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Health advocacy: a vital step in attaining human rights for adults with intellectual disability

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Abstract

Background People with intellectual disability (ID) experience health inequity compared with the general population, a key contributing factor being disparities in social determinants of health. The enactment of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) provides a platform for the progression and promotion of health and other interconnected rights to address barriers to the highest attainable standard of health for this populace. Rights can be brought to life through advocacy efforts. This paper explores the meaning, perceptions and experiences of advocacy by family members and paid support workers of adults with ID and locates the findings within a health and human rights discourse.
Methods As part of a larger randomised controlled trial, 113 parents and 84 support workers of adults with ID completed a telephone interview that included open-ended questions about their understanding and experiences of advocacy. Thematic analysis was used to identify relevant themes.
Results Five key themes were identified. The first underscored how advocacy to 'speak up' for the person with ID is integral to both parent and support worker roles. The second and third themes considered the contexts for advocacy efforts. Access to quality health care was a core concern, along with advocacy across other areas and sectors to address the person's wider psychosocial needs. The remaining themes highlighted the many dimensions to advocacy, including differences between parent and support worker views, with parental advocacy being an expression of 'caring' and support workers motivated by a 'duty of care' to protect the individual's 'rights'.
Conclusion Parent and support worker advocacy provides one means to address the social determinants of health and fulfilment of health rights of and for people with ID. Policy and practice in the context of governmental obligation under the CRPD should support advocacy and make health rights the reality not rhetoric for this group of men and women.

Keywords advocacy, disability support workers, health, human rights, intellectual disability, parents

Introduction

People with intellectual disability (ID) experience health inequity compared with the general popula-

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tion including higher mortality rates (Bittles *et al.* 2002) and unrecognised and poorly managed medical conditions (Beange *et al.* 1995; Webb & Rogers 1999). Disparities in social determinants of health influence inequities for this population (Graham 2005; Ouellette-Kuntz 2005; Krahn *et al.* 2006; Emerson & Hatton 2008; Emerson *et al.* 2011). Health rights offer one pathway to address such inequity, focusing on the provision of both timely and appropriate health care and the underlying determinants of health [United Nations (UN) Committee on Economic Social and Cultural Rights 2000].

A seminal statement on health rights is found in the preamble of the World Health Organization's (WHO) Constitution (1946): 'The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition'. Later, Article 12 of the International Covenant on Economic Social and Cultural Rights 1966 also provided a significant impetus to health rights, and was followed by other formative international documents. The most explicit affirmation of health rights, however, took place with the enactment of the UN Convention on the Rights of Persons with Disabilities 2006 (CRPD, Article 25). Grounded in the social model of disability (Dhir 2005; United Nations Enable 2011; WHO 2011), the Convention recognises the social and environmental conditions that contribute to the overall experience of disability including rights to education, social participation, work and employment, and adequate standard of living and social protection. Australia was among the first countries to ratify the CRPD, in 2008, and since then, has been obliged to integrate its provisions into domestic law and policy.

Advocacy for people with intellectual disability

CRPD rights, like all human rights, are mere words on paper unless there is energy and momentum to facilitate their respect, promotion and fulfilment. For people with ID, an important way that rights are lifted off paper and brought to life is through advocacy efforts (Cocks & Duffy 1993; Rapaport *et al.* 2006; Chambers 2007). A recurring definition from Wolf Wolfensberger's work on citizen advocacy in the 1970s is that of advocacy as 'functioning (speaking, acting, writing) with minimum conflict of interest on behalf of the sincerely perceived interests of a person or group, in order to promote, protect and defend the welfare of, and justice for, either individuals or groups, in a fashion which strives to be emphatic and vigorous' (Wolfensberger 1992; cited in Cocks & Duffy 1993, pp. 41–2).

