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Aida Husna¹
 Indar Wahyuni²

RAISING CHILDREN WITH DOWN SYNDROME TO BE INDEPENDENT; A CASE STUDY OF DSTAR COMMUNITY

Abstrak

Down syndrome adalah suatu kondisi di mana seseorang memiliki kelebihan kromosom, disebut juga Trisomi 21. Salinan tambahan ini mengubah cara tubuh dan otak bayi berkembang, yang dapat menyebabkan tantangan mental dan fisik bagi bayi. Karena sindrom Down adalah kondisi seumur hidup, anak-anak dengan sindrom Down memerlukan layanan di awal kehidupannya yang sering kali membantu mereka meningkatkan kemampuan fisik dan intelektual. Sebagian besar layanan ini berfokus pada membantu anak-anak dengan sindrom Down mengembangkan potensi mereka sepenuhnya. Faktanya, tidak semua orang tua dari anak-anak tersebut dapat menerima anaknya dengan kondisi seperti itu. Jika tidak, mereka tidak tahu bagaimana mendukung anak-anak mereka yang mengidap sindrom Down. Tulisan ini bertujuan untuk mengungkap praktik terbaik yang dilakukan anggota komunitas DSTAR dalam membesarkan anak penderita Down Syndrome menjadi anak mandiri. Penelitian ini menggunakan metode kualitatif, dengan 7 orang anggota komunitas DSTAR sebagai subjek penelitian ini. Hasil penelitian menunjukkan bahwa kasih sayang, perhatian, penerimaan, pengulangan, disiplin, dan keterlibatan anak dalam aktivitas keluarga merupakan praktik terbaik dalam membesarkan anak down syndrome menjadi anak mandiri.

Kata Kunci: Down Syndrome, Mandiri, Best Practice

Abstract

Down syndrome is a condition in which a person has an extra chromosome, also referred to as Trisomy 21. This extra copy changes how the baby's body and brain develop, which can cause both mental and physical challenges for the baby. Since Down syndrome is a lifelong condition, children with Down syndrome need services in their early life that will often help them to improve their physical and intellectual abilities. Most of these services focus on helping children with Down syndrome develop to their full potential. In fact, not all parents of these children can accept their children with such condition. Otherwise, they do not know how to support their children with Down syndrome. This paper aims to reveal the best practice of the members of DSTAR community on how they raise their children with Down syndrome to be independent children. This study uses a qualitative method, with 7 members of DSTAR community as the subjects of this study. The results show that loving, care, acceptance, repetitiveness, discipline, and child involvement on family activities are best practices how to raise children with Down syndrome to be independent children.

Keywords: Down Syndrome, Independent, Best Practice

INTRODUCTION

Family is regarded as a major social institution, that contributes to overall physical, social and intellectual development of their children. Attention and love of family to their children is the main factor in shaping a child (Rofiq, 1997: 240) and influencing their skills and values during these childhood development stages. These also help a child build a solid foundation that will affect their future relationships, work, health and sense of self.

^{1,2}Islamic Education Department, STAI Pati
 email: buaidahusna@gmail.com, azkiyaalyani@gmail.com

Each child has rights to survive, to grow up and develop socially and intellectually, and also to be independent. However, independence does not mean the same to every people. It could be different things for different people at different stages of life, but being independent whatever it may look like, is an essential component of personal fulfillment, including children with Down syndrome. It is because every child has rights of protection from threat of violence and discrimination (Djamil, 2013: 8, & Harjaningrum, 2017: 2).

Down syndrome (DS) is a condition in which a person has an extra chromosome, also referred to as Trisomy 21. This extra chromosome is related to non disjunction on chromosome cell division (Santrock, 2011: 82). Although it occurs in an average of 1 out of each 700 to 800 live births, but it is still unclear exactly what leads to this chromosomal anomaly. It is a fact that 1 in 400 babies with Down syndrome born to mothers older than 35 years old, while 1 of 1000 babies with Down syndrome born to mothers younger than 30 years old (Irwanto, 2019: 10). It means, most children with Down syndrome are born to women older than 35 years old, but many children with Down syndrome are also born to women younger than 30 years old.

The most common health condition experienced by children with DS are congenital heart disease, respiratory, visual and hearing problems, hypothyroidism, emotional and growth disorders (Nunes & Dupas, 2011). Most of these children also have moderate mental retardation. They can go through the normal phases of development, although it more slowly and needs early interventions and full family involvements (Nunes & Dupas, 2011).

Yet, not all parents can accept the fact that their baby are born with DS. Once they know their baby is with DS, they perhaps shock and even could not accept the condition (Prasastiwi, Hardjanta, 2017: 100-107). Besides, the daily and constant commitment to care that has to be provided to children with DS over a long term period also impact to personal lives of family members. Such condition can also trigger stress and depression. Basically, these situations are caused by the lack of knowledge on how to raise children with DS. Their refuses and lack of understanding hinder a child's growth and development. Thus, the child's independence may be affected.

