

Parents' Perceptions of Children with Disabilities

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ABSTRACT

Parents' perceptions of children with disabilities determine parents' acceptance of children with disabilities and the quality of care provided. This study aims to describe parents' perceptions of children with disabilities, and to examine whether there are differences in parental perceptions of children with disabilities based on the child's age at diagnosis, differences in parents' age and differences in parental education levels. This research was conducted by giving a questionnaire to 83 parents, of which 75% were women. Data were analyzed descriptively with percentages and analysis of variance was also carried out. The research findings conclude that most parents accept the diagnosis of their children with disabilities, and consider that having a disability is God's will. Most parents feel that their extended family and society can accept the existence of children with disabilities, they also understand the special needs of their children and are optimistic about the future of children with disabilities. On the other hand, most respondents felt that they were failures as parents, and most parents chose to place their children in dormitories. Based on the analysis of variance, it was concluded that parents' perceptions of children with disabilities did not differ based on differences in age at diagnosis, differences in parents' ages and differences in educational backgrounds.

Keywords: parents' perception, children with disabilities

1. INTRODUCTION

Parents' perceptions of children with disabilities determine how parents educate and care for the child. Parental acceptance of children affects children's development, social behavior skills, and adaptability (Carassco, Delgado, and Holgado-Tello, 2019). Parents who have children with disabilities often have negative perceptions, including feeling pessimistic, embarrassed, withdrawn and even rejecting the existence of children with disabilities. This may happen, especially when the efforts that are done seem to be fruitless, and even feel unable to educate and care for children with disabilities.

The existence of children with disabilities results in mental pressure on their parents. Based on Tunali's (1993) literature review, there are several factors that cause mental distress in parents who have children with disabilities. First, financial problems, the need for consultation, treatment, and purchasing equipment. Second, emotional problems, namely feelings of guilt, blaming each other, shame, and feelings of being rejected by other family members. Third, changes in family goals and expectations, the need for intensive care for children with disabilities, often hinders the work, careers of parents, and some even leave work to care for children with disabilities. Fourth, negative views and stereotypes from society, neighbors and friends. Fifth, related to the difficulty of finding adequate

educational and nursing institutions that are willing to accept children with disabilities. Severe-light disability conditions or disability diagnostic categories affect parental acceptance (Kandel and Merrick, 2007). Parents who have children with Cerebral Palsy (CP) have high levels of stress (Ketelaar, Volman, Gorter and Vermeer, 2008).

Research by Dalal and Pande (1999) found that the culture and values adopted by the local community influence the way parents perceive and accept children with disabilities. The availability of health, care and education support and services provided by the government is also an important part of the acceptance of parents for children with disabilities. The ability to coping or solving problems is a very important factor in overcoming mental stress due to having children with disabilities (Gupta and Singhal, 2004).

The development of inclusive education services in Indonesia has an impact on the development of public insights about children with disabilities and their categories. For example, slow learners, before the development of inclusive education, they - naturally - became part of the community in regular schools. When inclusive education is implemented, children with disabilities learn to be part of children with special needs who need to be served specifically, and are administratively recorded as part of children with

disabilities. It is in this context that it is important - although still at an early stage - to see how parents perceive children as having a disability by the education authorities, in this case the education office.

This study is a preliminary study, intended to determine whether there are differences in the perception of parents of children disabled by education level of parents, age of the parents and the child's age when diagnosed with disabilities. Through the study's findings are expected to be recommended to the Department of Education about the program to increase the capacity of the elderly so they can play optimally in the process of caring child disability and participatory partner for schools.

2. METHOD

Data was collected by distributing questionnaires to 95 parents whose children were identified as having disabilities by the Pasuruan City Education Office. Of these 83 questionnaires were filled in completely by respondents and were declared eligible for further analysis. Of these, most were women (75%). The age of respondents under 30 years was 12%, and 60.2% of respondents had an age between 31 s.d. 40 years. The age of the respondents was between 41 s.d. 50 years there is a number of 27.8%.

