

SUBMISSION TO PRODUCTIVITY COMMISSION

DISABILITY CARE AND SUPPORT

This response is related only to the Intellectually Disabled sector and is based on experiences over 40 years. It does not seek to address issues related to other sectors of the disability area. My son is now 45 years of age. During this time he has received from the Endeavour Foundation Queensland, outstanding services of schooling, supported employment and in recent years accommodation in a 24 hour care group home. I cannot thank Endeavour enough for what they have done for him and many others.

The Endeavour Foundation is the largest supplier of services in Australia to persons with an intellectual disability. It supports

- Over 1,800 people with supported employment opportunities including over 500 at Cumberland industries Sydney (since the end of 2009).
- Over 900 people with accommodation and support primarily in group homes providing 24 hour care.
- Over 800 people with learning and lifestyle opportunities
- Over 700 people through a range of services, e.g. post school services, respite services, assistance to people in open employment.

The Foundation was started in 1951 by a group of mothers seeking to provide some educational opportunities for their children. There were no services of this nature in Queensland and the official government policy at the time was that these children were ineducable. Over the subsequent years the organization was in the forefront of service provision, development and innovation, providing services which covered all aspects of an intellectually disabled person's life except aged care. The school services were taken over by the State some years ago.

The cost of all services and administration in 2009 was in excess of \$123m. This was funded broadly by Government subsidies \$72.3m, client contributions \$10.5m and Endeavour contribution \$41.3m. This excludes Cumberland Industries Sydney, which only became part of Endeavour at the end of 2009. It also needs to be noted that Endeavour clients contributed over \$300m to the economy in 08/09. In recent years the cost to service providers of meeting Government requirements in standards, quality, workplace health and safety, audits, chemical restraint etc has been very substantial. In most cases the cost of meeting these requirements has had to be absorbed and this takes funding away from service delivery and into paper administration. Government policies such as award based wages and case based funding have also had significant repercussions. In the case of Endeavour it has meant that additional income of \$8 million has had to be found

The Foundation is a very professional organization governed by a Board of Directors. It is supported by regional area committees which link with the parents/ service users. It is a transparent organization with numerous policies and procedures e.g. abuse, fees and charges, complaints, medication, workplace health and safety etc.. Its sole objective is

“to enhance the opportunities of people with a disability so they may increase their participation in every aspect of society” (2009 Annual Report).

In the case of the intellectually disabled the objective of any scheme needs to provide certainty for whole of life experiences and opportunities. Such needs to be acknowledged and recognized by society as a normal entitlement and enshrined in legislation. This needs to encompass, dependent on the individual's ability and wishes, post school services, learning and lifestyle services for those disabled adults who through no fault of their own are unable to attend a business service, supported employment, accommodation, 24 hour personal care and support where needed, community access and provision for early ageing. It needs to be remembered that in most cases any activity out of house, needs to be supervised/ assisted by someone else. Can you imagine living your life dependent on someone else and without this assistance you can't do it e.g go to a shop? go for a walk? go 10 pin bowling etc?

The Endeavour Foundation operates under a proven model which has strong governance. Its funding base is however far less than what it should be and there is urgent need for capital funding for accommodation and recurrent funding for community access and support workers. Because of early ageing the needs of the intellectually disabled can change as they get older and this also needs to be allowed for in any fair system of support.

The requirements of a new scheme need to ensure it

- is based on the principle of entitlement
- is funded such that anyone who needs accommodation, assistance with day to day living, supported employment, learning and lifestyle etc. can obtain it
- is universal offering the same entitlements in each State
- addresses the shortfall in regional areas
- provides for good governance
- is funded in such a way that individual needs are met including future needs
- is innovative in maximizing a person's abilities.

Eligibility

As this response is related to the intellectually disabled, eligibility should be based on need. It would seem reasonable for it to be first established by specialist diagnosis followed by assessment of level of disability by trained therapists including whether the person “lacks capacity”. Categories of limited, moderate or profound would seem appropriate. The needs across categories might be the same even though the level and extent of disability might vary across the range. .

Regrettably a person with a profound disability often has insufficient services to really meet his/her needs. Accordingly it is submitted that services should be funded in descending order of priority from profound to minimal.

Ageing

This is of particular concern to those caring for the intellectually disabled who may be attending a Business Industry Service or a similar entity or a learning and lifetime centre or similar. It is now clear that these persons can age earlier than the rest of the community. Because of this early process a person may be able to attend a facility part time or not at all. There may not be any clear aged symptoms but nevertheless it might be age related. This is not a matter for the aged care system but a matter for a disability scheme. It has yet to be addressed and will call for additional resources from Government to provide for additional in home support and out of home activities. Again this should be seen as an entitlement.

Funding

Individualised funding versus block funding to a service provider raises many issues. Block funding was the original method and was relatively successful while service providers were able to successfully raise substantial funds. This is no longer the case. Individualised funding enables an individual's needs to be addressed. At the same time the viability of the service provider must be allowed for. I strongly favour individualized funding in any new scheme but such also needs to ensure the viability of the service provider.

If it is to be universal and offer the same service entitlements in each State a scheme such as the N.D.I.S. will require that it be administered centrally as an entity of the Federal Government. In the light of this proposed centralisation it would also seem more practical and reasonable for the current State funding for disability services to be transferred to this central authority which would then become the funder of all disability services.

It is not unreasonable to expect services are available to provide a good quality of life. This can only be achieved if there is very substantial funding increases across the whole sector. There can be no or little improvement without such a funding increase and it is therefore the primary and most critical requirement for significant improvement in this area.

I favour a N.D.I.S which is attached to the medicare levy. This would have a greater potential for predictable funding. If it is retained as a budget item then the possibility of it being affected by other needs is significant.

Services

The types of services as described in the paper are appropriate and no type is more important than any other if the person is to have a good quality of life. At the moment a person with individual funding might receive a wider range of service types than a person where service is provided under block funding e.g. accommodation is important but so is community access and support. Where one or part of one of these services is missing then the person is disadvantaged and quality of life affected.

With the exception of a co-payment towards accommodation services I am of the view that other services should not be subject to a charge. In nearly all cases the person is in receipt of a disability service pension and such is only just sufficient for accommodation and care. Currently there are persons who are financially supported by their parents at considerable financial cost because without such support they would not be able to receive services. This flies in the face of the concept that these services should be able to be received as an entitlement.

The services should not be subject to a means test. The whole basis of the N.D.I.S is that the disabled person is entitled to assistance. The emphasis is on the disabled person not on the family. When the intellectually disabled person turned 18 the law decrees that the family has no responsibility for the person unless they are appointed guardian/administrator and then only to the extent of the appointment order. As the person will only be in receipt of a D.S.P. any means test would be on the family/carer and this is not consistent with the current situation.

With a Commonwealth entity being a central funder and responsible for funding all services it would seem reasonable for the administration to be delegated through the States, e.g. quality, governance, reviews, workplace health and safety etc. In such an arrangement a State should not be a service provider and where States are providing direct services they should transfer such service to a new or existing N.G.O..

Coordination

The need for coordination across the whole spectrum is obvious. It has been suggested previously that the disability sector should be funded centrally on the grounds of universality. It has also been suggested that the States should be delegated the responsibility of local administration. Cost shifting and the provision of the same services in each State cannot possibly be managed without a central funding authority.

To conclude I support the establishment of a N.D.I.S. based on a medicare model and all that this entails

- a very substantial increase in funding
- services based on entitlement and enshrined in legislation
- a centralized funding and policy entity with decentralized administration.

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