Intellectual and Developmental Disabilities

Informal Support Needs of Family Caregivers of Adults with Intellectual and/or Developmental

Disabilities in India
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COMPETING INTERESTS DECLARATION

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Abstract

Informal supports reduce stress and improve well-being for family caregivers of adults with intellectual and/or developmental (IDD) disabilities. A strengths-based mixed methods needs assessment was conducted with a convenience sample of 100 family caregivers in India, to understand their informal needs and ways to obtain informal supports. Results showed that fewer caregivers received informal supports. Unemployed caregivers had higher support needs to interact with others. Caregivers of adults who also had cerebral palsy were less likely to need opportunities to meet and talk with other caregivers. Caregivers believed that having more caregiver associations would help in better care provision for themselves and their family members with IDD. Seeking supports outside government/other formal systems seems like a promising family support strategy for caregivers in India.

Keywords: Intellectual and/or developmental disability; family caregiver; informal supports; mixed methods; needs assessment

Background

Caregiving is more difficult in non-Western countries such as India compared to their

Western counterparts because of lack of or difficulty in accessing supports and services for

individuals with intellectual and/or developmental disabilities (IDD) and insufficient money to

pay for the limited services (Ghosh & Magaña, 2009). Unlike the western countries where state

and international agencies provide supports and services to people with disabilities (PWD), in

India, much of the responsibility falls on traditional families and communities to care for their

family members with disabilities because of poor social security mechanisms (Mehrotra, 2011).

Despite India ratifying the United Nations Convention on the Rights of Persons with Disabilities

(UNCRPD) and having human rights-based disability policies to improve the situation and align

with a rights-based agenda for PWDs, the laws and legislation still fail to address the needs of

PWD and their family caregivers. There is a large gap between policy formulation and the

implementation of policies. While there is a broader issue of governance structures and

processes, and limited capacity at public and private levels, there is also a lack of motivation for

implementing disability policies (Dias, 2013; Lang, Kett, Groce, & Trani, 2011). There is still a

lack of support for improving the lives of PWD and their family caregivers in India. This isdue to

factors such as the government's lack of a strong commitment to inclusion, systematic exclusion,

stigma toward PWD, lack of job opportunities, limited future planning as parents and family

caregivers age, insufficient adult life planning, slow implementation of needed services,

inadequate trained personnel, and existing cultural norms (Cuskelly, 2009; Kalyanpur, 2008).

Gupta and Singhal (2005) found that demand for services exceeded the availability of

professionals, and that the services were very expensive. Similarly, Kumar and Akbar (2004)

found that almost 76% of the mothers of children who had IDD along with other co-disabilities

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did not receive the required government benefits. Failure of the government and the formal systems in India necessitates that family caregivers of people with IDD and other disabilities obtain supports from informal sources such as family, friends, and other caregivers. Studies have shown that when family caregivers of adults with IDD are either dissatisfied with formal services or do not receive adequate access to formal services, informal supports have been associated with greater caregiver well-being (Robinson et al., 2016).

Family caregivers of adults with IDD face unique challenges, such as continuing caregiving until their death or their incapacity, and providing personal care, complex medical and nursing tasks, financial and instrumental assistance, emotional support, home supports and much more (Heller et al., 2015). Family caregivers of individuals with IDD also report experiencing social isolation (Gupta, & Kaur, 2010). While many families adapt well to having a person with IDD, the lifelong impact of caregiving can affect their economic, health and psycho-social well-being (Heller & Schindler, 2009). Research indicates that caregiving for individuals with IDD is tiring and stressful, exacerbated by insufficient and unreliable support services (Griffith & Hastings, 2014) leading to a negative impact on quality of life (Girimaji, 2011).

Bronheim and colleagues (2006) mentioned that most promising and effective family supports are family-centered, and based on the values, preferences, culture, and family needs. Ethnicity and culture have a major influence how family support is provided, how caregiving is valued and how families engage in caregiving experience (Ravindran & Myers, 2012). For example, in Asian societies, the concept of collectivism shapes caregiving experiences, while in Western societies, it is individualism that plays a significant role. The family caregivers in collectivistic cultures rely more on family support compared to the caregivers from the Western cultures who tend to be more individualistic. However, there may be more shame and blame

associated with being a caregiver for a person with IDD in a collectivistic society as compared to caregivers in individualistic societies, thereby resulting in less family support (Ghosh & Magaña, 2009). Furthermore, in general, cultural beliefs about the causes of disability, such as the cycle of life, rebirth, and karma in Buddhist, Hindu, and Confucian philosophies, as well as ideas about fate or possession of spirits in Islamic cultures, influence the way caregiving is provided in non-Western societies compared to Western societies. Family caregivers may treat people with IDD more kindly so that they could earn merit for a better birth in their next lives (Ghosh & Magaña, 2009). Regarding the coping mechanisms used by family caregivers, the Western approach is usually problem-focused or emotion-focused, whereas the non-Western approach to coping is shaped by collectivism as a cultural value, interdependence as a social value, and using family for social support (Ghosh & Magaña, 2009).

