



## The Negotiation of Motor In/Capabilities by Two Children with Cerebral Palsy as Experienced by their Carers

Pravani Naidoo

**To cite this article:** Pravani Naidoo (2017) The Negotiation of Motor In/Capabilities by Two Children with Cerebral Palsy as Experienced by their Carers, Indo-Pacific Journal of Phenomenology, 17:sup1, 1-12, DOI: [10.1080/20797222.2017.1299288](https://doi.org/10.1080/20797222.2017.1299288)

**To link to this article:** <https://doi.org/10.1080/20797222.2017.1299288>



© 2017 The Author(s)



Published online: 15 May 2017.



Submit your article to this journal [↗](#)



Article views: 289



View related articles [↗](#)



View Crossmark data [↗](#)



## The Negotiation of Motor In/Capabilities by Two Children with Cerebral Palsy as Experienced by their Carers

by Pravani Naidoo

### Abstract

*The study reported in this paper utilised a qualitative approach to investigate the everyday lives of two children with cerebral palsy, as experienced by their carers. Analysis of the data collected through in-depth interviews with the girls' teachers, mothers and therapists was informed by the reflective lifeworld research approach of Dahlberg et al. (2008). The broader theme identified, negotiating motor in/capabilities, comprised the constituent sub-themes (i) identity and difference, and (ii) living motor in/capabilities in a disabling/enabling environment. The phenomenological approach employed revealed that, as experienced by their carers, the two girls, both of whom have quite profound forms of motor impairment, flourish by utilising their bodily and psychosocial resources towards experiencing enhanced autonomy and a sense of mastery. Overall, their respective carers served as resources for each of the girls, providing them with enabling social and physical environments that promote their optimal functioning. Theory-driven intervention efforts to promote social participation and well-being in children with cerebral palsy who have severe motor impairments would benefit from taking into account the nuances and complexities inherent in the everyday experiences of these children.*

### Introduction

In children, physical activity is a prerequisite for healthy growth and development. Children's movement, play and self-care abilities may enable life experiences that promote the development of skills for their subsequent participation in education, leisure activities, and social relationships (Chiarello, Palisano, Bartlett, & Westcott McCoy, 2011). In particular, the ability to walk without restrictions, to get from place to place without relying on others, and independently to explore one's own environment, is critical for both social and community participation, as well as for social development (Lipscombe et al., 2016; Palisano, Kang, Chiarello, Orlin, Oeffinger, & Maggs, 2009).

Cerebral palsy (CP) entails a syndrome of permanent

disorders of the development of movement and posture that cause activity limitations; these motor disorders are, furthermore, often accompanied by disturbances in cognition, sensation, perception, communication and behaviour, and by secondary musculoskeletal problems (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007). While extensive variability occurs in all domains of functioning, individual differences in the severity of the neuromuscular and musculoskeletal impairments associated with CP are particularly notable. While some children with CP walk with or without assistive devices and perform skills associated with age-appropriate play and recreation (e.g., running and jumping), others make use of wheelchairs, and may depend heavily on caregiver assistance for self-care and mobility (Chiarello et al., 2011). Most children with CP, however, do not walk without restrictions (Palisano et al., 2009).

The motor capabilities of children with CP have received little research attention within the fields of psychology and disability studies (Nexus, Academic Search Complete, and PsycINFO database searches, 19 August 2016). Where research has been conducted, it has entailed largely quantitative measurements of motor impairments and their impact on different aspects of individuals' development and functioning. As such, existing studies have often failed to achieve a holistic, contextual view of the functioning of children with CP. In addressing this gap, this study draws on carers' experiences and perspectives to investigate the everyday lives of two children with cerebral palsy along with severe motor impairments. Researchers, practitioners and policy makers are also directed towards focusing on building, reinforcing and extending existing strengths and capabilities as primary goals for intervention efforts that aim to optimise the functioning of children with CP and their families.

### Positive Psychology of Disability

While the tendency towards a pathogenically-oriented approach has dominated much of existing work within the fields of disability and psychology, researchers and practitioners (e.g., Peter, Geyh, Ehde, Müller, & Jensen, 2015; Shogren, 2013; Szarkowski & Brice, 2016; Tuckwiller & Dardick, 2015) have more recently shown increasing interest in the repertoires of strengths and resources available to individuals with disabilities and their families. Accordingly, the approach subscribed to in this paper is one that moves away from the tendency to focus on functional limitations and lack of ability (dis-ability), while nevertheless acknowledging that such features serve as challenges for individuals to adapt to, cope with and potentially transcend.

Characteristically, studies regarding children with CP who have profound motor impairments have made intermittent reference to positive aspects of experience in rather cursory ways. While they lack contextualisation within an overarching theoretical framework, constructs such as well-being, quality of life, and life satisfaction do feature in existing studies. However, existing work has, for instance, failed to find a statistically significant relationship between life satisfaction and functional walking abilities in children with CP (Chong, Mackey, Broadbent, & Stott, 2012; Shelley et al., 2008). Such results are useful, in that they point to the possible impact of a range of variables beyond severity of motor impairment as influential in the well-being of children with CP. As Read, Blackburn, and Spencer (2012) argue, socio-cultural context, including the social attitudes and practices, policy and services defining the environment within which children with CP and their families live, plays a major role in both producing and reducing experiences of dis-ability. Researchers, policy makers and health care professionals are thus alerted to a variety of person-environment interactions that need to be taken

into consideration when investigating everyday experiences and planning interventions to promote optimal functioning in children with CP and their families. As important is the task of grounding research more firmly within formalised theorising around positive constructs.

