

## **Challenges and forms of coping and support in the daily lives of Nepali mothers of children with intellectual disabilities: a qualitative study**

Namrata Pradhan<sup>a\*</sup>, Gørill Haugan<sup>b</sup>, Jennifer Infanti<sup>c</sup>

*<sup>a,b,c</sup> Norwegian University of Science and Technology (NTNU), Faculty of Medicine and Health Sciences, Department of Public Health and Nursing. Corresponding Author- Email: [namrata.pradhan@ntnu.no](mailto:namrata.pradhan@ntnu.no)*

The purpose of this qualitative study is to investigate the experiences and perceptions of Nepali mothers who care for their children with intellectual disabilities. These children require lifelong care that places significant emotional, social and financial burdens on their caregivers, who are predominantly mothers in low-income countries such as Nepal. In these contexts, cultural and social factors, such as gender inequalities, discrimination, exclusion and poverty, can exacerbate the caregiving challenges faced by these mothers. Therefore, the study aims to explore the specific challenges, the coping strategies and supports that these mothers use to manage them. Fourteen mothers were recruited through local disability organisations in Province 3 and interviewed individually. Using a systematic approach to thematic analysis, we identified numerous challenges associated with caregiving, including emotional, social and financial burdens. Despite limited formal caregiving support, the mothers relied on emotion-focused solutions to challenges as coping strategies, such as acceptance, peers and family as forms of support, resourcefulness and spiritual beliefs. These findings highlight the critical roles of mothers of children with intellectual disabilities in Nepal and the need for advocacy, research and interventions to promote the health and well-being of these caregivers and their families.

**Keywords:** Intellectual disabilities; caregiving; mothers; Nepal; challenges; coping resources

### **Introduction**

Intellectual disability (ID) encompasses a broad range of neurobehavioral conditions, including autism, Down syndrome and cerebral palsy, that reduce an individual's ability to comprehend new or complex information, learn and apply new skills, function independently, communicate and socialise (Schalock, 2011). Impairments related to ID typically emerge during childhood and persist throughout an individual's life (ibid, 2011). Because ID affects many aspects of daily life, it can have a great impact on families and caregivers, resulting in negative effects on social and leisure time, interpersonal relationships, personal health, economic circumstances and educational and employment opportunities (Baxter et al., 2000; Mbugua et al., 2011;

© The Authors. This work is licensed under a Creative Commons Attribution 3.0 License

McConnell et al., 2015).

Caring for children with ID (CWID) is a lifelong commitment that profoundly impacts all family members, although caregiving responsibilities are often unequally distributed and influenced by gender dynamics (Hassall et al., 2005). Mothers frequently bear the primary burden of providing intensive and unpaid care alongside other responsibilities, such as formal employment, household chores and the care of other family members, including other children, the ill and the elderly (Ghosh et al., 2017; Seedat et al., 2021). Care of CWID requires substantial resources and is undervalued globally. This lack of recognition perpetuates gender and economic inequalities, harming health, widening gender disparities in employment and wages, amplifying vulnerabilities, and reducing women's opportunities for rest due to time constraints (Coffey et al., 2020; Glenn, 2010). Furthermore, despite not having a disability, mothers of CWID can face discrimination and prejudice based on their association with disability (Ryan et al., 2008; Runswick-Cole et al., 2018), which affects the highly nuanced nature of care in different contexts.

Research conducted worldwide, although primarily in high-income countries, demonstrates that the unpaid domestic care of CWID can impose mental health burdens and adversely affect the quality of life for primary caregivers (Caputo et al., 2016; Ghosh et al., 2017). Studies conducted in low- and middle-income countries (LMICs), including Nepal, have also highlighted the negative impacts of informal caregiving within families, often carried out by mothers. These effects encompass overall health, including psychological distress (Maridal et al., 2021; Ryzewska et al., 2021; Scherer et al., 2012).

In LMICs, women and girls who care for CWID can face additional challenges due to a lack of social welfare systems and services, inadequate health facilities and limited infrastructure (Maridal et al., 2021; Thrush et al., 2014; Vadivelan et al., 2020). As a result, these caregivers often must sacrifice their basic rights to education, healthcare, employment and leisure time. The challenges of living in poverty further intensify or compound the physical and psychological stress experienced by primary caregivers of CWID (Lundy, 2012; Thrush et al., 2014). Moreover, inequitable policies related to CWID, particularly exclusion from education and employment, may disproportionately affect primary caregivers who are predominantly mothers in LMICs. While such exclusions can be observed in various regions worldwide, the challenges faced by these mothers in LMICs can be magnified and more burdensome due to specific contextual factors.

Nepal is recognised as one of the poorest countries, with approximately one-quarter of its population living below the poverty line (Government of Nepal [GoN], 2020). Illiteracy rates for women in Nepal are high, with approximately 40% unable to read or write (GoN, 2020). In addition, Nepal is a patriarchal society in which women bear the primary responsibility for unpaid care and household work, often in addition to their work in formal sectors. This burden

is further exacerbated by the lack of availability and access to public resources, services, high levels of migration of men, family structure and discriminatory gender norms and roles (Ghosh et al., 2017). As a result, mothers of CWID in Nepal face significant challenges that have a profound impact on their well-being.

Research on disabilities, particularly ID, in Nepal has historically been neglected (Aryal et al., 2022; Sonpal et al., 2012). Current evidence concerning the daily experiences of and psychological distress among mothers and other caregivers of CWID is still scarce, with some notable exceptions shedding light on these topics (Archarya et al., 2021; Maridal et al., 2021). Nevertheless, given that the specific factors affecting the stress and coping resources of mothers of CWID vary widely based on individual and family resources, among other factors, there is a need for further research that captures the diverse daily experiences of these caregivers. Such knowledge is a crucial starting point for raising awareness and informing the development of culturally relevant and context-specific interventions and policies that address the unique challenges faced by mothers and their families within the setting. In the longer term, this can contribute to the creation of more equitable and inclusive societies.

Within this context, this study explores the experiences and perceptions of Nepali mothers who care for their CWID, delving into the challenges they encounter and the forms of support they use.

## **Methods**

### *Study design*

Considering the diversity of experiences and perceptions associated with parenting CWID, we selected a qualitative design to explore the many subjective realities of Nepali mothers of CWID. Qualitative methods are useful for uncovering the meaning and context of people's experiences and for facilitating an in-depth exploration of individual perspectives and emotions (Maxwell, 2013). By using in-depth individual interviews, we aimed to capture the nuanced and complex nature of the daily experiences of 14 caregivers.

### *Study setting, participant recruitment and demographic profiles*

We used purposive sampling to recruit participants for this study. The leaders of CWID day care centres and the nongovernmental organisation Parents Federation of Persons with ID (PFPID) in Nepal helped identify potential participants who met the inclusion criteria. PFPID comprises parents and family members of CWID throughout Nepal, providing support and advocacy. They have an extensive network with other parents of CWID in Nepal and are involved in running local day care centres in and around the study setting, Province 3. These day care centres were established by parents due to the lack of inclusive schools for their CWID. Collaborating with PFPID was a vital step in contacting and recruiting parents of CWID

in the setting.

Province 3, located in the central region of Nepal, is one of the most populous of the country’s seven provinces, with a population of 5.5 million and characterised by rich geographic, ethnic and cultural diversity. It encompasses the Kathmandu Valley, a historical and urban hub, along with surrounding hills and mountains. Province 3 hosts high numbers of internal migrants in search of job opportunities and faces complex factors contributing to poverty, including a lack of social welfare programs, and gender and social inequality (Government of Province 3, 2019; Gyawali, 2020). While Province 3 represents an area with high socioeconomic development compared to other districts in Nepal, around 15% of the province’s population lives below the poverty line, and 16% is absent due to foreign employment (Govt of Province 3, 2019).

