Transition Issues for Deafblind Adolescents in the Family Following Graduation: Isolation or Integration?

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Abstract. Life after 12 years of compulsory education for deafblind adolescents is a crucial stage. Limited opportunities for deafblind adolescents' activities after graduation make the transition a critical thing to prepare for. This study aims to find the factors that influence the transition of deafblind adolescents after graduating. A case study was conducted in a family of deafblind adolescents with various barriers. In-depth interviews, observations, and documentation studies were used for data collection. NVivo tools were applied to analyze the themes found. In this study, we found four interrelated themes: 1) values, culture, and past experiences influence parenting paradigms;2) communication barriers;3) long-term parenting;4) parental consistency and commitment, and 5) parent involvement. The results of this study show that deafblind adolescents are isolated in the family. More studies are recommended to build collaboration between schools and parents to strengthen the transition to achieve independence for deafblind adolescents.

Keywords: Transition, multiple disabilities, deafblind, post-graduation, independence.

1 Introduction

Deafblind individuals have diverse characteristics and complex needs that have received less attention [1]. Even within the context of disability, deafblind is considered a minority group that is often ignored and not included in services [2]. The term used to describe children with visual disabilities accompanied by hearing simultaneously and followed by other obstacles is Multiple Disability Visual with Impairment (MDVI) or Deaf blindness. It is important to note that there is no equivalent term in Indonesian for this condition, highlighting the need for linguistic inclusivity in discussing disabilities [3]. Data [4] show that People with disabilities form the world's most significant minority, constituting about 15% of the world's population. As part of the variety of multiple disabilities, the blind and hard of hearing are often referred to as a hidden and poorly educated group. Global data shows that about 0.2% to 2% of the disabled population is deaf and blind [5]. In Indonesia, children with severe disabilities face many challenges in education and employment after school in Indonesia. 58% of children with severe disabilities aged 13-17 have the opportunity to go to school but with very low job opportunities after graduation [6]. In fact, specific data showing the number of multiple disabilities, mainly the visually impaired, was not found, but in general, if you look closely at the Person with Disabilities in Indonesia report, it shows that 4% of 11% of people with disabilities have a complexity of type diversity [7]. The limited amount of this data results in a lack of recognition and low fulfillment of needs services received by the deaf group [8]. This condition eventually causes the deaf group to be considered axiomatic, a minority, the most

vulnerable group, and invisible in the general public[8], [9], [10], [11]. So that it is often excluded from development programs and even in the disability program itself [9].In Indonesia, 144,102 Special Need Schools (SLB) serve students with all types of disabilities at all levels of education. However, only 4.2%, or 6,045, are in the Multiple Special Need Schools (SLBG) category, which serves students with multiple disabilities, both government-owned and private [12]. Unfortunately, the data does not provide specific details on the types of multiple disabilities served in these schools. This lack of detailed information underscores the urgent need for more comprehensive research and support [3].

In the field of education, the deafblind are a group under-researched, especially in terms of transition preparation and post-school outcomes [13], [14], [15], [16]. Even the findings of [16] question the long-term evidence of the relationship between transition planning and post-graduation outcomes. Worse, planning for children's transition from school to home life is often neglected and is not an important part of the disability education process. [14], [15], [16]. Several studies reinforce the grim picture of deaf-blind adolescents: unemployment, limited social life, lack of community involvement, difficulties in adulthood, and a decline in life skills, health, and independence. One of the critical goals in disability education is to prepare children for post-graduation. [17]. The findings [16] reinforce that very few individuals with hearing and visual impairments live independently after school. The decline in life skills to support children's independence is associated with decreased mental ability. Many reasons, including the impact of one-way teaching without involving others and the absence of transition preparation, surround children's independence and quality of life after school [18], [19]. Poor school-parent partnerships are predicted to influence the role of the family and the autonomy of post-school youth. The diversity of social, economic, and cultural conditions directly influences the family's understanding of the condition of the deaf-blind with the various obstacles surrounding it [20].

This often becomes a dilemma for the family and the environment. This situation has caused parents to lose hope and aspirations for their children. Given the inherent special needs throughout the life of their child's life child [21]. If allowed to continue, this impacts acceptance and automatically affects the child's quality of life after graduation. Interestingly, this is not easy to achieve for families with low income and diverse cultures and languages. [15] adds that the development of demographic characteristics, including race/ethnicity and socioeconomic characteristics, must be done to understand the factors that affect children's success after school. This implies that the location of the parents' homes will greatly influence parents' concern about the children's success after graduation. Supported by contextual factors in families and groups related to poverty and diverse cultures, it is the first layer that affects the transition process [22]. For this reason, the present study was conducted to investigate the factors that influence the running of the transition program of adolescents after graduating from school in the family.