Positive psychology has been defined as "the science of understanding human strengths and the practice of promoting these strengths to help people psychologically and physically" (Dunn & Dougherty, 2005, p. 305). In placing emphasis on the value of an enabling environment and building on the strengths of children with CP, this paper is grounded in the assumptions and principles of positive psychology. Proponents of positive psychology hold that treatment is not just about fixing what is broken, but instead entails nurturing what is best within the individual concerned (Seligman & Csikszentmihalyi, 2000). In accordance with this ideal, this paper proposes a focus on identifying the qualities that help children with CP who have severe motor impairments (as well as their families) not just to endure and adapt, but to flourish both within and beyond rehabilitation settings.

Positive psychology has been subject to a fair share of healthy criticism (e.g., Lazarus, 2003; Pérez-Álvarez, 2012; *Theory & Psychology*, October, 2008). Notably, Slife and Richardson (2008) have argued that positive psychology uncritically assumes an abstracted and decontextualised self. Informed by Slife and Richardson (2008), what is subscribed to here is a relational view of self that accords precedence to contextually situated aspects of experiences, actions and practices. More particularly, this paper proposes that, given its overarching prioritisation of strengths and capabilities, a significant part of positive psychology's appeal lies in its potential to extend current conceptualisations of impairment, disability, health and well-being, thereby addressing some of the gaps in existing disability research.

### Post-Conventionalist Theories of Embodiment and Selfhood

Budgeon (2003) posited that bodies can be thought of "not as *objects*, upon which culture writes meanings, but as *events* that are continually in the process of becoming – as multiplicities that are never just found but are made and remade" (p. 50). Following Budgeon, selfhood is here conceived of as "an embodied process involving particular experiences and engagements in certain practices which allow the body to make new, transformative connections" (2003, p. 48). Accordingly, in keeping with post-conventionalist work by Braidotti (2006) and Shildrick (2009), amongst others, this paper is grounded in the phenomenological position that the body is a "lived body". Moreover, post-conventionalist theories make a concerted effort to move away from pathologising conceptualisations of bodies as lacking and dis-abled (Goodley & Runswick-Cole, 2012), and

instead reframe disabled or “non-normative” bodies in terms of capacity, potential, and becoming. Also notable is an emphasis on interconnections; for, as Braidotti (2006) reminds us, bodies become through their relationships with others. The post-conventionalist view of ability as a response to environmental demands (Goodley & Runswick-Cole, 2012) is particularly informative for this study, implicit in its exploration of the everyday lives of two girls with CP and severe motor impairments being a move away from a deficit-oriented comparison with a normative “able” body, thereby allowing for understandings based on idiosyncratic strengths.

Loja, Costa, Hughes, and Menezes (2012) define identity as “an embodied construction that is influenced by subjective bodily experience as well as social and intercorporeal encounters” (p. 11). Research indicates that the dynamic reciprocal process of person-environment interaction influences the mobility of children with CP (Palisano et al., 2009). As stated earlier, the ability to walk without restrictions and get from place to place without being reliant on others is critical for social participation. Successful social participation entails “physical, social, and psychological engagement in an activity that is enjoyable and that promotes self-efficacy” (Palisano et al., 2009, p. 1313). Individuals with disabilities, however, experience both the intrinsic limitations of their impairments and the external barriers of stigmatism and societal discrimination. Thus, at one level, research has shown not only that children with CP have decreased levels of leisure participation, but also that those with greater functional impairments are the most restricted in terms of their participation (Palisano et al., 2009). At another level, with regard to societal attitudes, individuals with disabilities are perceived as lacking in autonomy and agency (Wang & Dovidio, 2011). However, following Palisano et al. (2009), it is imperative to note that children’s social participation is influenced by the extent to which environments are accessible and interactions are positive. It is to such environments and interactions that this study gives due attention in drawing on carers’ experiences and perspectives with regard to the negotiation of their motor in/capabilities by two girls with CP.

Informed by the theoretical frameworks of a positive psychology of disability as well as post-conventionalist theories of embodiment and selfhood, this paper investigates the everyday lives of two girls with CP in response to the broader need to investigate not only the incapacities but also the capabilities of children with CP who have severe motor impairments.

## Method

### Design

This study aimed to explore and interpret the everyday lives of two girls with CP and severe motor impair-

ments as experienced by their carers. Given its concern with the complexities and nuances of human meaning (Gergen, 2014), a qualitative interpretative methodology was used. Carers’ accounts of the girls’ everyday lived experiences were utilised toward building a case study (Yin, 2014) of each child.

### Participants

Natalie’s and Rachel’s respective carers, namely their mothers, teachers and therapists, served as appropriate proxies for the provision of elaborate locally produced, “situated” descriptive accounts of the girls’ embodied experiences and interactions. The girls were five and eleven years old respectively at the start of the two-year study reported in this paper. Both diagnosed with CP, the girls attended a segregated school which serves learners with a wide range of cognitive and physical impairments.

### Procedures

Ethical approval of this research was granted by the ethics committee of the local university under whose auspices the study was conducted. Permission to interview the girls’ teachers and therapists was also obtained from both the school principal and the girls’ mothers. As the girls belong to a group whose experiences are often invalidated in the broader society, particular care was taken in respect of ethical issues such as informed consent, avoidance of deception, beneficence, privacy and confidentiality. Moreover, in presenting the data in this paper, the names and identifying features of the various participants have been changed so as to ensure their anonymity.

