

# Exploring the factors that influence the perceptions of disability: a qualitative study of mothers of children with disabilities at a community-based rehabilitation centre in Sri Lanka

Michel D Landry<sup>1,2</sup>, Sudha R Raman<sup>3</sup>, Elise Harris<sup>1</sup>, Layla Madison<sup>1</sup>,  
Meera Parekh<sup>1</sup>, Cecile Banks<sup>1</sup>, Huda Bhatti<sup>1</sup>, Champa Wijesinghe<sup>4</sup>

## ABSTRACT

**Background:** The prevalence of disability is growing worldwide; however, perceptions regarding disability are not well understood. The aim of this study was to explore factors that influence the perception of disability among mothers of children with disabilities who were attending a community-based rehabilitation facility in Sri Lanka.

**Methods:** A descriptive qualitative research design was employed. Thirteen semi-structured interviews were conducted with participants receiving rehabilitation services at a community-based facility. Interviews were recorded, transcribed and coded using software for qualitative data.

**Results:** Three major themes emerged from the analysis: (i) level of family and community support; (ii) spiritual and cultural interpretations of disability; and (iii) outcomes of rehabilitation services. Perceptions of disability appeared to be strongly influenced by the social, community and spiritual/cultural support structure in which the mothers lived. In particular, the support from the participant's spouse emerged as a primary factor exerting strong influence on perception, and future outlook, among the participants. Engagement in community-based rehabilitation programming also reinforced positive perceptions, created a sense of hope among participants regarding their child's future, and established aspirations for future education and employment opportunities alongside social integration.

**Conclusion:** Knowledge of factors that influence the perception of disability can inform future implementation of public-health and community-based initiatives, and may improve social integration of children with disabilities in lower-resource settings.

**Key words:** children, community-based rehabilitation, disability

## BACKGROUND

The concept of “disability”, and what it means to live with a disability, is multifaceted because of the richness of public interpretation and personal meaning. The World Health Organization (WHO) defines disability as “... a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives”.<sup>1</sup> While this operational definition may provide a valuable framework for describing an individual's physical

impairments, activity limitations and participation restrictions as outlined by the International Classification of Functioning, Disability and Health,<sup>2</sup> it may not capture the depth and breadth of the interactions between political, environmental and social barriers that many people with disabilities regularly encounter.<sup>3-5</sup> In 2008, the United Nations Charter on the Rights of Persons with Disabilities (“The Charter”) established a foundation for international public policy regarding the inclusion of people with disabilities in all aspects of social, political, cultural and economic life, as part of their individual

Access this article online

Website: [www.searo.who.int/publications/journals/seajph](http://www.searo.who.int/publications/journals/seajph)

Quick Response Code:



<sup>1</sup>Doctor of Physical Therapy Division, <sup>2</sup>Duke Global Health Institute, Duke University, Durham, North Carolina, United States of America, <sup>3</sup>Duke Clinical Research Institute (DCRI), Duke University, Durham, North Carolina, United States of America, <sup>4</sup>Ruhuna University Hospital, Galle, Sri Lanka

### Address for correspondence:

Dr Michel Landry, Associate Professor and Division Chief, Doctor of Physical Therapy Division, Box 104002, Duke University, Duke University Medical Center, Durham, NC 27708, United States of America  
Email: [mike.landry@duke.edu](mailto:mike.landry@duke.edu)

and collective human rights.<sup>6-8</sup> The Charter recognized that people with disabilities must have equal access to sociopolitical infrastructure compared with members of the population who live without a disability, across the landscape of high-, middle- and low-resource countries. However, linking international public policy such as The Charter with local and community action can be challenging for a variety of reasons, including economic scarcity, societal priorities and public perceptions.<sup>9-11</sup> The Charter is intended to “level the playing field” in the quest for equal human rights for all people, regardless of the level of functional abilities, or the communities or country in which a person lives. Although 160 countries are signatories to The Charter, there remains a large gap in terms of equal opportunities and status for persons around the world who live with a disability.<sup>6</sup>

In 2011, WHO, in conjunction with the World Bank Group, published the first ever *World report on disability*, a compendium of what is known about disability and where significant gaps in knowledge persist.<sup>12</sup> This report described that there are now over one billion people worldwide who live with some form of disability, and that this point estimate represents a 5% increase from the previous decade.<sup>12</sup> Despite the relatively high prevalence, only 2% of the estimated one billion individuals with disabilities have access to features of basic human rights, such as security, education and access to care,<sup>13,14</sup> including 93 million children worldwide between the ages of 0 and 14 years that experience a moderate to severe disability. Children with disabilities (CWDs) are often unable to achieve an independent and productive lifestyle when compared with other children who may not have a disability.<sup>15,16</sup> Hence, the extent to which a person with a disability, and particularly a CWD, can achieve the goals of equal human rights as set out by The Charter may be particular arduous in lower-resource communities, where economic scarcity, food insecurity and poverty often occupy the public policy agenda.

