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Family-Centered Early Intervention to Support Communication Development in Children with Multiple Disabilities with Visual Impairment

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Abstract

This study aims to formulate an early intervention program based on family resources for parents to stimulate communication of MDVI children at home. This research was motivated by a lack of understanding of families in providing intervention efforts to optimize communication skills in children with MDVI from an early age. The subjects in this study were two parents who had MDVI children. The first subject was the family of a child with early AZs who had a visual impairment with autism. The second subject was the family of a child with an early K who had visual impairment and hearing loss. This research approach is a qualitative approach with three stages of research, namely assessment, validation, and implementation. The result of this study is that parents know the characteristics and needs of their children, there is a positive acceptance from parents, and parents begin to know the communication principles of MDVI children and begin to practice them in a way that directly positively affects the child's communication.

Keywords: Early Intervention, Communication, MDVI, Multiple Disability

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INTRODUCTION

Parents of children with special needs experience many challenges that can cause them to experience stress and stress which ultimately has an impact on self-efficacy in parenting in everyday life. One of the main factors that cause the condition is the acceptance of parents to the condition of their child who is experiencing disabilities. Parental acceptance is an active and conscious process that parents go through to understand the condition and needs of their child who has a certain specificity that is manifested in the form of warmth, affection, attention and support both physically and non-physically (Gargiulo & Bouck, 2019, p. 372; Rahayu & Mangunsong, 2020). Because understanding the condition of children is an important part in providing definitions to children and also parents, which has an impact on building relationships that trust, understanding and respect that have been proven to be effectively able to improve relationships between fellow family members (Gargiulo, 2012, p. 69).

Family plays a role in the main meaning of 'home' for all family members by being directly involved both physically and non-physically (McQuiggan et al., 2015, p. 65). Because, the family has an innate emotional dimension that can be seen in different ways, so an emotional map can be developed to see the positive relationships between family members through good communication to understand each other (Morgan, 2020). This is in line with the results of research conducted by Widiastuti et al., (2019), related to the ability of parents to provide support to children with compound obstacles to improving their self-care ability starting from building a family profile first. Therefore, it is very necessary for researchers to collect profiles related to family conditions related to the level of stress experienced, impacts and needs, so that researchers can identify various factors that hinder the involvement of parents in interacting with their children (Correia et al., 2021). So that

it can reduce people's stress levels and increase parents' acceptance of the condition of their children who are experiencing disabilities through good communication between family members (Sunardi et al., 2011).

Based on research conducted by Petcharat & Liehr (2017), it is known if stress, anxiety and depression affect the level of parenting caused by parents' acceptance of their children's condition. There have been many studies that discuss macro issues in the context of the environment, but there are some things that still need to be researched more deeply when talking about communication and interaction problems in micro contexts related to the context of the social life of children with special needs together with their family members. Because, the condition of children with special needs is different both in physical aspects, as well as social personal conditions that have an impact on the emergence of stigmatization, discrimination to shame which is not only faced by children with special needs, but also their families (Gargiulo, 2012, p. 3). Not to mention the heavier impact on families who have children with compound barriers, for example, such as children with Multiple Disabilities with Visual Impairment (MDVI).

For children with Multiple Disabilities with Visual Impairment (MDVI) currently in the world, the number of children with MDVI varies between 30% and 70% of the overall population of people with visual impairments (Kyriacou et al., 2015, p. 6), communication is one of the main obstacles they face. Loss of sense of vision accompanied by other constraints will have an impact on development in several key areas such as communication development, movement development, cognitive development, cognitive development, cognitive development, emotional development, social, as well as the development of concepts and self-image that have an impact on the main aspects of learning (Irvan et al., 2021; Sunanto, 2010).

