

Family and Community Factors on Social Inclusion of Children With Intellectual Disability: A Study in South Jakarta

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Abstract

Social inclusion is an important principle that means all human beings are entitled to participate in every aspect of human life. However, social inclusion of individuals with intellectual disabilities (ID) remains a significant concern in contemporary society, influenced by many factors and circumstances. This research explores the multifaceted role of family members and the wider community in shaping the social inclusion of individuals with ID. By employing a qualitative approach, the study examines the processes of perception development within families, as well as the barriers and enablers within community structures that impact social inclusion efforts. The case studies were conducted for one year in South Jakarta Indonesia, exploring 3 families with ID children. The method of data collection includes family observation, in-depth interviews of parents and community members and participant observation in community events. Key findings reveal that family resilience is critical in promoting social inclusion of its member with ID, the person with ID constrained by stigmas and limited community acceptance. The community's role, though essential for social inclusion, is frequently hindered by misconceptions about intellectual disabilities, lack of inclusive policies, and inadequate social support systems. This study underscores the need for enhanced collaboration between families, policymakers, and community organizations to create more inclusiveness.

Keywords: intellectual disability, family resilience, social inclusion, support systems

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Introduction

Intellectual disability (ID) was defined as a neurodevelopmental disorder characterized by significant limitations in intellectual functioning and adaptive behavior, affecting cognitive, social, and practical skills (American Association on Intellectual and Developmental Disabilities [AAIDD], 2010). ID is typically diagnosed before the age of 18 and influences an individual's ability to live independently and participate fully in society. This limitation is marked by a low intellectual function and some skills to live in a society, especially adaptability. Before, intellectual disability or to some extent will likely be called Intellectual Developmental Disorder (IDD) was categorized as a mental retardation, but the changes led us to dismiss the terminology, mental retardation bore a stigma and at the end impacting the individuals without reliable supports. Schalock et al., (2021) revealed 5 assumptions essential to the application of ID definition:

1. Limitations in cognitive functioning should be considered within the context of social and cultural setting and age, gender and peers.
2. Valid assessments consider cultural and linguistic diversity.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of elaborating limitations is to develop the support needed.
5. With the appropriate personalized support, we can expect the life functioning of the person with ID will improve.

It may be concluded that to comprehend individuals with intellectual disabilities, it is essential to evaluate their social and cultural context as well as familial background, while recognizing that each kid or individual possesses distinct limitations and capabilities.

This study will focus on the social aspect of the life of children with ID. ID as one of the important variants of neurodevelopmental disorders is still not researched a lot, generally the clinical assessment of the functioning of ID within life has been favorite topics. ID has tremendous consequences, from nearly normal functioning to total dependency. Despite that, the public is barely aware of what can be conducted to help ID people to be fully functioning individuals within a society.

In Indonesia, children with intellectual disabilities are recognized under the category of *penyandang disabilitas intelektual* as outlined in Law No. 8 of 2016 on Persons with Disabilities, which affirms their rights to education, healthcare, employment, and social participation (Undang-Undang (UU) No. 8 Tahun 2016 Tentang Penyandang Disabilitas, 2016). However, despite legal protections, individuals with ID continue to face significant barriers to social inclusion due to stigma, lack of access to inclusive education, and inadequate support systems (Suharto, 2020). It could be said that the infrastructures and superstructures of living in the cities in Indonesia lacks supporting facilities for ID individuals. Children with intellectual disabilities in Indonesia encounter multiple challenges, both at home and in broader society. Limited awareness about ID often results in negative societal attitudes, where children with disabilities are marginalized or seen as a burden (Kustanti et al., 2021). Additionally, access to specialized education remains uneven, with many children in rural areas having limited opportunities to attend inclusive schools (Hartanto et al., 2022). Even when educational institutions provide special education (Sekolah Luar Biasa), these schools sometimes reinforce segregation rather than promoting integration into mainstream society (Adioetomo et al., 2014).

The role of families is crucial in addressing these challenges and ensuring the well-being of children with ID. In many Indonesian households, caregiving responsibilities fall primarily on mothers, who play a significant role in their child's development and advocacy (Setiawati et al., 2021). Families with greater awareness and economic resources are more likely to access therapy, inclusive education, and community support programs. However, families with lower socioeconomic status often struggle due to financial constraints, social stigma, and a lack of government support services (Suharto, 2020). The extent of family involvement in seeking social inclusion for their child depends not only on economic factors but also on cultural beliefs. In certain communities, traditional views on disability may lead to isolation rather than empowerment (Kustanti et al., 2021).

