

# Fulfillment of Family Needs With Disabilities

Elis Noviati<sup>1</sup>, Ima Sukmawati<sup>2</sup>, Rudi Kurniawa N<sup>3</sup>, Dena Mustika Ningrum<sup>4</sup>, Fidy Anisa Firdaus<sup>5</sup>

<sup>12345</sup>Department of Nursing, STIKes Muhammadiyah Ciamis, Jawa Barat, Indonesia

---

## Article info

### Article history:

Received: August 23<sup>rd</sup>, 2022

Revised: November 21<sup>st</sup>, 2022

Accepted: November 21<sup>st</sup>, 2022

---

### Correspondent author:

Name: Elis Noviati

Address: Ciamis, West Java, Indonesia

E-Mail: [elisnoviati@gmail.com](mailto:elisnoviati@gmail.com)

---

International Journal of Nursing and Health Services (IJNHS)

Volume 5, Issue 6, December 20<sup>th</sup>, 2022

DOI: 10.35654/ijnhs.v5i6.641

E-ISSN: 2654-6310

---

## Abstract

**Background:** The level of independence of children with disabilities has a greater dependence on the family. Family is an essential component in meeting the needs of children with disabilities. **Objective:** This study aims to describe the needs of families with children with disabilities. **Method:** The method uses quantitative with descriptive research design. The research sample used a non-probability sampling technique with a purposive sampling approach at SLBN Ciamis as many as 156 with a sampling of (N=60) parents with children with disabilities. This research was conducted in February 2022. The research instrument used the assessment of Family Needs-FNS questionnaire. The research data that has been obtained is then carried out data processing using the Statistical Product Service Program Solutions (SPSS). **Result:** The results showed that the needs of families with children with disabilities, in order from the highest to the lowest scores, were the need for information (83.3%) and the need for professional support (81.7%), the need to explain to others (68.3%), financial need (65.0%), childcare (41.7%), support and social (33.3%). **Conclusion:** If the need for information and professional support is met, parents will know better how to care for and develop their children's potential optimally. It is recommended that further researchers explore the needs of families with children with disabilities qualitatively, specifically for each type of disability, because this questionnaire can be used in general but not specifically regarding the needs of families with children with disabilities according to the disabilities experienced.

**Keywords:** Children, Disabilities, Family Needs, Parent



This is an Open Access article distributed under the terms of the Creative Commons Attribution 4.0 International License CC BY - 4.0

## INTRODUCTION

Every child with a disability has different abilities and potentials despite their limitations, so to develop the abilities and possibilities of children with disabilities, it is necessary to know the fulfillment of their needs (1).

According to the Law of the Republic of Indonesia No. 8 of 2016, children with disabilities have physical, intellectual, mental, and sensory limitations and even have more than one type of limitation. According to UNICEF, the number of people with disabilities is 10 to 25% of the world's population. Rikesdas 2018, it is stated that 3.3% of children aged 5-17 years have disabilities aged 18-59 years in Indonesia (2).

The National Socio-Economic Survey (SUSENAS) 2018 reported that 33,320,357 people with groups Aged 2-6 years have disabilities. The soul of the bearer Disability moderate number 1,150,173 people, while people with severe disabilities 309,784 people. The age group 7-18 years amounted to 55,708,205 people, divided into people with mild disabilities, as many as 1,327,688 people and people with severe disabilities amounted to 433,297 people (2).

Data from the Central Bureau of Statistics (BPS). In 2018 there were five provinces, namely: West Java, East Java, Central Java, South Sulawesi, and North Sumatra, which had some children with disabilities ranging from mild to severe (3).

Data from Ciamis Regency noted that from 156 students, 8 students have a visual impairment, 25 with hearing impairment, and 39 with mild mental retardation. About 67 students with moderate mental retardation, two students with disabilities, 9 students with autism, and 4 Multi Disabilities with Visual Impairment (MDVI) students (SLBN Ciamis 2022).

