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Challenging with the Challenged: The Situation of the Caregivers of the Specially-Abled Children in Thiruvananthapuram, Kerala-India

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Abstract

Mental retardation is a condition that can be either present since birth or acquired at a later stage in life. The life of a child consists of enormous challenges and difficulties from birth to later stages of life. Behind every one of them exists their caretakers, mostly their parents or other close acquaintances, in instances where one might have lost their parents under any circumstances. Children with special needs require special care and assistance, which often serves as a task for their caregivers. The objective of this study is to examine the numerous challenges and experiences of the caregivers of the specially-abled children of Kerala, employing an exploratory research design and utilising qualitative data collected through case studies. The findings indicate that the caregivers experience depression and anxiety because of their occupational stress and taking care of the special-abled. Depression and anxiety are common challenges in the lives of caretakers of the specially-abled children. The prevalence of depression in the caretakers of the female, specially-abled children was observed to be higher than in the caretakers of the male children. The caregivers of the specially-abled face numerous challenges, such as exclusion, stigma, and depression, and these problems need social recognition and governmental programmes and policies.

Keywords: mental retardation, caregiving, specially-abled children

1. Introduction

Children with disabilities, often referred to as children with special needs, experience developmental, intellectual, sensory, physical, or a combination of these challenges. The term children with special needs or children with disabilities is more commonly and politely used (Qureshi et al., 2021). It is crucial to recognise that disability extends beyond a mere medical condition; it often arises from the interaction between an individual's impairment and various institutional, environmental, and behavioural barriers that hinder their full and effective participation in society (Murphy et al., 2006). The development of children with special needs, encompassing physical, emotional, social, and educational dimensions, is significantly supported by their caregivers. The demands of their roles, united with the responsibility of caring for individuals with disabilities, often lead caregivers to experience anxiety and depression. Those who care for children with special needs frequently face challenges such as depression, stigma, and marginalization. This study aims to explore the challenges and experiences of caregivers of children with disabilities.

2. Literature Review

2.1 Specially-abled: An overview

Disabilities manifest at different stages of the development of a child and in various forms. Common categories of disabilities include cerebral palsy, Muscular Dystrophy, spina bifida, limb deformities, visual impairment, blindness, developmental disabilities, and autism spectrum disorder, among others (Qureshi et al., 2021). In the current social order, children with disabilities often face numerous hurdles. The most significant challenges for children with special needs are social stigma and discrimination. Families and children with disabilities frequently encounter negative stereotypes, rejection, and even abuse, leading to social exclusion and the denial of basic rights (Cleary, 2003).

Children with disabilities often struggle to access many public spaces, transportation systems, educational institutions, and buildings due to the absence of ramps, elevators, accessible restrooms, and other necessary changes (Murphy et al., 2006). There is a significant shortage of trained special educators and support staff, and many mainstream schools lack the resources, qualified teachers, and adapted programs needed to educate students with diverse needs (Murphy et al., 2006).

Healthcare facilities are often ill-equipped with the tools and personnel required to address the unique needs of children with disabilities. For many families, the high cost of specialised care and therapies presents another major challenge (Pankajam, 2009). Families with children with disabilities are disproportionately more likely to experience poverty due to the higher costs of care, limited access to education, and fewer employment opportunities for caregivers. Children with disabilities are also at a higher risk of experiencing abuse, neglect, exploitation, and violence (Bhowate and Dubey, 2005).

2.2 Global Context

UNICEF estimates that around 240 million children globally, which is about 10% of the child population of the world, have disabilities, making them a notable minority. The occurrence and nature of these disabilities differ across regions and countries due to factors like early detection systems, environmental conditions, conflict, healthcare access, and nutrition (Dalton et al., 2020). In many developing nations, children with disabilities often remain unnoticed because of stigma, insufficient data, and their exclusion from social records and services. Despite global initiatives, these children frequently face significant and interconnected challenges (Scorza et al., 2013). Stigma and discrimination are widespread issues worldwide. Negative perceptions, biases, and misunderstandings about disabilities result in social exclusion, isolation, and a lack of opportunities (Higgins & Kruglanski, 2008). In severe cases, this can lead to institutionalisation or infanticide. There is a strong relationship between poverty and disability. Families with disabled children are more likely to experience poverty due to the costs of care, loss of income, and other related expenses (Kawanishi, 2009). Children with disabilities are among the most vulnerable and marginalised in emergencies and conflict zones. They often lose access to caregivers, medication, and assistive technology, and face a higher risk of violence and being denied humanitarian aid. The exclusion of these children from policy-making and resource distribution is often due to the lack of reliable, de-identified data (Andersson et al., 2023). Article 23 of the United Nations Convention on the Rights of the Child specifically addresses the rights of children with physical or mental disabilities to live full and dignified lives, characterised by dignity, independence, and active community involvement (Das, 2022). The United Nations Convention on the Rights of Persons with Disabilities is the most important international human rights treaty for people with disabilities, promoting a shift from a medical or charity model of disability to a human rights model (Das, 2022).