The family is the most important factor affecting the child's development because the family becomes the first environment in which a child grows and develops. According to ecological theory, the family is part of the microsystem, which is the environment closest to the child's person, which includes family, teachers, individuals, peers, schools, environments and so on that children encounter daily. Researchers found cases in the field, where there were two families who had MDVI children. The first is the AZ family who have a child with a visual impairment accompanied by autism and the second is the K family who has a child with a visual impairment accompanied by hearing loss. Based on the facts found in the field, it shows that the two families have not fully accepted their child's condition, there is still shame in them related to the condition of their child, there is still a feeling of rejection in each parent so that this has an impact on the child. Parents leave their children at home without providing meaningful activities that affect the communication of the child who becomes isolated. As revealed by Dammeyer (2016), it is currently very concerned about communication problems because most of all intervention programs are based on communication and aim to consolidate and advance the communication competencies of MDVI children, one of which is through cooperation with parents. This study aims to identify various needs that need to be met and developed in providing stimulation of parental communication to children in order to optimize communication skills between parents and children who have compound barriers, especially children with Multi Disabilities Visually Impaired (MDVI).

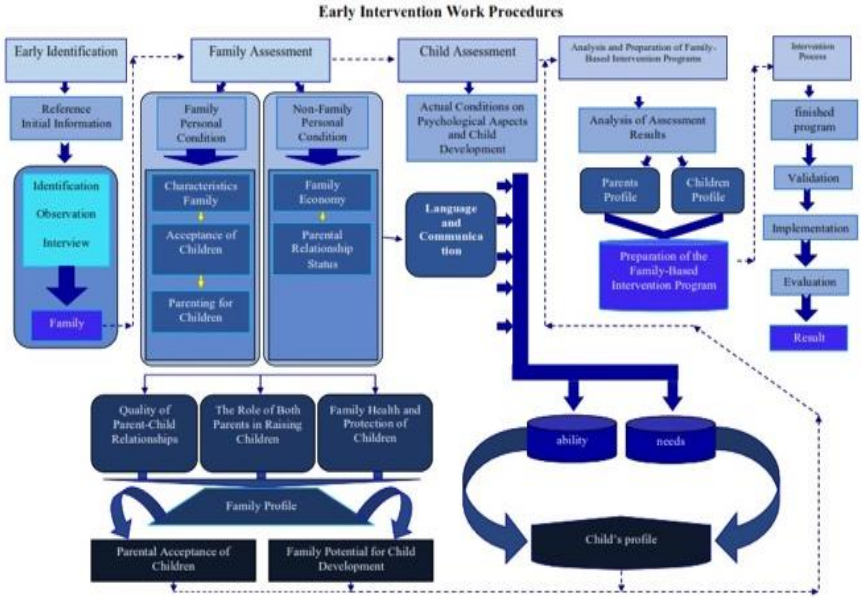
METHOD

This study used experimental studies in which parents were given several programs that became references to establish communication to their children who had visual compound barriers. This research has been approved by the university and two families who act as research subjects. Each family has the right to accept and refuse to participate in the three programs we have compiled. In this study, each program was carried out in full by both families with a total of 8 meetings for each program which was 60 minutes long for each meeting, for three months. The research subjects were obtained through observation and interviews with teachers at SLB A Wyata Guna, Bandung. Based on the results of the interview, the teacher recommended two families who had MDVI children who still had difficulty accepting their child's condition fully which had an impact on the child's communication development.

To provide a clearer context for the two families involved as research subjects, participant selection was guided by explicit inclusion and exclusion criteria. Families were included if: (1) the child had a clinical diagnosis of Multiple Disabilities with Visual Impairment (MDVI); (2) the parent(s) served as the child's primary caregiver at home; and (3) the family had not previously received a structured, communication-focused early intervention program. Families were excluded if the child was concurrently enrolled in another intervention program during the study period. Briefly, the AZ family consisted of a child with visual impairment accompanied by autism, while the K family consisted of a child with visual impairment accompanied by hearing loss; both children were of early childhood age. were also documented to provide a more comprehensive picture of each family's context.

