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Re

PARLIAMENTARY JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY INSURANCE SCHEME

Wednesday 17 May 2017, Penrith- Joint Committee Western Sydney hearing

The introduction of the National Disability Insurance Scheme (NDIS) has brought choice and control to people with a disability and changed the way services are provided and accessed. ParaQuad NSW is a not for profit organisation that has provided services to the community for over 56 years. In addition to providing specialised personal care in the home, clinical services and supported accommodation, our health products division BrightSky Australia supplies speciality health products to the home (continence, nutrition and wound care); mobility equipment and home modifications across Australia. ParaQuad NSW and BrightSky Australia has therefore been actively involved in providing a variety of services and supports to people utilising NDIS since its initial rollout in the Hunter region.

We would like to acknowledge in particular the support we have received from Donna Weekes and Mary Hawkins at NDIS in responding to our queries and concerns regarding the evolution of services under NDIS. The clarification from NDIS has allowed us to better support our participants.

Acquired spinal cord injury has both a physiological and psychological impact resulting in the need for coordinated complex care to enhance quality of life as those with spinal cord injury experience significant impairment in various aspects of their life.

Chronic complications experienced by people with a spinal cord injury are common and have an adverse effect on their quality of life (Sezer et al. 2015). Secondary complications identified by Sezer et al. (2015) include; respiratory, orthostatic hypotension, autonomic dysreflexia, bladder and bowel dysfunction, spasticity, pressure ulcers, pain osteoporosis and bone fractures, the authors further highlight appropriate management of secondary complications provides improvement in community participation.

The Australian study by Middleton et al. 2012 (p811) highlighted elevated mortality rates following onset of spinal cord injury and argued the need for “proactive attention to the way in which contextual factors, either personal or environmental, interact with age and impairment to contribute to reduce life expectancy after SCI [spinal cord injury]”. In addition research has shown people with a spinal cord injury experience earlier onset of conditions associated with ageing (Jensen et al. 2013). This necessitates the need to manage complications appropriately.

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We have some participants who clearly identify as having improved benefits when utilising NDIS and yet we have others who claim they are worse off under NDIS. However many state the planning process is where things became unclear and generally speaking most Local Area Coordinators (LACs) have little or no understanding of the participants spinal cord injured needs with resulting plans not necessarily representing the conversation they had at the planning meeting. Some participants report inclusion of needs and services not discussed or relevant to them; others report that needs clearly identified and definitely discussed in the planning meeting were not included within the plan.

To assist in the proactive management of complications associated with spinal cord injury in the community setting we have developed a specialised pre planning tool. However this relies on local area coordinators and planners having a solid understanding of the specific concerns of people with a spinal cord injury so that plans can cater to the unique and complex needs of people with spinal cord injury. To date we have not seen local area coordinators or planners who understand the unique needs of someone with spinal cord injury and are therefore not confident that this community will receive the quality of planning necessary to best service their needs. It should also be noted that people with SCI will have substantially greater cost to NDIS than other groups, if not the highest costs.

We are aware that continence management is core to the needs of people with SCI and if inappropriately handled will limit their community participation and life expectancy. A recent survey by Wicks (2016) of ParaQuad NSW members under the age of 70 investigated participant's readiness to continence management under NDIS. The survey was sent to over 1000 people and had a 32.4% response rate and highlighted the following

- 80.9% self-identified as not experiencing urinary complications yet indicated regular urinary complication symptoms
- 37.7% self-identified as not experiencing bowel program complications yet indicated regular symptoms consistent with bowel management complications.
- 85.5% did not know HOW to request a continence assessment and 84.7% did not know WHOM to request a continence assessment from

The results of the survey by Wicks (2016) would suggest that participants may not understand their continence management options and the associated ramifications of poor continence management. This is further compounded by our concern that local area coordinators and planners do not have expertise in spinal cord injury management. If continence needs are not addressed now, what is the NDIS future plan for the management of continence complications associated with poor continence care?

Most recently we have been asked to supply Coordination of Supports to people who have a newly acquired SCI prior to their discharge from a spinal unit. On one hand we welcome the recognition of our expertise, however we remain concerned that whilst there are no NDIS guidelines to manage this situation considerable time is taken in discussion to determine who has responsibility with regard to discharge equipment approval. At this stage we have responded to this demand and do not bill for all our time as we

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do not wish to reduce the participants allotted coordination of support hours that maybe needed within the community setting. However this is not something that we can maintain on an ongoing basis.

We appreciate this opportunity to detail some of the positives and negatives we experiencing with the rollout of NDIS and look forward to feedback from your review.

Yours sincerely

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