

# Advocacy for Disability Access and Inclusion Inc.

# CAPABILITY AND CULTURE OF THE NDIA

Submission of Advocacy for Disability Access and Inclusion Inc. SA

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# INTRODUCTION

This submission has been prepared by Advocacy for Disability Access and Inclusion Inc. South Australia (ADAI) for the Joint Standing Committee on the National Disability Insurance Scheme's Inquiry into the Culture and Capability of the National Disability Insurance Agency (NDIA).

Our submission addresses the following Terms of Reference;

The committee will inquire into and report on the implementation, performance, governance, administration and expenditure of the National Disability Insurance Scheme (NDIS), with particular reference to:

a. the capability and culture of the National Disability Insurance Agency (NDIA), with reference to operational processes and procedures, and nature of staff employment

*b.* the impacts of NDIA capability and culture on the experiences of people with disability and NDIS participants trying to access information, support and services from the Agency; and

c. any other relevant matters.

This submission will provide examples of ADAI's interactions with the NDIA and issues experienced by our clients. For the reasons outlined in this submission, ADAI considers that the NDIA has a poor culture. ADAI has advocated for clients who have dealt with feeling so disempowered and disrespected by NDIA staff and representatives that they have felt like giving up on the system, or "throwing in the towel", as one advocate put it. ADAI recommends urgent improvement to operational processes and procedures to ensure that the NDIS is as accessible and functional as intended.

Note: all persons referred to in this submission have been de-identified.

# WHO WE ARE

Advocacy for Disability Access and Inclusion (ADAI) are an advocacy organisation based in North Adelaide, South Australia. ADAI commenced as Parent Advocacy in 1986 after a group of parents acted as advisors to the then State Government in starting new and different disability services and to establish the Intellectually Disabled Persons' Services Act, 1986. At that time funds were provided by both the State and Federal Governments to establish Parent Advocacy. In 2006 Parent Advocacy changed its name to Family Advocacy Incorporated (FAI) and to Advocacy for Disability Access and Inclusion in 2015.

Today, ADAI is funded by the Department of Social Services (DSS) primarily through the National Disability Advocacy Program to provide independent advocacy to any person living with disability and or the family that supports them. ADAI has also been funded by DSS to provide advocacy and support to persons participating in the Disability Royal Commission process. ADAI has assisted over 160 people to gather information about the Royal Commission, make a submission, or assist someone to make a submission. ADAI is also funded to provide advocacy to people appealing an NDIS decision through the NDIS AAT Appeals Program. The South Australian State Government does not currently provide funding for ADAI to provide advocacy.

# **KEY RECOMMENDATIONS**

- 1. Enable LACs to provide more extensive and personalised assistance.
- 2. Increase funding to ensure LACs are available in all rural and remote regions to enable adequate service provision.
- 3. Ensure all NDIA procedures and policies promote a client focussed scheme.
- 4. Require mandatory involvement of participants in all decisions related to planning.
- 5. Increase funding for legal advice and representation for NDIS Appeals applicants within the AAT.
- 6. Increase funding for advocacy for applicants in the AAT.
- 7. Implement mandatory training for NDIA staff and legal representatives specifically focusing on appropriate interaction with unrepresented litigants and their advocates.
- 8. Implement a requirement that all NDIA staff and consultants must have experience working with people with disability, or have lived experience of disability, or have the ability to gain the knowledge and competence required to work with people with disability.
- 9. Implement procedures that enable the NDIA Community Engagement Team to resolve local complaints.
- 10. Lengthen the period Complaints Officers can have complaints open for.
- 11. Enable Complaints Officers to address systemic issues that arise within individual complaints.
- 12. MOUs or other documentation to provide clarification regarding what supports each Department will fund.
- 13. Amend the delegations of NDIA Officers to enable decisions on client plans to be made by the case manager if within NDIA regulations.

# DISCUSSION – CULTURE AND CAPABILITY

# 1. Access and implementation – Local Area Coordinators

## Accessing Information

ADAI receives many enquires requesting assistance with the NDIS. Of the 228 NDAP Advocacy files ADAI assisted over a six-month period between 1 January 2022 and 30 June 2022, there were 79 NDIS files. They included:

- 17 General NDIS enquiries
- 45 clients seeking assistance with NDIS Access or Planning
- 14 clients requiring support for an internal review
- 3 requests for support implementing their plan and accessing services

Many of these files were assisting clients with queries such as:

- Can I access the NDIS?
- What services are available in my area that would suit me?

Many of these queries could be answered by Local Area Coordinators (LACs) but ADAI hear from clients that often the answers given are not tailored to their needs. Instead, clients are directed to websites that they cannot navigate, or the LACs do not get back to them.

The NDIS Website explains that LACs can assist people to:

Understand and access the NDIS – This can include workshops or individual conversations about the NDIS.

Create a plan – If you are eligible for an NDIS support plan, your LAC will have a conversation with you to learn about your current situation, supports, and goals to help develop your plan. It is important to know that LACs cannot approve an NDIS plan, this is done by someone from the NDIA.

Implement your plan - Your LAC will help you to find and start receiving the services in your NDIS plan. Your LAC can also provide assistance throughout your plan if you have any questions.

Changing your plan – Your LAC will work with you to make changes to your plan through a plan reassessment. This generally occurs 12 months after your plan is implemented.<sup>1</sup>

<sup>&</sup>lt;sup>1</sup> National Disability Insurance Agency, *LAC Partners in the Community*, (Information Guide, 7 September 2022) <a href="https://www.ndis.gov.au/understanding/what-ndis/whos-delivering-ndis/lac-partners-community#role-of-local-area-coordination-lac">https://www.ndis.gov.au/understanding/what-ndis/whos-delivering-ndis/lac-partners-community#role-of-local-area-coordination-lac</a>

In ADAI's experience LACs do not always assist in this way. Clients may seek out advice and are emailed back a link to a website with no explanatory material. Or, they ask for a support that would suit them, and are emailed back a list of supports in the area with no information about why these supports would suit their needs. Many of our clients are mothers of children with disabilities and they find that they spend an unnecessary amount of their time navigating the NDIS, adding to their already high workload putting them at risk of carers burnout. If LACs were able to take more time and adopt a person-centred approach then they could provide specific and personalised information, as the NDIS website lists as their role.

#### CASE STUDY: A NEW WEEKEND ACTIVITY FOR JUSTIN

Justin's mum Marnie wanted to find a new weekend activity for him where he could also get support overnight while she was at work on night shift. They live in a regional area and Justin loves cars and cricket. Marnie emailed the local LAC to ask about a suitable support for Justin. She received back a list of websites for all the local and Adelaide weekend support options without any further explanatory information. Marnie was expected to call everyone and find out what they offer and most didn't have space available for when Justin needed it. Marnie wasted a few hours of her time and decided not to pursue this option for Justin.

#### CASE STUDY: MAX NEEDS HELP TO FIND AN APPROPRIATE SLES PROVIDER

Max is an 18 year old man who has a degenerative eye condition and is legally blind. He wants to work when he finishes school but he needs assistance to find a job. He contacted his local LAC and asked for help to find an appropriate SLES provider for him that would suit his needs. The LAC emailed back a list of SLES providers and their phone numbers with no further information about them and without asking Max what he needed from a SLES provider.