Social inclusion refers to the process of ensuring equal participation and opportunities for all individuals, particularly those who face marginalization (United Nations, 2016). For children with intellectual disabilities, social inclusion is essential for their psychological well-being, development of life skills, and long-term independence (Simões & Santos, 2021). In the Indonesian context, efforts to promote inclusion are gradually increasing, with programs such as the Inclusive Education Policy (Kementerian Pendidikan, Kebudayaan, Riset, dan Teknologi, 2009) and community-based rehabilitation initiatives (Hartanto et al., 2022). However, challenges remain in implementation, as inclusive schools often lack adequately trained teachers and resources.

This research aims to explore the role of families as a key factor in facilitating the social inclusion of children with intellectual disabilities in Indonesia, using a case study approach. Social inclusion has been proven to be significant, basic need and important intervention for people with ID. Social inclusion contributes to the most part of mental health for children and people with ID. This condition of mental health facilitates the process of learning and cognitive development, although experts say that it is not a guarantee for the increase of IQ in their life. Within the context of social inclusion, an individual with ID will get a precious moment for exploring his or her world and learning to become part of their environment. By examining real-life experiences and strategies adopted by families, this study seeks to comprehend the process of social inclusion and factors affecting social inclusion in the Indonesian context.

Research Question

How do the factors of family affect social inclusion of Intellectual Disability children?

Literature Review

Literature review was done first for the research of Owuor et al. (2018) about assistive technology for social inclusion of ID people, Bruun et al. (2024) on resources and approaches of end-of-life care planning for people with ID, Carnemolla et al. (2021) about improving inclusion for ID people and McMaughan et al. (2024) on meaningful social inclusion and mental well-being for autistic adolescents and emerging adults. The studies reflected the lack of consistency in defining social inclusion. All articles define social inclusion as a robust construct about the efforts which have been conducted by individuals and communities to promote and encourage the inclusion of those situated on the margins, including people with disabilities. Social inclusion cannot be limited into the efforts to make the marginalized people become included in the community, social inclusion is something intertwined from interpersonal relationships, community participation and the care by community to create an

atmosphere where all community members can bring respect and well-being to the marginalized people. Moreover, people with ID value cleanliness, safety, accessible information and respect (Carnemolla et al., 2021).

In this study, family resilience was constructed as the main framework of thinking, which guided the formulation of problems, data collection and analysis. Family resilience reflects the ability of family systems to cushion stress, recover from crises, reduce dysfunction and adapt to new circumstances (Lenz, 2016). This study by Lenz (2016) leads our understanding that family resilience is more than just a “crisis bouncing back ability”, but above all, the family regains its power to build a stronger tie and care for each other, as a love-oriented structure of relationships. Troy et al. (2023) came up with the refreshed views about psychological resilience, that can be applied in many contexts including family. Troy et al. (2023) integrates stress and coping with emotion regulation to explain resilience., and psychological resilience heavily relates to the affect regulation framework. This point of view is reflecting affect regulation that impacts affective experience, social processes, behaviour, physiology, cognitive effort, and engagement. Family as an important context can use psychological resilience strategies to assist the members strive for a better mental health.

Conducting an additional literature review on the studies of Hannon et al. (2023), Noroozi et al. (2024), Gao et al. (2023), and Zhang et al. (2024), it provided me with a new perspective on the research subject, particularly in comprehending the broader context of my research. Zhang et al. (2024) found that family resilience significantly mediates the impact of patient coping on caregiver burden and family resilience as a buffer in the stress process model. Noroozi et al. (2024) found that within a family with down syndrome child, the families actively seek support and information, emphasizing building social interaction skills for the child. Parents give endless support to children with down syndrome to be able to make friends and play with other children. Meanwhile, Gao et al. (2023) discussed family resilience among Chinese families who has ID children. Gao et al. (2023) found that family resilience was originated from value-based system on a sense of responsibility and the application internal and external family resources and of course the influence of China’s long-standing collectivists culture. Hannon et al. (2023) found that resilience – including family resilience – is influenced by multilevel and multisystemic processes. And women as participants of Hannon’s research prefers the words “empowering” than “coping” to describe resilience, the participants also endorsed the process of resilience to be an enhancement of mental health.

