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Bundaberg
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RESPONSE TO DRAFT PRODUCTIVITY COMMISSION 2011 *Disability Care and Support* DRAFT INQUIRY REPORT,CANBERRA.

This response is provided as a parent/disability advocate who has lived disability – for the past 40 years.

I commend the Report and welcome the recommendations contained there-in. Your joint efforts are very much appreciated. It is wonderful to see such a reputable body re-affirming what we, as families, have been saying, and living, for decades.

Having lived in the regions all my life, my comments reflect regional issues, which can sometimes differ from those of provincial, metropolitan and/or urban Australia. The comments, however, are based on actual life experiences both as a family carer and an independent advocate for people with disability – usually intellectual/complex/or dual.

AGED CARE TRANSITION:/INTERFACE *RECOMMENDATION 3.5*

This recommendation fails to address two existing, and growing problems:

1. As demonstrated in my original submission, & as personally experienced with my son, many people with disability age prematurely. Indeed premature ageing is an acknowledged clinical fact for some disabilities, particularly intellectual disability. This is confirmed by :

   The Influence of Intellectual Disability, on Life Expectancy – Bittles et Al- Journal of Gerontology;Jul 2002;57A,No.7;Academic Research Library, Pg M470-M472),

   Mortality of people with intellectual disability in Northern Sydney. Durvasula, Beange et Baker, Journal of Intellectual and Developmental Disability, Vol.27,No.4 ,pp.255-264, 2002

   www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm

   www.ninds.nih.gov/disorders/williams/williams.htm.

Our son had Williams Syndrome, a rare disorder in which “premature ageing” – is a clinical feature, but the “system” wouldn’t recognize it. Though clinically prematurely aged at 35, he would have had to live a further 30 years to obtain any Federal assistance with his day- to- day care. An increasing problem is now also visible in people with Downs Syndrome, who are also clinically ageing prematurely.

Premature ageing is aggravated by the fact that many of our people are now living longer, and no provisions have been made, within the current system to accommodate this. The existing criteria is a mandatory "pension age", for access to Federal assistance, but this perpetuates the growing problem, instead of addressing it.

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A younger threshold, (instead of a mandatory "age" threshold,) should be available to all – not just our indigenous population. But it should be *"based on medical assessment and needs"* to prevent abuse of the system.

Currently the younger threshold for our indigenous people can be, and is being used to disadvantage them. (***Refer confidential appendix . 1***). The reality is that where an indigenous person's rehabilitation and/or needs are better served in the community and/or home, it suits State Government budgets (States are responsible for service delivery under age 65) to place them in an aged person's home (A Federal cost burden) – simply because they (legally) can, even if it isn't the best placement. This shifts costs from the State to the Federal system, even though the best interests of the person with the disability are further compromised by being placed with people in the "twilight" of their lives.

It is the reverse for non-indigenous persons who are prematurely aged. The mandatory age threshold allows the Federal Government to cost-shift to the States until the person is aged 65.

Eligibility should not be based on a life expectancy ratio – across the board – as my attached case study demonstrates.

The current assessment process of the ACAT (Aged Care Assessment Team) has not been aligned with the increasing longevity of people with disability and/or their needs. This is not a criticism of the dedicated staff within that system, but the State v Federal budgets, which dictate the implementation of rigidity to the "pension age" – and this age is slowly increasing. I have been involved with people, obviously suffering early dementia – but not yet 65 – so not eligible. In fact, incontinency seems to be a more eligible criteria than Alzheimers.

Your recommendations do address the need for flexibility for people to move within the aged care and proposed NDIS systems, but this will not happen in the short term, and we have an increasing emergency, now, as the various levels of Government protect their budgets.

Recommended *flexibility within the existing ACAT system – in the interim* - , and a recommendation within *3.5* that "pension age" should be determined by *medical assessment and individual needs* would address the current problems for those who are *"prematurely aged" and/or "indigenous"*.

Family carers now have no recourse, as existing eligibility to Federal funds is based on mandatory age limits in an inflexible ACAT system and cost shifting between levels of Government.

OTHER INTERFACES:

Employment – Business services

I have already covered the interface between aged care – ageing - and the delivery of services, under different budgets, by Federal and State agencies, but the other area which does not seem to feature in your recommendations is that of employment.

In 2005 I represented Australian workers in business services before the AIRC, where, with the Unions, we negotiated the "safety wage" and "productivity" assessment tools for our business services.