Sri Lanka is categorized as a lower-middle-income country in south Asia, with a gross national income of approximately US\$ 9500 per capita.<sup>17,18</sup> The 2011 Sri Lankan Census declared that 1.7% of the population of about 20 million people had a functional disability.<sup>19</sup> Given that the *World report on disability* estimated that 15% of a population has a disability,<sup>12</sup> the published estimate of less than 2% is likely to be an underestimation of the actual number of people with disabilities in Sri Lanka. In general, Sri Lankan women devote a significant portion of their lives as caregivers for their children,<sup>20,21</sup> by extension, it has been noted that mothers of CWDs are often the primary decision-makers with regard to their CWDs, and hence understanding the perceptions of disability among mothers may have an influence on the health and rehabilitation decisions that are made on behalf of CWDs.<sup>22,23</sup> Although there has been some research regarding the perception of disability among mothers of CWDs in other countries,<sup>22-26</sup> to the authors’ knowledge, there are no studies that have explored the perception of disabilities among Sri Lankan mothers with CWDs. The purpose of this study was thus to explore factors that influence the perception of disability among mothers of CWDs who were receiving services for their children at a community-based rehabilitation facility in Sri Lanka. The aim of the study was to explore the experiences of these mothers,

and not necessarily to yield generalizable knowledge that is directly applicable to other settings. This work was also embedded within an ongoing effort to build local capacity and expertise in qualitative research skills.

## METHODS

A descriptive qualitative design was employed during this research study. Approval for the study was obtained from the research ethics committees of Duke University, Durham, North Carolina, United States of America (USA), and Ruhuna University Hospital, Galle, Sri Lanka. The location of the study was a community-based rehabilitation facility – “the centre” – located in southern Sri Lanka, which offers a large array of services ranging from medical assessments and rehabilitation therapy, to social activities and peer-support networks. This study was based on interviews and, although conducting such interviews in the local language is most appropriate, this was not feasible in this instance. Since this was the first study at this site, investigators complied with the request of the local research partner that interviews should be conducted in English and translated as described below. This followed the approach of a similar study done by Maloni et al. in Bangladesh.<sup>23</sup>

### Identification and recruitment of participants

Convenience sampling was used for this study. Potential participants were included if they (i) had a CWD receiving services at the centre; and (ii) were willing and able to participate in a one-on-one interview during the study time frame. A staff member not involved in patient care recruited mothers who met the inclusion criteria to attend project-information sessions held at the centre. This information session was led by the senior author, and potential participants were informed about the goals of the study and the methods (i.e. that the interviews were to be conducted in English). They were also informed that participation was completely voluntary, that all information would remain confidential, and that they would be free to withdraw at any time without consequence. A total of 13 participants expressed interest in the study and provided their consent to participate, and all completed the study. Owing to the time frame of the study, it focused specifically on the experiences and perceptions of mothers who had already decided to seek rehabilitative care for their CWD. Further exploration of the perceptions of mothers of CWDs not seeking rehabilitative care is an area that requires further investigation.

Qualitative data were collected through semi-structured face-to-face interviews in English, which was then synchronously translated into Sinhalese, the local language of the participants. Participant responses were then translated from Sinhalese back to English. The interviews consisted of open and close-ended questions (see Box 1).

The interviews were conducted by one investigator. The translator was the senior investigator on the study, a paediatrician, and a faculty member at Ruhuna University Hospital, Galle, Sri Lanka. Her interest in the question of perception of disability stems from the point of view of a

### Box 1: Interview schedule

#### Section 1:

**“The first set of questions is about you, your family and your children.”**

1. What is your name?
2. What is your age?
3. How many children do you have?
4. Do you have any other children with disabilities?
5. How far from the centre do you live?
6. How often do you attend the centre with your child?

