National Disability Insurance Scheme
Discussion Paper
Support Coordination

External Consultation

Occupational Therapy Australia submission

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Introduction

Occupational Therapy Australia (OTA) welcomes the opportunity to make a submission in response to the National Disability Insurance Agency's (NDIA) discussion paper addressing issues pertaining to the National Disability Insurance Scheme's (NDIS) support coordination service model, released in August 2020.

OTA is the professional association and peak representative body for occupational therapists in Australia. More than 23,000 registered occupational therapists currently work across the government, non-government, private and community sectors in Australia. Occupational therapists are allied health professionals whose role is to enable their clients to participate in meaningful and productive activities.

Please note that while this submission is modelled on the structure of the NDIA's discussion paper, it directly addresses only some of the specific questions asked. Owing to the necessarily anecdotal nature of the feedback received from occupational therapists working in the NDIS, much of our input is observational and has been inserted in the most appropriate section of the submission. Italicised comments are direct quotes from occupational therapists.

The role of occupational therapists in the NDIS

Occupational therapists work with people with a disability and their families to maximise outcomes in their life domains, including daily living, social and community participation, work, learning and relationships. Occupational therapists are highly skilled in assessing the degree to which a person's disability affects their level of function in daily tasks. Based on these assessments, occupational therapists make recommendations for, and then deliver, interventions that enhance and maintain an individual's functional capacity.

Given their expertise and area of practice, many occupational therapists deliver NDIS funded services to participants. These services include, but are not limited to, functional capacity assessments, interventions to promote participation in daily living skills and independence, minor as well as complex home modifications, prescribing assistive technology and providing positive behaviour support.

Inclusion of support coordination in plans

With regard to the factors that should be considered when determining if, when and for how long support coordination should be funded in an NDIS participant's plan, an OTA member has observed that the participant's capacity to make decisions should be the primary determinant:

> *My experience has been that clients with either complex pain or PTSD have not had support coordination, and yet these would potentially benefit most from effective support coordination.*

Another member writes:

> *Consideration should also be given to the participant's capacity to understand and implement their plan as well as engage with providers – considering their abilities (physical, cognitive, etc.) and resources (technology, family supports etc.). I once had a client who lived alone, was illiterate, had speech difficulties, did not have internet access, and no family in the country, and support coordination was removed from his plan making it very difficult for him to identify and engage with appropriate providers.*

With regard to how support coordination should interact with other NDIS supports and mainstream services, OTA believes the role should be to work with the participant to engage the supports that are necessary to achieve their goals, while respecting the participant's right to choice and control. It requires someone who can guide, without being prescriptive. And at no time should the support coordinator presume to dictate the clinical approach taken by appropriately qualified service providers.

End of plan reports should include an assessment of the value of any support coordination provided, and recommendations regarding future support coordination.

While there is sometimes a need for support coordinators, it is incongruous that the budget for them can be greater than the therapeutic capacity building budget.

There is also a lack of accountability around the support coordinator's budget, and this constitutes a double standard:

> *Support coordinators will bill for all communication, yet if a therapist bills a participant for contacting suppliers to organise trials, or for communicating with the support coordinator, the COS will often tell a participant not to pay and that they are being 'ripped off'.*

OTA members report that there are instances when it seems contact is made with a therapist primarily for the purpose of generating a 'billing' activity, which is clearly not appropriate.

Role of support coordination

The role of support coordination is, in theory, supported. When carried out well it can be very valuable to participants, particularly those who are isolated and/or do not have the capacity to arrange services themselves. The scheme is very complicated and can be difficult for participants to navigate, particularly in the early stages.

One OTA member states:

> *The role of support coordination is warranted in certain circumstances and certainly it is wise, if implemented correctly, to have this funded initially for participants and their families to gain understanding and knowledge of the scheme and its funding.*

However, as another member observes of the role:

> *It's not therapeutic, or advocacy, it's identifying appropriate supports and engaging with these. And ideally done in a way that recognises a person's autonomy.*

On page 5 of the discussion paper it states: "Support coordination is a concept that has evolved under the NDIS and was not previously a feature of the program-based disability service systems funded by state and territory governments".

This statement, while technically correct if one only references the non-injury related disability sector, is misleading. Support coordination and case management have been features of injury management programs in the injury insurance sector for many years, and there are highly developed skill sets and training processes under various state and territory government schemes which the NDIS has failed to acknowledge or learn from. This is regrettable.