In each program applied in this study, we used a qualitative multiple case study design, in which each family served as a single case unit of analysis. Within this design, we focused on two central foci in each study subject, namely parental acceptance of children with MDVI and parents' ability to communicate with their children. Each study subject completed three programs that were carried out in stages for the acceptance of their child's condition. The stage begins with the introduction of a well-known MDVI figure/figure (one of the ones we used was a Helen Keller documentary); the next stage is to do recreation together (family time); and the third is to build a positive relationship between parent and child (how long to interact with the child in one day, take time to play, build mutual trust). Based on previous research that shows that the importance of these three programs to be applied in the context of family acceptance of the condition of their children who have disabilities (Hathazi & Serban, 2021; Kamenopoulou et al., 2021; Rahayu & Mangunsong, 2020; Van keer et al., 2020). The data of this study were obtained from interviews with parents, observations of children's communication and observations of parents based on FQOL (Wiley et al., 2013), and documentation. This research approach is a qualitative approach with three stages of research, namely assessment, validation, and implementation. Data analysis is carried out by data reduction, data exposure, and drawing conclusions

In each program applied in this study, we used a mixed factorial design consisting of one factor in the study subject, namely parental acceptance of children with MDV and the ability to communicate parents with children. each study subject completed three programs that were carried out in stages for the acceptance of their child's condition. The stage begins with the introduction of a well-known MDVI figure/figure (one of the ones we used was a Helen Keller documentary); the next stage is to do recreation together (family time); and the third is to build a positive relationship between parent and child (how long to interact with the child in one day, take time to play, build mutual trust). Based on previous research that shows that the importance of these three programs to be applied in the context of family acceptance of the condition of their children who have disabilities (Hathazi & Serban, 2021; Kamenopoulou et al., 2021; Rahayu & Mangunsong, 2020; Van keer et al., 2020). The data of this study were obtained from interviews with parents, observations of children's communication and observations of parents based on FQOL (Wiley et al., 2013), and documentation. This research approach is a qualitative approach with three stages of research, namely assessment, validation, and implementation. Data analysis is carried out by data reduction, data exposure, and drawing conclusions.



Picture 1 Early Intervention Work Procedure

Hathazi and Serban (2021) explain that each case study in communication research should be contained in a reflective note regarding the communication profile of the beneficiary, the preparatory steps for the intervention plan (assessment tools, materials, long and short-term goals, strategies and techniques), a description of the intervention (strategies, resources, challenges), reflections on the observation techniques they have used during the intervention and finally the from self-reflection (challenges, progress, feelings about the relationship with the beneficiaries, aspects of improvement in their strategies, etc.).

RESULTS AND DISCUSSION

Results

Every parent wants their child to be born perfectly. Parents yearn to have healthy children, both physically and spiritually. However, not all children are born and grow up under normal circumstances (Faradina, 2017). In fact, there are children who are born with special needs conditions, one of which is a child with MDVI. Basically, being an MDVI parent is not an option, therefore no parent is ready to be the parent of MDVI children (M. Sunardi, 2018). The formulation of the intervention program is based on the ecological theory of Bronfenbrenner where the family is part of the microsystem, the environment closest to the child to help the child's development, while also referring to the Family Quality of Life by Brown et.al (2006)

Programs created for both families covered three programs; The first program is MDVI child recognition and its characteristics, since parents who have children with disabilities are often associated with excessive stress, most parents are not prepared to see their child's disability as a long-term problem. The purpose of this program is to provide parents with an understanding of their child's condition. The second program is Positive Acceptance to MDVI children, the purpose of this program is to build positive parental acceptance to their children. After starting there is acceptance from parents, the next program, namely the third program is the development of MDVI children's communication. The program aims to develop communication techniques in mdvi children by families. The activities carried out are to stimulate the communication of MDVI children which is carried out gradually at home. Such activities can be packed with interesting topics, have an equal position and face to face with the child, the right and comfortable position, imitation where the child is asked to follow the directions given, and the hand under the hand where the teacher's hand is under the child's hand to give the child's example and experience in knowing concrete objects and doing things, Scheduled activities (Lessons & Activities | Perkins ELearning, n.d.).

