

# Value of Children in Mother's with Autism Spectrum Disorder Children

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***Abstract** - Value of children is the perspective of the parents. This study aims to see the value of children mother's children with autism spectrum disorder (ASD). The method used is quantitative with descriptive techniques. There were 30 participants in the study using convenience sampling technique. The characteristics of the participants needed are mothers of children with autism spectrum disorder who are Javanese. The results of normality with an asymp value = 0.00 ( $p < 0.05$ ) stated that the data are not normally distributed. The results of the value of children for mothers of children with autism spectrum disorder are the family dimension, where parents give more social support and siblings give more empathy for their sibling with ASD. The presence of children with ASD can increase parental responsibilities such as parents being disciplined with household chores to ease the burden on the family. Parents are becoming more frequent interacting with children with ASD to provide stimulus to their children with ASD.*

**Key words:** *value of children, autism spectrum disorder, mother*

## INTRODUCTION

Research on life expectancy in Sweden explains that the life expectancy of people with children is higher than those who do not have children (Modig, Talback, Torssander, & Ahlbom, 2016). The risk of death for men aged 60 years who do not have children is as much as 1.41% and those with children is 1.24%. Meanwhile, the risk of death for women aged 60 years with children as much as 0.68% and those who have children as much as 0.52%. This is due to social support between parents and children, the life expectancy of people who have children is higher than those who do not have children (Modig, et al., 2016).

The results of research conducted by Srisusanti and Zulkaida (2013) stated that the existence of children in addition to influencing life expectancy, it also affects marriage satisfaction. The absence of offspring can lead to estrangement in the household, and even lead to divorce. In this condition, the position of women is on the weak side and is often cornered as the cause of

domestic problems, the wife is suspected of being the party experiencing infertility (Srisusanti & Zulkaida, 2013), therefore the existence of children is considered valuable in married life.

Children can improve the psychological well-being and self-esteem of their parents (Nauck, 2014). This is also explained in the value of children theory regarding how parents perceive the presence of children in their parents' lives (Prasanti, 2013). The perspective of parents towards children can be explained in the dimensions of the value of children. The dimensions of value of children consist of emotional, normative economic, family, and old age dimensions (Mayer, Albert, Trommsdorff, & Schwarz, 2005). In the first dimension, namely emotional, parents place more emphasis on emotional bonds with children through thoughts and feelings while interacting with children (Nauck, 2014). This emotional dimension can be shown by expressing the feelings of parental love for their children, and the feeling of satisfaction of parents seeing the child's development (Mayer, et al, 2005). The second dimension is the normative economic dimension, in this dimension parents expect their children to contribute to the family economy, by the way children work to get the family's economic income (Nauck, 2015) besides that children can also continue their offspring (Mayer et al., 2005). The third dimension is the family dimension which emphasizes the importance of the family due to the presence of children (Mayer, et al., 2015). This family dimension brings parents and family closer together, increases the sense of responsibility and communication between parents and children becomes more frequent. The fourth dimension is the dimension of old age, where parents expect their children to help their parents when their parents have entered old age, so they do not feel alone in their old age.

The perspective of parents according to the value of children can be influenced by the culture adopted by the parents, socioeconomic status, the sex of the child and the number of children in the family. (Thomson, 2015). Cultural values consist of knowledge, beliefs, arts, morals, laws, customs and other abilities experienced and studied by a particular society (Prasanti, 2013). In the research of Kagitcibasi and Ataca (2015), it is stated that families with the dimensions of the value of children in old age have a dependency on the loyalty of children and collective culture. Countries with a collective culture such as Turkey, Indonesia, the Philippines, Thailand and Taiwan have a higher dimension of value of children in old age than countries that do not have a collective culture such as America and Germany (Bulatao, 1979; Darroch et al., 1981; Fawcett, 1983; Kagitcibasi, 1982; Kagitcibasi & Ataca, 2015).

According to (Hoffman & Hoffman; Kohlman, 2002; Prasanti, 2013), the value of children is influenced by socioeconomic status. Low socioeconomic status makes parents expect their children to work and earn income to meet the family's financial needs. The value of children from parents who have low economic status tends to be a normative economy. Parents with high economic status tend to have their financial needs met, therefore parents do not expect their children to help the family economically, because these parents tend to be on the emotional aspect.

The value of children is influenced by the sex of the child (Thomson, 2015). Overall, parents have the same level of expectation between boys and girls. Parents perceive the roles of boys and girls as different. Boys are given a heavier burden to improve the family economy than girls, therefore the value of children in boys tends to be a normative economy. Girls are better prepared to manage the household than boys (Thomson, 2015).

