

PLANNING FOR PEOPLE WITH INTELLECTUAL DISABILITY

Caroline Livanos

Complex information

I have recently emerged, covered in red tape, from a prolonged period of planning for my 16-year-old son who has low-functioning autism. Michael's NDIS plan meeting coincided with his disability support pension eligibility in November last year and both processes have left me feeling frazzled and frustrated! After years of fighting for funding packages for things like school holiday activities, respite and nappies, I was excited to see how the NDIS might help Michael learn new skills and enjoy new activities.

My goals for Michael's first year in the NDIS were to improve his independence, communication and social participation. My aim was to find therapists (speech, OT and physio) to meet Michael and write assessment reports. I planned to implement their recommendations, with the help of his support workers, and work towards achieving his goals.

But no amount of planning could help me get past the barriers I faced along the way.

A complicated NDIS planning process

- Many important areas that were discussed in the planning meeting were not factored into Michael's plan. I was not able to view his plan before it was approved, so the only way I could address the errors was via a review. It's been six months since I submitted the review and I still haven't had a response. This means I have not been able to progress with some parts of his plan.
- Michael's plan did not have a holistic approach. For example, why include funding for support workers to achieve a goal of community access without funding travel? And why include funding for speech therapy without funding assistive technology?
- I have found there is no accountability for poor planning, poor communication, long delays for reviews and complex approval processes for things like therapy products or home modifications.

Difficulty finding quality services

- Good services are hard to find, especially when demand is high. This relates to therapists, continence specialists, disability support workers, support coordinators and plan managers. The only way to find quality services is via a good support coordinator, friends in the same situation or a lucky Google search. Now the NDIS has an up-to-date service provider list, but it still takes a lot of time and luck to find services that meet your needs. I think we need an NDIS 'Urban Spoon' for the disability sector! How else can we find out about exciting new products and services?
- I was able to find some great therapists to write Michael's assessment reports but they became unavailable for different reasons. I can't seem to find energetic, inspirational therapists who can help Michael to reach his goals, so this part of his plan has come to a stand-still.



Michael and Caroline Livanos

- In this new climate, services have developed a business-first approach. Many of our meetings have focussed on budgets rather than Michael's needs, which is disheartening.
- I have found that many support workers lack the skills and experience to provide quality care in the home and community. Most are underpaid and many don't have appropriate qualifications. I feel lucky to simply find people who are reliable. It seems like a big leap to ask these support workers to implement therapy activities during their shifts.

Complex information

- I found the information in Michael's plan to be complex, inconsistent and unreflective of everyday terms. For example, 'improved life choices' refers to 'plan management'; 'core supports' usually relates to support workers and the role of plan managers vs. support coordinators is confusing. Headings in Michael's printed plan didn't match the information in the NDIS portal. It took a lot of time to get my head around the language and rules about each section of the plan. I don't know how people with low English literacy manage – especially if they don't have support coordination in their plan.
- Paperwork is still the enemy of participants and their families. That includes the NDIS process, service agreements, therapy assessments and care plans. If only I could include all of Michael's information in one central portal with access provided to services as required.

As the first year of Michael's NDIS plan comes to end, I can say I'm grateful for the reliable respite and continence funding. But I am still a long way off helping Michael to achieve his goals of improved independence, communication and social participation. While I don't have the answers, it's clear to me that we can only achieve positive outcomes for people with intellectual disability and their families if we remove existing barriers to support and start thinking about the big picture.

LET'S MAKE IT EASIER FOR FAMILIES AND CARERS TO PLAN FOR PEOPLE WITH INTELLECTUAL DISABILITY

Improve communications

The NDIS and all service providers in the disability sector should provide information in plain language, Easy English and different languages as required. People should be able to understand important information and make informed choices.

Reduce paperwork where possible

Families and carers are well and truly over it! We need one central, streamlined record-keeping system.

Make it easier to find disability products and services

Can someone please create a user-friendly 'Urban Spoon' for the disability sector?

Let's get back to a person-centred approach

Avoid focussing on budgets and pricing in therapy meetings.

Improve the NDIS planning process

Understand the user experience and make (lots of) changes to improve the process.

Caroline Livanos

Accessible Information
Coordinator
Scope

clivanos@scopeaust.org.au

Post Script

A while ago I was taking Michael for a walk when I was stopped by an older woman who smiled at Michael and told me she has an adult son living in supported accommodation. She said she was unhappy with the way he was treated and wanted him to have better care. She had heard of the NDIS but felt anxious about 'another government program for people with disability.' She spoke broken English, had no car or computer and limited ability to use her phone. She felt hopeless and upset that she could not help her son.

In contrast, this year I met a woman who was visiting from Sweden. She said she had an adult son who had been diagnosed with autism when he was around six years old. As soon as he received the diagnosis, she was inundated with support, financial and otherwise, from the government. This support was not only clearly explained, it was easy to access and use. As a result, years later, her son is living semi-independently and is meaningfully employed. Thanks to this support, she and her husband were also able to work and live a balanced life.