

# Annual Healthcare Expenses Paid by Parents of Children with Special Needs

Tri Budi Santoso, Ph.D., OT

Senior Lecturer and Researcher

Dept. of Occupational Therapy, Poltekkes Kemenkes, Surakarta, Indonesia

## Abstract:-

### ➤ *Background*

Parents of children with special needs face financial challenges every year. This creates a financial burden for parents with special needs. This study aims to determine how much money parents incur annually to pay for children with special needs to receive health services. This study aims to investigate the annual cost of each health service item that parents spend on their children with special needs.

### ➤ *Method*

The researcher surveyed families with children with special needs, to determine the care costs based on the variables they identified. The study's sample consisted of 86 parents of children with special needs, selected through a Google Forms survey.

### ➤ *Results*

The cost of health services for children with special needs, namely for occupational services, Speech Therapy, Physiotherapy, Psychology, Doctor's Fees, Complementary Health, Medicines / Vitamins, and Children's Laboratory. Every month, most parents spend 0 -500.000 IDR (Indonesian Rupiah) to pay for each health service. The maximum total of all health expenditures for children with special needs in one year is less than 10. 000.000 IDR. The biggest expense for health care is to pay for therapy costs and most parents come to child development clinics to get health services for their children.

### ➤ *Conclusion*

Parents who have children with special needs incur significant costs to finance their children's health services and the largest expenditure is used for various types of therapy that the child needs generally parents come to the child development clinic for their child's therapy needs.

**Keywords:** - Health Care Costs, Children with Special Needs.

## I. INTRODUCTION

Having a child in the family is the dream of every husband and wife, the presence of a child will certainly bring hope such as happiness, and create a successor who can later provide good things for the family [1] In a family, a husband and wife undoubtedly yearn for the presence of a child who is

healthy and devoid of any deficiencies [2]. Every child who is born perfect is the happiness of all parents, they want to have children who are healthy, both physically and mentally. However, this wish cannot always come true, because when a child is born two things might happen, namely the child being born healthy and perfect or the child being born with some dysfunction [3].

In reality, parents who have less-than-perfect children must accept a fact that does not match their expectations and accept the condition of the child born. When a child is born with imperfections, both parents must remain ready to care for and care for the child [4]. Children with special health care needs, namely those who have or are at increased risk for health and who require health services beyond those required by children in general, also impact the use of health facilities and cost more than children in general [5].

According to UNICEF, there are approximately 93 million children with disabilities worldwide. According to the 2018 Basic Research Health Indonesian Ministry of Health in Indonesia, the proportion of people with disabilities in the 5–17-year age range reached 3.3% [6]. Children with special needs, due to their low ability to fulfill basic needs independently, tend to have dependencies related to their physical, mental, social, economic, and educational processes. This dependency often causes children with special needs to require special services from caregivers. Special needs refer to children who display deviations in their cognitive, interpersonal, or affective maturation during their growth and development. Consequently, they require specific services and focused care [7].

Parents are primarily responsible for caring for children with special needs, encompassing physical, social, financial, emotional, and familial relationships. Families with special needs often face negative stigma from society. Denial, sadness over the condition of their sons and daughters, or sadness for the misfortune they experience, generally parents will learn to accept. Something that cannot be taken lightly is financial problems. Enhanced financial stability in families with children with extraordinary needs promotes their advancement towards a condition of optimism and acceptance.

Considering the existence of these special conditions, it is necessary to make various efforts, such as consulting with experts, undergoing regular psychological medical examinations and treatment, involving children in more than one type of therapy, and equipping children with adequate

facilities to help with their daily activities or require paid special assistant special assistants [8].

Parents of children with special needs will face higher healthcare expenses in the United States. The medical costs for children with exceptional needs, excluding insurance premiums, range from \$2,669 to \$69,906, whereas those for children without special needs range from \$676 to \$3,181. [9,10,11]. Families with children who have special needs may experience financial pressure due to the cost of health insurance [12]. Financial obligations become more severe when a parent is completely responsible for taking care of a child without any professional assistance. This could result in a reduction in the parents' earnings due to unemployment, the inability to work standard or additional hours, the necessity to change shifts due to compensation disparities, or even the choice to resign from their jobs entirely [13, 14, 15].

