

“Our children have the right to an education too”: Strategies Employed by Orange Farm Caregivers of Children with Disabilities in Pursuit of the Right to a Basic Education

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ABSTRACT

Purpose: *This paper aims to understand the agency that caregivers who participated in a CBR empowerment component programme exercised, in order to promote the rights of their children with disabilities to a basic education.*

Methods: *An interdisciplinary theoretical framework and qualitative methodology were used to examine the agency and the opportunity structures within which the caregivers operate. Focus group discussions, case study interviews and secondary Programme data were analysed using manual thematic analysis.*

Results: *Thousands of children with disabilities in South Africa are effectively denied the right to a basic education as a result of discriminatory norms, stigmatising discourses and unjust power relations. Yet, a group of caregivers have successfully advocated for their children with disabilities in the township of Orange Farm, Gauteng. Their lobbying has contributed to the establishment, by the State, of a new school.*

Conclusion and Implications: *The findings suggest that human rights advocacy movements, as well as disability organisations, would do well to recognise and encourage the power and agency possessed by caregivers of children with disabilities. Catalysing civic action and providing opportunities for active citizenry and self-help seem to nurture increased efficacy and competence at navigating systems and accessing rights. While advocacy organisations may act as proxy agents, direct and collective agentic strategies should be nurtured.*

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In implementing inclusive education, policy makers and the Department of Education should recognise the role that caregivers of children with disabilities can play, and the potential contribution that their motivation, resourcefulness, and disability-related knowledge can make.

Key words: *Disability, children, self-efficacy, agency, strategy, empowerment*

INTRODUCTION

The role of caregivers in accessing human rights and education for their children is paramount (Engelbrecht, 2006). This paper details strategies used by a group of about 190 caregivers of children with disabilities in Orange Farm, near Johannesburg. They have banded together to take responsibility for accessing their children's human rights. Since early 2012 caregivers have actively participated in a non-governmental organisation (NGO) Community-based Rehabilitation (CBR) empowerment programme (hereafter referred to as the 'Programme').

In Orange Farm, Saloojee et al (2007) indicated that half of the children with moderate and high support needs are effectively denied access to education. Contextually, Orange Farm is a peri-urban, semi-formal township situated 40 kilometres south-west of Johannesburg. About two-thirds of the children with disabilities identified in Orange Farm have moderate to severe intellectual impairment. Common diagnoses include Cerebral Palsy, Epilepsy, Autism Spectrum Disorder, and specific learning difficulties (Gauteng Department of Education Johannesburg South District Education Operations and Support Sub-Directorate, 2013). When data collection for this paper was initiated in 2013, there were no schools located close to Orange Farm for children with high educational support needs. The closest schools were about 20 kilometres away, and had long waiting lists (Gauteng Department of Education Johannesburg South District Education Operations and Support Sub-Directorate, 2013).

This article analyses strategies employed by caregivers of children with disabilities in advocating for their children's right to education, either directly at individuals; by proxy- through the Programme; or collectively, as a self-help group. It will be demonstrated that, in the face of seemingly insurmountable attitudinal and environmental barriers, caregivers of children with disabilities can and do participate by exerting influence on the dynamic yet disabling social system that confronts them. While they are influenced by the opportunity structure within which they find themselves and their children, they in turn exert influence on and

change the opportunity structure by successfully lobbying for the establishment of a new school for children with disabilities.

Literature Review

During the pre-1994 era, education was fragmented not only by the apartheid laws that enforced separation along racial lines, but also by legislation and policy that separated 'ordinary' students from those categorised as having 'special needs' (Muthukrishna and Schoeman, 2000). Since that time, great strides have been made towards racial integration and equal access to education for children with disabilities. The South African government has committed to rectifying the inequities of the past by ratifying international conventions; developing a constitution that emphasises equal treatment of all people; enacting pro-disability legislation and developing inclusive policy (Watermeyer et al, 2006).