The research instrument consisted of 9 statement items with a Likert model. Reliability was tested with the Guttman Spilt-Half Coefficient, the value was 0.543. This value when viewed with the reliability criteria of the product moment coefficient is greater than the r value of 0.22 with an error of 5%. The data in this study were analyzed descriptively by percentage and inferential by ANOVA.

3. RESULTS

Descriptive data in this study includes 9 concepts, relating to respondents' perceptions of the existence of children with disabilities. In Table 1 below, the mean and standard deviation of respondents' perceptions for each statement item are presented.

An explanation of the data collected, 49.4% of respondents perceived that the accuracy of diagnosis as a child with a disability was in accordance with the actual situation. Conversely, some 37.3% of respondents felt that the diagnosis given was not appropriate. The remaining 13.3% of respondents felt they did not know about the suitability of the diagnosis with their child's special needs conditions.

The condition of disability as God's will was perceived by 86.7% of respondents, they felt that the

existence of children with disabilities was God's will. Only 5.9% felt that God was unfair to him because he gave children with special needs, and only 7.4% of respondents felt they did not know.

Table 1 Descriptive Data of Parents' Perceptions of Children with Disabilities

Item	N	Mean	SD	Min	Max
Accuracy of Diagnosis	83	3.13	1.124	1	5
god's destiny	83	4.27	.842	2	5
Family Acceptance	83	3.30	1.227	1	5
Community Acceptance	83	3.18	1.280	1	5
Feelings of Failure	83	2.81	1.329	1	5
Children Stay Home	83	2.84	1.234	1	5
Children's Future	83	3.41	1.148	1	5
Special Needs of Children	83	3.63	1.112	1	5
Potential in Children	83	3.61	.935	1	5

The acceptance of large families and the ability of parents to explain the existence of children with disabilities was perceived by 55.5% of respondents. A total of 33.7% of respondents felt that they could not explain to their extended family that they had children with disabilities. Only 10.8% of respondents answered that they did not know the family's acceptance of the existence of children with disabilities.

Some 56.6% of respondents stated that they could accept and understand if family members and neighbors said that they had children with special needs. There are 36.2% of respondents who still cannot accept it if family members and neighbors say that they have children with special needs. Only 7.2% of respondents said they did not know.

The perception of parents about the feeling of failing to be good parents when they are overwhelmed by caring for children with disabilities was agreed by 53% of respondents. Conversely, some 40.9% of respondents felt that they did not fail even though they were overwhelmed by caring for children with disabilities, and only 6.1% of respondents chose not to know.

A total of 48.2% of respondents chose to place their children with disabilities in a dormitory if there was an adequate hostel. A total of 12.1% of respondents chose not to know, and the remaining 39.7% of respondents chose to be educated at home, not in a dormitory.

A total of 57.8% of respondents felt optimistic about the future of their children with disabilities. On the other hand, 24.1% of respondents felt that they could not imagine their child's future, and 18.1% of respondents felt that they did not know their child's future. A total of 73.5% of respondents felt that they understood that their children had special needs. On the other hand, 7.2% of respondents stated that they did not know, and 19.3% stated that they did not understand their child's special needs. 62.7% of respondents stated that they could understand and recognize the potential of children with disabilities. On the other hand, 14.5% stated that they did not understand or did not recognize the potential of children with disabilities. A total of 22.8% of respondents stated that they did not know about the potential for children with disabilities.

One-way analysis of variance, as presented in Table 2, examines whether there are differences in the perception of parents' acceptance of children with disabilities based on differences in the child's age at diagnosis. Based on Table 1, it is known that the calculated F value is 1.704 with a probability of 0.189. Decision making is determined based on a probability value of 0.05. Due to the probability value $0.189 > 0.05$, H_0 is accepted, meaning that there is no difference in parents' perceptions of children with disabilities based on differences in the child's age when diagnosed with a disability, namely less than 2 years, 3 - 4 years and more than 5 years.

