"It's as if I'm the one suffering": Narratives of Parents of Children with Disability in the Philippines

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ABSTRACT

Background. Children comprise a significant proportion of persons with disabilities (PWDs) in the Philippines, and represent a major public health challenge. One under-explored topic is the "lived experiences" of their parents and guardians as well as the roles they play in caring for their children. This qualitative study responds to this research gap by eliciting and foregrounding their experiences and narratives.

Methods. Six focus group discussions (FGDs) were conducted among parents of children with disabilities (CWDs) in Davao City and Tagum City. These were complemented by 12 key informant interviews among healthcare providers in both cities.

Results. For many parents, coming to terms with a disability is a difficult and lengthy process, but one that ends with a measure of relief and eventual adaptation. Living with disability, meanwhile, is fraught with medical, financial, educational, and social challenges. A positive religious outlook allows them to make sense of disability, helping them to overcome these challenges. Support groups and the health care system are likewise crucial factors towards family resilience.

Conclusion. Our findings show that the experience of disability is shared among family members, particularly, the parents of CWDs; thus, underscoring the need for a family-centered approach in policies, clinical care, and communications efforts involving children with disability in the Philippines.

Key Words: disability, children with disability, family medicine, Philippines

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INTRODUCTION

The care and quality of life of children with disabilities (CWDs) are relevant challenges for the public health sector in the Philippines, but despite growing attention and scholarship, little is known about the experience of caring for them, particularly from the perspectives of their primary caregivers. Notwithstanding the clear intersubjectivity of disability, the lived experiences of those who are intimately involved in it have been largely overlooked in the scholarly literature, as well as in policy discourses in the country.

This paper aims to contribute to addressing this gap by foregrounding the experiences and narratives of parents and guardians of CWDs through a qualitative study conducted in two cities in Southern Mindanao. *How do the parents and guardians make sense of disability? How did they cope with their children's disabilities, from diagnosis to rehabilitation?*

What are the challenges they face in each step, and what factors can contribute towards building their family 'resilience'?

The importance of this exercise is underscored by the fact that plenty of parents in the country are faced with the challenge of taking care of CWDs. Estimates place that the number of Filipino children living with disabilities is at 5.1 million, and government statistics that indicate that 18.9% of all persons with disabilities (PWDs) were aged 0–14 years.[1,2] While the burden of disability is distributed across social classes, CWDs from poor families tend to have limited access to appropriate health programs and basic education, compared to their more affluent counterparts.[3] Significantly, 6.77% of low-income households are estimated to have PWDs, further indicating a high burden among the poor.[4] Moreover, while the Philippine government has programs for PWDs, there has not been a specific focus on children.[2] The country has also passed many relevant laws for the care of PWDs and CWDs, as well as committed to international conventions and frameworks that recognize their rights.[5] These figures and realities underscore the need to understand CWDs in the country, the challenges they face, and crucially for this study, the people with whom they face these challenges with.

REVIEW OF LITERATURE

Globally, scholarship on CWDs has been informed by the recognition that beyond "overmedicalized and individualist accounts of disability", due attention must also be placed on "social oppression, cultural discourse, and environmental barriers" that structure PWDs' experience.[6] Many of these researches focus on particular types of disability—visual impairment, auditory impairment, mobility, and intellectual (or neuro-developmental) disability. Based on a study by Wong that estimated the prevalence of disabilities based on these four domains for children aged 18 years and below, around 0.18% (75,000) have some form of visual impairment (VI), 3.69% (1.5 million) have some form of hearing impairment (HI), 0.31% (130,000) have some form of mobility impairment, and 3.74% (1.5 million) have some form of neuro-developmental impairment.[4]

Meanwhile, in the Philippines, studies on CWDs have focused on their inclusion in education programs, and there has been a proliferation of more diverse researches in recent years, accompanying policies and programs that recognize the significance of disability in the country.[2,7,8] Some of these studies have looked at school participation, health services and practices and the role of physical activity.[7–12]

Recently, there have also been a few papers that look into the parents of CWDs, but they are either narrowly focused on intellectual disabilities, or draw from a limited data set.[13–17] This paper, by covering the four above-mentioned domains of disability and involving two different sites, aims to contribute to this body of work that privilege caregiver perspectives. Given that parents are the main carers of CWDs and that they themselves are subjected to the various burdens of disability, this study can guide relevant policies and efforts to improve the health and well-being of many Filipino families, while adding geographic scope to qualitative studies that focus on parents of CWDs.

METHODOLOGY

Focus group discussions (FGDs) and key informant interviews (KIIs) were conducted in Davao City and Tagum City, Davao del Norte in July 2016. FGDs were conducted with 6 cohorts of parents and guardians of CWDs belonging to low to middle income households, identified and invited to participate in the study with the help of disability organizations in Davao City, as well as the city health office in Tagum City. KIIs were conducted with 12 healthcare professionals, particularly physicians practicing in various specializations relevant to the four disability types of focus: 7 in Davao City and 5 in Tagum City. Written informed consent was obtained for all respondents. FGDs and interviews took around 75 and 30 minutes, respectively (Table 1).

All participants were oriented about the nature of the study and its intended purpose prior to the start of the KII or FGD. A standard set of open-ended questions was administered for all study participants (Appendix A). Audio recordings of the FGDs and KIIs were transcribed verbatim and translated into English when applicable (the conversations were a mix of English, Cebuano, and Tagalog). Transcripts were then uploaded into an NVivo 10 (QSR) database for open coding and virtual pile sorting individually performed by four researchers. A group meeting was then held to arrive at the final themes by consensus.