There are many different forms of advocacy including self-advocacy, family/parent advocacy, citizen advocacy, legal advocacy, collective advocacy, peer advocacy, professional advocacy and systems advocacy (Teasdale 1998; Rapaport *et al.* 2005). The social model of disability emphasises self-advocacy, meaning that people with ID take an active role in advocating for themselves to overcome oppression and take control of their lives (Miller & Keys 1996; Goodley 1997; Goodley *et al.* 2003). While self-advocacy may be considered preferable, many people with ID require supportive advocacy to have their voices heard and their health rights met (Llewellyn & Northway 2008; Harrison & David 2009). Many factors influence the capacity of people with ID to engage in self-advocacy, including communication difficulties (Reinders 2002; Ziviani *et al.* 2004; McConkey & Alant 2005), limited life experiences/opportunities because of social devaluation (Cocks 1998), and reduced access to information, networks and resources associated with social disadvantage (Emerson 2007; WHO 2011).

Family and disability support worker advocacy

This paper is specifically concerned with advocacy by family members and paid support workers. Family members have a central, normative role in standing beside the person with ID to speak out for their rights (Cocks & Duffy 1993; Timmons *et al.* 2004; Wang *et al.* 2004; McConkey & Alant 2005; Van Ingen & Moore 2010). Parent advocacy is almost certainly the most common form of advocacy in Australia (Cocks 1998). A recurrent theme in literature exploring the perspectives and experiences of advocacy by parents of people with an ID is advocacy for their sons and daughters as a major and integral part of their role (Todd & Jones 2003; Wang *et al.* 2004; Ryan & Runswick Cole 2009; Neely-Barnes *et al.* 2010; Van Ingen & Moore 2010). Parents are likely to engage in advocacy to obtain or improve services and appropriate living environments for their sons and daughters (Minnes & Steiner 2009; Ryan & Runswick Cole 2009; Fereday *et al.* 2010; Neely-Barnes *et al.* 2010; Van Ingen & Moore 2010). However, advocacy can be stressful and exhausting for parents, at times involving conflict (Todd & Jones 2003; Wang *et al.* 2004; Fereday *et al.* 2010; Neely-Barnes *et al.* 2010). For a small minority of parents conflicts of interest between their own needs/vision and those of their son or daughter may also compromise their capacity for advocacy.

Advocacy roles undertaken by disability support workers are less clearly identifiable. There has been little empirical research on support worker advocacy, the main focus being on support provider perceptions and evaluations of formal UK advocacy organisations (Rapaport *et al.* 2005; Rapaport *et al.* 2006; Da Silva Martins *et al.* 2011). This likely reflects both the support worker role and characteristics of the workforce. Through their employment and associated organisational constraints, support workers may not be able to advocate with a free voice and conflicts of interest may arise (Cocks 1998; Harrison & David 2009). The high turnover of support staff (Stancliffe & Keane 2000; Jorgensen *et al.* 2009), limited resourcing of advocacy activities, and an environment where direct service delivery takes precedence (Pearson & Associates Pty Ltd 2009) also present barriers.

Nonetheless, support workers potentially play an advocacy role for people with ID (Clees 1992), especially in the context of deinstitutionalisation when adults with ID increasingly began living in the community supported by service providers (Young *et al.* 2000; Young & Ashman 2004). Advocacy 'leaders' who speak out for people with ID can be found in the disability human service system (Sherwin 2010), advantaged by their knowledge of 'the system' and those who influence it (Koch *et al.* 2009). Nevertheless, funding shortfalls for advocacy services in Australia (Pearson & Associates Pty Ltd 2009) mean families and support workers will continue to be called to stand beside adults with ID to help realise their health, as well as other human rights.

Despite widespread acknowledgement of the need for advocacy to promote health and interrelated rights of people with ID, there is little systematic research into the nature and outcomes of advocacy by family members and support workers. We aim to address this gap by exploring the perceptions and experiences of advocacy by parents and support workers of adults with ID, and locating the findings within a health and human rights discourse.

