



SUPPORTING DOCUMENTATION TO THE JOINT STANDING COMMITTEE ON THE NDIS – WESTERN SYDNEY HEARING.

Multiple Sclerosis Limited (MS) supports the introduction of National Disability Insurance Scheme (NDIS) as contributing to a significant transformation of the disability sector.

MS has been involved since 2013 in supporting the application of the NDIS for people with a Neurological disability. Since 2013 people with multiple sclerosis are receiving greater access to funded supports under the NDIS and lives of individuals and families are changing.

With the introduction to full scheme in 2016 MS acknowledges that the experiences of people have generally not been positive nor adequate and that the application and administration of the scheme has not been friendly nor consistent and has challenged and frustrated many participants, families, and our workforce.

Negative experiences range from planning through to application and review process, with adverse practices and processes hindering the successful introduction and acceptance of the scheme.

MSL supports the recommendations the NDS paper May 2017 – How to get the NDS on track.

Our experiences of the NDIS can be categorised into three areas:

1. Planning Process – information gathering and assessments used to develop a person's plan. Usually performed by a Local Area Coordinators (LAC).
2. Plan and plan implementation – plans approved by the NDIA and provided to a participant.
3. Plan Reviews – plans submitted for review usually due to an unmet need in the original plan.

Planning Process

MS has received considerable feedback from participants, their carers and other members of a participant's support network regarding the planning process. MS has also been heavily involved with a number of participants which has seen our staff involved at planning meetings with an LAC. The overwhelming theme of the feedback relates to the apparent lack of understanding of disability within most the LAC workforce, the absence of any specific understanding of multiple sclerosis or other progressive neurological conditions, the lack of experience in conducting assessments and the nature of the assessment. Applicants also report being hurried to complete the assessment or bullied into accepting a phone assessment rather than a face to face meeting.

Whilst MS is aware of a number of LAC's who have sound skills and knowledge when it comes to disability and sometimes progressive neurological conditions, it is not the norm. Conditions such as multiple sclerosis are characterised by many hidden symptoms which are often not being explored during planning assessment. Standing out amongst these hidden symptoms like fatigue, continence and heat intolerance is the changes that multiple sclerosis can have on a person's cognition.



Cognitive changes or deficits are difficult to identify when given ample time and exposure to someone with these symptoms. But when assessments do not explore such a possibility, assessors are not skilled or given scope to drill down and discover the extent of these symptoms, then the likelihood that they are given due attention is unlikely. Coupled with the push from LAC agencies in NSW to conduct these assessments over the phone then an appropriate outcome becomes impossible. MS can and does affect a person's ability to pay attention, retain short term memory, process information at normal speed and undertake executive functioning tasks such as planning, problem solving and flexibility of thought or insight. Not realising that these deficits could be affecting the answers being provided is, we believe, a major contributor to plans being developed which do not provide the necessary supports which can combat or help manage cognitive change. Supports like support coordination we believe should be mandatory for persons with a progressive neurological condition such as multiple sclerosis so that a plan can be implemented appropriately, in a timely fashion and without the potential risk that funds will be used inappropriately. Allied health support is also integral in managing some of the visible and hidden symptoms to MS and other neurological conditions. Funding to allow people to continue seeing trained professionals such as a physiotherapist or exercise physiologist, to manage pain, maintain mobility, reduce fatigue, reduce falls and improve a person's ability to remain in or re-enter the workforce. Often these supports are not understood by a LAC or their suitability and efficacy to someone with a progressive neurological condition is not understood.

Some examples experienced by MS and persons affected by multiple sclerosis in regards to the planning process are listed below:

1. Telephone calls – where the person with MS has not realised that this was their planning meeting.
2. Client says she had a phone conversation some time ago which she presumes was a planning meeting. Nothing has happened since and she is unaware of how to proceed. She feels she should have funding for a new wheelie walker and HC.
3. Telephone planning – as offered the only way to get a plan – or the person would have to wait weeks for a face to face visit and possibly miss out.
4. Planners speaking with husbands / daughters – and not checking who was the PWD and therefore seeing a plan developed that does not match the participant's goals and needs.
5. When asking for support coordination to be considered being told that they 'sound' like they could manage everything themselves.
6. Applicants being told they are not eligible for support coordination before the assessment has even begun.
7. Planners having no understanding of neurological disability and how it can impact a person's functionality – one planner questioning if MS was a permanent disability.
8. Planners following questions – without considering the overall context of what they were asking – several planners asking people severely compromised with no movement with arms legs etc. – can they brush their teeth; can they hang out the washing and so on.
9. Being told there is no such thing as exercise support in NDIS plans.
10. Being told that they can use core support monies to have a support worker give them exercise if they want it
11. Applicant being told that they seem to be able to move around the home ok so would not be eligible for a mobility aid which would enable community access.

