Health Services Research Centre

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Productivity Commission

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Submission: Productivity Commission Draft Report on More Effective Social Services

This submission begins with specific feedback on Chapter 10: Service Integration, followed by some comments on general themes raised in the draft report.

Comments on Chapter 10 Service Integration

The fragmentation described in Chapter 10 is an aspect I considered in my PhD research on autism policy. This lack of coordination, consistency, with overlaps and gaps can be considered a classic 'wicked policy problem', one that is messy and complex and for which there is not one simple linear solution. A recent blog post on the Public Address site on disability as a wicked policy problem – which has relevance to the issues raised here – has a long thread of informed comments many of which focus on aspects of this Productivity Commission report.

http://publicaddress.net/access/disability-as-a-wicked-policy-problem/

Findings and Recommendations in Chapter 10

On the surface the findings and recommendations of this chapter seem astute and reasonable. Lack of integration has been a problem with service provision for a long time, and there have been numerous attempts to address such fragmentation. Some historical examples are provided and a timeline of various, mostly unrelated, initiatives since 2000 feature in Fig 10.2.

The report recognises that 'services should be focused on the needs of the person' and that organisations have their own identities and cultures as players in a bigger system.

An example of the complexity of service integration is provided by the research of Stevens, Munford and Saunders (p 210) on young people who use services, which shows that service users are individuals with complex needs and effective coordination presents a challenge.

Incidentally, this research provides valuable evidence of the experience of real youthful New Zealanders already using social services and was an expensive multi centre project of the sort that is increasingly hard to get funding for these days.

An example given of service coordination providing choice through personal budgets (and one which also uses a version of the navigator which is provided as an example in this chapter) is Enabling Good Lives. This is a programme which came out of the disability sector which still keeps a governance role. The former Minister of Disability Issues approved the initial idea from the sector and funded it.

Three government departments – Health, Education and MSD - are required and funded to work together, which has been hard work, along with the coordination of numerous other agencies as needed by the individual disabled person at the centre who is seeking a 'good life'. Several years after its initial gestation it has only been trialled so for on very small cohort of very high needs school leavers in Christchurch. It is effective because it is intensive, person centred and expensive. Therefore the full model is unlikely to be rolled out across New Zealand to the hundreds of thousands of disabled people who need such wrap around support. A second small demonstration project in the Waikato has just begun.

To work, such initiatives need to be properly funded to enable them to be slowly and carefully developed, kept within the kaupapa of the sector, be person-centred, and constantly evaluated and reviewed (and that includes all service providers self-critiquing any ableist prejudices). Public servants and contract holders need to be incentivised, encouraged and rewarded for working together and building relationships across agency boundaries. In the current climate this is not encouraged. It is easier and cheaper to stay in your silo.

In the disability sector we have the problem of sometimes numerous organisations covering one impairment group such as autism. Alternative organisations have developed to promote a particular therapy or sometimes to reflect demands for consumer representation that the parent organisation has ignored. They would be more effective for their consumers if they were incentivised to work together and overcome any philosophical differences, rather than compete for funding.

F10.1 mentions the value of the navigator or lead agency role for the client. But to work well this navigator, facilitator role must be independent of any budget holding agency. Otherwise the navigator will always be looking at what can be funded out of a capped existing budget or fit an agency's eligibility criteria, rather than concentrating on what the person at the centre requires to participate in citizenship. The facilitation needs to be an ongoing role to keep the parties talking and meeting their commitments over time, rather than a one off meeting. Sustainability builds trust and effectiveness.

One model favoured by some in the disability sector is a 'circle of support' around the person. Such a circle could start as soon there was a diagnosis or indication of extra support. The circle could be lifelong with membership changing as the child grew and the person aged. For example an early childhood educator could be included at first on pre-school diagnosis but changed to someone with expertise of education at other levels, or employment support as the time neared for transition from school. Membership of this circle could also include 'natural supports' such as family members or neighbours. In this model a child's 24/7 needs would be met, rather than the child chopped up depending on the time of the day, as happens currently.

Eventually the disabled person would do their own facilitation or agenda-setting assisted by an independent professional facilitatator/navigator. This model would take stress off parents and families and would ensure that the most appropriate services for each person requiring support could be provided, which would also be culturally appropriate and could also be reviewed as the child grew. As a sustainable model it would also be cheaper over time as institutional knowledge and continuity would be retained. Such a model could also stop children being removed from their families, or families reluctantly giving up their children to residential care.

