

OUR FAMILY'S NDIS JOURNEY

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Over the rainbow: a journey needing courage, thought, heart and perseverance.

The National Disability Insurance Scheme (NDIS) promises great benefits for both individuals and our society. People with a disability, their loved ones, those who share their lives at home and at work, and all those who want an inclusive community enriched by the diversity within it, have much to gain through the implementation of this transformative social reform.

The NDIS is a visionary plan, built on a solid foundation of human rights and social justice. It acknowledges the benefits, both social and economic, of enabling the participation and contribution of all citizens. The Scheme is, however, still in the developmental stage and requires support and guidance from us all if it is to reach its potential and realise the promised outcomes. The enormity, complexity and challenges of the task of building this social reform, however robust the foundation, are evident in current discourse about the Scheme.

Our family advocated and fought for the NDIS and have defended it against its detractors. We have been involved in taskforces, working groups, workshops and seminars about the Scheme for many years. We were, therefore, in the privileged position of understanding the history, philosophy and intention of the Scheme better than most.

As the time approached to embark on our personal NDIS journey we were excited and optimistic. From a distance, the possibilities looked like glistening prizes at the end of a rainbow. The prizes were the new opportunities for our 33-year-old son, Nick, to build skills and independence, communication and friendship, and enjoy greater community participation. The path to those prizes, the rainbow, seemed enticingly real, close and affirming.

The reality of our journey has, however, been more difficult than we anticipated. It was challenging to get started; the route has been winding and at times unclear; and the prize has been elusive. For me, as for many others engaging with the Scheme for the first time, the experience has been enormously time consuming and emotionally exhausting, and, so far, the benefits have been modest. I have been fortunate to have, and relied heavily upon, the support of my family over this challenging time.

I involved Nick, as much as I could, in identifying, developing and articulating his goals, but the job of navigating his entry into the Scheme was mine. He has an intellectual disability and is not able to understand what the Scheme would or could mean for him, nor could he play an active role in the preparation required to enter the Scheme. I felt a tremendous weight of responsibility for getting it

“right” for him. If I “succeeded”, then his life experience and opportunities could be greatly improved and enriched, if I “failed” then he would miss out. I would have failed him.

In the year prior to rollout in our region, I sought information from the NDIS, service providers and other parents who had already commenced their NDIS journey. This was both helpful and confusing. The Scheme was, and still is, continuously changing and evolving, and different people in different regions at different times have widely different experiences. I understood that the Agency was learning from each new rollout, each new dilemma, each new situation encountered, but trying to stay up to date with the changes was a time consuming business.

When rollout in our area was imminent, I went to NDIS education sessions run by the NDIA, service providers and consultant groups. In each I learnt a little more, and in each I saw how much more there was to learn. I accompanied my son to several sessions, including one run by VALID, so he too had the opportunity to hear and see information about the Scheme presented in a variety of ways and from a range of perspectives.

I prepared Nick's pre-planning document for his planning meeting ... many, many times. I sought input, contribution and feedback from family and others who knew him well. I used different formats and templates; refining, re-prioritising and re-wording goals. In the end, his goals focused on increasing independence in communication, finding and building friendships, maintaining independent mobility, and exercising more choice and control in his life. I carefully considered and itemised the reasonable and necessary supports that would enable him to work, and make progress towards, those goals.

Formulating, developing, articulating and documenting those goals, in preparation for the planning interview, was both challenging and deeply rewarding. It enabled me to express on paper my vision for my son's future; to capture my knowledge of what is important TO him and FOR him; and to share that vision and knowledge in a way that would have lasting impact. As an older parent, I think about the time when I am no longer able to advocate for Nick. To be able to capture and share what I know, after spending much of the last 33 years together, was both a relief and, in a sense, liberating.

When the time came for the planning interview I was well prepared, but still felt anxious when considering the responsibility I had to present Nick's goals and support needs succinctly and effectively in order that he would receive the package of support he needed. I felt I had one chance to get it right, one 90-minute window of opportunity. If I blew it, Nick would miss out. The planner was knowledgeable, kind and listened well, but was under considerable time pressure. It was challenging to present the proposed plan, answer his questions, and complete the additional information required by the NDIS in the time available. By the end of the meeting, I felt we had been heard; the planner had met Nick, discussed his goals, and had the information he needed. Then we waited.