Studies have shown that family supports were most effective when caregivers received informal supports (extended family, friends, neighbors, and faith communities) in addition to formal supports (Boehm & Carter, 2016; Bronheim et al., 2006). According to Dunst and colleagues (1986), "social support" is a broad concept that encompasses formal supports (e.g., respite services, healthcare services) and informal supports (e.g., family, friends, neighbors, other caregivers), and includes emotional and psychological support, physical and instrumental assistance, and informational support or advice sharing. Additionally, social connections (Palamaro Munsell et al., 2012) and social activities (Cramm, & Nieboer, 2011) that include visiting family or friends and interacting with others in the community have been shown to decrease caregiver stress and improve their well-being.

It is important to understand the issues, needs and challenges of the family caregivers of adults with IDD who are often isolated, stigmatized, and marginalized in Indian society. In

addition to needing supports to care for their family members with IDD, caregivers also need supports for themselves that would help them to improve their social interactions and their own well-being. Additionally, there is a need to explore resources and supports outside of the formal support system that may help family caregivers to take care of themselves thereby reducing caregiving stress and improving their well-being. This research uses a mixed methods participatory approach to needs assessments by applying a transformative paradigm. This research design has the potential to empower the family caregivers of adults with IDD to identify their own needs, prioritize them and take action to solve the unmet needs. A human rights approach with UNCRPD framework are used in the study to address the contextual barriers and unmet support needs of the caregivers of adults with IDD, so that they could obtain equal opportunities and lead respectful and meaningful lives.

To better understand the assets and support needs (that help them interact with others and improve their well-being) of Telugu- and English-speaking family caregivers of adults with IDD in India, the following research questions were formulated:

1. Quantitative: a) How do the support needs for interacting with others differ by caregiver and family member with IDD characteristics? and b) What are the predictors (caregivers' and family members with IDD' characteristics) of the sum of and highest support needs for interacting with others?

2. Qualitative: a) What are the assets, strengths and supports of family caregivers? and b) What are the unmet support needs of family caregivers?

Methods

Design

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We conducted a concurrent mixed methods strengths-based needs assessment (NA) study using an exploratory and descriptive research design within the framework of a transformative paradigm. The study used a purposive sample of family caregivers of adults with IDD. The quantitative survey was administered to 100 caregivers, and 15 caregivers out of the sample participated in semi-structured interviews. Additionally, snowballing technique was used for recruitment. An advisory group comprising of agency director, agency staff members, and family caregivers of adults with IDD was formed to provide guidance on research design and implementation, cross cultural adaptation and translation of instruments, and proposing future action plans. To ensure cross-cultural adaptation of the instruments and culturally relevant translations, pilot testing was conducted with three family caregivers. They were asked to provide suggestions to improve the instruments. Based on the pilot testing, no edits, amendments or revisions were made because the participating family caregivers stated that the translations of the data collection instruments seemed culturally relevant and cross-culturally well-adapted. Separate quantitative and qualitative data analyses followed by integration during interpretation were done (Halcomb & Hickman, 2015). Institutional Review Board at University of Illinois at Chicago's (UIC) provided approval for the study, and for continuing oversight at the partner agencies in India.

Participants

The study was conducted in partnership with Durgabai Deshmukh Vocational Training and Rehabilitation Centre (DDVTRC) for Handicapped, Hyderabad, India, and National Institute for the Empowerment of Persons with Intellectual Disabilities (NIEPID), Secunderabad, India. The agency staff shared names and phone numbers of potential participants with the

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researcher. To be eligible for the study, they needed to be Telugu and/or English speaker, 18 years and above, and providing care to an adult with IDD. Paid caregivers and caregivers less than 18 years were excluded from the study. Both recruitment and verbal consenting process were conducted over phone.

Measures and Data Collection

Needs Assessment Survey

A 9-item survey on support needs for interacting with others was used to collect quantitative data from participants. "Survey on support needs for interacting with others" refers to any support needs that the caregivers required for improving their social interactions and well-being. This survey was part of a larger study with 37 items that included information needs, support needs for caring for the family members with IDD and service needs, in addition to support needs for interacting with others. Review of multiple caregiver needs assessments and incorporation of informal feedback from the advisory board and service professionals in India was used to finalize the survey. The Support Needs items of interacting with others were: 1) I need to have someone in my family that I can talk to more about my concerns; 2) I need to have more friends that I can talk to; 3) I need to have more opportunities to meet and talk with other caregivers of adults with IDD; 4) I would like to meet more regularly with a counselor (psychologist, social worker, psychiatrist) to talk about my concerns; 5) I need to talk more to a religious or spiritual person who could help me deal with my concerns; 6) I need to have more time for myself; 7) I need to find family to family connecting activities like support groups, parent-to-parent networks, advocacy organizations, etc.; 8) I need help to cope with the stress of caring for my family member with IDD; and 9) I need other help in interacting with others.