DSTAR Indonesia is one of community that concerns on children with disability in Indonesia. The members of this community consist of parents of children with special needs, including parents of children with DS. This community works for the independence of children with DS. The members of this community that are from around Indonesia, concern to learn on how teaching a child independence, especially to child with DS. Hence, the objective of this study is to reveal the best practice of the members of DSTAR community on how they raise their children with Down syndrome to be independent children.

METHOD

This is a qualitative field research. This method is used to explore the phenomena occurs on certain individual, group, or community (Husaini Usman, 2004: 5). In this study, this methods is used to explore the best practice of the members of DSTAR on how they nurse and raise their children with DS to be independent.

The informants of this study are the parents of children with DS, the members of DSTAR, that consist of 7 (seven) informants, chosen by purposive sampling. In-depth interview, observation, and documentation are used to collect the data. The method of data analysis that is used in this study consists reduction, data display, and conclusion drawing.

RESULT AND DISCUSSION

Loving, Care, and Acceptance

Family is the main foundation for their children to develop for their better. Although being a mother is challenging, but with sincerity and patience, it will not to be difficult to help children to grow. Great children are born to great mothers and supportive families. From them, children with special needs will grow being independent children.

In general, parents will accept their child's condition even though in the early phase of knowing their child is born, they will experience shock, disappointment, stress, inner and outer struggles (Mangunsong, 2011: 6). This study shows that at the beginning, some informants were

shock for the first time they gave a birth child with DS such as informed by Mama Inaz and Mama Ahda. Family is the major social institution that responsible taking care their children with love. Love is the main factor in the crucial developmental stages of children (Rofiq, 1997: 240). Parents could not refuse their children as their children have rights to care and love. So at the end, Mama Ahda and Mama Inaz realize that they cannot refuse their children, and they must love them without any condition.

In the civil law, there is a reciprocal law between parents and children; what the rights of the child are the responsibility or obligation of the parents, on the contrary what are the rights of the parents are also the obligations of the child, namely when the parents are unable to be independent due to physical and economic conditions (Ali, 2006:83). Children have rights of love and care despite of different gender, condition of children with special needs, culture, economic and social status, also various religions. (Miharet, 1993: 48)

According to Imam Yuwono, parents of children with special needs will meet many challenges and questions from the surrounding environment. Moreover, children with DS are high risk to experience health condition such as congenital heart disease, respiratory, visual and hearing problems, hypothyroidism, emotional and growth disorders (Nunes & Dupas, 2011). With such condition, parents will definitely continue to struggle in providing nurse for their children. So, one thing that should be considered by parents of children with special needs is parents must identify children who have problems or developmental barriers. This identification can be called as an early detection for children with special needs (Yuwono, 2015:4). According to Mama Ahda, the health issues that could be identified will be more accepted with love and care.

However, other informants can accept gracefully and are grateful for God's destiny, like Adit's mother, Kidung's mother and Raafi's mother. Even, some other informants decided to resign from their jobs when they find out that their child was born with Down syndrome and choose to focus on nursing or caring for their child, such as Mamah Kidung and Mamah Inaz, also Mamah Raafi. They belief, that their child with DS are the child of heaven, who will be a help in the hereafter. As child with DS has high risk on health issues, especially concomitant diseases or common diseases such as cough, influenza, or diary, so, according to Mama Adit, Mama Ahda, Mama Lala, and Mama Rafi, nursing their children with DS is their priority, especially for Lala that has health issue on congenital heart disease. The parents should concern on the child's healthy diet, sleep habit, and the pattern of treatment.

Repetitiveness

Independence does not mean the same to every people. It could be different things for different people at different stages of life, but being independent whatever it may look like, is an essential component of personal fulfillment, including children with Down syndrome. In general, there are some activities of daily living, such as grooming/hygiene, toileting, dressing, and feeding which are the skills often associated with independence and encourage children with DS to practice as they grow towards living independently.

Most of these children also have moderate mental retardation. They can go through the normal phases of development, although it more slowly and needs early interventions and full family involvements (Nunes & Dupas, 2011).

This study shows the informants must learn the habits of their children so they can implement some strategies they find most effective in teaching self-care skills to children with DS. Self-care refers to one's ability to take care of themselves children can self-care (Canada's Down Syndrome Magazine, 2022).

