

Early Intervention Program by Utilizing Family Resources to Achieve Autonomy for Children with Autism

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Abstract: Early intervention implementation must be carried out in its natural environment through family empowerment because it is more effective than an early intervention that focuses on children. This condition is based on home and family as a natural environment for children. The intensity of interaction and communication between children and families greatly influences achieving optimal child development. This study aims to optimize children who are known to have risks and children who have definitive obstacles in children aged 0 to 6. The implementation is focused on support, increasing the skills, and other positive aspects that exist in the family. The approach uses a qualitative method with a case study approach. Data collection was carried out through interviews, observation, and document study. The results show an effect of early intervention on the development of children who have communication barriers based on the subject assessment with parents. The conclusion of the implementation of the early intervention program is a change in the family paradigm towards the needs of their children, and the family also begins to understand that their children need a lot of vocabulary to increase their self-confidence.

Keywords: assessment, communication barriers, early intervention.

INTRODUCTION

Autism spectrum disorder (ASD) is an early childhood diagnosis that shows the most significant increase in recent years; its prevalence is estimated at 1 in 59 children (Baio et al., 2018). Parents do not yet know how to meet their child's needs, so parents worry and confuse their children regarding parenting, school, and their future. The efforts of parents have been less productive with their children's special needs so as not to have a significant influence on the child's development. Nevertheless, parents remain confident and expect their children to grow up normally.

The treatment of autistic children aims to overcome the late development following the development of his age. Autism child communication barriers, according to the American Psychiatric Association, 2013 at least show one of the characteristics that are speech delay or completely undeveloped speech ability, can talk. However, his speech is not used to communicate, often issue meaningless words for strange and repeated language. The way of playing is less varied, less imaginative, less able to imitate well. Obstacles in the development of communication in children significantly affect the behavior of the child. To know sooner the child is autistic, the faster the effort will be handled. Early intervention is very important for autistic children so that the treatment is faster and does not take a relatively long time.

Thus the early childhood family counseling model designed to reduce the stress of parenting faced by

families by creating interpersonal relationships, early intervention arrangements, family groups, support services, and home visits as the main pillars, is carried out with an interdisciplinary approach and experts as social support, as well as the responsibility of counselors as the leading and coordinators of all counseling service programs provided and it turns out that the family counseling model setting early intervention can reduce the stress of parenting faced by children with special needs (Sunardi & Sunaryo, 2017).

It is a lifelong challenge for parents in caring for their children who have ASD (Davis & Carter, 2008). Intensive and optimal early intervention can be beneficial for treating autistic children who are usually family-sourced therapies. Parents are the earliest learning facilities for children in the learning process in the developmental age and significantly influence a child's development. Unfortunately, changes will be experienced by many families that cause the family to be in a crisis.

Parents' ignorance about the condition of children with disabilities becomes a significant obstacle in the child's development. Parents who do not have information about the child's development can develop the child's potential. Therefore, parents need to have the ability, skills, and knowledge to provide optimal care to their children, especially for parents with autism. In intervention services for children with autism, family involvement is indispensable so that the intervention process can reach its desired potential. A family-sourced early intervention program is a research factor

to examine the intervene given to children and families so that families have the right and optimal mentoring and nurturing competencies for the development of children. At the same time, the future of autistic children depends on providing optimal therapy and education. Schack (2014) said that children with autistic disorders could perform tasks independently with very limited. As a result, they often rely heavily on teachers and caregivers to complete their daily skills. Dependence on adult encouragement can be a barrier for the child to become self-reliant. However, by using the schedule of daily activities, autistic children can learn to be more independent.

Daily life activities are essential for the life of self-reliance in children and autistic children. Previous research has said that daily life skills should focus on treatment plans for individuals with autistic disorders, especially for future children, as described by Ball et al.(2015). To date, research on parental-mediated interventions has shown that autistic children have high social validity, that is, considered to have relevant and important objectives, adequate procedures, and clinically significant results while also generating satisfaction among all stakeholders (Kazdin, 1997). The lack of parental knowledge and the ignorance of parents about the condition of autistic children are major obstacles in providing family-sourced interventions. Parents' acceptance of the condition of autistic children with their obstacles creates stress for parents to provide family-sourced interventions. Parents who do not have information about the child's development about the difficulty in developing the potential of their child diagnosed with autism. Therefore, parents need to have the knowledge, skills, and abilities in order for them to provide optimal care to their children, especially for parents who have two autistic children in the family.

