



National Disability Services

NEW SOUTH WALES

ABN: 52 008 445 485

RESPONSE TO QUESTIONS ON NOTICE TO NATIONAL DISABILITY SERVICES

The second phase of 'Stronger Together' and participant choice

- Your submission expresses concern that despite the second phase of the 'Stronger Together' program emphasising individual choice, the LTCS Scheme sometimes operates to limit participant choice. This issue also arose in the hearings we have held.
 - Can you elaborate on this concern? Do you have any examples?

Response:

The concerns regarding limiting participant choice was based on the views of NDS organisational members. This feedback emphasised the lack of an obvious transition within the LTCS Scheme, for individuals to move from the initial acute care phase after injury, to what needs to be a very different phase of building capacity and independence in the life of a person with disability. Disability service providers felt that clients experienced a highly prescriptive and managed process which largely ignored this reality in people's lives. In a person-centred environment, disability service providers noted that people needed to be seen as individuals with changing needs, goals and aspirations as soon as possible so that they could return to their family routines wherever possible.

Anecdotal evidence from disability service providers suggested to us that there is a fundamental conflict between the disability sector's move toward person-centredness, and the current process-driven approaches to service provision experienced by disability service providers when implementing the LTCS Scheme. An area for improvement put forward by disability service providers included reducing the prescriptive nature of the LTCS Scheme and avoiding defining an individual's needs by their injury only.

Feedback also highlighted that individuals accessing the LTCS Scheme often have difficulties in how to make the transition back into their family and/or community. Specifically, problems were seen to arise as a result of the interface between health and community and the reach of rehabilitation services into a person's life which can have a detrimental impact on an individual's capacity to access their community.

A specific example provided which also has relevance to this question, was a concern around the funding of travel costs. The LTCS Scheme allocated a certain amount of funding to cover the cost of an individual to travel to a specific activity. When the client wanted to change activities, the choice for an alternative was limited to activities that were physically located within a similar scope or distance. This nature of approach prevents individuals from exploring new options more in keeping with their changing needs.

Recognition of carers

- Your submission states that you would like to see a 'stronger expressed commitment to acknowledging the role of family and carers'. In its answers to questions on notice, the LTCSA stated that it would 'ensure that all staff are advised of the NSW Carers Charter'.
 - What more do you think that the Authority should do?

Response:

NDS NSW applauds the commitment from the LTCSA that it would ensure that all staff are advised of the NSW Carers Charter. In terms of additional steps that could be taken by the Authority, NDS suggests that this review needs to consider the principles outlined in the NSW Carers Charter and address any issues that may exist in implementation of the Scheme.

To provide some examples of current concerns relating to the recognition of carers under the Scheme, information from NDS members expressed that the LTCS assessment process placed a level of expectation on the roles and responsibilities of carers which in turn can put pressure on these informal care arrangements.

Flexibility is needed in the model if carers need additional support, and that difficulties can be faced when dealing with changes in family dynamics as these may not be recognised or considered. Carers are often overwhelmed with the changing needs of their family member, and those of other family members and their own personal issues.

Feedback suggested there was minimal provision for initial or ongoing training, support and information for carers. Of particular concern was the impact on and challenges faced by carers of people with an Acquired Brain Injury who find that their loved one is a changed person particularly in relation to their capacity to make decisions.

There was positive feedback that some aspects of the Scheme did consider and place emphasis on the needs of carers. One example provided was that the location of some accommodation services were prioritised to be close to the family network, and recognised the value of this in the life of the person with disability and the family.

Another positive comment provided by one NDS member also suggested that the LTCS Scheme had recently made moves towards providing the family unit with an income in the situation that the carer were unable to maintain employment as a result of an individual requiring full-time assistance.

