HAEMOPHILIA FOUNDATION AUSTRALIA

HAEMOPHILIA FOUNDATION AUSTRALIA SUBMISSION TO THE PRODUCTIVITY COMMISSION DISABILITY CARE AND SUPPORT INQUIRY

APRIL 2011

Summary of response:

- Haemophilia Foundation Australia welcomes the development of a national disability scheme to provide an integrated national support system that ensures that people in need of its services have improved access to the scheme and do not 'fall between the cracks' of support service schemes or schemes across sectors
- Haemophilia Foundation Australia is unsure how members of the bleeding disorders community would fit with the eligibility criteria for the proposed NDIS.

BACKGROUND

Haemophilia Foundation Australia

Haemophilia Foundation Australia (HFA) is a not for profit organisation which represents people with haemophilia, von Willebrand disorder and other rare inherited bleeding disorders in Australia. It is the national peak organization for bleeding disorders. It provides advocacy, education and support to the bleeding disorders commmunity and works to promote Australian based research.

Bleeding disorders

There are approximately 3600 people with inherited bleeding disorders in Australia, of whom 2000 are males with haemophilia.

Haemophilia is an inherited condition and occurs in families. In one third of cases it also appears in families with no previous history of the disorders. Haemophilia is found in all races and socio-economic groups.

Haemophilia occurs when blood clotting factors VIII (eight) or IX (nine) are missing in a person's blood or don't work properly. It is incurable and can be life threatening if not treated properly. Bleeding is internal, into muscles, joints and organs. Bleeding may occur as a result of injury, or as a result of surgery or invasive procedures; in severe haemophilia bleeding can occur spontaneously, from no obvious cause, up to several times a week. With appropriate treatment bleeding can usually be stopped. Episodes of bleeding over the long term can cause permanent damage to joints and muscles, resulting in arthropathy, pain, disability, reduced mobility and decreased quality of life. The likelihood of bleeds and the resulting joint and muscle damage is increased if the person has an inhibitor, a complication of treatment that reduces the effectiveness of treatments.

Today in Australia, children and young people who have been treated all their lives with the required replacement clotting factor are less likely to have the problems of older adults. However, many adults live with significant joint damage caused by inadequate clotting factor therapy in the past. They may require aids such as artificial limbs, crutches, wheelchairs, modified vehicles and housing and considerable support to manage the activities of daily life. Those who experience episodes of bleeding may need time off work to manage the bleed and attend clinic and allied health visits; sometimes they will require hospitalization. If this occurs often, it can impact on their ability to work and earn an income: they may have used up all their sick leave for the year and need to take unpaid leave, which in turn may mean they are unable to pay bills or support themselves adequately, causing a need for welfare support.

Von Willebrand disorder (VWD) is another inherited bleeding disorder caused when there is not enough of the von Willebrand clotting factor in a person's blood, or it doesn't work properly. It is thought that many Australians with VWD are undiagnosed as it is more common in a mild form, and most people do not need treatment unless they have surgery or an injury. However, some people have severe VWD with frequent bleeding episodes and joint and muscle bleeds. Some people with VWD can only be treated with clotting factor VIII concentrates made from human plasma, while others can be treated with synthetic hormones.

Each of these bleeding disorders is categorized according to levels of severity, eg mild, moderate and severe. The degree of disability as the person ages is specific to the individual. We note that NDIS is not aimed at the general ageing process, however draw the attention of the Commission to the early ageing for many people with haemophilia, particularly if the person has inhibitors or where clotting factor treatment was rationed in early life due to plasma supply shortages.

Blood borne virus co-morbidities

Some adults with haemophilia or Von Willebrand Disorder may also have been living with blood borne viruses, including HIV and hepatitis C, for more than 20 years due to treatment with infected blood clotting products before safe blood screening tests and viral inactivation procedures were introduced. For many, their co-morbidities have increased the complexity of their health problems and need for health and support services. They may have co-existing hepatitis C symptoms, such as severe fatigue, pain, nausea, concentration and mental health problems, or advancing liver disease complicated by haemophilic bleeding, or other health problems associated with HIV and HIV treatments, including peripheral neuropathy, muscle wasting, diabetes and cardiovascular disease. Many of those who have both a bleeding disorder and hepatitis C reported that it impacted on their ability to work and earn an income from the age of 35 onwards.

HFA's recent national hepatitis C needs assessment found that many experience overload with health problems and services, and need assistance to negotiate the health and social services systems[1]. Given affected community members' ill-health and disability, this assistance is required to help them understand and find the services that are available to them, support them in completing the applications and

[1] Haemophilia Foundation Australia (2007). *'A double whammy': living with a bleeding disorder and hepatitis C*. HFA, Melbourne.
http://www.haemophilia.org.au/documents/item/48
Haemophilia Foundation Australia (2009). *Getting it right: hepatitis C needs assessment evaluation and implementation report.* HFA, Melbourne.
http://www.haemophilia.org.au/documents/item/151.

assessments, and advocate for them to receive the services they require when they do not fit the “one-size-fits-all” criteria, which is often the case.