Plans and Plan Implementation



For many people MS, has had contact with since July 1st last year and who have approved plans their experience from the planning process has not improved once they have a plan. The NDIA announced early on that written plans sent out to participants are often incorrect and that they should not be seen as an accurate record of the supports in a person's plan. In addition, supports identified in the participants 'myplace' portal are also often incorrect. This leaves participants unsure of what exactly they are funded for. The language used in plans is laced with poorly understood jargon and/or just copied and pasted from one plan to the next. For those participants who have not received funded support coordination they are told they will receive 'support connection' from the LAC who was involved in their planning process. Unfortunately, the nature of the support connection delivered by the Local Coordinator agencies to allow a person to activate a plan, engage providers, develop service agreements, budget their funds and deal with issues is sparse, inadequate and often ineffectual. Support connection from agencies sometimes seems to entail giving someone a handout on what the 'mygov' system is, what the 'myplace' portal is, definitions of a support agreement and a list of recommended providers which the participant can contact to seek supports or slightly better providing a single face to face meeting. Local Area Coordinators are telling participants that they do not have the time to provide support due to other commitments in planning and plan reviews but they are there if there is a problem. Unfortunately, LAC's are impossible to contact, often leave the position and are not replaced or report that they still have no time available to support a person. Other LAC's are telling participants to ring us at MS to provide this assistance, unfunded. Staff at MS spend a considerable amount of time chasing LAC's to implore them to provide the 'support connection' services they are contracted to provide. MS staff are assisting participants to submit plan reviews because LAC's do not have time or no LAC is currently allocated.

The end result is participants and carers that are engaging with MS are highly stressed, anxious and find it impossible to get a response from any agency staff unless they complain via their local Federal Member. Currently MS is fielding more than 10 calls a week from participants asking 'What do I do now I have a plan?' As mentioned before, often due to the ineffectual nature of the planning process many of these people have cognitive change associated with their condition which hasn't been identified or addressed and as such struggle to comprehend what is required and are often putting the solution in the 'too hard basket'.

With the NDIA's announcement recently that from July 1st 2017 Local Area Coordinators will also be responsible for plan reviews we are concerned that participants will receive even less support.

Examples of issues that MS have had reported to NDIA or we are aware of include:

1. Plans missing basic support that was previously funded under ADHC.
2. Plans without funds for equipment – including mobility aids and continence equipment, services such as domestic assistance, yard maintenance, transport funds
3. 80% of plans where MS provides support coordination are returned for review because of inadequate funding not matching previous state funded supports, support needs not understood by LAC resulting in absent or minimal funding for reasonable and necessary supports, funds allocated against incorrect support categories.
4. Participants not knowing who their LAC providing support connection is or haven't heard from them for weeks sometimes months.



5. Often participants with MS have been incorrectly classified as general disability rather than having a progressive neurological condition and LAC's deem they do not have the ability to change this.
6. Participant with significant cognitive deficits cared for by mother who does not speak English, received no support coordination and has received no support from local area coordinator. Provider of personal care is billing participants plan for support coordination from core supports, lessening available funds for personal care and community participation. Mother unable to advocate for daughter and does not wish to 'rock the boat' and lose funding. Local area coordinator believes arrangement is reasonable as she cannot offer support due to workload yet will not submit a review to seek funded support coordination.
7. Participant with significant cognitive deficits received no support coordination. Family culturally and linguistically diverse. Care provider having undue influence on participant and makes decisions regarding spending of plan funds. Local area coordinator due to lack of time due to workload deemed it reasonable for the paid service provider worker to have access to participant's bank details to enable plan activation.
8. Local area coordinators not understanding the support categories and line items available. Participants told that exercise physiology was not an available funded support, personal training was not an available funded support.
9. Continence support i.e. monthly changes of supra pubic catheters by registered nurse not being funded due to NDIA deeming it a health issue but they will however fund the supply of the catheter to be changed. NSW Health deem that the catheter changes are an NDIA concern and are stopping support leaving participants at risk.
10. Participant contacted MS as he was told he had a plan dated October 2016 but had no idea how to activate it. MS contacted LAC and meeting was organised to go over plan. LAC indicated they deemed the person as being high risk and complex. At meeting, it was apparent the funded supports were not matching disability supports under State model by approx. \$30k, minimal community participation and no support coordination for a very complex participant. Participant has no internet access and lives alone on a semi-rural property with access issues and very minimal formal supports. LAC indicated that the participant could manage plan via portal. When questioned re lack of internet LAC indicated they could come out at request to help manage portal. Necessary changes were agreed to by LAC with an indication they would contact participant the next day. No contact was made for the next five weeks. Both MS and participant tried to contact LAC but they were never available. Participants funded supports had ceased causing high levels of anxiety and MS took case to agency to be dealt with at an assistant director level. New plan developed within 5 mins with all necessary supports put in place.
11. Recently contacted by a participant who had minimal support coordination in plan which began in August 2016. Nothing in plan had been activated, was unaware of what support coordination was or how to engage any providers under her plan. No information or assistance provided from agency after plan arrived, no options offered as to support coordination providers