Table 2 Summary of ANOVA, Parents' Perception when Diagnosing Children with Disabilities

Source	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	78.865	2	39.433	1.704	.189
Within Groups	1851.810	80	23.148		
Total	1930.675	82			

Table 3 Summary of ANOVA Perceptions Based on Parents 'Age and Parents' Education Level

Source	Sum of Squares	df	Mean Square	F	Sig
Corrected Model	110.348	7	15.764	.664	.701
Intercept	46294.201	1	46294.201	1950.557	.000
Age	37.864	2	18.932	.798	.454
Level of education	.713	2	.356	.015	.985
Age * Education level	39.478	3	13.159	.554	.647
Error	1780.038	75	23.734		
Total	79437.000	83			
Corrected Total	1890.386	82			

a. R Squared = .058 (Adjusted R Squared = -.030)

Two-way analysis of variance was used to test whether there were differences in parental perceptions of children with disabilities based on parents' age and parental education level. The age of the parents is grouped into three, namely the age of 20 - 30 years, 31 - 40 years old and 41 - 50 years. The level of education of parents is grouped into three, namely junior high school, senior high school and undergraduate.

Based on the data presented in table 3, it is known that the calculated F value for testing differences in the perceptions of parents towards children with disabilities based on differences in parents' ages is 0.798. This value has a probability value of 0.454 which is greater than 0.05 as the basis for decision making. Thus, H_0 is accepted, which means that there is no significant difference in parents' perceptions of children with disabilities based on the respondent's age or the parents' age 20 - 30 years, 31 - 40 years and 41 - 50 years.

Testing differences in the perceptions of parents towards children with disabilities based on the educational background of the parents, shows the calculated F value of 0.015. This value is at a probability of 0.985 greater than 0.05 as the decision-making criteria. Thus, H_0 is accepted, which means that there is no difference in parents' perceptions of children with disabilities based on differences in parental educational background.

Testing whether there is an interaction between the age of the parents and the educational background of the parents, shows the results of F count of 0.554. This value has a probability of 0.647 greater than 0.05, thus H_0 is accepted. This means that there is no interaction between differences in the age of parents and differences in the educational background of parents.

Shocked, confused and sad are common reactions that parents experience. The sadness of having a child with a disability is heavier than the sadness of death (Hughes, 1999), because having a child with a disability the sadness lasts a long time, throughout life. The grief of death lasts two or three months after which it can recover. The heavier the level of disability a child has, the more it makes parents feel confused and sad. This phase is called the crisis phase where parents feel mental pressure or stress. Furthermore, according to Hughes (1999) the causes of stress or stressors include the stigma of having a child with a disability, the need for medical care, especially if a child with a disability is accompanied by a physical condition that requires intensive care, feelings of isolation, financial inadequacy, pressure in the household, community acceptance, and hope about the future of children with disabilities.

The ability of parents to get out of inner stress and the ability to find solutions is called the coping mechanism. Some of the ways that parents with children with disabilities do coping, including social support. Examples of social support are parental involvement in the community of parents of persons with disabilities, as well as participation in special activities such as the Special Olympics (Hughes, 1999). Parents can also learn skills to solve problems related to how to care for children with disabilities, how to control the behavior of children with disabilities, and how to establish contact and communication with children with disabilities. This process requires the presence of professionals, and other parents who are experienced and can get through this crisis phase. This process is often effectively carried out in discussion forums in the community of parents with disabilities (Hughes, 1999).

Aspects of spirituality and religion are also studied in relation to the coping mechanism for parents who have children with disabilities. The findings of this study indicate that 86.7% of respondents have the perception that the condition of disability is due to God's will. Spirituality in general can reduce the stress level of parents who experience crisis due to problems with children with disabilities (Skinner et al. 2001; Tarakeshwar and Pargament, 2001).