Methods

The study was part of a larger randomised controlled trial that assessed the ability of two health assessment tools to improve health care for adults with ID living in the community (Lennox *et al.* 2005, 2010). The trial was conducted in Brisbane Australia between 2000 and 2002. The study methods are described in detail elsewhere (Lennox *et al.* 2005, 2010) but, in summary, researchers worked with 222 organisations to recruit people with ID aged 18 years or over living in private residences with family, alone or with other individuals in a shared arrangement, but not with 24-h support. Consent was obtained from the individual and/or their guardian, their main health advocate (parent or paid support worker), and their general practitioner prior to enrolment in the study (approved by the Behavioural and Social Sciences Ethical Review Committee, The University of Queensland).

At entry to the randomised controlled trial, parents and support workers were invited to complete a telephone interview questionnaire to collect quantitative and qualitative data. The qualitative component reported in this paper explored parent and support worker understandings of advocacy. We took a phenomenological position (Patton 2002) in that we sought to capture, describe and interpret the phenomenon of advocacy through participants' subjective lived experiences. This position guided our methods of data collection and analysis. We used a series of open-ended questions to elicit firsthand perspectives from participants and used thematic analysis to provide an account of those perspectives (Braun & Clarke 2006).

Interviews were completed by trained interviewers experienced in the disability sector. Demographic information was collected concerning the adult with ID (including age, sex, level of ID). Demographic data about parents (including reported household income, length of time at current residence, use of respite services) and support workers (including post-school training, length of time they had known the client) were also recorded. We report descriptive statistics for continuous outcomes as median (range) and categorical outcomes as frequency (percentage), using the number of respondents who answered the question of interest as the denominator for percentages.

Qualitative data were collected using four open-ended questions:

1. What is your understanding of advocacy?
2. What does an effective advocate do?
3. What do you see as barriers to effective advocacy?
4. Can you give an example of when you have used advocacy? This means you personally using advocacy, or getting help from somewhere else.

Responses were recorded as close to verbatim as possible using written notes. Being embedded in a structured telephone interview that was part of a broader study limited the scope for elaboration and clarification of responses. Responses tended to vary in length from a few words to several sentences. Analysis of responses of this type can pose a dilemma for researchers (O'Cathain & Thomas 2004) because such responses do not provide the rich narrative data set produced by data collection techniques such as in-depth or semi-structured interviews. Therefore decisions about analysis were guided by the overarching purpose for which the data were generated (O'Cathain & Thomas 2004) and by the research question and underlying theoretical assumptions of the study (Braun & Clarke 2006).

Thematic analysis was selected as being well suited to the study aims. Following standard guidelines (Braun & Clarke 2006) we sought to identify and categorise relevant patterns and themes based on the full data set of responses generated by the four open-ended questions. The responses were read multiple times by two research team members (CB; JD) who independently generated preliminary codes and categories. These codes were cross-checked and differences resolved through discussion. Numerical indicators, reported as percentages, are provided where appropriate to indicate how frequently responses were endorsed by participants.

Results

A total of 272 adults with ID agreed to participate in the study and completed the baseline interview. Participants nominated a parent ($n = 144$) or paid support worker ($n = 85$) as their advocate. The remaining participants nominated either no-one ($n = 19$) or a person other than a parent or paid support worker ($n = 24$). Of those nominated, 31 parents and 1 support worker did not respond to any of the questions about advocacy, leaving analysable data from 113 parents and 84 paid support workers.

The adults with ID had a median (range) age of 33 years (18–76) and 60% were male. Of individuals with known levels of ID, 40 (22%) were classed as having mild impairment, 76 (42%) moderate, 48 (27%) severe and 16 (9%) profound. Level of disability had a similar distribution for individuals cared for by parents or paid support workers. Most parents were mothers (89%), and 117 (82%) were co-residing. Those co-residing had been in their current residence for a median (range) of 24 years (8 months to 54 years), and 47 (41%) accessed respite services. There were 52 (46%) parents who reported having an annual household income of under A$30 000 (in 2003 the Australian median household income was approximately A$25 000). Paid support workers had known their clients for a median (range) of 5 years (3 months to 30 years), and 89% of workers had received post-school education or training.