The responses were given with a 5-point Likert-type scale, for each needs item, namely: this is already available to me (1); I definitely do not need help with this (2); I might not need

help with this (3); I might need help with this (4); and, I definitely need help with this (5). The independent measures included the caregiver and the family member with IDD characteristics. The outcome measures included the mean and highest frequency of the items for support needs for interacting with others.

In-Depth Interviews with Caregivers of Adults with IDD

Interviews with caregivers followed an open-ended semi-structured script designed to identify the strengths, assets, and resources of family caregivers, as well as their information, support, and service needs. A semi-structured interview guide was used for the interviews because it allowed flexibility and ease in facilitation. An interview protocol and guide for the interviews was created including 12 to 15 questions and probe questions to aid participants to discuss their needs and assets in-depth. The interview guide was structured around the three foci of the research: (a) interview questions on strengths, supports and resources; (b) interview questions on needs; and (c) interview questions on human rights. Some of the examples of the interview questions included: What supports do you have to help you care for the person with a disability? What are some of your support needs as a family caregiver that are not being met? What can the government do to better support your human rights as a caregiver of an adult with IDD?

The selection of the mode of interviews, i.e., telephone interviews or video interviews (e.g., Facetime, Skype, and WhatsApp etc.) was based on the participants' preferences. An appreciative inquiry model (Watkins, West-Meiers, & Visser, 2012) was used to be respectful and sensitive to the participants' cultural values and beliefs. Thirteen participants interviewed in Telugu and 2 participants interviewed in English. The interviews were audio-recorded and transcribed verbatim into Telugu. The transcribed interview responses were translated into English by bilingual English and Telugu-speaking experienced translator(s) and were further verified against the Telugu versions by the first author and a bilingual colleague.

Data Analysis

IBM SPSS, version 27 was used to conduct quantitative data analyses. Descriptive

statistics of caregivers and family members with IDD were conducted. Multiple logistic

regression analysis was conducted to examine associations between outcome variables and the

predictor variables. To determine the robustness of the model by selecting 1000 number of

random subsets from original dataset (Banjanovic & Osborne, 2016), bootstrapping method was

used. A standard level of significance associated with probability levels of P <0.05 was used. The

rigor of the quantitative data was established by ascertaining reliability (Cronbach's Alpha) of the

data (Plano Clark & Ivankova, 2016). The reliability (internal consistency) level is good at 0.86. Due

to the small sample size, factor analysis for content validity was not performed. For qualitative

data, thematic analysis was conducted using the six-step framework (Braun & Clarke, 2006).

ATLAS-TI (Version 8) was used to conduct index coding, with codes generated from literature

review, detailed field notes, and preliminary reading of transcripts (Deterding & Waters, 2021).

Triangulation was done using member check method with two participants to increase the

credibility of findings. Finally, integration of quantitative and qualitative data was done to

interpret data.

Results

Quantitative

Caregivers' and their family members with IDD characteristics

The mean age of caregiver participants was 46.15 years (SD = 12.13, range = 19–71

years). Majority of the caregivers were female (63%), less than 50 years old (60%), had

educational qualifications of at least some college (65%), had an intermediate or advanced

proficiency in English (58%), were not employed (53%), had four to five family members in the

household (59%) and had ₹ 5,00,000 (US $ 7,000) or less as their family annual income (89%) (Table I).

Insert Table I Here

The mean age of family members with IDD was 25.21 years (SD = 6.46, range = 18-47 years). Majority of family members with IDD were male (76%); between 18-24 years (60%); had no other conditions related to ID (48%) compared to autism (15%), cerebral palsy (6%), Down syndrome (15%) or other conditions (16%); and had moderate ID level (46.5%) compared to borderline (11.1%), mild (27.3%) and severe (15.2%) ID levels. There were no group differences in age, conditions related to ID and ID levels (Table II).

Insert Table II Here

Support Need Items for Interacting with Others – Distribution Scores

The most important support needs to promote interaction with others were to help: cope with the stress of caring for the family member with IDD (Mean = 3.99, SD = 1.15), find family-to-family connecting activities like support groups, parent-to-parent networks, advocacy organizations, etc. (Mean = 3.91, SD = 1.20), have more opportunities to meet and talk with other caregivers of adults with IDD (Mean =3.82, SD = 1.47), have more time for themselves (Mean = 3.75, SD = 1.40), and meet more regularly with counselor to talk about their concerns (Mean = 3.68, SD = 1.38).

Independent-samples T-Test and One way ANOVA

Independent-samples t-test showed that there was a significant difference in the sum of support needs for interacting with others for caregivers who were employed (Mean =30.68, SD=8.01) and those who were not employed (Mean =34.02, SD=8.75; t(98)=1.98, p = 0.047, denoting that unemployed caregivers had more support needs for interacting with others than employed

caregivers (Table III). There were no significant group differences in support needs for interacting with others among family member with IDD characteristics (Table IV).

