WORKFORCE INNOVATION *through* SELF-MANAGED SUPPORTS

A Project Report by the
National Alliance of Capacity Building Organisations

Workforce Innovation through Self-Managed Supports

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NACBO

Capacity Building for Inclusive Lives

The National Alliance of Capacity Building Organisations is a national network of not-for-profit, values based, capacity building organisations. We have a shared vision and belief that all people with a disability are valued citizens and have the right to contribute to society through social and economic participation.

We acknowledge that many people with disabilities are shut out from the richness of many ordinary experiences through outdated practices that limit people's lives. To shift this paradigm, members of the alliance provide information, education, mentoring, planning, peer support and leadership development.

Our aims as an alliance are to:

- Build people's knowledge, shift mindsets and strengthen values based leadership so that Australians with a disability are empowered to have full, meaningful and inclusive lives that are rich in relationships and
- Support and safeguard not-for-profit organisations in Australia who do this work, and
- Strengthen people's skills and competencies to enable social and economic contributions.

Collectively, the Alliance has an impressive online national presence that contains high-quality materials on global and local best-practice of community inclusion.

In 2015-16 year, NACBO worked with 10,000 people directly and had connected with 200,000 Australians online.

Our network includes the following organisations, who have more than 80 years of combined experience in regard to shifting mindsets.

JFA Purple Orange

As the lead agency on this project, JFA Purple Orange in South Australia may be contacted via their website www.purpleorange.org.au

Community Resource Unit Ltd.

Expanding Ideas; Creating Change

www.cru.org.au and
www.thegoodlife.cru.org.au

family ADVOCACY

www.family-advocacy.com or
www.resourcingfamilies.org.au

ImagineMORE

www.imaginemore.org.au

ValuedLives
Valued People

www.valuedlives.org.au

BELONGING MATTERS INC

www.belongingmatters.org

Acknowledgements

It is with much appreciation that we acknowledge the participants of this project; the people living with disability, their families, and their support workers, for sharing their personal stories for the benefit of many others.

Special thanks also to the interviewers who were able to help bring these stories out, and to the film makers who captured so many hours of wonderful footage... and then turned them into warm and informative films.

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Executive Summary

Self-management is not yet a common plan management arrangement under the National Disability Insurance Scheme (NDIS), with just 18% of participants self-managing in the first quarter of 2017–18. While there is some research on self-managed supports from the perspectives of the person and family members involved, there is little on self-managed supports that includes the perspective of support workers.

The Workforce Innovation Through Self-Managed Supports project addresses this gap by documenting experiences in self-managed employment relationships, Australia-wide, from the perspectives of the employer (the person living with disability, their family, or both) and theirsupport workers. This project draws on the experiences of 25 people living with disability and their families who have been self-managing their NDIS or state-based funding packages for some time, and 15 of their support workers. The goal is to identify and share the key factors for success or difficulty in these arrangements.

This report identifies key themes arising out of the interviews and the characteristics of these employment relationships. It covers practical aspects of the employment relationship of the 40 participants interviewed and details 25 different arrangements.

Most people and family members who self-manage reported they were motivated to choose self-management as it offered increased choice and control. Participants highlighted the ability to choose their workers and to use non-NDIS-registered providers; to choose who would come into their home; the ability to be flexible and creative with funding to focus on individual interests and goals; value for money; and the direct relationship they now had with their workers.

Before setting up their arrangements and during the early years, participants sought advice from formal and informal sources, including workshops run by organisations such as those involved in this project; the National Disability Insurance Agency (NDIA);, the Australian Taxation Office (ATO); the Fair Work Ombudsman; accountants; and peer networks, including friends who were self-managing. Many noted that they learnt from each other and from their mistakes.

Participants had various employment arrangements with their support workers, reflecting the diversity of ways people can self-manage. The common theme was that all the participants self-directed their workers. Some people/family members managed all employment processes and employed workers directly, often as a company or partnership. Those who took on the full responsibility were able to pay more than the award rate for 'good' workers and for specific skills or tasks. This group also included situations where workers had their own Australian Business Numbers (ABNs) and were paid on invoice. Others had some help from third parties. Where an agency or online employment platform was used to source workers, the worker was directed by the person/family member but paid by the agency or online service. The rate of pay in these situations was usually set by the service. Others sourced their own workers and employed them directly but contracted out the payroll functions. Some used a host organisation or financial intermediary that was the employer of record.

The main methods of recruitment were via personal networks such as friends, schools and community connections; online employment platforms and agencies, particularly for those with state-based funding where restrictions applied; and by advertising on websites such as SEEK and Gum Tree, in community locations such as shopping centres and libraries, TAFE institutions and universities, and in places where people with similar interests congregated. The latter was particularly pertinent when seeking a worker who matched the interests of the person being supported — in many cases a peer — or who had skills to help them reach their goals. Job descriptions were creatively designed to attract the 'right' person to be a match rather than a traditional disability support worker.

The interview process depended substantially on the recruitment process, with those sourced via their personal network not requiring a formal interview. Nonetheless, most participants did undertake some pre-employment reference or police record checks. Sometimes this task was contracted out to another service. For those family members who conducted formal interviews, this tended to be a two-stage process with the latter stage involving the person to be supported meeting the potential worker, perhaps at a coffee shop or in the home. This was an opportunity to interact and establish if there was a match as they had the final say on who would eventually work for them.

Induction and training tended to focus on individual needs and personalities. Two types of training were common, firstly 'buddy' shifts, where the new worker would shadow a more experienced worker and, in some cases, have access to additional information provided by a therapist or in writing. Some families had developed quite comprehensive documentation around expectations and information needed. A key worker or coordinator played the main role in induction for some participants. The second type of training focused on values and

was sometimes offered at a later stage of employment. Workers were encouraged to attend this type of training, often paid for out of the person's funding package.

The importance of two-way communication was emphasised, highlighting a greater focus on relationships in self-managed arrangements. Both formal and informal methods of giving and receiving feedback were important. Many participants held regular team meetings to enhance shared team values and goals, discuss issues and celebrate achievements. Innovative ways of staying in touch included the use of a Facebook page, or a key worker to deal with administrative tasks such as rostering. Good communication and team building was noted as a factor in worker satisfaction and stability.

Most people/family members who self-managed recognised the benefits of this arrangement for choice and control, value for money and the opportunity for them or their family member to have a valued life and to employ workers who shared their vision and values. However, there were some challenges in self-managed arrangements. This was mainly in the early stages of self-management around locating and understanding information about the responsibilities of an employer, dealing with the paperwork required by NDIS and navigating the NDIS portal. Another challenge mentioned was managing the employer–worker relationship, such as ensuring there were sufficient shifts to provide ongoing income for their workers, and handling workers leaving, whether voluntarily or not.

Participants were positive about advising others to self-manage, highlighting that people considering this arrangement can do this in stages and that support is available. This includes their peer networks that can provide practical help and advice, often by accessing the learning from other early-adopters. Participants saw this as preferable to the trial and error they themselves had been through.

One of the strong themes to come out of the support worker interviews was that people were attracted to this work because it was considered rewarding, aligned with their values and allowed for a deeper connection with the person they supported. Of interest, many workers did not identify as a 'support worker' nor did they undertake traditional support work such as personal care. This was reflected in their job titles — social connector, lifestyle coordinator, business mentor, executive assistant — and in the varied tasks they undertook, such as helping in a microbusiness or supporting community connections around an interest such as art.

Recruitment into the role also was related to the varying tasks performed by the workers. Some had been personally approached for the job, others heard about it from a friend or teacher or responded directly to an ad that they felt matched their interests and skills. For those who were interviewed, the process generally involved the person they would be supporting who had the final say. Workers who did not have a formal interview often underwent a 'meet and greet' to establish if they matched, often after a pre-screening process by the agency that was their employer of record.

Of those workers who participated in this project, seven were directly employed by the person they supported or a family member. Many had a formal agreement, which outlined the expectations of the position and/or goals of the person being supported. Most were also

paid directly by the person/family member, although one worker was paid by an organisation that handled the payroll. Four workers were employed by a host agency or online employment platform with their day-to-day work directed by the person they supported or a family member. The final four were self-employed as sole traders with their own ABNs; one was registered as an NDIS provider.

As previously, induction and training (where required) was mainly done via buddy shifts. Several of the workers felt that they did not receive enough training when they started working in their current role, suggesting that this might be a challenge for self-managed arrangements where workers had less back-up support from more experienced workers. However, where workers were recruited for their specific professional skills, induction was brief and focused on individual requirements. Responses to whether they had support to access ongoing training were mixed. Where this was provided, funding was often allocated to values-based training or to upskilling for future roles such as support coordination.

As the relationship between the worker, the person they support and (where relevant) the family member is arguably more involved in self-managed arrangements, workers may often 'give more of themselves'. This can give rise to concerns about boundaries — most workers felt that these were managed appropriately. Again, good communication via regular formal and informal feedback was considered important, for example, undertaken via the key worker role or via platforms like Facebook. Another important channel was regular team meetings, which provided a network of support and opportunities for collaboration and innovative practices and recognition of achievements.

Workers described the benefits of working in a self-managed arrangement as having a rewarding job with closer personal relationships. They emphasised that self-management allowed more flexibility, creativity and initiative as roles could be tailored to them; they could change activities on the day to suit the person rather than be restricted by agency priorities and requirements; and they could support beneficial, positive activities. The latter was considered the case as under self-managed arrangements, workers can be specifically selected based on age and interest and therefore facilitate more naturally occurring and age-appropriate activities. Another benefit mentioned was the flexible working conditions so that workers could balance other aspects of their life such as family and study.

Some workers raised challenges with self-managed arrangements. For example, pay was a concern, particularly where hours were shorter. Some people managed this concern by working for more than one person/family who self-managed, which required some juggling to deal with the varying expectations of each arrangement. The other main concern was isolation, where the worker had nobody to bounce ideas off or seek advice from, such as a more experienced worker. It was suggested that families actively create ways for workers to connect.

Most workers who contributed to this report would advise others to consider working in a self-managed arrangement. Some workers cautioned that it was not a job for everybody, as it required a deeper commitment and less certainty about what each day would bring. However, they said the work was much more rewarding than traditional disability work.

Introduction

To date, people living with disability who self-manage the employment relationships with their support workers have largely learnt the process by trial and error. The practical logistics of recruiting, training, remunerating and retaining workers is complex, with both social and legal requirements.

This project and accompanying report seeks to help others considering this approach to 'fast track' their understanding of the process by having ready access to practical information from those who have already experienced self-management arrangements. It is hoped that people considering direct employment as a support worker by a person living with disability or their family — particularly those new to the disability sector — will also benefit from access to information that can help them determine whether this type of arrangement will suit them.

Further, this report is likely to be useful for people even if they are not currently considering self-management. The collective wisdom contained in this report can be used by anyone who directs their support workers as the aim of the NDIS is to give participants choice and control to direct the support they receive, regardless of the type of plan management they have selected.

Definitions

The Independent Advisory Council of the National Disability Insurance Scheme (NDIS) defines self-management under the Scheme as:

> "a plan management option where a participant or their nominee takes responsibility for the whole or a part of the package with the Agency allocating the budget directly to the participant (or nominee) who is responsible for all aspects of administration of the package …. a participant who self-manages their supports can undertake all the above responsibilities themselves or pay an intermediary to undertake one or more of the functions on their behalf. The key point that differentiates self-management from other forms of plan management under the NDIS is that … [funds are] paid directly to the participant"(Independent Advisory Council of the NDIS 2017b, p. 8).

Self-direction, where people living with disability have control over the supports and their lives, and self-management have been described as "a market disruptor that has the capacity to enhance Scheme sustainability"(Independent Advisory Council of the NDIS 2017b, p. 4). Under this approach, NDIS participants have more choice and control over "the 'what, when, where and by whom' of support", and can "choose staff for their ability to assist them experience their lifestyle of choice" (Independent Advisory Council of the NDIS 2017b, p. 9).

NDIS data on self-managed arrangements

Self-management is not yet a common plan management arrangement under the NDIS. In the first quarter of 2017–18, 18% of plans were self-managed, up from 17% previously. Of these plans, 8% were fully managed and 10% partially managed (NDIA 2017b, p. 25).

These figures show an increase from the number of participants who took up self-management under the trial of the NDIS. While 2% of plans overall were self-managed as at 30 June 2014, differences were apparent across the trial sites from 0% in Victoria to 6% in South Australia (NDIA 2014, p. 22). The higher rate in South Australia reflects the composition of the NDIS participants in that trial site i.e., children under the age of 15 ,where take-up of self-managed supports may be more common in their families. It is possible that parents felt more confident in managing their children's supports than other groups of participants in the early rollout of the Scheme, and that packages for children were predominantly therapy and equipment based, which require less direct employment of support workers.

The NDIA set a target of 18% of participants fully or partly self-managed by 30 June 2018 (NDIA 2017a, p. 104) and is committed to increase the national rate of adoption of self-management to 30% of participants by 2020 (Independent Advisory Council of the NDIS 2017a, p. 3).

In the intermediate evaluation report of the NDIS, quantitative and qualitative evidence indicated self-management was "very uncommon" (Mavromaras, Moskos & Mahuteau 2016, p. xiv). Similarly, the final evaluation report (Mavromaras et al. 2018) noted that levels of uptake of self-management had not increased over the duration of the evaluation.

Research on individualised funding packages (Fisher et al. 2010) suggests that few people had experience of self-managing their own supports before the NDIS was introduced. This view is supported by data from the final evaluation report of the NDIS, where only 29% of evaluation participants had previously self-managed their funds (5% managed by the person themselves, 20% by a family member and 4% by someone else) (Mavromaras et al. 2018, p. 120).

Support for self-management

Promoting the option of self-management to NDIS participants requires a balance between providing assurance and letting people make their own choices — on an 'at your own risk' basis. Information from in-depth qualitative interviews as part of the NDIS evaluation (Mavromaras et al. 2018) showed that the option of self-managing was not always discussed in planning meetings nor understood by NDIS participants. Even by wave 2, when more participants were aware of the option, self-management rates did not increase mainly

because of "a reluctance to take on additional administrative activities" (Mavromaras et al. 2018, p. 120). However, the evaluators noted an increase in the use of financial managers by people who self-managed their NDIS packages, giving them the benefit of self-directing their supports with less administrative work. NDIA staff who were interviewed as part of the evaluation reported that "most participants continued to prefer that the agency manage their funding" (Mavromaras et al. 2018, p. 121).

The Independent Advisory Council to the NDIS has recommended that financial intermediaries be used as a strategy for increased participant self-direction and self-management. It noted that before the NDIS, "many … states and territories … used shared management as a valued strategy to provide the participant with choice and control with the support of an organisation that undertook the financial and legal responsibilities"(Independent Advisory Council of the NDIS 2017a, p.13). This conclusion was also reached by Fisher and her colleagues in their review of the effectiveness of individual funding approaches for disability support undertaken for the Department of Social Services (Fisher et al. 2010).

The NDIA provides a range of information products for people planning to self-manage their NDIS individualised funding package. These are available on its website. In addition, several organisations have produced their own guides, online tools and support materials. These are all available to help people who want to directly employ their own support staff. One of the biggest changes in the sector is the introduction of online services (or online employment platforms) [1] allowing people who self-manage to recruit and directly employ their own disability support workers. Mavromaras and colleagues (2016, p. 42) note that "this new approach was much desired by a number of respondents, as it was thought to provide better control over services and in particular, the ability to match support worker to the needs of the person with disability". These online employment platforms, often run by for profit enterprises, have been described as "a blend of UBER and Tinder-like features"[2] David and West (2017) give an overview of online payment arrangements and services.

[1] We have deliberately avoided naming the more popular online employment platforms used by people we interviewed or known to us, as we do not wish to endorse any specific organisation or company. The Tips and Traps sheet on recruitment available on the project website (http://selfmanagedsupports.org.au/) provides relevant information.

[2] https://www.carenavigator.com.au/ndis/5-most-searched-ndis-support-of-2017/

Traps sheet on recruitment available on the project website (http://selfmanagedsupports.org.au/) provides relevant information.

[2] https://www.carenavigator.com.au/ndis/5-most-searched-ndis-support-of-2017/

Literature review

Several recent reviews of the literature on self-directed/self-managed arrangements have focused on the individual benefits of self-management from the perspective of people with disability (Dickinson 2017; Rees 2013).

For example, Rees was commissioned by FaHCSIA (now the Department of Social Services) to interview people/family members who were currently self-managing and those who were interested in doing so to work out what would make these arrangements sustainable. She found that apart from participants in Western Australia, the choice to self-manage resulted from dissatisfaction with traditional forms of disability support and their priorities; costs such as overheads; and lack of flexibility. Rees (2013, p. 38) noted "making these arrangements work is not just a matter of luck, rather, there is a lot of work that occurs 'behind the scenes', with the assistance of other supporters around to help over time". Rees (2013, p. 45) highlighted the different employment relationship with support workers, including "the 'blurry line' between friendships and employment responsibilities, as well as the importance of trust".

Other work, such as the evaluation of a trial in Victoria in 2010, found several benefits including control over quality of workers and the hours they worked, more say in how support was provided and improved quality of support (Victorian Government Department of Health and Human Services 2016).

Disability workforce

There is little research on self-managed supports that includes the perspective of paid support workers (Leece 2010). The research on support work more generally shows that support workers employed in the disability sector in Australia are predominantly female (81%) and in the older age groups (64% were 40 or older) (Martin & Healy 2010, p. 7). Other research shows the support workforce concentrated in the 45 to 54 age group (Cortis 2017). Because of the dramatic increase in demand, the workforce may be becoming more diverse with a 'non-traditional employment pool' including men leaving previous careers in the fitness and music industries and younger staff (Mavromaras et al. 2016, pp. 47–48).

Research show support workers have low levels of satisfaction with pay and low agreement that they are paid fairly for the work they do (Cortis 2017). It is not uncommon for support workers to work for more than one employer (Cortis 2017). Martin and Healy (2010, p. 8) also found low satisfaction with pay and conditions but average satisfaction with the job compared with the 'average Australian'. However, of those who say they intend to stay working in this area, most say it is because they are "passionate about supporting people with disabilities" (Cortis 2017, p. 27).

Sakakini (2017, p. 478) emphasises the need to "make it more appealing to get started in this space [support work]". She suggests that recruiting workers as 'Homecare Heroes'who provide'light housework'or'outings'would make it"just as normal … as it is to work in a café. Much more appealing than going into a 'support worker role'". She suggests, "As independent contractors, they are motivated to listen to feedback … in order to get good reviews and continue to secure work." However, self-employment as an independent contractor can be risky as all the risks of employment are taken by the support worker, such as insurance, tax, superannuation, hours of work and pay rate.

International research

International research that includes the perspective of support workers employed in self-managed environments is sparse and may have limited applicability to Australia because of the different funding for disability supports and different industrial relations environment. However, one report from the United Kingdom (UK) (Leece 2010) compared the experience of direct employment with non-direct employment from the perspective of the support workers and involved interviews with workers and users. Leece (2010, p. 190) points out that "direct payments are not simply a transfer of money to individuals; they represent purchasing power, and this can change the dynamics between … [people living with disability] and their workers". Leece found an important difference was "the power to choose workers and shape the relationship … most of the direct payment users chose to employ someone already known to them".

As Leece noted, because people living with disability had the power to choose their workers, they could also decide how close or formal the relationship would be. As well as the boundaries of the relationship being more blurred, the workers completed a wider range of work beyond personal care than the more traditionally employed workers. They also had "the power to be more reciprocal and to set the agenda" (Leece 2010, p. 195). Many direct employers connected the ability to pay their workers directly and set terms and conditions of work with their power in the relationship: "I'm the piper, I pay the money" (Leece 2010, p. 196). Leece suggested that this power "ensured their interests took precedence in the relationship".

This research highlights some potential risks for support workers, such as working unpaid hours, because of the closer relationship (sometimes referred to as 'friendship hours') and lack of paid leave for sickness and other reasons (Leece 2010). However, Leece suggested that the trade-off may be "a friendlier working environment … and more satisfaction [than in non-direct employment arrangements]"(2010, p. 202).

Workforce Innovation through Self-Managed Supports Project

Project description and aim

The Workforce Innovation Through Self-Managed Supports project (IWF project) documents the experiences in self-managed employment relationships, Australia-wide, from the perspectives of the employer (the person living with disability, their family, or both) and their support workers.

Most people living with disability who receive individualised support in Australia do so from workers employed by a service provider agency. A small percentage have chosen to manage their paid support workers directly themselves. This project draws on the experiences of 25 people living with disability and their families who have been self-managing their support for some time and 15 of their support workers. The goal is to identify and share the key factors for success or difficulty in these arrangements.

Six organisations across Australia are collaborating on the project, with JFA Purple Orange providing the lead role. The project partners are JFA Purple Orange (in SA); Belonging Matters (in Victoria); Community Resources Unit (in Queensland); Valued Lives Foundation (in WA); Family Advocacy (in NSW) and Imagine More (in ACT).

This report identifies key themes arising out of the interviews and the characteristics of these employment relationships. Although the report is about self-managed arrangements, the focus of the project (and this report) is the employment/workforce practices of people who self-manage and those who work for them rather than the potential benefits of self-management, although there is likely to be some overlap between these two overarching themes.

Project methodology

A Co-design/Steering Group was set up to design the project materials. Members of this group were from the six organisations involved in the project (coordinated by the Project Leader from JFA Purple Orange) and included people with lived experience of disability and people who were previously employed as support workers in a self-managed arrangement.

Potential participants, recruited by each of the six project partners, received a flyer about the IWF project (see Appendix A). Those who expressed an interest in participating were provided with an outline of the interview topics (see Appendix B). Interviewers followed a common schedule of questions when interviewing people self-managing their supports (see Appendix C), and similarly for support workers (also Appendix C).

Before or at the interview, participants were asked to complete a short demographic survey. Three different sets of survey questions were used depending on whether the participant was a person living with disability, family member or support worker. (These three surveys are included in Appendix D.) Overall, 34 of the 40 participants completed the relevant demographic survey. Some participants received an email with a link to the relevant survey. This directed them to complete the survey online at the Survey Monkey website. While most of these participants reported that they had completed the survey, their responses were anonymous and information regarding their home state was not requested, making it difficult to determine which participants had failed to successfully complete the survey. Demographic data are therefore indicative of the project participants and may not fully match the details provided in the body of the report (e.g., numbers of participants who had an NDIS package).

Semi-structured interviews of between half an hour and two hours were conducted with 40 participants: 25 people living with disability or family members who self-manage their support and 15 of their support workers. Each project partner conducted at least six of these interviews. The interview format was based on an agreed set of questions/themes determined by the Co-design/Steering Group. Interviewers were expected to cover the themes and main questions in each interview, with additional agreed questions on sub-themes, where relevant.

Interviews were recorded and audio provided to the JFA Purple Orange Project Leader, who analysed the data and wrote the research report. Interviewers from each of the organisations recorded some preliminary summaries of the responses to the interview questions under the main themes, some quotes and personal reflections from each of the interviews they conducted.

All participants signed a form to confirm they gave informed consent to be interviewed and for their data to be used in the research report. Participants are referred to by pseudonyms throughout the report.

