

Parents Assistance on Down Syndrome Children: Pastoral Counseling Perspective

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Abstract: Researchers aim to find out how to strengthen and assist parents with strategies for children with Down syndrome to become independent. The method used is qualitative the procedure used for data collection by observation, interviews, and documentation. Furthermore, the data were analyzed using a data reduction model, data presentation, and verification. The resource persons for this study were ten parents with Down Syndrome children and servants of God involved in pastoral care for families with Down Syndrome children in Jakarta. The results showed that the community for parents with Down Syndrome children is essential because it provides reinforcement and support in mentoring children with down syndrome. After attending formal and informal therapy, Down syndrome children have significant developments that enable DS children to be independent. The primary model of parental assistance is holistically providing whole love and providing therapies, especially music and spiritual therapy.

Keywords: mentoring, parents, down syndrome, independent.



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Introduction

It is generally agreed that one of human society's actual units is the family. In addition, another term that is generally attached to this group is "the smallest community unit." Even though it is small, it is essential and decisive for forming a good and quality nation and/or world community. It is said to be essential and decisive because the potential and the most elementary basics of human life begin to be explored, discovered, and developed in the family. In addition, it is the main, first, and an ideal place to educate every individual human person to become a superior human being in all its aspects. The ideal of

home or family for forming quality human beings is possible because the scope is relatively small and easy to manage.

The family can be like a gateway to welcoming new people (descendants/children) to become an integral part of a warm and intimate community within the frame of sincere love. Within the framework of the Christian faith, children believe to be a special gift from God for every married couple. Therefore, the birth of a baby must be greeted with joy and gratitude to God regardless of gender, physical condition, and health (Setiawani & Tong, 2008).

Of course, a child born with perfect and healthy conditions is the desire or longing of all married couples and/or families. The facts show that not all children born in a family are in perfect condition and/or physically and psychologically healthy. One of the facts found is what is known as a child who has "Down Syndrome." The child "Down Syndrome" is a case that is not popularly known by the general public. If you look at the historical record of the emergence of the term "Down Syndrome," it seems that it is closely related to the name of a country, namely Mongolia. Because at first, down syndrome children were called mongoloids or mongolism (Rahma & Indrawati, 2017). Along with historical developments, the term Mongolian became foreign and/or forgotten. That is why the term Down Syndrome is currently used for children with the syndrome.

The concept that a child is a gift from God and that God's grace is a good one becomes a dilemma in this fact. If grace is good, why is the gift obtained not as expected? Why do some families have children with Down syndrome? Christianity firmly states that the child is still a gift from God entrusted to a specific family. The problem is, what are the methods and strategies of parents in educating and assisting children with Down syndrome to have an independent lifestyle. This study highlights that section to become an applicative contribution that parents and families with children with Down syndrome can read.

Based on the explanation above and reading books related to mentoring down syndrome children, the researchers are very motivated to learn more about the growth and development of down syndrome children's behavior. That is why the researchers conducted audition activities with the POTADS (*Persatuan Orangtua Anak Dengan Anak Down Syndrome*) foundation administrators. The primary purpose of POTADS is to empower parents of down syndrome children to remain passionate about helping their children grow and develop optimally so that their children can achieve and accept by the wider community. Down syndrome children have the same rights as other children, with the address JL. Jupiter 1C, No. 4, Villa Cinere Mas, Pisangan, Ciputat Tim, City of South Tangerang, Banten 15419, and several administrators at the TRI ASIH foundation addresses is at Jl. Great Carmel No. 2 Kebon Jeruk West Jakarta 11530. What the researchers got from the two foundations was just a comparison material to get information on how to assist down syndrome children. Besides that, it is also to obtain information on guiding parents of syndrome children, especially those who join the Foundation. Based on the observations and interviews of researchers with leaders, teachers, and parents of down syndrome children at POTADS, it was obtained that they generally realized that God entrusted children to each family. Thus, believe that God has the right to determine what is appropriate and who can entrust Him.