This model used to be utilised around disabled children before the 'New Deal' in disability support of the 1990s created silos and competitive markets. My family experience in the late 1980s was of a psychologist, speech language therapist, play specialist, paediatrician, Plunket nurse and other

professionals working together around a child such as mine who had a diagnosed learning disability or autism, which was initially identified through an agency like Plunket. This wrap around, collaborative service was provided at no cost or effort to the family. Since the 1990s it has been the parents' job to seek all these professionals out separately and pay as required, and they are likely not to communicate with each other, leading to inevitable gaps or overlap.

R 10.4 Data –Disability data is not easy to find as government departments have differing eligibility criteria and few resources for collecting it. Data on impairments is not collected by Statistics NZ and they are now going to drop the volunteering question from the 2018 Census.

In my PhD research I heard about many useful pilots and trials which had been undertaken, some very ambitious and some small scale. But the reports were often hard to find having fallen into some black hole, particularly if they did not provide the message the commissioning Ministry wanted to hear. Many of us have provided such reports and I managed to acquire some from other parties. These were often evaluations of innovative trials. However, if there were criticisms or other reasons such as the commissioning manager moving on, many of them were never signed off to become formal reports available through the departmental website. Some reports did find their way into departmental libraries, but many didn't. So the learnings are lost.

The Ministry of Health also administers the Health and Disability Ethics Committees which approve numerous research projects of relevance to service delivery. So a clearing house of government funded research, reports and evaluations of social service delivery would be a hugely valuable. An NGO Community Research (http://www.communityresearch.org.nz/) administers an archive of independent research, but not government evaluations. I have often waited for reports on projects in which I am interested and have seen tendered on GETS, but for some reason never appear.

Real Me, which is now how the government expects the public to interact with it, is a particularly unfriendly platform which requires for access a high level of computer literacy and resources. People need a computer, broadband internet access, a working paid up cellphone and a high level of technical literacy to use Real Me to access government. This is not the reality for many New Zealanders. It is particularly difficult for those without computers or with learning difficulties. There is an urgent need to simplify access to government departments, such as more opportunities for face to face discussions which could readily be done through regular travelling clinics.

Question 10.1

There is also one question posed in this chapter.

Should the government seek to align the geographical boundaries used by its social delivery agencies for defining service responsibilities? What are the advantages and disadvantages of aligning boundaries?

Geographical boundaries eg education, DHBs, MSD, local bodies, are part of the problem because they are not aligned and major work would be required to align them (although it could be done with some good faith from the Centre). But there are other boundaries which are just as problematic such as when a child becomes an adult, for which there is an age range of several years between government agencies. The other significant boundary is between the under 65 benefit and the over 65 benefit which have different language, eligibility and application requirements and are measured against different wage criteria. Yet the over 65 benefit (National Super) is seen as an entitlement, not to be touched, by Government even though it is a greater expense to the State, and rising, than all the other benefits combined.

Some general comments on aspects of the report

Workforce

The social services/disability support workforce urgently needs to be built up and upskilled. In service delivery in the disability sector the closer the employed person gets to the client or disabled service user the lower the status and pay. While negotiation and decisions about contracting and eligibility may be made by people higher up, it is the disability support worker who provides the service. They are likely to be female, unskilled and poorly paid. They may work long hours for multiple employers. Yet they are performing often intimate cares and vital services in the client's home which require a high level of competency and professionalism. They need to build trust and confidence. Their work needs to have much higher status. Therefore we need to improve training and supervision for disability support workers, professionalise the service into one of 'personal assistance' with its own professional association, career path and backed by union support. Disabled people themselves need to be involved in training and supervision.

In recent years there have been numerous reports of abuse of disabled people in residential settings. Michael Roguski's chilling report of the hidden abuse of disabled people living in the community provides a warning of how easily disabled people in the community can become victims of abuse from a care workforce which lacks professionalization and skills.

http://www.communityresearch.org.nz/research/the-hidden-abuse-of-disabled-people-residing-in-the-community-an-exploratory-study/

Natural Supports

Natural supports usually means family members doing support for free. There is a growing tendency to rely more and more on personal supports as they are free, and money is tight. But the service user may have relationships with family members that are not conducive to respectful support, or are not age appropriate. There are a concerning number of young carers of disabled family members. Some families are exhausted or absent. Others are potential abusers. Support needs to be paid, ethical and professional. The Funded Family Care policy is also unethical and needs to be repealed so that those disabled people who want their family member or spouse to be their paid carer, can have the work done safely and their family members properly remunerated.

