**Disabling Discourses and Some Implications for Parent Leadership in Special Education Policy and Practice**

The paper aims to explore ways in which mothers of children with cerebral palsy (CP) attempt to voice their concerns about current discourses and power imbalances enshrined in special education policy and provision. Mothers’ narratives are important in making transparent the multiple forms of ‘disablism’ experienced by them in their attempts to negotiate and counteract-on behalf of their children deficit-based and discriminatory discourses and professional practices that violate their children’s rights, notwithstanding international and national legal mandates promoting a rights-based approach to disability. Their narrated subjugated agency in disability politics highlights the imperative to introduce new forms of advocacy through parent leadership in order to enable parents to have a more active and strategic role in challenging disabling discourses and practices that undermine their children’s rights and entitlements.

**Key words:** mothers, power relations, disablism, human rights, parent leadership.

**Introduction**

A considerable body of research evidence has long suggested the multiple ways in which parents of children with special educational needs and disabilities (SEND) are disempowered by current official legislative arrangements and procedures. Parental voices, experiences and perspectives have been significantly ignored and undervalued (Burke, 2013; Hodge and Runswick-Cole, 2008; Honkasita et al, 2015;Mueller 2015; Ryan & Runswick-Cole 2008; Stanley 2015; Yuan and Vadebonouer 2012); this is an issue that also raises concerns about the role of legislation in safeguarding the rights of children with disabilities and their advocates to have their voices heard and perspectives valorized in designing and delivering disability-related services (Oliver 2013).

The notions of ‘voice’ and ‘participation’ are at the heart of the attempts to promote inclusion (UN 2008); a pronounced emphasis on hitherto marginalized voices is an important area of inquiry to document the profusion of power struggles and imbalances underpinning the processes and outcomes of special educational policymaking (Fulcher, 1999; Thill, 2015). The ‘voices’ of people with disabilities and their advocates should inform policymakers, service providers and professionals’ understandings of the experiential aspects of disability within the context of a human rights and social justice framework.

The notion of ‘voice’, however, needs to be problematized due to the heterogenous and complex nature of the ‘lived’ experience of disability that is contingent on an amalgam of biographical, social, cultural and historical dynamics. The plurality of ‘voice’ calls for devising diverse agendas of disability research to understand multifaceted and nuanced dimensions of social oppression experienced by individuals with disabilities and their advocates.

Simultaneously, the fluidity and multiplicity of notion of ‘voice’ also needs to be understood in relation to the ways in which the differing nature of disabilities evoke varied responses to disability experience, as well as different degrees of privilege/under-privilege (Goodley 2017). Hence, the metaphor of power that circulates throughout the social edifice can be applied to decipher unequal power relations amongst parents themselves.

Foucault (1978) theorizes the omnipresence of power that is not delimited to the governmental domain. In this respect, power is implicated in a network of relations and can be exercised throughout the social body. Even among parents themselves, the ‘balance of power’ slips in the direction of certain parents and not towards all of them. (Bolivar and Chrispeels 2011; Fitzgerald & Watkins 2006; Stanley 2015; Trainor 2010). This is an issue that will be discussed with reference to mothers of children with Cerebral Palsy (CP), who categorically denote the fact that their children are not only marginalized and discriminated against due to their disability, but also due to the nature of their disability, which is regarded in more negative ways than other disability-related differences.

The paper uses interview to explore the ways in which mothers of children with CP attempt to voice their concerns about the host of disabling discourses enshrined in special education policy and provision in Cyprus. In so doing, it will be possible to make transparent the power imbalances underpinning the policymaking process that undermine mothers’ ‘narrated potential agency’ (Honkasilta, Vehkakoski and Vehmas 2015, p.674) in challenging institutional barriers and discriminatory regimes that violate their children’s rights and entitlements. Their interview narratives also bring to the surface the multiple forms of ‘disablism’ experienced by them in their attempts to negotiate and counteract-on behalf of their children- deficit-oriented and discriminatory policy discourses.

‘Disablism’ is analogous to racism and sexism (e.g. Goodley 2011, 2012) and denotes the ways in which individuals with disabilities and their advocates experience multiple forms of social oppression and discrimination due to the hegemony of arbitrarily constructed notions of ‘normality’ (Campbell 2009). It is well documented that parents of children with disabilities-through their ‘liminal positions’ -of being ‘neither disabled nor non-disabled’- have routinely experienced various forms of disablism (Ryan and Runswick-Cole 2008, p.199) embodied in attitudinal and institutional barriers to fulfil their parental roles.

