

Queensland Productivity Commission Inquiry into the National Disability Insurance Scheme Market in Queensland

SUBMISSION FROM THE INSTITUTE OF PROFESSIONAL
ORGANISERS

IOPO



AUGUST 2020

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1. INTRODUCTION

1.1. About IOPO

The Institute of Professional Organisers (IOPO) is an industry peak representing professional organisers with over 130 members across Australasia. Our members provide professional organising services to a range of clients, including many National Disability Insurance Scheme (NDIS) participants. Our members are predominantly small or micro businesses who we support through strategies such as industry accreditation, training and development, an online business directory, research, industry advocacy and an industry insurance scheme. IOPO's vision for the professional organising industry is for:

- A well-articulated and universally recognised role for professional organisers;
- Well-established industry standards;
- Career pathways and training and development for our members; and
- Strong leadership from IOPO as an industry peak.

1.2. About this submission

Many NDIS participants benefit from the services of professional organisers and so our industry advocacy strategy includes work to raise the profile of these services in the context of the NDIS as well as to achieve a fuller understanding amongst NDIS participants, carers and families, other services and policy makers of our role and the outcomes it supports participants to achieve. This submission is an important part of this industry advocacy work.

In this submission we focus on:

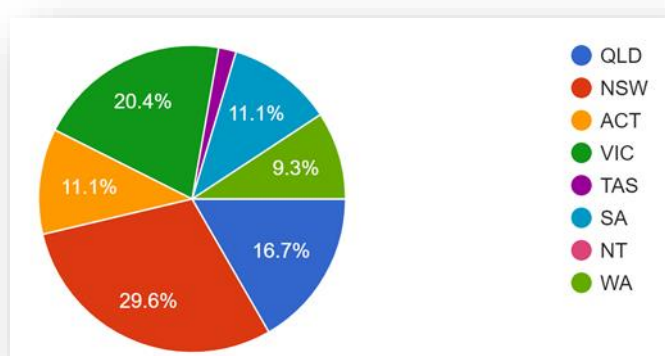
- Providing an overview of the contribution of the professional organising industry to NDIS participants and their families and carers;
- Describing the role professional organisers undertake, including through four case studies; and
- Responding to key issues and questions raised by the Queensland Productivity Commission (QPC) through this inquiry, particularly in the areas of barriers to entry to the NDIS market; the impacts of regulation; and NDIS pricing.

2. OUR INDUSTRY AND THE NDIS

2.1. Overview of the professional organising industry

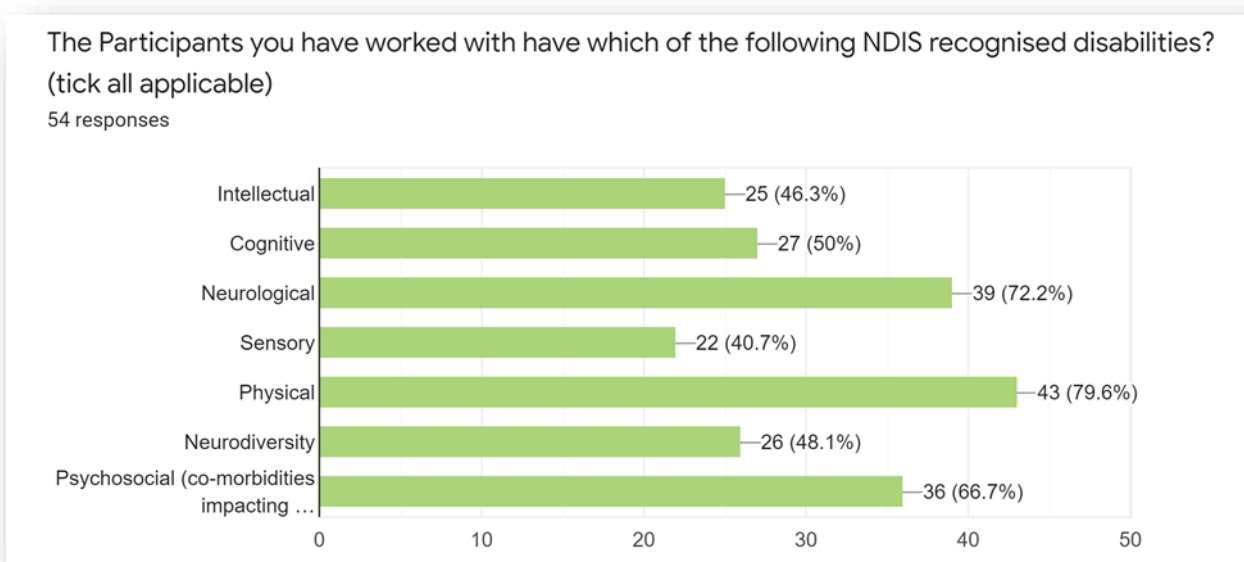
IOPO has over 130 members spread primarily across Australia and New Zealand. A recent survey of professional organisers shows that all 54 survey respondents deliver services to NDIS participants and that 16.7% of respondents primarily deliver services in Queensland.