Parents or families are the essential service providers for children with special needs in their growth and development. Therefore, parents need knowledge about how to deal with it, primarily to ensure the potential effect of their child with disabilities carries its burden in dealing with more complex needs. Children with disabilities

need more support from their parents and families because they cannot independently meet their basic needs (1).

The needs of children with disabilities and the requirements of families or parents are the most significant fundamental factors that need to be considered as the basis for planning and early intervention (4).

When family needs are met, the needs of children with disabilities can also be met, as one of the keys to success in meeting these needs is the fulfillment of family needs (5).

Based on this, the role of the family or parents is vital and needed in the care and education of children with disabilities to achieve better potential abilities. Hence, families play a critical role (6).

The findings from a preliminary study conducted by researchers at SLBN Ciamis on five cooperative parents showed that families had difficulty explaining their child's condition to others. In addition, the family or parents do not understand and do not know information about good care for children with disabilities, especially the type of therapy and treatment that should be given. Even treatment therapy is done alone without using a therapist.

The research conducted by Lestari, Yani, & Nurhidayah (2018) only shows that the needs of parents with children with disabilities, the needs of parents and children, has an influence on parents and higher education knowing the needs of their children with disabilities. At the same time, other aspects related to the six needs have yet to be studied. In comparison, research on the needs of families with children is essential in education, intervention, and family referrals. Families need knowledge of basic needs to improve services and care for children with disabilities, such as the need for information, support, the need to be able to explain to others about their child's condition, financial needs, child care, community, and professional help (4).

Based on the above, it is necessary to research the needs of families with children with disabilities in 6 domains of family needs, namely the domain of information needs, family and social support, explaining to

others, child care needs, and professional help.

## OBJECTIVE

This study aims to describe the needs of families with children with disabilities.

## METHODS

### Design

This research method uses a quantitative approach with a descriptive research design. This research was conducted in February 2022.

### Database

The research sample uses a non-probability technique. Sampling with a purposive approach in SLBN. 156 Ciamis with a sample of (N=60) are parents with children with disabilities. The variables in this study are univariate, namely the needs of families with children with disabilities consisting of 6 domains, namely the domain of information needs, family and social support, explaining to others, child care needs, and professional help.

The Primary data is obtained from the research object carried out by nurses distributing questionnaires to respondents. Respondents were asked to answer according to the respondent's opinions based on the instructions for filling out the questionnaire. The previous respondent asked for their willingness to participate in research with signed informed consent (a statement of desire for the respondent).

This study used an instrument in the form of a questionnaire. The questionnaire used is the Assessment Of Family questionnaire needs-FNS. This questionnaire is translated into Indonesian with the Back translation method by Hana alih Arintia S.Hum (Translator 1), Zesika Dwi Lusianov S.Hum (Translator II) (4). This questionnaire consists of 32 questions and includes information needs (questions 1-7), support needs family and social (questions 8-15), financial needs (questions 16-21), the need to be able to explain to others regarding the child's condition (questions 22-26), nursing

needs child (questions 27-29), need for professional support (question 30-32).

Assessment is given using a Likert scale with a score of 1-3 for each question item, namely (1) = I don't need help, (2) = I am not sure I need or doubt, (3) = I am sure need help. To find out the interval formula, divide the number of respondents by the number of answers according to (4).

Validity and reliability tests were carried out at SLB Negeri Ciamis to 10 respondents using 32 questions. The researcher will test the questionnaire again so that the questionnaire is proven wholly valid and reliable. Parents who have done the test validity are not used as a research sample. The results of the calculation of the validity test have been calculated using Statistical Product Service Solution (SPSS) program version 22.0 for windows. Questions from a valid questionnaire, namely r count, must be greater than the r table. The value of r calculates the Assessment of Questionnaire Family Needs-FNS is 0.932 with r table (0.05) = 0.632. Based on the results of the reliability calculation, the value of Cronbach Alpha of 0.842, greater than 0.632, indicates This questionnaire is reliable because the r-count is more significant than the r-table.

