MUSCULAR DYSTROPHY
QUEENSLAND

Disability Care and Support

Response to the Productivity Commission's Draft Report

Muscular Dystrophy Queensland is a not-for-profit community organisation incorporated under the Associations Incorporations Act.

Our vision is *'A Queensland where all people living with Muscular Dystrophy and other neuromuscular conditions are able to experience life to its fullest potential'*.

Our Association is committed to:

- working alongside people with Muscular Dystrophy and neuromuscular conditions to understand and meet their needs;
- raising awareness;
- supporting research;
- operating effective fundraising programs; and
- maintaining a sustainable organisation.

Our services include case management of over 500 clients throughout Queensland offering information, referral, advocacy, brokered respite, community networks and equipment loans/assistance with purchasing equipment including through the No Interest Loan Scheme (NILS).

It is Muscular Dystrophy Queensland's experience in supporting the independence and quality of life of people living Muscular Dystrophy and with other neuromuscular conditions and their families, that leads us to fully support the Commission's finding that the current disability support system in Australia is inequitable, under-funded, fragmented and inefficient. The Association also agrees with the recommended direction for a National Disability Insurance Scheme where people living with a disability receive support that is individualised to meet their needs for the whole of life.

The opportunity to create a system that provides fair and equitable support for all Australians with a disability is welcomed. Feedback we have received from people living with Muscular Dystrophy or other neuromuscular conditions in Queensland indicates strong support for a model which:

- advocates for human rights of people with a disability and their families;
- increases the range of services available;
- increases the ability to have lifestyle options (eg in choosing a provider of choice);
- enhances independence through the person with a disability and/or their families being able to choose if they wish to self- manage or self-direct funds; and
- meets the needs of individuals with a disability and enables them to live a quality lifestyle for the whole of life.

Muscular Dystrophy Queensland would like to submit the following response:

How a scheme should be designed and funded to better meet the long-term needs of people with disabilities, their families and carers

Individualised Funding: Individualised funding is crucially important. Every person is unique and has different needs. Just because someone is labelled as having a specific disability such as Muscular Dystrophy does not mean that their needs will be similar to another person with the same condition.

The need to maintain the Disability Support Pension and associated allowances in addition to the NDIS entitlement with continuing tax exempt status for all payments is strongly supported.

During the trial phase of the process it would beneficial to assess the interface of the individualised budget allocations and the various payments made to existing carers. *(Note: Issues regarding the amount of support provided to family members/carers will be part of the assessment phase).*

Early Intervention: Early intervention, particularly for people with newly diagnosed degenerative conditions such as Muscular Dystrophy and other neuromuscular conditions, would greatly enhance their quality of life. The Neuromuscular Alliance of Queensland, which Muscular Dystrophy Queensland is a founding member and is working with the Royal Children's Hospital in Brisbane to establish a Children's Neuromuscular Clinic due to commence in September 2011. In addition, the Neuromuscular Alliance has begun preliminary discussions with adult tertiary hospitals in Brisbane with a view to establishing an Adult Neuromuscular Clinic in direct response to this unmet need for support to people who are newly diagnosed with Muscular Dystrophy and other neuromuscular conditions.

Long-Term Support: There is a need for acknowledgement of *degenerative* conditions, such as Muscular Dystrophy and other neuromuscular conditions, within the disability spectrum. This reinforces the need for the scheme to focus on long-term support.

Equipment Provision: It is clear that people living with Muscular Dystrophy and other neuromuscular conditions experience significant added extra costs in order to maintain a quality of life and to respond to changing aspects of their disability, which in the case of Muscular Dystrophy, is progressive. We strongly support the policy that the extra costs of essential equipment are included in the individual funding package. Such equipment includes:

- Electric hi-lo beds (this item is currently not funded by MASS);
- Powered wheelchairs (including standing) and scooters;
- Modifications to enable a person to remain living in their home;
- Modifications to workplaces to enable access or sustainability of employment (Job Access currently provides this service);
- Wheelchair accessible vehicles and/or vehicle modifications;* and
- Transport costs eg wheelchair accessible taxis etc.

***Taxation Relief:** There should be increased taxation relief for families who have one or more members with a disability using a wheelchair so that vehicle modification is recognised as an essential requirement and not a luxury item.

