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Everyday functioning, social adjustment and caregiving challenges among children with intellectual and developmental disabilities and their families in three cities of Odisha

Monalisha Padhy[1], Dr. Kalyani Rath[2]
[1] School of Anthropology, Gangadhar Meher University, Sambalpur, Odisha, India
[2] Assistant Professor, School of Anthropology, Gangadhar Meher University, Sambalpur, Odisha, India
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Abstract
Globally, Intellectual and developmental disability is becoming an important area of concern which is mostly regarded as an inherited and most common developmental disorder. Such type disability is characterized with deficits in overall intellectual capacity and adaptive behavior that are well below average. Intellectual disability is diagnosed by measuring Intelligence Quotient (IQ) and is calculated by using the formulae IQ = mental age/chronological age × 100. Previous studies in India reported the prevalence of such disability in the range of 1–3%. It is estimated to be 3.1% in rural areas and 0.9% in urban areas. The current research attempts to understand the various strategies followed by parents and caregivers of children with intellectual and developmental disabilities to cope with and adjust to everyday challenges. Data for the study were collected from both primary and secondary sources. The disability categories of the participating children were made on the basis of the information recorded on their Unique Disability ID (UDID) cards. A total of 622 children with different levels of intellectual and developmental disabilities attending special schools of urban Odisha were studied. Information pertaining to daily activities, social adjustments of the studied children were collected from the care givers and parents of the children by using a structured interview schedule. This study intended to examine the various strategies applied by parents/caregivers to manage children with intellectual and developmental disabilities. The study results identified the intensity of problems that parents/caregivers face in handling such children, even though they have developed different strategies to tackle these challenges.

Keywords: Intellectual and developmental disabilities, children with intellectual disabilities, parental coping strategies, caregiver challenges

Introduction

Intellectual and developmental disability is one of the most distressing handicaps in any society. The development of an individual with such condition depends on the type and extent of the underlying disorder, associated disabilities, environmental factors, psychological factors, cognitive abilities, and comorbid psychopathological conditions (Ludwik, et al., 2001). Social development refers to the acquisition of the ability to behave in accordance with social expectations (Pati et al., 2001). Socialization involves three processes: 1) learning to behave in socially approved ways, 2) playing approved social roles, and 3) developing social attitudes (Hurlock, 1967) [7]. Coping strategies can be defined as "the cognitive and behavioral efforts required to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person." (Ganjiwale, et al, 2016) [6].

Earlier Intellectual and developmental disability was referred as Mental Retardation (MR) in general and according to the World Health Organization, mental retardation is defined as "an incomplete or insufficient general development of mental capacities" (Luckasson et al., 2002) [10]. According to the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, enacted in India, mental retardation means a "condition of arrested or incomplete development of mind of a person which is specially characterized by sub normality of intelligence". American Association on Mental Deficiency (AAMD). The American Association on Mental Deficiency (AAMD), now the American Association on Mental Retardation (AAID), also known as the American Association on Intellectual Disabilities (AAID), is more prevalent among service providers and institutions, with usage being more of academic interest than for operational reasons.

Intellectual and developmental disability is seen in 1 to 3 percent of the total population of the world (Accordo, 1998). The condition is present in 2–3% of the population, either as an isolated finding or as part of a syndrome or broader disorder (Daily, Ardinger& Holmes, 2000) [5]. In India the estimated prevalence of Mental Retardation in rural areas is 3.1% and in urban areas it is 0.9% (Panda, 1999; Venkataswamy, 1998). Among those with mental disability, the majority have mild disability. This is followed by severe, moderate, and profound mental disability (Ganesh Kumar, 2008). Incidence of such problem is 2-3 times higher in developing countries as compared to developed countries. The prevalence of severe mental retardation is about 3 per 1000 population and 30 per 1000 for mild mental retardation (Harper, 1993). The status of disability in India, particularly in the provision of education and employment for persons with mental retardation, as a matter of need and above all, as a matter of right, has had its recognition only in recent times, almost after the enactment of the Persons with Disabilities Act (PWD), 1995. Approximately 3% of the population has an intelligence quotient (IQ) of less than 70, among whom a cause for the mental retardation can be established in less than half of all cases (Flint et al., 1995).

