Contrasting perspectives of parents and service providers on respite care in Queensland, Australia

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Contrasting perspectives of parents and service providers on the role of disability support workers in respite care.

Background

Caring for a child with a disability can exact direct physiological health costs on caregivers (Bourke-Taylor, Howie, and Law 2010; Cummins et al. 2007; Tong et al. 2003). Long-term caregiving has been shown to impact on parent-carers’ psychosocial health and wellbeing, including depression, isolation, and on their family functioning and finances (Murphy et al. 2007; Shearn and Todd 2000; Singer 2006; Worcester et al. 2008). Recent studies further suggest that parents of children with intellectual and/or developmental disabilities (IDD) that impact on the children’s communication skills, social relatedness and adaption skills experience higher caregiver stress levels than parents of children without impaired communication and social skills, or those without disabilities (Dabrowska and Pisula 2010; Brobst, Clopton, and Hendrick 2009; Singer 2006; Khanna et al. 2011). Emotional and behavioural problems in children with IDD are significant predictors of poor physical and mental health and wellbeing for their parents (Bourke-Taylor et al. 2012; Khanna et al. 2011; Hastings et al. 2005). Finally, the ongoing care responsibilities for the child, the required constant supervision of the child (Doig, McLennan, and Urichuk 2009; Murray 2007), and being ‘on call’ all the time due to the unpredictable and uncontrollable nature of parenting a child with a disability (Murphy et al. 2007), mean that the level of support children with IDD require is high and unremitting.

The greater strain on the parent-carers’ physical, social, and mental wellbeing has not only been shown to affect their capacity to provide quality care (Murphy et al. 2007; Bourke-Taylor, Howie, and Law 2010), it has been associated with poorer outcomes for the affected child (Plant and Sanders 2007; Seligman and Darling 2007).
Exacerbated caregiver stress has been associated with the risk of the child being physically or medically restrained (Oliver, Murphy, and Corbett 1987), being excluded from services (Emerson 2001), experiencing abusive responses from caregivers (Seligman and Darling 2007; Emerson 2001), coercive parent-child interactions (Bor, Sanders, and Markie-Dadds 2002; Plant and Sanders 2007), and has been predicted to increase the need for placing the child in out-of-home residential care (McIntyre, Blacher, and Baker 2002).

**Support for the carers**

Support for carers is generally divided into two categories: Informal and formal. Informal support, that is those from friends and extended family, is useful and desired, but is not always readily available, and tends to diminish as the child gets older and more difficult to manage (MacDonald and Callery 2004; Caples and Sweeney 2011). As such, carers turn to formal supports, in particular, respite care to find some relief from their daily routine and responsibilities of caregiving (Robertson et al. 2010). Respite care provision can vary in location, duration, and timing of the care, and who provides the care, and also offer the care recipient the opportunities to interact with a wider range of people (Cramer and Carlin 2008; Merriman and Canavan 2007).

The evidence for the effectiveness of different types of respite care on parent wellbeing and family function is mixed, with many studies indicating that while respite breaks do alleviate exhaustion and reduce carer stress, the effects were generally only significant following more intensive interventions, or the positive effects were not maintained over time (e.g. Chan and Sigafoos 2001; Strunk 2010; Robertson et al. 2010).

It has been suggested that the respite care experience for parent-carers is not always positive. Parent-carers have been reported to find the haphazardness of service
responses, issues with reliability and continuity of care, inflexibility, and unavailability and insufficiency of services, stressful and distressing (Wilkie and Barr 2008; Collins et al. 2013; Neufeld, Query, and Drummond 2001). Unsatisfactory experience and skills of the support workers (Preece 2000; McGill, Tennyson, and Cooper 2006; Neufeld, Query, and Drummond 2001), and unease about the use of service in terms of its impact on the child (e.g. worsening behaviour after out-of-home short breaks), and on the parents themselves (i.e. guilt and/or embarrassment) (Wilkie and Barr 2008; Hartrey and Wells 2003) have also been found to contribute to their negative perspectives on formal support services. Importantly, studies have suggested that many primary caregivers who use respite care services do not perceive them as providing actual respite (Preece 2000; Neufeld, Query, and Drummond 2001).

