressed.

# Some observations

 We have serious doubts that the approach the Ministry of Health is taking to create a "transparent pricing model" will deliver either the transparency or pricing to address longstanding funding issues with residential and supported living services, especially if the exercise is predicated on "fiscal neutrality." Moreover, the idea that it will also address the sleepover funding legacy and the disparities with high and complex need support packages seems even more of a stretch. This is because the approach being taken is not based on robust benchmarking of pricing that reflects the actual costs of providing services – including variable costs in different parts of the country, as well as those related to demographic variances.

This inevitably leaves providers without the ability to adequately invest in infrastructure and workforce or maintain reasonable financial resilience. The

consequence is the maintenance of a contributory funding model that consistently undermines service quality – especially if the whole transparent pricing exercise has to be achieved within current budget baselines.

- In the high and complex needs context, particularly under the auspices of compulsory care orders, the issue of funding is further overlaid with the very real and significant health and safety risks that providers have to manage. These risks occur:
  - while waiting (sometimes for extended periods) for funding packages to be approved;
  - during the lifespan of the funding package because they are rarely adequate; and
  - following the expiry of the compulsory care order because there are rarely any graduated steps to the removal of high and complex needs funding.
- The Ministry's initiatives around Choices in Community Living, Flexible Disability Supports and Supported Living extensions for residential providers are moves in the right direction. However, without addressing the core pricing issue the risks for providers and the challenge of quality will remain. Supporting innovation and quality relies on the Ministry acknowledging the real costs of providing services and moving away from a system based on low wages and contributory funding.
- Much of the Ministry's thinking about the concept of "supported living" appears to be based on some curious understandings: that it's a model reserved for those with less intensive support needs only and that accessing natural supports in the community represents enormous potential for savings in funded supports. These understandings are at odds with the basic principles of Supported Living and the conceptualising of "natural supports."
- The basic premise of supported living is that of personalised choice and control about where and with whom one chooses to live. It is not related to ones perceived "level" of disability or "readiness" to live a good life. Supported living is also based on the principle that one's support services should be separated from the mechanism that provides housing so that changing the former does not mean having to change the latter i.e. my home really is my castle. The more complex and challenging a person's needs the more likely that they will need "bespoke" services that respond to their unique circumstances. Supported living does not exclude the possibility of people living in small group arrangements – the distinction is about the choice and control people have over if or when this might be an option they wish to pursue, and with whom.
- The concept of "natural supports" represents the importance of rich and varied social networks, along with engagement and contribution to civil society. It includes the naturally occurring networks we experience in our neighbourhoods, in the wider community through the interests we pursue, and in our working lives. In a disabling society these networks frequently require facilitating, navigating, supporting and, at times, replenishing. These activities are at the heart of emerging roles such as "navigators" and increasingly form part of the expectations around community facilitation that are a core part of the support worker role. In a disabling society the "community" that many take for granted requires organising and developing learning to embrace and support individuals who have historically been ignored and

rejected. Thus activity related to "building natural supports" is quickly becoming a core (if not well understood) part of providing personalised services.

The building of an inclusive society where everyone is welcomed and supported is a long term project. It is not one that can necessarily produce immediate savings from reduced demand on funded services as communities "naturally" and spontaneously embrace people they have previously not understood, rejected and actively discriminated against.

- It is likely that more responsive and personalised approaches to support and funding will actually increase demand as people who have previously lived outside funded supports seek to access a system in which they can now exercise real choice and control.
- The Ministry of Health's understanding of natural supports may also be predicated on the availability of community participation programmes funded through the Ministry of Social Development. These are funded at levels that make fully individualised approaches difficult to achieve, even with the most creative and innovative leadership in place.
- There is a significant disconnect between MSD funded community participation
  programmes and Ministry of Health funded living options. People are not able to
  integrate their access to both in a flexible way that makes sense on a day to day
  basis. Siloed approaches to funding and contracting result in ridiculous situations
  where, for example, an individual has to leave their place of residence in the morning
  to travel across town to attend a "day programme" that involves travelling back to the
  community in which they live to access a community activity of some kind. Hardly
  carbon neutral either!
- Aside from the pros and cons of a single national provider for behaviour support, there are some serious questions about the level of investment in this service given the variable access across the country. Many providers are having to maintain a level of specialist behaviour support (unfunded) because of those already "in services" don't always meet priority criteria. This creates pressure and risk for providers – and added vulnerability for the individuals concerned.