The causes of Intellectual and developmental disability are numerous and include genetic and environmental factors. Many times such problem is considered as a genetic disorder characterized by significantly below-average overall intellectual functioning and deficits in adaptive behavior. The issues is a particular state of functioning that begins in childhood and is characterized by decreased intelligence and adaptive skills; it is also the most common developmental disorder (Bregman, 1991) [4]. Such conditions in young children are often missed by clinicians. In at least 30–50% of cases, physicians are unable to determine the etiology despite thorough evaluation (Baird &Sadovnick, 1985) [3]. Diagnosis is highly dependent on a comprehensive personal and family medical history, a complete physical examination, and a careful developmental assessment of the child. This will guide appropriate evaluations and referrals to provide genetic counselling, resources for the family, and early intervention programs for the child (Rutter, 2006) [14]. The most common cause of Intellectual Disability (ID) in industrialized nations is fetal alcohol syndrome, with an incidence rate of 1 in 100 births. The second leading known cause of ID is Down syndrome, or trisomy 21, with an incidence rate of 1 in 800–1.000 births (Campbell, Morgan & Jackson, 2004). Sometimes It is also believed that behavioral or societal factors, such as poverty, malnutrition, maternal drug and alcohol use, and severe stimulus deprivation, can contribute to ID (McLaren & Bryson, 1987) [12]. Unfortunately, in approximately 30–50% of cases, the etiology is not identified even after thorough diagnostic evaluation (Cury et al., 1997; Schaefer &Bodensteiner, 1992). Some individuals have congenital brain malformations, whereas others have brain damage during a critical period of pre- or postnatal development. Acquired causes of retardation include near drowning, traumatic brain injury, and central nervous system malignancy. The first and most important step in the diagnosis of mental retardation is obtaining a comprehensive patient and family history. Previous gynaecologic and obstetric histories may reveal infertility or fetal loss (Matson&Sevin, 1994).

According to the Census (2001), there are 2.19 crore people with disabilities in India, constituting 2.13% of the total population. This includes persons with visual, hearing, speech, locomotor, and mental disabilities. Seventy-five per cent of persons with disabilities live in rural areas, 49% of the disabled population is literate, and only 34% are employed. As per Census 2011, out of 42 million people, 1.2 million were differently abled in the state of Odisha. People with visual impairment constituted the highest percentage (21.2%) and the intellectually retarded constituted 5.8%. The Constitution of India has made education a fundamental right for all children, including children with disabilities in the age group of 6–14 years. Section 26 of the Persons with Disabilities Act (1995) affirms the capacity of the Indian state to afford free education beyond 14 years of age, particularly in the context of children with disabilities (Ganjiwale, et al, 2016 [6]). From the source of IDEA data the child count in the mental retardation category comprises 8% students. The highest number of special education students was in the category of learning disabilities (44%).

Study Methodology

The current research was carried out in three major cities of Odisha i.e. Cuttack, Bhubaneswar, and Berhampur by considering the population size. The study was conducted among the children who attended the special schools located in the above-mentioned cities. All special schools located in these three regions were listed, and a total of seven schools were selected randomly to obtain an adequate number of samples. According to the records of the Social Security and Empowerment of Persons with Disabilities Department, Government of Odisha, 6,471 children attend residential schools, while 344 children attending non-residential schools are diagnosed with intellectual disabilities. The intellectual disability status and disability categories of the participating children were identified exclusively from their Unique Disability ID (UDID) cards. Informed consent was obtained from their parents, guardians, or caregivers. A structured interview schedule was used to collect relevant information from the participating children and their caregivers. The children's behavioural characteristics were observed to understand their coping strategies, self-care abilities, and social adjustment. Ethical approval was obtained from the Ethics Committee of Gangadhar Meher University, Sambalpur, Odisha. Written informed consent was obtained from parents or caregivers and permission was taken from the concerned school authorities prior to the study.

Result and Analysis

A gender wise analysis of the study subjects was performed and presented in table no. 1. From the analysis it is observed that about 65 percent of the special children were male and only 35 percent were female. Age wise analysis of the study population shows a higher concentration of study subjects in the age group 11-15 years of age followed by age group 6–10 i.e. 28.3%. Fewer percent of children were in the higher age group i.e. 16–18 (27.0%).

Table 1: Distribution of Children by Type of Intellectual and Developmental Disability and Sex

Age Group (Years)	Female n (%)	Male n (%)	Total n (%)
6-10	55 (31.3)	121(68.7)	176 (28.3)
11-15	103 (37.1)	175 (62.9)	278 (44.7)
16-18	61 (36.3)	107 (63.7)	168 (27.0)
TOTAL	219 (35.2)	403 (64.8)	622 (100)

The proportion of male children was higher across all age groups. However, the Chi-square test showed that the association between age group and sex was not statistically significant ($\chi^2 = 1.384$, $p = 0.501$). The strength of association, as indicated by Cramer's V, was negligible (0.047), suggesting that gender does not meaningfully influence the age distribution of children attending special schools in the study area.

