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ORIGINAL ARTICLE

Family Support For The Independence Of Children With Autism Disorder

FIKA NUR INDRIASARI

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ABSTRACT

Objective: To identify the influence of family support towards children with autism.

Study Design: Descriptive analytic with cross sectional approach.

Place and Duration of Study: This study was conducted for six months from April to September 2020 at Yogyakarta Special School, Indonesia.

Material and Methods: Purposive sampling was used for sampling technique. There were 30 parents of autistic children. Questionnaires were used to obtain data

Results: The study showed that family support influenced autistic children's independence [p value = 0.000 ($p < 0.05$)]. 63.3% of parents or most of the family showed their support, while the percentage of children's independence was 53.3%. It could be concluded that family support influenced the independence level of autistic children.

Conclusion: Support from family, especially their parents are important to build the independence of autistic children. Family support is provided by giving trust to children and providing facilities so children can have their own confidence and autonomy.

Keywords: *Family Support, Children's Independence, Autism*

INTRODUCTION

Children are the biggest gifts to their parents. Their existence is expected, waited and welcomed merrily and happily. All parents expect to have healthy, proud and perfect children, yet sometimes reality is not same as expectations. Some parents have children with special needs, such as children with autism.

Parents of autistic children have a higher level of stress experience compared to parents of other special needs,¹ higher levels of depression,² and more health-related problems.³ Autism is considered as a complex developmental disorder.⁴ Autism is complex because children

with autism spectrum have limitations in social interactions.

Parents of autistic children get many pressures especially from the society in a way that parents feel guilty and are more fragile towards critics on how they should handle problems related to their children. Commonly, the sources of stress in parents of children with ASD include the child's inappropriate and unpredictable behaviors/emotional problems,⁵ severity of the autism symptoms,⁶ as well as financial worries secondary to the need to spend for treatment intervention and education.⁷

Autism spectrum disorders (ASD) are characterized by deficits in social and cognitive

functioning. Many individuals with autism have poor executive functioning within the brain which inhibits their ability to initiate a task, to remain attentive, and to organize and sequence information. Poor executive functioning can also hinder a person's ability to generalize learned skills.⁸

Impairments in the social and communication domain, as well as engagement in restricted, repetitive, and stereotypic behaviors contribute to the challenges around independent performance. Deficits in the areas of joint attention and imitation are well documented and may limit an individual's ability to watch others in an effort to learn skills necessary for independent functioning.⁹ Delayed or limited communication and/or social interest may reduce overall spontaneity in skill demonstration, thus increasing the need for adult prompting and support.¹⁰ Parents' main task is to guide children to achieve full maturity. Independence is really important in children's life. Early training of independence to children will grow their confidence. In addition, children will be more responsible in fulfilling their needs. On the contrary, less independence will make children passive and less creative. Further, they will also be individuals who lack initiatives in conducting activities. Children who are less independent will also be less confident upon their acts, depend more to other people, are doubtful in taking decisions and scared in taking their own responsibilities.

All children have the same right to achieve happiness. It is right for children to have conducive and supportive environment to reinforce their growth and development, including children with autism. The fact shows an opposite reality. Many autistic children are unable to do their daily activities or are dependent in taking care of themselves not because of their disability but because of less supportive environment. Thus, there should be education to family and society so children with autism will be able to take care of themselves.

Social support from family is an aid, motivations and assistance given to individuals when they encounter problems or difficulties, because family also has a role as a resource in growing new strength to individuals. Social Support was found to be a coping mechanism that was frequently

reported in easing parenting stress.¹¹ Some types of social support include actions to give comfort, to take care and to appreciate.¹² If someone gets family support in terms of affection, love, appreciation, assistance and so forth, he/she will feel that the surrounding people are supporting him/her.