Insert Table III Here

Insert Table IV Here

Multiple Linear Regression

The results of the multiple linear regression for the outcome variable, support needs of interacting with others, indicated that only family members with IDD's cerebral palsy diagnosis contributed significantly to the model (B = -8.76, 95% CI [-16.60, -1.17]). It meant that the caregivers of adults with IDD who also had cerebral palsy needed less support needs to interact with others compared to those with ID only diagnosis. The overall model was not statistically significant for support needs of interacting with others, $F(14,84)=1.22$, $p=0.28$, $R^2_{adjusted}=0.030$, and the model explained 3.0% of the variance for the dependent variable that could be explained by the independent variables. Lower R^2 for both the models indicate that either there are other predictor variables that could contribute to support needs of caring for the family member with IDD and for interacting with others or that the individual support need items need to be considered as outcome variables rather than the sum of the individual support need items (Table V).

Insert Table V Here

Multiple Logistic Regression

To distinguish the individual needs and their predictors, we conducted multiple logistic regression analyses to examine the association between the characteristics of family caregiver and family member with IDD and their opportunities to meet and talk with other caregivers of adults with IDD. This item was chosen as the outcome variable for the analysis, as it emerged as

the most frequently reported support need for interaction with others (50%). Independent variables with a p value cut-off point of 0.20 in the univariate logistic regression analysis were included in the multiple logistic regression model along with basic caregiver (gender, age) and family member with IDD (gender, age, conditions related to ID, ID level) characteristics.

Results of the multiple logistic regression indicated that caregivers who had family members with IDD with IDD diagnosed with cerebral palsy (B = 2.61, 95% CI [-25.58, -19.63]) were less likely to definitely need more opportunities to meet and talk with other caregivers of adults with IDD (Table VI).

<div align="center">**Insert Table VI Here**</div>

Qualitative

Informal supports for the caregiver participants were provided by family, friends, neighbors, peers, community and their social networks. Having informal supports was one of the key components for caregivers of adults with IDD to take care of themselves and their family members with IDD with IDD better.

Informal support from family, friends, and other caregivers

Informal support to the caregivers was primarily provided in the form of emotional and/or instrumental support. While emotional support refers to "the verbal and nonverbal processes by which one communicates care and concern for another, offering reassurance, empathy, comfort, and acceptance" (American Psychological Association, 2022), instrumental support refers to providing tangible aid that includes financial support, material resources, or support in doing tasks such as household chores (Cohen & Wills, 1985).

Most of the caregivers (n=13) received support from their families, whether immediate or extended. They received support from their spouses, children, siblings, in-laws, and relatives.

Support from the spouse seemed to be the primary informal support available to some of the caregivers. One caregiver (CG4) said "I have my husband's full cooperation." The spouses provided both emotional and instrumental support in taking care of the adults with IDD. Emotional support obtained by the caregivers included reassurance and expressions of love and empathy for their family members with IDD. For example, one caregiver (CG4) felt relieved because her son-in-law reassured her that he and his wife would take care of her daughter with IDD. She said, "My son-in-law also gives full support. He says, if something unfortunate happens tomorrow, your daughter and I are there."

Another type of support provided by families was instrumental support. Instrumental support included any tangible and physical help provided to caregivers such as taking care of the adult with IDD when the caregiver had to go out for any errands, teaching family member with IDD about how to behave, support for self-employment, taking them to places like hospitals, visiting them and spending time with them if not living in the same house. For example, one of the caregivers said, "When I used to go for work related camps, I used to drop him in their home. So, they used to take care of him till I got back." The caregivers rarely received financial support from extended family members. A few caregivers said that their family was their strength. For those who lived in a joint family, they received huge support from their family members in taking care of their family member with IDD, when needed.

Many caregivers (n=10) said that they received emotional and/or instrumental support from friends and neighbors. They provided emotional support by showing encouragement and empathy, and by being welcoming and inclusive. For example, one caregiver (CG2) said, "I have got some good support here, like my neighbors and all. They are very caring. They will not feel awkward, or they will not feel bad, or they will not feel…any feeling of uneasiness, or something

like that. They are also very mingling with her." Regarding instrumental support, neighbors and friends would help the caregivers whenever needed, such as, taking them to hospital or calling a cab if needed, taking care of their family member with IDD till they came back from shopping or running any errands. One caregiver (CG14) said, "Whenever I go out, or I go to market and get late, they take care of him until I return. That means, they babysit him for that time."

Only four participants (n=4) mentioned that they received support from other caregivers. Some of these caregivers also established caregiver associations with other parents. What was unique about the support provided by other caregivers was that, in addition to the emotional and instrumental support, they provided informational support to the caregivers. For example, CG3 said, "…you see, there are experienced parents, we learn from them. Like that, we got Southern [disability certificate for the family members with IDD] done, applying, and things like these." It was understood that caregivers received emotional support from other caregivers when they mentioned that "I am not as close to the other family members as I am with school members and other parents" (CG4) or that "When I was with other parents, it got a little…there is sadness, at least we forget [our sadness] when [we are] with them [other parents]" (CG5). Other caregivers would also provide instrumental support by giving financial aid or buying medicines when the caregivers could not afford them.

Two participants mentioned that they got support from paid house help, when needed. One of the participants (CG4) talked about how paid house helps were more helpful than family members when needed and so she preferred to take help from the servant maids.