Treatment and care for bleeding disorders in Australia

In Australia most people with bleeding disorders use recombinant or plasma derived clotting factor treatment products to treat their bleeding disorder. The financial cost of all clotting factor products is shared by Australian governments under the National Blood Agreement. Treatment and care for people with bleeding disorders is best managed though a model of comprehensive care which is provided by specialist haemophilia centres. These are currently located in major public hospitals around Australia.

However, the complications of people’s bleeding disorders, their co-morbidities and the issues that occur as they age result in a need for a wide variety of health, social and support services. Most of these services will have to be obtained through referral outside the haemophilia centre. Co-ordination of these services is essential to the person’s health and wellbeing, but as the systems are fragmented, services are split across state/territory and federal systems and communication between services is difficult, this very rarely occurs.

COMMENT ON THE DISABILITY CARE AND SUPPORT DRAFT REPORT

Approach

HFA is pleased to see that the approach taken by the Productivity Commission to disability support and care is focused on enabling people with disability and their carers to have an improved quality of life, more control over decision-making related to care and support and greater opportunities for independence, participating in their community and living a rewarding life.

Proposed National System

There would be considerable community benefit in the development of a national disability scheme to provide an integrated national support system that ensures that people in need of its services have improved access to the scheme and do not 'fall between the cracks' of support service schemes or schemes across sectors. Although more specifically related to bleeding disorder and hepatitis C issues, HFA's recent consultation with community members highlighted the difficulties they experience due to gaps between the various existing state/territory and federal government schemes and community members' inability to find out or understand what services are available to them or negotiate the overwhelming complexity of the schemes.

Making the proposed National Disability Insurance Scheme (NDIS) information and referral services available to anyone affected by a disability would also be a welcome improvement to the accessibility of available support services.

Eligibility criteria

HFA is unsure how members of the bleeding disorders community would fit with the eligibility criteria for the proposed NDIS. We note that the assessment tools are yet to be developed, but that these are intended to define more specifically the person who has a "permanent disability", with "significant limitations in communication, mobility or self-care" who would be eligible to receive funded support from the NDIS.

Some people with bleeding disorders who have severe arthropathy will have more traditional support needs around mobility and self-care and fit more neatly with these criteria. However, some may experience episodes of severe disability or need; for example, managing haemophilic bleeds, or the complex issues resulting from living with co-morbidities such as a bleeding disorder and hepatitis C. Community members describe "erratic" health patterns, which can result in major social problems and support needs – being unable to work, needing psychosocial support, help with household activities, support with travel, family and financial issues.

Promoting employment

While the NDIS is not designed to replace existing social services/government support systems, HFA welcomes a scheme which encourages and supports employment: in the Australian environment this is an important factor in identity, self-esteem and self-management. Many community members with bleeding disorders are determined to work as long as possible, in spite of their level of disability and health problems. However, many report major difficulties in maintaining their work long before the official retirement age. For those also struggling with the effects of hepatitis C, it can be from the age of 35 years onwards. For those with inhibitors to clotting factor, HIV co-infection or other complications of a severe bleeding disorder, it can be from a much younger age.

While incentives to the individual to encourage a return to work or staying at work are important, it is also essential to support and provide incentives to employers to provide a flexible working environment and assist them with restructuring the workplace to minimize the impact of employees with “erratic” health problems.
In the case of people with bleeding disorders, this may include unplanned time off to manage bleeds, joint replacements or infections, pain related to arthropathy, severe hepatitis C symptoms, hepatitis C or HIV treatment side-effects, outcomes of advanced liver disease or HIV-related infections and diseases. A flexible environment allowing them to remain in the workforce would be tremendously valuable to the individual, while reducing the load on the social services system.

Insurance for catastrophic injury
In relation to the creation of a no fault insurance scheme for catastrophic medical injury we are uncertain whether people with bleeding disorders who have suffered iatrogenic outcomes as a consequence of their treatments would be eligible.

Financial insurance
We are uncertain whether the National Injury Insurance scheme is intended to address some of the issues for people with disabilities relating to financial insurance, or whether this is outside the scope of this report. However, it is essential that this issue is addressed by government at some point.

Financial insurance is a very significant problem for people with bleeding disorders. Insurance schemes often exclude people with pre-existing health conditions such as haemophilia and hepatitis C, and many individuals and families affected by bleeding disorders are often excluded from standard insurance policies for mortgage or income protection, life, health and travel, or the premiums are unaffordable due to high premiums. This means that progressive health problems may lead to catastrophic social and financial outcomes and affected individuals, unlike other Australians in the general population, have no way to protect themselves or their family. For example, someone with haemophilia and manageable joint issues, able to undertake “sitting down” work, may be forced to stop work due to advanced liver disease related to their hepatitis C. Uninsured, they may be obliged to sell their house and be unable to support their partner and children, while the entire family struggles with grief and loss issues on top of their financial needs.