

Submission to NDIS Planning, Supported Independent Living Inquiry

September 2019



NSW Trustee
& Guardian

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Role of NSW Trustee & Guardian

NSW Trustee & Guardian (NSWTG) is a statutory agency within the NSW Stronger Communities Cluster.

It supports the Chief Executive Officer of the NSWTG and the Public Guardian to protect the rights, dignity, choices and wishes of the people of New South Wales. Our services support and protect some of the most vulnerable members of the NSW community, as well as supporting people at critical moments in their life.

We do this by providing independent and impartial financial management and guardianship services that supports clients and helps them manage their health, lifestyle and financial affairs.

We are appointed for people with cognitive impairment which impacts their ability to make decisions in different areas of their lives. We can be appointed as financial manager or guardian by the NSW Civil and Administrative Tribunal (NCAT) or the Supreme Court.

Financial management orders appoint the NSW Trustee where there is no other appropriate option available. The Public Guardian is the 'guardian of last resort' and will only be appointed if it is determined a guardian is needed and a suitable private guardian - usually a family member or friend of the person who is willing to take on the role - cannot be identified.

The decision-making delegations are separated to ensure that staff employed to make guardianship decisions are different to those who make financial management decisions. This limits the influence a guardian or financial manager has over one client and removes any conflict of interest when making decisions.

Relationship with NDIS

NSWTG's relationship with the National Disability Insurance Scheme (NDIS) is through its role as a financial manager or guardian for people with cognitive impairment.

NSWTG has 4,500 financial management clients with an NDIS plan in place. There are

1,221 clients for who we act as guardian with an NDIS plan.

Where the Public Guardian is appointed as guardian, NSWTG is involved in the NDIS pre-planning and planning process, including releasing information to National Disability Insurance Agency (NDIA) planners and attending meetings. NSWTG negotiates with the NDIA on behalf of the participant about what is accepted as reasonable and necessary supports and seek reviews of plans when needed. The Public Guardian can be appointed to make decisions about services provided to the participant through the NDIS plan. Guardians advocate for the participant to receive funding for appropriate services and support, while negotiating with support coordinators about the selection of the most appropriate service provider for the participant. Guardians can decide which service providers will provide a service to the participant.

Staff appointed to make guardianship decisions in NSWTG made more than 5600 decisions on behalf of clients about the NDIS last financial year. These include service and support decisions.

For financial management clients, NSWTG performs the following roles:

- informs clients that they may be eligible for the NDIS
- provides the NDIA with financial information to assist in planning clients' NDIS packages and ongoing support to ensure the development of meaningful plan;
- provides the client a copy of their personal budget to take to their planning meeting or review
- manages their transport funding if they are unable to manage it themselves.

NSWTG also reviews NDIS service and accommodation agreements and agrees when the client needs to pay a personal financial contribution.

NDIS Planning Responses

All NSWTCG clients, whether they are guardianship or financial management clients, who are NDIS participants have a Local Area Coordinator (LAC). Despite having complex needs, not all clients have a planner appointed and the LAC develops the plan. Given the cognitive impairment and complex needs of our clients they should have a planner allocated in the first instance to ensure the plan reflects their needs.

Where possible, being able to maintain the same planner for a client would enable a faster response when issues arise. Delays occur when a new planner needs to be engaged to establish a relationship with the participant and ensure all factors in the client's life are reflected.

a. The experience, expertise and qualifications of planners

NSWTCG staff have observed varying experience of planners regarding disability, support needs and this is often reflected in the quality of the plans. A planner with solid experience and expertise in working with people with multiple disabilities will understand more readily the need for supports that are being sought. NSWTCG have observed a need for reviews of plans and decisions where necessary supports are not identified in the planning process.

Where NSWTCG clients' necessary supports have been underfunded in their NDIS plans, we have been unable to ascertain whether this is because of the lack of experience, expertise or qualifications of the planners. For example, NSWTCG was asked to approve a client contributing \$1792.60 of their own funds to cover a shortfall of funding for essential therapy and physiotherapy services between July 2019 and December 2019.

The underfunding of some clients has resulted in them having to pay for Supported Independent Living (SIL) services from their own funds. Other clients who have been underfunded and do not have additional

personal funds have been without services until a review of their plan takes place. This can result in homelessness, remaining in hospital for an extended period, or involvement with the criminal justice system.

b. The ability of planners to understand and address complex needs

NDIA has different interpretations of the support needs of a person with complex support needs with a criminal justice history. The interpretations can influence funding decisions including SIL approval and the proportion of funding for the participant considered to be reasonable and necessary due to their disability.

Similarly, NDIA planners have often excluded trauma in their disability diagnosis. NSWTCG believes that trauma should be considered. The traumatic impacts may have been caused by being placed into care, forced removal due to family neglect, victims of domestic violence or other abuse, and early childhood neglect.