In-depth interviews (each lasting between 30 and 60 minutes) were conducted at the convenience of the interviewees, typically at their family homes, or, in the case of the teachers and therapists, at the school. Organised around areas of particular interest, the semi-structured interviews (Kvale & Brinkmann, 2009) covered a range of issues, including the various carers’ respective experiences of each girl’s participation in daily living activities, social interactions, and relationships with family members, as well as with peers and adults at school. The girls’ health and participation in leisure activities, particular challenges associated with their impairments, and the strengths and resources of both the girls and their families were also explored. As the questions allowed for flexibility in scope and depth (Kvale & Brinkmann, 2009), it was possible to note, respond to, and follow up on issues raised by the interviewees, including perspectives that I, as the researcher, had not anticipated. My involvement in the administration of sport for children with disabilities appeared to add to my credibility as a researcher interested in disability issues, and assisted in building rapport with interviewees. In addition, I believe that having gender in common facilitated the process of sharing sensitive and, in the case of the mothers in

particular, sometimes painful experiences. Following Gergen (2014), I believe that, given a keen sensitivity on my part to my relationship with the interviewees, along with a continuing flexibility, the mothers, teachers and therapists shared richer and more enlightening views than a more standardised process would have elicited. With the interviewees' permission, all the interviews were audio-recorded. The audiotapes were subsequently transcribed verbatim, and the data treated as confidential.

### Analysis

Analysis of the data was based on the principles outlined by Dahlberg, Dahlberg, and Nyström (2008) of their phenomenological approach of reflective life-world research (RLR). This approach was considered appropriate for the present study in that it aims to describe human beings' lived experiences of a particular phenomenon so as to achieve a greater understanding of the meaning of the phenomenon. RLR is based on a stance of openness and flexibility towards the phenomenon under study – which in this context is the everyday lives of two girls with cerebral palsy – throughout the research process. Dahlberg et al. (2006, 2008) recommend that, in the search for the meaning of the phenomenon, we as researchers must learn how to “bridle” our emerging understandings of the focal phenomenon and its meanings. Instead of setting aside all pre-understanding, “bridling” means that we are to maintain an open, reflective and critical attitude in which we in effect “slow down” the process of understanding in order to see the phenomenon in a new way (Dahlberg, 2006). Throughout the research process, peer checking through reviews and discussions with an external auditor – a child psychologist with a doctoral degree and qualitative research expertise who was uninvolved in this study – was useful for noting my pre-understandings and highlighting hidden aspects. We discussed emerging understandings as I went back and forth between the carers' narratives and the possible meanings that I thought I saw. In this way, an attempt was made to ensure the trustworthiness of the data and the authenticity of the findings.

### Findings

In what follows, the data elicited is presented in the form of case studies of Natalie's and Rachel's everyday lives as experienced by their respective carers. This presentation is structured in terms of the interpretative theme, *Negotiating motor in/capabilities*, and its two constituent sub-themes: (i) *Identity and difference* and (ii) *Living motor in/capabilities in a disabling/enabling environment*. Highlighting the complexity and diversity of everyday lived experiences, these two sub-themes illustrate the ways in which two girls with CP who have severe motor impairments negotiate – and, in often subtle ways, transcend – their motor in/capabilities within their everyday life contexts.

### Natalie

Five-year-old Natalie is a member of a working class family with an inconsistent income, and lives within an extended family system on a smallholding in a semi-rural area 30 kilometres outside the city. She has a two-year-old sister, Magda, who is not disabled. Natalie has been diagnosed with spastic cerebral palsy, as well as diplegia, which entails the motor impairment of her legs, with also some definite, although relatively limited, involvement of her arms (Rosenbaum et al., 2007). As Natalie is unable to achieve and maintain an upright standing position, or to walk independently, she uses a wheelchair for the purposes of ambulation. Natalie does not, however, rely exclusively on this assistive device, but also bunny hops and crawls in order to manoeuvre herself physically to where she would like to be.

### Negotiating Motor In/Capabilities

#### *Identity and Difference*

In reflecting on what Natalie battles with, given a diagnosis of spastic diplegia, the child's mother, Carien, stated:

*I think it's a bit difficult for her to see her cousins and sister and everyone else running around and playing outside, and being able to do everything themselves, and she cannot. ... Because at a stage she asked if her sister can walk, is it still her sister. ... Then I said “Yes, it's still your sister”. Then she said ... erm ... if she cannot walk, am I still going to love her? So ... I think it's just a bit heavy for her.*

Taking up this issue, Natalie's teacher, Alida, declared:

*I think it is normal when a child starts to realise ... . And how her mother then explained to her is the truth. So she [Natalie] realises her limitations, and her mother tells her that she is not a child who can walk. Her little legs are not strong enough. So I think she has started becoming aware of that for the first time now when her sister started to walk. But in the class itself she is, in spite of her disability ... she lives her life, and she functions and she plays, and she is **active**.*

Her carers experience compassion for Natalie as she struggles to live out her motor capabilities and engage with her social and physical environment in more interactive and fulfilling ways. Natalie seems to have a somewhat ambivalent relationship to both her body and her physical impairment. The extracts above reveal that she pointedly reflects on and struggles to make sense of her disabled status. She is consistently aware of and self-conscious about the negative form of

difference and lack of ability signified by her impaired body and use of a wheelchair. Thus, her carers sense that Natalie finds it difficult to accept her “non-normative body” (Shildrick, 2009) and her limited participation in play and other everyday activities.

Her teacher, Alida, describes the process of Natalie developing a sense of awareness of her own difference and then reflecting on that difference as nothing out of the ordinary for children with disabilities who have reached a certain level of cognitive capability. Her carers are empathic and sensitive to Natalie’s vulnerability, for, in calling into play issues of identity and belonging, she seems to experience self-doubt with regard to her own humanity and ontological worth. Perhaps partly on account of the stigmatised image of individuals who use wheelchairs as signifying deficiency and incapability, the pervasive cultural message which Natalie seems to have internalised is that she is devalued, less loved, and occupies a lesser status in relation to her able-bodied two-year-old sister and perhaps society at large.