Five key themes were identified based on analysis of parent and support worker responses to questions about their understanding and personal experiences of advocacy. The first theme underscored how advocacy is integral to the roles of both parents and support workers, although some were *uncertain* about the meaning of the term. The second and third themes related to the contexts in which advocacy was particularly important. *Accessing quality health care* was commonly identified as requiring effective advocacy. However, parents in particular noted a diverse range of areas in which they participated in an advocacy role to address the person's wider psychosocial needs. The fourth theme highlighted the *many dimensions to advocacy*, including parents' strong concern that incorporating their knowledge and perspectives is key in successful advocacy. The final theme concerned the way *barriers to advocacy were the converse of effective advocacy*.

Theme One: Advocacy is integral to both parent and support worker roles

The term 'advocacy' was understood in a similar way by many parents and support workers as 'speaking up' for and on behalf of a person with ID. Almost half the respondents in each group viewed advocacy in this way. Respondents considered advocacy integral to their parental or professional roles.

> I am here to speak for him. I am his voice. (Parent 94)
>
> It means that I'm prepared to speak up for A and her rights. To speak up for her – protect her rights – anything contrary to A's benefit then I'd speak up – make a noise. (Support Worker 39)
>
> To assist [the] person who cannot speak up for themselves. To help them live a life like anyone else. (Support Worker 50)

Conversely, some parents (21%) and support workers (15%) were unsure what 'advocacy' meant, with responses highlighting their unfamiliarity with this term.

> I haven't the foggiest. (Parent 106)
>
> I don't really understand, but like [the] public trustee? (Parent 104).
>
> Not really sure – supplying information on someone's behalf? (Support Worker 83)
>
> I don't really know what that word means, what's that for? (Support Worker 18)

This uncertainty extended into the respondents' consideration about barriers to and examples of advocacy. Parents were more likely than support workers to report that they were 'unsure' of the barriers to advocacy and struggled to provide examples of their own advocacy efforts.

Theme Two: Advocacy to ensure high-quality health care

Parents (19%) and support workers (32%) most commonly identified health-care settings as examples of where advocacy had been used. A wide array of services were cited including speech therapists, psychologists, psychiatrists, physiotherapists, dentists, X-ray facilities, and primary and tertiary health services. Both respondent groups noted that advocacy went beyond accessing health services to ensuring that the services provided were appropriate and timely.

> Just relating to the doctors and specialists and making sure they do what is right for her. (Parent 40)
>
> Submitted formal written complaint to the Health Rights Commission about her treatment. (Parent 77)
>
> I had to keep going to doctors and to hospitals until someone would listen and make a decision about her condition and treatment. (Support Worker 3)
>
> Spoke up for [person with ID] in all medical settings and asked why. (Support Worker 44)

Theme Three: Advocacy to address the person's wider psychosocial needs

Respondents discussed a range of areas in which they had advocated relating to wider psychosocial needs of the person with ID. In particular, some parents (5–13%) identified a broad range of issues in which they had spoken up on behalf of their son or daughter, from housing, employment and respite to gaining legal and political support for issues of concern.

> Took the government to court to keep [person with ID] at school. (Parent 1)
>
> Had to fight for supported employment versus sheltered workshop which is where they wanted to put him. (Parent 25)
>
> Her disability support package was going to stop. She was going to be denied this because of some assessment decision by those in ivory towers so I went to my local member and explained my situation . . . with the local member's support I was able to have the disability support package reinstated. (Parent 73)

In contrast, support workers' advocacy efforts appeared more constrained, mainly occurring in relation to employment and housing (mentioned by up to 20% of the study participants).

Parents and support workers highlighted the importance of advocacy as a means of optimising social inclusion and access to community resources for the person with ID.

> Making sure he has the same opportunities and rights as any other person in the community. (Parent 25)
>
> Positive community awareness is created . . . Having the community 'on side'. (Parent 28)
>
> To make sure they have the same rights and choices as me. (Support Worker 84)
>
> [Person with ID lives . . .] valued life included in the community. (Support Worker 7)

Theme Four: Advocacy has many dimensions

Parents and support workers identified a range of abilities and expertise required by advocates for people with ID. Characteristics of effective advocates included personal attributes and communication skills.