While poor quality of support care appears to be a major point of contention for families with young children with significant disability, a comprehensive search through the literature yielded no studies that examined the subjective perspectives of disability support workers (DSWs) with regard to their professional role as paid caregivers. Existing research on DSW-perspectives focus mainly on burnout and stress related to their roles, and those that have investigated support workers’ perspectives on working with individuals with intellectual disabilities concentrated on those who work with adults with a disability, and/or in supported accommodation (Vassos et al. 2013; Forster and Iacono 2008; Windley and Chapman 2010). This focus on DSWs who work with adults in supported accommodation limits generalisability of their findings to other care settings, such as the family home, where majority of children with IDD live and are cared for by their parents.
The Australian context

In Australia, support services for family caregivers have been reported to be inaccessible, inflexible and unresponsive to individuals' needs and circumstances (Commonwealth of Australia 2011; National People with Disabilities and Carer Council 2009). Respondents to a nation-wide public consultation told of unavailable or infrequent services, poor quality, and most critically, of a one-size-fits-all approach. (National People with Disabilities and Carer Council 2009). In a major legislative reform of disability services, the Australian government has since established the National Disability Insurance Scheme (NDIS), which is currently being rolled out across the country. Its aim is to help people with disability access mainstream services and supports, maintain informal support arrangements, and provide them with necessary funded supports, that they can design and direct to fit their individual needs (Department of Social Services 2017).

With the implementation of the NDIS, it is important to ensure that the formal support services that are available, and/or new service providers, are responsive to the needs of the users and helps them maintain or improve the own health and wellbeing. As Kendrick et al. (2017, pg. 1335) state, it would be prudent of the NDIS to collaborate with the people with disability and their families, who have in the past provided much of the innovation and will continue to be the “change agents ‘on the ground’”.

The purpose of this study was to investigate the delivery of formal support services from both the parents’ and DSWs’ perspectives. A strengths-based approach was used to investigate and identify the positive experiences of both parents of children with IDD and DSWs, as users and as providers of respite care, in response to the research question: How do formal support services help parent-carers maintain their health and wellbeing.
Method

The study was conducted in two phases, using an abridged version of Appreciative Inquiry (AI) (Cooperrider and Srivastva 1987). AI was used to inquire into “the best of what is” as a foundation for generating “what could be” (Bushe 2011) in formal support services. In the first phase, the study examined parent-carers’ perspectives based on three core questions: “what is working well” with formal support services that helped them maintain their health and wellbeing, and “what might be better” and their “dreams for the future” for formal support services that will ensure their improved health and wellbeing in the longer term.

The second phase focused on examining how DSWs who work with young children with intellectual and/or developmental disability perceive their role in helping these families maintain or improve their health and wellbeing. In line with AI philosophy, interview questions for this phase also encouraged participants to give attention to the positives as the focus of inquiry (Cooperrider and Whitney 2001).

Ethical approval was granted by the Human Research Ethics Committee.

Recruitment & Data collection

Phase 1. Parents of children with significant IDD, who have absent or impaired verbal and non-verbal language, and are dependent for personal care were invited to participate in a focus group. This population was selected as research evidence indicates that they are more likely to experience chronic stress due to the nature of the care and support required, owing to the developmental and behavioural challenges posed by the children (McLennan et al. 2012; Redmond and Richardson 2003) and the stress due to the potential long-term dependency of the child (Boyd 2002).
Furthermore, only families that receive state-funded support packages to access respite care services provided by local non-government support agencies were included in the recruitment process. As they would have already been assessed by the government’s Disability Services department (DSD), which determines the eligibility of individuals for specialist support from the State or Territory government, as having “high needs”, this made the sample clearly defined. Recruitment was restricted to within a local government area\(^2\) to facilitate better response rates. All potential participants were provided an information sheet via email prior to their interviews, which allowed them ample time and opportunity to consider it before consenting to participate.

**Phase 2.** Participants were recruited through the same support agencies and had to have experience working with families with children with similar impairments as those in Phase 1. Individual interviews were conducted with DSWs to explore their perspectives on their role when working with families with children with significant IDD.

Preliminary analysis of Phase 1 data was conducted and its findings informed the interview questions for Phase 2.

**Data analysis**

Data from both phases were analysed by the researchers using thematic analysis, using the approach by Braun and Clark (2006). Transcribing the data verbatim formed the first step in the analysis and familiarisation with the data continued with the generalisation of the initial codes. The three core questions formed the global themes within which the data were analysed and the themes were developed. The codes were then analysed for their underlying meanings, relatedness, and repeating ideas (Braun and Clarke 2006). The relevant data extracts were then sorted and collated on the strength of their conceptual similarities (Saldana 2009). These were temporarily labelled
under sub-themes as the researcher continued to distil the data down to highly significant points that concisely answer the research question and objectives (Braun and Clarke 2006).

Research rigour was maintained through tools and techniques recommended by Lincoln and Guba (1985), which included established interview protocols, regular peer debriefings, achieving data saturation, thick descriptions of the research contexts and assumptions made throughout the research process, as well as detailed recordings of problem formulation, all raw data, interview observations and memos, data analysis decisions, findings, methodological process, and critical reflections.