Just over three quarters of respondents to the same survey operate as sole traders. 81.5% are not registered NDIS providers, with a further 11.5% indicating they have discontinued their NDIS registration. However, just over 25% of respondents have worked with more than 20 NDIS participants; just under 15% have worked with between 5 and 10 participants and almost half of the respondents (48.1%) have worked with 1 to 5 participants. This paints a picture of an industry that provides significant levels of service to NDIS participants, albeit an industry largely comprised of small or micro businesses that are not registered NDIS providers.



Our industry survey also indicates that professional organisers provide services to a wide range of NDIS participants with varying disabilities. The graph below explores the types of NDIS participants professional organisers provide a service to in terms of the types of NDIS recognised disabilities participants experience. The survey results demonstrate that professional organisers provide services most frequently to people with a physical disability, closely followed by people with a neurological disability and people with a psychosocial disability. This points to a service offering by professional organisers that supports differing needs disability types.

The case studies we present in Appendix One also reflect varying circumstances in which professional organiser services have been valuable, including across disability types. The case studies outline responses delivered to four different participants - one with a physical disability and developmental delay; one with visual impairment; one with Attention Deficit Hyperactivity Disorder (ADHD), Autism and Post Traumatic Stress Disorder (PTSD); and one with Obsessive Compulsive Disorder (OCD), PTSD and Hoarding Disorder.



The role of professional organisers

In essence, professional organisers work with participants to achieve goals in their NDIS plans by optimising their environments and bringing more order and efficiency to their lives. Professional organisers assist participants to make changes and to improve their quality of life and wellbeing by improving the relationship they have with their space, time and belongings. Capacity building is critical to this, as organisers aim to build a participant’s capacity by supporting them to develop new skills and by working alongside them to create sustainable solutions in their homes. To do this, professional organisers may fill the following roles:

1. *Reconfiguring home environments so they better meet participants’ needs.* Professional organisers work with NDIS participants to ensure that their environments better meet their needs. Organisers do this by designing, sourcing and implementing solutions that enhance the participant’s safety and independence; by reconfiguring home environments to maximise the participant’s choices about how they access their personal belongings; and by designing and implementing solutions that facilitate the participant’s independence and chosen lifestyle.

Examples include implementing recommendations from an occupational therapist for home modifications by sourcing and devising storage systems and working with the participant to reconfigure home spaces.

2. *Designing and implementing systems and processes that improve participants' lives.* Professional organisers work with participants in their homes to assess and redesign systems and processes that relate to daily life so that a range of tasks are better able to be undertaken by participants. Organisers can examine the effectiveness and efficiency of systems and processes and propose options for reconfiguring them to participants. Reconfigured options may be in response to the nature of the participant's disability (e.g., physical access requirements, cognitive processes or the nature of other services accessed) or to the participant's lifestyle choices. Examples of this role include reconfiguration of spaces and processes relating to food preparation, laundry or hobbies or accessing or storing belongings such as clothing or therapy equipment.
3. *Responses to hoarding and squalor.* Professional organisers use a range of strategies to support participants experiencing challenges relating to hoarding and squalor. Organisers work beside the participant to declutter their homes and to organise living spaces and personal belongings to optimise the participant's lifestyle. Organisers may also work to support participants to uphold their tenancy obligations and to resolve any issues about property condition that are raised by lessors. Organisers are also expert at co-ordinating responses such as forensic cleaning, home maintenance, pest control and storage solutions.
4. *Bringing services and supports together.* Professional organisers work with a range of other NDIS and community services and supports when delivering services to NDIS participants. In the NDIS space, this ranges from Plan Managers and Support Coordinators to Support Workers and Occupational Therapists. Professional organisers are also expert at project managing complex responses that source and coordinate a range of more generic community services such as tradespeople for home maintenance, pest control, cleaners and removalists. Organisers routinely work in a way that links participants to the resources and services they need in order to optimise outcomes.
5. *Advocacy on behalf of participants.* Professional organisers often spend considerable time working alongside participants in their homes. Depending on the nature of the NDIS package a participant is accessing, and its limitations, organisers may be in a position to understand the circumstances and home setting of a participant in more detail than other service providers. Organisers cite examples such as Plan Managers and Support Coordinators who have not visited participants in their homes and so do not see firsthand the setting in which services are delivered, the limitations posed by the participant's physical environment or the circumstances in which participants live. At times, participants may find it challenging to advocate about these issues themselves and don't have family or friends to advocate on their behalf. Consequently, organisers cite examples in which they have advocated on behalf of clients, and/or supported participants to articulate issues that impact on them, that have resulted in improvements to NDIS packages and to services and supports.

