

# Maternal Barriers in Raising Children with Special Needs in Rural Areas: A Qualitative Study

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**Abstract** It is not easy for mothers living in rural areas to raise children with special needs because various obstacles arise from both within and outside the family. This study aimed to explore various obstacles for mothers in raising children with special needs, especially in rural areas. The research design used in this study was descriptive qualitative. The sample in this study consisted of 55 mothers who were selected using purposive sampling method. Data collection was carried out through semi-structured face-to-face interviews and through focus group discussions. The data collected in this study was then analyzed using thematic analysis. There are 3 themes generated in this research including 1) family perception, 2) financials, and 3) access to health care services. Information obtained from this research can provide solutions for families to overcome or get out from the existing barriers and provide information to the government to provide health services to families with children with special needs in rural areas.

Keywords: *barriers, mothers, children with special needs, rural areas*

## 1. Research background

Children with special needs are children who need special treatment and attention because they have limited or impaired physical, mental-intellectual, social, or emotional development. These disorders significantly affect the growth and development process of children with disability, so they are different from other children of their age (Regulation of the Minister of Women's Empowerment and Child Protection of the Republic of Indonesia Number 10 of 2011; Desiningrum, 2016). In this regard, researchers in several countries use the term disability to refer to children who have physical, hearing, visual, mental or intellectual impairments, as well as communication problems, behavioral or emotional disorders.

Therefore, the World Health Organization considers this disorder as part of a person's life that at one point, a person can experience either temporary or permanent

impairment so that those who can reach old age will have more difficulty to function, given that disability is complex, dynamic, multidimensional, and contested (WHO, 2011).

The Ministry of Health through their Basic Health Research in 2018 classified disabilities into 3 age categories such as children (aged 5 -17 years), adults (aged 18 - 59 years), and seniors (aged  $\geq$  60 years). The study results showed that 3.3% of children aged 5-17 years in Indonesia had disabilities, where the proportion of boys is higher than girls. While, the proportion of children with disability who live in urban areas is bigger than those who live in the rural areas (Ministry of Health, 2019).

Raising children with special needs is not as easy as we imagine. As a primary caregiver a mother is the first family members who experiences the challenges and obstacles for handling a child with special needs at home. To articulate this, apart from the constraints that arise from a mother with a child with special needs, the environment and geographical location where she lives are also the inhibiting factors. Moreover, it is a general truth that Indonesia is a large country consisting of

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scattered islands where several rural areas do not yet have access to education and services for children with special needs. While individuals with disabilities should have the right to seek attainable highest healthcare standard without discrimination due to their disability. They also should be able to access gender-sensitive health services, including healthcare-related rehabilitation. However, these aforementioned services can only be accessed in certain areas at the sub-districts or urban level areas. Meanwhile, in rural areas, therapy services for children with special needs are not yet available.

Some obstacles in raising children with disabilities in rural areas are related to data information shortage, lawful protocol and regulations, rehabilitation and specificized service centers for people with special needs. A study by Riasat (2012) whose majority respondents came from households with low income found that mothers experienced various barriers in giving care for their children who have disability. For examples, picking and dropping (65.8%), teaching (79.8%), lack of interest in learning (47.5%), helpless and hopeless (72.5%), lack of confidence (64%), loneliness (75%) irritable and short tempered (88.3%) and mobility (77.5%). The obstacles faced by people with disabilities that related to environmental barriers faced by people with disability in urban and rural areas of research respondents from the urban areas of South Africa recounted that they met more barriers in terms of products and technology infrastructure as well as the naturally existing environment, and especially viewpoints. Furthermore, their study findings revealed that participants with disabilities from rural areas, in general (with the exception of attitudes), understood fewer barriers to their living environment than those living in informal urban communities. Meaning, rural communities have low expectations. As such, this may reflect the lower demands placed on rural residents compared to people living in urban areas. In this connection, the level of society's demands on each individual will be proportional to the obstacles that must be faced by an individual (Maart et al., 2007).