### Data Analyze

The research instrument used an Assessment questionnaire of the family. Needs-FNS. a questionnaire that has been translated with Back. Translations. by Hana Arintia S. Hum and Jesika Dwi Lusianov S. Hum. The questionnaire has been tested for the validity of 0.932 with r table (0.05) = 0.632 valid and Cronbach reliability. Alpha. 0.842 > 0.632 Reliable (4). The research data that has been obtained is then carried out data processing using the Statistical Product Service program Solutions (SPSS).

## RESULTS

This study aims to describe the need family with children with disabilities in the Ciamis State Special School (SLB) (N=60).

Based on the results obtained, the following results:

Table 1 Demographic Characteristics of Children with Disabilities (N=60)

Characteristic	F	%
<b>Gender</b>		
Male	28	46.7
Female	32	53.3
<b>Child's age</b>		
Children (2-10)	0	0
Adolescent (11-19)	60	100.0
Adult (20-60)	0	0
<b>Type of disability</b>		
Mild mental retardation	27	45.0
Moderate mental retardation	28	46.7
Blind	2	3.3
Quadriplegic	2	3.3
Autisme	1	1.7
<b>Childrens Education</b>		
Elementary School	0	0
Junior High School	60	100
Senior High School	0	0
<b>BBL</b>		
BBL < 2500 gr	34	56.7
BBL > 2500 gr/normal	26	43.3
<b>Age When Pregnant</b>		
4 - 7 Month	33	55.0
8 - 9 Month	27	45.0

Table 1 shows that most parents of children with disabilities in SLB Negeri Ciamis have children with disabilities aged 11-19 years, as many as 60 children or (100.0%). The highest disability experienced by children is moderate mental retardation, 28 (46.7%) people. Education of children with disabilities in SLB currently is SMP 60 (100.0%). The maternal gestational age for children with disabilities was mostly 4-7 months. 33 (55.0%) were born prematurely

Table 2 Demographic Characteristics of Parents with Disabilities (N=60)

Characteristic	other		ather	
	F	%	F	%
<b>Age (Year)</b>				
Early Teens (17-25)	7	11.3	8	12.9
Late Teens (26-35)	11	17.7	12	19.4
Early Adult (46-45)	25	40.3	28	45.2
Late Adult (45-66)	9	14.2	10	16.1
Early Elderly	8	12.9	2	3.2
<b>Religion</b>				
Islam	60	100	60	100
<b>Ethnic</b>				

Java	4	6.7	4	6.7
Sunda	26	43.3	26	43.3
<b>Education</b>				
Elementary School	15	24.2	10	16.1
Junior High School	25	40.3	15	24.2
Senior High School	15	24.2	25	40.3
University	5	8.1	10	16.1
<b>Parents Work</b>				
Soldier	0	0	2	3.2
Entrepreneur	15	24.2	35	56.5
Laborer	0	0	15	11.7
Housewife	40	64.5	0	0
Civil Servant	5	8.1	8	12.9
<b>Income</b>				
<UMR (1.897.867)	55	51.9	50	47.2
>UMR (1.897.867)	5	4.7	10	9.4

Table 2 shows that most parents with children with disabilities in SLBN Ciamis are parents aged 36-45 (Early Adults) for fathers as many as 28 (45.2%) and mothers 25 (40.3%). The mother's last education is primarily junior high school 25 (40.3%), and the father is in high school 25 (40.3%).

Table 3 Description of the Needs of Families with Children with Disabilities (N=60)

Domain	F	%
Information Needs	50	83.3
Family & social support	20	33.3
Financial Needs	39	65.0
Explain to others	41	68.3
Child Care	25	41.7
Professional Support	49	81.7

Table 3 shows the average score for each domain of the needs of families with children with disabilities in SLB Negeri Ciamis (N=60). It is sorted from the highest to the lowest value in the domain of information needs and professional support needs, which has a fairly high value of information needs (83.3%), and the domain of professional support needs (81.7%).