3. KEY ISSUES

3.1. Barriers to entry to the NDIS market

Key QPC questions

- What are the most important factors that affect providers' decisions to supply into the NDIS market?
- What are the characteristics of those providers that have not sought or not been permitted to register?
- Do providers face stronger incentives to operate in the NDIS rather than in other sectors, or vice versa?
- What are the key barriers to entering the NDIS market for those who operate outside the NDIS?
- Are there ways in which these barriers could be reduced without affecting the quality of service provision?

Survey respondents report a range of factors that influence their decisions about supplying to the NDIS market. One important factor is the view expressed by many that there are real benefits for NDIS participants from professional organising services and that it is rewarding to be able to achieve real outcomes for people with a disability facing significant challenges in their lives. Respondents also value the opportunity to build the capacity of participants through coaching and helping them develop new skills in their homes. In the words of one survey respondent:

“We educate, coach and motivate our participants... We transfer lifelong skills to help them live an easier life. We strive to understand the participant's own personal circumstances including grief, loss, stress and illness.”

Significant barriers to operating within the NDIS market are also reported. These include the costs of registration and regulation for small or micro business providing professional organising services, as well as a rigid approach to pricing that does not adequately reflect broader market pricing. 54 respondents to IOPO's recent industry survey indicated they provide services to NDIS participants. Of these 54 services, 75.9% are sole traders. In addition, 81.5% of respondents indicated that, while they are providing services to NDIS participants, they are not registered NDIS providers and a further 11% were previously registered but have chosen to discontinue their registration. The issue of incentives to move away from registration is further explored in Section 3.2 below on pricing.

Respondents also report limited industry recognition and a lack of role clarity. They often experience a lack of knowledge on the part of other service providers such as Plan Managers and Support Coordinators about the role of professional organisers and how they can support participants to achieve the goals in their NDIS plan. In addition, confusion occurs about the respective roles of professional organisers, cleaners and support workers. This lack of recognition and role clarity also has pricing consequences, which we discuss in Section 3.2 below.

These barriers to entry of professional organisers into the NDIS market can mean that there are greater incentives for professional organisers to operate outside the NDIS market and some organisers make this choice. Given the predominance of small or micro businesses in the industry, some aspects of regulation (e.g., standards, registration processes and pricing restrictions) may create disincentives. Nevertheless, there are many organisers who are committed to providing a service to participants and continue to do so. This is evidenced by the 66% of respondents to our industry survey who have undertaken professional development specifically to support their work with participants. In addition,

over a quarter of survey respondents have worked with more than 20 participants, thus demonstrating ongoing interest in such work. The challenge of how to ensure high quality services, whilst not unnecessarily burdening small or micro businesses with regulation, is a critical one for the ongoing contribution to NDIS services by professional organisers.

3.2. NDIS pricing

Key QPC questions

- In what ways could price regulation be improved?
- How is price regulation affecting market development in Queensland, particularly in thin markets?

Many respondents to IOPO's industry survey report the NDIS's rigid approach to pricing as a significant challenge. They indicate that NDIS pricing does not reflect industry pricing and so often provides a disincentive for professional organisers to work with participants. This, in turn, means that participants miss out on valuable services. 57% of survey respondents indicated they had taken a pay cut, or worked hours for free, to work with participants, thus evidencing that NDIS pricing is not aligned with market pricing for professional organisers. In addition, examination of a sample of the NDIS line items currently being used by organisers shows no clear path for charging using these line items with a range of items being utilised.

This is compounded by a lack of understanding of the role that professional organisers undertake. For example, it is not uncommon for Support Coordinators to suggest that professional organisers invoice using the line item for cleaning, whereas in reality the role an organiser takes on is more complex, requires different skills and is not adequately remunerated by cleaning rates. In addition, organisers commonly use a range of sub-contractors who bill at a higher rate (e.g., forensic cleaners @ approximately \$120 per hour) and this needs to be taken into account. Organisers also take on project management roles where they are coordinating a range of responses. For example, a response to a squalor and hoarding issue might necessitate project management of cleaning, pest control, maintenance and rubbish removal as well as direct provision of professional organising services. Pricing needs to be flexible enough to allow for adequate remuneration, based on the complexity of the work to be done and the skills it requires.

These challenges often result in unintended consequences, pushing many organisers who are providing services to participants to discontinue their registration so they are no longer required to use NDIS line items. A further unintended consequence is that the NDIS pricing approach encourages organisers to work with participants who are self-managing their plans and so have more flexibility about what they pay for services. For example, our survey indicated that 87% of organisers work with participants with self-managed plans, compared to 14.8% with NDIA managed plans. This in turn may mean that those in the most need are not be able to access a professional organising service. These price regulation challenges also hamper market development in Queensland, particularly in regional and remote areas where services are few and far between.