2 Method

The qualitative case study approach [23], [24] was applied in this study. The purpose sample focused on parents of deafblind adolescents with other disabilities such as autism, mental retardation, and motoric impairment. They have been absent from school for six months – two years and live with their families. This study involved four parents of different ethnicities and religions who reside in the Jakarta Indonesia area. The researcher worked for 12 weeks on the

data collection process.; The stages of the research include the first stage, documentation study focused on the transition program prepared for post-graduation adolescents; Second stage, data collection through in-depth interviews with four parents to explore the factors that influence the implementation of their children's transition after graduation; The third stage consisted of data analysis. Data analysis was performed using the NVivo tool using the stages of 1) transcribing the interview results, 2) coding the findings, 3) division into categorization, and 4) establishing themes. The detailed analysis refers to the themes found and used as significant factors in answering this research question[24].

3 Objective

The study explored factors influencing the family's implementation of the post-school transition program.

4 Results

To summarize the results of this study, a brief description of the cases in 4 families, as selected informants, among others, is presented.

4.1 Case 1

The first case describes the life of a single parent (PP) with a single deafblind adolescent (DD). Family members live below the poverty line and work in the informal sector as mobile laundry. PP has a sad story. Although PP is known as a committed individual, she attempted suicide with her child but failed. After the death of her husband, Covid-19, in 2021, she was unable to bear the burden of long-term care and life. Since his birth, the extended family of the wife and husband has rejected the existence of the DD. His extended family considers the birth of a child with multiple disabilities to be a shame and makes life difficult. Since graduating from school, PP has often engaged in tantrums and breaks. Her mother didn't know what to do. PP is usually locked up in her room to avoid trouble and receives a radio to fill her spare time. When DD is absent from work, a neighbor takes care of it. The neighbor is responsible for food, beverages, and other activities. In a tantrum, the neighbor leaves her in a locked room because they are confused about what to do. They have barriers to communication and understanding what DD wants. All DD activities are conducted in the bedroom without meaningful activities to avoid contaminating others and the environment. Parents believe children like to be comfortable in their rooms and not disturb others outside the home. Almost all DD activities are supported by others. DD independence and health have decreased after graduation from school.

4.2 Case 2

The second case describes the lives of visually impaired parents who are massagers (JK). They have two children: a deafblind adolescent (MJ) and a deaf sister (MI). These are images of families attempting to implement post-graduate programs by school regulations. They perform activities from waking up to night. Since his graduation, MJ has been responsible for cleaning the house. Economic conditions do not allow parents to pay for another person. Both parents support their children in becoming independent in the future. The engagement with the siblings in this family is also visible. The sister helps her brother shop at the booth and brings friends to the house. Parents believe their children are a gift that can bless their family.

However, due to obstacles around him, they doubt whether MJ can find a paid job after school. His sister, who has a low vision, is the only hope that her parents can help her later in her life.

4.3 Case 3

The third case describes middle-income HK parents. They have three children, one of whom is a deafblind (KJ). Since the beginning, this family has been involved in helping its younger sister (deafblind) with shopping and leisure activities. They also often involve KJ in activities outside the home with the family. One of the challenges is the communication and space environment that must adapt to the KJ ability. Since graduation, KJ have often had seizures and fever. The parents admitted that they did not have enough money to make KJ healthy. Despite her limitations, KJ fills her spare time by producing salted eggs, which she sells in the market. Unfortunately, the KJ-produced salt eggs produced by KJ are often not sold and are even rejected in the stands. The emergence of negative stigma makes people hesitate and fear infection when buying products produced by KJ.

4.4 Case 4

The fourth case is the parent of HN. They are a family that closely abides by local customs and beliefs. Despite living in Jakarta for a long time, they still believe in their ancestral values. They still believe that the existence of their adolescent/HN (deafblind) is part of forgiveness for past sins. The agreed transition program has been ignored. They believed that, although they agreed to the school to implement a transition program, it would aggravate their HN health. Consequently, since HN has graduated from school, no tasks have been given to them. Caregivers provide support for all activities HN. Parents believe that serving children is the same as serving God. Parents believe that the service of their children is the same as that of God, so HN spend a lot of time without meaningful activities. Six months after graduation, it is known that not only has the health situation improved, but it is also impossible to carry out light activities alone. HN activities are mainly in the bedroom, which is thoroughly cared for by the caregiver.

5   Discussion

Family is the closest system and impacts a child's quality of life. Parents' involvement strongly influences the priority of needs and the perception of school education [25]. Even the findings of [26] show that low income, culture, language, and family values impact how parents treat their children. This research shows that parents' expectations of children are strongly influenced by economic conditions, models, cultural values, and even religion. Although the transition programs were jointly designed to help adolescent become independent after school, many factors surrounding these programs are not optimal. The study explored five critical themes that emerged in four parents and indicated factors influencing the post-graduate life transition of deafblind adolescents, among others.

Theme 1. Values, culture, and past experiences influence parenting paradigms.

