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“I’m here to help”

The role of the support-worker within the NDIS



Professor Lesley Chenoweth
Dr Margaret Ward
Ms Jacquie Hughes

January 2015

“I’m here to help”

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A Credo for Support

Do not see my disability as the problem.
Recognize that my disability is an attribute.

Do not see my disability as a deficit.
It is you who see me as deviant and helpless.

Support me. I can make my contribution to the community in my own way.

Do not see me as your client.
I am your fellow citizen.
See me as your neighbour.
Remember, none of us can be self-sufficient.

Do not try to modify my behavior. Be still & listen. What you define as inappropriate may be my attempt to communicate with you in the only way I can.

Do not try to change me, you have no right.
Help me learn what I want to know.

Do not hide your uncertainty behind "professional" distance.
Be a person who listens and does not take my struggle away from me by trying to make it all better. Do not use theories and strategies on me.
Be with me.
And when we struggle with each other, let that give use to self-reflection.

Do not try to control me. I have a right to my power as a person.
What you call non-compliance or manipulation may actually be the only way I can exert some control over my life.

Do not teach me to be obedient, submissive and polite.
I need to feel entitled to say No if I am to protect myself.

Do not be charitable towards me.
The last thing the world needs is another Jerry Lewis.

Do not try to be my friend. I deserve more than that.
Get to know me, we may become friends.

Do not help me, even if it does make you feel good.
Ask me if I need your help.
Let me show you how you can assist me.

Do not admire me.
A desire to live a full life does not warrant adoration.
Respect me, for respect presumes equality.

Do not tell, correct, and lead.
Listen, support, and follow.

Do not work on me.
Work with me!

Dedicated to the memory of Tracy Latimer
1995 © Norman Kunc and Emma Van der Klift

Executive Summary

The dominant disability support-service narrative of a skilled-worker shortage, high staff turnover, and the need for broad-based training has dominated the debate on the National Disability Insurance Scheme (NDIS) workforce issues. There is, however, a second narrative. Smaller user-directed service alternatives pay less attention to developing a workforce with pre-requisite skills and more attention to developing individual teams, which are selected, trained and directed by the service-users to meet their goals.

This pilot study compared the issues for support-workers within traditional and user-directed services in meeting the Objects and Principles of the NDIS. Using four services, two in Brisbane (Australia) and two in Queensland (Australian) regional centres, the study also explored possible differences in urban and regional settings.

The study found that all participants were committed to the Objects and Principles of the *National Disability Insurance Scheme Act 2013* and suggests that a process of, rather than a model of user-directed service

could be adopted by most services if they addressed some systemic challenges. The process has seven key steps:

1. Start with the person
2. Follow (and develop) their vision and plan
3. Make a good match between the person and support-worker
4. Get to know the person well
5. Build a relationship of trust
6. Solve problems quickly and locally and
7. Work towards the person's independence and resilience

The challenges for traditional services were investment in congregate care and pre-requisite training, arbitrary limitations placed on the work-place relationships, and hierarchical problem-solving approaches. The challenges for user-directed services were advantage afforded to empowered service-users; conflicts of interest for informal supporters; and increased time and energy burdens on service-users. Providing paid support in rural and remote areas raises challenges both traditional and user-directed services. Nevertheless, the process of user-direction and the use of enabling strategies

are as applicable in rural and remote areas
and as it is in urban areas.

The study identified strategies to enable
both the support-worker and the service-
user in the process of user-direction. Further
research in enabling strategies for the process
of user-direction would be helpful.

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Researchers' Notes

The research team sincerely thanks the participants—managers, support-workers, and service-users or their nominees—for their time, generosity, and interest in this study.

Participants' names and locations have been changed to protect their identities.

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Definitions

Service-user

A person with disability who is receiving paid support, or his or her nominee

Support-worker

A person who is paid to carry out specific support tasks for a person with disability

User-direction

The act by the person with disability (or his or her nominee) of directing the type and quality of support they receive (This might include choosing, training, and directing the support-workers)

User-management

The act by the person with disability (or his or her nominee) of managing all facets of the support service they receive (This includes the direct employment or contracting of support-workers)

1. Introduction

I'm here to help: the role of the support worker in the National Disability Insurance Scheme was a pilot study which compared the issues facing support-workers within traditional and user-directed services in meeting the Objects and Principles of the National Disability Insurance Scheme (NDIS). The purpose of the study was to trial the methodology and to obtain a limited data-set to inform a (possible) larger national study.

Most studies on the implementation of the NDIS have focused on the basic tenets of "choice and control". This study extended the idea by exploring the Objects and Principles of the *National Disability Insurance Scheme (NDIS) Act 2013*, and by proposing five service-quality indicators to guide how "choice and control" can best be achieved.

Structure of the report

Chapter 1 gives the historical context for the provision of formal support to people with disability in Australia and identifies two

narratives that have emerged: the dominant narrative of the traditional service sector, and a secondary, less-known narrative of established user-directed service alternatives. It gives a brief overview of the NDIS and flags some future issues for both traditional services and user-driven services within a market-driven environment.

Chapter 2 outlines the research design, including the aims, methods and sensitising concepts. It proposes, as one of these concepts, a set of five service-quality indicators derived from the Objects and Principles of the *National Disability Insurance Scheme (NDIS) Act 2013*.

Chapters 3 and 4 report on the findings of the research. Chapter 3 compares the issues for support-workers in traditional and user-directed services, and Chapter 4 reports on the implications for support-workers in working towards the five service-quality indicators.

Chapter 5 proposes a process of user-direction which might guide support-workers

who are supporting people with disability and their families who direct their own services and suggests some strategies that enable the support-workers in their roles.

Historical context

Prior to the national reforms arising from the Handicapped Programs Review (1985), the provision of services to people with disability in Australia were, in the main, provided by charities established by worthy citizens, families of people with disability, or religious organisations. Governments took a hands-off approach; their limited funding programs lacked a cohesive policy direction; and the lack of information about what these services did, and who they served, impeded the development of a co-ordinated and coherent response to the needs of people with disability and their families (Lindsay, 1996).

A growing awareness of the social model of disability (Finkelstein, 1981), and the concepts of normalisation (Wolfensberger & Nirje, 1972) and (later) Social Role Valorisation (Wolfensberger, 2011) began to challenge the congregated and custodial responses to people with disability, and the government, service provider and broader community world-view of what was possible. Of particular concern was the lack

of influence that people with disability and their families had over the direction of their lives, and their exclusion from mainstream economic and social life (Lindsay, 1996).

The *Disability Services Act 1986* provided the much-needed national policy direction for Commonwealth-funded services. Its Principles and Objectives described its purpose as working towards the greater integration and participation of people with disability in community life, increasing independence, employment opportunities and community integration; and enhancing positive self-image and esteem (Commonwealth of Australia, 1986; Office of Disability, 1987). Although these reforms had bipartisan political support and were initially well-accepted by the broader community, the responsibility for change remained in the hands of the non-government service sector. Many service providers were reluctant to change, having invested heavily in residential and training facilities and professionalised staffing structures over a long period. Furthermore, many families were frightened that they would lose what little support they had already acquired.

New programs relied on organisations’ submissions to the Commonwealth Government as funding became available.

Inevitably, there was an inadequate and inequitable distribution of funds. The devolvement of some of the programs to the States and Territories in 1992 exacerbated this situation, and obfuscated efforts to obtain reliable data on who received support and who did not. The result was widespread program dysfunction and unmet need (Baume & Kay, 1995; Lindsay, 1996). In spite of the reform agenda of the *Disability Services Act 1986*, and the best efforts of many professionals, people with disability remained beholden to a dysfunctional specialist service system. They had little choice and control over the type and quality of service they received, and little recourse through government intervention. The new policy agenda did, however, catalyse many people with disability, and their family members and allies, to imagine how their lives could be improved (Office of Disability, 1987). As a result, a number of small service alternatives were established in the 1990s, which allowed people with disability and their families to design and direct their own service.

The West Australian Government, through its *Disability Services Act (1993)*, led the way by providing people with disability and their families with small amounts of funding to purchase their own support, under the guidance of the Local Area Co-

ordinators. Individuals could plan a mix of ongoing paid support and one-off purchases to complement the informal supports that were already in place (Lord & Hutchison, 2003). Another example was Mamre Association Inc (2014) in Queensland, which transferred funding directly to families for them to manage. With the assistance from key workers, families bought what they needed. They were encouraged to envision what they considered to be a 'good life', and to plan a mix of paid and unpaid support towards their individual goals. In response to the failure of the traditional service system to support 'an ordinary quality life' (Hole, 2007, p. v) for their adult children, a small group of families in Brisbane (Australia) established Homes West Association Incorporated in 1990. This family-governed service delegated authority to people with disability to direct their support service, with the assistance of their families, so they could live in a home of their own and to adopt a lifestyle of their choosing.

These and similar initiatives that delegated authority to service-users to direct their own service developed across Australia. They demonstrated unequivocally that people with disability with their families could direct their own service and their lives could be significantly improved by this approach (Burke, 2012; Dyke, 2013; Kendrick, 2011).

As noted earlier, these service alternatives were developed by people with disability, their families and allies who rejected the traditional service system. They rarely attracted attention and, with the exception of the West Australian government’s initiative (Lord & Hutchison, 2003), their achievements were poorly documented. They appeared also to have little impact on the traditional services they had originally rejected. Kendrick (2009) explains:

Since very few services in the present era are actually steered by service-users acting on free agency, [user-directed] arrangements are outside the usual experience of most administrators and professionals, making it extremely difficult for them to imagine anything other than what they have seen thus far. (p. 92)

Kendrick suggests that, along with the legacy of capital and human resource investments, traditional services were hampered by their hierarchical administration, complex methods of operation, and the professionalisation of decision-makers who were often distanced from the people they served. These traditional organisations serviced many people with disability for generations; they had little concept of an alternative, and

were considered by the organisations as “permanent entities” (p. 91).

The broader community, however, witnessed significant progress for people with disability since 1986. The social inclusion of all people has become a policy cornerstone (Australian Government, 2012). The importance of informal networks in the lives of people with disability is now acknowledged, and with it, comes a greater understanding of the tensions between rights and protection (Young & Quibell, 2000). The idea of citizenship is inextricably linked to having a home of one’s own, a family, work, leisure, and opportunities for meaningful contribution (Shakespeare, 2006). Anti-discrimination legislation (Australian Government, 1992), State and Territory guardianship legislation, and the ratification by Australia of the United Nations Convention on the Rights of People with Disabilities (United Nations, 2007) provide a legislative framework for inclusion, familial relationships and citizenship (Australian Government, 2011). Further, researchers have a more sophisticated understanding of the consequences of congregate care (Bigby, Knox, Beadle-Brown, Clement, & Mansell, 2012; Chenoweth, 2000; Epstein-Frisch, Van Dam, & Chenoweth, 2006). These developments serve to highlight the current day-to-day plight of people with disability

and their families who have little or no support from a dysfunctional service system and few opportunities for self-determination.

In 2009, the Shut-Out Report, a national review to prepare for a national disability strategy, described the service sector as "irretrievably broken and broke, chronically under-funded and under-resourced, crisis driven, struggling against a vast tide of unmet need" (National People with Disabilities and Carer Council, 2009, p. 19). The Commonwealth Government appointed the Disability Investment Group (2009), followed by the Productivity Commission (2011) to advise on an economically sustainable plan for reform.

The outcome was the National Disability Insurance Scheme (NDIS) to "enhance the quality of life and increase economic and social participation for people with disability and their carers" (Productivity Commission, 2011, p. 93). The ensuing *National Disability Insurance Scheme (NDIS) Act (2013)* entitled people with disability to reasonable and necessary supports throughout their lifetime, and offered individuals' choice and control over how these supports would be provided. It embraced an insurance model that aimed to be financially sustainable in the long-term by focussing on prevention, early

intervention, independence, and economic and social inclusion. The *NDIS Act (2013)* sets out some objects and principles (See Appendix 3.) to guide its implementation. For traditional services, the NDIS is seen as "a fundamental shift in social policy and require[s] a parallel transformation in the structure and nature of the workforce needed to implement it" (National Disability Services, 2014, p. 1). For the user-directed service alternatives, the NDIS constitutes more an institutionalisation of their current practices than a fundamental policy shift.

Two narratives

Two narratives have emerged with regard to the implementation of the NDIS and the workforce that is affected, and these reflect this historical context. The main narrative, led by National Disability Services (NDS), the national peak body for non-government disability services, identifies imminent workforce risks. Traditional services anticipate workforce shortages (particularly in specialist, indigenous and rural and remote services), increased fragmentation of jobs; a lack of appropriately skilled workers; and a decline in the capacity and number of informal carers (National Disability Services, 2014, p. 3).

