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Family-Based Early Intervention Based on Family Outcomes for Families with Children with Multiple Disabilities

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Abstract: *This study aims to formulate a family-based early intervention program for parents who have children with Multiple disabilities based on Family Outcomes. The background of this study is the lack of family information related to the identification of children with multiple disabilities, family confusion in handling children who experience multiple disabilities, and the absence of family confidence in the situation of their children in the social environment. The subjects in this study were parents who had Children with Multiple Disabilities in this case were children with Cerebral Palsy who experienced obstacles in motor, cognitive, social & emotional, and language aspects and intellectual barriers. This research approach is a qualitative approach with three stages of research, namely assessment, validation, and implementation. The result of this study is an increase in family understanding of the child's condition, the occurrence of stimulation carried out by the family to the child, the family has begun to want to socialize their children in the surrounding social environment. The results and discussion of further research are discussed in this study.*

Keywords: *Early Intervention, Family Outcome, Multiple Disabilities.*

Abstrak: Studi ini bertujuan untuk merumuskan program intervensi dini berbasis keluarga untuk orang tua yang memiliki anak dengan Disabilitas Ganda berdasarkan Hasil Keluarga. Latar belakang dari penelitian ini adalah kurangnya informasi keluarga terkait identifikasi anak dengan disabilitas ganda, kebingungan keluarga dalam menghadapi anak-anak yang mengalami disabilitas ganda, dan ketidakpercayaan keluarga dalam situasi anak-anak mereka di lingkungan sosial. Subjek dalam penelitian ini adalah orang tua yang memiliki Anak dengan Disabilitas Ganda dalam hal ini adalah anak-anak dengan Cerebral Palsy yang mengalami hambatan dalam aspek motorik, kognitif, sosial & emosional, bahasa, dan intelektual. Pendekatan penelitian ini adalah pendekatan kualitatif dengan tiga tahap penelitian, yaitu penilaian, validasi, dan implementasi. Hasil dari penelitian ini adalah peningkatan pemahaman keluarga terhadap kondisi anak, terjadinya stimulasi yang dilakukan oleh keluarga kepada anak, keluarga telah mulai ingin menyosialisasikan anak-anak mereka di lingkungan sosial sekitar. Hasil dan pembahasan penelitian lanjutan dibahas dalam studi ini.

Kata-kata Kunci: Disabilitas Ganda, Hasil Keluarga, Intervensi Dini.

INTRODUCTION

Families of children with special needs experience many challenges and obstacles in parenting in everyday life. One factor is parents' acceptance of the conditions experienced by their children who experience special needs. Parental acceptance is an active and conscious process that parents go through to understand the conditions and needs of their children who have certain specificities that are manifested in the form of warmth, affection, attention and support both physically and non-physically (Gargiulo & . (Gargiulo & Bouck, 2019; R & Mangunsong, 2020)

Based on research conducted by it is known that stress, anxiety and depression affect the level of parenting caused by parental acceptance of their child's condition. There have been many studies that discuss macro issues in the environmental context, but there are some things that still need to be investigated more deeply when talking about communication and interaction problems in the micro context related to the context of 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 personal social conditions which have an impact on the emergence of stigmatization, discrimination to shame that is not only faced by children with special needs, but also their families. (Petcharat & Liehr, 2017)(Gargiulo, 2012)

Family is the most important factor affecting a 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 a 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 everyday. Researchers found cases in the field, where there are families who have children with multiple disabilities where the child has severe cerebral palsy accompanied by intellectual barriers, because the baby has asplasia (pinched placenta) so that oxygen does not reach the brain and causes cells in the brain

to die, the baby does not cry and responds to anything when it comes out of the mother's stomach, The condition makes the child forced to be treated in hospital for one month. Currently, the condition of the child with the initials C is only lying on the bed and his limbs are withered. C is now four years old but C's physical, motor, language and cognitive development still tends to be in the five-month-old infant stage.