In family-sourced intervention services for autistic people, family involvement is indispensable because they are longer with their children to reach the desired potential and independence. Therefore, the preparation of this family-sourced intervention program is the focus of researchers to review interventions given to children and families so that families have the right and optimal mentoring and nurturing competencies for the development of children.

The formulation of this study is directed at the "Family-Sourced Intervention Program to maximize the family to achieve the independence of autistic children." Based on the above problems, an intervention service is required in adult autistic people, with the family's implementation process. Because families spend more time with their children at home than at school, and children learn the most important learning from the family.

METHOD

The approach used qualitative methods with a case study approach. Data collection is conducted through interviews, observations, and document studies. This study aims to optimize the development of children who are already known to have risks and children who have definitively had obstacles performed in children aged 0 - 6 years, wherein its implementation is focused on support, improvement of skills/competencies, functions of other positive aspects that exist in the family. This study was conducted by the discrete method of analytics using secondary data obtained from interview reports, observations, and assessment results with families. The data is then processed and analyzed descriptively using logical thinking associated with the concept of public health. Library studies are also conducted to enrich and sharpen the data analysis performed.

FINDING AND DISCUSSION

Finding

The finding of the current study can show in Tables 1, 2, and 3.

From the subject's ADL aspect, only taking off their clothes and using the toilet did not experience any obstacles. However, at the same time, other ADL activities still need to be accompanied and directed.

The condition of the potential family looks father and mother began to show their competence to involve the subject speak so that the subject can boost its development and family know the positive changes taking place in their conditions of potential subjects, it appears the subject began to be able to maintain its focus for 50 minutes on subjects even if they have not been consistent, Blow out the candle well to practice breathing pressure, begin to verbalize the names of objects around him, and can recognize the order of brushing teeth correctly.

Discussion

Based on the findings of observation data and interview results of quality of life and family functioning on actions in conducting early intervention to autistic children, stimulation of the communication development needs of autistic children shows that it takes understanding the concept to educate parents about relationships within the internal scope of the family microsystem to the pattern of early childhood parenting with the need for communication development, utilizing free time in common between father, mother and child with residential and outside settings.

Table 1. Subject ADL Profile Overview

Aspects of ADL	Subject ADL Profile Overview (Actual Condition)	Obstacles Subject Experienced
Independence wash hand	Can prepare equipment for hand washing. (Soap, Towel / Hand Wipe)	Not yet able to wash your hands cleanly, there are still soap vapors on her hands.
Brushing Teeth	a. Can set up and clean the toothbrush. b. Can gargle properly. c. Can re-clean the toothbrush equipment.	Difficulty in putting toothpaste on the toothbrush appropriately, so still need help.
bathe	a. Can prepare clothes and toiletries. b. Can take care of clothes and toiletries again.	The stages of doing a bath still need to be directed. Especially when soaping all over the body.
Undress	a. Can undress the top. b. Can undress the bottom.	No obstacles.
Wearing Clothes	Can wear the bottom and top clothes in the correct position.	When pairing the top, clothes are still having difficulty, so it needs help. Difficulty in determining the concept of front and rear clothing.
Using The Toilet	a. Can perform the steps using the toilet. b. Take the initiative to go to the toilet.	No obstacles.
drink	a. Can drink by using glass. b. Can drink using a straw.	Barriers when drinking are still spilled if directly using glass, but the child can be alone using a straw. However, often when drinking likes to choke.
eat	Can prepare cutlery. However, cutlery is not glassware.	When eating is still fed by parents because the food is still messy

Table 2. Evaluation of the program on the family is seen based on observation, interview, and documentation

Actual Family Condition (Judging by Assessment Results)	Developed Potential	Intervention Program	Potential Family Conditions
<p>Parental acceptance:</p> <p>Parental acceptance of the child is quite good, and this is seen when the parent never hesitates to invite the child to meet a new person (not hiding the child from the outside world) and not expecting too much the child's obstacle. As a result, there is no sense of regret too long and deep.</p> <p>Parental understanding:</p> <p>Understanding parents with suitable hearing barriers look like parents know what autism is</p>	<p>Togetherness:</p> <p>spend more time with the child, follow his development, provide the stimulus needed by the child,</p> <p>Involvement of children in the family:</p> <p>Start involving the child with parental activities so that familiarity is formed that will help the child be more confident to communicate to grow as an individual and social being.</p>	<p>Making a father and subject togetherness has been widely seen, such as diverging every activity that will be done shortly after waking up. However, involving the child in the family is still not very visible because the parent is the subject who has not understood what the parents want to convey. At first, parents are complicated to spend time with the father, Finally, slowly the father and mother begin to show their competence in speaking to the subject, but it is necessary to be consistent in running this until the subject can be independent in understanding the sentences of others</p> <p>Parental competencies to improve the way children communicate</p>	<p>father and subject togetherness has been widely seen, such as diverging every activity that will be done shortly after waking up. However, involving the child in the family is still not very visible because the parent is the subject who has not understood what the parents want to convey. At first, parents are complicated to spend time with the father, Finally, slowly the father and mother begin to show their competence in speaking to the subject, but it is necessary to be consistent in running this until the subject can be independent in understanding the sentences of others</p>