### **Recommendations to Government**

- **Recognise** that the future lies in a transformed system based on personalised budgets that requires *additional investment* in order to establish the new policy and operational framework needed for effective implementation.
- **Recognise** that developing and implementing a transformed service system on the basis of significant future savings because of natural supports and the lower cost of supported living is a completely untested and very risky proposition.
- **Develop transparent pricing** that recognises the full costs of providing services and is consistent with the Ministry's own quality objectives (instead of undermining these).

- **Recognise** that risk is a shared endeavour and that responding to the needs of individuals with high and complex needs is where bespoke services/supports are arguably most needed. This is not the place for "cut price alternatives" and a retreat to congregate care approaches (which ironically, can be a major causal factor for individuals developing complex needs in the first place).
- **Accelerate** the availability of Flexible Disability Supports and Enhanced Individualised Funding as default purchasing strategies.
- **Integrate** the purchasing of community participation services with living options (as a first step towards a single point of responsibility for funding disability services).
- **Review** and monitor access to specialist behaviour support services.

# NZDSN's commitment

- **Promulgate** the transformation agenda and personalised approaches to services and supports through its Provider Development Programme and planned Enabling Good Lives Roadshow.
- **Continue** to bring to government's attention the gaps between the rhetoric of transparent pricing models and the reality faced by providers around achieving financial resilience and managing risk.
- Assist government to better understand the concept of "natural supports," the investment needed to build inclusive community and the broader reach of supported living beyond just those in residential services who have less support needs.

# AFFORDABLE AND ACCESSIBLE HOUSING

A key component to achieving personalised living options whereby disabled people have real choice and control about where and with whom they live is being able to get into affordable and accessible living accommodation.

Physical accessibility is often an issue. It is very difficult getting long-term housing in the rental market with even basic accessibility features such as level entry access, wide doorframes and corridors, and wet-floor showers. Many disabled people do not have their own vehicles and therefore need housing that is close to public transport and to community amenities.

As we know many disabled people face significant barriers to getting work and are therefore on long-term benefits. Their choices for rental accommodation are often limited. A decision to move out of the family home or out of residential care to achieve greater independence can mean that people are faced with having to move into inferior, poor quality housing and pay rent that equates to a very high percentage of their total income. Few have the opportunity to own their own home and receive all the benefits that brings unless their families are in a position to purchase one.

Disabled people are increasingly being shut out from being able to access suitable housing. Two key factors are contributing to this -a) rising house values and increasing demand for affordable housing that is impacting on many areas of New Zealand; and b) current government social housing policies.

## Rising house values and related increased demand for affordable housing

Rising house values have impacted on the ability of many individuals and families to purchase suitable houses in communities that are close to public amenities and in areas that are safe. Particularly in Auckland, housing in areas that were once deemed to be affordable are no longer so<sup>6</sup>. While house price rises are particularly apparent in Auckland, the trend is increasingly evident in other regions.

The rise in house prices is impacting significantly on disability support providers.

# Government social housing policies

Social housing is for people with low incomes and those with special housing needs. Housing New Zealand (HNZ) provides the majority of social housing properties with Income Related Rent (IRR), which is calculated based on the tenant's household income. A number of community housing providers are funded by government to provide IRR subsidised housing. HNZ and the Ministry of Social Development (MSD) use the term 'social housing' to refer specifically to that which is provided by HNZ and community housing providers registered to receive the IRR Subsidy.

Eligibility to social housing within this process is confined to people who are determined at risk (priority A) or in serious housing need (priority B). Housing need refers to individuals/households lacking their own housing or living in housing which is inadequate, unsuitable or unaffordable, and who are unable to meet their housing needs without assistance (eg because they are discriminated against in the housing market<sup>7</sup>).

Many disabled people applying to Work and Income for social housing are declined as they are assessed not to be at risk, or as not having a serious housing need. They qualify for social housing if they have "special housing needs", however it is very difficult to be assessed as being a priority for housing in the current environment where there is a high demand for housing that is significantly exceeding supply.

# Some observations

- Provider organisations that own housing properties used for "group homes" are increasingly doing "in-fill" builds on existing properties in order to increase their housing stock in a way that is affordable. This approach risks the (re)emergence of cluster housing – where small living units are grouped together on a single site separate from the local community.
- Some disability support service providers are registered social housing providers. Social housing providers have little control as to who they provide housing to as referrals for housing are made by Work and Income (MSD). Housing stock owned by disability support service providers is being rented out to non-disabled people.
- Providers are often in an unenviable position of supporting people to move into housing that is inferior to that in which they might be living (eg in residential care services or with their families) in order to achieve their goals to live more independently.

