

Partnership in practice: what parents of a disabled child want from a generic health professional in Australia

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Abstract

Despite the love that exists between children with disabilities and their parents and the positive contribution that children with a disability make to families and communities, caring for a child with a disability can be difficult and demanding for parents, carers and the family. Their interaction with the many and varied health professionals they encounter can serve to either ameliorate or exacerbate these difficulties. In this paper we report on a qualitative needs analysis undertaken as part of a project to develop disability awareness resources for generic health professionals (GHP). Data were collected through focus groups ($n = 5$) and individual interviews ($n = 7$) with 34 parents/carers and was analysed using a process of thematic analysis. 'Partnership' was identified as the overarching theme that answers the question 'What do parents/carers want from a GHP?' Three further themes were identified that together tell the partnership 'story'. These are: 'The GHP–parent partnership', 'Qualities of a GHP', and 'The role of advocacy in the GHP–parent partnership'. Implications are presented that highlight the importance of advocacy in GHP–parent partnerships and suggest improvements in GHP education and preparation.

Keywords: advocacy, disability, generic health professional, partnership

Accepted for publication 23 March 2010

Introduction

In this paper we report on a qualitative needs analysis undertaken as part of a South Australian project to develop disability awareness resources for generic health professionals, exploring the experiences of children with a disability and their families and carers. A generic health professional (GHP) is a person who does not work specifically with children with disabilities and their families or carers, but who provides an element of the 'general' health service provision that children with a disability and their families may be likely to access, in

either a hospital or community setting. The professional could belong to any of the following disciplines – medical practitioner, dentist, nursing or allied health.

Caring for a child with a disability is a fact of life for many Australians. It is estimated that around 320 000 children aged 0–14 years have a disability and the majority of these children live with their families (Australian Bureau of Statistics 2008). Living with a child with a disability can impact on parents, carers and the family more generally (Davis & Gavidia-Payne 2009). Researchers have reported that caring for a child with a disability can be physically exhausting due to the 'relentless demands'

(Fox *et al.* 2002, p. 446) of caring for the child 24 hours a day, 7 days a week (Green 2007). It can also place carers under high levels of stress and worry and lead to social isolation (Fox *et al.* 2002, Green 2007, Murphy *et al.* 2007).

The families of a child with a disability interact with a wide range of health professionals involved in providing health and support services for the child. The quality of these interactions plays an important role in these families' lives. They can be positive and supportive, thus enhancing child and family outcomes or they can be negative and unsupportive, further exacerbating the difficulties faced by parents and families (Keen 2007, Dempsey & Keen 2009). For example Davis and Gividia-Payne (2009) found that professional support was one of the strongest predictors of family quality of life when compared with child and family characteristics and support from the extended family. Similarly, Summers *et al.* (2007) found that parents' ratings of service adequacy were a significant predictor of family quality of life for families in Early Childhood Service Programmes.

Given the importance of positive parent-professional relationships, it is unfortunate to note that parents and carers of children with a range of disabilities are generally dissatisfied with these interactions (Dyke *et al.* 2006, McGill *et al.* 2006, Green 2007). As Case *et al.* (2000) have pointed out: 'Families of disabled children are unique in terms of their child's specific problems, but share a commonality of experience in ... their conflictual, dissatisfactory relationships with professionals ...' (p. 272).

Parents and carers generally define positive parent-professional relationships as partnerships (Case 2000, Knox *et al.* 2000, Blue-Banning *et al.* 2004, Kasahara & Turnbull 2005, Goodley & Tregaskis 2006). While there is no single definition of partnership in this context, it can include the following: equality, mutual respect, open communication, genuine caring, provision of information, commitment, skills, trust, quality, empathy, service co-ordination, advocacy, honesty, mutually agreed-upon goals and shared planning and decision-making. Relationships that fulfil these requirements have been shown to promote empowerment in parents (Dempsey & Dunst 2004, Dunst & Dempsey 2007). While partnership is undeniably important to the parents and carers of children with a disability, research continues to point to a lack of partnership in parent-professional relationships (Case 2000, Farrell *et al.* 2004).