**Findings**

**Phase 1**

Thirteen individuals consented to participate in focus groups 1 and 2, and only seven mothers were able to attend one of the three focus groups that were held (see Table 1). Five themes emerged: Flexibility in service provision; and flexibility and adaptability of parent-carers; communication and collaboration; valuing parent expertise; and professionalisation of disability of support work. They are discussed here within the three core questions that guided the analysis.

*What is working well*

*Flexibility in service provision.* Study findings suggest that for formal support services, in particular, respite care, to be effective in reducing parent-carer stress, all parties concerned have to maintain flexibility in the way they approach service provision. Services that were adaptable and integrated flexibly into families’ lives reduced
disruptions and helped them enjoy a familiar routine that was part of ‘normal’ life, and as such, effectively removed one or several stressors for the parent-carers.

In particular, the availability and ability of the DSW to work around the busy and complicated routines of families of children with disabilities provides welcomed flexibility that is often missing in the complex routines of the parent-carers’ lives. However, as parents had different preferences as to the type of help that suited them, a DSW’s flexibility with the type of support she could provide was particularly valuable in improving parent wellbeing. For example, one participant favoured the DSW focusing on caring for the child, because the mother “actually prefer[s] to be doing the dishes” (NP, *parent-carer*), while another preferred if the DSW could occasionally attend to the household chores “because sometimes you just want to bath your own children” (KD, *parent-carer*).

Parent-carers valued help not only with their child, but also with everyday tasks in the household. Furthermore, many appeared to expect DSWs to be able to meet these needs as they arose, without being prompted, and despite it not necessarily being in the DSWs’ job description. As one participant described to unanimous agreement:

…we've had [DSWs]¹ who've gone ‘Hey she's fine. Can I go hang some clothes out?’ And I go ‘I love you!’ [gestures triumph]. [NP and BD nod in agreement.] That's the kind of help you need. … people who can just see, know what a house needs and just get in there and help. …God that makes a difference to your day! (KD, *parent-carer*)

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¹ Square brackets hold information added by the authors to provide better context or observations of non-verbal communication.
Flexibility in support provision afforded not only immediate relief for the parent-carer from a stressor, but a residual effect of reprieve even after the service had ended.

*Flexibility and adaptability of parent-carers.* Parent-carers’ personal resourcefulness and determination appeared to be assets that helped them stay flexible and able to adapt to and/or overcome shortcomings of service provision practices. Those who were resourceful and found ways around problems inherent in any service or altered them to fit their needs, appeared to be more satisfied with services. For example, a mother’s initiative of creating her own set of guidelines for new DSWs circumvented new stresses for herself and her family:

I've written a book for my kids. Sixty pages! Before any support worker sets foot in my door, they *have* to go through this. … You can organise that. I’ve organised that with the agency. It's clear in the notes that the carers have to help me tidy up. (CR, parent-carer)

These parents not only understood the limitations of the funding and services, and spoke about the need to be pro-active in seeking out alternative or new ways (e.g. “…if you really need it, go and find it yourself.” (NP, *parent-carer*)) to improve existing access to supports, but also showed strong determination to maintain family function and wellbeing. Many emphasised how hard they try to resolve issues that impact their health and wellbeing, and their narratives revealed a tenacity in their actions. For example,

I think you've *really* got to take charge, and constantly re-evaluate where the family’s at, to get the best out of it. And then do it. Don't be scared. Don't sit back

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2 Italics denote words that participants placed particular emphasis on.
and go ‘Oh, woah, this is my life and it’s miserable and I hate it.’ It is what it is.
(NP, parent-carer)

For these parents, determination and persistence were necessary to maintain
good family function and wellbeing was necessary to survive or overcome the
challenges they face. As another mother stated, she was “determined… I’m not going to
sink with this ship.” (KD, parent-carer).

What might be better
Communication and collaboration. Many participants reported having to decipher the
complicated disability and health care systems on their own, or to rely on word-of-
mouth between parent-carers to discover the types of formal supports that are available
and/or the processes to gain access to them. One participant summed it up by stating:

You’re just out on your own trying to figure out a lot. (KD, parent-carer)

Importantly, participants spoke extensively of how the application and approval
processes for services involves the subjective judgements of the DSD staff, which
results in the need for the parents to beg, or to have their backs up against the wall, to be
heard.