<sup>&</sup>lt;sup>6</sup> http://www.stuff.co.nz/business/81461753/modest-twobedroom-home-in-mangere-bridge-fetches-17million-at-auction

<sup>&</sup>lt;sup>7</sup> http://www.workandincome.govt.nz/map/social-housing/assessment-of-eligibility/discrimination-as-abarrier-to-suitable-housing-01.html

• There is significant incongruence between social housing policies and the work going on with EGL and other disability support systems that are encouraging and enabling disabled people and families to have choices about where to live and with whom.

# **Recommendations to Government**

- Review current social housing policies and investigate the barriers disabled people face in accessing appropriate long-term housing. There is an urgent need for housing policies to be better aligned with EGL principles and the associated work that is already occurring.
- **Recognise** that many disabled people have housing requirements that are not easily met in the open rental market, and can become very vulnerable if their housing needs are not appropriately met.
- **Require** all new houses being built in Special Housing Area projects for fast-track development of housing (including affordable housing)<sup>8</sup> and other government-initiated building programmes to incorporate Universal Design features, complying with a minimum 3 Star Lifetime Design rating<sup>9</sup>.

# NZDSN's commitment

- Work with government to better understand the barriers disabled people face in accessing appropriate long-term housing and identify changes that are needed to align housing policies with EGL principles.
- Lead a project to explore how to transfer resources currently tied up with residential support service providers to provide greater flexibility and choice in housing for disabled people.

# **EMPLOYMENT AND COMMUNITY PARTICIPATION**

We have travelled some distance since MSD proposed its first iteration of a new framework for employment and community participation services in March 2015. Through a series of consultation workshops we have arrived at a point where, with regard to employment support services, we have a new funding and payments system to trial over the coming 12 months. While some issues have been addressed with what was originally proposed, several concerns remain. For community participation services the EGL principles now form part of the outcomes being sought, but these overlay what was already in contracts, including anachronisms like attendance and operating hours. Funding for community participation remains at levels that can only be described as woefully inadequate.

# Some observations

# Employment

 Employment support contracts now incorporate what was employment placement and supported employment into a single service description with a common pricing matrix based on a service intensity rating, continuous employment milestones and hours employed. The pricing matrix and associated milestone payments along with the reporting framework are being trialled in the current financial year (current funding and payment schedules remain in place until the end of June 2017).

<sup>&</sup>lt;sup>8</sup>www.aucklandcouncil.govt.nz/EN/ratesbuildingproperty/housingsupply/Pages/specialhousingareas.aspx

<sup>&</sup>lt;sup>9</sup> http://www.lifemark.co.nz/official-star-rating

- The pricing matrix is sensitive to the support needs of the individual and incentivises maximising hours and duration of employment. On the surface at least, this should encourage providers to retain commitments to those with more significant employment barriers and maximise employment outcomes both in terms of hours worked and duration of employment (through 6 and 12 month employment milestone payments). However several concerns remain:
  - It will be important to monitor the new contract framework for unintended consequences, particularly whether the activity hours are enough to ensure that those with more significant barriers to employment continue to be served.
  - Because Government "social investment" policy in this area is focused entirely on reducing the numbers of people on benefits (Better Public Service Target #1) it is possible that the pricing matrix is only geared to this outcome, ignoring the wider health and economic benefits of working (even for a few hours a week) that are well supported by research evidence. This could result in providers being drawn away from serving people whose hours of work and ongoing support needs will not deliver substantive benefit reductions. This would be highly discriminatory. Such an approach ignores the wider health, wellbeing and increased financial security outcomes that can be achieved with even a few hours of employment.
  - The incentives in the pricing matrix may draw providers away from a personcentred approach whereby undue pressure might be put on people to work longer hours and could easily undermine people's health and wellbeing.
  - The emphasis on incentivising permanent full time employment (at the expense of a range of options) is increasingly at odds with a labour market that is rapidly evolving casualised/seasonal and part time work is growing rapidly (particularly in lower waged jobs); contracting and self-employment also make up a growing proportion of the workforce.
- As the government's investment approach is based on a very narrowly defined target of reducing people on benefits there is a significant risk that an increasing cohort of people will not be regarded as worthy of investment and their employment aspirations ignored. This would be a perverse outcome and in direct contradiction to the government's commitments to the Enabling Good Lives Principles – as well as being highly discriminatory.
- The Productivity Commission Report on More Effective Social Services highlighted this very problem and as pointed out by Rosenberg<sup>10</sup> the report recommended that the government's social investment approach 'should be further refined to better reflect the wider costs and benefits of interventions' and observed that 'slavish application of an investment approach based purely on costs and benefits to government might lead to perverse outcomes'.
- The moves by MSD in its new employment framework for employment support for disabled people may well result in a classic example of a perverse outcome. It ignores the fact that if this group are not in employment they will likely be still drawing on funded support through community participation programmes. Would it not make sense from an investment perspective to prioritise funding an employment outcome