The number of children in the family will affect the value of children (Thomson, 2015). Each additional child in the family will affect the amount of family expenses, either in the form of finances or time spent with the child. Therefore, the more children in the family, the family expenses will also increase. Therefore, parents hope that their children can contribute financially to the family.

The value of children or the perspective of parents will affect the parenting style of parents to children (Prasanti, 2013) and planning for their families (Nauck, 2014). The parenting style that is formed is not only based on the parents' point of view, but also involves the conditions of the child. This is explained by Darlig and Steinberg's (1993) research that parenting is an arrangement for children based on the concepts that parents have for their children and that adapt to the needs of the child (Bibi, Chaudhry, Awan & Tariq, 2013). This statement reflects that each child has different needs, therefore the researcher wanted to focus on children who have certain characteristics and needs.

There is qualitative research on the value of children in children with special needs (Suparmi, 2016). First value of children in children with special needs, namely emotional. Parents see their child as valuable and still accept their child even though the situation is different from other children. The second value of children is religion as parents view their children with special needs as a gift. The third value of children is family, namely children as encouraging parents to continue working. There are different things between Suparmi's research results compared to

Hoffman and Nauck's previous theories, because in Suparni's research there was a religious value in the perspective of Indonesian parents, especially Javanese.

The research conducted by Suparni was not specific to one diagnosis of children with special needs, considering that each diagnosis of children with special needs had different abilities. As written in DSM V regarding children with attention deficit / hyperactivity disorder who have barriers to focus, hyperactivity and impulsiveness (Hoeksema, 2014). Children with autism spectrum disorder have barriers to social interaction and engage in repetitive behaviors. Children with intellectual disabilities have weak intellectual abilities such as problem solving, planning, and abstract thinking. These different abilities ultimately make children's needs different, thus requiring different parenting styles. Darlig and Steinberg explain that parenting is also related to children's needs (Bibi, et al., 2013).

Individuals with autism spectrum disorder (ASD) have characteristics that are difficult to meet the dimensions of the value of children. This is made clear in research conducted by the National Autistic Society (Griffths, Giannantonio, Hurleyhanson and Cardinal, 2016) which states that 85% of individuals with autism spectrum disorder cannot be financially independent, where individuals with ASD have limited communication and interaction at work. (Paul, Laird, & Tune, 2016). These limitations will prevent the individual from conducting an interview when applying for a job, because at the time of the interview he will be asked about the behavior of the prospective worker in certain situations or behavior that has already been done (Campion, Campion, & Hudson, 1994; Paul, et al., 2016). Meanwhile, individuals with ASD find it difficult to project themselves into situations that are not real (Tickle, 2009; Paul, et al., 2016), so they require greater effort. Therefore, individuals with ASD will find it difficult to meet the normative economic dimensions according to the expectations of parents so that their children can contribute to family finances.

Individuals with ASD have neurodevelopmental barriers in communication interactions, making it difficult for children with ASD to interact with others (World Health Organization, 2013). Children with ASD also find it difficult to smile and laugh in social situations (Pullen, 2014). This can be an obstacle for children with ASD in fulfilling the emotional and family dimensions. The emotional dimension according to Nauck (2014) emphasizes the emotional bond between parents and children, and the thoughts or feelings of parents during their interaction with

children. The family dimension also requires interaction between parents and children; therefore, the difficulty of this interaction can be an obstacle in fulfilling the emotional dimension.

Individuals with ASD have obstacles in focusing their minds, receiving and processing information, conveying and regulating emotions (Bruggink in Griffiths, et al., 2016), while this ability is an asset to help others. With these obstacles, it makes it difficult for children with ASD to help others, therefore individuals with ASD will find it difficult to fulfill the dimensions of old age. Because the dimension of parenthood emphasizes children to help their parents when their parents have entered old age and do not feel alone in their old age (Mayer, et al., 2005)

According to research by Rapin & Tuchman (2008) in children with mild spectrum ASD, children are less able to socialize and communicate. Children with mild spectrum ASD are more sociable than those with moderate and severe levels (Shardell, 2013). Children with ASD at moderate levels tend to have a diagnosis of intellectual disability, depression, anxiety problems, compared to mild levels (Zablotsky, Bramlett, & Blumberg, 2016). The heavier the spectrum on ASD, the higher the level of intellectual problems, conduct problems and levels of anxiety (Zablosky, 2016).