…after hell of a lot of crying on the phones, and getting doctors to ring and
hammer. It was only really because she was incredibly sick at Christmas time that
we used that as the prop to go we need help. (KD, parent-carer)

Many reported that support services were only offered after being put into
further distress by having to convince DSD administrators that they genuinely needed
the support.

I find the most stress in this job is not my child, for me personally, it’s trying to
work with all these services. I feel like I have to justify all the time. I can’t just say,
I need help. …Trust that I'm an adult. I know what I need, and I'm telling you the truth. (LF, parent-carer)

As such, it appears that parent-carers are only being allocated support services when their wellbeing is already poor, rendering it less effective in reducing stress or preventing burnout. It was, therefore, not surprising when parent-carers suggested that they could possibly be enjoying better mental health and hence be providing more effective care to their child if they had been offered respite sooner, and they likely would have required quantitatively less respite care, if the DSD had been more responsive to the family’s initial appeals:

We didn't [receive support] for the first 12 years of her life, but now we actually receive a lot of support. Yea, we didn't qualify, apparently. [laughs] And then when they finally did, they're like ‘Wow! You needed this a long time ago’. I go ‘Really? Yeah, thanks for that … [laughs] probably wouldn't need as much as we do now if we had it earlier. (DN, parent-carer)

Poor communication and lack of a collaborative approach were also evident in participant reports that when they were approved for a service, they were given minimal information about the scope of the service. Parent-carers were left to discover through time and experience what the service actually entailed, and its parameters for use:

…you sort of get rung up and here you go, you can have this service, but you don't really know what it's about, until you start using it. (BD, parent-carer)

There was a sense of ambiguity of the goal of respite, as parent-carers appeared to have a different expectation of the role and responsibilities of a DSW than what some DSWs perceive their role to be. This was evident for one participant:
…when I came out [from a nap], she (the DSW) was reading her Kindle while Maddie\(^3\) was on the computer watching some crap on YouTube... That was the last straw for me … I had … some dishes that could have been wiped up. … I was exhausted... and I just thought, wow, that was not helpful at all. (KD, parent-carer)

More importantly, participants reported that they were provided a prescribed service without consultation or negotiation to achieve the best service fit to the families’ actual needs or requirements, when it may better serve a more useful or a more restorative function. For example, respite care was often only offered on stipulated days and at times that suited the support agencies but were not ideal for the parent-carers:

They want you to have them in the middle of the day or tacked on just on in the afternoons and finish by six, or those of things, and it's not really useful! (NP, parent-carer)

Essentially, the parent-carers were of the opinion that service providers failed to consider the needs and values of the parent-carer and the family unit when designing and/or delivering support services for families of young children with disability. As another mother shared:

…when I was ringing up about the community access service that we get [for our 7 year old son], I said to her, “You want what?” ‘Ah, we're gonna take your son out into the community.’ I said, “What about you come to my home, I'll drive and we'll take the girls and [Tom] out altogether.” ‘We don't do that.’ And I said, ‘Excuse me?’ She said, ‘No, no, we're a service that does community access for the person with the disability.’ And I said, “How is that normal? (NP, parent-carer)

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\(^3\) Names of all research participants and support providers and agencies have been substituted with pseudonyms.
This lack of collaborative discussion contributed to parent-carers’ sense of lack of voice and of control in the process. However, many reported a reluctance to express any disagreement or to negotiate the scope of the service for fear of losing the allocation completely. The power differential is evident in a parent-carer’s statement:

You just get given something… I don't say no to anything! (KD, parent-carer)

_Dreams for the future_

*Valuing parent expertise.* The issue of communication and collaboration rose again when parent-carers were asked to project five to ten years into their future, to imagine how formal support services might have helped achieve their much-improved health and wellbeing. Parent-carers saw themselves as a source of expertise and knowledge that DSD and support agency administrators can draw on (e.g., during the process of hiring and training of DSWs). For example,

…have some parents give some feedback and either sit in on interviews or even in their training. … let them know what their expectations are when they come into a home. (TN, parent-carer)

In general, many wanted to be able to make the decisions and choices about supports and services that they believed were best for their children and their families, and that would reduce their stress more effectively. They wanted to be able to use their allocated funding flexibly, for example, to modify their homes for access and safety, to help ease the stress of constant supervision of their pre-adolescent children. One mother proposed being allowed to become a paid caregiver for her affected child, rather than hiring an unfamiliar person to care for the child, as it would ensure better continuity of care, and the parent could focus on the child’s development, and their personal and
family’s wellbeing, without suffering the financial and social disadvantages because of being the unpaid primary carer.

