Submission to the Productivity Commission Inquiry into Disability Care and Support

Australian Leukodystrophy Support Group (ALDS)

Introduction

This submission comments on a number of issues raised in the Disability Care and Support Issues Paper in terms of their impact on people affected by a leukodystrophy.

The term leukodystrophy covers more than 34 separate diagnoses, as well as many conditions that present with signs of leukodystrophy or leukoencephalopathy that cannot be further classified using currently available diagnostic testing. Regardless of the classification, however, leukodystrophies all involve a genetic, progressive neurological degeneration resulting in loss of hearing, vision, cognitive function, mobility and/or other aspects of nervous system function. The rate of degeneration varies between different disorders and between individuals.

Due to the hereditary nature of leukodystrophies, care and support for the resulting disabilities is often in the context of family as well as individual impact. Many leukodystrophies present in early childhood, with a young child progressively losing skills and abilities previously achieved. Siblings may also be found to be affected or to be carriers, while parents and extended family members are often faced with issues concerning their own future reproductive options. Other leukodystrophies present in adulthood, with diagnosis sometimes occurring after the affected person has had children who, in turn, may be affected and/or carry the affected gene. Clearly, disability services must reflect the needs of individuals and extended families, must address holistic impacts (on all aspects of an individual's life and identity, and in the context of the extended family), and must be flexible over the life cycle.

Access to a coordinated network of services in both health and welfare sectors is essential, encompassing both acute and community-based services, and extending from the point of diagnostic investigation (which may take weeks, months or longer as new diagnostic capacity develops) through to palliative care.

Eligibility and access

The Australian Institute of Health and Welfare's definition of disability, as contained in the Issues Paper, is a good starting point for determining eligibility. Eligibility must be determined by the effect of the condition and the level of current and, where possible, anticipated need, not on a diagnostic label alone.

The question of breadth of coverage cannot be effectively addressed with an 'either/or' debate. To focusing 100% of available resources on the highest level of need would result in a lack of capacity at the point of early intervention, which in turn may perpetuate a level of ongoing demand at the high end. A 'double-hump' approach may be more useful, so that there is capacity for early response, while also supporting people in urgent need. Although we acknowledge that wide coverage can lead to cost blowouts due to 'needs inflation', failing to intervene early can also lead to increased levels of need in the longer term.

Where it can reasonably be expected that an individual's condition will deteriorate, this must be given consideration in planning and allocation of funding. Access that is only assessed on the basis of current need may effectively exclude from service those whose condition is worsening. This is the lived experience of some families suffering from leukodystrophy who have been referred via intake processes that consider only current circumstances; by the time a service becomes available, often months and in some cases years later, the circumstances of the original referral may no longer apply. This results in further delays, potentially even a return to the beginning of a waiting list for a different service or piece of equipment, a situation that is clearly unacceptable.

In theory, applications may be reviewed periodically, but unless there is a requirement that agencies take responsibility for actively maintaining contact with families on their waiting list, it becomes one more demand placed on stressed individuals and carers. Allocation must be based on continual re-prioritisation of need, and not simply on a first-come-first-served basis. People experiencing progressively degenerating conditions such as leukodystrophy, particularly children, simply do not have time to spend on waiting lists. Apart from the exacerbation of symptoms that occurs in the absence of supportive and therapeutic care, they can literally die waiting.

As the question of access to disability services is essentially one of human rights, the primary concern of a disability support and care plan should be availability of a universal service to ensure that the rights of all people with disabilities are addressed, with availability of additional services according to individual need. This infers a level of service that is available regardless of income or assets.

ALDS acknowledges the reality of resource limitations and the necessity to prioritise access to available resources. However, funding for disability services does not exist in isolation of other government-funded programs. People with disabilities, and their families, are understandably frustrated by arguments of limited resources when confronted with media stories of government funding that appears to prioritise sport and industry over the quality of life of our family members. To paraphrase Hubert H. Humphrey, the moral test of a Government (and society) is in its care of its most vulnerable members. The creation of a Disability Care and Support framework provides an opportunity for Australia to demonstrate its commitment to this ethic.