To be included in the study, participants had to be primary caregivers for CWID residing in Province 3, have CWID aged 5–18, have CWID admitted to day care centres and were willing to be interviewed via Zoom or telephone with audio recording. Recruitment continued until we reached data saturation, which occurred when no new information or themes emerged from the data.

The final sample comprised 14 volunteer participants who were mothers of CWID aged 7–18, representing different socioeconomic and educational backgrounds, including illiteracy. Table 1 presents some demographic characteristics of the study participants. All participating caregivers were mothers, reflecting the patriarchal nature of Nepali society. The mothers’ ages ranged between 25–50 years. Half of the mothers had completed at least primary education and reported more stable living conditions, while the other half had no formal education and reported a poor socioeconomic background. A few mothers were engaged in some form of income-generating activity, such as teaching or small-scale businesses.

*Table 1: Demographic profiles of participating mothers of CWID*

<b>No.</b>	<b>Age</b>	<b>Education</b>	<b>Occupation</b>
<b>1</b>	50	Higher secondary	Homemaker
<b>2</b>	32	Bachelor’s degree	Homemaker
<b>3</b>	30	No education	Housekeeper
<b>4</b>	45	Master’s degree	Teacher
<b>5</b>	35	Higher secondary	Shopkeeper
<b>6</b>	34	Higher secondary	Homemaker
<b>7</b>	35	Master’s degree	Homemaker
<b>8</b>	36	Higher secondary	Homemaker
<b>9</b>	50	No education	Homemaker
<b>10</b>	34	No education	Homemaker
<b>11</b>	45	No education	Homemaker
<b>12</b>	40	Bachelor’s degree	Banker

13	33	Bachelor's degree	Homemaker
14	30	Primary	Shopkeeper

*Data collection procedures*

We conducted 14 individual interviews over a three-month period in the spring of 2021. Each participant was assigned a unique study number and provided informed consent before the interviews.

We developed an interview guide based on the study aims, which was reviewed by a panel of experts in qualitative research. The guide was piloted with two participants who met the inclusion criteria but were not included in the final sample. The questions in the guide were open-ended, focusing on the following questions: ‘How does a typical day look for you? Can you take me through it?’. Additional questions addressed the participants’ everyday caregiving challenges, personal well-being, family interactions, resources and support.

The interviews were conducted in the Nepali language. One mother preferred to use the local language of Newari. The first author, who conducted all the interviews, was fluent in both languages. The interviews lasted between 45 minutes and two hours, with an average duration of one hour. The first author took written notes during each interview, and all conversations were recorded offline on a Dictaphone. To ensure the validity and reliability of the data, the interviewer confirmed her understanding of the participants’ statements several times during each interview. Thereafter, member checking was performed by sharing the preliminary findings with some of the participants to validate the interpretation of their data.

Because of the COVID-19 pandemic, we conducted interviews via Zoom or telephone. The leaders of the local day care centres collaborated with the PFPID to arrange the time and place for the interviews. The local day care centres arranged telephone interviews or Zoom calls for the participants who did not have smartphones or internet access. The participants without literacy were assisted by leaders of the day care centres in using the digital platform for the online interviews. The Zoom cameras were on during the online interviews, but the participants were allowed to turn them off if they preferred.

*Ethical considerations*

The study received ethical approval from the Nepal Health Research Council (reference number 4063) and was registered with Sikt—the Norwegian Agency for Shared Services in Education and Research (reference number 735910). Prior to participation, the first author verbally informed the participants about the study, while the day care centre leaders provided detailed explanations about the nature of the interviews, recording process, the voluntary nature of participation and the participants’ right to withdraw from the study at any time without facing

any consequences.

To address potential concerns about confidentiality and anonymity, pseudonyms were assigned to each participant, ensuring confidentiality throughout the study to protect the participants' privacy. Additionally, the audio recordings of the interviews were securely stored in compliance with the institutional policy of the Norwegian University of Science and Technology (NTNU), and access to the recordings was limited only to the first author.

Verbal consent was obtained from the participants, considering the low literacy rates prevalent in Nepal, especially among women, and cultural attitudes that often foster scepticism and mistrust towards signing formal documents. The informed consent process involved clear explanations of the study procedures, risks and benefits, and the participants provided their consent directly to the researcher prior to the interviews. Furthermore, the first author ensured that the participants received compensation for the internet/data usage on their smartphones during the Zoom interviews. No additional financial payment was provided to ensure that their involvement in the study remained voluntary and unbiased. By implementing these ethical measures, we aimed to protect the rights, confidentiality and well-being of the participants while ensuring the scientific rigour of the study.

#### *Data analysis*

During the data collection, the first author conducted a preliminary analysis, constantly revising the interview guide, taking reflective notes and recording keywords for each interview. The 14 interviews were transcribed verbatim in Nepali and then translated into English by the first author and a research assistant (RA), both fluent in Nepali. The first author reviewed the RA's translations to ensure accuracy. To protect the participants' confidentiality, their personal information was removed from the transcripts.

The data were analysed using Clarke et al.'s (2015) five-step thematic analysis. During the first step, the first author read and reread each transcript to become familiar with the text and identify important quotes and phrases. The author made reflective notes, documented similarities among transcripts and described notable characteristics of the participants' experiences. During the second and third steps, the researchers collectively generated codes by examining the transcripts for identifiable topics or aspects. Then they compared and related the text in different transcripts, asking questions about the data and writing notes. Emerging themes were reviewed in relation to existing literature on the caregiving experiences of mothers of CWID in LMICs (see for example Fernández-Alcántara et al., 2017; Oti-Boadi, 2017; Rodrigues et al., 2019) and compared across the 14 transcripts to identify connections and revise into sub-themes. In the final stage, the sub-themes were aggregated into superordinate themes and given descriptions, resulting in a thematic network.

Figure 1 below summarises the progression of the data analysis from codes to sub-themes to descriptive superordinate themes. The first column shows the codes representing broad identifiable topics or aspects generated from the transcripts. The second column provides the codes grouped into sub-themes, such as ‘emotional burden’, ‘social hardships’ and ‘family, community, peer support’. The third column shows the sub-themes further aggregated into the descriptive superordinate themes of ‘challenges’ and ‘forms of coping strategies and support’ used by mothers of CWID.

*Figure 1: Data coding process and theme development*

<b>Codes</b>	<b>Sub-themes</b>	<b>Descriptive superordinate themes</b>
sadness, constant worry, depression, fear, stigma, discrimination, exclusion, fatalism, unpaid caregiving, loss of employment, financial strains, out-of-pocket healthcare costs, rehabilitation	Emotional burden Social hardships Poverty and financial hardships	Challenges affecting the daily lives of mothers of CWID → <i>Mothers of CWID experience unending care, fear, worry, and negative emotions. They also face exclusion, stigma, discrimination, financial losses and relentless unpaid caregiving, which negatively affects their emotions and overall well-being.</i>
acceptance, gratitude, children provide life purpose, helpful family and peers, spiritual beliefs, self initiation, resourcefulness	Emotion and solution-focused coping Family, community and peer support Spiritual beliefs	Forms of coping and support in the daily lives of mothers of CWID → <i>Mothers of CWID focus on positive aspects of their lives, such as having supportive families and spiritual beliefs. They use coping strategies actively and passively, and initiate efforts to provide care for their CWID, including opening day care centers and supporting other mothers in similar situations.</i>

Finally, two in-depth interviews with mothers referred to as ‘Deena’ and ‘Rita’ were selected for presentation as extended narratives in the following section. These accounts provide a comprehensive and poignant summary of the challenges (Deena) and supportive factors (Rita) experienced by most of the participants, thus serving as summary frameworks or references for the study findings.

