More Detailed Examples of What to Record in Preparation for First NDIS Funding Planning Meeting:

Below are examples of the information that I recorded regarding my daughter, when I was working through the three NDIS planning booklets in preparation for my first NDIS funding planning meeting.

Of course, your own teenager with ASD/Aspergers is unique, but hopefully the examples that I have provided below will give you an idea of the sorts of things a teenager with what I sometimes like to call Aspergers might need, and what you might need to tell the NDIA Planner/ LAC consultant at your first planning meeting:

Booklet 1 – Understanding the NDIS:

I simply read through this booklet on the NDIS website. The consultant I spoke to at Autism SA went through this booklet with me over the phone, but didn't email it to me, because I don't think there was anything I felt I needed to record in this booklet.

Booklet 2 – Planning:

Understanding Your Current Supports:

(Where the booklet says "your", it means your teenager with ASD/Aspergers, not you, the parent. However, because I completed the booklet on behalf of my daughter, the notes I recorded say "my daughter").

Your Personal details:

What condition/disability/disabilities or developmental delay do you have: ASD.

How does this impact your day-to-day life?

My daughter does not cope well with change, and needs for any changes in her life to be implemented gradually. It takes her a lot of time to adjust to change.

She goes through phases of what she will or won't eat. If we don't have the specific food in the house that she feels like eating, she finds it difficult to eat anything. She prefers to eat soft food, and sometimes, she doesn't feel like eating any solid food. I believe her eating issues are at least partly due to sensory issues. When she was younger, I had managed to get her into a routine of eating a decent range of nutritious foods. However, her current eating habits are causing poor nutrition and poor physical health.

It is difficult for her to be in public places where there are a lot of people, such as a face-to-face school, or the shops. Hearing the noise of a lot of people overwhelms her. When there is a lot to see, it overwhelms her, and she says she doesn't know where she is. When people invade her personal space, she gets very distressed.

She can only cope with being out in public for short periods of time, and if she has a support person with her *(at this point, my daughter did not have any paid support workers, because she had only just been diagnosed with ASD, and I could not afford to pay for such things, hence I was applying for NDIS funding – therefore, my daughter's main support person was myself).* After she has been out in public she feels very tired, and needs some down time to recover. She only feels comfortable with a few people, and not with new people. Therefore, she does not socialise very much at all.

She has trouble managing her emotions, and easily gets very anxious, which makes her avoid things.

She often finds it difficult to concentrate and focus generally, and especially on schoolwork, and to understand abstract concepts. She needs someone to break things down into manageable, simple steps, and she needs more time to do things.

She has difficulty with finding her way around, and gets lost if she tries to go out on her own.

Your current support networks:

(Include formal and informal support – 'formal support' means a paid therapist or support worker, 'informal support' means, e.g., help from family members or friends):

Name	**Relationship to you**	**Describe how they are involved in your life**
	Mother	XXXX (i.e., my daughter) lives with her mother, who helps her with everything (*I explain this in more detail under the heading "Carer Statement", on pages 9-14 of this section*).
	Grandmother	She takes XXXX to appointments/school when her mother is at work. XXXX stays at her house when her mother is out of the house for more than a couple of hours, as XXXX doesn't feel comfortable to be home alone for too long.
	Father	XXXX stays with him two days out of every fortnight. He takes XXXX to appointments/school when her mother is at work. XXXX stays at his house when her mother is out of the house for more than a couple of hours, as she doesn't feel comfortable to be home alone for too long.
	Friend's mother	She supervises XXXX when she visits her friend.
	Friend's father	He supervises XXXX when she visits her friend.

What does your week usually look like?

(You need to base this information on your teenager's worst days, and give examples of things like:

- *How long it takes them to get ready in the morning;*
- *How long it takes them to have a shower;*
- *How long it takes them to get ready for bed;*
- *How much help they need (if any) in getting to sleep;*
- *Whether they need certain food;*
- *Whether they need your assistance to do things which most teenagers would be able to do by themselves - this includes needing you to simply prompt them or accompany them).*