2.3 Indian Scenario

India has achieved notable progress in legal and policy measures to safeguard the rights of children with disabilities. The country revised the Persons with Disabilities Act of 1995 by enacting the landmark Rights of Persons with Disabilities Act of 2016. The legislation ensures inclusive and free education, protection from abuse, violence, and exploitation, as well as provisions for reservation, legal capacity, guardianship, and accessibility in both public and private spaces (Roy et al., 2019).

According to the Right of Children to Free and Compulsory Education Act of 2009, all children between the ages of 6 and 14, including those with disabilities, have the right to free and compulsory elementary education. This law guarantees access to special education, free school admission, and accessible facilities (Hazra & Bala, 2025). Furthermore, the Mental Healthcare Act of 2017 ensures the right to treatment in mental hospitals, with specific provisions for separate accommodations for minors under 18 and the state government's responsibility for treatment costs, unless covered by the family (Hazra & Bala, 2025). The Indian government carries out various programs and initiatives, mainly through the

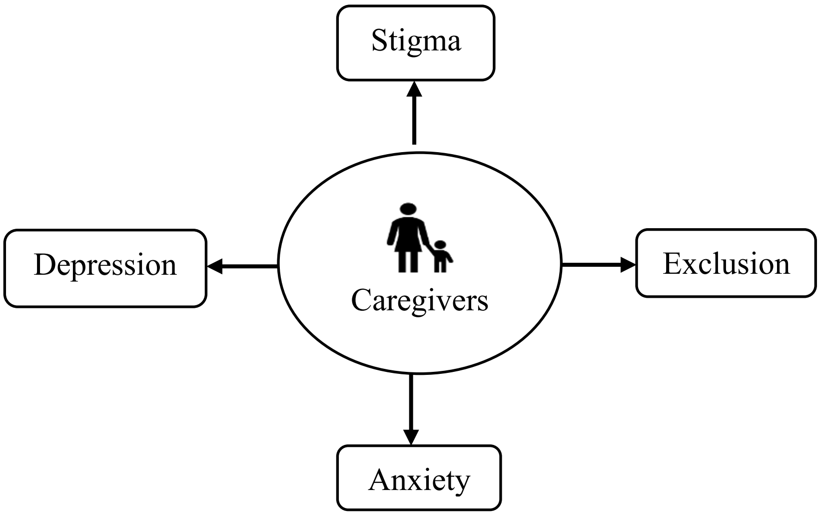
Department of Empowerment of Persons with Disabilities, which is part of the Ministry of Social Justice and Empowerment (Hazra & Bala, 2025). Despite these significant advancements, challenges remain in raising public awareness, ensuring fair access to quality services, and combating widespread societal stigma. To enable children with intellectual disabilities in India to live independent, fulfilling, and dignified lives, all stakeholders must persist in their collaborative efforts.

3. Research Methodology

This study aims to investigate the various challenges and experiences faced by caregivers of children with special needs in Kerala. This research employs an exploratory design and utilises qualitative data obtained through case studies. Fieldwork was conducted at Asha Deepam Buds School, Malayinkeezhu, Thiruvananthapuram, Kerala. The parents of the specially-abled children from the Asha Deepam Buds School constitute the study population. Purposive sampling was employed to select the case studies, and pseudonyms were used to ensure the privacy of the respondents.

4. Conceptual Framework

The physical, emotional, social, and educational growth of the specially-abled children is supported by their caregivers. Their roles, tied with the responsibility of caring for individuals with disabilities, often result in caregivers experiencing anxiety and depression. The caregivers of children with special needs face challenges such as depression, stigma, and marginalisation. The current study aims to evaluate the challenges and experiences of the caregivers of the specially-abled children.