In principle, POTADS and TRI ASIH are effective means to share experiences of parents' struggles who bless with down syndrome children. Through this community, parents of children with Down syndrome can strengthen, support, and exchange ideas on how to provide good mentoring techniques. The POTADS community brings enthusiasm for parents not to waste their Down syndrome children. POTADS always tries to help restore the confidence of parents of Down Syndrome children to educate their children to be independent according to their strengths and weaknesses. In addition, POTADS also informs the broader community that Down Syndrome is not a hereditary disease or curse that needs to be feared. With parents' love and guidance, these children with Down syndrome can be trained and educated. What is extraordinary is that quite many of them have achieved achievements in their daily lives.

Method

Research Design

Because the problem being studied is a particular social community and is dynamic in daily life, the research method used is qualitative. Qualitative methods are used to obtain descriptive data in written and spoken words from people and behaviors that are the object of observation (Moleong, 2014). With this

method, a clear picture of a matter is obtained according to the view of the human being studied. Qualitative research deals with the ideas, perceptions, opinions, or beliefs of the people being studied, and all of them cannot measure by numbers. Following the researcher's title, this research is parents with down syndrome children who live in the Jakarta area. The subjects in this study were ten parents of children with down syndrome who live in the Jakarta area. This data was obtained from the Foundation for the POTADS and the TRI Asih foundation. Data was collected using data triangulation techniques with observation, documentation, and interviews (Sugiyono, 2015). The data source is primary data, namely research subjects or informants relating to the variables studied or data obtained from respondents directly. At the same time, secondary data comes from graphic documents such as tables, notes, SMS, photos, and others (Suhartimi, 2010). Data analysis begins with conducting in-depth interviews with key informants, namely someone who understands and knows the situation of the object of research. After the researcher wrote the interview results into a transcript, the researcher had to read it carefully and then make data reduction.

Results and Discussion

Down Syndrome Children

According to Gunarhadi, down syndrome is a condition of retardation of physical and mental development in children caused by chromosomal developmental abnormalities. Furthermore, Gunarhadi said that Down Syndrome is a collection of symptoms resulting from chromosomal abnormalities, usually chromosome 21, which cannot separate during meiosis resulting in individuals with 47 chromosomes. Actually, down syndrome was first discovered and/or introduced by Seguin in 1844. Down Syndrome is a doctor from England whose full name is Langdon Haydon Down. An aneuploidy individual has a deficiency or excess in his body cells. In the 1970s, experts from America and Europe revised the name of the disorder that occurred in the child by referring to the first discovery of this syndrome with the term Down Syndrome and until now, it is known by the same term (Gunarhadi, 2005).

In addition to having distinctive physical characteristics, down syndrome children also have distinctive physical characteristics. As for these characteristics, among others, do not like many friends, DS children are children who do not have many friends. Lack of Patience, down syndrome children, do not have a sense of patience. They are temperamental, easily irritated or angry, and difficult to control. Some like to fight; maybe some children have lousy character or temperament. However, unfortunately, the characteristics of down syndrome children also like to fight and do not like to be ordered. Difficulty Focusing is the main point in detecting down syndrome children where the focus is the main distraction of this child. Easily upset and angry for children expect, they sometimes cannot achieve what they want. Developmental delayed, down syndrome children, tend to have stunted development. Delayed development also indeed occurs in all children with down syndrome.

According to Yanet, the factors causing Down Syndrome are divided into two groups, namely: the Biomedicine group, which consists of Prenatal (can occur due to infection during pregnancy, metabolic disorders, irradiation during gestation between 2-6 weeks of gestation, chromosomal abnormalities, malnutrition); Natal Anaxia (obstructed blood supply to the brain), asphyxia, prematurity, postmaturity, brain damage), Postnatal (can occur due to malnutrition, infection (meningitis and encephalitis). The second is a socio-cultural group. This etiologic group is influenced by psychosocial processes in the family (APA, 2000). While Davis put forward three kinds of theories, namely (i) Stimulation theory (Generally, people with Down Syndrome are classified as mild, due to lack of stimulation, or lack of opportunities from the family); (ii) Disruption theory (failure of the family to provide adequate protection against stress in childhood, resulting in disturbance of mental processes); (iii) Hereditary theory (this theory uses the relationship between parents and children is weak so that children experiencing stress will react in various ways to be able to adjust).

