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The practice of partnerships: A case study of the Disabled Children's Action Group, South Africa

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Background: Children with disabilities stand to gain from an array of services and interventions to support their development. However, relationships between parents of children with disabilities and professionals can be fraught, with the potential that professionals undermine the role of parents and overlook their agency.

Aim: The aim of this study was to examine the nature of partnerships between parents of children with disabilities and professionals in the Early Childhood Development (ECD) sector, and the influences that shape partnerships within a particular context.

Setting: This article documents the experiences of parents of children with disabilities from a national organisation, in respect of their partnerships with professionals.

Methods: The research was a qualitative case study of a national organisation of parents of disabled children, the Disabled Children's Action Group (DICAG), that has engaged in many different partnerships within different provinces of South Africa. Data generation techniques were document analysis and focus group discussion with staff and provincial branch members of the national DICAG office in Cape Town.

Results: The findings of the study provide a nuanced and contextually situated understanding of the complexity of parent–professional partnerships in the disability sector. A key issue that emerges is that to recognise and disrupt pervasive dominant discourses and their potential to weaken partnerships, professionals need to critically attune themselves to the situated experiences of those whom they seek to support.

Conclusion: The findings suggest that there is a need for a rights-based social justice agenda to underpin parent–professional relationships, to address the power dynamics and pervasive discourses that oppress the parent actors.

Keywords: parent–professional partnerships; children with disabilities; parents; disability; partnerships.

Introduction

Young children with disabilities can benefit from an array of services and social support structures to promote their well-being (Britto et al. 2014). Accessing and navigating these services and the associated relationships with professionals are among the additional responsibilities that parents of children with disabilities are required to assume (Ambikile & Outwater 2012; Olawale Deih & Yaadar 2013; Taderera & Hall 2017). Internationally, an intersectoral approach has been found to enhance interventions aimed at improving child well-being and addressing social determinants of health (Kim et al. 2017). Indeed, Redfern, Westwood and Donald (2016) argue that intersectoral collaboration between the education and health sectors in particular is essential to promote the inclusion of children with disabilities, and to ensure that they do not fall through the cracks in the service provision system. However, while community and parent participation is cursorily acknowledged, most research internationally on intersectoral collaboration is from the perspective of service providers (from the health, nutrition and education sectors) (e.g. Adeleye & Ofili 2010; Corbin 2017; Rudolph et al. 2013), with little attention paid to agency of parents in partnerships to heighten collective action. Furthermore, within the international literature, the dearth of studies on intersectoral partnerships from the global South has been noted (Corbin 2017).

The focus of the study presented in this article is unique in that it specifically explores the complexity of partnerships between parents of children with disabilities and professionals in the Early Childhood Development (ECD) sector. Early Childhood Development is recognised as a national priority in South Africa, and included in several of the Sustainable Development Goals (SDGs) (United Nations 2015). The emphasis of the SDGs on the importance of 'leaving no one

behind' (United Nations 2015:3) is particularly significant for children with disabilities and their families.

Parent–professional partnerships: Possibilities and tensions

Partnerships between parents of children with disabilities and professionals have been defined as 'mutually supportive interactions … focused on meeting the needs of children and families, and characterised by a sense of competence, commitment, equality, positive communication, respect and trust' (Summers et al. 2005:66). Keen (2007) pinpoints the features of effective partnerships highlighted in the literature as being mutual respect, trust and honesty, jointly agreed-upon goals, as well as shared planning and decision-making. However, research has shown that achieving these ends has been fraught with complexities in many contexts. We highlight some of the tensions, dilemmas and possibilities in the subsections below.

The power dynamics within partnerships

While often lauded as an 'unquestionable ideal' (Hodge & Runswick-Cole 2008:638), deeper probing of the nature of parent–professional relationships reveals that they are underpinned by notions of power and power imbalances, within particular historical and social contexts (Swain & Walker 2003). Squire (2012) holds that weak partnerships generally have different levels of commitment, resourcing and relations of power. Often parents do not have an equal relationship with professionals, and lack the knowledge, expertise or power to shape decisions, direct interventions or negotiate the types of services that their child requires. Research by Hodge and Runswick-Cole (2008) found parents of children with disabilities to experience a distinct hierarchy of knowledge:

> Parents continue to be disempowered in their relationships with professionals … their intimate knowledge of the child is devalued within the context of the parent–professional relationship and, in contrast, professional knowledge is privileged. (p. 639)

Indeed, parent–professional partnerships have tended to reinforce unequal power relations in which parents are posited as passive 'unpaid quasi-professionals instructed to carry out a series of developmental tasks set by the "real" experts' (Hodge & Runswick-Cole 2008:465). Yet, especially for young or severely disabled children, 'parents hold the key to accessing their personal experiences and background' (Case 2000:272).