An OTA member writes:

> *As a case manager under a state-based Return to Work scheme, I have been following discussions on a private e-forum for NDIS occupational therapists. They write about their various experiences of support coordination, and their observations are in line with mine. While there are some very good support coordinators who do indeed fulfill the role as stated by the NDIA, there also seem to be many who are either completely incompetent or who see their role as making it as difficult as possible for the participant to access and utilise their funds.*

Too often, support coordinators undermine, and at times invert, correct clinical process.

> *I have experienced support coordinators recommending equipment items for participants without consulting an appropriate therapist. Likewise, some support coordinators encourage clients to 'shop' for the equipment item they would prefer, then request a report from the therapist – rather than requesting an assessment from the therapist at the outset.*

There is serious concern among OTA members about directives or service requests coming from support coordinators:

> *Many support coordinators will 'instruct' or 'tell' a therapist what the participant needs or wants, e.g. 'the participant needs an assessment for an adjustable bed', rather than enabling the occupational therapist to complete an unbiased, objective assessment of goals, function and need. Occupational therapists are often castigated if they do not do what the support coordinator has stated.*

This is clearly an unacceptable practice, given that occupational therapists working in the NDIS have university qualifications in their area of expertise and are duly registered by, and answerable to, the

Australian Health Practitioner Regulation Agency (AHPRA). In contrast, as the discussion paper itself notes, "Support coordinators do not generally have to hold any particular qualification to undertake their role and there are no specific measures or outcomes expected to demonstrate a quality service" (page12).

Such a state of affairs clearly undermines one of the scheme's five fundamental objectives, as stated in the *National Disability Insurance Scheme Act 2013*: **promoting the provision of high quality and innovative supports to people with disability.**

Moreover, this can have a decisive effect on the viability of businesses trying to operate within the NDIS:

> *Support coordinators, without any training/qualifications, are dictating the success/failure of many businesses, i.e. they refer to who they like or who makes business easy. There are many 'allegiances', and collusion is rife.*

Many support coordinators misunderstand their fundamental role, believing it be one of case management. As one OTA member notes:

> *Many support coordinators are 'doing for' rather than 'doing with' i.e. connecting with providers, which is case management rather than capacity building. The majority of support coordinators' work is done from an office, not in the participant's home or community.*
>
> *In many circumstances, funding for this role appears to be a financial black hole for the taxpayer, with no outcomes. There is little clarity or oversight regarding the role of the support coordinators. In our experience, we are aware that therapists or practices that 'push back' in order to maintain professional and ethical standards, are often marginalised and their services not utilised as they are dubbed as 'difficult' to deal with.*
>
> *We have had occasions when a support coordinator requested us to 'meet' a participant to discuss services and provide a quote back, however, the participant has opted to commence services immediately. This has enraged the support coordinator – that the instruction 'was not followed'. No further connections have ever been made by the support coordinator in question (punitive).*

OTA members report that support coordinators often fail to discuss goals and funding budgets with participants. This results in an inordinate number of therapists having to operate within an unrealistically small budget, a state of affairs that, under most circumstances, cannot be expected to deliver an outcome.

> *Participants need to be educated in the idea that during the course of a plan they may only be able to access a single therapy, or a limited number of therapies, in order to achieve outcomes and, hence, ongoing funding.*

Other concerns raised by OTA members around the role of support coordinators relate to advocacy and privacy.

> *Most support coordinators do not understand the* Privacy Act *or privacy principles. Practices are often contacted to release information without a signed privacy consent, or information is requested 'just to have on my participant's file' (which is an inappropriate request for information).*

While there may be a limited advocacy role in support coordination, it is imperative that this not be confused with the right to be directive towards those providing clinical supports. Support coordinators should not lobby, let alone seek to dictate to, appropriately qualified clinicians.