Table 2: Distribution of Disability Types by Sex among the Study Participants

Disability Type	Female n (%)	Male n (%)	Total n (%)
ID	148 (67.6)	265 (65.8)	413 (66.4)
CP	29 (13.2)	55 (13.6)	84 (13.5)
ASD	8 (3.7)	22 (5.5)	30 (4.8)
DS	7 (3.2)	22 (5.5)	29 (4.7)
OTHERS	27 (12.3)	39 (9.7)	66 (10.6)
TOTAL	219	403	622

$\chi^2 = 3.546$, df = 4, p = 0.471

Table no. 2 shows the distribution of disability types by sex. Intellectual disability is the largest category, accounting for 66.4% of participants, followed by cerebral palsy (13.5%), other disabilities (10.6%), autism spectrum disorder (4.8%) and Down syndrome (4.7%). However, the association between sex and type of disability was not statistically significant ($\chi^2 = 3.546$, df = 4, p = 0.471). The strength of association was negligible (Cramer's V = 0.076), indicating comparable distribution of disability types among males and females. The findings suggest that gender does not appear to influence the type of disability among children attending the selected special schools.

Table 3: Distribution of Reported Eating Behaviours and Mealtime Difficulties among Children

Behavioural Attitudes	Yes n (%)		No n (%)		Total n (%)	
Do they eat fast?	222	35.69	400	64.30	622	100
Do they refuse to take certain foods?	185	29.74	437	70.25	622	100
Do they skip any meal in a day?	187	30.06	435	69.93	622	100
Is he/she able to say when hungry?	237	38.10	385	61.89	622	100
Is he/she able to indicate when full?	216	34.72	406	65.27	622	100
Does he/she have a tendency to spit out food?	189	30.38	433	69.61	622	100
Does he/she have a tendency to vomit the food immediately after consuming?	176	28.29	446	71.70	622	100
Does he/she have frequent stomach upsets?	219	35.20	403	64.79	622	100
Does he/she take normal time to finish the meal?	77	12.37	545	87.62	622	100

The table summarizes reported eating and mealtime behaviours among the children affected with Intellectual and developmental disabilities. The most commonly reported behaviour is "taking a normal amount of time to finish a meal" as parents or care givers of about 88% children have expressed "No" for the question. About 62 percent of them expressed that children are unable to indicate when hungry. Around one-third were reported to eat fast (35.69%), skip meals (30.06%) or refuse certain foods (29.74%).

Table 4: Independence in Selected Activities of Daily Living among Children

Daily Activity	Yes n (%)		No n (%)		Total n (%)	
Is he/she able to take a bath on his/her own?	221	35.53	401	64.46	622	100
Does he/she get ready for school on his/her own?	432	69.45	190	30.54	622	100
Does he/she go back to sleep on its own or need the mother's presence?	233	37.45	389	62.54	622	100

The table no. 4 reports functional independence in selected daily activities. A majority of children were reported to get ready for school independently (69.45%), whereas 35.53% were reported to bathe on their own. For the item concerning returning to sleep independently or needing the mother's presence, 37.45% were recorded positive and 62.54% reported negative responses.

Table 5: School Participation, Social Engagement, and Reported Negative Social Experiences among Children

Social Events	Yes n (%)		No n (%)		Total n (%)	
Does he/she take part in different school functions?	444	71.38	178	28.61	622	100
Does he/she attend different social gatherings?	246	39.54	376	60.45	622	100
Does he/she experience rude behaviour from relatives or strangers?	406	65.27	216	34.72	622	100

The table describes children's participation in social events and reported social experiences. Most children took part in school functions (71.38%), while 39.54% attended social gatherings. A substantial proportion (65.27%) were reported to experience rude behaviour from relatives or strangers.

Table 6: Self-Care Skills, Functional Abilities, and Participation in Daily Activities among Children

Actions Done By The Child	Yes n (%)		No n (%)		Total n (%)	
Does he/she know the usage of the toilet on their own?	433	69.61	189	30.38	622	100
Does he/she know to wear clothes on their own or need any help?	231	37.13	391	62.86	622	100
Does he/she prefer to eat food on their own or take anyone's help?	407	65.43	215	34.56	622	100
Does he/she volunteer themselves to take part in cleaning purposes?	214	34.40	408	65.59	622	100
Does he/she know how to take care of their personal hygiene?	248	39.87	374	60.12	622	100
Does he/she prefer to roam around in the community?	442	71.06	180	28.93	622	100
Does he/she know to purchase goods from the market?	23	3.69	599	96.30	622	100
Is he/she interesting in communicating with the outside members?	238	38.26	384	61.73	622	100
Does he/she know the usage of technology?	499	80.22	123	19.77	622	100
Does he/she perform the tasks given?	237	38.10	385	61.89	622	100
Do they take medications (if any) on their own?	197	31.67	425	68.32	622	100
Does he/she socialize within the household?	246	39.54	376	60.45	622	100
Does he/she have any special interest towards learning new things?	440	70.73	182	29.26	622	100
Does he/she like any co-curricular activities?	367	59.00	255	40.99	622	100