How to determine the people most in need of support, the services that should be available to them, and service delivery arrangements

Information and access to services: There is a need for a consistent source of information regarding support services and a consistent referral process for people newly diagnosed with Muscular Dystrophy and other neuromuscular conditions. Currently there is not a central register available to Muscular Dystrophy Queensland that records these types of disabilities. As a result, people who need support and do not know how to access it are currently slipping through the net.

Advocacy: Muscular Dystrophy Queensland works closely with people with NMDs throughout Queensland. Our Client Services Team is dedicated to advocating on their behalf to protect their rights. With the phasing in of the NDIS throughout Australia our organisation would be committed to continuing to offer advocacy to people who live in Queensland with Muscular Dystrophy and other neuromuscular conditions to ensure they are supported and guided through the process, particularly where they are in a transitional period, eg between Tiers 2 and 3.

Regional Queensland – lack of services: There are currently insufficient supports and a lack of services throughout regional Queensland for people with disabilities, and, in particular, Muscular Dystrophy. There need to be innovative responses to meet the challenges posed by such unmet needs. Muscular Dystrophy Queensland has identified that currently there are significant time lags for families waiting to receive support from Disability Services and, in some cases their family member is at risk as a result.

Assessment: The varied types and degrees of Muscular Dystrophy and other neuromuscular conditions result in confusion and inappropriate services being offered to people with these conditions. An assessment process that includes self assessed function rather than disability type would be much more effective for people with Muscular Dystrophy and other neuromuscular conditions. The assessment should also include employment and social participation which are currently not considered. It is crucial that the NDIS should reassess people’s needs for funded support as their circumstances change, especially during key transition points such as leaving school, obtaining a job or moving out of home or losing a natural support. Assessment tools used should identify the person’s needs through a respectful and considerate process.

Assessments and information should be portable across the system – subject to protection of privacy – so that people would not have to repeat information already given to different providers or government agencies (such as repeated proof of the person’s disability). Support packages should also follow people across state and territory borders.

It is reassuring to read in the draft report that:

- *the Commission proposes a coherent package of tools (a ‘toolbox’) to be used across Australia, with different tools to suit particular needs for support (for example, aids and appliances compared with needs for job readiness training);*
- *the assessment tool/s would be developed within the widely accepted International Classification of Functioning, Disability and Health; and*
- *the assessments will be designed to be as objective as possible. Those making assessments would need to be independent from the client (unlike treating GPs), be properly trained in the use of the tools and be approved or appointed by the National Disability Insurance Agency for the purpose of conducing NDIS assessments. The agency would monitor assessors for their appropriate use of the assessment tools.*

Therapies and Counselling: Muscular Dystrophy Queensland believes that there is a need for accreditation of and support to mainstream counsellors and therapists to mitigate the risk of injury arising as a consequence of a specific Muscular Dystrophy and other neuromuscular conditions. Education, training and awareness are required among the broader community regarding muscle-wasting conditions as they are currently misunderstood and this can put people at high risk if they are not given the correct treatment and therapy.

Transition: This is an issue of major concern to people and their families living with Muscular Dystrophy and other neuromuscular conditions. Muscular Dystrophy Queensland urges that consideration be given to time-limited additional supports being provided to people with Muscular Dystrophy and other neuromuscular conditions during transitions so as to enable them to enter or leave school, interface with Health, Housing and other mainstream sectors as well as plan their careers and future. In particular, men with Muscular Dystrophy and other neuromuscular conditions require specialist support during their transition from school to employment. Many do not obtain employment because of the lack of supports.

Carers: There is a huge unmet need for appropriate services for carers. It is usually the case that individuals with a significant type of Muscular Dystrophy and other neuromuscular conditions require at least one parent or family member to be with them at all times. This results in reduced family income, stresses on families and reduced quality of life. Muscular Dystrophy Queensland supports the proposal for a respectful assessment methodology which includes the impact on the carer and allows for the carer's valuable and insightful input to the process to enable them, and their family member with Muscular Dystrophy and other neuromuscular conditions, to live a full and quality lifestyle.