#### Section 2:

**“The next set of questions is more about your child and their disability.”**

1. How did you find out about your child’s disability?
2. When did you find out that your child had a disability? Who informed you?
3. Do you know the name of the medical term of the disability your child has?
4. How did you feel when you found out that your child had a disability?
5. How has your role changed since [child’s name] has come into your life?
6. How does religion impact how you feel about your child’s disability?
7. What do you believe caused the disability in your child?
8. What does disability mean to you?
9. How does your community view disability?
10. How does your community view your child’s disability?
11. How does the rest of your family view your child’s disability?
12. Do you have support from your family or the community?

#### Section 3:

**“The last set of questions is about the rehabilitation services and your child.”**

1. What made you decide to pursue rehabilitation treatment for your child?
2. How did you hear about the centre?
3. What are the other treatments (medical/non-medical) you have used to treat your child?

local health-care provider actively involved in the day-to-day direct care of patients and families, alongside an interest in the exploration of mechanisms to improve outcomes at the population health level. She was not directly or indirectly involved in the care of any of the children or families who participated in this study. All 13 interviews were conducted during the months of March and April of 2012 at the centre, and all were audio recorded and transcribed verbatim by a second translator, who was an external consultant not involved in this research. All transcribed interviews were then reviewed and matched for accuracy against the audio recording, by

members of the research team. The duration of the interviews ranged from 30 minutes to 55 minutes and, at the request of the community-based facility, no direct incentives were provided for mothers participating in the study, although light snacks and water were available during the interview. It is acknowledged that language, and the process of translation from Sinhalese to English, then back to Sinhalese, presented a challenge during this study. All efforts were made to clarify ambiguities, and, given that the all interviews were conducted by the same research team members, there was a degree of consistency in the process.

The confidentiality of participants was maintained at all times, as required by the ethics review committees at Duke University and Ruhuna University. Confidentiality was maintained in the following ways: (i) only the participant and two researchers were present during the interviews; (ii) each participant was provided a de-identified number and no names were mentioned on any documents or audio recordings; and (iii) only aggregated data were used in final reporting, which includes this paper.

## Data analysis

The transcribed interview data were entered into a software package for qualitative data analysis (NVivo 2.01, Sage Publications Ltd, California, USA), for systematic coding. Consistent with the qualitative content analysis approach, the research team then performed qualitative content analysis using the English translated interviews, in order to identify themes that emerged from collective perceptions and experiences shared by the participants during the key informant interviews.<sup>27,28</sup> Qualitative content analysis has been reported to be useful when the description of phenomena is desired, and has been used in similar research studies.<sup>23-26</sup> Each member of the research team began by reading all of the transcripts independently, and then met regularly to review and discuss each of the interviews. The discussion of the content of the interviews resulted in the development of a large set of overarching concepts, and the research team consolidated and

arranged these concepts into codes. Once all the codes were generated within the interview data, the research team reviewed the codes and discussed any discrepancies and the extent to which the codes were related to each other. Once a set of codes was agreed upon, two members of the researchers coded each of the 13 interviews. Once the coding of the interviews had been performed, two other members of the research team re-coded all of the interviews, and then compared the results of the coding. A few codes were consistently found to be coded differently between the two investigators; however, after discussions among the investigators, there was an agreement and the issue was resolved by merging the codes. Once the coding process was completed, the research team then met and discussed the codes, and decided on the main themes that were related to the guiding research objectives. The identified themes were based on collective perceptions and experiences shared by the participants.

## RESULTS

A total of 13 participants, between the ages 32 and 53 years, participated in this study. Among the participants, six identified their child's specific diagnosis as "Down syndrome", while one reported a general diagnosis of "seizures and tuberculosis". The remaining six participants could not report a specific diagnosis (see Table 1). Given that the purpose of this study was to explore factors influencing the perception of disability,

**Table 1: Participant demographics**

Participant number	Age of mother (years)	Mother's description, definition or diagnosis of disability	Sex of child with disability	Age of child with disability (years)	Total number of children in the family unit
1	53	The child has a lot of problems remembering things, there is no communication	F	9	3
2	33	The child was not walking, was very angry and aggressive	F	6	2
3	39	Seizures, does not write or talk like other people, there's a speech impairment	M	11	3
4	45	Down syndrome	M	2.5	2
5	52	Slow to learn; developmental delay, child's milestones are delayed	M	14	2
6	44	Down syndrome	M	11.5	2
7	n/a	Down syndrome	M	n/a	3
8	50	Intellectual impairment; delay in achieving developmental milestones	M	17	2
9	n/a	Down syndrome	M	14	2
10	39	Down syndrome	M	5	2
11	32	Seizures and tuberculosis	M	1	2
12	39	Child may walk, has a protruding tongue, and will be short in stature according to physician	F	3	1
13	39	Down syndrome	M	2	3

n/a: not available.

and not the perception of a specific diagnosis, the research team did not seek clarification of the ambiguous descriptions of diagnosis. It is acknowledged that there may be variances in mothers' perceptions when a child has differing qualities and abilities but this was not a focus for this study; however, it does represent an area for future essential research.