According to the results of research by Sharabi and Marom-Golan (2018), it is known that mothers are more involved with children with autism spectrum disorder than fathers. Mothers participate more in child therapy and are more active in playing with their children than fathers. Mothers are also more responsible for parenting than fathers. Besides that, the mother is also the main caregiver for her child (Koydemir & Tosun, 2009; Jose, Gupta, Gulati, & Sapra, 2017; Desiningrum, Suminar, & Surjaningrum., 2019).

The role of mothers in families with children with autism spectrum disorder is to create a framework for family structure (McAuliffe, Thomas, Vaz, Falkmer, & Cordier, 2019). Mother makes plans every day, for example, find a therapist and a therapist schedule. Lack of mother's contribution to the family makes the family situation less orderly. Based on these reasons, the researcher wanted to see the value of children in mothers, because mothers understand their children's development better than fathers.

In Indonesia, the number of children with autism spectrum disorder is quite high (Desiningrum, et al, 2019). In 2010 it was estimated that the number of children with ASD were

90,000 with ages 5 to 14 years and in 2015 it increased to 134,000 people. Departing from the above phenomena, the formulation of the problem in this study is "how the value of children to mothers of children with autism spectrum disorder"

## **RESEARCH METHODS**

A quantitative research method was used in this study. Quantitative research methods identify problems based on phenomena in the field or require an explanation for the reason why such phenomena happen (Creswell, 2012). This study used a survey method, namely a quantitative method procedure that was administered to a sample to identify phenomena, attitudes, opinions, behavior or characteristics of a group of people without predicting the results of the study (Creswell, 2012). The results of this study would reveal mothers' opinion about their children with autism spectrum disorder. The type of survey used in this study was a cross sectional survey design in which the data collection was done once without collecting data at a later date (Creswell, 2012).

This study used surveys because the researchers wanted to identify the value of children or mothers' opinions about their children with autism spectrum disorder. Descriptive quantitative method was applied in this study. Descriptive quantitative method was used to describe the variables under study in numbers without being manipulated and to draw conclusions based on the phenomena that occurred when the study was carried out (Arikunto, 2006; Putra, 2015). The variable under study was the value of children in mothers of children with autism spectrum disorder. The study used the value of children instrument with 12 items, each item consisting of a scale of 1 indicating "very inappropriate" to 5 indicating "very appropriate".

The operational definition of the value of children in mothers of children with autism spectrum disorder regarding the emotional, normative economic, old age and family dimensions was identified by calculating the mean of each domain on the value of children questionnaire. The sample needed in this study was mothers who have children with autism spectrum disorder who were cultured and adapted Javanese cultural upbringing. It is because the researchers narrowed down the characteristics of the participants.

The data in this study was collected using non-probability sampling, in which the researchers select the participants in an easy way and the participants are willing to become participants and according to the characteristics required by the study (Creswell, 2012). The

approach used was convenience sampling, a technique to select participants in which those participants are willing and capable to be participants. The researchers collaborated with Autisma Indonesia Foundation, Cinta Harapan Indonesia Foundation, and the Buah Hatiku Therapy Center to distribute the questionnaires. The distributed questionnaire was in the form of a link, so that the participants could fill in the link without having to communicate directly with the researchers.

## RESULTS AND DISCUSSION

The data were collected on April 23, 2020 to May 9, 2020. The participants were 30 mothers who have children with *ASD* with an age range of 20 to 59 years, mostly in the age range of 40 years to 44 years. Regarding the demographic data on the number of children, the participants were classified into two groups, namely the participants who had one to two children and the participants who had more than two children. Based on the data collected, there were 56.66% of participants or as many as 17 participants who had one to two children, while the remaining 13 participants or 43.33% of participants had more than two children.

*The Number of Children Participating Distribution*

No	Number of Children	Total	Percentage (%)
1	1-2	17	56,67
2	More than 2	13	43,33
Total		30	100

The demographic data on socioeconomic status can be determined using a socioeconomic status questionnaire. The questionnaire has 21 questions, with each question having 4 multiple choices. Therefore, the value of the lowest socioeconomic status was 21 with 1 x 21. The highest socioeconomic status was 84 because it is 4 x 21. The data diversity is indicated by the standard deviation of 10.52. Based on demographic data, the lowest socioeconomic status was 54 and the highest was 89. The average socioeconomic status of the participants was 71.23. The average value on socioeconomic status was classified into the category of moderate socioeconomic status.