Healthcare and health insurance expenses may differ significantly depending on the geographical location of a family with a child with special needs [16]. Furthermore, the overall proportion of children with special needs varies across different states. The prevalence of children with special needs in the Western United States ranges from 13.6% in Hawaii to 24% in West Virginia. The

implementation of the Affordable Care Act in 2010 has led to a continuous increase in health insurance expenses [17].

UNICEF (2023) reported that children with disabilities and their caregivers in Indonesia encounter numerous barriers when trying to obtain crucial services such as education, health care, nutrition, water, and sanitation, as well as social and child protection services. Various stakeholders must act immediately based on this report to alleviate all the problems faced by children with disabilities in Indonesia [18].

The objective of this study, drawing from the aforementioned literature, is to analyze the yearly costs related to each healthcare service that parents bear for their children with special needs.

## II. METHOD

The researcher conducted a survey of families with children with special needs to determine the cost of care based on the variables they identified. This study involved 86 parents of children with special needs, selected through simple random sampling. The Research Ethics Committee approved this survey study.

## III. RESULTS

**Table 1. Participants Characteristic**

Variable	Frequency	Percentage (%)
<b>Age of Parents, yr</b>		
< 30	9	10.5
30-45	75	87.2
> 45	2	2.3
<b>Gender</b>		
Male	4	4.7
Female	82	95.3
<b>Education Level of Parents</b>		
Senior High School	11	12.8
Some College	15	17.4
Bachelor's	53	61.6
Master's	7	8.1
<b>Job of Parent</b>		
Homemaker	49	57.0
Private Business	4	4.7
Private Employer	15	17.4
Government Employer	18	20.9
<b>Residence</b>		
Java Island	56	65.1
Outside of Java Island	30	34.9
<b>Distance of Health Care Institution from home</b>		
0 – 3 Km	24	27.9
4 – 6 Km	23	26.7
7 – 10 Km	16	18.6
> 10 Km	23	26.7

Table 1. shows that the characteristics of the research sample based on parental data showed that most parents were in the 30 - 45-year age range, which is included in the productive age category. The gender of the parents in this study was the majority female, with the profession being homemaker. The majority of parents' education is Bachelor's, which is in the higher education

category, and most residents are located on Java Island. Meanwhile, most distances from home to health care institutions (hospitals or pediatric clinics) are 0 – 3 km.

**Table 2. Participant Characteristics (Children with Special Needs)**

Variable	Frequency	Percentage (%)
<b>Age of Child, yr</b>		
< 5	32	37.2
5-10	48	55.8
> 10	6	7.0
<b>Gender</b>		
Male	64	25.6
Female	22	74.4
<b>Diagnosis</b>		
Autism Spectrum Disorder (ASD)	51	59.3
Dyspraxia	1	1.2
Cerebral Palsy	1	1.2
Sensory Processing Disorder	4	4.7
Atypical Autism	1	1.2
Attention Deficit Hyperactivity Disorder (ADHD)	16	18.6
Global Developmental Delay	3	3.5
Speech Delay	4	4.7
Microcephaly	1	1.2
Epilepsy	1	1.2
Expressive Language Disorder	1	1.2
Down Syndrome	1	1.2
Cerebral Palsy	2	2.3
<b>Year Child was Diagnosed</b>		
< 2 tahun	15	17.4
2- 4 tahun	63	73.3
> 4 tahun	8	9.3

Table 2 shows that the majority of children were in the 5 - 10-year age group with the majority gender being male. The majority of children's diagnoses are autism spectrum disorder (ASD) which is diagnosed at the age of 2 – 4 years.