Further, Alida approvingly appraises mothers like Carien as having done what is best for their children (given the reality of their severe and chronic impairments), by explaining to them that they are disabled. As Natalie struggles to make sense of the severe effects of her motor impairments on a day-to-day basis, such painful confirmations of her irreversible disability status seem to be unavoidable and inevitable. At the same time, Alida reaffirms that Natalie *transcends* the limitations of her impaired body by being active and well integrated into her group of peers. What distinguishes Natalie from the rest of her group of peers is not only her motivation and zest for life. Rather, by translating these particular attributes into interacting with her social and physical environments in autonomous, meaningful ways, as her carers have noticed, Natalie also achieves a remarkable degree of functionality.

### ***Living Motor In/Capabilities in a Disabling/Enabling Environment***

The capabilities and capacities of a child are important prerequisites for the actual performance of activities (Ketelaar, Gorter, Westers, Hanna, & Verhoef, 2014). Accordingly, it is notable that, in considering the challenges that Natalie experiences as a consequence of her motor impairments, her teacher commented further:

*The only way that Natalie can move herself forward is to almost bunny hop, and she must also be taught to cross with her alternating feet, and not to bunny hop. ... Then, what is positive for me is that she will still move and she can get herself to a place where she wants to be. ... Another thing*

*with her is she tries to be independent. Especially to help herself up onto her wheelchair independently. **She really tries.** I think she does want to be independent as far as possible.*

While Natalie’s motor impairments are of a severe nature, she is not completely immobile without her wheelchair. Rather, Natalie gets herself out of her wheelchair and propels herself forward by crawling on her hands and knees or bunny hopping. Such efforts have a profound transformative impact on her body, as well as her sense of self. As she is able to engage with her environment in active ways, Natalie’s efforts may be interpreted as negotiating her experiences of her impairments, and challenging and undermining the conventional view of disability as lack of ability, associated with passivity.

Here Alida adopts a strengths-oriented view, framing Natalie’s particular adaptive mode of mobility in terms of an understanding that developmentally she still has to learn, and therefore needs to be taught, the precise motor patterns and co-ordination that walking entails. As post-conventionalist theorists such as Shildrick (2009) would argue, Alida sees Natalie’s body and life in terms of possibility and capability. Alida’s validating attitude toward Natalie’s potential for independent mobility and further development exemplifies a critical aspect of the enabling social environment that she provides to Natalie and other learners at the school.

For her carers, a critical strength that sets Natalie apart from her peers is that she is highly motivated to function independently. She translates this intrinsic motivation into interacting with her physical environment in idiosyncratic, agentic ways. Thus, while generally poor motor control and an inability to achieve an automatic righting posture means that she is not capable of walking, her carers respect and admire that Natalie uses her existing motor skills and bodily capabilities and determinedly gets herself to where she wants to be. Following Goodley and Runswick-Cole (2012), a phenomenological lens here affords us a view of Natalie’s body as her active vehicle for her being-in-the-world. Moreover, it is argued that Natalie’s intrinsic motivation and perseverance constitute psychosocial resources that are instrumental in driving her efforts at unassisted, independent mobility. Through such influences as her intrinsic motivation, tendency to act autonomously, and perseverance, then, the challenges that Natalie faces on account of her quite profoundly impaired physicality are effectively negotiated and minimised.

At the same time, an enabling psychosocial and physical environment provides Natalie with ample opportunity to exercise her autonomy and capabilities. In this regard, her mother, Carien elaborated:

*If we have finished eating, she wants to take the plates to the kitchen ... or the cups or the tumblers. But she cannot, because if she crawls then she smashes them if she places her hand in front, and then the glass breaks, so she cannot take it to the kitchen. But she can take plastic things to the kitchen.*

Here Carien indicates that Natalie is highly enthusiastic about participating in seemingly mundane domestic activities such as clearing the dining table after meals. However, because she usually crawls on her hands and knees, performing such tasks places her at risk of injury. Notably, Carien has recognised Natalie's need to assist her in this particular domestic task as *valid*. Consequently, she has made a concerted effort to create an enabling environment, facilitating Natalie's participation in clearing the dining table by replacing glassware and other fragile items of crockery with unbreakable plastic items. Carien thus promotes what Palisano et al. (2009) describe as successful social participation or "physical, social, and psychological engagement in an activity that is enjoyable and that promotes self-efficacy" (p. 1313). Furthermore, like the mother of 12-year-old Mimi, a girl with a rare neuromuscular condition in Gibson, Carnevale, and King's (2012) study, Carien facilitates her daughter's "activities, practices and well-being by constructing a set of bounded possibilities for action" (p. 1895). Thus, by virtue of her mother's initiative, Natalie is empowered to utilise her existing motor skills and capabilities in effective ways. In this manner, she is included in, and feels that she contributes to, a routine domestic task that is meaningful for her. Heightened self-efficacy beliefs and experiences of autonomy, along with positive developmental implications for Natalie's experiences of a sense of mastery, are inferred here.

### Rachel

Hailing from an English-speaking upper middle-class family background, eleven-year-old Rachel is, like Natalie, diagnosed with diplegic cerebral palsy. Rachel has experienced a significant developmental delay with respect to gross motor functioning, in that she started to walk for the first time well into her ninth year of life. However, on account of her weak postural control and ataxic limbs, manifested as an abnormal pattern of posture and/or movement, along with a loss of orderly muscular co-ordination (Rosenbaum et al., 2007), she continues to require the physical support of an adult in order to stand up and struggles to walk without this assistance. Like Natalie, Rachel, too, makes use of a wheelchair for the purposes of ambulation. Apart from severe cognitive impairments, Rachel has little or no functional speech. Unlike her peers, she attends the primary school on a part-time basis, so as to have social contact with other children, and for therapy sessions. Rachel is home schooled by Anna, a private teacher,

with lessons taking place in the family home's double garage that has been converted into a well-equipped classroom. Two full-time aides also assist Rachel with daily personal care tasks such as eating and toileting.

