

## A Description of The Psychological Well-Being of Parents Who Have Children With Special Needs at Slb Asuhan Kasih Kupang

*Maleakhi Ludji<sup>1</sup>, Yeni Damayanti<sup>2</sup>, Mernon Yerlinda Carlista Mage<sup>3</sup>*

<sup>1,2</sup>Faculty of Public Health, University of Nusa Cendana

e-mail: [\\*1Maleakhiludji05@gmail.com](mailto:*1Maleakhiludji05@gmail.com), [2yeni.damayanti@staf.undana.ac.id](mailto:2yeni.damayanti@staf.undana.ac.id),  
[3mernon.mage@staf.undana.ac.id](mailto:3mernon.mage@staf.undana.ac.id)

**Abstract.** This study explores the psychological well-being of parents with children who have special needs and physical disabilities at the Asuhan Kasih Kupang special school. Six participants, selected through purposive sampling, were involved based on predefined criteria. Using qualitative methods, data was collected through interviews and analyzed using thematic analysis, revealing three key themes: acceptance, caregiving, and social support. The findings indicate that parents' psychological well-being is shaped by their ability to accept their child's condition, develop effective parenting strategies—such as fostering independence and offering positive affirmations—and rely on social support, including emotional, practical, and moral assistance. The study highlights the importance of coping strategies, such as engaging in spiritual activities to enhance gratitude, spending quality time with children, and fostering communication between schools and parents to alleviate anxiety. These insights provide valuable recommendations for enhancing parental well-being and caregiving practices.

**Keywords:** *Psychological Well-being, Parents, Disabled*

**Abstrak.** Penelitian ini mengeksplorasi kesejahteraan psikologis orang tua yang memiliki anak berkebutuhan khusus dan disabilitas fisik di Sekolah Luar Biasa Asuhan Kasih Kupang. Enam partisipan, yang dipilih menggunakan teknik purposive sampling berdasarkan kriteria tertentu, dilibatkan dalam penelitian ini. Dengan menggunakan metode kualitatif, data dikumpulkan melalui wawancara dan dianalisis menggunakan teknik analisis tematik, yang mengungkapkan tiga tema utama: penerimaan, pengasuhan, dan dukungan sosial. Temuan menunjukkan bahwa kesejahteraan psikologis orang tua dipengaruhi oleh kemampuan mereka menerima kondisi anak, mengembangkan strategi pengasuhan yang efektif—seperti mendorong kemandirian dan memberikan afirmasi positif—serta memanfaatkan dukungan sosial berupa bantuan emosional, praktis, dan moral. Studi ini menekankan pentingnya strategi coping, seperti melakukan aktivitas spiritual untuk meningkatkan rasa syukur, menghabiskan waktu berkualitas bersama anak, dan membangun komunikasi yang baik antara sekolah dan orang tua untuk mengurangi kecemasan. Temuan ini memberikan rekomendasi berharga untuk meningkatkan kesejahteraan orang tua dan praktik pengasuhan.

**Kata kunci:** *Kesejahteraan Psikologis, Orangtua, Tunadaksa.*

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## **Introduction**

The presence of children in a family is considered a gift that brings happiness and hope for the future (Muzfikri in Budiarti & Hanoum, 2019). However, not all parents are blessed with healthy and normally developing children; some have children with special needs, including children with disabilities (Pasyola, Abdullah & Puspasari, 2022).

Children with special needs have different characteristics from children in general and are classified into several categories, including disabilities (Budiarti & Hanoum, 2019). Based on data from the Central Statistics Agency (BPS, 2022), the number of children with special needs in Indonesia is quite significant, including in East Nusa Tenggara (NTT). In NTT, the number of children with special needs reaches 17% of the total population, with 3.5% of them being children with disabilities. This data shows that many families in NTT face similar challenges in raising children with special needs.

This study was conducted at the Asuhan Kasih Kupang Special School (SLB), which provides inclusive facilities for children with disabilities, such as wheelchair ramps and accompanying teachers. These facilities are beneficial in meeting the special needs of children, but parental anxiety remains. Although the facilities are quite good, parents still feel anxious about their children's conditions at school. One of the parents interviewed expressed his anxiety even though there were adequate facilities and continued to accompany his child to school to reduce his stress. This shows that physical facilities alone are not enough to overcome parents' emotional concerns.

Physically disabled, or children with physical limitations, experience various difficulties in carrying out daily activities (Yulianasari, 2022). This condition causes

psychological stress for parents, including feelings of panic, shock, and shame (Santana & Istiani, 2019).

According to Ryff (1989), psychological well-being involves a balance between negative and positive impacts, as well as the ability to manage stress and accept various aspects of self-identity. Yulianasari (2022) added that psychological well-being reflects individual satisfaction and happiness, involving acceptance, affection, and achievement. Social support provided by the family can be in the form of emotional support, information support, appreciation support, or instrumental support. Conversely, lack of social support can hinder their well-being, increasing the risk of stress, anxiety, and depression (Wangi & Budisetyani, 2020).