IOPO advocates for further work to be done on an improved approach to NDIS pricing for professional organising services. We believe that more appropriate options are urgently needed. To be successful, pricing options need to:

- Reflect current industry charges for services;

- Allow for differing degrees of remuneration depending on the complexity of the work to be undertaken for the participant and the skills needed to successfully undertake the work; and
- Incorporate an approach to project management where the work necessitates complex coordination of a range of services.

4. CONCLUSION

Professional organisers are uniquely positioned to assist participants to improve their lifestyle. The services our members and colleagues provide play a vital part in supporting participants to cope in their homes. In this submission we have focused on some of the key market issues for our industry and highlighted necessary improvements for the consideration of QPC. The results we are able to support participants to achieve are articulated well by the words of one of our survey respondents:

“Feedback is consistently that this engagement helps clients to manage their physical and emotional health because they feel in control of their living spaces and learn ways to move forward feeling capable and competent.”

5. CONTACT DETAILS

| |
|--|
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Appendix One: Case studies

Case study one: Mary¹

Mary is a young woman of 18 years of age who lives in a Brisbane suburb with her parents and two teenage siblings. Mary has a disability that means that she generally uses a wheelchair, has frequent seizures and requires a high level of personal care including assistance with eating, incontinence and a range of medical needs. Mary also has a significant developmental delay and is unable to speak. The nature of Mary's seizures means that she is at risk during the night and so requires overnight support. Mary also requires access to a hoist, various therapy aids and significant volumes of medical supplies. At the moment, Mary's mother is her carer and no other support services come into the home. Mary's mother spends each night sleeping in a reclining chair in a small verandah area adjacent to Mary's room to provide her daughter with the overnight support she requires.

The house that Mary and her family live in is slab on ground so it could be made to be accessible to Mary but does not currently meet Mary's needs. Mary's bedroom has insufficient space to store her personal belongings and the wheelchairs, therapy aids, equipment and medical supplies that she needs. This issue has been exacerbated by the Covid-19 pandemic, as supply of the medical supplies Mary requires has been uncertain and so Mary's parents have ordered bulk supplies to ensure that Mary's needs can be adequately met. The house and the yard are now overflowing with these supplies, including some stored under tarpaulins outside. The layout and the large amount of general clutter in the house means that Mary has difficulty moving around in her wheelchair and cannot access outdoor areas. There is also inadequate space for a support service to provide overnight support.

An NDIS plan for Mary has recently been finalised and has resulted in approval by the NDIA of significant ongoing support services, as well as a major home modifications package. An occupational therapist has been engaged, along with a professional organiser, to plan and deliver the home modifications package which will result in construction of a purpose designed "suite" that will become part of Mary's family home. Mary's suite will include storage for her wheelchairs, hoist, therapy aids and medical supplies, a nurse's station and an adjoining area to accommodate an overnight carer and will have direct access to the outdoors.

Bridie, the professional organiser engaged by Mary's family will work closely with the occupational therapist who is designing and overseeing the home modifications package. Bridie's role will include:

- An initial assessment of the home including design work on options for features such as storage;
- Development of precise specifications for storage in Mary's new suite, including for wheelchairs, hoist, therapy equipment, medical supplies and personal belongings. Storage design will also support Mary in her goal for more independence in her NDIS plan by ensuring she can better access her personal belongings and make choices about what she wears;
- Working alongside Mary's parents to declutter the home and dispose of unneeded belongings;
- Packing up and organising storage for personal belongings to enable construction work on Mary's suite to occur;
- Assisting Mary to move into her new suite by:
 - Unpacking and organising equipment and personal belongings to optimise Mary's access to her belongings and facilitate greater independence and choices for her about using them;
 - Establishing efficient storage for equipment and supplies to ensure good access by support providers to what they need and to allow for care routines to occur effectively and efficiently; and
 - Organising the suite to facilitate access by Mary to other parts of her home and to the outdoors.

¹ Participants' names, and other identifying details, have been changed to preserve their privacy.

Case study two: Sam

Sam is a retired man of 60 years of age who lives alone in a trailer in a retirement village in a suburb of Western Sydney. He worked as a hairdresser for many years and retired as a result of deteriorating eyesight and is now legally blind. He is still adjusting to the fairly recent loss of his sight. Sam bought his trailer with his superannuation balance and now lives on a disability pension. He has one sister who is over 20 years older than him and is experiencing some health issues of her own. Sam has an NDIS package and in 2017 Janet, a professional organiser, was contacted by Sam's Support Coordinator because the agency that had been engaged to provide Sam with a support service to assist him to do shopping and cleaning indicated their support workers were unable to enter Sam's trailer as it was in such a squalid state that it constituted a workplace health and safety hazard.