A study conducted with caregivers in South Africa found that some service providers pitied and empathised with parents of disabled children, while others simply ignored or tried to avoid engaging with them, thereby failing to plan services that reasonably accommodate children with a spectrum of support needs (Department of Basic Education & UNICEF 2015). Singogo, Mweshi and Rhoda (2015:4) found a similar trend of (healthcare) professionals being 'unhelpful and disrespectful'

towards parents. In their study on the challenges of caregivers of children with disabilities in Tanzania, Ambikile and Outwater (2012) found that parents spent a great deal of time and their limited financial resources searching for appropriate services (schools, in particular) for their children. In South Africa, similar findings were evident in the study by Muthukrishna and Ebrahim (2014). Ambikile and Outwater (2012) and Muthukrishna and Ebrahim (2014) also found that parents were held responsible for their child's challenging behaviour, and had to take the blame for the consequences of it.

The question these findings raise is: Why do parents find it difficult to challenge or stand up to professionals? International research has documented that many parents are concerned that their assertiveness could have a negative impact on the provision of services for their child (O'Connor 2008). Often parents are labelled uncooperative, difficult to work with and maladjusted if they do not acquiesce with the decisions and recommendations of professionals (Hodge & Runswick-Cole 2008). They are therefore under pressure to conform to expectations of professionals, ignore their own instincts and defer to professional expertise.

What constitutes equitable partnerships?

A number of studies conducted in various countries have examined the conditions under which equitable partnerships thrive (Summers et al. 2007). O'Connor (2008) noted that parents valued the interpersonal elements of their relationship with service providers as much as they valued the services themselves. Caring relationships with professionals were seen to be key to sound partnerships. In the study by Ambikile and Outwater (2012:8) in Tanzania, parents expressed their appreciation of the research process that accorded them a voice. This was not about services being provided, but simply having someone interested in and acknowledging their journey.

Another key factor contributing to equitable partnerships was seen to be professionals' acknowledgement of parents' expertise (Hodge & Runswick-Cole 2008):

> Within a successful partnership, professionals do not always have to get it right, but they have to be perceived by parents as trying to do so and by taking on board the parents' expertise. (p. 645)

Underpinning the above argument is the recognition and valuing of parent's unique insights into the needs of their child, with an assurance that parents' contribution has the same validity as that of professional inputs (O'Connor 2008).

There is limited research on parent partnerships per se in respect of parents of children with disabilities emanating from South Africa and the global South. The present study was based on the premise that strong partnerships with parents are essential for the well-being of children with disabilities and their families (Sandy, Kgole & Mavundla 2013). The aim of the study was to examine the partnership

experiences of parents of children with disabilities, and the influences that shape partnerships within a particular context. The research questions were threefold: How do parents of children with disabilities in a rural context experience and navigate partnerships? What influences shape parents' experiences of partnership practices? How can the voices of parents inform and enhance the quality of partnerships between parent and professionals?

Theoretical framing

The study presented in this article links disability studies, development studies and studies in ECD. Models and embedded discourses that inform these disciplines are summarised in Table 1 and examined in the subsection below. We argue that that these discourses are useful in explaining the complexity of partnership actions and enactments evident in the present study.

Discourses of disability

Keen (2007) holds that relationships of parents of children with disabilities and professionals are reflective of the constructions of disability and the perceived role of parents in respect of their child's care and education. Understanding the way in which disability is determined and perceived is important because prevailing attitudes in society and the language used to describe persons with disabilities influence expectations, relationships and interactions (Haegele 2016). From the perspective of the *medical/individual model*, disability is seen as the defining characteristic of a disabled person, who is viewed in deficit terms as inherently defective, and therefore less than human. The challenges that they face are assumed to be independent of the wider sociocultural, physical or political environment, with the role of society in creating and sustaining mechanisms of inclusion and exclusion being ignored. Often the 'failures' of individual children with disabilities are attributed to parents, who then have to bear the responsibility for their children not succeeding within existing social systems (Murray 2000; Muthukrishna & Ebrahim 2014). A further manifestation of the medical/individual model is the influence that medical and other professionals have over the treatment of persons with disabilities and their families. As gatekeepers of benefits and resources, professionals control the processes of diagnosis and labelling that are applied to determine who receives services (Case 2000).

TABLE 1: Discourses shaping parent–professional partnerships.

Discourse	Key elements
Discourse of disability	Medical/individual
	Social
	Corporate/managerial
	Human rights
Discourse of partnerships	
Development sector	Professional as expert
	Parents as consumers
	Negotiation model
ECD sector	Parents as deficient
	Parents as agents of change

ECD, Early Childhood Development.