## DISCUSSION

### Information Needs

The needs of family or parents show that information needs occupy the highest order. In the "information needs" domain, the results show in table 4.4 the average value of the domain of needs information at SLB

Negeri Ciamis (N=60), with the highest score of 83.3% of parents mentioning it as the most dominant need. Needs information included in the priority needs family needs most needed is the research instrument no. 5 "needs" information about the condition and disability of children" and no. 6 "needs" regarding information about available services "96.8% mothers" stating "need help."

That means the information needs for priority needs that are most needed and need help occurs due to the lack of access to information about types of services and lack of information on caring for children with disabilities related to therapy and treatment. Another needs such as resources to overcome family conflict problems, etc. In addition, the study's results showed that the mother's last education was junior high school (40.3%). Thereby, this significantly influences the information obtained or owned by mothers for correct medical care for children with disabilities (7).

### **Family and Social Support Needs**

In the domain of "family and social support needs," the results show dimensions of family and social support needs both entered the last sixth of the six domains of family needs. This indicates that the need for support for family and social needs is not among the most needed needs of people parents with children with disabilities. In the domain of family and social support needs, no 2 "have" friends to talk to "as many as 80.6% of parents said they needed" help."

That means most parents need friends to share experiences and solutions to problems they get as parents of children with disabilities. Parents of children with disabilities will later experience an adjustment process after they learn to cope with children with disabilities and try to accept their feelings and the process of understanding they go through (8).

### **Needs to Explain to Others**

Needs in the "needs explain to others" domain. The domain explains to others has a score of 68.3% or enters the third order of the highest needs needed by families with

children disabilities from six parts. Needs were present to others who prioritize, and 90.3% of mothers stated that they needed assistance, such as question no. 26 on the instrument "find reading materials about" other families with children with disabilities."

Parents of children with disabilities need more knowledge about how to provide for their children's needs. Apart from that, most parents of children with disabilities need views from the viewpoints of other families with children with disabilities. Families need more experience than other families to understand what it's like to be a parent of children with disabilities and how to be good parents of children with disabilities so that later the parental care provided can be given following the needs of their children (5).

### **Financial Needs**

Needs in the "financial need" Financial domain needs are basic needs (9). This financial need includes needs from clothing, food, shelter, or transportation to the need for job consultation. In addition, this financial need is also related to financing related to the disability conditions experienced by their children.

Needs financial needs, including the four most needed needs of the six domains. In financial needs, only 65.0% of families stated that financial need was the dominant need of families with children with disabilities. In the financial needs domain, the family's most priority needs at SLB Negeri Ciamis is "the need to pay such as food, housing, health, clothing, or transportation. It also obtains equipment for children and pays for child therapy and other services children need, as well as special equipment for children" as much as 82.3% of parents stated that they needed help (Appendix 9).

Financial needs for children with disabilities need to be considered in terms of financing their needs considering that children with disabilities have special needs that differ from other children. However, in this domain of needs, the need that is not

needed is "paying for care/care during their child's vacation ."This is because most parents or mothers are 64.5% housewives, so mothers take care of their children independently (10).

### **Child Care Needs**

Needs in the domain of "child care needs" Parents who make the care of their children the primary and most needed needs of the family (11). In the domain of child care, the immediate need most needed by families with children with disabilities is "appropriate care for children with disabilities in places of worship during worship." As many as 80.6% of parents said they needed help". Based on this, it shows that the care parents need the most is a place of worship, as they need to carry out their worship comfortably, safely, and quietly (12).

The current condition in Indonesia is the lack of facilities for disabled children, such as places of worship. So for that, the government must be able to provide worship facilities for the community and children with disabilities because they have the same rights to these facilities as ordinary people in general (13).