True to this vision, the new South African government has signed and ratified three primary international legal instruments pertaining to the rights of children with disabilities, including the United Nations Convention on the Rights of Persons with Disabilities (hereafter, the CRPD) (United Nations, 2006), which deals most comprehensively with the right to equality and education for persons with disabilities.

Definitive legal reform at the local level began with the adoption of the Final Constitution of the Republic of South Africa (Republic of South Africa, 1996), in terms of which the right to a basic education was extended to 'everyone', without direct or indirect discrimination on the grounds of disability (section 29(1) read with section 9(3)). The priority of disability as a human rights issue was clearly and quickly articulated in State policy. Various policy papers outline the principle of education as a basic human right; among these, the Department of Education adopted White Paper 6: Special needs education, building an inclusive education and training system (hereafter, the 'WP') (Department of Education, 2001). The WP outlines the Department's commitment to promoting 'inclusive education and training', defined as '[e]nabling education structures, systems and learning methodologies to meet the needs of all learners'; '[b]roader than formal schooling and acknowledging that learning also occurs in the home and community, and within formal and informal settings and structures; and '[c]hanging attitudes, behaviour, teaching methods, curricula and environment to meet the needs of all learners' (section 1.4.1.).

The compendium of legal and policy reform which the State has undertaken in the last two decades demonstrates a clear commitment, in theory, to children with disabilities' right of access to a basic education. Despite this, however, structural discrimination persists as implementation gaps and service access inequalities remain (Department of Social Development, Department of Women Children and People with Disabilities and UNICEF, 2012; Human Rights Watch, 2015). Factors amounting to this situation are clearly articulated in a recent Human Rights Watch report (2015) entitled 'Complicit in Exclusion: South Africa's Failure to Guarantee an Inclusive Education for Children with Disabilities'.

METHOD

This paper is based on three sources of data. Focus group discussions and interviews were supplemented with secondary data from the Programme.

Convenience sampling was used in the selection of 22 female participants (20 mothers of children with disabilities and 2 grandmothers) who attend weekly self-help meetings as part of the Programme. Most caregivers were single (59%) and though none of them were formally employed, 4 were self-employed (17%). Most of the children with disabilities in the care of respondents were boys (77%) of compulsory school-going age (73%). Most had an intellectual impairment (55%) or multiple disabilities (27%) commonly associated with Cerebral Palsy; however, some had neurodevelopmental disabilities like Autism (13%), or a hearing impairment (5%).

In 2013, two dedicated focus group discussions were conducted on the children with disabilities' right to education. The 22 respondents were divided into two parallel focus group sessions that were facilitated by the researchers. The discussions were allowed to proceed in the participants' language of choice, and their comments were translated back into English by bilingual members in the discussion. Participatory exercises were used to stimulate semi-structured discussion, including ranking exercises and stakeholder mapping. Audio recordings were transcribed.

Two semi-structured interviews, one year apart, were conducted with 4 mothers of children with disabilities. Purposive sampling was applied to select a sample that represented a diversity of access to the education system. Interviews were conducted in English, recorded, and transcribed. Supplemental secondary data from Programme files were used to complete the details of the case studies presented in the findings.

The transcribed primary material and secondary data were analysed thematically as informed by the theoretical framework introduced above. Programme management consented to the use of Programme data. Secondary data was collected from Programme monthly reports, materials produced by the self-help group, information in the case study participants' individual case files, and written correspondence with the Department of Education.

A strict ethical protocol was adhered to. Written informed consent was obtained from caregivers, following a thorough explanation of the research process and their rights with regard to their contributions made during data collection. For ethical and methodological reasons data was not collected directly from children with disabilities. Identifiable information was eliminated from case studies and pseudonyms were used to ensure confidentiality. The research will be disseminated for use by the participants.

RESULTS and DISCUSSION

The following section explores how caregivers devised strategies and demonstrated direct, proxy and collective agency, in the pursuit of educating their children with disabilities. Three case studies provide real examples of the strategies used and the agency exercised follows in the discussion.