Meanwhile, respondents to a research conducted by (Iezzoni et al., 2006) in rural

America said it was difficult for them to find medical doctors who understood disabilities. As a result, they needed to go to larger health centers to get the special medical care they need, and they also had difficulty accessing public transportation to urban areas where the larger health centers are available. In their research on 168 mothers with mental impairment children Ergun and Ertem (2012) found the difficulties experienced by these mothers range from 64 mothers felt sadness (38.1%); 72 mothers felt anger (42.9%); to 32 mothers felt lonely (19.1%). As many as 92 mothers or 54.8% were put on blame by their in-laws for having children with disability. In contrary, only 29.8% or about 50 mothers in this study revealed that they sometimes experienced a sense of acceptance regarding having disabled children.

Therefore, this study aimed at exploring the various obstacles faced by mothers in raising children with special needs in villages. It is expected that with these obstacles, governments can find solutions for handling children with special needs in rural areas. Thus, families with children with disabilities have equal rights in terms of getting equal health and education services, and families can have solutions in dealing with children with disabilities.

## 2. Research method

This research is a qualitative descriptive study. According to (Sandelowski, 2000) a qualitative descriptive study is the method of choice when straight descriptions of phenomena are expected to provide an overview and summary of events happening in everyday life. This research was conducted in Rasau Jaya sub-district, Kubu Raya Regency, West Kalimantan Province Indonesia. This study was conducted from January 2020 to February 2020 with a total of 55 participants consisting of mothers with children with special needs. Samples were selected using a purposive sampling technique. The criteria for participants are mothers who have children or teenagers with special needs living in rural areas, who are able to communicate using Bahasa Indonesia and agree to be participants of this study, as well as filling in and signing the consent form for being a respondent.

This research has passed the ethics test on the ethics committee of the Pontianak Muhammadiyah Nursing School Number: 34/II.I.AU / KET.ETIK /I/ 2020. In this study, adherence to ethics and procedures set by the committee was prioritized by the researchers. For example, researchers maintain the confidentiality of information provided by the participants of this study. Researchers also apply the values of honesty and the benefits of this study for participants. Participants are also given the freedom during the research period to make choices regarding their participation in this research, as part of respect for their human dignity. So, at the beginning of this study, before being involved in the research process, the participants were given an information sheet and an agreement sheet.

Two techniques of collecting data such as in-depth semi structured interview and focus group discussion were employed in this study. As the tool for collecting data a set of interview guides was designed based on the objectives of this research. Meanwhile, the semi-structured interviews were conducted in person using a voice recorder device. Similarly, the focus group discussion was carried out face-to-face in the period of 30 - 40 minutes. Questions prompted for interview and focus group discussion include: 1) what obstacles do you face in caring for children with special needs at home? 2) what difficulties do you face in raising a child with special needs? 3) What is your family viewpoint about having a child with special needs? 4) How is the support from your spouse and other family members in caring for children with special needs.

To analyze the data collected from the research, the researchers employed a thematic analysis technique. According to Braun and Clarke (2006) it is a way to determine, analyze and report the stages transcribed verbatim data which are then coded in text line by line, and afterwards is going on such processes as determining the themes, reviewing the themes, defining and naming the themes, and then making reports. In this case, carefulness is guaranteed by paying attention to the main principles of consistent qualitative interviews such as developing trust and good relations with people who are involved in the study. Besides doing triangulation, the researcher read the

transcript for couple times and made a cross-check with the research members and study participants regarding the interpretation of the study findings.

### 3. Result and discussion

The educational characteristics of mothers who have children with special needs are 43.63% graduated from elementary school, 16.37% from junior high school, 23.63% from senior high school, and 16.37% never going to school. Based on this educational background, the researchers concluded that most mothers who have children with special needs in rural areas have low education and do not even go to school and have no job. This means that around 75.55% are housewives. Meanwhile, for the age characteristic of children with special needs, 49.10% of children are 12-17 years, most of whom have intellectual disabilities.

Table 1. Description of Characteristics of Children Including Age and Types of Impairment

	Sex		N	%
	Male	Female		
<b>Age</b>				
6-11	7	6	13	26.36
12-17	18	9	27	49.10
18-21	10	5	15	27.27
<b>Types of Impairment</b>				
Blind	1	1	2	3.63
Deaf	9	6	15	27.30
Intellectual Disability	12	7	19	34.54
Physical Disabilities	2	1	3	5.45
Autism	5	2	7	12.72
Down syndrome	6	3	9	16.36

The three themes generated in this study based on interviews and focus group discussions were 1) family perception, 2) financials, and 3) access to health services.