DAY	**WHAT I DO *("I" means your teenager with ASD/Aspergers)***	**TO DO THESE THINGS I GET SUPPORT FROM**
Monday	• Get up in morning, brush teeth. • Have breakfast and tablets. • Attend online school lessons. • Have lunch. • Do some homework. • Relax. • Go grocery shopping with Mum. • Have dinner. • Walk the dog. • Mum helps XXXX with her homework after work. • Have a shower. • Watch TV. • Go to bed.	Mum reminds XXXX (i.e., my daughter) of what activities she has the next day, so she knows when to set her alarm for. Mum looks out XXXX's tablets, and reminds her to have breakfast and take her tablets, otherwise, XXXX would forget to eat or take her tablets until lunchtime. At the start of any new school year, Mum helps XXXX by printing up a timetable which XXXX can easily read and understand. *(cont'd over page)*

DAY	WHAT I DO *("I" means your teenager with ASD/Aspergers)*	TO DO THESE THINGS I GET SUPPORT FROM
Monday (cont'd)		Mum makes sure XXXX eats something appropriate for breakfast, lunch and dinner. Mum cooks an appropriate dinner. XXXX sometimes helps with cooking, but cannot cook a proper meal without supervision. Mum goes with XXXX when she takes her dog for a walk, as she is not comfortable to do so on her own, because, among other things, she is afraid that she might get lost, and/or that strangers might approach her and talk to her, and, due to her sensory issues, she cannot cope with collecting dog poop. Mum helps XXXX with her homework by breaking down the assignment into manageable steps, and also sometimes by teaching a concept which XXXX has not managed to understand during the lesson, and by giving XXXX examples to practise. *(cont'd over page)*

DAY	**WHAT I DO *("I" means your teenager with ASD/Aspergers)***	**TO DO THESE THINGS I GET SUPPORT FROM**
Tuesday	• Get up in morning, brush teeth. • Have breakfast and tablets. • Every 2 – 4 weeks attend appointment with psychologist/psychiatrist. • Have lunch. • Relax. • Mum helps XXXX with her homework after work. • Have dinner. • Walk the dog. • Have a shower. • Watch TV. • Go to bed.	Mum does the same as for Monday, and also drives XXXX to the appointment, and takes note of any further appointment dates, as XXXX would forget. Psychologist/psychiatrist will advise Mum of things to support XXXX with. Sometimes Gran or Dad will take XXXX to appointment.
Wednesday	• Get up in morning, brush teeth. • Have breakfast and tablets. • Do some homework. • Have lunch. • Practise violin. • Mum takes XXXX to violin lesson. • Have dinner. • Walk the dog. • Mum helps XXXX with her homework after work. • Have a shower. • Watch TV. • Go to bed.	Mum does same as for Monday, and also drives XXXX to violin lesson. *(cont'd over page)*

DAY	WHAT I DO *("I" means your teenager with ASD/Aspergers)*	TO DO THESE THINGS I GET SUPPORT FROM
Thursday	• Get up in morning, brush teeth. • Have breakfast and tablets. • Do some homework. • Have lunch. • Relax. • Have dinner. • Walk the dog. • Mum helps XXXX with her homework after work. • Get ready for TAFE. • Have shower. • Watch TV. • Go to bed.	Mum does same as for Monday.
Friday	• Get up in morning, brush teeth. • Have breakfast and tablets. • Mum drops XXXX at her Gran's. • Gran drives XXXX to TAFE. • Attend TAFE all day. • XXXX catches bus from TAFE to Gran's. • Mum collects XXXX from Gran's. • Have dinner. • Walk the dog. • Have a shower. • Watch TV. • Go to bed.	Mum does same as for Monday, and also Mum and Gran assist XXXX to get to TAFE. Mum took XXXX on two practise runs on bus to/from TAFE, including walking into the TAFE campus and showing XXXX where her classes were. Mum also worked out bus timetable for XXXX, and drew a map of the bus route and where TAFE was, so XXXX knew how to get to bus from TAFE, and where to get off bus, etc. *(cont'd over page)*

