MUSCULAR DYSTROPHY
SOUTH AUSTRALIA

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Disability Care and Support
Response to the Productivity Commission's Draft report

The Muscular Dystrophy Association of South Australia is a not for profit association incorporated under the Associations Incorporation Act.
The Association exists to:

1.1. to facilitate and promote the provision of optimal care to persons affected by Muscular Dystrophy or another neuromuscular disorder and to ensure the best possible quality of life for them;

1.2. to provide information, services and activities for the welfare of those affected by Muscular Dystrophy or another neuromuscular disorder and their families;

1.3. to promote public awareness of Muscular Dystrophy and other neuromuscular disorders and their effects;

1.4. to organise fund raising and to administer the proceeds for the benefit of those with Muscular Dystrophy or other Neuromuscular Disorders

1.5. to represent, promote and advocate the interests of those affected by Muscular Dystrophy or other neuromuscular disorders;

1.6. to initiate and encourage research and study pertinent to Muscular Dystrophy or other neuromuscular disorders; to do all other things incidental to the attainment of these objectives.

It is MDASA's experience that in supporting the independence and quality of life for people living with a neuromuscular disorder and their families, lead us to support the commissions finding that the current disability support system in Australia is inequitable, underfunded, fragmented and inefficient. The association also agrees with the recommended direction for a national scheme whereby people living with a disability receive individualised funding in line with their support needs.

The opportunity to create a system which provides fair and equitable support for all Australians with a disability is welcomed. Our feedback from people living with a neuromuscular disorder indicates support for a model which recognises the basic human rights of people with a disability and their families, increases the range of services available and increases the ability to choose a provider and/or to self manage funds.

The MDASA consultations have indicated support for;

- **Equipment** – To overcome delays in provision, inappropriate equipment, delays in repairs to equipment, delays in replacement, inadequate meeting of individual needs e.g. same type of equipment in two locations.
- **Information about and access to services**- People indicate they are not aware of available services or how to go about accessing them when they find they exist. There is no consistent source of info about support services or a consistent direct referral process for newly diagnosed people. . This situation is exacerbated with groups such as MDASA having on-going difficulty in identifying and locarting people with MD type disabilities, particularly as there is no one central register available to MDASA that records all people with those disabilities.
- **Country and NT clients** There are significant challenges in identifying and providing timely relevant supports to rural and remote communities. Distance contributes to slow response to a request and lack of flexibility in responding to a request. The client is invariably the "expert" and would much more effectively be able to manage their condition (with appropriate support if required).
- **Assessment** – the varied types and degrees of NMD's result in confusion and inappropriate services offered to people with NMD's. An assessment process that considered self assessed function rather than disability type would be much more effective for people with NMD's. We believe the assessment should also include employment and social participation which currently are not considered because of the high need for other more basic life services.
- **Therapies and Counselling** – MDSA believes there is a significant need for accreditation and support to mainstream therapists to mitigate the risk of injury arising as a consequence of a specific neuromuscular condition.
- **Transition periods** – this is an area of major concern to people living with NMD and their families. The Association would like to see a consideration of time limited additional supports to facilitate progress through transition periods such as entering or leaving school, interface with Health, Housing and Other mainstream sectors, as well as planning to retire. In particular men with DMD require specialist supports to transition from school to employment and most do not obtain employment because of the lack of supports.
- **Carers** –There is a massive need for appropriate services in this area. It is usually the case that individuals with a significant type of NMD require at least one parent or family member to be with them at all times which results in the recognized factors of reduced family income, stresses on families and reduced quality of life. The Association supports the proposal for an assessment methodology also includes the impact on the carer and the carers input to the caring situation.
- **Accommodation-** people with significant NMD's usually require extensive modifications to their environment to maximize their care and independence. Access to their home, room within the home, room for specialized equipment and access for powered mobility are basic essentials.

- **Community Access and Participation –** high level physical support needs means that a significant number of clients are unable to even leave the house without a support person. The level of disability leads to isolation and lack of socialization which in turn results in many clients only engaging with family members or paid staff. Many community facilities or organizations are not physically accessible and almost certainly are not able to provide the level of personal support that people require.
- **Transport –** any person using powered wheelchairs or scooters will require a specifically adapted vehicle for transport or they are dependent on taxis. There is a significant cost to purchasing an appropriate vehicle and undertaking any modifications. We believe there is merit in the inclusion of the "additional cost" of purchasing and modifying equipment and vehicles within the individuals allocated package.
- **Domestic Assistance –** there is a need to include provision for house cleaning, maintenance or gardening. To contribute toward the quality of life of the person.
- **Personal Care –** managed by the individual can result in the double benefit of increased services and supports and reduced costs. Currently a minimum 1 hour shift for a task such as providing lunch can mean that the entire time is not used but paid for and other tasks such as paying bills are not done. The other significant factor is that people with NMD's can require more than the available maximum number of care hours to live independently. This leaves no individual choice about where or how an individual will live their lives and is particularly relevant to people with significant NMD's.

