DISABILITY DISCUSSION PAPER

Where to from here for Disability?

INTRODUCTION

United**Future** supports the intentions and direction of the NZ Disability Strategy, but believes that there is an unacceptable gap between policy and practise in many service areas. The inquiry held by the Social Services Select Committee which at the time of writing this discussion paper is yet to be reported back on, highlighted some key concerns.

Through this paper it is United**Future**'s intention to make sure key stakeholders help shape our policy direction on this important area and so we invite you to comment on the ideas below and on what priorities exist. For this reason much of the content in this document has been deliberately phrased as questions and/or with space provided for feedback.

United**Future**'s goal is to have a working relationship with whoever is forming a government after the election this year and that going into any negotiation process, we are clear of what our priorities are. A note of caution, however: our powers of negotiation are only ever as strong as the numbers we supply.

OVERALL QUESTIONS

1) Does our emphasis as a nation on embracing and celebrating *diversity* include those with disability?

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2) To what extent do the models of care facilitate *inclusion and participation?* Where does the balance lie between medical and social models of care? How do we identify and dismantle systemic barriers?

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3) Do you believe that the consumer/family model of governance put *authority* for decisions into the right hands and does it reflect the interests of those most directly affected by service outcomes? Is it able to respond to the needs of the whole family affected by the needs of the disabled person?

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CURRENT PROBLEMS

In this section we have a list of what we believe to be some of the more pressing problems. We invite your comments.

1. People with impairment are rarely allowed to manage their own support budget. As in June 07 there were only about 90 people receiving *individualised funding*. Currently this provision is only available to those with high or very high needs. For most people, services are pre-determined rather than self-determined. This means that money is wasted. Contracts are between funders and service providers and do not include the client or their support people in a contractual or a consultative sense.

   Agree / Disagree

2. There is a shortage of *respite care.*

   Agree / Disagree

3. A huge disparity exists between those dealt with by ACC and those who have impairments that have no origin in trauma.

   Agree / Disagree

4. The *workforce* that those with impairment rely on are poorly paid, poorly planned for, poorly trained without clear scopes of practise and therefore without appropriate qualifications and career pathways.

   Agree / Disagree

5. *Family* members who "didn't choose their lot but always choose to love" (quote from a Mum who has a son with Global Developmental Delay and Autism), are poorly recognised and supported in the work they do.

   Agree / Disagree

6. *Maori and Pacific* Island people with impairment are identified as some of the most marginalised people and often they rely on family who themselves are clearly marginalised.

   Agree / Disagree

7. There is no government funding for *advocacy* services. There is a complaints service run by the Health and Disability Commission but

uptake is low. Is this due to the ongoing relationship that disabled folk have with their providers?

Agree / Disagree

8. Needs Assessment and Service Coordination (NASC) agencies do not appear to operate under consistent guidelines and criteria and consumers and their families are often unaware of their rights under needs assessment. There appears to be little transparency between funders, service providers and assessment teams. The NASC process has limited the responsiveness and flexibility of disability support services. There are questions about how often a client is required to undertake an assessment.

Agree / Disagree

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POLICY POSSIBILITIES

Included in this section are a range of policy possibilities. It is by no means exhaustive and so we welcome additional suggestions as well as feedback on those listed.

AUDIT

The Ministry of Health has had work done on this by the "Disability Services National Quality team". The developmental-evaluation model is preferable to the audit compliance approach but it is unclear whether this is being recommended for wide-spread use. Which of the following do you recommend audits include:

- Standards should be customised and focused on the quality of life not just compliance to systems. Clients should be central to the audit process and supporting friends and family should be consulted.
  Agree / Disagree

- Focus needs to be not just on compliance and risk management, but on the ongoing development of both the philosophical base and services of providers.   **Agree / Disagree**

- Compliance and risk management audits could be simplified and streamlined into an online format that is available to all funders needing this assurance to avoid duplication. These should be updated regularly and inexpensively. On-site audits could then focus on service development and client satisfaction.
  Agree / Disagree

- An independent review of current audit and monitoring provisions be carried out. **Agree / Disagree**

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ADVOCACY & COMPLAINTS

- Establish Community-based brokerages (advocacy services) to ensure that every disabled person and their family have a case manager who

ensures that clients are given every support they are entitled to and want.

Agree / Disagree

- Provide advocacy training for brokers and for clients themselves.
  Agree / Disagree

- Develop clear protocols between Disability services and related services like mental health, health, education, income support etc.
  Agree / Disagree

- Support the development of "family governance groups".
  Agree / Disagree

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ACCOUNTABILITY & COLLABORATION

- More accountability needed to track where the money from unfilled carer hours goes and is spent.
  Agree / Disagree

- The sector needs to be client-driven not provider-driven. Better collaboration between what clients want and what services are available. This will require a change in the funding and contracting. Where possible the client should determine the contract.
  Agree / Disagree

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HOUSING

In providing housing for people with disabilities we need to be committed to maximising the idea of "home" as a priority (Michael Kendrick).