Based on the analysis from this study, three major themes emerged regarding factors that seem to influence perceptions: (i) level of family and community support; (ii) spiritual and cultural interpretations of disability; and (iii) outcomes of rehabilitation services. Collectively, these three themes appeared to exert strong influence over the participants' perceptions of disability.

### **Theme 1: Level of family and community support**

The level of family and community support received appeared to be an important factor that influenced overall perception. Most of the mothers who participated in this study expressed some level of family support, although the level of support was variable. Mothers who reported both emotional support and logistic help with care for their CWD from their immediate and extended family seemed to perceive disability more positively. In this study, the term "positive" is used to indicate that the participants expressed some level of acceptance of their child's disability and/or felt that it was possible for the child to improve their level of function. This may be an important distinction from a possible biomedical interpretation of "positive", which may suggest that mothers felt that the disability could be cured or resolved. Throughout this study, the use of the term "positive" implies the former.

The participants shared that there was variation regarding the roles that the father played in the life of their CWD. All of the participants were married and living with their spouse at the time of the study, and some mothers stated their spouse was supportive of the child immediately after understanding the extent and implication of a lifelong disability. Other mothers reported that their husbands were initially emotionally distant, but eventually came to love and be supportive of the child. A small minority of the participants, however, indicated that their spouse was completely non-supportive of the child, and that this lack of support had an important and long-lasting negative emotional effect on the mother. In this study, the term "negative" is used to indicate a sense of despair for the future, and limited hopes and aspirations for the child's future. As one mother described:

... I think it's because all his [the father] dreams are shattered that he won't care for the child. He even wanted to destroy the child, even ... and he doesn't like the child to be taken out, he wants the child to be kept in the home .

While only a few participant opinions were reflective of the statement above, the lack of support of a spouse seemed to emerge as insurmountable for the mothers who participated in this study. This finding is in contrast to the alternative scenario, where strong spousal emotional support was described as a tremendously important and positive aspect of overall support of the mother. It appeared that all other factors of family support

were secondary to spousal support for the child in terms of a mother's perception of disability.

A frequently described source of additional emotional pressure for all participants was the influence of the husband's family. There were several instances where participants indicated that their husband's family viewed the CWD as a source of negative stigma for the entire family, to the extent that some wanted to hide the child within their home and community. Although extended family pressure was perceived to exert great anxiety on the participants, one participant suggested that an advocate internal to the family could have great influence over the perceptions of others. For example, one participant described the benefits of having someone within the family to advocate for the child's acceptance, in the following way:

In the beginning, there were the problems from ... the in-laws. They were saying that this is a sin to have a child in the family, having to look at him. So, initially there were negative reactions from ... the in-laws. My family of course, was very supportive because we had an uncle who is an obstetrician ... who explained to the others about the child's condition. They [the in-laws] were then more accepting of the child. But after a while, their attitudes changed [towards being more accepting of the child].

Very few mothers felt the local community was at all supportive of their children. However, among a few mothers, community support served to positively influence the mothers' perceptions of disability. As described by one respondent:

And then, there was a friend of mine... [he] also encouraged me to take the child out, saying that, if the child is exposed to this new experience 10 times, [the child] will learn at least one thing. So, that helped me a lot to bring the child out. Also, the child is now getting on very well with the neighbours, everybody loves [the child] and everybody is very supportive.

It may be important to underscore that the above sentiment was not widespread among the participants, and the majority felt the community maintained that a CWD was overall a "bad omen" that stigmatized the community. Participants also recounted that some community members openly and consistently stated that the CWDs should not be encouraged go to school, play sports, get married, have a family, or even use public transportation. Overall, the participants described varying levels of support for their CWDs from their families and the community; nevertheless, support of immediate family and spouse appeared to influence the perception of disability. Overall, it appears that the perceived support of a spouse, then family, and then community are important; but the support of the husband and father of the child appeared to exert the greatest positive influence on the participants.

