Disability Care and Support: Submission to Productivity Commission.
12th August 2010.

Background to submission

Friedreich ataxia (FRDA) is the commonest genetic cause of ataxia. The average age of onset of this neurological condition is between 10 and 15 years however onset can be as late as 25 years. The major symptoms of this condition are ataxia (incoordination), changes in sensation, muscle weakness, hearing and visual loss, diabetes and heart conditions. The hallmark of this condition is the *relentless and progressive nature of the functional decline.* Typically someone who is diagnosed at the age of 10 will require full time use of wheelchair by the end of their teens. As they move through their early adult life and reach mid-life they will gradually lose the capacity to mobilize, transfer independently, care for themselves and participate in vocational and community activities. To date there are no proven therapies available to halt the progression of this devastating condition. The age average of death is 37 years.

People with FRDA have typically found it difficult to access experienced specialist multi-disciplinary professionals able to offer long-term management. They were often told their condition was “incurable therefore there was nothing to be done” and advised to get on with what little life they had left. Fortunately the advent of the Friedreich ataxia clinic at Monash Medical Centre in 2000 has changed the way people with FRDA can maintain their health, well-being and quality of life. Needless to say people with FRDA remain in desperate need of disability, accommodation and community access services. Documentation of the experience of people with FRDA provides an excellent mode of examining the overwhelming deficits in the current system of disability services and providing suggestions as to how a new national disability care and support scheme could improve their daily life. The critical aspect of FRDA is the *relentless progression of the symptoms*. Whilst the individual mode of change over time is not easy to either predict nor anticipate, functional decline is inevitable. As such this condition is not unlike other progressive neurological conditions such Multiple Sclerosis, Huntington Disease, Motor Neurone Disease or Parkinson’s Disease. Indeed, the case of FRDA can be used to illustrate the cumulative burden of a progressive condition and as such the issues that face a person with FRDA are highly relevant to this inquiry.

Currently disability services are unable to effectively manage and respond to a progressive condition such as FRDA in a timely manner. To illustrate this point we have a few examples: Moving to full time use of a wheelchair is an emotionally and physically difficult time for a young person with FRDA. As their peers are starting tertiary education or pursuing employment, having a vibrant social life, forming relationships and so on, young people with FRDA are facing full time use of a wheelchair for mobility and societal perceptions and restrictions associated with the use of such a piece of equipment. This is compounded by the fact they often have to wait for up to year for partial funding for a wheelchair through the Aids and Equipment (AEP) system. Top up funding is then sought via a range of Department of Human Services (DHS) or philanthropic funds to ensure this young person obtains the specialized piece of equipment they so desperately require. In the meantime their functional status further declines, they become socially isolated and often experience periods of depression. The underlying issue in this situation is the *lack of ability to fund essential equipment in a timely and efficient manner.*

Young people with FRDA often become socially isolated as they are unable to participate in community activities due to lack of support. For example a young woman in her early thirties living with a partner who works full time finds she is increasingly dependent on her partner to assist with personal and domestic care tasks and community access such as attending medical appointments. The relationship is beginning to flounder due to pressure on her partner to financially, emotionally and physically support her while maintaining a full time job. She desperately requires carer support to assist her with personal care tasks, community access or even just to assist her to attend medical appointments. HACC funded community services are not able to provide this level of support. She is assisted to complete applications to DHS in the form of a ‘target group assessment’ and once identified as having a disability, her name is placed on the ‘disability service register’ (DSR). This process may take many months and is often dependent on assistance from her treating health professional (if she is fortunate enough to have one). When her place on the DSR is finally approved she is told she will have to wait many months or maybe years for funding for an ‘Individual Support Package’ (ISP) to be allocated. Needless to say the desperateness of her situation is palpable. One may ask why was her name not placed on the DSR a year earlier so services would be available for her when they were required? This has been attempted in other situations however the current situation is so inflexible one cannot *anticipate* needs, rather apply only on current functional status. The layers of documentation and bureaucracy in this process should be noted. Each step providing more confusion and further stepwise delay in the process. This process is neither realistic nor appropriate in a setting of a progressive condition such as FRDA. Furthermore, in cases of the annual updating of ISP funding we have met with blocks if we have attempted to anticipate how needs will change in the next year and as such, by the time funding is allocated it is often completely inadequate to meet changing needs of the person with FRDA. Like any person with a progressive condition, people with FRDA require access to services in a timely manner – to ensure they have the services they require when they require them.

Response to issues paper

The Productivity Commission issues paper raises some important points that are pertinent to people with FRDA. Our comments and response are briefly summarized below:

- The current system fosters cost shifting and lack of accountability particularly in the blurring of lines between state and federal funded services (ie: availability of HACC funded services vs DHS). A new system would need to be transparent in the process of funding allocation and ensure each system is not “played off” against the other.