Caring for children with Down syndrome

Taking care of children is not easy, especially for those with down syndrome. However, with persistence and gratitude, because the child's gift is given, it becomes fuel to encourage oneself in taking care of the child. Therefore, parents must have much understanding about Down Syndrome, and this knowledge will impact specific strategies and ways that are applied to care for children with down syndrome. Next, give love and affection that are of duration and quality. Avoid talking while doing other

work that makes the child's mental decline. Family love, especially parents, is essential for the development of down syndrome children is a condition that will experience for life, but love from families, especially parents, can make down syndrome children live longer, healthier, and happier.

The principle of Parental Assistance

According to the Kamus Besar Bahasa Indonesia, mentoring means a person who accompanies; process, method, an act of accompanying or assisting (Kemendikbud, 2016). The Bible records that God's first institution or organization was the family. The family becomes an environment that all believers appreciate. In the family, children learn from their parents to live according to the truth of God's Word taught from generation to generation. This is explicitly recorded in Deuteronomy 46:4-6. It was even used as a sentence for the Israelites' creed, namely "God is One, God is our God." This verse is the Foundation upon which the families of the Israelites are built (Lasor, 2012). God made this affirmation because of the big problem experienced by Israel, namely syncretism with the culture and beliefs of other religions. That is why the descendants of Israel must understand and know the depth of their God (Blommendaal, 2012). While the New Testament records how Jesus welcomed the children who came to him. He taught the importance of paying attention to children so that the Lord Jesus gave strong sanctions to anyone who misled a child to drown in the sea (Matt. 18:1-6), the Lord Jesus himself as a Son showed His obedience to the Father in heaven (Matt. 18:1-6). John 5:36; 8:19, 42, 49).

This pattern becomes a tool for Allah to reveal his existence as a savior and protector in the family. Within the scope of this family, children can find out their life goals with full support from their parents in the process of seeking and achieving them, which certainly does not conflict with God's Word. Parents can carry out teaching activities balanced, namely discussing, playing, and telling God's Word. Other actions are also with life examples and the correct response when faced with problems. If this is done, then the mention of parents as mandates of God can be saved. So the responsibility that parents carry is basically to God. Children's spiritual development must accompany universal attention to the pattern of growth and development of children, including physical, social, psychological, and spiritual aspects (Gunarsa, 1987). Of course, it is not easy to do this. That is why the goal becomes a force that encourages parents to keep paying attention and educating their children (Wiriadinata, 2010).

Pastoral Role of Parents for Down Syndrome Children

Roles are a series of behaviors that others expect towards someone according to their position in the system, which can be influenced by social conditions (Poerwandari, 2009). In this context, parents can also be called shepherds for their children and their families. Pastoral care means a process carried out by someone willing to give attention, care, maintenance, protection to someone in need. Collins said that effective counselors must be able and skilled in using counseling techniques, and this is also a must-have for parents as a counselor. In general, this technique is a way to love and appreciate others with genuine love (Collins, 2017).

The purpose of assisting children with down syndrome is to help holistically. They are starting from the needs of the body or Physical. Because he has special needs, his body situation is different from most children's. This is where parents must regularly pay attention to their sleeping hours, hours of taking medication, and specific diets, and parents also take care of their physical wellness. Second, mentality and resilience in treating with different energies. Social needs must also be considered by having empathy and a sense of neighbor. Moreover, it is spiritual. Where the belief in God's plan and God's love is in it, Christian parents cannot walk alone in assisting down syndrome children. The church is one of the most effective parent partners in helping to assist down syndrome children to live independently.