### **Theme 2: Spiritual and cultural interpretations of disability**

All of the participants identified themselves as culturally Sinhalese and, like many Sri Lankans living in the south of the country, all were all practising Buddhists. Spiritual and

cultural interpretations of disability, as either the cause of their child's disability or the reason for improvement/worsening in the function of the child, were widespread among the participants. When asked about the cause of their child's disability, most participants suggested that the child was given a disability because of a sin of the child, mother or father in a past lifetime. One mother described a possible reason for her child's disability as being related to the fact that she looked at people with disabilities while she was pregnant. She described this experience in the following way:

I have a brother who has a disabled child. The child has cerebral palsy because the child can't see or move his limbs ... he is just bedridden. So, I didn't know I was pregnant initially so I went to see this child very often. ... So, I think maybe that would have had a bad effect on my pregnancy .

In addition to viewing spiritual and cultural underpinnings as a causal factor in acquiring a disability, the majority of the mothers also relied on religious (or in the specific case of all the mothers in this study, Buddhist) practices, such as prayer, as treatment for the child. One mother stated:

We go to the temple and make him listen to the Buddhist chanting called Puja, which is supposed to be a kind of blessing for the child.... So, I let the child listen to those things. And the other thing, I have tried some traditional methods, also, like making the child wear a protecting charm, an amulet, something like that ...

A few participants also reported that religious practices were important ways that the mother used to cope with the fact that their child was born with a disability, providing them with spiritual hope for the future and allowing them to better manage their child's disability. Given that spirituality and religion were described as both a cause and a potential treatment of disability, it may be important to note that participants in this study also appeared to ascribe equal importance to both medical rehabilitation treatments and spiritual and religious practices. Half of the participants either explicitly or implicitly vocalized this duality and the tension between a fatalistic perspective of disability being controlled by a higher power and wanting the child to receive rehabilitation to actively improve their abilities. The following discussion illustrates this point:

It's mental, the planetary things. My belief in those things, it soothes me I think, knowing that the Saturn will return ... I have that in my mind but I am still willing to continue with the therapy .

Overall, spirituality and culture appeared to play an important role in the lives of the mothers and the children. The roles of spirituality/religion alongside rehabilitation services, were perceived to be important factors that affected their perception of disability, albeit from different viewpoints.

### Theme 3: Outcomes of rehabilitation services

Access to and outcomes of rehabilitation services was a third theme that participants reported generated positive perception of their CWDs. The participants who witnessed tangible

improvements in their child's physical functional level during or after rehabilitation also expressed more positive perspectives regarding their child. Some of the participants reported a positive effect on their emotional status when they could see or witness improvements in their child with rehabilitation, even when these improvements were short lasting.

Witnessing the tangible outcomes of rehabilitation was placed in very high regard, because participants frequently reported that rehabilitation services eased their worries about their child's disability. After receiving services and becoming familiar with rehabilitation, some participants felt "less worried" and "they realized that physiotherapy helps a lot to improve the child's condition". For instance, as recounted by one participant:

Initially, the child couldn't do anything but now the child can walk after physiotherapy. But he had this speech impairment, so after that he was brought to XXX and after the speech therapy, even the speech got better .

Another commonly reported aspect was the notion that continued access to services would lead to more improvements in the future. As one mother stated:

The physiotherapist, he is like God to me because he allowed the child to do so many things. He taught me how I can help the child to sit. So, now the child is doing it on his own. So, I am sure that he will be able to walk and that's what I want to see, as soon as possible, to see the child walking .

Participants described feeling much less scared when they witness functional improvement, and were seemingly more able to cope with their child's disability. One participant suggested that having exposure to informal peer-support networks obtained through rehabilitation was an important factor for her and her family. She recounts:

I was initially scared because I was scared that the child wouldn't become normal again. But then, when I saw that there are other children with the same disabilities in the hospital, I was less worried. And then, afterwards, I got to know about physiotherapy. And [when] the child was put in the physiotherapy room, I felt that the child could be developed. She [the physiotherapist] showed some improvement in development in the child. So, I [was] less worried [about my child ] .

When participants had more positive levels of perceptions, they also seemed more likely to contextualize goals for their children in concepts such as accessing education and obtaining sustainable employment. A consistent concern was the emotional and economic well-being of the child beyond the parents' lifespan; as such, participants described economic self-sufficiency and employment as critical to securing a stable future. For instance, as one participants put it:

I expect the child to stand on his own two feet, to be independent, to learn some craft, because even though there is a sister, we cannot be sure ... whether the sister will look after him or not. So, I want him to be independent, to learn some craft so that he can make his own living ... and maybe attending this centre can help ...