From the viewpoint of service-users, the quality of traditional disability services is already in question and needing reform. The current system is inequitable, of poor quality, and offering little choice or flexibility. Most services are centred on organisational needs, rather than responding to the needs and aspirations of the individuals they serve (National People with Disabilities and Carer Council, 2009, p. 19).

Service-users in these traditional services also report significant workforce issues, including poorly trained support-workers who, in turn, provide inadequate and poor-quality service. The turnover of staff is considered unacceptably high, suggesting that the sector is having difficulty in attracting and retaining quality and qualified staff. This is considered a particular issue in rural and remote areas (National People with Disabilities and Carer Council, 2009; pp. 23-24).

An alternative narrative comes from the user-directed services. These services typically pay less attention to the development of a full-time workforce with pre-requisite training, and rely more on part-time and casual workers who are chosen and trained by the service-users to meet their particular needs (Burke, 2012; Hole, 2007). The trial sites of the NDIS now offer a range of opportunities to service-users, including

the receipt of payments to employ support-workers directly. Early indicators point to ready acceptance by service-users of the responsibility for directing their own service. They prefer support-workers who are trained on-the-job and value the choice and control afforded to them. Overall, they consider they receive a better quality service and have achieved better outcomes as a result (HDG Consulting Group, 2013).

Although established alternative user-driven services are small in size and comparatively few in number, they now have significant practice-knowledge with regard to user-direction and personalised support. Their practices serve to question the dominant narrative of the traditional services with regard to workforce risks, including investment in pre-requisite training, availability and conditions.

It is useful at this point to consider some ideas that have shaped support services, and the way in which decisions are made. Nearly forty years ago, Illich, McKnight, Zola, Caplan, and Shaiken (1977) argued that the task of “enabling those who lack the capacity to fend for themselves to lead fuller, safer and healthier lives” could be considered in two ways. It can be seen as a service where people are considered to need professional help, or as a service where people can craft a

good life for themselves with the guidance of others in trusting relationships.

Professionalised service

Illich et al. (1977) argue that the professionalisation of services emerged in the middle of last century when it was thought that people with disability could be fixed. "People had 'problems', experts had 'solutions' and scientists measured imponderables such as abilities and needs" (p. 11). This professionalisation necessitates people with disability to be identified by their deficits (for example, a person is paralysed and now unable to care for him- or herself) and to address these deficits, the professional requires the many tasks to be broken down to specific, singular and measurable components (for example, the person needs showering, bowel care, and skin care to a prescribed standard). Pre-requisite training and certification ensures that the professional will perform these tasks properly, and can transfer these skills across a wide range of people. The professional's self-worth is measured by their level of training, their length of service, and commensurate remuneration.

Crafted service

On the other hand, a user-directed service suggests a "crafting" of support to meet a person's "need or fancy" (Illich et al., 1977,

p. 17). Ideally, the support-worker comes unfettered by expectations or limitations, and works with people with disability to fulfil their personal plans and goals. Over time, support-workers learn how best to do this guided by service-users. Support-workers gain trust by getting to know the people well, by following their direction, and by assisting them to discern what is best for them within the complexity of their personal relationships, capacities, and situations. Given that support-workers are properly remunerated for their work, they measure self-worth more through their achievements, problem solving and trust building with people with disability, their family and allies.

Crafted professional service

Illich et al. (1977) suggest that there is also a middle ground. There can be a liberalisation of professionals so that they can bring particular skills to the process of working closely with individual people with disability over an extended time. Professionals and service-users build an understanding and trust so that, together, they can discern the best action/s to take.

The direction of the NDIS and future issues

As previously noted, the NDIS provides people with disability with certainty of

reasonable and necessary support and the opportunity “to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports” (Australian Government, 2013, Clause 3 1d, & 1e).

Service-users are required to have a plan that can be revisited at any time, and a number of options for its implementation (Disability Care Australia, 2013). For example, they can:

- decide to manage their plan themselves
- nominate another person—a ‘plan nominee’—to manage their plan
- choose to use a registered plan-management provider
- ask NDIA to manage the plan for them or
- choose a combination of these options

The NDIS not only offers service-users choice and control, but also the capacity to review their situations. Most importantly, the NDIS shifts the authority of service-direction from the service-provider to the service-user. Support services are now required to respond to a user-driven market, and that market is anticipated to change as people with disability imagine a better life for themselves.

The NDIS has yet to be fully implemented and evaluated. The universal support for the program and the anticipation of significant new funding has hampered reflection on its possible shortcomings. The British

experience of increasing choice and control for older people and people with disability does suggest that there are some issues ahead for the Australian context. The market-style mechanisms for exercising choice are likely to benefit those with the capacity to envision a good life for themselves, and to plan and direct their support accordingly; however, they may do little for those who do not have this capacity, are socially isolated, and/or have come to accept a less than optimal lifestyle after years of struggle and disempowerment. Furthermore, people with disability will make decisions, in most cases, with the help of family and friends. The outcomes and benefits for individuals and this broader network might not always align and, within this individualised user-directed model, there are few mechanisms to address any conflict of interest. Finally, individualised responses might not benefit from the economies of scale provided by larger services, and leave people with disability and their families relatively time-poor and energy-depleted (Glendinning, 2008).

Nevertheless, it is generally accepted that greater choice and control over one’s own support will increase personal autonomy, and that personal autonomy is fundamental to achieving citizenship, human rights, and social inclusion (Shakespeare, 2006). Families and friends are typically considered

to have the least conflict of interest among the many stakeholders in service provision with regard to the empowerment of people with disability (Kendrick, 2013) and the practice of user-direction has been found to build capacity and resilience in people with disability and their families (Lord & Hutchison, 2003).

So what is required of support-workers within this new paradigm? Will the support-workers who provide traditional services be able to transit to a user-directed model? Mentioned earlier, the NDIS Act (2013) offers some direction through a set of Objects and Principles guided by the UNCRPD and allied conventions (Australian Government, 2013, Sections 3-4, Clauses 3-7) (See Appendix 3). The success of funded support through the NDIS could therefore be assessed against these Objects and Principles. To this end, this study derives five service-quality indicators from the Objects and Principles to provide a framework within which to consider the issues facing support-workers as follows:

1. Dignity, privacy, and self-determination
2. Social and economic inclusion in mainstream community
3. Capacity for innovation and responsive change
4. Respect for informal networks and
5. Safety of the person with disability

These indicators are outlined in full in the following sections which compare the issues for support-workers generally, and within this service-quality framework.

2. Research Design

At the time of the study, significant change was occurring within the disability sector, as all services prepared to implement the NDIS. This pilot study used four cases of service provision to explore the issues facing support-workers: two traditional services and two user-directed services—all with over fifteen years' experience. The researchers anticipated that, because of their maturity and experience, these services would add to the understanding of the workforce issues for support-workers gained from the more recent evaluations within the NDIS trials. Further, the previously mentioned service-quality indicators, derived from the Objects and Principles of the *NDIS Act (2013)* provided a more complex theoretical framework to consider the role of the support-worker within the NDIS.

Aims

The study asks:

- What are the issues for support-workers in traditional services and user-directed services?

- What will challenge their efforts to meet the Objects and Principles of the *NDIS Act (2013)*?
- What might enable their performance?

Method

This qualitative study uses four cases: two traditional cases that direct the services provided for people with disability, and two cases where users have been delegated the authority to direct their own services. This multi-case method compares traditional services with user-driven services, and urban (Brisbane, Australia) settings with regional (Australian) settings (See *Figure 1*).

Data selection

The study uses three embedded units of analysis: the perspectives of the service manager; perspectives of the support-worker; and the perspectives of the service-user (See *Figure 2*).

The four service organisations are based in Queensland (Australia). They currently receive funding under the *Queensland Disability Services Act (2006)*, and intend to

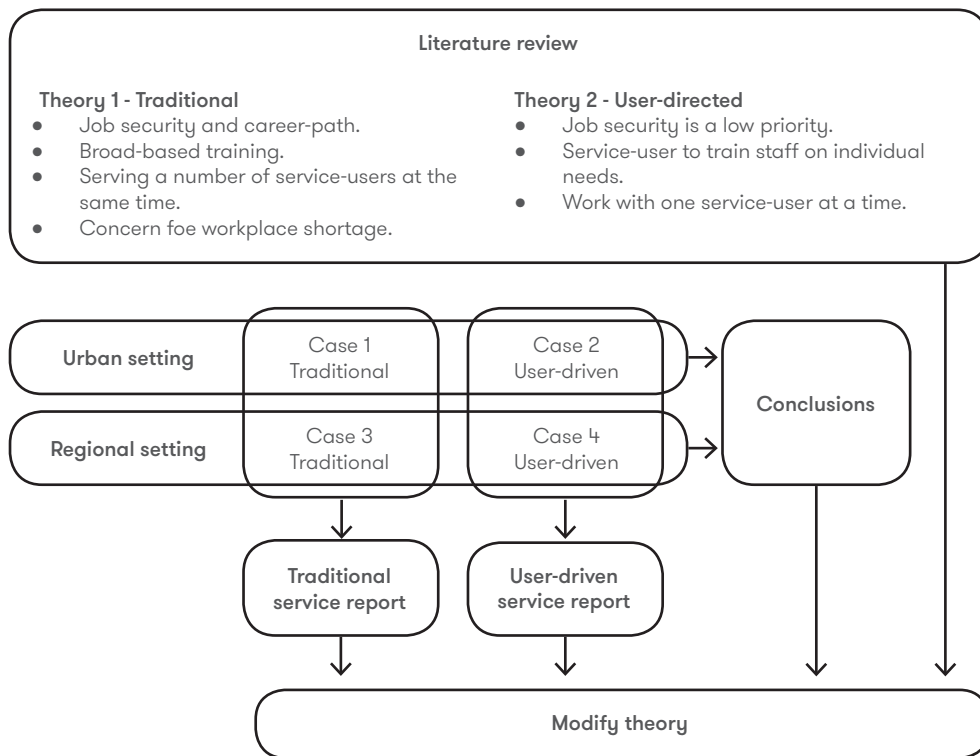


Figure 1. Multi-case design in both regional and urban settings

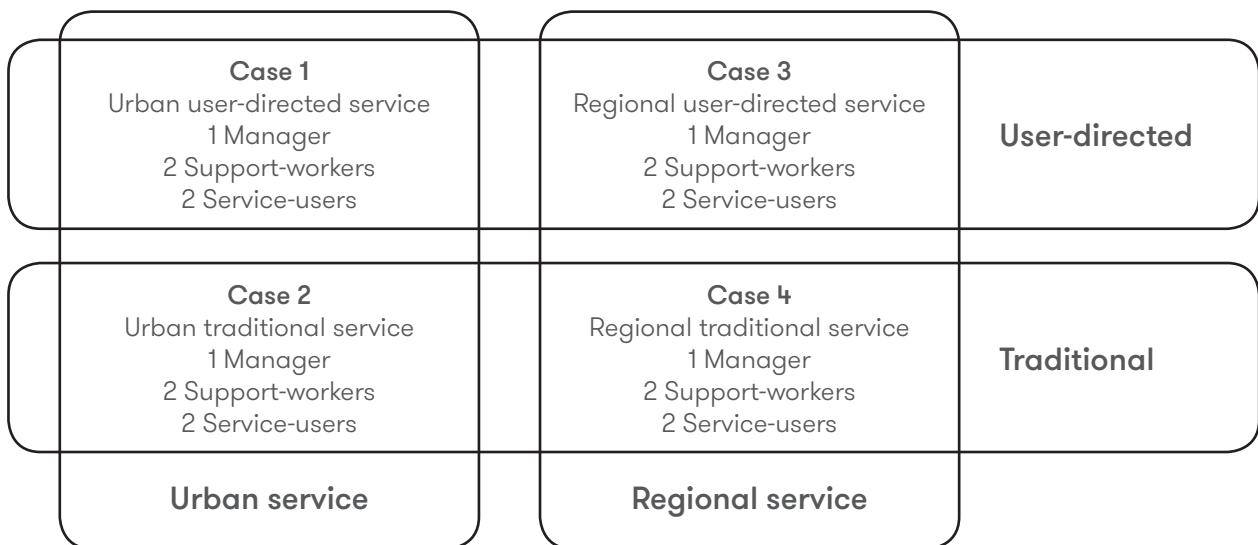


Figure 2. Multi-case design with two embedded units of analysis

continue to provide services under the *NDIS Act* (2013). The four cases were chosen for their particular features, which are described below.