The study was approved by the research ethics board of Southern Philippines Medical Center in Davao City.

FINDINGS

The themes that emerged from our FGDs can be organized in three interrelated domains that follow the life course of the children's disabilities, though not in a linear

Table 1. List of study participants

	Davao City	Tagum City
Parents	3 FGDs, 20 participants	3 FGDs, 11 participants
Key informants	7 interviews Southern Philippines Medical Center	5 interviews Davao Regional Medical Center and City Health Office
Total participants	27	16

way. Firstly, *coming to terms with disability*, that is, how the parents discovered the disability of their children and the challenges they faced through this process. Secondly, *living with disability*, or the lived experiences of disability as narrated by the parents. Finally, *making sense of disability*—that is, the explanatory models and other cognitive frameworks with which parents think of their children's conditions.

Part I: Coming to terms with disability

Coming to terms with disability was a two-fold, interrelated process: one that is physical and medical (e.g., detecting signs of disability going through the healthcare sector, and receiving diagnosis), and another that is mental and emotional (e.g., accepting and coping with the diagnosis).

The recognition of disability depended on the nature and particular manifestation of a child's condition. In some cases, as in cases of premature birth, the recognition was immediate; in others, as in many intellectual and hearing disabilities, it was delayed. Many factors, often inter-lapping in a single narrative, can be identified in this delay in recognizing disability and acknowledging its existence.

Some parents failed to recognize disability because they did not know what normal development meant to begin with. For instance, Jane (28 years old, mother of a girl with hearing impairment) attributes her daughter's disability to a normal delay in development:

> *Yes, she can't hear. If you call her, she won't pay attention; but, if you poke her, she'll turn to you. So when she reached two years old, we decided to bring her to the doctor.*

Others, while feeling that something might be wrong, did not entertain the thought of disability because of its grave implications in what we can consider a form of denial. Lara (51 years old, mother of a child with attention-deficit and hyperactivity disorder or ADHD) narrates:

> *…I didn't think that my eldest son has a problem. But my father urged me and told me that we have nothing to lose if we consult a doctor; so, I said okay, and we tried… I denied the thought and said to myself that maybe the doctor was just exaggerating so I told him, "Doc, perhaps you are just exaggerating." Although the signs were positive, it hurts to accept even just the thought of it. But the doctor said, "I didn't say that your child has ADHD, but you have to visit and have a serious talk with your Pediatrician; she may refer something or someone to you."*

There are also financial considerations that kept from a medical consult. The account of Rommel (44 years old, father of child with intellectual disability) demonstrates how this consideration overlaps with the two others we discussed above:

> *When my wife gave birth to our daughter, the midwife immediately informed us that our daughter shows signs of abnormality. But we just observed her behavior while growing up, and we were in denial about her condition and thought that she's only developing late. Then we decided to send her to school, and they required us to have a medical check-up. We didn't have her checked up right away because it was expensive and we didn't have enough money during that time. When we finally had her checked, that's how we knew about her condition and disability.*

Other accounts are interspersed with explanatory models of disability. Angie (50 years old, mother of a child with autism) for instance, associated the onset of her son's condition with a vaccination:

> *At that time, my child was still adjusting to the weather in England. When my son got his MMR injection, that's when I noticed that he doesn't have eye contact; it felt like he lost his senses. So I got concerned and asked the doctor about it. After six months of going through the assessment, he was diagnosed with an autism spectrum disorder. Of course, I was in denial at first. I can't accept the fact that the only child I have has autism spectrum disorder.*

As doctors are relied upon to provide a diagnosis, the doctor-patient relationship figures in these accounts. Some parents, like Yolanda (57 years old, mother of a boy with Down syndrome), blame doctors for not detecting the disability early:

> *The doctor didn't tell me that my son has Down syndrome when I gave birth to him. After a month, I went back to the hospital and a doctor approached me and asked if I know about my child's condition.*

On the other hand, there are times when the doctors were quick to diagnose, but the parents themselves were reluctant to accept their advice. Many of them revealed that they sought the opinion of alternative or traditional medicine practitioners:

> *I thought duendes (dwarves) were inside our house so I consulted an albularyo (folk healer). I even offered a white chicken as what the albularyo told us to do to get rid of the duendes. (Betty, 47 years old, mother of a child with autism)*
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> *And when she cries, other people will say that we should do toob (traditional belief, usually done by burning dried leaves to please the spirits, to cast away the bad ones, and to heal sickness or the curse of buyag). But after that, we never visited a quack doctor again. (Gina, 46 years old, mother of a child with cerebral palsy)*

Eventually, most of the parents accepted the medical diagnosis, accompanied by initial feelings of denial and pain:

> *I told myself that maybe the doctor was just exaggerating. So I told him, "Doc, you are exaggerating." Although the signs were positive, it really hurts to accept the thought that my child has disability. (Betty, 47 years old, mother of a child with autism)*

Despite these sentiments, the parents also share an eventual sense of "relief" or "feeling better" when accepting the final diagnosis, as these accounts reveal:

> *When we finally knew that he has autism, we felt relief compared to before when we didn't have any idea about his condition. We even thought that he was just a late bloomer, and that eventually, he'd be able to speak, reasoning that we believed to justify his behavior. So now that we know about his autism, we can focus on taking care of his needs. Number one, we looked at institutions that will cater to the needs of my son here in Davao City. The bottom line is it felt a lot better when we knew about his autism; at least now, we are aware how to address it. (Ron, 54 years old, father of child with autism)*

In many ways, their trajectories resonate with the 'stages of disability' that have been proposed by various scholars.[15] While their specific trajectories vary, what many of the accounts have in common is a point where disability is acknowledged, and the parents' focus shifts to how they can cope with the disability in their everyday lives. Ultimately, the certainty of disability brings relief and eventual adaptation, which includes having a worldview that allows them to make sense of their children's conditions.