Over the last six months MS has undertaken an outbound calling project – contacting clients who we know are NDIS Participants to gauge the issues – of these:

- More than 30 stated that they didn't know how to implement their plan, did not have sufficient support from their LAC to implement their plan, did not know who their LAC was, or did not receive calls back from the LAC.



- At least six Participants had a LAC assigned to them, who subsequently resigned and they were not allocated with a new LAC.
- 14 participants reported they had insufficient funds in their plan and were receiving less than before they entered the scheme
- Five Participants stated they were not aware that the conversation they were having with the LAC was a formal planning meeting and many would have preferred to meet face to face rather than have the meeting conducted over the phone.

Plan Reviews

The number of people which MS is aware of that have submitted or are planning to submit a plan review is substantial. Of the approximately 140 participants which MS is providing support coordination to over 80 per cent have required a review due to errors in plans, underfunding of supports previously provided under the State model or unmet needs that were not understood or addressed at plan design. The process for submitting and waiting for a response from the NDIA is just another cause of stress for those people that are most vulnerable. The fact that a total plan reset is required to change a solitary item in a plan or to amend an error by the agency is causing a strain on the resources within the agency which is then transferring to participants and staff involved. Once reviewed plans are often seeing changes to support areas which were not included in the review which does lead to reductions in funding for core supports in particular. These reductions then lead to yet another review and the cycle begins anew. What we at MS struggle with, as do participants is the lack of communication around the progress of a review. Complaints will see a response that the issue has been escalated but to where and how that will impact on the time of resolution is not forthcoming. Staff at the NDIA, if you are fortunate to speak to someone, will often state that they are understaffed and can do no more than escalate the issue. Again, MS is approached by increasing numbers of people seeking assistance in formulating and submitting plan reviews or appeals, something which again is unfunded and should be delivered by local area coordinators.

Examples of issues we have heard of surrounding the plan review process:

1. Client seeking advice to appeal her NDIS plan. She said the plan was created by NDIA and her husband without her input. It fails to address her issues including provision for a wheelchair and a ramp. She reports having MS, COPD, a broken back and an ulcer. She said the COPD is made worse by her MS and she has had multiple hospital admissions for pneumonia. She reports that Life Design where going to provide a wheelchair but advised her today that they can no longer help because she has a NDIS plan.
She is seeking some support around appealing or seeking an urgent review.
2. Client says he put in a request for a review in December for his plan to include a larger monitor for his work place computer as his vision is deteriorating. He has not heard anything back. His LAC resigned in December and has not been replaced, he has called NDIA numerous times yet has not heard back. He is struggling with the portal and payment system.
3. Client is uncertain if she has support coordination, she feels her NDIS funds are less than her ISP she had before. The Client feels a review has occurred, however she