Limitations

The project participants were a self-selected group and may not be representative of all people who self-manage or workers who are employed in these arrangements. Nonetheless, interviewees came from six states and territories and the organisations involved sought to interview a range of people with varying experiences of self-management. Forty interviews constitute a reasonable sample size for qualitative research which is rich and deep. So, while generalisations cannot be made, the findings of the report can be used as examples of current and innovative workforce practices. Of note, people interviewed were those with an NDIS or state-based funding package (one participant self-managed her motor vehicle compensation package), some of whom had self-managed for a decade or more.

One notable limitation of the sample is that it included very few voices of people from culturally and linguistically diverse backgrounds.

The findings section of the report that follows is divided into two parts. The first covers the responses from people who self-manage and people who manage a package for a family member. The second part covers the responses from support workers.

Findings part 1:

People who self-manage/family members

Responses from people who self-manage their own package or manage for a family member reported in this part are structured under the four main interview themes agreed by the Co-design/Steering Group. These were:

- **What** are your arrangements? (e.g., type of supports provided and how many hours a week)
- **Why** were you attracted to self-manage?
- **How** do your arrangements work?
    - structure: employer of record, where you sought advice
    - recruitment
    - interview
    - contract of employment
    - induction and training
    - communication and feedback
- **Benefits and challenges** and advice for others who might want to self-manage.

Demographics

Eight people who self-managed completed the demographic survey. Results are displayed below. This is followed by demographic data for 12 family members who manage funding packages. Because numbers are small, the results are shown as raw numbers and not percentages.

People who self-manage

Figure 1: People who self-manage – gender

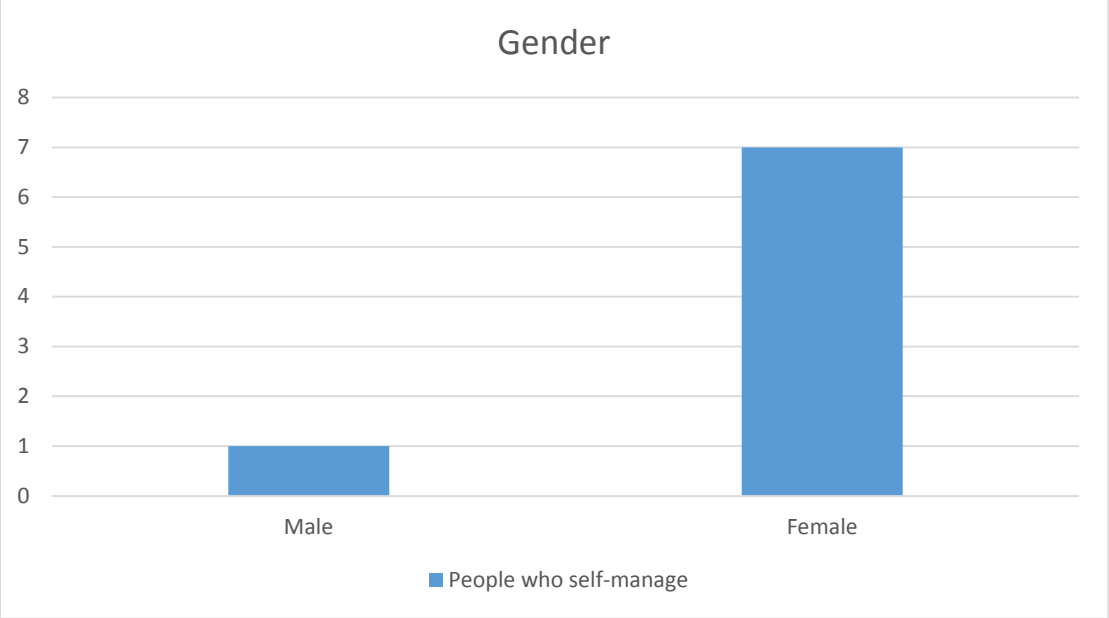


Figure 2: People who self-manage — age

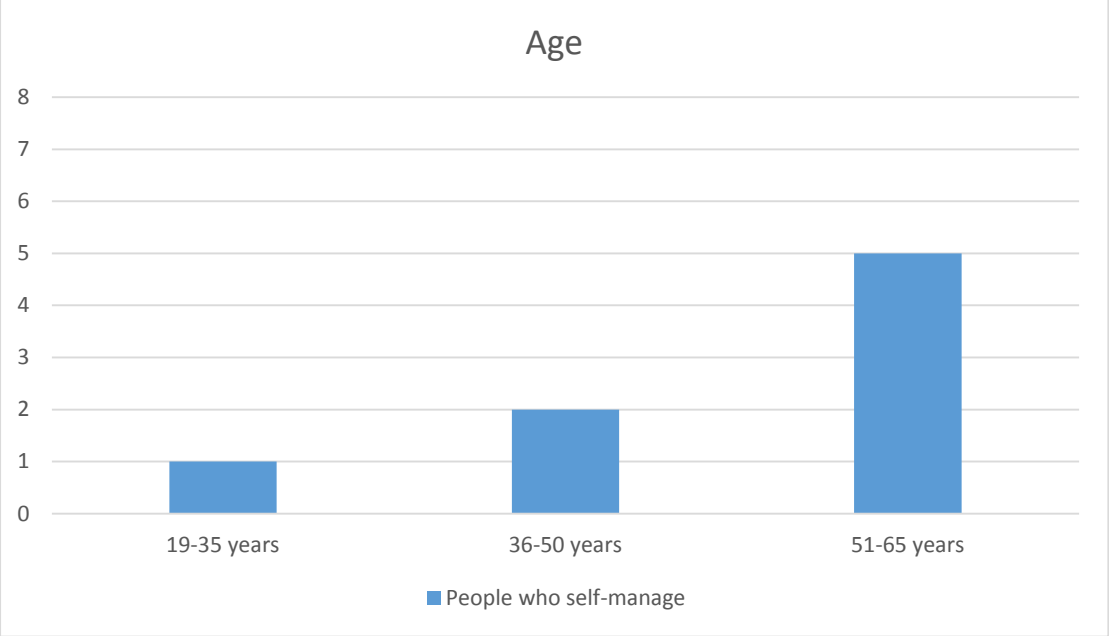


Figure 3: People who self-manage who identify as an Aboriginal or Torres Strait Islander

Figure 4: People who self-manage — cultural or language background from somewhere other than Australia

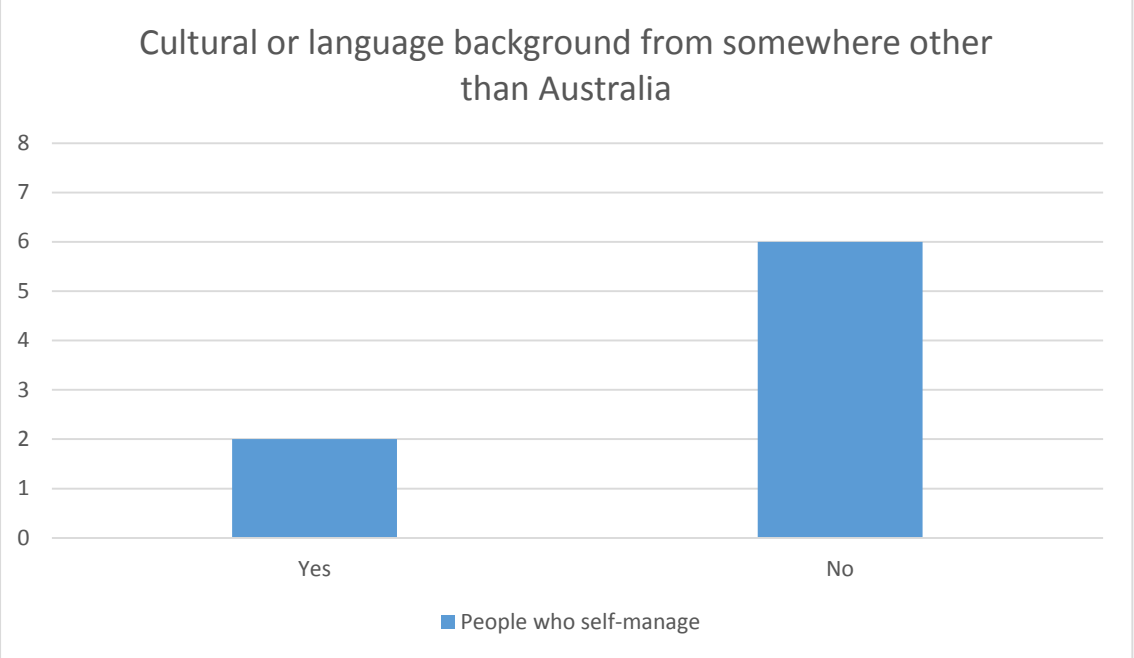


Figure 5: People who self-manage — location

Figure 6: People who self-manage — employment

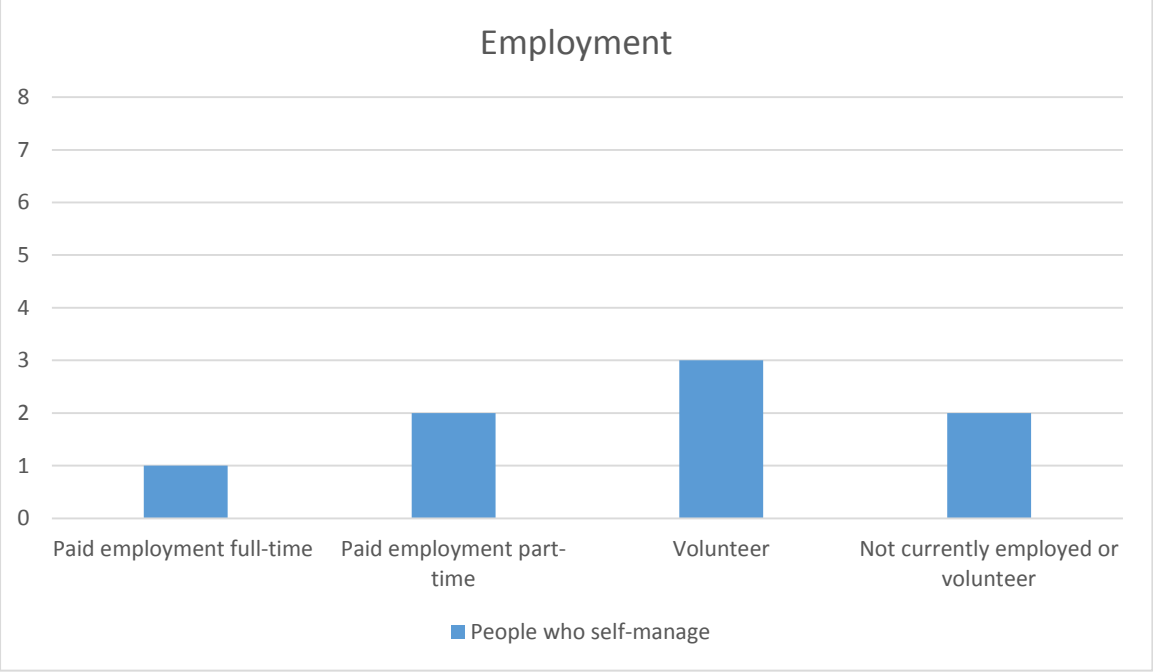
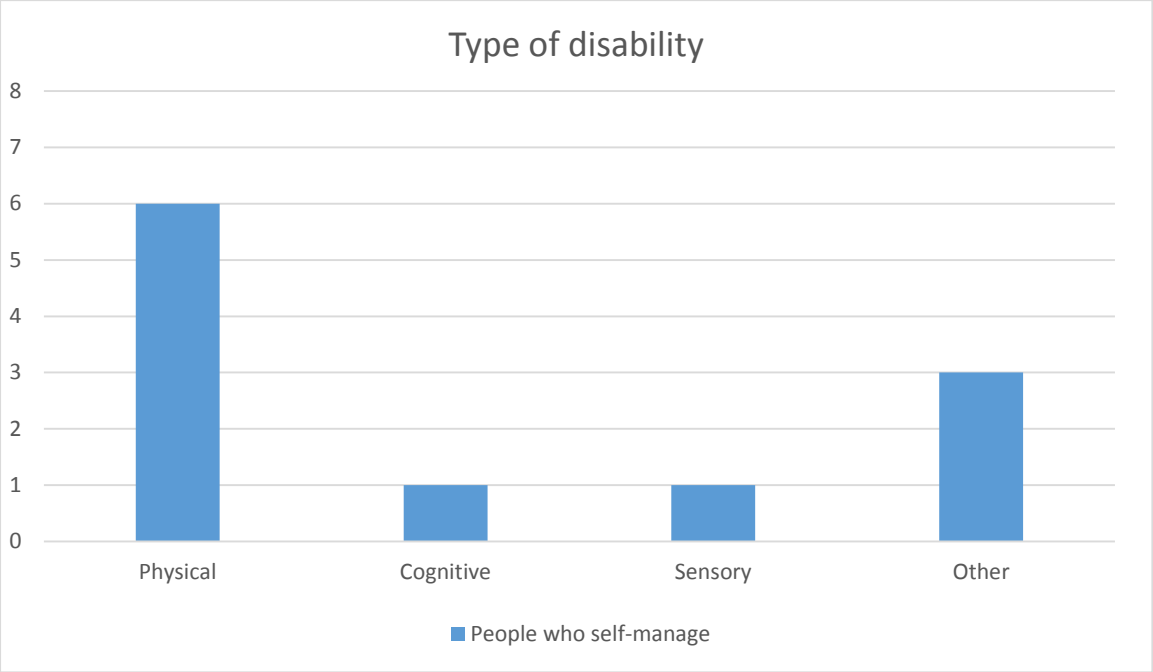
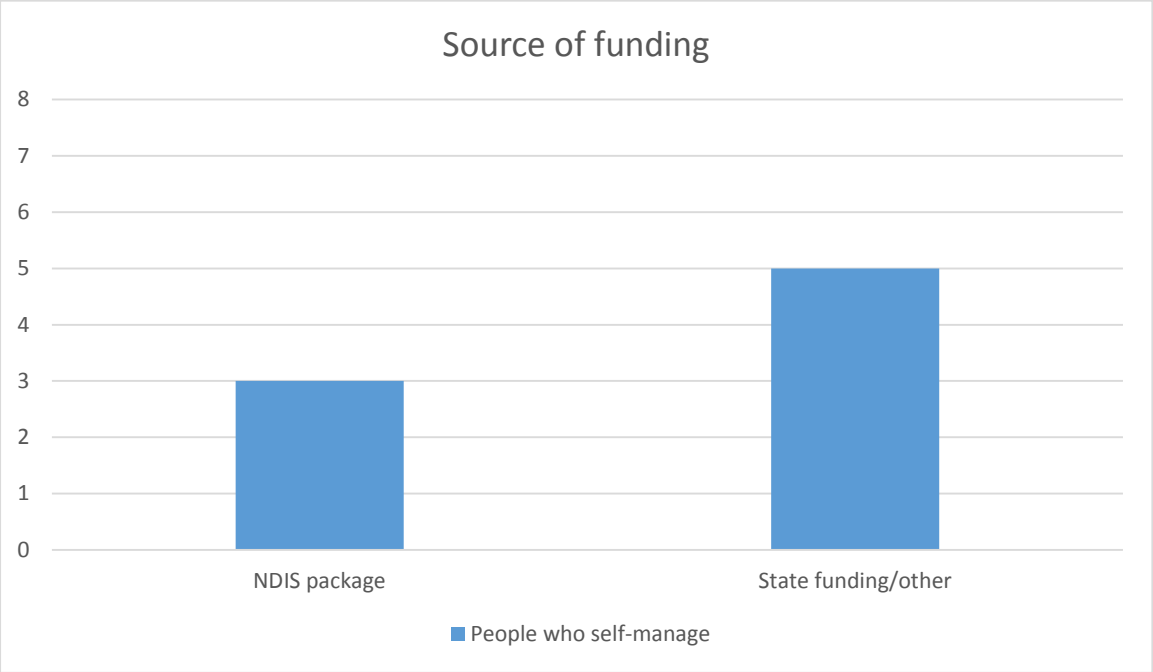


Figure 7: People who self-manage — type of disability



The question about the type of disability the respondent lives with allowed multiple responses. Other includes psychosocial and neuro-muscular.

Figure 8: People who self-manage — source of funding



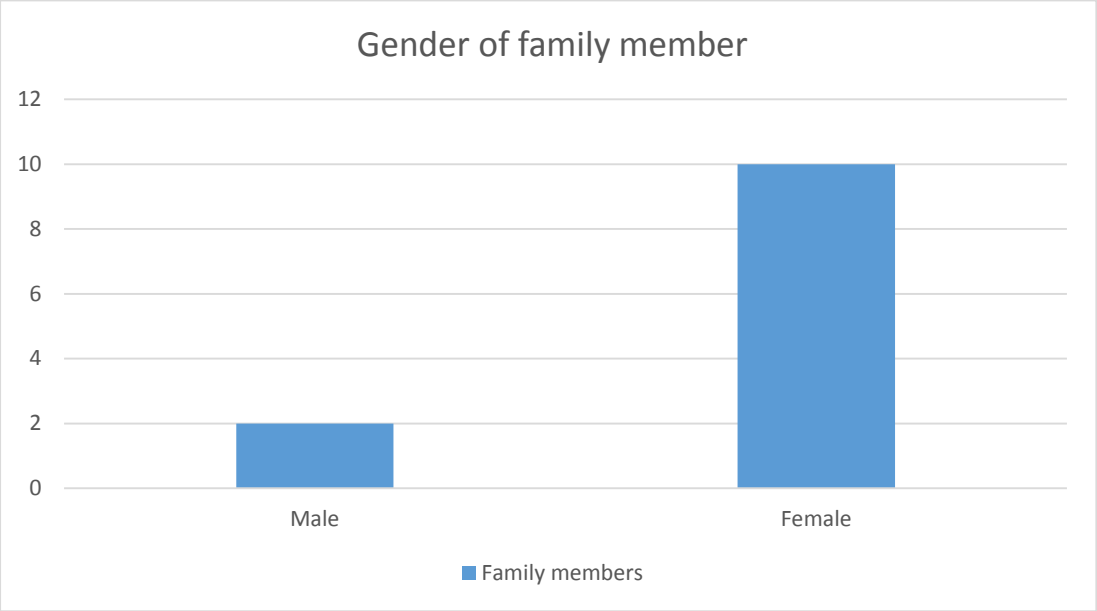
Other includes motor accident compensation.

The number of hours of support managed per week ranged between 4 ½ hours to 80 hours.

Family members

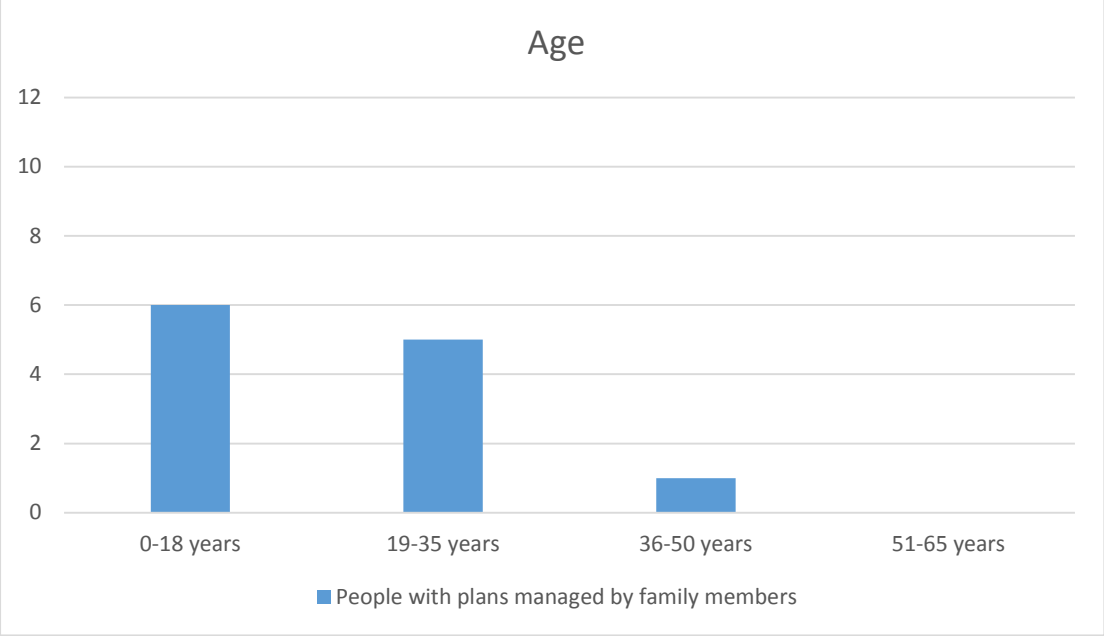
Twelve people who managed an NDIS or state-based funding package for a family member completed the demographic survey. Their responses are displayed below. Please note except for gender, responses refer to the person being supported.

Figure 9: Family members — gender



The following charts refer to the person being supported.

Figure 10: Person being supported — age



As would be expected, the age of the person living with disability was younger in the group where the package was managed by a family member than in the group of respondents who self-managed.