Parents who receive a diagnosis of autism for their child are faced with a plethora of feelings and information through which to sort. In the immediate aftermath of receiving a diagnosis, the encouragement and assistance gained through the mutual aid process of a support group can be invaluable in helping parents to get through a challenging time.¹³

Social support provision in families with autistic children will improve family's resilience so it will also provide good coping strategy.¹¹ Formal and informal support towards autistic children will influence their growth and development.¹⁴

Special school Pembina is one of the biggest special schools in Yogyakarta. It has 230 children with special needs as their students. The Initial study conducted to 3 parents of autistic children revealed that their children were not able to do basic self care such as taking a bath, getting dressed and washing hair. Parents told that they had tried their best in teaching them how to do self care but with their children's limited ability and less supportive environment (such as less supportive facility and parents' busy activities), their independence was not built well. Based on the result of the previous study, the researcher wanted to find out the influence of family support towards autistic children.

MATERIAL AND METHODS

The study used descriptive analytic and cross sectional approach as its design. The study was conducted in April – September 2020 at Spesial School Pembina Yogyakarta, Indonesia. The study also used purposive sampling as its sampling technique by looking at data of parents of autistic children based on inclusion and exclusion criteria that were set by the researcher. inclusion criterion was the parents who willing to become responders. Meanwhile, exclusion criterion was the parents who were unable to complete questionnaire or their children did not go

to school during one month. Questionnaires were used as the instrument of the study. The first questionnaire was about family's social support, which consisted of 20 questions using Guttman scale.^{15,16} There were two options to the questionnaire: Yes = 1 and No = 0. Family support was in good category if the score was more than 3. If the score was less than 3, it meant the family support was bad. This family support consisted of four factors: information, scoring, instrument and emotional support.

The second questionnaire was addressed to know the level of independence that children with autism had. It consisted of 15 questions and was measured using Guttman scale^{15,16} by choosing either of the two options: Yes = 1 or No = 0. Children independency was in good category if the score was more than 8. Meanwhile, if the value was less than 8, children independency was weak. There were two data analysis techniques used in this study: regression analysis and partial correlation.

RESULTS

Special school Pembina is one of the biggest special schools in Yogyakarta. There were 230 children with special needs. Thirty of them had autism disorder. Below is the distribution of number based on respondents' characteristics data

TABLE 2: The influence of family support towards children with ASD

Model	Non-standardized Coefficients		Standardized Coefficients Beta	T	Sig
	B	Std. Error			
Constant	4.225	0.887		4.766	0.000
Family support	0.456	0.052	0.856	8.763	0.000

a. Dependent variable: Independence of the child

According to table 2, the value of significance is 0.000 (<0.05). Hence, it can be concluded that there is an influence of family support towards autistic children.

TABLE 3: Cross Tabulation of Parents' Support and Independence of Children with ASD

	Children's Independence		Total
	Good	Fair	
Parents' Support	Good	13	06
	Fair	03	08
Total	16	14	30

TABLE 1: Distribution of number of respondents' characteristic

Respondent	Number	Percentage
Parents' Age		
30-39 years old	11	36.7
40-49 years old	11	36.7
≥ 50 years old	8	26.7
Education		
Under Graduate	11	36.7
Senior High School	13	43.3
Junior High School	4	13.3
Elementary School	2	6.7
Job		
Civil Servant	2	6.7
Employees	4	13.3
Labor	6	20
Entrepreneur	18	60
Parenting		
Parents	26	86.7
Other than parents	4	13.3
Children's Sex		
Boys	25	83.3
Girls	5	16.7
Children's Age		
5-10 years old	11	36.7
11-16 years old	10	33.3
≥ 17 years old	9	30

Based on data on table 1, the majority of respondents' children or 83.3% of them were boys. 36.7% of the children were on a range of 5 - 10 years old.

Based on Table 3, the cross tabulation presented there were 13 parents who showed good support towards their children's independence, while 6 parents showed fair support. On the other hand, there were 3 parents who showed fair support with their children's independence while there were 8 children with fair independence.