Selina has three children. Her husband lives and works in Johannesburg and offers little help. For more than two years she tried to find a place at an appropriate school for her 10-year old son who uses a wheelchair and needs to wear nappies as a result of his physical impairments. Several schools were approached and the boy endured multiple assessments. Eventually Selina consulted a public interest lawyer who alerted the Department of Education about the situation. After that her son was eventually placed at a special school about 20km from home. He loves going to school, has made friends and is now an independent wheelchair-user. He is extremely proud of his uniform, and Selina describes the dedication with which he polishes his shoes every evening before school. Selina continues to play a central role in the self-help group and now works as an administrator for the programme.

Unathi's 21-year old son kept failing Grade 10. In 2012 his teacher humiliated him by forcing him to read in front of the class. Shortly after being publicly ridiculed, he dropped out of school. Unathi was then told that her younger son was a 'slow learner'. In 2013 she managed to find a mainstream school that would accept him.

She was worried about finding him a place in a 'training centre' for 2014, but managed to have him admitted to a private school in a neighbouring town. More recently, her son was offered a place in the newly opened classes for children with disability in Orange Farm. Unathi continues to attend self-help group meetings regularly and is an outspoken member of the group.

Boitumelo was just 16 years old when she had her son, who is now 14. As a single parent, she coped with her son's Autism Spectrum Disorder as best she could, despite her neighbours calling him "the monster". She was sent back and forth to find an appropriate school for him. Eventually she found a school located in the city centre. Boitumelo initially relied on a chaperone to take her son to school on the train each day. Unfortunately, the escort was unreliable and her son was expelled for absenteeism. Having had to fight to have him readmitted and to get fee exemption, Boitumelo decided to sacrifice her time and now spends her days taking her son to school early in the morning by train, waiting for him and bringing him home again.

Many caregivers described themselves as powerless in relation to State actors like school principals and educational psychologists. The Department of Education was perceived to be relatively more powerful than individual caregivers:

"They won't take you seriously. They will just tell you to "tell the school to find a place. We are very busy". They act like they are very important people. So they are not treating us with respect" (Caregiver).

Low self-efficacy inhibited direct agency as some caregivers felt unable to voice their complaints with regard to school admission, safety or quality. The repercussions of taking action were also considered:

"He has just started school there, so I don't want to complain. They might start to hate him" (Caregiver).

Various situations were described that leave caregivers disempowered and hopeless. Boitumelo demonstrated decreased self-efficacy when she did not know her rights and was sent backward and forwards with repeated cross-referral:

"Some things I didn't know: That I could stand on my feet and tell schools to find a place for me! Going from school to school, I was doing everything with a blank eye. I just didn't want my child to stay at home" (Caregiver).

Caregivers also described being ignored or "laughed at" by State education and health personnel.

Caregivers relayed experiences of discrimination at every turn- within their families, their community and when approaching the education system. Selina's family thinks she was "crazy" for going to the trouble of finding a school for her son:

"They say I must stay with this child at home. They say I am wasting my money" (Caregiver).

This attitude extended beyond the household:

"My neighbours are laughing at me. They are just judging. Other children call him "big head". Some mothers say that he is punishment from God. I just want to close my door and sit in the house because when we go on to the street, people are laughing at us. But I tell myself that I can't hide because of the disability" (Caregiver).

Despite this, some respondents demonstrated efficacious behaviour in their 'fight' for their children with disabilities' rights by standing up to people with exclusionary attitudes. For instance, Selina stated:

"I am in charge. I will fight for his rights. Even professional people don't think he has a right. People say he can't access education because he is using Pampers [disposable nappies], he is not normal, he won't cope. Those who are well-educated say that the disabled can't go to school. I will fight to get him to school."