#### No LACs in some Rural and Remote Areas

In South Australia some rural and remote areas, including Kangaroo Island, do not have a LAC. ADAI run a very successful Kangaroo Island Outreach program. One of the questions we get asked regularly is, who is the LAC for Kangaroo Island? Unfortunately there isn't one. If a Kangaroo Island resident contacts any other LAC they are usually turned away. Kangaroo Island clients miss out on having information about their local area available which makes the NDIS much harder to navigate. Local residents feel discriminated against because they live remotely.

#### This NDIS website states the following:

Some areas of South Australia do not have partners. If you live in one of these areas, someone from the NDIA will work with you to connect you to the NDIS or to supports in your community.

You can contact the NDIS by phone 1800 800 110, email enquiries@ndis.gov.au or using webchat.<sup>2</sup>

People with disability living in areas which do not have access to a LAC, such as Kangaroo Island, are disadvantaged and miss out on a crucial service. Eligible persons are at risk of not having appropriate services or knowledge of systems that enable them to live their life equal to those who live in a metropolitan area.

#### CASE STUDY: WHO IS THE KANGAROO ISLAND LAC?

A Support Coordinator rang the ADAI office to see if we knew who the allocated LAC for Kangaroo Island was because they weren't getting any clear message from the NDIA. The advocate sent an email to the general enquiry email.

#### Morning

I am trying to find out the contact details for the LAC on Kangaroo Island South Australia. I know Mission Australia has LAC services for Fleurieu Peninsula but not for Kangaroo Island. Can you please direct me?

Best regards,

This email was responded to with no answer but a request for the advocate to call the general telephone line between 8am and 8pm.

It took a number of calls to find out what LAC a person on Kangaroo Island should contact, and the answer was, it will be allocated randomly once an Access Request is made.

## Accessing Support to Navigate a Plan

Many NDIS related enquiries received by ADAI are from NDIA participants who require advice and assistance.

These queries are frequently:

- I need to get my plan reviewed what reports will I need to gather?
- I'm not happy with my services what can I do?
- I think I'm being overcharged, what do I do?
- I need more supports than I am funded for, how do I access them?

Many of these questions should be able to be answered by LACs. We find that clients come to ADAI seeking answers to these questions even after contacting a LAC.

As noted above, LACs can create NDIS plans, and are meant to discuss with the client their current situation, supports and goals to help develop a plan. We are frequently hearing that

<sup>&</sup>lt;sup>2</sup> National Disability Insurance Agency, "South Australia", *The NDIS in Each State* (Information Guide, 11 November 2022) <a href="https://www.ndis.gov.au/understanding/ndis-each-state/south-australia">https://www.ndis.gov.au/understanding/ndis-each-state/south-australia</a>.

this is not being done in depth. Many ADAI NDIS Appeals clients could have avoided the AAT process if they had had proper support from, and an in-depth conversation with, an LAC. We see a number of plans that do not reflect the lived experience of the client and could not have been produced in conjunction to the client, after reflecting on their needs.

#### CASE STUDY: JORGA'S PLAN REVIEW – WITHOUT JORGA

Jorga received a phone call on a Friday from a LAC who was conducting Jorga's plan review with an NDIA Planner from Tasmania at that time. The LAC wanted to confirm some details about Jorga's plan, and it was clear to Jorga in this call that the LAC didn't understand what Jorga's NDIS needs were. Jorga asked to join the meeting but was told that was not allowed because the planner had refused attendance. When it was released, it was clear the Plan was not suitable. Jorga went through a stressful 14 month review process to appeal the plan whereby eventually all of her necessary supports were reinstated. This process would have been improved or made redundant had Jorga been included in the planning meeting or had an in depth conversation with the LAC prior to the planning meeting.

# RECOMMENDATIONS

- 1. Increase funding to ensure LACs are available in all rural and remote regions to enable adequate service provision.
- 2. Ensure all NDIA procedures and policies promote a client focussed scheme.
- 3. Require mandatory involvement of participants in all decisions related to planning.

# **2.** COMPLAINT MECHANISMS - MAKING CHANGE

A number of ADAI clients have had serious concerns about the handling of their NDIS plans. Many want to make a complaint to the NDIA or do make a complaint. Rarely is a complaint taken and resolved by the general complaints team.

Often ADAI receives queries which we cannot answer. In these situations ADAI will contact the Community Engagement team in the NDIA. We have had regular and frequent contact with the regional Community Engagement team Assistant Director which has led to positive outcomes. Unfortunately for matters already in the AAT this is not an appropriate pathway. Recently the Community Engagement team has been expanded and ADAI would prefer to see it resourced further.

#### CASE STUDY: NICOLE - NDIS DECISION MAKER UNAWARE OF RURAL NDIS POLICY

Nicole was working with an ADAI advocate and her mental health support worker to prepare her NDIS Access Request forms and collect her evidence from her treating doctors. Nicole lives in a remote area of South Australia and is lucky enough to access a local psychologist who is connected to the area hospital. The ADAI advocate advised Nicole that even though the NDIA prefer a report from a treating psychiatrist, for rural and remote areas they understand this is sometimes impossible and will accept a report from a psychologist. This is outlined in their Access Policies. Nicole put in her Access Request and it was denied. The NDIA Officer wrote in their refusal letter that Nicole must provide a report from a psychiatrist and they must answer a list of questions already answered by Nicole's psychologist. The advocate double checked the policy and contacted the Community Engagement team with Nicole's consent. After a few days Nicole was sent a letter advising her that her application had been successful.

# CASE STUDY: THANK YOU FOR RAISING YOUR COMPLAINT/I AM HELPING YOU WITH THIS COMPLAINT/I HAVE NOW CLOSED THIS COMPLAINT

A client emailed a complaint to the NDIA Complaints team while a matter was in review. They raised numerous issues, including that they never received an Outcome Letter. The advocate followed up months later as we had heard nothing. This was the response we received.

Subject: NDIA Complaint 8100XXXX [SEC=UNOFFICIAL]

Good afternoon

Thank you for raising your complaint with the National Disability Insurance Agency (NDIA) relating to complaint number 8100XXXX.

My name is Chris and I am the Complaints Officer helping you with this complaint.

I acknowledge that you are not satisfied with the recent decision on the funded supports however I am unable to comment on the specifics of the approved or declined supports.

The outcome letter for the S100 Review of a Reviewable Decision raised on 2 May 2022 was sent on 20 May 2022. This letter was sent via email to both the participant as well as the advocate.

I am unable to assist any further on this matter and will now close the complaint.

Kind regards,

Chris CHXXX Complaints Officer - Complaints Resolution Internal Reviews and Complaints Branch Operations and Support Division National Disability Insurance Agency

Neither the client nor the advocate ever received a copy of the outcome letter, which delayed the application of an NDIS External Appeal. Even though the review had moved to the AAT stage there were a number of systemic concerns the client had raised that could have been escalated or considered. No aspect of the complaint was resolved.

Complaints officers should be able to address systemic issues within complaints. It is clear that the shorter a complaint is open, the better for NDIA's data. By requiring Complaints Officers to close complaints quickly (by having KPIs that aim for the shortest file open time) this disallows any productive response. A short complaint turnaround in ADAI's experience not a well-considered complaint. The time period allowed to resolve a complaint should be lengthened. Complaints Officers should be able to escalate or collate systemic issues to address concerns that multiple clients have raised and allow for systemic change within the NDIA.