### Negotiating Motor In/Capabilities

#### Identity and Difference

Rachel's mother, Grace, identified the disabling impact of impaired gross motor functioning on Rachel's social relations with her peers as a significant concern. She observed:

*You often see her, when we are with kids and the kids are running around ... she would love to be part of that, you know ... She can't get there, and then you put her with those kids that are playing and they're there for a second and then they run off.*

In similar vein, Anna, Rachel's home schooling teacher, stated emphatically:

*It definitely has an impact. Because they see her as being a bit strange, you know. They all can go and do activities, "Why can't she?" "Why can't she partake the same way they can?" And that makes them question things and they look at her and think, you know, "What's going on?"*

Rachel has a very real need for social interaction with other children. However, her carers are concerned that Rachel's lack of independent mobility, in interaction with her impaired language skills, hinders the expression of her sociality. These challenges contribute directly to her psychologically isolating experiences of marginalisation and social exclusion from her peer group. Moreover, experiences of social isolation and exclusion can pose a threat to the basic human needs for positive self-esteem and belonging or a sense of community (Lindsay & McPherson, 2012). Rachel's carers are aware of Rachel's vulnerability in this regard, and they empathise with the sense of psychological isolation that Rachel experiences when her peers consistently fail to include her in their everyday social play activities. Consequently, negative implications are inferred for Rachel's experiences of self-acceptance, autonomy and social participation.

Clearly Rachel's peers have noticed that she is not capable of participating in their activities with a similar degree of involvement, and they regard her as a less than eligible playmate. Their perception of her as "being a bit strange" implies that they experience Rachel as different from themselves in significant, observable ways, and therefore Other. The extract above indicates that her mother, Grace, feels a sense of despair,

and perhaps a tinge of resentment, that Rachel seems almost invisible to other children who typically exclude her from their social play activities, and show no further interest in her. In contrast, her teacher, Anna, reports that Rachel's disabled peers are curious about and interested in the profound form of disability that she embodies. Rachel's limited communicative skills and severely impaired gross motor skills constitute features of her functioning that her more perceptive peers deem to be worthy of questioning and contemplation. In Anna's experience, they appear to grapple with and try to make sense of Rachel's noticeable deficits with respect to these skills and capabilities. Thus, in sum, her carers highlight the nuanced and somewhat messy nature of Rachel's social relations with her peers.

### ***Living Motor In/Capabilities in a Disabling/Enabling Environment***

Arguably more so than in the case of Natalie and the rest of her disabled peers, given the severe nature of her impairments, adult care serves as an important psychosocial and practical resource for Rachel. Elana, her occupational therapist, identified Rachel's very limited opportunities for engagement with her environment as problematic. She stated:

*I think Rachel is anyway a lot more over-protected. ... Little Rachel is held like this [cups hands tightly indicating tightly held, suppressed].*

Echoing Elana's view, Rachel's home schooling teacher, Anna, declared:

*I think people sometimes help a bit too much. If you leave her, she'll eventually try and figure a way to get to something. ... On Monday she was in her chair in front of the TV and she wanted a book. So she pointed and she called and stuff, and I was [turns her head to indicate that she looked away and tried to ignore her]. So then she started to try and get there. So first she squeezed herself down so her bum was on the edge, and she was trying to get off that way and that didn't work. So she leaned over and had to go onto her hands. So she is trying to find ways of doing it. And I think if we try not to help her too much, but encourage her to try to do things herself, she will do it.*

Here, Anna problematises the dynamics at play with respect to Rachel's dependence on adult care by her parents and the two aides employed to assist her on a full-time basis. She experiences Rachel's parents' and aides' responses as disempowering Rachel. While doing things for her might be less time-consuming, her parents' and aides' efforts also tend to reinforce and exacerbate Rachel's dependence on their care. Not only

is Rachel afforded few opportunities to apply and rehearse the problem-solving skills and capabilities she has, but she is also effectively denied the necessary freedom and opportunities to engage with her physical and psychosocial environment in active, autonomous ways. In other words, she has limited opportunity to experience her body as "a body that works". Anna makes implicit reference to the reality that, as a result, Rachel misses out on important learning experiences. In this regard, McKenzie and Müller (2006) remind us that there is also a risk of decreasing an individual's intrinsic motivation to learn through spontaneous interaction with her environment. Thus, it is also likely that Rachel could be missing out on opportunities to develop and enhance her self-efficacy beliefs by learning that her actions are effective. At the same time, however, the criticisms by her teacher and occupational therapist do not take into account the motivations underlying Rachel's parents' seemingly overprotective manner. I wondered whether Rachel's parents' own experiences of society as largely unaccommodating and excluding of children with disabilities such as Rachel (who are typically stereotyped as deviant, deficient, and therefore lesser) accounts for their tendency to be overprotective.

Anna offers her subtle efforts to stimulate Rachel's motor functions and mobility as evidence of her own concerted attempts to foster independence in Rachel. Indeed, Anna experiences Rachel as *motorically capable* in that, when left to her own devices, she is able to move around her environment independently and actively participate in activities that require the use of her motor skills while successfully applying her problem-solving skills to the context at hand. The example of Rachel's efforts to get down from her chair to retrieve a book that she wanted highlights the element of intentionality that has featured as a recent development in her behavioural repertoire. While her attempts to reach for items that she wants of her own accord could perhaps be glossed over as a somewhat negligible gain, for Anna such efforts are actually representative of significant developments along cognitive dimensions of Rachel's functioning.

Subscribing, thus, to an enabling, strengths-oriented perspective, Anna reasons that, in order to foster greater functional independence, Rachel should be presented with more frequent opportunities to actively utilise her existing cognitive and motor skills across different settings. Indeed, Anna is optimistic that Rachel is likely to flourish under caring relations that are facilitative, supporting and empowering.