The acceptance of extended family, neighbors and society towards children with disabilities is influenced by the values believed by the local community. Research by Riany, Cuskelly and Meredith (2016) shows that people in Indonesia still believe in traditional values such as prohibitions that must be followed by pregnant women, so that their children are not born with defects, for example avoiding deformed children, and not slaughtering animals or killing animals. Even though some parents do not believe in this belief, they still do not dare to violate the intended prohibition. Traditional beliefs like this have an impact on the attitude of blaming parents with children with disabilities because they do not adhere to traditional values.

4. DISCUSSION

Based on the analysis of variance in this study, it is known that there is no difference in parents' perceptions of children with disabilities based on the child's age when diagnosed with a disability, based on differences in the age of the respondents and based on differences in the educational background of the respondents. This is in line with the research of Gusrianti, Winarni, and Faradz (2018),

which states that the economic level, education level and age of parents do not have an impact on the level of acceptance of parents for children with intellectual disabilities.

Based on the descriptive analysis it is known that the highest average (4.27) is the respondent's perception that the condition of a disability is God's will. This means that most respondents have a positive perception that conditions with disabilities are God's will. In contrast, the lowest average perceptions (2.81 and 2.84) were feelings of failure as parents and placement of children with disabilities at home. This means that most respondents feel that they are failures as parents when caring for and educating children with disabilities, and most respondents want their children not to stay at home, but to live in a dormitory.

In line with the findings of this study, Hughes' (1999) study found that 56% of parents when having children with disabilities had negative feelings. Some 91% of respondents reported that their belief in God got better, after having children with disabilities. Regarding the future of children with disabilities, 94% of parents have positive expectations for the future of their children with disabilities.

The existence of children with disabilities in the family and society can be explained through the theory of "Triadic Experience". This means that there is the involvement of three parties, namely individual children with disabilities, families, and the environment (Falik, 1995). At first, the father or mother or family close to the child feels or sees dysfunction or abnormality in the child. In these early days, families usually experience difficulties and shocks, not infrequently parents then give negative reactions (Marvin and Pianta, 1996), and even reject the diagnosis about their child's disability (Falik, 1995).

Shock, confusion and sadness are common reactions that parents experience. The sadness of having a child with a disability is heavier than the sadness of death (Hughes, 1999), because having a child with a disability the sadness lasts a long time, throughout life. The grief of death lasts two or three months after which it can recover. The heavier the level of disability a child has, the more it makes parents feel confused and sad. This phase is called the crisis phase where parents feel mental pressure or stress. Furthermore, according to Hughes (1999) the causes of stress or stressors include the stigma of having a child with a disability, the need for medical care, especially if a child with a disability is accompanied by a physical condition that requires intensive care, feelings of isolation, financial inadequacy, pressure in the household,

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The acceptance of extended family, neighbors and society towards children with disabilities is influenced by the values believed by the local community. Research by Riany, Cuskelly and Meredith (2016) shows that people in Indonesia still believe in traditional values such as prohibitions that must be followed by pregnant women, so that their children are not born with defects, for example avoiding deformed children, and not slaughtering animals or killing animals. Even though some parents do not believe in this belief, they still do not dare to violate the intended prohibition. Traditional beliefs like this have an impact on the attitude of blaming parents with children with disabilities because they do not adhere to traditional values.

5. CONCLUSION

The parents perceive the existence of children with disabilities positively. Most parents accept a diagnosis of their child with a disability, and consider that having a disability is God's will. Most parents feel that their extended family and society can accept the existence of

children with disabilities, they also understand the special needs of their children and are optimistic about the future of children with disabilities. On the other hand, most of the respondents felt that they were failures as parents, and strangely, most parents chose to place their children in dormitories. Based on the analysis of variance, it is concluded that parents 'perceptions of children with disabilities do not differ based on differences in age at diagnosis, differences in parents' ages and differences in educational backgrounds.

This research needs to be followed up with research that further reveals the acceptance and care of parents for children with disabilities. It is also necessary to explore the needs for interventions to facilitate parents in increasing their capacity in care. Further research also needs to look more specifically at the response characteristics of parents based on the severity of the disability and the type of disability. The involvement and role of parents in collaborating with schools also needs further attention.

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