THE HAWKEVALE TRUST
Creating Long-term Living Solutions for People with Disabilities

Submission to the Productivity Commission Inquiry into Disability Care and Support by the Hawkevale Trust Incorporated.

Introduction

The Hawkevale Trust is a not for profit, non government funded charity that provides services to people with developmental disabilities and their families. The Trust is an incorporated body founded in 1989. Services provided by the Trust include:

- Wills and Estate Planning and Guidance
- Managed Trust Funds
- Personal Support Services (arranged visiting and advocacy)
- Personalised Accommodation Options

The Hawkevale Trust's mission is to provide a means for families of people with developmental disability to make reliable plans for the future and assist in the implementation of those plans when family are no longer able. The Trust came about as a result of parents asking 'what will happen to my child when I am no longer here?'.

This submission is representative of the views of a number of the families that the Trust works with. They are not conclusive by any means instead are the types of things that families and the Trust are consistently encountering. The submission offers solutions where possible as to how these issues might be addressed under a new system of care and support.

The submission is written relating to people with developmental and intellectual disability only.

Firstly, the Trust agrees with the overall premise that the current system needs to be completely overhauled. The Trust also agrees that control should lie with the individual and their family through individualized funding in order to provide more choice and more accountability by service providers. That funding however must be controlled and monitored to ensure correct use of public funds. The Trust disagrees that any new system should focus on people with disability who are under age 65. As the population ages so do people with disability and ongoing services must be made available post age 65. The submission discusses some of the ageing issues. The Trust also disagrees with the idea that the system needs to be centered around people with diagnosed profound or severe disabilities. People with moderate to mild intellectual disabilities also need support for life and it cannot be assumed that they will be cared for in some other way or by some other means.

1. Older Parents as Carers

Much has been said in the media and within the sector about parents and particularly ageing parents continuing in the role of carers of their adult children with disability. Any new scheme must address this issue as one of paramount importance. Parents should not be expected to be the carers of their child with disability by default.

Any new scheme must recognise the need or desire for people with disability, and especially those with intellectual and developmental disability, to live an independent life. Once assessed, early in life and once only, as having a lifelong disability, funding must then be made available for each step in the person's life. That funding can then be taken up by parents who decide the best care options for their child. If parents decide, without duress, that they want to be the care givers then they need to be provided appropriate support and respite for them to be able to do this effectively. If they decide otherwise then funding needs to be available so that all the alternative options can be explored. No longer should people in their 50's, 60's and 70's be expected to look after their adult child with disability.

2. Provision of Care in the Future

Currently families attempt to make a plan for the future that might include their adult child remaining living in the family home after the parents have passed away. This allows them to stay in the community where they have lived all their lives and where all their supports and networks are and this would be seen as a positive. Whilst parents can arrange a plan for the physical assets etc they are unable to arrange in advance the care that might be needed so this is left up in the air for either other family members or for a service provider such as ourselves to take on arranging care once the parents have deceased. This can mean the individual is moved into respite care while this is being arranged which is far from ideal given this is already a traumatic transition time in their lives.

What these parents would like is to be able to have the Government Funding Body, be it now or in the future, acknowledge the plan they have made for their adult child regarding the future and to be provided a guarantee with regard funding for the provision of necessary care when the time comes. At present, families who go through the CAP process (Western Australia) and get approved for Intensive Family Support are told they will lose the funding if it remains unused for over 12 months. Parents would like to be able to apply for and be approved for funding well in advance of the time when it is need. Pre-approved funding can then be deferred and can be taken up when the family and individual are ready. This also applies to Accommodation Funding Support whereby parents would have a guarantee of a funded group home place for their child in the future but are not forced to take up a place immediately. Families need time to prepare for such a move and not all parents want their child to live in a group home but want the peace of mind in to knowing it's available if needed in the future with the service provider of their choice.