In contrast, the *social model* takes a social–contextual approach to disability. It holds that it is society that imposes disability on individuals with impairments, and thus solutions should not be directed at the individual but rather at society (Samaha 2007). This model posits that there is nothing inherently disabling about having an impairment, but disability is imposed by the way that individuals with impairments are isolated and excluded from full participation in their community (Case 2000). However, the social model has been criticised in its failure to account for differences between persons with specific impairments and the related disability, and for ignoring the reality of physical debilitation, pain and suffering in the lives of certain individuals with disabilities (Retief & Letsosa 2018). Furthermore, in rejecting the medical/individual model, the social model could ignore the possibility that in certain social realities medical interventions can produce positive changes in disabled people's lives (Gabel 2005).

Macartney (2011) draws attention to the *corporate–managerial* discourse that constructs disability as a management issue. Within this discourse, the fixation of government departments and social institutions is on mechanisms, strategies and systems for allocating and dispensing resources, timeframes and technical outputs. A corporate–managerial discourse may hold power and influence through its access to funding arrangements, professional and social networks and structures, and private sector resources, often to the detriment of human rights and social justice agendas. In line with a managerial discourse, Macartney (2011) points out that the New Zealand government's responses to the education of learners with 'special needs' is mainly about distributing, dispensing, monitoring and managing resources. The result is a fragmented, professional workforce providing services to individuals with disabilities. In such a scenario, issues of parent voice and agency in partnerships are not a concern or priority.

Taking the debate beyond embedded social and contextual influences that shape constructions and experiences of disability, the *human rights model* endorses a human rights approach to disability. It builds on the social model, and the view that disability is a social construct, but acknowledges that some individuals with disabilities may experience challenging life situations, arguing that such factors should be taken into account in the development of relevant rights-based theories, social justice policies and social services. This model stresses that individuals with disabilities are rights-holders and human rights subjects, and 'that impairment may not be used as a justification for denial or restrictions of human rights' (Degener 2016:1). The model would argue that social structures may limit, constrain or ignore the rights of people with disabilities, leading to social injustices and exclusion. The human rights model focuses on a range of social rights – civil, political, economic, social and cultural rights (Degener 2016). The United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2008) advocates the human rights model of disability.

A key question that the above discussion raises for the present study is: How do the discourses of disability embedded in these models inform or shape parent–professional partnerships in the study context?

Models and discourses of partnerships

Swain and Walker (2003) have proposed various models of parent–professional partnerships debated in development studies. In the *expert model*, professionals assume control over decisions, with parents seen as passive consumers of services and professional advice. This approach positions parents as being powerless and subordinate (Case 2000; Hodge & Runswick-Cole 2008). In the *consumer model*, the knowledge and rights of parents are recognised, with the assumption being that they could shop around for their choice of services. But in reality, choices for parents are extremely limited, and the balance of power still resides with professionals (O'Connor 2008). Finally, the *negotiation model* is characterised by joint decision-making, towards a shared perspective on issues of mutual concern. This model reflects a relationship within which 'professionals view parents as key decision-makers rather than simply consumers or clients of a service' (Keen 2007:343).

Cottle and Alexander (2013) have identified distinct discourses of partnership in the early childhood sector, which provide useful insights into relationships between parents and professionals. The *discourse of deficiency* casts parents as 'needy', 'vulnerable' or 'deprived', and as failing or lacking in some way. Parents who are less involved are seen as being reluctant to support their children's learning or development. Intervention programmes are designed to compensate for parents' (or children's) perceived inadequacies, with practitioners, social workers or therapists posited as role models. In practice, they are gatekeepers of resources and knowledge as they decide what a particular child needs. This may result in the 'right' way of doing things being pitted against the 'wrong' way. This discourse entrenches power disparities between those who know and have, and those who don't know and don't have. In contrast, in the *discourse of agency* parents are viewed as essential contributors to their child's well-being. Because parental involvement is affirmed as necessary for achieving quality outcomes for children (Prieto 2018), parents are seen as 'drivers of excellence' (Cottle & Alexander 2013:3).

Research indicates that the above discourses are mirrored in the disability sector (Brandt 2015). The discourse of deficiency views individuals with disabilities (and their families) as tragic victims of unfortunate circumstances, who are unable to look after themselves, and thus need either cure or care. In contrast, the discourse of agency is based on the view of persons with disabilities being rights-holders. This has direct implications for parent–professional partnerships because it requires a re-orientation from the (default) view of individual responsibility to one in which disability is seen as socially and environmentally determined.

The focus of the study was on parents of children with disabilities and their experiences of partnerships with professionals. We contend that the nature of such partnerships is determined and shaped by the model and the underlying discourses that are at play. It is important to critique these discourses to make sense of the impact of particular knowledges and enactments within partnerships. Critical questions need to be posed, such as: Is the voice of the parent a pivotal element of the partnership? Is the partnership enabling or is it creating dependency and vulnerabilities? Who holds power in the partnership, what is the role of power, and how does power play out?