Synthesizing the literatures review, all studies used family resilience as a central concept. Family resilience within this study refers to the dimensions of emotional and psychosocial adjustment, coping and support strategies, cultural and structural context, and information and resource gap. First, be it down syndrome or ASD, we must look deeper into emotional challenges of the individuals and how the caregivers respond and accepting these everyday problems. Second, families have their own belief systems, flexibility and how do they search for community supports. Third, cultural values and social system where people live affecting how the families can encourage their member with limitations to go on with social inclusion. And last, when the support system from is not reliable, the families will become experts by being self-taught.

This research employed a qualitative case study design to gain an in-depth understanding of the social inclusion experiences of children with intellectual disabilities within the specific context of selected schools in Jakarta. A case study approach is particularly well-suited for exploring complex social phenomena within their real-world settings (Yin, 2018), allowing

for a rich and nuanced exploration of the perspectives and experiences of the parents involved. Each case functions as a lens for comprehending how a family with ID child navigates their life with a special member, meanwhile motivating this ID child to be able to adapt to social situations. Unlike quantitative approaches that focus on generalizability across a large population, the strength of a case study lies in its capacity to provide detailed and contextualized insights into a particular phenomenon (Stake, 1995). In this study, each participating family and their child's school environment constituted a "case," allowing for an examination of the unique factors and interactions that shape social inclusion within these specific contexts. The bounded nature of these cases – the specific families and their respective school communities in Jakarta – enabled a focused and intensive investigation of the research questions.

The participants in this study were 3 parents of children with intellectual disabilities attending *Tunagrahita* or Type C Special School for ID children in Jakarta. Participants were recruited through purposive sampling, a strategy commonly used in qualitative research to select information-rich cases relevant to the research question (Patton, 2015). Initial contact was made with the principals and relevant staff of several schools in Jakarta that were known to have programs supporting the inclusion of children with intellectual disabilities. Following school approval, information about the study was disseminated to potentially eligible parents through letters and/or informational meetings organized by the school. Interested parents were invited to contact the researcher directly to express their willingness to participate. Prior to their involvement, each participant was provided with a detailed information sheet outlining the study's purpose, procedures, potential risks and benefits, and their rights as participants (including the right to withdraw at any time). Written informed consent was obtained from each parent before the commencement of any data collection activities.

Data for this study were collected primarily through in-depth semi-structured interviews and non-participant observations. These methods were chosen to provide rich, qualitative data on parents' perspectives and experiences of their children's social inclusion. Semi-structured interviews were conducted with each participating parent. An interview guide was developed based on a review of relevant literature and the study's research questions. The guide included open-ended questions designed to explore parents' understanding of social inclusion, their experiences with their child's social interactions at school and in the community, perceived facilitators and barriers to inclusion, the role of support systems, and their hopes and concerns for their child's social future. In addition to the interviews, non-participant observations were conducted in the family's home. The purpose of these observations was to gain a first-hand understanding of the social interactions and environments experienced by the children, as perceived by the researcher. During observations, the researcher adopted a non-intrusive role, observing and documenting interactions, social dynamics, and the overall atmosphere related to inclusion.

The data collected through in-depth interviews and field notes from observations and were analysed using thematic analysis. This method is a widely used in qualitative approach for identifying, organizing, and reporting patterns (themes) within a dataset (Braun & Clarke, 2006). The goal of thematic analysis in this study was to systematically identify the key themes that emerged from the parents' accounts and the observational data regarding the social inclusion of their children with intellectual disabilities. I started from familiarization of data, generating codes, searching for themes, reviewing themes, naming and refining themes. Within the processes I organized once a member-check event and expert judgement, to get a more reliable data and information about the cases.

Results

The study cases in this research comprise three families with children who have intellectual disabilities; these families have been engaged in advocating for social inclusion for these children. Below is the table of family data of cases who have been interviewed and observed:

Table 1

The Family Data

Name and location family's home	ID children's data	Additional data
<ol style="list-style-type: none"> 1. Family A lives in South Jakarta – Indonesia. The distance of home and school around 2 KM 2. Mother is 42 years old and Father 45 years old; both are bachelor's degree graduated 3. The family has 3 children and the ID one is the youngest 4. The Father works at a business company and the mother is a fully housewife 5. At home lives the grandmother from Father's side 	<ol style="list-style-type: none"> 1. The ID child (A) is a female, 13 years old and an active student at a special school around the family's home 2. She cannot read, write and calculate and barely speak 3. The parents send her to "Taman Pendidikan Al Quran" or school for Quran recital 	<ol style="list-style-type: none"> 1. From the school I had information that this ID child is very eager to go to school and looks enjoying every activity 2. The teacher informed me that this student is highly obedient and endeavours to complete tasks calmly. 3. She loves to play within the tent in the class and playing with dolls or books
<ol style="list-style-type: none"> 1. Family B lives in South Jakarta – Indonesia. The distance of home and school around 5 KM 2. Mother is 41 years old and Father 41 years old; both are bachelor's degree graduated 3. The family has 2 children and the ID one is the youngest 4. The Father is the teacher, and the mother is a fully housewife 5. Only this nuclear family lives I the house 	<ol style="list-style-type: none"> 1. The ID child (B) is a female, 13 years old and an active student at a special school around the family's home 2. The mother motivates and facilitates this ID kid to experience many activities 	<ol style="list-style-type: none"> 1. B is a shy kid and very calm, she becomes calmer around her teacher 2. She cannot stare directly to the eyes and tend to avoid any contact with individuals that she never closes in contact 3. Her brother is the one who helps her a lot for understanding the world around her, besides the mother, her father looks in full effort to be a friend for B

<ol style="list-style-type: none"> 1. Family C lives in a lavish neighbourhood in southern Jakarta. This family is an upper middle class, the father works in a multinational company and the mother stays at home as a full housewife 2. The mother takes her ID kid seriously, she even learnt in Singapore for learning about ID 3. The family has 3 kids and the ID one is the eldest 4. They live a big house with 2 maids 	<ol style="list-style-type: none"> 1. The ID child C, a 15-year-old female, is unable to read, write, or perform calculations; nonetheless, she can speak, however her speech is unclear and difficult to comprehend. 2. She can draw good, but it is depending on her mood and health 3. The parents pay therapist very well and help C to get back from backwardness, every time the situation happens 	<ol style="list-style-type: none"> 1. In the last 5 years ago, the parents did not send her to schools based on some reasons 2. C plays and stays at home with her siblings after they come from school
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Case A

Social inclusion has been based primarily on the awareness of parents that their ID child deserves a chance to understand human interaction. Although it is always felt as something frightening, A is always motivated to play with her community kids. Yes, it was not always smooth and the community kids welcome A, but the parents let their kid to be able to survive the pressure of interaction.

“I know it was unpleasant sometimes, but the interaction basically impacted good on my kid. ID child does not mean a burden and always stay in the dark.” (Mother of A, at home)

“Sometimes this neighbourhood kids playfully treat my daughter as something to laugh at, I cried and A run with fear, I am the one who is mad them.” (Mother of A, at school)

“I still hope there will good change with my daughter, I always have this optimistic view.” (Father of A, at home)

Case B

For the parents, social inclusion should be referred to a process of learning from the family, the community and school. It will never be easy, the kids with ID according to mother of B, needs a very supportive community. Like she said:

“How do I have to say this, it is a process to understand that B is a special child, the processes are long, and the neighbour or extended family can see by themselves, this kid needs to be treated differently.” (Mother of B, at home)

“I always ask her sibling to involve in the process of learning, for example B wants to hold a pencil for drawing, her brother will help and patiently show the way. Moreover, with inclusion, let all the families learn together, it is good for B.” (Mother of B, at school)

The processes of social inclusion as taught family some values, aligned with the families’ values, that ID child is a precious member of the community. The Father said:

“I am looking for some ways of getting to know ID well, so I can help her optimally, especially, to be able to make a human contact.” (Father of B, at home)

Case C

Social inclusion has been applied by the parents ever since C was a toddler. C was sent for a kindergarten, the school that accepted all types of kids' intelligence. At first, C was diagnosed with speech delay, but as the times continues with many progresses in Indonesia about intellectual disability, the parents found some medical doctor who can help treating C as an ID kid. But when the family moved to other city in Indonesia, C was having problems.