#### Theme 1: Family Perception

Various perceptions arise from the family towards mothers who have children with

special needs and the children themselves, some of which are positive, but there are more negative perceptions. Negative perceptions consist of blaming each other, self-blaming and giving up. Meanwhile, a positive perception is like accepting the presence of a child with special needs by giving attention and affection. As expressed by mothers as follow:

*“My parents in-law blamed me by saying that when I was pregnant, I liked to eat carelessly and didn't care to avoid certain foods so that my child was born with disability ....”*

*“I was said to have failed to maintain my pregnancy and liked not to watch over my speech, my behavior so that it affected my child ...”*

*“my husband also blamed me because when I was pregnant, I did not want to follow his parents' advice to watch over my eating habit and my speech ....”*

Similarly, some mothers blame themselves for giving birth to children with disabilities, as articulated in the following expression.:

*“...I was wrong because during pregnancy I did not take care of my health and food, I did not really care if the food was good or not for my health and my baby ...”*

Another perception by mothers says that children with special needs are children who have no future so that their parents are giving up, as expressed by some mothers in the focus group discussion:

*“.... Why does he have to go to school? other than that the school is far away, and if he goes to school, what will he do when he grows up ....”*

*“All I can do is surrender, having a child with special needs like this the important thing is that he eats and drinks enough, just stay at home and help out...”*

*“there are many things that we have to take care of, so it's enough. The most important thing is that we meet his needs of food and drink, and if he is sick, we take*

*him for treatment, if he goes to school, for what? in the end he's still like this, nothing has changed...”*

However, some positive perceptions on children with special needs were found both during interviews and in the FGD, such as accepting the presence of children as a gift from God, as stated by mothers in these following expressions:

*“Like it or not, we have to accept what God has given and it is God's way for our family...”*

*“Regarding attention, my husband and I prioritize our attention as number one for him above his siblings because we know that no child wants to be disabled, this is all God's power...”*

*“This child is special to us even though he has imperfections but Allah gives advantages that other children don't have, so we are always grateful and take lessons from this...”*

*“We are grateful to God, behind his limitations Allah has given him the strengths, and hopefully the strengths can become a career for his future ...”*

Having children with special needs creates various perceptions and impacts from the family. The impact that appears can be positive or even negative. The results of the research by (Merve et al., 2018) on the Life Experience of Children with Intellectual Disabilities, explained that some mothers rejected the results or diagnoses stating that their children had intellectual disabilities. They believed that their children will recover after going to school. On the other hand, some mothers showed positive reactions when they first heard that their children had intellectual disabilities by accepting the diagnosis. They still believed that their children are important and continue to improved their spirituality so that they could calm down. Still based on the results of research by (Merve et al., 2018) some mothers experienced problems in self-care management. For instances, children were not able to clean themselves after using the

bathroom. There was also a concern about the future of their children so that some mothers tried to prepare assets and properties for their children's future and entrusted their future before God. A study by (Allison, 2013) argues that many mothers who have children with Autism Spectrum Disorder (ASD) continue to experience being blamed, including self-blame as their children develop differently from other children. Additionally, in the same time they also experienced the feelings of guilty, blamed and judged by others.

According to researchers, family perception of blaming each other and mothers blame themselves is a form of reaction towards stress that cannot be managed properly. The level of stress experienced for having children with disability of course is also higher. This is in accordance with the opinion of (Bonab et al., 2017) that mothers who have mentally retarded children have a much higher amount of stress and family burdens. Especially, the inability to care for children with disabilities increases stress and family burdens on parents. However, if parents and families can manage stress well, positive values will grow in the related individuals to accept whatever condition the child has; for examples, giving the child affection, as well as accepting the child's strengths and weaknesses. Likewise, Kandel and Merrick (2007) assert that a family that accepts children with disabilities is defined as a balanced family. Meaning, they can manage between acknowledging the children's limitations and trying to compensate for children's limitations, so they can provide good love and attention to children. Additionally, they ultimately can accept and respect children's boundaries, and have a realistic view of children.