**Table 3 Presents the Characteristics of the Research Sample based on the Cost of Health Services for Children with Special Needs in a Given Month.**

Variable (Cost of Service in Indonesian Rupiah) in a month	Frequency	Percentage (%)
<b>Occupational Therapy</b>		
Have never received therapy	2	2.3
0 - 500.000 IDR	31	36.0
500.000 - 1.000.000 IDR	21	24.4
1.000.000 – 2.000.000 IDR	17	19.8
2.000.000 – 3.000.000 IDR	11	12.8
3.000.000 – 4.000.000 IDR	3	3.5
Above 5.000.000 IDR	1	1.2
<b>Speech Therapy</b>		
Have never received therapy	5	5.8
0 - 500.000 IDR	33	38.4
500.000 - 1.000.000 IDR	20	23.3
1.000.000 – 2.000.000 IDR	16	18.6
2.000.000 – 3.000.000 IDR	11	12.8
Above 5.000.000 IDR	1	1.2
<b>Physical Therapy</b>		
Have never received therapy	22	25.6
0 – 500.000 IDR	39	45.3
500.000 – 1.000.000 IDR	12	14.0
1.000.000 – 2.000.000 IDR	6	7.0
2.000.000 – 3.000.000 IDR	4	4.7

3.000.000 – 4.000.000 IDR	2	2.3
Above 5.000.000 IDR	1	1.2
<b>Psychology</b>		
Have never received psychological service	10	11.6
0 – 500.000 IDR	44	51.2
500.000 – 1.000.000 IDR	17	19.8
1.000.000 – 2.000.000 IDR	10	11.6
2.000.000 – 3.000.000 IDR	4	4.7
3.000.000 – 4.000.000 IDR	1	1.2
<b>Medical Doctor</b>		
0 – 500.000 IDR	48	55.8
500.000 – 1.000.000 IDR	19	22.1
1.000.000 – 2.000.000 IDR	7	8.1
2.000.000 – 3.000.000 IDR	5	5.8
3.000.000 – 4.000.000 IDR	4	4.7
4.000.000 – 5.000.000 IDR	1	1.2
Above 5.000.000 IDR	2	2.3
<b>Complementary Health</b>		
Have never received complementary health service	22	25.6
0 – 500.000 IDR	48	55.8
500.000 – 1.000.000 IDR	8	9.3
1.000.000 – 2.000.000 IDR	1	1.2
2.000.000 – 3.000.000 IDR	4	4.7
3.000.000 – 4.000.000 IDR	2	2.3
Above 5.000.000 IDR	1	1.2
<b>Medicines and Vitamins</b>		
Have never used medicines and vitamin	4	4.7
0 – 500.000 IDR	38	44.2
500.000 – 1.000.000 IDR	16	18.6
1.000.000 – 2.000.000 IDR	11	12.8
2.000.000 – 3.000.000 IDR	11	12.8
3.000.000 – 4.000.000 IDR	4	4.7
Above 5.000.000 IDR	2	2.3
<b>Laboratory Services</b>		
Have never received laboratory services	15	17.4
0 – 500.000 IDR	53	61.6
500.000 – 1.000.000 IDR	5	5.8
1.000.000 – 2.000.000 IDR	3	3.5
2.000.000 – 3.000.000 IDR	4	4.7
3.000.000 – 4.000.000 IDR	2	2.3
4.000.000 – 5.000.000 IDR	1	1.2
Above 5.000.000 IDR	3	3.5
<b>Total Child Health Expenditures Per Year</b>		
< 10 million	29	33.7
10 – 20 million	18	20.9
21 – 30 million	12	14.0
31 – 40 million	4	4.7
41 – 50 million	7	8.1
> 50 million	16	18.6
<b>Biggest Expenditure for Health Service Needs</b>		
Medicine and Vitamin	16	18.6
Medical Doctor	4	4.7
Therapy	61	70.9
Providing Therapy Equipment at Home	3	3.5
Cost of Transportation	2	2.3
<b>Health Care Service Provider</b>		
Government Hospital	19	22.1
Private Hospital	25	29.1

Child Development Clinic	31	36.0
Home Care Service	7	8.1
School Service	4	4.7

From Table 3, the characteristics of the research sample are based on the cost of health services for children with special needs in a month, which includes occupational therapy services, speech therapy, physiotherapy, psychology, doctor's fees, complementary health, medicines/vitamins, and children's laboratories. In general, parents spend per item of health services 0 – 500.000 IDR per month, with a total annual health service cost of < 10.000.000 IDR. The largest expenditure is to cover therapy costs such as occupational therapy, speech therapy, physical therapy, and so on. The majority of parents prefer to send their children to child development clinics for therapy.

