

Family Support in Enhancing the Independence of Children with Intellectual Disabilities in Daily Living Activities

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Abstract

This study aims to determine the role of family support in increasing the independence of children with disabilities in carrying out daily activities. This study uses qualitative methods as a research approach with research subjects, namely four families who have children with disabilities, so the technique of selecting informants uses purposive sampling. Data were collected through non-participant observation, in-depth interviews, and documentation studies. Data analysis techniques used data reduction, data collection and conclusion drawing. The results showed that family support is crucial in increasing the independence of children with disabilities. The family is the first person to be present and accept the child's condition as a whole. The forms of support include informational support by providing advice and information to children so that they can carry out various activities on their own but are still accompanied; recognition support, which gives appreciation to children when children successfully complete a basic job well; instrumental support, which provides complete facilities such as therapy and skills training; emotional support, which is concerned with concern, sympathy and empathy, acceptance, and affection from the family to children. These forms of support contribute to improving children's ability to carry out daily activities independently. In addition, the importance of synergy between family and social environment in shaping children's independence in a sustainable manner.

Keywords: Children with Intellectual Disabilities; Family Support; Independence

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Introduction

Independence is a critical factor in a child's development, serving as a foundation for active participation in various activities. According to Steinberg (1995), independence refers to an individual's ability to self-regulate and self-direct, demonstrated by emotional autonomy from others—particularly parents—along with the ability to make decisions, uphold personal values of right and wrong, and determine what is important (Berlianti et al., 2024). Children with disabilities often face challenges in carrying out daily living activities, which may hinder their ability to achieve optimal independence (Sunan et al., 2023). In this context, independence is defined as the child's capacity to perform daily tasks without relying on assistance from others (Sumantri, 2024). Children with intellectual disabilities (ID), commonly referred to in Indonesian as *tunagrahita*, experience delays or impairments in mental development (intellectual functioning) accompanied by difficulties in learning and adapting to their environment (Gabe, 2008). According to the American Association on Mental Deficiency (AAMD), intellectual disability is characterized by below-average general intellectual functioning, with an IQ score of 84 or lower, based on standardized tests. Contributing factors to intellectual disability include prenatal factors, perinatal complications, and postnatal events. Genetic disorders, such as chromosomal abnormalities originating from defective parental gametes, lack of environmental stimulation, and accidents are also identified as potential causes (Sudiarti et al., 2024).

Raising a child with a disability presents both challenges and significant responsibilities for parents (Rachman et al., 2023). While some parents may initially perceive having a child with a disability as a source of shame, emotional responses tend to evolve as they progress through a process of acceptance (Adani, 2022). In caregiving and daily support, parents and family members play a vital role. Consistent family support significantly contributes to the development of independence in children with intellectual disabilities (Sumantri, 2024). This support extends beyond fulfilling basic needs, encompassing emotional and social aspects that foster the child's adaptive and independent functioning. Through such support, the child feels accepted, valued, loved, and respected (Stevanny & Laksmiwati, 2023). The success of children with disabilities is largely influenced by the roles and support provided by their families (Stevanny & Laksmiwati, 2023). Key forms of support include informational, appraisal, emotional, and instrumental assistance (Nurhayati et al., 2023).

A literature review by Nurhayati et al., (2023) on family support for children with special needs highlights the importance of consistent encouragement, motivation, and reward in optimizing the child's potential across life domains. Rahayu (2019), in a literature study on family resilience, emphasized that resilience is crucial for families of children with disabilities, influenced by factors such as religiosity, locus of control, coping mechanisms, social functioning, intra-family communication, self-awareness, and social support. Kumala et al., (2022) further found that family social support significantly enhances self-confidence, openness, and courage in children, particularly among children with hearing impairments, by improving their communication with family and the social environment. Unlike previous studies, the present research focuses specifically on how family support enhances the independence of children with intellectual disabilities, utilizing Friedman's (1998) framework of social support, which includes: (1) informational support; (2) appraisal support; (3) instrumental

support; and (4) emotional support. This study aims to examine the role of family support in fostering independence in children with intellectual disabilities in performing daily living activities. The findings are expected to contribute to the advancement of social welfare studies, particularly in the field of disability, by offering insights into how families support the development of independence in children with intellectual disabilities. Furthermore, the results can serve as a foundation for social work practitioners in designing family-based interventions to support the child's growth and autonomy.