Decision-making

Individualised funding allows people with disabilities to have maximum control of their own lives. This should not result in governments and service providers abdicating their responsibility to provide assistance and support. Most families who experience leukodystrophy are well-placed to make informed decisions regarding resourcing of the care of themselves or their affected family members, but it must be remembered that these families are also fully engaged in day-to-day care.

Sufferers of leukodystrophy have many and complex needs, and are usually in contact with numerous professionals. Navigating and coordinating the service system is a significant challenge for many, over and above their direct health and welfare needs. While some are skilled and capable self-advocates, others struggle with bureaucratic processes due to language, culture or social issues, or simply because of multiple competing demands on their time and energy, and must be able to access assistance to identify options and implement their choices.

For this reason, ALDS advocates a decision-making process that is based on individualised funding, but with a default position that each recipient of funding would have an identified service coordinator or key worker to provide practical assistance, advice and support to implement these decisions. In instances where a person with a disability and their carer/s disagree on the use of funding and other supports, this worker would have an important facilitation role to ensure that funds are spent appropriately and effectively.

Within this 'default' model, there would be capacity for individuals and families to choose to self-manage and coordinate their own service system without additional professional support. This is in contrast to current experiences that require affected people and their carers to actively advocate in order to receive and, equally importantly, to retain that support (as is currently the case for many). Any accountability mechanism must be of a design that is not unduly onerous, and should take into account diverse language and literacy levels.

The nature of services

ALDS members have experienced wide variation in the availability and quality of service coordination, advocacy and specialised equipment across Australia. Some families receive excellent support and their ability to self-determine is enhanced by the assistance of a service coordinator and/or advocate. Others have little or no access to such support; they may not be aware of relevant services to which they are entitled, or conversely may be receiving multiple and sometimes duplicated services.

A critical issue in this aspect of the debate is a well-articulated and uniform definition of the terms ‘case management’, ‘service coordination’ and ‘advocacy’. In some sectors in which people with disabilities may be engaged, ‘case management’ assumes both direct casework and service coordination. In others, ‘service coordination’ is seen as a separate service. Individual advocacy is rarely funded separately, although a model of funded independent advocacy in Scotland demonstrates the value of this approach.

Most agencies and workers would wish to see themselves as advocates for people with disabilities, and yet there is the inherent potential for tension between agency and client views and priorities. True advocacy requires an advocate’s primary concern to be the interests of the client, independent of the interests of the service provider/employer. Where an agency’s priorities or interests do not align with this, for example when different clients are competing for limited resources, workers may find themselves confronted by a conflict of interest.

As a result, ALDS recommends that the Productivity Commission include ‘service coordination’ and ‘advocacy’ as discrete services within the service system, and clearly define ‘case management’ for the purposes of effective service provision for the benefit of people with a disability who interact with a range of health and welfare sectors.

Home-based services are also critically important. Our experience is that the vast majority of carers, whether parents or partners, are willing and able to care for their family members at home; in fact, most would want to do so if at all possible. However, to do this requires adequate hands-on support from skilled attendants who can undertake tasks such as airway suction, enteral feeding, and specialised personal care. Consistency of such staffing is also important, requiring adequate training and acknowledgement of staff. High staff turnover due to inexperience or inadequate staff support increases the drain not only on the family but also on the wider service system. In contrast, our experience is that where families affected by leukodystrophy have access to experienced, skilled and consistent care attendants, outcomes are markedly improved.

One of the impacts of having a family member with high support needs is that parents or spouse of the affected person commonly has to reduce or leave their paid employment in order to care for their family member. This has huge ramifications, with some ALDS members even losing their homes as a result of their reduced income. Relocating (sometimes with the added challenges of a period of homelessness) compounds the trauma of the leukodystrophy itself, with disruption for siblings as well as parents, and the need to establish new local service networks, with all the challenges that entails.