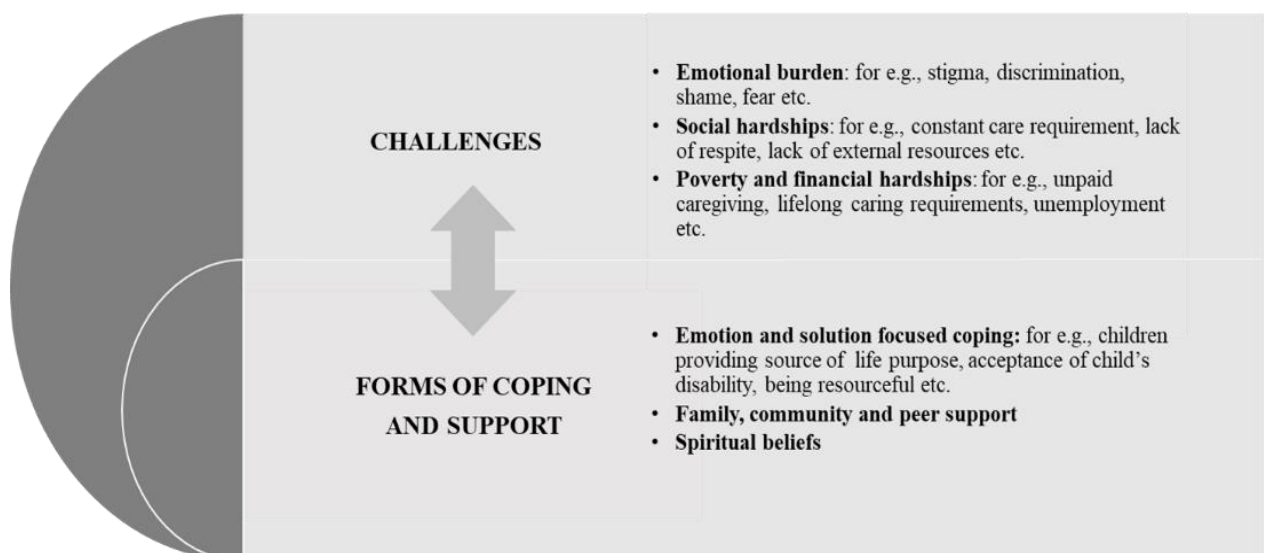
## Findings

In the interviews, the participants revealed a nuanced and complex picture of their everyday caregiving experiences of their CWID. These caregivers appear to face a multitude of

challenges and stressors that impact their emotional, social and financial well-being. However, we also observed that these challenges co-exist alongside a range of forms of support, acceptance, spiritual beliefs and adaptive coping strategies that enable mothers to navigate their caregiving responsibilities.

To illustrate these findings, Figure 2 depicts the interconnected challenges and forms of support that shaped the caregiving experiences of the participants. In the remainder of this section, we first present the challenges these mothers face, highlighting the emotional, social and financial dimensions of their experiences. Then, we turn to the ways in which mothers use or receive support or draw upon other resources to manage their challenges.

*Figure 2: Interconnected challenges and forms of support and coping described by mothers of children with intellectual disabilities*



### ***Challenges experienced by mothers of CWID***

The mothers of CWID in this study described facing various and persistent challenges in the caregiving context, from discriminatory social perceptions of disabilities to present and anticipated future financial concerns, insufficient time for other children and a lack of social support. These challenges were presented as significantly impacting the mothers' emotions, social lives, finances, health and well-being. We present the described challenges below, drawing on the voices and experiences of the participating mothers to illustrate their impact.

#### *Emotional burden and social hardships*

Deena's story exemplifies some of the stressful daily realities of life for mothers of CWID.



Deena has a 10-year-old son diagnosed with Down syndrome. Her husband began working abroad four months after their wedding, leaving her lonely and without a confidante. She struggled to care for her son, who was often sick and frail, and moved to the capital city to access better healthcare facilities. Deena's in-laws taunted her after learning about her son's diagnosis, adding to her emotional distress. Deena shared the following information:

I look after my son and help my husband in the shop besides household chores. We used to live in the village. My husband went abroad for a better job four months after our wedding, when I was only two months pregnant. I felt lonely after that, and there was no one to talk to. Village life is hard; I hardly had time to rest. My in-laws never cared for my well-being. After the birth, I felt lonelier, there was no one I could confide in...I was in so much pain due to loneliness.

My son was frail and sick all the time. I hardly had time for my son due to household chores, and nobody in the household helped me. Therefore, I decided to move to the capital with my son, where I have access to better healthcare facilities and could spare more time for my child. Now my husband is back and runs a shop in Kathmandu. I am relieved that he is with me and my child. However, catering to the well-being of my child and his constant needs is very stressful for me.

In addition, my in-laws taunted me, used harsh words, and tortured me mentally after they learned about my son's diagnosis. They said that my son inherited it from my side of the family. Even though I know it's not true, I can't say anything, and I know they will not understand. I have never had their support. All I have is my husband.

My son's health has improved; he is better than before. But, whenever he is away or at school [day care centre], I constantly worry about his well-being.

I used to get negative thoughts all the time. I constantly thought of killing myself and felt that living a lonely and hard life like I do has no meaning. Before [marriage], I used to be strong, but my son's condition has made me very weak, and I worry about his future constantly.

Two years ago, I started having neck pain...My husband took me to the doctor. The doctor prescribed some medicines [that] caused side effects like gastritis. But still, the pain on one side of my body remained; medicines didn't help me at all. I wanted to cry all the time, especially when I saw my son. But now I am on a different medication, which makes me calm, and my pain has disappeared. I am quite dependent on this medication, but I take it for my son.

Deena's situation was not unique among the research participants. All the mothers in our study

whose husbands worked abroad expressed similar challenges and experienced many negative emotions that affected their mental well-being. Some mothers expressed that a lack of awareness about disabilities among family members and others in their lives caused them deep pain and sorrow. For example, Maya, a 29-year-old mother who was a housekeeper, also described her constant fear and anxiety regarding her son's well-being while she was working:

It is difficult for me. Wherever I go, I can't stop thinking about my son's whereabouts. I am constantly worried, but it's not possible for us to always be with him due to work. Sometimes when I must leave, I seek help from different households in the neighbourhood.

In addition, mothers of daughters with ID expressed concerns about sexual abuse, rape and violence towards their daughter with ID. This extended to a sense of distrust among relatives and family members. For example, Rama, a 50-year-old mother, expressed:

I do not want to leave my daughter alone with anyone, we hear a lot of cases of rape and abuse, and unwanted pregnancy among daughters with ID. I don't even trust my close male relatives.

There was a strong desire among these mothers to protect their children from negative behaviours and attitudes. The mothers perceived their children as vulnerable to violence. As a result, constant worry and fear were common emotions among the mothers in our study. Several mothers also reported experiencing emotional pain that manifested in physical symptoms, for example, as described by Deena whose neck pain subsided only after taking a 'calming medication'.