Figure 11: Person being supported who identifies as an Aboriginal or Torres Strait Islander

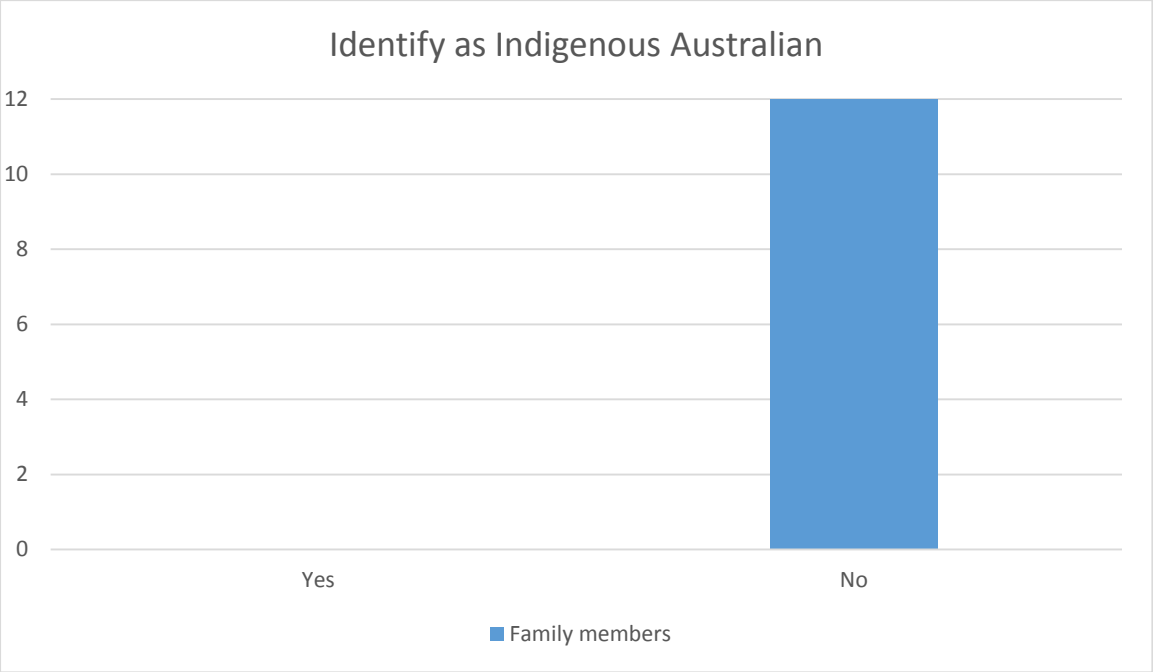


Figure 12: Person being supported — cultural or language background from somewhere other than Australia

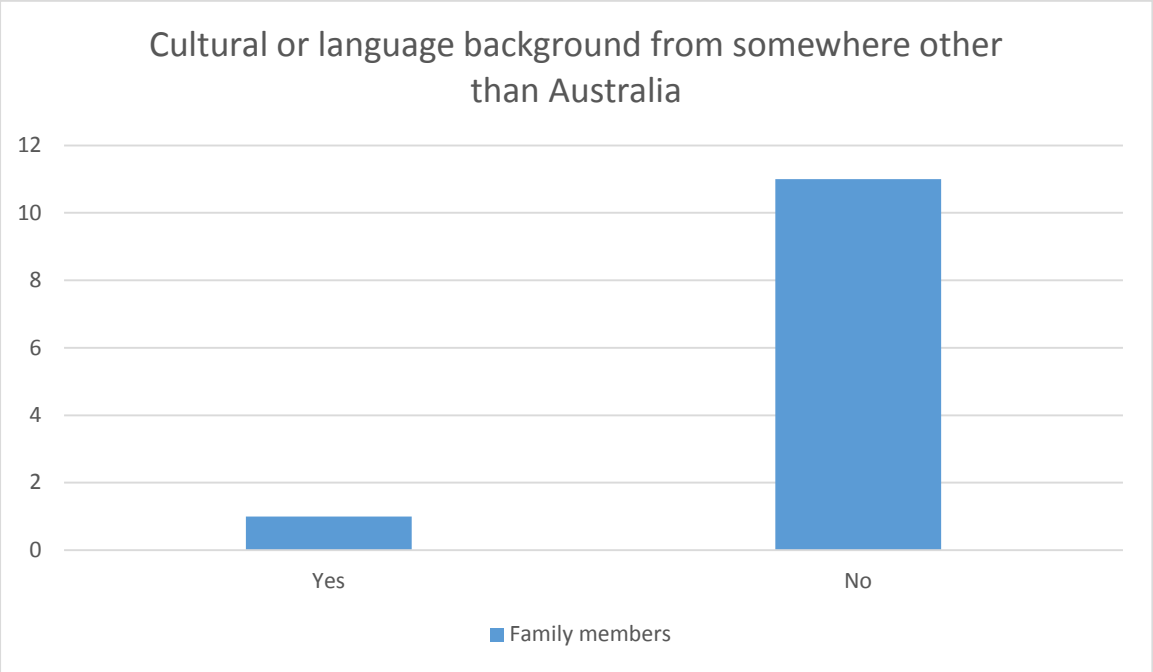


Figure 13: Person being supported — location

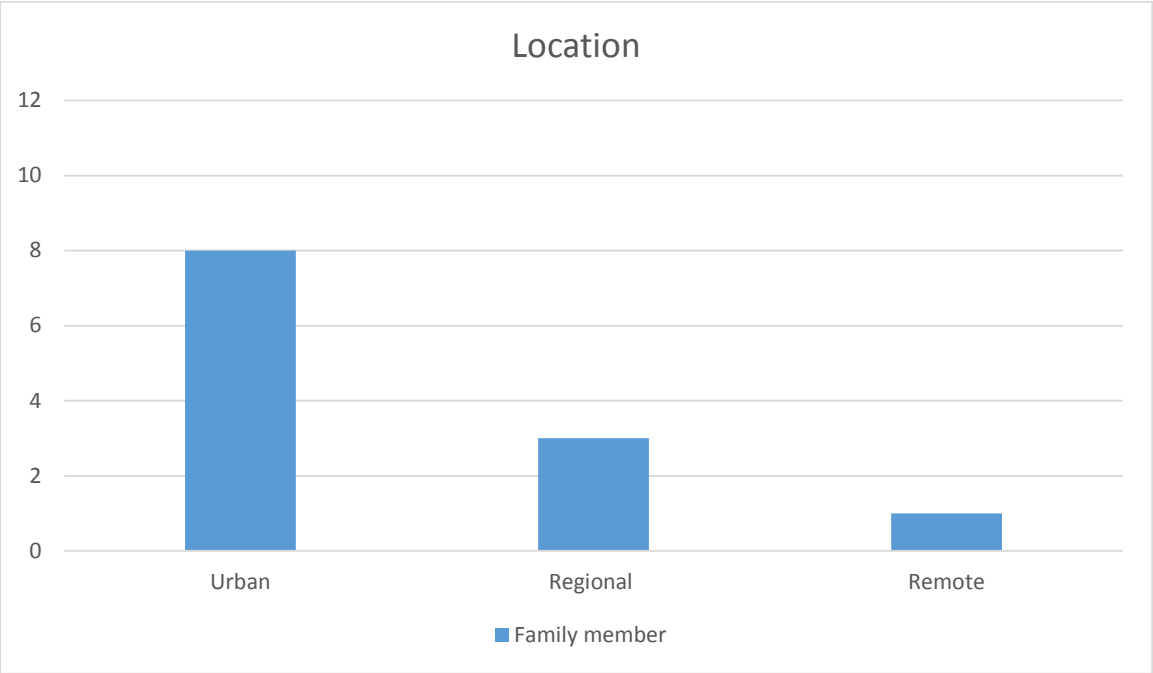
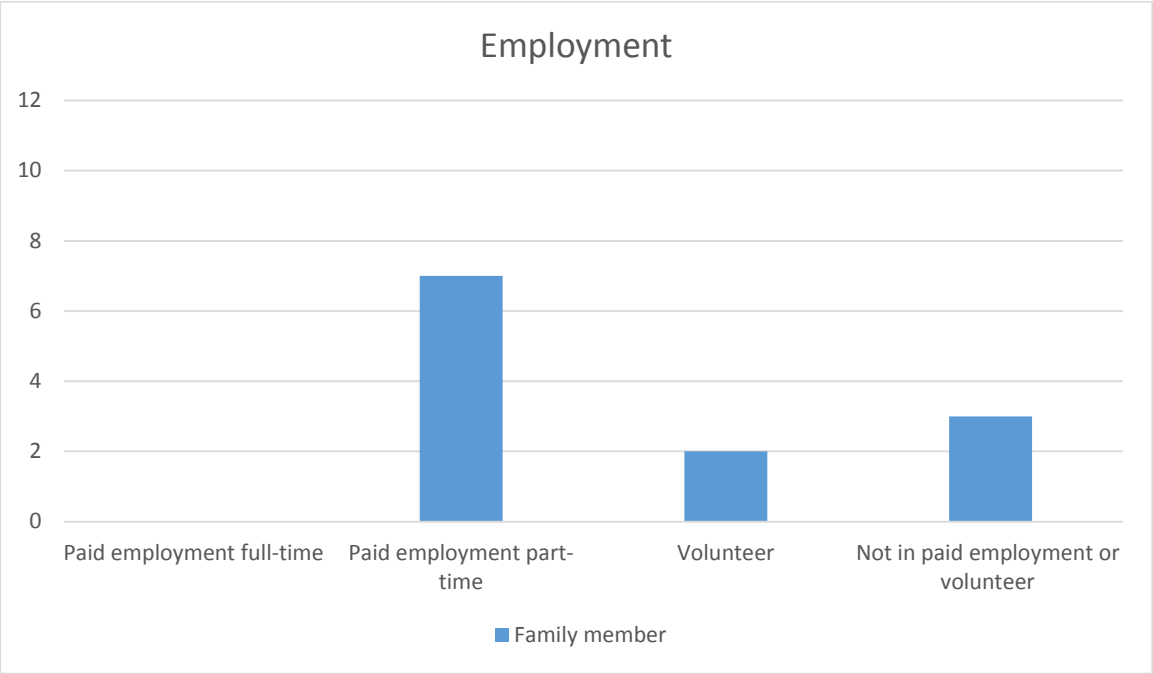
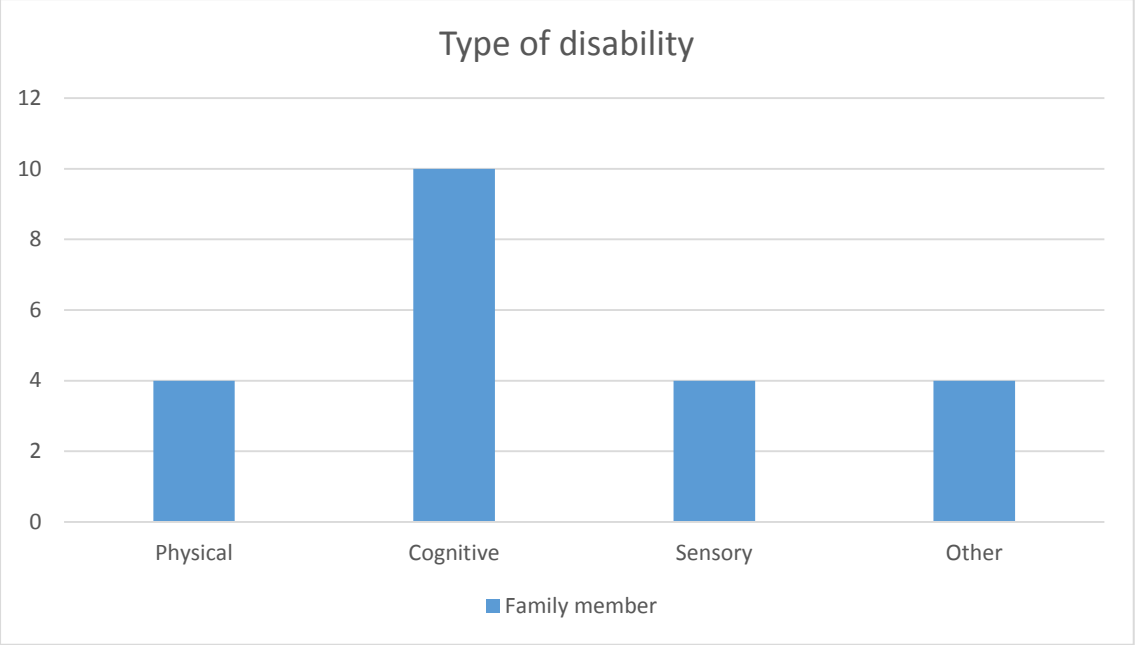


Figure 14: Person being supported — employment



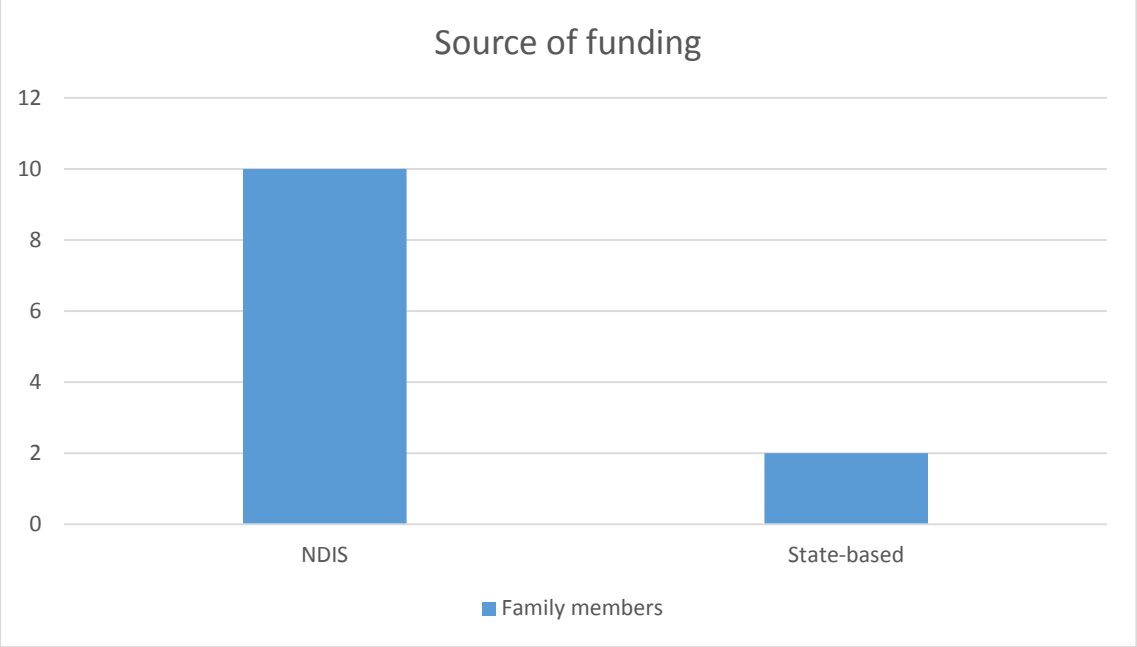
Part-time employment includes own microbusiness. Not in paid employment or volunteering includes school students.

Figure 15: Person being supported — type of disability



The question about the type of disability the respondent lives with allowed multiple responses. Other includes psychosocial and epilepsy and autism.

Figure 16: Person being supported — source of funding



The number of support hours ranged from four hours a week to most days and overnights. Around half of the respondents reported that their family member received 25 hours or more of support a week.

Self-management arrangements

This section profiles the eight people who self-manage their individualised funding packages and the 18 family members who manage a funding package for their son or daughter. (A total of 25 interviews were conducted as one participant manages her own NDIS package as well as the NDIS package for her son.)

One important point to note is the diversity of supports that are being funded. Unlike traditional support work that is predominantly personal care and housework, people who self-manage and their family members mentioned a range of other supports including exercise; capacity building for personal and social skills; school participation and sports; gardening and home maintenance; social and community participation; drama, sport, gym and other interests; therapy; creating resources such as social stories; daily activities; specific roles in microbusiness; finding and maintaining employment; setting up businesses; healthy lifestyles; phone prompting around morning routines; support coordination and recruitment of workers; communication skills; executive assistant; mentor; and community connector.

People who self-manage

Amanda

Amanda self-manages a state-based funding package. Amanda lives in her own home and leads an active life including involvement in several volunteer and not-for-profit organisations, visiting her friends, shopping and gardening. Amanda has set up her home to maximise her independence. She has a team of nine workers who provide support for daily living and personal care. The number of support hours a day vary from seven to 15 depending on Amanda's plans. She averages around 40 hours a week of support.

Diane

Diane self-manages a state-based funding package. Like Amanda, Diane lives in her own home. She has support for daily living and personal care, and housework. Diane also involves her workers in supporting her to continue to do activities she enjoys such as gardening and cooking, often using ingredients sourced from her own garden. Diane employs five people for 20 to 28 hours a week.

Jenny

Jenny self-manages her accident compensation funding package. She has support worker assistance for daily living and personal care, as well as for exercise, housework and for activities she enjoys such as swimming. Jenny has 25 to 30 hours of support each week. Several support workers share these hours.

Katie

Katie lives in a regional area and self-manages a state-based funding package with the help of her good friend Brian. Katie works as a volunteer with a peer support group. Katie receives some help with housework, gardening and general home maintenance, and to participate in a weekly Pilates class. She employs four people for around four hours a week: each worker provides a specific service weekly or fortnightly.

Edward

Edward self-manages his NDIS package. He also self-managed his previous state-based funding package. Edward works fulltime, volunteers and enjoys spending time with family and friends. He receives 35–40 hours of support per week. His workers help him with daily living and personal care, transport, housework and shopping. He also receives 8–10 hours of support through a flexible on call night-time service that provides drop-in support to help with turning or other needs throughout the night.

Helen

Helen self-manages her NDIS package. Support includes help with social and community participation, employment, housework and daily activities. Helen employs a personal assistant for 16 hours a week to be with her when she is pursuing her university studies or volunteering at the law centre. Helen also has two hours a week support for housework and gardening.

Tess

Tess self-manages her state-based funding package. Tess lives with her husband in their own home. Tess was working full-time, now she has her own family business. Tess works when she is well, and the business provides her with some security at other times. She has a team of four workers who provide regular personal care and some over-night support. Support for other activities is flexible, depending on Tess's needs, interests and health. Tess receives between 70 and 80 hours of support a week.

Karen

Karen self-manages her NDIS package and manages an NDIS package for her son Jack. Jack's worker supports him to follow his passion for drama and sport as well as regular playdates with friends. Karen pointed out that any child does not gain independence or social skills when their parents are present at the classes. However, when the support worker is there they can also upskill the staff in the relevant locations by sharing their knowledge of Jack, enabling them to eventually take over. Jack's support workers also help him with life skills and appropriate social interactions. Jack receives between seven and ten hours a week of support. Karen has anywhere from 3 to 12 hours depending on her health. The support Karen receives is flexible and is used for day-to-day tasks such as cleaning and gardening.

Family members

Kim

Kim manages an NDIS package for her teenage son Liam. Liam did not have any paid support before the NDIS. Currently, he has a careers mentor for 15 hours a week and a sports coach for six hours a week. The careers mentor works on various projects focusing on increasing Liam's self-esteem and confidence to participate in school, such as presentation skills and participation in discussions. His sports coach was recruited to help Liam learn to ride his bike, upskill him in soccer and support him to participate in other games or athletic activities. Kim has help from Liam's circle of support.[3]

Lisa

Lisa manages an NDIS package for her daughter Becky "who is a social butterfly, always happy to be out in the community". Lisa wants Becky to be "as independent as possible and live a rich and full life where she is a contributing member of society". Lisa said, "The rule in our house is that we do not enable Becky's disability. We make her help in whatever way she is able." With NDIS funding, Lisa employs a live-in support worker for Becky. As Lisa said, "This is our main support. She helps care for her, and do therapy with her, which I have been doing for ten years with no support." The support worker has been trained to handle Becky's night-time seizures. She spends two consecutive nights with Becky so that Lisa and her husband can get two full nights of sleep. Hours of support vary from week to week, from 15 hours to 35 hours, in addition to the two overnights.

Sharon

Sharon manages an NDIS package for her son Josh. Sharon described herself as "a very resilient and creative person who likes to think outside the box". Josh is a deliveryman who loves his job and the opportunities it gives him to meet and interact with people. Sharon said, "Although Josh is nonverbal, his drive and enthusiasm, along with the support of his family, friends and support workers have enabled him to pursue and achieve the good things in life." Josh's microboard — an incorporated association formed by the people in his life — works to build a life where he is fully included in his community. Sharon described Josh's microboard (comprised entirely of volunteers) as "the backbone of his supports". Josh also receives around 50 hours of paid support from a team of four support workers whose tasks range from personal care to creating resources such as social stories.

[3] A circle of support involves a group of people gathering around a person with disability at the centre to assist with the thinking, planning and actioning of their personal goals. For further information, for example go to https://www.ric.org.au/learn-about/building-support-networks/circles-of-support/

Roger

Roger manages an NDIS package for his young teenage daughter Eloise. Roger decided to employ workers to provide one-on-one support for Eloise for several afternoons a week instead of out-of-school-hours care. Roger explained: "This way, Eloise can receive support for the activities she is interested in as well as be with her siblings at home on days when she has nothing scheduled." Eloise receives five to six hours of support over two nights.

Colin

Colin manages an NDIS package for his adult son Michael. Michael has a team of five support workers (with two back-up workers) to provide daily living and personal support and to help him in his volunteer work for businesses in his local town in regional Australia. Michael receives 98 hours of support a week. Colin described the work that the support workers do each day as "being driven by Michael". He added, "By directly employing support workers, they do what you want them to do and are not influenced by an agency or organisation."

Lucy

Lucy manages an NDIS package for her adult son Tim who lives in his own home. Lucy has always wanted Tim to have "a typical life full of the experiences and opportunities that were naturally offered to his brothers who do not have disability". Tim's support workers help him to live independently and run his own business. Tim receives about 20 hours a week of support.

Barbara

Barbara is the mother of three daughters and lives in a country town. One of her adult daughters, Alice, lives with intellectual and physical disability and communicates through an electronic device. Alice has an NDIS package, which Barbara manages. Alice receives support six days and nights per week to live in her own home and pursue her love of horses. Barbara employs a team of six support workers. Alice refers to them as her 'assistants'. Some of Alice's assistants have been working with Alice since she was at school.

Elisa

Elisa and her husband also live in a country town. They have helped their adult daughter Amy, who lives with them, to set up and run a microbusiness. Elisa uses funding provided by the NDIS to employ four workers who are matched to specific roles, for example, baking, selling and recreation. Amy receives around 28 hours of support a week.

Iona

Iona has three children who live with disability. She manages a state-based funding package for her adult son Max. Max has recently been assessed for NDIS funding. Max has support to increase his independence and develop roles in the community, such as a gym member. Iona directs one support worker whose main aim is to help Max find and keep employment. Previously, Max had an additional support worker who had a strong music background and helped Max with his TAFE studies in music. Iona said, "The focus of the support that Max receives is strongly related to his goals and the support worker's skills and experience are matched to meet Max's goals."

Anne

Anne manages a state-based funding package for her adult daughter Claire who lives independently. With the help of Claire's circle of support, Anne has set up a microbusiness based on Claire's love of people and interest in craft. Claire has a team of three support workers who mainly work with her in the microbusiness. In addition, another worker helps with housework. Claire has between 15 and 20 hours of support a week.

Rima

Rima manages an NDIS package for her teenage son Ari who lives with her. Rima and her husband have a clear vision of the good life they want for Ari. This vision includes being employed and being part of his community. They are working towards Ari having his own business now that he has left school.

Kristie

Kristie manages an NDIS package for her daughter Grace. Grace receives 32 hours of support from a team of four workers. They help Grace with her microbusiness, recreation and health, and integration into the community.

Viola

Viola manages an NDIS package for her teenage daughter Georgia. Georgia receives about 25 hours a week of support. Viola employs one worker, although she is looking to recruit another two or three support workers to help Georgia with community and social activities.

Judy

Judy manages an NDIS funding package for her adult daughter Rachel. Rachel has her own home and receives around 100 hours of support a week. Workers help Rachel with personal care and to attend events, run her home, shop, clean, build her social support and maintain her health. Rachel's workers have specific roles, for example, personal trainer, fashion assistant, well-being and health coach, and communications coach.

Petra

Petra manages an NDIS package for her adult son Simon. Simon has around 40 hours a week of support from a team of five workers. They work with Simon to help him fulfil different aspects of his life and goals.

Lorraine

Lorraine manages NDIS funding for her two adult daughters Charlotte and Sarah who live together independently of their mother. Charlotte and Sarah have a team of six support workers. Each daughter has six hours of individual support a day. The rest of the time there is a worker for both daughters, as they need 24-hour support. On weekends, family and friends also provide support. The workers provide daily living and personal care support and help Charlotte and Sarah to engage in activities they enjoy. They also help Charlotte with her job putting up posters for gigs in a local coffee shop.

Elaine

Elaine lives in a remote area and manages the NDIS packages for her two daughters Jo and Ava, who are young adults. Elaine employs nine support workers. Both daughters have similar supports: phone prompting for morning routines, transport into town, fitness and activities at home. Jo and Ava have four hours of support each weekday (some one-on-one and some together) and some longer periods of weekends away so Jo and Ava can pursue activities that relate to their individual interests.