DISCUSSION

Autism spectrum disorder (ASD), also known as autism, is a common, highly heritable and heterogeneous neurodevelopmental disorder that

has underlying cognitive features and commonly co-occurs with other conditions. Manifestations of autism include impairments in social communication and interaction, sensory anomalies, repetitive behaviors and varying levels of intellectual disability. Together with these core symptoms. There are co-occurring psychiatric symptoms on neurological disorders are common in people with autism, of which hyperactivity and attention disorders (such as attention-deficit/hyperactivity disorder (ADHD)), anxiety, depression and epilepsy are fairly prevalent. A diagnosis of autism is reached after obtaining a detailed developmental history, often from the parents, and on observation of the individual interacting with parents or other individuals.¹⁷

As shown depend in table 1, most of autistic children or 83.3% of them were boys. The boys were four times more vulnerable to autism compared to girls. Autism is caused by disorders of the development of the nervous system in boys and genetic disorders in girls.¹⁸ Males with ASD are found to show more externalizing behavior problems than females, such as aggressive behavior, hyperactivity, reduced prosocial behavior, and increased repetitive/restricted behaviors and interests.¹⁹

86.7% or most of the parents take care of their children under their guidance. This number indicates good percentage of family support to children for 63.3%. Family support is actions, attitudes and family acceptance towards the sick members of the family.²⁰ Social support is important and is needed for all individuals. One of the forms of environment roles in helping build independence of children with autism is by giving social support. Individuals who receive social support will feel loved, precious and part of their social environment.¹² This is because individuals are part of family, classmates, or other groups. Family is a place of growth and development for individuals. The environment of family directly influences how a child is educated, because children need assistance from their family and other people from the moment they are born and for the throughout their life.

In line with table 1, most of the parents or 60% of the parents were entrepreneurs. Some parents said that they had more flexible time and their job could be done from home so they could take care

and observe their children while working at the same time. In terms of parenting, 86.7% of the parents took care of their children under their guidance. Parenting means parents give responsibility and attention including affection and relationship, material needs such as food, clothing and housing, access of medical need, responsible discipline to avoid accidents and harsh criticism as well as dangerous punishment, moral and intellectual education, and preparations to be responsible as mature individuals upon children's actions towards wide community. Parenting can also be an action or a dynamic process in taking care of children properly. Parenting patterns will form children's independence. Difficulty with independent functioning impacts the overall outcomes for individuals with ASD. Several studies indicate that adults with autism, despite good IQ scores, rely heavily on others for support in employment, living, and relationships. In a study of 68 adults with ASD who had IQs above 50 in childhood, over 50% had outcome described as poor or very poor.²¹ Difficulties in independent functioning also create challenges for young people with ASD in school. In a survey of over 700 school personnel serving students with disabilities in a variety of capacities (teachers, paraprofessionals, administrators), respondents indicated that students with disabilities, including ASD and other impairments, spend more than 86% of their day with a paraprofessional within 3 feet of them.²² Most children or 53.3% of the children in this study had good level of independence. Environment and good parenting enable children with autism to be independent in accordance with their condition and ability.

Independence is not an instant skill but it needs to be taught and trained to children so it will not hinder next child development tasks. Based on table 3, there were 6 children with fair independence despite their good family support. There were some contributing factors to the children's independence: internal factors including psychological and physiological factors and external factors including environment, love and affection, parenting (family support), life experiences. Fair independence of children with autism is also affected by the children's intelligence abilities and social interactions. 2 out of 3 children with autism with bad prognosis are predicted to have a problem with independence.

Children with good prognosis of autism shows progress with social and education domains although there still remains a problem with behavior. Meanwhile, 1 of 4 child with autism has a good prognosis and has a normal or almost normal social life, while 1 out of 10 child with autism can function well both at school and at work. Independence is one of important needs in humans life, and so is with special needs children, especially the autistic children. Children with autism will grow and develop in accordance with their ability and skill if they get education, guidance, direction and intensive training. The level of children's independence is also supported with adequate facilities both at home and at school. Schools have provided lessons about independence each week to help children and identify children's ability including taking care of, organizing of and helping themselves. Parents' stimulus and supporting facilities will encourage independence of children with autism.