Urban setting

Case 1: user-directed

The urban user-directed service case assists people with disability or their families who currently receive a funding package to direct or manage their services. In this sense it either holds the funds to pay the support-workers or it transfers the funds into the service-users' accounts for them to manage. It attracts service-users who want to make their own decisions about the type and quality of support they receive. It offers varying levels of support, which are negotiated with the service-user or a family member on a 'user pays' basis, and are formalised in a written agreement. This level of support can vary according to the service-user's requirements.

Case 2: traditional

The urban traditional service case currently provides support in residential facilities, in private homes, and in community activities. The support-workers are employed by the service and are given broad-based training before they enter the organisation's workforce. People with disability and their families are given some opportunity to

choose which support-workers would best suit their needs, and to change them if they consider them unsuitable.

Regional setting

Case 3: user-directed

The regional user-directed service currently supports people with disability in their own homes, and in their community activities. The service employs individual teams of support-workers who have been chosen by the service-users. With the active involvement of the service, the service-users and their families train and direct the support-workers. These support-workers rarely work for more than one service-user within that service.

Case 4: traditional

The regional traditional service currently supports people in residential facilities, in their own homes, and in community activities. Its support-workers are given broad-based training before they enter the organisation's workforce, and work across the service types; for example, in its residential facilities, in service-users' homes, and in community settings. Service-users and family members are invited to sit on the service's interview panels for the appointment of new staff. When placing the support-workers within the service, effort is made to match the interests of support-workers and service-users. Service-users can

request a change if they consider a support-worker to be unsuited to their needs. This is more difficult to do in the congregated care settings.

Each service-manager provided the names of four service-users and four support-workers who agreed to participate in the study. The research team then randomly chose two participants from each group. (See Appendix 1)

Data collection

The study collected data from:

- Publicly available information provided to support-workers from each service and
- Semi-structured interviews with:
 - 4 service-managers
 - 8 support-workers and
 - 8 service-users (or their nominees)

Data analysis

The interviews were transcribed and coded (using NVivo10) into themes and categories within the interview questions (See Appendix 2). All documents were also analysed and similarly coded.

The collection and analysis of the data within these four case studies were guided by three sensitising concepts (Blumer, 1954):

- Dahler-Larsen’s (2001) constructivist program theory

- Quality indicators identified within the Objects and Principles of the NDIS Act (2013) (See p. 13) and
- Kendrick’s (2004, 2011) levels of substantive empowerment

Constructivist program theory

Constructivist program theory provides a framework for an understanding of how individual agents can affect a program or initiative, in this case, the provision of support in accordance with the NDIS Objects and Principles. In the NDIS setting, the framework suggests that direct support-workers can either help or inhibit their organisation to achieve suitable outcomes for service-users, and that enabling strategies could be employed to assist them to do better.

There are other influences that are independent of the service (such as the family life of a person, or a particular society’s capacity for social inclusion) that might negatively impact on user outcomes. These influences should also be acknowledged. On occasions, however, the service can have an impact on external issues and *vice versa*; for example, a good service might be able to ameliorate poor social acceptance (See *Figure 3*).

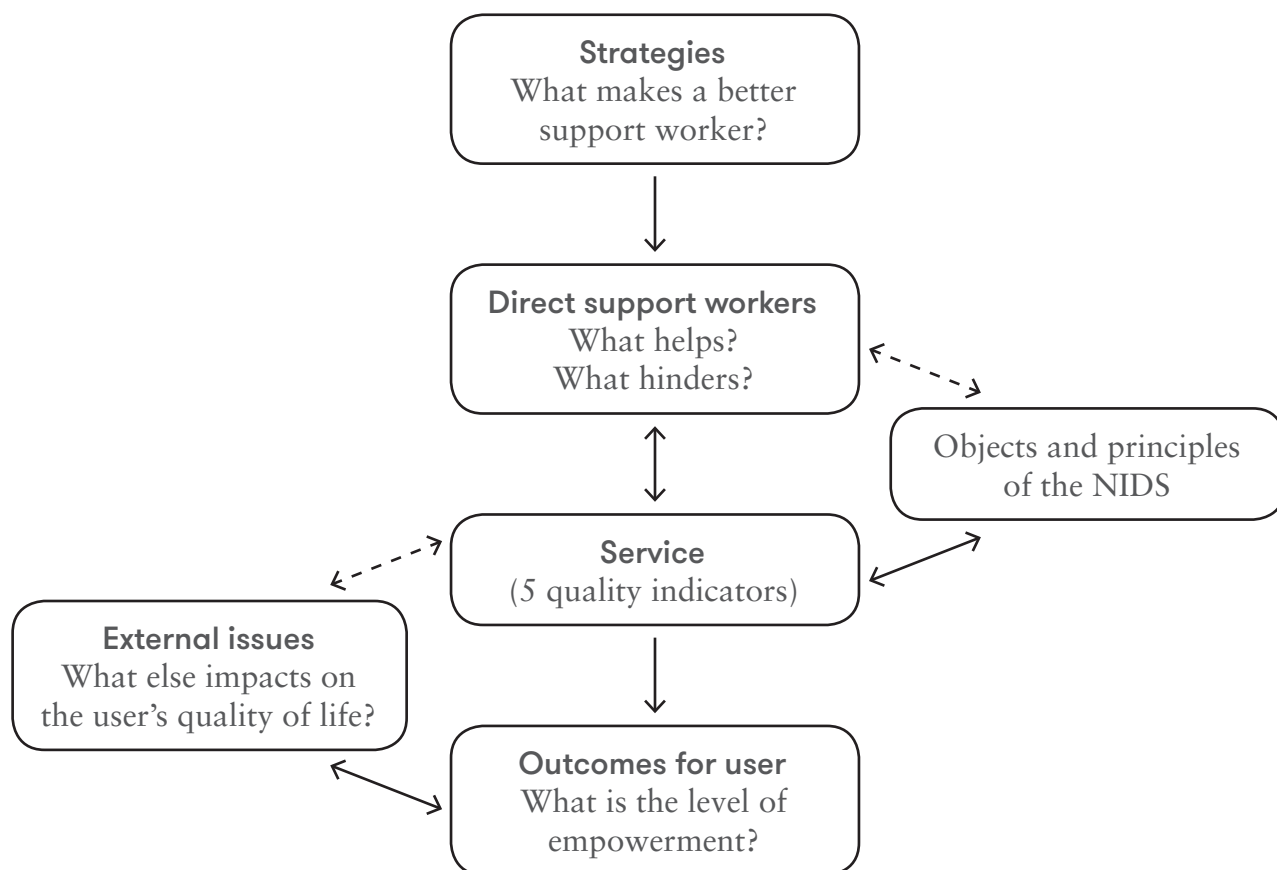


Figure 3. Elements of the study: constructivist program theory

NDIS service-quality indicators

The study proposed five indicators of service-quality based on the Objects and Principles of the *NDIS Act (2013)* (See Appendix 3):

1. Dignity, privacy, and self-determination

The service respects the plans and aspirations of the person with disability, supports reasonable risk-taking, and safeguards privacy and personal dignity (Section 4: Clauses 4, 8, 10).

2. Social and economic inclusion in mainstream community

The service optimises opportunities for

equity, independence, engagement, and social and economic inclusion of the person with disability in mainstream community (Section 3, Clause 1(c); Section 4, Clauses 1, 2).

3. Capacity for innovation and responsive change

The service innovates and continuously improves its efforts to meet the individual needs of the person with disability, and

to implement contemporary best practice (Section 4: Clauses 4, 15).

4. Respect for informal networks

The service recognises, respects, and works constructively in supportive relationships with the person with disability, and with their friends who have informal connections with them [Section 4: Clauses 12, 16; Section 5(e)].

5. Safety of the person with disability

In its activities, the service safeguards the person with disability from abuse, neglect, exploitation and misunderstanding, and provides assistance in investigating their grievances (Section 4: Clauses 6, 7, 9).

These indicators were used to interpret the implications of the Objects and Principles of the *NDIS Act (2013)* for support-workers in their day-to-day practice.

Levels of substantive empowerment

Accepting the perspective of the NDIS that people need to exercise choice and control over their lives, Kendrick (2004) offers a framework for assessing the level to which service-users are empowered to make decisions, that is, to the extent they are “actually being enabled to make a significant difference, *through their own actions*, on the character of the service they are receiving” (p.

6). Kendrick suggests there is a continuum of empowerment, rather than an absolute; the study used his simple six-level empowerment scale:

Level 1.

The person does not make any substantive decisions about his or her service.

Level 2.

The person does not make any substantive decisions about his or her service, but is routinely informed about the decisions others make on his or her behalf.

Level 3.

Actual decision-makers routinely consult service-users about their personal service.

Level 4.

The person begins to personally and routinely make *a significant minority* (in statistical terms, this might range from 25%-45%) of the substantive decisions relating to their personal service.

Level 5.

The person routinely begins to make *a significant majority* (in statistical terms, this might range from 55%-90%) of the substantive decisions relating to their personal service.

Level 6.

The person is making the vast majority of key decisions so routinely that they simply no longer believe that there is an "empowerment" issue.

This framework was used as a "ready-reckoner" of the level of empowerment perceived to be attained by the users of each service.

3.

Issues for Support-workers in Traditional and User-directed Services

When comparing the issues for support-workers in traditional services and user-directed services, the participants were asked three questions:

- What makes a good support-worker?
- What impedes the performance of a support-worker?
- What might assist a support-worker to improve their performance?

What makes a good support-worker?

Three themes emerged:

- Aptitude for the work
- Good match with the service-user
- Capacity to manage relationships

Aptitude for the work

A constant theme was that support-workers are most effective when they come with a willingness to serve, a respect for people with disability as fellow citizens, and a commitment to their development as human beings. A support-worker summarised these attributes when he said:

Do to others as you would wish them to do to you—as far as this job is

concerned, that phrase just fits it in. You’re just giving human dignity back to someone who has lost some sort of ability.

Participants consistently identified trustworthiness, respect, common sense and confidentiality as important personal attributes of a support-worker. These attributes cannot be taught, and the challenge is to find ways to identify them in a candidate before an investment of training and orientation are made. All the support-workers interviewed came to this field of work through “life circumstances” rather than as a considered career choice. Some were surprised at the initial idea of working as a support-worker, and were pleased to discover that they were suited to the work. A support-worker explained:

My marriage had broken down so I had to support myself. . . . I didn’t know much about people with disabilities, or I didn’t know anything really. . . And then someone took me to the information night at [the service], and the thing that

*stood out to me was [service]'s motto. .
. I thought 'I can do this job'. <laughs>
So I applied for it and I got a job. It's
amazing, I love it!*

In the appointment, training and employment of support-workers, two points of difference among the cases emerged: how support-workers were matched to the task; and how they managed relationships. These differences are detailed below.

Good match with the service-user

The traditional services valued the capacity of the support-worker to be compatible with a wide cross-section of people, at the same time offering the service-user some choice within a limited selection. The user-directed services, on the other hand, gave priority to the compatibility of a particular support-worker and service-user, by delegating authority to the service-user to select, train and direct their own team of support-workers.

A support-worker from a traditional service her skills and attributes suited her working with a number of people at the same time:

I think just my positivity and just general bubbly nature makes me suited to working with people who otherwise might be a bit down because they might

have a disability and find that hard to live with.

In contrast, a support-worker from a user-directed service explained the importance of relating well with the one person she supported and getting to know her well:

I'm instant with her, absolutely. As soon as I met her, I knew that this will be fine and this is where I'm supposed to be. But it did take a little bit to get to know her, you know, and [I thought], "Was that, like oh, is that a worry? Or no, you're being silly, forget it." So once we got to know our personalities, she got to know mine, I got to know hers, we were fine.

Capacity to manage relationships

The traditional services preferred that support-workers maintain a friendly, yet professional relationship with the person with disability and their family. A traditional service manager explained the importance of maintaining this professional distance:

So you have to be able to connect yourself and be intimate with the family, but be able to detach yourself enough so that you're not a hindrance in some of their decision making . . . so it's a constant juggle I think at times

for support-workers—because you are in a deeply intimate role but you’re being asked to continually maintain professional boundaries.

One service-user in a traditional service suggested that he preferred to maintain some distance in his relationship with his support-workers, as his busy life was full of relationships already. He expected support-workers to do their job and the service to train them adequately. Nevertheless, the effectiveness of his service did depend on a meaningful, close relationship with the manager of the service:

Like she went away a couple of weeks . . . and it kind of all went to [pieces] during that time. I mean, everything still happened . . . but the communication between staff, and us knowing what was going on, it wasn’t very good . . . [and it] actually caused a lot of upset in our house with our workers.