# RECOMMENDATIONS

- 1. Implement procedures that enable the NDIA Community Engagement Team to resolve local complaints.
- 2. Lengthen the period Complaints Officers can have complaints open for.
- 3. Enable Complaints Officers to address systemic issues that arise within individual complaints.

# 3. NDIS INTERNAL REVIEWS AND AAT APPEALS

### Reviews and Support - NDIA Lawyers and Case Managers

ADAI is funded to provide advocacy services for people in relation to NDIS Appeals in the Administrative Appeals Tribunal (AAT). The Department of Social Services funds ADAI to assist 37 clients a financial year with their NDIS Appeals. This funding enables ADAI to currently employ an appeals advocate at 0.6 FTE.

The demand for NDIS appeals support is very high due to the large number of appeals in the AAT. During 2022 ADAI assisted 133 clients. ADAI also has a waitlist of clients seeking support for appeals. As of December 2022 we have 11 clients on the NDIS Appeals waitlist.

Whilst our focus in this submission is on AAT appeals the processes used by the NDIA to finalise plans and conduct internal reviews are also very important. In our view it is vital that NDIS participants are included in all decision making concerning their plans. If a participant is unhappy with their plan internal reviews and other processes the NDIA should allow reasonable adjustments to be made to plans which in turn reduces the likelihood of participants seeking further changes via an AAT appeal.

Our role as advocates is to provide support and information. Advocacy is provided to people with disabilities and their families to understand their rights, responsibilities and empower them to resolve their issues. We also assist clients to build capacity, knowledge and increase self-advocacy skills. We walk alongside our clients as we assist them in their matters.

In an AAT Appeal our assistance involves

- Explaining AAT processes and providing information about AAT requirements
- Assisting clients to gather evidence for the AAT
- Educating clients about AAT Procedure and enabling them to self-advocate
- Ensuring the wishes of the client are heard and included

#### ADAI advocates do not

- Represent clients at the AAT
- Provide legal advice
- Draft legal documents

#### However, ADAI advocates often find themselves

- Translating NDIA lawyer emails from legalese into plain language
- Assisting clients to apply for legal aid, or contacting other legal services to apply for free legal assistance as they require legal advice to decide whether to continue their matter or accept an offer

- Explaining to NDIA lawyers how a client's disability impacts their function, which in turn directs what support they require
- Explaining to clients why a lawyer's email is drafted in such a way that makes them feel offended or outraged

Whilst the AAT focusses on trying to conciliate appeals it is still a complex legal process which can be very confusing and intimidating for applicants. In our view it is a process where participants should have access to legal representation. However, most of our clients do not have their own funds to pay a private lawyer to assist with their appeal. In addition, access to free or low cost legal advice is very limited in South Australia. The Legal Services Commission (LSC) provides one hour advice appointments and representation in house for only a small number of people with NDIS appeals. Representation is limited to clients where their applications satisfy certain public interest criteria and the LSC has the resources to take on their case. The Uniting Communities Law Centre is also funded to provide legal assistance for clients with NDIS Appeals. JusticeNet also provide a service which attempts to link people unable to access any representation with a private lawyer who acts for them on a free or low fee basis.

Due to a lack of free or low cost legal assistance for NDIS appeals only a small number of applicants are legally represented in the AAT. As the NDIA assigns either an inhouse or external solicitor to every appeal this creates a significant power imbalance if an applicant is not legally represented. Whilst advocacy services such as ADAI provide some information and support we are not allowed to provide legal advice and representation. However, we are often treated like a quasi-legal service by both NDIA Case Managers and the NDIA's lawyers. This is beyond our scope and increasingly concerning. A further issue is that due to the high number of appeals there are more clients who require legal advice and assistance to continue their matters to the hearing stage. The legal assistance required at this stage is beyond the scope of our work as advocates.

# RECOMMENDATION

1. Implement a requirement that all NDIA staff and consultants must have experience working with people with disability, or have lived experience of disability, or have the ability to gain the knowledge and competence required to work with people with disability.

# Model Litigant Requirements

It is well established that the Commonwealth has a duty to act, and be seen to act, as a model litigant. This expectation has been set as legal principle in common law in all civil practice and procedure in *Morley & Ors v Australian Securities and Investments Commission*.

The legislation also sets out an expectation in *Section 55ZF of the Judiciary Act 1903 and the Legal Services Directions 2017* that state and federal government agencies must act honestly and fairly to ensure the 'just, quick, cheap resolution of proceedings.'<sup>3</sup>

The Office of Legal Services Coordination works to make sure Australian Government agencies receive consistent and well-coordinated legal services. They aim to ensure that legal services should be of a high standard, uphold the public interest, (and) be sensitive to the context that Commonwealth interests may be broader than those of any one agency.<sup>4</sup>

## A. Consistency in the handling of claims and litigation

The Commonwealth and Commonwealth Agencies are required to act consistently in the handling of claims and litigation.<sup>5</sup> ADAI do not consider that this is occurring.

Of the 134 AAT NDIS Appeals files managed by ADAI from January to December 2022 62 of these clients listed autism as their primary disability. The approach, management and outcome for these 62 files were significantly different. It is useful to approach each file consistently and consider each person as an individual and each matter on its merits, but there are areas in which consistency can be utilised.

ADAI manage many NDIS Appeals matters for clients under 18. There is a huge variation in these files, with a lack of consistency in the NDIA considering what should be provided by the NDIS and what should be provided by the Department for Education. One Case Manager will say 'we never pay for transport' (for services to visit children at school), the other Case Manager will automatically include funding for transport as they know the child cannot drive to the appointment and it should be undertaken in the school environment.

There are ongoing inconsistencies between what the NDIA believes it funds and what it considers the Department for Education or the health system should fund.

# RECOMMENDATIONS

- 1. Increase funding for legal advice and representation for NDIS Appeals applicants within the AAT.
- 2. Increase funding for advocacy for applicants in the AAT.
- 3. MOUs or other documentation to provide clarification regarding what supports each Department will fund.

<sup>&</sup>lt;sup>3</sup> Legal Services Directions 2017, made under section 55ZF of the, Judiciary Act 1903, Appendix B s2.

<sup>&</sup>lt;sup>4</sup> Attorney-General's Department, *Office of Legal Services Coordination*, (Information Guide, undated) < https://www.ag.gov.au/legal-system/office-legal-services-coordination>.

<sup>&</sup>lt;sup>5</sup> Legal Services Directions 2017, made under section 55ZF of the, Judiciary Act 1903, appendix B, s2 (c).

# B. Overburdening of Applicant

The Commonwealth should not be placing an unfair burden on the applicant.

- ADAI have been witness to multiple matters whereby the Commonwealth has required the unrepresented party to source evidence over and above what is necessary. This can include:
  - Requesting that our client provide a breakdown of their morning routine in 15 minute increments to justify the need for a support worker. A 35 page Occupational Therapist report had been previously provided that outlined the client's requirements in the morning.
  - Request the client go over in detail information provided by the OT that discusses their limitations, with no understanding that this may be distressing to the client.
  - Request a client provide two to three page documents in response to questions asked by the NDIA with turnaround times of 24-48 hours.

Clients are overwhelmed and burnt out. Some are feeling pushed to make decisions without proper consideration. Some want to withdraw or do withdraw due to the burden placed upon them as unrepresented litigants. Rarely do advocates receive communication that they don't have to translate to clients. The AAT process is not accessible and overburdens the applicant in ways the respondent lawyers rarely understand.