If I have any trouble, I will rather take help from the servant maid, but I will not go to relatives. I had an operation a while ago, I had an accident once. Those three days, I

asked the servant maid to stay and take care of my daughter. During those times, the

servant maids were more helpful than family members.

Overall, availability of informal support played a very important role and served as a

strength for the caregivers in providing care to their family members with IDD.

Informal support needs

Though some of the caregivers received informal support from family members, friends,

neighbors, and other caregivers, many others felt that they needed more informal supports from

family, friends, and peers. A few caregivers mentioned that they did not receive support from

family and friends. Some of the reasons for not getting family support were family members

being selfish and not cooperating, not being inclusive, having their own problems or because

they live far away. A caregiver (CG 11) said, "Before, I used to think that my daughters would

take care. My sons-in-law…they do not allow them also to take care of him. There is no way my

younger daughter can take care of him, her house is very far."

One of the caregivers mentioned that, to get support from friends, they need to be able to

spend time with them at some point, which they are unable to do because of their caregiving

responsibilities: "I lost my social contacts because of them. With social contacts, I have to spend

time with them. So, if I give my time to them, I won't have time for social contacts. So, because

of them, my family life too has gone bad" (CG7). Many caregivers felt that they get more such

support in villages than in cities. For example, a caregiver (CG5) said, "No one talks to anyone

much. No one gives support here. Not at all. If it is a village, there might be some support but

here, there is nothing."

Only four caregivers mentioned that having more parent peer support groups and parent

associations like Parivaar and better communication among them would be helpful for them to

get support. A caregiver (CG11) said, "…there should be more parents support, there should be parents support, there should be communication among parents, you should come as groups, then we can do anything." Five caregivers mentioned that they wanted their family members with IDD to get supports to participate in social activities, spend quality time with others and engage with people meaningfully, even if it's on like, WhatsApp. One of the caregivers (CG8) mentioned that there are no support groups for adults with IDD: "I want him to have a…his social life. That is what…I want to give him a social life, a respectable life, where…a place where he can spend quality time, learn and even serve the people."

Clearly, there is an imminent need to look for alternative informal support systems for those who do not receive enough informal support from family and friends, such as peer support groups for caregivers, caregiver associations, and support groups for adults with IDD.

Recommended initiatives and strategies to improve informal supports

Caregivers listed some strategies that could improve informal supports as well as improve ways in which caregivers could equip themselves to take care of their family members with IDD better. The caregivers believed that, instead of depending on external help, they would be able to take care of themselves and their family members with IDD better, advocate better for themselves, and access more information about disability related laws and policies, if the caregivers came together and supported each other or if they established more caregiver organizations.

So, people in this area, whoever has kids like these, if they all gather to do something, find ways for betterment of kids, change will come in that particular area. Like that, everywhere it will… people will become aware, so, slowly if it increases slowly, instead

of depending more on the institutions, if individuals who can take care of themselves increase, or these ten people doing it themselves, then betterment will come. (CG1)

Conversations with the caregivers clearly indicated that, in addition to the need for a robust formal support structure in place, there clearly is a need for a strong informal support system, whether traditional or unconventional.

Discussion

Though India ratified the UNCRPD and enacting disability-related laws and policies, there is still a lack of support from the government for providing supports to family caregivers of adults with IDD in India because of factors such as lack of commitment to inclusion systematic exclusion, slow implementation of needed services, inadequate trained personnel (Cuskelly, 2009; Kalyanpur, 2008). Furthermore, Lang and colleagues (2011) and Dias (2013) described that, while there was a broader issue of governance structures and processes, and limited capacity at public and private levels, there was also a lack of motivation for implementing disability policies. Therefore, supports outside the government and other formal systems, may play an equal, if not more important role in improving the caregiving experiences of families caring for people with IDD. As Kaufmann and colleagues (2018) rightly said, "the formal institutions capture rules and government structures, while the informal institutions focus on ideology and culture" (p. 387). By seeking out supports from outside the government and other formal systems, caregivers can try to move away from red tape and bureaucratic hurdles, and embrace like-mindedness in cultural beliefs and political ideology.

The quantitative analysis results shows that the following were the most important support needs to interact with others: needing help to cope with the stress of caring for the family member with IDD; finding family to family connecting activities like support groups, parent-to-

parent networks, advocacy organizations, etc.; having more opportunities to meet and talk with other caregivers of adults with IDD; having more time for themselves; and meeting more regularly with a counselor to talk about their concerns.

Furthermore, family caregivers who were currently not employed had higher support needs to interact with others compared to those who were employed. It has been shown that employed family caregivers report higher well-being compared to non-employed family caregivers (Coughlin, 2010). The quantitative finding that non-employed family caregivers have higher support needs for interacting with others compared to those who are employed suggests potential benefits of employment, such as increased social support through interactions and socialization with colleagues, and financial security (Coughlin, 2010). The availability of respite services for family caregivers and day programs for their family members with IDD can provide a break from their caregiving responsibilities and allow them to work.

