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## The Family Role in Fulfilling the Activities of Daily Living (ADLs) among Children with Autism Spectrum Disorder



Suprajitno<sup>1</sup>, Frizcha Illah Arisky<sup>2</sup>

<sup>1</sup>Nursing Department of Poltekkes Kemenkes Malang, Indonesia

<sup>2</sup>Nurse Practitioner of Public Health Center of Blitar City, Indonesia

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### Abstract

Children with autism spectrum disorder (ASD) have difficulty of activity and readability so that dependently to a parent or others. The study purpose to describe the family role in fulfilling of the Activities of Daily Living (ADLs) for children with ASD who gets service at Autism Center of Blitar City (Bahasa: Pusat Layanan Autis Kota Blitar). The study used descriptive-survey as a design to determine family roles among ASD children, the researcher purposively selected 34 families to be part of the study. Questionnaires were developed inspired by the theory of basic human needs and self-care and underwent validity and reliability tests. This study result showed that the family role in fulfilling the ADLs for children with ASD in the good category as many as 67.6% (23 families), in enough category as many as 29.4% (10 families), and in less category as many as 3.0% (1 family). Fulfillment of ADLs for children with ASD who need attention is the fulfillment of nutrition because parents must ensure that food that has entered into the mouth should be swallowed. Results also found out that inadequate nutrition affects child's with ASD growth and development. The study strongly recommends the roles of parents as vital in meeting the needs of the children and stimulates development.

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✉ Correspondence Address:

Poltekkes Kemenkes Malang - East Java, Indonesia

Email: [bedonku@gmail.com](mailto:bedonku@gmail.com)

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## INTRODUCTION

Children with special needs are children who are significantly experiencing abnormalities or deviations (in terms of physical, intellectual, social, emotional, and neurological sensory) in the process of growth or development compared with other peers (normal children) so they need a special education. Children with autism spectrum disorder (ASD) needed a special education (Ginintasaki, 2016: 35). The term autism derived from an auto which means yourself, which means a stream; if combined means a tenet that is interested only in his own world (Ginintasaki, 2016: 37).

The ratio of normal children and children with ASD di United States as many as 1: 150, in England as many as 1:100, and in Indonesia data is not accurate. Predictions of autism patients in Indonesia from year to year increasing. Children with ASD is estimated that one per 5.000 children in 1990, the year 2000 increased to one per 500 children, the year 2010 is estimated that one per 300 children, and in 2015 it is estimated that one per 250 children (Hasdianah, 2013: 71). Autism people in Indonesia in 2015 more than 12,800 people and was predicted more or less 134.000 peoples with ASD (Labola, 2018).

Children who have been diagnosed autism more visible emotional, characterized by the presence of disorder and delays cognitive, language, behavior, communication, and social interaction. Activities of Daily Living (ADLs) in the children with special needs including children with ASD often referred to term of Self-Establishment (Fadhli, 2010). The family function was to provide an environment that improve the personality development naturally to protection psychological steady. Therefore, the family role here is very important in fulfilling the Activities of Daily Living for children with special needs in order to be an independent.

Independence of children with ASD is required as a provision for the development of adult life in order to have minimal dependence to people around. The study was described the family role in fulfilling the Activities of Daily Living (ADLs) of children with Autism Spectrum Disorder (ASD).

## METHODS

The study used descriptive. The subject study was all family that has a child with ASD who gets service at Autism Center of Blitar City as many as

34 families and selected using the total sampling technique. Data collection used questionnaire which was developed based on the theory of the basic needs of human life, especially self-care. The inclusion subject were families with children with ASD aged 2-17 years, children with ASD live in the same house, and live in Blitar City. The data was collected at Autism Center of Blitar City and family home on 29 March - 29 April 2017. Data analysis used descriptive.

## RESULT

The characteristic of parents and children with ASD who gets service in Autism Center of Blitar City presented in Table 1.

**Table 1 Characteristic family and children with ASD who gets service in Autis Center of Blitar City in May 2017 (n=34)**

No	Characteristics	f	%
1	Gender of subject:		
	Man	27	79.4
	Women	7	20.6
2	Age of child:		
	2-5 years old	9	26.5
	6-10 years old	21	61.8
	>10 years old	4	11.8
3	Age of parent:		
	21-40 years old	30	88.2
	41-65 year old	4	11.8
4	Parents education:		
	Junior School	3	8.8
	Senior School	20	58.8
	College	11	32.4
5	Parents occupation:		
	Retired	1	2.9
	Farmers	3	8.8
	Entrepreneur	21	61.8
	Civil Servants	4	11.8
	Housewife	5	14.7
6	Number of children:		
	1 child	9	26.5
	2 child	18	52.9
	3 child	7	20.6
7	Birth order of children:		
	1st child	18	52.9
	2nd child	13	38.2
	3rd child	3	8.8
8	Who is a role in fulfilling the ADLs:		
	Father	3	8.8
	Mother	31	91.2
9	Family ethnic: Javanese	34	100,0

The family role in fulfilling of the Activities of Daily Living (ADLs) presented in Table 2 and 3.