Whilst I appreciate that business services are covered by a different Federal Department, and understand why your Inquiry could not fully cover them, I would feel more comfortable if the link between business services and Disability Care and Support – albeit from another Federal department – was acknowledged.

The reason might not be immediately obvious to those who do not live disability, but the reality is that there is, despite the best attempts of many of us, a connecting link between the two. It costs money for people to attend a "day service". You get paid, probably not enough, if you attend a business service, but it does complement your pension, and provides more disposable income for the recipient. Additionally, if you reside in supported accommodation, and attend a business service, you have more disposable income than a fellow resident who attends a day service, and has to pay for that service – as well as the residential costs faced by all residents, regardless of whether they attend a day, or a business service.

In speaking from experience – because we lived it – the loss of income and prestige when a trainee is no longer able to attend a business service, and is forced to pay to attend a day service, can be emotionally devastating to the person with the disability. Whilst it will bring howls of disapproval – there is a "pecking" order, even in disability – and within the various types of disability…

Business services are now more competitive – because they have to be. The result is that ageing and varying complex health issues continue taking their toll on the capacity, capability and productivity of the employees. The movement of business service employees to "open" employment has always been low – and often not sustained. The transition, by an employee, from business services (Federally funded and personally income producing for the employee) to (State based) fee-for-service day activity signals a loss of the disabled person's personal esteem, loss of income, change in social structures and activities – and creates some additional concerns for family carers, and service providers dealing with the emotional and financial impacts.

Whilst I acknowledge the difficulty faced by the Productivity Commission in incorporating this aspect, in any detail, within your Report, it remains an important part of Disability Care and Support. I know it would be helpful, when dealing with different Government Departments if the link is acknowledged and incorporated as part of an extensive, independent Report by such a reputable body as your own. Not "teasing out" this aspect, even marginally, perpetuates the ability of Governments to see it as "not **OUR** responsibility" – just as they are now doing with aged care and premature ageing.

SUBSIDIARY PAYMENTS INTERFACES;

Income Support: I agree that Income Support should remain external to the NDIS

Carer's Payment and Allowance should, I suggest, also remain external to the NDIS – at least initially. That's not to say this could be the best decision, in the long term, but I feel the initial goal is to concentrate on the person with the disability. These payments are now linked to the Centrelink agency, and a gradual transition of a new system might include not touching, initially, those parts of the existing system where their inclusion could dilute the transparency of accountability and reporting of the new NDIS system.

MOBILITY ALLOWANCE

This allowance requires the recipient to perform a minimum 32 hours per month on a continuing basis to participate in learning skills etc. It is exactly what it says it is – a "**mobility**" allowance to move from point A to point B:

There are two problems:-

a) eligibility and
b) reporting.

Eligibility:

Confidential Appendix 2 provides an actual scenario where the eligibility interface between this allowance and persons who are ageing is now being "whittled" away. We would all support the need for transparency and honesty, but the requirements of eligibility are now being more rigidly applied, and this is disadvantaging those who are ageing, but whose financial position has become dependent on the allowance to cover mobility costs – particularly taxis. Existing taxi subsidies do not cover the full costs but taxi fares are increasing, and access to the local library, the shopping centres and day activities are a necessary part of inclusion for people with disability – especially those who are ageing. As the appendix indicates if you don't do the hours, you don't get the subsidy and you must pay the increased costs of taxis from your Pension, without any "mobility" assistance. – just to get anywhere. This is an added burden for those who live regionally, and/or in, supported accommodation and have little left from their DSP after paying residential and personal costs.

Reporting:

Continued eligibility depends on the completion of regular review forms to substantiate eligibility and advise changes in circumstance. If not completed within the time frame, or if the hours have not been performed, then the payment is suspended. We should not allow "rorting" of the system, but there needs to be a better balance between capacity and/or probability. Surely some data sharing and positional flagging could indicate those within the system, whose circumstances are never likely to change – let alone improve..

> I mean – how difficult would it be to flag certain disorders, and known outcomes- to ensure that some form-filling could be exempted from the regular “mail-outs”, and reviews – and the impossible time-frames they require for completion. I accept it is a necessary part of spending tax-payer funds, but people like my son were NEVER going to improve (sadly). Having to complete forms – regularly – to ensure he continued to get his mobility allowance – when things NEVER changed, and weren’t likely to – was another burden for me, and was a waste of public funds.