Of interest, some of the participants who have chosen self-managed arrangements do this with the involvement of other family members or use a formal arrangement such as a circle of support or a microboard. For example, Kim has help from Liam's circle of support and Sharon has Josh's microboard; Lisa and her husband together manage Becky's supports; Rima and her husband have different skills that complement each other in managing their son Ari's NDIS plan; Colin and his wife have a company where they are the two partners; and Katie has help from her friend Brian.

Why self-manage?

Several (somewhat overlapping) reasons were given by respondents for why they chose to self-manage.

Choice and control

One of the main reasons people give for choosing self-management under the NDIS is the ability to choose their workers and to use non-NDIS-registered providers. For example, Karen said, "I chose to self-manage from the get-go because I wanted to work with people that were not NDIS registered, and not having to worry about that has been an amazing benefit." Anne said that self-managing allows them to "employ the right type of people who are a good match for Claire rather than a 'typical disability-trained worker'".

Barbara has been managing funding for Alice in the previous state-based system and now under the NDIS. Barbara originally started with one day a week and then she was encouraged to self-manage all of Alice's funding, as traditional services did not suit. Colin did not want a group situation for Michael and chose self-management because it is "led by what Michael wants and how he responds". Colin felt that limited funds could be used better under self-management. He described it as "having as much control as possible without doing everything".

Closely related to the concept of choice is control. Both Katie and Lisa self-manage because it gives them more control. Lisa explained: "I was tired of being told who would come into my house, who we could have as a therapist, what hours they would be allowed to do."

Past experiences and perceptions

Another common reason is past difficulties with using an agency to provide support workers (a reason given by Elaine, Judy, Tess, Viola, Amanda and Diane). For example, Elaine chose to self-manage because of cash flow issues, the inflexibility of using an agency and being told when and how the hours could be used and having no say in the workers allocated to Jo and Ava. Tess had been self-managing for ten years and had several bad experiences with agencies. Tess was feeling "suffocated by services" and "institutionalised in my own home" and "in relationships not of my choosing".

For others, the view they had about service agencies was not one that matched their vision for their family member and they were determined not to use large agency services (Lorraine, Rima, Kim, Iona and Elisa). For example, Kim was not interested in using any service that "would take Liam out of their lives and out of the community". Kim felt self-managing would be more beneficial for Liam and the family if she were "able to tailor any paid supports to fit Liam's vision and help him realise his goals".

The low expectations expressed by service providers was the catalyst for Iona to try managing Max's funding. Iona was told by two organisations that ran day programs that Max was 'unemployable'. Iona attended several events held by one of the organisations involved in this project that made her realise that nothing was going to change if she did not take control and focus on new goals for Max. Elisa expressed a similar view. If she wanted Amy to be independent and have her own microbusiness, she needed to take control. Self-directing meant that they could "match goals with support worker skills".

Flexibility and creativity

Flexibility of supports and being able to be creative, such as setting up a microbusiness, is another related reason (Petra and Lucy). Lucy said, "Self-management offered the flexibility and individualisation to set up Tim's business." Similarly, Petra chose self-management because of the flexibility it offered as "supports could be arranged creatively with personal goals as the outcomes".

Value for money

Better value for money and being able to do more with limited funding was another motivator (Diane, Amanda, Helen, Roger, Sharon, Jenny and Edward). For example, Helen had experienced self-management when she lived in the UK but finds the process for claiming and acquitting funds much easier in Australia. She uses her funding to negotiate good rates with the contractors that support her, and this increases the hours of support. She felt she had "choice and control over the whole budget and therefore ownership of the plan". Roger chose to self-manage because it was the best way to maximise the funds for Eloise, especially after the NDIS plan was reviewed and the available funding halved. Similarly, Sharon said "choice, flexibility and being able to get more 'bang for your buck' by not having to pay for an organisation's rent and utilities, all of which are usually factored into a support worker's wages" motivated her.

Edward had a range of reasons for self-managing that focused on value for money and on the direct relationship he has with his support workers. Edward explained that he does not have to go through a coordinator to arrange supports and he can negotiate directly with his workers about rostering and any changes in hours or relief work when another worker calls in sick. As Edward said, "Support workers are committed to me as an individual and accountable to me."

How to self-manage

Where to go for advice

Workshops and peer networks

Some participants sought or received advice when they were considering self-management, or when they first started. For some (Karen, Rima and Iona), attending a workshop run by an IWF project partner was the first step in deciding to self-manage or in gaining the skills and confidence to 'have a go'. For example, Karen said that the workshop she attended gave her "a wealth of knowledge" on how to self-manage. Karen also sought help from an accounting firm that took part in the workshop. Similarly, Rima pointed out the importance of workshops and courses run by IWF project partners as she saw "how other families were successfully self-managing and had developed a clear vision for their son or daughter".

Viola attended a peer support network, which "assisted with understanding how I could work with the funding and make it work well and plan well for my daughter". Viola mentioned that guest speakers at the network meetings and her own support coordinator provided some advice, particularly around tax, super and the requirements of self-managed funding.

Katie also received advice from a peer support network she regularly attends. She noted that unlike her network, which encouraged her desire to self-manage, the state disability body was unenthusiastic and tried to talk her out of self-management. Katie said, "They asked if I was sure I wanted to do this and questioned whether I could manage the financial acquittals required."

Roger used his network, including peer support from other parents managing their children's NDIS packages, and attended events run by NDIA and disability organisations. Tess used her network to get advice in the first year or two of self-managing and a host service for help and extra advice.

Other sources of advice

Others such as Elaine and Lorraine received advice from existing agencies used by the family that had a strong self-management culture and good supports for this approach. Elaine approached the local area coordinator for support but was told that they could not provide advice "because of a conflict of interest". Elaine was concerned that there was no training provided by NDIA and suggested that a short course would be useful. Lorraine has been self-managing for 25 years and said there was not much information available when she first started.

Some people did their own research or already felt competent about taking self-management on. For example, after some research, Kristie talked to the host organisation to negotiate which parts of the process she would manage and which parts she wanted the organisation to pick up for her. Jenny asked the motor accident insurance body what her options were, and felt she had the skills to manage her funds from day one. Like Jenny, Diane did not seek formal advice from anyone. As she pointed out, "I have always managed my life and lived within a budget. I didn't need help."

Sharon felt that the NDIS website "is fairly clear on what needs to be done". She also sought advice from an accountant, the ATO and the Fair Work Ombudsman, and talked with members of her son's microboard. Lisa did some research and found an unregistered service that provided a database of support workers for the type of support Becky needed. Petra contacted several organisations for advice, including the Fair Work Ombudsman and the ATO.

Kim had worked for a disability service before, so she understood the recruitment process for support workers and she sought the advice of an accountant to ensure that they were doing everything legally and efficiently. Kim said, "While I did not really know what was involved initially, we decided that we would learn as we go, and the benefits have proven to be significant."

Not enough support

Some people had been self-managing for some time and did not get any formal support when they first started. For example, Amanda said, "I learnt from my own mistakes and from other friends who were also trialling self-management of state-based funding." She noted that although she was told she would get training and back-up support, this never happened.

Ways to structure self-management

Participants used a variety of ways to monitor their spending and employ and train staff.

Managing everything yourself

Around a third of the people or family members interviewed self-manage everything (Kim, Sharon, Viola, Helen, Judy, Elaine, Tess, Karen and Rima). Rima said that her husband is "very organised" and he does the financial components of Ari's NDIS package while she does "the creative bits" such as planning Ari's community activities and what will be spent on this. Rima explained, "As a safeguard, my husband is teaching me how to do the finances and my goal is to teach other families how to self-manage." Tess now completely self-manages after using a host agency for two years. She described this as "a gradual shift to sole responsibility". However, Tess reported that if she is busy or unwell she will outsource recruitment to a third party.

Colin and his wife operate a company run as a partnership, as does Barbara and her husband. Barbara noted that they have run a business previously so setting up a business was familiar to them. Barbara felt that "setting up the company will future proof the arrangements". Barbara explained that she and her husband are the current company directors and, in the future, the company can be taken over by an accounting firm with the involvement of Alice's siblings and cousins.

Diane and Amanda self-manage as much as possible under their state-based funding package rules — they are required to use specific agencies to recruit support workers rather than recruit directly. Diane noted that some of her workers are people she found herself, who then joined the required agency at her suggestion so she could hire them.

Using some assistance, a host organisation, or both

Lisa and Roger use an online database of support workers who are pre-screened. Jenny uses a mix of agency-supplied staff and web-based platforms. Katie also uses a mix of methods depending on the type of support she needs (e.g., lawn mowing) and her friend Brian helps with the monthly reconciliation.

Several participants discussed their use of host agencies (Lucy, Elisa, Iona, Anne, Lorraine, Petra and Edward). Lucy uses a third-party organisation that handles payroll, insurance, tax and super for the staff they directly employ. Elisa decided not to take on the role of employer as "this could be detrimental, draw us into other roles, and detract from Amy's life". Elisa has a good relationship with the host agency she uses, and chose it because it "supports innovation". Elisa explained that there is no formal agreement in place with the host agency — it is based on verbal agreement and trust. The host agency charges a fee for this service based on each individual's arrangements e.g., number of workers.

Iona and Anne use a financial intermediary. In Iona's case, the intermediary pays invoices to the online employment platform used to recruit workers. Anne has an agreement with a host agency that charges 10% of Claire's package to perform the host role. This includes all employer obligations, invoices and reporting to the family on the balance of funds. Anne has just started a trial of an online employment platform and found the process "easier and quicker". Both Anne's and Iona's families are part of a family-governed service hosted by the same agency that was set up ten years ago and is currently block funded to employ a co-ordinator, who is a shared resource to eight families. The coordinator helped to screen and shortlist workers. Anne reports that this will no longer be block funded under the NDIS.

Petra uses a third-party organisation that employs the people she has hired to work with Simon. The organisation covers payroll, insurance and taxes. Lorraine uses a host agency for several components of the employment process. Lorraine reported that the host agency "holds the money and assists with financial stuff as this is not my strength. I can then focus on the right mix of people. This is more important to me".

Kristie used a host agency for some parts of the process in the first year because "I didn't want to do the payroll and all of that stuff, interviewing, sacking". She said, "A year in, I was a lot more confident and knew what I wanted to happen for Grace."

Edward has tried three different models of self-management. For four years he used a host agency but when the fees increased he began to self-employ his workers with the support of a volunteer accountant, who helped him to set up the required processes. Edward felt this was "too much for me to manage and have a life". For the past 12 months, Edward has had an agreement with an agency that employs the support workers he chooses. The host agency provides staff recruitment, coordination and back-up for rosters or staff absences, holds and manages funds, completes employment checks and contracts, and provides other human resources services. Edward designs his roster, directs his staff and is involved in selection interviews. Edward described this arrangement as "all the benefits of self-management without the work".

Recruitment

The tasks of advertising and pre-employment screening were two areas that were 'out-sourced' by several of the interviewees.

Roger, Jenny, Lisa, Rima, Anne and Iona use an online employment platform — either solely or in conjunction with other recruitment methods. This allows them to specify the type of support needed in a profile that applicants can read, and they can view the profiles of potential support workers to create a shortlist for interview. Applicants are pre-screened by the service for references, certification and police checks. Roger explained that the profile he uses is a bio about Eloise and her interests. He found the feedback loops that the site has useful for shortlisting potential workers. Anne said one of the benefits of using this platform is "if you don't like a worker you don't have to use them again".

While Iona mainly uses an online employment platform, sometimes she has found someone suitable through networking at events held by an IWF project partner. Iona has received advice and guidance on recruitment and designing ads from networking. As well as the online employment platform, Jenny recruits workers through two agencies that provide the job description and screening checks. Rima uses an online employment platform. She also advertises at TAFE and on the community noticeboards at shopping centres and the library. Rima said she gets lots of responses from these sources. Rima previously advertised at the university but does not do this anymore as she needs stability in hours of work and university students have too many timetable changes each semester. Rima routinely checks references and asks to see proof of first aid qualifications.

Anne has just started using an online employment platform. Previously, they advertised and selected their own workers. Anne said that they made many mistakes in advertising the position when they first started. They now try not to be too wordy or have too much "disability language" and instead focus on match and interests.

Advertising on Gumtree and Infoxchange, and at the TAFE, have been more successful than ads in community venues. Anne finds local papers are too expensive. Anne finds the employment process easier and quicker now. As the workers are pre-screened and she can look at their profiles online, this means that the worker could start the next day. Anne said that the site she uses "will also employ your own workers. They can make the worker's profile confidential and not available to others".

Diane and Amanda self-manage state-based funding packages. The rules require them to use support workers employed by specific agencies only. This means that their workers are pre-screened, although Amanda said that you must trust that the agency is doing these diligently, and she was not sure that this was always the case in the past.

Edward uses a position description that was modified for his needs when he was using a host agency for recruitment and other services. When he was responsible for all the tasks involved in self-managing, he advertised in the local paper, did his own reference checking, and ensured that all his workers had a current police check. Now, a host agency does the recruiting and checks but he still can choose or refuse any of the workers.

Other participants (Petra, Judy, Helen, Lorraine and Tess) did the recruitment process by themselves, with an occasional 'buy-in' of specific services. Sharon makes sure that the ads she places looking for staff for Josh are "colourful and attractive, written to reflect Josh's life and personality, in order to attract people with the right values". As well as the usual websites, Sharon said, "I put up ads at places where people with similar interests to Josh might congregate such as music and sporting venues".

Judy advertises on the employment website SEEK and by word of mouth. Helen advertised on Gumtree, at the local shopping centre and by word of mouth. Her personal assistant was a woman Helen had an informal relationship with, who she was able to engage when she set up her business. Helen does reference and police checks herself. Petra now has a key worker to do reference and police checks.

Lorraine has two job descriptions she uses: one for the key worker and one that details the specific role they are looking for at the time (i.e., a gap in the team to fill such as someone to do sleepovers). She advertises on Gumtree and sometimes uses an employment service that does a first cull. This may include some notes on the shortlisted applicants. Of interest, a previous worker runs the employment service. Lorraine does the reference checks and regards these as important. Lorraine said, "This is a 'real' job. I need to safeguard Charlotte and Sarah."

Tess designs the job description around "what is happening in my life right now". The focus is on her life and goals, what the worker is good at, and where they will fit. Tess said, "The description reflects my personality and sells the work environment and my team". Tess said she uses SEEK, although it is expensive as "free sites get a particular demography and I am

looking for a level of professionalism and what they will introduce into my home". Tess uses a recruitment agency to do the post-interview reference checks "as I want to protect my identity".

Viola uses Gumtree and advertises on the Facebook page of her daughter's school and other Facebook groups. Kristie mainly uses social media, particularly Facebook, where she belongs to a large online support group, and another Facebook page, which is for families looking for support workers. Kristie adapted the job descriptions from templates she found online. She does the reference and police checks and ensures that workers have a current drivers licence and comprehensive car insurance.

Kim explained, "At the core of the recruitment process is identifying the role of the support worker in Liam's life." She gave this example, "For Liam to achieve his goal of being a valued soccer team member and a competent bike rider to join his school's mountain bike-riding club, we needed someone who had an interest and good skills in these sports … [who] also … had that cool factor to motivate Liam." Kim advertised at the university as she felt someone studying sport at university would be a good fit. She said, "Rather than focus on Liam's disability, [the ad] focused on his interests and invited students who might want to coach Liam in these sports." The ad was on "bright yellow paper so it would stand out". Kim asked for a working with vulnerable people check and personal referees, which she called before employing the worker.

Using personal networks

Elaine lives in a remote area and points out that she "knows everyone". She asks around and approaches people she might be interested in employing and sometimes uses local resources that relate to Jo's and Ava's specific interests. She often employs students from the local school her daughters attend. She said she does not need to do formal references or police checks as she can speak to teachers or their parents. Elaine said, "A police check won't tell if they are doing drugs".

Location is an important factor in the recruitment method chosen. Recruiting via their own network is also the main process used by people who live in regional areas such as Katie, Karen, Barbara and Lucy, or where support is needed for a child or young person. For example, Karen prefers to hire people to work with her young son Jack who have been recommended by teachers or friends.

Katie said that she does not need to advertise or check references as she knows people and can use informal networks like the church. Katie employs people for housework and home maintenance who have their own ABNs and relevant licences. She said, "You soon know if someone is not very good in a small town." Similarly, Lucy found all her son's support staff through her own social networks. Lucy approached people she thought had aptitude for the role and had good rapport with Tim. However, in contrast to some of the other people who use personal networks, Lucy said, "Even though these people are known to us, they still undergo police and working with children checks." Colin said he rarely needs to advertise as he has a clear idea of the sort of people he is looking for to work with Michael (i.e., his peers)

and feels he can find the people he needs via his networks in the local community. However, Colin like Lucy, does police and references checks, noting that the latter are often provided by other workers.

Barbara recruits for specific roles. The workers are usually people they know through their networks or through the horse industry. They advertise on Alice's Facebook page and other Facebook pages and the ads are often shared through the equestrian community. Barbara noted "word of mouth is another successful method of recruiting. Some workers have been recommended by connections or current workers". In contrast, Elisa has not been so successful in recruiting via her networks and has found it difficult to recruit in a country town. Elisa is planning to trial a recruitment agency to screen applications and "send us the best candidates".

Interview process and what to look for in a support worker

Roger prefers to select workers with a specific skill set such as those studying a disability-related course like occupational therapy. Eloise is involved in the interview. She talks to the worker about what she is interested in and what activities she wants to do in the afternoon after school. Roger said he looks for a worker who is "dynamic with Eloise and communicates well with her".

Lisa wanted a female worker for Becky, because it was a live-in role. Like several other people, Lisa sought someone close in age to Becky. Lisa said, "There obviously needs to be a level of maturity, as it is a job that requires a lot of responsibility. I also need to have a comfortable rapport with them, as this person is going to be spending a lot of time in my house. I tend to eliminate the applicants who have no questions for me — if you don't have questions about the position that you are coming into and the person you are supporting, then you can't really be interested in the job." Lisa conducts two interviews: "It is at the second interview that applicants are introduces to Becky and told more about the role."

Elisa said, "Amy has her own criteria for the workers: young, preferably female, enthusiastic, honest and trustworthy." Elisa looks for other attributes, such as use of initiative, good with people and good social justice values. Elisa emphasised the importance of values as she felt "you cannot change a person's values such as respect and social inclusion but can teach the workers the skills involved in assisting Amy to operate her business". Like Lisa, the interview process is twofold. Elisa meets potential workers first and questions them about their values. Elisa has a key question that she always uses: "What do you think a good life looks like?" Suitable applicants go onto the next stage: a hot chocolate with Amy. This gives Elisa an opportunity to observe the applicant to see how they relate to Amy. Similarly, for Petra, "attitude is more important than training". She looks for people who support her vision for Simon to live a typical and meaningful life in the community.

Barbara and one of Alice's coordinators conducts the interviews for Alice's assistants. Alice is also involved in the decision. Barbara said, "To match Alice's interests, most of her assistants are required to have good 'horse' skills, be well-presented, a good fit for Alice, confident, can

deal with the unexpected, have good values around human rights and living in the community and most importantly Alice likes them!"

Although Edward uses a host agency to do the recruitment process, he sits in as part of the interview panel. When choosing staff, Edward said, "It's a feel. I have been around a long time."

Several people (Lucy, Colin and Katie) who use their network for recruitment do not conduct formal interviews. Instead, they approach the individual they identify as a potential worker and talk one-on-one. Similarly, Helen's personal assistant was someone who was already known to her. Helen said, "I have a number of essential and desirable criteria such as flexibility, respect, respecting privacy, other skills and professionalism."

Kim asks people who see her ad at the university to email her first. As Kim explained, "I then send them an eight-page information pack with details about Liam and his disability, our vision for his life, while still keeping his identity confidential. The pack also includes an application form with selection criteria to address." Kim has chosen to have an informal interview as the next step so that Liam can be involved. At one of these informal interviews (when Liam's sport coach was selected), they went to a local oval and kicked a soccer ball around. Kim could then watch for "how they interacted, spoke and engaged with Liam". Afterwards, Kim conducted an interview at a café and shared more about Liam and their goals for him.

Kristie likes to have a variety of support workers in Grace's team and looks for people who can work well in the team. Kristie described the interview process as "quite informal. It is really down to gauging whether they are a good fit for Grace or not". Viola uses a checklist and sometimes a trial. Viola said, "I would appoint the ideal candidate based on how well they match the job description, if they interact well with Georgia and can form a good relationship and have a successful trial."

Sharon and Josh's microboard runs a large recruitment drive every so often, where it hires a community venue and sets up group interviews. According to Sharon, "The day is carefully scripted, with activities that are specifically designed to test the suitability of candidates." Individual interviews are conducted including questions about hypothetical situations, to check for appropriate responses. Josh is always involved in the events and has a job, such as distributing handouts. Sharon explained, "We typically look for a younger male [although] we have also had older people who do well in the role. It is about the right person, their relationship with Josh and their ability to enable Josh to be part of the community." Other things Sharon listed were "an ability to think on your feet and be a creative problem-solver, be tech-savvy to be able to use Josh's communication device and to be reliable". As Sharon emphasised, "[Workers] need the right attitude as we can teach everything else." (This view came up quite a lot.).

As Diane uses an agency for her support workers, she runs a 'meet and greet'. Diane said, "I have no specific preferences. I give everyone a go and see by their work if they are suitable. If it feels right, I decide on the spot." Diane looks for people who are assertive and self-confident. Similarly, Amanda holds a mini-interview with potential workers sent to her by her

agency to select the most suitable candidate. This agency knows that Amanda has some specific requirements that she needs for safety reasons and is able to shortlist applicants based on these criteria.

Elaine prefers to match the worker based on gender, age and the interests of her two daughters. Elaine does not use a formal interview process. Instead, as she explained, "I invite the prospective worker to spend time in an activity with one or both of my daughters and observe how it goes."

Lorraine and her daughters' key worker conduct the interviews. They always use a public place, usually a library, for the first interviews. Lorraine explained this choice: "A coffee shop is too casual." The ads they use do not have much detail about the job. Lorraine said, "I am looking for someone with a bit of life experience who is creative and practical. I have no preference for age or gender." The interview focuses on these qualities and experiences rather than the role. Lorraine emphasised that "no personal information is given about Charlotte and Sarah at the meeting, only general

information. I don't answer personal questions about disability". Lorraine prefers her daughters to introduce themselves — this happens at a 'meet and greet' where Charlotte and Sarah have a cup of tea or coffee with potential workers.

Rima likes to match the interests of Ari and his potential support workers. Rima conducts the interview in her home and asks specific questions about how potential workers would connect Ari into the community and help with his interests. Scenarios requiring problem solving are also used. Rima described some of the other activities she does to establish if they are a good match for Ari. "I get them to do a puzzle together and see how they go. I check if they communicate with Ari and not using their mobile phone instead. Sometimes I get them to undertake an activity in the community and see what they do during the 45 minutes in the car. Do they communicate with Ari?"

