

October 2016 Information update around the National Disability Insurance Scheme

Family Advocacy has conducted a survey with families around their experiences accessing and using the NDIS. We will continue to ensure real family experiences inform our systemic work. [Please do keep us informed.](#)

The key results from the survey and other discussions with families are:

Accessing the scheme

- It is important for families to be well prepared so that the goals and aspirations of their family member are more likely to come to fruition in the plan. Read our ideas to assist on the next page to understand how to be prepared.
- There are obvious inconsistencies in the knowledge of the planners across locations.

Having your voice heard

- Many people felt that as long as the goals fitted a predetermined idea of the planners it worked however anything 'out of the box', unique or less traditional was more difficult for the planner to understand.
- Some had limited time and felt a bit rushed to proceed - so the more prepared the better
- Many felt there was still confusion and miscommunication occurring.
- Service agreements are being signed off in goodwill by families with their providers. Families need to have input into their service agreement so as to better safeguard their arrangements.
- The 'My First Plan' is designed to streamline and expedite people into the scheme, however it is important that the plan is useful and covers key support needs, so beware not to be pushed into a plan that is not good enough as the NDIA do not want to review these for 12 months.

What can you do if you are not satisfied with your plan?

- Know that there is a review process and a complaints process, find out more on our [/the-importance-of-advocacy-in-a-changing-disability-sector/ webpage](#)
- Families can also complain to the Human Rights Commission or write to the Disability Discrimination Commissioner if they feel their human rights are not being upheld either through direct or indirect discrimination. Alastair McEwin, the new Commissioner, has identified the choice and control aspects of the NDIS as a priority for his time in the role.

Obstacles

- Slow response to questions families are asking the NDIA
- A lot of confusion about the role of support coordinators
 - Coordination of support provides
 - 1) Connection –identifying options, providing ideas, building capacity
 - 2) Coordination - Organising and arranging these connections, addressing issues and barriers
 - 3) Specialist - Requires specialist qualifications to deliver support coordination
- Service providers 'selling ' themselves to attract your family member's NDIS funding
- Needing clarity around the coding and the claiming through the portal

- Being told that it will be necessary to have some assessments done when previous assessments should be enough or when assessments are not relevant in determining supports needed.
- Being encouraged to adopt traditional service driven programmes as seen as more economically viable. Being refused some supports as the scheme needs to be sustainable
- Plan management is often overlooked and self-managed often discouraged by planners and providers which mean families can feel the only option is agency managed with limited choice.

Family Advocacy Ideas to assist

- Keep connected - with other families and organisations aligned with your values who truly wish to see better outcomes in the lives of people with disability.
- Gain ideas and inspiration from other families' stories, [visit the Resourcing Families website](#) and Family Advocacy's [YouTube channel](#) to hear more from families and other speakers about having a good life and how this can be distinctly different from the more traditional programmed approaches for people with disability.
- Be flexible around what you want in the plan and how to achieve the life and goals for your family member. Remember it is not one plan for life it will be changed and adjusted as goals and needs change for the person.
- Revisit planning ideas to continue to improve and nurture the goals and vision around your family member, see [Planning tools](#) on the Resourcing Families website.
- If your family member hasn't gone through the NDIS process yet then pre-planning is the key to the development of a beneficial plan. If you are short of ideas then enlist the support of family and friends to help generate some valued roles for your family member. Call Resourcing Families for an individual chat- 18007740764 or 9869 7753. Consider starting a [circle of support](#). This [video](#) shows what can be achieved with the help of a circle of support.
- Write the plan down with clear rationale about how this is meeting the needs and aspirations of your family member and bring to the planning meeting. Attached is an example of a plan that links the overarching goals to the practical implications of the goals. Please note, line items and goals may be framed differently in your family members plan and their goals should be personalised to them.
- Enhance your advocacy skills to speak out for your family member and view some great clips and articles to help become an effective advocate, at [advocacy - making it happen](#)
- Never underestimate your [natural authority](#) as a family; you are the experts on the life of your family member, have confidence to shape the plan.
- Consider the power of developing Valued Roles for our family member - see [The Purpose of Life is a Life With Purpose: Creating Meaningful Lives Through Valued Roles](#), [Valued Social Roles: Pathways to Full, Meaningful and Inclusive Lives](#)
- The [rethinking respite](#) article by John Armstrong and Lynda Shevellar provides a new way of thinking around this program.

This is national reform that provides an important opportunity to reach for more ordinary and normative pathways for people with disability. We have a chance to really push for a system that focuses on meeting the needs of individuals rather than services. Our advice to all families is to **'dream big'**.

CALL FAMILY ADVOCACY- 1800 620 588 (outside metro Sydney)

OR 02 9869 0866

Our role is to assist families to make this scheme work in the best interests of your family member.