Janet visited Sam and spent some time getting to know him. It was clear that Sam was struggling to manage his trailer and that this had meant things had got into a very poor state. The trailer's verandah and steps were unsafe. When he was cooking for himself, Sam could not see that he was dropping significant amounts of food onto his carpet and this had resulted in hygiene issues and an infestation of cockroaches. Sam's washing machine was broken and so he had not been able to wash his clothes for six months. His hot water wasn't working. Sam's furniture had deteriorated significantly and was dirty and in disrepair. His trailer was in a very poor state and needed lots of repairs. Even though he could not see the extent of the damage, Sam was embarrassed to invite any of his neighbours in and so was socially isolated. Sam had been sent a number of visual aids to help him with his loss of sight, but they had become lost in his trailer and he could not see to unpack them, set them up and learn how to use them. No assistance to do this had been provided when the aids were supplied.

Janet put forward some options to Sam and they worked out a strategy to get his trailer into a better state. The first submission to Sam's Plan Manager was refused due to insufficient funding. The Support Coordinator then came back to Janet because Sam's situation had deteriorated, and new funding had been approved, and so she was engaged.

Janet hired a storage container to put on Sam's trailer site. Sam went into respite care while work occurred on his trailer. Janet and a team of professional organisers then started working through Sam's belongings to identify what he wanted to keep, to clean these items and to store them in the storage container while work on the trailer was done. A laundry service was organised for all his clothing and household linen. Janet hired a forensic cleaner and a pest control service to work on Sam's home. Sam's washing machine was repaired. As work continued, it became clear that the trailer was in much worse disrepair than either Sam or Janet had realised. Sam's shower and kitchen sink had been leaking for some time and so water had damaged other parts of the trailer, including the floor. Sam could not afford the extent of work needed to get his trailer into good repair. Janet liaised with the trailer park manager and was able to identify that the trailer had in fact been sold to Sam in a state of disrepair, which Sam had not realised at the time. Janet also established that Sam had been paying insurance on his trailer since he moved in and so worked with Sam and the park manager to put in an insurance claim that meant that repairs could be done.

This work occurred in gradual steps over a long period of time. Over this time, Sam had a knee replacement and was then hospitalised as a result of a post-surgery infection. For some of this time, Sam stayed with his sister but always with the objective of returning to his trailer. Eventually, work was completed and Sam was able to move back into his trailer. Repairs had been done and Janet had sourced new furniture through donations. Sam was pleased to discover that his neighbours had been looking after his plants while he had been away and so felt welcomed back to the retirement village. He was also able to access the support service that he had not been able to access because of the state of his home.

Case study three: Rebecca

Rebecca is a woman in her 40s. She lives in a bungalow on her family's farm outside a small rural town in Victoria. The region Rebecca lives in was a fire-affected area last Summer. Other family members, including Rebecca's father, live in the other two properties on the farm. Rebecca moved into the bungalow a year ago after her partner died and this loss, and a number of other traumatic events, resulted in her needing to move out of her home in Melbourne. She does not see her current home as an ongoing option and has identified living in a more independent setting as a goal in her NDIS plan.

Rebecca also has goals in her plan about safety and being supported in the home. Rebecca experiences Obsessive Compulsive Disorder, Post Traumatic Stress Disorder and Hoarding Disorder. She also suffers from Crohn's disease. In addition, Rebecca experiences insomnia and somniphobia.

Rebecca was referred to Theresa, a professional organiser, through a disability services organisation that had been providing Rebecca with support but wanted some specialist skills in response to hoarding issues as Rebecca was experiencing challenges in this area resulting in not being able to use or clean some parts of her home. When Theresa first met Rebecca in her home, they decided to start working on sorting through Rebecca's possessions. Together, Rebecca and Theresa set a goal for Rebecca to discard 10% of her possessions. Work started in areas that Rebecca uses the most, including the areas around her favourite chair in the living room.

Over time, Rebecca and Theresa have worked on other areas. It has been a slow and gradual process. One of the goals of the work was to reduce visual clutter and stimulation to assist with sleep patterns. Theresa describes the work she is doing with Rebecca as providing her with "scaffolding" to support her to achieve her goals at home and to better support her to develop skills that she finds challenging such as planning, organising and completing tasks.

Theresa also worked with Rebecca to implement strategies recommended by her psychologist, such as reorganising photos on her phone so she could download apps to assist Rebecca with her insomnia. In terms of Rebecca's goal about safety, Theresa worked with Rebecca to develop an emergency evacuation plan given the fire risk in the area Rebecca lives in.

At the beginning of the Covid-19 pandemic, Rebecca's GP recommended that Rebecca needed to remain in isolation as a result of her vulnerability to infection because of Crohn's disease. Rebecca also had other support workers coming into her home from time to time but this was discontinued for a while when she went into isolation. Given Rebecca's need to self-isolate, Theresa has also worked with Rebecca so she can better use technology for purposes such as telehealth.