*The Distribution of Mothers' Socioeconomic Status of Children with Autism Spectrum Disorder*

No	Interval	Category	Total	Percentage (%)
1	54-65,6	Low	12	40
2	65,7-77,3	Moderate	8	26.67
3	77,4-89	High	10	33.33
Total			30	100

Based on demographic data, as many as 16.67% of participants or five participants have daughters with *ASD*. The remaining 83.3% of participants or the same as the other 25 participants have sons with *ASD*. The researchers made groups of participants based on the spectrum in children with *ASD*.

*Children' Gender Distribution in the Study*

No	Gender	Total	Percentage %
1	Male	25	83,33
2	Female	5	16,67
Total		30	100

The researchers divided the spectrum into mild, moderate and severe as in Zablotsky (2016). Based on demographic data, there are 40% or as many as 12 participants who have children with mild spectrum *ASD*. The participants who have children with moderate *ASD* spectrum are 50% or the same as 15 participants. There are 10% or as many as three participants who have children with heavy spectrum *ASD*.

*The Distribution of Spectrum in Children with Autism Spectrum Disorder*

No	Spectrum	Total	Percentage (%)
1	Mild	12	40
2	Moderate	15	50
3	Severe	3	10
Total		30	100

The results of this study showed that the value of children in mothers who have children with autism spectrum disorder was family. It is because the majority of mothers who have children with ASD, namely 46.67%, emphasize the family dimension more than the other three dimensions, namely emotional, economic and old age. Because the value of children in mothers of children with ASD is family, the presence of children with ASD makes the family more meaningful, strengthens relationships within the family and increases parental responsibilities.

*Value of Children Distributing in Mothers of Children with Autism Spectrum Disorder*

Value of Children Dimension	Participants' percentage	Total Participants
Family	46,67 %	14
Emotional	40%	12
Economic	6,67 %	2
Old Age	6,67 %	2
<b>TOTAL</b>	<b>100%</b>	<b>30</b>

The researchers also found that there was no difference between low, moderate, and high socioeconomic status with the value of children in mothers of children with autism spectrum disorder. Regarding the gender of the children, the number of children and the spectrum of children, there was no difference with the value of children in mothers who have children with autism spectrum disorder.

**CONCLUSIONS AND SUGGESTIONS**

This study revealed that the value of children in mothers of children with autism spectrum disorder was family. The value of children with the family dimension indicates that parents interact more frequently with children (Mayer et al., 2005). It is in line with a study conducted by Chodidjah and Kusumasari (2018) revealing that mothers who have children with ASD often

interact with them by encouraging the children to sing and talk in order to provide stimulus to the children. Children with ASD who have difficulty in interacting with others make mothers the first individuals and most often encourage the children to interact compared to others (Barnes, Hall, Roberts, & Graff, 2011). This makes children with ASD have the strongest attachment to their mother.

The family dimension of the value of children shows that children can increase parents' responsibility (Mayer, et al., 2005). A study conducted by Boyd (2012) has revealed that the presence of children with ASD in the family makes parents more responsible, especially in terms of household activities (Meadan, Halle, & Ebota, 2010). In addition, the results of a qualitative study have shown that the presence of children with ASD makes mothers enthusiastic to recover from illness so that they can take care of their children (Barnes, et al., 2011).

The family dimension in the value of children shows that the presence of children can strengthen family relationships (Mayer, et al., 2005). Families that are able to be strong enough to accept the condition of children with *ASD* are proven to be stronger families (Meadan, et al., 2010). The family will provide mutual support so that they can reduce anxiety about childhood with *ASD*. The relationship between parents will also be stronger because parents provide social support to each other (Ilias, Cornish, Kummer, Park, & Golden, 2018). Social support from partners is the most important thing compared to social support from other parties.

The presence of children with *ASD* in the family can strengthen the relationship between siblings. The siblings of children with *ASD* become more empathetic, such as they are more worried that something bad will happen and will be more patient in teaching their siblings with *ASD* (Barnes, et al., 2011). The siblings of children with *ASD* show that they do not want to be separated from their siblings and love their siblings with all the conditions of children with *ASD* (Hartman, 2012).

A study conducted in Yogyakarta involving the participants with Javanese culture revealed that Javanese people have a collective culture (Nashori, Iskandar, Setiono, Siswandi, & Andriansyah, 2009). This collective culture allows individuals to maintain their relationships with family, friends, and other individuals in their environment. Collective culture with the value of children in terms of the family dimension has the same meaning, namely maintaining relationships

with the family. Therefore, this study focused on the value of children of Javanese cultured mothers who emphasized on the family dimension.