### **Discussion**

In exploring carers' experiences of the everyday lives of two girls who have CP and severe motor impairments, this paper has highlighted the nuanced ways in which Natalie and Rachel respectively negotiate their motor in/capabilities. Consistent with existing research which



indicates that those children with CP who have greater functional impairments are more restricted in terms of their participation (Palisano et al., 2009), Natalie and Rachel's *relative capabilities* for independent mobility have impacted on the degree and quality of their engagements with their environments, and have specifically influenced their social participation in significant ways. Both girls found themselves in an environment of peers who were not always willing to include them. Thus, disabling social attitudes were expressed in nuanced ways by their peers who often neglected to include the girls in their play activities. In particular, Rachel's experience of comparatively less favourable attitudes from her classmates is consistent with the findings of Colver et al. (2011) that their classmates displayed less favourable attitudes toward children with greater intellectual impairment.

Research indicates that individuals with disabilities are widely perceived as lacking in autonomy and agency (Wang & Dovidio, 2011). A significant finding was therefore that both Natalie and Rachel tended to utilise their bodies, the site of their impairments, and the source of their experiences of difference, othering and social exclusion, to engage with their environments and social others in their own idiosyncratic and agentic ways. And, by virtue of the tendency to negotiate and often transcend their impaired physicalities, Natalie and Rachel were perceived by their carers as motorically capable and indeed functionally autonomous, although to differing degrees. Adopting an understanding of autonomy primarily in terms of "individual preferences" as opposed to "general competencies" (Cardol, de Jongh, & Ward, 2002) means that Natalie and Rachel's idiosyncratic bodily ways of engaging interactively with their environments can be affirmed and validated. Their embodied experiences of transcending their motor impairments also serve to challenge deficit-oriented thinking around the capabilities of individuals with profound forms of physical disability.

Natalie and Rachel live in a developing country that is relatively resource-poor and often struggles to meet the health care, educational and rehabilitation needs of children with disabilities (Maart, Eide, Jelsma, Loeb, & Ka Toni, 2007). With regard to socioeconomic status, it is striking that Rachel's domestic environment and social relationships offered highly resourced options for stimulation, and yet fostered passivity and dependence on adult care. In contrast, Natalie's relatively under-resourced domestic environment but enabling social relationships provided a platform for fostering autonomous behaviours and engagement with her environment. Nevertheless, despite differences in terms of the socioeconomic status of their respective families, both girls were well cared for in their immediate social and physical environments. In other words, both Natalie's and Rachel's everyday experiences were contextualised within environments that have elements of disabling as

well as enabling features with regard to social attitudes and relationships. Yet, the girls' experiences of engaging with their environments differed in subtle, even though significant, ways. And, to differing degrees, their carers, who constitute an essential part of their social worlds, recognised, were responsive to, and indeed accorded precedence to the children's propensity for negotiating and transcending their impaired physicalities. Accordingly, based on the data derived from carers' experiences and perspectives, this paper suggests that future research needs to pay further attention to the interaction between children's bodies, psychosocial aspects of experience, and enabling as well as disabling environments.

Results of a study by Cunningham, Warschusky, and Dixon Thomas (2009) point to the relationship between parental overprotectiveness, behavioural autonomy and children's social outcomes. In particular, it was found that parents of children with CP and cognitive impairments were less willing to allow their children to express themselves and attempt new experiences independently (Cunningham et al., 2009). Majnemer, Shevell, Law, Poulin, and Rosenbaum (2010) similarly found that children with CP experienced impediments to mastery and were less able to explore their environments freely. This was, in the authors' view, exacerbated by over-protective and overly helpful teachers and parents. For Rachel, too, caring adults, probably unwittingly, provided a rather disabling environment by failing to recognise and offer her opportunities to fully live out her existing strengths and capabilities. However, as stated earlier, this finding needs to be interpreted within the context of the relatively profound nature of Rachel's impairments, and her dependence on adult care for daily functioning needs. Further to this, the finding that therapists and teachers were largely enabling in their attitudes toward and efforts with the girls is promising. It echoes the finding of the study by Colver et al. (2011), which pointed to similarly favourable attitudes on the part of therapists and teachers toward children with all levels of impairment. Overall, thus, their respective carers served as resources for each of the girls in the current study, providing them with enabling social and physical environments that promote their optimal functioning.

## Conclusion

This study has contributed to existing scholarship regarding the psychology of disability by analysing the negotiation of motor in/capabilities in two children with cerebral palsy through the lens of positive psychology. As the findings have indicated, two girls with quite profound forms of disability utilise their bodily and psychosocial resources towards experiences of enhanced autonomy and a sense of mastery, and as such to flourish. These findings represent a significant shift from the pathologising orientation that has been assumed in much psychological work within the field of disability

to date. Accordingly, it is proposed that the nascent field of positive psychology needs to be developed further so that disability and impairment come to be utilised as their own frames of reference. In so doing, the field could contribute to the psychological study of disability by evolving into a positive psychology of disability.

This study having been qualitative, the findings are not generalisable but instead particular to the context in which the research was conducted, as well as to the experiences of the participants. As Martins, Walker, & Fouché (2013) remind us, those conducting further research in the field would need to make a transferability judgement regarding the appropriateness of applying these findings in other settings.

Those contemplating conducting future research into the phenomenon of negotiating motor in/capabilities in children with CP should note that social class needs to be further examined as a factor which impacts on access to quality care, educational and therapeutic resources, and stimulation in often materially significant ways. Future research could, for instance, investigate the role that social class plays in facilitating the development of both enabling and disabling psychosocial and physical environments for children with disabilities.

Researchers could also take into account that, within multicultural contexts, autonomy might not necessarily feature as a critical part of the experience of living well

for all individuals in society. In more collectivist-oriented cultures, social responsibility and the good of the group are highly valued attributes (Moleko, 2012). Certainly, a more culturally diverse sample would afford an opportunity to further examine, as well as corroborate and/or contradict, this study's findings. It might also be worthwhile for future studies to explore experiences of autonomy in terms of interdependence and interconnectedness with particular reference to children with CP who require forms of assistance with their daily care and functioning that differ qualitatively from that of their able-bodied peers.