Simultaneously, mothers’ narratives provide useful insights into their advocacy and leadership role in disability politics. Reid et al (2011) discuss the ways in which disability ‘advocacy’ has been an integral aspect of the lives of parents of children with CP. (Reid et al 2011). Parent advocacy and leadership is a relatively recent phenomenon in Cyprus, not only due the belated parents’ lobbying for educational change, as will be discussed later, but also due to the scarcity of single-impairment parental associations so as to empower distinct parental groups, such as parents of children with CP, to engage in collective forms of activism to claim their children’s rights and entitlements. (Symeonidou 2007)

Even though our target population included fathers of children with CP, only mothers accepted our invitation to participate in this study. The sole representation of mothers in our sample is a testament to the prominence of mothers in education decision-making processes as well as in special education decision making processes (Stanley 2015; Yuan and Vadebonouer 2012), whereby mothers are regarded as being more ‘than allies to their disabled children’ (Hodge and Runswick-Cole 2008, p.202) in comparison with other family members.

Nevertheless, despite their central role in their children’s lives, mothers of children designated as having SEND have had according to Ryan and Runswick-Cole (2008: 199), ‘a complex, contradictory and marginal position within both disability studies and the disabled people’s movement’, while their activist role in facilitating the process of transformative change has been significantly underestimated (Lai and Vadeboncoeur 2012). Hence, mothers’ narratives are important in exploring their leadership and advocacy role in disability politics (Burke et al 2018; Trainor 2010), as well as understanding the forms of ‘disablism’ (Goodley 2017; Ryan and Runswick-Cole 2008) experienced by them.

In particular, the study aims to address the following questions:

1. In what ways are asymmetrical power relations manifested in the context of special education policy and provision?
2. In what ways do mothers of children with CP attempt to counteract dominant discourses that undermine their children’s rights and entitlements?
3. What kind of changes do they envisage in order to reinstate their children’s rights and entitlements?
4. What is (should be) their advocacy and leadership role in disability politics?

The following sections are given over to providing the policy and theoretical backdrop against which this study was framed. This is followed by a brief overview of the research methodology deployed while the final section reports on the empirical findings of the study.

**Parents and special education policymaking: Setting the context**

While aiming to investigate the ways in which mothers of children with CP attempt to reverse the asymmetrical power relations within the Cypriot context after the latest and ostensibly more inclusive law introduced in 1999 and revised in 2014, it is initially important to provide a brief description of the current policy landscape on the island. Following international legislative trends and, more specifically the legislative changes in the UK context, Cyprus introduced policies that are allegedly more inclusive and proclaim the rights of children designated as having special educational needs and disabilities (SEND) to be educated along with their peers in mainstream schools. After more than a decade of unofficial integrative attempts, the placement of children with SEND in ordinary schools was eventually granted statutory recognition with the introduction of the 113(I)/1999, 69(I)/2001 and 2014 (N.87(1)/2014) Special Education Law, supplemented by the Regulations for the Implementation of the Law (KII 186/2001 and Κ.Δ.Π. 416/2013Ministry of Education and Culture 1999, 2013).

Even though the consecutive discussions about a string of white papers prior to the introduction of the law represented a linguistic and, hence, a perceptual evolution towards more inclusive discourse predicated on a human rights approach to disability and difference, this evolution is arguably merely rhetorical. This is because it is directed only at the ‘embellishment of the surface’ and leaves intact exclusionary linguistic entrapments that undermine the process of transformative change towards inclusion (Liasidou, 2008). An example of the ‘linguistic embellishment’ that the latest white paper underwent during the intense negotiations prior to the passing of the 1999 Special Education Law, is an addition made to the final version of the official legislative documents that points to the necessity to ‘create mechanisms for the information and support of the parents’ (Article 6). Parents are, thus, given the right to be formally informed and supported throughout the processes of identification and assessment of their children. Moreover, adding an adjective in Article 8(1) reinforces the duty of the committee for implementing adequate assessment procedures.