*Professionalising the disability support role.* Parent-carers in this study questioned the quality and content of current training for DSWs who support children with IDD. Findings suggest that parent-carers have to assume that the DSWs, assigned by support agencies to work with their child, are appropriately qualified to perform the role. They voiced frustration with some DSWs’ lack of appropriate skills and experience:

> they don't have the experience, they don't have sometimes the motivation, you know. They just don't have the education to stimulate them [the children] and to, you know. … I have an issue with people who do an 8-week course and all of a sudden they're qualified to work with children with special needs and high needs, you know. They might be okay working in a group home, 24-hour house, something like that, …But to come into my home and work with my child who has high support needs is just not suitable. (TP, parent-carer)

Many expect that DSWs who work with young children with IDD would have had adequate professional training in what they consider the basic skills of being able to engage with non-verbal children, and in the use of alternative communication methods and devices, particularly when agencies have assigned them to work with children who have limited or no functional communication. However, as one mother described,

> They don't even say hello to David. They don't even know how to engage with him at all. (TP, parent-carer)

Others noted their DSWs’ lack of skills in managing challenging behaviours with their children, and spoke of how it diminishes the benefits of respite for the parents.
They have no idea that they come into our house full of behaviours. They just...they have NO idea... they stand there and stare at you as if to say "What do I do??" And "Your’re the support worker!" The whole idea of you being here is so I don't have to do this. So I can go to work sane today. (DN, parent-carer)

In short, participants expected the paid supports who provide respite in the family home to be able to step into the parent’s role almost seamlessly to relieve stress they face daily. They also expect their child’s team of carers to continue the parents’ efforts in working towards bigger and long-term goals by teaching or encouraging in the child independent living skills. That is, rather than fostering dependence through doing for the child, parent-carers want and expect that the DSWs teach and encourage in their child communication, self-help skills, and social skills. One parent spoke of a DSW who spoon fed the child, rather than taking the time to encourage or teach the self-help skill:

I think it comes back to ‘It's just easier if I do it’. It's completely disenabling them. It's just easier if ‘I do it’. … The fact that then tomorrow, when it's my turn, and she's not going to do it for me and she expects me to do it for her, because you did it for her! (DN, parent-carer)

These parents were thus left feeling frustrated and even more burdened by the enabling of the child’s learned dependence, and there was a sense that such support is not effective in helping reduce their stress levels in the longer-term.

Finally, there was a perception amongst parents that the DSWs were not in the role out of choice:

There's a lot of casual kind of jobs and lot of times they're doing it in between… they don't really want to do disabilities for the rest of their life. That's just an in-between job, that kind of thing. (CR, parent-carer)
Under the current system, parent-carers therefore cannot expect consistency in the skill sets of the DSWs that are deployed to support their child in the home, and consequently cannot expect stability in their paid support team. This led to demands for regulation around the professional training and certification of DSWs.

**Phase 2**

Eight DSWs participated in individual interviews in the second Phase of the project (see Table 1). Four themes were identified – Motivation; client-worker relationships; ambivalence; and work conditions, and they provided corroborations and contrasts to the experiences of the parent-carer participants in Phase 1.

**Motivation**

There was a sense that being engaged in disability support work was a calling or vocation for some participants. In general, many participants also expressed how they find it personally rewarding to help with the development & independence of the child, and to provide their primary carers a break.

However, many of the DSWs held multiple roles (see Table 1) and findings suggest that for some DSWs, their entry into the field of disability support work was due to the difficulty of finding employment in other sectors within this study site. For example,

[I] relocated from Victoria. I had had seven weeks of no pay at that time. And [I said to my friend] ‘Oh, what do I do? What do I do?’ And she said ‘Why don’t you do the induction to be a disability worker? You’d be a shoo-in because of your experience in teaching.’ And I thought ‘Oh, okay. Why not?’ (DL, DSW)

Notably, although many of the DSWs interviewed indicated they had had training in manual handling methods, disability support training appears to be inconsistent between
workers, and unregulated. DSWs reported only receiving disability support training on-the-job.

I’ve had a client who was PEG-fed and I learned that through... just on the job training. That wasn’t through a special course for me. Like I had a couple of buddy shifts and then [had some training] with the father… (DL, DSW)

Client-worker relationships

Findings indicated that participants were aware that parent-carers needed to have faith in their DSWs’ skills & abilities to manage their child’s needs. They spoke of often having little information about the child and family and having to build their knowledge and understanding of how to manage the child quickly when allocated the job. Some expressed a preference for working in homes where the parent-carers communicated their needs and preferences, and who collaborated with them more enjoyable and the role more fulfilling.