Support-workers from the user-directed services differed on this issue; they valued the challenge of managing complex relationships, not only with the service-users and their family, but also with other members of the team around the service-user. A support-worker described how her capacity to manage and maintain these

relationships was not only valued, but paramount in the person’s wellbeing and community connections:

We can be randomly somewhere and they’ll say, “Hello Joan.” I think that comes from [knowing] her mum. Or they’ll say, “That’s Beryl’s Joan isn’t it?” I go, “Yeah.” They go, “Oh gosh I knew Beryl” and whatever. So you get them sort of people. That can happen regularly . . . always the connection with Mum.

Yeah, and we’re the team, we’re her team, and the office gets involved. They’re fantastic; they’re there at the end of the phone all the time, just concerns and yeah.

What impedes the performance of a support-worker?

When participants were asked, “What gets in the way of support-workers doing a good job?” four themes emerged:

- An assumption that broad-based training provides professional authority
- Limited meaningful relationships between user and worker
- Perceived lack-of-purpose for the support
- A fear of taking risks

These themes were evident in both traditional and user-directed services.

An assumption that broad-based training provides professional authority

The participants in the user-directed services expressed concern about the value of the current broad-based training in the area of disability support. The manager in one user-directed service took a "hands-off" approach and delegated the authority for training to the person with disability or their family. The manager in the other user-directed service considered this more a collaborative effort; once the support-worker was appointed, the service worked with the service-user, the family and the support-worker to develop the particular support strategy.

Service-users identified there were difficulties in employing support-workers who arbitrarily transferred their practice knowledge from one person to another. One parent expressed her frustration about support workers who would not follow her directions:

There is nothing worse than when someone comes in and we're trying to train them and they say "Oh, I've done that. Oh you don't need to show me that, I've done that"—because Michael's needs are very complicated.

She described how a traditional service that she used found it difficult to accept her knowledge and experience with regard to her son's needs:

I feel as if they get the impression that I try to take over and I don't. I've been called a radical mother and I'm not that, I just want the best for my son, that's all. I just want the best care ever for him <sighs>.

One traditional service manager conceded that broad-based training was limited in its effectiveness:

We went through a real process of training people very well and saying the training was the most important thing. We've reassessed that and we don't believe that that has worked as well as—. You know, it's been counterintuitive, but people with disability have said that for years. So there's no surprise there, but I think we've disproved our own theory.

The other traditional service manager, however, took the opposite stance. He understood that many good support-workers came without training, and that broad-based training and certification was the key strategy for their career development:

We will employ people who have had no background in the field. So I think [we are] moving into an era where you will have to have a Certificate 3 or a Certificate 4 in disabilities and I think that’s great in terms of professionalising the field so that it actually does get the respect that it deserves.

Limiting of meaningful relationships between service-user and support-worker

Each service had a different strategy for the management of relationships between support-workers and service-users. A common theme, however, was support-workers’ yearning to develop meaningful relationships with service-users and, for most service-users, this was reciprocated. While participants acknowledged that these relationships could become problematic, both service-users and support-workers considered that better outcomes were obtained by allowing relationships to develop and addressing any issues as they arose, than by maintaining a “professional” distance. A support-worker in a traditional service gave an example:

We are specifically trained not to [hug]. You have to take hold of their hand or touch them on the shoulder—there’s no hugging. Whereas to me, if a client opens up their arms and wants a hug,

I’m going to hug. That is what upsets me a lot because, I think, when I leave at the end of the night, the last person that some of them might see is me and the last thing they had was a handshake instead of a hug.

Participants in both of the traditional services acknowledged there was a legacy of fractured and untrusting relationships between the service and service-users. Building trust was difficult for them. An older parent described her experience:

You used to be excluded and back then I didn’t know any better so I never asked many questions either. But by crikey, you soon learn if you don’t ask and don’t get involved you’re just left by the wayside.

Her strategy had been to remain involved in her son’s service; however, respectful relationship-building between support-worker, service-user and the family remained difficult:

The support-workers just don’t turn up for so many days and I [saw] Craig get really cranky. And they said, “Why is he cranky?” and I said, “Well, so and so went on holidays. Did they tell Craig they weren’t going to be here for a couple of weeks?—No.” I said, “Well if

you go on holidays, you tell your mates, don't you? They want to know."

The traditional service manager explained how maintaining professional distance was difficult for dedicated support workers: *[It] is very difficult because when you're in the support-worker role you're trying to build solid relationships with families.*

The user-directed services, on the other hand, considered that good support could not be provided until the support-worker knew the service-user well, and had built a trusting relationship with them. A support-worker explained how he could make important decisions about safety because he knew the person well:

We had a safety issue a few months ago now –we were going up a [travelator] and he put his wheelchair in reverse. There was a bank of people behind us just building up. I had to come around the front and move the chair and if I didn't have . . . rapport with him you know he would have told me to bugger off. But he trusted me because we have built that relationship up.

The manager of a user-directed service summed up the fundamental importance of trusting relationships for people with

disability, who need direction and good judgement from their support-workers from time to time:

We encourage people to build relationship. . . How on earth are [people with disability] going to take the direction from you, if you haven't got a relationship with them? There are people in this place who could [have a problem], which could turn into a very big deal, in some public place. [The support-worker] might need to say, "That just needs to stop right now." Because it comes from such a basis of relationship, it's not someone being bossy . . . it's someone saying, "You need to pull this in." [There's] something powerful about that, what you can do and how you can be with people once you've proven that you're worthwhile, that you've got something to offer that person.

She summed up this dilemma of "How far do you go?" with relationships by suggesting that an element of chaos is inevitable when working closely and effectively with people who require support, and that setting arbitrary professional boundaries will inevitably fail:

So this idea that to be professional, you have to not ever have a blurred boundary—I think there's a lot of blurred edges. But I think those blurred edges, as long as they're managed properly, are not a problem. When they become a problem, deal with it then. Not this don't, don't, don't.

Lack of purpose for the support

Each service understood the importance of goals and planning for the support provided, and that the lack of such direction resulted in poor outcomes for both service-user and support-worker. This was most evident when people were grouped in order to receive adequate support, and are affected by the support needs of the others. A parent in a traditional service said:

They do try and get out a fair bit but sometimes someone—like today, Mary's sick—so there'll be one person taking Mary to the doctor, then there'll be two looking after everyone else and trying to work out activities. So every day's different. You never know depending on what the situation is.

Even in individualised support, the service-user is at risk of his goals and plans being ignored. A support-worker described the

dilemma of a service-user who could not communicate well:

[The support-workers] are doing only half their job by going in and doing the mundane things like cleaning and washing clothes . . . this gentleman can't talk but his communication is still important to him . . . And a lot of people forget about it. You can't throw these people in a little corner and say, "Hey, sit there for the rest of your life." And that is what we tend to do sometimes.

Sometimes, the benefits from support-work may not be easily measured. A support-worker explained his need to change his expectations for improvement:

I was working on something for months and months and I would say, "Nothing is really happening." Then they would present me with all this progress, which they saw as big progress that we'd made. It's just on a different kind of time scale I think that I had to get used to—working on his time.

One manager of a traditional service cautioned that without explicit purpose and planned outcomes for their support, support-workers can disempower people with disability and their families. Indeed, they

can create further dependence and diminish resilience. He explained:

[With support] people can actually become less resilient rather than more resilient. They may physically have greater capability, but their capacity to be able to navigate their own lives in their own communities, in their own families, can be diminished.

He challenged his colleagues to examine their commitment to service-users' self-direction and empowerment:

The biggest challenge is looking at yourself in the mirror to say, "What am I really here for? Am I here because I'm handing over control to the person that I'm supporting and meeting what they want? What they choose?" Recognising choice is a two-edged sword. "Or am I here because I want to save them because I'm the expert and because that's what actually [feeds] my esteem?"

Fear of risk

The theme of risk-taking followed a similar pattern. The traditional services were more cautious about risk in general and used formal policies and procedures to manage it. The user-directed services, on the other hand, were generally willing to take greater risks,

and to consider particular risk issues on a case-by-case basis.

The limited individualised support available within the traditional congregated care environment could not respond to the safety needs of each service-user, thereby denying opportunities on safety grounds. A mother explained her son's experience:

At the moment Craig can't go to that hydrotherapy. Something happened with insurance . . . I forget how it works. Craig's not included in that scheme. He was for a little while but one of the therapists organised it, and then all of a sudden, no, he's not covered. I don't quite know what they mean. They just didn't get anyone—couldn't get anyone to go just with Craig because it's a "one on one" of course—swimming in the pool. I think they had trouble getting staff to do that sort of shift.

Arbitrary decisions regarding the safety of service-users were seen to undermine their personal dignity. In the example below, a support-worker explained how she was hampered in her efforts to problem-solve with an individual because of the service's inflexible risk-management strategy:

He needed a grocery item and one of the carers said, “No, it could wait until the next week.” But he wanted this grocery item and I think he would’ve been quite capable of going in his chair, the shop is just up the road from him, safe to cross, all on the same side, that he would’ve been quite capable of going and getting this grocery item by himself and coming back safely, quite capable.

But he’s not allowed to. He has no empowerment and I’ve asked on many occasions, “Would you do it?” he said “Of course I would” but he’s not allowed to go out and do it by himself.

The user-directed services, on the other hand, considered risk was best managed by knowing the person well and by making sound judgements at the time. Although all services are required to have formal risk-management strategies, these informal, person-by-person measures continued to be the most effective. As one manager said:

The [staff] who are here are the people who have got good judgment. So that, combined with that knowledge of the person, means that generally people are not putting themselves or people into risk situations.

We review every incident report, and we identify risks at every business meeting. We have a risk register that we look at and review and talk about every month. Before we ever had any of those gimmicks, for all the years that we’ve been doing this, embracing working with the most complex people, we’ve never had a major workplace health and safety claim.

One user-directed service devolved the responsibility of risk-management to the service-user, requiring only the basic requirements of employment and work-place safety to be in place. This was based on the understanding that service-users knew best how they should be supported, and sound support practice would result from this knowledge. The manager of this service explained why this typically worked well:

For the longest time we didn’t have any WorkCover claims through anybody that was self-directing—which was interesting. Because people were training [staff] the way they needed for themselves, we weren’t having those claims. . . It’s a very small percentage because it’s about a relationship.”

The manager of a traditional service, who had experience in both traditional and

user-directed services, considered that support-workers who were committed to empowering service-users usually gravitated to services where risk was managed by knowing the person well and by their taking responsibility for themselves:

The group of [support-workers] who are attracted to work in those less controlled environments, are also more interested about self-determination for the individuals they're supporting. So therefore they are self-determining themselves. They take responsibility for their own actions and don't assume that "an organisation has to make my environment safe for me, so therefore I don't have to think about is this a safe thing to do."

Restrictive staffing arrangements

Participants agreed that the best service was provided when the support-workers could respond flexibly and creatively to the service-users' needs. They identified that unexpected changes in staff, and the inability to respond to changes of circumstances were issues that got in the way of good service. A parent commented on the impact of unnecessary staff changes, without consideration being given to the established relationships:

Last year I think they decided to change the staff in Craig's house, put in new people and really mix and match it. It didn't work. It was terrible. Everyone was on edge, the clients felt it. You could see their facial expression—it was just awful. Everyone was getting cranky.

The manager of this traditional service suggested, however, that there were good reasons to change support-workers around; it kept them from becoming complacent, and tired or stale in their approach to their work. He explained:

So I'm constantly watching out for where staff are getting burnt out or where I can see they might be getting stale in their work and, as much as people hate change, sometimes I need to step in and make change and move people around to work with different families and individuals—so that that kind of fatigue doesn't become a negative influence around the person we're supporting.

One service-user switched from a traditional service to a user-directed service because she could not cope with the changes in personnel. She said: *I [used to] feel like, "Who's coming in today? Who's not coming in today?"* Another service-user complained

of the difficulties experienced when the service was inflexible:

It’s very frustrating . . . the worker that we have from [the traditional service] at the moment is excellent. He’s really good, but he’s having a lot of personal issues. We’re prepared to stand by him, and he’s done the right thing, but they, because of the way [the service] operates, [they] don’t have people that can back him up. So they’ll ring up and just say, “Sorry.”

Another service-user considered there was little point in trying to shape his traditional service to his particular needs: *I don’t argue with the support staff because if I argue with the support staff they just—either they won’t do it or they’ll just walk out.*

Creating and maintaining a suitable team of workers was considered difficult at the best of times, and the user-directed services also experienced some issues in this regard. One manager explained that the service-user might experience a turbulent time with a high turnover of staff until the team is established:

[With user-direction] there’s always a big turnover of staff to start off with, and it’s all that learning process where you’re

just going and working out what you need in your team and who you want there and having a look, and then you get all these great people and then it sort of stabilises.