Another modification of interest is Article 11(2) which follows; this concerns the role of the parent in decision-making procedures. In the initial version of the white paper, it was stated that: ‘The parent of the child, whose needs are to be assessed under the light of the present article, has to conform and would also have the right to be present at the examination.’ The sentence was later rearticulated and the word ‘conformity’ was deleted, presumably in order to foreground the rights of parents in more poignant and explicit ways. Moreover, a significant addition was made, according to which the parent can take a specialist of their choice to the examination, in order to have a more substantial participation and intervention in the decision-making process. (Article 11(2)).

Some other indicative modifications are also evidenced in the Regulations for the Implementation of the Law (Κ.Δ.Π. 416/2013 MOEC, 2013). While the previous version of the Regulations (KII 186/2001 MOEC 2001) suggests that parents can have access to the confidential archives held by the regional committee for each child with disabilities without, however, being able to obtain a copy of them, the latest Regulations stipulate parents’ right to not only access these archives but to also get a copy of them (article 6)

These legislative changes were the result of the collective efforts of organizations of people with disabilities and parental groups. Parents of children with hearing impairments were the first to collectively demand the integration of their children in mainstream schools, something that was achieved in 1993. Albeit unofficially, integration efforts, were gradually directed to all children with disabilities and paved the way for the introduction of the Integration of Children with Special Needs Act (1999) (Phitaka 2003).

The relatively belated appearance of disability-related parental activism and leadership in Cyprus (Symeonidou 2007), can be attributed the fact that Cyprus was mainly an agricultural society (Pantelis 1990:94). Hence, in direct contrast to other Western countries and British colonies, there were very few middle class and affluent parents- equipped with cultural and social capital to value education, and to demand more effective and non-discriminatory educational opportunities for their children. As Symeonidou (2007;46-47) suggested: ‘The social, political and historical context of Cyprus explains their [parents] belated engagement in lobbying the state for educational improvement’

Arguably, it is due the underdeveloped character of parent activism and leadership that there is a patent lack of educational accountability not only in terms of disabled students’ learning but for all students’ learning (Liasidou and Symeou 2018). The latest report of the World Bank on Teacher Policies in the Republic of Cyprus (2014) points out that accountability regimes and evaluation of teachers in Cyprus do not take into consideration any measures of teachers’ effects on student outcomes (including learning). Understandably, within an educational system that schools and teachers’ assessment criteria take ‘no account’ of ‘students’ outcomes’ (World Bank, 2014; 25), parent activism and leadership needs to be strengthened, in order to protect and promote the rights of all children to access quality forms of educational provision. Advocacy and leadership skills can act synergistically to enable parents to access disability-related support services and decision-making procedures that affect their children’s lives and educational trajectories. (Hutchinson et al 2014; Schuh et al 2017; Shepherd and Kervick 2016).

**Research Methodology**

The paper draws on data from a larger project aimed at fostering greater inclusive education policies and practices through universal design for learning and creating a society, where equal opportunities are guaranteed for all through a ‘community building process’. The latter approach is intended to bring together perspectives and experiences from diverse user groups (teachers, students, parents, policy makers) in order to inform the process of education reforms towards inclusion and social justice.

The interview data for the strand of analysis reported in this article were gleaned to make transparent the unequal power relations inscribed in the special education policymaking process, as these have been experienced by mothers of children with CP in Cyprus.

Mothers of children with CP were deliberately chosen due to the complex profile of their children’s needs, and their subsequent need to undertake a more active role in seeking access to and coordinating different disability-related agencies and services in comparison with other parents, whose children’s disability-related needs might be less complex. Access to our target population was achieved through a parental organization of children with CP, as well as through professionals who offer remedial and therapeutic services to children with CP and/or counselling services to their parents. All approval procedures and ethical considerations were adhered to.

The sample consisted of 25 mothers of children diagnosed with CP. All mothers were holders of higher education degrees and were married. Their ages ranged from 32 to 43 years old. The ages of their children with cerebral palsy were from 2.5 to 14 years. Most of these children could not communicate orally and needed substantial support throughout the day. Some of them had eating problems and received medication related to epileptic conditions. Many of these children used assistive technology in their education and daily activities and attended a special unit in mainstream schools.