Members of the Programme's self-help group decided to combat negative attitudes by attempting to teach people about disability, and inclusion. Selina is a good example. She describes how it is impossible to change her son's "big head" but her mission is now to change attitudes. She feels that "changing [people's] attitude can make him to be less disabled, and they will see he is just a boy like any other. "Educating people may not change the boy's hydrocephalus, but could stop people calling her son a "brown loaf of bread". She has made public speeches about equality for children with disabilities at events like Human Rights Day in 2013, and an event at the Constitutional Court about the Bill of Rights in 2014. She helps facilitate courses on disability, human rights and inclusion. She also participates in the regional disability forum and is a member of a task team that cooperates with the district office of the Education Department. The task team successfully lobbied for a new school to be established in Orange Farm for children with high educational support needs.

Caregivers cited faith, persistence and patience as essential personal resources that they had to draw upon for intrapersonal empowerment. Religion was

described as helping families to cope and buoy self-efficacy:

“Before I wasn’t accepting that I have a disability child but one day I say, “God, that is my child”. I got peace. From that day everything was different. Even now I forget that my child has a disability” (Caregiver).

Drawing strength from faith, caregivers emphasised that it is important not to give up:

“Through faith you will get your goals. You must have a strong heart. I know it’s hard, but have faith” (Caregiver).

Demonstrations of persistence included hours of queuing for documents and assessments, and endurance of discriminatory practices. The grandmother of an undocumented child with disability shared the following:

“They shout at me, they were rude to me. They say I must go back to Lesotho.”

Often caregivers endured lengthy queues, carrying- as Selina described- their children with disabilities on their backs. Caregivers described coping with loss of their children’s files by service providers, poor interdepartmental communication and lack of service coordination, often resulting in repeating processes, waiting and disappointment.

Obtaining all the requisite assessments and attending appointments added up to between R600 and R900 per month. This should be understood in the context of extreme poverty- families of the respondents survived on the mean household income of R2080 per month. Just more than half the respondents (55%) were receiving the Care Dependency Grant of R1250 per month for their children with disabilities. However, 27% of the children were not receiving a Grant at all. Environmental barriers, resulting from the socio-economic status of respondents, are echoed throughout the findings below.

Having undergone the tedious process of assessment, caregivers then had to apply to between 3 and 7 different schools. The majority of children have been on the waiting lists of various schools or have been denied entry. Caregivers were given various reasons for refusal: insufficient documentation; the school is ill-equipped or full; the child wears nappies; the child lives outside “the school’s district”; the child is dangerous, illiterate, or cannot speak English. One mother described her son being expelled from 2 different schools after a few days because teachers said his intellectual impairment and behaviour were disturbing the other learners.

Although she has applied at 8 schools, her son continues to remain at home under her full-time supervision.

Multiple examples of direct agency were observed throughout the process of admissions. For example, one caregiver spent 6 years trying to find a suitable school for her child with disability. Caregivers were selective when they were not satisfied with schools. For example, Boitumelo refused several schools, because of mixed age-group classes, safety concerns or inhumane practices such as putting children with disabilities “in cages” or tying them “to chairs” (Caregiver). Where school admission was yet to be granted, some caregivers had resorted to teaching their children with disabilities themselves.

Most caregivers felt concerned about the quality of available education. Unathi was furious that her older son was made to pass from one grade to the next without having a foundation in literacy. He did not finish high school. Another child reportedly stayed in the same class for years without progressing. Boitumelo relayed a story of her son’s frustration in class leading to self-harming and destructive behaviour- at worst, breaking a window with his head.

The caregivers exercised direct agency by making official complaints. Unathi encouraged active citizenry:

“Watch your child at school. Don’t sit around; go and tell the principal that you are having a problem. Stand up!”

She had frequently gone to the school to talk to teachers, and complained when she was not kept abreast of her son’s progress. Selina also voiced her complaints at school when her child’s school lunch was being taken from him and shared by his classmates.

Most caregivers were worried about their children’s safety when they were away from home. Tales of bullying, teasing, harassment and stealing from children with disabilities emerged - in one incident leading to the child having a seizure. Use of marijuana and knives by peers were concerns. Poor supervision on school transport and on school grounds before the arrival of teachers, was a concern for Selina. She shared that her son had fallen from his wheelchair twice, because of older children at his school. Another mother sympathised, describing how she found bruising on her child.