Data Sharing Interface

The existing Centrelink/medicare interface currently has direct data sharing with the Taxation Office. No such interface exists for anyone else – despite the best efforts, at very high levels , of some of us. The refusal to share relevant information with other agencies and statutory bodies creates un-necessary duplication and wasted resources. Now is the opportunity to remedy that, as well as reduce the unnecessary paper-work and reporting burden on people with a disability and their carers.

WORKFORCE TRAINING

Whilst there are benefits in having “no minimum training requirement” to work as a personal support worker in a system which is based on Not –for- Profit service provision, this also rings some alarm bells.

A “no training” approach can create a lack of career path, increase staff turn-over and might not attract the best people to the industry. In my own career path spanning 40 years I have always insisted on some level of “training”. Whilst I understand that academic “pieces of paper” don’t necessarily dictate personal value systems, caution is needed to ensure that a loose interpretation of “no training” terminology does not have adverse effects on quality and accountability. The last thing we want is a lot of highly qualified support people who have little empathy or understanding, but we surely should have some “minimum” standard – or a path that aspires to same. Whilst this could be problematic in regional/rural/remote Australia – where services are few, and choice is limited, education is something that is now within reach of all.

The disability sector has relied, for decades, on volunteers. This is a critical component of service delivery – especially in regional Australia. It has been my experience that a community will always support that which it owns- or creates. I have seen good outcomes from volunteers who have been given a “training” regime that provides a goal as an outcome for them – and their carees.

In developing a new national system we would all recognize that people with different types of disability have different needs. Surely those with higher support systems require people who understand those needs. I’d be surprised if the Education or Child Care systems employed people with “no training”

The incidences of rare disorders, like my son’s, are no longer an uncommon phenomenon, as more and more people live longer, and survive premature births. Whilst those providing support should have good value systems – I would have been very hesitant to see his care pass to someone with “no training”. After 40 years I was still being “trained” as his needs changed. Surely there could be a subsidy system for providers to employ people with the right value systems but, that should incorporate an appropriate “training” path – as well – for both personal support workers and family carers.

MARKET FORCES/FUNDING

Having worked in private enterprise all my professional life I am familiar with the gist of neoliberalism, but an over concentration on “price efficiency” and market forces could, in fact, be detrimental.

Regional/rural/remote Australia has very different needs and possibilities to metropolitan or provincial areas. Queensland is particularly different because of its de-centralisation. Nationally, the tyranny of distance from city-centric services has seen, historically, the creation of necessary services by communities, aided by Not-for-Profits. We have a tendency, sometimes, to assume that what works well in England, small overseas countries, NZ or even Victoria, for that matter, will adapt and work well in Western Australia, Queensland or Western NSW. History proves that deduction doesn’t always translate to a reality.

Yes – service delivery will change – over time – as people with disability have a surety of service, but we need to ensure that services remain viable in an era where there are increasing red tape, administration, reporting and paper-work expenses. Not-for-profits, the very foundation of our Australian services, are now required to make a “profit”. Block funding has been accepted as necessary for rural/remote communities, but I would suggest that it should also incorporate regional centres – as opposed to regional areas – depending on the spread of existing services and the possibility of creating new ones. Regional centres are obliged to provide services for areas larger than those indicated by information readily obtained from statistical and population agencies – and relied on by decision makers. Many centres have service obligations for outlying catchment areas- and these vary in relation to distance and social infrastructure.

Whilst there should be a diversity of funding options, we should learn from the historical fact that neither block funding nor individualized funding “packages”, per se, delivered the best outcomes for all. Ruling out block funding to other than rural/remote ignores the realities of those regions, throughout Australia, which are based in larger centres but provide valuable “outreach” services to other communities. Sometimes economies of scale and price efficiencies could suffer in regions where there is a growth of smaller services, each with their own overheads and costs, to the detriment of an efficient, larger service whose security of funding has been reduced by a blanket disapproval of block funding.

Australian people with disability, and their families, learned this lesson, especially in the regions, – at a cost to the availability, equity and quality of services – post de-institutionalisation.

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I thank you for the opportunity of making these comments on your Draft Report, and for your diligent work in producing it. My perspective is that of a parent advocate who has “been there – done that”, and been privileged to love and support our son during his life-time. I now share that experience with others as part of his legacy, because I know how hard it can get.

I now look forward to reading the Final Report

…….Compiled by *Mary Walsh OA*