<sup>&</sup>lt;sup>10</sup> Rosenberg (2015) The 'Investment Approach' is not an Investment Approach. Policy Quarterly, 11-4 p35

where the individual is paying some taxes and drawing a wage that enables them to consume additional goods and services - in addition to the wider health benefits of working? This narrow investment approach is also at odds with the Governments own revised New Zealand Health Strategy developed through the Ministry of Health, which emphasises the health benefits of work.

- It is important to point out that job placement in and of itself is not an outcome, but an output. Employment outcomes are what happens because a person secures paid work: Is the work sustainable? Does it improve financial security? Does it contribute to increased health and social wellbeing? Not all paid work is good for you, particularly if you have existing vulnerabilities around physical and mental health and income security.
- What is needed is a comprehensive employment strategy (rather than a narrow benefit reduction target). Such a strategy should be a cross-government initiative with clearly established leadership responsibility and a co-design approach with the sector. The focus of an employment strategy needs to be on achieving sustainable employment outcomes that enables all disabled people to pursue their employment aspirations. Such a strategy needs to consider the full range of factors creating barriers to employment and the full range of benefits that accrue for disabled people and society. Disabled people have the lowest workforce participation rates of any group in New Zealand. We cannot afford to have disabled people missing out on the wider health and economic benefits of working and have the economy miss out on their significant economic contribution as participants in the paid workforce.

# What is needed is a comprehensive employment strategy (rather than a narrow benefit reduction target)

Such a strategy should be a cross-government initiative with clearly established leadership responsibility and a co-design approach with the sector.

- Government has invested significantly in its own service delivery through Work and Income to improve employment outcomes for its clients with health conditions and disability - including hiring 120 health and disability case managers, initiatives such as "Opt In"<sup>11</sup>, and Project 300<sup>12</sup>. This investment in the Government's own service delivery raises several issues:
  - At this stage it is difficult to discern the impact of the considerable investment in these initiatives from what would be Work and Income's "business as usual" particularly in achieving sustainable employment outcomes where individuals are achieving 6 and 12 month milestones in work. Data on these outcomes is sketchy at best.
  - There is a sense that this investment is about getting as many "quick wins" and "runs on the board" to ensure government meets its better public service target of reducing the numbers of people on benefits – a target that is now being described by government as aspirational only!

<sup>&</sup>lt;sup>11</sup> http://www.workandincome.govt.nz/look-for-work/job-search/opt-in/index.html

<sup>&</sup>lt;sup>12</sup> http://www.odi.govt.nz/nzds/progress-reports/2015/project-300.html

- Nevertheless, the idea of improving Work and Income's performance with a group whose employment aspirations have historically not been taken that seriously by this agency has merit. The challenge is to overcome significant and longstanding trust and performance issues with Work and Income from the perspective of disabled people and the contradictions that people experience from engaging with an agency that is supporting employment aspirations on the one hand and perceived to be minimising access to income support on the other.
- Rather than just compete in the same space as contracted providers it might be better to:

a) Make use of the considerable expertise available within contracted specialist employment providers to train Work and Income health and disability case managers and to support initiatives such as project 300.

b) Develop clear protocols between Work and Income and contracted providers so that they collaborate more effectively in the interests of the people being served.

Government is examining alternatives to minimum wage exemption as part of a commitment in the Disability Action Plan and as a signatory to the UN Convention on the Rights of People with Disability. NZDSN supports the removal of minimum wage exemptions. It will be important that alternatives recognise that a range of options may need to be considered, including expanding access to employment support services and to quality community participation services. We trust that alternatives will not rely on mechanisms like wage subsidies (essentially a minimum wage exemption with another name) that would have the impact of perpetuating artificially constructed (and expensive) arrangements that enable government to merely "tick" compliance with international conventions.

We note that some business enterprises are now operating on a commercial basis that enables all employees to be paid at least the minimum wage and would support a business mentoring approach to get others into the same position.

- NZDSN is leading a project to develop sector wide practice guidelines for employment support services. This is an opportunity to build consensus about best practice (across providers, government and disabled people) and to include more emphasis on dimensions such as confident employers as well as drawing more directly on the voice of disabled people.
- Transition from school is an area where effective practice remains variable and often elusive. The education system and post-school providers continue to struggle with funding silos and restrictive contracts. Policy and contracting arrangements need to facilitate collaboration, not put up barriers. The idea that employment support providers are not able to engage with schools until the students last year of school is entirely at odds with evidence-based transition practice.

