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Neuro Muscular Alliance Tasmania

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Disability Care and Support inquiry
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

The Neuro Muscular Alliance of Tasmania (NMAT) represents seven non-profit organisations that support people with neuro muscular conditions. The alliance was established in October 2006 in recognition of similar issues affecting client needs across Tasmanian neurological and muscular organisations. The Alliance collectively represents approximately 2000 clients.

NMAT would like to stress that it is vital for underlying service provision requirements to be in place to meet the demand that will arise as a result of any new disability care and support scheme, including housing, respite, medical services, allied health services, education for people with disability, and transport. This must be addressed concurrently with any Disability funding scheme.

It is imperative that the states continue to provide funds while this Inquiry is taking place. Any results from the Inquiry will at best be four or five years away and service provision needs to be continued during this transition period. The implementation of any radically different scheme for funding disability services will require a huge shift in culture towards a system which is people driven, rather than system driven as it is currently.

Which groups are most in need of additional support and help?

Individuals with lifelong, chronic, progressive neuromuscular conditions:

- Require relatively prompt access to care support at home as their needs dictate, to ensure that their health and wellbeing is maintained. This may be anything from 3 to 34 hours per week and more. If an individual isn't able to access timely care support in accordance with their needs, hospitalisation or premature entry to residential aged care (before the age of 65) can result.

How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

- People with progressive neuromuscular conditions and their families should play a vital role in contributing to the planning process. It is fundamental that there is a shared understanding of the lived experiences of people and the many challenges that they may face not only in the short term, but in the long term as their condition deteriorates. This of course lends itself to a 'person centred' approach and one that is espoused by our State and Federal governments. The recent review of the Tasmanian Disability Services Act 1992 clearly stated, *"The major emphasis of the Operational Framework for Disability Services (from which this review stemmed) was developed to provide a clear direction and operational model...the major emphasis is on building stronger partnerships between*

government, the community sectors and people with a disability and their families or carers...creating a more contemporary disability services system".
Nationally, in fact globally, there has been a shift in community attitudes in regards to the principles of human rights and the provision of flexible support for people with disability. Beginning with this premise, an adoption of a National approach to consulting and including people with progressive neuromuscular conditions and people with disability, their families and carers should be a priority in the planning and implementation of a National Insurance Scheme.

- **Appeal system**
  Any such system would need to be local, be very accessible and quickly responsive. Decisions are often needed for immediate action – time is of the essence. Perhaps a small team chaired by a mediator where the client/family could appear in person, with an advocate if they chose, together with the person/service whose decision is being challenged. Ideally, a negotiated final decision would be reached. In the event of a stalemate arising, the client/family decision should take preference with adequate provision made to absolve the service involved of any liability in the event of the action going wrong.

What kinds of services particularly need to be increased or created?

- Additional services for direct care and support provided to an individual at home.

- Flexibility and availability of hours if an individual's care needs suddenly or rapidly increase which is a feature of many neuromuscular conditions.

- *Streamlining of service provision:*
  Currently in Tasmania individuals are not able to receive funding from both HACC funded services and Disability Services. This becomes an issue when an individual's care needs increase beyond the scope of HACC funded services, as it becomes necessary to obtain funding to 'take over' the HACC support in addition to the increased support hours that the person now requires. For example, if a person was receiving 6 hours per week of personal care support funded by a HACC program, if their needs increase to requiring a total of 15 hours per week then that whole amount needs to be obtained from Disability Services, rather than just the increase of 9 hours per week.

- *Respite options for younger people with physical disabilities:*
  Residential respite options for younger people with a physical disability are required. Disability Services in Tasmania provides residential respite options for individuals with an intellectual disability, which are not an appropriate option for younger people with physical disability. The only options for residential respite are aged care facilities, which are inappropriate environments for individuals under the age of 65, or even 75. Aged care facilities are not designed or well-equipped to provide support to younger people with high care needs.

  In addition to younger people with neuromuscular conditions, it has also been identified from client feedback received that respite is an issue that affects all age groups, regardless of their condition. This is both beneficial for the carer and for the person with a neuromuscular condition. It is crucial that carers receive adequate respite in order for them to be well and supported, in turn offering strong support to the individual receiving the care.

- *Increased funding for the provision of equipment*
  Currently in Tasmania, the community equipment scheme caps the contribution at $6,000. It has been at this level for 15+ years while the cost of equipment has in many instances doubled.

  Access to equipment can actually play a role in preventing hospital admissions or premature admissions to residential aged care. Individuals who have transitioned into residential aged care can no longer access the community equipment scheme for funding as they fall under commonwealth funding. They are frequently unable to meet the costs of often expensive equipment which aged care facilities cannot provide. Access should be available depending on need regardless of the client's care status.

How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

- *Co-ordination*
  A case management approach could be adopted whereby an individual's needs could be assessed, with support allocated, coordinated and monitored as per individual needs dictate. This would provide a central contact point for the client who may be receiving input from a number of multidisciplinary areas and services. The case manager can become familiar with each client/family unit's needs and can co-ordinate in consultation and in partnership with the client/family.
  Case managers may need to either have a broad knowledge of a range of conditions, or specialist service providers could be implemented for groups of similar conditions.