One of strategies that parents do is by understanding and detecting the child's pee pattern every few hours, for example, if the children have a habit of peeing every two hours, then every two hours they are invited to the bathroom to be taught to pee in its place. Setting an example for children with DS is a very acceptable learning for children with DS because they are the best at imitating or in terms of being a great imitator of what they see. Kidung, Raafi, Inaz, Adit, Fikri are among children with DS who mastered toileting faster than other children with DS, at around 3 years old. Ahda has only managed toileting at 7 years old. Ahda needs more time, because the lack of family support in teaching Ahda. It is only succeed until her mother worked

at home (WFH). At the pandemic era, for two years, she trained directly by her mother intensely every day with the same pattern. It bore sweet results that Ahda managed to be independent to go to the toilet. Can you imagine wearing diapers every day for 7 years it costs a lot of money? But really, hard work to teach children with DS being independent is a top priority for Ahda's mother.

Parents must be patient in teaching children with DS. They have to repeat intensely since the children with DS have a below-average IQs. The more repetition, the more they can memorize it. So, the next strategy is to practice and repeat one learning material more and more, before they learn another material. According to Mama Adit, this repetition not only needs one or two months, but sometimes, it needs almost one year, depends on the IQs. So, the parents need to know the IQs of their children and they do not compare their child to another.

Another strategy they implement to teach their child with DS is modeling. Even, Mama Ahda experienced in teaching her daughter in toilet training, start by demonstrating how toileting or brushing the teeth. While demonstrating, she also uses specific language to narrate the process.

In order to succeed with these skills, Parents first need to ensure that the child has the basic foundations. The Skill Development Pyramid below can be a helpful way to conceptualize this (Coles, 2022). At the base are the sensory systems. The way that an individual process sensory information is central to our ability to self-regulate, learn, and perform in the other areas. Once the sensory systems are in place, an individual can work on developing gross motor skills (or the skills that are required to do things like keeping our balance, walking, and running), followed by fine motor skills (required for tasks requiring dexterity, including dressing, feeding, and grooming). Self-care skills can begin to develop following a solid foundation in these three areas.

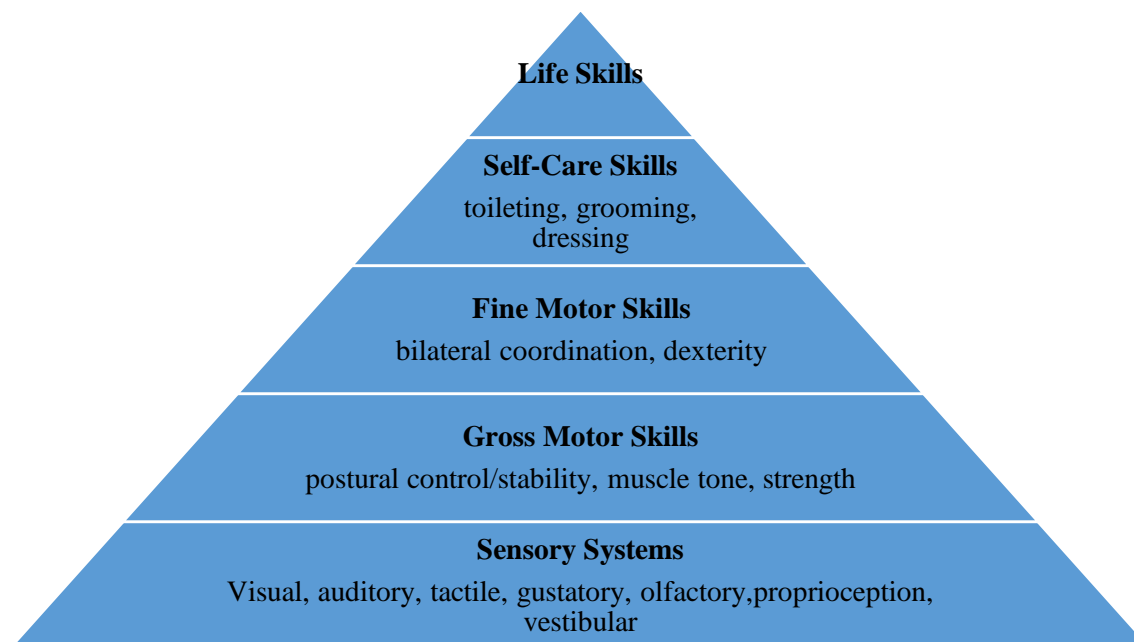


Figure 1 Skill Development Pyramid

Some of the strategies that most effective in teaching self-care skills to children with Down syndrome include modeling, using visuals, backwards chaining, and practicing through play.

Discipline

In nursing a child with DS, Mama Kidung practices discipline. According to her, it is one her strategy in conditioning her daughter to complete such competence, such as self-control, following the some rules, or also to minimize some actions that potentially endanger herself or others. For example, whenever Kidung plays dolls or puzzle with her friends, Kidung must clean up her toys after that.

Another example is Inaz. She mastered reading and numbering when she was only 4 years old. She success to master reading and numbering because her parents control her schedule on every day. Inaz goes to school in weekdays from 7 am to 1 pm. At afternoon, she practices keyboard on Wednesday and swimming on Tuesday and Thursday. At the evening, she also practices reading Al-Qur'an. She can do all her activities because of her family support.