# **Community Participation**

Community Participation Services are a key part of facilitating community with disabled people and are based on an individualised approach that has at its core facilitating natural supports. The service system is still learning about effective

practice in this regard and the kind of investment that is required to essentially build community in a way that is authentic and enduring for the individual concerned.

- More effective approaches are seeing programmes move away from centre based provision to approaches where support is personalised and reflects individual preferences. These developments reveal several challenges:
  - Woefully inadequate funding levels for community participation services that have not changed in over a decade (which has effectively meant reduced funding). Even with the most creative and resourceful leadership many programmes struggle to achieve the level of flexible individualised community participation with natural supports that they and the people they support aspire to.
  - While EGL principles and outcomes are now a part of contracts, features such as "centres," attendance and hours of operation are retained. This sends mixed and contradictory messages to providers. The implication is that "the good life" is only available between 9-5, Monday to Friday!
  - The inadequate level of funding in this area is being increasingly recognised by Government and we look forward to some movement sooner rather than later.
  - Families struggle with the idea that their family members will not be in the same place for the same hours each weekday. Established understandings need to be re-negotiated to a point where family members should be able to say that "although I'm not always exactly sure where he/she is I am confident that they are having a reasonably varied, stimulating and rewarding day/week, is appropriately and respectfully supported, and is safe". These assurances are difficult to provide and sustain with funding at such low levels –meaning that centre based and congregate/group support often has to be resorted to.
  - Current contracting and purchasing arrangements, along with pricing and funding levels make it very difficult to integrate community participation, employment and living arrangements into seamless, ordinary life in the community. Simultaneous use of these funded supports should be a central pillar of access to services. If someone is in part time work it should be entirely possible to access a community participation programme when one is not working.
  - There are monetary costs to participating in community activities that are frequently beyond the financial resources of many disabled people. This is exacerbated with additional accessibility requirement costs, for example mobility transport. Poverty and a lack of financial security are real barriers to community participation. Accessibility of community venues and places is also too frequently still an issue, further restricting options.

# Recommendations to Government

# Employment

• **Carefully** monitor the trial of the proposed new employment support contracts for unintended consequences, particularly the very real potential for excluding people with more significant employment barriers.

- **Broaden** the social investment approach to include an **employment strategy** that recognises the wider health, social and economic benefits to ensure that all disabled people are able to pursue employment aspirations (even if benefit abatements are not significant). Such a strategy needs to take account of the rapid changes within the labour market as it becomes more part time and casualised.
- **Provide** information on sustainable outcomes being achieved by the additional investment in Work and Income services, particularly increases in people with health conditions and disability achieving 6 and 12 month milestones in work.
- Look to develop clear protocols between Work and Income and contracted providers to ensure the strongest possible collaboration in the interests of the people being served.
- **Focus** on removing policy and contracting barriers that get in the way of the collaboration needed to facilitate effective transition from school.

# **Community Participation**

- Review the funding levels for community participation services as a matter of urgency.
- **Review** contracts for community participation services with a view to removing contradictions and emphasise desired indicators of "best practice" (even if it is aspirational to some extent while funding levels remain low).

# NZDSN's commitment

## Employment

- **Work** constructively with government to monitor the impact of the new employment contracts for unintended consequences.
- **Continue** to emphasise the importance for a social investment approach to take a broader view of the health, social and economic benefits of work.
- Advocate for an employment strategy to achieve meaningful gains in workforce participation. Highlight and bring to the attention of government the research and evidence that already supports such an approach.
- **Offer** input into the development of protocols to promote effective collaboration between Work and Income and contracted providers.
- **Collaborate** with the Donald Beasley Institute on a national research project to explore the health and economic benefits when people are working less than 15 hours per week.
- **Develop**, publish and promulgate employment support practice guidelines as a vehicle to drive quality and outcomes.
- **Provide** input into the development of alternatives to minimum wage exemptions.
- **Continue** to highlight transition best practice through the NZDSN Provider Development Programme and encourage further uptake of our website hosting service for the "What's Next?" transition directory template.

## **Community Participation**

• **Continue** to disseminate innovation and best practice in community participation through the NZDSN Provider Development Programme, annual conferences and through the planned Enabling Good Lives Roadshow.