- *Costs*
  A national scheme that is comprehensive, flexible, lifelong, responsive, unlimited and accessible by either the client or carer is required. Costs may be reduced by streamlining service provision, reducing duplication that exists currently in HACC programs and state disability services.
  Care should be transportable across states so that clients/families can continue to receive the same level of support after relocating. This 'transportability' is essential. People may need to move interstate to be closer to family, to access services not available in their state or to a climate that better suits their condition.

- *Timeliness*
  The ability to respond to both planned and unexpected needs is required, particular with progression of neuromuscular conditions which can be unpredictable. However, to a certain extent the likely needs of an individual with neuromuscular conditions can be estimated and planned for, and reviewed as their needs change or remain stable.
  Any scheme should not be founded on a 'crisis driven' premise. Needs should be able to be met immediately or as rapidly as possible after the need arises.

- *Innovation*
  It should be a client/family focussed system where the key is flexibility – where service provision is not system driven – where providers and client/families have the opportunity to think outside the square if that is what best suits their needs. For example, flexible respite for parents/carers who work and enabling them to earn more without being penalised and becoming ineligible for a carers' pension. Employment can in itself be a

form of 'respite' and can be extremely beneficial not only financially, but for social and emotional purposes also.
Flexibility for families as their needs change even from week to week is required – for example, some families may require more support on a given week than another and being able to access more or less assistance as their needs dictate.

Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

Individuals with neuromuscular diseases, in particular those with a somewhat predictable disease course such as motor neurone disease and muscular dystrophy, would benefit greatly from forward planning from the time of diagnosis to ensure that their needs were met throughout the course of their disease – for example:

- Children with muscular dystrophy require planning for lifelong needs so that at each stage, the required support/equipment can be put in place as required – not some two years later as is often the case. It is possible to plan the relevant needs throughout the disease course as they are reasonably predictable.
- For individuals with motor neurone disease, care needs typically increase rapidly as the average life expectancy is 2-3 years from diagnosis.
- Forward planning for all individuals accessing the disability care and support scheme could be achieved as suggested previously via a case management approach, where the individual's needs are assessed upon entry to the scheme and monitored/reviewed on an ongoing basis as their individual needs dictate. Early intervention would help to prevent many hospital and residential aged care admissions for individuals with neuromuscular conditions by providing support at the time of need, rather than the individual having to endure lengthy waiting lists. An early intervention approach would also prevent a crisis driven system.

How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

- The first priority is a scheme which enables clients/families to build a sense of trust for the 'system' – to know that the scheme will respond to their individual needs as opposed to the individual needing to fit into a particular category which does not reflect their circumstances.
- Adequate support systems including the provision of aids and equipment, transport, and respite to alleviate the difficulties faced by people unable to access their community and work.
- It is necessary for the new scheme to have flexibility regarding the use of support hours, from an individual requiring a carer to attend work/functions/social outings to one requiring access to their place of work. Currently, many Individual Support Packages do not offer flexibility for the hours being utilised for community access or support in the workplace (except under funding from the federal Government regarding employment, however there is not a lot of flexibility built into this arrangement). In addition, many services operate only from 9am to 5 pm while the service is needed outside these hours.
  e.g. a young mother who has alternate week respite for her severely disabled son – he can require medical intervention during the night which requires a qualified nurse to administer. The mother has been trained in this and on her respite weeks has to be on call at night as nursing personnel finish at 5 pm.

- Support to employers, particularly services offering education in specific conditions to staff. A national community awareness campaign showing the abilities of people with disability and the contributions they make to our society would serve to create a more inclusive society.
- Ensuring those with a disability have access to community facilities.

- A review of the rules covering Pension and Income Tax penalties for both the client and carers. The opportunity to participate in a work environment has enormous benefits for both those with a disability and carers, as it can often be the one thing that keeps carers going and sane. The rules currently take away the incentive to try to work and force families into the low income stream when the costs of disability are enormous. Losing the pension through exceeding income limits not only takes away the pension but also the associated benefits placing excessive financial burdens on clients and families.

What should be done in rural and remote areas where it is harder to get services?

- Transport to access services, education, employment and social activities. This can make all the difference in quality outcomes for general health and well being.
  This could mean heavily subsided transport or transport provided within a National Insurance Scheme free to those who require it for appointments with health services (including specialists and allied health appointments). To be equitable, it would need to be a provision for all those who would require such a service in regional and metropolitan areas.
- Provision for scheduled visits to more rural and remote regions by specialist, medical and allied health teams and support services – this would need adequate funding.
- Develop small allied health teams housed in regions where they are more accessible and closer for people to travel to - with regular visits from specialist and medical professionals.

In conclusion, the 2010-2020 National Disability Strategy underpins the purpose of this inquiry into a national long term disability care and support scheme - to reduce the impact of disability upon people with disabilities and their families/carers, and to improve opportunities for social inclusion across many areas, particularly in the community and employment. NMAT looks forward to the continuing implementation of the National Disability Strategy.

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On behalf of Alliance members:
Alzheimer's Australia Tasmania
Australian Huntington's Disease Association (Tas) Inc
Motor Neurone Disease Association of Tasmania Inc
Multiple Sclerosis Society of Tasmania Inc
Muscular Dystrophy Association of Tasmania Inc
Parkinsons Tasmania Inc
Spina Bifida Association of Tasmania Inc