Finally, caregivers who had family members with IDD with IDD diagnosed with cerebral palsy were less likely to "definitely need" more opportunities to meet and talk with other caregivers of adults with IDD. This finding is consistent with findings from studies that compared the needs of caregivers of individuals with cerebral palsy and autism (Blacher & McIntyre, 2006; Kumar et al., 2013), which showed that individuals with cerebral palsy had less maladaptive behaviors compared to individuals who were diagnosed with autism. Moreover, compared to family caregivers of individuals with other developmental disabilities including cerebral palsy and intellectual disability, family caregivers of individuals with autism had greater difficulties accessing services (Boulet, Boyle, & Schieve, 2009; Krauss, Gulley, Sciegaj, & Wells, 2003) and had higher unmet needs (Cadman et al., 2012). These studies allude to family caregivers of individuals with cerebral palsy may need less support compared to other family

caregivers. However, more research needs to be conducted comparing caregivers of individuals with cerebral palsy to caregivers of individuals with other developmental disabilities to understand the complex relationships between family member with IDD level of functioning and behavioral issues, and other contributing factors such as support from spouses and ability to participate in community events.

The qualitative analysis shows that very few caregivers received support from other caregivers or caregiver associations, in addition to receiving support from family members and friends. The distinctive quality about the supports received from other caregivers was that, in addition to the emotional and instrumental support, they received informational support as well. Some of the caregivers believed that having more parent peer support groups and parent associations like Parivaar (National Confederation of Parents Organization, 2023) would be helpful for them to get support and do anything, and that they could depend upon other caregivers more if there was better communication amongst them. The caregivers strongly suggested that instead of depending on external help, having more caregiver associations and organizations would help them to take care of themselves and their family members with IDD better, advocate for themselves better, and access more information about disability related laws and policies. For example, a caregiver came up with a novel idea that, instead of expecting the government to help with future planning of their family members with IDD, parents should collaborate to establish a township that they can manage themselves so that family members with IDD could live there independently. However, the caregivers asserted that even if such caregiver associations were established, real change would happen only when caregivers' attitudes regarding disability changed. There is clear evidence from the study that besides the need for a robust formal support system place, there is also a need for a strong informal support system,

whether traditional or unconventional, that would help to take care of themselves and their family members with IDD better. One example of such a system is a caregiver association called 'Parivaar' (NCPO, 2023) which has more than 200 parent organizations at present, with the main objectives to create awareness, promote services, helping in the process of receiving benefits and services, and advocate for the issues of people with IDD. The NIEPID (known previously as NIMH) began awareness programs for parents, siblings and grandparents of people with IDD at national level regarding independent living and also took the initiative of helping families to form small self-help groups with the goal of empowering families. The self-help groups registered with the government to receive financial support, run welfare programs and form a Trust. These parent associations thus formed Parivaar (NCPO, 2022). Parivaar is involved with advocacy initiatives for achieving universal accessibility, inclusive education, skill development and innovative schemes for rehabilitation of people with IDD, and awareness-building strategies. Parivaar also supports self-advocacy among people with IDD, by running a Self Advocates' Forum of India (SAFI). Other examples of caregiver associations in India are Asha Deep Parents Association for the Mentally Handicapped (Asha Deep, 2023) and Parent's Association for Children with Special Needs (PAC, 2023). Asha Deep is an association of the parents with intellectual disability, Autism, Cerebral Palsy and Multiple Disabilities, whereas PAC caters to parents of children as well as adults with special needs including intellectual disabilities.

Additionally, it is crucial to establish more peer support groups, also called self-help groups, as sought by the caregivers in the study. Mead and colleagues (2010) define peer support as "a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is beneficial," (p.6). Because peer support groups are "run by members for members so the priorities are directly based on their needs and

preferences" (World Health Organization, 2019, p.1). Researchers have found that peer support groups help establish networks based on shared experiences, obtain important information that informs to make decisions and receive services (Heller & Caldwell, 2006; Thompson- Janes et al., 2016), and also alleviate social isolation (Griffith & Hastings, 2014). Boehm and Carter's study (2016) showed that interventions in which peer support groups of parents with children of same disability are included would be the most beneficial. Peer support groups could either use a traditional model of meeting in person regularly or use unconventional ways such as utilizing online platforms, telephone discussions, video calls, or message boards if the caregivers have the resources. Some of the parent peer groups in India include, Nayi Disha (Nayi Disha, 2023), and Special Child Assistance Network (SCAN) (GuideStar India, 2023). These parent peer groups have active Facebook groups where parents meet, discuss and share their experiences of having a child with special needs. However, enough information was not found on caregiver support groups specifically for adults with IDD. Caregivers of adults with IDD could emulate such already existing and established peer support groups so that the issues specific to them can be discussed and shared.