Accommodation: People with significant Muscular Dystrophy and other neuromuscular conditions usually require extensive modifications to their environment to maximise their care and independence. Access to their home, room within the home, room for specialised equipment and access for powered mobility wheelchairs or scooters are basic essentials and the costs of these items should be included in the funding packages provided through the NDIS.

Muscular Dystrophy Queensland supports the Productivity Commission's idea of an entirely new model for housing for people with long-term disability based on 'cashing out' the costs of public housing and specialised accommodation. People with disabilities can then decide where they might live and what type of dwelling they might like. They (and their families) would be able to add their own finances to any housing decision. This model would require cooperation with State and Territory governments.

Community Access and Participation: The need for a high level of physical support needs means that a significant number of people with Muscular Dystrophy and other neuromuscular conditions are unable to leave their homes without a support person or an appropriate vehicle. This level of disability leads to isolation and lack of socialisation which, in turn, results in many people with Muscular Dystrophy and other neuromuscular conditions only engaging with family members or paid staff. Many community facilities or organisations 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 specifically-adapted vehicles for transport will be dependent on taxis. There is a significant cost involved in purchasing an appropriate vehicle and undertaking modifications making it unattainable for most families. Muscular Dystrophy Queensland strongly recommends, after many years of advocating for clients and seeing the negative effect it has on them (and their families) when modified vehicles are not attainable, that the cost of purchasing modified equipment or vehicles MUST be included in an individual's funding package. It is NOT a luxury item.

Domestic Assistance: There is a need to include provision for house cleaning, maintenance or gardening as these all enhance quality of life. Under the current guidelines services are very limited and tend to focus on compliance and service delivery rather than on meeting the person's needs.

Personal Care: Muscular Dystrophy Queensland recognises that currently many people with Muscular Dystrophy and other neuromuscular conditions are not receiving funding for personal care support and this must be rectified through the NDIS. Those people with Muscular Dystrophy and other neuromuscular conditions who do have funding often require far more than the number of care hours they have been allocated through their funding package. As a result this leaves no individual choice on where or how a person can live their life and particularly affects people with Muscular Dystrophy and other neuromuscular conditions as their condition is progressive. In addition, they have to pay for three hours (minimum) when they may only require a shift of one hour or two hours in the morning. This is not cost-effective or using their funding to the optimum.

Respite: Muscular Dystrophy Queensland offers brokered respite to people with Muscular Dystrophy and other neuromuscular conditions and their families. It is essential that this much-needed respite is offered giving them choice of service providers and, as identified in the personal care arrangements above, in a manner that can be managed by the individual optimising their respite hours and ensuring the services received meet their needs.

Self-directed funding: It is very uplifting to read in the Productivity Commission's draft report that self-directed funding is encouraged. As highlighted in the report it is an opportunity for people with disabilities to take control of their own funding. To foster this approach, agencies could develop and provide training sessions on self-directed funding.

How the scheme will interact with the health, aged care, informal care, income support and injury insurance systems

The interface with such other systems is an area of concern for people living with Muscular Dystrophy and other neuromuscular conditions. For example, when a person with a disability transitions to another system such as health or aged care, it is essential that there is adequate funding within that jurisdiction to cover the long-term needs of that person. This could have a significant negative impact on the person with a disability faced with a situation where there needs are no longer met. This is a critical area to be considered in order to ensure interfaces with Health, Education, Aged Care and Mental Health is seamless for people with disabilities. The consumer-choice model also gives options of continuing with NDIS or transitioning to Aged Care which is giving the person with a disability the opportunity to ensure the appropriate support is meeting their ongoing needs without any confusion or disruption.

Muscular Dystrophy Queensland strongly urges the establishment of protocols and Memoranda of Agreement between services to avoid any confusion or anxiety to those people with disability who are faced with changing needs that require health or aged care support where previously it was not required. Bearing in mind that people with Muscular Dystrophy and other neuromuscular conditions have progressive conditions - this is a major area of concern for our clients who are faced, on a daily basis, with uncertainty about their future – where one day they may be independent, the next requiring a different and more complex range of services to meet their needs.

