

MULTIPLE SCLEROSIS AUSTRALIA

NDIS Consultation on Supported Independent Living

19 October 2020

Deidre Mackechnie
Chief Executive Officer

About Multiple Sclerosis Australia

MS Australia (MSA) is the national peak body for people living with multiple sclerosis (MS) in Australia. Our role is to work on behalf of all state and territory-based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with MS, their carers and the broader MS community.

Our Vision

Is consistent with the vision of the Multiple Sclerosis International Federation – **'A world without MS'**

Our Mission

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member organisations through advocacy and communication.

Our Purpose

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**
Supporting ongoing research to pursue further knowledge in causes, prevention, improving treatments, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**
Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about positive change to the lives of people living with MS.
- **Communication and Information:**
Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations and our key stakeholders.
- **Support for our member organisations:**
Who, as MS specialists, are providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, which addresses their changing needs.
- **International Collaboration:**
Representing the MS cause and promoting collaboration with our domestic and international partners.

Introduction

MS Australia (MSA) is pleased to provide a submission to the NDIS Consultation on Supported Independent Living.

The focus of the comments provided in this submission are on key areas that will impact on people affected by MS and other neurological conditions for which our state organisations provide services and support. As stated above, MSA's role is to work on behalf of all state and territory-based member organisations to provide a voice for people living with MS across the country.

MSA's member organisations are:

- MSWA (providing services and support in Western Australia)
- MS SA/NT (providing services and support in South Australia and the Northern Territory)
- MS QLD (providing services and support in Queensland)
- MSL (Multiple Sclerosis Limited providing services and support in Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services to people living with multiple sclerosis, including Support Coordination, regardless of age, and, in some cases, to a broader group of people with other progressive neurological diseases. These services vary from state to state and include: phone information support and advice, on-line resources, MS clinics, specialist MS nursing, physiotherapy, allied health services, education and information workshops, seminars and webinars, psychology, financial support, supported accommodation, residential and in home respite, peer support co-ordination and employment services.

This submission

This submission has been informed by information provided by our state member organisations and their clients and seeks to address each of the questions posed in the Consultation Paper.

Introduction

'Kate', diagnosed with MS when she was 33 years old, has been loving her new home at Butler in Perth's northern suburbs.

"It makes me appreciate the simple things like having friends over for a coffee or going to my parents' house which has proved difficult whilst living regionally. The on-site care and support allows me to lead a fulfilling and independent life – I can take myself to physiotherapy sessions or go grocery shopping and I can't begin to tell you what that means to me."

Initial steps taken to address these issues

1. From a provider and sector perspective, what drives the 1.3% month-on-month cost increases to SIL participant plan budgets, with particular note to FY2019/20?

Our state organisations provide specialist accommodation for participants with progressive, degenerative neurological conditions. Function and symptoms worsen over time which is to be expected with their disease course. Also, participants are getting older. This adds new complexity to their care needs as many develop dementia and other comorbidities that require a higher level of support needs.

This may result in one or more residents with changed needs, requiring additional support hours, for example, a client requiring a Care Support Worker (CSW) to provide 1:1 mealtime support due to the onset of dysphagia (difficulty in swallowing) and needing a modified diet plan to preventing choking/aspiration; which may take up to 40 minutes.

Examples of other drivers of increases to SIL participant plan budgets:

- A client's previous plan was in fact under-funded and the new roster of supports better reflects the needs of the resident and therefore costs more
- Increased wages – a CSW with Certification receive higher wages – also 24/7 care incurs evening, overnight, weekend and public holiday penalties
- Improved sector understanding of the roster of care and how to more accurately cost the additional supports required
- Inconsistency in plan development and level of funding provided resulting in increases
- Providers seeking increases in the plans to assist with covering vacancies - the delay in filling vacancies impacts on the provider – loss of the SIL to help cover all shifts and loss of rent

2. What could the NDIA do to help providers and the sector address plan budget inflation?

- Test the perception that there seems to have been large funding amounts made available to clients living at home, including 24/7 supports, through a review
- Consider that the estimates and modelling were inaccurate to begin with. There was unmet need in the community in most states and this saw many clients with insufficient supports in their home, leading to the onset of secondary complications e.g. pressure injuries, and overall decline in their health. They may well now require SIL. In the future this will be less likely to occur and supports will be available when needed and adjusted as their needs change so longer term demand for SIL for some of these groups may well diminish.

3. What are the most significant challenges that participants face when receiving person-to-person support in shared living arrangements?