All the mothers in this study mentioned encountering insults, shame, blame, cruelty, rudeness, exclusion and discrimination due to the prevailing social perceptions and stigma surrounding ID. These negative attitudes were often attributed to a belief in curses or sins from previous or present lives, which caused the mothers significant social and relational stress. These experiences were so devastating that some of the mothers expressed a sense of regret or despised having given birth to a CWID. Particularly mothers from lower castes described experiencing discrimination from strangers. Maya, the 29-year-old domestic worker previously mentioned, stated the following:

Giving birth to [a CWID] is accompanied by a lot of contempt and discrimination. Even though it's my village and community, people's thoughts, perceptions, and the way they talk...they despise (*hela*) us and discriminate...People say things like... 'she gave birth to such a child' in a very negative way and state whatever they like about us.

The mothers participating in this study were excluded from social events and felt isolated

because they could not bring their children. They reported being physically and mentally bullied and being stigmatised because of cultural beliefs related to sin and karma. For example, Tara, a 40-year-old teacher, expressed:

One of my relatives said that your child was born “like this” [with an ID] because you have sinned. It was hurtful. It felt like a deeper cut, more than a pinch, but I think it’s okay letting people talk whatever they want to...I still remember it though—it still hurts.

There is the social stigma and shame of having CWID, which significantly stresses mothers and makes them even more vulnerable to poor health. A number of mothers reported receiving direct or indirect support from their families and in-laws, and for many, family members were a source of stress. Swara, an employed 40-year-old mother, expressed sorrow about how others avoided and stigmatised her CWID, leading to social isolation:

They avoid her [daughter] and treat her badly. A couple of times, people have dragged her out of functions, gatherings. I couldn't tolerate it. That’s why I only attend those ceremonies that must be attended compulsorily. Otherwise, I have cut such gatherings and parties out of my life.

#### *Poverty and financial hardships*

The mothers in our study reported that financial hardships and poverty were their main life stressors. The constant need to provide care caused many of these mothers to lose employment. Similarly, they mentioned that because they had to stay at home to care for their children, they could not seek employment. Unplanned expenses on treatments, rehabilitation, transportation costs and loss of employment pressured the mothers to make ends meet, which left them in a vulnerable position and caused them more stress.

Rashmi, a 50-year-old housewife residing in a suburban area in the Kathmandu Valley, described that she has faced financial hardships in feeding four children, one of whom required constant care. She desired to make some income on her own to support her family and stated: ‘I just wish if my child had been healthier and normal like other children, I could work and make some income...This would have made our life so much easier.’ Several mothers also mentioned that the loss of employment opportunities because of their caregiving demands was anticipated to last for their lifespan.

Other mothers shared that their husband provided just enough income for the family but said that they experienced abuse and hurtful behaviour because of their financial dependence. For example, Sobha is a 35-year-old mother who cares for a child with multiple disabilities, including an ID. She is also her husband’s second wife. Sobha lived in the same household with her 14-year-old son and her husband’s first wife. Sobha described her husband as abusive

and unsupportive and explained that he had abandoned her in many ways. While he provided for Sobha's basic needs, he was hardly present at home. He complained or made her feel guilty about any extra or unplanned expenses, even though they were for their only son. Sobha shared the following:

My son also gets seizures. The doctor changes his medicine often. It is very costly. We never have money. He used to get admitted to a hospital a lot. So, on these instances, my husband always complains about expenses due to hospitalisation [of] our son. It hurts a lot. I always think if my son was normal, everything would have been better. I don't work, so I must depend on my husband. If I had some income, I wouldn't have to hear anything from him. If only I had a paying job, I could say the money that is mine. Now it's not my money. When the expenses are high, my husband says a lot of hurtful things.

Some mothers were highly educated but chose to stay home to give their full attention and care to their CWID. Salana, a 38-year-old homemaker, made it clear in her interview that she was ambitious when she pursued her master's degree but stayed at home after that to care for her child because it made her feel better and she did not want anyone else to care for her child. Salana said, 'When I found out about [my son's] condition, I left my job and invested all of my time [in] him.'

### ***Forms of coping strategies and support used by mothers of CWID***

Despite the multitude of challenges, the mothers of CWID in our study coped with their situations. Some expressed that they felt a sense of purpose and reward when they saw their children progress. Swara, a 45-year-old mother, expressed pride in her daughter as she improved her social behaviour and became independent in various activities of daily living. When Swara's daughter was first diagnosed with ID, she felt devastated for many months. However, she found parenting to be a purpose in life and explained, 'I have trained her well, and now she is independent and healthy...Nobody can tell she has an ID.' This helped Swara develop a sense of purpose, contentment and pride, and she focused on the positive aspects of helping her daughter learn life skills.

Similarly, other mothers intentionally focused on the positive aspects of their lives. Those with well-employed husbands mentioned that they could care for their children exclusively and did not need to obtain formal employment. Some living with in-laws said that their extended families were understanding and that helpful friends were critical sources of stability and support. Rama, aged 50, indicated that she had supportive relatives and friends who loved her daughter and a large family to help when needed. She expressed that her husband was supportive and caring and loved their daughter. She felt lucky to have a supportive family. According to Rama, having a supportive family and focusing on the positive aspects of life

helped her cope with the stressors of caregiving:

[Our daughter] is the centre of our lives. She makes us happy; she makes everyone around her happy. I like to be with her, and I am happy that I can stay at home taking care of her, and I do not have any pressure to earn a living. My husband has been supportive, as well as my family.

Rama's words indicate that acceptance from family and the community can play a critical positive role in coping. It is a resource for mothers who have it, helping them develop feelings of purpose, contentment and pride.

Some mothers indicated that they accepted their children's disabilities as part of life. Connecting with other parents of CWID through the day care centres reminded these mothers that they were not alone. Shoba, a 34-year-old homemaker, explained that her thoughts, feelings and perceptions about her child's multiple disabilities changed after she began to work as a caregiver at a day care centre, where she learned about different kinds of disabilities and realised that there were more severe and challenging conditions. Most importantly, Shoba recognised that she was not alone and that other parents had challenging life situations. Shoba stated:

I used to work as a caregiver at the day care centre where my son was admitted... [Previously], I thought it's just my child like this...but I met lots of children like him...and I finally realised it is not just my child, but there are several others with worse conditions. I don't cry anymore.

This realisation articulated by Shoba was also mentioned by other mothers; it seemed to help them gain perspective and made it easier for them to adapt to their children's disabilities and caregiving needs. In addition to acceptance, the mothers in this study used spirituality as a coping tool. Maya, a 40-year-old teacher, believed that she had a spiritual purpose in life and that she was chosen for her parenting role. She described her coping as follows:

I am from a religious family. My father [a devout Hindu man] gives me motivation whenever I feel low. Therefore, I can cope with the pain. Now I also think God gives special children to parents who can take care of them and are strong enough to care for them.'

The findings in our study suggest that acceptance, hope, spirituality, and supportive peers and family are essential coping strategies for mothers of CWID. The mothers also showed resourcefulness by learning more about disabilities and caregiving and helping the community and other mothers in similar situations. For example, the mothers established day care centres to support CWID with limited resources. Reena, a 36-year-old homemaker and former day care

centre leader who has two CWID, started a local day care centre in the absence of inclusive education. Reena reported that she felt like a resource to parents in similar situations. This self-empowerment was part of Reena's coping, as she redirected her energy and focus to helping other CWID and their families. She discussed starting a day care centre:

I contacted the local public school to give us a small space for CWID...We cleaned...painted and decorated rooms...I am grateful to the principal of the school who agreed to my proposal, and of course, it is a great relief to all the parents of CWID in our municipality.