Another common hope for mothers was that their children would one day become “normal”. The meaning of “normal” varied significantly among the participants, from being able to write and walk, to securing gainful employment. This move towards so-called normality was not, however, to suggest that the CWD would be cured of their condition or disability, but rather that he or she would be able to perform the roles and responsibilities as a member of society in their unique fashion. A conflicting view was identified when asked if marriage was a possibility for their child in the future. Several mothers dismissed the idea as highly unlikely, and only one mother discussed the possibility of marriage between her child and another child with disability:

When I took him [her child with disability] to a function [social event], there was another organization that provides similar services like this, and she [another child with disability] is going there also. I met another person who told me that a person known to him, a Down’s person, married another Down’s person. So, in future, sometimes there is the possibility, but I am not very hopeful ... we can’t say about the future, this moment .

Mothers with more positive perspectives on disability also expressed hope for acceptance and integration of their CWD in society, with equal opportunities in the areas of education and employment based on their capabilities. Mothers believed that creating such opportunities would not only benefit their children, but also serve as a message that those with disabilities have a right to a place within society. As expressed by one mother:

The change should start from the schools, they have to show the others [children without disabilities] that these children [CWDs] are part of the society and they feel and sometimes they think like others. So, they should not be discriminated, they should give equal opportunities like other children, to make the other children understand that they are also part of the society. So, it starts from the schools, it will go and catch on. Society should change their attitudes and the people in the immediate surrounding should also make them aware. And after a few generations, generations change, sometimes the attitude might be changed .

## DISCUSSION

This investigation sought to explore factors that influence the perception of disability among mothers of CWDs already receiving care in a community-based facility. This study has reported that the family, community, spirituality/culture and outcomes of rehabilitation can exert a positive influence on perception, and it has highlighted that the influence of the spouse is a particularly important factor. Some participants regularly faced an internal struggle when family members, especially their husbands and extended family, had a negative view towards their CWD. However, when their spouse, members of their family and community demonstrated support of the CWD, there seemed to be a more positive perception by the mother towards the child, and a greater likelihood of contextualization of goals well beyond impairments, and into maximizing social integration for their CWD.

In practical terms, it may be important to examine and understand the degree to which any one influencing factor might be most important to an individual mother, or even to a community of mothers, at any given moment. Given the study design, while it was not possible to determine that there was a critical time order or sequence of when one influencing factor might be more important than another across the life-course trajectory of a CWD, it stands to reason that there may be moments when particular factors are more important than others. We propose, for instance, that the influence of spousal support might peak at the time when a diagnosis or determination of a disability is made, and that, over time, the family and community support factors might then take their turn as primary factors. Although further research is warranted, assuming positive influence on perception is desirable, it might be important therefore to consider the timeline of events, or life-course of the child. We postulate that when an influencing factor is not present at the right time and place, a mother might seek support elsewhere, and this may be where access to a medical, social, rehabilitative or public-health infrastructure becomes a critical substructure to replacing the support that would be preferably obtained elsewhere. It may be reasonable to also ask whether a community-based rehabilitation centre can effectively act as a temporary proxy for family and community support.

Moreover, given that this study has highlighted that spousal support emerged as a primary influencing factor, it is interesting to consider whether community-based facilities that influence perceptions by creating specific and targeted awareness programmes, or peer-support networks, to more fully engage the fathers of CWDs early in the process, would affect the perceptions of the mothers and ultimate societal integration for their CWDs. Raman et al.,<sup>24</sup> Daudji et al.,<sup>25</sup> and Ahmed et al.<sup>29</sup> have suggested it is important for health-care providers to educate both the family and community about CWDs and to organize social support for these children; and Parker et al.<sup>30</sup> and Juneja et al.<sup>31</sup> have also suggested that the family unit exerts strong influence and control over health-seeking behaviours. However, given the present findings, it may be that a missing link in the advocacy strategy is education and support for the father, who, in turn, might exert an influence on overall perception in a setting like rural Sri Lanka. Although the present data do not allow these questions to be answered with any certainty, this represents a next step in our research process.