I think [the children] have got a lot of work to achieve goals and families who are involved and who work with you…it’s more of a team thing rather than you coming and being a staff involved. So that type of environment is what I really enjoy. (TK, DSW)

Ambivalence

Since findings from Phase 1 indicated that parents saw themselves and their family as the client, not just their child with disability, participants in Phase 2 were asked directly, who they considered the client. All the participants responded that the child was. However, many also immediately added to their response that they too considered the parents and the family as their client.
Probably the child. Yeah, I would say. [8-second pause] I do see the families but I suppose you feel your greatest responsibility is to the child. (RP, DSW)

Significantly, it was evident that they often had to rely on their own values and judgements to decide how they should best support the client.

[The father] was kind of hoping that I would volunteer to take on the [other children] too for part of that time. …I kind of made it clear that I couldn’t do that. But you could tell he was disappointed … stressed. So I felt that I was working with all of them and had to manage all of the…and be accountable. (DL, DSW)

Work Conditions

Work conditions for DSWs emerged as another significant theme for this Phase. Having access to consults with line managers and co-workers were deemed important for job satisfaction. Opportunities to debrief and consult with other staff members was key to the DSWs wellbeing and their ability to carry out their responsibilities well.

If you work in a group home or day-program centre, it’s much easier just because you can talk to the other staff, share the experience. You can debrief. It helps a lot. (YK, DSW)

Clearly, this is not always possible when working one-to-one with a client in their family home.

Notably, participants indicated that working as DSWs in the longer term would only remain a supplementary job as they pursued their main careers. As shown in the following quotation, there was a sense that it is field that does not offer opportunities for permanent, full-time employment:

As a support worker, I’m still working as a casual. I’m looking for a full-time job, but especially in [region], they only give you casual work. (YK, DSW)
Many thus work for multiple employers in the same or different sectors to gain more hours of employment, or appeared to see their role as supplementary to their study commitments.

**Discussion and practice implications**

This study’s research design generated findings that identified several important implications for disability and support services provision for families of children with IDD, particularly for those supported in their homes. Findings indicate that formal support services need to be timely, flexible, and responsive to needs of both the child and the family.

Flexibility in the type of supports received and in the way funding may be used to best support the person with disability (PWD) is likely to be further enhanced with the introduction of the NDIS. With the NDIS, individuals and their families would, theoretically, no longer have to rely on supports and services based on what their local disability support service agencies (DSSAs) had available. They would instead be able to design supports that make sense and to meet their needs, and to choose who will provide it. This would circumvent some of the issues raised by parent-carers in this study, namely, the type of supports their child and family need to function best, and the quality of the DSWs assigned to them. However, families living in more remote geographic areas are still likely to face challenges in finding services or activities suited to their child’s and family’s needs, or suitably qualified DSWs, especially if there is already a current shortage of qualified DSWs in their area.

**Access and availability**

Interestingly, parent-carers spoke of only being allocated support services when their wellbeing was already poor. The issue is not new (Llewellyn et al. 2005; Victorian
Equal Opportunity and Human Rights Commission 2012), and as this and past studies (e.g. Gottlieb and Johnson 2000; Sloper and Turner 1993) suggest, this has led to misgivings about the effectiveness of existing policies and practices of the disability support system in preventing carer burnout and its attendant impacts. The delay in providing much needed respite support is significant not only for its adverse impacts parent-carers’ long-term health outcomes, but the added and/or prolonged stress, exhaustion, and depression can contribute to poorer impacts and outcomes for the child (Nankervis, Rosewarne, and Vassos 2011; Plant and Sanders 2007; Seligman 2002). Furthermore, the sense of a power differential created from having to plead for support can further intensify parent-carers’ lack of perceived control and empowerment, potentially lowering their sense of wellbeing (Raina et al. 2005). Given that dealing with service providers is known to be one of the most stressful aspects of care-giver responsibilities (Beresford 1995), findings here underscore the need for a policy shift to one that facilitates transparency and openness by making the goals and actions of the disability support services system and service providers clear to the service recipients.

