PRODUCTIVITY COMMISSION SUBMISSION

While I have not counted all the questions in the Issues Paper and I haven't attempted to answer them all, I have endeavoured to provide a comment about some of those which I have had to consider or for which I have been forced to consider.

I have chosen to work in the disability industry not because it is the most rewarding or best paid industry, not because it has the highest status or recognition and not because most people think it is important but because I think it is an important field of endeavour.

This industry has given me some of the most rewarding highlights of my life, as I have watched or walked with someone who has struggled to achieve their dreams and they have done so despite all the extra challenges they have had to face, despite all the extra weight they have had to carry by working their way through the bureaucratic maze. I know that I and the people I come in contact with each day are better for my experiencing these struggles and witnessing these achievements.

This industry has also given me some of the most frustrating experiences and sleepless nights. I have experienced the innumerable conversations of "what happens to my child when I die?" I have not been able to provide a good enough answer to let these parents die in peace. Or the conversations I had with a mum who was born and lived in Australia and whose son was born in Australia but who had remarried and was living in Britain where her son was diagnosed with a disability.

When she said to me that her family wanted to return to Australia and that in Britain her son was guaranteed the following list of things and services and supports and she wanted to know what he would have been able to access here and what was my advice? Telling her that Australia could not offer her anything like what her son could and was getting in Britain was confronting and a conversation that still haunts me.

I also cannot forget the conversations that I have had with families who have told about what they had to do to get services for their child with a disability. Giving up their child to the care of the state, to a system designed to protect children from abuse and neglect was the only option they felt they had to ensure that their loved child with a disability could access the support and services they needed.

I do not want to try and articulate all the things that are wrong with the current system but I have tried to outline some of the ones above that deeply concern me. I do know for certain one of the things about change in disability in Australia, that is more money and more of the same will not be anywhere near enough change that people with a disability, their carers and families need and deserve. Australians deserve much better than that.

I was involved in the establishment of the first stand alone disability department in Queensland, something that I am proud of but it has not delivered enough change despite a very large increase in the disability budget.

Disability rights are basic human rights that cannot be put on the back burner any longer.

Key Questions and Key Responses

Who should be the key focus of a new scheme and how may they be practically and reliably identified?

In Australia we appear to have a number of methods for identifying who amongst our population are identified as having a disability. Each of these methods or schemes seems intended to regulate access to scarce resources by identifying people with a disability.

Do we need to invent another way of doing this or is there a better way of using the current schemes and methods?

Is the most universal method of identification that which is used for access to the social security safety net? Does this identify most people with a disability?

The Productivity Commission Discussion Paper then seems to move toward prioritising to people with a severe or profound disability and there appears a rather compelling logic to that as well. Targeting the people with highest need.

However if we do that only, does this not mean that to gain access to supports then there is a perverse incentive for people to overstate their disability rather than emphasise their capacity and coping?

What would we need to have in place for people to access something that promotes and facilitates coping and not entry into high cost tertiary systems? If we are using the Health Medicare model then maybe there is a relationship in part of the approach to the wellness community health approach to people who with a disability do not find themselves toward the severe and profound end of the scale.

What groups are most in need of additional support and help?

Do we need to say that children, even if they are not toward the severe and profound end of the continuum, should also receive priority? Are their long term coping skills and capacity to not progress toward the severe and profound end of the continuum best impacted on if they receive timely and intensive assistance? Eg Can we focus on the communication skills and getting these to best functioning level and by doing so lessen the long term reliance on more intensive services or lessen the likelihood that these children as they grow will progress toward the severe and profound end of the continuum?

Again we do not want to create perverse incentives like some experiences where a child with a disability comes into the care of the State through their Child Protection system in order to get access to services that they could not access while they were at home with their family.

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

Location should not be a key determinant in someone with a disabilities life chances. Living away from where services are based does provide additional challenges but it should be challenges in how these services are delivered and by whom rather than if there are appropriate interventions available. Surely when we have a growing penetration of tele-medicine we should be able to counter the issues of distance and where services have chosen to locate.

Family circumstances are critical and developing resilience and appropriate levels of support to families to undertake their caring role without having to carry the burden of replacing services is critical. Mums, dads and families need to play these roles and be supported rather than feel they must replace and take up the slack that comes from the absence of appropriate supports. Otherwise we will continue to grapple with the perennial question mums and dads ask “who will care for … after I die?”

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

This is a perennial problem when trying to regulate scarce resources. Unless you have a universal system and say that everyone who has a severe or profound disability and/or every child with a disability is eligible for support I don’t know how you can.

Even if you do go toward the universal approach you will still revert to having a needs based approach where by virtue of your status or label you end up with a different response to someone who may perceive themselves as having similar status or label.

This however may be a way of saying to people that the universal approach gets you this much and if you require more then you need to be able to demonstrate that there are other needs and this will require you to go through a range of assessments and other measures to access additional resources. Some people may choose not to do so and others who do will at least have some idea of what they are choosing to embark on.

How should the scheme address disability associated with natural ageing and why?

What implications would the resulting eligibility criteria have for people outside the system?

Is a point of divergence that many people with a disability experience the onset of conditions associated with ageing at an earlier chronological age? How do we cope with someone with Downs Syndrome who starts to experience dementia in their 40s and 50s unlike most of the population?

There are many very high quality aged care services and facilities but having someone who is not old live in these is not a choice many of us would choose to make.

Similarly people who work in aged care are trained to do so and having someone who is not aged and who has a disability unrelated to ageing is not necessarily in their core skills set.