DAY	**WHAT I DO *("I" means your teenager with ASD/Aspergers)***	**TO DO THESE THINGS I GET SUPPORT FROM**
Friday (cont'd)		Mum also drew a map of TAFE campus and where XXXX's classes were. The maps were simpler and with obvious landmarks, as opposed to a map that could be downloaded.
Saturday	• Get up in morning, brush teeth. • Have breakfast and tablets. • Do some laundry. • Clean rabbit hutch. • Lunch. • If XXXX goes to visit friend, Mum takes her. • If XXXX goes to movies or to do personal shopping, or any other fun activity, Mum takes her, or occasionally XXXX's friend's parents take her out with her friend. • Sometimes XXXX does online shopping. • Have dinner. • Walk the dog. • Have a shower. • Watch TV. • Go to bed.	Mum does same as for Monday, and also drives XXXX if she goes anywhere. When XXXX does personal shopping, Mum goes up to the counter for XXXX, to pay for the item she has bought (i.e., using XXXX's money). If XXXX does online shopping, Mum assists with check out. Mum helps XXXX to do her laundry, as she has difficulty sorting out her pile of dirty laundry. Mum helps XXXX clean rabbit hutch, due to her sensory issues.
Sunday	• Same as Saturday. • Every other weekend XXXX goes to her Dad's.	

Carer Statement:

A Carer Statement is a letter that is written by someone who cares for a person with a disability (i.e., your teenager with ASD/Aspergers), to describe in detail how that person's disability is impacting their own life, and the lives of those around them. When applying for NDIS funding for your teenager with ASD/Aspergers, you can write a Carer Statement to provide to the NDIA Planner/LAC consultant at your first planning meeting. When the NDIA Planner/LAC Consultant sends the NDIS funding plan to the NDIA for approval, they will send your Carer Statement along with it. The NDIA will take your Carer Statement into consideration when deciding how much NDIS funding they should allocate for your teenager.

It is not compulsory to provide a Carer Statement when applying for NDIS funding, and you might not be specifically asked to provide one. However, it is certainly your right to provide one, and it can help strengthen your application for NDIS funding for your teenager.

There is a very helpful free community service called MyCareSpace, which provides easy to read information about the NDIS, and connects people with a disability (and their families and carers) with disability supports. Their website contains some very helpful information about preparing a Carer Statement, which I highly recommend you take a look at, if you would like to provide a Carer Statement when you apply for NDIS funding for your teenager.

To access this information:

- Go to the MyCareSpace website home page (**mycarespace.com.au**). Up the top, you will see some headings. Click on the heading called "Resources". This will bring up a new page with a long list of further headings.

- On this new page, at the top of the list of headings, you should see a box for typing in a 'keyword'.

- In the 'keyword' box, type (or start typing) "Writing an NDIS Carer Statement", and click search (you might not even have to click search).

- This should bring up a tile with the heading "Writing an NDIS Carer Statement (template)". If you click on this tile, it will bring up a new page with a lot of very helpful information about preparing a Carer Statement.

In preparation for my first NDIS funding planning meeting, I wrote down some details to tell the LAC consultant, to try to give a clearer picture of my daughter's everyday difficulties, and the sort of care and support she needed. I cannot actually remember if I provided a printed copy of these details, as a Carer Statement, to the LAC consultant at my first NDIS funding planning meeting. However, these details that I wrote down, could still give you an example of the sorts of details you could include in a Carer Statement:

> If I did not remind my daughter to eat, she would not eat regularly. She recently asked me if I would allow her to not eat anything for dinner. Obviously, I said no. She also recently told me that she wanted to try a liquid only diet. I told her that I did not think this was a good idea. If I did not supervise her, she would not always eat a suitable diet.
>
> She goes through phases of what she will and won't eat. I have to come up with recipes which incorporate what she will eat. I have to buy the foods that she will eat. If we have plenty of food in the house, but not the specific thing she feels like eating, she won't eat anything, or I have to really coax her to eat something.
>
> Sometimes she doesn't feel like eating solid food, so we have 'Up and Go' in the house in case that's all she wants to have for breakfast. However, I insist that she eats solid food for other meals.
>
> If she attends any appointments, face-to-face lessons, goes to the shops, or meets a friend, I drive her (or sometimes her Gran does). I cannot always do this, depending on my work hours, and having chores to do at home. This means she will simply not go out unless I can take her.
>
> She does not take her dog for a walk of her own accord. I have to encourage her to come with me to take the dog for a walk. She is afraid that strangers will approach her and try to talk to her, or that she will get lost. Due to her sensory issues, she also finds it difficult to collect the dog poop, and needs me to do this.
>
> When she buys something at the shops, she gives me her purse, so that I can go up to the counter to pay for things for her. She can use the self-serve at Woollies, but if she needed to ask for assistance, she would need me there.