Changes in Parental Understanding of the Child's Condition

The program consists of eight meetings. The first two meetings were used as the initial baseline of the situation before being given the program and the next 6 meetings consisted of program trials and the last 2 meetings consisted of evaluations and results of the program. In the first program of the AZ family, there was a change from the parents at the 5th meeting where Mom and Dad began to realize the characteristics of their child who needed more attention and the characteristics of the child with MDVI. In K's family, there was a change in the seventh meeting, where so far K's parents only let K be at home with their caregivers and both are busy at work but now K's parents have begun to understand the importance of knowing the characteristics of their children so that parents can know their children's needs.

Change in Parental Attitude of Acceptance

The implementation of the second program, in AZ families there was a change at the seventh meeting where there has begun to be positive acceptance from parents, parents have begun to want to take their children out of the house, families invite AZ to spend time in the panda garden, there is positive acceptance from parents and the shame of parents having children MDVI can slowly be arranged. In K's family there was a change at the eight meeting, at the end of this second program, parents had begun to care about K's needs and invited K to go to Jakarta, see rawinala school (one of the schools for MDVI children in Jakarta), parents began to know K's needs so far.

Change in Parental Communication Behavior

The implementation of the third program, after parents have begun to know the characteristics, needs, and importance of positive acceptance. Parents learn to stimulate their children at home. At the sixth meeting, parents have begun to slowly be able to invite their children to communicate in accordance with the communication principles of MDVI children. In the third program, there was a change in Family Z at the seventh meeting where parents had slowly begun to know the principles of mdvi children's communication and practiced them directly to the child. Mdvi children's communication principles include making turns, interesting conversations, imitations, hand under hand, exploring together, children starting to know concrete objects, and scheduled activities. (Lessons & Activities | Perkins ELearning, n.d.). The child has begun to

want to respond when his name is called, the child has begun to hit his self-concept, the child has also begun to know the concrete objects around him. Parents have begun to hand-underhand the recognition of objects around the child's environment.

Taken together, these three thematic changes, namely understanding, acceptance, and communication behavior, reveal a consistent developmental sequence in both families, in which understanding preceded acceptance, which in turn preceded functional communication practice. However, the pace at which each theme emerged differed between the AZ family and the K family, a pattern that is examined further in the following Discussion.

Discussion

Rahayuningsih & Andriani (2005) parents who have children with special needs will initially experience stress accompanied by other negative responses. Children whose development experience obstacles, disorders, slowness or have risk factors in achieving optimal development require special treatment or intervention. The stress experienced by parents will affect the child. Family support can be divided into three categories, including emotional, material, and informational. On informational support, it is important for parents to be informed about 1) their child's disability, (2) available services, (3) child development in general, and 4) strategies to use with their child. (Graham, Steve & Haris, 2010). Self-acceptance of parents who have children with visual impairments greatly affects the child's ability, the more parents cannot overcome the negative impacts and the difficulty of accepting their situation, the more disturbed the child's developmental condition is (Melati, 2013).

An important nuance emerging from this study is that the pace and character of change differed between the two families, corresponding to the different additional impairments carried by each child. In the AZ family, whose child had a visual impairment accompanied by autism, parents' change in understanding emerged relatively early, at the fifth meeting, and their acceptance followed at the seventh meeting, yet translating this into consistent communication practice required the full third program, reflecting the additional social-communication barriers commonly associated with autism. In the K family, whose child had a visual impairment accompanied by hearing loss, parental change in understanding and acceptance emerged comparatively later, at the seventh and eighth meetings respectively; however, because K had almost no functional channel of communication with the surrounding environment prior to the intervention, once basic tactile and hand-under-hand strategies were introduced, parents were able to apply them in a fairly direct way. This finding is consistent with Kamenopoulou et al. (2021), who note that children with multi-sensory impairment present highly heterogeneous profiles of need, so that family-based interventions cannot be applied uniformly and must instead be adapted to the specific combination of impairments experienced by the child. The difference between the two families therefore does not indicate that the program succeeded for one family and failed for the other; rather, it underlines the importance of individualizing the intervention approach to the child's particular comorbid condition, a point that has not been sufficiently addressed in prior communication-focused early intervention literature (Dammeyer, 2016; Parker & Ivy, 2014).