Comprehensive versus narrow scheme/coverage

A key tenet of whatever scheme should be the mechanisms that determine entry or exclusion should be modest in cost. If the assessments costs are high should we not dedicate those resources to supporting more people.

Maybe there is an argument for a Universal scheme where there are some clear and hard to dispute criteria that determine whether you are eligible or not.

As stated earlier if you are eligible you may then elect to undertake a further more comprehensive assessment to gain access to a more intensive support approach. If you are eligible and you do not choose to undertake further assessment then you should be able to access temporary or low level supports; transitional supports; supports that relate to a life stage and early intervention.

You really want to avoid creating systems so complex that you devote large amounts of resources to maintaining the assessments associated with the system.

All people or only new cases of disability?

I wonder whether setting a date for eligibility will just cause people to complain about the effects of acquiring a disability at 11.59pm versus midnight rather than focus on what can be achieved.

I would favour a universal scheme so that all people know where they stand.

It may be possible to provide a transition to this new approach where people can opt to stay with what they have or elect to go into the new scheme – a no disadvantage requirement is probably required.

To what extent should eligibility include people experiencing short term disability (7-12 months) compared with people whose disability (and associated needs) is expected to last many years?

I have mentioned a number of times the idea of a universal system with people being eligible or not and for those who are eligible they may then elect to undertake a further more comprehensive assessment to gain access to a more intensive support approach.

If you are eligible and you do not choose to undertake further assessment then you should be able to access temporary or low level supports; transitional supports; supports that relate to a life stage and early intervention.

You really want to avoid creating systems so complex that you devote large amounts of resources to maintaining the assessments associated with the system.

How often should eligibility be reassessed?

In the approach I have proposed re-assessment would occur if and when you decided to seek to go from the short term, time limited eligibility to the more comprehensive ongoing approach.

Once in the more comprehensive system segment it becomes a question of what returns on your re-assessment investment do you get? You do not want to create a system that is so complex to regulate that you spend significant resources on regulation.

How can people with a 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?

Simple control over the resources at their disposal rather than someone else making these choices.

People with a disability have greater control over their lives, not being reliant on others to decide who they should live with and where they should live so that they can access a level of support.

Understanding that paid support is only part of their life needs and it is paid for by other people.

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

Simply asking what is it that governments are good at and what is it that service providers are good at is a good start. Neither is particularly good at articulating the needs of people with a disability and therefore should not be trying to do this.

Service providers should be focussed on developing flexible, innovative and responsive approaches to the sorts of needs and desires that people with a disability, their carers and advocates are saying they want. Services need to be good at monitoring the quality of these and ensure the fit with what they are providing and what people are asking and requiring.

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?

General response is yes to both – there may need to be some agreed upper and lower limits.

There is a later question about being able to cash out benefits from a basic appliance and use this toward a more advanced appliance with a wheelchair being used as an example. My response to this would also be yes.

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?

All people should have access to individualised funding to maximise their control over their life and future. Access to advocates to support this is essential to ensure that people maximise their control.

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?

Should people be able to treat funding as ordinary income and do what they like with it?

General comment is that there should be the ability to maximise the flexibility of the funding to achieving the desired outcomes. There does need to be a link between the funds and the desired outcomes.

Should primary carers or other family members be able to pay themselves for providing care?

General response is yes but.

I think there is a good case for some funds to be available to reimburse carers for the costs associated with their caring role and it probably links to the next question.

A key question is how it is judged that this is a real choice for the person with a disability and promotes their independence and access to a good life.

How would individualised funding work in rural and remote areas where service availability is poorer?
There may be a link with the previous question where the choices in rural and remote areas mean that there is a greater reliance on the roles of carers and other individuals who are close to the person with a disability.

Again a key question is how is it judged that this is a real choice for the person with a disability and promotes their independence and access to a good life?

Who would be responsible for monitoring individualised funding?
Is this one of the things that governments consider they are good at and could it be done in a way that involves other people in the process?

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

Generally the impact on service providers could be that they need to be more responsive and focussed on the needs of individuals with a disability which would seem to be a positive outcome.

However if the only money flowing to service providers was individualised it may provide a paucity of choices to the person with a disability. Recent experience from families who have accessed support under the Autism program has been that it has been difficult to get some of these services. Service providers did not have the certainty to engage clinicians who might undertake this work. Without the service provider knowing that they had enough work so that they could pay the clinicians it appeared that they were making the choice not to engage additional clinicians.

This may lead to a lessening of the number of service providers or a concentration of service providers to those who could carry these costs or cross subsidise.

Are there ways other than individualised funding that empower people with disabilities and their families?

I think that a mixed economy model which encompasses individualised funding and capacity funding of service providers and advocacy organisations so that there is strong choice, maximising the person with a disability being in control and them having support outside of the service provider, or family or carer.

Are there any services not provided now that should be part of a national disability scheme?

I think that there needs to be an increase in the funded capacity of individual advocacy and individual planning so that people with a disability are empowered to clearly articulate what it is they want and the steps they need to take under a new disability system.

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

The current systems at play are largely about compliance with checklists and do not go to real quality measures.

One of the best quality measures will be individualised funding supported by individual advocacy support. Simply put people could move their money if they are not getting what they want or have been promised.

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?

General comments are that most obstacles occur around a boundary issue, whether this a transition due to age child adolescent, adolescent to adult, adult to ageing or through interaction with another system metal health, health, housing or criminal justice.

Trying to have meaningful engagement with a person with a disability as a whole person, rather than someone who is being bounced between systems or across boundaries is likely to have a better result.

Having access to an individual advocate or guide to help navigate the vagaries of these transitions and various systems is also critical.