Between normality and abnormality: Understanding the social support of people with physical disabilities among family

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Abstract

People with physical disabilities in Indonesia face a multitude of challenges, from physical barriers to social stigmas. This study examines the complexities of how people with physical disabilities navigate these challenges, focusing on the role of social support within families. The stigma of disability is often shaped by perceptions of "normal" versus "abnormal," which deeply influence the social support of people with disabilities. By analyzing two case studies in Yogyakarta, Indonesia, this article highlights how differing family perceptions (whether they see the disability as normal or abnormal) affect the nature and effectiveness of the social support provided. The research reveals that families who view disabilities as a normal variation tend to offer more supportive environments, fostering better psychological well-being and greater participation in family life. Conversely, families who perceive disabilities as abnormal often provide less emotional support, negatively impacting the individual's sense of belonging. This study underscores the importance of shifting societal and familial perceptions to reduce stigma and improve the quality of life for people with physical disabilities. The findings contribute to the ongoing discourse on disability inclusion and provide a foundation for policy recommendations to foster a more supportive and inclusive environment.

Keywords: *people with physical disabilities; social support; stigma*

Introduction

Humans, as social beings and entities living within society, possess equal rights and responsibilities. This fundamental principle applies not only to individuals deemed "normal" in a physical or mental sense, but also to those experiencing limitations or disabilities. According to (Stucki et al., 2002) and (Mitra et al., 2013) disabilities may arise from various causes, including congenital conditions, accidents, health issues, or the aftermath of natural disasters. Like other individuals, people with disabilities have the same rights and responsibilities in societal and state life. The issue of people with disabilities in Indonesia is a multidimensional problem encompassing both structural and social challenges. People with disabilities face not only physical limitations but also various obstacles in accessing basic rights such as education, employment, healthcare, and public facilities (Banks et al., 2017; Kafaa & Nurhadi, 2023; Mitra

et al., 2013). The challenges they encounter are often exacerbated by socio-economic conditions, structural inequalities, and persistent social stigma(Krahn, 2011; Mitra et al., 2013; Mitra & Yap, 2022).

According to the latest data in 2020, the number of people with disabilities in Indonesia was estimated at approximately 22.97 million, or 8.5% of the total population (Mustari, 2018; Sullivan, 2020). This figure is expected to rise, considering the various risks that could lead to disabilities, such as social conflict, accidents, and natural disasters. Putri (2023) and Wahat et al. (2021) assert that social conflicts and natural disasters, such as earthquakes, tsunamis, and landslides, significantly contribute to physical disabilities, thus increasing the number of people with disabilities in Indonesia.

A concrete example of the impact of disasters on the rise in physical disabilities can be observed in the earthquake that struck the Special Region of Yogyakarta in 2006. This earthquake not only caused severe physical destruction but also led to an increase in the number of people with disabilities. Data from the DIY Social Service Department indicates that the number of individuals with physical disabilities rose significantly, from 6,656 in 2005 to 8,122 after the earthquake in 2006, and continued to rise to 9,197 in 2007 (DIY Provincial Social Service, 2017).
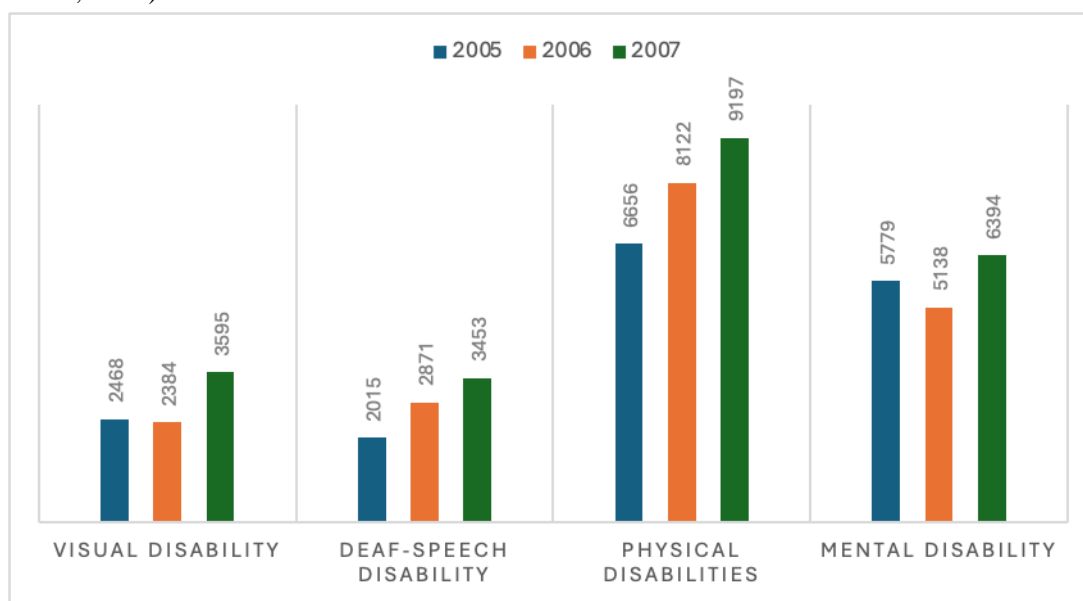
Figure 1. Number of People with Disabilities by Type in the Special Region of Yogyakarta, 2005-2007