Caregivers did not take these issues lying down. After multiple incidents, including his schoolbag being stolen, one mother stated:

"In 2008 I decided to leave [my] job for his sake. So I said, "Now you are doing Grade 12, I am going with you to school up until you pass Matric with flying colours". Now he is 23 years. He is a man! I am proud of myself."

When her son was physically abused by a teacher, Boitumelo took her complaints as far as the School Governing Body and Child Protection Unit of the South African Police Service. Instead of helping her they seemed "irritated and bored", deflecting her complaints and discriminating against her son:

"I went to the police station but the lady gave me attitude. She said, 'The baby can't speak, so we can't make a case. There was no witness, nothing' " (Boitumelo).

As so few local schools in Orange Farm include children with disabilities, those that manage to get admission at appropriate schools need to travel far to get there. Transport to and from school was identified as a significant barrier to accessing education- both in terms of the expense of using taxis, and the dangers of children with disabilities using public transport. Boitumelo's son relies on her chaperoning him to school daily, using trains and minibus taxis at considerable expense. Physical access to designated pick-up points was also a challenge. Selina overcame this by carrying her 10-year old on her back for 40 minutes to meet the taxi twice a day, until she got a wheelchair for home. Considerable discrimination against children with physical impairments and wheelchair-users was experienced- including charging extra or refusing permission to ride on the taxi. In some cases, caregivers were able to act as proxy agents on behalf of their children to negotiate with taxi drivers. For instance, Selina was able to broker a more convenient pick-up point, and had the driver promise to better supervise the children with disabilities in the back of his bus.

The disempowering effect of the substantial cost incurred by sending children with disabilities to far-off schools was felt acutely, especially by single mothers:

"I have no power. They can tell [him] at any time to go [home], because I can't pay" (Caregiver).

Most caregivers needed to cover household expenses, as well as cater for the special needs of their children, like nappies, frequent hospital visits, special food and emergencies. Monthly school fees cost from R150 to R1500, over and above the R350 – R650 spent on transportation. These costs amount to far more than the minimal expense of sending children to local State schools in Orange Farm- many of which are within walking-distance, are free and offer feeding schemes.

A variety of strategies were employed to cope with disability-related financial strain. Though in many cases caring for children with disabilities hampered permanent full-time employment, caregivers found informal ways of making money by renting out rooms, working when possible or asking family, NGOs or the church for assistance. The self-help group members have started selling donated clothes and toys with the aim of starting an emergency fund to which members will be able to apply in times of need. Boitumelo and her mother started a day-care business from their home, for 26 children with disabilities. Boitumelo also successfully applied for fee exemption at her son's school. This involved obtaining a police affidavit and having a social worker visit their home.

Examples have been given of caregivers acting as proxy agents for their children with disabilities. However, caregivers were also able to exercise agency 'through' the Programme- particularly where self-efficacy had taken a knock after multiple failed attempts to access the system. Programme staff were viewed as relatively more powerful. Complaints and follow-up referrals made by the NGO were perceived to get "taken seriously" (Caregiver). The Programme staff acted as proxy agents by utilising resources such as telephones, email, networks of professional contacts and transport to undertake activities on behalf of caregivers. These included emailing and calling, drafting letters of referral, taking children with disabilities and caregivers to meetings and assessments, advocating for school placement and arranging to host service providers in Orange Farm to undertake screening and assessment activities. Where caregivers felt disempowered by the constraints of their knowledge of rights and processes, Programme staff were said to:

"Know more about the government than us" (Caregiver).

In the self-help group setting, caregivers exercised collective agency and demonstrated empowered behaviour. They felt that they were able to enhance their knowledge by participating in the group and attending educational workshops provided by the Programme. New knowledge, networks of support and an understanding of community resources engendered intrapersonal and interactional empowerment. Caregivers felt enabled to play a role in helping other caregivers navigate systems, as well as tackle discrimination with a "united front" (Caregiver).

"We want children to be educated. We want to teach our community not to discriminate... That's the message we are trying to give out" (Caregiver).