Personal attributes

The attribute most commonly identified as needed for advocacy was being 'protective'. More than one in four parents and support workers spontaneously nominated this attribute, but there were clear contrasts in the way the two groups discussed the nature of other personal qualities required. Parents tended to refer to their central role as carers and nurturers, identifying attributes such as empathy ('Walk in the other's shoes' Parent 18), loyalty ('Do what is necessary. Do whatever you have to do until you get a result' Parent 14), determination ('Be tough, and do research [on] what is fair and just' Parent 19) and taking initiative ('What she can't ask for I will' Parent 58). Parents also emphasised the long-term nature of their support role.

> If I don't advocate on my son's behalf no one else will. It is never finished and I can't always be there for him. (Parent 18)
>
> Our life is entwined – whatever he needs I'm it. (Parent 36)
>
> I'm tired at 83 years! I can't do it [advocacy] anymore . . . I'm doing at 83 what I did at 53 for [person with ID]. (Parent 56)

In contrast, support workers tended to explicitly refer to a 'rights' basis behind advocacy efforts: identifying the need to protect and promote the 'rights' or best interests of people in their care, highlighting their duty of care and the importance of respect.

> Protect their rights in whatever aspect . . . be prepared to be 'out there' for the person with intellectual disability, speak up for them. (Support Worker 25)
>
> Promoting people's interests and rights . . . being prepared to pick up the sword and tally forth. (Support Worker 26)
>
> [It is part of our] duty of care that T. accesses whatever she needs to throughout her life . . . ensure that people are listening to them. (Support Worker 3)

Communication skills

Strong communication skills were considered to be a key advocacy skill, with communication taking place at multiple levels including with the person with ID, their families and other carers, with government departments and other agencies, and in the wider community. Respondents emphasised the need for highly skilful communication with the person with ID: providing the person with appropriate information and supporting them to understand this information; listening to and respecting the needs of the person; and in turn, ensuring that others listen to the needs and wishes of the person through acting as a voice on his or her behalf.

> That appropriate information is given to them [and] that they understand this information. (Support Worker 3)
>
> Listen to the needs and goals of the person with intellectual disability. (Support Worker 39)
>
> To give opinions that are in his best interests not the advocate's best interests. Walk in other's shoes. (Parent 18)

Information gathering and problem-solving skills were also identified as important. Advocates needed to have a clear grasp of the issue, rights and options available, to 'Delve into problems and issues' (Parent 92) and 'Ask lots of questions . . . [gain an] accurate, clear and concise history' (Support Worker 22).

Including parent knowledge and perspectives

Parents strongly emphasised that an effective advocate should genuinely engage and consult with families to include their knowledge and perspectives, noting the importance of 'speak[ing] with family and [the] person to find out what their needs are' (Parent 1) and 'being aware of the family's role and emotions' (Parent 45). Parents described negative experiences such as support workers 'talking down to the family members of the person with intellectual disability' (Parent 81) or 'not listening to family members – got to be open to all approaches not just one narrow approach' (Parent 29). While several support workers noted that barriers to advocacy lay in 'not communicating with the family' (Support Worker 33), most support workers did not spontaneously refer to the need to include parent's perspectives or knowledge.

Theme Five: Barriers to advocacy are the converse of effective advocacy

Unsurprisingly, barriers to advocacy tended to mirror the characteristics of effective advocacy. Many parents (42%) emphasised that a barrier to effective advocacy lay in some support workers not sufficiently valuing the person with ID or their family, and not taking enough care to understand their perspective.

> Imposing personal views on the individual and the family. (Parent 1)
>
> People expressing their own opinions instead of the person with intellectual disabilities. (Parent 6)
>
> Lack of understanding and compassion. (Parent 31)

Interestingly, a number of support workers themselves (17%) observed that some in their role lacked the skills needed for effective advocacy.