An OTA member observes:

> *Support coordinators often act in the role of advocate. They will contact a provider to cease services, placing providers in the awkward position of needing to call a participant to verify cessation; often times, the participant cannot provide a reason or will avoid contact with the therapy service (no known issues or complaints prior to disengagement). Support coordinators are often 'referring' rather than 'connecting' participants, i.e. contact comes from the support coordinator not the participant.*

OTA made the following observations on the role of support coordinators in a recent written submission to the Queensland Productivity Commission's (QPC) *Inquiry into the NDIS Market in Queensland*:

> *Support Coordinators do not necessarily have qualifications or a background in therapy. Despite this, they will often prescribe assistive technology for clients at level 1 and level 2.*
>
> *Though this may be perceived as saving their clients' time, they often prescribe incorrect equipment. This puts the client at risk and wastes valuable NDIS funds. For example, one OTA member reports that a 7-year old girl was prescribed an adult toilet and shower seat by her Support Coordinator.*
>
> *Some Support Coordinators also attempt to prescribe interventions for the occupational therapist to complete. This undermines occupational therapists who are specifically trained to assess the needs of their clients; engage in person-centred evaluation of their goals, tasks and environments; and provide interventions or advise adjustments to maximise function and independence.*
>
> *There is also concern that Support Coordinators are not well-informed about the function of multidisciplinary care teams. They often request highly structured plans with itemised hours of support for each discipline which does not provide practitioners or the participant with the necessary flexibility.*

This is particularly problematic in rural and remote areas where many providers operate as 'rural generalists'. In towns with a limited number of health professionals, NDIS plans must have the flexibility for participants to continue receiving care from whichever practitioners are most suitable.

This submission to QPC included these two recommendations:

Recommendation 5: Enhance client, family and support worker understanding of capacity building – and the allotted funds – so that participants can prioritise and achieve their goals in this area.

Recommendation 6: Clearly define the role of Support Coordinators to ensure that assistive technology and other interventions are prescribed by qualified professionals, including as part of a multidisciplinary care team.

Quality of support coordination

OTA is concerned that there is a lack of training for support coordinators and too few stated expectations to guide the performance of the role.

The criteria and training to be a case manager or coordinator under the Lifetime Care and Support Scheme (a role very similar to that of an NDIS support coordinator) is intense and strict, so that people filling these roles operate at a very high standard. This does not seem to be the case for the role of support coordinator. I am puzzled as to how the NDIA can claim that high quality support coordination is important, and then expect to achieve a high standard in this role with no qualification requirements, no training and no standards set. Why didn't they access and utilise the wealth of information available to them from the experience of support coordinators and case managers working in schemes such as Lifetime Care and Support? It is hard not to wonder if the reason is a matter of cost.

What and where are the outcome measures for support coordinators? The apparent absence of KPIs encourages 'case management' style services, which ensures that the support coordination role continues to be 'required' when perhaps it is not.

Support coordinators appear at times to encourage 'shopping around' for therapists. While participant 'choice and control' is important, not understanding how to liaise effectively with providers or to 'work issues out' can result in participants spending thousands of dollars on the same service repeatedly (i.e. initial assessment, functional assessment, assistive technology applications), with no significant movement being made towards the achievement of goals. Planners can then interpret this lack of progress as grounds for reduced funding in subsequent plans. As a consequence of this misunderstanding, the therapist can then be expected to provide services in the context of a diminishing budget.

Concern has been raised about the hourly rate paid to specialist support coordinators. Whilst these coordinators are expected to be tertiary qualified, there are no assessment tools or speciality skills required other than a more thorough understanding of mainstream and disability services, and the coordination of more complex issues.

> *There is no requirement for investment in assessment tools, post graduate qualifications or advanced skills, and while the work seems to involve only minor face to face consultation, it is paid at a therapy rate.*

With regard to measuring the effectiveness of support coordination, whether or not a participant achieves their goals should obviously be taken into account. However, support coordination pricing should not be based on the progression of participant goals and outcomes:

> *The risk of that is it forces support coordinators to move quickly to achieve the participant's goals, and they move in a direction that is not in the participant's best interests.*

With regard to examples of good practice, one OTA members writes:

> *I work with some support coordinators who know what the participant needs and wants, and work to achieve that by getting the right team around the client. Then there is the flip side, where support coordinators feel they know best what the participant needs, but that may not actually be the case.*

Building capacity for decision making

> *Our experience with support coordinators is that the negative far outweighs the positives for the scheme and participants, insofar as the purpose of support coordination is meant to be capacity building but, in actual fact, in most cases it is fostering 'dependence'.*

There are obvious challenges in assisting the informed decision making of participants with a functional limitation associated with cognitive impairment or a mental health condition. It takes particular skill to map out options for these participants.