Funding leisure and recreation activities

- Your submission emphasises the importance of community participation for people with disabilities. In its answers to questions on notice, the LTCSA stated that it is 'not funded to pay for participant's leisure and recreation costs... [but]... will fund leisure and recreational activities for participants when the activity is part of a rehabilitation program and will assist the participant to develop independent living skills.'
 - What are your views on this approach? Does it strike the right balance?

Response:

NDS NSW does not believe that this approach strikes the right balance when considering the changing nature of disability services in NSW, as outlined in our submission. Disability service providers are part of a sector that is experiencing a paradigm shift towards person-centred approaches, individualised funding and an emphasis on a lifespan approach.

In considering this and in the context of a possible National Disability Insurance Scheme (NDIS) and National Injury Insurance Scheme (NIIS), NDS NSW believes it would be problematic to pursue an approach that attempts to separate and compartmentalise an individual's needs and life choices. It is NDS members' view that when you consider that in the wider community, people don't choose to participate in leisure activities to simply improve their independent living skills, then why should people with disability be treated differently?

The NIIS and other service models place a high level of importance on the individual having choice, voice and control over the services they receive. NDS NSW feels that the LTCSA should be positioning itself to be at the forefront and ready to adopt this new approach.

A specific example which demonstrates the shortfall of the current Scheme can be seen from the experience of one disability service provider. In this instance, the LTCS Scheme did provide funding for leisure and recreation, however placed parameters around this so that the activity had to align with the previous interests of the individual prior to their accident. A number of immediate concerns arise from this approach including, that a person's physical and emotional state has been altered and maintaining a previous interest may not be possible or practical depending on the individual. Instead of focusing on exploring options it demonstrates a lack of recognition of changed individual needs and choices, and recognition that a person's interests and abilities are different at various stages of recovery.

As further evidence of a lack of flexibility in the Scheme, the individual was required to continue with the activity for up to 3 months before changes in funding were approved. At this time a suggestion of what was deemed an appropriate alternative was put to the provider without consultation with the individual about what they were interested in. This highlighted the focus on the injury rather than the individual. The premise cannot be based on the view that all people who require the use of a wheelchair would enjoy wheelchair basketball as a leisure activity.

Information for service providers

- Your submission makes the point that there needs to be better information provided to service providers about the functions of the Scheme generally, as well as 'service compliance requirements and standards'. A similar suggestion was made by the Australian Medical Association in our hearing last Monday.
 - Can you elaborate on what might be the most effective way to keep service providers informed?

Response:

A key consideration that requires exploring is the number of not-for-profit disability service providers in NSW, compared to the number actually involved in the LTCS Scheme. Anecdotal evidence from NDS members suggested that organisations providing attendant care were the key focus for information distribution about the Scheme.

Feedback from NDS member organisations has suggested that information is limited about the mechanisms for becoming an approved provider of the Scheme. There are a number of possible ways to keep disability service providers more informed that include, though are not limited to targeted information on the website including a contact point within the Authority, and greater collaboration with peak bodies such as NDS.

Consideration needs to be given to changing the perception of providers already within and those potentially interested in joining the Scheme. One of the clear messages NDS NSW heard from disability service providers was the perception that nursing services and those run under a medical-model were the preferred providers within the Scheme.

The information provided also needs to encompass all aspects of becoming an approved provider of the Scheme. This includes being transparent in the information provided on the actual cost related to meeting the service compliance requirements and standards, as well as the ongoing cost implications of audits.

Deterring service providers

- Your submission states that ‘the LTCSA needs to ensure that they do not enforce unnecessary barriers for new providers and deterrents for becoming involved in the Scheme’.
 - Can you tell us what some of those barriers and deterrents are?

Response:

The compliance requirements were identified as one of the key deterrents and barriers for disability service providers. The first point to highlight is the extensive costs associated with this process. The upfront payment and time commitment involved for new organisations wanting to participate in the LTCS Scheme is shown to be significant disincentive due to the relative risk in the event an organisation is unsuccessful in their bid.