Part II: Living with their children's disability

Our informants come from diverse backgrounds: teachers, clerks, tricycle drivers, families with OFWs, but they are united in saying that past the initial phase of diagnosis and acceptance, their children's disabilities were life-changing in the sense that it required major adjustments in their lives and careers.

Financial challenges

The first of these adjustments has to do with the toll of disability on the family's financial and human resources. Raul (50 years old, father of a child with autism) spoke of leaving his job entirely:

> *…I quit my job, and I joined therapy training to learn about handling children with autism; and then, I applied what I learned from that to my kids. Our house looks like a daycare center right now.*

Others, instead of quitting jobs, are forced to take more jobs in order to cover the costs of therapy. May (38 years old, mother of a girl with HI) says that their child's disability actually marked the turnaround of their fortunes; the business they set up has grown bigger:

> *In our case, he had to stop driving because the income that he got was never enough especially since there are lots of competitors nowadays, like single motorcycles. That's why we decided to work together as agents in the company. Sad to say, we got really busy most of the time and barely had time for her. But it's okay, it doesn't matter now as long as we can buy everything she asks us.*

Medical challenges

The second adjustment is a normalization of therapies and medical consults as part of their everyday lives. Parents find themselves having to navigate and negotiate with the healthcare system, in ways that are inexorable with the disability's financial burden. Paul (41 years old, father of a girl with HI), laments:

> *So, meaning the child is being deprived of his rights to access health services of the government. Not everyone can afford, not everyone is like the children from the private that can pay the developmental doctors for assessment. Others are poor who cannot afford. How about them? How can they access the programs of the government?*

Decision-making based on the parents' treatment and life goals for their children is engaged in this area, as Alex (52 years old, parent of a child with VI) says:

> *We don't want our child to undergo an operation for it might kill her…She still has her eyesight, which is better. Such action will just make her condition worse; she might even lose her sight!"*

Although the medical challenges are mainly financial, there are also logistical and informational challenges, especially among our interlocutors from Tagum City. As Paul (41 years old, father of a girl with HI) explains:

> *How can they pay if the city is too far from them, aside from it's already hard to look for the money to pay? Also, those who don't know about this service, how will they be able to avail of the services?*

The parents acknowledge the helpfulness of benefits like having a PWD card that gives their children discounts, and certain procedures and tests where CWDs receive discounts or waived fees. However, in relation to these benefits, some parents lament that the government considers the chronological, not the "mental age" of their children in determining eligibility for certain benefits (e.g., waived examination charges), despite the fact that they would have to treat them as such beyond their 18th year.

Educational challenges

For many parents, a CWD's ability to go to school or have some form of education means a lot, as it signifies a form of triumph over disability. However, the act of sending the child to school poses social, economic, and emotional challenges. Ron, 54-years-old father of a child with autism, for instance, takes issue at the teachers' inability to appropriately deal with his son:

> *I feel like we should not intervene with teachers because they're licensed, and maybe they'd feel offended. So, it's better if you let them decide. But of course, if I notice that the rights of my child are neglected, I will defend him and speak up.*

Lara (51 years old, mother of child with autism), for her part recounts an incident in which her son's teacher nearly compromised his health by feeding him something with gluten. Due to this incident, Lara removed his son from the school:

> *Now, the lecturing is home-based. So, everything that I got from my son's previous therapy sessions or even online lectures, I do it to him at home. For the past years, I can see that he has developments.*

For many forms of disability, education also means specialized therapies, which form part of the financial toll of disability. On top of the cost of schooling per se, which is also relatively expensive, these therapies contribute to further making education one of the biggest challenges for parents.

Social challenges

Another strong theme that emerged in the everyday lives of the families is stigma and discrimination, which is closely related to the educational challenges articulated above for children who go to school. Jane (38 years old, mother of a child with hearing impairment) recounts:

> *We can't remove the fact that there will always be some kids who bully her. It is hard for us, but I always tell her not to pay attention to those kinds of kids who focus on another person's disability rather than their attitude…Sometimes they'd shout at my kids because they know that my daughter can't hear them: "Amang! amang!" (local term for mute, often derogatory). Of course, as a parent, I feel sorry for my daughter. It's as if I'm the one suffering.*

For his part, Rachel (38 years old, mother of a child with congenitally-amputated limbs), references the term *'pungkol,'* which *"hurts her"* whenever she hears it said to her son. Articulating the emotions of most of the parents we interviewed, Alex (52 years old, father of a child with visual impairment) shares his frustration:

> *I got used to it. I'm just very particular about verbally hearing things or being told stuff. Stop telling me that my children are blind because I already know. Stop emphasizing things. I don't care if you look at my kid so bad or small, but never let me hear the words inside your mind because I would answer you or get mad at you. My children are visually impaired, but stop rubbing it in our faces.*

The heavy emotional toll on the parents can be accounted for not just by their feeling sorry for their children, but by the stigmatization for bearing a child with disability that they themselves experience. *"They think we are to blame. They think we must have done something wrong,"* Sara (50 years old, mother of a child with HI) explains. Indirectly, the notion that disability is *"infectious"* also points to an insinuation of parental responsibility, which makes it particularly disconcerting for parents. Of course, it also leads to their ostracism, as Lara (51 years old, mother of a child with ADHD) explains:

> *They are afraid because they think that they might get infected…They believe that they should stay away from children with intellectual disabilities because they tend to be violent.*

On the one hand, some parents try to explain to their child to understand other people despite the bullying and discrimination. One of the concerns of the parents is to instill good attitude to their children despite the difficulties they encounter in their environment.