Since family support is most effective when caregivers receive both informal and formal supports (Boehm & Carter, 2016; Bronheim et al., 2006), it's imperative for the Indian government to not only prioritize, improve, and disseminate services and programs for family caregivers of adults with IDD, but also to conduct awareness campaigns targeting family caregivers about the existing supports and services. Nevertheless, seeking supports outside government and other formal systems have emerged as one of the most beneficial family support strategies for caregivers of adults with IDD. By associating themselves with groups and organizations that are akin to their belief systems and understand their lived experiences, the

caregivers of adults with IDD have an increased chance of attaining physical, mental and emotional well-being.

Study Limitations

Because a small convenience sample was used, generalizability and transferability of the findings could not be established. However bootstrapping method was used to compensate for the small sample size. Cross-cultural research issues such as inappropriate instruments or inaccuracy of data collected to answer research questions could be a major limitation. However, translations with semantic, conceptual and normative equivalences were ensured.

<div align="center">

Conclusion

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The present study contributed to represent the voices of the neglected family caregivers of adults with IDD in India. The study underscored the importance of supports that the caregivers could garner outside of the government and other formal systems, such as informal supports from family, friends and other caregivers, caregiver associations and peer support groups, to help them care for themselves and their family members with IDD better. Needs could be regarded as deficits imposed upon the family caregivers rather than deficits within communities. The study's efforts could help protect the values, needs, and dignity of the family caregivers of adults with IDD in India. Consequently, the study could direct a long-term goal of reducing inequities among these family caregivers by helping them to garner non-formal supports as well as formal supports by revising and improving policies to increase access to family caregiver supports and services, and consequently increase their overall well-being. Furthermore, educational programs and awareness raising strategies on human rights, advocacy and empowerment need to be designed, developed and implemented by researchers, practitioners, and policymakers so that

caregivers of adults with IDD are empowered to advocate for themselves and their family members with IDD.

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TABLES

TABLE I

CAREGIVER CHARACTERISTICS (N=100)

	M	SD
Age	46.15	12.13
	(Range: 19-71 years)	

	N	%
Age groups		
<50 years	60	60.0
≥50 years	40	40.0
Gender		
Female	63	63.0
Male	37	37.0
Education		
8th grade or less	12	12.0
Some high school	15	15.0
High school graduate	8	8.0
Some college	11	11.0
College graduate	27	27.0
Postgraduate or higher	27	27.0
Proficiency in English		
None	19	19.0

Basic	23	23.0
Intermediate	36	36.0
Advanced	22	22.0
Current employment		
No	53	53.0
Yes	47	47.0
Number of family members in household		
0 to 3	25	25.0
4 to 5	59	59.0
6 and above	16	16.0
Family annual income		
Less than ₹ 1,00,000 ($1,400)	42	42.0
₹ 1,00,001 ($1,400) to ₹ 5,00,000 ($7,000)	47	47.0
More than ₹ 5,00,000 ($7,000)	11	11.0

TABLE II

FAMILY MEMBER WITH IDD CHARACTERISTICS (N=100)

	M	SD
Age	25.21	6.46
	(Range: 18-47 years)	
	N	%
Age groups		

18-24 years	60	60.0
≥25 years	40	40.0
Gender		
Female	24	24.0
Male	76	76.0
Conditions related to ID		
ID only	48	48.0
Autism	15	15.0
Cerebral Palsy	6	6.0
Down syndrome	15	15.0
Other	16	16.0
ID level		
Borderline	11	11.1
Mild	27	27.3
Moderate	46	46.5
Severe	15	15.2

TABLE III

T-TEST AND ANOVA – DIFFERENCES IN CAREGIVER NEEDS BY CAREGIVER

CHARACTERISTICS

Caregiver Characteristics	Support needs – for interacting with others	
T-test	M (SD)	t

	M (SD)	t
Gender		-0.475
Female	32.76 (8.70)	
Male	31.92 (8.34)	
Age Groups		-1.198
<50 years	31.62 (9.13)	
≥50 years	33.70 (7.50)	
Current employment		1.980*
No	34.02 (8.75)	
Yes	30.68 (8.01)	

ANOVA	M (SD)	F
Education		0.549
High school graduate or less	33.51 (8.93)	
Some college or college graduate	32.34 (9.05)	
Postgraduate or higher	31.22 (7.31)	
Proficiency in English		0.874
None	33.84 (8.43)	
Basic	33.43 (10.19)	
Intermediate	32.58 (8.05)	
Advanced	30.00 (7.52)	
Number of family members in household		0.217
0 to 3	33.40 (9.81)	

4 to 5	32.22 (8.18)	
6 and above	31.81 (8.14)	
Family annual income		0.500
Less than ₹ 1,00,000 ($1,400)	33.43 (9.29)	
₹ 1,00,001 ($1,400) to ₹ 5,00,000 ($7,000)	31.87 (8.36)	
More than ₹ 5,00,000 ($7,000)	31.18 (6.23)	

*Note. Results after bootstrapping, *<0.05, **<0.01, ***<0.001*

TABLE IV

T-TEST AND ANOVA – DIFFERENCES IN CAREGIVER NEEDS BY FAMILY MEMBER

WITH IDD CHARACTERISTICS

Family Member with IDD Characteristics	Support needs – for interacting with others	
T-test	M (SD)	t
Gender		0.295
Female	32.00 (7.92)	
Male	32.59 (8.77)	
Age Groups		0.788
18-24 years	33.00 (8.03)	
≥25 years	31.63 (9.28)	
ANOVA	M (SD)	F