C. Ensuring that arrangements are made so that a person participating in any settlement negotiations on behalf of the Commonwealth or a Commonwealth agency can enter into a settlement of the claim or legal proceedings in the course of the negotiations.6

In previous months ADAI advocates have noticed a trend of agencies offering a limit of three hours of daily support each weekday and commonly two hours on a weekend. This offer has been made regardless of a person's disability whether it was schizophrenia or juvenile arthritis. In two recent final conferences ADAI advocates and their clients were told during negotiations by the case managers that they (the case managers) had been given authority to offer three hours only and no more and if the client needed further support they would have to take the matter to a hearing. Often at this point of the process it has been around a year since the client put in their Appeal and they are unable or unwilling to wait another three months for a hearing date. In one instance a client had been recommended for 16 hours a day of personal support by the Occupational Therapist and the NDIA was only willing to offer three hours.

In one pre-conference negotiation advocates asked the NDIA Technical Advisor in attendance why only three hours was being offered as in the OT report it clearly stated the client needed 2.5 hours in the morning and 2 hours in the evening of support for personal tasks. The Technical Advisor responded by explaining that 'we believe it is reasonable and necessary that people have three hours a day for personal tasks' and that it is generally understood by the

<sup>&</sup>lt;sup>6</sup> Legal Services Directions 2017, made under section 55ZF of the, Judiciary Act 1903, appendix B s2(iv).

NDIA that 'most people only need three hours a day' for personal daily supports. This is in direct opposition to the aims of the scheme as supporting the needs of individuals.

### Without Prejudice – and the Overuse of Legalese

"Without prejudice" is a phrase used to evoke a legal privilege attached to written or verbal communication made by a party to a dispute in a genuine attempt to settle that dispute.<sup>7</sup> It is a rule of evidence that parties can have 'without prejudice' discussions to try to settle a dispute out of court. Stating 'without prejudice' at the start of a letter makes the contents inadmissible in any future court proceedings; those communications cannot then be compelled to be produced in evidence or referred to in proceedings.<sup>8</sup> The aim is for these communications is for them to be made without an intention to affect the legal rights of the person making the statement, but ADAI see the increasing use of without prejudice to mean that there is an expectation that all communication between an NDIA Lawyer and the unrepresented applicant and ADAI are private. Clients are concerned that when they are sent material that states 'without prejudice' they are not allowed to discuss it with anyone. There is a significant power imbalance between NDIA lawyers and unrepresented applicants which leads ADAI clients to feel intimidated by AAT processes and procedures.

#### CASE STUDY: LILY- POOR COMMUNICATION AND FILE MANAGEMENT BY NDIA LAWYER

Lily's mother received an email from the NDIA lawyer late one afternoon (almost 5pm) requesting that she provide over two pages worth of evidence by close of business the next day. Lily's mother forwarded the email to the Registry, concerned by the email, as the Tribunal Member had at the last conference three weeks ago set a date for the Agency to provide their own answer to a different query by COB tomorrow. Lily's mother was very concerned about providing adequate responses to these questions as she had a full day of work tomorrow alongside parenting duties. She was also confused as to why the NDIA lawyer wasn't following the Direction set out by the Tribunal Member.

The Registry received the email from Lily's mother and emailed the lawyer asking for an explanation as to why they were requesting these questions be answered when they were meant to be providing X.

#### Phone Call from NDIA Lawyer to Advocate

The lawyer was very concerned by the email from Registry. He said he wasn't trying to force Lily's mother to reply, but he couldn't respond to the Direction without the information. The advocate outlined that the email was misleading and didn't have that information in it. The advocate also stated that the Direction was made three weeks ago and the Agency has had more than adequate time to request this information prior to today.

<sup>&</sup>lt;sup>7</sup> Armstrong Legal, *What Does "Without Prejudice" Mean?*, (Article, undated)

<sup>&</sup>lt;a href="https://www.armstronglegal.com.au/commercial-law/national/litigation/without-prejudice/">https://www.armstronglegal.com.au/commercial-law/national/litigation/without-prejudice/</a>.
<sup>8</sup> Ibid.

The lawyer explained he was trying to put together an offer and that was why he was asking the questions. The advocate asked him to put this in writing for Lily as this was not at all clear in the email.

The advocate commented on the inappropriate choice to email this crucial information at 4.50pm which was 5.20pm his time. Lily's mother couldn't get a hold of anyone for more advice when she saw the email after work and panicked. She had to work all the next day. This NDIS Appeal is not her job.

The lawyer was adamant that it was inappropriate for Lily's mother to email the Registry. He asked the advocate why she had not explained that to Lily's mother. He said Lily's mother should not have emailed Registry to tell them what was going on. The advocate said it was not clear in the email what the answers were for and that Lily's mother doesn't know he didn't want her to email the AAT. As advocates we provide support and cannot explain every unwritten legal process. The lawyer offered his mobile number from his email signature for 24 hrs access. The advocate said 'I hope not to use that and I work 9-5 I expect communications to be sent during work hours'.

The lawyer said to the advocate, 'when ONE sends an email in confidence, ONE would expect that that communication would not be shared with the Registry Office.' He then asked the advocate to remind Lily's mother of the 'rules'. The advocate reminded him that she was 'merely' an advocate supporting Lily's mother who was the unrepresented applicant.

The advocate also asked the lawyer to be mindful of his language so she didn't have to translate every email he sent.

# RECOMMENDATION

# 1. Implement mandatory training for NDIA staff and legal representatives specifically focusing on appropriate interaction with unrepresented litigants and their advocates.

#### Case Managers

It is our understanding that the role of NDIA Case Managers is to provide technical, professional, policy, operational support and advice to the NDIA to manage NDIS Appeals from the respondent side.

In ADAI's experience Case Managers are often faceless and nameless. Most do not turn on their cameras in any meetings or conferences and are usually only referred to by their first names and an initial of the surname. This can be intimidating and confusing for clients who feel they are up against a 'faceless enemy'. Sometimes they don't even speak during a conference, leaving all communication up to the Agency lawyer.

Our advocates have experienced asking for the name of the case manager managing the file and being told the Case Manager doesn't want to share their details. To prepare for a video or phone conference advocates will sit with clients and go through who will be in attendance, what everyone's roles are and what we expect to happen. Not knowing the name or role of a case manager makes this very difficult.

ADAI understand that it is part of the Case Manager's role to interpret policy and legislation and provide advice to the Agency regarding how to resolve an NDIS Appeal matter. ADAI find that this does not always occur when it is needed. This may be due to a number of factors including lack of experience working with people with disabilities, lack of clear policy or other systemic barriers.

ADAI find that Agency staff, including case managers, lawyers and technical advisers, often fail to understand how to apply the rules clearly and correctly, most often in regards to the following:

- People with autism/autistic people
- People with fluctuating conditions, such as ones that causing them to need supports sometimes but not all the time
- People with rare conditions

In case conferences with clients who have conditions that fluctuate the NDIA has struggled to propose or agree to a plan that accommodates their needs. Case Managers have admitted that the NDIS doesn't accommodate people with fluctuating conditions. Case Managers have stated the NDIA has a 'binary approach' towards plans, and if a client 'doesn't need a support regularly then it is unreasonable that they need it at all', and therefore it will not pass the reasonable and necessary test.