Children and adolescents with CP are at greater risk in relation to experiencing restricted participation in everyday activities, and at greater risk too of social isolation. Practitioners therefore need to plan psychosocial interventions that aim to optimise, rather than normalise, the everyday functioning of children with CP as well as their carers. In recognising idiosyncratic strengths and promoting enabling environments, efforts can be made to promote optimal well-being and prevent secondary disorders, including experiences of social exclusion, poor self-acceptance, reduced self-efficacy and low self-esteem. Both researchers and health care professionals need to maintain a reflexive stance with regard to the assumptions around in/capabilities and person-environment interactions that underpin practices and programmes for children with CP who have severe motor impairments.

## Acknowledgements

The author wishes to thank Christel Troskie-De Bruin and Grahame Hayes for commenting on drafts of this paper, and Anneke Denobili for technical assistance.

## Referencing Format

Naidoo, P. (2017). The negotiation of motor in/capabilities by two children with cerebral palsy as experienced by their carers. *Indo-Pacific Journal of Phenomenology*, 17 [Special Edition: *Positive Psychology*], 12pp. doi: 10.1080/20797222.2017.1299288

## About the Author

Pravani Naidoo  
Lecturer, Department of Psychology  
University of the Free State, South Africa  
E-mail address: [naidoop@ufs.ac.za](mailto:naidoop@ufs.ac.za)



Dr Pravani Naidoo lectures in the Psychology Department at the University of the Free State (UFS) in Bloemfontein, South Africa, where she supervises research within the field of Positive Psychology, including studies regarding adolescent well-being, mindfulness, and leisure engagement.

Dr Pravani is also interested in the application of Positive Psychology principles and constructs to understanding the experiences of individuals with disabilities, as reflected in the current paper.

Based on her interest in interventions to promote well-being amongst individuals with disabilities, combined with her interest in the Psychology of Disability, she co-ordinates a therapeutic horse riding community service learning project at the UFS.

## References

- Braidotti, R. (2006). Affirming the affirmative: On nomadic affectivity. *Rhizomes: Cultural Studies in Emerging Knowledge*, 11/12. Retrieved from [www.rhizomes.net/issue11/braidotti.html](http://www.rhizomes.net/issue11/braidotti.html)
- Budgeon, S. (2003). Identity as an embodied event. *Body and Society*, 9(1), 35–55. doi: 10.1177/1357034X030091003
- Cardol, M., De Jongh, B. A., & Ward, C. D. (2002). On autonomy and participation in rehabilitation. *Disability and Rehabilitation*, 24(18), 970–974. doi: 10.1080/09638280210151996
- Chiarello, L. A., Palisano, R. J., Bartlett, D. J., & Westcott McCoy, S. (2011). A multivariate model of determinants of change in gross-motor abilities and engagement in self-care and play of young children with cerebral palsy. *Physical & Occupational Therapy in Pediatrics*, 31(2), 150–168. doi: 10.3109/01942638.2010.525601
- Chong, J., Mackey, A. H., Broadbent, E., & Stott, N. S. (2012). Children's perceptions of their cerebral palsy and their impact on life satisfaction. *Disability & Rehabilitation*, 34(24), 205–206. doi: 10.3109/09638288.2012.669021
- Colver, A. F., O'Dickinson, H., Parkinson, K., Arnaud, C., Beckung, E., Fauconnier, J., Marcelli, M., McManus, V., Michelsen, S. I., Parkes, J., & Thyen, U. (2011). Access of children with cerebral palsy to the physical, social and attitudinal environment they need: A cross-sectional European study. *Disability and Rehabilitation*, 33(1), 28–35. doi: 10.3109/09638288.2010.485669
- Cunningham, S. D., Warschausky, S., & Dixon Thomas, P. (2009). Parenting and social functioning of children with and without cerebral palsy. *Rehabilitation Psychology*, 54(1), 109–115. doi: 10.1037/a0014748
- Dahlberg, K. (2006). The essence of essences: The search for meaning structures in phenomenological analysis of lifeworld phenomena. *International Journal of Qualitative Studies on Health and Well-Being*, 1(1), 11–19. doi: 10.1080/17482620500478405
- Dahlberg, K., Dahlberg, H., & Nyström, M. (2008). *Reflective lifeworld research* (2nd rev. ed.). Lund, Sweden: Studentlitteratur.
- Dunn, D. S., & Dougherty, S. B. (2005). Prospects for a positive psychology of rehabilitation: Commentaries. *Rehabilitation Psychology*, 50(3), 305–311. doi: 10.1037/0090-5550.50.3.305
- Gergen, K. J. (2014). Pursuing excellence in qualitative inquiry. *Qualitative Psychology*, 1(1), 49–60. doi: 10.1037/qup0000002