Ron (54 years old, father of a child with autism), for instance, spoke of orienting neighbors and schoolmates alike, leading to more pleasant environment for his son:

> *When my child got transferred to mainstream classes, I asked permission from their teacher to spare some time for me to orient my child's classmates. I spent an hour explaining to them about autism, and their behaviors and how can they support him, how can they help. After that, his classmates were supportive of him and when other classes bully him, his classmates defend him and explained to them about his situation. It's important that they know.*

Although Ron is an exception among our interlocutors, his account opens the possibility for neighborhoods to be safe spaces with proper orientation.

Beyond the family: the role of support groups

Amid all the above challenges, support groups that build communities among parents of CWDs seem to make a big difference. While parents in Tagum City lamented that they had no one to turn to, those in Davao City frequently cited their belonging to organizations like the Davao Autism Society and the Parent Advocates for Visually Impaired Children (PAVIC). Alex (52 years old, parent of a child with visual impairment) shares:

> *It's a good thing that there's PAVIC; you have people who can relate to what you're going through. The other parents who have children with VI, they're like family to us.*

On the side of health care providers, Ron (30 years old, medical resident in a hospital in Davao City) acknowledged that hospitals lack the staff to cater to the needs of CWDs, and parent-volunteers from disability organizations help them in implementing programs by reaching out to parents.

Making sense of disability

Alongside the process of coping and living with disability, parents also try to make sense of it, and their conceptions of disability are worth documenting as they can offer clues as to which messages can find resonances among other parents of CWDs.

Much of the parents' explanations about the origin and purpose of their children's disabilities are couched in religious or spiritual terms. Lara (51 years old, mother of a child with ADHD) recalls asking of God: *"Am I that big of a sinner, for you to give me this kind of child?"*, following the same explanatory model of guilt and shame that informs outsiders' stigma. But most of the time, the parents' discourses conclude on a positive note, as can be gleaned from these statements:

> *I sometimes wish it happened to other children and not to my precious daughter. But then I realized it's God's blessing and it's part of his plan. (Jenny, 45 years old, mother of a girl with autism)*
>
> *That's why I prayed to God, "Lord thank you for giving me such a sweet child." Because there are a lot of healthy kids out there, but they're not kind to their parents, they don't appreciate simple things and efforts. At her age, most of the children will roam around, but she just stays at home; so somehow, I feel relieved and happy, but I would like to send her to school. (Raul, 50 years old, father of a child with autism)*

Notions of *"karma"* and other non-Christian principles also inform these discourses. Lara, for instance, speaks of the Visayan notion of *"tunglo,"* which approximates *"curse due to past misdeeds,"* She laments,

> *"Some of our neighbors suspect that I got tunglo which means I must have done something wrong in the past, specifically to my parents, and so my children paid for what I have done that resulted in their disability."*

When voiced by outsiders, these discourses are offensive, as we discussed in the earlier section about stigma and discrimination. Rey (45 years old, father of a girl with visual impairment), for instance, recalls:

> *[They say] maybe karma went back to you that's why your child got blind. It sounds awful. But other people comfort me instead of being rude.*

Overall, however, parents voice a largely positive outlook drawing from a Christian perspective. Indeed, many of the parents speak of their children as a gift and a blessing, not as a burden or curse. Ultimately, these connections of disability may allow them to overcome negative feelings such as guilt or experiences such as stigma and discrimination.

DISCUSSION

The heavy burden of disability is very clear from the parents' narratives: a burden that is not just financial and physical (i.e., the need to attend to the CWDs' needs), but also emotional and mental, in light of the stigma and discrimination that parents face alongside the children. Arguably, and as corroborated by previous scholarship, the experience of disability is first borne by the parents; only after awareness of disability and (perceived) difference, and interactions with peers do the children themselves share in this experience.[18]

Disability studies scholars underscore the role of resilience which Heiman (2002:160) defined as "successful adjustment in terms of self-esteem, social support, various aspects of social life, problem-solving, and coping strategies, notions of social integration, interdependence, and close relationships."[19] Resilience is what allows families to cope with the above burdens, raising the question of which factors contribute to it.

One factor seems to be conceptions of disability that frame it in positive terms, e.g., as a gift and a blessing. Implicit in this source of resilience is a repertoire of spiritual and/or religious resources. Although the theme of religion was not fully explored in this paper, this finding resonates with the scholarship that draws connections between religion and disability.[20–22] As one study drawn from in-depth interviews of parents with CWDs concludes: "Religious support can be a stable coping strategy used throughout the family life-cycle,"[22]

Another factor is the absence or presence of social support. On one hand, the parents were at their most emotional when they spoke of the social exclusion they faced. On the other hand, they were enthusiastic in affirming the value of support groups where they find acceptance and belonging. The benefit of support groups is supported by literature in other countries. One mixed-methods study in the US, for instance, found that parents belonging to such groups identified three distinct forms of support: sociopolitical (i.e., in dealing with the outside world), interpersonal (i.e., sense of belonging within the group), and intraindividual (i.e., self-change and a sense of identity).[23] Similar studies done elsewhere have affirmed the benefit of peer support to parents, underscoring the value of '"solidarity as care."[24.25]