She also indicated that even the best relationships can sour over time and support-workers can reach their ‘use-by’ date:

Familiarity—you know that term—breeds contempt. That happens as well. So people are there for a while and, before you know it, they want to take over . . . because of that rapport. You know, you [can] have such a good rapport that, that the boundaries get crossed.

What enables support-workers to improve their performance?

Five themes emerged:

- Clearly defined vision and plan for the support
- A good match with the service user
- Relationships built on trust
- An individually crafted support team
- Problem-solving strategies

Clearly defined vision and plan for the support

All participants in both traditional and user-directed services understood the importance

of having a vision and a plan for the support to be provided. Support-workers in the traditional services were required to work across a wide range of service-users and to adapt to each of their plans. The user-directed services used individual teams specifically chosen for, and by, the service-user, thereby allowing that team to have a deeper understanding of the service-user's vision and plan, and the purpose of the support. A manager said: *We recruit people to become experts on the person they're working with, not 'disability' experts.*

A good match with the service-user

Although participants in all cases acknowledged the value in matching a support-worker to the service-user, traditional services appeared to place greater value on the skill and capacity of a support-worker to adapt to a range of different service-users. User-directed services, on the other hand, gave priority to matching the support-worker's values, interests, and approach to life with those of a service-user and ultimately the service-user would know best who that might be.

Relationships built on trust

Although participants in all cases acknowledged the inevitability of relationships developing between support-workers and service-users, the user-directed

services used the development of trusting relationships as an intentional strategy to improve service quality and managed issues as they arose. The traditional services, in contrast, set limits to relationship development with training, policies and procedures.

An individually crafted support team

Although participants in all cases acknowledged the need to work in a team, user-directed services assisted individual service-users to craft their own team that could meet particular goals, and work well with their informal support networks. The traditional services, however, appeared to use team-building more to co-ordinate rosters and minimise staffing issues.

Problem-solving strategies

Both traditional and user-directed services understood the importance of problem-solving back-up for support-workers and service-users. The two traditional services required both support-workers and service-users to seek resolutions to problems through the services' management structure. The two user-directed services took different approaches: one service preferred a flat organisational structure and resolved issues through an ongoing consultative process with service-users and their families. The other offered assistance in problem-solving

on a user-pays basis within the service agreement to be used as required by the service-user.

Summary

The participants in the traditional and user-directed identified more issues in common for support-workers than separated them.

They were:

- Being able to respond to the service-users’ vision and plans
- Being matched well with the service-user
- Having the opportunity to know the service-user and their informal network well, to build a relationship of trust
- Having strategies to solve problems quickly and creatively

These issues point to a process of user-direction that could be used in any service model, which would address some of the impediments, such as the assumption that broad-based training provides professional authority, lack of purpose of the support. Structural policy changes would be required to address the fear of risk-taking and the arbitrary limiting of the development of relationships. The finding that support-workers are enabled in their work by developing trusting relationships and working in individually crafted teams also supports the idea of a process of user-

direction, which is proposed in the next chapter.

The report now considers the implications for support workers in meeting the proposed five service-quality indicators developed from the Objects and Principles of the *NDIS Act (2013)*.

4. The Implications of the NDIS Objects and Principles

The study considered the implications of the following service-quality indicators for support-workers in their day-to-day practice:

1. Dignity, privacy, and self-determination
2. Social and economic inclusion in mainstream community
3. Capacity for innovation and responsive change
4. Respect for informal networks and
5. Safety of the person with disability

1. Privacy, dignity and self-determination

Service-quality indicator

The service respects the plans and aspirations of the person with disability, supports reasonable risk-taking, and safeguards privacy and personal dignity.

All participants supported this service-quality indicator and considered it important for support-workers; however, its interpretation within the traditional and user-directed services differed. Service-users within the user-directed services typically came to the service with a considered vision and plan

for their life. A family member using a user-directed service explained why she now directs her own service: *I just believe that Toby deserved a good life. We've always held onto that dream that he would have a good life—and he has.* Another family member, who directed his brother's service, considered that the service-user also had a responsibility to meet this service-quality indicator by expressing his plans and aspirations:

Doug is just as much a member of [this family] as anybody else in the house. He has the same rights and privileges and duties in a way. He can't physically contribute very much but he is, I mean, his responsibility is to express himself and to be part of the process. And [to] let us know about his needs and his observations—what he likes and doesn't like.

The manager of one of the user-directed services considered that the responsibility for the vision and plan rested entirely with the service-user. She said:

If you didn’t have a disability, nobody would be coming in and telling you how to, you know, do those things, so it’s being really careful about that. And who says that they’re having a crummy life? . . . It might seem crummy to me, but, I just can’t make those calls really.

The other manager saw the development of a personal vision and plan to be a creative, collaborative process. She described how she worked with service-users:

I want to know what your passion is about and I want to know what you love to do and what your dreams are, and by the way, I see you’ve got these [problems] and we will need to work out how we’re going to get around them.

On the other hand, some participants in the traditional services had low expectations. An example came from a parent of the service-user in a group home. She described the extent of her son’s decision-making with regard to his daily routine:

They give him options. He’s always given options of most things. You’re not just having this for dinner. They are given choices and this is our menu for the week. [They ask,] “Is everyone

happy with that?” Most of the staff will go through everything in their day.

Participants in the traditional services reported that the service-users who had their own plans and vision, and who could negotiate well with the service got those plans implemented. One service-user explained: *I want to work. I want to do a whole bunch of other things that have nothing to do with managing my disability supports.* She went on to describe how the service was able to respond well more because of good management, than because of her personal direction:

We’re quite choosy and picky, so we always feel comfortable saying, “No, no, not that person,” or “No, no, not this person.” But in the last two years we’ve had a new [manager] who’s actually just thrown herself into the role quite well and is highly aware of our needs. I actually don’t think she would bring anyone to meet us that wouldn’t be suitable.

Two other service-users indicated that the traditional service model worked well because they had clearly defined needs and routines, and did many of their activities in the community independently.

Participants in all the cases suggested that without the service-users remaining vigilant about their plans, the services lost focus. One parent who directed her son's service described how quickly this could happen:

We've had problems in the past where two carers have come on . . . together it's like a talkfest. They haven't seen each other all weekend and they're standing over Michael and he's being rolled from one side to the other and I've really put my foot down there. I've said, "No, you're not treating him like that."

Another participant despaired at the support-workers' lack of basic communication skills, and at the fact that they were not taking the time to understand the service-user who could not speak up for himself:

A lot of carers do not take time to talk to the client—they tell the client what to do and they don't try to find out what the client wants. No matter how deep the disability is they still have their own rights. The biggest problem is a lot of people do not respect that—do not talk to them.

Participants identified that over and above having a clear vision and plan to work to, support-workers needed the time and

skills to communicate well, and regular opportunities to review what was important for the individual. One parent described her strategy of constant monitoring:

[I'd say,] "Try and put yourself in his shoes. How would you feel?" And they're all really, really good working with him with that in mind. I've got prompts everywhere written . . . to remind them about that.

Another parent explained how regular meetings kept everyone focused on what was important, and gave her son an opportunity to learn to speak up for himself:

They have team meetings—not staff meetings—they have team meetings. Then, if there are things that are being worked out, I'll often have little readings around different issues where they'll have Toby come in [to speak].

2. Social and economic inclusion in mainstream community

Service-quality indicator

The service optimises the independence, engagement, and social and economic inclusion of the person with disability in the mainstream community.

The participants supported this service-quality indicator and recognised that strategies for inclusion needed to take into account a service-user’s age, interests, and circumstances. For example, a young service-user expected her service to support her plans for economic independence:

We both have to get up and go to work, and if we can’t do that, then we’re just on the pension or we’re living very poor lives. So our roster is structured around our work responsibilities, and getting to work, and workers know that.

The support-worker of an older woman saw inclusion differently:

There are times you pick and choose her mood, where you take her, what you do. But there’s other times where you just, you think, “You know what, we’re going to be home today and we’re going to do some cooking.” . . . But as much as we can, whatever we’re invited to, we go for lunch . . . It’s all about keeping . . . Joan in the community—and it works.

Participants identified that sharing support got in the way of trying to include service-users in normal life. One parent described the limitations for service-users when they went into the community in groups:

You have to plan things for the whole group, or as much of the group as possible. But behaviours and things can get in the road of that being a perfect scenario, being able to do . . . things well. Because if someone decides on the day to act out or something, it spoils it for everybody else and it’s like you know, you may have to pack up and go home.

Participants acknowledged that service-users had more opportunities for inclusion when they had the active involvement of family and community networks. In this case, it was then a matter of building on opportunities as they arose. This required support-workers to recognise these opportunities and to take the time and initiative to build on them. A manager described how a young service-user’s life changed when the service organised for him to share his home with two flatmates:

That was amazing . . . to see how that man’s life just changed, as a result of having these lovely young people living with him. People who we’ve engaged . . . to build some kind of potential for a friendship, and help people get more connected into their communities . . . that is fabulous work.

The commitment of the service to social inclusion was also considered an important factor in meeting this indicator. To overcome the barriers of community apathy and the personal challenges of some service-users requires tenacity and a belief that all people belong. A manager of a user-directed service described how inclusion could be strategised and measured so that no-one becomes complacent:

[We ask], "What is the person doing when they're out and about? What are they doing? . . . I don't understand why people don't ask of every service how much development and growth has there been in the people you support this year? Because here we want that, that's the measurable thing, what's happening this year that this person could do they couldn't do last year?"

3. Capacity for innovation and responsive change

Service-quality indicator

The service innovates and continuously improves its efforts to meet the individual needs of the person with disability and to implement contemporary best practice.

All the participants supported this service-quality indicator and acknowledged that

a capacity for innovation and responsive change required a particular attitude. The traditional services identified that in order to meet individual needs, both staff and service-users would be required to change. One manager described how the organisation had already been challenged:

So sometimes we have to raise our own expectations of what the person can be involved in—so that we continue to look for more and more and more and engage them in different experiences rather than getting stuck into a bit of a rut. Because if you have some letdowns and you find something that works, often it's easy to get stuck with that and just go with what works.

In contrast, a user-directed service manager described how they were working to embrace change:

We just keep on saying there are possibilities, so that when people are ready, we're ready to step in. I think there's a saying that says good luck is when great planning meets opportunity. I think that's what we try and do. We set the scene up; we tell people what the possibilities are; we give them opportunities to know what that is. At

different points different people turn up with an idea that now is theirs. Yeehaa!

In traditional services, a legacy of mistrust as the result of past experiences appeared to get in the way of change. Some support-workers and service-users suggested that the service might not support change when an opportunity presented itself, because it did not do so previously. One support-worker in a traditional service said:

You can ask. You can email. You can make suggestions. They always say they have an open policy, but I find that there’s a scare factor—that you’re going to lose your job if you’re too forceful. So you tend to feel the waters. No response, you don’t push it, you just leave it.

On the other hand, a family member who had known the traditional service for many years could not contemplate the loss of any service that had been hard won:

Look, I’ve had so many ups and downs with the service over the years but I couldn’t have survived without them. . . . When I heard that . . . you could buy packages or buy services, my worry would be if I took [my son] away, where would he go? Who would look after

him then? . . . No way. Not now. No, I couldn’t go through that. No. No.

A support-worker within a user-directed service experienced a different problem. Although there was no hierarchical management to negotiate, a lack of communication with families could have a similar blocking effect: *People are quick to react to what they think is right instead of finding out what’s going on and then putting their two-bobs’ worth in—yeah, family.*

Participants identified that, for those who were nervous about change, good communication and regular discussions in a trusting environment allowed for innovation and change to be accepted over time. The manager of a user-directed service suggested that the service had an active role to play in assisting everyone to embrace change. She described her process:

Most of the families are prepared for a certain level of innovation, or a certain level of change, but you just have to be ready to pick up the opportunity when it comes.

4. Respect for family and informal networks

Service-quality indicator:

The service recognises, respects, and works constructively with those in supportive relationships, friendships, and informal connections with the person with disability.

All participants supported the involvement of families and friends. They acknowledged that many service-users and families had been hurt by the behaviour of services in the past. Participants acknowledged that these relationships were complex but valuable in service-users' lives. The strategies for working with families varied between a 'hands-off' approach to taking a caring paternalistic approach.