## Limitations

This study set out to explore the perceptions of disability among mothers of CWDs in Sri Lanka. There were limitations to the study; firstly, the sample of participants included in the study were those individuals who were already accessing care at a community-based rehabilitation facility, and they may have already been generally supportive of the rehabilitation process. Secondly, the interview was conducted in English, which was then translated to Sinhalese, and participant answers were initially in Sinhalese, and then translated to English. There are always challenges in interpreting meaning and intentions during multiple translations, but to the extent possible, this

was minimized through asking for clarifications when required during the interviews, in order to understand the meaning of what was said by the participant. At times, this required the participant to re-state their commentary, and at other times it meant that the translator re-stated their interpretation of what the participants said when it was not clear to the researchers.

## Conclusion

Several complex and interrelated factors appear to contribute to perceptions of disability. When participants seemed to have perceived high levels of support (especially from their spouse), they also seemed to have greater positive perspectives or perceptions regarding disability, which, as reported in this study, leads to goal-setting beyond physical improvement and into areas such as social integration and education. This study may provide perspectives regarding the necessity to implement rehabilitation programmes that are inclusive of broad and multidimensional strategies that not only facilitate physical rehabilitation, but also incorporate the family and community. Given the findings of this study, such programming could lead to improved functional outcomes, but, equally notably, to outcomes related to achieving improved independence and social participation in the community. Knowledge of factors that influence the perception of disability can inform future implementation of public-health and community-based initiatives, and may improve social integration of CWDs in lower-resource settings. Overall, these findings underscore the importance of creating patient- and family-oriented, community-based, and participatory approaches to health and rehabilitation services, as part of a process to facilitate the laudable goals of equal human rights as set out by the United Nations Charter on the Right of Persons with Disabilities.<sup>6</sup>

## REFERENCES

- World Health Organization. Health topics: disabilities (<http://www.who.int/topics/disabilities/en/>, accessed 2 November 2015).
- World Health Organization. International Classification of Functioning, Disability and Health (ICF) (<http://www.who.int/classifications/icf/en/>, accessed 2 November 2015).
- Parnes P, Cameron D, Christie N, Cockburn L, Hashemi G, Yoshida K. Disability in low-income countries: issues and implications. *Disabil Rehabil.* 2009;31(14):1170–80.
- Ullenhag A, Krumlinde-Sundholm L, Granlund M, Almqvist L. Differences in patterns of participation in leisure activities in Swedish children with and without disabilities. *Disabil Rehabil.* 2014;36(6):464–71. doi:10.3109/09638288.2013.798360.
- Chacala A, McCormack C, Collins B, Beagan BL. “My view that disability is okay sometimes clashes”: experiences of two disabled occupational therapists. *Scand J Occup Ther.* 2014; 21(2):107–15. doi:10.3109/11038128.2013.861016.
- United Nations. Convention on the Rights of Persons with Disabilities (CRPD) (<http://www.un.org/disabilities/convention/conventionfull.shtml>, accessed 2 November 2015).
- Kelly BD. An end of psychiatric detention? Implication of the United Nation’s Convention on the Rights of Persons with Disabilities. *Br J Psychiatry.* 2014;204(3):174–5. doi:10.1192/bjp.bp.113.135475.
- Fyson R, Cromby J. Human rights and intellectual disabilities in an era of ‘choice’. *J Intellect Disabil Res.* 2013;57(12):1164–72. doi:10.1111/j.1365-2788.2012.01641.x.
- Toldra RC, Santos MC. People with disabilities in the labor market: facilitators and barriers. *Work.* 2013;45(4):553–63. doi:10.3233/WOR-131641.
- Schiappacasse C, Longoni M, Paleo MA, Vitale M. Reflecting on the World Report on Disability: a short report from Argentina. *Am J Phys Med Rehabil.* 2014;93(1Suppl. 1): S39–41. doi:10.1097/PHM.000000000000020.
- Kleintjes S, Lund C, Swartz L. Barriers to the participation of people with psychological disabilities in mental health policy development in South Africa: a qualitative study of perspectives of policy makers, professionals, religious leaders and academics. *BMC Int Health Hum Rights.* 2013;13:17. doi:10.1186/1472-698X-13-17.
- World report on disability. Geneva: World Health Organization; 2011 ([http://www.who.int/disabilities/world\\_report/2011/en/](http://www.who.int/disabilities/world_report/2011/en/), accessed 2 November 2015).
- World Health Organization. Global burden of disease ([http://www.who.int/topics/global\\_burden\\_of\\_disease/en/](http://www.who.int/topics/global_burden_of_disease/en/), accessed 2 November 2015).
- United Nations. Protect human rights (<http://www.un.org/en/rights/>, accessed 2 November 2015).
- Hinojosa J, Anderson J. Mothers’ perceptions of home treatment programs for their preschool children with cerebral palsy. *Am J Occup Ther.* 1991;45(3):273–9.
- McConkey R, Mariga L, Braadland N, Mphole P. Parents as trainers about disability in low income countries. *Int J Disabil Dev Educ.* 2000;47:311–17.
- The World Bank. Newest country classifications released (<http://data.worldbank.org/news/newest-country-classifications-released>, accessed 2 November 2015).
- The World Bank. GNI per capita, PPP (current international \$) (<http://data.worldbank.org/indicator/NY.GNP.PCAP.PP.CD>, accessed 2 November 2015).
- Sri Lanka Department of Census and Statistics. Population and housing (<http://www.statistics.gov.lk/page.asp?page=Population%20and%20Housing>, accessed 2 November 2015).
- Russell S, Gilson L. Are health services protecting the livelihoods of the urban poor in Sri Lanka: findings from two low-income areas of Colombo. *Soc Sci Med.* 2006;63(7):1732–1744.
- Attanapola CT. Changing gender roles and health impacts among female workers in export-processing industries in Sri Lanka. *Soc Sci Med.* 2004;58(11):2301–12.
- Dansec ER. Parental beliefs on childhood disability: insights on culture, child development, and intervention. *Int J Disabil Dev Educ.* 1997;44:41–52. doi:10.1080/0156655970440104
- Maloni PK, Despres ER, Habbous J, Primmer AR, Slatten JB, Gibson BE et al. Perceptions of disability among mothers of children with disability in Bangladesh: implications for rehabilitation service delivery. *Disabil Rehabil.* 2010;32(10):845–54. doi:10.3109/09638280903326063.
- Raman SR, Mandoda S, Hussain LK, Foley N, Hamdan E, Landry M. Exploring the meaning of childhood disability: perceptions of disability among mothers of children with disabilities (CWD) in Kuwait. *World Health Popul.* 2010;11(4):49–60.
- Daudji A, Eby S, Foo T, Ladak F, Sinclair C, Landry MD et al. Perceptions of disability among south Asian immigrant mothers of children with disabilities in Canada: implications for rehabilitation service delivery. *Disabil Rehabil.* 2010;33(6):511–21. doi:10.3109/09638288.2010.498549.
- Simkhada, PP, Shyangdan D, van Teijlingen ER, Kadel S, Stephen J, Gurung T. Women’s knowledge of and attitude towards disability in rural Nepal. *Disabil Rehabil.* 2013;35(7):606–13. doi:10.3109/09638288.2012.702847.
- Pope C, Ziebland S, Mays N. Qualitative research in health care: analysing qualitative data. *BMJ.* 2000;320:114–16.