> Lack of communication skills, for example, trying to guess what he's thinking. (Support Worker 69)
>
> Assuming instead of asking. (Support Worker 40)
>
> Level of interest in the person and in issues the person is confronting. Being overly or under zealous. (Support Worker 26)

In contrast to parents, support workers tended to identify barriers located within organisations and agencies such as inadequate resourcing and lack of a person-centred approach.

> Lack of services . . . and linking services. (Support Worker 39)
>
> Bureaucracy, policies and paperwork. (Support Worker 12)
>
> Put some of those pencil pushers in the Department at the coal face to see what it's really like. (Support Worker 32)

Both sets of participants also identified negative community attitudes as barriers to advocacy.

> People don't understand intellectual disability and disability in general – the fear of the unknown does not help advocates or people with intellectual disabilities. (Parent 19)
>
> Also community perceptions – a lot of ignorance. (Parent 31)
>
> Attitudes and prejudices and lack of exposure and education regarding people with intellectual disability. (Support Worker 78)

Discussion

While the language of health rights and advocacy may be far removed from everyday realities of parents and paid caregivers who support adults with ID, this study shows that 'speaking up' for the person with ID is integral to their roles. The range of areas and sectors in which parents and support workers had 'spoken up' underlines the importance and potential of advocacy as a strategy for addressing and improving social determinants of health and, ultimately, the promotion and fulfilment of health and interconnected rights of people with ID.

Despite many commonalities of response, parent and support worker views on the fundamentals of effective advocacy were qualitatively different. These contrasting perspectives largely reflect the inherently different relationship with the person with ID for the two categories of respondents. Consistent with other studies, parents viewed the advocate role as a natural extension of the parental role (Todd & Jones 2003; Wang *et al.* 2004; Ryan & Runswick Cole 2009; Neely-Barnes *et al.* 2010; Van Ingen & Moore 2010). The unique bond between parent and child, the knowledge gained from a relationship spanning a long period of time and a singular emphasis on achieving best outcomes for their son or daughter was at the heart of effective advocacy for parents. Advocacy was an expression of caring and nurturing for parents motivated by loyalty and empathy for 'their child'. Support workers in the study more often perceived advocacy as a form of rights protection, with an effective advocate (in their paid role) being motivated by a duty of care to protect the individual's rights and values.

Many parents were acutely attuned to this difference in orientation and emphasised failure of some support workers to value and incorporate the family perspective as a particular barrier to effective advocacy. Notably, this was also raised by support workers as one of a number of potential skill shortfalls alongside broader organisational factors they perceived undermined effective advocacy on their part.

This difference in responses illuminates how parents may be less likely to expressly link advocacy efforts, and motivations behind those endeavours, to a broader human rights agenda. Although many parents may not explicitly realise it, they are in fact rights advocates. For example, parents described how they had been involved in advocacy endeavours striving for access to justice for their son or daughter (Article 13 CRPD) and equal recognition before the law (Article 12 CPRD), freedom of expression and opinion, and access to information (Article 21 CRPD), work and employment (Article 27 CRPD), as well as participation in political and public life (Article 29 CRPD).

Strengths and limitations of the study

This study provides a glimpse into how parents and paid support workers perceive and perform advocacy on behalf of adults with ID. A study strength is the inclusion of a relatively large number of parents and support workers. Although only limited socio-demographic information was obtained, participants were caring for a wide cross-section of adults in the community. A trade-off of that strength is the loss of detail and contextual information. The data collected were based on a small number of open-ended questions that formed part of a structured questionnaire. The potential for sample bias also exists. All participants had agreed to take part in a larger trial designed to improve health-care delivery and their views on advocacy may not generalise to those who chose not to participate in the study or to the wider population of parents and support workers. It is also important to acknowledge that 31 parents did not complete the advocacy questions and were not included in our analysis. Had their views been documented, unfamiliarity about what advocacy entails may have emerged as a more salient theme for parents in particular. Being part of our larger trial may have led participants to focus on health issues, although advocacy in areas other than health did receive some prominence. To optimise transparency and enhance analytical rigour the research team made ongoing efforts to be sensitive to the data collection context and analysis processes including the impact of our personal and professional backgrounds and potential biases (Finlay & Gough 2003; Padgett 2012).