Other mothers also stated that they redirected their energy and focus to cope, expressing pride in their resourcefulness in caring for their CWID. Rita's story exemplifies many of the support systems and coping resources used by the mothers in this study. Rita, a banker and the mother of a CWID, explained how she eventually accepted her circumstances:

We were not aware of [my son's] condition until he was six months old. He looked like any other normal kid, but as he was growing up, he couldn't do many activities like other kids. When he couldn't talk, we realised that he was perhaps not normal. The doctors couldn't diagnose him.

He looks normal. He needs help with his toilet activities still, but lately, he has been able to use a spoon to feed himself. It's only when he talks that he appears different. He imitates others, makes noises and voices. Sometimes, I feel it would have been better if he was enrolled in a typical school since he has a habit of imitating others, and he could learn a lot, but typical schools do not take him. However, he likes the day care centre.

One of my relatives asked us to go to church and confess and told us that 'this will make your child normal'. This surprised me because Christianity is not even our faith, but we did it. We did everything we could, whatever people suggested to us. We performed many rituals, like *puja* [a worship ritual], donating, reciting mantras. We did everything they said. We went to doctors, to God-women, to priests, and what not. My co-workers sometimes say, 'Poor you', but this does not upset me. I can understand why they say that, and even though they say, 'Poor me', I don't feel that. Now this is my normal.

Young children from our neighbourhood used to misbehave with my son because they [didn't] know him. However, others who know him, like him. He is social and has a great affinity for the elderly, and everyone in our life loves him. I feel that my husband and I bonded a lot more because of our son. When we just had our eldest, we were both in our own worlds, but with my younger son, we bonded more as a family.

## **Discussion**

This study aims to explore the experiences and perceptions of Nepali mothers of CWID, including their daily challenges, unmet needs, coping strategies and supports, ultimately to better understand the dynamic and multifaceted nature of their caregiving journeys within Nepali society. The findings demonstrate that these mothers face a range of difficulties compounded by cultural norms, constant caregiving demands, worry, stigma and financial hardships. Such challenges align with findings from studies in various contexts that link similar factors with higher risks of stress, anxiety and other forms of mental distress among caregivers of CWID compared to caregivers of children without disabilities (see for example Altiere et al., 2009; Ambikile et al., 2012; Magaña et al., 2020; Seedat et al., 2021; Tomanik et al., 2004). Moreover, the intersectionality of social determinants, such as gender, stigma, poverty and the caring of CWID, further exacerbates the vulnerabilities already faced by these mothers in a patriarchal context. In response to these challenges, the mothers employed emotion- and solution-focused coping strategies. They were acceptance, spirituality, peer support, family support, search for purpose in life, management of day care centres in the absence of inclusive education and kindergartens, and pride in behavioural improvement and independent activities of daily living of their CWID.

### *Challenges: emotional burden and social hardships*

One of the major challenges experienced by the mothers participating in our study is gender inequality, which is pervasive in Nepali society and perpetuates a lack of female autonomy (Acharya et al., 2021). In Nepal, women are often perceived as liabilities and expected to carry out domestic duties solely (Dahal, 2022; United Nations Population Fund [UNFPA], 2012). Motherhood is a primary source of status and security, with a strong preference for male heirs, which places mothers of only daughters in disadvantaged positions. Mothers are frequently blamed for their children's upbringing and being unsuccessful (Prajapati, 2008; UNFPA, 2012; Vaidya, 2016).

The mothers participating in this study face a multitude of burdens and responsibilities in the realm of caregiving and household management, which are deeply influenced by the cultural context of a patriarchal society and one wherein family care serves as the primary means of support for CWID. Specific caregiving tasks such as feeding, bathing, dressing and toileting are predominantly assigned to mothers due to gendered social norms. In addition, mothers must assume domestic chores and engage in activities outside the home, such as making appointments, ensuring and providing transportation and income generation (Kaniyattam et al., 2022; Ryan et al., 2008). Collectively, these tasks become limitless and can also be experienced as repetitive and physically demanding (Seedat et al., 2021). In Nepal, this burden can be particularly pronounced among impoverished women, for whom this type of caregiving and domestic work can be overwhelming, time-consuming, arduous and unrelenting due to lack

of trained health professionals, inclusive education and well-implemented social benefits (Seedat et al., 2021). Consequently, these mothers endure the need to provide constant care and support for their children throughout their entire lives, with little respite (Vaidya, 2016).

Furthermore, these mothers expressed constant preoccupation with the well-being and safety of their children, even when they were away due to work. Their concerns about potential abuse and violence against their daughters align with reports and studies indicating increased risks of rape for females with ID (Puri et al, 2015; Save the Children and Handicap International, 2011). This highlights a pressing need for future research on violence experienced by CWID in a country like Nepal with high prevalence rates of all forms of gender-based violence (Clark et al., 2019; Lord et al., 2016; Puri et al., 2015; Van der Mark et al., 2019).

Our findings also illuminate the profound impact of Nepal's cultural context on how disability is perceived, as well as the attitudes and stigma by mothers in these circumstances. Within the Nepalese context, deeply ingrained fatalistic attitudes, rooted in concepts like karmic ties and the interconnectedness of past lives, along with the belief in the predetermined nature of events and outcomes beyond individual control, contribute to a sense of resignation and limited agency concerning disabilities of all kinds (Aryal et al., 2022). This fatalistic perspective, identified as a prevailing worldview in Nepal by anthropologist Dor Bahadur Bista in 1991, is further supported by the results of a study conducted by the United Nations Children's Fund (UNICEF) in 2001. This report revealed that nearly one-third of Nepali people attributes disability to metaphysical causes (UNICEF, 2001). Within this worldview, disability is seen as the manifestation of destiny, divine will, or karma, fostering a conviction shared by some of our study participants that little can be done to alter or improve the situation. This fatalistic mindset finds reinforcement in social interactions, shared narratives and cultural norms that permeate society (Solomon, 2003). Additionally, Gutierrez et al. (2017) found that perceived fatalism tends to be more pronounced among women and individuals with limited education, a pattern that aligns with our own findings. However, research across diverse context challenges the conventional view by suggesting that fatalism might also positively impact mental health and motivation by fostering acceptance of challenging circumstances (Kizilarlan, 2020). This perspective could have significance in alleviating caregiving burdens (Demir and Yilmaz, 2023) and potentially enhancing coping abilities. These contrasting perspectives emphasise the need for additional research and interventions supporting caregivers of CWID in Nepal, potentially leveraging fatalistic attitudes for effective coping and societal benefits.

As argued by Ryan et al. (2008), the mothers of CWID in this study face forms of disablism despite not 'being disabled' themselves. Disablism refers to discrimination and prejudice based on disability or association with disability, which the mothers in this study encounter through societal attitudes, inadequate support systems and challenges in navigating their environments. More recently, Runswick-Cole and Ryan (2019) introduced the concept of 'unmothering',



which disrupts the idea that the mother alone is solely responsible for raising children and calls for collective activism to challenge individualisation and power imbalances within families and society. Exploring these ideas in future theoretical and empirical research may be particularly relevant in Nepal, a collectivist society, where valuable insights can be gained into the diverse realities faced by mothers of children with all types of disability, the impact of disablism on their lives and the importance of support and recognition (Kaniamattam et al., 2022).