Anne uses an informal interview process to engage workers for Claire. Anne and the coordinator of the organisation she is part of meet applicants in a coffee shop, as Anne feels meeting at her home is "too risky". Anne said, "Having a conversation rather than writing answers down enables the ability to read body language and help the applicant to relax. We look for match, maturity, flexibility and someone who can multitask! Gut feeling is as important as responses to the questions." Potential workers then attend another meeting. Here Claire takes the lead. She asks about the applicant's interests. Claire prefers people around her own age "with a positive personality and a good sense of humour". Anne said, "At the end of the interview, Claire responds with 'I really like them', 'I'm not sure' or 'I'd like to think about it'. If she likes them they're employed, however, the other two responses are an indication that it is not the right person."

Iona also meets potential workers, whom she has sourced from an online employment platform, in a coffee shop. Iona has a list of qualities she looks for. Again, more focus is given to values, flexibility and matching interests. Other qualities Iona looks for include if the person can "think on their feet, a bridge to community, mindfulness of workers that 'this is our home', well developed in their own life and a good role model". If Iona thinks they are a

good match, Max meets them. Iona explained, "Max is very intuitive, and a high priority is placed on how the potential worker interacts with him, that they talk to Max and not me and equality is present. Max decides who gets the job based on feel for the person." Iona added, "The goal is eventually for Max to learn more about the technical aspects of hiring staff so he can have more control and independence."

Tess looks for "young independent women who reflect my personality" to be in her support team. She said, "I never ask for experience as I can mould people. However, their values must match". Tess pointed out some of the pros and cons of different locations for the interview. "Public spaces such as the library have free rooms. However, my preference is to interview at home as I get a sense of how they interact." Tess chooses to interview on a weekend or early in the day "as a test to see who shows up". If she cannot decide between two people, she gives them a paid trial.

Jenny's workers are a mix of people sent by the agencies she uses or selected from an online employment platform. Potential workers meet Jenny face-to-face first in her home so that she can observe them and check that their personalities match and that they can follow instructions. Jenny said, "Communication is the key." Sometimes Jenny gives potential workers a trial to check their suitability. Jenny explained, "The web-based agency gives you a free trial and you can give them feedback about the workers sent to you."

Sometimes, of course, it does not work out so well. An example of the importance of matching is illustrated by Naomi who spoke about the time when they recruited a young man to work with Tim to build his independence. As with the other workers employed by Tim, they recruited a person close in age (a peer). This was not so successful for this role because the young man did not know how to cook or use a washing machine. They realised that although the team comprised young, vibrant people, they needed someone more mature for this particular role.

Pay and conditions: contract of employment

Pay and conditions are closely linked to the recruitment process. People who use an online employment platform (Iona, Jenny. Roger) or those required to use specific agencies (Amanda and Diane) often said they had no discretion about the amount paid as it was a set rate. (A commission may also be payable to the online provider by each party.) In addition, workers who are mainly employed for tasks such as home maintenance and cleaning are likely to have their own business (with an ABN) or charge an hourly rate. This type of employment applied in the case of Helen and Katie. Helen develops a basic written contact and job description for her support workers. Her personal assistant has an ABN and invoices her.

Several participants use a host agency to employ their support workers (Anne, Judy and Edward). Anne noted that the host agency pays according to the relevant award, which takes, into account qualifications and experience. Anne said, "We like to pay a bit over this, so we can keep good workers." Under Edward's current arrangement, the host organisation contracts with the workers. Edward said that he has always paid award wages under the three types of self-managed arrangements he has tried. Based on his previous experiences, he warned people who are self-managing all aspects of the arrangements about engaging workers through an ABN. "I feel the risks are too great in regard to insurance. I have had some advice that workers in this situation are not 'self-employed' as the person is directing them."

Directly employed

Other participants employ their own workers and therefore can be more flexible about rates of pay and conditions. For example, Tess pays the award rate. All her workers are casuals except one who is permanent part-time and who receives holiday and sick leave. Barbara pays all of Alice's assistants a flat rate of pay. Alice's coordinator is paid a higher rate. Elisa said that "the key currency with support workers is relationship — it's not just monetary". Nonetheless, she pays workers above the award "so they will stay". Elisa also said, "We like to give workers consistent hours to ensure a sustainable income."

Rima has a formal contract with Ari's support workers and she pays based on the award and the NDIS price guide. When deciding what to pay support workers, Lisa considers a range of factors such as the rates on the NDIS website, industry pay scales and performance. Lisa said, "When I had a support worker who did an excellent job, I was happy to increase her pay." As Elaine lives in a remote area, she bases payment on the NDIS price guide rate for remote areas. All her workers are casuals who are paid for the days they work only. Elaine explained, "Sometimes I pay above the rate if I have agreed with the worker on a set price." Elaine also found the checklist developed by one of the organisations useful as it provided a step-by-step guide to setting up the formal employment relationship.

Viola said, "Pay depends on their age and experience and is reviewed after trials are completed." Kim said, "We contacted [the] Fair Work [Ombudsman] when deciding what to pay. This was something we felt a bit overwhelmed with and working out what level to pay

your support workers from the website felt a little confusing. After discussing with [the] Fair Work [Ombudsman] and working out the minimum rate, we considered what the support was worth to us and paid our workers above the award wage." Petra also received advice from the Fair Work Ombudsman about pay and conditions. Colin said, "I pay above the average, based on the award, and depending on available resources, I am generous with flexibility … if they need an hour off during the day."

Kristie initially employs Grace's support workers for a three-month probation period as "that helps gauge whether things are working out". She then employs them part-time. Kristie pays "the maximum I can, and I am flexible with them. I want long-term

support workers and I believe good working conditions are required for that". Sharon determines wages by considering the award rate, the person's skills and the responsibilities of the role. Sharon said, "I make sure there is room for increasing pay, and make sure a pay rise is given when specific goals are achieved."

Lorraine said that she likes to pay above the award for Charlotte and Sarah's workers as "in the past, we kept losing good workers to government jobs which paid more". Karen also prefers to pay a higher rate, which she said "has been a benefit of self-managing". Karen explained: "If a support worker has been with us a long time, and is absolutely phenomenal, it makes sense to pay her more than the standard rate. I tell them that I am doing this because I value them. I want to see them grow and attain their professional dreams."

Induction and training

The type or level of training given to or expected of paid support workers depended on whether a host organisation or online employment platform was used, the method of recruitment, or both. As Jenny uses both an online employment platform and an agency, she expects that workers are already trained. She provides an orientation that focuses on her routine and "little things that are personal to me" but does not provide any ongoing or additional training.

Sometimes no induction or training is required because of the nature of the work (e.g., Katie and home maintenance) or is more about orientation to the home, expectations and safety issues (Roger and Eloise's after school activities). This is more common when the person is employed for a specific task or the worker is already trained. For example, Helen said, "My personal assistant already had a good idea of what was required of her but did undertake training in orientation and mobility."

Others reported a more formal and extensive induction period that varied because of the type of support required, level of responsibility and complexity of the work. For example, Lisa sends out an introductory book she has put together. "This includes information about Becky, the family, how we all work together and what the general routine is from week to week." During the first few weeks, workers learn about the routine and about Becky, then Lisa trains them to provide therapy assistance, so after eight weeks they are fully inducted into supporting Becky, while continuing to learn on the job.

Similarly, Elisa provides training over six weeks. This includes "a handover from the previous workers, watching others, my feedback, feedback from other workers and also formal training related to the tasks for Amy's microbusiness". Elisa explained, "We feel we need to invest in people and give feedback as this is more than a job — support workers are more like a life coach—it's not a 'mickey mouse' job."

Anne has an informal induction process where the new worker spends time with Anne or the team coordinator and sometimes does a shadow shift. Anne follows this up with feedback over a coffee. Anne explained, "The host agency provides a two-day induction training, but it is not relevant as it is mainly aimed at staff working in group homes. However, we invest well in training as it increases the knowledge of support workers — particularly in the area of values. Conferences and workshops are paid for through Claire's package." Iona reported a similar arrangement: "Training is around values and mindset, e.g., not a 'caring' role. Workers are encouraged to attend relevant workshops … paid through Max's funds."

Kim provides induction and training that she described as "fairly informal, but ongoing". "I feel that overloading people with information in the beginning isn't necessarily helpful, as they don't take it all in, so we take a more informal approach where they learn as they go," she said. Like Anne, Kim invests in values-based training for her workers: "We felt that the speakers were really going to help motivate them towards achieving our expectations for the role as Liam's mentors in seeking out those valued roles for him." Judy echoed this, "I provide in-house training and staff are encouraged and paid to attend other training, particularly values-based training and medical-based training around specific needs and conditions."

Buddy or shadow shifts

The use of 'buddy' or 'shadow' shifts was common (Anne, Edward, Viola, Sharon, Barbara, Colin, Kristie and Tess). For example, Sharon has formalised the induction and training she needs for Josh's workers. This involves both online training on a system set up by Sharon, then up to eight buddy shifts with Sharon or an experienced worker. Sharon explained, "The training system is always a work in progress, where workers are invited to fill in their own reflections, ask questions and provide feedback. During buddy shifts, one person will video the other, which gives everyone a great opportunity to learn what works and what doesn't and to brainstorm strategies on how things could be done better."

Barbara provides training via shadow shifts, detailed notes and time with Alice's communication therapist. Barbara explained, "Alice's funding does not allow enough for training. When we can, we invest in values-based training." Colin also gets new workers to 'buddy' with one of the experienced workers on Michael's team and gets feedback: "We focus on getting resourceful and trustworthy workers who can be trained on an ongoing basis by Michael."

Edward has previously paid for manual handling training out of his package. This is now provided by the host agency. Like Colin, Edward requires workers to do three shadow shifts and gets feedback from his existing workers.

Petra and Lucy provide on-the-job training specific to their sons' situations. Petra explained, "I see no need for people to come ready with generalist training when it may not be relevant to Simon." Diane had a similar view: "I provide my own on-the-job training about me and my house and about my views on disability theory and rights." Amanda said that the agency she uses provides some training for her workers specific to her needs (e.g., her equipment) and new workers have three training shifts. When she gets new equipment, her workers also receive further training.

Elaine provides on-the-job training where the worker starts with simple tasks, which they can practice. She talks to the worker before and after they perform the task. Tasks are gradually increased in complexity. It is only once they can do the tasks on

their own in the home that Elaine has the workers do activities away from home. Ongoing training has an action-learning focus.

Lorraine runs on-the-job training, lasting 6–8 weeks, which includes tasks such as safe transfers. Lorraine has a checklist of tasks that need to be mastered during the training period. As she explained, "I never expect people to jump in at the deep end." Like Tess, Lorraine also offers help with ongoing training such as positive behaviours. Lorraine pays for the training course and workers receive the day's pay as well.

Kristie requires new workers to complete at least two weeks of buddy shifts. Kristie said, "We also provide a package, which provides … all relevant information so … [workers] have a 'whole picture' and know what resources there are, like contacts." Kristie encourages further training with a host agency if the worker has not done support work previously.

Karen ensures that Jack's therapy support assistants receive ongoing training from Jack's speech and occupational therapists: "The therapists work out a program for six

months and then train the support workers on how to use the program. This has proven [valuable] … you pay a therapy support assistant one third of what you pay a therapist … [and get] three times as much intervention."

Tess gets workers to undertake hoisting-specific training and will provide support to get a certificate of manual handling, if required. Tess said, "I organise buddy shifts but make clear that any questions are directed to me and not other workers." Tess provides ongoing training through support to attend conferences, with the cost negotiable.

Communication and feedback

Most of the participants emphasised open and timely communication with their employees and two-way feedback to ensure issues are dealt with promptly. Careful matching and making job expectations clear are important components that help to reduce staff turnover. For example, Rima felt that there are few problems "if you select people very well. Matching is important. Even when one of our support workers left to join the police force, he still wanted to be involved. They see it as a positive job and a positive role". Petra and Helen echoed this sentiment. Helen said, "Finding the right person took time but once the team was established there have been no major issues. Having some understanding about resolving issues means it has been easier to get over hurdles, particularly in regards to friendships and relationship overlaps." Karen said, "I am a firm believer in open communication and I am committed to handle any issues that arise as professionally as possible. By approaching it as a business while trying to take care of and nurture these people as well, I really haven't had significant issues so far."

Similarly, Lisa likes to address issues immediately: "I am conscious of having to think like an employer… and deal with things professionally while being polite and empathetic. The rapport that is already established between myself and the support worker will help us in dealing with any issues that arise." Kim also emphasised the importance of "continuous open communication … a positive relationship and being mindful that there are always two sides to consider." Kim said, "We always check in on how they are going, as we know they may sometimes feel intimidated. There have been a few instances where things haven't gone well, but there was no harm done, and we've always considered those learning opportunities." Elaine also deals with areas of concern by talking with the worker. She encourages workers to make suggestions for improvements. Some of Jo and Ava's support workers have been with them for several years. As Elaine said, "They either last one or two sessions or stay." Diane reported a similar approach: "I am training myself to seize the moment and speak up for myself now. Workers either last six weeks or are keepers."

Regular team meetings and key worker/coordinator

Several participants highlighted the role of regular team meetings (Lorraine, Judy, Iona, Sharon, Kristie and Elisa) — a more formal feedback mechanism — and/or the involvement of a key worker or coordinator. This person could be a paid coordinator external to the family (Iona, Anne and Sharon) or an experienced support worker who has been with the person or their family long term (Lorraine, Barbara, Petra and Diane). Lorraine referred to her key worker as 'a buffer'. For Lorraine, the key worker (a senior member of the team) takes on some of the day-to-day tasks of managing the team. She said, "I delegate tasks to her such as appraisals and team meetings … set up [of] interviews … training and [as] first point of contact for issues. This is her job whereas I am 'Mum'." Lorraine felt this arrangement "provides clarity about where workers go for advice on specific issues".

Iona also mentioned the role of coordinator (in her case external to the team) who has regular contact with Max and helps him address issues with workers. The coordinator attends the regular monthly meetings with Iona, Max and his team. Anne also uses an external coordinator. She said, "I might ring or text for simple issues and support workers can talk to the team coordinator … for more serious issues. The coordinator might then speak to me to work out a strategy. The host agency can provide advice, but this would need to be paid for." For Judy, regular meetings are an important factor for the low staff turnover in the team.

Sharon holds weekly team meetings facilitated by an external coordinator. She said, "Josh's thoughts and feelings about his support workers are a chief consideration. His communication book includes a page on people, as part of his ability to communicate his thoughts about the people in his life." Similarly, Barbara preferred that the assistants talk to Alice's team coordinator first if they have an issue: "We like to solve problems through conversations which include Alice. Updates, general info, shifts and roster changes are communicated through a private Facebook page."

Kristie said that she likes to be open and "make that a culture of the team". Kristie holds monthly meetings where "there is an expectation for everyone to bring feedback, ideas or any issues to the meeting". Like Barbara, Kristie has a Facebook group page where they have regular posts after shifts: "This is helpful particularly when working on certain goals, and this helps the support workers work as part of a team."

Elisa has regular team meetings and said, "We address each of Amy's goals and examine what workers need if the goal is not addressed. There is a continual reflection on Amy's views and perspective. If the worker has issues, they are encouraged to take it up with the person concerned. If workers are concerned they can debrief with me."

Social media and other communication methods

As well as using social media such as Facebook, some participants have come up with other innovative methods of communication and feedback. Tess and her team of support workers use an app to manage rosters and other human resources issues, which Tess said, "provides a barrier or invisible wall between support and HR". Issues that arise can be directed through this app or to an informal support such as Tess's mother. Tess said, "If a worker has an issue, they can address it at the beginning or the end of the shift. The rest is *my* support time. The team does get together regularly, four times a year. We do not call this a 'team meeting' as this makes me feel as if they have 'ownership' of my life. It is now called 'a gathering'."

Colin said that Michael's support workers can text him at any time. He has back-up mechanisms in place, although these are rarely used. Colin keeps an eye on the way things are going at Michael's house: "I arrive at varying times of the day, so I see how each person is working out. Most people who are not a good fit with Michael or are not good at working under low supervision self-select out. I look for people who maximise Michael's satisfaction and protect his image rather than correct him." Edward said that if particular behaviours become a habit he has a conversation and "asks … 'How would you feel?' This is often an epiphany as there has been little consciousness in making decisions *for* me. For example, throwing away food or toiletries without asking". Edward takes up more serious grievances with the host agency.

External involvement

Dealing with feedback or issues that arise may be different when the support worker's contractual arrangement is with an agency, or they run their own business. For example, Amanda and Jenny deal with most issues one-on-one and directly to the agency for more serious issues. Jenny said, "I talk to the coordinator/team leader or email them for advice or a change of people. The process is two-way. Workers can also contact the agency directly."

Katie said that in a small community, relationships are based on trust and reputation. The people who work for her are people who run their own business and she does not need to use them if they are not reliable: "I am the boss. I don't kowtow to people who come on site."

Roger said that because Eloise's support workers are with her for after-school activities, he has little face-to-face contact with them. Instead, they communicate via a weekly email detailing how Eloise's week has been. Roger emphasised the importance of two-way feedback and considering Eloise's views about how things are going. In addition, the online employment platform Roger uses has a two-way feedback mechanism for either party to give positive or negative feedback. Similarly, Iona highlighted that the online employment platform has a process for grievances to be raised but does not provide mentoring or staff development.

Use of a host organisation and other 'buy-in' support

Fifteen people interviewed use a host agency or other purchased supports to help them in the various tasks involved in self-management as outlined above. Table 1 summarises the details of the diverse ways that people used these services.

Table 1 refers to the self-management processes in place at the time of the interview. For some participants, this represents the arrangements that have been in place from the beginning. Other participants may have had more (or less) involvement with a host agency in the past.

Table 1: Level of external support accessed by people who self-managed or family members

Participant	Type	Recruitment and checks	Interview	Employment and payroll	Rostering and choice of support workers	Other assistance
Edward[1]	Host agency	X	X (with Edward)	X		X
Roger	Online	X		X		
Lisa	Online	X				
Elisa	Host agency	X (Host agency is paid to do pre-employment checks)		X		
Barbara	Family company					
Colin	Family company					
Lucy	Host agency			X (payroll only)		
Kim (& Liam's circle of support)	Fully self-manage NDIS funds					
Kristie	Fully self-manage NDIS funds	X				
Viola	Fully self-manage NDIS funds					

Participant	Type	Recruitment and checks	Interview	Employment and payroll	Rostering and choice of support workers	Other assistance
Katie[2]	Use workers who have ABN					
Sharon (& Josh's microboard)	Fully self-manage NDIS funds					
Karen	Fully self-manage NDIS funds					
Tess	Fully self-manage funds	X (checks only: done by a recruitment agency)[3]	X (agency may pre-screen and be involved in interview if Tess is unwell)			
Lorraine[4]	Fully self-manage NDIS funds	X (some pre-screening by a recruitment agency)				
Helen[5]	Fully self-manage NDIS funds					
Judy	Fully self-manage NDIS funds					
Jenny	Mix of host agencies and online	X		X		X (dealing with issues)
Rima	Fully self-manage NDIS funds					
Anne (& Claire's circle of support)[6]	Host agency & online	X (some assistance from another agency)		X		X (holds funds & reports to State)

Participant	Type	Recruitment and checks	Interview	Employment and payroll	Rostering and choice of support workers	Other assistance
Iona[7]	Host agency & online	X (Online & some assistance from another agency)		X (Online)		X (Host agency holds funds, pays online agency for staff & reports to State plus another agency helps with dealing with issues)
Diane[8]	Host agency	X (some pre-screening & checks)		X		
Amanda[8]	Host agency	X (some pre-screening & checks)		X		
Elaine[9]	Partly self-manage funds (Host agency manages rest)			X (Host agency provides advice & has step-by-step guide)		
Petra	Host agency			X		

1. Edward has tried three different self-managed arrangements, including self-employing his supports. This details his current arrangements.

2. Katie mainly engages people who have their own business because of the type of support she requires: cleaning and home maintenance.

3. This is to protect Tess's privacy by safeguarding her identity.

4. Lorraine's daughters have a key worker who does some of the recruitment and direct management of other support staff.

5. Helen's workers have their own ABN or uses a Statement of Supply.

6. Anne's daughter Claire has a key worker/coordinator who does some of the recruitment and direct management of other support staff. Another coordinator from a family-governed agency (not the host agency) helps to recruit workers. This role is block funded and is unlikely to continue under the NDIS.

7. Iona mainly uses an online employment platform for recruitment. The employment platform is the legal employer and the host agency pays on invoice from the online employment platform. Iona also uses the services of the coordinator from the same family-governed agency as Anne.

8. Diane and Amanda have state-based disability funding that requires their support workers to be employed by a limited number of agencies.

9. Elaine self-manages some of Jo and Ava's funds and a host agency manages the rest.

What makes a good employer?

Self-management means that participants become an employer. Each participant was asked what they think makes them a 'good employer'.

Edward: "A good employer is respectful, meets obligations, not nit-picky, a bit flexible, mutual, sees the bigger picture and doesn't make it too hard on staff. Without reliable, competent staff I wouldn't be able to work, that's my income. It's everything."

Lisa: "With live-in support workers, the relationship with me and with Becky can alternate between family member and friend to employee. My honesty, sense of humour as well as my respect and care for the support workers makes me a good employer. It is important that they feel comfortable and secure. I just try to be fair and treat people the way that I would want to be treated."

Elisa: "You grow into being a better employer. It is important to match staff well, enable job satisfaction and ownership, be part of something better, have a key role that is worthwhile, offer training and follow-up, have open communication and be a good example yourself. It involves trust and growth. It's organic."

Barbara: "Alice has a close relationship with her assistants. She likes them, they feel like sisters and are the same age and demographic. I believe that a good employer is relaxed, accepting, treats workers as part of the family and has occasions to celebrate."

Colin: "A good employer is approachable, not judgemental, knows when to intervene, listens, and is generous, and then people are willing to go the extra mile. You need to trust yourself to trust people."

Kim: "Regular and honest communication … connecting with them, giving them positive feedback when they do well and using opportunities that come up to learn how we can do better, are all things we try to do. Liam is our best teacher, and we don't always listen to what he is trying to tell us, so it's about helping them be in tune with that as well."

Katie: "I give positive feedback and I am friendly but firm. Being firm is important so as not to be taken advantage of."

Anne: "To be a good employer you need to care about your workers, recognise they have their own life/needs/family, avoid phoning them on their personal time, work together as a team and offer opportunities to understand the vision."

Iona: "The key is to look after them … make sure that the role is rewarding and the relationship positive, being as interested in the support worker's life as you would like them to be in your son's/daughter's life. Also, flexibility goes both ways!"

Diane: "Be flexible, fair and provide good systems to help the support worker. They get good instruction and training by me."

Amanda: "You need a good work relationship, but you are not buddies. I always pay for their time. I don't expect them to do anything off the books."

Elaine: "I am open and approachable and give clear instructions. I let them work the hours they want to work and pay a good wage. I value their opinions and suggestions."

Karen: "Jack and I enjoy great relationships with everyone on our support team, communicating regularly and keeping the team apprised of the ups and downs in our lives. Ongoing relationships that are not merely limited to support hours makes support workers more invested in their success and invested in reaching the goals outlined in the NDIS plan."

Tess: "I provide a nice environment — more natural, not clinical. I do an annual review and provide feedback. I am thankful; I want workers to feel valued in what they do. I used to feel upset when workers left. Now I understand that maybe they have learnt everything they needed."

Lorraine: "In the long run, I look after Charlotte and Sarah's workers. I take the employer role seriously. Charlotte and Sarah are flexible around hours and can be very generous with their workers."