The condition of children with multiple disabilities is a condition where a person who has more than one disabilities, so that it requires support such as communication, mobility, self-care that is useful in his life in the community. In this study, the subjects were families who had children with severe cerebral palsy accompanied by intellectual barriers. Cerebral palsy is the most common physical barrier in children and occurs in 1 in 500 births, initially the diagnosis was made between the ages of 12 and 24 months but can now be made before establishing communication with the child who has multiple disabilities. This study has obtained permission from six months Before the age of six months there are three tests that can be done whether children have a tendency to experience Cerebral Palsy, including; (1) neonatal magnetic resonance imaging (MRI), the Prechtl Qualitative Assessment of General Movements (GMs), the Hammersmith Infant Neurological Examination (HINE). After six months of age, the best test tools that can be used are MRI and the Developmental Assessment of Young Children or better known as the child's developmental test (Milestone). Motor dysfunction occurs in children with cerebral palsy which causes the quality of movement to decrease so that this can affect many aspects, one of which is mobility. Cerebral Palsy is that motor impairment must cause limitation of activity (Novak et al., 2017).. (Te Velde et al., 2019).

The condition of Cerebral Palsy is very heterogeneous depending on the type and severity of symptoms experienced, the level of function, and quality of life also varies greatly. (Boel et al., 2019). In certain conditions, especially severe severity, it can

cause children with cerebral palsy to experience multiple disabilities because severe brain dysfunction not only results in motor disabilities but is accompanied by other obstacles such as in terms of cognitive, language, and social emotions. Higher levels of anxiety, depression, sadness and stress are reported in parents of children with cerebral palsy especially with severe cerebral palsy conditions; parents should be proactive, skilled and conscious in their parenting. While intellectual disabilities are conditions where children experience obstacles to their adaptive and intellectual functions. (Spittle & Morgan, 2018)

Based on the facts found in the field show that the family has not fully accepted the condition of the child, there is still shame in them related to the condition of the child, in this case the family never wants to invite the child out of the house to socialize with others around him. Families also do not know how to provide stimulation or what their child needs, so the child is never treated and only spends time in bed every day. Parents also cannot fully accept their child's condition and think that with their child's current condition, their child cannot develop. This study aims to identify various needs that need to be met and developed in providing parental stimulation to children with multiple barriers, in this case children with severe cerebral palsy in order to optimize child development. Family outcomes in interventions given to families serve as a benchmark of benefits experienced by families after the intervention program is completed (Hughes-Scholes & Gavidia-Payne, 2019).

RESEARCH METHODS

This study used experimental research where parents were given several programs that became a reference for the parents of the child. Every 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 one family with a total of eight meetings for each program with a duration of 60 minutes each, this study was carried out for three months. Subjek research was obtained through

observation and interviews with teachers at SLB Pelita Adinda, Bandung. Based on the results of the interview, the teacher recommended one family that has children with multiple disabilities. The family is still unable to get to know their child as a whole, still does not know how to stimulate their child's development, nor does they want to invite their child to socialize with the environment.

In each program applied in this study, we used mixed factorial design consisting of one research subject factor, namely family acceptance of children with multiple disabilities based on family outcomes. This research project completed three programs that were carried out in stages. The stage begins with the identification of children with severe cerebral palsy experienced by their children, the next stage is for parents to learn to stimulate their children at home according to the child's most important needs; And the third is that parents build socialization with the environment. Based on previous research that shows that the importance of these three programs is applied in order to accept the family's condition of their children with disabilities. The data of this study were obtained from interviews with parents, observation of children's communication and observation of parents based on FQOL, 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 conclusions. (Hathazi & Turban, 2021; Kamenopoulou et al., 2021; R & Mangunsong, 2020; Van Keer et al., 2020) (Wiley et al., 2013).

RESULTS AND DISCUSSION

Result

The formulation of intervention programs is based on Bronfenbrenner's ecological theory where the family is part of the microsystem, the environment closest to the child to help the child's development, in addition to referring to the Family Quality of Life by Brown et al (2006). In addition, the program refers to family outcomes derived

from theory (Bailey, 2006) including; Families understand their child's strengths, abilities and special needs, Families help their children develop and learn, Families have support systems. The development of children, especially children with special needs, cannot be separated from the environment, the importance of intervention is not only for child care but should be the family environment of both parents and siblings to be an opportunity in the development of children with special needs. Families can work together or collaborate with supporting service components (experts) both health, social, and education services. (Webster et al., 2004).