The concept of partnership is, furthermore, reflected in the South Australian Government's policy statement: 'Equity of Access to Health Services for People with Disabilities' (Department of Human Services 2001). While the term 'partnership' itself is not used in the policy document, the policy principles reflect the importance of many of the partnership qualities mentioned above in achieving the aim of ensuring equity of access to public health ser-

vices for people with disabilities. These include, for example, respect, consultation and involvement in decision-making, provision of information, effective communication and integrated and co-ordinated care.

The project reported here involved four phases: planning and scoping, conducting a needs analysis, the development of resources and launching and evaluating the resources. In this paper we focus on the second stage of the project and share the results of a qualitative exploratory study undertaken with parents/carers of a child with a disability. We focus particularly on what parents/carers want from a GHP. We then discuss how this relates to the emergent literature on partnership and explore the implications of this research for the education of GHPs.

Methods

A qualitative, interpretive approach (Braun & Clarke 2006) was used to gain an understanding of the experiences of parents/carers of a child with a disability in relation to their interactions with generic health professionals. Qualitative methods of inquiry are used extensively in child and family health research for their considerable strengths in exploring and interpreting the many ways in which people articulate and understand their experiences (Darbyshire *et al.* 2001, Pope & Mays 2006, Hatch 2007). The study received approval from the Human Research Ethics Committee of the relevant institution.

Recruitment of participants

Purposeful sampling was used to ensure the participation of parents/carers who had direct experience of caring for a child with a disability, of interacting with generic health services and GHPs and who were willing to discuss these interactions (Patton 2002). The study was publicised through 34 disability and parent/carer organisations that provide support and information to these families. A project flier was circulated to members through organisation-based newsletters and websites and parents/carers contacted the researchers directly if they were interested in taking part. All participants were informed that their confidentiality would be protected and that they could withdraw from the study at any time without penalty. Participants signed a consent form at the start of their interview.

Sample

Focus Groups ($n = 5$) involving 27 parents/carers were conducted across both rural and metropolitan areas. Seven individual interviews were also conducted. In total, 34 parents participated including three foster

parents and three grandparents. The term parent will be used to include parents, foster parents or a person who acted in the role of a parent and provided the day-to-day care for the child with a disability, e.g. a grandparent.

The majority of respondents were female (88%), within the 31–50-year age bracket (73%) and were mothers undertaking the primary care of the child who has the disability (73%). Most of the children being cared for were less than 10 years of age (57%) with an even gender ratio. Information on specific disabilities was not collected for two reasons. First, the study aimed to explore parents/carers experiences and perceptions rather than provide a comparative analysis across disabilities. Second, the study was funded by one of the major local providers of services to families with a child with a disability and it was felt that including information about specific disabilities could compromise the anonymity of participating families.

Topic guides

The focus groups and individual interviews were semi-structured around a topic guide. The guide was developed based on the study aims, the existing literature and consultation with the Project Advisory Group. Focus group and interview participants were asked to consider the various GHPs that they had encountered when responding to the open-ended questions in the topic guide.

Focus groups

Five focus groups, four metropolitan and one rural, were conducted with 27 parents/carers, with between four–six participants in each group. Focus groups allow data to be collected across a broad range of opinions, experiences and feelings within a group without a need for conformity or consensus (Rice & Ezzy 1999). Each focus group was moderated by either PD or JF, both of whom are experienced focus group facilitators. The focus groups took place in a variety of comfortable and convenient settings and were held at times that maximised the opportunity for parents/carers to attend. These interviews were natural, informal conversations that helped the participants to speak openly about ‘their’ most salient experiences and perceptions (Sweet & Darbyshire 2009, p. 543) in relation to GHPs and health service provision for their child.

Individual interviews

Individual interviews were offered to parents who were unable to attend a focus group. The majority of inter-

views were conducted over the phone, with one interview being held at the hospital where the participant’s child was an inpatient. The broad question format was congruent with the approach taken to the focus group interviews.

Interview analysis and interpretation

All focus group and individual interviews were audio-taped with the consent of participants. The tapes were transcribed verbatim and all identifying names were removed. Transcripts were then coded using a thematic analysis technique (Braun & Clarke 2006) discussed below. Coding was assisted by the qualitative data management software QSR NVivo 7 (QSR International Pty Ltd 2006).