Source: (DIY Provincial Social Service, 2017)

One of the biggest challenges faced by people with disabilities is social stigma (Banks et al., 2017; Barnes & Mercer, 2003; Officer & Posarac, 2011). This stigma arises from misconceptions about disability, which portray people with disabilities as less capable and powerless (Barnes & Mercer, 2003). Labels such as "abnormal" or "disabled" are often used to describe them, which not only diminishes their dignity but also hinders their full participation in social life. Social stigma towards people with disabilities creates social segregation, where they are viewed as a "burden" to society. This not only impacts their social interactions but also affects their psychological well-being, leading to low self-esteem, depression, and anxiety.

Some studies by (Banks et al., 2017; Kafaa & Nurhadi, 2023) found that stigma against people with disabilities in low- and middle-income countries, including Indonesia, has a strong correlation with poverty levels, thereby exacerbating their economic situation. Society often views people with disabilities through a deficit lens, focusing on what they cannot do rather than on their abilities. This stereotype worsens discrimination across various sectors, from education and employment to political participation. Shakespeare (2006) highlights that one of the root causes of social stigma is a rigid concept of "normality," where those who do not meet this standard are deemed undeserving of equal rights and opportunities.

Amidst these challenges, social support emerges as an essential factor that can help people with disabilities cope with stigma. Strong social support can come from various sources, particularly from family. This support not only helps meet physical needs but also provides emotional encouragement that can enhance the mental well-being of individuals with disabilities. According to research conducted by the World Health Organization (WHO), social support plays a significant role in helping people with disabilities lead more meaningful and independent lives (Kafaa & Nurhadi, 2023). Support from family, for instance, can offer a sense of security and confidence needed to face daily challenges. Furthermore, social support has been proven effective in reducing the negative impact of social stigma. Banks et al. (2017) found that people with disabilities who have strong social networks are more capable of confronting discrimination and have better psychological well-being compared to those who lack adequate social support. Social support not only helps individuals cope with stigma but also increases their participation in various social and economic activities.

Given this background, this study focuses on examining how social support for people with physical disabilities operates within the context of the family, as the primary and fundamental institution, while considering the stigma attached to such individuals. To effectively analyze the elements of social support, a classification based on relevant aspects of social support is required. The aspects of social support used in this study have been summarized from relevant literature (Encorporado et al., 2023; Kent et al., 2020; Sarafino & Smith, 2014; Sheridan & Radmacher, 1992; Xi et al., 2020) including: (1) Instrumental support: This form of support involves the provision of material resources that can offer direct assistance in the form of services and/or goods. (2) Emotional support: This form of support involves empathy, consistent companionship, warmth, and care, which help individuals feel comfortable, confident, cared for, and loved by their social support sources. (3) Esteem support: This form of support involves positive reinforcement for the individual, encouragement, agreement with their opinions, and positive comparisons with others.

Thus, this article has the potential to contribute to a deeper understanding of how social support functions as a protective factor against stigma and can help design more targeted interventions. Ultimately, the findings of this study are expected to raise broader public awareness of the importance of eliminating social stigma against people with disabilities. The eradication of this stigma is a crucial step towards creating a more inclusive society, where every individual, regardless of physical ability, has equal opportunities to contribute and thrive.

Methods

This article discusses the social support provided to people with physical disabilities at the family level, drawing on an empirical study of two families with physically disabled members in Sitimulyo Village, Piyungan Subdistrict, Bantul Regency, Special Region of Yogyakarta. The selection of these two families was based on unique characteristics essential to

this study, namely comparing positive (normality) and negative (abnormality) stigma within the family. The location was chosen due to its being one of the areas severely affected by the 2006 earthquake.