One user-directed service delegated all responsibility for the relationships between support-workers, families and service-users to the person directing the service. Consequently, apart from their relevance to the formalities of employment and workplace health and safety, the manager did not know (and had no wish to know) about these relationships or how well they were working. He explained: [*We don't actually know those workers because . . . the recruitment is up to the person or the family.*

So the attributes that they have—they could be anything. As noted earlier, the service-users who chose this service typically had rejected the traditional service system, made clear decisions about their vision and plan for service, and chosen this service because of this hands-off approach. In this sense, the service was wholly shaped by the requests of service-users.

The other user-directed service actively provided guidance and advice, even though they had delegated the authority to direct the service to the service-user. The service considered that working with everyone involved in a respectful and trusting relationship led to a better outcome for the service-user. As the manager said:

It's about the relationship we hold with the family and the individual. So all those things, it's like a dynamic tension, it's all the balls are going around like that, and that shapes how people work.

She acknowledged the complexity of working in this way, and that it was not an approach for everyone, as it required families to engage in the day-to-day service-user's support issues.

Both traditional services understood that they had a responsibility to work respectfully

with families. They also recognised that families were idiosyncratic by nature and required different approaches. The flexibility of approach, however, was limited by the capacity of support-workers who were already employed and the willingness of the family ‘to be helpful’. One support-worker said:

If you’ve got an excellent family who are willing to kind of embrace you as part of the family, it makes your job a lot easier and you feel a lot more comfortable with the client.

Again, the relationship with families became more difficult in situations where service-users were in congregate care. When a family member took an active role in the day-to-day activities of her son’s group home, she found she was more the voice of the support-workers within management, rather than a partner in the direction of her son’s support:

I think I’m their voice in some areas because I see and observe and I will go further up to get things noted and changed if I can because when the house is running well everyone’s happy, the clients are happy, the staff are happy, things get done better.

Participants identified that the complexity of these relationships was a factor that hampered attempts to meet this fourth service-quality indicator. One support-worker described his difficulty:

The families are there . . . then there’s the agency . . . and then the person. I’ve got, as a worker, really three loyalties that don’t match up really well all the time.

Participants wanted assistance and the time to manage relationships well. Even when service-users and their families chose their support-workers, these complex relationships still challenged them, particularly when they occurred in the private space of a home. One parent described her husband’s stress:

He doesn’t like—neither of us like—all of these people through our house but we can’t do anything about it. . . He said ‘I don’t want them through talking to me like that’.

Nevertheless, participants considered not having the authority to choose support-workers was more detrimental to service-users and their families. One family member compared the two levels of authority. She first described her experience with the traditional service system: *It was the system’s*

inability to respond, that was just—it just really irritated me. I couldn't believe it. She then outlined her vision: What we wanted was a life that our child could enjoy life as much as was humanly possible, and that the breaks for her came from natural opportunities experienced by other children. She described the solution as the situation where there are:

People who know you well, understand what the issues are for you, who build a proper relationship with you that is respectful, where your internalised locus of control is respected and supported, and where people have expectations of you and for you.

It was acknowledged that relationships with families improved when this “locus of control” was situated as closely as possible to the service-user. Service-users, families, and service-workers were more able to develop meaningful and trusting relationships when there were no arbitrary limits placed on these relationships.

5. Safety of the person

Service-quality indicator

In its activities, the service safeguards the person with disability from abuse, neglect and exploitation, and provides assistance

to pursue their grievances.

The participants in the four services acknowledged the need for safeguards within formal service provision, including the management of restrictive practices, workplace safety practices, and police checks. As noted earlier, the user-directed services focused their training strategies on meeting the needs of the individual service-user, whereas both traditional services invested more in pre-service training for their support-workers who worked with a wide variety of people.

All services acknowledged the importance of good personal values. A manager of a traditional service assigned priority to desirable personal values over experience when choosing staff:

We have desirable criteria around if you've had experience or if you've got any qualifications that might align but mostly we're looking for the values. That if we find people who are passionate, have integrity and respectful of others then we think we can provide the training that a support-worker would need.

The user-directed services relied on the discernment of service-users and families to

decide what were ‘good personal values’. The vigilance of all people involved in the support service was also identified as an important safeguard. One traditional service manager said:

What you need to have is a process that’s going to minimise the opportunity [to do wrong], or picks it up very, very quickly, so you can identify it and highlight it very quickly after that.

The other traditional manager acknowledged that his service relied on trust to a significant extent: *You can’t always have someone there supervising them—nor would you want that. You have to be able to trust in your support-workers that they’re doing the right thing and 99% of the time they are.* He also acknowledged that community inclusion provided a natural safeguard in the conduct of service initiatives in institutional settings:

It’s easier for a staff person to take advantage of a person with a disability when there’s no-one else around. I think that’s where our move to community has enhanced the safeguard of people with disability because when you’re in an institutional setting no one is there.

One user-directed service manager considered that vigilance was a team effort,

with the service and families working together—through a process of matching, training and trust-building—to use good judgement when required:

It starts from the matching, the recruitment. Then the induction process is all about joint work, keeping safe at work, the fact that we need people to use their judgement about the situation, and their knowledge of that person to keep them and the person safe.

There was an understanding of the importance of people in the community who knew the service-user well. One mother described how she intentionally built on that interest for future possible situations:

I love it when people come up to me and say, “I saw Toby out with . . . his worker.” Most times they just say he was having a great time. I said, “Yeah well, that’s really good.” I thank them, and I say, “Well, I’d hope that if you saw him and you were concerned about something, you’d come and tell me that as well.”

These natural networks appeared to be harder for the traditional services to develop. One support-worker in a traditional service described her dilemma when she

did not have enough informal contacts or information:

I know when I had to take a client to hospital and I tried to get hold of people and get information on my client there was none available so I had to just think out the box and do my own thing.

Participants indicated that one of the best safeguards was the confidence of service-users and their families to make changes to the service if they were not feeling safe. One service-user explained that she worked with her service to develop a plan for when her wheelchair broke down. Another service-user who used a traditional service relied more on mainstream assistance when he was in the community: *I've always got my mobile phone with me, and I can always contact the police if I was unsafe. I've got many [contacts] from the police and the City Council and that's all pretty good.*

Where service-users are not connected to community networks and have difficulty communicating, safeguards are more difficult to put in place. A parent explained that to rely on the service alone was not enough: *He's never indicated anything like [abuse] has ever happened to him. But then again . . . how would I know? He can't tell me.*

Service-users and families identified that the capacity to make changes to the service was an important safeguard in itself. The two traditional services aimed to respond promptly when a service-user complained. One service-user in a traditional service considered that the service listened to her and responded appropriately when she was not happy. Another was less confident and found that making changes was arduous and intimidating. Indeed, it was difficult to separate her son's issues from those of the staff in the group home:

I speak up if I see issues because when I'm in the house, so often I pick up on things that I see, observe, and I can tell that other staff members are getting uptight. But they don't want to upset the apple-cart, so I'm a voice for them too. [I] try not to overstep the mark as well.

Changes to the service were considered much easier when the service-user had the authority to direct the service; however, one parent acknowledged that the best outcomes were achieved through building good relationships with the support-workers in the first place.

I've always tried to develop that relationship with the support-workers where I've always said to them if

anything comes up for you, just come and talk to me . . . so I have generally not had too many problems . . . You get a few workers that haven’t worked out, I’ve always hated having to go and talk to them about that, and sometimes some of them have been a bit—they haven’t taken it very well. But Toby’s welfare has always got to come first hasn’t it? That’s what I’ve always said to them—that we’ve got to just make the right decision for Toby.

Participants identified three issues that impeded the safeguarding of service-users from abuse, neglect, and exploitation:

- an over-emphasis on workplace health and safety requirements
- staff with poor values
- cumbersome change processes

One traditional service manager considered that, given the importance of workplace safety, there were very few instances when the safety of the service-user and the safety of the support-worker conflicted, and an emphasis on the safety of one at the cost of the other hampered the ability to keep both individuals safe. A manager of a user-directed service concurred, suggesting that when this occurs, the service loses focus on the person in favour of the organisation. She said:

I’m very invested in the people that we work with staying safe and having great lives. That’s the whole point of our work. But I think that sometimes services get really into this kneejerk reaction to things. . . Whatever it is they’re doing . . . the organisation starts to get more important than the work.

Participants suggested that support-workers with poor values increased the vulnerability of service-users to abuse and exploitation. One parent, who chose her own staff and directed the service, acknowledged that, even with these safeguards, bad things happened: *A lot of things have happened down through the years—terrible things. We had to put Michael into hospital just through staff not doing their job.* One manager concurred that with all the best effort in the world, poor service still occurs: *If you have a worker who is committed to doing the wrong thing, no amount of policies, plans, processes, will stop someone doing it.* He offered his strategy for this situation: *What you need to have—is that it’s picked up really . . . quickly.*

Where service-users and support-workers had to use complaints processes that were cumbersome, they were tempted not to complain at all. One support-worker described her strategy to make change in a

traditional service: *I can only start small. I can't make changes in a big organisation, it's not possible, But in-home support—I'm lucky in that I can make small changes.* A service-user also felt unable to complain until he could no longer manage the alternative: *Then I would act at breaking point. Then I would do something about it.*

Participants suggested that service-users were better protected from neglect, abuse and exploitation by:

- everyone involved taking responsibility for a service-user's development
- problems being rectified quickly by, or on behalf of, service-users
- service-users and families developing confidence in service-direction
- service-users developing capacity and resilience over time

The manager of a user-directed service suggested that managing risk required everyone taking responsibility for a service-user's development:

What we're trying to do is actually work on something a bit different that says, in order to grow and develop, you have to have some risk. You can't be in a world where you have no risk. So people have to be out and about in the world, doing what they're doing, and our relationship

with their families has to be so strong that if anything happened we take joint responsibility for any decisions that we made.

There was general agreement that service-users were safer when they undertook problem-solving quickly and locally themselves, or when it was undertaken by people close to them. This required service-users and their families to have the confidence to direct staff and problem-solve. The manager of one user-directed service suggested that service-users came with a wide variety of skills, and that the best strategy was to respond on a case-by-case basis:

So when people are ringing it's usually when there's something that's gone wrong, and you know, the person might ring and say, you've got to do this [and then] they'll want you to be a service provider again because something's gone on or whatever, and that agreement is fabulous because you're able to go, no worries. Each person—it's all very different. Some know straight away. And they're really clear. They look at their host agreement and they go, "Yeah that makes sense to me. That sounds great. Very happy." And if you do try to ring them it drives them crazy.

The manager of the other user-directed service identified that their service-users will require some intentional assistance to respond to the NDIS. He explained: *It is a really interesting thing. Because we have, we took a lot of things off families that they didn’t need to worry about. But now families need to get on their game, quickly, to understand what’s coming.* Nevertheless, active involvement at any level was important. One manager explained why: *The more a person is an active participant and involved in their life, and that there are others involved in their life, the less opportunity you have for abuse and neglect to occur.*

The final strategy was the intentional involvement of service-users so that they developed independence and resilience. This required significant effort and risk over a long time. One manager described how her service reviewed their work:

People are really encouraged to think about doing themselves out of a job. Even though we know some people will always need support, the way we do it should not build up dependency in people. We [now] have got people with disability who are much more independent and able to do for themselves.

Summary

The participants universally supported the service-quality indicators. The findings also pointed to the idea of *a process of user-direction* and identified a number of strategies that could be used to enable the process. They also suggested that structural barriers in both the traditional services and the user-directed services would need to be addressed.

5. A process of User-direction

Participants reported that support-workers typically came to the job because of life circumstances rather than intentional career planning. They brought a wide range of skills and experiences with them. Their personal commitment to meeting the needs of service-users and to doing the job well was evident, and they supported and respected the idea that service-users had individual plans and goals. Although some support-workers came with training, this training was not considered to be a reliable predictor of their suitability for the work. A respectful attitude, shared values and respect for the service-user were more reliable indicators.

A process of user-direction emerged with seven steps:

1. Start with the service-user
2. Follow (and develop) their vision and plan
3. Make a good match between the service-user and support-worker
4. Get to know the service-user well
5. Build a relationship of trust
6. Solve problems quickly and locally and
7. Work towards the service-user's independence and resilience

The process gave a logical sequence of steps which built on each other. When something went wrong, or was not working well, the process indicated the need to go back a step or two to rectify the situation. For example, if a service-user did not trust a worker, the support worker may not have had the opportunity to understand what was required or it may have not been a good match from the start (See *Figure 4*).

1. Start with the person

Fundamental to user-direction is the needs of the service-user remain the central purpose for the support. For user-direction to begin, the support-worker comes without assumptions about how, when and where the service will be provided.