In this world no one is fully prepared to be a parent of an MDVI child, they do not expect their child's condition to become MDVI, this is characterized by the occurrence of rejection by parents at first, In the view of ecological theory, human behavior is the result of its social context, and the family is a system. Therefore, the family is the most important ecology in human development. (Sunardi, 2018). Parker & Ivy (2014) measures the exchange of information of children with visual impairments or MDVI with people in the surrounding environment who do not understand how to communicate with them, reducing the opportunity to establish communication.

A child with MDVI has many learning needs and often has difficulty learning in the classroom without support, children with MDVI can learn academic skills and non-academic skills, one of which is communication that can benefit their lives (Young et al., 2019, p.165). Ayyıldız (2016) explained that communication is very important for humans, including for people with disabilities because the disabilities experienced by children with MDVI make the obstacles more complex, one of which is in the aspect of communication. Az and K's families began to realize the importance of being central to their child's development. Starting from the stage of knowing the characteristics of children in advance, building positive acceptance, and starting to start their child's communication at home. Mednick (2004) explains that the importance of establishing a child's communication with MDVI, people in the surrounding environment

sometimes have to find different ways or paths to communicate with them in order to get the message in a different way, people in the surrounding environment need to have a perspective that children with MDVI struggle to understand the world with the same potential as other children. Although the way they achieve it is different.

Implementing an early intervention program that has family resources involves all family members, especially their fathers and mothers. Early Intervention Program Family resources are heavily involved in parents in their implementation. This research program is an early intervention program to overcome communication problems experienced by children starting from the importance of receiving their children and positive support so as to create communication with their children. This program is a guideline for families in self-intervention to their children at home to build positive things with their children into the most important things to do, one of which is in the aspect of communication (Chen, 2014, p.86).

After the implementation of the program in the family was completed, the researchers collected data using interview and observation techniques. The data were analyzed to see the results of the implementation of the program prepared with the family. Observation activities and interviews were carried out to parents regarding the implementation of the early intervention program that had been carried out and to see the changes that occurred in the family. Parents' knowledge of their child's characteristics, positive acceptance from parents, and parents' understanding of the correct form and way of communicating with the needs of their child experiencing MDVI. The knowledge possessed by parents can now intervene in the child and develop the understanding of the parents in intervening in the child. With early intervention, parents are satisfied with the results and the child's progress is seen after the intervention is given.

CONCLUSION

Based on the results of the previously described analysis, it can be concluded that the family resource early intervention program formulated to optimize the communication of MDVI children can be understood by parents, they intervene to the child independently. Parents intervene consistently to optimize their child's communication development.

The family becomes part of the microsystem in development, where the family becomes the closest in the development of their child at home. Families have a major role to play in stimulating their children at home. One of the difficulties experienced by children with MDVI is communication. Communication becomes important to stimulate so that they are not alienated from the environment and can live independently. Children's communication with MDVI starts from home with their families. Therefore, parents need to know the impact of communication on MDVI children and how to communicate with them so that parents can stimulate their child's communication at home.

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AUTHOR CONTRIBUTIONS

CAM **:** Conceptualization, Methodology, Formal Analysis, Investigation, Writing – Original Draft, Supervision.
LAS **:**Data Curation, Investigation, Validation, Writing – Original Draft.
MAT **:**Formal Analysis, Validation, Resources, Writing – Review & Editing.
KNN **:** Data Curation, Project Administration, Visualization, Writing – Review & Editing.

DECLARATION OF COMPETING INTEREST

The authors declare no known financial conflicts of interest or personal relationships that could have influenced the work reported in this manuscript.

DECLARATION OF ETHICS

The authors declare that the research and writing of this manuscript adhere to ethical standards of research and publication, in accordance with scientific principles, and are free from plagiarism.

DECLARATION OF ASSISTIVE TECHNOLOGIES IN THE WRITING PROCCESS

The authors declare that Generative Artificial Intelligence and other assistive technologies were not excessively utilized in the research and writing processes of this manuscript.

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