- Currently cost shifting occurs on many levels. This is apparent in funding for equipment (limited AEP funding which necessitates top up funding from ISP packages) and importantly who completes the extraordinary amount of paperwork associated with accessing disability services. On a personal level these authors have noted an extraordinary increment in the time required to complete paperwork associated with requests for services. Though it is understood this is the responsibility of DHS staff, allied health professionals are increasingly asked to complete these tasks, lack of time and expertise in the areas being cited as the most compelling reasons to shift this responsibility. It should be noted that these health professionals are paid by a state health system which has not allocated funding for this increasingly demanding duty. Furthermore, the current system involves considerable layers of bureaucracy usually based on repeated requests. In order to navigate the system an individual either has to acquaint themselves with the layers of the disability system or have a professional assist them. At its simplest and worst, this process is humiliating and invokes guilt. A new system would need to have a clear process of documentation and adequate funding and training to support this process.
- Long delays in service provision often result in avoidable ill health which results in unnecessary presentations with trauma and other illness to tertiary hospital emergency departments (with or without an associated admission). Furthermore, long delays result in reduced independence and participation in the community and associated feelings of depression and helplessness.
- Young people with FRDA are, like any other young person, keen to leave the family home to forge an independent life. To do so the person has to apply for wheelchair accessible accommodation (usually through the Department of Housing), carer support (usually through the DHS) and appropriate equipment to support their independence (usually through AEP or PADP). Applications for these processes are made to three independent bodies that rarely communicate with each other. Bringing this process together in a timely manner is often too daunting a task for the young person to consider. Furthermore the extraordinary wait in one component (for example up to 5 years for accessible housing) means that moving into independent accommodation is not possible. Why should a young person with FRDA be denied the opportunity available to their peers just because they have a disability? Furthermore, why should they have to “beg” the system or cite imminent family breakdown in order to be considered a priority? Surely the right to live independently and with dignity is the right of all young Australians? A new system would need to consider how the parallel processes of service delivery communicate with each other to provide a timely and seamless process.
- The current criterion for “severe of profound disability” provides an inadequate need for support. A disability may be on many levels: physical, cognitive, emotional/psychological. A new system needs to

focus on the impairment an individual presents with and what services/systems/environment/equipment are required to reduce the effect of such impairment on their functioning. Furthermore, a new system should ensure decision making and analysis of need is allocated to health professionals that are better equipped than administrators who may not have a clear understanding of the priorities of the person and not the system.

- The current system does not accommodate a progressive condition. A new system needs to be flexible to provide for anticipated needs in a timely and appropriate manner. It needs to have at its core the promotion of services that will be **proactive** in maintaining independence and not reactive in providing a service when independence is lost. This means that when extra services are required (such as transport and a carer to get to a gym programme to improve functional status after a short illness such as ‘flu) they are available immediately and can then be withdrawn when no longer required. Such a system has the capacity to be responsive to immediate needs, flexible with services and therefore proactive in maintaining the health, well-being and independence of the person with the disability.
- The issue of eligibility for a disability service becomes a significant issue in terms of a progressive, permanent and life-shortening condition such as FRDA. A new system should have the flexibility to ensure those who have such a condition do not have to endure repeated assessments regarding eligibility. Furthermore, the process of establishing eligibility needs to respect the role of the allied health professional working with the person who often has extensive knowledge of their functional capacity. Finally, the decision to accept the classification should be universally accepted across many jurisdictions (ie: DHS, superannuation/insurance agencies) to avoid repeated assessments (often at the cost of the person with a disability).
- Whilst the capacity to save some of the annual payment in individualized funding is helpful, measures should be taken to ensure this is not used inappropriately to address and fill the gap in other systems (such as inadequate funding for equipment).
- Current assessment tools are problematic as they are not necessarily specific to the condition nor are they sensitive to needs changes (current tools have floor and ceiling effects therefore do not represent true functional status). Adequate funding of the assessment process needs to factor in the use of appropriate assessment tools by trained clinicians and suitable training for DHS staff in the interpretation of such tools.
- The right for access to disability services should not be means tested. Disability does not discriminate. Furthermore means testing is a disincentive to people with a disability seeking employment.

Summary

To summarise, the current system is not responsive to immediate or anticipated needs. People with a life-shortening condition such as FRDA cannot afford to wait for funding to become available. They need services that can be delivered in a timely manner and accommodate the specific need of a progressive condition. The current system is in urgent need of major overhaul and we look forward to a positive future based on the findings of the Productivity Commission into Disability Care and Support.

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