The made-for-family program includes three programs; The first program is Sharing Knowledge About Children with multiple disabilities this is related to parents' imagination of the child's condition, because parents who have children with multiple disabilities are often associated with excessive stress, most parents are not ready to see the obstacles possessed by his child 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 Home Parenting for Children With multiple disabilities, the purpose of this program is to build positive acceptance of families towards their children and also help families by providing homevisit therapy that can provide direction to families how to stimulate their children at home. The third program is socialization, this aims to build family confidence with the surrounding environment.

The program consists of eight meetings. The first two meetings were used as the initial baseline of the situation before the program was given and the next 6 meetings consisted of program trials and the last 2 meetings consisted of program evaluations and results. In the first program families still did not know the details of their child's condition, they only knew that their child was only bedridden and they helped their child carry out his daily activities, when the intervention was given the parents were very cooperative in receiving and processing the information provided. The eighth meeting of parents had a fairly mature concept of their child's condition with multiple obstacles. In this case the outcome of the family that occurs is that the Family understands the strengths, abilities, and special

needs of their child.

The implementation of the second program, in family C there was a change at the seventh meeting where parents had begun to be able to stimulate their children at home, previously the family had never given therapy to their children at home, researchers invited therapists to the home to provide stimulation from what their children needed most at home, Parents slowly begin to understand what they need to do to support their child's development. Parents have begun to want to touch their children in doing simple movements in helping children's motor development. Parents already want to stimulate children's language by introducing self-concept and the surrounding environment to children and the activities carried out, in this case children have begun to want to respond when their names are called, children slowly begin to respond to emotions from their families. In this case the outcome of the family that occurs is that the Family helps their children develop and learn.

The implementation of the third program, after the family begins to recognize the characteristics, needs, and importance of positive acceptance. Families began to want to take their children out of the home environment to socialize with the surrounding environment. Families are slowly beginning to understand what they must do in support of socialization with the environment. The family has begun to want to ask C out of the house and do simple things such as asking C to set foot on the grass and at the eighth meeting the family wants to invite C to go to a convenience store near their home. The result of the family that occurs in this case is that the family has a support system

Discussion

Early intervention for families with children with special needs can have a positive impact on their Family Quality of Life (FQOL), FQOL itself is the result of family interaction at different levels: among them the concept of the family unit which is the dynamics and characteristics of the family), the concept of individual members, the concept of performance (referring to support, services, and practices), and the concept of systemic (i.e., systems, policies,

and programs). Early intervention can result in family outcomes that are benefits to the family as a result of the services received. Family outcomes consist of five outcomes, including; (a) families understand their child's strengths, abilities, and needs; (b) families know their rights and advocate effectively for their child; (c) families help their children develop and learn; (d) the family has a support system; and (e) families can gain access to desirable services and activities in their communities. (García-Grau et al., 2019). (Bailey et al., 2003)

Basically, according to families, they want education and information such as training for families in skills to help and (Palit & Chatterjee, n.d.)stimulate their children who experience special needs at home, as well as emotional support and other support so that it can be a motivation for parents. This is the reference for the implementation of early intervention programs where families get information related to their child's condition. The implementation of the intervention is carried out by home visits, In this case it is assessed that the family benefits and shows that this is one form of positive activity to support them at each visit In(Crossman et al., 2018). the process of implementing the intervention, warm and responsive parenting and a conducive home environment are proven to have a positive effect on child development . Families in this case parents play an important role in making early intervention for their children. (Spittle & Morgan, 2018)

The implementation of early intervention programs that have family resources involves all family members, especially fathers and mothers. Early Intervention Program Family resources involve parents a lot in its implementation. This research program is an early intervention program to overcome communication problems experienced by children starting from the importance of accepting their children and positive support so as to create communication with their children. This program is a guideline for families in intervening with their children at home to build positive things with their children to be

the most important thing to do, one of which is in the aspect of communication (Chen, 2014, p.86 (Chen, 2014). Parental involvement and collaborative goal setting can also influence the direction and focus of the intervention given, knowing the parents' goals as the most important priority in planning a given program.(Gmmash & Efgan, 2019)..

CONCLUSION

This study revealed that students experience academic burnout which is influenced by several factors, one of which is student self-efficacy, adding evidence that academic fatigue is a warning signal for a decline in student academic achievement on campus. Therefore, it is recommended by the institution to facilitate students and encourage students to cooperate with interprofessional, collaboration, and communication. .

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