Furthermore, the association of shame with having CWID and the resulting social exclusion and isolation experienced by mothers in our study highlights the intersecting dimensions of stigma and social identity (Aryal et al., 2022; Buettgen et al., 2010; Oti-boadi, 2017). The presence of a child with a disability challenges societal norms and threatens the perceived social order (Aryal et al., 2022). Reports from Human Rights Watch in Nepal demonstrate the stigmatisation and exclusion faced by families of all types of disabilities, reinforcing strong societal beliefs that disabilities result from sins in a past life, fate or God's will (GoN, 2020). This also corresponds with studies in other contexts documenting the systematic discrimination, stigmatisation, negative community attitudes and societal myths that can cause intense emotional distress for mothers of CWID and contribute to stress and depressive symptoms (Masulani-Mwale et al., 2016; Ngo et al., 2012; Oti-Boadi, 2017).

#### *Poverty and financial hardship*

Unpaid but constant caregiving, places women in precarious economic situations, intensifying their financial reliance or dependence on husbands or other household members (Seedat et al., 2021). Our findings underscore that mothers experienced economic distress due to leaving their jobs to meet the caregiving demands of their CWID and manage additional out-of-pocket expenses like medical and rehabilitation costs. This scenario echoes other studies that emphasise the enduring financial strain borne by mothers of CWID, which often persists throughout their lives (Masulani-Mwale et al., 2016; Neoh et al., 2022; Oti-Boadi, 2017; Vadivelan et al., 2016). The strong connection between disability and economic poverty is also evident in a recent systematic review on poverty and disability in LMICs (Banks et al., 2017a).

Shrestha et al.'s (2009) study revealed that 75.7% of people with disabilities in Nepal were considered as the 'poorest of the poor' in the country, highlighting poverty's multidimensional aspects. These encompass limited access to education, employment, health care and participation in social, family and political spheres (United Nations Development Program [UNDP], 2010). In such a context, poverty extends beyond mere economic hardship to encompass social exclusion and marginalisation among society's most impoverished, including families and individuals with disabilities (Banks et al., 2021). Recognising poverty as a pivotal factor in the experiences of these mothers is crucial in comprehending the breadth and depth of the challenges they confront. However, the interplay between poverty and caregiving in Nepal is complex, underscoring the necessity for further research and the establishment of

comprehensive support systems, interventions and policy actions. These measures are necessary to alleviate the burdens experienced by mothers of CWID in Nepal, and ultimately to enhance their overall well-being.

### *Coping strategies and support*

Despite facing challenges, the mothers in our study exhibited various coping strategies and drew upon social support mechanisms, including peer support and social networks, which have been identified as essential positive factors influencing individual responses to stress and the ensuing distress (Beighton et al., 2019; Shorey et al., 2019). These strategies can also act as protective factors, aiding individuals in navigating through stressful situations and mitigating negative psychological impacts (Shahrier et al., 2016; Furrakh et al., 2020). Our findings align with this perspective, as some mothers engaged in emotional expression, sharing solutions, and seeking emotional support within their peer networks, leading to positive coping. Similarly, some mothers turned to passive or emotion-focused coping strategies rooted in acceptance, spirituality, religious practices, hope and gratitude. These commonly adopted strategies can serve as coping mechanisms for emotional adjustment to stress (Karaca, 2021), potentially altering perceptions of adversity and fostering pleasant emotions (Wu et al., 2014). Additionally, some mothers demonstrated solution-focused coping strategies, proactively seeking knowledge and solutions to manage challenges associated with their children's ID and leverage family and peer support, for instance, establishing the day care centres and active listening and sharing, which had meaningful impacts. This resourcefulness mirrors findings from other studies of mothers and primary caregivers of CWID in different LMIC contexts, underscoring caregivers' capabilities in managing their challenges and stressors (Adithyan et al., 2017; John, 2012; Luong et al., 2009; McNally et al., 2013; Oti-Boadi, 2017; Tilahun et al., 2016; Wang et al., 2011).

Furthermore, our study revealed the significant positive role and influence of peer support and social networks among mothers of CWID. The informal support of peers through the day care centres served as a crucial coping strategy, offering a platform for active listening, sharing experiences and worries, and practical exchange of advice and emotional support with other parents who had travelled similar journeys. These interactions provided reassurance, validation and a sense of belonging, social companionship and community, helping to reduce feelings of isolation. Peer support also enhanced mothers' self-efficacy and sense of fulfilment in their role as mothers. Research by Bray et al. (2017) further highlights the transformative impact of peer support on caregivers' emotional and psychological well-being, while other studies emphasise the importance of maintaining stable social networks and peer support for family adaptability and well-being (Bray et al., 2017; Peer et al., 2014).

The study findings also highlighted that coping strategies are influenced by living situations and available family support. We must acknowledge that some of the mothers in our study did

not have positive experiences with their family, partners, friends, neighbours, and community. Mothering a child with a disability is a complex and often contradictory experience at many levels, shaped by varying perspectives within families and communities (Ryan et al., 2008). In addition, as our findings highlight, coping is not a 'one-size-fits-all' approach. Different coping strategies can be adaptive in different situations. Nevertheless, recognising the adaptability and resourcefulness and uncovering the diverse coping strategies used by mothers caring for CWID is important for developing targeted interventions and support programs tailored to caregivers' specific needs. Further research is needed to delve into the nuanced coping strategies and support of mothers of CWID in Nepal and other LMIC settings.

#### *Study limitations and future research*

This study has some limitations that should be acknowledged. First, it was conducted in an urban and semi-urban setting among a specific population utilising day care facilities in Province 3 of Nepal, and we did not consider the severity and level of dependency of CWID. Consequently, the findings may not be generalisable to mothers of CWID who do not attend day care facilities or reside outside the setting. Additionally, most of the population in Nepal resides in rural settings that are not represented in this study, thus limiting the broader applicability of the findings. Furthermore, the study's qualitative design and the constraints imposed by the COVID-19 pandemic necessitated conducting interviews online or by telephone rather than in person. While efforts were made to establish strong relationships with the participants through communication in their mother tongue and introductions from trusted organisations, the absence of face-to-face interactions may have impacted the depth and richness of the collected data. These limitations indicate the need to consider broader social and structural contexts when interpreting the findings.

Future research should encompass diverse geographic areas and participants from rural settings, adopt inclusive and participatory approaches that empower participants (for example, peer interviewing) and employ methods that facilitate in-depth data collection. Since informal supports were seen as crucial for the mothers in this study, these could be further developed as mothers' support groups, peer-mentoring groups or activities, self-care and ID awareness-raising initiatives. Policies for families of CWID and people living with ID should also be reviewed to address stigma and to provide low-cost, accessible services.

#### **Conclusion**

The findings of this study elucidate complex and culturally specific challenges faced by Nepali mothers caring for their CWID, particularly in the context of gender inequality, societal discrimination, stigma towards disability, financial hardships and limited access to formal support and resources. We also gained insights into some forms of coping strategies and support that these mothers use to manage their challenges, such as peer support, pride in

resourcefulness and spirituality. These findings indicate a pressing need for culturally appropriate and targeted support, resources and interventions to help these mothers manage emotional and social hardships and thus establish themselves as valued caregivers and advocates for their children.

### **Declaration of Interest**

The authors declare no conflicts of interest.

### **Acknowledgements**

The authors are grateful to the mothers who voluntarily participated in this study and acknowledge them for sharing their experiences with the researchers.

