Submission to Productivity Commission Inquiry into Disability Care and Support

Introduction

As a mother and principal carer of a twenty-two year old son with Down Syndrome, I read the overview of the Productivity Commission's Draft Inquiry Report on Disability Care and Support with some concern and disappointment.

While I agree with and applaud the underlying philosophy and objectives of the draft report, I believe there are some fundamental aspects of the basic scheme that is being proposed that need to be reconsidered.

Absence of a no disadvantage test

Why do I feel so disheartened after reading the Commission's proposals? Because after twenty-two years of advocacy for services and support for my son, through dealing with a plethora of government and disability bodies and agencies, I am told that there will not be a "no disadvantage" test in the transition to the proposed new regime.

My advocacy for my son's rights commenced many years ago when I represented him in a hearing before the ACT Discrimination Commissioner in *Dalla Costa v The ACT Department of Health* (1994) EOC 92-663. This was one of the first hearings under ACT discrimination legislation.

In what has been described as a landmark decision in relation to disability discrimination, the policy of the ACT Department of Health of excluding children who were students in ACT special schools from speech therapy services offered by the Department was found to be exclusionary and discriminatory.

As stated in *Alex Purvis on behalf of Daniel Hoggan v The State of New South Wales (Department of Education)*[1]*:*

> *"Dalla Costa v The ACT Department Of Health (1994) EOC 92-633, makes it very clear that provision of a segregated service - because of it being innately exclusionary - is discriminatory per se, and that even if inclusive education provides an inferior service, that service would have to be greatly inferior in order to counterbalance the loss by the person with the disability caused by the innate exclusion."*

This was an outcome that I struggled for years to achieve. But my advocacy for my son did not end there - it has continued throughout his life. This has included completing what seems like a million forms, and attending hundreds of assessment interviews, goal setting interviews, "getting to know you" sessions every time there is a change in relevant personnel, planning sessions and review sessions in an attempt to demonstrate my son's level of disability, substantiate his support needs and acquire a reasonable level of support for him. The progress in both identifying relevant services and obtaining access to them has been slow, protracted, time consuming, painstaking and exhausting.

The Commission dismisses the need for a no disadvantage test by stating that the NDIS will be well funded and that a person's support needs will be comprehensively and objectively assessed.

However, after decades of experience with a multitude of different assessment processes, I am yet to encounter any genuinely comprehensive and objective assessment process to assess the support needs of a disabled person. I admire the Commission's confidence in the ability of a new Agency to deliver an outcome that to my knowledge has never been delivered before. However, based on my experience, I remain highly sceptical that such an outcome can be achieved and am absolutely dreading having to start all over again from square one to prove and substantiate my son's support needs.

Disabled persons and their carers have been worn down by decades of dealing with the complex

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[1] Human Rights and Equal Opportunity Commission, Matter 98/127,13 November 2000, Commissioner G Innes

mosaic of disability services. Many disabled persons and their carers simply do not have the energy and capacity to start all over again in their quest for access to support services.

While I note that complaint and appeal processes will be available, I question whether it is realistic to expect many disabled persons and their carers to have the strength and personal reserves to avail themselves of such processes. I suggest that forcing disabled persons and their carers to prove and substantiate their need for support yet again may push many of them to breaking point. Facing the possibility (however remote the Commission may consider it to be) of losing some or all current supports will, I am sure, be extremely stressful for many families.

The Commission appears to consider it appropriate to have a no disadvantage test when a person moves between the NDIS and the aged care system. So why not give worn down and exhausted carers some reassurance that in moving to the NDIS we will not have to start from the beginning to prove yet again that our sons or daughters are in fact disabled, and to substantiate their support needs? Why not at least use access to existing services and supports as a default starting point and place the onus on the NDIA to justify any derogation or diminution of such services or supports?

Personal plans, goals and objectives

It appears that our community considers that it should be compulsory for people with a disability to document extensive personal goals, personal plans and personal profiles if they wish to access appropriate support services. Regimented goals and plans must be established and documented in relation to areas as diverse as skills development, training, communication, personal development, lifestyle development, health and wellbeing, employment, flexible options, recreation, community participation, social activities and mobility. These plans and goals must be reviewed and updated regularly to meet audit and the service provider’s requirements.

While the non disabled section of the community is permitted to muddle through their lives without documenting any particular plans or goals, this is not permitted for disabled people who wish to obtain appropriate support services. If a disabled person receives services or supports from multiple agencies, the amount of paperwork, time and effort involved in putting together and updating these documents is mind boggling. In my experience, the benefits to the disabled person associated with this enormously time consuming process of regimentation are either minimal or none at all.

I certainly do not have such detailed documented plans for my life, nor do I wish to have such plans.

I ask all those who are reading this submission:

- Are you required to have documented and detailed plans and goals for each aspect of your life?
- Are you required to submit these personal plans and goals to a range of organisations?
- Are you required to have regular and frequent meetings with these organisations to review your personal plans and goals and assess your progress in achieving them?
- Are you denied access to appropriate support services if you do not document and submit your personal plans and goals and attend regular review meetings?

If they wish to receive appropriate levels of support, disabled people are not allowed to have just the simple goals of being happy and healthy.