(Source: Own formulation based on findings)

5. Depression and Anxiety

Children with disabilities necessitate special care, which often presents a significant responsibility for their caregivers. The quality of care afforded to these children is influenced by the psychological well-being of the caregivers. It is common for caregivers or parents of children with disabilities to encounter psychological challenges as they contemplate the future of the child, associated difficulties, and life beyond the caregivers' presence. Furthermore, the presence of a child with mental disabilities can affect siblings and familial relationships, extending beyond the parents alone.

Factors such as age, gender, level of disability, as well as social class, economic status, and family coping mechanisms, such as acceptance of the child's diagnosis and perception of stigma associated with the disorder, significantly impact the stress experienced by the caregivers. Assuming the role of a caregiver necessitates the adoption of new responsibilities, requiring the reorganisation of priorities and redirection of energy. Consequently, caregivers should remain vigilant for any alterations in their mental state, such as increased irritability, dissatisfaction, depression, confusion, or other indicators of declining mental health.

The experience of children with special needs presents significant challenges, and the role of caregivers is of paramount importance. Concerns regarding the prospects of their child, a perceived loss of personal autonomy due to the condition of the child, a lack of recreational activities or outdoor engagements, economic instability, feelings of isolation and stigmatisation, and increased illness or behavioural differences in the child contribute to elevated stress levels among caregivers. This stress frequently shows as anxiety, which is expressed through symptoms such as fatigue, impaired concentration, racing or intrusive thoughts, hypervigilance or irritability, excessive worry, fear, a sense of impending doom, insomnia, nausea, palpitations, or trembling.

Mostly, caregivers are women, often housewives or individuals who have left their jobs to care for a child. The demands of household duties and managing family affairs frequently prevent them from finding personal time. Consequently, they do not experience the same pleasures or happiness as their peers who are parents of normal children.

> *Daisy (pseudonym), 64 years, said,*
>
> *(" These days I never get time to rest, even to watch TV. Every time I need to be with her, taking care that she does not destroy the things around, I rarely find any time to rest... I used to find time for myself and other household*

> *chores when she went to school. With schools being closed at that time, I faced the worst".*

The narrative highlights the level of patience required of a caregiver. The caregiver finds it challenging to enjoy their time or to spend time in front of the television, which serves as a primary source of solace for many older housewives. Thus, the continuous engagement in demanding tasks and the absence of entertainment can render one's mind like a deserted room. The psychological and emotional challenges faced by caregivers include distressing thoughts, emotional disturbances, unavoidable situations, and communication difficulties. A significant concern of the caregivers is the future well-being of the child, stemming from the child's inability to fulfil personal needs, which include developmental tasks expected at certain ages, such as brushing teeth, toileting, dressing, and eating.

The severity of mental retardation can lead to varying levels of depression in the caretakers. It was observed that the prevalence of depression was high in caretakers of children with severe mental retardation or disability. Meanwhile, among caretakers of children with moderate and mild mental disability, the level of depression was found to be low. Thus, the severity of mental retardation, clubbed with any further bodily disability, can be considered as a factor that impacted the depression level of the caretakers. However, the results were varying too.

Table 5.1 Level of depression

Respondents	The IQ level of the child	Level of depression
A	30	Severe depression
B	38	Moderate depression
C	40	Severe depression
D	28	Mild mood disturbance
E	65	Mild mood disturbance
F	45	Borderline clinical depression
G	63	Moderate depression
H	39	Severe depression
I	60	Moderate depression
J	25	Severe depression

(Source: Own Formulation Based on Findings)

Out of the 10 respondents, four of them were diagnosed as having severe depression with a scores of 32 and 31 in the Beck Depression Inventory Scale. Three of them were diagnosed as having moderate depression with a scores of 26,22, and 21. Two of them were observed to be suffering from mild mood disturbances with a score of 15 each, and one was diagnosed with Borderline Clinical Depression, with a score of 19.