- Disease process is challenging with progressive, degenerative neurological conditions and residents progress at different rates and require differing levels of care
- Privacy of care is a challenge in some shared living arrangements, depending on the model
- Choice and control for a particular resident when taking into consideration other residents
- Availability of personal space. A private ensuite bathroom is not always available, so the bedroom becomes the only place that is the resident's "own space", depending on the type of accommodation

4. What has been the impact of recent SIL changes to provider operations and participant experience?

- In terms of participant experience, the discussion that takes place between the Manager of the accommodation and the participant regarding rostered supports improves the participant's understanding of the level of support that is to be provided or is available for them.
- From a provider perspective, one of our state organisations has noted an inconsistent approach by the NDIA SIL team since the process changed from the 1 July, 2020
- The changes are not well understood, the process is becoming more complex in some respects and its harder to get in touch with a person from the NDIA SIL team if there is a query
- The recent SIL changes have increased the administrative burden on our state organisations when developing and claiming under the new SIL tool. The separation of irregular supports has also impacted budgeting and distribution of costs over the year.
- Manual inputs create the risk of incorrect entries.

Proposed short term changes

5. What advice do you have for the NDIA working more closely with participants regarding their SIL supports?

- The NDIA needs to be considerate of the SIL provider when working with participants more closely. Approaching participants with questions about their living arrangements and supports may create doubt in the participant's mind that was not present prior. There will also be no guarantee that another provider would provide better support than is currently supplied.
- The NDIA needs to consider the impact on participants if they are questioned about their roster of care taking different cognitive levels and understanding into consideration.
- The SIL provider needs to have a strong relationship with each participant to ensure we understand and meet their needs. The resident needs to have trust in the SIL provider.
- Dealing with individuals in a shared environment also needs to be accounted for, any review of arrangements should be across the whole unit/house/ complex for context on impact.

- We recommend greater than 1 hour for this review of arrangements to occur to ensure all aspects are covered.
- Consideration should be given to using objective measures for quality of life.
- Consideration should be given to the differences between SIL providers and Community Participation providers.

6. What are some effective ways for providers and participants to jointly work through and agree on an appropriate roster of care?

- These can be done individually with each participant and also as part of a shared meeting with all participants in the home / setting attending.
- Consideration should be given to allow for the presence of an “advocate” type role (though further consideration needs to be given as to how this role would be funded)
- More support should be given for Community Volunteer Visitors (where available) who can provide feedback and a report on resident’s feelings and perception of care.

7. What could the NDIA do to help assist providers in communicating the rationale behind a change in a participant’s circumstance?

- Make the communication process easier and build a rapport with the proposed provider to gain a real understanding of the requirements and rationale.
- For existing clients in SIL make additional, temporary, “supplementary” funding packages available to facilitate quicker access to the necessary supports rather than going through the whole process of ‘change in circumstance’ with its delays. The individual can then receive the necessary additional supports without delay and the provider can claim for services provided.
- The whole process for participants living in the community and requesting SIL, and often having been on a waitlist for some time for their chosen option, needs to speed up. The time taken to create the ‘change in circumstance’, then assess it, then to get the quotes and then to finalise the process causes vacancies for months while we wait for approval. The participant wants the placement and has the necessary level of disability and requirement for 24/7 supports and they are left either at home or in a rehab facility for unnecessary lengths of time, while a SIL option sits vacant.
- Be clear on the documentation required to support a change in circumstances and what discipline (allied health professional or other) can provide these; consider introducing a template to ensure consistency.
- NDIA needs to be clearer when providing details of their decisions on approving a roster of care and any amendments to what was requested.

8. How are providers currently informing participants and their families about the supports that they should be receiving? What has been more effective in your experience?

- The Manager of the accommodation considers acceptance of the client based on the client expressing a desire to move in to that SIL option and a visit with the client; they are usually already on a waitlist. There are several assessments conducted including a nursing assessment, a meeting with the proposed client and often their family and/or Support Coordinator to ensure the client’s needs can be met safely. The Manager/nurse identifies their needs (which can be difficult to completely assess until after they move in), they discuss the roster of care with the client and explain the types of supports that

are provided on a weekly basis, including all attendant care, cleaning, cooking and laundry services.

- Outcomes of assessments are shared with participants and families as appropriate.

9. What might explain variability in support levels across providers for participants with similar circumstances?

- Not all SIL options are the same - some are group home models and some are high care and provide nursing home level care within the SIL surroundings (which may be SDA level but not registered as such). For this reason, the DSC in WA, for example, had profiles of each residential/group home option with details of the actual environment and the clients residing there so an accurate picture would then assist in identifying why funding varied and what model was best suited to each individual. NDIS may better understand the breadth of difference in models if this occurred.
- Not all clients of SIL are homogeneous even within similar cohorts. For example, two individuals diagnosed with MS, with the same length of time since diagnosis, and a similar age and sex may still be completely different in terms of needs – both may be wheelchair dependent but one may be very high care, PEG fed¹ and with a SP catheter², and the other may have reduced mobility and high falls risk, swallowing problems requiring 40 mins 1:1 feeding at each mealtime, significant cognitive impairment and epilepsy. The funding will vary – for one person this may include community access, the other person may be mainly housebound due to high levels of fatigue.
- The quality of care offered by an organisation. It may be that a certain level of staffing would provide more basic care for a group home with more independent clients than a home with higher staffing ratios due to behavioural issues for example.
- Level of service provided - some providers will be providing gold standard level of care and staffing levels for a participant which leads to higher staffing costs than is translated in the roster of care. Potentially, if the difference in SIL between a higher support roster of care and a lower roster of care does not offset the direct salary costs and associated costs with agency replacement if needed, then there is an incentive to provide lower care than required.
- The level of community participation impacts significantly on the roster of care. Some providers set these up as “aspirational” goals and many residents want high hours of community participation, but in reality, the individual may not have the capacity or stamina to attend those hours. These hours need to be considered in consultation with the SIL provider.