In the first level of analysis (JF and PD) initial codes were generated from the data and were then clustered to form themes. In the second level of interpretive analysis (JF and CO), the themes were further explored and data re-coded to answer the questions identified by Braun & Clarke (2006) as salient for an interpretive analysis, namely: What does this theme mean? What assumptions underpin it? What are the implications of this theme? What conditions may have given rise to it? Why do people talk about this thing in this particular way (as opposed to other ways)? What is the overall story the different themes reveal about the topic? (p. 94). This second level of analysis is presented here with the central theme of ‘partnership’.

Findings

The theme ‘partnership’ is the overarching theme that answers the question ‘What do parents want from a GHP?’ The term ‘partnership’ was not itself mentioned all that frequently by the participants and overall only three participants used the term, including: ‘they need to be in partnership with us’; ‘It’s about a partnership and that’s the key’; and ‘the paediatrician said it’s got to be an equal partnership ... and I think that makes such a difference’. This is not too surprising as ‘partnership’ tends to be a professional as opposed to a lay term. However, after reading the available literature on the parent–professional relationship, we found that the qualities of this relationship that participants identified as important are broadly the same as those identified as encompassing a partnership and hence we identified this as the overarching theme.

There are three further subthemes that together tell the partnership ‘story’ (Braun & Clarke 2006) of the analysis. These are: ‘The GHP–Parent partnership’, ‘Qualities of a GHP’ and ‘The role of advocacy in the GHP–parent partnership’. These themes are introduced below.

As this was not a comparative study looking at differences between GHPs, participants were asked to think about their experiences of GHPs in general. Thus while particular GHPs are referred to in some instances, most of the quotes refer to a more generalised experience of GHPs.

The GHP–parent partnership

There were three main elements to a partnership relationship that were important to the participants: the provision of professional health care services, respect and trust.

The provision of professional health care services

One aspect of the GHP–parent relationship that is central to what parents want from their GHP is the provision of what we have described as ‘professional health care services’. We have used this term to define the codes that refer to the services that GHPs provide to parents and their children with a disability. These include: the provision of co-ordinated services and care; adequate provision of information; having time; continuity of care; open-communication; and family-centred care. Overall, parents identified significant gaps in the provision of professional health care services by GHPs.

Participants identified that they want GHPs to provide co-ordinated services for their children and communicate with other specialists to provide co-ordinated care. In most cases service co-ordination was not provided and this parent’s comment was typical:

Then from hospital getting into the system of the disabled world was so unbelievably left in the lurch, the hospital had no idea where to send us. (Parent Interview 5)

In the rare instances when services were co-ordinated parents considered themselves to be ‘so fortunate’ (Focus Group 1).

Not only is it important for GHPs to link parents to the array of services their children need, but these services also need to co-ordinate with each other. When GHPs did not communicate with each other and co-ordinate the care they were providing for children, parents felt overwhelmed by the array of activities they were expected to do with their children:

... that was this thing that their discipline was the only discipline and you had a list of activities and things to do and they would kind of check up on you and you had this guilt trip going on. (Focus Group 3)

In addition to the lack of co-ordinated care, parents identified that they were not properly equipped for caring for their children due to the inadequate provision of information by GHPs. One area in which information

was seen as lacking was in relation to entitlements, such as carers’ payments and additional services for children with a disability. For example, one parent noted how after complaining about inadequate care in the Emergency Department, ‘... somebody said there’s a special needs file if you have an emergency and we didn’t know about this until now, this is our fourteenth admission’ (Parent Interview 1).

Having time to adequately care for a child with a disability was another aspect of the provision of professional health care services that parents considered important:

... a nurse never noted a seizure in the whole 2 weeks ... because they actually didn’t even take the time to recognise, they’re very busy. (Focus Group 3)

Continuity of care is a further element of the professional GHP services identified by parents. Parents described positive experiences of the quality of care when they know the GHP and the GHP knows the parents, their families and their needs. Continuity of care allows parents to ‘build up some really good relationships’ (Focus Group 1) with GHPs. Parents found that when they were able to build these relationships, GHPs would go out of their way to help these families: ‘Our own GP ... would always fit me in no matter what’ (Parent Interview 7). A further benefit of continuity of care is the child’s familiarity with the GHP:

I don’t know how [the GP] does it but he looks in [child’s] ears and his throat without me even helping. I suppose it’s because we’ve seen him more, familiar I suppose ... (Parent Interview 7)

Parents also saw value in open communication to facilitate a positive relationship between parents and GHPs. Open-communication involved GHPs referring on when they did not know how to deal with the issue, acknowledging a lack of knowledge and being communicative and honest about the disability.