has no funds for OT, or continence products nor social connection

4. Client has tried to advocate for herself with her funds, however she still is short in the costs of continence supplies and Personal Care. She requires 4 Personal Care shifts per day. She is exhausted from trying to manage her funds, and has requested MS assistance for advocacy which is needed to request a review in her plan to provide Support Coordination and funds for continence and Personal Care.
5. *I am almost at breaking point. How do I engage support for my wife when I have no Support coordination funding? How do I engage support for her when Catholic care advise me of a \$500 engagement fee? When I have no funding? Others have indicated a \$350 one off engagement fee. All have indicated a \$90 monthly fee for ongoing support coordination. How do I do anything to help her when every time I try I don't have the answers to the questions. How do we support her with the NDIS when I can't access the funds in her plan? I have been trying to engage carers/domestic help for three months and no one can seem able to help her! Everywhere I turn it's the same. Do you have a support coordinator, answer no! Do you have funding for same, answer no! Response you need to request a review, she has had two already, the second submitted by the MS Society requesting 60 hours' support coordination at the end of 2016. No success there it seems - she is currently on her third plan and still we cannot expend the support budget for her. Is there a point to any of all this? She is supposed to be better off with NDIS. NOT SO!! Stress exacerbates MS and we are experiencing extreme levels of stress.*
6. G. is 60 years old, lives alone. The last 6 months have been very stressful and emotional after the death of both parents within days of each other. G had a LAC who resigned late last year and no one has contacted him since. As a consequence, G has not seen a plan and has no services in place. G was very appreciative when I suggested MS NDIS team will contact him to discuss a way forward
7. The client submitted her ARF in September, her GP included a letter requesting consideration of the purchase of a wheelchair given her lack of mobility. The agency requested a letter from her Neurologist re same. Both letters were sent to the Agency. The client has an email dated 12/10/16 from - NAT Assessor confirming that her ARF was received (it was sent 14/09/16). The client was told by the agency on 30/11/16 that there were no notes on her screen and she is still waiting to find out when she can expect a planning meeting. She had a major relapse and was hospitalised for three weeks. This did not improve her health, she is now back at home, she lives with her husband in their own home they do not have a network of informal supports as they moved to the area three years ago from Sydney. Her husband is a truck driver and travels for work, he took compassionate leave to care from her when she came home from hospital, he is now back at work and she is home alone. As her only carer her husband does all the domestic work around the house, the grocery shopping and getting her to and from medical appointments when he can. He is considering resigning from work to look after her. Client is unable to mobilise without a walker, her fatigue levels since her relapse are so high that she has difficulty walking from one room to another, she is unable to shower unless her husband is home. Several weeks ago, she had a fall when he was at work and she lay on the floor for two hours until he could drive back up to Lake Macquarie to lift her off the floor and back into a chair. She has a bucket in case she needs to go to the toilet. She is not only very distressed by the amount of



time it is taking for the Agency to respond, but also that she has been told that there are no 'notes' that have been kept regarding her previous interactions with the Agency.

8. Her goal was to keep volunteering with MS and running the group. She phoned me today to tell me she can't facilitate the group any longer as "The stress of the NDIS has taken my health. "The stress has done her harm and she is now wheelchair bound and catheterised and unable to leave her home as she needs a ramp and transport. Her plan has a car modification in it. She lost her mobility allowance last October but has no transport.
9. The client has an NDIS plan however he is having great difficulty in implementing his plan. He does not have a LAC, nor has he ever actually seen anyone in person regarding his plan. All his contact has been via the phone, and it is always with a different person. He does not have a contact person at the NDIA and is having great difficulty engaging them to assist in getting his plan up and running. He is currently struggling because some of his previous supports have been stopped because of his plan. He is currently living at home with his wife who cares for him, and their two children: 18 months old and 8yr old. The 8 yr. old is currently going through the diagnostic process of Autism. He said his wife is struggling, and both have a lot on.
10. The client believes that she does have a plan, although she says she has never seen it and it is not activated, she was very confused. She says that she has had contact with the NDIA via phone, email and face-to-face. She couldn't tell me if her planning meeting was with the NDIA or a LAC but said she did recall having a meeting in Bankstown. The meeting was held a couple of months before Christmas she believes. She received an email from the NDIA with a PDF link but that the document was blank. She had been given a log-in to the portal but couldn't get into it in time before it expired. She feels that her needs have changed since her original contacts with the NDIA and that she now needs more support than before.
11. The client has \$190,000- allocated to her, for HC, PC, gardening, maintenance, meal prep. She asked for Support Coordination which was not approved. She has not been able to access any services at all. No LAC calls are returned, and she is told that there is only one Service Provider in her area (Blue Mountains) and they have told her they need to recruit before shifts can be in place. Currently she has two shifts per week via HACCC which she pays for herself.
12. Due to the client's eye sight, she cannot access the portal to enter her details and is uncertain of what to do next. There are funds for assisted technology which she needs for her computer but she is uncertain how to access OT. She stated she would like support coordination and would appreciate a call from MS NDIS to give her advice on what she should do.
Review submitted on 22/2/17 with no response to date after attempts to contact from participant and support coordinator. Original plan did not include necessary funding for health and wellbeing to attend specialised rehabilitation group with exercise physiologist which participant has been attending for a considerable period and is now unfunded.