Children with Intellectual Disabilities (*Tunagrahita*)

According to Law No. 8 of 2016 on Persons with Disabilities in Indonesia, individuals with disabilities are defined as those who have long-term physical, intellectual, mental, or sensory impairments that, when interacting with their environment, may encounter obstacles and difficulties in participating fully and effectively in society on an equal basis with others. Disabilities are categorized into four types: (1) physical disabilities, (2) intellectual disabilities, (3) mental disabilities, and (4) sensory disabilities. This study specifically focuses on intellectual disabilities, characterized by impairments in cognitive functioning due to below-average intelligence. Subcategories of intellectual disabilities include learning difficulties, Down syndrome, and intellectual disability known as *tunagrahita* (Ministry of Social Affairs, Republic of Indonesia, 2021).

According to Apriyanto (2014), children with *tunagrahita* face cognitive development challenges and difficulties in adaptive behavior, resulting in a range of functional limitations (Graces Maranata et al., 2023) Brown (1991, as cited in Maranata et al., 2023) outlines several defining characteristics of children with *tunagrahita*, including: (1) slow acquisition of new skills, difficulty grasping abstract concepts, and a tendency to quickly forget recently learned information; (2) difficulty generalizing knowledge and learning new tasks; (3) limited verbal communication abilities, particularly in children with severe intellectual disabilities; (4) physical limitations such as the inability to walk or stand without assistance, difficulty performing basic tasks, and impaired motor coordination; (5) lack of self-help skills, including challenges in feeding, personal hygiene, and dressing—indicating a need for assistance in acquiring these basic life skills; (6) children with mild intellectual disabilities may interact with peers, whereas those with severe disabilities often struggle to engage in social play due to difficulties maintaining attention and responsiveness; (7) repetitive and purposeless behaviors are also common, such as hand-flapping, self-biting, or head-banging, which may pose risks to their well-being. These characteristics highlight the wide-ranging impact of intellectual disabilities on a child's ability to function independently, socially, and physically. As such, specialized care, educational support, and sustained family involvement are crucial in enhancing their quality of life and autonomy.

The Role of Family Support in Enhancing the Independence of Children with Intellectual Disabilities (*Tunagrahita*)

According to Friedman (1998), family support can be categorized into four distinct types: (1) informational support, which involves the provision of information, advice, guidance, and ideas to help someone facing challenges; (2) appraisal or esteem support, referring to expressions of value or appreciation for a person's condition or achievements; (3) instrumental support, which includes tangible assistance such as access to adequate facilities and resources; and (4) emotional support, which encompasses affection, empathy, sympathy, and trust. Findings from this study indicate that family support plays a critical role in the growth and development of children with intellectual disabilities (*tunagrahita*), particularly in fostering their independence in performing daily activities. Based on data coding and interviews with four informants, the study analyzed family support through Friedman's framework.

First, informational support is often provided gradually to help the child understand daily routines, such as bathing, dressing, eating, organizing personal items, and maintaining hygiene. Parents also provide guidance on appropriate and inappropriate behaviors. This form of support is essential not only for children but also for parents, who benefit from receiving accurate and relevant information to better support their children. For instance, Yayasan Biruku Indonesia provides monthly education sessions to strengthen families' capacities in caring for children with disabilities. Second, esteem or appraisal support plays a vital role in reinforcing children's self-confidence. Positive reinforcement—such as praise for completing a task like independent toileting or eating—is often given by parents using affirming language (e.g., “You’re amazing” or “Good job!”). These expressions of encouragement strengthen the child's sense of self-worth and promote further efforts to perform tasks independently. All four informants reported using praise and recognition to motivate their children toward greater self-reliance. Third, instrumental support involves direct assistance and the provision of resources necessary for the child's development. Families demonstrated this by creating home environments conducive to learning, supporting daily routines such as dressing, toilet training, and toothbrushing, and encouraging children to engage in therapy. Parents also invest time, effort, and finances to ensure access to therapies and skill-building activities. Yayasan Biruku Indonesia facilitates this process by offering therapy services and skills training programs tailored to the needs of children with disabilities. Fourth, emotional support refers to the affection, warmth, and unconditional acceptance provided by the family. Children with *tunagrahita* particularly need stable emotional environments and strong familial bonds. The informants emphasized the importance of showing consistent love and acceptance, which creates a sense of security and comfort for the child. Parents are central figures in the caregiving and developmental support of children with intellectual disabilities. They bear the responsibility of ensuring the child's emotional and physical needs are met and facilitating an environment that supports growth. Raising a child with a disability brings unique challenges, which is why parental acceptance of the child's condition is essential. Acceptance becomes the foundation for providing comprehensive support across informational, esteem, instrumental, and emotional domains, which are vital for the child's development and independence.

In addition to these support types, families can engage children in structured training programs to further enhance their skills. These include: (1) occupational

therapy, which focuses on improving fine and gross motor skills; (2) play therapy, which utilizes play as a therapeutic tool; (3) life skills training, which prepares children to handle everyday tasks; and (4) vocational training, aimed at equipping children with work-related skills. Yayasan Biruku Indonesia offers various training options, but based on findings from the four informants, only occupational and play therapies have been implemented, as the children are categorized as having moderate to severe intellectual disabilities. Therefore, more advanced trainings such as life skills and vocational programs have not yet been pursued.