# **COMMISSIONING OF SERVICES**

We are using the term commissioning to include tasks such as procurement and purchasing. The Productivity Commission Report on More Effective Social Services offers some useful insights into how we might better conceptualise the role and tasks involved in commissioning. It outlines the multiple aspects involved including determining objectives, needs, funding, pricing, quality, performance measurement, outcome monitoring and issues of market sustainability. The report comments that newer models such as those represented by developments like Enabling Good Lives requires government to shift its approach to commissioning from one of direct control to one of "stewardship" where the focus is on enabling and oversight through performance monitoring and evaluation of commissioning choices and approaches.

## Some observations

- Many providers (and the NGO sector generally) often experience commissioning as a one sided, even combative approach. A lack of transparency with tendering processes and the absence of any consistent benchmarking around the true cost of providing services are common observations. The complexity of tendering and contract negotiation processes and consequent costs have to be borne by providers – often for contracts that are for relatively small amounts and for short periods of 12 months.
- Government seems strong on an approach to commissioning based on a strict commercial and business ethos however this seems to evaporate when it comes to fair and transparent pricing resulting in funding levels that are only contributory (even though the full reporting on all outputs and outcomes is required!). It is essential that government recognise that pricing must also include the indirect costs of providing services to ensure financial resilience for organisations.

# Government seems strong on an approach to commissioning based on a strict commercial and business ethos

However this seems to evaporate when it comes to fair and transparent pricing resulting in funding levels that are only contributory. It is essential that government recognise that pricing must also include the indirect costs of providing services to ensure financial resilience for organisations.

 NZDSN is part of a working group led by Hui E! looking at developing some principles and guidance that might offer a more collaborative and productive approach to procurement – for providers and for Government. Some of the initial thinking of this group on commissioning includes:

- beginning with the assumption that the community sector and government are "on the same side";
- developing outcomes jointly;
- > open book benchmarking processes; and
- contract reporting that doesn't just add outcome reporting to the already onerous activity based reporting regimes.

# **Recommendations to Government**

- **Draw on the work of the Productivity Commission Report** as a template to guide commissioning.
- **Develop some model coherency** if a commercial/business model is to guide commissioning and tendering then extend this to include pricing! based on transparent benchmarking of the full costs of providing services.
- **Recognise** that because government is the predominant funder of providers it essentially creates and dictates the market and therefore has a responsibility to ensure the financial resilience and sustainability of providers. This means recognising direct and indirect costs of providing services as part of a fair pricing framework.

# NZDSN's commitment

- **Contribute** to the Hui E! working group to develop a framework and principles that would lead to a more productive and collaborative approach to commissioning.
- **Support** providers to access advice and guidance around competitive tendering processes.

# SAFEGUARDING

Safeguarding is a concept that can operate at personal, community and system levels and takes a much broader view than just regulation and legislative provision. The Ministry of Health established an External Working Group in 2014 to co-design proposals for changes to the regulation of quality and safety in disability support. NZDSN was represented on this working group. While the impetus for this work was driven by concerns about the need for the system to improve performance around the prevention and management of neglect and abuse, it also sought to embrace wider quality of life elements that are key to a safeguarding approach. The working group eloquently summarised the principles behind the concept of safeguarding simply as: *"the things that keep people safe are really the things that are needed to have a good life – caring relationships, opportunities to participate, and power over the conditions of everyday life."* 

The synergies with the Enabling Good Lives principles are clear.

# Some observations

 Some considerable time has passed since the working group completed its deliberations and we understand that a report has been prepared for the Minister based on the group's concept of a safeguarding framework. In addition, the Ministry of Health is preparing a set of guidelines on the prevention and management of abuse in Disability support services based on the broader approach to safeguarding envisaged by the working group. NZDSN commented on a draft in August 2015, but have yet to see publication.

- The approach also included a strong emphasis on promulgating and cementing the concept of supported decision-making as well as the development of a code of ethics for the disability support workforce. NZDSN is keen to see both these elements firmly established as core elements of a quality service system that takes a strong preventative stance on neglect and abuse.
- We trust that the lapse of time does not mean a retreat from the approach and recommendations adopted by the working group and a return to a system heavy on regulation and compliance, and a consequent emphasis on reactive rather than proactive approaches that focus on prevention.

# **Recommendations for Government**

- **Develop** a plan of action based on the working groups recommended approach which includes an emphasis on a Safeguarding Framework, supported-decision making and a code of ethics for the disability workforce.
- **Understand** that systemic abuse can arise out of current service configurations and contract specifications that do not allow enough scope for people to have the necessary choice and control over where, how and with whom they live.
- **Recognise** the synergies between the safeguarding approach and a service system based on Enabling Good Lives principles.