Pastoral, as described in the pastoral explanation of parents in down syndrome children, means someone willing to care for with the heart, protect with care, and care for with love. According to the researcher, when connected with church services, the meaning of "pastoral" is Christian counseling service-oriented to the maturity of every congregation member both in character, knowledge, and so on (Johni Hardori, 2014). According to Trisna, counseling does not only mean "advising." However, the term counseling has a broader meaning, including exchanging thoughts, guiding, affirming, accepting, listening, and, most importantly, empathy (Trisna, 2012). In general, church counseling pastoral services for DS children are focused on optimizing what the child has. This will refer to "self-actualization, self-realization, fully functioning and self-acceptance" (Lestari & Mariyati, 2016).

Based on the researcher's interviews with the parents of down syndrome children, especially those who are Christian, it can conclude that the function of pastoral assistance carried out by parents to down Syndrome children begins with acceptance of God's sovereignty which will have an impact on the recovery of hearts and feelings so that their psyche is not disturbed. Furthermore, it encourages mental strength in overcoming the illness, and acceptance should be the main task of the counselor.

All children will be delighted if they are treated well by the people around them. Likewise, children miss and are happy with Down syndrome if they treat it like a child. According to researchers, the aim of pastoral counseling that the church can do for down syndrome children is to build the spirituality of down syndrome children, build the self-confidence of down syndrome children, and build the talents of down syndrome children. Therefore, parents who have children with down syndrome must know the emotions and characteristics of the child. By doing so, it will be easy to recognize and treat them. In providing care and assistance, it is crucial to give more affection. This action is standard, but more intensity for down syndrome children is needed. Because then they do not feel lonely.

Furthermore, parents must also understand and recognize the unique skills they have. Next, please consult a doctor to regularly monitor the progress of their child's health, find and send them to a suitable school. As for parents, joining a community of parents with a down syndrome such as POTADS will be a separate reinforcement. How to treat children with down syndrome can also be through therapies. Taking care of the next child can be holistic through therapy, especially spiritual therapy.

Conclusion

The risk of having a child with down syndrome is related to the mother's age at the time of pregnancy. When pregnant over 40 years, maternal age can reach 1 case out of 50 live births. Abnormalities in children with down syndrome can find early or during the womb. In pregnancy tests, doctors can determine if the child they are carrying has Down syndrome. In addition, down syndrome children have special characteristics both physically and psychologically (intellectual). Parents who face the fact that the child conceived is a Down syndrome child are not accessible. When they first heard that their child had down syndrome, the parents were surprised and had difficulty accepting this fact. Then, they can accept and understand that children are a gift from God. Acceptance from parents impacts how parents take care of children with down syndrome. The first thing parents do is understand by learning in detail the knowledge related to down syndrome. It aims to understand parents about Down Syndrome and the things that their children need. In addition, down syndrome children also need family love, especially parents. Love must give sincerely because the conditions experienced by DS children last a lifetime. Parents must also understand what their child's talents are to help develop their talents.

Parents can use various strategies, such as joining a community or special school, because down syndrome children cannot enter public schools. Parents need extraordinary communities for Down Syndrome to obtain the information they need. In addition, down syndrome communities such as POTADS and the Tri Asih foundation can be a means to do therapy for down syndrome children and even develop their talents. A congenital disease or disorder usually follows down syndrome, and they need therapy to treat the congenital disorder. Many therapies can be done, such as talk therapy, cognitive therapy, sensory therapy, behavioral therapy, craniofacial therapy, nutritional intake therapy, etc. These therapies are beneficial for the development of children with down syndrome. Down syndrome children can experience good changes when they are brought to God. In this study, researchers found down syndrome children who can experience changes when taught to go to church, pray, listen to God's word, and even get baptized. Therapy - therapy is needed, but spirituality also needs to be improved so that down syndrome children have good spirituality and can experience good development.

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