**Table 4. Sample Characteristics Based on Health Insurance Ownership and Parental Expectations**

Variable	Frequency	Percentage (%)
<b>Have Social Health Insurance (BPJS Insurance)</b>		
Yes	76	88.4
No	10	11.6
<b>Private Insurance</b>		
Yes	24	27.9
No	62	72.1
<b>Use Social Health Insurance for Health Service</b>		
Yes	42	48.8
No	44	51.2
<b>Parental Expectation</b>		
The therapist's educational qualifications are upgraded to a minimum of Diploma IV/Bachelor level	40	46.5
The number of therapists must be increased	17	19.8
The number of specialist doctors must be increased	5	5.8
The number of Institutions providing child development services must be increased	13	15.1
Services for children with special needs should be provided at the Community Health Center	8	9.3
Others	3	3.5

Table 4 shows the characteristics of the research sample based on ownership of health insurance and expectations of health services for children with special needs shows that the majority of parents of children with special needs have Social Health Insurance or in the Indonesian language called Badan Penyelenggara Jaminan Sosial (BPJS) insurance provided by the government. 88.8% of the respondents have Social Health Insurance (BPJS) and 27.9% of respondents have private insurance. Only 48.8% of the respondents use Social Health Insurance (BPJS) to obtain health services for their children.

Parents also hope for an increase in therapist education to a 4-year diploma or bachelor's level. They also anticipate an increase in the number of specialist doctors and therapists, enabling health professionals to offer a broader range of services to the community. Parents of children with special needs also request that the number of institutions serving children with special needs should be increased and if possible, therapists can be employed in community health centers so parents are easier and closer to accessing health services for their children.

#### IV. DISCUSSION

This research aims to survey to determine the annual health service costs borne by parents of children with special needs. The results of the research show that parents seek the services of various professionals such as occupational therapy, speech therapy, physiotherapy, psychology, doctors, complementary health, medicines or vitamins, and children's laboratory. The cost of each item of those services amounts to 0 – 500,000 IDR and the total cost of child health per year is < 10.000.000 IDR. The biggest expense of the parents is paying for therapy services and parents generally come to get therapy services at the child development clinic.

In a study investigating the cost of developmental therapists for children with neurodevelopmental disabilities in Qatar, Shaban & Amin (2024) documented that all children must take part in a daily program that includes a therapy program, academic program, and social interaction skills with a duration of 3-5 hours and parents must pay a monthly fee of QAR 3.000 to QAR 20.000 [19]. The number of payments that must be paid per month depends on the frequency of therapy per week, the therapist's background, and the client's economic background. Compared to Indonesia, if parents want health services at a private clinic, they can choose a payment package that suits their financial capabilities. Payment fees vary depending on the type of

therapy service, frequency per week, and therapist qualifications.

Parents who have children with special needs in Indonesia have to pay significant costs to obtain health services and experience a heavy financial burden. For parents with limited income, even though health services are covered by health insurance provided by the government, parents still have to spend an extra budget on vehicle fuel or public transportation, money for food and drink, and parking fees. For children with special conditions, parents have to buy the child's needs such as assistive devices, wheelchairs, or other medical equipment that the child needs. Those parents who were not using insurance had to spend more extra budget to pay for health care services. A similar finding was documented by Micai et al., (2024) where parents with autism spectrum disorder must pay the cost of a therapy session per hour and the largest expenditures are for paying individual therapists (89.13%) and psychologists (76.00%) [20].

Our findings indicate that parents prefer to visit private child development clinics and private hospitals, where they can make an appointment with doctors or therapists for consultation or therapy sessions. In public hospitals, patients must wait patiently in long lines to get health services. Nguyen, Tariq, Hinchcliff, and Dunne (2023) conducted a study in Vietnam that documented that parents prefer private healthcare institutions due to various factors such as word-of-mouth advertising, better social interaction, attitude, service, and marketing [21].