When the plan arrived, it reflected our planning conversation well and provided Nick with funds for the supports he would need to work towards his goals. I was tremendously relieved. There were some details I wanted to discuss and refine, and there were some relatively minor errors that needed correction. I was, however, unable to make contact with the planner to have these addressed and, after several attempts, I gave up and decided to work with what we had.

Then came the job of implementing Nick's plan. That has been much harder than I anticipated. Despite having Support Coordination and Plan Management, I have struggled to bring to life the vision I had for Nick's plan. We are now 6 months into the plan, and full implementation is still far from complete.

On the plus side, Nick now has a wonderful speech pathologist and physiotherapist who are sharing the responsibility with me for addressing his communication and mobility goals. He has a great relationship with them both and is making real progress. This is a tremendous relief for me, both in terms of the success of their work with him, and the sense of shared responsibility I now feel.

On the other hand, there are some important aspects of his plan I have not yet been successful in activating, despite having the funding to do so. This concerns me as it means we are likely to underspend for this year, and therefore it may be assumed by NDIS decision makers that Nick does not need the same level of funding in his next plan. This is not the case. The reason for unspent funds is the difficulty I have had in identifying and organising the people and services to do the work required. Half way through this first plan I am tired but know I need to step up the time and energy I invest to ensure the plan is realised and Nick can benefit from the opportunities the funding offers both this year and into the future.

In addition to the difficulties I have encountered in bringing Nick's plan to reality, there remain other areas of great concern that I share with many other families. Nick does not communicate through speech and, in the past, has expressed his distress, both physical and psychological, through changes in his behaviour. These have, at times, been labelled 'behaviours of concern' and we have needed the assistance of specialist behaviour support professionals to understand and resolve the issues for Nick, his family, and others who live and work with him. Behaviour support is not included in his current plan as it is not required, however if unanticipated events occur and Nick once again needs behaviour support, his plan will need to be reviewed and amended quickly. This is a concern as NDIS processes appear not well suited to the flexible and timely response required in urgent and crisis situations. Likewise, if Nick requires hospitalisation for any reason, he will need 1:1 support in hospital. Once again, if this were an unplanned and unanticipated event, it is unclear to me how support would be funded and arranged in a timely manner.

At present, our family feel very fortunate. Nick is happy and well. He lives with people whose company he enjoys and is supported by a staff group who know him and care for and about him. He enjoys the educational, recreational and social activities he does during the day, and the company of those with whom he shares them. He has a family who love and support him, and enjoy his company and contribution to family time and events.

Nick's NDIS journey is our family's journey too. So far, it has been more challenging than we anticipated; the route is still being mapped, the path still being graded, and destination still being built. We can, however, see the enormous potential in the many opportunities the NDIS offers Nick to build experience and skills, independence and autonomy, participation and friendship, connection and contribution. We are optimistic about the changes the NDIS can bring to Nick's life, our family and our community and look forward to contributing to the development of the Scheme so it can fulfil its promise for Nick, and all those who follow him. We are on this journey together.

Summary

- The NDIS is a transformative social reform built on a solid foundation of human rights and social justice.
- It acknowledges the benefits, both social and economic, of enabling the participation and contribution of all citizens.
- There are concerns about aspects of the planning and implementation process with heavy reliance on people with disabilities and those who advocate for them to drive and enact the plan.
- There is a need to develop the Scheme's timely responsiveness when unanticipated needs arise or crises occur.
- The Scheme is still in the developmental stage and requires support and guidance from us all if it is to reach it's potential and realise the promised outcomes.



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Want to read more from Jane Tracy?

Jane Tracy (2014) Building Partnerships between Service Providers and Families of People with Disabilities: One Family's Journey, *Research and Practice in Intellectual and Developmental Disabilities*, 1:2, 128-141, DOI: [10.1080/23297018.2014.961592](https://doi.org/10.1080/23297018.2014.961592)