The recommendation that The Australian Government take full responsibility for funding and operating the proposed NDIS adds confidence to the principle of consistent operational, governance and compliance matters and is supported.

MDASA appreciates the complexities and challenges in considering such a fundamental set of changes to address the shortcomings in the current disability support system. The issues identified by the commission clearly need to be addressed, MDASA are concerned that the time frame for implementation leaves a considerable number of people living with a disability in a less than acceptable situation for a very long time. MDASA would like to see an increased financial commitment from the Australian Government in a shorter time frame. This could occur through an interim allocation to individuals or agencies to address urgent need.

MDASA believe there is merit in the introduction of the scheme in more than one region as a trial. We believe the regions should be selected in a way which enables an assessment of market forces within the Government, non government and private providers while also considering differing population sizes and the needs of rural/remote communities.

MDASA agree that assessments must be as objective as possible and we believe this will best occur in conjunction with the person living with a disability and significant people in their lives.

The report raises the need for a complaints system and suggests the appointment of an independent person to act as a 'complaints" officer as part of the NDIS. MDASA believe the complaints system should be transparent, accessible and easy to use. It is clear that many people with existing experience in the disability sector are reluctant to complain. It is believed essential that complaints are dealt with fairly and are seen to be dealt with fairly.

It is clear to MDASA that people living with a disability experience significant added costs to maintain a quality of life and to respond to aspects of their disability. We suggest that the added costs that are necessary to meet the persons needs be included in their support package. These items could include:

- The cost of modifications to enable a person to remain living at home.
- The cost of modification to enable access or maintenance of employment.
- The additional costs associated with the need to run air conditioners to overcome reactions to heat and cold.
- Modifications to motor vehicles to maintain community access.
- Specific allocations to enable transport by taxis capable of transporting people in wheelchairs.

The need to maintain Disability support pension and associated allowances outside of NDIS entitlements with continuing tax exempt status for all payments is supported. Issues regarding the amount of support provided to family members will be part of the assessment phase. There may be a need within the trial phase of the process to assess the interface of Individualized budget allocations and various payments to existing carers.

Areas of Concern

MDASA supports the concept of a Tiered approach to the NDIS we are concerned at the possible gap in supports available under Tiers 2 and 3. We would request consideration of a mechanism to provide time limited supports to address transitional or short term extra ordinary needs associated with the persons disability.

Our consultations indicate a significant concern that the benefits of a National scheme can be reduced by the level of bureaucracy and the possibility of a ‘one size fits all’ approach. We would like to see administrative costs minimised and processes developed to ensure assessment and planning are client responsive and straight forward. The role of assessment in the operation of a fair, efficient and sustainable scheme is clear. We are aware of a multitude of issues with existing assessment tools and would like to see nationally consistent streamlined and responsive tools developed.

The interface with other systems has always been an area of concern for people living with a disability. We remain concerned that cost shifting from another sector or inadequate funding within other jurisdictions could have a significant negative impact on the proposed way forward. This appears to be critical in considering the interface with Health, Education, Aged care and Mental Health. We support the establishment of protocols and memorandum of understanding with a range of systems to address this matter.

MDASA supports the direction of self managed funds. We would request specific consideration of models to be well structured to enable good outcomes without compromising the requirement that a scheme meet public expectations of appropriate management of funds and accountability. We would also like to see the appeals mechanism facilitate supportive responses when things go wrong with the implementation of a support package.

Summary

MDASA welcomes the broad directions recommended for the improvement of services to Australians living with a disability. We agree that the current system is in crises and people will significantly benefit from, by the proposed direction. It is our opinion that the acknowledgment of the shortcomings of the current system together with a set of recommendations proposed to address fundamental services, human rights and citizenship for Australians living with a disability is a much needed and vital improvement for this large sector of our community.

Phil Martin
CEO
Muscular Dystrophy Association South Australia

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