What of the healthcare system? Although it is not the objective of this paper to identify healthcare-related gaps, their prominence in the parents' narratives is worth noting for policy-guidance purposes, particularly their complaints over the dearth of information on services. It is very telling that while the Five-Year Strategic Plan Report 2013–2017, published by the Department of Health's Degenerative Disease Office, acknowledges various gaps including the lack of capacity and the low priority placed by government agencies and LGUs on disability, the 66-page document does not mention the words "parents" or "family", let alone acknowledge them as key stakeholders.[26] Neither does the DOH's Action Framework for the Health and Wellness Program of Persons with Disabilities.[27] In contrast, there is growing international recognition of the value of a family-centered model among health systems.[28]

CONCLUSION

Our findings suggest that in the Philippine context, the family, not the individual, may very well be the unit of disability. That is, the experience of disability is a shared experience among family members, particularly the parents. From the moment a child is diagnosed or discovered to have a disability, the parents take part in it: from the stigma and discrimination they receive to the financial burden they incur. Though the centrality of the family is well established in researches done in other countries, our study sought to illuminate the specific ways in which Filipino parents experience their children's disability in their everyday lives, identifying their conceptions of disability, support groups, and the health care system as factors affecting the resilience of their families.[29–32]

In terms of public policies, a family-centered approach would involve looking at financial assistance and other forms of support that go beyond medical care, including employment and healthcare-related benefits that enable parents to economic and therapeutic roles. As Barbosa and others (2012:195) stressed, "Providing care to families who experience life with a disabled child is essential to the task of enabling them to cope with adversities arising from their children's disability and to maintain healthy family interactions and functioning." As suggested by the parents themselves, these policies should also acknowledge and act on the lifelong burden of disability.[33]

As for education and communications efforts, they should also take into consideration the stigma that family members face, particularly those of the parents' and those that stem from a misunderstanding of the causes of disability. Moreover, the family-based experience of disability, including their own ways of making sense of children's conditions, should be considered in the communication strategies of programs that seek to improve the health of CWDs. Our informants were very empathetic to fellow parents who share similar predicaments, suggesting that they will be receptive to messages and appeals from their fellow parents.

Finally, clinical care should be more attentive to the parents' vital, albeit fraught position, recognizing the "primacy of the parent-professional relationship in which decision-making and planning around mutually agreed upon goals are shared between parents and professionals who engage in a relationship defined by mutual respect, trust, and honesty."[34]

Though we focused on the lived experiences of parents, a significant entity that emerged in their accounts are the support groups. While parents in Tagum City lamented that they had no one to turn to, those in Davao City highlighted the invaluable assistance of organizations like PAVIC. In line with the DOH's aim "to strengthen collaboration and synergy with and among stakeholders and sectors of society to improve response to a disability inclusive health agenda through regular dialogues and interactions," enabling these groups to broaden their reach can likewise be considered in government policies and programs.[27]

As an exploratory study, our study can serve as a starting point for further research. The fact that we were able to access the patients means that they were already somehow reachable, either through a registry (i.e., the Tagum City Health Office) or via support groups. But we were not able to reach parents who are, deliberately or by circumstance, disconnected to health services. Methodologically, we were also limited by not having an opportunity to observe the families or to stratify our sample by different demographics. In this, our understanding can be better served by longer fieldwork or broader studies that can also explore how gender ideologies (i.e., motherhood vs. fatherhood), class, and status influence the way disability is perceived and experienced at the family level.

Indeed, much work needs to be done to illuminate the lived experiences of parents with children with disability, but we know enough to confidently recommend a family-centered approach to caring for children with disability in the Philippines.

Acknowledgment

The authors would like to thank Ms. Febe Matthews and all members of Davao Autism Society for providing much-needed assistance in the conduct of this research, as well as the local government officials of Davao City and Tagum City, Philippines for their hospitality and support.

Statement of Authorship

GL led in the conceptualization and drafting of the paper. CEN, MLN, and FRAF contributed in data gathering, analysis, and drafting, and editing of the paper, while JB, DIC, and RB contributed in subsequent drafts. All authors contributed to the development, organization, and implementation of the study. They also edited and approved the final version.

Author Disclosure

The authors declared no conflicts of interests.

Funding Source

This study was funded by UNICEF Philippines through an interdisciplinary research project led by Alliance for Improving Health Outcomes, Inc.

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APPENDICES

Appendix A. Mapping of policies and programs relating to CWDs[1,2,3]

The Philippine government, as early as 1917, expressed concern for the welfare of persons with disabilities (PWDs) as well as national concern for rehabilitation that was manifested by non-government organizations (NGO). The Philippine Foundation for the Rehabilitation for Disabled Persons (PFRD) and President Marcos signed Presidential Decree (P.D.) No. 1509 on January 16, 1978, creating the National Commission Concerning Disabled Persons (NCCDP). NCCDP was then tasked to prepare and adopt an integrated and comprehensive long-term Rehabilitation Plan (NRP) on January 16-20, 1978. From the time of the inception of NCCDP in 1978, the PFRD assisted the NCCDP Board in the implementation of its objectives and functions. This arrangement stayed in effect until P.D. 1509 was amended by P.D. 1761 on January 4, 1981.