Actual Family Condition (Judging by Assessment Results)	Developed Potential	Intervention Program	Potential Family Conditions
<p>Parenting patterns:</p> <p>Parents have an excellent parenting pattern for the child. Parents have their schedules for children from school to sleep at night.</p> <p>Treatment planning:</p> <p>Parents always discuss what stage of education and what kind of good for the child, discussing the methods of communication that the child will use.</p> <p>Learning and playing environment:</p> <p>Dominant parents allocate children time to learn, while play is only allocated on weekends, even with very little time and little.</p> <p>In the school environment itself, the child is active and fast in capturing learning materials or learning activities that are being done. The teacher responded positively to the child's behavior.</p>	<p>Improving children's competence to increase vocabulary and ADL:</p> <p>Realizing the child's need to communicate is that a mature vocabulary and oral preparation will help parents develop creative ideas of playing and learning to improve the child's vocabulary and independence.</p> <p>Increase the child's confidence to communicate:</p> <p>Inviting children to play and learn together is one way to increase confidence in themselves so that children do not have to be ashamed of their shortcomings.</p>	<p>Reduce maternal concern for children's activities, especially in the case of ADL</p> <p>Involvement of children in the family</p>	<p>At first, the mother was very worried about what was done to her son. Researchers here assessed there were still deep maternal concerns to the subject, but when the subject could produce new vowels, both parents rethink how important oral exercise was. Finally, the mother begins to be seen trying to find a solution so that the subject can suck or smell something through the nose because the subject still has difficulty in sucking through the mouth and nose. Here it appears that the mother began to include herself so that the subject can promote its development.</p>

Table 3. Program evaluation on subjects is based on observations, interviews, and documentation

Subject's Actual Condition (From Assessment Results)	Parents' Expectations of the Subject	Program (Bringing The Subject's Actual Condition Closer to Parental Expectations)	Potential Conditions
<p>Basic skill capability</p> <p>Basic skills to pay attention to the child well enough, sit quietly ± 15 in learning, and pay attention to instructions (communicate) with his parents ± 3 minutes.</p>	<p>Subjects can follow the learning process in school during each lesson hour well, meaning they can focus for 1 hour of a complete lesson without covering their face (a form of boredom of the subject towards something).</p>	<p>Learning to use reinforcement and limiting the duration to use rewards, gradually, the reward is eliminated. Communication uses picture cards in advance so that the child can understand what is communicated so that his attention will last a long time.</p>	<p>Subjects begin to focus for ± 50 minutes on lessons that emphasize reward and vary (this is seen during an intervention at home). However, it can still not be said to be consistent because it has not been able to last for 50 minutes with one homogeneous lesson.</p>

Subject's Actual Condition (From Assessment Results)	Parents' Expectations of the Subject	Program (Bringing The Subject's Actual Condition Closer to Parental Expectations)	Potential Conditions
Oral Motor:			
The oral condition of the child's motor is quite good, the child can chew, puff the cheeks, and blow, but the force of the blow is not strong enough. For imitation, the child can imitate bilabial "pa" with the help of hands touched to the mouth.	The subject can speak "mother," "father," can mention his name "Rasya" if the subject asks for something, the subject can say "ask" or "want."	Oral motor and respiratory exercises: Blow out candles and balloons. Touch the upper lip with the tip of the tongue. Lick the candy. Puffing cheeks. Touching the ceiling with the tip of the tongue. suck smell	The subject can blow out the candle well (the candle used magic candle if blown and there is still coal in the thread of the candle then the fire will be able to live again. Using this candle aims to train breathing pressure on the subject).
Receptive language:			
The child's ability in receptive language is seen to equate the objects in the picture with those around the environment. Can know the functions of familiar objects such as spoons and forks to eat, pencils to write. The child understands by nodding to "yes," shaking to "no."	He can understand the instructions of his parents with	Playing a word card is to paste a picture of an object that corresponds to the object in the bedroom and hint at its function. Identify the images of the commands (show and imitate).	The subject's receptive language looks even better. The subject can attach the original image to objects that match the image, clearly know where the objects are in the house and exempt the names of objects around the house.
Daily Living Activity (ADL):			
ADL capability, children can already do some activities such as preparing hand washing equipment, toothbrush, bathing, undressing. Nevertheless, unfortunately, these activities have been habituated by parents in a polarized time.	Subjek know or know the steps of brushing teeth and bathing	Schedule various activities visualized with images (sequence image of brushing teeth and bathing)	The subject begins to recognize the sequence of brushing teeth by playing sequence cards and then attached to the container that has been provided. The sequence card is marked 1,2, and so on as a sequence code. At first, the child cannot know the correct order in brushing teeth but continues to be introduced and combined with natural objects. Finally, the subject is exciting, and can begin to remember brushing teeth with the parent.