This research employed a qualitative case study method. Additionally, in line with the article's objective of examining the dynamics of social support for physically disabled people, the data were explored and interpreted through the lens of the study's subjects (Stake, 2013). The article is also the result of field research conducted in February-March 2023. Primary data were collected in two stages. First, observations and direct involvement in the subjects' interactions were conducted. This aimed to "highlight the use of unique empirical information as a basis for drawing causal inferences in qualitative research" (Blatter & Haverland, 2012). Second, in-depth interviews were conducted with 10 key informants, including people with physical disabilities, their spouses, relatives, neighbors, and community leaders in their environment. These informants were selected based on their ability to "provide the case study researcher with insights into a problem and also initiate access to sources of evidence that either corroborate or contradict" (Yin, 2018).

To enrich the study's discussion, secondary data were also used by gathering and reviewing literature related to disability and social support issues, such as previous research articles, newspapers, and reports. Furthermore, to interpret and process the data, the study employed the explanation-building technique. According to (Yin, 2018), this technique aims to analyze case study data by constructing explanations about the case. Using this technique, the critical insights generated "can lead to recommendations for future policy actions" (Yin, 2018).

Results and Discussion

Normal and Abnormal: Family Perceptions Toward Physically Disabled Members

The family serves as the most fundamental context for an individual's growth and development before entering a broader social environment. Family dynamics greatly influence an individual's attitudes and behaviors, and perceptions within the family play a significant role in shaping these aspects (Grusec & Hastings, 2014). Often, family perceptions act as a foundation for how members approach their daily activities. Therefore, family perceptions of each member become critical, particularly within the context of this article.

In this discussion, the author examines how the family's perceptions of a physically disabled member influence the development of that individual. To simplify the comparison between the two research subjects, the author divides them into two categories: Physically Disabled Person 1 (PD 1), a 45-year-old male who is married, and Physically Disabled Person 2 (PD 2), a 77-year-old male who is also married.

The physical disability of PD 1 is located in his left leg, which is completely immobile. PD 1 works as an electronics repair technician, operating from his home, which also serves as his family residence. In his work, PD 1 is well-known and frequently undertakes repair projects for various institutions.

> *"My daily activity is fixing electronics that are brought to my home. Mostly, it's from friends, but occasionally I get projects from institutions."* (Interview with PD 1)

Regarding his personal perception, PD 1 views his disability as completely normal and resents being pitied by others. He strongly dislikes receiving sympathy for his condition, which he sees as merely a physical limitation affecting his left leg's mobility, rather than a reason to be pitied or treated differently. However, he acknowledges that he accepts help from others, though he hopes that such assistance is given out of respect for his work, such as repairing electronics, rather than out of pity. In simple terms, PD 1 appreciates help when it is offered in recognition of his abilities rather than out of compassion for his disability.

In the context of his family, PD 1's condition is viewed as normal. Consistent with PD 1's attitude toward his disability, his family is very accepting and supportive. They are particularly proud of PD 1's efforts to provide for his family and improve their livelihood, even with his physical limitations. PD 1's family admires his resilience and determination to enhance the family's financial well-being without relying heavily on external assistance.

> *"We never see dad's (PD 1) condition as a deficiency. We're actually very proud of him. Despite his condition, dad never complains and is incredibly motivated to improve our family's well-being, whether it's in terms of finances, health, or anything else."* (Interview with PD 1's family)

Based on the interview data, it is clear that the family holds no negative perception or view toward PD 1's physical condition. The family is entirely supportive and does not perceive him as different from others. Despite PD 1's physical differences, both he and his family regard this as just one of many human variations, similar to differences in personality, abilities, or other characteristics. Moreover, the family considers PD 1 to be an essential member of the family, regardless of his physical condition. This is also evident in the social support PD 1 receives from his family, whether emotional or practical.

These perceptions are crucial and serve as the foundation for PD 1's daily activities. Although these are merely perceptions, PD 1 feels at peace, happy, and motivated to continue working hard, not only for himself but also for his family. PD 1 believes that as long as his family supports, trusts, and relies on him, he will continue to strive to improve his family's living conditions, regardless of how the world views him.

In contrast to PD 1 and his family, PD 2 and his family hold different perceptions. PD 2 is an elderly man. His household consists of PD 2, his wife, and a caregiver appointed by his children to look after him, as they live far away with their own families. PD 2's attitude toward his disability is one of acceptance, seeing his condition as normal. However, he deeply longs for the warmth of his entire family's presence to provide comfort and motivation as he continues his life. While the caregiver provides necessary assistance, they cannot replace the familial presence that PD 2 desires. Nevertheless, the caregiver plays a crucial role in helping PD 2 with daily tasks.