In theory, the principles of the NDIS address many of the issues discussed above. For example, with the NDIS, the intake process can be initiated by the PWD, their family, a service provider, or from the National Disability Insurance Agency (NDIA) itself. Applicants are then assessed for eligibility to receive funded support, and those who are assessed as eligible are allocated a NDIS planner, who is in charge or exploring the goals and functional needs of the PWD and ascertaining the size of the package (that is, the dollar amount) the PWD is to receive for the year (National Disability Insurance Agency, 2017b). This more transparent and simplified intake process will no doubt reduce the incidences of individuals or families who may miss out on disability support services due to lack of familiarity with the disability care system.
However, it does not completely eliminate the issue of transparency and power differentials, as eligibility to receive funded support and the size of the package approved is still dependent on the NIDA planner. Although support is determined by the PWD’s or family’s needs and goals, they would only be approved by the planner if deemed “reasonable and necessary”. This reliance on an NDIA personnel, who may not be an allied health professional, to determine what is “reasonable and necessary” can be subjective. Indeed, because a main objective of the scheme is to enable the PWD to exercise choice and control “in the pursuit of their goals and the planning and delivery of their supports” (Australian Government, 2013), it would be incumbent that the new system has much improved means of communication and collaboration, so that PWDs and/or their families can have the benefit of more input and influence in the types of supports they need to function most optimally.

**Family- and person-centred approach**

Clarity must also extend to the definition of respite care. DSWs in this study maintained that they take into consideration the needs of the family as a unit when working in the home environment, contradicting the parent-carers who claimed that DSWs generally tend to be child-focussed when providing respite in the home. This highlights not only an ambiguity of who the client is, which is particularly pertinent for families who access in-home respite, but an incongruity of the definition and scope of respite care. More importantly, it suggests a segmented and siloed approach to the care of children with disability and their families.

To address these issues, DSD and support agency administrators need to acknowledge that support needs are dependent upon each family’s circumstances (Collins et al. 2013). There also needs to be a shared understanding of what parents mean by respite. As other studies have shown, how parent-carers benefit from respite
care depends on how they understand the service and what they expect from it (MacDonald and Callery 2004; Mansell and Wilson 2009). DSDs and support agencies must distinguish respite care use from actual respite, where caregivers actually feel that they are getting a break from care-giving, because the experience of respite comes from changes in the caregivers’ environment that enables them to relax or to attend to other tasks without having to worry about the safety or wellbeing of the person they are caring for (Neufeld, Query, and Drummond 2001; Mansell and Wilson 2009). Only then would the respite support “positively impact on the quality of life for the carer and the cared for” (Mansell and Wilson 2009, pg 266).

For families with young children with IDD, this study indicates service providers need to view the family as the unit of service delivery. These parents wanted services that respond to family-identified priorities and to the changing priorities of families, and services that recognise and promote child and family strengths, all of which are the catch cries that resonate with the principles of family-centred practice (McWilliam, Winton, and Crais 1996).

Past research has, however, indicated there tends to be a lack of support from the organisational administrators to use family-centred approaches (King et al. 2000), and that although many service providers are familiar with its philosophy, they often find it challenging to put the principles of the family-centred approach into everyday practice (Moore and Larkin 2005). This inability to integrate family-centred practices within the current person-centred approach can severely limit the full benefits of respite care, as family-centred practices have been shown to contribute towards greater parent satisfaction with services, reduced stress, and improved wellbeing, and is thus one of the strongest predictors of family quality of life (Moore and Larkin 2005; Davis and
Gavidia-Payne 2009). It will be interesting to observe the responses of families to the new NDIS, which adopts the person-centred approach.

If support services are to make a more significant difference to the daily lives of the affected children and their families, then DSDs and support agencies will need to better embrace a person- and family-centred approach both at the planning level and at the delivery of services. A starting point might be to initiate discussion with parent-carers, prior to commencement of a service, to each clarify and negotiate the parameters and expectations of the service.

**Quality of service provision**

As family circumstances change, parental needs for respite also change over time (Olsen and Maslin-Prothero 2001). Support agencies would need to implement more effective methods of record-keeping and communication between DSWs and support agency staff, so that information specific to each child and family is adequately conveyed to other or new DSWs working with the family. This would reduce parent-carers’ frustration with having to repeat themselves with each new worker, which has been found to be burdensome and stressful by caregivers (Cowpe Jebson, Hanson, and Smith 2014).

The lack of adequately trained DSWs who parent-carers of children with significant disability can trust and rely on to provide quality in-home respite care is a recurrent issue (Neufeld, Query, and Drummond 2001). A study focusing on staff supporting people with intellectual difficulties found that up to 75% of support staff working with people with learning disabilities are unqualified (e.g. Hatton and Lobban 2007), while other studies have documented poor staff attitudes towards individuals with learning disabilities (e.g., Thompson and Emira 2011). Findings here clearly reveal similar scenarios where staff working with families with young children with specific
conditions (e.g., Autism Spectrum Disorders), who present with issues of limited functional communication, social interaction, and challenging behaviours, exhibit inadequate training. Yet, research has frequently shown that parent-carers prefer respite experiences that serve a dual or multiple functions, as it gives them a break from caregiving and meets the social and developmental needs of their child simultaneously (Federico, Jackson, and Black 2010; Victorian Ombudsman 2010; Preece 2000). To have DSWs meet this fundamental expectation in respite care would not only allow parent-carers to enjoy immediate benefits for themselves, but longer-term gains for their child and family (McConkey, Gent, and Scowcroft 2013; Cortis et al. 2013).