In table 1, 43.3% or most of respondents graduated from Senior High School. The parents' education background plays a role in determining children's development. Different level of education causes different level of knowledge. The higher level of education parents have, the easier they get and develop knowledge and technology so productivity is raised and family welfare is also increased. Parents with high level of education will find it easy to receive source of information, change behavior and take decisions in educating their children.

According to statistics test, the result of p value = 0.000 ($p<0.05$), showed that family support influenced children's independence. The value of coefficient correlation between the variable of family support and children's independence was 0.856 with significance value of 0.00 (<0.05). It can be concluded that there was a very strong, significant and positive correlation between the variable of family support and independence of children with autism.

Family support provision has a very great implication on independence of children with autism. Family support is one of contributing factors to children's independence. Family support for children with intellectual disorders plays a very important role in fulfilling psychological needs, improving competence and autonomies to decide

their own future.²³ Parents of autistic children received a higher level of stressor.²⁴ This is in line with the other research which showed that providing education to parents is important to give awareness in providing family support to children by not labeling negatively to their children and changing their mindset that autism is not a mental disease or a type of disability.²⁵

Family support in independence of daily life activities takes an important role because families especially parents are the closest circle the children have. If there is a good family support, children's growth and development will also be improved. Someone who gets good family support will likely be able to face or solve the problems they encounter compared to those who get poor family support.²³ Good family support will influence children's growth and development. Children's independence will be formed through children's characteristics and personalities. Parents' trust in a way of giving chances and responsibilities to their children will create self concept, self esteem and ability to manage themselves. The formation of behavior followed by habituation and support from the people around children will build their independence.

CONCLUSION

Support from family, especially their parents are important to build the independence of autistic children. Parents' education background plays an important role in children's growth and development. The total of 63.3% of the parents has given good family support. Meanwhile, the total of 53.3% of autistic children showed good level of independence. Family support is provided by giving trust to children and providing facilities so children can have their own confidence and autonomy.

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Authors' affiliation

Fika Nur Indriasari,
Pediatric Nursing Department, Stikes Notokusumo Yogyakarta, Indonesia