# NZDSN's commitment

- NZDSN is keen to promulgate the safeguarding approach to the prevention of abuse and neglect. It is working collaboratively with several project partners, including the Ministry of Health to design and deliver a series of workshops through our Provider Development Programme.
- **Ensure** that content in the new level Health and Wellbeing 4 and 5 qualifications reflects a safeguarding approach.
- Work with interested parties to promulgate and cement supported decision-making as core practice in disability services.
- **NZDSN is keen to partner with the government** and other relevant stakeholders on the development of a Code of Ethics for the disability support workforce.

# **CULTURAL RESPONSIVENESS**

NZDSN hosted two series of workshops over the past year – one through Le Va on growing leadership around services for Pacific Peoples and one on Bi-Cultural Journeys where several providers shared their journeys to date. Uptake of these learning opportunities by providers was modest.

# Some observations

• NZDSN is keen to support the review of Whaia Te Ao Marama: The Maori Disability Action Plan. We are aware of the variable responsiveness amongst providers with

some demonstrating clear leadership and others yet to start a journey. NZDSN itself has made some beginning steps by creating a Kaumatua role (that has recently been filled) to provide advice and guidance to our Board and staff.

- There are opportunities in front of us to use the proposed NZDSN leadership mentoring and community of practice programmes to stimulate Maori and Pasifika involvement in leadership development and in facilitating culturally responsive practice.
- Government has provided frameworks to guide sector development and it is important that providers now take the opportunity to commit to implementation.

# **Recommendations for Government**

• Pursue the planned revision of Whaia Te Ao Marama.

# NZDSN's commitment

- Ensure further opportunities to facilitate cultural responsiveness through its provider development programme over the coming year, and include this dimension in planned community of practice and leadership mentoring programmes.
- **Look** to host a further round of Le Va leadership workshops in 2017 as part of our Provider Development Programme.

# **INCLUSIVE EDUCATION**

Despite a consultation process referred to as the "Special Education Update," we are no clearer about what changes might be ahead to further develop access to inclusive education. Energy still seems consumed over concerns about resourcing rather than about leadership and practice that would facilitate inclusion. While additional funding for teacher aides was announced in the budget the broader policy settings that might advance and structurally embed inclusive education are still absent.

# Some observations

- There is still the absence of a legislative and regulatory framework that would enable parents to truly exercise their rights to enrolment of disabled children in their local school.
- The absence of independent mediation at a local level for enrolment and attendance issues remains a glaring gap.

Special education is still plagued by a level of complexity that defies understanding, even by those charged with responsibility for its administration and delivery.

- To the Ministry of Education's credit there are growing learning resources and material to support inclusive practice, but in the context of devolved decision making and accountability to individual schools, getting widespread traction is problematic.
- Transition from school is an example where embedding a widespread commitment to effective practice is challenging, despite clearly articulated guidelines from the Ministry of Education being in place for some time. This area is further complicated

by a lack of coherent integration of policy and funding between the Ministry of Education and the Ministry of Social Development.

- A "transition from school" project is getting underway as part of the Disability Action Plan. This is a potential opportunity to address some long standing barriers to effective transition practice. NZDSN looks forward to an opportunity to contribute to this work.
- There is some thinking and work to do around the inclusion of people with significant learning disability in tertiary education settings both in the context of specific course design and the wider participation opportunities that tertiary campuses potentially offer.
- A Good Start is a project that forms part of the Disability Action Plan and addresses the need for a "beginning early" approach, including effective transition to school. It is hoped that one of the outcomes of this project is a move to establish an overarching framework for delivery that enables the integration of Child Development Services provided by DHBs and Early Intervention Services provided through the Ministry of Education. The current separate provision creates duplication, contradictions and is very difficult to navigate for families/whanau.

# **Recommendations for Government**

- **Undertake** to sort out the policy and funding quagmire that currently sits around transition from school. It is hoped the transition from school project about to get underway starts to address this area in a substantive way.
- Ensure that the Special Education Update deals to the complexity of special education services and funding.

# NZDSN's commitment

- **Contribute** to the Transition from School and Good Start projects in whatever way it can.
- **Continue** to support the production of its online template "What's Next?" so that regions can develop their own transition directories and guidelines<sup>13</sup>.

<sup>&</sup>lt;sup>13</sup> http://www.nzdsn.org.nz/whats-next/

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# **APPENDIX 1**

## Enabling Good Lives principles

There are eight principles based on what is needed to improve the quality of life of disabled people. These are:

Self-determination Disabled people are in control of their lives

### Beginning early

Invest early in families and whānau to support them to be aspirational for their disabled child, to build community and natural supports and to support disabled children to become independent

#### Person-centred

Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach

### Ordinary life outcomes

Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life

#### Mainstream first

Disabled people are supported to access mainstream services before specialist disability services.