> *I'm old, and I can't do much anymore. But I accept this condition and am grateful for it as something normal. I just want my family, especially my children, to visit me, even if only for a short time. Their presence, even briefly, gives me peace and renewed energy to continue living.* (Interview with PD 2)

PD 2's wife initially struggled to accept his condition. She sought various treatments, from traditional to modern methods, in hopes of curing his paralysis. Over time, however, she came to terms with the situation, recognizing it as abnormal and requiring someone capable of caring for PD 2.

> *At first, I didn't want him (PD 2) to be like that. I wanted him to be healthy again and active like he used to be. But over time, I accepted it. However, he needs someone to take care of him since I'm not young anymore. So, during the 2014 Eid al-Fitr, I discussed with the children, and we all agreed to hire a caregiver.* (Interview with PD 2's family)

This sentiment is also reflected in one of PD 2's children's views of his condition. PD 2's children collectively agreed to see their father's condition as abnormal and requiring assistance. The decision to hire a caregiver was made during a family meeting in 2014, based on the need for someone who could properly care for PD 2.

> *Dad sees it as something that happens naturally at his age, and many people his age experience the same thing. He wants us to treat his condition casually, without needing a caregiver. He would be happy if we visited him often, but since we have our own families and live far away, and with mom's limited abilities, we had to bring in someone to take care of him.* (Interview with PD 2's family)

From the interview data, it is clear that there is a difference in how PD 2 and his family perceive his disability. PD 2 views his condition as normal, something that can happen to others his age, and believes that he does not need help beyond his family. However, his family sees his condition as abnormal and requiring assistance. Due to the distance between them and PD 2, they hired a caregiver to provide the necessary care.

Nevertheless, PD 2's family continues to regard him as an important and cherished member of the family. Despite his current condition, the family is highly supportive and strives to provide the best care for him. However, it should be noted that the family views PD 2's physical disability as abnormal and requiring professional assistance.

Social Interactions Within the Family: Concern for People With Physical Disabilities

Social interaction refers to the social relationships manifested through various actions in society. These actions can include communication and relationships between individuals. Interaction does not only occur in broader societal contexts but also within the family environment, which is an inevitable part of social life. In essence, interactions within both society at large and within the family highlight the significance of social relationships, whether these have been established for a long time or are newly formed.

On the other hand, the patterns or dynamics of social interactions in society are often influenced by perceptions or views of an individual, group, or institution (Hogg & Vaughan, 2018). Simply put, if the perception of a person or object is positive, the social interaction that

follows will likely be positive as well, and vice versa. This section discusses how family perceptions of people with physical disabilities become a key factor influencing the dynamics of social interaction, which subsequently impacts the context of family social integration. This concept is further linked to the categorization of perceptions as normal or abnormal, as explained in the previous section.

In the case of PD 1, the family perceives the disability as normal. This perception aligns with PD 1's own views as a person with a disability. Both PD 1 and the family share the belief that the physical condition is a natural part of life. They assume that as long as PD 1 is determined and motivated to lead a fulfilling life, both for himself and for his family, the disability is merely a difference, like any other variation between individuals. Regardless of PD 1's physical or mental condition, the family continues to support him and views him as a normal person, just like any other human being.

This perception is not merely theoretical but is implemented through the communication processes within PD 1's family. In daily life, PD 1, as the head of the family, communicates with his wife and children in a normal manner, just like any other family. PD 1 regularly discusses matters related to his daily experiences, as well as issues concerning his family, including his wife, children, and those outside the immediate family. The family responds positively, which is evident in how they remain open and communicative with one another.

This is further confirmed by PD 1's family. In their daily life, PD 1's wife treats him as both a husband and father to their children, and also as the head of the family. When the family faces any issues, they openly communicate with PD 1, leading to a joint problem-solving process. They also regularly communicate with PD 1 about various topics, ranging from household matters to the children's future aspirations. PD 1 and his family agree that openness is a principle they must uphold, regardless of any circumstances.

The strong communication within PD 1's family was also confirmed by the author during field research. There were no notable differences in the communication between PD 1's family and other families. In terms of participation, there is no difference in the treatment or involvement of family members. Since the family highly values the principle of openness, this extends to the participation of every family member as well.