And building a participant's independence is a skill:

> *It is done by identifying what the participant wants to achieve, finding out what the participant knows about achieving it, and then working with the participant to fill in the gaps – in a respectful way.*

Conflict of interest

OTA members are concerned that there is a lack of transparency around the selection of NDIS service providers by support coordinators. Some fear there is collusion occurring in the market, i.e. between support coordination, therapy, the supply of equipment, and tradespeople.

Participants are not well enough informed about issues such as cost differences within the scheme, the level of expertise of service providers, or the varying quality of services provided to participants (e.g. why a therapy assessment and report at one practice might be a few hundred dollars, but several thousand dollars at another). Very often, support coordinators encourage participants to go with the cheapest option, which may not necessarily be the most appropriate, or the service most likely to achieve the best outcome.

The attitude of some support coordinators can be punitive and personal, failing to take into consideration the participant's best interests. A more skilled or specialised service provider might be sidelined by a support coordinator who only 'refers' to a service provider they like and wish to work with.

As a result of this attitude, some support coordinators have disrupted longstanding and highly beneficial clinical relationships, or disengaged participants from promising therapeutic relationships upon their appointment.

There is also a lack of transparency around what is, and what is not, billed for support coordinators' services:

> *Many participants think a support coordinator is visiting them at home with coffee and cake because they are nice people and 'are my friend', but fail to understand that this 'social visit' is being billed.*

General

OTA members acknowledge that the support coordination service model does have some important strengths.

Participants in rural and remote communities tend to require assistance to locate and connect with service providers in what can be very thin markets, and support coordinators can be very helpful in this context.

Support coordinators can also play a role in education in rural and remote communities.

Recommendations for the improvement of the model include:

- Retain support coordination for participants who have significant impairments to learning/understanding, and do not have an informal support network.
- Retain support coordination in first plans, but include among the plan's goals an expectation as to what the participant will be able to do at the end of that support. If possible, support coordination should not be included in subsequent plans. A good support coordinator is one who puts themselves out of work.

- Do not permit support coordinators to attend planning meetings, as this can influence conversations and limit the ability of the planner to ask questions regarding satisfaction with existing supports or determine how new supports are chosen and implemented.
- Data should be provided to the NDIA on the length of time a participant has been connected with a particular provider, the number of providers accessed, and reasons for disengagement/cessation.
- Only Capacity Building activities should be billed for, not all activities as is currently the case.
- There should be a checklist of capacities provided to, and signed by, the participant (i.e. portal access, understanding the varied providers/expertise in local area) crosschecked against cognitive capacity indicated by therapist/s.
- With regard to billing for support coordination, face-to-face should attract payment of the current rate but office-based work should be charged at a lower rate, thereby increasing the incentive to actually interact with the participant.
- Training modules should be developed for support coordinators around accessing the NDIS portal, choosing a service provider, interacting with service providers, explaining price differences to participants, etc.
- Increase the capacity of Local Area Coordinators, thereby addressing what is currently an excessive need for support coordinators.
- Address the disconnect that often exists between the allied health components of a plan and other support services.
- Address delays in the processing of provider invoices.
- Enhance communication between all interested parties to a plan.

Housing

One OTA member working as a housing specialist writes:

> *I have seen, time and time again, the importance of working with knowledgeable and trained support coordinators when exploring housing options for participants with disability. In my experience, many of the support coordinators supporting clients in this area have poor understanding of housing options, NDIS criteria, and the actions that need to be taken to adequately support participants, engage the right experts, and efficiently manage funds in this area.*
>
> *Housing, for the purpose of this consultation, means bricks and mortar and associated supports. As an occupational therapist, I know how vital and essential housing is to a person. I also know that with appropriate housing and supports, OTs enable people with disability to remain safe and be as independent as possible within their community.*
>
> *To my knowledge, support coordinators are not currently required to undertake specific training in housing as a core criterion to supporting clients in this area. There is limited training and professional development courses across the full range of housing options available that adequately prepares support coordinators for the complex work in this field. While there are some training opportunities specifically for Specialist Disability*

Accommodation (SDA) and Supported Independent Living (SIL), there is minimal training in other types of housing options.

We know that only 6% of people who have a disability and housing needs meet the eligibility criteria and are approved for SDA. That leaves 94% of people with a disability who have alternate housing needs. In a webinar presented by Alana Dobra (Summer Foundation) on 22 July, 2020 it was noted that 127,000 people with a disability have unmet housing needs and/or live in inappropriate housing (and who do not meet SDA criteria). Support coordinators need training to assist people with a disability to find appropriate housing.