To manage the current ad hoc nature of training for DSWs, governments may need to consider reviewing current training programs in disability care. Certificate courses could be revised to include augmentative and alternative communication methods (e.g. basic sign language and/or protocols of use of communication software or apps) and behaviour management as core rather than elective or specialisation components. They could be widened to offer elective units of study that differentiate between supporting clients with different functional challenges, care for different age groups (i.e. young children, young adults, older adults), and in-home and centre-based care. Such differentiation would ensure more comprehensive training in those particular fields, provide clarity about job role, and potentially result in higher perception of job status and satisfaction amongst DSWs, and therefore better staff retention (Baldwin et al. 2003). Importantly, the quality of certification would need to be examined to ensure that registered training organisations are not providing ‘rubber-stamp’ training that produces graduates who may possess the qualification but not the competencies, as reported by the parent-carers in this study.
Accordingly, it might be appropriate to consider regulating disability support work by legislating that support staff possess professional training and certification that recognises their vocation as a para-profession, rather than one thought of as transitory employment. Making disability support work a para-profession would potentially necessitate regular and enforced supervision that many other health and social care workers benefit from. Enforced access to supervision is especially important for DSWs who work autonomously in family homes. Although DSWs in this study spoke highly of their workplace, providing many examples of a supportive work culture within their organisations, DSWs who work within family homes cannot benefit from the same level of collegial support as they would be able to in a respite-centre setting. In respite-centre settings, there is likely to be other staff on duty who may be able to offer assistance or back-up support. Alongside perceived low job status, lack of supervision or support within the workplace, has been indicated for worker burnout and/or poor job satisfaction, which leads to higher staff turnover among support workers (e.g. Baldwin et al. 2003; Vassos et al. 2013). As such, provision of regular supervision is necessary, particularly for DSWs who work mainly within home settings, to prevent burnout, and which can have positive flow-on effects for families caring for persons with disability. Studies have shown that DSWs who are skilled and well-supported by their support agencies are in the best position to foster capabilities and cooperation with their direct clients, build and sustain care relationships, and meet the support needs of the children and their families (Blyth and Gardner 2007; Cortis et al. 2013).

**Limitations**

The differences in the disability support systems within each of the states and territories in Australia limits generalisation outside of the study site, as does the relatively homogenous sample of parent-carers and the purposive nature of sampling, which limits
the generalisability of this study’s findings to the wider population. Furthermore, focus group attendance was affected by the nature of caregiving, where many parent-carers expressed interest in participation but several were unable to attend at the eleventh hour due to caregiving emergencies or demands.

Future research will need to consider how to better engage the often time-poor parent-carers to participate, as well as consider the benefits of interviewing the DSWs who actually work for the parent-carers in the study, so as to provide a more accurate comparison of reflection of the support service provided. Including other stakeholders, such as the support agency co-ordinators and line managers, would also add valuable input on the policies and procedures that direct their practices.

**Conclusion**

The findings reported here suggest that flexibility and adaptability of both support service providers and service users are key to respite care reducing caregiving stress more effectively, at least in the short-term. The need for more adequately and appropriately skilled support workers was also indicated, as was clearly defined job descriptions for support workers, in particular for those who work in the homes of their clients. This new knowledge offers support agencies insight into the expectations of parent-carers of their young clients that can help them adapt or innovate their business models to meet the structural changes created by the NDIS’s consumer-driven model.

For formal support services to help parent-carers achieve improved health and wellbeing in the longer term, findings highlight the need for much improved communication and collaboration between the government departments, support agencies, and the families, which would reduce unnecessary distress for parent-carers and aid in the more accurate matching of services to the distinctive needs of each family. Significantly, parent-carers of young children with IDD want a client- and
family-centred approach to formal support services, where the support needs of themselves, their affected children, and their families are acknowledged and addressed together so that they can function more as a normal family inside their homes and within their communities.

Disclosure statement

No potential conflict of interest was reported by the authors.

Notes

1. Local government areas are the Australian Bureau of Statistics’ approximation of officially gazetted subdivisions by each state and Territory in Australia.

References


Merriman, B., and J. Canavan. 2007. Towards best practice in the provision of respite services for people with intellectual disabilities and autism. School of Political Science and Sociology, National University of Ireland: Child and Family Research Centre.


