Presentation Paper

On The

Disability Care and Support Issue Paper May 2010

By

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Introduction

My wife Anne and I are both 71 years old and are the parents of Paul who is 40 year-old, and is severely disabled, suffering from cerebral palsy requiring 24 hours care. Paul lived at home until the age of 23 but due to being unable to health reasons he went into care. This has provided us with a wealth of knowledge regarding what is wrong with the disability sector and what is required to fix it. I have decide to present my response by referencing Sections, Paragraphs and page numbers by dropping in selections and providing responses beneath them.

Responses

Section 4 – Rationales for and objectives of a long-term disability care support scheme

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- giving people complete choice and power over the use of disability funding may raise accountability issues for what is public money and may not always serve all people well

Once a funding package has been agreed to and allocated it shall be held by the issuing authority until Care Provision, Social inclusion and any special equipment that is required has been arranged. At that point the funding shall be transferred to the Care Provider, Social inclusion organisation and the supplier of special equipment. This should provide accountability of the funding.

- more choice for individuals and families may also mean greater uncertainty for service providers and coordinators, potentially leading to less coordination and greater costs.

More choice for individuals and families shall ensure that the Care Providers are preforming well, those who don't shall be weeded out of the system.

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What are the specific design implications of the UN Convention?

The eight guiding principles of the UN Convention should become the core issues for the creation of a new National Disability ACT.

What weight should be given to each of the various objectives? How should the various objectives be traded-off against one another if they conflict?

Equal weight should be given to each of the various objectives. If any conflict comes up then it is imperative that it is tackled in a manner that any proposed chances do not have an averse affect on those with disabilities.

Section – 6 Who should be eligible?

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Is need the appropriate basis for eligibility?

As need covers such a wide demographic section of the population I do not think it is appropriate basis for eligibility. Eligibility should be based on severity of the disability with the most severe being the most important.

What groups have the highest needs or have been most disadvantaged by current arrangements?

Those with severe disabilities have the highest needs and at the moment are the most disadvantaged by current arrangements. This is because of their inability to communicate leaves them in a very vulnerable to abuse, neglect and intimidation.

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How does need overlap with core activity limitations or other criteria for identifying the severity of disability?

As long as eligibility is based on Severity of the disability being those requiring 24 hour care as defined by an assessment carried out by an independent commercial company then there should not be any overlaps.

Is 'severe or profound' disability an appropriate criterion for the need for support?

Yes. See above.

To what extent should other facets of a person's life: their location, access to services, family circumstances and any disadvantages affect eligibility?

How should carers' needs be factored into eligibility?

As the person with the disability is the most important factor in all of this. Then once the assessment has been completed and eligibility established then both of the above could be looked into.

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How do you ensure that eligibility processes are consistent, fair and transparent?

By having a national assessment scheme that has the capability of producing consistent results. Ensure that the person with the disability and their family have input to and are kept informed during the process.

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What are the implications of adopting more or less generous eligibility criteria on fairness, adequacy of services, costs and incentives, and how could these be addressed?

Adopting a more generous eligibility criterion shall result in a cost blow out mainly because it shall see an increase of people being accepted. A less generous eligibility criterion would result in the opposite occurring. To achieve balance and fairness, cost control etc. The answer is above

Should the scheme apply to new cases of disability or to all people with existing disabilities?

The scheme must apply to all people with a disability otherwise two tiers would be created, the new cases obtaining a far better deal, leaving those with existing disabilities stuck in a rut with what they have.

Section 7 – Who Makes the decisions?

Page 24

How can people with disability and their carers have more decision-making-power in a national disability scheme? How would the success or failure of new approaches be tested?

I have previously touched on this subject and still say that the decision-making-power must be given to those with disabilities and their families, they would then sit down with Care Providers and negotiate a “Contract of Care” a document once implemented would have to be complied to. Success or failure could be tested by an independent Quality Audit, which would involve the person with the disability their family and the Care Provider.

What should be the decision-making powers of governments and service providers?