## V. THE STUDY'S LIMITATIONS

This research has several weaknesses. Firstly, the survey only included 86 parents with children with special needs from all over Indonesia, resulting in an uneven distribution of respondents. Thus, the results of this study are only an incomplete picture of the cost incurred per year by parents with children with special needs. Second, this research does not specifically discuss the costs of each child's diagnosed condition, whether in the mild, moderate, or severe category. This is because parents will incur different fees for each child's condition. Third, this research does not link the relationship between parental characteristics and the respective costs incurred to obtain health services for their children. We can conduct further studies with a larger sample to investigate the relationship between parental characteristics and each child's diagnostics, and the severity of the child's condition (mild, moderate, or severe).

## VI. CONCLUSION

87.2% of parents of children with special needs are between the ages of 30 and 45, which falls into the productive age category. The majority of parents in this study were female (95.3%), and their profession was homemade (57.0%). The majority of parents' education is a diploma (4 years) or bachelor's degree, which is in the higher education category (61.6%), and the majority of respondents are from

Java Island (65.1%). Meanwhile, the majority of distances from home to health facilities are 0–3 km (27.9%).

Most children are in the 5–10-year age group (55.8%), with the majority being male (74.4%). Autism spectrum disorder (ASD) accounts for the majority of children's diagnoses (58.1%), with 73.3% of diagnoses occurring at the age of 2–4 years. The costs of caring for children with special needs include occupational services (36.0%), speech therapy (38.4%), physiotherapy (45.3%), psychology (51.2%), doctor's fees (55.7%), complementary health (55.7%), medicines and vitamins (44.2%), and the children's laboratory (61.6%). In general, parents typically spend between 0 and 500,000 IDR on each item of health care services, resulting in total annual child health care costs of approximately Rp. 10,000,000 (33.7%).

The largest expenditure is on therapy costs (70.9%), with the majority of parents using services at the Child Development Clinic (36.0%). The majority of parents of children with special needs have health insurance, or BPJS (88.4%), and parents use their social health insurance for health services (48.8%). Parents expect that for therapists, the minimum formal education will be at the Diploma IV or Bachelor level (46.5%).

## REFERENCES

- [1]. Khorini'mah, S., M., & Kamala, I. (2020). Peran orang tua dalam melatih disiplin pada anak tunagrahita (The role of parents in training discipline in mentally retarded children *Journal on Teacher Education*), 2(1),5965. <https://doi.org/10.31004/Jote.V2i1.909>
- [2]. Pasyola, N., E., Abdullah, A., M., & Puspasari, D. (2021). Peran parenting self-efficacy dan optimisme terhadap psychological well-being ibu yang memiliki anak intellectual disability (The role of parenting self-efficacy and optimism on the psychological well-being of mothers who have intellectual children). *Psymphatic: Jurnal Ilmiah Psikologi*, 8(1), 131-142. <https://doi.org/10.15575/Psy.V8i1.12645>
- [3]. Putri, B., P., P., & Paryontri, R., A. (2022). Psychological well-being a housewives who have children with special needs. *Academia Open*, 7, 10-21070. <https://doi.org/10.21070/Acopen.7.2022.5098>
- [4]. Sari, S., F., M., Binahayati, B., & Taftazani, B. M. (2017). Pendidikan bagi anak tuna grahita (Studi Kasus Tunagrahita Sedang Di SLB N Purwakarta) (Education for mentally retarded children - Case Study of Moderately Mentally Impaired at SLB N Purwakarta). *Prosiding Penelitian Dan Pengabdian Kepada Masyarakat*, 4(2). <https://doi.org/10.24198/Jppm.V4i2.14273>
- [5]. Lindley, L., C., & Mark, B., A. (2010). Children with Special Health Care Needs: The Impact of Health Care Expenditures on the Family Financial Burden. *Journal of Child and Family Studies* 19(1):79-89. DOI:1007/s10826-009-9286-6