Jenny: "Support work is a physical job. The pay must be reasonable. It can't be too low."

Rima: "Our relationship is mutual. He [support worker] is looking after my son, so we look after him too. I want the support worker to be part of the family. He does the best for Ari and our family."

Benefits of self-managing

Choice and control

Most participants said that one of the main benefits of self-management was more choice and control over every aspect of the arrangement (Elaine, Amanda, Diane, Anne, Rima, Jenny, Helen, Tess, Karen, Sharon, Katie, Viola, Colin, Barbara, Lisa, Elisa, Roger, Edward and Lucy). For Elaine, this meant "flexibility in choosing who you want and how they do it". For Amanda, it was "knowing who I am expecting to show up". For Diane, it was "I can use money for other things, for example, I can pay for my shopping to be home delivered rather than pay for a worker to help me with shopping". Anne saw the benefit of self-managing as being able to "focus on the right match. We can oversee, adjust and revise roles and plan the way we want". Helen said, "Self-control and ownership of the plan and support I receive is key. This gives me a sense of empowerment and capability to be more independent." As Diane summed up: "I'm the boss."

Tess said, "Self-managing makes things happen more quickly. There is no waiting for approval." As Karen reiterated, "The ability to hire people who are not NDIS-registered, and that your child and you already have a relationship with, is one of the chief benefits. This allows people to hire a neighbour, someone's older brother or sister, or anyone in the community who has the necessary skills and that your child responds to. I think this is a more natural and organic way to find support workers."

As Sharon explained, "Prior to NDIS … there was no choice or flexibility as to the support worker arrangements, and since the funding was tied to the organisation, we did not have the option to move. Now, having the freedom and control to get really good supports has been so rewarding for Josh and made it so much easier for me."

Lisa said, "I can choose what therapy Becky does, based on what works for her, and I don't need to explain or justify it to anyone. I also get to choose who comes into our house to support Becky, what their level of skill is, and what their personality is like, rather than having to deal with a stranger from an organisation."

Edward said, "It's a win-win! Workers I have chosen work well with me. It's two way. They [workers] deal with someone directly, not a third person. They feel more ownership and I have more control on who is coming and when they are working. No more having an agency worker turn up for a shift and saying 'I don't do that'."

Personal values

Many participants highlighted how self-management aligned with their personal values, particularly about the opportunity for a better life for them or their family member (Iona, Anne, Rima, Kim, Colin, Barbara, Elisa and Lucy). For example, Colin said, "I can confidently build a good life for Michael and not just be seen as an over-protective parent who doesn't trust services. I can ensure that efforts are going to build a good life for Michael rather than satisfying bureaucracy and their agenda." Barbara said, "Alice now gets to what she wants with who she wants. Her assistants have a deeper personal relationship and responsibility and are determined that Alice is happy … it is just life changing." Elisa said, "We don't do 'special'. Not disability-specific attitude … when you don't self-direct, you can't sustain workers in the role … we have had employees for four years."

Value for money

Another main benefit was better value for money (Amanda, Jenny, Helen, Katie, Edward and Roger). Amanda said, "More hours and not being ripped off." Jenny said, "Less middle party and lower cost per hour." Helen said, "With a provider, you do not have as much control over things you are billed for. Self-managing gives you more flexibility with negotiating rates with support workers."

Personal growth

Karen has found some additional rewards of self-managing related to personal growth: "The skills I have learned in putting together the financial structure of self-managing my plan and my son's NDIS plan have enabled me to find other work opportunities." Helen also felt a sense of "personal empowerment about learning new skills and building capacity in bookkeeping and researching employment contracts and workers compensation".

Challenges of self-managing

Lack of information and advice was a challenge mentioned by several people (Helen, Rima and Amanda) and navigating the NDIS. Related to this, Roger said one challenge was "claiming weekly on [the] NDIS portal. Coding changes and changes in definitions have been frustrating". Like Roger, Katie found keeping up with "the ever-changing NDIS rules was daunting at first. Now I would like to be able to help other people with this". Similarly, Barbara, Lisa, Judy and Edward found the logistics challenging. Barbara suggested, "Changes to the NDIS portal would help, for example, the ability to put an invoice number next to expenditure would make it easier to track."

Lisa said, "It can … be challenging to manage the payroll, since the workers' hours vary from week to week". Edward said, "You're an employer [when you directly employ] and can't hide behind your disability if something goes wrong. You have to be on top of everything — insurance, payroll, legal requirements and professional responsibilities."

Viola had some difficulty when she first started in tracking the budget and was initially fearful about some aspects of self-managing , particularly around tax and super. However, Viola said, "Once the spreadsheets were established and I could use the portal, it was good." Katie also found using a spreadsheet useful: "Budgeting and working out how much I had left was easy to control once I set this up." Elaine also talked about the importance of planning so she knows how much to spend each month.

Amanda said, "I had lots of fears when I first started self-managing — most haven't eventuated. I was able to get lots of help from friends. When I started, I tried to get training working with the system which was not set up for people living with disability." She said that under conventional support arrangements she was not able to check that she was being charged for the correct number of support hours. Although under her state-based disability-funding package, Amanda is still required to use certain agencies to recruit and pay workers, she said, "Now, I can check and pick up mistakes. I keep a timesheet and my workers do their own timesheets, so I make sure it is correct and I tell my workers to check their payslips too." Similarly, Karen said, "I'm not afraid of risks and challenges. I fully embrace the learning experience, pitfalls and all, because you can learn by your mistakes."

Tess said, "Self-managing supports is a double-edged sword but worth it. The hardest thing was to get out of the service mindset. I don't have to go to bed at 10pm! Language is important … workers stay in the 'sleepover room'… not 'the carer's room'. There are no signs on the walls, checklists or rosters. It is their workplace, but it is still my home."

Iona said, "It can be a challenge with other children's needs and a little intrusive when workers come into the family home. However, most support is … in the community, for example, at work, in TAFE, in the library. Staying motivated can [also] be a challenge. Peer support is vital."

Lorraine said, "Underspending is worse than overspending. I review every quarter and have a sense each fortnight about how it is going." Jenny said, "Cross-checking records against invoices can take time and if you are sick it is hard to communicate and explain why the payment is late. Electronic billing is best as it is too easy to lose a paper bill." Similarly, Barbara and Colin raised cash flow problems and who could do the payroll when they were not around. Barbara noted, "Cash flow can be difficult as NDIS does not pay in advance." Anne said that self-managing has led to a reduced family income at times, when she has had to cut her work hours to fit in the extra self-management tasks. She is working on getting the team coordinator to take on additional responsibilities.

Elisa summed up, "It take more time and effort, but I probably would have had the same workload anyhow, for example, turnover of staff."

Several people raised the challenges for their workers in their interview. For example, Kim said, "Support workers don't have the safety net of working for an organisation, and that if we are going to be away or any other instances when they are not required to support Liam, may impact on their livelihoods. I engage them to provide other indirect supports during such times, such as scoping for new opportunities in the community for Liam or planning activities." Anne also acknowledged, "Staff can be isolated in a self-managed arrangement and there is a need to build in team meetings."

Kristie said, "The hardest part is seeing support workers leave, particularly ones that Grace is attached to. It makes it difficult on me, as I have to step in as the work falls back on me. Another difficult task is dismissing someone if they are not a good fit. It is not about them being a bad person. It is just because it isn't working out between the two."

Anne identified several challenges to fully self-manage under the NDIS (she currently uses a host agency). "We don't want to use the host agency anymore as they're increasing to full NDIS unit cost. However … we can see lots of vulnerabilities in [fully self-managing], for example who pays wages if you are sick? We may self-manage using [an online employment platform] to employ staff."

Elaine lives in a remote area and has used an agency (set up by a previous support worker) to help her source workers for Jo and Ava. "Self-managing is a lot more work than I thought. We live in an isolated rural area with no infrastructure. We need to start from scratch. I am more comfortable now that everything is on track. Self-managing Jo and Ava's funds provides employment in country towns where there are few employment options … money is being spent in country towns — your money and support workers' money."

Barbara employs Alice's support through a family company. She suggested that there should be an option to self-manage support coordination.

Advice for anyone contemplating self-management

At the end of their interviews, participants were asked if they had any advice for others who might be considering self-management.

Go for it!

Some people were enthusiastic about recommending self-managing with little reservation (Iona, Viola, Rima, Amanda, Diane and Lisa). For example, Iona said, "Absolutely do it — there are no regrets, only why didn't we do it sooner? It really, really works. No one in a disability service gets a good life." Rima said, "Go for it. It was the best thing for us, gave us peace of mind. Be creative. Self-managing is not hard to do. You can ask people around to help [who do this]."

Lisa said, "I don't think you need to have it all worked out to self-manage. Everything is dynamic, ideas change, the way we do things change, employees change. You've just got to get in there and give it a go."

Advice from experience

Others were positive and offered practical advice from their experience. "Have the costs of a bookkeeper in your plan if you need it" (Diane). "Get all your friends together and work out the easiest ways to manage your funds, for example, using a voice-activated application to fill in your spreadsheets" (Amanda). "Build a network around you of people that are self-managing, so you feel more confident in taking that step"(Kim). "Ask for forgiveness rather than permission. Trust your intuition. You are probably right. Be thoughtful, not rash. Make it happen" (Colin,) and, "Be very thorough and methodical. Make sure you have all the bits of paper" (Katie).

Elaine said, "Decide what you want and find the right person. Always have back-up (not the NDIA). Get training. There is less stress when you know what you are doing."

Similarly, Anne said, "Give it a try — but make sure you have support to call on — good values and good training." Helen said, "Self-management is something that should be embraced by more people and not be afraid of … there are people around you who might be experienced in self-management or have enough knowledge and skills to assist you on the right track. Come and see me. I am happy to help you."

Edward said, "If someone can take on the legal responsibility and employment obligations but delegate the authority to you, it's less work. It's about finding a partnership — someone willing to listen to you, support you and trust you to direct your own staff."

Kristie said, "I recommend you have an organisation who is flexible … as a back-up in case self-management does not work out, especially if things are overwhelming. It can be difficult to take on such a huge system and responsibility when self-managing. So, you have to be ready to deal with a lot yourself." Similarly, Lorraine advised, "Have a succession plan."

Others suggested taking on self-managing in stages. For example, Sharon said, "My advice is to get help, and not try to do it all yourself. Having a microboard or circle of support is a key enabler for self-managing. Self-managing also doesn't have to mean self-employment — [you] can do it in steps you feel comfortable with, rather than going the whole way as I have. Do it in a way that works for you." Barbara agreed: "If you can do it, absolutely do it! Get advice if you have never had a business that employs people. Start small — manage part of the budget."

Tess summed it up, "You need patience and a good understanding of chaos theory."

Not for everyone

In contrast, some people who self-managed felt that it was not an arrangement that would suit everyone. For example, Jenny said, "You need time, good communication and be good with numbers. Get help if you are not confident in all three." Elisa said, "Get and keep the right people. Don't share staff as it leads to taking staff away. I would recommend self-direction, but I think there are some people who may not have the resources and capacity to take it on." Roger advised, "Review. Compare agency [NDIA] managed and self-managing to decide. The size of the budget is important. Some [NDIA] stuff is not properly set up yet. Self-managing may be labour intensive, but you pay a premium for someone else to do it for you."

Findings part 2: Support Workers

This section covers the responses from the 15 support workers who were interviewed as part of the IWF project. All of these participants were working in self-managed support arrangements, and most worked for self-managers who were also also participating in this project and whose responses are detailed in part one of the findings.

Themes covered in interviews with people who work in a self-managed environment were:

- **What** are your arrangements? (e.g., type of supports provided and how many hours a week)
- **Why** were you attracted to work for someone who self-manages?
- **How** do your arrangements work?
    - recruitment
    - interview
    - contract of employment
    - induction and training
    - communication and feedback
- **Benefits and challenges** and advice for others who might want to work for someone who self-manages.

Demographics

Fourteen support workers completed the demographic survey. Results are displayed on the following pages.

Figure 17: Support workers — gender

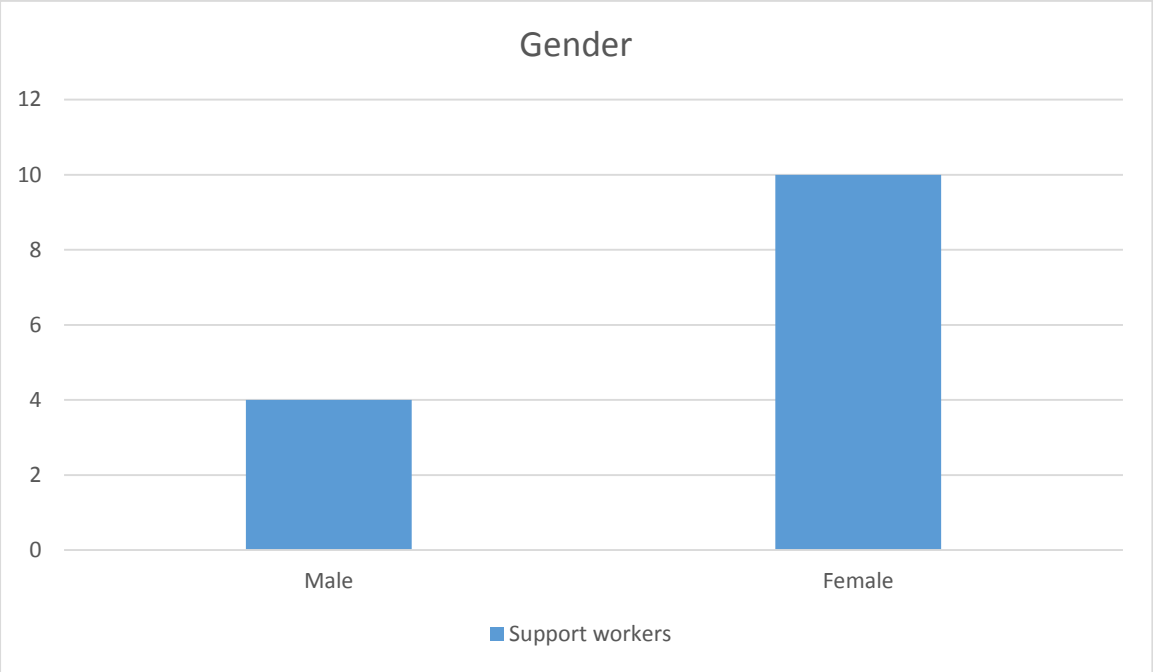


Figure 18: Support workers — age

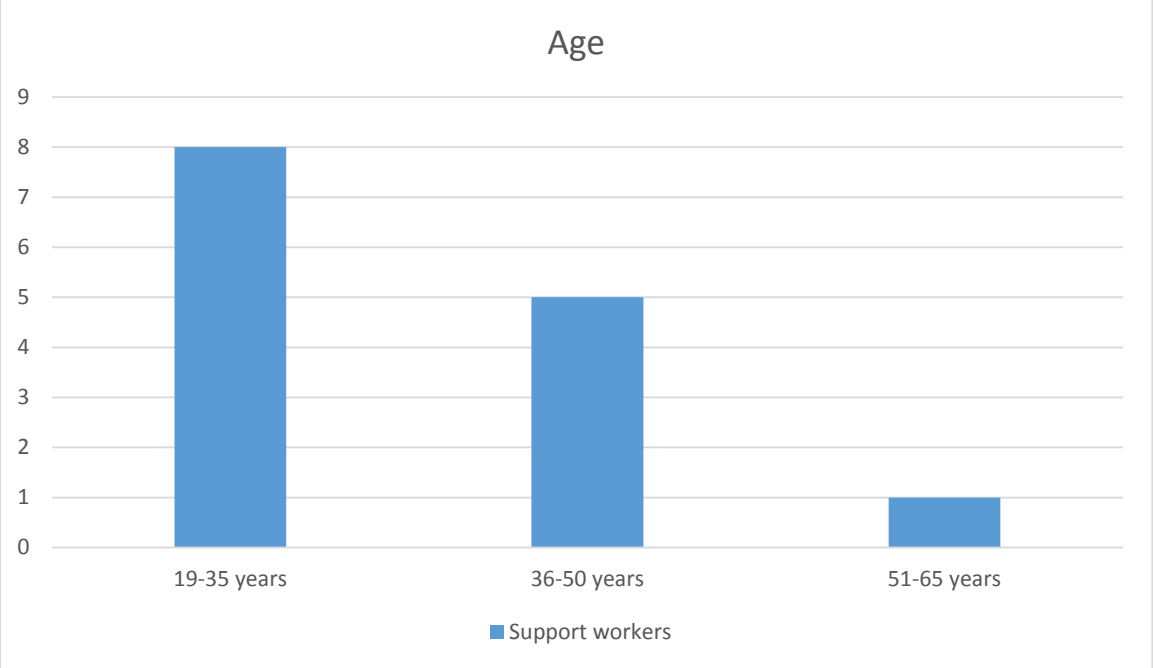


Figure 19: Support workers — identify as Aboriginal and Torres Strait Islander

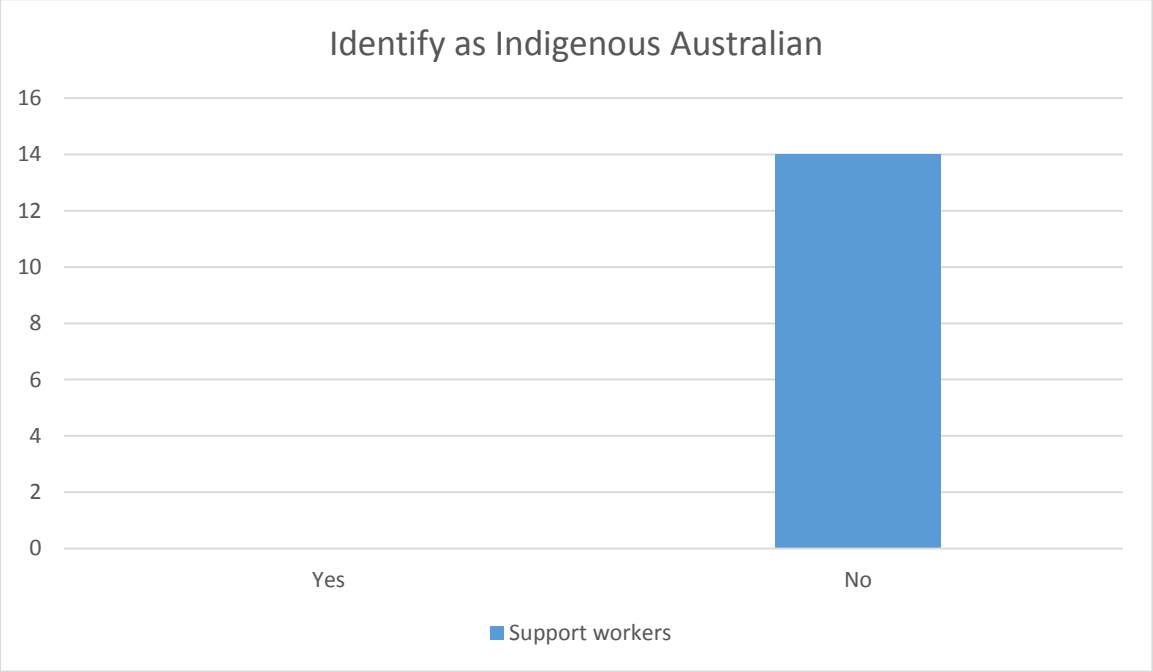


Figure 20: Support workers — cultural or language background from somewhere other than Australia