Research methodology and design

A qualitative case study was undertaken of a national organisation of parents of disabled children, the Disabled Children's Action Group (DICAG), that has engaged in many different partnerships within different provinces of South Africa. The Disabled Children's Action Group came into existence in 1993, and has become a primary voice for children with disabilities and their parents, having participated in lobbying and self-advocacy from local and international level.

The Disabled Children's Action Group's vision is for all children with disabilities and their families in South Africa to enjoy their human rights. Its mission is to empower local parent branches in all provinces of the country, where parents meet, learn from each other, work together and stand up for the rights of their children (DICAG 2017). The Disabled Children's Action Group sees its role in working with different sectors as twofold, namely advocacy for the rights of their children and holding service providers accountable (DICAG 2017). To achieve this, it has been necessary for DICAG members to have knowledge of the rights of their children as well as the policies that give effect to these rights.

Recognition of the need to engage different sectors has been a key feature of DICAG practice, simply because 'our children need a basket of services' (participant 4, DICAG focus group). The most recent DICAG national conference was structured around four priority areas: health, social development, education and protection. There were presentations from different government departments in respect of their roles in implementing the provisions of the *White Paper on the Rights of Persons with Disabilities* (Department of Social Development 2016). There was an opportunity for parents to critique the rights of their children in each of these areas. In presenting the achievements of DICAG over the past 5 years, the national co-ordinator cited various intersectoral structures in which the organisation has been involved, including Disability Round Tables; the Right to Education for Children with Disabilities Alliance and the Disability Task Team of the Children's Bill Working Group that participated in crafting the South African Children's Act No. 38 of 2005 (DICAG 2017; Jamieson & Proudlock 2009).

A qualitative case study methodology was selected for this study as it enables the analysis of complex phenomena within a bounded context in all its complexity and uniqueness (Baxter & Jack 2008). Furthermore, it seeks to explore 'how' and 'why' questions, which was the intention of our study. In the study, the phenomenon in question was parent–professionals partnerships. Furthermore, the case study employed a variety of data sources as this allowed for the exploration of multiple facets of the phenomenon to be uncovered and understood.

Data from a variety of sources were converged in the analysis to foster a more in-depth understanding of the phenomenon of parent–professional partnerships within DICAG. Several data sources enabled triangulation during the data analysis process. Firstly, there was perusal of recent organisational documents, particularly the report of the national DICAG Conference 2017 and the organisational strategic planning document 2017 (DICAG 2017). In addition, various submissions made by the organisation were reviewed. These include a critique of the Millennium Development Goals in respect of children with disabilities, submitted to the South African Human Rights Commission (DICAG 2009); a submission on the Rural Education Draft Policy to the Minister of Basic Education (DICAG & DART 2018); and a Shadow Report on Article 24 (education) of the CRPD (the Right to Education for Children with Disabilities Alliance 2017).

Secondly, a focus group discussion was undertaken with staff and provincial branch members at the national DICAG office in Cape Town. The four participants included the national co-ordinator, the Western Cape provincial chairperson, a local branch member and a community development worker. Both convenience and purposive sampling were utilised. We selected participants who were easily accessible and available at the time, and who could provide in-depth and detailed information about the issue under study. The four participants selected represented a range of perspectives about the organisation. The objective was to seek out concepts, opinions, values, actions and enactments of DICAG in the context of partnerships. The interview questions related directly to the research questions of the study, and were open-ended and qualitative in nature to allow the participants to respond from a variety of dimensions, for example: What do you consider to be the role of the DICAG? What would you ascertain are its strengths in this process and why? What are some of the lessons you have learnt in encouraging/supporting/ promoting partnerships? What are some of the struggles and challenges DICAG faces around partnerships, and how do they play out? This approach also allowed for probing by the researcher on key issues raised. Using a laptop computer, notes of the focus group discussions were taken by the researcher, the first author, during this discussion. The researcher was vigilant in ensuring that the note taking did not interfere with the discussion. Once compiled, they were sent to group members via email for verification.

As suggested by Yin (1994), the objective in the data analysis process was to draw together converging evidence from the multiple data sources, organise and systematically review the data, and analyse the convergence. This process sought to understand and explain the social phenomenon under focus, and to examine experiences, views and meanings of the participants. Data analysis entailed thematic analysis using the research questions to group data. The data were read numerous times with the aim of identifying key themes. The process involved searching for actions, processes, similarities, contradictions, differences and assumptions embedded in how DICAG navigated partnerships. Through the process, key topics and the emerging recurrent patterns and themes were isolated.