The following are points Kendrick makes for consumers, families and staff to consider as they strive towards building a proper and rich sense of "home" into their residences.

- The residents served should assist in the selection and location of the home.

- They should help to decorate and furnish their home environment.

- They should decide who they want to live with.

- They should have a voice in staff selection

- Agencies should hire staff whose personal orientation, commitment, and attributes are targeted towards helping people make a home for themselves.

- Programming, treatment, and related practices are either kept out of the home setting, or if necessary blended carefully into the home-life so they do not disturb the home setting.

- Agencies should not bring their bureaucracy into the home. This means agency materials, meetings, offices, or equipment.

- Home sites should be integrated into their neighbourhoods. The houses should be attractive, well cared for, and similar in appearance to neighbouring households.

- The home should be close to work, family, recreation and convenient to other interests of the people who live there.

- Intimacy, sharing, personal ownership and possessions should be encouraged.

- Regulatory concerns of funding agencies should be addressed in such a way that the home remains a home.

- The house is at all times, legally and otherwise the home of the residents, and not the staff or the agency.

- The agency should stress in its mission, and in its communication to staff, consumers and families that the concept of home in its residences is a worthy and pre-eminent goal of the organisation.

List any particular housing concerns you have:

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WORKFORCE

Society should not just be judged by how it treats its most vulnerable members, but also by how it treats those who care for them.

- Introduce a "Caregivers Allowance" for those currently providing unpaid support.
  Agree / Disagree

- Ensure that appropriate respite care is available in every region.
  Agree / Disagree

- Intensify workforce planning so that greater certainty is gained around issues of:
  - * Scopes of practise
  - * Qualifications
  - * Pathways to qualifications
  - * The availability of academic training, theory and learning
  - * Assistance for voluntary agencies (like RDA) to train volunteers
  - * Fund regular evaluations and up-dates of training content by the Industry Training Organisation, including input from clients.

  Agree / Disagree

- Ensure wage rates are included as part of all government contracts with providers (CTU recommend that the starting rate should be $18/hr)
  Agree / Disagree

- Ensure that ongoing staff training is part of govt contracts.
  Agree / Disagree

- Develop compulsory content for all participants in Teacher Education regarding teaching students with disabilities
  Agree / Disagree

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MAORI & PACIFIC ISSUES

Interdependence is often more highly prized than independence by those with strong whanau and iwi connections. A social model of care that reflects the fact that care is largely delivered in the extended family context is vital.

- Develop flexible funding packages and a model of care that fits the whänau.

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FUNDING

- Extend contract times to allow sufficient time for planning and service development in a sustainable way.
Agree / Disagree

- Ensure ORRS funding is not pruned if a student makes academic progress but remains disabled.
Agree / Disagree

- Allow bulk funding for services separate from benefit income.
Agree / Disagree

- Create a separate funding stream for workforce including wages so that wage increases can be tagged separately from general operations funding to Providers.
Agree / Disagree

- Establish an innovation fund to encourage the development of new opportunities for the sector.
Agree / Disagree

- Develop individualised packages of support.
Agree / Disagree

- Provide education information for NGO Funders on where to invest, how to respond to innovation, experimentation and risks, the importance of both long-term and short-term goals, forming funding partnerships, how to best get accountable feedback and the like.
Agree / Disagree

- Increase the flexibility between household management funds and personal care funds.
Agree / Disagree

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ADDITIONAL PRIORITIES

- It is highly unlikely that disability services are going to improve considering that the Disability Services Directorate has now been joined to other parts of the Ministry of Health that include services like health screening programmes. The need to establish a Disability Commission as a first port of call for clients wanting advice and support seems vital. This Commission should come under MSD not Health.
  Agree / Disagree

- Wider *public education* regarding inclusion.
  Agree / Disagree

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PRIORITIES

1.   **If you were to list in order of concern the problems facing you, clients or the organisation you support, how would that look?**
(rank 1 – 10 … 1 being of greatest concern)

Lack of individualised care packages
Shortage of appropriate respite
Inflexible Funding
Disparity between ACC and non-trauma disability services
Workforce
Support for Family/Whanau caregivers
Lack of advocacy to help access services & funding
Difficulty laying complaints
Needs Assessment and Service Coordination
Housing
Other

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2.   **Please rank in order of priority, the top 5 policy ideas you think would improve outcomes for yourself and/or others reliant on disability services.**

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