The negative impacts of carers’ inability to maintain their jobs and careers also affect the workforce, due to the effective loss of contributing members. With adequate supports for carers, people may be able to remain linked in to their employment, if they choose to do so, with benefits to the individual, the employer, and to the broader community.

Parents need to be able to decide whether they require additional assistance with the care of their affected family member so that they can address other demands, such as the needs of other children, or with other tasks and responsibilities so that they are freed up to provide consistent care to the affected family member/s. This will vary from one family to another according to the specific set of circumstances, needs and informal support networks. The needs of other children in the family are easily overlooked in determining the supports a parent carer requires, but they should also be considered in planning a holistic disability care and support approach for any given family.

High-quality respite accommodation options that can manage the complex and technical medical aspects of leukodystrophy care are also critical. Currently, the residential options for children are primarily through the palliative care system. There is some benefit to this model for families affected by leukodystrophy, in that a relationship may be built up with a service as a child's condition progresses and needs change and increase. However there are few alternatives, families sometimes travel very long distances to access these services, and in several states they are not available at all.

Residential respite services that can provide both complex medical care and sensitive palliative care should be available to families in every state and territory, and should have the capacity to accommodate whole families as well as individuals. Bear Cottage, in Sydney, and Very Special Kids, in Melbourne, are examples of residential services that provide valuable support to families affected by leukodystrophy.

The cost of services and the issue of co-payment are central to future planning. ALDS is greatly concerned by the degree of inconsistency across Australia and is strongly in favour of a national approach to both funding and provision of a range of services. An example of this inconsistency is in the area of enteral nutrition. Leukodystrophy frequently affects peoples' ability to swallow, requiring enteral feeding via a nasogastric tube or, in the longer term, a PEG or similar.

In May 2009, the Dieticians Association of Australia prepared a submission for the Australian Health Ministers' Advisory Council on the issue of Australian home enteral nutrition services. That submission identified major inconsistencies in eligibility, clinical care, supply/access, central database and cost/funding. For example, in Victoria enteral feeds are fully funded and multidisciplinary clinics are available to provide clinical support; in New South Wales, by contrast, patients pay the full cost of feeds and tubing, and clinical support is limited, with a lack of uniformity across the state. (Dieticians Association of Australia, 2009, Appendix 2)

One of the greatest single barriers to people's ability to move between services is simply the absence of a national scheme. A national scheme should provide capacity to access consistent and equitable funding regardless of location, including portability of funding

packages across service and state borders. Similarly, specialised equipment should be allocated to individuals for the period required, regardless of re-location.

Specific challenges face people with a disability living closer to a major centre in another state than to their own state centre. For example, people living in far northern New South Wales may travel to Brisbane rather than Sydney; those living in south-west New South Wales or north-west Victoria may travel to Adelaide. In this situation, people may find that they need to access medical equipment such as walking aids or wheelchairs through one state, and medical and allied health services through another. A national system would greatly enhance effective and equitable service provision for people in this situation.

Some elements of a nationally consistent service system can be achieved with changes within existing resources, rather than requiring an injection of additional funds. Individual portability of equipment and funding packages requires changes to existing policies and procedures, without necessarily changing the net availability of either equipment of funding (considering resources globally rather than locally).

However, expanding the availability of services/funding to allow national consistency benchmarked at the highest level of current practice may require additional funding, as specific gaps in service delivery are addressed to bring them up to the level available elsewhere. These costs cannot be considered in isolation from the benefits in terms of efficiency, streamlined services and, most importantly, improved quality of life.

Although conceptualisation of disability services in a national rather than local context may also require additional funding, in order to create an agreed taxonomy and education of services and the wider community, this cost would be incurred only in the transition phase rather than as an ongoing cost once a national system has been established.

The quantity of services

There is no question that the quantity of existing services is currently inadequate but, as noted in the Issues Paper, measurement is difficult. Waiting periods are one measure of unmet need; families who have a child with a leukodystrophy commonly wait months, and in some cases years, for allocation of specific services. However, waiting lists do not provide a full picture, as many families are either unaware of services that may be relevant to them (effective service coordination or advocacy services would help here) or may have given up trying to access services, and struggle along within their own informal networks, to the extent that these are available, often leading to carer fatigue and burnout.