Studies on mothers who have children with autism spectrum disorder have revealed that the old age and economic dimension are the least prominent. The dimension of old age according to the value of children theory is the hope of parents so that their children can help them in old age (Mayer et al., 2005), while children with ASD are difficult to be independent, so that the expectation of mothers to their children to help them in old age is difficult to fulfill. According to the National Research Council in a book entitled *Educating Children with Autism*, independent ability is doing one's own job and carrying out instructions without help from others (Hume, 2004). Studies from various countries focused on participants with autism spectrum disorder, intellectual disability, learning disabilities and emotional disturbances revealed that individuals in young adults with ASD are individuals who live with their parents or guardians the most when compared to other disabilities (Heasley, 2013). Individuals with ASD are the most supervised and the fewest individuals who live independently after completing their studies. Difficulties in terms of independence may make mothers who have children with ASD difficult to hope that their children will be able to help them in old age.

The economic dimension of the value of children was not prominent compared to the family and emotional dimensions of mothers who have children with ASD. The economic dimension shows that parents expect their children to contribute financially to the family (Mayer, et al., 2005). A study conducted by the National Autistic Society (2016) has revealed that 85% of individuals with autism spectrum disorder cannot be financially independent, but 69% of them want to be able to work (Paul, et al., 2016). The salaries of individuals with ASD are lower than those of other employees. Individuals with ASD also have greater challenge to become employees than individuals with non-ASD. This is what makes parents of children with ASD worry about their children's future, especially regarding their children's ability to live financially independently. For these reasons, mothers of children with ASD do not show the economic dimension of the value of children.

Based on the results of the chi-square statistical test, there was no categorical difference in the value of children for mothers of children with autism spectrum disorder. There was no difference in low, moderate and high socioeconomic status with the value of children for mothers

who have children with ASD, as well as for the gender of the children, the number of children, and the spectrum. This is because there may be other factors that influence the value of children, such as beliefs and information obtained (Fawcett, 1973; Kagitcibasi, 1982; Nauck, 2014).

The variations affecting the value of children have each other's dynamics. Based on the value of children theory, increasing the number of children will increase the number of parents' financial expenses so that they hope their children will contribute to their family economy (Thomson, 2015). For example, the economic burden of a family with a large number of children with high family socioeconomic status will be lighter than a family with one child with a low socioeconomic status. It could be concluded that the category of the number of children cannot stand alone, because it depends on the socioeconomic status of the family.

This study has some weaknesses regarding the understanding and implementation of the culture. Therefore, the researchers only focused on mothers of children with ASD who are Javanese. It was done because the researchers wanted to narrow the scope of the study. The researchers also did not examine the level of understanding and implementation of cultural values held by the participants. Therefore, this study does not describe the influence of culture on the value of children of the participants, because each participant has a different level of understanding about Javanese culture.

Further, this study linked the spectrum with the value of children in mothers of children with autism spectrum disorder. The spectrum was illustrated in the demographic data. The researchers only provided mild, moderate, severe and unknown answer choices without explaining the indicators on each spectrum, so that the participants could be wrong in determining the spectrum since the spectrum in children with ASD can change along with the children' development.

One item on the value of children instrument and five items on the socioeconomic status instrument were stated not reaching the minimum value of validity, because the participants answered on the same scale. The validity test is used to test whether the item used can measure the construct to be tested (Nunnally & Bernstein, 1994). Thus, it can be said that items that do not pass the validity test cannot be used to test the construct to be used and the items cannot describe the value of children as well as the participants' socioeconomic status.

Invalid item on the value of children instrument was "love between me (the participants) and the children" on the emotional dimension. It can be said that it is very common between mothers and children, so that the majority of mothers would answer on the same scale. Therefore, these items could not classify participants on the emotional dimension.

The suggestions for parents of children with ASD are they should not be pessimistic because children with ASD can provide meaningful families. In fact, parents of children with ASD feel depressed and pessimistic about the characteristics of their children (Desiningrum, et al, 2019). However, the results of this study showed that the value of children or the perspective of mothers who have children with autism spectrum disorder was family. Children with ASD have a positive value for the family. The presence of children with ASD makes the family more meaningful, can increase parents' responsibilities and strengthen ties in the family.

This study revealed that the economic dimension and the old age dimension were the least prominent dimensions for mothers of children with autism spectrum disorder. Most of the participants or mothers of children with ASD had little expectations about their children being able to contribute financially to their families. This concern does not need to occur, because many companies and agencies have employed people with special needs according to the required criteria. Therefore, individuals with ASD still have to improve their abilities and skills so that they can get jobs and are able to be financially independent to meet their needs.

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