> She needs a support worker to regularly assist her with going up to the counter at the shops, so that, eventually, she can be more independent.
>
> I have taken her for many walks around our neighbourhood, following the same few routes, including going past the local shops. However, she still cannot remember how to get to the local shops by herself. I would have to draw her a map, and she would be worried about getting lost. She needs to build up confidence to do this on her own, so she can become more independent.
>
> I have shown her how to catch the bus to a few different places, many times. She has caught the bus by herself a few times in the past, when she was seeing a psychologist once a fortnight to work on this (among other things). This also involved me doing a trial run with her, working out the bus timetable for her, and drawing a map. She only did it when she had to do it as 'homework' for the psychologist. She has not continued to do it of her own accord. Therefore, she has not done it regularly, and has not done it for many months. She now seems to have forgotten how to do it.
>
> She needs a support worker to assist her with catching the bus regularly, so that, eventually, she can be more independent.
>
> If she has to apply to enrol in new subjects for school, I have to assist her. When she starts a new term or semester at school, I have to help her by printing out her timetable in a format that is easy for her to understand. I have to provide her with a lot of support with her homework.
>
> If she unloads the dishwasher, it's because I have reminded her.
>
> Because of my daughter's fragile mental health, and all the things I have to do for her, I have had to quit my paid job.

In hindsight, I probably could have provided a lot more detail about my daughter's everyday difficulties, and how her ASD issues impacted her life and mine, in the form of a Carer Statement. However, at the time, my daughter had only recently been diagnosed with ASD, and I think I was still processing, and still discovering, all the ways in which it affected her. I knew better than anyone just how severely her 'difficulties' impacted her life and wellbeing (and my own). However, I think I found it difficult to talk about what she <u>couldn't do</u>, without feeling like I was being negative about her, or complaining about her.

Difficult as it might be, if you want to write a Carer Statement to provide when you apply for NDIS funding for your teenager, I would advise you to think about the following:

The truth is:

- Most teenagers do not need to attend psychology sessions to enable them to manage difficulty with change, sensory needs, or emotional issues.

- Most teenagers do not need to attend psychology sessions or a social skills group to help them learn strategies to enable them to take part in social/community activities.

- Most teenagers do not need to attend psychology sessions to help them learn strategies to enable them to process information.

- Most teenagers do not need to attend sessions with a food/eating therapist to enable them to simply manage to eat enough nutritious food to prevent them from becoming physically ill.

- However, many teenagers with ASD/Aspergers do need one, some, or all, of the above sorts of therapies, and a ‘support person’ at home to spend a lot of time assisting them with one, some, or all, of the above sorts of difficulties.

- Further, most teenagers do not need a ‘support person’ to enable them to carry out daily activities, to take part in social/community activities, or to use public transport.

- However, many teenagers with ASD/Aspergers do need a ‘support person’ to enable them to carry out, or take part in, the above sorts of activities.

Ask yourself:

- Who arranges your teenager’s psychology (or other therapy) sessions?

- Who takes them to and from these sessions?

- Who accompanies them into these sessions, or waits for them whilst they are in these sessions?

- Who prompts them to get up and ready in time to go to these sessions?
- Who prompts or assists your teenager to carry out daily activities?
- Who arranges, or helps them to arrange social/community activities that they want to take part in?
- Who prompts them to get up and ready in time to go to these activities?
- Who takes them to and from such activities?
- Who accompanies them and stays with them during such activities, as moral support, if needed?
- Who makes sure your teenager eats enough nutritious food to sustain their physical health?
- Who makes sure your teenager takes any medication that they require?

If your teenager does not have a paid support worker, the answer to most of the above questions is, most likely, you, the parent, who is acting as your teenager's unpaid 'support person'. Even if you obtain NDIS funding to pay for a support worker to assist your teenager with some of the above activities, most likely, you will still be your teenager's main 'support person', who does many of these things.

The support that you provide to your teenager most likely takes up a lot of your time. Therefore, how are you supposed to be able to work many, or any, hours in a paid job? Providing support to your teenager with ASD/Aspergers can also take a physical and mental toll on you.

Your teenager might have other family members and/or friends who provide them with some support. However, if you are the one applying for NDIS funding on their behalf, most likely, you are the one providing the bulk of the support that your teenager needs.