Governments and Service Providers powers should be more of an administrative nature and less about how the services are provided. At the moment that is one of the major problems because some Service Providers are locked into the “One Size Fits All” which results in the person with the disability living the life defined by the Care Provider and unfortunately something that the Government department that provides the funding is quite happy with.

Should individualised funding include the capacity to save some of the annual payment for future purchases of services or borrow from future payments to pay for current services?

Once the funding amount is agreed to then a portion it could set aside of it in a “Reserve Account”, which would be held by the issuing authority. I don’t think borrowing from future payments is good idea because it must have a negative impact on the total available funding.

How should the national disability scheme support people’s decision-making under individualised funding, taking account of the spectrum of disability — both in terms of the nature and severity of disability? Should all people be able to access individualised funding, and if not, what guidelines would be appropriate?

If the person with the disability lacks the ability to understand funding issues then the scheme should have the avenue available for parents or an advocate to control the funding. As long as they have been assessed and deemed eligible then all should be able to access individual funding.

What are the risks of individualised funding and how can they be managed? What guidelines would be appropriate? How would any accountability measures be designed so as not to be burdensome for those using and overseeing the funding?

The major risk is misuse and having touched on this earlier the answer is to have strict controls on the funding. An independent auditor could be appointed to track accountability

Should people be able to treat funding as ordinary income and do what they like with it? Should primary carers or other family members be able to pay themselves for providing care?

Simple answer is NO as it leaves it open to the misuse mentioned.

Who would be responsible for monitoring individualised funding?

An independent auditor

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What would be the impacts of individualised funding on service providers and do these impacts matter?

It would create competition resulting in better service to those with disabilities.

Section 8 – The Nature of Services

What are the most important services, their costs, their likely demand and who would be the predominant users?

For the most disabled that can't do anything for them selves, the most important service is personal care this is because a high ratio of care workers to client is required which comes at a very high cost, followed by community access, leaving the person with the disability to select either one to one or group. The demand for these services would be high.

How should service providers be monitored and regulated with respect to quality, outcomes and cost effectiveness?

By independent audit which includes parent input.

Should all services be free or should there be scope for co-payments? To which services and/or people might a co-payment be applied? How would the size of co-payments be determined?

Services should only be free to those that lack financial resources. All others based on a means test shall contribute.

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To what extent, if any, should people be able to cash-out the benefits from a basic service/appliance/aid (for example, a wheelchair that met assessed need) and use it as a part payment in purchasing a premium service (a more advanced wheelchair)?

Simple answer is NO, because again it would create a two class system.

How are service needs likely to change over time and how should that be accounted for in designing a long-term care system?

As the person with the disability ages they are more likely to see there condition worsen, leading to a requirement for increased care. Annual assessments should be carried out to determine if increased care is required.

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Should a nationally consistent tool be used (and what process would be used to achieve consistency quickly)?

Yes

What are the risks associated with different approaches and how can these be minimized?

Different approaches should be avoided because they could lead to inconsistent results being produced this can be minimized by the use of a National Assessment system.

How would data from assessment be used? (for example, should it be available to a range of service providers?)

The data from assessment would become a mandatory care document that the care provider would have to comply to.

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What are the obstacles to a cohesive package of disability services, where do the problems most arise, and how can they be fixed? What processes might be needed to fix them?

The two areas where we have encountered are the government department that deals with disabilities and the Care Providers, both of these left our son my wife and I out of the negotiations ending up with our son receiving inadequate funding to cover his needs. The way to fix this situation is to have a fully transparent system where the person with the disability and their parents involved all the way through and for them to sign off the agreed funding package.

How do you prevent cost shifting between services inside and outside of the scheme?

Auditing!

Page 30

Should income support and disability service provision be coordinated as part of a package, and if so, who would do that and how? What conflicts or synergies could arise between a national disability scheme and income support?

No, this scheme should be for disability service provision only.

How could the capacity for people to move between services — both intra and interstate — be made easier?