A final element of professional GHP service provision is the need for family-centred care. Parents felt that GHPs that did not consider the family context were likely to ignore the broader impact of the disability on parents’ and siblings’ physical and mental health and on the family’s ability to function. Furthermore, a lack of family-centred care was identified as being a cause of overload when GHPs proposed treatments that impacted negatively on the ability of the family to function as a whole. Parents wanted GHPs to:

... understand me and my child in the context of everything that’s going on in our life, we don’t exist in a vacuum and separate from everything else that’s going on in our family ... (Focus Group 4)

All of these elements of the provision of professional health care services facilitated the development of GHP–parent partnership. Another crucial factor described by parents is respect and the role it plays in developing partnerships.

Respect

Parents identified that demonstrating respect for both the parent and the child was a necessary element in an effective GHP–parent partnership. Respect for the parent includes respecting their deep and extensive knowledge and understanding of their child and not treating them as if they are ‘stupid’ or ill-informed. Parents highlighted the importance for GHPs to respect the fact that parents have a different, but equally valid knowledge that can contribute to better care for their children. One parent described this mutual respect with GHPs as follows:

I have become an expert ... they have understood that I know what’s going on so they respected me. (Focus Group 2)

Demonstrating respect also involves being attuned and sensitive to the needs of the parents and not only those of the child. This is particularly important as parents often identified that they were stressed and in need of support. One parent described a good relationship with a doctor where:

... he was saying, ‘How are you coping with [child]?’ ... not just saying ‘How’s [child] going?’ ... (Parent Interview 4)

Another parent pointed out that ‘when parents with a child with disabilities ask for help 99% of the time it’s genuine’ (Focus Group 3).

Respect for the child was also considered to be important in the GHP–parent partnership. There were numerous discussions of instances where GHPs had been respectful or disrespectful in their interactions with the child with a disability and the positive and negative impact these behaviours had on the parents and their children. Parents also highlighted the importance of GHPs respecting the children’s rights to medical treatment.

Indications of disrespect included talking down to or ignoring the child, treating the child as an exhibit, as well as making negative comments about the child’s disability in front of them. In addition to their discussion of GHPs lacking respect for their children, parents recalled numerous instances where respect was shown and consequently expressed their positive regard for these GHPs.

Trust

Trust is an important element of the partnership relationship. In particular, the provision of professional

health care services and the demonstration of respect for parent and child were identified as fostering trusting relationships. Parents described the trust, or lack of trust that they experienced in various relationships with GHPs. Parents gave examples of where they had built up a relationship of trust with health professionals:

I can ring [my GP] at home if I want to and he’s happy for that because he knows that I’m not going to abuse it so you build that trust thing, both ways. (Focus Group 1)

By contrast, parents described experiences of not trusting nursing staff to properly take care of their children in hospital and of ‘not feeling safe to leave them’ (Focus Group 3):

... I know the care they get when I’m not there is not going to be the same ... (Focus Group 3)

When there was no trust, parents felt they had to take sole responsibility for their children:

At [hospital] we had a bad experience there because [child’s] so different and so difficult we don’t get approached by nurses at all down there ... we are completely and totally responsible for [child] when she’s down there one hundred per cent of the time (Focus Group 4)

This lack of trust in GHPs and the consequent increased responsibility taken on by parents further impacted on their stress levels and on family functioning more generally.

Qualities of a GHP

Having outlined the parents’ perspectives of a GHP–parent partnership, we now turn to a discussion of the qualities of a GHP that parents believe influence whether or not a partnership is possible, namely: ‘GHP experience, knowledge and understanding of disability’; and ‘GHP attitudes towards disability in general and children with a disability in particular’.

GHP’s knowledge and understanding

Parents highlighted the importance of whether or not GHPs are knowledgeable about the disability and about how to interact with children with a disability more generally, and whether or not they understand the issues facing parents and children. Parents highlighted that while they do not expect GHPs to know everything about the disability, they would ‘like a basic understanding, this is a disabled child, okay we’ve got to do things a bit differently then’ (Parent Interview 6).