Jacob (pseudo name), 65 years said,

> *" How will he survive after our lives? That remains a crucial question in front of me. He needs support in all spheres and activities of his life, like a small child. From awakening him to making him lie down in the bed, either mine or his mom's hands are needed for help. Until my other son's marriage, I strongly believed that he would take care of my child. But things have changed now, and he is busy with his affairs. However, my daughter claims to take care of him, but that is not a reliable solution, as per I as she lives in another family. This thought always creates in us an emotional grievance."*

The following narrative reflects the concerns of a father experiencing significant tension and anxiety regarding his son's future. Given that disability transcends gender, all respondents expressed similar anxieties. Caregivers, in particular, were troubled by the demanding nature of caregiving responsibilities, which necessitate substantial effort and constant availability to meet the child's needs. Concerns were also raised about ensuring the child's care and security following the parent's demise.

Despite having prior knowledge of the consequences of the condition, it remains a critical concern for all caregivers. The condition can induce significant behavioural changes in the specially-abled children, mainly negative, leading to increased stress and depression in the household. The financial burden associated with purchasing additional medications and covering medical expenses or emergencies is often substantial for many families. The trauma and vulnerability of the child to seizures instil fear in the caregivers, exacerbating their anxiety. The respondents confirmed that their child was vulnerable to seizures, with some sharing the distressing impacts of this condition.

Tara (pseudonym), 59 years, said:

> *"After the occurrence of a seizure, she has been continuously administered medicines for the same. And we witnessed gruesome behavioural changes*

> *in her. We were so sad and depressed because until then, she had never caused us any trouble."*

Several respondents stated experiencing challenges with a specially-abled child. They express significant stress due to the child's overt misbehaviour, which not only distressed the parents but also affected the neighbours. The respondents were particularly concerned about the child's behaviour when it manifested as violence, destructiveness, restlessness, or hyperactivity, resulting in noise and disturbances.

Siona (pseudonym), aged 50 years, said:

> *"I always feel an agony deep inside me whenever I see her being seated alone with her thoughts and the other two children playing, studying, and engaging in other activities. I always expected that some development would occur, but it did not."*

Depression and anxiety are prevalent among caregivers. Notably, the incidence of depression is higher among caregivers of female children with intellectual disabilities compared to those caring for male children. This suggests that the gender of the child significantly influences the level of depression experienced by the caregiver. The pain experienced by caregivers stems from high expectations placed on their children, comparisons of their children's deficits and behaviours with those of typically developing children, perceptions of the irreversibility or culmination of the disability, irrational beliefs that the condition is a divine punishment for past transgressions, and concerns about the future. These factors contribute to increased stress and anxiety, which lead to depression. Additionally, it was observed that the COVID-19 pandemic and the related lockdown, which resulted in behavioural changes in the children, further worsened the mental health challenges faced by caregivers.

The persistent concerns regarding recurrent illnesses and evolving behavioural patterns significantly impact the emotional well-being of caregivers. Factors such as loss of appetite, irregular sleep patterns, and the absence of recreational facilities, compounded by the child's disability, undermine the caregivers' positivity. This situation often results in emotions such as sorrow, agony, fatigue, disinterest, impaired decision-making abilities, and weakened self-esteem and satisfaction.

6. Social exclusion and stigma

The issue of social exclusion of the specially-abled is exacerbated by societal attitudes and behaviours that hinder their ability to fully contribute to society. Similarly, caregivers also experience exclusion. Society often perceives those with special needs as distinct from others.

Their unique modes of interaction, spontaneous conversations, and physical appearance, often influenced by their disabilities, contribute to the stares and comments they receive. While such instances may cause minor disturbances for the specially-abled children, and can also significantly impact their caregivers.

Mr. Jacob (pseudonym), 65 years said:

> *"The public viewed him as something strange and different. Wherever we went, people used to stare at us. At first, we felt some insecurities about it, but later we got used to it. Some came and asked about what was happening with him. My wife always had tears for them, and that was the only thing she knew. A mother is the one who is always more concerned about her child than the father. So, I answered them.*

This observation highlights the vulnerability of both individuals with disabilities and their caregivers in public settings. Such scrutiny can sometimes lead to feelings of intimidation. The indifference displayed by individuals towards those with disabilities renders them susceptible to mockery, teasing, and harassment. This behaviour indicates a lack of awareness among the individuals who perceive disabilities as humorous.