The views of people with ID themselves on advocacy and self-advocacy were not explored and the focus was on advocacy at the individual level only. The study also was conducted before the CRPD came into effect and was ratified by Australia. Although unlikely, it is uncertain whether more contemporaneous data would reveal a different picture.

Implications for policy, practice and research

Advocacy is about power – influencing those with power on behalf of those without (Teasdale 1998; Jenkins & Northway 2002) and the potential for conflict exists. Advocates can be viewed as 'pushy and aggressive' (Fereday *et al.* 2010), considered 'trouble makers' by some health professionals (Carver & Morrison 2005) and other service staff who may perceive their views as criticism (Harrison & David 2009). Such conflict can place support worker advocates in vulnerable positions with their employing organisations (Jorgensen *et al.* 2009), making it reasonable to assume that capacity for advocacy is likely highly variable, *ad hoc* and limited. Research is needed to ascertain the propensity and capacity of support workers to engage in effective advocacy on behalf of adults with ID. The outcomes of those advocacy efforts that support workers, parents and self-advocates currently engage in also need to be evaluated. Systematic data of this type would provide a sound basis for a strategic and evidence-based approach to advocacy.

It would be simplistic to conclude the answer lies in providing training to improve advocacy skills of parents (Allen & Hudd 1987) and support workers (Jorgensen *et al.* 2009). Initiatives must be considered in the context of wider policy and resourcing agendas, including workforce strengthening. The role of advocacy in promoting people-centred health care could be included across government and organisational policy documents, along with the development of formal health advocacy policy (World Health Organization 2007). Building institutional cultures where advocates are welcomed, valued and empowered requires incorporating voices of health-care providers experienced in providing quality care for people with ID (WHO 2011) and engaging in a range of systems responses to promote among health professionals a greater understanding of the role of advocates, their potential to enhance care and strategies for effective partnerships. Providing opportunities for students to experience the 'everyday reality' of supporting individuals with disability could also prepare them for professional roles that include effective advocacy (Fereday *et al.* 2010).

The respondents in our study highlighted that an effective advocate listens, respects and communicates with the person with ID so their voice is heard and understood. This participatory-based advocacy, listening to the adult as opposed to telling 'them' what to do (Servaes & Malikhaob 2010), is again congruent with the CRPD, which recognises the importance for persons with disability being actively involved in decision-making processes that directly concern them [Section (o) Preamble CRPD].

The parents in our research expanded participatory-based advocacy to include not only ascertaining the views of the adult with ID, but concurrent consultation of themselves as family members to elicit a deeper, rounded understanding of the individual's needs. In a study of children with ID, Fereday *et al.* (2010) also found Australian parents wanted respectful and positive relationships with health practitioners. In health matters, inclusion of family members' views seems especially important 'to obtain the highest attainable standard of physical and mental health' given the poor communication between health-care providers and people with ID leads to problems with adherence to interventions, medication reviews, oversight of preventive health-care measures, non-diagnosis or misdiagnosis and treatment delays (Lennox *et al.* 1997).

Conclusion

Parents and support workers can, and report that they do, play important advocacy roles. These roles are vital to people with ID attaining the highest standard of health, receiving timely and appropriate health care and gaining equal access to the underlying determinants of health. However, individual advocacy efforts need to take place in the context of governmental obligation under the CRPD to make health rights the reality not merely rhetoric for adults with ID. There are a variety of strategies that can be taken proactively by governments to enact health rights, such as developing a national health-care strategy with specific goals for people with ID, implementation of health assessments to a wider population, funding systemic and individual health advocacy including training and support for parents and support worker advocates, and increasing access to professional advocates at different levels of the health system and in the wider social system. Ultimately, people with ID will flourish and live ordinary healthy lives in the context of a rights-based culture that values, includes and respects them (Reinders 2002).

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