Case study four: Gail

Gail is a woman of 52 years of age and lives in a town in Northern NSW with her 12 year old son Nathan. Gail experiences Attention Deficit Hyperactivity Disorder (ADHD), Autism, anxiety and Post Traumatic Stress Disorder. In addition, Gail's son experiences Autism and ADHD and also has an NDIS package. Gail struggles with communicating her needs to others. In addition, ADHD really impacts on her memory and so she experiences challenges in completing tasks.

Gail's NDIS plan establishes goals about becoming more independent and organised and building functional capacity in her daily life. As part of this, Gail's plan identifies the need for a professional organiser to work with her. Gail also wants to be better able to look after herself and her son.

Gail contacted Catherine, a professional organiser, to engage her to do some work with her as Catherine has specific experience in working people with ADHD as a professional organiser. Catherine is based in Western Australia rather than NSW, but Gail preferred to engage someone who had specific expertise even if the service needed to be delivered by video conferencing.

Gail indicated she had poor prior experience of working with support coordinators and support workers as she felt they had limited experience of working with people with ADHD and so, from her point of view, things hadn't worked well. She gave Catherine an example of support workers doing her laundry but not working with her to store clean laundry in places that she could find it. She felt frustrated that support workers were not working with her and that they didn't understand how ADHD and Autism impacted on her need for very specific household routines and systems.

When Gail and Catherine started looking at Gail's home it became clear that there were areas that Gail clearly wanted to improve. Gail identified that getting household routines in place was her priority, rather than decluttering. She wanted to establish and manage processes, systems and time for key home routines and she wanted these systems and processes to ensure that she became organised and stayed organised.

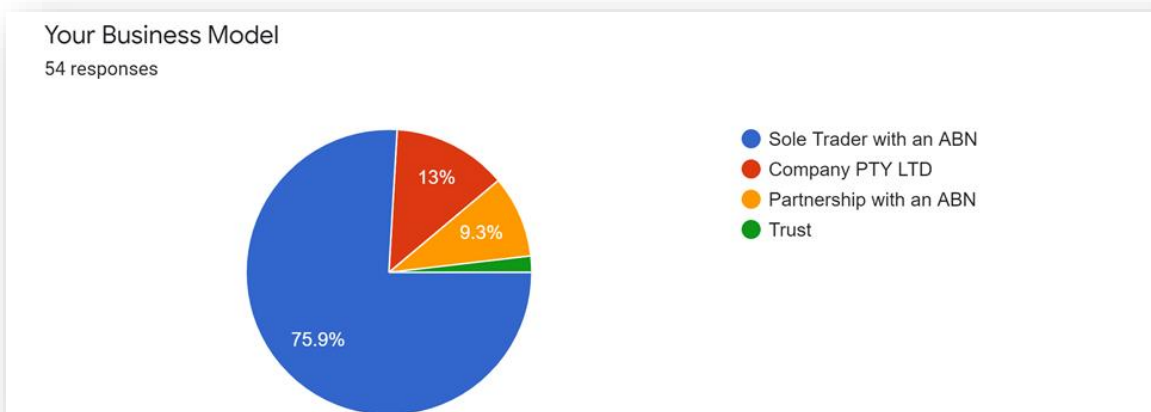
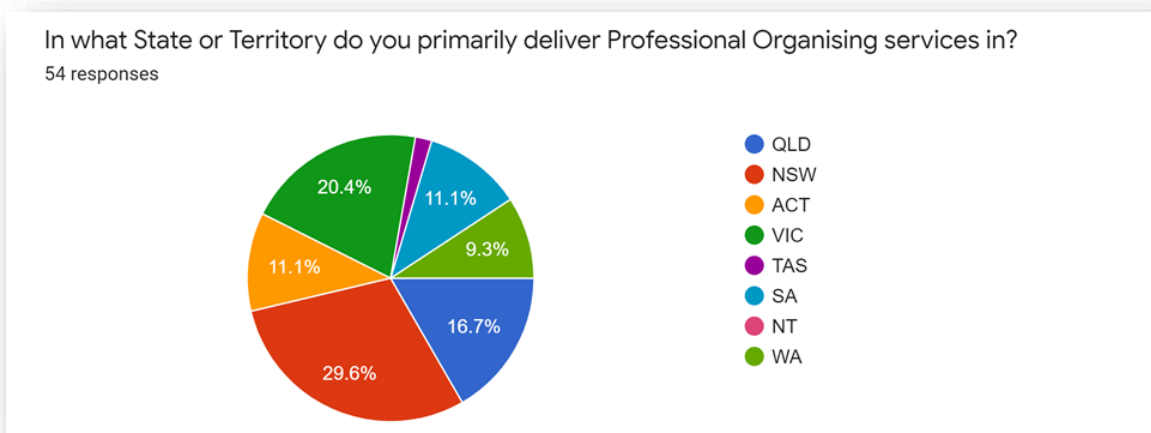
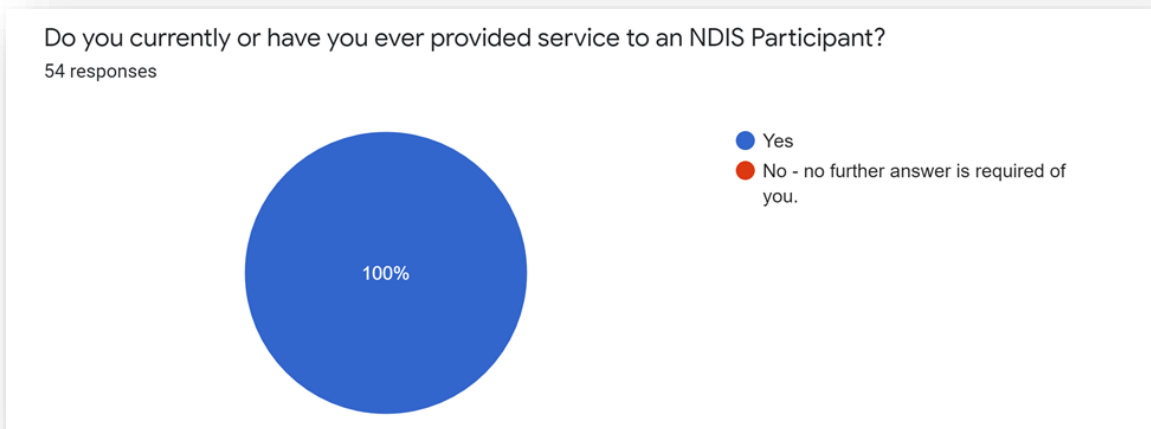
Gail and Catherine worked on establishing more effective household routines, executing these routines and building good, sustainable household habits. For example, they started work on doing dishes and then on setting up morning routines as the latter was a challenging and stressful time of day for both Gail and Nathan. Catherine and Gail also worked on technological resources that would put reminders in place for both Gail and Nathan about key routines and allow checklists for these routines to become electronic.