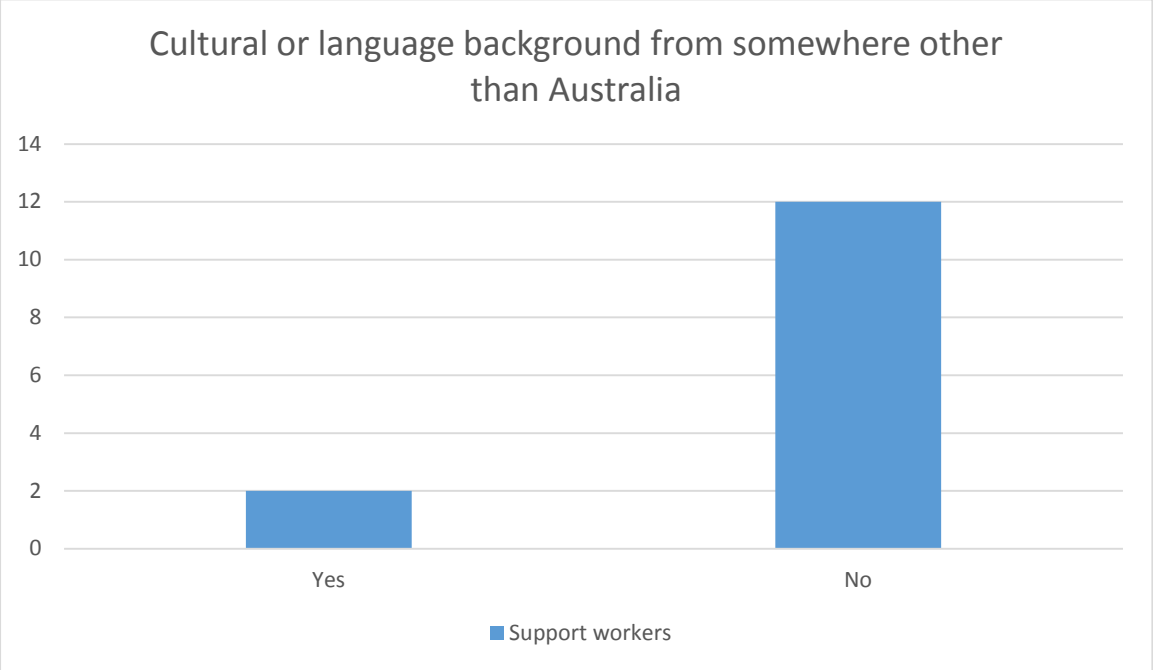


Figure 20: Support workers — location

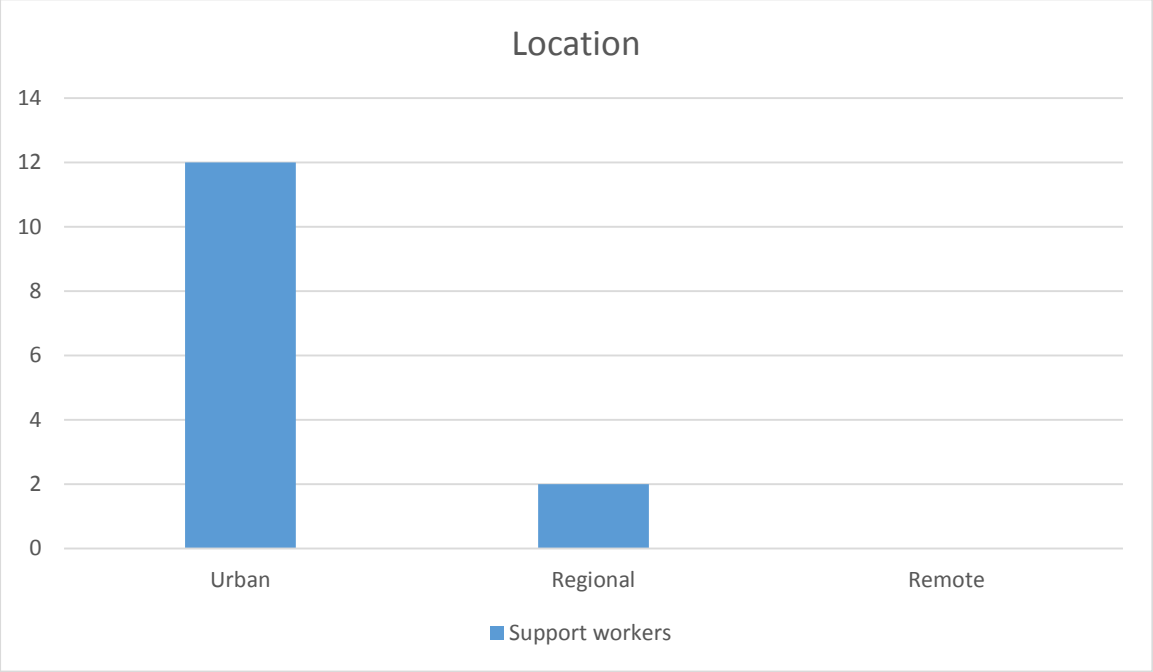
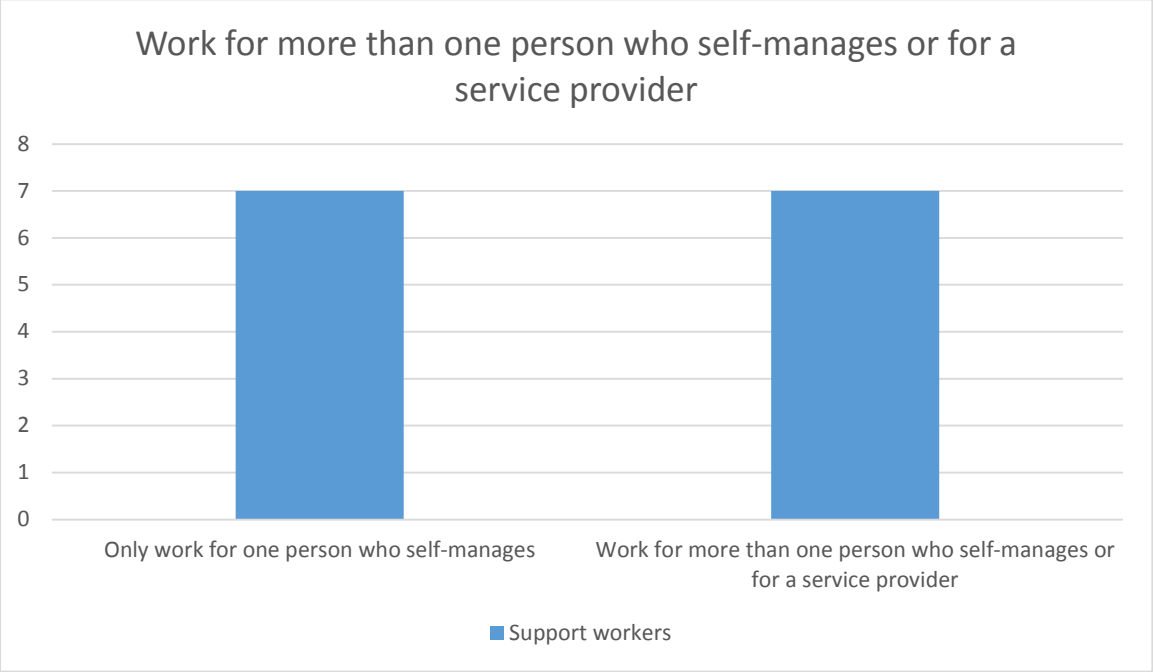


Figure 21: Support workers — work for more than one person who self-manages or for a service provider



Employment

Half of the support workers had worked in the current self-managed support arrangement for one to two years, and half for three years or more (maximum six years). The overall range of working for anyone who self-managed (including arrangements not included in this project) was between one and eight years.

The 15 support workers interviewed had a diverse employment history. Only three workers had previous employment in the disability sector. Other occupations were varied: vacation care and childcare, aged care, student, public servant, retail, cleaner, real estate, own business, communication and barista.

Hours of support provided ranged from 4 to 40 hours a week. Five respondents provided up to ten hours of support, six up to 20 hours of support and three provided more than 20 hours of support a week.

Work arrangements

This section profiles each of the workers and their current roles.

James

James is in his first role as a support worker. He has been supporting Simon for four years. Simon is a young man who lives with his mother who manages his NDIS package. James described his role as a 'social connector'. He and Simon are peers — both young men around the same age. James helps Simon with personal care and they do things together that Simon enjoys such as football, swimming and catching up with friends or, as James describes it, "social stuff like a mate".

Olga

Olga works as a 'lifestyle coordinator' for a young man, Josh. Olga previously worked in the public service, but after studying in a related field around eight years ago discovered that "this was where her true calling was … [in a role that was] more people focused and made a difference in the community". As lifestyle coordinator, Olga undertakes a range of tasks to coordinate Josh's supports, working with Sharon (Josh's mother who manages his NDIS package) and Josh's microboard to fine tune his goals and undertaking the recruitment process for the workers who provide one-on-one support.

Sarah

Sarah provides support for a teenage boy, Liam, for 8 to 15 hours a week. She helps Liam with communication skills, literacy and numeracy, and as a mentor as he begins work experience and start building a career. Sarah also helps Liam with his goal of building more meaningful connections in the community. Sarah previously worked in after-school care and is thinking about studying to be a teacher.

Naomi

Naomi is an 'executive assistant' for Tim who has his own business. Naomi, who has a background in communication and digital media, has been working for Tim for six years and helps him in all aspects of his business such as managing his emails, organising his engagements and campaigns, networking, and marketing. She also helps Tim with coursework and mentors other workers who will accompany Tim to conferences and other speaking engagements. As well as working five to ten hours a week for Tim, Naomi works fulltime in her own business.

Steven

Steven has been Max's primary support worker for 18 months. Steven's main role is to help Max find and keep employment and to become a gym member. Steven also helps Max to plan his day, work out a calendar and understand his health and nutrition. His hours vary from 5 to 15 hours a week depending on what Max is doing (e.g., he worked fulltime when Max had a casual job with fulltime hours). Steven previously worked as a barista, skills that Max was keen to learn for his own employment.

Bianca

Bianca is a support worker for Diane and another person who self-manages. She has been working for Diane for three years. She helps Diane with personal care and a range of household and other tasks and is Diane's key worker. Bianca described this work as "whatever needs to be done". Before working for Diane, Bianca worked in the services sector as a cleaner and supervisor.

Bree

Bree works 25 hours a week providing personal care and other assistance (e.g., housework, shopping) for several people who self-manage. Bree has been a support worker for two years and previously worked in real estate.

Gisele

Gisele works four hours a week as a 'business mentor' in Claire's microbusiness. She advises on artwork, stock, business etiquette, customer relations, branding and sales. She also helps Claire with her personal image, role modelling and talking her through new opportunities. Gisele has been Claire's business mentor for 18 months.

Ruth

Ruth has a similar work arrangement to Gisele — four hours a week in a microbusiness. Ruth also works in another job in an unrelated field. Ruth has been working with Amy for five years. Ruth helps Amy to run her business by driving her to the cafés that stock her products, building relationships with café owners, collecting money and increasing Amy's independence. Before working for Amy, Ruth had a range of jobs including in banking and hospitality.

Fiona

Fiona works 13 hours a week with Michelle, a young woman whose family manage her funding. Fiona also works for two other families who self-manage and for an agency. The activities Fiona helps Michelle with differ depending on how Michelle is feeling and what she wants to do each day, for example, go to the gym or the pool, go out to lunch, paint or draw. Before this role, Fiona worked for an agency for four years and then with other families who self-managed.

Gayle

Gayle works between 40 and 44 hours a week providing personal care and assistance with shopping, meal preparation and cooking and weekly swimming sessions. She also has a coordinator role for the team of support workers (e.g., staff handover, training, general organisation and helping the family with their NDIS package). Gayle has more than 20 years' experience in the disability sector including program coordination, school holiday programs and support work via an agency, and private and self-managed arrangements.

Mel

Mel is in the process of establishing herself as a registered provider for the NDIS. Mel is part of a team that provides support to Helen in her volunteer role and in social activities. Mel works 4 to 12 hours a week. After working in a range of jobs in customer service, Mel wanted a career change and studied Australian Sign Language, which led to volunteer work in this area.

Matt

Matt supports a young man, Chris, in his community activities, in particular his artwork. Matt is part of a team that supports Chris. Other team members provide personal care and overnight support. Matt said, "I don't see myself as a support worker, nor Chris as a client. He is just a member of the art centre." Matt has a family member who lives with disability. While at school, Matt worked as a volunteer and then with a large service provider in day support.

Izzy

Izzy works 15 hours a week and supports four people. She provides a mix of personal support, housework and community activities, particularly artwork. Izzy described her role as "helping people to learn and pursue their interests. I set up situations that encourage creativity, where people can learn new skills such as Photoshop, and opportunities for running a small business".

Dan

Dan works 30 hours a week for Evan who lives in his own home. Evan's funding package is managed by his family. Dan has worked for Evan for five years, initially providing overnight support. Dan helps Evan to build his community connections, for example, by trying new things, building relationships and volunteering. Dan started working with Evan when he was a university student studying psychology. Dan has also worked in more traditional disability sector jobs.

Why work for someone who self-manages?

Support workers were asked what motivated them to work for someone who self-manages.

Values and rewarding work

Many of the interviewees talked about the satisfaction they get from working in a self-managed environment and how it aligns with their values (Fiona, Ruth, Steven, Bree, Olga, Sarah and Mel). For example, Fiona said, "I love self-management. The families I work with are very driven to achieve goals, and to me goals are very important." Similarly, Ruth described her work as "the best job in the world. It's not really a job; it's like working for your best friend. You are given the space to facilitate someone's life the way they want it". She added, "I particularly liked the job description as it described someone who could be flexible, tolerant, honest and it spoke about relationship."

A friend on social media introduced Bree to this work. Bree had moved on from her previous job because she felt that it was not satisfying and, unlike her current role, "there was nothing about that job that made me go 'wow'". "I like working with people who self-manage because I am actually helping people and not just helping them to make money." Bree also noted that she can choose her own hours and can develop genuine relationships with the people she supports. Like Bree, Olga found that there was something missing from her previous work that left her feeling unfulfilled. "I was feeling like I wasn't making much of a change or any kind of difference," Olga said. "But in this role, every little step, every little action that you take has a massive implication on someone's life."

This job

Many of the workers interviewed were specifically attracted to their current job (James, Naomi, Izzy, Matt and Sarah). For example, James saw an ad on Gumtree that caught his attention. It said, "Would you like to help someone to achieve their dream?" James comes from a marketing background and said, "It was totally unexpected that I was applying for support work at that time. Now I like the openness and personal nature of the work." Similarly, Naomi was attracted to a specific position. Naomi does not see herself as a support worker. She was approached by Tim and his mother who felt she had the right skill mix to be Tim's executive assistant. This was also the case for Izzy who wanted to work with people who had a shared interest in art. In her current job, Izzy said, "I feel valued, I have a good relationship with the people I work with and I enjoy the lack of bureaucracy." Working in an art-related role also was attractive for Matt, who said, "The job ad appealed to me as it came directly from the artist and was not disability sector work."

Gayle likes working for someone who self-manages because "you all want the same outcome — what is best for the person being supported. It's a diverse role, and every day is different which I love". Gisele liked the idea that the position she applied for was to support Claire to work and to live in her own home. "The family sounded friendly and it was not too intense, and they were happy to employ new people to work who had no experience working for a person with disability."

Better than traditional disability work

Dan has worked in both self-managed and traditional disability settings. He says, "I am more motivated to work in self-management arrangements because you can form a deeper connection with the person, more flexibility and autonomy are allowed, it is a more fulfilling role as the person is the central focus, and you are more likely to be assisting people to have access to the good things of life." Bianca also mentioned flexibility of the job and that she felt she has learnt so much.

Recruitment

Several workers spoke about being personally approached to take on their current job (Gayle, Mel, Naomi, Steven, Sarah, Ruth and Fiona) because they knew the family. Often, this meant they did not have a formal interview for the job.

Others heard about the work through friends or teachers. For example, Bianca and Bree were encouraged by a friend to apply for support work and both joined an agency that mainly matches support workers to people who self-manage state-based disability funding packages. Bree has since moved on to working with people who self-manage under the NDIS. Dan heard about his current job through a friend. Gisele was completing her disability studies at TAFE when she heard about the job from a teacher who had been asked by Claire's mother for potential workers.

For Matt, Izzy, Olga and James, they responded to ads looking for specific skills and interests that matched the individual interests of the person they now work for.

Interview process

For those who went through an interview process, a range of different approaches were used to select the right person. Mostly, interview processes included the person they would be supporting (if they were interviewed by the family), and this person had the final say. For example, both Fiona and Dan described the process as 'informal' and involved the person they would support. Dan was first interviewed by Evan's parents in their home, and then met Evan. Gisele also had a less formal interview where she met with Claire's mother at a coffee shop. However, Gisele said that although it was casual, she was asked questions and given scenarios. She then met Claire. Once Claire approved her, she met Claire's key worker who had her own questions and scenarios. Others reported a similar staged process. Ruth had an interview and then spent some time observing another person supporting Amy. Ruth said, "This was to see if Amy was happy for me to be part of her life. If Amy doesn't like you, you don't get the job!" Steven was approached by Max's mother and then had a phone interview.

After that, he met Max to see if they connected. Gayle and Izzy also had interviews that involved the person they support and the family.

The interview process involved fewer stages when family was not involved. For example, Bree and Bianca work for an agency who pre-screen applicants to find potential matches for people who self-manage. They meet the people they will potentially support in their own homes (often referred to as 'a meet and greet') and if there is a match, start work.

Olga had a more formal interview process. She saw the support coordinator job on a website. First, she had to answer questions around her strengths and interests. She then had a group interview with three or four other applicants, which included Josh's entire microboard. Josh was also present for some of the interview. However, Olga said, "It wasn't an intimidating process at all — it's a process that aims to draw out people's strengths. It has a lovely community feel about it."

How support workers are employed

Support workers reported having a range of employment arrangements. These can be broadly classified as:

- directly employed by the person they support or family member;
- directly employed but the payroll function is outsourced;
- employed by another body such as an agency, host organisation or online employment platform; or
- self-employed.

Direct employment

Some workers were directly employed by the person self-managing or by a family member (Gayle, Olga, Sarah, James, Ruth and Fiona). For example, Ruth has a work agreement with Amy's mother. The agreement sets out the expectations of her role; hours of work; use of the car; what to expect from the family; and what to do if cancelling a shift. This is also the case for James and Olga. Olga noted that in her role as Josh's lifestyle coordinator, she designs the work agreements of the other support workers. Olga said, "The work agreements are linked to Josh's goals, and revisited every three months to see what has been achieved and what needs to be worked on. The agreement … has a reward mechanism built into it at the end of the year [with] … a bonus or pay rise if things are going really well." In contrast, when Gayle started work with a family that directly employed her, there was no formal agreement in place. Gayle helped the family to create a formal agreement that is used for other workers.

Dan's arrangement is like Gayle's, Olga's and others in the group above in that he has an employment contract with Evan. However, he is paid through an organisation that handles the payroll and other related tasks for Evan's family.

Other arrangements

Gisele is employed through a host agency that takes care of contracting, payroll and other employer obligations. Steven is employed via an online employment platform that covers all the insurances and employer obligations and does police and other checks. Steven noted that it was easy to do all this online. Bree and Bianca are employed by an agency that manages the payroll and other obligations. They have verbal agreements with each of the people they support about hours of work and tasks required.

Self-employed

Several workers have their own business with an ABN (Mel, Matt, Izzy and Naomi). Mel is self-employed and has her own service agreements with Helen. Mel has applied for registration as an NDIS provider. Matt, Naomi and Izzy have a contract with the person they support and describe themselves as sole traders.

Induction and training

As noted in the responses from people who self-manage and family members, the types of training support workers received, and how this training was funded, varied considerably among the 15 interviewees.

Induction

On-the-job training and buddy shifts were the main form of training. For example, Fiona did several buddy shifts as did Izzy, Bree and Dan. Similarly, Matt had only a quick induction where he learnt about the person he would support and spoke to the worker he would be replacing. He then did a buddy shift with Chris's mother.

Olga did some one-on-one shifts with Josh to get to know him and his needs and a subsequent reflective practice to share her experience. Olga is now adapting the induction process for other support workers and uses their feedback to fine-tune it further. Ruth also noted that Amy's family has invested a lot in training. First, Ruth spent time with Amy to develop a relationship. She was then given documents to read and discuss and asked for her opinion.

Bianca was positive about the on-the-job training she received and emphasised how important this type of training was to her: "They can train you in what they want." In contrast, some of the workers interviewed felt they did not receive enough training when they first started the job. For example, while both the key worker (who was the main point of contact) and Claire's mother provided information about the role, Gisele said, "I felt that the role was a little unclear and learning was by trial and error." Similarly, Dan commented, "Looking back it seemed quite abrupt, getting too personal too quickly for me and Evan." Steven described the on-the-job training he received as "getting to know Max's needs and how to work with him." Steven added, "I felt that the orientation was a bit unclear … at times, I was unsure if I should be doing something and was unsure of the best way to teach Max specific things. In hindsight, more training would have been beneficial, especially in how Max learnt skills." These concerns suggest that this might be a challenge for some self-managed arrangements and that additional strategies might need to be in place to help where workers had less back-up support from more experienced workers.

Naomi, Gayle and Mel were recruited specifically for their current job and received no additional training because of their existing professional skills. Naomi said, "You don't need qualifications as much as understanding [the person]. You can't buy a manual about this."

Ongoing training

Investment in ongoing training varied. This appeared to depend on the employment type, need and priority placed by the person self-managing/family on training and what funds could be used to support it. For example, Bianca received some ongoing training from the agency that employs her while Dan reported no access to formal training in this job or professional development, although he accessed formal training through other roles in the disability sector. In contrast, some families invested in ongoing training, particularly values-based training. For example, Ruth was sent to a conference run by an IWF project partner.

Ruth said, "This helped me to see how others had developed microbusinesses so that I could get ideas, discover things I might have overlooked and to give me encouragement." Similarly, Gisele, Steven and Sarah have been able to attend other training and conferences paid for by the families. Steven noted that the family saw this training as an opportunity to skill him up for a future role as a coordinator of Max's supports. Olga also has access to ongoing training and an annual retreat where they have guest speakers. Matt said that Chris's family is aware of training options and are willing to provide training, but he has not done any yet as he received training via a previous service provider.

Communication and feedback

Several interviewees mentioned open communication and bringing issues (such as crossing boundaries) to the attention of the person concerned (Gayle, Mel, Dan, Naomi, Steven, Gisele and Fiona). These are more informal and 'natural' ways of feedback and dealing with issues. For example, Bree noted, "Issues can be resolved if you have common sense and respect and you are aware that you are in their home, so you work to their standards." Mel said, "Initially I was worried about family relationships and how my friendship with Helen could be affected or affect others, however this was not the case. It is important for everyone to have a good understanding of boundaries and what was expected of everyone." Dan also talked about boundaries: "You have to give more of yourself when working closely with families."

Sarah highlighted the role of day-to-day communication with Liam's parents. "We always had conversations, either at the beginning or the end of my shift, discussing what the day was like, what went well and how things could be done better." Similarly, Olga said, "In my previous work experience, I felt that everyone was disconnected from their work — it wasn't their problem at the end of the day. Whereas in this role, you are part of the problem, and part of the solution. And you're all there for each other, which makes the work so much more interesting and engaging."

Sorting out issues can sometimes not be so straightforward. For example, Gisele found that "seeing Claire as my boss but being answerable to Claire's family [is] a balancing act. Building a relationship has helped with this". Another way to deal with this is to have someone else, such as a key worker or coordinator, as an additional resource. For example, Izzy noted, "Everyone has a key worker, and this helps to give me other people to talk with and resolve any conflicts with the family or other staff."

Regular team meetings

Dan, Gisele, Ruth, Izzy and Matt emphasised the role of regular team meetings. Again, these involve family members and the person being supported as part of the team. As Matt said, "You need to listen intently and offer your contribution. You don't know everything even if you have been a support worker for a while. [In a self-managed arrangement] there is more opportunity for collaboration. We can sit down together and nut things out. The buck stops with them — no manager or CEO." Izzy said, "Hearing what you are doing right is very important. I would go the extra mile, mostly because the family would do this for me. It is more than work." Similarly, Ruth pointed out the benefits of regular team meetings: "Getting to know other workers rather than just calling a phone number and advice from previous workers. It's a great support network. I feel well backed up and encouraged to have a relationship with other support workers and the family — not a two-hour shift then get out."

Other methods

James has both formal and informal mechanisms for feedback. He has a regular formal review where he can raise issues as well as being actively encouraged to give feedback informally. They also use Simon's Facebook page for communication among team members, for connecting, team social events and training opportunities.

Benefits of working for someone who self-manages

There was quite a lot of agreement among the interviewees about the benefits of working in a self- managed arrangement. These centred on choice and having a valued life for the person they support and therefore a rewarding job, natural and deep relationships, flexibility and creativity. As Gisele said, "You are not doing [work] *for* [them] but *with* [them]." Bree said, "It is most rewarding having someone happy that you are there and have done a good job."

Flexibility

Flexibility in what they do each day and in work arrangements was raised by many support workers (Sarah, Olga, Dan, Gayle, Izzy and Ruth). For example, Izzy said, "Roles can be tailored to suit staff, and most importantly the needs of the person." Olga made a similar point: "The way I provide support to Sharon and Josh is nothing like you'll see in an agency-managed environment. For instance, we have an IT-based system that captures all the knowledge around a person with disability —his goals, who his workers are at any given time, the lessons learned and more. I think agency-managed plans tend to go by the book and miss out on these kinds of opportunities." Sarah appreciated the flexibility of working in a self-managed environment and "not having to deal with multiple people to address any issues as you would have in an organisation". Ruth highlighted the opportunity for the role to develop: "Self-direction allows fluidness, Amy's business looks different now than when I first started."

Gayle explained why flexibility is so beneficial: "If the person I am supporting isn't having a particularly good day, we can change the day to suit. However, when working for an agency, the day is outlined and whatever condition the person being supported is in, isn't necessarily catered for when the agency is trying to meet the plan." She added, "I get paid to have fun, it's great."

Several people also mentioned flexibility of work hours that suited their study and family life (Ruth, James and Olga).

Opportunities for creativity

Self-managed arrangements can provide more opportunities to be creative and for the worker to use their initiative (James, Steven, Fiona and Mel). Steven said, "It is about learning together with the aim of making the person more independent. You can be creative — think outside of the square. So much you can do, so many opportunities." Similarly, James said, "You can also take risks and be creative — say why not?" As an example, James talked about when he and Simon went stand-up paddle boarding. Because of Simon's high support needs, James felt this would not have been allowed in a traditional disability service arrangement.