## **Theme 2: Financial Difficulty**

Some parents who have children with special needs experienced financial difficulties to cover the costs of therapy and medication needed in the long term, as expressed by the following mothers in interviews and FGDs:

*"... We used to take our child for treatment, but due to cost issues we stopped our child's therapy..."*

*"...no money, because we are farmers, you know exactly how much we earn daily as farmers, it's just enough for our everyday living expenses..."*

*"At first, we took him to the Community Health Center (Puskesmas), but at the Puskesmas there were no health services related to the type of disability my child suffered, so we were told to go to the city and we took him there, but due to cost and long-distance issues, we no longer continued..."*

*"In the city there is a free service, but to go there every day needs transportation costs, while my husband and I have to work..."*

Raising children with special needs certainly needs a large amount of money due to the amount of expenses spent both therapy and medication in either short or long term. This research findings reveal that most mothers complain about costs issues that their children cannot be able to take therapies as needed suiting the type of impairment they have. The high-cost therapies only can be afforded by families with high earning and income, and it is not an issue for them. However, the high-cost therapy is obviously a barrier for those who have low income to handle their disabled children. Based on this research, most of the household heads (husbands) are farmers while their wives are housewives. The high cost of therapy seems to be the main factor of why parents do not maximally provide therapy and medication for their children with special needs.

In line with this matter, (Meyer et al., 1998) stated that children from underprivileged families are at high risk for disability and chronic health problems. Meanwhile, to care for these children requires the family to pay a lot of money. Mothers as caregivers for children with disabilities also appear to tend to not working. As a result, their family indirectly lost additional income. Therefore, these high medical and therapy expenses appear to have a noteworthy impact on the economic welfare of families who care for disabled children. Mothers living and giving care for children with autism spectrum disorders in Egypt considered

financials issue the main concern faced by the mothers. The majority of the mothers reported severe and expensive financial difficulties when conducting interventions, talk therapy, buying very expensive drugs, and for private special education. Even some mothers had to stop speech therapy and medication for their children due to financial problems (Gobrial, 2018).

### **Theme 3: Access to health care services**

One of the obstacles the mothers highlighted in the interviews and FGDs is the difficulty to access health care centers. Long distances to reach hospitals and special health services are the main barriers for parents with children with special needs to seek assistance and therapy for their children, as expressed by the following mothers.

*“to have therapy for three times a week in the city takes about an hour by a motorbike, and he can't stay still during the trip, so I stopped taking him for the therapy... incapable because of the long distance”*

*“it's very far to get there and I am incapable of doing it everyday so that I decided just to stop his therapy...”*

In addition, several mothers also revealed that the Puskesmas health facilities in their villages could not yet handle types of children with special needs such as autism. So, parents had to go to the city but it takes them about one and half or two hours to reach the city, as expressed by a mother in this following transcript:

*“I once brought my child to the Puskesmas here, but the Puskesmas could not handle my autistic child, and I was sent to city but it is far away and I had to work so that I postponed it and until now my child does not have a therapy...”*

There are many obstacles faced by parents in rural areas in handling children with special needs such as time availability, long distances, the transportation used. Additionally, health facilities such as Puskesmas in rural areas are not yet fully ready in terms of personnel or human resources and

facilities for handling children with special needs. As confirmed by (Lezzoni et al., 2006) based on their study findings that parents needed to travel regularly to a larger or more complete health center to get the special care needed where available public transportation becomes an obstacle for parents to bring their children for a therapy to the city. In addition, individuals with disabilities have a higher level of unmet health needs compared to non-disabilities. For example, in the rural area of Madwaleni in South Africa, disabled people clearly faced more obstacles to go to the healthcare centers than those without disabilities. Barriers increase along with the level of disabilities severity, but decrease with increasing levels of education. Not to mention, living in households without members with disabilities and as people age (Vergunst et al., 2017).

## **4. Conclusion**

Families living in rural areas who have children with special needs experience financial constraints in providing therapy and treatment to children. Thus, most children with special needs do not get proper care because of the high costs that must be incurred by the family. This condition is further exacerbated by the negative perception of families who blame each other and self-blaming for the presence of children with special needs in the midst of their family. Another obstacle experienced by families is the barrier to accessing health services that can handle children with special needs. Since such facilities can only be found in urban areas, it takes time, money, and transportation costs to bring children to undergo therapy.