You might even be the only family member (or friend) who is willing and/or able to provide your teenager with the support they need.

If you write a Carer Statement, you should describe all of the sorts of things listed in the dot points above. In doing so, you are not being negative about your teenager with ASD/Aspergers, or complaining about them. Rather, you are simply telling the truth about just how much difficulty, and therefore suffering, your teenager's ASD issues are causing them to experience. You are doing this with the goal of obtaining the level of funding your teenager needs to access the supports and therapies they need, in order to make their life much easier, and greatly relieve their suffering, to enable them to achieve their full potential, and live their best, most fulfilling, happiest life, which is, after all, the kind of life they deserve.

If your teenager can get to a point where they are living the life they deserve, then I can almost guarantee you, that you, as their parent, will be the happiest and healthiest that you can be.

(I realise that the above examples of what I recorded about my daughter might seem like a lot of detail, and I realise that some parents might find it too difficult to record that level of detail about their teenager with ASD/Aspergers. However, I can assure you that the above level of detail is NOT too much to provide at a first NDIS funding planning meeting. The more information you can provide, the better. I strongly encourage you to record as much detail as you can, so that you are prepared to provide as much information as possible at your first NDIS funding planning meeting).

Creating an NDIS plan to achieve your goals:

Setting goals:

Some examples of some goals suggested for my daughter were:

- Manage sensory needs and be able to eat a wider range of foods for health and wellbeing.

  (Therefore, at my first planning meeting, I would need to ask for NDIS funding to pay for psychology sessions, and/or sessions with a food/eating therapist, for this purpose).

- Increase social and community participation, enjoy new experiences outside of home, and meet and make new friends.

  (Therefore, at my first planning meeting, I would need to ask for NDIS funding to pay for psychology sessions, a social skills group, 'helpful activities', and a support worker, for this purpose).

- Catch public transport by herself, so she can socialise more and meet with friends.

  (Therefore, at my first planning meeting, I would need to ask for NDIS funding to pay for psychology sessions and a support worker, for this purpose).

- To learn how to better regulate emotions and manage anxiety, stress and frustration so she can function better at home and in the community.

  (Therefore, at my first planning meeting, I would need to ask for NDIS funding to pay for psychology sessions, for this purpose).

Booklet 3 – Using Your NDIS Plan

Once the NDIS funding plan is approved, the funding will be allocated to different budgets:

Support Budgets:

Core Supports Budget:

This Budget is used for anything to do with assistance with daily living, and social and community participation, such as support workers, mentors, social skills groups, or 'helpful activities'. This Budget is flexible. The money allocated to this Budget can be switched between different categories in this Budget.

Some of the categories in this Budget are:

Assistance with Daily Life/Daily Activities: e.g., support worker(s) to help with shopping, cooking meals, and catching public transport, which are independent living skills.

Consumables: e.g., noise cancelling headphones to cope with sensory needs.

Assistance with Social & Community Participation/Social, Community & Civic Participation: e.g., social/community activities, including a social skills group, and support worker(s) to take her to some of these activities. (*I have provided some suggestions of 'helpful activities' under the section on this website called "How to Apply for NDIS Funding", at pages 10-12*).

Capacity Building Supports Budget:

This Budget is used for therapy, such as sessions with a psychologist, occupational therapist, speech pathologist, or food/eating therapist. This Budget is not flexible. Certain amounts of money will be allocated for certain categories. These amounts cannot be switched between different categories in this Budget.

Some of the categories in this Budget are:

Improved Daily Living/CB Daily Activity: e.g., a psychologist to help my daughter with the following:

- To be able to manage anxiety, build tolerance, flexibility to reduce rigidity of thinking and cope with change in daily activity, learn to calm self when sensory overloaded, e.g., around self-care tasks, develop strategies to decrease anxiety and regulate emotions in all life settings, improve emotional regulation, communication and interaction strategies to increase relationships with peers and family.

- To identify the sensory difficulties and information processing difficulties she has with doing certain things, and help her be able to find ways to do things such as shopping, daily chores, school participation, and take part in social activities.

- To be able to communicate in a range of settings.

Improved Health and Wellbeing/CB Health and Wellbeing: e.g., a food/eating therapist to help my daughter to be able to eat enough nutritious food to improve her physical health.