Impacts on the workforce

Muscular Dystrophy recognises that, with the implementation of the NDIS (and the NIIS), there will be a significant positive impact on the disability workforce. The new system would translate into greater pay, more job opportunities, better working conditions, the capacity for innovative practice, enough resources to the job properly, recognition of the critical role of workers, more choice of employers, and greater satisfaction from working in a system that achieves better outcomes for people supported. These outcomes will be critical to attracting the workforce needed to underpin the expansion of the NDIS.

Education and training with incentives for innovation should be part of the NDIS to enable support workers to gain a true understanding of how valuable their roles are and what a significant difference they can make to the lives of those they support.

It is also of critical importance that support workers have such essential skills such as empathy, a capacity for listening and social skills and adopt a person-centred, strengths-based approach that empowers and enables the supported person with a disability to gain greater independence and self-esteem. For too long our system has operated on the basis of an institutionalised approach focusing on medication, paperwork and rosters rather than focusing on stimulating and engaging those people supported to improve their quality of life. At the other end of the workforce spectrum, if more people with disabilities have the opportunity, through the NDIS, to be supported in the workplace this will have a positive impact on the workforce as a whole. It would mean that society would become much more inclusive. The benefits, both to the person with a disability and to the country as a whole, through increased productivity, would be profound. To have as many active and engaged citizens in the workforce as possible is an ideal outcome. If this alone is achieved through the implementation of the NDIS it would make a significant difference toward changing the mindsets of our society to appreciate the contribution that can be made by people with a disability in our workforce.

It is noted that the NDIS would fund ‘job readiness’ programs (such as the ‘Transition to Work’ program in NSW) and other specialised employment services. Muscular Dystrophy Queensland believes that such programs will require transparent social auditing to ensure that they meet the needs of people with disabilities and also ensure that they are NOT exploited. The Job Network specialist employment services therefore must have benchmarks (other than simplistic job outcomes) that show that the person with a disability has achieved a goal and attainment commensurate to their ability.

How any scheme should be introduced and governed

Muscular Dystrophy Queensland supports the recommendation that the Federal Government take full responsibility for funding and operating the proposed NDIS. This will mean consistent operational, governance and compliance matters under the new scheme. It should NOT, however, become another disability service that is fragmented, under-funded and not equitable in its distribution of funding and support to people with disability.

Our consultations have identified concerns among many that the benefits of the NDIS would be reduced significantly by there being too much bureaucracy and adoption of a ‘one size fits all’ approach. Our recommendation is that administrative costs are minimised by processes being developed that ensure assessment and planning are client responsive and straight forward. Assessment must be fair, efficient and sustainable. There are also concerns about existing assessment tools. Muscular Dystrophy Queensland would like to see them reviewed as soon as possible and become nationally consistent; streamlined; effective; responsive and respectful.

Each State and Territory should also be given clear guidelines as to its role and how it meshes into the proposed Federal Government's NDIS.

Muscular Dystrophy Queensland sees merit in the introduction of the scheme in more than one region initially as a pilot. The regions should be selected to enable an assessment of the roles of Government, non-government and private sector, while also considering differing population sizes and the needs of rural/remote communities.

It is understood that there will be a Joint Taskforce established which will report back regularly to Heads of Treasury meetings and COAG on milestones reached in the planning for the commencement of NDIS by January 2014. Therefore with the NDIS pilot commencing in early 2014, proposed for a particular region of Australia providing high quality services to many thousands of people, it is critical that this initial phase be followed by a review which includes monitoring and evaluation (including feedback from people with disabilities and their families, Government, non-government and private sector). Regular reviews should also occur over the period 2015-2018 when the scheme progressively expands across all regions of Australia.

Muscular Dystrophy Queensland supports the tiered approach to the NDIS although we have identified gaps in supports available under Tiers 2 and 3. We strongly urge that a mechanism be implemented that provides time limited supports to address transitional or short term extra-ordinary needs associated with the person's disability.

It is understood from the draft report that the National Disability Insurance Agency would be a federal agency created by, and reporting to, all Australian governments. It would have strong governance, with an independent board, an advisory council of stakeholders, clear guidelines to ensure a sustainable scheme and legislation that protects the scheme from political influences. It is also understood from the draft report that the needs of people with a disability and their carers would be assessed rigorously by NDIS-appointed local assessors, with careful management to avoid assessment 'softness' or 'hardness'. Assessment would lead to individualised support packages. Strong governance would be necessary to contain costs and ensure efficiency in Tier 3, in particular, good governance will be critical to ensure both high quality supports and ensuring that the scheme is sustainable.