There are issues with planners understanding the difference between the need for support and whether the participant engages with the supports. This has meant the participant may need support but not engage with the level required, resulting in the NDIA removing that level of support as if it is no longer needed.

When making guardianship decisions, NSWTCG has generally had a positive experience with the Complex Support Needs Pathway (CSNP) and the specialist planners within this pathway (including their skill and expertise). NSWTCG believes the CSNP was a much-needed response pathway. It can however be difficult to convince mainstream planners to make a referral to the CSNP. It is unknown whether this is because of a lack of understanding of the CSNP by the planners and NDIA service delivery staff, or lack of expertise in dealing with participants with complex needs. NSWTCG has seen examples of plans not covering major items, e.g. a custom-made wheelchair, and underestimation of costs for consumables or other core supports, e.g. continence aids, therapeutic podiatry, etc.

Given the cognitive impairment and complex needs of NSWTC clients, they require ongoing funding for a high level of support coordination and to be allocated to experienced NDIA planners. Where this has not occurred planners have not displayed the ability to understand and appropriately address the individual needs. NSWTC clients will not have the capacity to self-manage or manage their plan without professional support. It is not the role of NSWTC to manage these packages.

c. The ongoing training and professional development of planners

No comment.

d. The overall number of planners relative to the demand for plans

While NSWTC does not have insight into the number of planners relative to the number of plans, it seems that an escalation process has been introduced for clients who are participants that experience delays. These delays often leave the participant in crisis or without support. Between November 2018 and August 2019, the Public Guardian has made 24 referrals to the Critical Service Issues Response (CSIR).

Where there are delays with planners and other issues matters are often referred between teams, leaving no avenue for guardians to obtain consistent communication or an update on progress of plans. Planners are often reluctant to give their contact details. Providing an avenue of contact for urgent matters would assist.

Where it is apparent that the funding is inadequate to meet the participant's needs, it is very difficult to have a plan reassessed. Plan reassessments are requested and do not occur. It is unclear whether this is because of a lack of planners.

e. Participant involvement in the planning processes and the efficacy of introducing draft plans

The inclusion of decision making support for participants with cognitive disabilities would ensure participants maximise their involvement in the development of their plans. The involvement of key people, such as family members, in the creation of a plan suggests planners needing to consider including funding for a decision-making support and capacity development to be included in a participant's plan. Currently, the responsibility to establish what support the participant needs to be fully involved in the NDIS planning and implementation process is determined by the NDIA and their planners. Guardians have observed instances where planners and support coordinators are focussed on seeking advice from stakeholders rather than the participant to complete the plan. Where all the information for the plan is sought from or provided by stakeholders this should reinforce the need for capacity building to be included in the participant's plan to maximise the person's autonomy. The inclusion of capacity building in these cases does not reflect NSWTC's experience.

The introduction of draft plans would give the person, their family, supporters, advocate or guardian the opportunity to see if everything has been covered in the proposed plan and amend where necessary. This could also reduce the need to request reassessments and be a more efficient use of everyone's resources. Where NSWTC is the financial manager, this could also provide an opportunity to identify supports currently paid by the individual that should be included. In crisis situations there needs to be a way of expediting this.

f. The incidence, severity and impact of plan gaps

Where NSWTC is appointed as guardian, significant gaps occur when NDIA disputes the currency of stated disability needs or lack of recent functional assessments. These gaps in information can occur due to barriers in getting this from the participant, e.g. affordability, being

in prison, insecure housing or when homeless. When a person has multiple diagnoses, the planner may not have the experience to understand the links between a person's disabilities, the functional impact of these disabilities and their need for reasonable and necessary supports. On occasion NDIS take the view a requested support is a 'health matter' and not a matter related to the disability.

Where there are gaps in plans, the personal funds used by the participant to support the continuance of the plans until review is not claimable or reimbursed. Where NSW TG is appointed as financial manager the need for participants to pay for supports not included in NDIS plans impedes achieving their identified goals, participating in the community and reduces their quality of life.

Given there may be plans that have a shortfall in funding for items such as continence aids, therapeutic podiatry, etc., a mechanism is needed to provide for plan adjustments for such items. The financial burden on participants when their plan funding runs out can leave them out of pocket by thousands of dollars.

Where NSW TG is financial manager, we have observed that initial Young People In Residential Aged Care (YPIRAC) plans had errors. For example, services provided by the aged care facility as part of aged care support were missing from the funding package. The resolution of these funding adjustments continues. NDIA report that there is a backlog for the review of the original plans. In many cases the plan review is overdue.

Currently NSW TG has identified approximately \$200,000 owing to NSW TG clients who are participants in NDIS.

The appointment of YPIRAC-specific planners has significantly reduced errors in new plans. NSW TG understands that the backlog in reviewing initial plans is progressing slowly.