Gail's son Nathan also experiences sensory issues with eating and his medication suppresses his appetite and so it is hard for Gail to get Nathan to eat anything other than junk food. Catherine worked with Nathan to teach him to cook his favourite meal, spaghetti bolognese.

Gail and Catherine also work together on strategies for organising other things in her life. For example, the best ways for Gail to brief support workers on the household routines and systems that had been established and on her specific preferences.

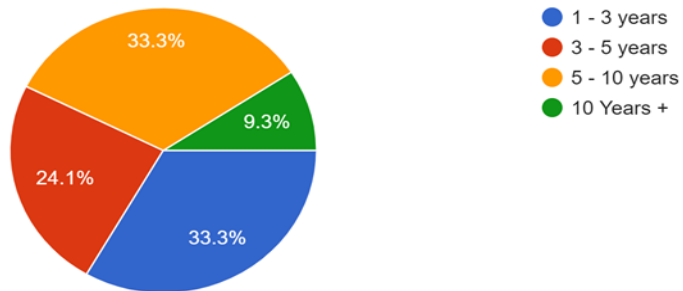
Appendix Two: Selected data from industry survey

In July 2020, IOPO conducted a survey of professional organisers to inform industry advocacy work for professional organisers providing services through the NDIS. 54 organisers responded and selected data is presented in this Appendix.



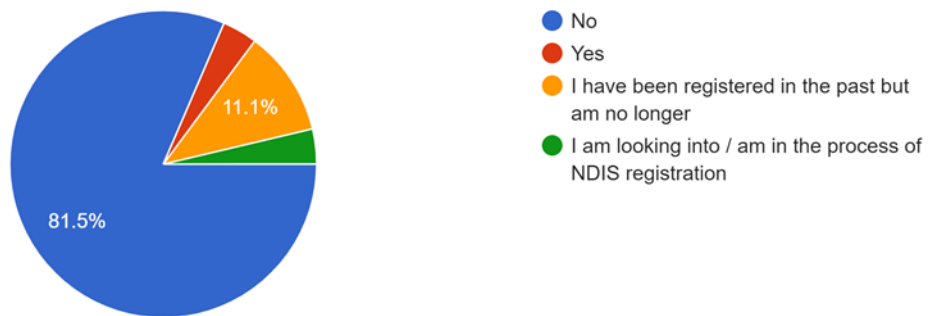
Time in the Professional Organising Industry

54 responses



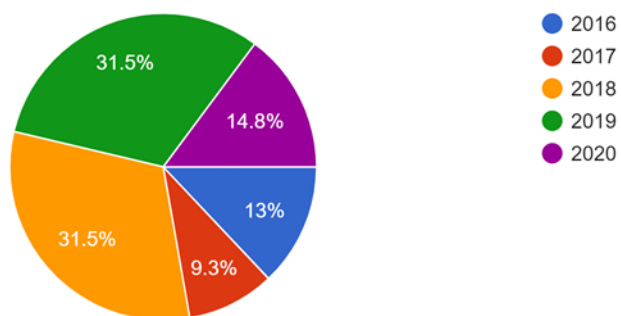
Are you an NDIS Registered Service Provider?