Culture of Fear in public service and community sector

There is a culture of fear in the public and community sector. I recently had a short contract with a government agency and was shocked at the time and effort put in to not upsetting the ministers. There was a culture of bullying evident in the ministerial directives that filtered down to the staff. It was unlikely in that environment that that Ministers were getting free and frank advice. I often encounter public servants who are dedicated to their work but feel they have to be loyal 24/7 to the Government to the extent of not participating in civil society or in voluntary work for advocacy organisations in their spare time. The example of the public servant who was censured by his boss and threatened with lack of promotion for being spotted among a crowd in a book shop at the launch of Dirty Politics is a good example of how such cultural fear and surveillance works.

Community Groups also fear speaking up if they have any government contracts for fear of losing those contracts. The Problem Gambling Foundation and Relationships Aotearoa serve as examples for what happens to organisations who challenge government policy and speak up for their clients.

Individualised Funding – client directed budgets

IF as an example of Client Directed Budgets is mentioned throughout the report as a way forward. But there is a risk that IF could drive down wages and conditions as the most attractive parts of the IF package are budget holding and HR while the person actually providing the service to the disabled person has the poorest wages, conditions and lowest status. Evaluations of IF other countries have shown that it is most likely to be taken up by white middle class people and their packages tend to be bigger than those not using IF. Extra attention to issues regarding gender, ethnicity, remoteness, family relationships and age need to be addressed for it to be taken up more extensively. Disabled people themselves must be involved in governance and evaluation of IF.

Removal of 'old cultural elements'

The recommendations of this report are interesting in the context of the forced closure of Relationships Aotearoa. Here was an organisation which helped vulnerable children and adults through many complex issues, including facilitation of strengthening families meetings, and dealing with family violence. Yet they somehow angered the government which raised the compliance bar and steadily decreased funding, before forcing its closure. Another organisation with limited expertise was then given a much larger amount of government money than RA owed to take on some of the RA clients. There is a hint as to why this happened in a comment on page 17 of Appendix D of this Productivity Commission report called 'Services for People with Disabilities'. Not only is the message that disability is a burden, and lived experience not valued, but there is a clear message for resistant organisations and people.

Appendix D: Services for People with Disabilities p 17

"The Commission has previously noted five principles for managing cultural change:

1. Survival anxiety must be greater than learning anxiety. That is, the fear that something bad will happen to the group if they do not change must be greater than the group's fear of learning new ways of operating.

2. Leaders should look to motivate change by reducing fear of learning new things, rather than increasing survival anxiety.

3. The change goal must be clearly defined in terms of the specific operational problem to be fixed (as opposed to the culture problem that must be addressed).

4. Old cultural elements can be destroyed by removing the people who carry those elements. But new cultural elements can only be learned if the new behaviour leads to success.

5. Cultural change is always transformative change that requires a period of unlearning and psychological pain. (NZPC, 2014, p. 108)"

Lessons from the Australian National Disability Insurance Scheme

My final comment is that there was a chance with this Productivity Commission report to recommend a National Disability Insurance Scheme as they have begun in Australia. With our ACC scheme and its current surplus funding we have the perfect opportunity to address inequities in disability support between Health and ACC, between impairment caused by accident as opposed to other causes, by extending a levy system.

The National Disability Insurance Scheme was a recommendation from the Australian Productivity Commission in 2011. It was promoted by the first Australian Minister for Disability Issues, Bill Shorten, championed by PM Julia Gillard, and passed into legislation in 2013. It was to be a universal federal disability scheme, funded out of taxation and levies, state and federal. The most similar model is the NZ ACC scheme. Although while ACC only covers injury by accident, the NDIS theoretically covers impairment from any cause. It is overseen by the National Disability Insurance Agency (NDIA), which seems to have a similar role to ACC.