In the first step of analysis, two themes that linked to the first two research questions were identified. These provided insight into how the parent organisation experienced and navigated professional partnerships, and what influences shaped the enactments of partnerships in context. In step 2 of the analysis, a third theme emerged that centred the voices of the parents on what would comprise authentic partnerships between parents of children with disabilities and professionals. In this article, we focus on three themes: dominant discourses within parent–professional partnerships, enactments of partnerships and towards authentic partnerships.

Ethical considerations

Prior to conducting the data collection for this research, the researcher corresponded with both the national chairperson of DICAG and the national co-ordinator. Both expressed full support for the study, and its aim of exploring the experiences of DICAG and the role of parents in working with different sectors. At the beginning of the focus group discussion, informed consent and ethical approval was obtained from DICAG and the participants. The researcher explained to participants the intention of the focus group, assuring them of anonymity, and impressing upon them that their participation was voluntary, and that they were free to withdraw at any point in the process. The discussion took place in the DICAG offices in Wynberg, Cape Town, further confirming that the research was sanctioned by the organisation. During the consent process, the agreement made with DICAG was that the identity of the organisation would be disclosed in a publication.

Consent was obtained from participants of the study as well as from the national chairperson of the Disabled Children's Action Group. Ethical clearance number: HSS/0250/013.

Findings and discussion
Enactments of partnerships: Discourse and power

This theme links to the first two research questions: How do parents of children with disabilities in a rural context experience and navigate partnerships? What influences

shape parents' experiences of partnership practices? In examining the second research question, the study interrogated the dominant discourses embedded in the enactments of parent–professional partnerships, specifically in the context of the work of DICAG.

Professional as expert and gatekeeper

The findings indicate that DICAG as an organisation operates from a discourse of agency and a rights discourse with recognition that the strength of parents is not only in their intimate knowledge of their children, but also in their knowledge of policy and the rights of their children (Philpott 2014). The Disabled Children's Action Group has articulated its vision that children with disabilities enjoy the same rights as all other children and have opportunities to develop to their full potential. Furthermore, the organisation recognises the importance of the CRPD in the struggle for human rights of children with disabilities and their families (DICAG 2017), with its premise that disability is, to a large extent, socially and environmentally determined. Parents are conceived not only as having the ability to provide nurturing care for their children, but also as agents of change on a collective level. However, in practice, the experience of the participants is that the agency and rights of parents are often ignored and infringed within partnerships. There appears to be an asymmetry between the models and discourses that underlie the work of DICAG as an organisation and the actions and behaviours of partners with whom they engage. In the study, the work of DICAG provided a lens into how parents experience services and the professionals whom they engage.

A critical concern for DICAG is that professionals are often gatekeepers to services. A key issue is that lack of information undermines the potential for sectors to work together effectively in support of children with disabilities, and perpetuates unequal power relations. Other studies have shown that many new parents of children with disabilities lack information and understanding about their child's disability, including diagnosis and its implications (Olawale 2013; Resch et al. 2010; Sandy et al. 2013). At their recent conference, DICAG members made reference to the 'problem of information asymmetry between parents and health professionals' (DICAG 2017), indicating that (medical and therapy) professionals do not adequately share relevant information with parents about their child's disability, such that it is 'understandable' for parents (DICAG 2017). In addition, parents often do not know about the rights that their children have – such as the right to education, to health or rehabilitation services. Owing to the lack of information about available services and being referred 'from pillar-to-post' for support (DICAG 2017), parents find themselves isolated and distressed. In contrast, Sandy et al. (2013) found that providing access to relevant information lets caregivers of children with disabilities feel empowered and places them in a position to act confidently and with agency in a role of advocacy on behalf of their children.

The experiences of DICAG illustrate the perpetuation of the perception of the 'professional as expert', located in the medical/individual discourse of disability. Other forms of knowledge about disability, about individuals with disabilities and their parents, are excluded and devalued in pervasive ways.

On another level, parents in the focus group questioned the so-called 'expertise' of many professionals. They cited their experience of a lack of knowledge about disability and the experience of disability on the part of many service providers. The participants explained that parents of children with disabilities need counselling and social support, but often social workers do not understand disability and the contextual influences that impact the family (DICAG 2017), and are therefore unable to support them appropriately. Participants asserted that when service providers do not understand disability, they often judge disabled children and treat them punitively, seeing them as disobedient or insolent. Members of DICAG attribute the lack of knowledge and awareness of disability to poor training of staff (DICAG 2017). The focus group parents indicated that lack of information about disability meant that many service providers do not appreciate the significance of their services and the difference that they can make for children and their families.