Relationships

Many of the workers interviewed noted the critical role of relationships — with the person they support, their family, the team — as Dan said, "A deeper connection than conventional arrangements." Or, as Izzy said, "The more natural relationships are the key for good work and low turnover." Relationships was a benefit highlighted by Fiona, Dan, Ruth, Gisele, James, Steven and Izzy. Gisele saw the benefits of this arrangement as being "tailor made, it is intimate and provides warmth and connections". Similarly, James described the relationship between him and Simon as "more natural but having a responsibility of care not expected in previous jobs". Fiona said one of the benefits is "working for a close team and having the ability to problem solve together is always a plus, it is more consistent and there is less change of staff. Everyone is working towards the same goals, with the same vision in mind".

Matt said, "I feel valued as a support worker. This is why it works well. We are always talking about people with disability having a valued role. Support workers needed to feel valued, to do a job that has value and purpose." Matt added, "I would like to still be in Chris's life even if I am not in a paid role. You can't really do this in other support worker roles." Ruth made a similar point about remaining friends after the formal role ended.

Other

Naomi raised a benefit that she sees as specific to self-managed arrangements: "Having an ABN is attractive to the person with disability and their parents as they don't need to think much about the payroll and other things. They can focus on self-directing the person's goals and life, building the team and connecting people."

Challenges of working for someone who self-manages

Expectations were a challenge for some workers. Bree said, "You can be vulnerable working in someone's home. It can be unpredictable at first when you don't know them or their expectations and you might be the only contact they have." Gayle and Gisele mentioned managing family members of the person supported as a challenge. Gayle said, "Sometimes the needs and expectations of all parties do not completely match up and it can be a balancing act."

Pay and working conditions

While some workers (Olga and James) noted that payment rates and working conditions were excellent, pay and working conditions were a challenge for several workers. For example, Mel found negotiating payment challenging as the person sets the price: "Sometimes you have to do the love jobs to get the good jobs." Dan and Izzy raised the issue of work being casual and having less job security. Izzy said, "I worry about [this] … I can't get a loan. You need to have a second job or work in a two-income household. This is the reality of this type of work in the gig economy. Employing someone with an ABN may be less paperwork but support workers may stay if they are paid more. Workers should be remunerated appropriately for the responsibility. If not, they don't feel valued, they burn out and shutdown."

Bianca finds the hours and spread of work challenging as it often involves early starts, late nights and short shifts. Similarly, Sarah sometimes finds working out schedules to be challenging as her timetable at school is always changing, requiring compromise on both sides.

Izzy works for four people and each have different arrangements for communication (e.g., via key worker or directly with the family). She sometimes finds this a challenge to manage and to attend all the meetings.

Steven felt there is more organisation in this model as a support worker: "It's like running my own business, for example keeping track of incidental hours, phone calls made from home. I am also concerned about the transparency of [online employment platform] and how to get IR advice. I feel there was more responsibility on the support worker to be well informed about IR."

Gisele felt that working with a host organisation could be challenging if they do not provide full and timely information to the family and that having no oversight body for people self-managing meant that the organisation could take advantage of the person or the worker.

Isolation

Some people have worked in both traditional and self-managed arrangements and saw some challenges that seem unique to self-managed arrangements. Matt said, "There is more support in a team environment where you can bounce ideas off others, compared to a self-directed arrangement." Dan also talked about how the work can be demanding and isolating as you are less likely to have a coordinator or supervisor that you can go to with questions or when difficulties arise or to connect with a broader network of support workers. Gisele and Fiona also raised working by yourself as a challenge. Fiona said, "Some days are hard, especially when the person I support is having a bad day." Steven felt that people or families who self-manage need to actively create opportunities for workers to connect with others involved in the social inclusion movement.

Advice for anyone contemplating working in a self-managed arrangement

Support workers were asked for one piece of advice that they would give to someone contemplating working in a self-managed arrangement.

Go for it!

Like the participants, some workers were enthusiastic with little reservations. For example, James said, "Give it a go. The more you give, the more you get back. It is up to your imagination as to how far you can go." Fiona said, "Everything about it outweighs the disadvantages that could arise, and having a family that self-manages means you are part of a team and have that personal experience with everyone you work with."

Others focused on their values and the personal rewards of this work. For example, Olga said, "In this work, you actually see the impact you are having on the person, you can see someone going from being socially isolated and having anxiety issues to building confidence and participating in community events. Being part of this journey is such a privilege." Sarah said, "I've found it encourages me to think on my feet. I enjoy working directly with the family. It does stretch you, but in really good ways."

Dan said, "I just enjoy working in a self-managed way a lot more than in the agency-directed way. Just because I could build a relationship a bit better … the agency wanted support workers to be replaceable. When I started working for an agency, I could see some of the benefits … [I thought] maybe it is good to have these types of professional boundaries. But then the negative impact of that sort of negative thinking became obvious to me … it became clear to me that to give people a good life you have to actually care about them."

Naomi said, "It is hard work but once you have the processes in place it is sustainable. You learn first and then get someone else in [buy in supports] to do it your way."

Bianca gave a piece of practical advice: "Listen and follow direction and, most importantly, put things back where you got things from."

Not for everyone

Some workers felt a self-managed arrangement was not for everyone. For example, Bree said, "Only do it if you think you are going to love it." Steven said, "The arrangements should be about looking after and respecting each other. Support workers should not have to sacrifice themselves. They need to look after health and well-being and be happy with the arrangement."

Mel said, "It is important to be across the type of work that is going to be undertaken as well as the expectations. Pay itself is also a factor to be considered when working for someone who self-manages. You could potentially be relying on that income."

Gayle said, "Think about it, it isn't as easy as you think. With an agency, you have guaranteed work and you have everything set down from days, hours, activities, and you have the staff and stuff you need. There are a lot of things you don't think of, and once you have the hang of it and everything is in place, it [working for someone self-managing] can be beneficial and better [than working for an agency]. It is worth giving it a go."

Discussion:

Self-management is being embraced by a range of people under the NDIS and in the prior state-based funding environments. Based on data from the demographic surveys, most people who self-manage their own supports identify as living with a physical disability while family members more often manage a funding package for someone who lives with a cognitive disability. While this makes intuitive sense, responses could be biased by the self-selected nature of the group interviewed, that is, people known to, and consequently approached to participate by, one of the six organisations involved in the project.

Overall, the views on self-managed arrangements across the 40 interviews were positive and likely to motivate others to self-manage or work for someone who does.

Choice and control

Choice and control ("I'm the boss") was a key theme that emerged from most of the interviews with both people who self-manage/family members and support workers. While choice and control are integral to the NDIS, it is in self-managed arrangements that ultimate choice and control goes down to the level of the individual worker. This appeared to be particularly important for people who had support workers in their home as they felt strongly that they should have the right to determine who comes into their home. As Tess said, "[Previously] I was institutionalised in my own home … [and] in relationships not of my choosing."

As can be seen from the interviews detailed in this report, there are several main ways that self-management can be undertaken. Support workers can be:

1. directly employed, where one person (or sometimes a partnership) undertakes all aspects of self-managing;
2. directly employed with some processes outsourced such as payroll; or
3. employed by a host or other entity (such as an online employment platform) with workers chosen and directed by the person self-managing/family member.

In addition, the support workers can be self-employed (with their own ABN) and payment made on invoice. This would apply in situations one and two, the difference being who would be making the payment. Around one in three of the people self-managing/family members had an arrangement where they did everything themselves, while the remainder had some level of assistance, from minor (e.g., pre-screening of job applicants) to a more extensive host role.

The interviews revealed that there is also a myriad of ways that responsibility for components of the processes can be shared — for example, informal assistance such as self-managing with the support of a microboard or circle of support (already in place to help the person living with disability), friends or other family members. More formal support can involve having a key worker or (external) coordinator to help with aspects such as recruitment, training and rostering. Finally, support can be 'bought in' by, for example, using a host organisation, online employment platform, or service to manage payroll. Edward described this arrangement as "all the benefits of self-management without the work". Further, some family members felt that having someone else handle the paperwork and processes that go with employment such as payroll allows them to concentrate on the person's goals and building and maintaining relationships with workers.

Many of the respondents interviewed pointed out that self-management can be done in steps, perhaps starting from one small part of the NDIS plan (often referred to as 'partly self-manage') until people are confident to take on the entire plan. Alternatively, people may only ever want to manage some parts and not others.

Others talked about how people can change the level of responsibility they take on when they self-manage and can, like the example provided by Edward, move back from full responsibility to buying in support for components. In all these cases, the main aspect of choice and control — self-directing workers — is retained. In addition, some interviewees mentioned that they have tasks like reference checks undertaken by someone else so that they can retain their privacy.

Research elsewhere suggests that self-management might be an option taken up by more people if the perceived administrative 'burden' was reduced (Independent Advisory Council of the NDIS 2017a, Fisher et al. 2010). They suggest that financial intermediaries be used as a strategy for increased participant self-direction and self-management. An evaluation of the NDIS (Mavromaras et al. 2018) noted an increase in the use of financial managers by people who self-managed their NDIS packages, giving them the benefit of self-directing their supports with less administrative work. Examples of how this can work 'on the ground' are illustrated throughout this report.

Many of the eight people who self-managed were still operating under state-based funding and had not yet moved to the NDIS. This funding often came with rules about direct employment (such as sourcing workers from specific agencies with set wage rates) that do not apply under the NDIS, which apart from prohibiting the employment of family members, gives full choice of worker to the person self-managing.

Valued life

One aspect of self-managing that was highlighted in the interviews was the way that self-management and self-direction lines up with people's personal values, particularly about the type of life they want for themselves or their family member, for example, employment. Several of the interviewees had set up a microbusiness and employed workers to help with this. Self-management allows people to select workers who share their values. Support workers also spoke about the importance of values and the rewarding nature of working in this environment. This has benefits such as feeling they are in a valued role as a worker and is likely to help team cohesion and stability. As Fiona said, "Everyone is working towards the same goals, with the same vision in mind." Moreover, these are the priorities of the person themselves and not imposed from an agency or other source.

As Chenoweth, Ward and Hughes (2015, p. 49) have explained, "Good support workers gravitate to employment with service-users who can envision and plan a good life … they have had opportunities to foster their imagination, to build informal networks of support, and develop resilience and independence."

Flexibility, creativity and matching

Many of the interviewees spoke about the flexibility and creativity that occurs in self-managed arrangements where they are not constrained by traditional disability sector job roles, for example, being able to advertise and recruit for a specific skill or interest such as art, soccer, or being a barista. Potential workers can be found through personal networks and approached directly or located in places where their 'ideal' worker might be found, such as school. Social media, such as personal or school Facebook pages, was used by some people to recruit workers in innovative and engaging ways. In addition, many interviewees mentioned the use of the online employment platforms to recruit workers, particularly the capacity to read profiles and match interests, skills and values of potential workers and the feedback mechanisms.

Descriptions appear important to attract and retain people. Workers were employed as 'social connector', 'lifestyle coordinator', 'business mentor' or 'soccer coach' rather than 'support worker'. Jobs can be matched to the individual interests, specific skills required or peer group. For example, Steven was specifically employed to help support Max into employment because of his skills as a barista and in hospitality. This knowledge and experience is unlikely to be found if the family advertised and recruited a generalist support worker with disability-specific qualifications.

In the same way, activities undertaken by the workers were diverse and sometimes 'risky' in a good way. Of note was the younger demographic for support workers in self-managed arrangements than in the general disability workforce, where workers are predominantly in the 45 to 54 age group (Cortis 2017).

Value for money

Self-management, particularly when all the tasks are done by the person or their family member, means that there are less overheads built into the wages paid (i.e., no agency overheads).

It may be, however, that personal time taken to do the paper work and organisation required to fully self-manage is not entirely 'free'. Glendinning (2008), who reviewed the situation in England, has suggested that this additional administrative work may leave people "time-poor and energy-depleted". Nonetheless, the interviews suggest this might be a trade-off that some people are prepared to make to be completely in control. Further, as the NDIS matures, it is likely that some of these tasks will get easier and more streamlined and people can learn tips and traps from others. (In part, this is the aim of this project.) In addition, some of the interviewees noted that the costs of outsourcing some services such as payroll are cheaper than paying the larger agency overheads that they were previously.

Another benefit mentioned by respondents is being able to negotiate rates and pay more to retain or reward good workers. In addition, as many respondents pointed out, self-managing allows them to be creative about how the funds are spent.

Some of the support workers raised issues about potential downsides of negotiating pay or being in less secure employment. These are challenges in self-management that have come up in the overseas research, such as the trade-off between rewarding work and working conditions such as stability of hours (e.g. Leece 2010). Good employers who want to retain workers will not want to underpay them or make them feel insecure.

Relationships

Both support workers and people who self-manage/family members mentioned deeper connections with people that happen — sometimes intentionally — in self-managed arrangements. Support worker talked about 'giving more of yourself', but also that this made the work more rewarding. Some people described the relationship as friendly' or 'being part of the family'.

Some interviewees added that this can occasionally raise boundary issues as previously noted in the research by Rees (2013, p. 45) as "the 'blurry line' between friendships and employment responsibilities". Most of the participants emphasised open and timely communication to provide two-way feedback and ensure issues are dealt with promptly. Careful matching and making job expectations clear are important components of this.

Relationships can be more reciprocal than in traditional disability employment. This relates to both the closeness of the relationship and not needing to maintain a professional distance, and the type of work that can be done (e.g., agency staff not being able to feed pets). For

example, Izzy said, "I would go the extra mile, mostly because the family would do this for me. It is more than work." In addition, Matt said, "I would like to still be in Chris's life even if I am not in a paid role. You can't really do this in other support worker roles."

Sharing good practice

Regular team meetings, sharing information on a specific Facebook page or other more social gatherings were mentioned by people who self-manage/family members and support workers. This can help with team cohesion and goal setting and allow feedback and an opportunity to learn from achievements and mistakes.

Some support workers raised concerns about isolation and limited peer or supervisor support. David and West (2017, p.11) noted "the reduced scope, if any, for collection of data for service innovation and development [in self-managed arrangements]" (see also Fisher et al. 2010).

Informal or formal peer networks were raised as a resource that people could use for advice and so that they could learn from each other. Some interviewees (family members and support workers) talked about the role of values-based organisations in this space running conferences and workshops sharing stories of people/family members who successfully self-manage. Hearing how others do it can demystify the process and give people confident to tackle self-management themselves.

Where attendance of support workers at training can be paid for in part or full out of the person's funds, this provides an opportunity to reduce isolation and make valuable connections with other workers in self-managed environments. This would particularly be the case in self-managed arrangements where workers had less back-up support from more experienced workers.

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Appendix A

JFA
Purple Orange

Are you a person living with disability or a family member/friend who currently is self-managing your support package? Do you want to help other people who might be interested in self-managing to give them the information and confidence to self-manage?

Would you and one of your support workers like to share your experiences: what works and what you have learnt along the way?

We would like to invite you to be part of a new research project that aims to build a body of knowledge on workforce arrangements that deliver good outcomes for both the person living with disability and the workers involved in their supports.

The project looks at the workforce arrangements for people living with disability who self-manage their supports from two perspectives: the person living with disability and the support worker. There are two ways that we will be seeking people to participate, through interviews and some through video.

One-on-one interviews will be conducted with a range of people living with disability and their support workers across Australia. We want to collect and collate your knowledge and experiences. This project will help people make informed choices about which support model can best deliver the supports they seek and will help illuminate an employment option that might attract and retain support workers.

The Workforce Innovations Through Self-Managed Supports project will produce a report covering the key practice themes and trends emerging from the interviews. None of your identifying information will be used in the project report, except if you're involved in a video. In addition, the project will produce a range of Quick Guides covering key practical issues for self-managed supports. These will be made available on a dedicate website to assist people interested in self-managed supports to take the first steps in gathering information about their options.

This research is funded under the Workforce Innovation Fund (Department of Social Services) managed by National Disability Services. The research is being undertaken by an alliance of organisations across Australia: JFA Purple Orange (SA), Belonging Matters (VIC), Community Resources Unit (QLD), Valued Lives Foundation (WA), Family Advocacy (NSW), and Imagine More (ACT).

If you are interested in finding out more about how you can be involved in this project, please contact [redacted] at JFA Purple Orange on (08) 8373 8333 or [redacted]

Appendix B

INTERVIEW QUESTIONS FOR PERSON MANAGING THEIR SUPPORTS OR SUPPORTS ON BEHALF OF THEIR FAMILY MEMBER

WHAT:

Tell me a bit about yourself (and your family member)

What type of supports do you receive?

How many people do you employ?

How many hours of support do you direct/receive each week?

WHY:

When did you choose to self-manage your supports and why?

HOW:

Practicalities

Tell me a bit about how you **set-up** your arrangements?

- *Where did you go for advice?*

Do you have any help in recruiting and managing your supports, either from family or through buying in assistance?

- *What mechanisms do you use to employ your supports? For example do you self-employ, use a host agency or something else?*
- *If totally self-manage: Is it a lot of work? (If so) What assistance would be useful?*

Can you tell me a bit about your recruitment process?

- *How do you design the positions of the workers that you need?*
- *Job descriptions – what do they look like? Do you have any specific preferences (cultural/age range/gender/LGBT) that you mention in the ad?*
- *Where do you advertise?*
- *What interview process do you use?*
- *How do you undertake reference checking and employment screening? What sort of checks do you routinely do: e.g., references from employers, character references, confirmation of qualifications, police and other screening?*
- *How do you decide who gets the job?*
- *How do you decide how much to pay people?*

Can you tell me a bit about employment of your support workers?

- *What induction and training do you provide for workers?*
- *Do you provide any ongoing training or development for your workers?*
- *How do you address any issues that might arise and manage feedback from support workers about areas of concern?*
- *How long, on average, have your staff worked for you?*

(If you have assistance from a third party or service provider to run the employment relationship).

What was the third party/service provider's involvement in?

Recruitment

- *designing the role description*
- *advertising*
- *selection*
- *reference checking*
- *contracting (i.e., setting up the formal relationship)*

Employment:

- *induction*
- *on-going training*
- *dealing with issues that might arise for you or your support worker (performance reviews, staff grievances)*
- *exit*

(For families managing support on behalf of a person with disability) *How is the person with disability involved in the managing of their supports e.g., how do they participate in the recruitment or performance management aspects?*

Describe your relationship with your support workers

What are the most important skills you look for in a support worker?

How do your support workers enable you (your family member) to be part of the community and work towards your (your family member's) goals?

People want to work for a good employer. What do you think you do that makes you a good employer?

Benefits/challenges

What have you found to be the benefits of self-managing?

What has worked well?

How have you dealt with having workers come into your home (i.e., your home is also their workplace)

What are the challenges of self-managing and how have you handled them?

- *Managing the budget to ensure that funds are not under or over spent*
- *Was there anything about your assumptions you had before self-managing such as barriers and fears that were not realised?*
- *If you have tried conventional support arrangements, how does self-managing compare with other/previous arrangements?*

If you had one piece of advice to give to other people wanting to self-manage what would that be?

Anything else you want to add that we have not covered?

Appendix C1

MAIN THEMES FOR INTERVIEW QUESTIONS: PERSON MANAGING THEIR SUPPORTS OR ON BEHALF OF THEIR FAMILY MEMBER

1. WHAT: your arrangements (set the story)

e.g., what supports are provided, how many hours etc.

2. WHY: why were you attracted to self-manage?

e.g., reasons, motivations, past experience

3. HOW: mechanics of self-managing, working for someone who self-manages?

PRACTICALITIES

For person self-managing:

- How you set yourself up (structure such as limited company, who is the employer of record, who you approached for advice etc.),
- recruitment (advertising, job description), pay and conditions, risk management (character v employment reference, qualification checks, police or other checks)
- appointment (contract of employment)
- induction and training
- Troubleshooting issues that arise

BENEFITS/CHALLENGES

How do your support workers enable you (your family member) to be part of the community and work towards your (your family member's) goals?

What worked well, what were the challenges, how these were overcome, advice to others etc.

How to deal with your home also being a workplace

Comparison with conventional support arrangements (where relevant)

Appendix C2

MAIN THEMES FOR INTERVIEW QUESTIONS: SUPPORT WORKERS

1. WHAT: your arrangements (set the story)

e.g., what supports are provided, how many hours etc.

2. WHY: why were you attracted to self-manage?

e.g., reasons, motivations, past experience

3. HOW: mechanics of self-managing, working for someone who self-manages?

PRACTICALITIES

For support worker:

- how you heard about the job
- what attracted you to the job
- interview
- agreement (negotiations, contract)
- induction (introduction into home, family etc.) and training
- dynamic: being your boss and person being supported, their home is your workplace, – practical challenges of this

BENEFITS/CHALLENGES

Does your work enable the person you support to be part of the community and work towards their goals, and if so how?

What worked well, what were the challenges, how these were overcome, advice to others etc.

How to deal with your home also being a workplace

Comparison with conventional support arrangements (where relevant)

Appendix D

For Family members self-managing

Q1 Person living with disability is:

Male

Female

Other identity/prefer not to say

Q2 Person living with disability is:

0-18

19-35

36-50

51-65

Over 65

Q3 Person living with disability identifies as Indigenous

Yes

No

Q4 Person living with disability has a culture or language background from somewhere other than Australia?

Yes (please describe)

No

Q5 Location:

Urban

Regional

Remote

Q6 Person living with disability is:

In paid employment fulltime (35 or more hours)

In paid employment part-time

Volunteer

Not currently employed

Q7 Tick all the disability types that the person lives with:

Cognitive e.g. intellectual, learning or developmental

Sensory e.g., visual, hearing

Physical

Psycho-social (mental health)

Other (please describe)

Q8 Is this an individual funding package under the NDIS?

Yes

No

Q9 Hours of usual support used each week (range is okay)

For people self-managing

Q1 Are you:

Male

Female

Other identity/prefer not to say

Q3 How old are you:

0-18

19-35

36-50

51-65

Over 65

Q3 Do you identify as Indigenous

Yes

No

Q4 Do you have a culture or language background from somewhere other than Australia?

Yes (please describe)

No

Q5 Location:

Urban

Regional

Remote

Q6 Are you:

In paid employment fulltime (35 or more hours)

In paid employment part-time

Volunteer

Not currently employed

Q7 Tick all the disability types that you live with:

Cognitive e.g. intellectual, learning or developmental

Sensory e.g., visual, hearing

Physical

Psycho-social (mental health)

Other (please describe)

Q8 Is this an individual funding package under the NDIS?

Yes

No

Q9 Hours of usual support used each week (range is okay)

For Support Workers

Q1 Are you:

Male

Female

Other identity/prefer not to say

Q2 How old are you:

0-18

19-35

36-50

51-65

Over 65

Q3 Do you identify as Indigenous

Yes

No

Q4 Do you have a culture or language background from somewhere other than Australia?

Yes (please describe)

No

Q5 Location:

Urban

Regional

Remote

Q6 How long have you worked with this person?

Q7 How many hours of support do you usually provide per week (range is okay)

Q8 Are you currently working in more than one workplace (e.g., with more than one person self-managing or also for a service provider?

Yes

No

Q9 How many years have you worked in self-managed arrangements?

Q10 What area of employment were you in before you worked in a self-managed arrangement?

Disability sector

Other (please specify)

WORKFORCE INNOVATION
through SELF-MANAGED SUPPORTS

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National Alliance of Capacity Building Organisations
July 2018