Productivity Commission

THE DISABILITY DOLLAR

The questions

The Issues Paper poses one key question – ... *how to build a good system* followed by one hundred and sixty six questions. The Key Questions Paper asks seventeen key questions.

> Are you surprised that of the submissions received to date, not one has responded to the 166 questions posed? Just a few addressed the seventeen.
>
> When you consider the number of PWD and the number of service providers across Australia alongside the number of submissions received, I am wondering how widespread your advertising went (newspaper ads don't hit your target group!). Was any thought given to a mailout to everyone on a DSP, in receipt of an ISP, to every service provider from GPs, CHCs through to the larger organisations? In view of the small number of responses, "Your views will help us prepare a draft report" is a real concern as people's views have not really been canvassed.

The authors

This is the first Productivity Commission Issues Paper I have read. It appears to be similar to the increasingly-used bureaucratic practice of a decision being made followed by a process of its justification through consultation.

> Who is the author? If there were a team of writers, who were they and what positions do they hold?
>
> Did Assistant Treasurer Nick Sherry write the Terms of Reference himself? Or were those who wrote the Issues Paper involved in developing the ToR as well?
>
> I note that Associate Commissioner John Walsh (and Sarah Johnson) from Pricewaterhouse Coopers prepared *Disability Investment Group National Disability Insurance Scheme Final Report*. FaHCSIA commissioned PwC to prepare the report. How much did this report cost? Was it put out to tender?

The report

The report itself is dreadfully dry. There was no celebration of the things that are working! To spearhead the enormity of the change required I would like to remind you that *Big Change comes from a succession of Little Changes*! So please make your recommendations little!

The key design elements

I would strongly urge future diagrams of the key design elements of a disability care and support scheme to start with the person with a disability and their family first instead of burying them in the third tier, “scope”.

The costs

About us – Without us. I laboured through the economic rationalism behind the PwC DIG NDIS report. What was missing was the <u>human factor</u> of disability.

Alongside all the data available on program costs, it is important to know the costs to the family, and the hidden and often overlooked costs as well. What does it cost to raise a child with cerebral palsy or autism? what does it cost to readjust your life as an adult after an ABI?

It is just as important to know the family costs and the circumstances which influence these costs as well as how you are going to fund them. The costs of economic burden include such things as: respite, equipment, medication, home renovations, support workers, travel costs, child care, telephone, special clothing, etc. and then time costs such as time from work to provide care, foregone income, lost leisure time. etc. And the social circumstances of the caregivers should also be considered, for example, is this now a single-parent family unit?

> Why did the PwC DIG NDIS report only consider program costs and not include family costs?

The language

English is one of the most delightfully expressive languages, yet we tangle ourselves in its use. (I personally don’t think the word “disability” should be used at all! Is a parent who provides care for their child with a disability really a carer? Maybe they are just a parent [and in need of extra income to provide!] Is a person with a disability really a person with a disability? Maybe s/he is just a person.)

One hundred years of discriminatory language has enabled segregation to fester. If we had talked about *difficulty* rather than *disability* over the last 100 years, what a difference that would have made! The concept of “body difference” needs a rethink!

The statistics

An inordinate amount of current disability dollar goes towards a less than ideal national collection of disability data (the Quarterly Data Collection which eventually feeds into reports produced by the Australian Institute of Health and Welfare, viz. *Disability support services: national data on services provided under the Commonwealth State/Territory Disability Agreement*).

There are also many other government departments, federal, state, local, collecting data (for example, FaCHSIA undertakes the Disability Services Census) and these should also be reviewed and questioned.

> Just how much data is needed? To what end? For what purpose? But more importantly, what saving there would be if this administrative burden on service-providers across the nation were to be abandoned!

Certainly a statistical data collection system needs to monitor the extent of disability across Australia, disability type, demographic information etc., but this can quite easily and more appropriately be gathered by one body, the Australian Bureau of Statistics.

The information network

To have the right to decide what disability service is best, one must have the information so a decision can be made! Reading the personal experiences of many Australians who have exposed their struggles in life through the submissions presented shows a basic lack of information available when people needed it the most.

Beyond Blue: the national depression initiative has a fantastic one-stop-shop approach to providing information. From an Info Line to a website of information, this service has not only demystified the condition but helped countless Australians across the nation. *Diversity: the national ability initiative* could similarly become a centralised national clearing house of information, providing real and reliable information that would otherwise have to be sought by good luck and a fair measure of chance.

From pre-birth to death, a suite of ability and disability affects us all. There are a number of excellent websites already established, but now there is a proliferation. The internet is a valuable source of information, but a one-stop-shop to avoid the costly replication is required. And how wonderful it would be if you were a mother with a child who had recently been diagnosed with autism, to be able to telephone just the one *Diversity* telephone number for all the advice you will need.

The NDIS

The National Disability Insurance Scheme began with enormous heart but little practicality. How the Productivity Commission, our peak independent research and advisory body, can remain independent from three tiers of government complexity, and turn the dream into a practical reality, will be seen in the draft report to be made available for public comment next year.

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