REFERENCES

1. Kuusikko-Gauffin S, Pollock-Wurman R, Mattila

- ML, Jussila K, Ebeling H, Pauls D, et al. Social anxiety in parents of high-functioning children with autism and asperger syndrome. *J Autism Dev Disord.* 2013;43(3):521–9.
2. Hayes SA, Watson SL. The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *J Autism Dev Disord.* 2013;43(3):629–42.
 3. Giallo R, Wood CE, Jellett R, Porter R. Fatigue, wellbeing and parental self-efficacy in mothers of children with an Autism Spectrum Disorder. *Autism.* 2013;17(4):465–80.
 4. Bashir, U. Bashir, A. Lone ZA. Challenges faced by families of autistic children. *Int J Interdiscip Res Innov* [Internet]. 2014;2(1):64–8. Available from: <http://www.researchpublish.com/download.php?file=Challenges%20Faced%20by%20families%20of%20Autistic%20Children-153.pdf&act=book>
 5. Estes A, Olson E, Sullivan K, Greenson J, Winter J, Dawson G, et al. Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain Dev* [Internet]. 2013;35(2):133–8. Available from: <http://dx.doi.org/10.1016/j.braindev.2012.10.004>
 6. Rivard M, Terroux A, Parent-Boursier C, Mercier C. Determinants of stress in parents of children with autism spectrum disorders. *J Autism Dev Disord.* 2014;44(7):1609–20.
 7. Thomas KC, Williams CS, DeJong N, Morrissey JP. Examination of parent insurance ratings, child expenditures, and financial burden among children with Autism: A mismatch suggests new hypotheses to test. *Pediatrics.* 2016;137(February):S186–95. Hume K, Loftin R, Lantz J. Increasing independence in autism spectrum disorders: A review of three focused interventions. *J Autism Dev Disord.* 2009;39(9):1329–38.
 8. Hume K, Loftin R, Lantz J. Increasing independence in autism spectrum disorders: A review of three focused interventions. *J Autism Dev Disord.* 2009;39(9):1329–38.
 9. Thurm A, Lord C, Lee LC, Newschaffer C. Predictors of language acquisition in preschool children with autism spectrum disorders. *J Autism Dev Disord.* 2007;
 10. Charlop, M., & Haymes L. Speech and language acquisition and intervention: Behavioral approaches. In J. Matson (Ed.), *Autism in children and adults: Etiology, assessment, and intervention.* Belmont: Thomson Brooks/Cole Publishing Co; 1994. 213–240 p.
 11. Xue J, Ooh J, Magiati I. Family functioning in Asian families raising children with autism spectrum disorders: The role of capabilities and positive meanings. *J Intellect Disabil Res.* 2014;58(5):406–20.
 12. Sarafino, E. P. & TWS. *Health Psychology: Biopsychosocial Interactions.* 7th ed. America: John Wiley & Sons, Inc.; 2011.
 13. Banach M, Iudice J, Conway L, Couse LJ. Family support and empowerment: Post autism diagnosis support group for parents. *Soc Work Groups.* 2010;33(1):69–83.
 14. Searing BMJ, Graham F, Grainger R. Support Needs of Families Living with Children with Autism Spectrum Disorder. *J Autism Dev Disord.* 2015 Nov 1;45(11):3693–702.
 15. Maggino F. Guttman Scale: Encyclopedia of Quality of Life and Well-Being Research. In 2014. p. 2626–2630.
 16. Michalos AC. Encyclopedia of Quality of Life and Well-being Research. In: Reference Reviews. 2015. p. 22–22.
 17. Lord C, Brugha TS, Charman T, Cusack J, Dumas G, Frazier T, et al. Autism spectrum disorder. *Nat Rev Dis Prim* [Internet]. 2020;6(1). Available from: <http://dx.doi.org/10.1038/s41572-019-0138-4>
 18. Gamsiz ED, Viscidi EW, Frederick AM, Nagpal S, Sanders SJ, Murtha MT, et al. Intellectual disability is associated with increased runs of homozygosity in simplex autism. *Am J Hum Genet* [Internet]. 2013;93(1):103–9. Available from: <http://dx.doi.org/10.1016/j.ajhg.2013.06.004>
 19. Mandy W, Chilvers R, Chowdhury U, Salter G, Seigal A, Skuse D. Sex differences in autism spectrum disorder: Evidence from a large sample of children and adolescents. *J Autism Dev Disord.* 2012;42(7):1304–13.
 20. Friedman, M. M., Bowden, V. R., & Jones EG. *Family Nursing Textbook.* 5th ed. Jakarta, Indonesia: EGC; 2014.
 21. Howlin P, Goode S, Hutton J, Rutter M. Adult outcome for children with autism. *J Child Psychol Psychiatry Allied Discip.* 2004;45(2):212–29.
 22. Giangreco MF, Broer SM. Questionable Utilization of Paraprofessionals in Inclusive Schools: Are We Addressing Symptoms or Causes? *Focus Autism Other Dev Disabl.* 2005;20(1):10–26.

23. Taylor WD. A family systems perspective on supporting self - determination in young adults with intellectual and developmental disabilities. *J Appl Res Intellect Disabil.* 2019;(January):1116–28.
24. Krishnamurthy V. A clinical experience of autism in india. *Journal of Developmental and Behavioral Pediatrics.* 2008. p. Vol.29, No.4.
25. Selman LE, Fox F, Aabe N, Turner K, Rai D, Selman LE. ' You are labelled by your children ' s disability ' – A community-based , participatory study of stigma among Somali parents of children with autism living in the United Kingdom Kingdom. *Ethn Health.* 2017;7858(March).