- Gibson, B. E., Carnevale, F. A., & King, G. (2012). "This is my way": Reimagining disability, in/dependence and interconnectedness of persons and assistive technologies. *Disability and Rehabilitation*, 34(22), 1894–1899. doi: 10.3109/09638288.2012.670040
- Goodley, D., & Runswick-Cole, K. (2012). The body as disability and possibility: Theorising the 'leaking, lacking and excessive' bodies of disabled children. *Scandinavian Journal of Disability Research*, 15(1), 1–19. doi: 10.1080/15017419.2011.640410
- Ketelaar, M., Gorter, J. W., Westers, P., Hanna, S., & Verhoef, M. (2014). Developmental trajectories of mobility and self-care capabilities in young children with cerebral palsy. *The Journal of Pediatrics*, 164(4), 769–774. doi: 10.1016/j.jpeds.2013.11.070
- Kvale, S., & Brinkmann, S. (2009). *InterViews: Learning the craft of qualitative research interviewing* (2nd ed.). Thousand Oaks, CA: Sage.
- Lazarus, R. S. (2003). Does the positive psychology movement have legs? *Psychological Inquiry*, 14(2), 93–109. doi: 10.1207/S15327965PLI1402\_02
- Lindsay, S., & McPherson, A. C. (2012). Experiences of social exclusion and bullying at school among children and youth with cerebral palsy. *Disability and Rehabilitation*, 34(2), 101–109. doi: 10.3109/09638288.2011.587086
- Lipscombe, B., Boyd, R. N., Coleman, A., Fahey, M., Rawicki, B., & Whittingham, K. (2016). Does early communication mediate the relationship between motor ability and social function in children with cerebral palsy? *Research in Developmental Disabilities*, 52–54, 279–286. doi: 10.1016/j.ridd.2016.02.013
- Loja, E., Costa, M. E., Hughes, B., & Menezes, I. (2012). Disability, embodiment and ableism: Stories of resistance. *Disability & Society*, 28(2), 190–203. doi: 10.1080/09687599.2012.705057
- Maart, S., Eide, A. H., Jelsma, J., Loeb, M. E., & Ka Toni, M. (2007). Environmental barriers experienced by urban and rural disabled people in South Africa. *Disability & Society*, 22(4), 357–369. doi: 10.1080/09687590701337678
- Majnemer, A., Shevell, M., Law, M., Poulin, C., & Rosenbaum, P. (2010). Level of motivation in mastering challenging tasks in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 52(12), 1120–1126. doi: 10.1111/j.1469-8749.2010.03732.x
- Martins, C. D., Walker, S. P., & Fouché, P. (2013). Fathering a child with autism spectrum disorder: An interpretative phenomenological analysis. *Indo-Pacific Journal of Phenomenology*, 13(1), 1–19. doi: 10.2989/IPJP.2013.13.1.5.1171
- McKenzie, J., & Müller, B. (2006). Parents and therapists: Dilemmas in partnership. In B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestly (Eds.), *Disability and social change: A South African agenda* (pp. 311–323). Pretoria, South Africa: Human Sciences Research Council Press.
- Moleko, A.-G. (2012). Cultural and cross-cultural psychology. In M. Visser & A.-G. Moleko (Eds.), *Contextualising community psychology in South Africa* (2nd ed., pp. 163–176). Pretoria, South Africa: Van Schaik Publishers.
- Palisano, R. J., Kang, L.-J., Chiarello, L. A., Orlin, M., Oeffinger, D., & Maggs, J. (2009). Social and community participation of children and youth with cerebral palsy is associated with age and gross motor function classification. *Physical Therapy*, 89(12), 1304–1314. doi: 10.2522/ptj.20090162
- Pérez-Álvarez, M. (2012). Positive psychology: Sympathetic magic. *Papeles del Psicólogo*, 33(3), 183–201. Retrieved from <http://www.papelesdelpsicologo.es>
- Peter, C., Geyh, S., Ehde, D. M., Müller, R., & Jensen, M. P. (2015). Positive psychology in rehabilitation psychology research and practice. In S. Joseph (Ed.), *Positive psychology in practice: Promoting human flourishing in work, health, education and everyday life* (2nd ed., pp. 443–462). Hoboken, NJ: John Wiley & Sons. doi: 10.1002/9781118996874.ch27
- Read, J., Blackburn, C., & Spencer, N. (2012). Disabled children and their families: A decade of policy change. *Children & Society*, 26(2), 223–233. doi: 10.1111/j.1099-0860.2012.00435.x

- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., Dan, B., & Jacobsson, B. (2007). A report: The definition and classification of cerebral palsy April 2006. *Developmental Medicine & Child Neurology*, 49(Supplement 109), 8–14. doi: 10.1111/j.14698749.2007.tb12610.x
- Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist*, 55(1), 5–14. doi: 10.1037/0003-066X.55.1.5
- Shelley, A., Davis, E., Waters, E., Mackinnon, A., Reddihough, D., Boyd, R., Reid, S., & Graham, H. K. (2008). The relationship between quality of life and functioning for children with cerebral palsy. *Developmental Medicine & Child Neurology*, 50(3), 199–203. doi: 10.1111/j.1469-8749.2008.02031.x
- Shildrick, M. (2009). *Dangerous discourses of disability, subjectivity, and sexuality*. London, UK: Palgrave Macmillan.
- Shogren, K. A. (2013). Positive psychology and disability: A historical analysis. In M. L. Wehmeyer (Ed.), *Oxford handbook of positive psychology and disability* (pp. 19–35). New York, NY: Oxford University Press.
- Slife, B. D., & Richardson, F. C. (2008). Problematic ontological underpinnings of positive psychology: A strong relational alternative. *Theory & Psychology*, 18(5), 699–723. doi: 10.1177/0959354308093403
- Szarkowski, A., & Brice, P. J. (2016). Hearing parents' appraisals of parenting a deaf or hard-of-hearing child: Application of a positive psychology framework. *Journal of Deaf Studies and Deaf Education*, 21(3), 249–258. doi: 10.1093/deafed/enw007
- Tuckwiller, B., & Dardick, W. R. (2015). Positive psychology and secondary transition for children with disabilities: A new theoretical framework. *Journal of Interdisciplinary Studies in Education*, 4(1), 3–20. Retrieved from <http://itc-web.astate.edu/ojs/index.php/jise/issue/view/VOL.%204%20Issue%201>
- Wang, K., & Dovidio, J. F. (2011). Disability and autonomy: Priming alternative identities. *Rehabilitation Psychology*, 56(2), 123–127. doi: 10.1037/a0023039
- Yin, R. K. (2014). *Case study research: Design and methods* (5th ed.). Thousand Oaks, CA: Sage.