54 responses



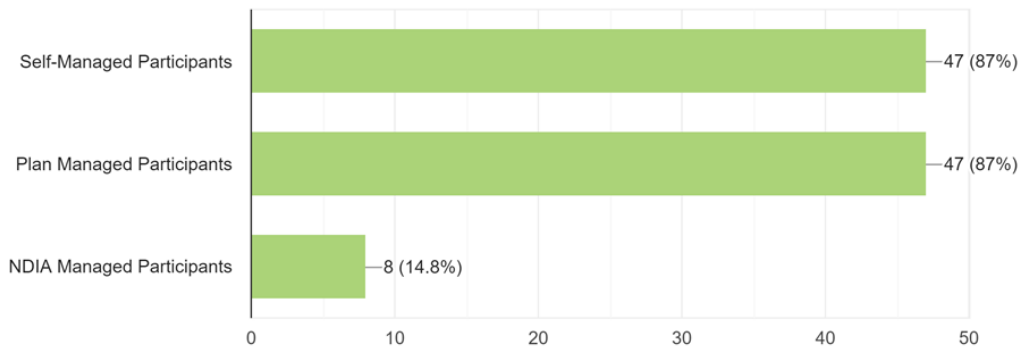
In what year did you first provide services to NDIS Participants?

54 responses



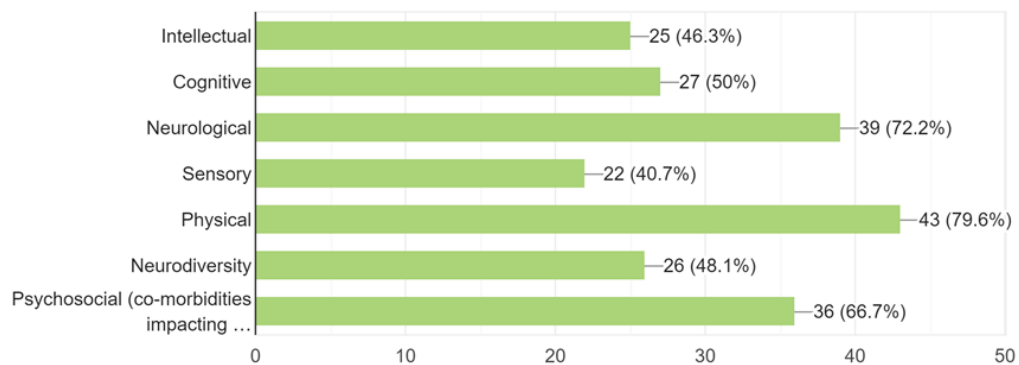
Have you worked with the following?

54 responses



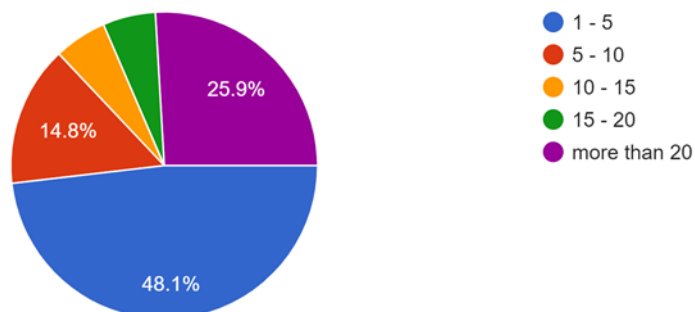
The Participants you have worked with have which of the following NDIS recognised disabilities? (tick all applicable)

54 responses



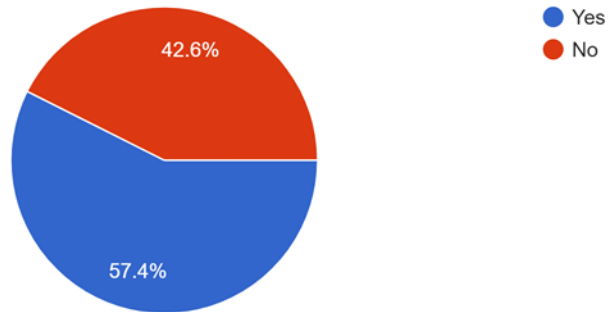
How many Participants have you worked with?

54 responses



Have you ever taken a pay cut, charged less or worked hours for free to provide service to an NDIS participant?

54 responses



Appendix Three: References

1. National Disability Insurance Agency, *Price Guide 2020-21: Version 1.0.5*. 2020.
2. Queensland Productivity Commission, *Inquiry into the National Disability Insurance Scheme market in Queensland: Issues Paper*. 2020.
3. Queensland Productivity Commission, *Short form Issues paper: Inquiry into the NDIS market in Queensland: The provider's experience*. 2020.