In line with previous comments about transparent information, there is further evidence from NDS members to suggest that inconsistencies exist in the cost structure for potential providers. Although the fee is dependent on the size of organisation, discrepancies can occur in the parameters of what is included when determining size. It has been found some organisations request a variation of audit inclusions. Specifically, whether the audit will cover LTCS clients only, certain services only, or all clients. It can therefore be dependent on the organisation’s ability and willingness to push for a reduction in the scope of audit, as to what ends up being included.

The audit has a health-related focus and is managed from New Zealand by a health-care auditing company. Much of the required proof and evidence is very focused on medical-model requirements (discharge, transfers, etc). This is considered out of line with the NSW disability service standards, indeed only two service standards have been ‘mapped’ to align with the requirements of ADHC and services undergoing this audit process will be required to seek validation for the other eight standards which are only partially met within this system.

The end result can be a requirement to produce a large amount of what then becomes irrelevant information which does not relate to how the service supports people to make their own decisions and choices. Certainly, there is a large conflict between the way ADHC approaches attendant care services (people self direct their services) and the approach taken in the audit process by the LTCS Scheme.

An audit process for attendant care assumes one approach fits all. This is not so in NSW. Whilst there may be commonalities which should be addressed in an audit, the documentation requirements should be broad enough to address the continuum which is currently in play. One mechanism for addressing this could be to consider the definition of attendant care services, which provides the basis for inclusion in an audit. Currently NDS NSW is told that the definition is so broad that it picks up a whole range of other services provided by organisations which has given the authority to the Scheme to then audit those services even though they are not related to or funded by the LTCS Scheme.

This can prove difficult for large and complex disability service providers in particular as the auditors expects that procedures and practices will be organisation-wide, which is not practical when dealing with diverse service types which are not health related.

That such a small number of organisations have 'passed' suggests that there is a problem. Indeed literature put out by ACSIA states that 'passing' will probably take between 6 months and 2 years. Given that many disability service providers have undergone a range of other compliance audits during this timeframe, this suggests a discrepancy between the audit requirements here and the wider sector requirements.

Consideration should be given to the acceptance of other quality frameworks which organisations have undertaken and qualified for. This is a direction ADHC is exploring to lessen the administrative load on organisations who often have limited resources to apply to audit procedures. That the auditing process is required every 3 years at a further cost and time impost to the organisation, was also considered to be an issue, particularly as one disability service provider reported spending up to 8 months completing this process.

The lack of symmetry between the LTCS Scheme and the changing philosophy within the wider disability sector becomes starkly apparent within the audit process. Feedback received by NDS NSW described the Scheme as a bureaucratic process that is highly prescriptive and paper driven. This medical-model of service delivery, including terminology and practice, results in a lack of focus on person-centred approaches and individual needs thus measuring the person with a disability as a patient and not as a person. There is also minimal acknowledgement of the nature and value of community-based disability service providers.

Lifetime Care and Support Advisory Council

- What involvement have you had with the Lifetime Care and Support Advisory Council since the last Review? Are you aware of the work it has undertaken in this time?

Response:

NDS NSW does not have an ongoing involvement with the LTCSAC and has relied upon feedback from NDS member organisations and information garnered from previous reviews of the Advisory Council.

It was evident that a number of providers felt it was appropriate that the Advisory Council include representation from full range of providers as this may address some of the barriers noted above for not-for-profit providers. It was suggested that tension occurred between medically driven organisations and those who are focused on community and social inclusion.

Organisations questioned how appointments are made to the Board, which may demonstrate a need for greater transparency in this process and information sharing with those affiliated with the Scheme.

Biennial review of the LTCSA

- The Committee is considering whether the review of the LTCSA should be conducted biennially. What are your views about this idea?

Response:

NDS NSW would support a move to review the LTCSA biennially in light of the significant changes that are currently on the National agenda in particular. As outlined in NDS NSW's submission and in a number of the responses above, the role and function of the LTCSA may evolve as a result of an impending NIIS.

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