The results of this study are expected to provide solutions for families to overcome and get out of negative perceptions that can hinder families in raising children with special needs. Likewise, positive perceptions of the family can increase self-confidence in both parents and children, and increase parental acceptance of children which has a positive impact on both the family and the child. On the one hand, nurses and health workers need to make health education and counseling efforts for families with children with special needs. So, parents are willing to accept the presence of children with special needs as a gift and a mandate from God.

Likewise, the government needs to provide health services in rural areas so that families with children with special needs can easily access health facilitation and provide health assistance and therapy for their children. Lastly, increasing the resources of health personnel in Puskesmas in rural areas and in hospitals in general is crucial, so that they can function properly in providing services to children with special needs.

## Bibliography

- Allison. S (2013). Autism and Mother Blame: A Lingering Fallacy. Dissertation presented in partial fulfilment of the requirements for a Post Graduate Diploma in Social Science Research Methods, University of Auckland. DOI: 10.13140/RG.2.1.3972.2725
- Bonab. B.G., Farzaneh Motamedi, Fazlolah Zare (2017). Effect of Coping Strategies on Stress of Parent with Intellectual Disabilities Children. *Asian Education Studies*; Vol. 2, No. 3. DOI:10.20849/aes.v2i3.187
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), p.77-101.
- Desiningrum. D. R. (2016). Psikologi Anak Berkebutuhan Khusus. Psikosain: Yogyakarta
- Ergun, S., & Ertem, G. (2012). Difficulties of mothers living with mentally disabled children. *Journal of the Pakistan Medical Association*, 62, 776–780.
- Gobrial, E. (2018). The Lived Experiences of Mothers of Children with the Autism Spectrum Disorders in Egypt. *Soc. Sci.*7, 133; doi:10.3390/socsci7080133
- Kandel I, Merrick J. (2007). The child with a disability: parental acceptance, management and coping. *Sci World*;(7):1799–809. DOI 10.1100/tsw.2007.265
- Kementerian Kesehatan RI Pusat Data dan Informasi. (2019). *Disabilitas. Hari Disabilitas Internasional 3 Desember 2018. Indonesia Inklusi dan Ramah Disabilitas*. Jakarta: Indonesia
- Iezzoni.L.I, Mary B. Killeen, and Bonnie L. O'Day (2006). Confront Substantial Barriers to Obtaining Primary Care. *Health Services Research* 41:4, Part I. DOI: 10.1111/j.1475-6773.2006.00534.x
- Merve Inan Budak, Leyla Küçük & Hatice Yaprak Civelek (2018) Life Experiences of Mothers of Children with an Intellectual Disability: A Qualitative Study, *Journal of Mental Health Research in Intellectual Disabilities*, 11:4, 301-321, DOI: 10.1080/19315864.2018.1518502
- Meyers M, Lukemeyer A, Smeeding T. (1998). The cost of caring: childhood disability and poor families. *Soc Serv Rev. Jun*; 209 -3
- Omar TE, Ahmed WM, Basiouny NS. (2017). Challenges and adjustments of mothers having children with autism. *Alex J Pediatr*; 30:120-9
- Peraturan Menteri Negara Pemberdayaan Perempuan dan Perlindungan Anak Republik Indonesia Nomor 10 Tahun 2011
- Riasat. A. (2012). A Study of Problems Faced by Mothers of the Disabled Children in Rural Areas of District Faisalabad. *Global Journals Inc. Volume 12 Issue 12 Version 1.0*
- Sandelowski M. (2000). Whatever Happend to Qualitative Description? *Res Nurs Health*; 2(23):1–13.
- S. Maart, A. H. Eide, J. Jelsma, M. E. Loeb & M. Ka Toni (2007): Environmental barriers experienced by urban and rural disabled people in South Africa, *Disability & Society*, 22:4, 357-369.

Sandelowski M. Whatever Happend to Qualitative Description? Res Nurs Health. 2000;2(23):1–13.

Vergunst, L. Swartz, K.-G. Hem, A. H. Eide, H. Mannan, M. MacLachlan, G. Mji, S. H. Braathen & M. Schneider. (2017). Access to health care for persons with disabilities in rural South Africa BMC Health Services Research 17: 741. DOI 10.1186/s12913-017-2674-5

World Health Organization (2011) *World Report on Disability*. Geneva: WHO/WorldBank.[https://www.who.int/disabilities/world\\_report/2011/report.pdf](https://www.who.int/disabilities/world_report/2011/report.pdf)