The table presents children's reported skills and activities related to coping and everyday functioning. Technology use (80.22%), interest in learning new things (70.73%), independent toilet use (69.61%) and preference for eating independently (65.43%) were commonly reported. Purchasing goods from the market independently was reported for only 3.69%, while 37.13% were reported to dress independently.

Table 7: Caregiving Responsibilities and Reported Psychosocial and Financial Challenges among Parents or Caregivers

Actions Done By The Parent	Yes n (%)		No n (%)		Total n (%)	
Do you assist your child in all matters both outside and inside the house?	495	79.58	125	20.09	622	100
Do you suffer from decreased leisure time for yourself?	418	67.20	204	32.79	622	100
Do you face negligence from relatives or strangers because of your child?	192	30.86	430	69.13	622	100
Do you suffer from any marital distress for the care and upliftment of your child?	422	67.84	200	32.15	622	100
Do you face social embarrassment because of your child?	201	32.31	421	67.68	622	100
Does it become difficult for you to have a balance between your affected child and a normal child?	218	35.04	404	64.95	622	100
Do you suffer from any financial implications in the maintenance of your child?	428	68.81	194	31.18	622	100

The table summarizes caregivers' reported experiences and responsibilities. Most respondents reported assisting their child inside or outside the home (79.58%). Financial implications (68.81%), reduced leisure time (67.20%) and marital distress related to care (67.84%) were also frequently reported. Smaller proportions reported neglect from relatives or strangers (30.86%), social embarrassment (32.31%) or difficulty balancing the needs of the child with a disability and another child (35.04%).

Discussion

The present study examined coping strategies and everyday adjustment among children with intellectual and developmental disabilities and the experiences of their parents or caregivers in selected special schools in Cuttack, Bhubaneswar, and Berhampur, Odisha. Data were collected from 622 children using a descriptive and diagnostic study design incorporating quantitative and qualitative approaches. The findings provide insights into children's daily living skills, social participation, and continuing support requirements, as well as the practical, emotional, and financial challenges experienced by their caregivers. The findings were compared with previous studies conducted in India to identify similarities and differences in children's functional independence and family caregiving experiences.

In the present study, boys constituted 64.8% of the sample, whereas girls accounted for 35.2%. Children aged 11–15 years formed the largest age group, representing 44.7% of participants. However, the association between age group and sex was not statistically significant ($\chi^2 = 1.384$, $p = 0.501$). Intellectual disability was the most frequently recorded disability category (66.4%), followed by cerebral palsy (13.5%) and other disabilities (10.6%). The association between sex and disability type was also not statistically significant ($\chi^2 = 3.546$, $p = 0.471$). These findings indicate that the observed distributions of age and disability category did not differ significantly by sex within the study sample.

A similar male predominance was reported by Naaz et al. (2025) in their study of 160 children with cerebral palsy in Odisha, in which 61.3% were boys and 38.8% were girls. The similarity between the two studies suggests that boys constituted a larger proportion of participants in both study populations. The findings of the present study demonstrated considerable variation in children's independence across daily living activities. Approximately 69.45% of children were reported to get ready for school independently, while only 35.53% could bathe without assistance. In the coping-mechanism table, 69.61% were reported to use the toilet independently, and 65.43% preferred to eat on their own. However, only 37.13% could wear clothes independently, 39.87% could manage personal hygiene, and 3.69% were able to purchase goods from the market. These findings indicate that functional independence varies according to the nature and complexity of the activity.

The findings can be compared with the study by Bunga et al. (2020), where the study included 100 parents of children with intellectual disability and found that 56.63% experienced an impact related to the physical care of their children. The authors also reported that the impact on physical care increased with the severity of intellectual disability. These results complement the present findings by demonstrating that children's functional limitations and dependence on others can translate into additional caregiving responsibilities. Further evidence of the relationship between children's functional abilities and family burden comes from Naaz et al. (2025), who studied 160 children with cerebral palsy in Odisha. In their study, 46.9% of children were classified at Gross Motor Function Classification System (GMFCS) level V, indicating severe limitations in gross motor function. The researchers found that 52.5% of families experienced severe financial burden, while 46.9% experienced moderate financial burden. Only 0.6% reported no financial burden. The particularly low proportion of children able to purchase goods independently in the present study (3.69%) indicates a substantial limitation in this specific community-based functional skill. The findings support the need for individualized training in self-care, personal hygiene, dressing, money management, and community-based activities.