2. Follow the vision and plan

Service-users need a vision for a good life, and to plan in order to direct their service. Some service-users might have modest visions and plans to begin with. The Objects and Principles of the *NDIS Act (2013)*, however, confirm that it is the responsibility of all stakeholders to work towards goals

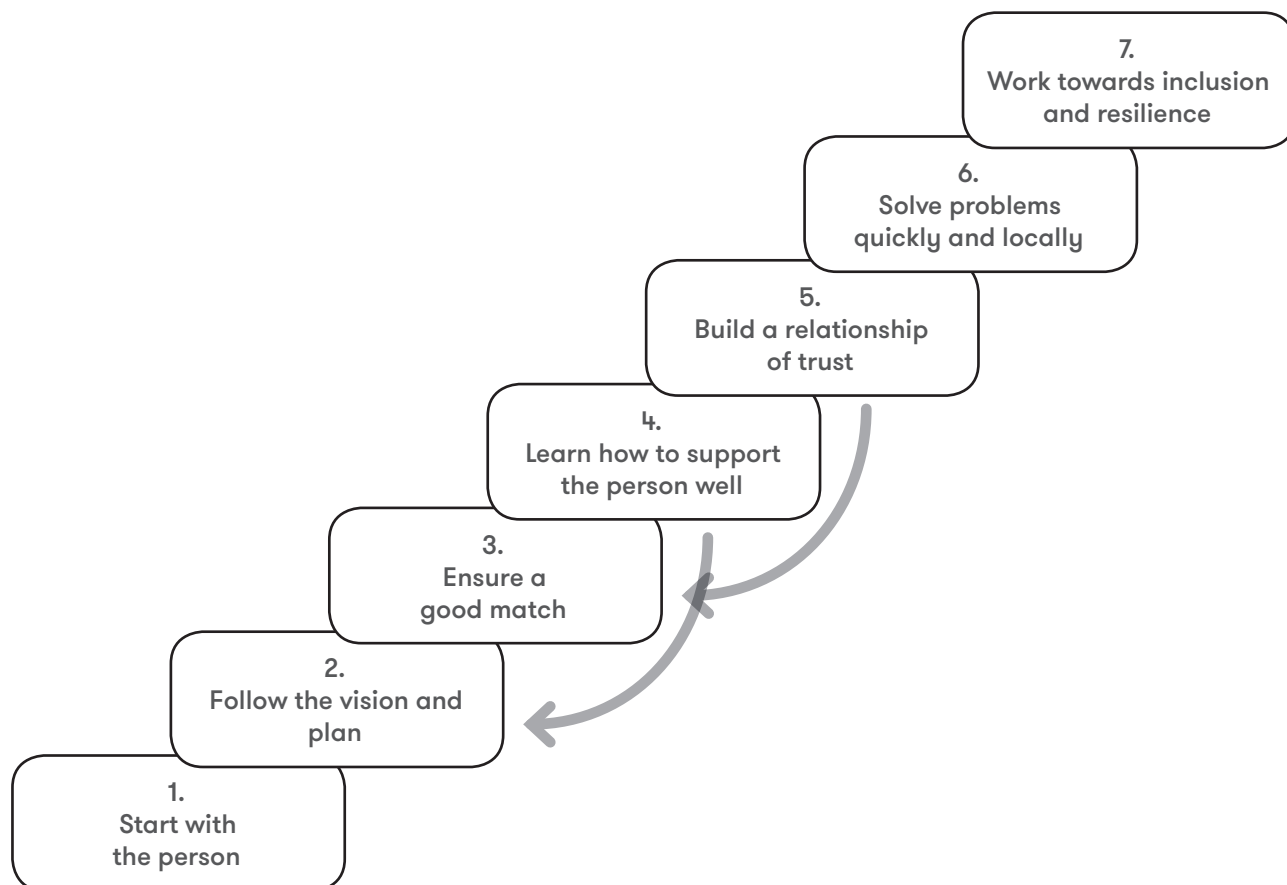


Figure 4. Process of user-direction

of equity, inclusion, and personal growth. In this regard, the support-worker honours the service-user’s plans, and provides opportunities to consider a better life.

3. Make a good match

Service-users are the people most likely to know if support-workers meet their support needs. When user-direction is working well, the service-users have the authority to choose their support-workers and to build a personally-crafted team. The aptitude, interests, and values of support-workers and how they align with those of the service-user are likely to be more important than pre-service training.

4. Get to know the service-user well

The service-user directs the support-workers on how to be supported. It takes time for a support-worker to get to know the service-user well and to understand his or her needs, idiosyncrasies, and relationships. It was found to be preferable that the support-worker works with fewer rather than more service-users simultaneously.

5. Build a relationship of trust

If the previous two steps—the matching of the support-workers to the service-user, and getting to know the service-user’s needs—are well-executed, a relationship built on trust can develop. It is within this trusting

relationship that the support-worker can use his or her knowledge, discernment, and common sense to make timely, informed decisions with and on behalf of the service-user, particularly with regard to identifying opportunities for inclusion and for managing risk. Once trust is built, the support-worker can then work more effectively with the established informal supports.

6. Solve problems quickly and locally

Problems are best solved quickly and locally. Problems are also averted when support-workers meet regularly with service-users and their informal networks, to revisit their vision and plan, and to share strategies and experiences. Service-users and their families tailor their problem-solving strategies by sourcing particular skills and knowledge when required. Formal complaints and workplace incident claims are less likely when the support-worker and the service-user have built a trusting and ethical relationship built on regular communication.

7. Work towards independence and resilience

The process of user-direction will develop service users' resilience and independence over time. The support-worker can intentionally assist in this process.

Challenges within traditional services

This study identified some challenges for traditional services in adopting this process of user-direction. They are:

1. A prior investment in congregate care models
2. Reliance on pre-requisite training and rules for quality control and risk-management
3. Arbitrary limitations placed on the development of relationships and
4. Hierarchical problem-solving.

Prior investment in congregate care models

The traditional services have made prior investment in congregate care models, such as group homes or day centres. The findings suggest that they might be tempted to personalise the support within the constraints of these existing services, rather than individualising the support and assisting service-users to imagine a vision and plan for a good life. It will take significant organisational courage to go beyond this amelioration to respond to each service users' vision and plan for a good life. It will also take significant personal courage and resources for service-users and their families to leave what is known, even if they can envision a better life for themselves.

Reliance on pre-requisite training and rules for quality control and risk-management

As previously noted, the study also found that the traditional emphasis on pre-requisite training and rules is not a reliable predictor of a support-worker’s suitability for the task or quality of work. Assumptions made by support-workers based on pre-requisite training can actually lead to inappropriate responses and poor service. This does not mean that support-workers should be unprepared, exploited, or put at risk. It means that within a framework of good employment practices, individualised training by the service-user or their family leads to better service.

This idea challenges traditional service practices of training staff to work across a wide range of service-users and work sites, and regarding this training as the foundation for the service’s quality assurance and risk-management. While a broad training strategy might work for some service-users whose needs can be interpreted simply, an alternative preparation is likely to be needed for support-workers to develop a deeper understanding of a service-user’s needs and to build a trusting relationship over time.

Arbitrary limitations placed on the development of relationships

The study also suggests that when services place arbitrary restrictions on the development of relationships, this leads to the assumption that support-workers cannot manage relationships in an ethical way without clearly articulated boundaries. This reliance on prescribed behaviour limits the capacity of support-workers to act with common sense, to make good decisions, and to build trust.

Hierarchical problem-solving

Another challenge for the traditional services is a reliance on hierarchical problem-solving. Prescribed performance, behaviour, and relationships also limit the capacity of support-workers, service-users and their informal networks to resolve issues and to find solutions themselves.

A user-directed service relies on problem-solving strategies that are timely and preventative, and where the locus of decision-making is as close as possible to the service-user. Once a trusting relationship is established, problem-solving becomes easier and the responsibility of all parties.

Challenges within user-directed services

This study also identified some challenges for user-directed services in adopting this process of user-direction:

1. Advantage afforded to empowered service-users
2. Competing interests of service-users and their informal networks and
3. Economies of scale provided by larger traditional services

Advantage afforded to empowered service-users

Some service-users are more able to envision and plan a good life, and direct their support-workers. They have had opportunities to foster their imagination, to build informal networks of support, and develop resilience and independence. Support-workers that value these attributes gravitate to support these service-users. In this sense, a self-selection process emerges where the more empowered service-users attract support-workers who value user-direction and are willing to take initiative themselves. The challenge for user-driven services will be to support service-users who are less empowered.

Competing interests of service-users and their informal networks

Support-workers in user-directed services have more complex environments in which to work, with service-users learning how to direct their service, and the additional involvement of families and informal networks. Support-workers have to navigate what might be considered to be conflicts of interest among the many stakeholders. Service-users and support-workers are, however, unlikely to return to more structured support arrangements; rather, they prefer to develop the skills and discernment to navigate the messiness of these relationships.

Undue time and energy burdens for service-users

The user-directed services offer greater choice and control for the service-users; nevertheless, the service-users and their families commit significant time and energy in directing their support-workers. Again, user-directed services attract those service-users who have the capacity to take the added responsibility, or who are willing to make personal sacrifice to gain this choice and control. Services have the challenge to make the process of user-direction accessible to any service-user regardless of their capacity.

Enabling strategies for support-workers in user-directed service

Participants identified the following strategies for both support-workers and service-users to **enable the process of user-direction**.

Strategies for support-workers:

- Participate in regular meetings to keep focused on the service-user’s vision and plan and to review progress
- Develop problem-solving methods that involve the service-user
- Expect respectful employment conditions where a sense of mutual trust can develop and
- Gain skills to communicate with the service-users, families and informal networks, community connections and other service providers
- Work with the service user and their family to develop their resilience and capacity in user-direction.

Strategies for service-users:

- Develop and articulate a vision and plan for a good life
- Use processes which attract support-workers that have good personal values, common-sense and reliability and are a “good match” with regard to age cultural background and interests

- Actively engage in problem-solving strategies
- Develop a network of people (in the service, informal networks and community) who will remain vigilant about the welfare of the person with disability.

See *Figure 5* for the process of user-direction with enabling strategies.

Other comments

The high level of support for the Objects and Principles of the *NDIS Act (2013)* and the proposed process of indicators among the participants in both traditional and user-directed services was a welcome finding. This is an extraordinary time in the history of disability services, and the unilateral support for user-direction suggests that the process of self-direction could be used in a range of models of support, with consideration of the systemic barriers listed above.

A surprising finding was that no participant raised the issue of remuneration for their work, and only one participant identified an importance of building a career in support-work. The researchers did not intentionally seek this information; however, there were adequate opportunities within the interviews

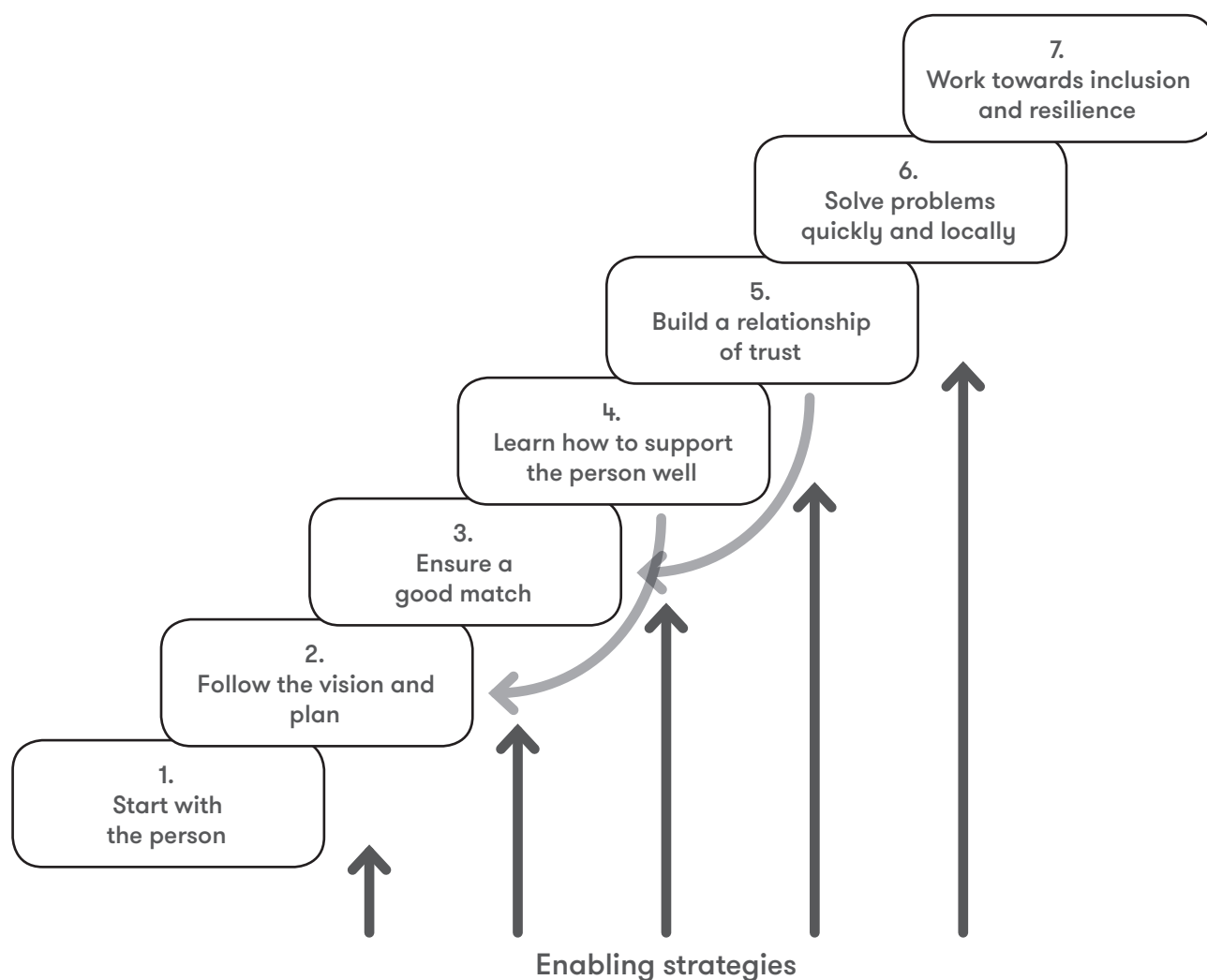


Figure 5. Process of user-direction with enabling strategies

for the participants to raise these topics if they were deemed important.