Some GHPs were able to do things ‘differently’ in terms of how they interacted with the child or the ways they made ‘allowances for the fact that [the child] did have a disability’ (Parent Interview 3). Parents also

described many interactions with GHPs where they clearly had very little knowledge or understanding. One parent described the difficulties in finding an 'understanding' dentist, as 'none of them thought that it would be such a major issue for [child] to sit in a dentist chair for half an hour with his mouth open' (Parent Interview 2). Another parent described the staff in the casualty department of a hospital as: '... very ignorant of disabled children' (Parent Interview 6). In general, parents saw GHPs' knowledge and understanding of disability as an issue that could be dealt with through appropriate education, particularly through direct experience of children with a disability.

GHP attitude towards disability and children with a disability

The GHP's attitude towards disability and children with a disability was also identified as impacting on parents' ability to form a partnership with their GHPs. At one level parents were concerned about GHPs viewing children with a disability as abnormal and using inappropriate language to express these views. Parents also described health professionals expressing the commonplace 'tragedy repertoire' (Vehkakoski 2007) that these children have no quality of life and should not be treated or resuscitated:

... numerous times it's been suggested that we not medically treat our daughter and allow her to die. ... most of the medical people are very supportive but there's a few who look at a kid with disabilities and think that they're not worthwhile treating. (Focus Group 1)

One parent even expressed fear that if she stated that her son had an intellectual impairment he would not receive quality treatment from GHPs. Parents ascribed these views to both the individual perceptions of particular GHPs and also more broadly to value systems and cultures endemic in health care organisations 'that maybe ... is too strong (for GHPs) to fight against' (Focus Group 3). Education was also seen as an avenue for addressing negative attitudes.

The role of advocacy in GHP-parent partnership

In this study, advocacy – generally defined by parents as 'fighting' for their children's needs and rights – was identified as the means by which parents attempt to redress any imbalance in GHP-parent relationships by 'hounding people' (Parent Interview 5) for professional service provision and respect. In addition to fighting for their children's rights by demanding services and respect, another strategy adopted by parents included actively choosing and rejecting health professionals based on their professionalism, treatment of parents and

children and their knowledge, understanding and values:

... they just talk down to you if they think you don't know anything and they treat you like an idiot, so now I pick the doctor I want ... (Focus Group 1)

While advocacy can be an effective process to facilitate a partnership relationship it can also be an exhausting, 'emotionally draining' (Focus Group 1) and never-ending process: 'Everything's a fight, always fighting' (Focus Group 1). Advocacy furthermore has the potential to have negative consequences for parents. For example, it can lead to too much responsibility being placed on parents: 'These days there's an expectation that the parents will do it all' (Focus Group 3). Adopting the position of advocate for a child with a disability can also lead to parents being viewed as 'pushy':

And half the time I think they cringe every time they see me walking in the door... (Parent Interview 2)

Parents also noted that such advocacy can result in GHPs viewing them as coping well and not needing assistance, when in fact they are stressed, overwhelmed and in need of help and support.

Discussion

The somewhat obvious answer to the question 'What do parents want from the GHP?' is that parents want a partnership relationship, grounded in respect, sensitivity and understanding of their child's needs and the wider orbit of their family life. This is perhaps unsurprising given that there is a growing body of international research literature highlighting partnership as important for parents and carers (Case 2000, Knox *et al.* 2000, Blue-Banning *et al.* 2004, Kasahara & Turnbull 2005, Goodley & Tregaskis 2006).

Parents in this study defined their desired relationships with GHPs as encompassing many of the partnership qualities identified in other studies. These include the provision of professional health care services and respecting parents and children, which foster trusting relationships between parents and health professionals. Parents furthermore identified the influence of GHPs' knowledge and understanding of disability and their attitudes towards disability and children with a disability, on the formation of a partnership relationship.

Advocacy was found to play an important role in the development of parent-GHP partnerships. In some studies the lack of equality in parent-professional relationships is seen to inhibit parents' ability to advocate for their children (Case 2000, p. 272). By contrast, in this study advocacy was identified as a strategy drawn on by

parents and carers when partnership is absent. This was also found in Wang *et al.*'s (2004) study of parents' experiences of advocacy. Parents in other studies have also pointed to the need for advocacy in order to receive adequate service provision for their children with a disability (Wang *et al.* 2004, Green 2007, Minnes & Steiner 2009).