The present study revealed both positive opportunities for participation and continuing social challenges. A majority of children (71.38%) participated in school functions, and 59.00% expressed an interest in co-curricular activities. However, only 39.54% attended social gatherings. Although 71.06% preferred to roam around in the community, only 38.26% were reported to be interested in communicating with people outside the household. Furthermore, 65.27% reportedly experienced rude behaviour from relatives or strangers. These findings indicate that children's interest in participation does not necessarily translate into meaningful social interaction or consistently positive community experiences.

Comparable concerns about social restrictions were reported by Bunga et al. (2020). In their study of 100 parents of

children with intellectual disability, 36.75% reported an impact on maintaining social relationships with friends and neighbours because of social restrictions. At the same time, 71.72% of parents reported that they did not feel embarrassed about their child with intellectual disability. The qualitative study by Gopichandran et al. (2020), which explored the experiences of mothers caring for children with cerebral palsy in rural and peri-urban Tamil Nadu, also identified social isolation, discrimination, and limited participation in social events as important dimensions of caregiving. The present study identified substantial practical and psychosocial demands among caregivers. Approximately 79.58% reported assisting their children with activities inside or outside the home. Reduced leisure time was reported by 67.20%, marital distress associated with care and upbringing by 67.84%, and financial implications by 68.81%. In addition, 35.04% reported difficulties balancing the needs of their child with a disability and those of another child in the family.

A comparable pattern of financial and social impact was reported by Bunga et al. (2020). In their cross-sectional study of 100 parents of children with intellectual disability, 58.87% reported financial problems, 56.63% reported an impact associated with physical care, and 36.75% reported difficulties maintaining social relationships with friends and neighbours because of social restrictions. Further support for the financial and psychosocial dimensions of caregiving comes from Naaz et al. (2025), who assessed family burden among 160 children with cerebral palsy in Odisha. They found that 52.5% of families experienced severe financial burden and 46.9% experienced moderate financial burden. With respect to family leisure, 58.8% reported moderate disruption and 27.5% reported severe disruption. The qualitative research by Gopichandran et al. (2020) also described the difficulties experienced by mothers of children with cerebral palsy in balancing caregiving, household responsibilities, and paid work. Participants described financial strain, limited support from husbands and other family members, and difficulties providing adequate attention to other children in the household. Overall, the present study demonstrates that children with intellectual and developmental disabilities possess varying levels of independence and social participation while continuing to require support in specific areas of daily living. Their caregivers experience practical, financial, and psychosocial demands that may affect leisure, relationships, and family responsibilities. The similarities between these findings and previous Indian studies emphasize the importance of individualized skill development, family-centred interventions, caregiver support, and inclusive community environments.

Conclusion

The study of 622 children attending selected special schools in Cuttack, Bhubaneswar and Berhampur indicates that children with intellectual and developmental disabilities and related disabilities show varied levels of independence in self-care, daily routines, communication and community participation. Many children participated in school functions and showed interest in technology, learning or co-curricular activities, while several continued to require assistance with bathing, dressing, personal hygiene, completing tasks and other activities of daily living. These findings emphasize the importance of recognizing each child's abilities and providing support tailored to their individual needs.

The findings support several practical priorities. First, individualized training should be provided to strengthen self-care, dressing, personal hygiene, toileting, money management, and other age-appropriate daily living skills. Second, schools and rehabilitation professionals should encourage communication and participation through structured group activities and safe community-based experiences. Third, caregivers should have access to guidance, counselling, peer-support opportunities, and information about available disability-related services and financial assistance. Finally, schools and communities should promote respectful attitudes and inclusive environments to reduce negative social interactions and improve the participation of children with disabilities.

The study recommends that special schools and support agencies promote life-skills training, safe social participation and family-centred guidance. Community awareness is also important to reduce rude or exclusionary treatment of children and their caregivers. As the research covers children attending selected special schools in three cities, the findings may not represent families outside these settings. Further studies involving a wider range of locations and caregiver-focused measures could explore coping strategies in greater depth. In conclusion, effective support requires coordinated attention to children's functional skills, social inclusion and the well-being of their parents and caregivers.

Conflicts of Interests: The authors declare no conflicts of interests.

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