The Philippines had three major laws that created the legal bases for measures to achieve the objectives of full participation and equality for persons with disabilities:

Legislation	Short Description
Accessibility Law (Republic Act 344) *otherwise known as the "Accessibility Law"*	An Act to enhance the Mobility of Disabled Persons by Requiring Certain Buildings, Institutions, Establishments and Public Utilities to Install Access Facilities and other Devices *(approved in 25 February 1983)*
White Cane Act (Republic Act 6759)	An Act Declaring the first of August of Each Year as White Cane Safety Day in the Philippines and for Other Purposes *(enacted in 18 September 1989)*
Magna Carta for Disabled Persons (Republic Act 7277) *otherwise known as "Magna Carta or Disabled Persons"*	An Act Providing for the Rehabilitation and Self-Reliance of Disabled Persons and their Integration into the Mainstream of Society and for Other Purposes *(approved in 24 March 1992)*

Globally, the United Nations (UN) has also called upon government agencies all over the world to develop and provide programs to promote the welfare of PWDs. At the forefront of this agenda is the proclamation of the "Asian and Pacific Decade of Disabled Persons." This proposed measure seeks to promote employment opportunities and strengthen existing employment facilitation processes of the government for PWDs, particularly at the local levels. It also seeks to establish Persons with Disability Employment Facilitation Offices (PWDEFO) in all capital towns of provinces, key cities and other strategic areas. These community-based, local government unit (LGU) and NGOs offices shall ensure prompt, appropriate, and timely implementation of the said employment facilitation services for PWDs, complemented with the dissemination of relevant information, education and communication (IEC) materials that specifically target PWDs in search of productive employment opportunities. The PWDEFO will also serve as a referral and information center on the various services and programs being provided by the Department of Labor and Employment (DOLE) and other government agencies relating to welfare and employment of PWDs, and likewise provide a venue for PWDs who are seeking training assistance for possible employment ventures. Through these employment opportunities being provided by the State, it aims to help boost the Person with Disabilities' self-confidence and also enable them to be self-reliant and productive members of the community.

The Philippines is also a signatory to the United Nation Millennium Development Goals (UN MDG). The Philippines also abides by the UN Convention on the Rights of Persons with Disabilities, which is "an agreement among countries aimed at ensuring that people with disabilities have the same rights and freedom as any other normal person." In the past, persons with disabilities were often invisible and viewed as *objects* of protection and assistance rather than subjects of rights. Consequently, persons with disabilities were excluded from mainstream society, and were provided with special schools, sheltered workshops, and separate housing and transportation as well as denied equal access to basic rights and fundamental freedoms, such as healthcare, employment, education, vote, participation in cultural activities, that most people take for granted due to the assumption that they are incapable of coping with the society and its life activities.

Several national efforts were undertaken by the Philippine Government to usher in a major change in the philosophical, social, and developmental thinking in the approach to helping people with disabilities. The National Council for the Welfare of Disabled Persons (NCWDP) was created as the lead government agency tasked to steer the course of program development

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[1] *Council on Disability Affairs retrieved from http://www.ncda.gov.ph/about/historical-background/.*

[2] *Rotor E. Parent-Professional Partnership in Early Intervention of Children with Developmental Disabilities. Submitted in Partial Fulfillment of the Requirements for the Degree in Master of Arts in Education (Special Education) in the Division of Curriculum and Instruction College of Education University of the Philippines Diliman, Quezon City, 1998.*

[3] *Disability Rights Promotion International., Section 2 – Disability Rights Protections and Mechanisms in the Philippines.*

for PWDs and the delivery of services to them. More importantly, it was also tasked to monitor and coordinate the efforts made by different agencies in implementing The Republic Act No. 7277, also known as the Magna Carta for Disabled Persons, which was first passed in 1992. The Magna Carta provides rehabilitation, development and provision of opportunities towards self-reliance, and the integration into the mainstream of society for PWDs. Disability Rights Promotion International, Section 2 – Disability Rights Protections and Mechanisms in the Philippines. The Magna Carta calls for the prioritization of the needs of persons with disabilities and has paved the way for greater inclusion of PWDs by providing them full participation to, and the equalization of opportunities in seven major areas of concern: employment, education, health services, auxiliary social services, telecommunication, accessibility in transportation and communication, and recognition of their political rights.

President Gloria Arroyo, through the Office of the President, signed the Executive Order No. 676, which reorganized the NCWDP by detaching the sector of Department of Social Welfare and Development (DSWD) from NCWDP. This reorganization aims to closely monitor and improve the actions and programs of the government for persons with disabilities. By virtue of Presidential Executive Order No. 709, issued on February 26, 2008, the functions and organizational structure of NCWDP is further redefined, and it is renamed as the National Council on Disability Affairs (NCDA). NCDA is tasked to strengthen the database on disability for policy formulation and program development, and conduct policy review and consultation dialogues with different stakeholders, right holders and duty bearers in preparation for the participation on the United Nations Convention on the Rights of Persons with Disabilities.

Several programs of the government also respond from a sectoral perspective to the needs of the PWDs in the country. The Land Transportation Office (LTO) conducts seminars to promote accessibility in transportation in accordance to the Accessibility Law. Complementary to this, organizations for PWDs also orient *jeepney* and bus drivers and other transport operators on the requirements of the Accessibility Law. In large establishments, parking spaces are designated for the exclusive use of PWDs. To further increase their mobility, this law was implemented in 1992, thereby enabling persons with disabilities who meet the criteria of the policies and guidelines set by the LTO to apply for a driver's license. In addition, A Manual on Assisting Disabled and Elderly Persons Who Travel (ADEPT) in Land, Sea and Air Transportation was developed in 1995 and disseminated to the concerned sectors. ADEPT training was conducted for personnel and crew of sea, land and air transportation firms starting 1995. Accessibility law has been included in the curricula of architecture and engineering programs, and in the Philippine National Building Code of 1993 through the efforts of the United Architects of the Philippines, to monitor buildings, transportation and establishments in installing access facilities for the disabled people.