One of our clients required passive overnight support on the nights of the week that she works, as her condition is aggravated by a day of work. The NDIA wouldn't agree to fund overnight support 'as required', as they couldn't clearly quantify it. The NDIA Technical Advisor who was in the meeting asked the client to move her work days so she only worked part-time therefore the Technical Advisor believed so she wouldn't need overnight support. Our client was outraged that the NDIA asked her to change her work hours to suit the NDIA and advised them that if she worked part time everyday, she would need overnight support everyday instead of a couple of times a week. The Case Manager said the Agency will not fund supports that are needed 'sometimes'. Eventually after another month of negotiations the Agency agreed to fund the required supports and have the client use them 'as required'.

#### CASE STUDY: MELANIE – THREE CASE MANAGERS, THREE DIFFERENT APPROACHES

ADAI were assisting Melanie with her AAT appeal for a number of months. After multiple preconference meetings, and one conference, Melanie was able to argue to the Case Manager why the supports requested by the OT in her very through report were both reasonable and necessary. Melanie and the case manager came to a part-agreement and the case manager agreed to get a plan variation written up to enable the agreed supports to be implemented, and allow the remaining two supports to be discussed in conference. Prior to the first conference this Case Manager moved on and a new one was allocated. In the first conference

Melanie asked for the Terms of Agreement and the Case Manager informed her they would not agree to a partial variation, only a final variation. The advocate was able to send all parties a copy of their file notes that demonstrated that an agreement had been consented to. The Tribunal Member was very frustrated with the Case Manager.

The NDIA lawyer took instructions and drafted up a Terms of Agreement following the case conference. Melanie signed and returned them. Two weeks after this conference the NDIA lawyer rang ADAI to alert them to the allocation of another new case manager to Melanie's file. This case manager was refusing to implement the signed Terms of Agreement and was requesting further information from Melanie such as a quote for the cost of a new wheelchair. This was extremely frustrating as there had been in-depth discussions in the pre-conference meetings that a quote couldn't be provided without the funding for a lengthy OT report, which won't be undertaken without approval for funding for a new wheelchair. Melanie now has to explain to another Case Manager (the third in six months) why this is not feasible. It has now been a month since the final Agreement was consented to by both parties and Melanie still doesn't have her new plan.

# CASE STUDIES: WITHOUT ADVOCACY, WHAT WOULD HAPPEN?

Without advocacy clients are disempowered, overwhelmed and at risk of not having their matters properly presented to the AAT. The following case studies provide some examples of the lack of capability of the NDIA, and a concerning culture of bureaucratic dependence, rather than person centred support.

# Case Study #1: Harriet – Agency concerned client's mental health crisis may 'delay proceedings'

Harriet is a 32-year-old woman with a rare, terminal, neurodegenerative condition who approached ADAI for help with the AAT process in February 2022.

Harriet told ADAI she was feeling disempowered and not heard by a system that is ignorant of cognitive disabilities and fluctuating disabilities. This is compounded by the ineffective nature of the appeals process, the pushback from the NDIA, the limited services available, and the fact that the NDIA "don't want all supports going to one person … [they] ignore expert evidence to the point that Harriet feels like 'throwing in the towel'."

Harriet's rare disorder requires a significant number of treatments and external supports to maintain her quality of life. Her treating doctor explains that it is a progressive, asymmetric movement disorder characterized by various combinations of akinesia, rigidity, dystonia, focal myoclonus, ideomotor apraxia, and alien-limb phenomena and ultimately results in death within 5.5 to 7.9 years, the most common cause of which is from complications of dysphagia, such as aspiration pneumonia and sepsis. Its natural history can be quite variable among individual patients.

Initial presentations may vary widely and, apart from the movement disorder, which causes frequent falls, may include an onset with cognitive or behavioural abnormalities. The abnormal movements usually affect the person near the peak of their productive life and because of the progressive nature, may lead to an inability to maintain meaningful employment.

Like so many other clients who have approached ADAI with stories of the flawed system, Harriet is not getting enough support with her NDIS plan. Harriet is also very fragile mentally, which is further compounded by her efforts to navigate her way through the NDIS system. The thwarting nature of her neurological condition coupled with her constant emotional dysregulation and turmoil at having to confront a flawed system has resulted in multiple admissions to the Adelaide Clinic for depression, suicidal ideation, and post-traumatic stress disorder, one recent admission of which lasted several months.

Harriet has solid medical evidence supporting the fact that her most recent NDIA Plan is grossly underfunded and highlighting that there is only a small number of medical professionals who can offer her the consistent, special support that she needs. Her psychiatrist explains in his report that Harriet's condition requires a "multidisciplinary team" to manage symptoms, and to "attempt to maintain functionality and movement. These support needs include psychological and physical therapy – including podiatry, physiotherapy, massage, chiropractic, neurology, and Botox appointments to lessen both physical pain and impact of symptoms, and, as Harriet herself says, to "improve my functional quality of life." She experienced a small 20% underspend in her previous plan, as due to covid restrictions she was unable to use some of her funding. The NDIA claims that is this evidence that her funding needs to be reduced. It was reduced by a third.

Recently in addition to the physical and psychological treatments required Harriet requires an increase in the number of hours she requires support from her support worker. This is due to both the degenerative nature of her disability, her inability to drive, and the increased frequency of appointments. Combined with the added complexity of the pandemic, [the support worker] is working significantly more hours than she was at the beginning of the funded period.

Harriet explains, "as an immunocompromised vaccinated person, using ride-sharing services and taxis isn't the safest option, as drivers often don't wear masks, or wear them incorrectly ... and having multiple people throughout their vehicles significantly increases my risk of exposure to Covid-19," Harriet says. "In addition to this, the frequent nature of my appointments – days are often filled navigating from one appointment to the next – makes it difficult to organise safe transport, so the assistance of a support worker to manage safe access to my care needs is essential."

"The physical and psychological symptoms mean additional support is required from a support worker to help me navigate things like shopping, cleaning my house, loading the dishwasher, removing laundry from the washing machine (which is currently unsafe to access due to the NDIS' refusal to provide upgrades as suggested by the occupational therapist), and managing daily living activities.

"Failure by the NDIS to provide the reasonable and necessary improvements to the rear of my home have increased my risk," Harriet writes, describing "multiple falls" that have resulted in "further injuries, which, in turn, have increased my need for regular treatments."

"I do not unnecessarily utilise funding," Harriet explains, "and the initial estimates provided by the NDIS for my treatment requirements were clearly insufficient, which isn't surprising given the rarity of my diagnosis and the lack of information on the required supports to maintain quality of life. An extension of funding is essential for my ongoing well-being, as in an increase in the amount provided by my current NDIS plan."

Harriet requires bimonthly botox cycles. She requires more support at the end of these cycles as the botox wears off than at the start. The NDIA has struggled to formulate an effective plan for her as they only look at a single week in Harriet's life.

"Harriet's affected by not only her condition but trying to work her way through the system," her ADAI advocate explains. "She has a huge amount of medical evidence to support her condition and it's really baffling why the NDIA has taken this position.

Harriet's own doctor was unrestrained and taken aback. He wrote;

'What the hell do I have to say to make you guys understand what she needs?' That just shows you the disconnect between what is happening with this woman and the NDIA's pushback on supporting her needs. They keep pushing back on modifying her home, telling her that as they have modified the front there is no need to modify the back, meaning she can't undertake any gardening, which she enjoys, or sit in her garden.

The NDIA has no real understanding of what the impact of something actually is and what they support her to do."