Solving problems through problem solving due to children's development by focusing the impact on children's development, coordinate collaboratively on the role and responsibility of parents in parenting patterns and impacts for child development needs, family behavior control, affective response and engagement, how to communicate with the child, involvement of each internal family member in parenting for child development needs, stimulation through early intervention by parents by providing educational instructions and exercises to parents to help

parents and the developmental needs of early childhood autistic children through family-based expressive developmental intervention programs. The family undergoes a change in understanding /paradigm to realize the need for early intervention for the child and increase confidence with the will always to teach the child to learn the word, eye contact exercises with duration at each level to overcome the development of the child's eye contact resistance, communication skills transfer exercises to change communication behavior, combination communication exercises are

not accompanied by shaking the head. Children are introduced to many different words, starting from one word and combining them into 2-3 words, which the child hopes in the future can be more independent and not dependent on others.

Parent-mediated interventions are one of the strategies that promise to start interventions early and support families while they wait for direct intervention with a child (Green et al., 2017; Ministry of Health & Social Services (MSSS), 2017). The role of the family is very important in the process of child development, especially parents (father and mother) in providing learning experiences to children through family-sourced intervention programs in adult autism. Interventions can help a person experience, organize, understand and respond better to the information he receives from the surrounding environment.

Intervention is a process of mediation between an individual and his environment. Interventions can help a person experience, organize, understand and respond better to the information he or she receives from the surrounding environment. Research on the effectiveness of early interventions against children with autism barriers shows that early intervention effectively develops the child's potential, supports the child's development, and maximizes interaction between family members. Interventions are carried out in the early stages of development of the child (Steiner, Koegel, Koegel & Ence, 2012; Koegel, Koegel, Ashbaugh, & Bradshaw, 2014; Huang & Wheeler, 2006).

Early intervention of family resources provides support and resources shown to families with children with early childhood special needs that directly or indirectly affect children, families, and family functions. The underlying theory is an ecological social system that provides the basis for early intervention in the family environment. In contrast, the theory of social constructivism provides a foundation in stimulating the development of children so that children can achieve optimum development by basing on the concept of the zone of proximal development. Ecological system theory is often conceptualized as a concentric circle with individuals at the center (Graves & Sheldon, 2017).

Ecological theory confirms that the development experienced by an individual is the influence of the environment and the environment closest to the individual that will determine the form of intervention to be given. Family is the first setting for the child to learn how to satisfy his life and face the world. Every child owns learning opportunities in a natural environment, and how the child obtains diverse experiences and opportunities from his natural environment has a significant impact on the child's development.

In the early intervention of family resources, aspects of children's individual development are crucial to note. For example, Chan et al. (2012) explain that the development achieved by a child is the result of learning, not the other way around the development characterized by maturity becomes loaded for learning. Therefore to know and understand the development achieved by a child, it is done by asking the following question: 1) what the child does independently (without help), called actual development, 2) what the child can do but must do with help (potential development), 3) what the child cannot do, despite being given help. It means it is beyond the reach of the child's development.

The American Psychological Association (2016) found difficulties in the expressive language aspects that autistic children experience when expressing what they feel, lack of skill in verbal or non-verbal language, incomplete sentences, facial expressions, minimal gestures, vague arithmetic, and short speech. Beuker supports the results of this study, et al. (2013) explained that although able to talk, but not used to communicate or interact, words and sentences are spoken short or repetition of others when speaking and do not understand spoken language.