With regard the CAP process many parents say that you have to make the application sound as bad as possible to even be considered for funding and even then it's a lottery. Many parents of children with intellectual disabilities often do not wish to describe their lives in this way. They are loving parents who just need appropriate support and any application process and assessment methodology must be considerate of this fact.

3. Ageing With Disability

The Hawkevale Trust has a number of clients residing in group homes run by various service providers. What we have found is that while they are working, usually in supported employment, the arrangement of work/home seems to work well. Once however they are retired from their work due to age or to failing health there is little, or often, no transition plan for them. Suddenly they find themselves at home all day alone just with carers with little to do to occupy them on a day to day basis. We find that this can have a devastating effect on health and wellbeing after being actively employed each day. At present the group home service provider will then apply for Alternatives to Employment (ATE) funding that allows the individual to get out and do something on a regular basis to fill the large gap in their lives. To get this funding however takes time as they are back in the funding queue and usually many attempts are made before funding is achieved, if at all.

It would be a very positive step if a new system (or even the existing one) could ensure that the transition to this life stage is considered, planned and funded, for each individual. By this time many clients no longer have parents who are alive. Many are not able to actively speak for themselves so unless they have an independent advocate in their lives who can ensure service providers are doing the right thing in seeking ATE activities the person in at risk. It is unacceptable to assume that because they are retired they do not need to be kept involved and active. Some are retired early for many different reasons and even those that are retired at age 60 or 65 are not ‘old’. When compared to the general population this is a time people look forward to, a time to take up hobbies, travel and play sports. It shouldn’t be different for people with disabilities and any new scheme must consider this transition period more appropriately (as it should each life stage transition such as school to work which has similar issues).

4.   Ageing and Accommodation

The other issue with ageing is appropriateness of accommodation. At present aged care services and disability services do not work together in order to provide the best solution for the individual. As people with a developmental or intellectual disability age they need age appropriate accommodation to be available to them and the transition to that accommodation made easy. They need the option to choose, to be able to say they wish to stay living in their own home with additional supports, to say they prefer to stay in their group home with people they know and be provided additional supports to do so, or to choose to live in age appropriate accommodation within the community such as retirement village or nursing home if necessary through an ACAT assessment.

A collaborative approach and relationship needs to exist between aged care services and disability services for this to happen effectively. There is a large question mark on this issue at present.

5.   Individualised Funding and Ageing

As previously stated the Trust is in favour of individualized funding as it can see the benefits in families having more control. Consideration however needs to be given to individuals with developmental disability whose family are not involved in their life or have passed away. Who then has the authority to help these individuals decide how their funds are used?

From our point of view this is likely to be either a sibling or an advocate either appointed by a Tribunal in cases where that is deemed necessary or appointed by parents who have left that instruction prior to their passing away. Advocates in any new system need to be both formally recognised and valued by the system. Advocates become extremely important in the lives of an older person with disability and the new system needs to properly address the role of advocates so they have capacity to be involved but without reduction to an individual’s independence.

The post parental stage is particularly important and not well considered at present. What needs to be considered in a new system includes:

- Creating a climate of positive expectations for ageing people with disabilities and particularly intellectual disabilities through innovative housing options and care support and through extending support to informal carers and advocates that replace parents.

- Reducing vulnerability and being controlled by others through the introduction of formal mechanisms to challenge inappropriate decisions by service providers.

- Ensuring that older people with disability including intellectual disability are visible within the aged care system and that aged care services are responsive to their needs.

- Recognition and nurturing of lifelong friendships, informal supports, and community links.

- Effective and seamless transition from parental care to independent living at whatever stage in life that might occur.

- The removal of funding and program barriers that don’t work in support the ageing process through collaborative programs, cross sector planning and joint funding.

- Recognition of, and planning for, the changing needs of people with disabilities through each life stage through to old age.

Ultimately a new system must incorporate an overall life plan that is funded from the start of a person's life with that funding being able to be taken up as needed at each life stage by the individual in order to live a good life from childhood through to old age.

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