#### Mana enhancing

The abilities and contributions of disabled people and their families are recognised and respected

#### Easy to use

Disabled people have supports that are simple to use and flexible

### Relationship building

Relationships between disabled people, their whanau and community are built and strengthened

# **APPENDIX** 2

## disAbility caucus key messages



#### info@disabilitycaucus.nz

#### What do we want?

We seek a good life for people with disabilities.

This is a life lived alongside others in community as fully contributing citizens where disability is simply part of who we are as community.

We see this being measured through key outcomes including:

- rich and varied social lives
- · participation in education and employment
- having a home of their own
- having independent transport
- being able to save towards financial goals
- · and participating in civic life

### Political and Policy Leadership

We believe there needs to be a single point of leadership for public policy and programme development and the implementation of a transformed system. This leadership needs to be independent of the current Ministries that have split responsibilities for disability policy and resourcing.

A Disability Commission could contribute to an effective cross-government approach to disabled peoples' supports.

Leadership needs to be addressed in accordance with the Report of the Social Services Select Committee "Inquiry into the Quality of Care and Services Provision for People with Disabilities", September 2008.

Political leadership of disability should be undertaken by a budget-holding Minister.

### An Investment Strategy

The economics of disability need to be re-framed using a long term perspective with each person and their whanau.

An actuarial foundation for disability support services funding should be employed and with that a capital fund built to enable funding certainty and independence from annual government budget cycles.

Funding should be ring-fenced and guided by a set of legislated principles based on Enabling Good Lives principles.

### Self Direction and Independent Facilitation

We need significant community change whereby communities are generally supportive and welcoming of disabled people.

There needs to be significant investment in development of disabled people and their allies (friends, family, whanau and disabled persons and community organisations) in order to develop capacity for self-direction.

Independent Facilitation is central to a new 'front end' of the disability support system as it invests in disabled people and their families to build their understanding of what may be possible and assists them to achieve their goals irrespective of formal funding frameworks.

Independent Facilitation has many parallels with the Whanau Ora model of practice and is culturally versatile in that it intrinsically involves 'walking alongside'. Therefore the work of Independent Facilitators can be readily interpreted into many cultural contexts.

### Personalised Resources - Purchased Supports

It is critical that the default position for funding of the majority of purchased services is personalised and self-directed.

Moving to personalised funding as a default will be a substantial transition that will need to be managed with care and in partnership with all stakeholders and participants.

Highly specialized and small scale services where there is unlikely to be a viable market will require state-funded direct support.

People need to have options for how they manage their personalised resources – ranging from full self-management, to fully hosted options. Investment is needed to ensure that everyone can participate with confidence.

Disabled people and their allies (friends, family, whanau and disabled persons and organisations) are the key people in the design, implementation and contribution to monitoring and evaluation processes.

There should be active market stewardship<sup>14</sup> on the part of Government.

We agree with the Productivity Commission statement that: "Government needs to take responsibility for system stewardship, and for making considered decisions that shape the system. This includes overarching responsibility for monitoring, planning and managing resources in such a way to improve system performance".<sup>15</sup>

### **Resource Allocation**

People need to be trusted to do the right thing. Trust first – check second.

Allocation of resources for supports required should be transparent and as administratively light as possible.

People need to have certainty about funding availability over time.

<sup>&</sup>lt;sup>14</sup> 'Market stewardship' is conscious oversight of the system as a whole. As recommended by the Productivity Commission Report 'More Effective Social Services' August 2015. pp 123 -124

<sup>&</sup>lt;sup>15</sup> Productivity Commission Report 'More Effective Social Services' August 2015. Rec 5.3 pp105

#### Next Steps for Government

Implement the Select Committee recommendations in accordance with the Report of the Social Services Select Committee "Inquiry into the Quality of Care and Services Provision for People with Disabilities", September 2008 by creating a single point of reference for the political and policy leadership of disability by implementing a Disability Commission as a priority.

Create a ring fenced structure for all current and future disability funding under the auspices of legislated principles (based on Enabling Good Lives Principles) and underpinned by an actuarial foundation that enables the development of a sustainable capital base.

Decide on and implement a self-directed resourcing model with Independent Facilitation as the "front end".

Seek bi-partisan political support for these next steps.

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# Leading and influencing change that supports inclusive lives