Harriet had some modifications done to her home which were of poor quality and incomplete. The NDIA had paid for these modifications in Harriet's plan. When the work was 'complete' Harriet didn't know where to go to get the issues addressed. The Contractor sent her a threatening email and said he would take her to the small claims court if she didn't pay for the final modifications, even though they were not up to the quality Harriet required to use the modifications. The NDIA had no process to manage this complaint. Harriet's advocate notified the NDIA Lawyers and asked for advice as they were in the AAT Appeal process, and this request for advice was responded to with an email asking what would Harriet like the lawyer to do with this information? No advice was forthcoming. Harriet and the advocate searched the NDIA website for clues for what to do next and didn't find any answers.

This threat was so concerning to Harriet, and she was so exhausted by the NDIS Appeal process that Harriet checked herself into the Adelaide Clinic for urgent mental health treatment. Harriet's advocate sent an email to the NDIA Lawyer letting them know her health had declined and the lawyer responded with an email ending that ended with:

'I will also pass on the information regarding Harriet's declining mental health. The Agency does not wish to unnecessarily delay these proceedings, however in the absence of further evidence, its position remains as set out in the last SOI.'

The advocate was appalled at the email and decided not to send it to Harriet as it would have absolutely aggravated her condition. The advocate decided to transfer the file to another Senior advocate, as they considered that working with the lawyer was also affecting their own health.

# Case study #2: Elliot and Charlene - Completely Fed Up With the System

Elliot is a 29-year-old man with Down Syndrome. He and his mother Charlene live in where support services are very limited because of the rural location.

Elliot works on a farm, which offers opportunities to engage in a broad range of activities and build a wide range of skills. Which, in turn, leads to increased confidence and a greater capacity for independence and participation in the community and workplace. This placement is funded through his NDIS Plan.

All the activities in which Elliot engages on the farm are individually tailored for him, in line with his interests, choices, and NDIS goals. He had been supported on a one-to-one basis for all the activities in which he engaged on the farm, which require very active and focussed support to ensure he gains the knowledge and the skills to undertake them confidently and safely.

Elliot's skills, independence, and confidence have increased significantly in the time he has been working on the farm. However, given the nature of the farm work and his need for constant support and supervision, Elliot's Developmental Educator believes it is necessary for Elliot to continue to be supported on a one-to-one basis. The Developmental Educator believes it would not be practical or possible to provide support at a higher ratio. Elliot and his mother, Charlene approached ADAI in January 2022 for help with their AAT appeal.

Elliot, the ADAI advocate notes, also does not have an acceptable ratio of carers, which should be 1:1 but the system likes to "spread support around" rather than designate it to one person. Additionally, the Covid pandemic made it even more impossible to receive services. His mother thus describes being withdrawn and completely "fed up" with the flawed system.

Elliot's mother's works part-time in hospitality in a senior role, which involves mostly latenight and evening shifts. Charlene wants to be able to work around 25 hours a week, and needs to, to be able to pay the bills and mortgage for her and Elliot. Charlene has supported Elliot on her own since he was born. His father left after his diagnosis with down syndrome.

"She's wanting care for Elliot but also wants to work," the ADAI advocate explained. "The system pushed back and basically said, 'is this about the child, or is this about you?' They're also stonewalling in terms of the ratio of support workers. Multiple reports state that Elliot should be 1:1 support when he has support workers, as he is at risk of absconding and has in the past taken support staff keys and driven and crashed their cars.

The Agency consider that these are not 'dangerous behaviours' and tend to only fund 1:1 support for clients with intellectual disabilities who are a risk to others.

The NDIS does not consider Elliot as being potentially violent and causing harm to others – but rarely considers that lack of stimulation is, in itself, harmful. If every day he is doing the same, meaningless tasks, and not having people to speak to, "he has a risk of absconding," the advocate notes.

The advocate describes Elliot as being capable in many areas, but says he has difficulty with his executive function and impulse control. "If Elliot is not actively supported to engage in the task he is undertaking, he may act impulsively on his thoughts. This may range from ignoring requests, to wandering off and/or attempting to operate equipment and vehicles unsafely." As a result, Elliot requires constant support and supervision throughout the day.

"There is one developmental educator in particular who has been really good with Elliot, explains the advocate. Charlene struggles to find good supports for Elliot because they live in quite a rural area and she feels lucky she has found this Developmental Educator who provides 2 hours a week support to Elliot.

"However, "[the NDIA] don't like all the support going to one person or organisation. They like to spread the support around," she adds. "I think it's an underlying mistrust of some providers or provider that have permeated the system. I'm guessing they do not want to put the developmental educator hours into this one provider at the moment, so Charlene has become so fed up, disempowered, not heard [and] frustrated that they just seem to ignore the expert evidence." The NDIA would prefer to fund 30 minutes a week with an OT and 30 minutes with a Developmental Educator. Charlene feels that as Elliot has missed years of support due to a lack of local providers, the current level of support has been excellent for improving his skills and she has really noticed a difference in his mood and ability to undertake small tasks at home.

It's now at the point, notes the advocate, that Elliot's mother is trying to get legal aid in advance of the final hearing date on 14 December. "[That rarely happens] in these matters," says the advocate. "Charlene is having a great deal of difficulty, [so myself and another advocate] are trying to keep her supported during the appeal process. And we've got the agency's lawyers yelling at us, saying, 'What are you going to do about this?' She's feeling like throwing the towel in. And in the meantime, Elliot is not getting the support that he needs and Charlene is not getting the support that she needs as his carer."

The Agency has said they will not fund supports so Charlene can work, and that Charlene should reduce her work hours. Charlene needed legal advice on this issue. Advocates didn't believe this was a necessary and reasonable request to make of Charlene but felt unable to provide a legal reasoning. Charlene had received a single hour of advice early on in the AAT Appeal and was no longer eligible for Legal Aid once-of funding. She could ring the Legal Services Commission advice line, but they would not provide such specific advice. There were no Community Legal Centres in her area. Uniting Communities must not have considered Charlene and Elliot eligible for their service, as they did not return the advocate's call.

Charlene became burnt out and frustrated and withdrew from all support. She continued the AAT Appeal alone. ADAI Advocates had to notify the AAT Registry that they were assumed to be able to provide legal advice to clients such as Charlene which is untenable and inappropriate.

# Case Study #3: Matilda and Catherine – A family in crisis

Issues:

- No pathways or support options from the NDIA for clients and families in crisis
- No support for families moving interstate
- Poor communication from NDIA lawyer

Matilda is a young woman living in South Australia with her mother, Catherine, and her father Dane. Matilda has complex needs and is cared for by her mother. Olivia's diagnosis is Autism Spectrum Disorder, Intellectual Disability, Learning Disorder, Severe Anxiety and Severe Separation Anxiety.

Dane's workplace often requires him to move states, and the family were transferred from Queensland around the beginning of 2022. They were notified of the new posting in late 2021.

At the end of 2021 Matilda received a new NDIS Plan, and Dane was notified of his new work posting in South Australia. Catherine and Dane applied for a s100 Internal Review to request support coordination to assist them with the move and to gather new supports and therapists for Matilda, to be set up prior to the move interstate.

The NDIA rejected this request and the matter went to the AAT.

The family contacted ADAI for assistance in April as they required help with the AAT process. By the time of the first conference in June the matter had become a crisis file as Matilda had no supports in Adelaide and was using some interstate supports still, Catherine had had had no respite in six months, they had been unable to find support workers and the NDIA were strongly refusing to fund support coordination, instead requesting the mother utilise an LAC. Matilda's behaviours were escalating without the correct support and the family was becoming distressed.