Many caregivers viewed the self-help group as a source of support and power and made reference to trust, love and passion in the group as sources of strength. They were able to share problems, and “learn from each other” (Caregiver). Boitumelo shared that the group had helped her leave depression and thoughts of suicide behind. She experienced intrapersonal empowerment:

“We share our problems. Sometimes I feel bad that my problems are not as bad as others but it makes me feel stronger every day. There is no point feeling sorry for myself or blaming myself. You must fight if you want something” (Boitumelo).

Unathi experienced intrapersonal empowerment as evidenced by the following statement:

“Since I have come here I am open, my heart is free and I am happy. My role model is myself actually” (Unathi).

Selina also described how interacting with group members has provided comfort as well as practical assistance- both intrapersonal and interactional empowerment:

“This group is my baby...I feel that I have a family. In my home no one supports me and now if I have a problem, I will call one of the mothers...and I know that they are not going to judge me, they will help me and advise me” (Selina).

Their statements were reinforced by other caregivers sharing their experiences of the group:

“When I first came here, I cried tears and everyone came and hugged me. They started talking to me. It was easy for me now, not angry anymore. I treat my child with more calm and understanding. But when you are at home, thinking it is me against the world- it’s sad. There are people like you who face the very same problems, its better now, because we come and talk and laugh” (Caregiver).

“I am a strong mom for my child and thank you for all the knowledge I got” (Caregiver).

“I have found love. I didn’t know that there were children like [my daughter]. I would like to thank [the group]” (Caregiver).

The sentiments shared by caregivers interviewed more recently described the “growth” of their group to include learning opportunities, the completion of courses with certificates, and the starting of a small business. Selina described:

“Now we are growing, we have a learning opportunity. We are attending a computer class to have skills. These things tell us that the group is growing.”

Developments also included the establishment of a committee where some group members were nominated to take on specific responsibilities. Selina is an administrative assistant, and Unathi is responsible for organising the next Christmas party.

Unathi shared how much she still looks forward to the weekly meetings of the self-help group:

“My children ask me when Friday is near if I am going to the support group, I respond with excitement. When Thursday comes, I prepare my clothes to save time so that I am here early Friday morning and I do not want to be late. I feel happy.

Even if I have to go for treatment on the day, I will call someone to tell them that I will be a little late but I am not going to miss the meeting” (Caregiver).

Beyond fellowship, self-help group members were able to exercise collective agency by mobilising as a group, engaging in political participation, and forming links with larger advocacy networks. They have engaged in activities such as marches, the launch of a Disability Desk at the local police station, and have accompanied a person with disability who was a sexual abuse victim to court hearings. They gathered names and details of out-of-school children in the area and contributed to building a database of children needing education support and provision in Orange Farm. The group participated in successfully lobbying for the establishment of a new school by writing letters to local ward councillors; raising the issue in community forums; vocalising their needs in meetings with the Department of Education and with the provincial Premier’s office; and making written submissions to the Mayor of Johannesburg and the parliamentary committee responsible for the implementation of the Convention on the Rights of Persons with Disabilities. In addition, some group members had begun offering educational workshops on disability and human rights to others, including high-school girls, and a disability support group in a neighbouring township.

The outcomes of their efforts became known in late 2013, when State officials announced at a self-help group meeting that a new school would be budgeted for and built in Orange Farm. It was reported that the submission had been approved and the need for a school was ‘urgent’. The Department of Education committed to putting in place temporary measures to ensure the right to education, and in

early 2014 four classes catering for children with disabilities opened in the empty classrooms of a local school. A year after the school was established, the principal of the school announced that 342 learners were enrolled, in 14 classes (Tshoeu, 2015).

This triumph was celebrated by self-help group members who described the achievements of the group in 2013 in terms of “gained information and knowledge”; “strong relationships with other mothers”; the ability to “understand rights”, “stand up” and “express themselves”. As one mother shared:

“The fact that families with people with disabilities come together to support each other, and go out and embrace people with disabilities is a great achievement” (Caregiver).