**Table 2 Family role category who is fulfilling the ADLS to children with ASD in May 2017 (n=34)**

No.	Role category	f	%
1	Good	23	67.6
2	Enough	10	29.4
3	Less	1	3.0
<b>Total</b>		<b>34</b>	<b>100.0</b>

**Table 3 Type of the ADLs fulfilled by parents to children with ASD who gets service in Autism Center of Blitar City in May 2017 (n=34)**

Type of ADLs	Fulfillment category						Total	
	Good		Enough		Less			
	f	%	f	%	f	%	f	%
Bath	32	94.1	2	5.9	0	0.0	34	100,0
Dress up	25	73.5	6	17.6	3	8.9	34	100,0
Eating / drinking	17	50.0	12	35.3	5	14.7	34	100,0
Toileting	26	76.4	5	14.7	3	8.9	34	100,0

contact with the child, as a housewife, nanny, child educator, and the main protector for the child (Suprajitno, 2004; Setiadi, 2008). Also, the mother escorted and accompanied the child with ASD for therapy and school (Muliana, et al, 2014). Thus, mothers have an active role in managing all household needs including caring for children. According to researcher assumption, that mother is more dominant to care and educate children with ASD, especially if get support from family member including the husband.

Based on the results of the study of 34 families, obtained the result that more than half of the autistic children's work is autonomous entrepreneurs 61.80% (21 respondents).

According to Friedman (1998: 311) social class backgrounds affect the structure of informal and formal roles in the family. Based on the results of Muliana's research, et al (2014) it is said that parents working in the private sector have more working hours than parents who work as civil servants. It can indirectly affect the quantity of interaction between parent and child. According to the researchers any work done by parents, will affect

## DISCUSSION

Around two-thirds (68%) of families have a good role in ADLs fulfillment for children with ASD, this condition reflects the attention, love, and affection of the family (parents and siblings) (Rachmayanti, 2007). The affection is needed by children with ASD because an affection is a mental development nutrient and greatly helps to grow optimally (Napolion, 2010).

As many as 91.2% who roles to fulfilling of ADLs to children with ASD is the mother (table 1). The reason is that the mother has enough time to

the role given to the child, especially families who have children with autism will need a deeper role in caring for children.

Based on the results of the study of 34 families almost entirely 94% of families have a good role in the fulfillment of ADLs autistic children, especially in the needs of bathing/hygiene. According to Wilkinson in Boham (2013) bath/hygiene is the ability to perform or meet the activity of bath/hygiene. Among them: a) Taking toiletries, b) Entering and exiting the bathroom, c) Obtaining or providing water, d) Cleaning body or limbs, e) Drying the body. According to researchers this is due to children with autism, the ability to care for self is reduced and need help to do so the family care and help autistic children to fulfill the ADLs fulfilled independently.

On the parameter second, of 74 percent of the families have a role in enough in fulfilling ADLs children autism in terms of dress. According to Wilkinson in Boham (2013) dress/ornate is a the ability to meet the activity of getting dressed complete and ornate self. Including: a) take or replace clothing, b) with clothes on the upper body and the bottom, c) take off the clothes. 9 percent

the role of family that have children with ASD lacking in the fulfillment of ADLs in terms of dress, according to researchers children autism are running into problems in garments, as in terms of buttoning the buttons, it or close resetting in pants, so the role of family is needed to make the fulfillment of ADLs children autism met independently.

On the parameter third, of 50 percent of the families have an important role lacking in the fulfillment of ADLs children autism in terms of to drink. According to Wilkinson in Boham (2013) eat/drink is the ability to meet or sufficient activity eat/drink. Including: a) food prepared for of ingesting, b) holding cutlery, c) bribing food from the mouth, d) chew food, e) swallow food, f) finish eat, g) take cup or glass. Fifteen percent the role of family whose children had autistic lacking in the fulfillment of ADLs in terms of eating and drinking, according to researchers autistic child there has been so much understand it really in the use of a spoon to eat, while for the portion of eating which are chewed and swallow as food that is in the mouth, autistic child was already able to gauge for how food needed to get in the mouth to be chewed and swallowed. While the autism are more understand in terms of eating/drink, families however have an obligation to ever and help meet ADLs the autism that met independently (Suprajitno & Aida, 2017).

On the parameter last, of 76% of families have the role of good in fulfilling ADLs children autism in terms of toileting. According to Wilkinson in Boham (2013) toileting that is making or furnish activities elimination. Including: a) to put the small or performs activities elimination, b) take off the clothes when elimination, c) purge away after elimination, d) with clothing after elimination, e) flush a toilet. Nine percent the role of family that have children autism lacking in the fulfillment of ADLs in terms of toileting, according to researchers family need to remind and set an example to the autism about flush a toilet after use, that the toilet clean and the after use.

## CONCLUSIONS

Based on the research done can researchers concluded that the role of family in fulfilling ADLs children autism in Autism Centre City Blitar have an important role good is as much as 68%, a 29% having a level the role of enough, and 3% have an important role less. The role of family less because children autism has been able to perform ADLs

independently but still in supervision family.

The role of family in fulfilling ADLs children autism based on parameter as a whole is good which includes help, guide and teach children autism in terms of bathroom/hygiene of 94%, dressed/ornate of 74%, to drink of 50%, and toileting 76%.

## SUGGESTIONS

(1) For the center autism City Blitar increase counseling and observation about knowledge and the act of the fulfillment of ADLs (Activity the Daily Living), so that it can be developed into therapy next on independence child in ADLs (Activity the Daily Living) that involves the family of a autism so can increase a generation of kids able autism to daily activities. (2) For other researcher it was expected that the result of this research can be used as a baseline for do further research about the effort that families make in improving the ADLs (Activities of Daily Living) the child is autistic, and of factors affect the family in the fulfillment of ADLs (Activities of Daily Living) the child is autistic .

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