The Department of Health (DOH) also has programs for the benefit of PWDs. In partnership with the private sector and other government agencies, DOH conducts advocacy campaigns in the area of prevention of the causes of disabilities. Prevention measures undertaken by DOH include: immunization and vaccination, screening of newborn babies, free distribution of vitamin A capsules as a way to prevent blindness, iron tablet supplementation, production and distribution of iodized salt, mother and child care program, prenatal and postnatal care, nutrition education and PhilHealth card and Zmorph packages.

The Department of Environment and Natural Resources (DENR) has likewise implemented an action program in support of measures to prevent causes of disabilities through: prevention of accidents as a major cause of disability, information, education and communication (IEC) campaigns on ill-effects of pollution and environmental degradation, and the provision of first aid and safety procedures for emergency treatment. DOLE, on the other hand, through the Occupational Safety and Health Center, conducts safety regulation programs for the prevention of accidents in workplaces in order to prevent occupation-related disabilities.

At the local level, LGUs through the Social Welfare and Development Offices, undertake the following programs towards the prevention of the causes of disabilities: nutrition programs and classes on proper food preparation and handling, supplemental feeding programs, classes on responsible parenthood, classes for caregivers, training of community health workers, parents, and paramedic professionals on preventive pediatrics and genetic counseling, and identification, screening and referral to proper service providers of patients identified with cataract.

Appendix B. Interview guide for focus group discussion

1. **Informed consent**: Explain the nature and objectives of the study. Administer informed consent, assure confidentiality, and seek permission for the audio recording of the interview.

2. **Umpisahin natin sa pakikipagkilala.** Ask about pertinent data such as:
   a. Age, educational attainment, school (public vs. private), occupation
   b. Activities, relationships, and regular diet and supplement/chemical use
   c. Family tree and origins (i.e., originally from the city vs. migrated from Manila)

3. **Pwede pong malaman ang kwento ng inyong anak?** (Illness narratives) Inquire in particular about the following:
   a. Time of diagnosis and initial responses (i.e., What were the reactions of the family? When did they first consult? Who did they consult? What was the diagnosis?)
   b. Treatments done and interactions with the healthcare sector (i.e., existence of facilities, personnel, satisfaction, difficulties encountered, adherence to treatment, therapeutic itineraries, etc.)
   c. Lived experiences of being a parent (i.e., elicitation of stigma, financial burden, etc.)
   d. Lived experiences of the child (i.e., bullying, relating with peers, siblings, challenges in schooling, play and growing up, family dynamics, etc.)

4. **Ano pong naging paliwanag ng mga taong pinatingnan ninyo sa kondisyon ng inyong anak? Sang-ayon po ba kayo dito? Ano pong sarili ninyong pananaw tungkol dito?** (Explanatory models) Inquire in particular about interaction with the following:
   a. Professional sector: What medical diagnoses and prognoses did they receive?
   b. Folk sector: Did they consult any traditional healers? Did the midwives have any commentaries on the baby? (consider traditional birth attendants, albularyos, hilots, alternative medical practitioners, etc.)
   c. Popular sector: How did the family members, members of the community respond?

5. **Isa po sa mga layunin ng aming pag-aaral ay ang magkaroon ng mga programa na katanggap-tanggap sa mga magulang ng mga CWDs. Maaari po ba naming malaman ang mga salita na para sa inyo ay katanggap-tanggap, at di-katanggap-tanggap**:
   a. Test them with particular words; cite examples based on domain (i.e., for vision - bulag, visually impaired; for hearing - bingi, hearing impaired, for mobility - pilay, putol, amputee, etc.; for neurodevelopmental problems - autistic, retarded)
   b. Take note of words that were used in the initial part of the interview and ask them to reflect on the connotations of those words as well.

6. **Ano po ang inyong masasabi sa karaniwan o popular na pananaw ng mga taumbayan sa [child's condition]?**
   a. Ask for their knowledge of experiences other than their own i.e., peers, public figures
   b. Invite them to refer to popular culture sources i.e., films, TV episodes, etc.
   c. Elicit their overall sentiments about CWD welfare in the Philippines.

7. **Ano po para sa inyo ang mga paraan upang mas mahikayat ang mga magulang na magpakonsulta sa mga doctor ukol sa [child's condition]?**
   a. Baseline knowledge and expectations about the role of government in helping CWDs.
   b. Elicit financial, social, cultural barriers to consultation and follow-up.
   c. Best practices (i.e., What made them consult? What attributes of HCPs allowed them to earn the trust of the parents? etc.)

8. **Saan niyo po nalalaman ang mga iba't-ibang programa ng gobyerno para sa mga PWDs o CWDs?**

Appendix C. Informed Consent

**Part of the packet submitted to and approved by the Southern Philippines Medical Center (SPMC) Ethics Board*

Informed Consent (English) — Focused Group Discussion

My name is [   ], a researcher for the project on Improving Access to Assistive Technology and Rehabilitation Services for Children with Disabilities - a UNICEF-supported project in coordination with Physicians for Peace Philippines, Inc. and the Philippine Health Insurance Corporation (PhilHealth).