Boitumelo said:

“Helping me to get [my son] back to school was a big thank you to me.”

Despite their achievements, and the opening of a new school, not all caregivers were convinced that their collective efforts were successful or effective. It was stated that caregivers in Orange Farm were not unanimous in their dedication to work together towards realising their children’s rights:

“In Orange Farm there are many children with disabilities, but their parents don’t want to stand up and show them. That is why we don’t have power. There are only a few people who show their children. But if we come all together, I think we can do something” (Caregiver).

Some environmental barriers to accessing the group-like money for transport were raised, but caregivers also felt that not everyone had the same views as the group, or believed in their common mission. The slow change of the all-powerful education system was also found to be cause for demotivation and decreased belief in self-advocacy efforts. Many still felt “there is nothing we can do” even when “fighting” together because the powerful and influential people they had sought to engage do not seem to hear them or respond to their concerns. Despite the school having opened, just 10 children of caregivers in the group have been admitted. For many remaining group members the battle has not yet been won.

CONCLUSION

Despite the negative effects of the opportunity structure on self-efficacy, caregivers showed that they were capable of exercising remarkable direct, proxy and collective agency. Against all odds, caregivers showed irrepressible persistence in navigating the rocky process of attending preliminary assessments, collecting documentation, applying for school acceptance and lobbying for the establishment of new education services for their children. They drew on faith, shared knowledge and the collective agency of the self-help group in order to campaign for change at various levels.

These findings would suggest that human rights advocacy movements, as well as disability organisations, would do well to recognise and encourage the power and agency possessed by caregivers of children with disabilities. Catalysing civic action and providing opportunities for active citizenry and self-help seem to nurture increased efficacy and competence at navigating systems and accessing rights. While advocacy organisations may act as proxy agents, direct and collective agentic strategies should be nurtured. In implementing inclusive education, policy makers and the Department of Education should recognise the role caregivers of children with disabilities could play, and the potential contribution that their motivation, resourcefulness, disability-related knowledge and models of inclusionary behaviour could make.

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REFERENCES

Department of Education (2001) Education White paper 6: Special needs education: Building an inclusive education and training system. Pretoria: DoE.

Department of Social Development, Department of Women Children and People with Disabilities and UNICEF (2012). Children with disabilities in South Africa: A situation analysis: 2001-2011. Pretoria: Department of Social Development/Department of Women, Children and People with Disabilities/UNICEF.

- Engelbrecht P (2006). The implementation of inclusive education in South Africa after ten years of democracy. *European Journal of Psychology of Education*; 21(3): 253–264. <http://dx.doi.org/10.1007/BF03173414>
- Gauteng Education Department Johannesburg South District Education Operations & Support Sub-Directorate (2013). Submission for: LSEN school facilities in Orange Farm. Johannesburg: GDE.
- Human Rights Watch (2015). *Complicit in exclusion: South Africa's failure to guarantee an inclusive education for children with disabilities*. New York: Human Rights Watch.
- Muthukrishna N, Schoeman M (2000). From 'special needs' to 'quality education for all': A participatory, problem-centred approach to policy development in South Africa. *International Journal of Inclusive Education*; 4:317. <http://dx.doi.org/10.1080/13603110050168023>
- Republic of South Africa (1996). *The South African Constitution number 108*. Government Gazette 17678. Pretoria: Government Printer.
- Saloojee G, Phohole M, Saloojee H, Ijsselmuiden C (2007). Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township. *Child: Care, Health and Development*. 33: 230–235. <http://dx.doi.org/10.1111/j.1365-2214.2006.00645.x> PMID:17439434
- Tshoeu A (2015). *Community meeting on progress in implementing the Duzenendlela LSEN School*. Hosted in Orange Farm: Arekopaneng.
- Watermeyer B, Swartz L, Lorenzo T (2006). *Disability and social change - A South African agenda*. Pretoria: HSRC Press.
- United Nations General Assembly (2006). *Convention on the Rights of Persons with Disabilities A/RES/61/106*. Geneva: United