### **Professional Support Needs**

The need for "professional support needs" is one of the most urgent needs of families. In terms of carrying out the role of the family to meet the needs of children with disabilities, families need an essential part from various health experts such as nurses, doctors, therapists, etc. Indonesia today, according to the Ministry of Women's Empowerment and Children's Rights (2018), it is stated that many families do not understand and know how to handle and care for children with disabilities (14).

In the domain of professional needs, the most and most needed is "More time to talk to the teacher or therapist" as much as 96.8%. Parents said they needed help. The second most urgent need is "meeting with a counselor (psychologist, social worker, psychiatrist)" needed to maximize care for their child with a disability (15)

### **CONCLUSION**

The need for information and professional support is the most needed by families with children with disabilities. So it is necessary to have access to the information required to meet these needs. With fulfilling parental information needs and professional support, parents will know better how to care for and develop their child's potential.

### **REFERENCES**

1. Desriyani Y, Nurhidayah I, Adistie F. Burden of Parents in Children with Disability at Sekolah Luar Biasa Negeri Cileunyi. *NurseLine J*. 2019;4(1):21.
2. Ndaumanu F. Hak Penyandang Disabilitas: Antara Tanggung Jawab dan Pelaksanaan oleh Pemerintah Daerah. *J HAM*. 2020;11(1):131.
3. Apriani K, Budjang G, Imran. Peran Orang Tua dalam Pendidikan Anak. *MediaNationalgeographicCoId*. 2018;7.
4. Lestari S, Yani DI, Nurhidayah I. Kebutuhan Orang Tua dengan Anak Disabilitas Parents ' Need of Children with Disability Data dari Survei Sosial Ekonomi Sipil Kabupaten Bandung pada tahun pengkajian International Labour Organisation Komunitas Ikatan Keluarga dengan. *J Nurshing Care*. 2018;1(1):50-9.
5. Naufal WI, Rahmandani A. Pengalaman pengasuhan ibu yang memiliki anak disabilitas fisik berprestasi: sebuah studi fenomenologis deskriptif. *J empati*. 2020;9(4):43-54.
6. Sdlb DI, Tahun B, Syahda S. Kemandirian anak retardasi mental. 2018;2(23):43-8.
7. Onainor ER. Prespektif orang tua terhadap anak berkebutuhan khusus di sekolah inklusif. 2019;1:105-12.
8. Hikmawati E, Rusmiyati C. Kebutuhan pelayanan sosial penyandang cacat Eny Hikmawati dan Chatarina Rusmiyati ABSTRACT. 2018;16(1):17-32.

9. Azlin N, Nordin M, Shan EH, Zanudin A. The Unmet Needs of Parents of Highly Dependent Children with Cerebral Palsy. *Int J Environ Res Public Health*. 2019;16(5145):1-11.
10. Febri Tri Hanunangan, Kili Astarani DI sari P. *Jurnal penelitian keperawatan*. 2020;6(2).
11. BFZ. Membebaskan Anak Tunadaksa Dalam Mewujudkan Masyarakat Multikultural Demokratis. *J Al-Maiyyah*. 2018;11(1):171-88.
12. Equilibrium J, Sosiologi P. *J urnal E equilibrium J urnal E equilibrium*. 2015;III(1):38-46.
13. Vani GC, Raharjo ST, Hidayat EN, Humaedi S. Pengasuhan (Good Parenting) Bagi Anak Dengan Disabilitas. *Share Soc Work J*. 2014;4(2).
14. Sukmawati i, rahayu y, noviayanti d. *Jurnal stikes muhammadiyah ciamis : jurnal kesehatan Competition Strategy In Moms With Special Needs Children Strategi Koping Pada Ibu Dengan Anak Berkebutuhan Khusus*. 2020;7:1-7.
15. Noviati E, Sukmawati I, Rahayu Y. Stress Level of Mothers with Children with Special Needs. *Sci Midwifery*. 2021;10(1):114-6.