Muscular Dystrophy Queensland supports the proposed governance arrangements but urges that they be initially reviewed, monitored and evaluated during the pilot phase to ensure they are adequate before the NDIS rolls out nationally.

What protections and safeguards should be part of the scheme

The nationally consistent standards that are being suggested in the draft report would be desirable as they would apply to all funded specialist service providers and disability support organisations. This would provide greater national consistency in service quality and facilitate equivalent treatment of service providers across jurisdictions. As proposed in the draft report, in a consumer choice model (supported by disability support organisations), the degree to which these different suppliers might flourish or decline would depend on their performance. However, it is important to ensure that the consumer choice model does not favour the large providers over the smaller NGOs that often have the best knowledge of highly complex conditions; are specialists in their fields and, in some cases, are operating in remote settings.

Muscular Dystrophy Queensland strongly recommends that there be a watchdog in each State and Territory overseeing the NDIS through its implementation phases. Such a body would need to have a Complaints and Grievance process that is transparent and accessible.

In addition, and very importantly, Muscular Dystrophy Queensland believes that every safeguard possible must be put into place to prevent early admission into nursing homes. One example of a safeguard is to create circles of support around each person with a disability.

The costs, benefits, feasibility and funding options of alternative schemes

The proposed NDIS should be given ample opportunity to work effectively before any other alternative schemes are considered. It is already ground-breaking that the NDIS is being considered by the Productivity Commission. This has given hope to many people with disabilities that the new approach will give them a better quality of life through service provision being fair, equitable and able to meet their needs for the whole of life.

According to a study by National Disability Services and the Queensland University of Technology, if only 2% of people with disability received supports to enable them to work, the economy would benefit by $6 billion per year and if 20% of carers could return to work because their family member with a disability received support, the return would be $13 billion per annum.

Taking this information into account, the proposed additional $6.3 billion that is anticipated to be put into the NDIS to support the needs of all people with disabilities living in Australia should be reviewed annually as it generates productivity and a return twice that being injected. Therefore it is important to ensure that the expenditure will meet the needs of ALL people with disabilities living in Australia and should be revised accordingly, knowing that it is being offset by income being generated as a result of the implementation of the scheme.

SUMMARY

Muscular Dystrophy Queensland, like Muscular Dystrophy South Australia, welcomes the broad directions recommended for the proposed NDIS to improve the services offered to all Australians living with a disability.

The current system is in crisis and the proposed new scheme offers an alternative that addresses existing shortcomings and gives hope to many people with disabilities that they can feel valued and included. The new system must be responsive to their needs for whole of life.

Muscular Dystrophy Queensland acknowledges that this reform will have significant implications for service delivery under the NDIS consumer choice model including:

- the adoption of a new way of thinking for service providers and (the newly created) disability support organisations who will be supporting people with a disability;
- the phasing out of block funding to service providers;
- the opportunity for people with a disability to access mainstream services placing additional pressures for high quality performance by specialist agencies. This, in turn, would have the impct on where suppliers flourish or decline in importance according to their performance; and
- the implementation of significant IT infrastructure associated with an integrated disability system.

It also appreciates several significant opportunities for services providers under the NDIS:

- the amount of funding for disability services would be much greater and there will be strong incentives for innovative practice (with providers as well as people with a disability 'unshackled' from block funding);
- the introduction of an innovation fund that providers would use for developing and/or trialling novel approaches to disability services;
- the implementation of a scheme that encourages the diffusion of best practice throughout the disability sector; and
- nationally consistent standards.

Indeed, this is an opportunity for Australia to lead the way in reforming our current disability services to a scheme that responds to the individual needs of people with disabilities. By way of hearing their stories, reading over 1,000 submissions forwarded to the Productivity Commission and feeling the pain (through recent public hearings) currently being experienced by so many families due to the inadequacy of the current system, the proposed National Disability Insurance Scheme will give every person with a disability HOPE!

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