In my current role, not only do I experience firsthand the lack of support coordinator knowledge around housing options, there are too many SDA reports being requested and other instances where other providers are completing SDA reports for people who do not even meet the criteria for SDA. Time and funds are being mismanaged, and this significantly impacts participants and their ability to progress independence and housing goals.

One solution offered to the issues raised, is to consider appointing support coordinators who specialise in housing. There are many things that support coordinators need to know to find successful long-term housing solutions for participants. For example, someone who is specifically trained in housing will have the skills and tools to know what is available in housing and to explore these options with their participants. Support coordinators who specialise in housing should understand schemes like National Rental Affordability Scheme (NRAS) and Individualised Living Options (ILOs), Supported Independent Living (SIL) and flexible supports so they can advocate for appropriate funding and then use it optimally to get the best outcomes for clients. Each of these schemes are complex in nature and therefore it is unreasonable to expect all support coordinators to be skilled in this area unless they have undergone specific training.

Support Coordinators also need to know where to find housing, how to apply, and the processes involved. It should also be noted that it is extremely difficult to find this information online, so support coordinators spend an unreasonable amount of time trying to find basic information about housing. Lastly, support coordinators who specialise in housing would also need to be trained in cultural considerations, specifically their impact on housing.

An alternate solution to the lack of support coordinator knowledge in housing, would be to enable a suitably qualified therapist to take on a larger part of the housing role. This is not currently possible as the NDIS model positions support coordinators as the gatekeeper to participant funding. Therapy funds are drip fed to providers and therapy is often under-valued and under-utilised.

Recently, I was asked to assess a gentleman who was homeless and had been living out of his car for two years. When I initially met this person, the support coordinator flagged that they had minimal skills in housing. I recommended a specialist support coordinator become involved. This resulted in this client being supported from homelessness to having a home within four months. For the client, this resulted in reduced behaviours of concern, reduced

anxiety, increased engagement in therapy and positive outcomes relating to productivity, work and wellbeing. Suitable housing was key to not only positive therapy outcomes, but to meaningful engagement in everyday life. This specialist support coordinator had sufficient experience and knowledge about housing and the NDIS, and was able to support this client to find a house to meet his needs. In my experience, there are too few support coordinators with this sort of knowledge and skill set.

Another example is a complex client who had both Multiple Sclerosis and a mental health diagnosis who was homeless and had been for a few years. This client did not have a support coordinator trained in housing and after a period of time in which there was no movement towards her housing goal, the client ceased all services. It is likely the client is still homeless and very unsafe on the streets.

There are multiple examples where a participants' ability to mobilise declines and they are unable to complete steps or shower transfers, and therefore rely on their carers and supporters for 1:1 support. If they were provided with a support coordinator better skilled in housing, these participants would be better supported and linked with treaters more quickly, thereby addressing their housing options and needs more appropriately.

In summary, housing is complex and difficult to navigate. Without support coordinators skilled in housing there will continue to be an unacceptable number of people with disabilities who are unsafe in their homes or communities. The NDIS should ensure support coordinators have the education and resources they need to assist people to find appropriate housing solutions. Alternatively, there should be a change to the NDIS model that would enable participants better access to clinicians and case managers with expertise in housing.

Assistive Technology

An OTA member was particularly concerned about support coordinators overruling occupational therapists on issues around assistive technology, which is, of course, fundamental not just to the achievement of participants' goals but to their physical safety.

I am a regional sole practitioner and do not have the resources to make a full response. I would like to add my small voice though. My practice is affected by some support coordinators who, according to some participants, promise them that the OT will recommend assistive technology that is, in fact, clinically unsafe or contraindicated.

I have not experienced this anywhere else in my 35 years of generalist rural practice involving many, many organisations. It can have an unnecessarily negative effect on the rapport between OT and participant (and, in a small rural town, that can put the OT in a difficult social situation as well). Valuable time is then taken demonstrating why the 'promised' AT is not recommended.

This would appear to be something very easily corrected with improved support coordinator training, and would make what is already a heavy workload so much easier. Support

coordinators should enable the OT and participant to work together to assess needs; they shouldn't intrude in this clinical relationship.

Conclusion

OTA once again thanks the NDIA for this opportunity to make a submission in response to its discussion paper addressing the National Disability Insurance Scheme's support coordination service model.