Method

This study employed a qualitative research method, focusing on children with intellectual disabilities. As stated by Filisyamala et al. (2016), qualitative research is characterized by the in-depth exploration of a topic and the direct engagement of researchers with participants in the field to obtain accurate and contextual data (Afiffah & Musik, 2024). The sampling technique used in this study was purposive sampling, where participants were selected based on specific research criteria, particularly their relevance and capacity to provide rich information aligned with the study's focus. The informants consisted of four families with children with intellectual disabilities (tunagrahita), all of whom were affiliated with the Biruku Indonesia Foundation in Cihaur Geulis Subdistrict, Bandung City. Data sources in this study were divided into primary and secondary data. The primary data were collected directly from informants, namely the families, through interviews. Secondary data were obtained from various relevant documents, including Law No. 8 of 2016 on Persons with Disabilities, statistical data from the Central Statistics Agency (BPS) on the number of children with disabilities, information from the Ministry of Social Affairs regarding service programs for children with intellectual disabilities, and existing literature that supported the theoretical framework of this research, particularly studies related to social support, family involvement, and intellectual disabilities.

The data collection techniques consisted of non-participant observation, in which the researcher observed behaviors and situations without engaging in the activities being studied; document analysis, which involved reviewing books, brochures, and credible academic articles sourced from platforms such as Google Scholar and ResearchGate, focusing on topics related to family support and intellectual disability; and in-depth interviews conducted with three parents of children with intellectual disabilities to gather detailed and experiential data. Data analysis was conducted through three stages: data reduction, which involved organizing, categorizing, and selecting relevant data to focus the analysis; data presentation, in which information was structured in narrative form to reveal emerging themes and patterns from field notes; and conclusion drawing, where the analyzed data were interpreted to form insights that could guide practical actions or further research.

Findings and Discussion

Informant Characteristics

This study was conducted in the Cihaur Geulis subdistrict, Cibeunying Kaler District, Bandung City. Based on data from the Biruku Indonesia Foundation, several families in the area continue to raise children with disabilities. As a social organization, Biruku Indonesia Foundation is committed to supporting families of children with disabilities, including those with intellectual disabilities (tunagrahita). The foundation provides ongoing guidance and offers emotional, educational, and social support to ensure that families do not feel alone in facing the challenges of caregiving and raising children with special needs. The various programs and approaches developed by the foundation emphasize the crucial role of family support in fostering independence in children with disabilities.

The informants in this study were families who have children with intellectual disabilities. The following describes the general characteristics of each case:

Informant 1 recognized that their child was developmentally different at the age of three, following a high fever that led to developmental delays and physical impairments.

Informant 2 observed differences during the child's early education in kindergarten, where the child exhibited learning delays. Upon the teacher's recommendation, the child underwent an IQ test, which revealed below-average intellectual functioning.

Informant 3 noted that their child began to show signs of developmental issues at the age of two after falling from a stroller. Initially, the parents did not perceive the injury as serious. However, the child later developed a fever and seizures, prompting an emergency hospital visit. MRI results and a physician's diagnosis revealed neurological damage. Since then, the child's growth and development have differed significantly from typical age-related milestones.

Informant 4 identified their child's condition as atypical when the child was around four months old. At four and a half months, the child suffered a high fever accompanied by measles and seizures, resulting in hospitalization. These events triggered developmental delays: the child began walking only at two and a half years of age and was able to speak—albeit with difficulty—only at nine years old.

Field data suggest that the intellectual disabilities experienced by the informants' children were not congenital but rather developed as a result of medical conditions in early childhood. Most of these conditions stemmed from severe illnesses such as high fever, which subsequently affected the nervous system. These findings support the notion that intellectual disabilities can be caused not only by genetic or prenatal factors but also by postnatal factors, particularly illnesses or accidents occurring in early developmental stages.

Conclusion

Based on the results of the research, it can be concluded that family support plays a vital role in fostering the independence of children with intellectual disabilities (tunagrahita) in carrying out their daily activities. Comprehensive family support enables these children to perform basic self-care, complete simple household tasks, and engage in social interactions within their environment with greater confidence. This suggests that, although they may still require supervision and guidance, children with tunagrahita do not always have to depend entirely on others. The forms of support identified in this study include informational support, appraisal or esteem support, instrumental support, and emotional support. The synergy between strong family support and a positive social environment is a key factor in successfully cultivating the independence of children with tunagrahita. An inclusive environment helps reduce the risk of discrimination and allows children to participate more fully in social life, thereby supporting their adaptation and integration into society.

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