When reviewing the literature on advocacy in the disability arena, it is apparent that advocacy is seen as a necessary and important part of the lives of parents who have children with a disability (Wang *et al.* 2004, Hess *et al.* 2006) – so much so that teaching parents how to advocate for their children is increasingly becoming part of the information and education provided to parents (Stewart *et al.* 2006, Glang *et al.* 2007). The Australian Government has also recognised the role of advocacy in the lives of people with a disability and their families, with the development of a National Disability Advocacy Program that provides funding to a range of advocacy organisations. The role of these organisations is to assist people with a disability to overcome barriers, for example physical access, discriminatory attitudes, abuse and neglect.

While advocacy is generally seen as a positive strategy for parents to adopt, we have also identified the negative consequences of advocacy for parents and families. These include exhaustion, stress and the possibility that too much responsibility is being placed on parents to care for their children (Wang *et al.* 2004, Green 2007). A further issue is the possibility of parents being viewed as pushy and aggressive, which could further impact on the quality of care provided to their children. This highlights the potential dangers of expecting parents to continuously fight for their children with a disability to receive proper care, rather than addressing the issues underlying the inadequacies in health care provision for these children.

The irony here will not be lost on parents and carers. Rather than educate and prepare GHPs to provide the quality of relationships and service that such parents and their children should be able to access without this being a 'battle', we seem content to overlook this while shifting even more of the responsibility on to parents by expecting them to learn the 'advocacy skills' that will enable them to fight the system more effectively on behalf of their child.

The needs analysis reported here was commissioned to identify what educational resources are required for GHPs to better care for children with disabilities and their families. It is acknowledged that education alone is not the panacea for improving the health experiences of these families in the absence of other resources. However, it is a foundation recognised by others authors (Byron & Dieppe 2000, Minnes & Steiner 2009).

The overwhelming priorities for these families were for GHPs to have the knowledge and skills to form effective partnerships by providing educational opportunities for GHPs to examine their values and attitudes towards disability; for direct experience with children with disabilities outside a clinical setting; and to hear the stories from families directly in order to develop an understanding of the need for GHPs to recognise and support the advocacy role parents have been forced to adopt. We agree with Murray that we cannot expect sustainable change to our current system until 'disabled children are centrally and positively placed within the relationship between parents and professionals' (Murray 2000, p. 683) and until a true partnership model of working exists where GHPs and parents together advocate for and bring about the long-awaited improvement in health care provision for children with a disability. With this in mind, we make the following suggestions for the development of improved GHP education and preparation:

- 1 Develop online resources/webcasts/podcasts and interactive DVDs that convey the experiences of children and young people with a disability and their parents/carers. These would include 'real life' narrative examples of families and children living with a disability and incorporate the authentic voices of children and young people.
- 2 Create opportunities for GHP students to experience the everyday reality of caring for a child with a disability, outside a clinical setting. This would involve developing a list of suitable 'experiences' for students. Each training organisation would be provided with a description of the experiences, including availability and contacts. The experience would be linked with a learning package where students reflect on their experiences of being with a family.
- 3 Develop communication skills guidelines and educational resources for GHPs, incorporating a DVD that demonstrates how to interact with a child with a disability including non-verbal children.
- 4 Develop a train-the-trainer programme for key nominated staff within a training or educational organisation and for participating parents/carers. Following the lead of the UK's 'Partners in Practice' program (<http://www.bris.ac.uk/pip/>), it would be critical to have a 'Disability Champion' at senior level within the end user organisation who is equipped with up-to-date knowledge and skills in relation to disability and is able to teach others.

As a founding principle, the development of improved GHP education and preparation are best undertaken as

an ongoing and sustained partnership between end user organisations, parents/carers of children/young people with a disability and wherever possible, involving children and young people themselves. The slogan of the international disability movement: 'Nothing about us without us' (Charlton 2000) is a crucial cornerstone of any future disability education initiatives.

Limitations

As this was an exploratory rather than a comparative study, only a minimal amount of demographic data were collected. Further research is needed comparing the impact of a range of contextual factors, such as ethnicity and diagnosis on parents/carers experiences with GHPs.

Acknowledgements

The 'Training and Development Project – Improving the links between health care services, children and young people with a disability' was led and managed by Novita Children's Services. We would like to acknowledge the support of the Project Steering Group and Project Manager Merry Frogley.

Funding

Funding for this project was made available from the South Australian Government, through the Office for Disability and Client Services.

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