Furthermore, DICAG members identified other encounters with service providers that serve to undermine the potential of partnerships with parents. In respect of education, DICAG parents note a lack of commitment on the part of teachers to support the education of all children, including those experiencing barriers to learning and participation (DICAG 2017). They related experiencing service providers who are lethargic and 'can't be bothered' to attend to their concerns efficiently. One participant further explained:

> 'Many people providing services for children with disabilities … are not passionate about disability issues. They are just doing their work, they are there for money.' (Participant 1, DICAG focus group)

The participants explained that when parents challenge government officials or service providers, the response is: 'Who are you to tell us what to do? We are qualified people and you are not educated!' Similarly, a study by Resch et al. (2010) found that parents experienced trying to access services for their children as 'demeaning', as many service providers were disrespectful of their views and towards them as individuals. The individual/medical discourse shapes these behaviours and actions of professionals as they position themselves as 'experts' in relation to what they deem to be 'uneducated and uninformed' parents, whose views and opinions are treated with disdain.

The voice of the DICAG participant in the study cited below provides insight into how a government social institution, the Department of Education, as gatekeeper, abdicates

responsibility for a child, with the premise being that the child's behaviour is not the problem of the school or educational system, but that of the parent:

> 'Recently, a parent came to me for help. Her child is 13, she is out of school. But at this age, she still needs to be in school. When her child was 12, she got bad behaviour – she would lash out at other children. So the school said to her [the parent] they can't cope with her any more, she must remove her from school. She asked where she would place her child. The world is so cruel. Now the child is open for the world – she will get into bad influence. Now the responsibility is on the parent to find another school. She is so despondent. She took her child to the clinic to get her assessed – she has ADHD [attention deficit hyperactivity disorder]. So she asked for help. Education is important – but she doesn't know where she is going to place the child now.' (Participant 2, DICAG focus group)

This narrative suggests that the education department and the school have adopted a dominant, deficit, medical discourse through which parents and their children are further disabled. The knowledge regimes of professionals construct disability as an individual deficit and the individual problem of parents and their children.

This study shows that often individual parents do not have the agency to resist or challenge the exclusionary and oppressive positions of service providers and professionals, and to disrupt the unequal power relations. The lack of agency on the part of parents to transform power relations was also evident in the study by Muthukrishna and Ebrahim (2014). Macartney (2011) highlights the social construction of meanings around 'disability' and points to the importance of interrogating how these meanings are produced and sustained within particular, localised contexts. What is pervasive is that disability is socially constructed to serve certain ends, and often, to maintain existing exclusionary practices and actions. There is a need for adoption of alternate models and discourses that have the power to uncover and undermine pervasive discourses that operate within parent–professional partnerships, such as the human rights discourse that foregrounds parent agency and voice.

Hierarchical and alienating culture of partnerships

A significant challenge that DICAG parents have experienced is the hierarchical and often alienating culture of the partnership, and the inflexibility of some of the partners with whom they work. Some partners assume that there is a 'right way' to do things and that all others are 'wrong', instead of jointly establishing ways of working together. There is no evidence of a model of negotiation and shared decision-making. One of the parents, who runs her own ECD centre, related her experience of an ECD service provider with whom she partners:

> 'In my centre, a service provider came and asked to look at my daily programme. I showed it to her. Then she took it down and replaced it with her own, the "right" one. Then another person came and asked me to take that one down and put a

different one. So now I just put them all up! But it needs a strong person [not to bow to all these demands].' (Participant 3, DICAG focus group)

Clearly, power rests with the service provider and individual actors in the organisation in question. In South Africa, a mandate for collaboration between sectors is articulated in ECD and disability policies, reflecting a shared understanding of goals and priorities. However, Burgess (2015) cautions against programmes directed from higher structures that are not developed in consultation with local groups and users. There is a danger of underestimation of the value of community-based knowledge in understanding development issues and identifying possible policy and systems interventions to address them (Rudolph et al. 2013).

The power relations inherent in an approach imposed by a partner is particularly difficult to deal with when the partner is a funder, and stipulates that things need to be done in a particular way if funding is to be granted. For example, DICAG members described the need to compile a 65-page business plan for a funder, which parents perceived as a daunting administrative challenge. It does seem that the funder's technical procedures, complex processes, outputs and time frames are more important that issues of partner needs, capacities and competences. Here, one can see the corporate–managerial discourse playing out, and the neglect of concerns about human rights, building the agency of and giving voice to parents of children with disabilities. An unequal balance of power and control is one of the barriers to strong partnerships (Squire 2012). Such an asymmetrical relationship highlights the embedded discourse of deficiency – such a discourse has the potential to reinforce and reproduce existing power inequalities, and impedes prospects of real collaboration between partners (Lister 1999). Reid (2016) suggests that three key elements need to be at the heart of cross-sector partnership: equity, transparency and mutual benefit. The findings of the study show that respect for these principles may be lacking in DICAG's partnership with professionals.