The immediate impact that children with autism have on expressive communication difficulties is the opportunity to communicate, recognizing the condition to display appropriate behavior (Ledford & Wolery, 2013). Communication skills are essential for children with autism aged five years, and it is based on milestones language development and communication of the child. Communication is closely related to social interactions between individuals and their surroundings, particularly father-mother parents who are longer with children. Family functioning to the condition of children's expressive development is vital because the function of the family (parents) operationally, namely as the overall welfare of the family unit in the domain of health, competence, conflict, cohesion, leadership, and expression of emotional (Ghazanfar & Sameera, 2016). The influence of the environment in the development of each individual is the result of reciprocal interaction between the individual and the environment that is very influential in shaping the individual. Interaction is defined as mutually influencing activity between internal and external. The concept of individual development occurs continuously, intensively, and continuously in a dynamic and mutually affecting, mutually beneficial process (Somad, 2013).

The ecological theory is the theory that underlies the provision of early intervention programs by involving the closest environmental interactions of children (family-sourced) parents (father and mother) is considered as a microsystem that is the environment in which the individual lives (including individual families, peers, schools, and residential environments).

There is a direct interaction between the child and the parents in microsystems, setting when the interaction process occurs. The child is not a passive recipient but also actively forms a microsystem setting. Children get experience from every activity and have a role in building interpersonal relationships with their microsystem environment (i.e., parents, siblings, friends, and educators). However, this study is more focused on parents.

CONCLUSION

The conclusion of the implementation of the early intervention program is a change in the family paradigm to the child's needs, and the family also understands the child needs a lot of vocabulary and is involved in family activities to increase his confidence. However, further research advice needs to be researched on the effectiveness of early interventions sourced from families in the autistic child.

REFERENCES

- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorder (DSM-5)*, Fifth Edition. American Psychiatric Association (APA)
- American Psychological Association. (2016). Guidelines for the undergraduate psychology major: Version 2.0. *The American psychologist*, 71(2), 102-111.
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., ... Durkin, M. S. (2018). Prevalence of autism spectrum disorder among children aged eight years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *MMWR Surveillance Summaries*, 67(SS6), 1–23.
- Ball, V. H., Kim, S. H., Cheong, D., & Lord, C. (2015). Daily Living Skills In Individuals With Autism Spectrum Disorder From 2 To 21 Years Of Age. *Autism*, 19(7): 774–784.
- Beuker, K. T., Rommelse, N. N., Donders, R., & Buitelaar, J. K. (2013). Development of early communication skills in the first two years of life. *Infant Behavior and Development*, 36(1), 71-83
- Chan, C.K., Zorina, Z.A., Jesse, R.S., & Ornat, S.L. (2012). Lev Vygotsky's Theory of Development
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38, 1278–1291.
- Ghazanfar, L., & Sameera, S. (2016). Coping Strategies and Family Functioning as Predictors of Stress among Caregivers of Mentally III Patients. *International Journal of Clinical Psychiatry*, 4(1), 8-16.
- Graves, D., & Sheldon, J.P. (2017). Recruiting African American Children for Research: An Ecological Systems Theory Approach. *Western Journal of Nursing Research*, 40(10): 1489-1521.
- Green, J., Pickles, A., Pasco, G., Bedford, R., Wan, M. W., Elsabbagh, M., ... Charman, T. (2017). Randomized trial of a parent-mediated intervention for infants at high risk for autism: Longitudinal outcomes to age three years. *Journal of Child Psychology and Psychiatry*, 58, 1330–1340.
- Kazdin, A. E., Holland, L., & Crowley, M. (1997). Family experience of barriers to treatment and premature termination from child therapy. *Journal of consulting and clinical psychology*, 65(3), 453.
- Koegel, L. K., Koegel, R. L., Ashbaugh, K., & Bradshaw, J. (2014). The importance of early identification and intervention for children with or at risk for autism spectrum disorders. *International journal of speech-language pathology*, 16(1), 50-56.
- Huang, A. X., & Wheeler, J. J. (2006). Effective Interventions for Individuals with High-Functional Autism. *International Journal of Special Education*, 21(3), 165-175.
- Ledford, J. R., & Wolery, M. (2013). Peer modeling of academic and social behaviors during small-group direct instruction. *Exceptional Children*, 79, 439-458
- Schack, E. (2014). Promoting independence among individuals with autism spectrum disorders. The Review: *A Journal of Undergraduate Student Research*, 15(1), 23-27.
- Somad, P. (2013). *Teori Ekologi sebagai dasar Pengembangan Keterampilan Komunikasi Siswa Tunarungu Usia Pra-Sekolah*. JASSI_Anakku, 12(1), 97-111
- Sunardi, & Sunaryo. (2017). *Intervensi Dini Anak Berkebutuhan Khusus*. Jakarta: Departemen Pendidikan Nasional.