Shyla (pseudonym), 57 years said:

> *“It was so uneasy to handle him. When out, people used to come and ask us why he was yelling. What is his actual problem? Etc. Some people moved away disgustingly as his saliva would fall off his mouth as he kept his mouth open most of the time. This happened especially in buses. People would jump*
>
> *away from the nearby seat, saying, “disgusting.” I suffered a lot.”*

The statement highlights the insecurity and exclusion experienced by a caretaker while utilising public transportation. A common issue faced by many caretakers is the abrupt distancing by others upon observing the behavioural differences of individuals with disabilities. Economic constraints often prevent the caretakers from hiring taxis or owning a vehicle, compelling them to rely on public transportation as their sole option. The most prevalent exclusionary practices include avoidance, rejection, bullying, and harassment. Children with disabilities frequently encounter derogatory remarks such as 'slow,' 'stupid,' 'insane,' 'crippled,' and 'handicapped.' Additionally, there have been instances where educators have attempted to avoid students with disabilities, specifically encouraging parents to express concerns to the school principal regarding their children attending classes with a disabled student. Consequently, students with certain levels of IQ have been compelled to transfer to another school.

> Jaya (pseudonym),63, said:
>
> *"Even today, he knows whatever he has learned. But, unfortunately, the teachers in his first school never wanted him there. They held a council meeting and informed us that they could not let him study there any further, as some parents had raised issues with the behavioural differences of Vishnu and the concerns about their children sharing the classroom with him. Following which, we admitted him to the Buds School."*

The statement reflects the experiences of a mother who was compelled to discontinue providing her child with access to quality education, like that received by others. Children with disabilities frequently encounter exclusion within educational settings due to their physical and cognitive impairments. Educators often fail to recognise the unique challenges faced by these children. Consequently, even those with mild intellectual disabilities struggle to integrate with their peers.

Caregivers have reported instances where their children were treated less favourably than their non-disabled counterparts. Examples include being required to pay additional fees for the education of their child, being informed that their children could only attend school for a limited time in a day, or that their right to education was contingent upon the availability of teacher support. Furthermore, these children were subjected to discrimination, being labelled with derogatory terms such as 'idiots' or 'stupid.' Additional concerns include exclusion from the curriculum and school activities, as well as experiencing bullying, often perpetrated by teachers.

> Siona (pseudonym),50 years old, said:
>
> *"Sania is quite different compared to other children at the school. She will scream and strike her head on the wall or with her bare hands and all. Also, at times, due to her behavioural instability, she had beaten a few children. And their parents complained to me either in a parent meeting or the teacher would call me up to inform me that so and so had complained about Saniya's acts. So, when it comes to parents' meetings, I have a thought inside me that at least some of them have complained about my child. This creates an insecurity and a sense of exclusion in me."*

The statement reflects the experiences of a caregiver who perceives a sense of exclusion among fellow caregivers. As the parent of a child with severe intellectual disabilities, Siona has encountered numerous grievances from other parents at the school, as well as from teachers who, at times, were compelled to relay these concerns. This situation has often resulted in a sense of isolation for her. According to Siona, she has been susceptible to remarks from other parents, and the lack of understanding, coupled with the feeling of not being accepted and her child being perceived as different within the peer group, has engendered feelings of loneliness and exclusion.

7. Discussion

With one exception, all respondents were female or mothers of children with intellectual disabilities, aged between 50 and 65 years. Half of the participants identified with the Hindu community, while the other half identified as Christian. All but two respondents had attended school; of these, two discontinued their education in the fourth and eighth grades, respectively, while the remainder achieved a minimum qualification of the Secondary School Leaving Certificate (SSLC) in the tenth grade, with three pursuing further education. One individual resided in a semi-urban area, whereas nine were from rural areas within the district. All respondents, except one, owned their residences. The income of the respondents varied, with two earning between Rs 80,000 and Rs 1,000,000, while the remainder earned Rs 1,000,000 or more.

Caregivers of children with intellectual disabilities often experience depression and anxiety. Research findings indicate that caregivers of female children exhibit a higher prevalence of depression compared to those caring for male children with similar conditions.

This finding suggests that the gender of the child influences the level of depression of the caregivers. Factors contributing to caregivers' distress include high expectations for children with intellectual disabilities, comparisons with typically developing children, perceptions of the disability's permanence, irrational beliefs regarding divine punishment for past transgressions, and concerns about the future. These factors exacerbate stress, leading to persistent tension or anxiety, which may culminate in depression. Furthermore, the restrictions imposed during the COVID-19 pandemic and the consequent behavioural changes in children have been observed to further impact caregivers' mental health.