This study aims to describe the psychological well-being of parents who have children with special needs and physical disabilities at SLB Asuhan Kasih Kupang. By understanding their psychological condition, it is hoped that effective ways can be found to support them in this important role.

### **Method**

The type of research used in this study is a descriptive qualitative research type that aims to describe the picture of the psychological well-being of parents who have children with special needs and physical disabilities at SLB Asuhan Kasih Kupang. The data collection technique used semi-structured interviews with 5 parents who have children with special needs and physical disabilities as participants. The data analysis technique used thematic analysis which was arranged into several themes and sub-themes based on each participant's answer, then analyzed based on the theory of psychological well-being dimensions put forward by Ryff (1989) and supported by other studies.

This research was conducted in Kupang City, East Nusa Tenggara. The participant selection technique in this study used purposive sampling, namely biological parents (mother and/or father) who have children with special needs and physical disabilities who attend elementary school at SLB Asuhan Kasih with a

classification of moderate and mild special needs, biological parents who live under the same roof as their children, residing in Kupang City, willing to sign informed consent as research subjects.

## **Result**

### **1. Acceptance process**

This acceptance process also reflects the dimensions of self-acceptance and personal development based on the theory of psychological well-being dimension development (Ryff, 2013), which involves the ability of parents to see and accept all aspects of themselves and their children's physical limitations including good and bad qualities of life in the past and present, and parents also have good personal growth because of the self-acceptance they have, allowing parents to gradually have an increase in gratitude over time.

#### **a. Tragic situation**

This tragic situation is also related to Ryff's (2013) theory of developing dimensions of psychological well-being in the dimension of life goals, namely that someone who does not have a sense of meaning in life has a low score in the dimension of life goals in his theory of psychological well-being. This was expressed by the participants as follows:

*"At first, it felt like I couldn't accept it because everything seemed normal during the pregnancy. The father also found it hard to accept and felt disappointed." (MS)*

*"Shock, of course, sadness too, and it was difficult to accept at first, but it is a gift from God, so we must be patient and grateful." (A)*

*"If we feel sad, then yes, it's sad, but we must accept the reality as it is—perhaps it's destiny too." (YK)*

*"In the beginning, I couldn't accept it; I was in shock and felt sad when the doctor diagnosed that he had brain nerve paralysis." (IR)*

*"Honestly, as a father, I feel very disappointed and deeply hurt—it's a mix of emotions, and overall, I just can't accept it." (MR)*

**b. Feelings of gratitude**

The feeling of gratitude experienced by parents is also connected to Ryff's (1989) dimension of psychological well-being, namely self-acceptance, where the feeling of gratitude reflects the ability of parents to accept conditions and situations that cannot be changed, both those that have occurred in the past, but still feel valuable and meaningful in their lives. This was expressed by the participants as follows::

*"We cannot measure how long it takes to accept, but we just go through it with time and be grateful for this gift from God." (MS)*

*"So, it will definitely be troublesome, but we must always go through it and be grateful." (MS)*

*"No, because I believe this is a gift and blessing from God, so we must be grateful and accept it as it is" (A)*

*"Now I am grateful to have him, although it is challenging, there are many things he can't do, but that is where God tests us, and yes, I have managed to get through to this point."(IR)*

*"Now, I am just grateful, so my hope now is at least that he can walk, so his life won't be as difficult anymore." (MR)*

*"Yes, it takes extra effort and time to raise him this far, and we are grateful for that." (NK)*

*"To be honest, I am very grateful to God. Although he has special needs, I love him very much, and every day I always pray and hope to God that my child will be able to walk and improve so that, when we are no longer here, he will be able to be independent." (MR)*

**2. Parenting**

This parenting is in line with the dimensional theory proposed by Ryff (1989) namely about independence and positive relationships with others. In this context, the dimension of independence refers to the ability of parents to feel competent and

effective in caring for their children with special needs so that parents need to develop appropriate strategies and support to help their children develop independence.