32

Conditions related to ID				2.105
ID only		32.54 (8.64)		
Autism		34.93 (6.61)		
Cerebral Palsy		24.00 (8.81)		
Down syndrome		31.27 (8.20)		
Other		34.13 (8.86)		
ID level				1.595
Borderline		29.00 (8.50)		
Mild		31.00 (9.14)		
Moderate		34.28 (7.72)		
Severe		32.60 (9.29)		

*Note. Results after bootstrapping, *<0.05, **<0.01, ***<0.001*

TABLE V

SUMMARY OF THE MULTIPLE LINEAR REGRESSIONS FOR SUPPORT NEEDS

OF INTERACTING WITH OTHERS (N=100)

Variables	B	SE	95% CI	p value
Caregiver characteristics				
Gender				
Male (Ref)				
Female	0.57	2.36	[-4.28, 5.15]	0.811
Age	0.07	0.09	[-0.10, 0.26]	0.446

Education	0.01	0.80	[-1.57, 1.59]	0.996
Proficiency in English	-0.68	1.43	[-3.46, 2.19]	0.629
Current employment				
No (Ref)				
Yes	-2.39	2.47	[-7.40, 2.25]	0.348
# of family members in household	-0.41	0.57	[-1.28, 1.03]	0.373
Family annual income	-0.45	1.63	[-3.71, 2.80]	0.785
Family member with IDD				
characteristics				
Gender				
Male (Ref)				
Female	-0.39	2.21	[-5.11, 3.51]	0.884
Age	-0.08	0.17	[-0.43, 0.23]	0.604
Conditions related to ID				
ID only (Ref)				
Autism	2.14	2.50	[-2.82, 6.89]	0.395
Cerebral Palsy	-8.76	3.95	[-16.60, -1.17]	0.020
Down syndrome	-1.02	3.38	[-7.22, 6.21]	0.761
Other	0.93	3.01	[-5.06, 6.73]	0.747
ID level	0.98	1.19	[-1.13, 3.42]	0.439
Final Model	$F_{(14,84)}=1.22$, p=0.28, $R^2_{adjusted}=0.030$			

Note. Results after bootstrapping

TABLE VI

SUMMARY OF THE MULTIPLE LOGISTIC REGRESSIONS FOR THE SUPPORT NEEDS OF

INTERACTING WITH OTHERS (N=100)

| Variables | Highest support need of interacting with others | | | |
| | *(Definitely needed to have more opportunities to meet and talk with other caregivers of adults with IDD)* | | | |
	B	SE	95% CI	p value
Caregiver characteristics				
Gender				
Male (Ref)				
Female	-0.18	1.01	[-2.29, 1.62]	0.795
Age groups				
<50 years (Ref)				
≥50 years	-0.50	0.86	[-2.38, 1.05]	0.448
Education				
High school graduate or less (Ref)				
Some college or college graduate	0.18	1.25	[-2.07, 2.73]	0.826
Postgraduate or higher	-0.67	1.17	[-3.14, 1.46]	0.422
Proficiency in English				
Basic (Ref)				

None	0.88	2.57	[-1.14, 4.31]	0.310
Intermediate	0.31	1.32	[-2.36, 2.74]	0.722
Advanced	-0.52	1.92	[-3.94, 2.28]	0.579
Current employment				
No (Ref)				
Yes	-	-	-	-
Number of family members in household				
0 to 3 (Ref)				
4 to 5	-	-	-	-
6 and above	-	-	-	-
Family annual income				
Less than ₹ 1,00,000 ($1,400)				
₹ 1,00,001 ($1,400) to ₹ 5,00,000 ($7,000)	-	-	-	-
More than ₹ 5,00,000 ($7,000)	-	-	-	-
Family member with IDD characteristics				
Gender				
Male (Ref)				
Female	-1.10	1.41	[-4.03, 0.28]	0.118
Age Groups				
18-24 years (Ref)				

≥25 years	0.07	0.82	[-1.49, 1.86]	0.918
Conditions related to ID				
ID only (Ref)				
Autism	0.53	1.62	[-1.50, 3.91]	0.545
Cerebral Palsy	-21.43	2.61	[-25.58, -19.63]	0.003
Down syndrome	-0.95	2.39	[-3.86, 0.98]	0.256
Other	0.31	1.55	[-1.61, 2.98]	0.732
ID level				
Borderline (Ref)				
Mild	0.65	3.23	[-1.56, 4.05]	0.455
Moderate	0.93	3.23	[-1.27, 4.64]	0.306
Severe	0.46	3.50	[-2.96, 4.45]	0.654
Final Model		$\chi(16)=28.29$,		
		p=0.03, Nagelkerke $R^2 = 0.33$		

Note. Results after bootstrapping based on 999 samples