> *The NDIS is a key plank in the National Disability Strategy 2010–2020, a cross agency cross jurisdiction agreement between all federal and state governments …. While the Strategy is the overarching Australian policy approach to disability, the NDIS is its most prominent—if not iconic—contemporary element. As such, the NDIS has been widely debated, because its architecture, implementation, and implications, hold considerable importance for disability and indeed Australian social policy in general.* (Goggin and Wadiwel, 2014)

It is aligned with the principles of the UN CRPD

> *The NDIS is, at least rhetorically, informed by a rights approach, in the form of the United Nations Convention on the Rights of Persons with Disabilities. The NDIS legislation specifically states an aim to 'give effect to Australia's obligations under the Convention' … and cites other international obligations, such as that under the International Covenant on Civil and Political Rights.* (Goggin and Wadiwel, 2014)

Before it could be rolled out agreement was required from all states which had to agree to give up some of their state disability budgets for the national scheme. Additionally there was a lot of work done aligning ICT systems, assessment and support pathways and other requirements. Some of the states which had fully agreed to the scheme under state Labour leadership changed their minds or made funding less of a priority after Coalition wins. However, there is now a general agreement on the existence of the scheme itself (again similar to political manoeuvrings over ACC) and varying levels of state support.

In 2013 at a conference in Adelaide I was told by a speaker from the Canberra HQ developing the NDIS that eligibility would be wide and anybody could come through the door and ask for support. There would also be attractive individual funding packages for people to choose their own provider for wrap-around person centred support, which would be easy to change if they chose to as there would be multiple providers vying for their business, or they could employ their own.

States were able to decide their own implementation priorities and how to roll them out. For example, South Australia chose to start with children. The state implementations had just started when the Gillard government lost office. The Abbott government promised to keep the by then already popular scheme.

Last week I went to a symposium at the University of New South Wales in Sydney on the NDIS. The speakers mainly came from critical disability studies and associated disciplines with varying degrees

of hands on involvement with the scheme (eg disabled people's organisations, provider organisations, advocacy, and evaluation). My colleague (a wheelchair user) and I went with some degree of NDIS envy – which was the title of his keynote – which bemused our Australian colleagues and it didn't take us long for us to have a reality check.

> *One of the early sites of political contestation in relation to the development of the NDIS was the question over which supports would be considered 'reasonable' to be provided by the Scheme … After a public review conducted by the National Disability Insurance Agency, the supports that are now considered 'reasonable and necessary' are largely restricted to those supporting 'daily personal activities' and employment related support.* (Wadiwel and Goggin, 2014)

We also learned:

- Only 10% of disabled people are currently considered to be eligible. Eligibility criteria and assessment is very tight and age restricted to under 65 (which also means certain impairments such as those with post polio syndrome which mainly affect older people are not covered). There is a tier hierarchical system of funding.
- Disability and support are apparently not defined in the Act so decisions are largely left to the all-powerful NDIA about who is eligible and what supports are needed.
- The state government of NSW agreed to give all its budget to the federal scheme so has nothing left for monitoring or evaluation or other disability provision in its own right.
- Residential support is provided but not housing itself – so shortages of suitable housing cause problems (as is the current situation in NZ).
- There is limited success in working across sectors/silos. For example, it is still unclear how things like adaptive technology such as for children with autism who need it at home and at school, will be funded or provided.
- Remoteness and racism mean much of the Aboriginal population and other minority groups have minimal access.
- Advocacy and political participation which were part of the original alignment with human rights principles are contentious and not funded.

So the NDIS is still a great idea in theory but implementation depends on political whim and good faith. Many aspects of the original ideas have apparently been easy to undermine while others are still evolving. There are many similarities to our history with ACC – regular cut backs, sudden change, expansion, little stability or predictability. As with any insurance scheme, actuarial objectives, not equity principles, prevail. However, having one federally-controlled disability insurance system is valuable and needs protection and development as it is better than the fragmented, inequitable system it succeeded. Private, contestable disability insurance will never provide as affordable or widespread cover. With political support New Zealand could extend ACC into a universal disability scheme, learning valuable lessons on implementation from the NDIS.

National Disability Insurance Scheme http://www.ndis.gov.au/

Goggin, Gerard and Dinesh Wadiwel (2014). 'Australian disability reform and political participation' *Australian Review of Public Affairs* http://www.australianreview.net/digest/2014/09/goggin_wadiwel.html (full article online via this link - both these writers were impressive speakers at the symposium I attended).

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