ADAI tried to find a pathway that could be followed for a family in crisis. There was no such intervention available at the time. Catherine was calling in tears asking for help.

#### What went wrong

Advocates and the family negotiated with the NDIA's lawyers to attempt to resolve the issue and have capacity building increased, and support coordination included.

#### Early June – First Case Conference

In a first case conference the Agency lawyers offered to increase core and increase capacity building supports, and to have support coordination included in the current plan. Only 15 hours of support coordination was originally offered. The family had requested 60 hours.

Then, the lawyers offered to instead include 15 hours of support coordination for the remainder of the plan (6 months), and to have 1 day per month STA, and around \$1000 increased capacity building funds.

The Agency also wanted clarification on the STA, and what support ratio it would be, even though this evidence had already been supplied. The family was told that once that information was provided an agreement could be made.

The family provided that information again.

#### June – No contact from agency lawyers

Nothing was received from the Agency lawyers until the advocate again prompted them around a month later.

#### Late July

It was now the end of July and the family had been in crisis for nearly two months. The mother's sister was then diagnosed with an inoperable cancer. The family's new rental accommodation was also deemed unliveable around this time due to extensive mould damage. Most of their possessions were damaged by mould and had to be destroyed. The family advised the Agency of these issues. Due to these external concerns they had not been pressuring the Agency for a response, and they assumed the urgency of their matter had been stressed, and was understood by the Agency.

#### August

By August Catherine had been unable to find and set up all of the supports for Matilda, and her capacity building supports were sitting unused. They were still accessing some therapists from interstate. Unused supports could not be used for support coordination. At this point the family just wanted support coordination for the rest of the plan so they could get supports going for Matilda. It was only due to the extensive delays caused by the NDIA and their lawyers, the funds were not being used.

But, the Agency used the issue of unspent funds as an argument that they would not agree to the original offer, because there were now 'excessive funds' in Matilda's plan and they retracted their previous offer.

This caused further delays while the Agency decided what their new offer would be.

The next offer was: no STA and no new funds, instead they offered to transfer core funds to capacity funds.

#### 7 August

In phone conversations the Agency lawyer suggested that to resolve the matter, they will transfer unused core funds to capacity supports and include 15 hours of support coordination to be used until the end of the plan. The Lawyers requested the mother email through a total amount of funds she would require for capacity building for the remainder of the plan. This was even though they had the ability to calculate this amount based on information already provided. To make things easier Catherine sat down and calculated what they would require and provided this information to the lawyer. The Agency lawyers said they will write up an agreement. The mother approved the verbal offer.

8 August – Case Conference Two

In the conference the next day the family was informed that they could not transfer funds and that this offer was no longer tenable. It was not explained why. The NDIA lawyer then asked the mother to provide further financial information including a breakdown of each section of the approx. \$11,000 they were requesting in capacity building. The mother felt blindsided as this request could have been made six weeks earlier, and the NDIA had all of these supporting evidence and quotes, and access to Matilda's current plan.

The NDIA refused to negotiate further without this, despite having previously offered to increase the supports without this information. The lawyers were waiting on internal NDIA advice which we were advised would take up to three weeks, despite this conference date being set for months. The NDIA did not appear prepared for the conference and the Case Manager had obviously not been given the authority to make an offer to resolve the matter. The advocate and Catherine had gone into the conference assuming that the matter would be finalised. The lawyer informed Catherine that a new Statement of Issues was to be drafted and to expect it within a week. This was in direct opposition to what the advocate and the lawyer had discussed the day before.

Catherine outlined how many delays the NDIA had caused and again explained the external stress in the family's life. The Agency's case manager suggested in response to this that the family put in a change of circumstances form. As the matter was already in the AAT this would not be a useful process, as the matter would have been reassigned and re-started with different staff and the family would have to start again. Advocates could not understand why the case manager would suggest this, as once a matter is within the AAT any issue can be considered. Nothing was resolved that the conference as the Agency was not prepared to make an alternative offer and only wanted to request further evidence. The Registrar did not appear experienced.

Also, because of the delays the Agency informed the family that they were no longer considering making changes to the current plan, but creating a year long plan. This raised concerns as the mother did not have the capacity to review the whole plan, and we had not been negotiating any other supports, and we had only been considering what the family's need would be until the end of this plan. If a whole new plan was to be introduced new reports would need to be submitted, new evidence collected, and further considerations to what Matilda would need for a whole year after having reduced supports for the last 7 months. This was very upsetting for Catherine as the day prior to this conference we believed we were about to sign an agreement based in their verbal offer, and now we would be conducting an entire plan review which would take months.

The Senior Advocate requested that if a change was to be made, and a whole new plan to be considered the Agency should agree to a variation agreement, to ensure that Matilda had support coordination in the meantime.

The Registrar set another conference date for three weeks time.

20 August

The mother provided the breakdown of the approx. \$11,000 in the lead up to the following conference with the hope that we would be able to request the required capacity building supports now whilst still reviewing the new plan as the Agency had suggested.

#### 7 September – Conciliation Conference

During the conference it was advised that this was not an option and the mother reluctantly agreed to the increase in capacity building supports, 15 hours of SC and the remaining core supports to remain the same.

The Senior Advocate asked if we could do a variation of the plan, instead of a final agreement as it was urgent the family get support coordination right now and the other supports were still not agreed to. The lawyer said there was no way they could vary the current plan and the Agency could only offer a final agreement. The lawyer said something along the lines of 'the agency did not do variations and there was no way to do that'. The Registrar was unhelpful. When the Senior Advocate asked the Registrar to confirm this and they were unable to do this. The Senior Advocate said they had done two variations in proceeding weeks and the lawyer still denied this was something that could be done.

The NDIA refused to agree to a 42D variation, and their lawyer told the Tribunal Member this would "not be possible" – rather than that the NDIA wouldn't agree to it. The language used led Catherine and the advocate to believe there was a legal reason it was unavailable. A s42D would have allowed the family some security, and much needed support coordination, while a complete plan was negotiated. Regardless, the NDIA would not negotiate on this matter and would only settle on a s42C or go to hearing.

The lawyer also informed Catherine and the advocates that 'there would be no variation or short term arrangement. And the agreement is only for the end of the plan, there will be no new plan'. The advocate recorded this clearly in their file notes. The advocates and Catherine discussed the offer and agreed to 15 hours support coordination, a small increase to core supports to see them through the end of the plan. This was only acceptable to Catherine because the plan was coming to an end in four months and she calculated that this would suffice. The advocates assured Catherine that they would help with the upcoming review to ensure that there was adequate evidence to support the funds that Matilda required. Catherine's decision was to agree to the offer as she no longer wanted to deal with the agency lawyer, who had caused so many delays.

#### The Agreement

The terms of agreement arrived and were not drafted clearly. Even the Senior Advocate, a qualified lawyer, was unable to decipher the meaning of some of the terms. This caused further delay due to confusion regarding whether the 15 hours of support coordination would be pro rata for the remainder of the plan or a total of 15 hours for the plan. The agreement was not drafted in a way that the mother understood. Advocates sought to clarify this.