### **Funding Information**

A three-year doctoral student grant from the Liaison Committee for Education, Research and Innovation in Central Norway (reference no. 2019/3888) funded this study.

### **References**

- Acharya, S. and Sharma, K. (2021). Lived Experiences of Mothers Raising Children with Autism in Chitwan District, Nepal. *Autism Research and Treatment*, 2021.
- Adithyan, G. S. and Jacob, J. (2017). Positive and Negative Impacts on Caregivers of Children with Intellectual Disability in India. *Disability, CBR & Inclusive Development*, 28(2), 74-94.
- Altiere, M. J. and Von Kluge, S. (2009). Family Functioning and Coping Behaviors in Parents of Children with Autism. *Journal of Child and Family Studies*, 18, 83-92.
- Ambikile, J. S. and Outwater, A. (2012). Challenges of Caring for Children with Mental Disorders: Experiences and Views of Caregivers Attending the Outpatient Clinic at Muhimbili National Hospital, Dar es Salaam-Tanzania. *Child and Adolescent Psychiatry and Mental Health*, 6, 1-11.
- Aryal, R. P. and Aryal, B. (2022). Disability Stigma and Discrimination in Nepal: A Study of Pokhara Metropolitan City. *Asian Journal of Population Sciences*, 23-31.
- Banks, L. M., Kuper, H. et al. (2017). Poverty and Disability in Low-and Middle-income Countries: A Systematic Review. *PloS One*, 12(12), e0189996.
- Baxter, C., Cummins, R. A. et al. (2000). Parental Stress Attributed to Family Members with and without Disability: A Longitudinal Study. *Journal of Intellectual and Developmental Disability*, 25, 105-118.
- Beighton, C. and Wills, J. (2019). How Parents Describe the Positive Aspects of Parenting their Child who has Intellectual Disabilities: A Systematic Review and Narrative Synthesis.

- Journal of Applied Research in Intellectual Disabilities*, 32(5), 1255-1279.
- Bista, D. B. (1991). *Fatalism and Development: Nepal's Struggle for Modernization*. Calcutta: Orient Longman Ltd.
- Bray, L., Carter, B. et al. (2017). Parent-to-parent Peer Support for Parents of Children with a Disability: A Mixed Method Study. *Patient Education and Counseling*, 100(8), 1537-1543.
- Buettgen, A., Gorman, R. et al. (2015). Employment, Poverty, Disability and Gender: A Rights Approach for Women with Disabilities in India, Nepal and Bangladesh. In N. Khanlou and F. Pilkington (eds.). *Women's Mental Health: Resistance and Resilience in Community and Society* (pp. 3-18). Cham: Springer International Publishing.
- Caputo, J., Pavalko, E. et al. (2016). The Long-term Effects of Caregiving on Women's Health and Mortality. *Journal of Marriage and Family*, 78, 1382-1398.
- Clark, C. J., Ferguson, G. et al. (2019). Mixed Methods Assessment of Women's Risk of Intimate Partner Violence in Nepal. *BMC Women's Health*, 19, 1-8.
- Clarke, V., Braun, V. et al. (2015). Thematic Analysis. In Smith, J.A. (ed.). *Qualitative Psychology: A Practical Guide to Research Methods* (pp. 222-248). London: SAGE Publications.
- Coffey, C., Revollo, P. E. et al. (2020). *Time to Care: Unpaid and Underpaid Care Work and the Global Inequality Crisis*. UK: Oxfam. Available at: <http://hdl.handle.net/10546/620928>.
- Dahal, T., Topping, K. et al. (2022). Patriarchy, Gender Norms and Female Student Drop out from High Schools in Nepal. *Compare: A Journal of Comparative and International Education*, 1-19.
- Demir, O. B. and Yilmaz, F. T. (2023). Religious Coping and Fatalism on Perception of Care Burden in Caregivers of Patients with Cerebral Palsy in Turkey: A Cross-Sectional and Correlational Study. *Journal of Religion and Health*, 1-15.
- Fernández-Alcántara, Manuel, et al. (2017). Parenting a Child with a Learning Disability: A Qualitative Approach. *International Journal of Disability, Development and Education*, 64(5), 526-543.
- Furrukh, J. and Anjum, G. (2020). Coping with Autism Spectrum Disorder (ASD) in Pakistan: A Phenomenology of Mothers Who Have Children with ASD. *Cogent Psychology*, 7(1), 1728108.
- Ghosh, A., Singh, A. et al. (2017). *A Trapeze Act: Women Balancing Paid Work and Unpaid Care Work in Nepal* (Institute of Development Studies). Sussex, UK: University of Sussex.
- Glenn, E. N. (2010). *Forced to Care: Coercion and Caregiving in America*. London: Harvard University Press.
- Government of Nepal. (2020). *Beyond graduation: Productive transformation and prosperity* (National Human Development Report of Nepal). Kathmandu, Nepal: UNDP.
- Gutierrez, A. P., McCurley, J. L. et al. (2017). Fatalism and Hypertension Prevalence, Awareness, Treatment and Control in US Hispanics/Latinos: Results from HCHS/SOL

- Sociocultural Ancillary Study. *Journal of Behavioral Medicine*, 40, 271-280.
- Gyawali, G. P. (2020). Provincial Poverty in Nepal. *Patan Pragya*, 7(1), 66-77.
- Province Policy and Planning Commission, Government of Province No. 3, Hetauda, Nepal (2019). A Province with Many Prospects. Available at: <https://nepalindata.com/resource/A-PROVINCE-WITH-MANY-PROSPECTS---AN-INTRODUCTION-TO-PROVINCE-NO--3/>.
- Hassall, R., Rose, J. et al. (2005). Parenting Stress in Mothers of Children with an Intellectual Disability: The Effects of Parental Cognitions in Relation to Child Characteristics and Family Support. *Journal of Intellectual Disability Research*, 49, 405-418.
- John, A. (2012). Stress Among Mothers of Children with Intellectual Disabilities in Urban India: Role of Gender and Maternal Coping. *Journal of Applied Research in Intellectual Disabilities*, 25(4), 372-382.
- Karaca, A. and Şener, D. K. (2021). Spirituality as a Coping Method for Mothers of Children with Developmental Disabilities. *International Journal of Developmental Disabilities*, 67(2), 112-120.
- Katharine Runswick-Cole and Sara Ryan (2019). Liminal Still? Unmothering Disabled Children. *Disability and Society*, 34 (7-8), 1125-1139.
- Kizilarslan, V. (2020). Turkish Validity and Reliability Study of the Fatalism Scale. Master thesis. Atatürk University in Erzurum, Turkey.
- Kaniamattam, M. and Oxley, J. (2022). Unpacking the Varied Roles of Mothers of Children with Developmental Disabilities in South India. *Disability & Society*, 37(1), 38-62.
- Lord, A., Sijapati, B. et al. (2016). Disaster, disability, & difference: A study of challenges faced by person with disabilities in post-earthquake Nepal (UNDP Nepal). Available at: <https://dpnet.org.np/uploads/files/A%20Study%20of%20the%20Challenges%20Faced%20by%20Persons%20with%202019-04-03%2009-35-04.pdf>.
- Luong, J., Yoder, M. K. et al. (2009). Southeast Asian Parents Raising a Child with Autism: A Qualitative Investigation of Coping Styles. *The Journal of School Nursing*, 25, 222-229.
- Lundy, H. F. (2012). Parental Stress, Socioeconomic Status, Satisfaction with Services, and Family Quality of Life Among Parents of Children Receiving Special Education Services. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 73, 85.
- Magaña, I., Martínez, P. et al. (2020). Health Outcomes of Unpaid Caregivers in Low- and Middle-Income Countries: A Systematic Review and Meta-analysis. *Journal of Clinical Nursing*, 29, 3950-3965.
- Maridal, H. K., Bjorgaas, H. M. et al. (2021). Psychological Distress Among Caregivers of Children with Neurodevelopmental Disorders in Nepal. *International Journal of Environmental Research and Public Health*, 18.
- Masulani-Mwale, C., Mathanga, D. et al. (2016). Parenting Children with Intellectual Disabilities in Malawi: The Impact that Reaches Beyond Coping? *Child: Care, Health and Development*, 42, 871-880.