Recent examples of services that are not available within an appropriate timeframe for children with a degenerative condition include access to respite, therapies such as speech

pathology, case management (including, but not limited to, service co-ordination), adequate levels of in-home support, and equipment such as customised wheelchairs.

Appropriate accommodation is another service that is in drastically short supply. Adults suffering the effects of advanced leukodystrophy have few suitable accommodation options. Access to 24-hour care in the home is extremely limited and in most areas is not available. Alternative residential accommodation is primarily through the aged care system, which is not appropriate for younger adults who may have little or no cognitive impairment or who, regardless of cognitive ability, may have the interests and preferences of a younger age group. Many publicly-funded disability residential services are geared towards people with an intellectual disability, and so are generally equally inappropriate for young people whose disability is limited to the physical domain.

Families affected by leukodystrophy frequently experience an inadequate level of access to in-home support and respite. Leukodystrophy can affect both children and adults, depending on the specific condition and type. Children with leukodystrophy require 24-hour care, with needs increasing as the condition progresses. Carers (most commonly the parents of one or more affected children or adolescents, or the partner of an affected adult) become, in effect, 24-hour intensive care nurses, but may only be able to obtain additional assistance for a few hours a week, and sometimes less than a single day per week.

Workforce

Staff turnover, with resulting gaps in service delivery and variable levels of expertise, is a significant barrier to effective service delivery for people with a leukodystrophy and their carers. A Disability Care and Support Scheme must provide adequate funding to recruit, develop and retain a skilled workforce. An adequate salary structure and capacity for career advancement is an important element in achieving this goal. National strategies for training and streamlined data collection, portability of entitlements, and consistency in professional standards between states/territories, will all be important in retaining a skilled and experienced workforce.

The most effective staff members in the disability sector, however, are those who truly respect and value the people for whom they provide a service, and there must be a means of valuing and recognising people who demonstrate a commitment to excellence. Scholarships and assistance to provide student placements are approaches that will raise the profile of working in the disability sector, while also attracting a strong future workforce.

The balance of direct and indirect services (increased numbers of direct service staff, adequate training and support of these staff, and other relevant infrastructure) is important if the whole system is to function effectively. Resourcing one component of the service system without recognising the interactions between these aspects, will not improve

services to people with disabilities. There is a critical need for additional direct staffing, as seen in waiting times for current services and in the level of turnover experienced by people with disabilities and their carers. To recruit and retain these staff requires a broad view of workforce development.

Conclusion

The complex needs of leukodystrophy require contact with an equally complex service system. At its best, such a system demonstrates an integrated, co-operative alliance that is driven by the individual's needs and decisions regarding their preferred care. At its worst, services are fragmented, duplicated, inaccessible or non-existent.

In this submission, ALDS has highlighted some of the potential for future improvement in services, in the context of leukodystrophy. As it progressively attacks the nervous system, leukodystrophy leads to increased levels and complexity of need, and involvement with many different service types across the health and welfare sectors, both in acute and in community-based settings. Leukodystrophy reminds us that disability affects not only the individual, but also the immediate and wider family, and disability services cannot operate effectively if they do so in isolation.

This submission has focused on:

- The importance of viewing disability services from a rights-based perspective
- Gaps in existing service availability, in particular regarding service coordination, advocacy, appropriate complex-needs residential care, and realistic levels of support for carers.
- The importance of developing a consistent national framework for the provision of services and equipment.

It has also recognised the important role that a skilled, experienced workforce plays in providing an effective service system.

The Disability Care and Support Inquiry is an exciting opportunity to address the current barriers faced by people with a disability and to work towards a system in which people are truly valued and supported.

References

Dietitians Association of Australia (2009) Towards a National Home Enteral Nutrition Service for patients requiring nutritional support at home.
http://www.daa.asn.au/index.asp?pageID=2145870837