You are being invited to participate voluntarily in the study entitled Children with Disabilities in the Philippines: A Mixed Method Study on Health-Seeking Behavior under the supervision of Paul Gideon Lasco, MD, Msc, PhD (candidate)

Before you agree to join in this study, you need to know the risks and benefits so you can make an informed decision. This process is known as "informed consent". This consent form tells you about the study that you may wish to join. Please read the information carefully and discuss it with anyone you want. This may include a friend or a relative. If you have questions please ask the Principal Investigator or study staff to answer them.

This study is one specific component of the said project, with the specific purpose of acquiring the perspective and experiences of families of children with disabilities in the country, particularly in relation to health-seeking behavior. The results of the study shall be used to develop a communication plan to complement the PhilHealth benefit packages that will be developed by the project.

We would like to involve you as part of this Focused Group Discussion (FGD). You are chosen to participate in this study because inputs will greatly help us understand better the actual experiences of families, parents of, and children with disabilities in the country. Rest assured that our interview will be confidential, and you can trust that your privacy will be protected with utmost regard.

The FGD will take around one (1) hour, and will flow casually like a conversation and storytelling.

There are no expected risks from the interview. Personal details and contact information will only be collected for the purpose of possible follow-up correspondence, and will be deleted upon completion of the study. With your permission, the interview will also be audio-recorded, and notes will be taken by the interviewer.

There will be no monetary costs to you for participating in this study. You will be given (compensation) for your participation to cover expenses such as transportation and meals.

You may withdraw your consent from participation in this study at any time. It is important that you inform the Principal Investigator in writing. The Principal Investigator will continue to retain and use any research results that have already been collected for the study evaluation. No further study-related activities will take place. The choice to withdraw from research participation will have no repercussions.

Your participation in this study is voluntary and you may cancel this consent at any time and without any reason. If you do so, your participation in the study will end and the study staff will stop collecting information from you.

You can call or ask questions anytime regarding this study. The contact person for further information or for consultation on diverse events is (Name, telephone number, affiliation).

This study has been approved for implementation by (Name of the Institution). If you have questions related to your rights as a research subject, please contact:

Name of the institution:
Address:
Email:
Telephone No:
Cellphone No:

Thank you very much.

Your signature indicates that you have read and understood the information provided above, that you are 18 years of age or older, that you willingly agree to voluntarily participate, that you may withdraw your consent at any time and discontinue participation without penalty, and that you have received a copy of this form, and that you are not waiving any legal claims, rights or remedies.

I have read this document/had its contents explained to me. I understand the purpose of this study and what will happen to me in this study. I do freely give my consent to join in this study, as described to me in this document. I understand that I will receive a copy of this document as signed below.

Printed Name and Signature *(Survey Participant)*	***Printed Name and Signature*** *(Field Enumerator)*
Printed Name and Signature *(Legally acceptable representative)*	***Printed Name and Signature*** *(Investigator)*

Date:

For additional questions and concerns, you may contact Christian Edward L. Nuevo via 294.7808.

Informed Consent (Filipino) — Focused Group Discussion

Ako is [ ], isang researcher para sa proyektong "Improving Access to Assistive Technology and Rehabilitation Services for Children with Disabilities" - isang proyekto ng UNICEF na isinasagawa sa tulong ng Physicians for Peace Philippines, Inc. at ng Philippine Health Insurance Corporation (PhilHealth). Ang pag-aaral na ito ay isang bahagi ng nasabing proyekto, na may layunin na makakalap ng mas malalim na kaalaman patungkol sa mga karanasan at estado ng mga batang may kapansanan sa bansa. Ang magiging resulta ng pag-aaral na ito ay gagamitin upang makabuo ng kalakip na estratehiya upang mainam na maipaalam at maipabatid sa publiko ang mga PhilHealth "benefit packages" na mabubuo ng proyekto.

Nais namin kayong imbitahang lumahok sa isang Focused Group Discussion (FGD) para sa pag-aaral na ito. Ang FGD na ito ay inaasahang tatagal nang humigit kumulang isang (1) oras. Para lamang itong kwentuhan at wala naming inaasahang mga risks o panganib sa panayam. Ang inyong kooperasyon at katapatan sa paglahok sa panayam ay magiging malaking tulong upang mas mapalalim ang aming kaalaman patungkol sa mga karanasan ng mga pamilya, magulang at mga batang may kapansanan. Ang lahat ng impormasyon na makakalap ay pananatalihing pribado. Ang mga personal na impormasyon na hihingiin ay gagamitin lamang para sa posibilidad ng muling pakikipag-ugnayan sa hinaharap, at agad na buburahin matapos ang pag-aaral. Hinihingi rin namin ang iyong pahintulot na i-rekord ang ating FGD; ang tagapanayam ay magtatala rin ng ilang mahahalagang detalye.

Maraming salamat.

Ang iyong lagda ay nagsasagisag na iyong lubos na naunawaan ang mga impormasyong nabanggit, na ikaw ay nasa legal na edad na 18 o pataas, na ikaw ay boluntaryong nakikilahok sa pag-aaral na ito, na maaari mong bawiin ang iyong partisipasyon anumang oras nang walang kaakibat na kabayaran, at na ikaw ay nakatanggap ng kopya ng consent form na ito, at wala kang anumang karapatang tinatalikdan.

Pangalan at Lagda *(Kalahok)*	***Pangalan at Lagda*** *(Tagapanayam)*

Petsa:

Para sa mga karagdagang katanungan, maaaring makipag-ugnayan kay Christian Edward L. Nuevo sa numerong 294.7808.