Parents' views can influence how they support adolescents' growth and development after school. Although the initial transition program was agreed upon between parents and the school, the paradigm of parents not fully accepting their child's condition and not supporting the program that has been designed was adopted. Family values and culture influence how families handle and treat deafblind adolescents. Furthermore, 80% of the informants admitted

that they mainly leave the quality of education to the school's responsibility. The cases found in this study reveal that past experiences will be integrated into the form of parenting applied to deafblind adolescents in the family. For families who accept the uniqueness of deaf-blindness, they will be more inclusive. This research also shows that independence, as the goal, can fail due to past values and experiences that still stigmatize disability in the family.

Theme 2: Communication Barriers

Communication barriers and lack of communication partners cause problems of isolation and depression for deafblind adolescents [27]. Communication barriers due to the lack of communication partners for deafblind adolescents were found in all families in this study. Almost all informants stated that it was challenging to be an effectivecommunication partner for their children. This fact results in the slow independence of deafblind adolescents due to the interaction gap. Deafblind adolescents do not have adequate access to communication and interaction with their families. This situation makes deafblind adolescents vulnerable to mental health problems, thus exacerbating their emotional state. Parents admitted that they do not consistently use the recommended forms of communication with their children. Parents assume that after schooling, children will be able to understand their parents' intentions with daily sign language. This study also found that children often show emotional overload because they feel they are not understood, and their wishes are not understood. This leads to depression, moodiness, feelings of disrespect, and uncontrollable emotions that lead to social isolation.

Theme 3: Long-term parenting

Long-term parenting requires the commitment, consistency, and preparedness of parents to face the challenges of livingwith a blind adolescent for a long time. Caregiving becomes a crucial issue after adolescents finish high school. The cases found in this study illustrate that deafblind adolescents with various barriers need the help of others in all dailyactivities. Hence, they need the support of others throughout their life. For single-parent families with an only child, this condition is undoubtedly a challenge. In the context of deafblind adolescents, long-term care emphasizes consistencyand ongoing support. As adolescents age, the need for access to health services increases due to the decline in cognitive, sensory, and motor functions. The informants often recognize the physical and psychological needs as the most difficult to meet for families with unstable economic conditions. Parents even lose hope for their adolescent's future. The implication of this analysis is the importance of strengthening the role of parents in providing holistic and sustainable support for deafblind adolescents after school.

Theme 4: Parental Consistency and Commitment

Consistent parental support and commitment to activities designed for the lives of deafblind adolescents   strongly influence adolescents' independence after school [28]. The key to successful learning for deafblind adolescents is consistency. Therefore, parents who consistently support the unique needs of deafblind adolescents will help create independence according to their potential. This study found inconsistencies in parents' implementation of transition programs at home. The reasons that emerged included time constraints, children's activities at home, activities supported by caregivers, and reasons for children's health.This is counterproductive to the transition program designed to support post-school independence.

Theme 5: Parent Involvement

Parental involvement in each transition stage significantly impacts adolescents' post-school capabilities. The trigger for parental participation is driven by a thorough assessment of parents' needs, priorities, and perceptions of schooling. [25]. Teacher-parent collaboration [29] and it should be established early in the evaluation[30]. However, parental involvement is trapped in the school academic calendar rather than the learning process. This study revealed that parental participation is done at the beginning and end of the semester. Parent involvement is a relationship between participation and attendance in school activities. Parents are vital in ensuring their children receive an education that suits their needs. 80% of the informants expressed being unprepared to accept that their children had to graduate and return home. This is a crucial challenge for all parents involved in this study.

6 Conclusion

Ideally, schools and parents should jointly design the transition of deafblind adolescents to school graduation. Schools and parents should jointly design schools and parents. This study shows that it is not enough to create a transition plan; schools also need to understand the factors surrounding the transition so that it can be carried out correctly when children return to their families. Parents' parental paradigm is essential in ensuring no differences in the perception of acceptance, expectations, and assistance for adolescents with various obstacles after their school. The transition program also focuses on the child's potential and forgets the preparedness of parents who will live together for a long time. Parents should also strengthen and acquire basic skills to raise children who graduate from school. On the other hand, most parents face communication barriers with their children. They don't know what their children want and what they should do. The lack of communication partners results in aggravation and isolation of the blind teenager's situation, as they cannot develop interaction and communication skills in the family and in the neighborhood. Therefore, the factors surrounding parents' preparations for the departure of their children from school are critical to discuss at the beginning of the transitional program.

7 Limitations and Recommendations

The results of four family cases limit this study and cannot be generalized to general situations. The quality of life of deafblind adolescent with various barriers cannot be generalized to deafblind adolescent without additional obstacles. The study focused only on parents' perspectives and did not explore collaboration with schools and teachers. In the future, more excellent in-depth studies will be conducted to strengthen the cooperation between parents, schools, and other resource systems in implementing multi-disability transition for adolescents, especially those with deaf blindness. They will need to be carried out with a broader landscape.

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