- Maxwell, J.A. (2013). *Qualitative Research Design: An Interactive Approach*. Los Angeles: Sage.
- McConnell, D. and Savage, A. (2015). Stress and Resilience Among Families Caring for Children with Intellectual Disability: Expanding the Research Agenda. *Current Developmental Disorders Reports*, 2, 100-109.
- McNally, A. and Mannan, H. (2013). Perceptions of Caring for Children with Disabilities: Experiences from Moshi, Tanzania. *African Journal of Disability*, 2, 1-10.
- Mbugua, M. N., Kuria, M. W. et al. (2011). The Prevalence of Depression Among Family Caregivers of Children with Intellectual Disability in a Rural Setting in Kenya. *International Journal of Family Medicine*, 2011.
- Neoh, M. J. Y., Airoidi, L. et al. (2022). Mental Health of Mothers of Children with Neurodevelopmental and Genetic Disorders in Pakistan. *Behavioral Sciences*, 12(6), p.161.
- Ngo, H., Shin, J. Y. et al. (2012). Stigma and Restriction on the Social Life of Families of Children with Intellectual Disabilities in Vietnam. *Singapore Medical Journal*, 53, 451-457.
- Oti-Boadi, M. (2017). Exploring the Lived Experiences of Mothers of Children with Intellectual Disability in Ghana. *Sage Open*, 7(4). Available at: <https://doi.org/10.1177/2158244017745578>.
- Peer, J. W. and Hillman, S. B. (2014). Stress and Resilience for Parents of Children with Intellectual and Developmental Disabilities: A Review of Key Factors and Recommendations for Practitioners. *Journal of Policy and Practice in Intellectual Disabilities*, 11(2), 92-98.
- Prajapati, P. K. (2008). Feminist Movements from Global to Local: Has it helped Women Empowerment Process? Patriarchy and Status of Nepali Women. Nepal Research.
- Puri, M., Misra, G. et al. (2015). Hidden voices: Prevalence and Risk Factors for Violence against Women with Disabilities in Nepal. *BMC Public Health*, 15(1), 1-11.
- Rodrigues, S.A., Fontanella, B.J. et al. (2019). A Qualitative Study about Quality of Life in Brazilian Families with Children who have Severe or Profound Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, 32(2), 413-426.
- Runswick-Cole, K. and Goodley, D. (2018). The 'Disability Commons': Re-thinking Mothering through Disability. In K. Runswick-Cole, T. Curran and K. Liddiard (eds.). *The Palgrave Handbook of Disabled Children's Childhood Studies* (pp. 231-246). London: Palgrave.
- Ryan, S. and Runswick-Cole, K. (2008). Repositioning Mothers: Mothers, Disabled Children and Disability Studies. *Disability & Society*, 23(3), 199-210.
- Rydzewska, E., Dunn, K. et al. (2021). Mental Ill-health in Mothers of People with Intellectual Disabilities Compared with Mothers of Typically Developing People: A Systematic Review and Meta-analysis. *Journal of Intellectual Disability Research*, 65(6), 501-534.
- Schalock, R. L. (2011). The Evolving Understanding of the Construct of Intellectual Disability. *Journal of Intellectual & Developmental Disability*, 36, 227-237.

- Scherer, N., Verhey, I. et al. (2019). Depression and Anxiety in Parents of Children with Intellectual and Developmental Disabilities: A Systematic Review and Meta-analysis. *PLoS One*, 14(7), e0219888.
- Seedat, S. and Rondon, M. (2021). Women's Wellbeing and the Burden of Unpaid Work. *BMJ*, 2021, 374.
- Shahrier, M. A., Islam, M. N. et al. (2016). Perceived Stress and Social Adaptation of the Primary Caregivers of Children with Intellectual Disabilities. *The Spanish Journal of Psychology*, 19, E87.
- Shorey, S., Ng, E. D. et al. (2019). The Parenting Experiences and Needs of Asian Primary Caregivers of Children with Autism: A Meta-synthesis. *Autism*, 24(3), 591–604. Available at: doi:10.1177/1362361319886513.
- Solomon RC. (2003) On Fate and Fatalism. *Philosophy of East and West*, 53(4), 435-454. Available at: <http://www.jstor.org/stable/1399977>.
- Sonpal, D. and Kumar, A. (2012). 'Whose Reality Counts?': Notes on Disability, Development and Participation. *Indian Anthropologist*, 71-90.
- Shrestha, S., Shrestha, N. K. et al. (2009). A Community Assessment of Poverty and Disability among Specific Rural Population Groups in Nepal. *Asia Pacific Disability Rehabilitation Journal*, 20(1), 83-98.
- Thrush A. and Hyder, A. (2014). The Neglected Burden of Caregiving in Low- and Middle-Income Countries. *Disability and Health Journal*, 7, 262-272.
- Tilahun, D., Hanlon, C. et al. (2016). Stigma, Explanatory Models and Unmet Needs of Caregivers of Children with Developmental Disorders in a Low-income African Country: A Cross-sectional Facility-based Survey. *BMC Health Services Research*, 16.
- Tomanik, S., Harris, G. E. et al. (2004). The Relationship between Behaviors Exhibited by Children with Autism and Maternal Stress. *Journal of Intellectual and Developmental Disability*, 29, 16-26.
- UNICEF, National Planning Commission (NPC), & New Era. (2001). *A Situation Analysis of Disability in Nepal*. Kathmandu, Nepal: NPC.
- United Nations Development Programme. (2010). *Human Development Report, 2010: The Real Wealth of Nations— Pathways to Human Development*. London/New York: Palgrave–Macmillan.
- UNFPA Annual Report (2012). Promises to Keep. Available at: <https://www.unfpa.org/publications/unfpa-annual-report>.
- Vadivelan, K., Sekar, P. et al. (2020). Burden of Caregivers of Children with Cerebral Palsy: An Intersectional Analysis of Gender, Poverty, Stigma, and Public Policy. *BMC Public Health*, 20, 1-8.
- Vaidya, S. (2016). *Autism and the Family in Urban India: Looking Back, Looking Forward*. India: Springer.
- Van der Mark, E.J., Conradie, I. et al. (2019). 'We Create our Own Small World': Daily Realities of Mothers of Disabled Children in a South African Urban Settlement. *Disability & Society*, 34(1), 95-120.



- Wang, P., Michaels, C.A. et al. (2011). Stresses and Coping Strategies of Chinese Families with Children with Autism and Other Developmental Disabilities. *Journal of Autism and Developmental Disorders*, 41, 783-795.
- Wu, C. S. and Liu, Y. J. (2014). Religious Coping in Life Difficulties: A Case Study of Taiwanese Folk Religion Female Believers. *Mental Health, Religion & Culture*, 17(2), 210-218.