The interview process took place in three phases in 2015-2016. In Phase A, we interviewed eight mothers of children with cerebral palsy while in Phases B and C we held focus group interviews with eight and nine mothers of children with cerebral palsy, respectively Data derived from the combination of individual and focus groups interviews can provide a more comprehensive account of individual and collective experiences of disability advocacy, while enabling researchers to compare, contrast and cross-validate diverse experiences, perspectives and insights. (Creswell 2012; Lambert and Loiselle 2008)

The following section draws on individual and focus group interviews with mothers of children with cerebral palsy with the aim of documenting the ways in which these mothers negotiate, manage and experience the current special education policy and provision in Cyprus, while attempting to challenge the dominant discourses and institutional regimes that work to the detriment of their children’s education, development and wellbeing

Thematic and content analysis was deployed for the purposes of which the following codes were developed in order to address the research questions: a) Mothers’ experiences of unequal power relations and their struggles for inclusion b) Mothers’ vision for transformative change c) Mothers’ activism and leadership.

**Analysis and Discussion**

**Mothers’ experiences of unequal power relations and their struggles for inclusion**

The mothers of children with CP who participated in our research expressed their utter dissatisfaction, frustration and anger about the current special educational provision which is inadequate and violates their children’s rights to have access to quality forms of education provision and support services. All of them referred to the patent lack of support in view of the complex and idiomorphic nature of their children’s disabilities. Almost all mothers acknowledged that they had to deal with insurmountable difficulties as soon as their children were born. The signs of fatigue, both physical and emotional, were evident on their faces while some of them had to quit their jobs in order to respond to the huge responsibilities that emerged from giving birth to a child with CP.

Most mothers admitted that when they were informed about the ‘diagnosis’ of their child’s condition, they did not understand the nature of the diagnosis and its associated nomenclature and they were overwhelmed by feelings of fear, confusion and uncertainty. Despite their feelings and their desperate attempts to seek relevant advice and support, they did not receive any advice or psychological support to help them deal with the unknown situation. Only one mother mentioned that she was receiving psychological support, although all mothers thought that access to psychological support/ counselling was important and they admitted that they would consider asking for some support in near future.

The existence of communication channels and support services that target the whole family is imperative, in order to ensure the physical and emotional wellbeing of both children and their parents. Considerable evidence suggests that a lack of these services results in enhanced levels of stress and mental health problems for parents (Smithers‐Sheedy, Hayley, et al, 2014; Parminder et al, 2005; Rosenbaum 2003) that are exacerbated by the various forms of ‘disablism’ experienced by them (Ryan and Runswick-Cole 2008).

All mothers referred to the lack of governmental support, while discussing their motherhood role and the increased responsibilities that have emerged since their child’s birth. The increased demands of their role are in stark contrast with the less prominent role of their husbands, whose role in the lives of their children with disabilities is, according to them, non-existent. Most mothers were explicit about their feelings of loneliness which they frequently experience within their families and their anxiety over their children’s future. Apart from these hardships, they also articulated the ways in which they had to constantly deal with discriminatory attitudes in schools and society in general, while striving to claim their children’s rights and entitlements.

A great percentage of our respondents pointed out that children with other disabilities, such as children with hearing difficulties or children with visual impairments, do not face the magnitude of discrimination experienced by their own children. This is because teachers and other professionals are more positively predisposed towards these groups of children. Understandably, students with disabilities do not form a homogeneous group. The differing nature of disabilities evokes different responses to disability, as well as different degrees of privilege in accessing support services and procedures (Goodley 2017). Riddell, Tinklin and Wilson (2005), for example, discuss the ways in which male, middle-class students with specific learning difficulties such as dyslexia are afforded a more privileged status in accessing disability-related support services and procedures.

While trying to be more explicit, respondents referred to the discriminatory culture that exists in schools around CP, which is frequently equated with mental retardation. They mentioned that classroom teachers seem to hold the view that children with CP are ‘different’ and they are not one of their students. As a result, teachers think that these children are the responsibility of the special teacher or speech and language therapist, while having very low expectations for these children, who are routinely withdrawn from mainstream classrooms to receive ineffective forms of educational provision by support teachers who have no specialist knowledge and expertise in dealing with their needs. The majority of these children spend a great percentage of their school day in segregated settings that are euphemistically called ‘resource units’, which, according to Slee (2007, 179), embody ‘the assimilation imperative of neo special educational rhetoric and practice’ that ‘often has little to do with establishing an inclusive curriculum, pedagogic practices or classroom organisation to reconstruct schools’

All respondents, except one, believed that their children should be educated alongside their peers in mainstream schools. They held the view that segregated forms of provision are not the right place for their children, whose inclusion in mainstream schools should be the harbinger for their empowerment and their entitlement to quality and non-discriminatory forms of education provision.