“I don't know what happened, when we move to other city, C went back to the situation when she didn't have the ability to identify numbers and letters. At that time we met a doctor that gave us for the first time of this term ID” (Mother of C, at home)

“We slowly know that C is an ID kid, she cannot communicate and adapt to any situation, except home and her closest family.” (Mother of C, at home)

“What we, as the parents, dream about is C able to communicate properly and interact with other kids.” (Mother of C, at home)

“We aspire for our child to exhibit greater composure in social situations and to independently manage her hygiene and other responsibilities.” (Mother of C, at home)

Discussion

This study aimed to explore the lived experiences of families raising children with intellectual disabilities (ID) in Jakarta, with a focus on how social inclusion is perceived and facilitated in the school and community contexts. Using a qualitative case study approach, the study revealed both shared and unique challenges across three families, highlighting the central role of family resilience in navigating social inclusion. The findings align with existing literature while also offering nuanced insights into the Indonesian context.

Reconceptualizing Social Inclusion: Beyond Participation

The present study affirms the assertion by Carnemolla et al. (2021) and McMaughan et al. (2024) that social inclusion is not merely about physical presence or access to shared spaces but involves deeper dimensions of belonging, interpersonal respect, and emotional safety. Parents in this study emphasized the emotional costs and triumphs embedded in their children's inclusion, echoing the multidimensional nature of inclusion as described in the literature. For instance, Family A's efforts to motivate their daughter to interact with neighbourhood children—even when such interactions were met with rejection—demonstrates that inclusion is a dynamic and emotionally charged process, not a static outcome. The study indicates that social inclusion at the basic platform requires family resilience, as the source of energy, because social inclusion involves the awareness of ID kids' surroundings, to accept them with their limitations.

Family Resilience as a Mediating Mechanism

A central finding is the way family resilience mediates the experience of social inclusion, consistent with the frameworks presented by Lenz (2016), Troy et al. (2023), and Zhang et al. (2024). Families in this study exhibited various resilience strategies including emotional regulation, active caregiving, community engagement, and adaptive learning. For example, Family B's approach—mobilizing both the sibling and parents in scaffolding the child's daily activities—demonstrates how resilience manifests through collective problem-solving and shared caregiving. As Zhang et al. (2024) suggested, such resilience helps buffer the stress of caregiving and fosters a more hopeful trajectory for both child and family. The concept of family resilience as the buffering factor for families with ID children should be explored and make a deep exploration more on the role of family resilience to enhance the position of the family in the society.

The Cultural Specificity of Resilience and Inclusion

The findings also underscore the importance of understanding resilience and inclusion within the sociocultural context. Like the work of Gao et al. (2023) who emphasized value-based family systems within a Chinese cultural framework, the Indonesian families in this study drew heavily from values of familial responsibility, religious belief, and community orientation.

Conclusion

This study explored the experiences of families in Jakarta who are raising children with intellectual disabilities, focusing particularly on their efforts to foster social inclusion within school and community settings. Through a qualitative design with case study type, the research provided rich, contextualized insights into how family resilience plays a pivotal role in navigating the challenges and complexities of social inclusion for children with ID.

The findings highlight that social inclusion is not merely about placing children with ID in mainstream environments but about cultivating meaningful interactions, emotional safety, and acceptance and how the community cope with ID children in general. Parents in all three cases demonstrated a strong sense of advocacy, patience, and resourcefulness in supporting their children's social participation. These families consistently mobilized internal strengths—such as emotional bonds and caregiving commitment—as well as external strategies, including community engagement and professional support, to enhance their children's inclusion experiences. Although the families are aware that they face crisis and pressures in everyday life, with the understanding of family resilience as a primary factor in family dynamics, social inclusion becomes a path to bind the family. Moreover, the study confirms that **family resilience**—encompassing emotional adjustment, belief systems, support-seeking behaviours, and adaptive strategies—acts as a vital buffer against the stresses associated with caregiving. Cultural values and structural factors were also found to influence how inclusion is perceived and enacted in everyday family life.

These findings offer important implications for practice and policy. I recommend schools, community organizations, and policymakers to recognize and support the central role of families in promoting inclusion. Initiatives should go beyond educational placement to ensure that community members—including educators, neighbours, and peers—are equipped to support meaningful engagement with children with intellectual disabilities.

In conclusion, this study contributes to the growing body of literature that frames social inclusion not only as a societal obligation but as a deeply relational and contextual process. It underscores the significance of family resilience as both a theoretical lens and a practical resource in efforts to support the well-being and social development of children with intellectual disabilities. Although the study has a limitation, which is it was based only on qualitative approaches, in the future I hope many researchers will come up with more research about the implication of family resilience to social inclusion of children with ID, with different research approaches and recommendations.

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