#### Mid-September

Two weeks later the advocate followed up with Catherine to see whether the funds had been allocated. Catherine had found that instead of a variation to her current plan, a new 12 month plan was created instead. The Senior Advocate checked the Terms of Agreement again, and

due to the poor drafting if they were not read alongside the advocate notes of the case conference it could be interpreted that the end date of the new plan was not clear. It was more than likely that there had been a failure to communicate between the NDIA Case Manager, the NDIA Lawyer and whoever drafted the Plan, usually someone from a different Department.

The new plan did not include sufficient, agreed to, core supports and only included 15 hours Support Coordination for 12 months instead of what should have been approximately three months. The only reason Catherine had agreed to the 15 hours was because it was to be for three months.

As the family had believed (as agreed to in the conciliation) that the plan would be only until the current end date calculations for what core support Olivia needed was done based on the remaining core supports and the remaining weeks. There were enough core supports left in the plan based on these calculations.

As the new plan was suddenly 12 months it was never considered whether the core supports, per the old plan, would be enough. No calculations had been done and no negotiations occurred on this issue. The mother has calculated Olivia's needs and the funding provided and deems there to be an approximate \$40,000 gap in core funding supports.

The new plan now meant that STA was not included in the funding as Catherine had agreed to drop this request nothing the plan only had a few months left and she was desperate for support coordination.

Catherine, in dire need of supports drafted new service agreements with the supports she currently had to ensure that there was no break in support for Matilda.

While considering the new plan Catherine also noticed that all of the capacity building supports were listed as agency managed. This was not what was agreed to, Catherine had only wanted one support to be agency managed. The plan also only provided for agency managed support coordination, rather than plan managed support coordination. Catherine contacted the lawyer about these issues.

As it was clear from the Agreement that the capacity building supports had been incorrectly categorised as agency managed, the lawyer notified the Plan drafted and had this corrected. The lawyer did not communicate with Catherine or the advocates prior to taking this step. As a result, a new Plan with new plan dates arrived in Matilda's portal. This meant that Catherine had to organise new service agreements with every service provider again.

#### NDIA Response

The advocate contacted the lawyer about the Plan being 12 months instead of supports added to the original plan. The lawyer said the plan being 12 months was an error, but that they were never going to be able to keep the original review date. The lawyer explained that it had to be a three or four month plan. This was never raised during the conciliation.

The lawyer then presented three options for the family

- Add the Capacity Building and 15 hours of support coordination to the original plan (agreed within negotiations at conference) This would be a three month plan due to review mid-November, possibly during the family's next move interstate and Christmas. The family wanted something at least six months to give them a chance to settle in.
- 2. Use the current plan for four months pro rata and then review would be due at the end of four months and plan for the next year then issue with that was the timing would have been again in the middle of Christmas and Posting away so it would have been a change of circumstances after the posting (which would have been two weeks after the review)
- 3. Accept the Plan as offered and then put in the Change of Circumstances but it was only 15 hours support coordination for the full 12 months.

Catherine decided she couldn't do this anymore, their family was at breaking point. She agreed to keep the 12 month plan and put in a change of circumstances when she was feeling strong enough to review the plan.

As of November 2022 Catherine was still struggling to find a support coordinator that was agency managed as most are not registered. Catherine had not pursued the need to change the support coordination from agency managed to plan managed, as she didn't want the plan to restart again. She would have had to redraft all of the service agreements.

Catherine was also pursing backpay for invoices she paid during the time period of the first and second new plans as she had paid out of pocket for some supports and was not alerted to the incoming new second plan (with the corrected plan managed supports and new date). This meant that the supports could not be claimed against the current plan and NDIA had not provided assistance with this issue so far.

The AAT process was possibly an unnecessary process for the family to undertake due to the extensive delays. It provided a high level of stress for the family and, as the agreement was only made in September and by November Catherine had still been unable to find a support coordinator, they may have been better off waiting an entire year and going through the regular Plan Review process.

# Case study #4: Mary - Bombarded with requests for information

Mary is an 18-year-old woman with an intellectual disability. She had been in the child protection system since she was a toddler and had suffered many traumas during the course of her short life. When Mary approached ADAI for assistance she had just turned 18. In the lead up to her 18<sup>th</sup> birthday there was no plan for her transition from care but fortunately Mary's foster mother stepped in at the last moment and agreed to continue caring for her.

Mary needs a lot of support due to her intellectual disability. She doesn't understand what people say to her and needs to debrief with her former foster mother who helps her with understanding and managing relationships. Recently Mary has had contact with members of her birth family which was very upsetting and has created more emotional turmoil for her.

Recently Mary was lured to the home of an online predator who told her she was his girlfriend. However, when she got there he took all of Mary's possessions including her life savings and forced her out of the house. Mary is now back living with her former foster mother but due to the emotional trauma caused by this event she needs constant care and attention. Her former foster mother is helping Mary recover and counsels Mary about what happened and has taken steps to make sure the abuser does not have any further access to Mary's money. Even when Mary is out without her former foster mother she will text or call her to let her know where she is and that she is safe.

In light of this vulnerability, Mary's OT has requested further support funding from NDIS to keep her safe as well as support her to have some employment with a specialist employer such as Bedford Group or Barkuma. The funding for her most recent NDIS plan was exhausted well before the review date, suggesting that the funding level was insufficient for her needs, however the NDIA has disputed the requested support funding and Mary's NDIS plan is now being processed through the Administrative Appeals Tribunal. The Occupational Therapist's report states Mary needs 16 hours of support a day. In discussions with the advocate the NDIA's lawyer stressed that there was no way would get this amount of support as he (the lawyer) didn't understand how more support would keep her safer. The advocate had to explain how having a support worker around will allow support in her decision making and ensures that she is not alone with strangers when she is vulnerable. The NDIA lawyer did not know this was how a support worker could work.

Mary's NDIS appeal was very difficult due to the amount of information that the NDIA wanted from Mary including a statement about what she does every 15 minutes of the day to justify a request for 4 hours of daily support. These types of requests are very difficult and draining for someone in Mary's situation. They wanted it in writing from Mary rather than taking this from the OT report or through a phone call. Mary is illiterate and needs someone to help her write this down.

Mary's advocate commented that, "the culture is just to wear people down. The NDIA's staff and lawyers bombard applicants with requests for information just to save a dollar here and a dollar there."

The NDIA is also suggesting that there is a conflict of interest as Mary's foster mother is a registered NDIS provider and stands to 'gain financially' from Mary's support being increased.

This is despite the fact that she receives no payment for costs incurred for having Mary live in her home as the NDIA refuse to pay foster parents after young people turn 18. When Mary's advocate asked for the NDIA policy around payments for foster parents or supports for young people in care she was told no such policies exist.

The NDIA have also made suggestions of a guardianship order as they are uncomfortable with Mary's disability and feel she should have someone making decisions for nher. The NDIA asked the advocate to make a determination about whether they should request she apply for guardianship which the advocate was appalled by, as Mary has previously been through this process and been found competent, and the making of this decision is not the role of an advocate. There has been no appreciation of the work Mary's foster mum has done, or thanks from the Department that she is allowing her to stay in her home for free. The NDIA repeatedly refer to her as Mary's informal support, and emphasise the need for everyone to have unpaid, informal supports.

Mary feels that the NDIS has let her down. She feels that the NDIS hasn't listened to or understood her needs. Mary's foster mum is feeling burned out from providing full-time care for a young person who has very high needs, with absolutely no financial compensation or respite.

# REFERENCES

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