However, applying discipline is not easy thing to do. For example Mama Ahda experienced that it is hard to discipline her daughter. It is still hard for Ahad to follow the rules. She often leaves the home without any permission to her parent or caregiver. Although Mama Ahda always gives some advice, Ahda still does that. So, for Mama Ahda, discipline is still big problem for her.

The success in applying discipline in child with DS depends on how the parents practice it. It needs fulfill family involvement, not only one person such as the mother. All of the members of the family must committed practicing discipline in their daily live, so it will be habituation for the child with DS. It is because a child with DS is the best in modeling.

To maximize the development of children with Down syndrome, it is crucial that therapies, early education, and early intervention are started at birth and continued until at least age 5 (Kinder, 2019). Kinder explains that this is a period of time when the brain is still developing and when proper physical development sets a foundation for a lifetime. So, this is the golden time to develop such things as clear speech, closed-mouth posture, the ability to read, expressive and receptive language, and to promote proper fine and gross motor skills.

Child Involvement on Family Activities

Being independent is an essential component of personal fulfillment for a child with DS. According to Julia Kinder (in Mackenzie, 2019), the biggest misconceptions are that children with DS cannot learn or understand, and that they have low intelligence. I.Q. scores for people with Down syndrome vary, with the average cognitive delays being mild to moderate, not severe. In fact, normal intelligence is possible. If a person with Down syndrome has difficulty with hearing, it can be misinterpreted as a problem with understanding. Likewise, problems with speech can be mistaken for low cognitive abilities. People with Down syndrome often have trouble with the physical ability to produce speech due to low muscle tone. This can result in speech which is hard to understand, and tongue protrusion. This barrier to speech clarity is not a reflection of intelligence, but rather a reflection of difficulty with muscle control. It must be understood that I.Q. tests and scores are controversial and flawed, and are not good indicators of a successful and fulfilling life (Mackenzie, 2019).

According to the informants of this study, the involvement of the children with DS on family activities is one of best practices in nursing children with DS being independent. For example, Inaz and Kidung have been involved on daily family activities since they were 2 years old. Inaz and Kidung are involved in cooking, doing laundry, and cleaning the house.

A child with DS can learn through the interactions between the rest members of the family, that they will carry for the rest of their life in regards to how to treat others. Through this socialization with family, a child with DS also will learn how to trust, seek friendships from others, and find comfort with others as well (Children's Bureau, 2017).

In general, the parents of child with DS have to learn how to make and sustain relationships. These skills are started and strengthened with the family. In addition, giving the children the tools for interpersonal development before they learn the skills of technology is vital. These skills can ultimately help the children avoid some of the common effects of technology on children.

Learning how to have face-to-face interactions is also critical in a child's development. Face-to-face interactions require immediate responses, facial expressions, cues, certain tones of voice, and much more that we do not receive through texting or other online message systems. This is exactly what the children with DS is looking to their family to learn. By making sure family members are putting away their smartphones and spending at least a portion of the day "off the grid," it will ensure that interpersonal connection is happening between the parents with their child.

CONCLUSION

A child with DS is a special child that needs special caring and nursing. Down syndrome is also referred to as Trisomy 21, that is an extra copy changes how the baby's body and brain develop, which can cause both mental and physical challenges for the child. Although it could be different things for different people at different stages of life, but being independent whatever it may look like, is an essential component of personal fulfillment, including children with Down syndrome.

This study shows there are some best practice experienced by the parents members DSTAR community to maximize the development of children with DS, especially how to nursing them being independent. Firstly, they care and nurse their child with DS with loving, care, and acceptance. Although it is hard to accept the condition of their child for the first time, but at the next time, they realize that as a parent, they could not refuse their child with DS. Otherwise, they find that loving, care, and acceptance are the main factor in nursing their child with DS. These will help them to cope the challenges they often face in nursing the child with DS that is sometimes may trigger stress and depression.

Secondly, repetitiveness. Parents must be patient in teaching children with DS. They have to repeat intensely since the children with DS have a below-average IQs. The more repetition, the more they can memorize it. So, the next strategy is to practice and repeat one learning materiel more and more, before they learn another materiel.

The next strategy is discipline. Although it is not easy to practice discipline, but one of participants succeed to nurse a child with DS, namely Kidung. Discipline is the best practice to complete such competence, such as self-control, following the some rules, ar also to minimize some actions that potentially endanger herself or others.

Finally, child involvement on family activities is also one of best practices how to raise children with Down syndrome to be independent children. A child with DS can learn through the interactions between the rest members of the family that they will carry for the rest of their life in regards to how to treat others. Through this socialization with family, a child with DS also will learn how to trust, seek friendships from others, and find comfort with others as well.

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