In contrast, PD 2's family views his disability as abnormal, which significantly impacts their interactions with him. PD 2 perceives a communication gap within his family, as they seem to misunderstand his true needs and desires. When PD 2 attempts to initiate conversations or express his feelings, he frequently encounters a lack of response, leaving him feeling isolated. This communication breakdown is not only frustrating for PD 2 but also has a profound effect on the way he is treated within the family.

As a result of this poor communication, PD 2's role within the family has diminished, particularly in terms of participation in decision-making. Once an active member, he is now excluded from important family discussions. The family assumes that due to his physical disability, PD 2 is no longer capable of offering meaningful input. This belief, rooted in their perception of his condition as abnormal that, leads them to overlook his potential contributions.

This exclusion from family decisions reinforces the emotional distance between PD 2 and his family. Feeling undervalued and misunderstood, PD 2 struggles with a sense of helplessness. His family's assumption that his disability equates to an inability to participate actively not only undermines his autonomy but also further alienates him from the social fabric of the family. This lack of emotional and communicative support highlights the need for better

family dynamics that can promote inclusion and mutual understanding, regardless of physical limitations.

Conclusion

This article captures an overview of how social support within the family is provided to members with physical disabilities. The family's perception—whether they view the condition as normal or abnormal—significantly affects the type of social support given to the family member with a physical disability. This social support can be observed in three main aspects: instrumental support, emotional support, and support for self-esteem.

First, instrumental support from the family refers to the provision of material resources that can offer direct assistance, either in the form of services and/or goods. In the case of PD 1, the instrumental support provided by the family is exemplary. This is based on the family's perception that PD 1's disability is considered normal. The family always offers help in any form whenever it is deemed necessary. Although the family views PD 1 as a normal person, instrumental support remains in place, ranging from assistance provided by PD 1's wife for daily needs to support from the family when PD 1 faces difficulties. As in any typical family, mutual help remains a necessity for PD 1's family. Similarly, in PD 2's family, instrumental support is also considered good. Despite the family viewing PD 2's disability as abnormal, assistance is still provided. For example, the hiring of a caregiver to assist PD 2 with daily activities reflects the family's instrumental support. Although there is a mismatch between PD 2's desires and the family's actions, the caregiver's presence shows that the family is still assisting PD 2 in overcoming basic accessibility issues.

Second, emotional support from the family addresses the psychological aspect of family members, involving empathy, care, warmth, and creating a sense of comfort, security, and love. In the context of PD 1's family, emotional support can be considered good due to their perception of his disability as normal. The family's daily interactions create a positive atmosphere of warmth, comfort, and security. There is also empathy, care, and the sense of being loved and valued. Effective communication, respectful behavior, and active participation among family members have created a supportive environment, especially for PD 1. Consequently, these factors lead to the development of strong emotional support within the family. In contrast, PD 2's family lacks emotional support. While empathy and care towards PD 2 are present, the family does not create enough a warm, comfortable, and secure environment, nor does PD 2 feel loved and valued. Differences in perception, poor communication, lack of participation, and misaligned expectations between PD 2 and his family contribute to PD 2's emotional instability.

Third, support for self-esteem refers to positive reinforcement of individuals, encouragement, agreement with their opinions or ideas, and positive comparisons with others. In PD 1's family, self-esteem support is exceptionally strong, driven by the family's perception of his condition as normal. Effective communication, respectful behavior, and PD 1's active involvement in family activities also contribute to enhancing PD 1's self-esteem. This is in stark contrast to PD 2's family, where his condition is viewed as abnormal. The family does not maintain proper communication with PD 2, nor is he included in family discussions, which negatively impacts his self-esteem.

Based on these findings, this article makes several recommendations for both families and society. First, for families of individuals with disabilities (of any kind), it is essential to consider how they perceive their family member's disability. Families must position themselves as the first and primary support system for the person with a disability. They should embrace their disabled family member, foster good communication, provide necessary assistance, and create a warm and comfortable atmosphere. This will help inspire and motivate the person with a

disability to improve their life, or at least prevent them from losing hope. Second, for society, it must be emphasized that people with disabilities are human beings and members of society who also have rights and responsibilities, just like anyone else. As with the family, society must act as a supportive environment for the development of individuals with disabilities. While it may be challenging to shift from a mindset of pity to one of respect when viewing someone's disability, society should begin by gradually recognizing and valuing people with disabilities. This can start by fostering good communication, cooperation, and inclusion in community activities.

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