



Senate Standing Committee

Impact of NDIS

Muscular Dystrophy SA and Muscular Dystrophy Foundation welcome the introduction of a visionary set of processes to fundamentally improve quality of life for people living with a neuromuscular condition.

1 The NDIS was introduced with great fanfare and a considerable advertising campaign which created high expectations and excitement across the disability sector. Regrettably the vagaries of the political decisions and the inconsistency in the parameters of the trial sites have created circumstances where clients and agencies are required to “second guess” what will be supported and how the support will be provided in an emerging market. The initial expectations of the NDIS are yet to become evident to our clients in a majority of cases

2 many of our direct service workers and our clients (families) are overwhelmed with the volume and changing nature of the information. Organisational plans are, by necessity more complex in this circumstance. We have been encouraged by the early support through sector development initiatives, and in SA the collaborative readiness support strategies. These initiatives through project and block funding appears to be creating opportunities for the development of community support initiatives which will be vital to the long term success of the NDIS and are currently under developed in the sector.

We ask the committee to maintain a commitment to initiatives of this nature through the trial phase of the NDIS

3 NFP services and models have historically been established against a background of scarcity and under developed community integration. The early experiences from many clients indicate that the economic scarcity and under developed integration remain prevalent.

We would ask the scheme administrators to consider an increased flexibility in modelling through the trial phase. We believe it is vital that 3 issues be considered

A-The historical system was dominated by scarcity. Many clients simply gave up. We are encouraged by recent initiatives to offer the opportunity to reengage such clients and ask that these be increased to facilitate long term outcomes

B- Data in the sector is less reliable than required for the level of planning being undertaken. WE ask that the scheme continue to support initiatives that improve accuracy of data for planning and preventative research

C-In the age cohort trialed in SA we are working with individuals and Families. WE are also working across departments such as Health and Education. WE ask the NDIS to consider methods of leading changes and enhancing early intervention in a way which removes the current SILOS of government departments. Early diagnosis and prevention of hospital admission will significantly contribute to social integration and participation. This will require leadership from the NDIS/NDIA and a degree of risk. We do however believe there are significant medium and long term benefits to individuals and the scheme

4 At the present time we have inconsistency in trial parameters, inconsistency in roll out of the scheme and decisions by various state governments to introduce considerable change initiatives outside the NDIS trial parameters. As a service provider we appreciate the good intent of these initiatives however must indicate the possibility that energy could be redirected from essential services to meet short term planning. This will be to the schemes detriment in the long term

5 A consequence of long term underfunding of the sector has been a less than desirable focus on developing communities with an objective of integration in a social and economic manner. We ask the committee to consider methods of supporting outcome driven and measurable programs to build and sustain social programs (Duke of Edinburgh, Transition from school to Work/University)

Plan Management

1 We have found it beneficial to our clients to discuss service plans with them prior to attendance at NDIA. The wide ranging and profound nature of neuromuscular disability, combined with our clients lack of knowledge of what to expect at their initial NDIA assessment makes our pre-planning crucial to ensure reasonable and necessary outcomes are achieved. There is a clear and compelling need to facilitate attendance at planning sessions by an independent (Of NDOA) support worker

2 Also, Feedback received from parents of recently diagnosed children suggests that the possible access to NDIA is a good idea but can be overwhelming in line with the array of emotional, social and economic adjustments they are coming to terms with.

3 The NDIA and planners lack information about rare conditions such as MD and in particular degenerative conditions. This is placing our community at risk. There is a risk of losing specialist information and services. It also seems unrealistic to expect a NDIA planner to be familiar with a broad range of disability specific requirements

4 Quality of the plan very dependent on the training and ability of the planner we ask your consideration of ensuring that an "advocate" be invited to the planning session to ensure the individuals needs are comprehensively and coherently presented (especially if the family or individual are newly diagnosed, as they will be dealing with a considerable range of emotions (other than seeking NDIA support)

5 We have spent many years developing activities and programs that specifically increase the wellbeing and opportunities of people with MD eg camps, wheelchair sports, DOE however no activity or program costs are currently included in the NDIS and are being rejected when people are asking for them to be in their plan. People don't just need the financial support and carer support to get there but money to participate in the activity

6 We welcome the recent decision to fund "disability support organisations" as a means to build capacity through support groups and parent groups .This ,combined with a reconsideration of support for "advocacy" at a client level will significantly increase the opportunities for people with a disability to turn the NDIS objectives into a reality.

Thank You

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