Inevitably, the relevant organisations become increasingly insistent and anxious that the paperwork is completed and planning and review meetings are conducted prior to an audit being carried out or prior to the end of a financial year. From a service user's perspective the entire rigmarole appears to be process driven rather than driven by the needs of the disabled person to be supported.

While I understand the need for funding and services to be appropriately targeted to needs and the necessity for accountability, I implore the Commission to attempt to keep such regimentation, paperwork, planning and goal setting requirements to a minimum in the design of the new Scheme. Service users should be empowered to determine when an update to personal plans, goals and profiles needs to be undertaken. Surely disabled persons and their carers are in the best position to know when significant changes occur in their lives and circumstances and they should not be subjected to frequent automatic and compulsory review meetings that achieve very little, if anything.

Living independently

There is significant pressure placed upon disabled adult children and their carers for the adult disabled person to leave the family home and live independently. I am frequently asked about my plans for my son to live independently, but no one inquires as to when my other adult non disabled children will be moving out of the family home. It appears to be socially acceptable for non disabled adult children to live at home indefinitely, but if you are severely disabled, both you and your carers are subjected to pressure for you to live independently. If I am unable to produce a plan for my son to live independently I am made to feel that I am being somehow irresponsible or failing in my duties to my son to plan his future.

I urge the Commission to recognise the increasing incidence of non disabled adult children residing with their parents almost indefinitely, and to acknowledge that disabled adult children should not be placed under any more pressure than non-disabled adult children to leave the family home. I suggest that pressure placed upon disabled adults to leave the family home, when no such pressure is placed on their non disabled siblings, is unfair and inappropriate.

Employment v continuing education

I note that the Commission has been asked to examine the feasibility, costs and benefits of replacing the current system of disability services with a new national disability care and support scheme that provides for people to participate in education, training and employment where possible.

In my view, the role of continuing education for intellectually disabled people beyond school age is extremely important. Due to delayed development, the standard age for leaving school may not be appropriate for intellectually disabled people. In my experience, intellectually disabled people have enormous capacity to learn well beyond the usual school leaving age. They can gain vast benefits from attendance at TAFE courses aimed at adult literacy and numeracy and through educational courses such as the "Latch On" literacy and technology program conducted by the Endeavour Foundation in Queensland. This program was developed by the School of Education at the University of Queensland and is specifically targeted to the needs of young people with an intellectual disability[2].

I have also encountered system bias and community pressure for my son to transition directly from school to work, whereas the optimum outcome for my son has been to continue his full time education through his attendance at TAFE and the Endeavour Latch On course.

I request that in considering its final recommendations, the Commission refrains from any automatic assumption that employment will always be the optimum outcome for a person with a disability. I request that the Commission take account of the vast benefits that can be achieved through continuing educational opportunities for disabled persons well into their adult years.

Disability support organisations

The Commission envisages that disability support organisations could support disabled persons in relation to their package of supports.

I suggest that if disability support organisations are to be granted any such functions, then strict accountability requirements should be established and enforced.

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[2] See http://latchon.endeavour.com.au/what.html

By this I mean accountability both to the NDIA and to the service user. If resources are placed in the hands of a third party organisation, then I believe that organisation should be under a duty to fully disclose to the disabled person and their carers the amount of funds or resources entrusted to them for the disabled person, the amount they deduct for their services, and the net amount available for the use of the disabled person. I believe such disclosure should be required at least quarterly.

Taxi costs

The Commission has sought community input on ways to ensure taxi costs are kept within reasonable bounds. As noted by the Commission, taxis play a vital part in the transportation needs of many disabled persons, and enable them to take advantage of many options that would otherwise be unavailable to them.

The Taxi Subsidy Scheme that operates in Queensland provides a 50% subsidy up to a maximum fare of $50. Any amount of the fare that exceeds $50 must be paid for without the benefit of the subsidy. The $50 limit has been in place for many years, and its value has been significantly eroded over time by inflation. I also note that use of a Cabcharge card attracts a surcharge of 10%, which must be paid for in full by the consumer, without the benefit of the subsidy.

Overall, I think that opportunities for reducing taxi costs are limited, especially in relation to disabled persons with a significant intellectual disability. Increasing traffic congestion in our major cities and escalating costs make increases in taxi costs inevitable. Any reduction in funds available for taxi transportation is likely to severely impact on the options and opportunities available to disabled persons. Taxi costs for disabled consumers in Queensland have been progressively increasing over many years due to the static $50 limit on subsidies.

Conclusion

As stated above, I support the thrust of the majority of the recommendations in the draft report, and believe the Commission's proposals represent a major step forward for disabled people and their carers.

However, in considering its final recommendations, I request the Commission take account of the issues I have raised above

In particular, I request the Commission give particular consideration to the issue of a no disadvantage test. As acknowledged in the Commission's draft report, disabled people and their carers comprise one of the most disadvantaged and vulnerable groups in our society. Forcing this vulnerable section of our society to substantiate yet again their support needs, without any guarantee that existing supports will be maintained, may push many past breaking point.

I believe that the way in which a society treats such vulnerable groups is an accurate gauge of the value and worth of our society as a whole. Surely, if ANY group ever deserved the protection of a no disadvantage test, it would have to be disabled people and their carers.

I would be pleased to provide any further information that may assist the Commission in its deliberations.

Claire Elliot