They expressed their dissatisfaction with the deceptive proclamations of the current law regarding parents’ empowerment through their participation in the decision-making process. Even though it is clearly stated within the law that the Special Education Committee, which reviews the implementation of the relevant legislation and submits suggestions to the Minister, should include four parents (N.113 (1)/ 1999, Article 24.1), this is not the case. Parents are thus excluded from the bureaucratic and decision-making discourse and are institutionally disempowered from having their voices heard. The majority of mothers expressed their desperation and their disempowering ignorance, and as one of the mothers pointed out:

Who are these parents, who allegedly have an active role in the decision-making processes of the Special Education Committee and why do they never communicate with the rest of us regarding the work of this committee? (Mother 5)

Notwithstanding their legal rights and entitlements, all mothers documented their constant battle to reinstate the rights of their children. One mother mentioned that she had to go to the Ministry of Education several times, in order to secure a ground floor class for her child who had mobility difficulties.

The respondents also unanimously referred to the lack of co-ordination between the various professionals who should jointly discuss and solve the various problems, always in co-operation with the special teacher and parents (Liasidou and Antoniou 2014; Todd 2007; Trainor 2010). This issue is further complicated because children with CP have educational as well as health-related needs and as a result, coordination becomes an even more thorny issue, especially considering the fragmented nature of the services offered.

Through their lived experiences and their constant battles to gain access to the dominant discourses to reclaim their children’s rights, they effectively portrayed the dismal condition of existing services and forms of provisions to meet the needs of their children. Their narratives document their lived experiences of ‘disablism’ in their attempts to negotiate and counteract on behalf of their children deficit-oriented and discriminatory policy discourses and professional practices.

As a final comment, all mothers expressed their determination to alter the disparaging situation for their children and they demanded that the state should recognize and respect the human rights of their children. They clearly articulated their own experiences; these are essentially an attack to the government and its failure to foster greater inclusive policies and practices across education, health and social care domains. This being the case, mothers of children with CP seemed to be aware of the means to their empowerment. They expressed their determination to challenge the inimical conditions that dehumanize and subjugate their children. They appeared to have increasing knowledge of their children’s rights as well as knowledge and skills to confront the state and the disempowering discourses that underpin the current state of special education policymaking in Cyprus and to actively engage in ‘policy development and systemic change’ (Shepherd and Kervick 2016:33).

**Mothers’ vision for transformative change**

Mothers’ envisaged changes are closely aligned with the ideological underpinnings and pedagogical principles of an inclusive discourse. They exhibited impressive knowledge of the ways in which inclusion can be enacted. For example, many mothers referred to the necessity to promote co-teaching and UDL in mainstream classrooms, to introduce accountability measures so as to ensure that students with disabilities reach the maximum of their potential, to establish procedures for early assessment and intervention, to introduce mandatory teacher education for inclusion and to promote personalized learning in mainstream classrooms

Our data suggest that female parents’ understandings of their children’s disabilities are congruent with a human rights model of disability enshrined in the United Nations Convention on the Rights of People with Disabilities (UNCRPD) that recognizes the impact of ‘impairment effects’ on disability experience (**Degener 2016;** Thomas 2004). Without negating their children’s complex disability-related needs, mothers strive to assert the rights-bearing identities of their children, whose ‘impairment’ is considered as being an endemic ontological and experiential aspect of their identities, as well as an invaluable aspect of human diversification, which needs to be valorised and celebrated through action-oriented initiatives and institutional arrangements (UN 2008).

The acknowledgement of impairment as a constitutive element of disability experience, **dictates that individuals with disabilities are entitled to have access to the whole spectrum of human rights and educational entitlements in order to experience inclusive values and practices. (Degener 2016).** For instance, our respondents pointed to the crucial role of assistive technology in accommodating the needs of their children. Currently, the use of assistive technology to support their children’s disability-related needs is scant, due to the lack of knowledge and skills of various professionals to utilize technological means to facilitate the process of their children’s learning. They were critical of the ways in which expensive equipment is not utilized due to the lack of educational professionals’ knowledge and expertise to harness the power of technology to meet disability-related needs. Interestingly, even in cases when the purchase of specialist equipment and assistive technology by the school is decided on by the professionals involved in the education of the child, the procurement process is severely delayed by prolonged bureaucratic procedures. As a result, some of the respondents mentioned that they opted to pay from their own funds so as not to deprive their children of essential equipment and assistive technology.