The need for broader community engagement

The identified external impacts on the lives of service-users suggested that the implementation of the NDIS will be limited by the level of commitment to COAG's National Disability Strategy (Australian Government, 2011). Support-workers and service-users alike are at risk of being

expected to take full responsibility for social and economic inclusion when, clearly, it is the responsibility of all Australians. Without this broader commitment, the NDIS is limited in making a real difference to the lives of people with disability.

The study suggests that the process of user-direction is applicable, regardless of the size or location of a community. The challenge for support-workers in regional areas, including rural and remote communities, is

to optimise the creativity and flexibility that user-direction allows.

Review of methodology

This study found the methodology to be robust, and suitable for a larger comparative case-study research project. Participants in this sector have much to say, and generously share their time and knowledge. The ethics process provided an adequate framework to safeguard participants’ privacy and dignity. The three sensitising frameworks that guided the the collection and analysis of data were found to be useful, though greater use could have been made of Kendrick’s (2011) levels of substantive empowerment framework.

6. Conclusion and Recommendations

This pilot study compared the issues facing support workers in traditional and user-directed services in meeting the Objects and Principles of the *NDIS Act (2013)*. It tested the methodology and obtained a limited data set to inform a larger research project. The study revealed a commitment by both traditional and user-directed services to the Objects and Principles of the *NDIS Act (2013)*, and a genuine interest in how best to respond to the individual service-user. The study also suggested a *process of user-direction* that both service-users and support-workers could follow.

The study identified that both traditional and user-directed alternative services have some systemic barriers to user-direction being available for everyone. To this end, this report recommends that future research focuses on what enabling strategies would optimise this process of user-direction.

Future research

The study identified two questions to guide further research. These are:

1. What strategies are most effective in enabling service-users and their informal networks to direct their services well?

Although service-users clearly benefited from opportunities to self-direct, further research could identify what might enable them to imagine better, to optimise their support and to become more resilient and independent in this process over time.

2. What do support-workers need in order to work in ethical and respectful relationship with service-users who self-direct?

Participants did not raise issues of career stability, remuneration and conditions of employment as important issues; however, these concerns have been consistently raised by industry advocates. Furthermore, the efficacy of current training in relation to user-direction deserves exploration.

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Appendices

Appendix 1. Information sheet for participants

NDIS Workforce study INFORMATION SHEET

Who is conducting the research?

Professor Lesley Chenoweth

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au

Why is the research being conducted?

The study is looking at different ways to employ direct-support-workers through the National Disability Insurance Scheme (NDIS) so that people with disability can participate socially and economically in community and family life. One strategy is to train staff to work across a variety of people, thereby offering greater capacity and flexibility within the service. Another strategy is to appoint staff to focus on one person's individual needs, and to manage the limitations of a small team.

The study aims to identify what employment conditions might assist a worker to do the best job possible for people with disability and their families, and to offer them attractive work conditions.

Griffith University's School of Human Services and Social Work has a particular interest in this area and encourages its students to contribute to research projects. A student will be involved in this study.

What will I be asked to do?

The researchers will invite you to take part in an hour-long interview. You can choose to participate or not.

How have I been selected?

The service manager has identified a number of people (both support-workers and service-users) who might benefit from being part of this research and have agreed to participate. The researchers have selected you from this group. Your participation is therefore confidential.

What are the benefits in participating?

The study aims to clarify some of the issues facing support-workers in their efforts to work within the intent of the NDIS, and what can be done to assist them to do a better job. This has potential benefits for you and the service.

What are the risks?

A risk in participating in this research is that you may be identified by what you say. The researchers will ensure your identity remains confidential and that no-one else connected with the study knows who you are. The disability sector, however, is small and some risk always remains.

Can I change my mind?

You can change your mind if you do not want to continue once you have started, or when the interview is finished. This is not a problem. The researchers will find someone to take your place. No one but the researchers will know and there will be no repercussions for you.

How do you keep my identity confidential?

Once the interview has been transcribed, your name, location and any other names will be de-identified, and the recording of the interview will be destroyed. The research will be stored in a locked filing cabinet in

a locked room at the Griffith University at Logan Campus.

Any identifying information collected will not be disclosed to anyone, except to meet government, legal or other regulatory authority requirements.

A de-identified copy of this data may be used for other research purposes. Your anonymity will at all times be safeguarded. For further information consult the University's Privacy Plan at <http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan> or telephone (07) 3735 4375.

Who do I contact if I have any further questions?

If you would like further information on the study, please contact Margaret Ward on margaret.ward@griffith.edu.au or phone 07 3382 1453.

Who do I contact if I am unhappy about the research?

The study has met the conditions outlined in the National Statement on Ethical Conduct in Human Research. If potential participants have any concerns or complaints about the ethical conduct of the research project they should contact the Manager, Research Ethics on 3735 54375 or research-ethics@griffith.edu.au.

Appendix 2. Interview structure

Introduction			
Can you tell me about yourself?	What makes you suited to this job?	What gets in the way of you doing the things you think need to be done?	What would you change if you could?
Can you please describe your job?			
How long have you been working in this job?			
We are now going to talk about the NDIS and what might be expected of you as a support-worker. (give handout of 5 indicators of service quality)			
1. Can we now talk about the idea dignity, privacy and self-determination? (Read quality indicator)			
What does this mean for you in the work you do?	What assists you to give the person: <ul style="list-style-type: none"> • dignity? • privacy? • the chance to make his/her own decisions? 	What do you think gets in the way of you giving the person: <ul style="list-style-type: none"> • dignity? • privacy? • the chance to make his/her own decisions? 	What would help you to do these things better?
2. I want now to talk about social and economic inclusion in the community? (Read quality indicator)			
What does this mean for you in this job?	What assists you to support the person be part of the community?	What makes it hard for you to do this?	What would help you to do these things better?
3. Can we now talk about your capacity to innovate, continuously improve and respond to changing situations? (Read quality indicator)			
What does this mean for you in this job?	What allows you to respond easily to changing situations and to work creatively?	What gets in the way of you changing and working creatively?	What would help you to do these things better?

4. Working with family, friends and neighbours is our next topic. (Read quality indicator)			
What does this mean for you in this job?	What assists you to work with families and others?	What gets in the way of these relationships?	What would help you to do these things better?
5. Now the final one is keeping the person safe. (Read quality indicator)			
What does this mean for you in this job?	What helps you to keep a person safe	What concerns do you have about keeping the person safe?	What would help you to do these things better?
What else (other than the service) impacts on the service-user’s quality of life?			
Which of these statements best describes how you feel about how decisions about your service are made?			
<ol style="list-style-type: none"> 1. The service-user does not make any major decisions about his/her service. 2. The service-user does not make any major decisions about their service, but he/she routinely informed about the decisions others make on his/her behalf. 3. The service-user is routinely asked to give advice, by the actual decision-makers, about the service decisions they make on his/her behalf. 4. The service-user makes some of the major decisions about his/her service (say, 25%-45% of key decisions). 5. The service-user makes most of the major decisions about his/her service (say, 55%-90% of key decisions). 6. The service-user makes the vast majority of key decisions and there is no issue of “empowerment” for him/her. 			
Do you have any other thoughts or comments you would like to share?			

Appendix 3. Objects and Principles of the NDIS Act 2013

Section 3 — Objects of the Act

- (1) The objects of this Act are to:
- a. in conjunction with other laws, give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities done at New York on 13 December 2006 ([2008] ATS 12); and
 - b. provide for the National Disability Insurance Scheme in Australia; and
 - c. support the independence and social and economic participation of people with disability; and
 - d. provide reasonable and necessary supports, including early intervention supports, for participants in the National Disability Insurance Scheme launch; and
 - e. enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports; and
 - f. facilitate the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability; and
 - g. promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the mainstream community; and
 - h. raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability; and
 - i. in conjunction with other laws, give effect to certain obligations that Australia has as a party to:
 - i) the International Covenant on Civil and Political Rights done at New York on 16 December 1966 ([1980] ATS 23); and (ii) the International Covenant on Economic, Social and Cultural Rights done at New York on 16 December 1966 ([1976] ATS 5); and

iii) the Convention on the Rights of the Child done at New York on 20 November 1989 ([1991] ATS 4); and

iv) the Convention on the Elimination of All Forms of Discrimination Against Women done at New York on 18 December 1979 ([1983] ATS 9); and

v) the International Convention on the Elimination of All Forms of Racial Discrimination done at New York on 21 December 1965 ([1975] ATS 40).

(2) These objects are to be achieved by:

- a) providing the foundation for governments to work together to develop and implement the National Disability Insurance Scheme launch; and
- b) adopting an insurance-based approach, informed by actuarial analysis, to the provision and funding of supports for people with disability.

(3) In giving effect to the objects of the Act, regard is to be had to:

a) the progressive implementation of the National Disability Insurance Scheme; and

b) the need to ensure the financial sustainability of the National Disability Insurance Scheme; and

c) the broad context of disability reform provided for in:

i) the National Disability Strategy 2010-2020 as endorsed by COAG on 13 February 2011; and

ii) the Carer Recognition Act 2010; and

d) the provision of services by other agencies, Departments or organisations and the need for interaction between the provision of mainstream services and the provision of supports under the National Disability Insurance Scheme.

Section 4 — General principles guiding actions under this Act

- 1) People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development.

- 2) People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability.
- 3) People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.
- 4) People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.
- 5) People with disability should be supported to receive reasonable and necessary supports, including early intervention supports.
- 6) People with disability have the same right as other members of Australian society to respect for their worth and dignity and to live free from abuse, neglect and exploitation.
- 7) People with disability have the same right as other members of Australian society to pursue any grievance.
- 8) People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.
- 9) People with disability should be supported in all their dealings and communications with the Agency so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs.
- 10) People with disability should have their privacy and dignity respected.
- 11) Reasonable and necessary supports for people with disability should:
 - a) support people with disability to pursue their goals and maximise their independence; and
 - b) support people with disability to live independently and to be included in the community as fully participating citizens; and

- c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the mainstream community and in employment.
- 12) The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected.
- 13) The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:
- a) promoting their independence and social and economic participation; and
 - b) promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and
 - c) maximising independent lifestyles of people with disability and their full inclusion in the mainstream community.
- 14) People with disability should be supported to receive supports outside
- the National Disability Insurance Scheme, and be assisted to coordinate these supports with the supports provided under the National Disability Insurance Scheme.
- 15) Innovation, quality, continuous improvement, contemporary best practice and effectiveness in the provision of supports to people with disability are to be promoted.
- 16) Positive personal and social development of people with disability, including children and young people, is to be promoted.
- 17) It is the intention of the Parliament that the Ministerial Council, the Minister, the Board, the CEO and any other person or body is to perform functions and exercise powers under this Act in accordance with these principles, having regard to:
- a) the progressive implementation of the National Disability Insurance Scheme; and
 - b) the need to ensure the financial sustainability of the National Disability Insurance Scheme.