NSW TG has found that some NDIS and other providers will not accept the cohort of NSW TG clients with complex needs. This has limited the available options for these clients and reduced their choice and control.

Several participants where NSW TG is the financial manager, have Specialist Disability Accommodation (SDA), SIL and support coordination provided by the same organisation. In some circumstances this may work well in terms of familiarity. However, it could cause a conflict of interest where the one provider is responsible for accommodation, personal care and support coordination. If the provider does not meet the needs of the participant in any of these areas, it is difficult for any NSW TG client to raise or resolve these issues.

g. The reassessment process, including the incidence and impact of funding changes

The delays for reassessment of plans for some participants have meant that reassessments are not performed until the original scheduled review date.

The delay in the review of the initial YPIRAC plans has been outlined above.

h. The review process and means to streamline it

Where a guardian has been appointed, there have been instances where planners have set a time and date for a planning meeting without reference to the person, services, Coordinator of Supports (CoS) and/or a guardian. This results in a lack of representation of the person's will and preferences and a lack of advocacy for improved plans.

It is rare for service providers to be willing to carry on providing services when there is a gap in funding and the client is waiting for a review. The length of the waiting periods for the review to occur can result in anxiety for families, service providers and the person themselves. These delays also require increased resources for guardians to organise reviews, changes of circumstances, increased CoS hours, etc. Waiting periods place the person at risk of losing their support services. Where the service provider is not receiving payment they may not be in a position to continue.

To obtain sufficient funding for a person many reports may be required to provide evidence of current disability and needs. The cost of reports is high and comes directly from the person's funds. This reduces what is available to spend on their actual support services. The lack of weight given to the person, their supporters/family and guardian about their knowledge of the person's support needs does not reinforce the dignity of the person.

Where NSWTC is appointed as guardian, it would assist if contact could be made with the planners directly to discuss review. Communicating with generic emails and calling a '1800' phone number impedes efficient resolution.

Where a participant is considering a review, a timeline for the process would manage the expectations about a review. The length of time taken for a review has been an ongoing concern given it can be from six to nine months. NSWTC has some clients with complex needs who do not have formal or informal supports, where the requirement to submit a review in writing disadvantages them.

i. The incidence of appeals to the Administrative Appeal Tribunal (AAT) and possible measures to reduce the number

NSWTC hopes the introduction of draft plans, improved practice of planners and improved engagement in the planning process could reduce the number of AAT appeals.

Appeals to the AAT cannot take place until the internal review of the decision has been completed by the NDIA. So a clear timeframe and information about the internal review of decision process, would assist participants.

j. The circumstances in which plans could be automatically rolled-over

If a participant and their stakeholders are satisfied that a roll-over would still meet their

needs they should be able to nominate to have it rolled over. There needs to be safeguards to allow for a review within a reasonable timeframe if there is a change in their needs and circumstances.

k. The circumstances in which longer plans could be introduced

There have been circumstances where, when appointed as the guardian, NSWTC has advocated for longer plans to increase confidence of the participant in the availability of stable supports. The circumstances where this would be appropriate are where the evidence is strong that no significant change in the participant's circumstances is forecast. Where a longer plan is implemented it needs to be monitored and processes put in place to ensure there is no assumption that the person, their support needs and choices in life are stagnant. These may change and evolve over time.

l. The adequacy of the planning process for rural and regional participants

While access to services can be an issue in regional and rural locations NSWTC has no comment on the planning processes in these locations.

m. Any other related matter

The Public Guardian has difficulty being listed as a contact for the NDIS or having their legal authority recognised. This may result in the guardian not being informed or involved in the planning process, not receiving a copy of the plan until after the plan is established, and in some cases not at all.

As guardians or financial managers, NSWTC often experiences problems with the NDIS not sharing information about the participant or their plan and not liaising appropriately if there are any issues or concerns regarding clients. This limits our ability to ensure clients are not paying for services or supports that are already funded

in their plan, and that if a need arises we know what they have available in their NDIS funding.

Case examples

1. A guardian provided a copy of the Guardianship order to the NDIA in October 2018; the guardian did not receive any further contact or information. After following up multiple times the guardian was informed by NDIA that there was no registered Order. The person's plan expired in November 2018, it was not extended, no new plan was made, and the guardian was not contacted. The guardian re-resent the order in March 2019 at the NDIA request. They were then asked to go to a local NDIA office to provide their personal identification. It was then NSWTC found that the participant plan had expired.

2. A Guardianship Order was emailed to the NDIA and uploaded onto the NDIA system. After confirming that the orders had been received by the NDIA, the guardian was still refused a copy of the client's plan.