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**Parent activism and leadership in disability politics**

Notwithstanding the linguistic modifications to the consecutive white papers and the subsequent statutory acknowledgment of parental rights in the 1999 law, along with more recent official rhetoric articulated in the First Report of Cyprus on the implementation of the UNCRPD about the alleged existence of ‘a modern and powerful legal framework…for the protection and promotion of the rights of persons with disabilities, including general and specific laws in every aspect’ (Department for Social Inclusion of Persons with Disabilities, Ministry of Labour and Social Insurance 2013, p. 3), the study documents the ways in which parents still have to strive for their children’s rights and entitlements.

Currently, their efforts to counteract disabling discourses in policy and professional practice are embryonic in nature, but can provide a platform to encourage more powerful and coordinated forms of parent leadership in Cyprus aimed at exposing and challenging the illusory nature of governmental rhetoric of inclusion and disability rights (e.g Pancyprian Alliance for Disability 2016). Parent leadership is premised on some fundamental prerequisites that relate, among other things, to the extent to which parents have ‘knowledge of rights’ in order to mobilize collective action to challenge disabling policies and practices that undermine their children’s rights (Hutchinson et al 2014:350).

It has recently become evident that their activism and leadership role has been strengthened. Many of our respondents referred to their active membership in a parental organization of children with CP that was formulated in 2008 with the aim of protecting and promoting the rights of their children. To this end, our respondents referred to individual and collective letters sent to the Commissioner of Administration, the Parliament and the Ministry of Education in order to complain about the inadequate and discriminatory practices that undermine their children’s rights and educational entitlements. They also referred to their forthcoming organized protests at the Ministry of Education so as to dynamically vocalize their concerns about the absence of an inclusive education system in Cyprus. Going even further, some mothers articulated their intentions to take legal action, if the state does not respond to its legal obligations that derive from the ratification of UNCRPD in 2008.

In a recent press release, on 16th March 2018, parents of children with CP outlined the host of discriminatory practices and behaviours that violate their children’s right to have access to inclusive, equitable and socially-just forms of educational provision and called the government to take relevant action. Even though their issues and concerns were discussed at the Parliament, no governmental action was taken and as a result, parents have already taken legal action against the Government. It remains to be seen whether their legal battles will bring about the changes they envisage.

**Conclusion**

In the previous section, the aim was to present the experiences and perspectives of mothers of children with CP regarding the current legislation and depict their attempts to challenge ‘disabling’ discursive orthodoxies enshrined in special education policy and practice. Mothers’ narratives document their daily struggles to advocate for their children’s rights and entitlements, while having to deal with a myriad of personal and professional challenges. Rather than being supported by the state and its health-related and educational institutions, they have had to constantly battle against inimical conditions and hostile attitudes that have given rise to their cumulative feelings of frustration, insecurity, anger, desperation and pessimism.

Mothers’ experiences of the current situation constitute ‘a counter-narrative’ to the governmental rhetoric and the alleged progress achieved in the enforcement of the UNCRPD in Cyprus (Department for Social Inclusion of Persons with Disabilities, Ministry of Labour and Social Insurance 2013). These ‘counter narratives’ call for the development of more dynamic and organized forms of disability activism through parent leadership in order to challenge ideological and institutional discourses that violate disability rights and entitlements.

The study has provided useful insights into the ways in which female parents have an informed understanding of their children’s’ rights and the ways in which these rights are violated by current special education policies, practices and procedures. This kind of knowledge can provide the springboard in order to lead collective advocacy efforts to challenge the status quo and to facilitate the process of change towards inclusion. Parent leadership can be instrumental in effecting policy and procedural changes to challenge discriminatory practices and systemic inequities that undermine a rights-based approach to disability (Shepherd and Kervick 2016; Hutchinson et al 2014; Shuch et al 2016).

The notion of ‘voice’ in disability policies, as articulated in the UNCRP needs to be supplemented by action-oriented efforts to develop parent advocacy and leadership in order to be actively involved in policy development and ‘to use their voices to contribute ideas on how to address the issues that directly impact upon them’ (Schich et al 2016:242).

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