The emotional well-being of caregivers is adversely affected by persistent concerns regarding recurrent illnesses and fluctuating behavioural patterns. Factors such as loss of appetite, irregular sleep patterns, limited recreational opportunities, and the child's disability hinder caregivers' ability to maintain a positive outlook, leading to emotions such as sorrow, distress, fatigue, disinterest, impaired decision-making abilities, and diminished self-esteem and satisfaction.

Coexisting with a specially-abled child requires substantial strength and determination to confront significant challenges. Consequently, individuals with disabilities and their caregivers often exhibit reluctance to leave their homes, face difficulties in expressing their thoughts and opinions, encounter limited social interaction opportunities, experience physical exclusion, incur substantial medical expenses, lack access to rehabilitation services, endure bullying in educational settings, face barriers in voicing their concerns, and encounter obstacles in accessing public transportation, leading to experiences of mockery and discrimination. The lives of caregivers are characterised by uncertainty. The child's disability engenders a sense of isolation within the entire family, particularly for the primary caregiver.

Numerous mothers responsible for childcare report that their friends, family, and neighbours often fail to comprehend their experiences. The mothers frequently experience overwork due to the dual duties of childcare and household management. Mothers possessing higher levels of education and awareness of human rights are more inclined to seek support, articulate their concerns, and comprehend the needs of their child. Social exclusion is compounded by other forms of exclusion, such as institutional and physical barriers. Caregivers and the children face multiple challenges, including inadequate physical adaptability and accessibility, limited access to information and expertise, insufficient rehabilitation services, exorbitant medical costs, and discriminatory attitudes and behaviours. Institutions contribute to social exclusion through indifference, trickery, favouritism, and ineffective law enforcement. When interacting with institutions, individuals with disabilities often encounter avoidance, rejection, bullying, and harassment, which are frequently perceived as reflections of the caregivers' mental health.

When specially-abled children encounter stigma, significant consequences ensue. Such individuals are often subjected to differential treatment and are denied opportunities for education and training, employment, and other forms of support, as well as access to public health services and other essential services. This exclusion extends to their full participation in all societal aspects, including decision-making processes, due to stigma.

Discrimination rooted in stigma and the denial of fundamental rights adversely affects the specially-abled children as well as their families, on both social and economic levels. The stigma and the resultant feelings of value and illness render them more vulnerable to psychological and physical abuse, including neglect, domestic and sexual abuse, and exploitation. The majority of prejudice and exclusion experienced by these individuals frequently originates from stigma. In the formulation of development policies, programs, and other initiatives, individuals with disabilities are often underserved. Therefore, the stigma they endure is inadequately addressed, perpetuating their marginalisation and adversely affecting their personal, societal, and economic well-being.

It is essential to educate the public about different types of impairments and appropriate ways to interact with people with disabilities. With the correct information, more people will be understanding and compassionate to those who have impairments, fostering a climate of respect.

Conclusion

The journey of a child with special needs is marked by considerable hurdles and difficulties from birth onward. At the heart of their support network are their caregivers, usually parents or other close individuals. These caregivers face a multitude of challenges, such as social isolation, stigma, depression, and anxiety, primarily due to the stress of their role and societal expectations related to caring for children with special needs. Ongoing worries about recurring health problems and unpredictable behaviour patterns negatively impact the caregivers' emotional health. Caring for children with special needs requires bravery and determination to overcome significant challenges. Both children with special needs and their caregivers often encounter exclusion and stigma from society. Different forms of exclusion, including institutional and physical, intersect with social exclusion. Institutions contribute to social exclusion through inaction, dishonesty, favouritism, and poor law enforcement. People with disabilities frequently experience avoidance, rejection, bullying, and harassment in their interactions with institutions, which are often seen as a reflection of the caregivers' mental health. Discrimination stemming from stigma and the denial of basic rights negatively impacts individuals with disabilities and often their families, both socially and economically. It is crucial to educate the public about various types of impairments and the appropriate ways to engage with individuals with disabilities. Campaigns and seminars can be used to promote this civic education. With accurate information, more people will develop empathy and understanding towards those with impairments, fostering a respectful environment.

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