From the discussion above, it is evident that particular dominant discourses and underlying power imbalances operate in insidious ways within the parent–professionals involving DICAG. Professionals need to understand that particular forms of knowledge influence their enactments and their views of parents and children with disabilities (Macartney 2011). Professionals need to interrogate the knowledges they draw on, and question, contest, resist and disrupt practices that are based on deficit discourses, for example. Spaces need to be created for dialogue between parents and professionals. Drawing on Riane Eisler's cultural transformation theory, Frimoth (2018) explains that systems of domination and systems of partnerships operate at opposite ends of a continuum. Systems of domination operate according to a top-down, authoritarian regime. Dominant actors in partnerships are those in power and

authority over others, and they govern the fate of those who are vulnerable, for example disabled children and their families. Frimoth (2018) argues that enacting partnerships is about instituting social justice and equity, and that equity is the key principle that drives systems towards authentic partnership and away from domination. This requires professionals to renounce their established identities as expert knowers.

Limitations

A limitation of the study is the fact that the focus group interview was not audio recorded. It is conceded that the use of an audio recorder would have enhanced the richness and accuracy of the data, and that there is a possibility that the researcher may have had lapses in memory leading to inaccuracies, and may have interpreted some of the responses from her own perspective. However, the verification of the detailed final notes by the focus group participants would have minimised this risk.

Towards authentic partnerships

Batti (2017) concedes that:

[P]artnership is an emergent and dynamic process and working in collaboration with others is never easy especially when it involves organizations with diverse and sometimes conflicting mandates, cultures, capabilities and aspirations. (p. 158)

The complexities of parent–professional partnerships is evident in the study. The Disabled Children's Action Group as an organisation has been reflecting critically upon how it can become a change agent to enhance partnerships between parents and professionals. The parents' voices became evident in the various documents analysed and in the focus group discussion. The study indicates that the process has to involve disrupting dominant discourses that limit the potential of parents to play the role of change agents. Below the article highlights two key subthemes that were significant in the data.

'Atmosphere' of partnerships: Shared vision, values and purpose

Research on partnerships across sectors provides insights into authentic and weak partnerships (e.g. Barnes et al. 2009; Batti 2017). This body of literature suggests that partnerships must be guided by a shared vision and purpose that builds trust and recognises the value and contribution of all members. Research has also highlighted that the culture of partnerships is the collective experience of the actors and it is what makes a partnership unique. In this sense, culture is the sum of beliefs, values, goals, attitudes, behaviours, relationships, language, shared assumptions and interactions (Reid 2016).

Disabled Children's Action Group members spoke about an 'atmosphere' of partnership that needs to be developed, with partners acknowledging one another and the role that each plays. In the focus group, a parent explained:

'You should not work like an island on your own, saying "this is my thing, these resources are mine – we worked hard for them". It's like a secret. Like a recipe that you share some of the ingredients, but not all of them.' (Participant 4, DICAG focus group)

Disabled Children's Action Group participants in the study were of the view that genuine respect for the various participants, institutions and organisations involved is a key principle of authentic partnerships. Lister (1999) asserts that true partnership respects the identity of each institution involved, its goals and values, its strategic directions and its well-being. If this is not evident, power imbalances tend to operate. Macartney (2011) adds an important dimension when she explains that:

An ethic of care and obligation to others challenges developmental, neo-liberal and individualistic views of children and adults as autonomous subjects who are personally responsible for their position in society. (p. 328)

She states that the underlying positioning of obligation and responsibility to the 'other' is the thinking that people's lives are co-dependent and reciprocal, and that they learn and develop in relation with and to one another.

Furthermore, an important element of sound partnerships is the resolution of major power disparities, as power differential in a partnership could have a negative impact on the future sustainability of collaborative efforts, according to El Ansari and Phillips (2001). Batti (2017) also stresses that power imbalances within partnerships eventually impacts sustainability.

The findings in the study suggest that the collaborative process should involve reciprocity, building trust, maintaining open communication, being responsive, ensuring flexibility, giving space for all ideas to be heard, and prioritising learning and capacity building as an ongoing process. Learning would involve creating spaces for drawing on and capitalising on one another's skills, knowledge and experiences of local needs, concerns and priorities. This principle relates to human rights and valuing diversity (Barnes et al. 2009).