Individual funding under the control of the person with the disability and their family would provide them with the flexibility to take that funding to another service, intra and interstate. At the moment is almost impossible for a person with a disability to move interstate and in many cases to easily change service provider.

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How should insurance arrangements for catastrophic injury link in with a disability scheme?

If a current insurance scheme is working well then leave it alone (no need to re-invent the wheel). Insurance payouts would be used to provide care and any special equipment, thereby taking the load of the disability scheme.

Section 10 – Financing options

Funding Consolidation?

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What would be the best way of financing a national disability scheme and why? What are the strengths and weaknesses of alternative financing arrangements, including 'pay-as-you-go' and funds that take account of future liabilities?

A Medicare levy has been mentioned as a way of financing a national disability scheme and even though this would probably work but because it could be seen as another tax slug it could prove difficult to sell. I would like to propose the setting-up of a "National Lotto System" with two draws a week and I am confident that it would bring in a large amount of funding, maybe even enough to fully support the system. Also as it would be

voluntary it would be more appealing to the general public and would take pressure off other forms of funding.

12 Governance and infrastructure

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- *should government departments or an independent statutory body administer the scheme?*

An independent body should be the administrator of the scheme and should be a commercial company; this should lead to a lesser cost than government control.

- *to what extent could one agency act as the fund holder and overall decision maker (the role performed by the Transport Accident Commission in Victoria for people affected by catastrophic motor vehicle injury)?*

The national independent statuary body mentioned above should be the fund holder and overall decision maker. This would enable those with disabilities to utilise their funds anywhere in Australia and ability to select their Care Provider.

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How can we reduce the need for form-filling and unnecessary re-assessment?

Recently we had 12 forms from the Care Provider to fill in all of this can be eliminated by taking away control from Care Providers and giving it to those with disabilities and their families leading to a drastic reduction in paper work.

- *making complaints (for example, a disability ombudsman; complaints devolved to service providers or a centralised complaints arrangement process)*

A National Ombudsman should be appointed; this would give commonality nation wide.

- *reaching determinations in any disputes (for example, internal departmental arrangements, independent boards, courts or tribunals, or a process involving a number of layers)?*

Independent boards would be the best way to resolve disputes.

How would people find out about what they were entitled to (online, one-stop shops, service providers)?

One-Stop shop is the best method because it puts to end the “Bouncing Ball Routine”. At a meeting with Bill Shorten I offered to set-up and run a One-Stop shop, providing my time for free but he did not show any interest in it. I have mention the One-Stop shop to many people and they all say, “Why does it not exist”.

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Implementation Issues

What is the realistic time plan and sequence of initiatives for implementing a national disability scheme?

The current plan for implementation to occur on around 2013 is too long it should be aimed to occur no later than the end of 2011. Even during the time that this report is being produced all parties should start in earnest discussion on implementation issues.

Are there some aspects that can be implemented early (for example, some service expansion, support to a targeted group, key infrastructure)?

As they shall not cost a lot to immediately implement, Individual funding and taking control from the Care Providers and given to the person with the disability and their family. This would go a long way to resolving some of the contentious that exist at the moment.

Section 13 – Appraising costs, risks and benefits

Benefits

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What are the benefits from a new disability care and support scheme? Which are most important? Who would benefit most from a new scheme? Where would additional resources be best spent? What level of funding maximises the gains from a new scheme?

The major benefits of a well structured scheme would provide the proper level of funding to ensure that those with a disability at long last have a lifestyle they deserve and provide their families with confidence that they shall be well looked after. The most important are the people with disabilities. Additional resources must bypass managerial level and be used to ensure the number of Care Workers is increased.

Conclusion

As I went though the document, noticed that some questions were repeated in a different manner and wondered why!

Concerns

The main concerns my wife and I have is the time that it is going to take to implement the scheme which at the moment is around 2013 or later, as we are both 71 and our son is 40, this is far too long and as Bill Shorten MP has stated that it may never occur believe that it is unreasonable and unacceptable to ask those with disabilities and their families to wait this amount of time for something that may never occur.