- [6]. Kemenkes. (2018). *Risikedas (Riset Kesehatan Dasar-Basic Health Research) year 2018*. [https://kesmas.kemkes.go.id/assets/upload/dir\\_519d41d8cd98f00/files/hasil-risikedas-2018\\_1274.pdf](https://kesmas.kemkes.go.id/assets/upload/dir_519d41d8cd98f00/files/hasil-risikedas-2018_1274.pdf)
- [7]. Darsana, G., M., & Suresh, V. (2017). Prevalence Of Caregiver Burden Of Children With Disabilities. *Int J Inform Futuristic Res*, 4, 7238–7249.
- [8]. Krisnandari, W., Rahyanti, S., Asih, S., Sari, C. (2023). Beban Orang Tua dalam Merawat Anak Berkebutuhan Khusus di Bali (Parents' Burden in Caring for Children with Special Needs in Bali). *Malahayati Nursing Journal*, [S.l.], v. 5, n. 4, p. 1221-1233, apr. 2023. ISSN 2655-4712.
- [9]. Buescher, P., Brunnsen, S., Whitmire, J., Klutz-Hile C. (2006). Children who are medically fragile in North Carolina: Using Medicaid data to estimate prevalence and medical care costs in 2004. *Maternal Child Health.10* : 461–466
- [10]. Newacheck P, Inkelas M, Kim S. (2004). Health services use and health care expenditures for children with disabilities. *Pediatrics*.114:79–85. [PubMed: 15231911]
- [11]. Shenkman E, Knapp C, Sappington D, Vogel B, Schatz D. (2007). Persistence of high health care expenditures among children in Medicaid. *Medical Care Research and Review*. 64 :304–330. [PubMed:17507460]
- [12]. Davidoff A. (2004). Insurance for children with special health care needs: Patterns of coverage and burden on families to provide adequate insurance. *Pediatrics*. 114 : 394–403. [PubMed: 15286222]
- [13]. Freidman D, Hilden J, Powaski K. (2005). Issues and challenges in palliative care for children with cancer. *Current Pain and Headache Reports*. 4: 249–255.
- [14]. Miedema M, Easley J, Fortin P, Hamilton R, Mathews M. (2008). The economic impact on families when a child is diagnosed with cancer. *Current Oncology*. 15: 173–178. [PubMed: 18769610]
- [15]. Montes G, Halterman J. (2008). Association of childhood autism spectrum disorders and loss of family income. *Pediatrics*. 12 : e821– e826. [PubMed: 18381511]
- [16]. Glickman, A., & Weiner, J. (2019). The burden of health care costs for working families. *LDI Issue Briefs*, 23(3). <https://ldi.upenn.edu/brief/burden-health-care-costs-working-families>
- [17]. Ghandour, R. M., Hirai, A. H., & Kenney, M. K. (2022). Children and youth with special health care needs: A profile. *Pediatrics (Evanston)*, 149(Suppl 7), S1–S17. <https://doi.org/10.1542/peds.2021-056150D>
- [18]. UNICEF. (2023). Landscape analysis on children with disabilities in Indonesia Embracing diversity and inclusion for all. Landscape analysis on children with disabilities in Indonesia | UNICEF Indonesia
- [19]. Shaban, S., & Amin, H. (2024). Childhood disabilities and the cost of developmental therapies: the service provider perspective. *International Journal of Qualitative Studies on Health and Well-Being*, 19(1). <https://doi.org/10.1080/17482631.2024.2345816>
- [20]. Micai., M., Fulceri, F., Salvitti, T., Romano, G., Scattoni, M.L. (2024) Access and cost of services for autistic children and adults in Italy: a carers' perspective.
- [21]. Nguyen, M., P., Tariq, A., Hinchcliff, R. (2023) Mengapa konsumen memilih layanan kesehatan swasta daripada layanan kesehatan publik? Catatan reflektif penyedia layanan kesehatan di Vietnam. (Why do consumers choose private healthcare over public healthcare? This study provides an in-depth analysis of healthcare providers in Vietnam.) *BMC Health Serv Res* 23, 900. <https://doi.org/10.1186/s12913-023-09892-9>