Voice and agency of parents

The findings of this study indicate that the voices of parents of children with disabilities are often unheard, and need to be privileged and amplified at different levels. At an *individual level*, debriefing and counselling is a critical part of parent support, giving parents an opportunity to express their emotions, uncertainties and hopes for their children. According to participants in the focus group, unless parents are able to do so, inappropriate expressions of emotions of grief, stress and anger may continue to negatively affect them and their parenting as their children grow older. In

addition, information about rights and services is also necessary for parents to take informed decisions in respect of the unique needs of their children. As is evident from DICAG members, parents have much to offer in terms of insights about disability and addressing barriers to participation. The Disabled Children's Action Group has recommended that parents collaborate in developing and leading disability awareness training initiatives, and sharing their experiences of disability rights and inclusion (DICAG 2017). At a *collective level*, agency of parents can be enhanced through peer support and joint action and capacity building for change. As one parent said: 'We are empowered by other parents … it's because we can identify with them' (Participant 3, DICAG focus group). There are common concerns and parents of children with disabilities can create spaces to act collectively to support one another. At an *institutional and systemic level*, parent representation on community and disability structures (e.g. Disability Forums) can help to ensure that issues related to children are raised, and professionals are held accountable. Specifically, DICAG members call for improvement in accountability of health professionals, who through negligence may contribute to primary or secondary disability, a call that is echoed within the health sector itself (McKerrow 2016).

Among the goals of DICAG is that children with disabilities and their parents become self-advocates, with local and national advocacy campaigns and lobbying among the activities contained in the DICAG strategic plan (DICAG 2017). Building agentic, well-informed, confident parents who have the ability to engage assertively with different sectors is a long process and may require parents changing how they have been used to functioning and developing a different culture. A DICAG participant shared what this had meant for her:

> 'When I was growing up, I was always being told 'don't ask too many questions'. I absorbed this, and so I have found it difficult as an adult to question things. But I have developed strategies to do so – like in a meeting writing down the questions I want to ask.' (Participant 4, DICAG focus group)

Another DICAG member shared how she had honed independent critical thinking abilities, taking advantage of opportunities to give feedback and question what different service providers do and how it impacts children with disabilities. An important component of developing parent advocates is that parents know their rights and those of their children. This is one of the short-term outcomes identified by DICAG in its most recent strategic planning document (DICAG 2017). Furthermore, in respect of new members, the organisation has recognised the need to familiarise the sector with legal literacy, and to align their programmes with international conventions, such as the CRPD (DICAG 2017).

A further element that needs to be addressed in the relationship between parents and professionals is that of access to relevant information. Parents need to know about the diagnosis, cause, consequences and prognosis of their own child's condition, and to understand strategies for 'managing' it. They also need information about their child's needs and their right to participate in early learning, education and play. Parents also need information about what services are available, what they can offer and how they can be accessed. Disabled Children's Action Group members emphasised the need for service providers to share information with parents in a way that is respectful, taking cognisance of their experiences and questions and not treating them as empty vessels to be filled:

> 'We have had many people supporting us. People not intimidating us, but guiding us. Treating us with respect. They pulled knowledge from us in a good and respectful way.' (Participant 4, DICAG focus group)

In the study by Ambikile and Outwater (2012), booklets on how to manage child behaviour were found to be helpful to parents.

The study shows that effective communication and strong feedback is critical to granting voice and building the agency of parents in partnerships. This links to the issue of accountability in the form of evaluation and monitoring systems. It is evident from DICAG's experiences of partnerships that although there are rights and entitlements enshrined in South African legislation and policies, there is no guarantee that these are understood, protected and acted upon by service providers and social institutions such as departments of education and schools. Disabled Children's Action Group members indicated that an open approach within partnerships creates the opportunity for reflection and dialogue with the aim of strengthening the partnership. Research by Van Hove et al. (2008) suggests that the voices of parents of children with disabilities must be central to collaboration within partnerships. Listening to parents and being open to collective learning and genuine dialogue helps disrupt discourses, knowledges and meanings that create particular identities and entrench oppression and exclusion.

Conclusion

Partnerships are critical to the effective implementation and scaling up of ECD services for children with disabilities. Sindall (1997:6) argued that to make partnerships work 'we need to be developing not only the capacity for joint working, but also our ability to read, interpret and ultimately to shape the context in which collaboration occurs'.

This study is significant in that it provides a nuanced and contextually situated understanding of parent–professional partnerships in the disability sector. A key issue that emerges is that to recognise and disrupt pervasive dominant discourses and their potential to weaken partnerships, all partners and actors need to critically attune themselves to the situated experiences of those whom they seek to support. The findings suggest that there is a need for a rights-based, social justice agenda to underpin parent–professional relationships, to address the power dynamics and pervasive

discourses that oppress the parent actors. It highlights the need to create spaces that illuminate how power and resistance through embedded discourses circulate in partnerships in complex and dynamic ways, and in multiple directions and levels.

This study indicates that, when amplified, the voices of parents of children with disabilities not only have the potential to contribute to the well-being of their children and the agency of parents, but also collectively to hold professionals to account through the vision of inclusion (Van Hove et al. 2008). To ensure that this is institutionalised, an evidence-informed learning and enhancement strategy for multi-sectoral partnerships is required, providing a space for constant monitoring and evaluation to ensure that all voices are heard and valued.

Acknowledgements

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