10. What support from the NDIA would be most helpful to providers to reduce administrative challenges?

- A state-based dedicated point of contact for each organisation for SIL. Our state organisations can then build a relationship and have their queries answered in a timely fashion.
- In one state, numerous emails have been sent to the SIL team to try and clarify a number of issues regarding outstanding bookings but no responses received. In this

¹ Percutaneous endoscopic gastrostomy (PEG) is a procedure to place a feeding tube through your skin and into your stomach to give you the nutrients and fluids you need

² A suprapubic catheter is a hollow flexible tube that is used to drain urine from the bladder. It is inserted into the bladder through a cut in the stomach

case there is a significant level of funding unable to be claimed due to transition plans not including SIL for clients in SIL accommodation.

- The model needs simplification. For example, half hour time slots are unreasonable on the roster of care. This only gives a small snapshot in time and puts an unrealistic expectation on how care is actually provided.
- In some instances full 24-hour care is required and provided for high care needs residents though a model more closely matching that seen in residential aged care . The NDIS SIL model does not align with this service and therefore creates significant administration burden.

11. What are a provider's pain points in working with NDIA on SIL rosters of care, and what else could the NDIA do to simplify processes?

- The points of pain regarding roster queries applied more to the processes before 1 July 2020, when multiple queries re the rostering calculation spreadsheet were received; querying the service model and requesting changes that amounted to cents. The main point of pain since has been the inability to receive replies from the NDIA to enquiries for the clients we are seeking clarification on, so we can claim for the 24/7 supports provided.
- The NDIS really needs to engage more with SIL providers and understand the diverse models available and the diverse range of clientele; especially for those living with acquired disability and progressive, degenerative conditions.
- It is difficult in some instances for providers to provide accurate SIL rosters of care prior to a client moving in; often the reality of their needs across the 24 hours has not been fully evident through the assessment process. Clients adjust to the availability of 24 hour supports and the greater freedom that can provide around bedtime etc.
- 'Feedback' is a new step that is acknowledged and appreciated although there are significant delays in receiving and going through this feedback with the NDIA. There is no central email or phone number for point of contact. Consider establishing Relationship Managers that are responsible for this.
- Ensure NDIA staff are properly trained in the use of the roster of care given its complexity and that they understand providers' restrictions and requirements to meet these.

Developing a long-term roadmap

12. Do these guiding principles appropriately shape SIL reform?

The guiding principles seem appropriate, though it would be good to have greater discussion with the sector around how these are interpreted and how they impact on the participants and providers. Will our submissions help inform adjustments?

13. What items should a Home and Living Policy address?

- The Home and Living Policy seems appropriate, but the NDIA must also consider that not every SIL occupant is able to increase their independence and reduce their supports. Those with acquired disability due to trauma or disease, especially those with progressive, degenerative conditions may well require additional supports.
- Most SIL residents form a "community" and friendships with other like-minded residents whilst also maintaining their natural external relationships with family and

friends; reducing the social isolation often experienced when living alone in the community with drop in supports.

- This policy should adopt a focus on Quality of Life for residents

14. Are there any other comments or suggestions? What have we missed?

(i) Vacancy management

The NDIA provides no payment from the date a person leaves our accommodation and the delays experienced in filling the vacancy when someone has sought the vacancy and is waiting for weeks when they really need 24/7 supports and security, is very frustrating.

(ii) External support coordinators and planners not including the SIL manager in discussions about a SIL participant

The facility knows the client as they are there 24/7 and they may have cognitive impairment that is not obvious to those who do not know them. Being able to clarify details and provide some commentary would help. Our state organisations use a wholistic model of care and support and often have very detailed historical information that would enhance individual plan building.

Example:

A NDIA planner visited a SIL client, excluding the manager and the clients next of kin, and started to plan for his exit into an ILO. This man has a history of comorbidities associated with a mental health diagnosis, a history of self-harm and cognitive impairment that makes him unsafe to live alone due to impaired decision-making as well as his physical condition. This resulted in excessive angst for his estranged wife and unfulfilled anticipation for the individual as it was not a safe nor appropriate option. This could have been avoided by discussing this with those who knew his history in depth.

(iii) SIL as the safest option

Understanding that many SIL clients are in SIL as provides the safest option for them, giving them access to 24/7 supports and safety and security - it is not a decision that has been made lightly. There are occasions where there may be some improvement in an individual's ability and with NDIS they may be able to seek an ILO with appropriate levels of funded supports; in this instance SIL providers can work with the client and their support coordinator and others to facilitate a smooth transition into the new option.

KEY FACTS ABOUT MS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.
- There is no known cause or cure