3. A financial management client advised NSWTC that he wanted to buy a laptop. The client had an NDIS plan which was not available to NSWTC at the time. We used the client's personal funds to purchase the laptop. When we were given a copy of the NDIS plan it included funds for the purchase of a laptop to support the client's education needs.

Supported Independent Living (SIL)

a. The approval process for access to SIL

The SIL application process is lengthy and complicated. There is a need to provide a significant amount of evidence that can be inconsistent between planners. This leads to significant cost, drain of resources, and time in obtaining further assessments. Where participants do not have formal or informal supports to articulate their needs the process is

very difficult. NSWTC has financial management clients that have encountered barriers in this process.

Where the Public Guardian is appointed to represent NDIS participants, the SIL arrangements are often the subject of the referrals through the CSIR process. There is a lack of clarity about how SIL is determined. Where NSWTC is the financial manager it is unclear who chooses the SIL provider when the client is unable to do so themselves or does not have formal or informal supports to do so on their behalf.

The lengthy delays in the approval process have caused distress and financial loss to some clients. In particular, clients who cannot be discharged from hospital without SDA and SIL funding may experience financial hardship during the approval process where they are incurring hospital fees. Young people in residential aged care are also not able to exit their aged care facility without SDA and SIL funding and may be financially disadvantaged by the SIL approval process.

b. The vacancy management process, including its management and costs;

Guardians have found that NDIA is often reluctant to recommend any providers. A more central vacancy list may help ensure efficient transition and placement of participants.

c. The funding of SIL

In the experience of NSWTC when appointed as guardian, the level of funding for behaviour support in the SIL funding is often inadequate. It does not routinely allow for the full process of behaviour support to occur, including:

- developing behaviour support plans
- training staff in the implementation of plans
- monitoring, review, and allocated hours for 1:1 counselling for the person. The counselling may be required due to the development of trauma that is related to

the 'behaviour of concern'. This means that plans can remain stagnant.

Discussions about restrictive practices with NDIA, in the context of intensive supported SILs where 2:1 or 3:1 ratio of supports, is constantly challenged. These require detailed behaviour support plans to justify how the ratio of supports will deliver reasonable and necessary supports.

Where NSWTC performs the role of financial manager, concerns have arisen where clients attempt to complete the funding tool, however lack the support needed to assist them to complete it accurately.

d. Any related issues.

During consultation forums between the former NSW Department of Justice and NDIA, it was noted that SDA is not the preferred option for housing. The NDIA want planners to explore the possibility of alternative housing in the first instance. NSWTC clients may not be able to explore alternative options due to time limitations (e.g. exiting the justice system or discharge from hospital) or the complexity of their needs, which cannot be met in a community setting.

NSWTC financial management clients do not have the legal capacity to enter into contracts or agreements related to their estate. Equally, clients for whom we are appointed guardian with authority to make health and lifestyle decisions cannot sign contracts relating to these functions. If a client does contravene the Order by signing an agreement which relates to the functions where we are appointed, this contract would not be valid.

Service agreements currently outline the rights and responsibilities of both the client and their service provider including clauses relating to client behaviour, complaint and exit processes. Should a client breach the terms of an agreement, for instance through their behaviour, the client can be exited from a service, placing them at risk of homelessness or lacking essential services. The introduction of a free market in disability support has created the requirement that service agreements are

signed, exposing participants with limited capacity and supports to this risk.

Many clients under a financial management or guardianship orders are viewed as having challenging behaviours in addition to their complex needs. These clients also have varying capacity to communicate effectively and may exhibit distress, anger or frustration through behaviours which could be considered inappropriate. Furthermore, clients who have NSWTC appointed as either financial manager or guardian as decision makers may have limited or no support networks in place. The value of a participant's package does not form part of their estate and therefore are not administered by NSWTC.

NSWTC represents a small but significant cohort of people with complex support needs involved in the criminal justice system, particularly as guardian. This group face significant challenges in receiving appropriate funding and supports that will enable a smooth transition into the community.

Some of these issues include:

- limited NDIS supports provided while in prison. Justice Health and Corrective Services do not have clinicians and other resources to undertake clinical assessments and reports for NDIS
- transition planning being delayed or not occurring due to inconsistent information regarding what can be provided by the NDIA
- difficulty conducting assessments required by the NDIA to support NDIS applications, plan reviews and SIL quotes. Without these assessments funding cannot be obtained and service support and accommodation will not be provided. Further, SIL quotes will not be processed by NDIA unless the person has secured 'bricks and mortar'. This is compounded as Housing NSW cannot support a housing application if there is no guarantee of supports in place and guarantee of funding. We have at least one client who has been detained unnecessarily due to this process.

Submission to NDIS Planning and Supported Independent Living Inquiry

I trust that the above information assists the Parliamentary Joint Standing Committee with its Inquiry.

Adam Dent
Chief Executive Officer

6 September 2019