28. Weber RP. Basic content analysis, 2nd ed. New Park: Sage Publications; 1990.
29. Ahmed S, Bryant LD, Ahmed M, Jafri H, Raashid Y. Experiences of parents with a child with Down syndrome in Pakistan and their views on termination of pregnancy. *J Commun Genet.* 2013;4(1):107–14. doi:10.1007/s12687-012-0124-y.
30. Parker JA, Mandleco B, Olsen Roper S, Freeborn D, Dyches TT. Religiosity, spirituality, and marital relationships of parents raising a typically developing child or a child with a disability. *J Fam Nurs.* 2011;17(1):82–104. doi:10.1177/1074840710394856.
31. Juneja M, Jain R, Singhal S, Mishra D. Availing services for developmental disabilities: parental experiences from a referral center in developing country. *Indian J Pediatr.* 2012;79(9):1213–17. doi:10.1007/s12098-011-0653-0.

**How to cite this article:** Landry MD, Raman SR, Harris E, Madison L, Parekh M, Banks C, Bhatti H, Wijesinghe C. Exploring the factors that influence the perceptions of disability: a qualitative study of mothers of children with disabilities at a community-based rehabilitation centre in Sri Lanka. *WHO South-East Asia J Public Health* 2015; 4(2): 150–158.

**Source of Support:** Nil. **Conflict of Interest:** None declared. **Contributorship:** MDL, SRR and CW conceived the study and participated in the design and coordination, as well as drafting the manuscript drafts. SRR, EH, LM, CB and HB participated in drafting the introduction and discussion components of the manuscript. MDL, EH, LM, MP, CB and HB performed all analyses and wrote the methods and results. All authors (MDL, SRR, EH, LM, MP, CB, HB, CW) read and approved the final manuscript.