**a. Challenges for parents of children with disabilities**

The challenges of parents with special needs and physical disabilities are also connected to the theory owned by Ryff (1989), namely the dimensions of independence and personal growth. Independence involves the ability of parents to manage their own lives and make decisions more freely. This was expressed by the participants as follows:

*“We have to bathe them until they reach middle school age, and even small daily activities like putting on shoes, we still need to help them.” (MS)*

*“We used to have difficulty taking my child to medical appointments because we didn’t have a vehicle, so we had to use public transportation while carrying our child for long distances to reach the treatment center. Especially since my husband had a stroke in 2007, we haven’t been able to seek medical treatment anymore.” (A)*

*“The challenge is that we always have to keep an eye on him because sometimes he can suddenly fall off the chair and tumble. The second challenge comes from outside the home, like when people talk about him, saying things like “he can’t do this or that,” which makes us think a lot. But, well, we are the ones living with it, and they don’t know what we feel.” (YK)*

*“For example, when taking care of him, when he was 1-2 years old, we could still carry him around, take him anywhere, but as he grows older and gains weight, it’s becoming more difficult to manage his condition. Carrying him is hard now, and if we want to take him to a playground, it was easier before. But now, it’s difficult to bring him anywhere without a wheelchair.” (IR)*

*“When she starts to get sick, we begin to stress because she will likely experience seizures, and her body will become stiff, causing nerve disruptions.” (NK)*

*“From my perspective, when he gets sick, I won’t be able to focus or concentrate on my work at the office. I mean, he’s different from his younger siblings, so he requires extra care to look after him, which means we automatically have to give him more attention.” (MR)*

Participants received negative stigma from neighbors because the participant had a child with special needs which made the participant feel hurt and resigned. This was expressed by the participant as follows:

*“Initially, they mocked us when we were still at the old house, and my younger brother often defended us because, well, this situation is not something we asked for.”*

#### **b. Stress/pressure**

This feeling of stress is also related to the theory of psychological well-being developed by Ryff (2013) in the dimension of life goals, namely someone who does not have a sense of meaning in life in the future or does not have confidence in the future, has a low score in the dimension of life goals in the theory of psychological well-being. This is based on the pressure or stress obtained by parents, stress itself arises because parents lose independence and control over their lives because a lot of time and energy is spent on raising and caring for their children. This was expressed by the participants as follows:

*“We are stressed too, but even if we are stressed, there’s no one to help, so we can only accept it with sincerity and keep praying. Especially since the father got sick, I’ve had to take care of everything, from feeding him to having to spoon-feed him one by one.”(A)*

*“Indeed, even though we take care of him like this, we still feel pressured, like we want to get angry, but it’s useless. He wants a lot of things, so we always have to follow what he wants because if we don’t, he will definitely sulk.” (YK)*

*“If the pressure is too much, it’s not really stress, but it feels like it when we’re exhausted. It’s like we face this and say, “Why does he have a child like this?”*

*But then we also remind ourselves, "Just go through it, just try to be sincere."*

(IR)

*"Humanly speaking, of course, there is stress, but I don't let it affect me because I think maybe this is also a test from God. My principle is, what you sow is what you will reap. So, if I think about being stressed, then who's going to take care of them, who's going to provide for them?" (MR)*

*"From my side, it's definitely stressful. So, when she's sick, I get worried, but I still try my best to take her to the doctor, whether it's with medication or by giving her a massage." (NK)*

Participants have anxiety about the future of their children where parents will not live forever with their children so they are afraid that their children will not be able to be independent in the future. This was expressed by the participants as follows:

*"Worried, because with those physical limitations, parents are bound to be concerned. How will they manage when they get married? Will they have a partner who truly accepts them and cares for them?." (MS)*

*"Yes, that's definitely worrying, because if we pass away, who will take care of them? But fortunately, now they are quite independent. However, even though there are relatives, uncles, and aunts, their way of caring and looking after them will never be the same as ours. For a day or two, people might be patient, but over time, they will definitely get tired, and they will probably get bored of helping." (IR)*

*"Yes, I do have concerns, of course. Right now, he still needs help, for example, when he wants to go to the bathroom, he still needs assistance, he isn't independent yet. As for eating, he can do it slowly." (YK)*

*"This anxiety is clearly present because there are many things he still depends on us for, but I remain determined to help teach him and motivate him for the small things he might be able to do. So, I do feel anxious, but I hope that someday he will be able to do many things like that." (NK)*



### **c. Coping stress**

In carrying out coping strategies, parents need to develop self-acceptance, build positive relationships with others, maintain autonomy, master their environment, find a purpose in life, and continue to grow personally, as explained in Ryff's psychological well-being theory (1989) which includes 6 dimensions. This was expressed by the participants as follows:

*"Be silent, take a deep breath, and let everything flow, but it's good that the people at home already understand, so when I go silent, they will take over at 65. Then, when I'm tired, we also talk and share thoughts with my husband, so we can be supportive of each other."* (MS)

*"I pray, perform ablution, and then read the Quran."* (A)

*"Stay calm and maybe just pray so you don't get too caught up in the situation."* (IR)

### **3. Social support**

This social support is in line with the theory put forward by Ryff (1989), namely the dimensions of independence, positive relationships with others and mastery of the environment.

#### **a. Family**

The existence of social support from the family allows parents to develop themselves and achieve their maximum potential to achieve life goals and have self-acceptance of their child's condition and of themselves, in accordance with the dimensions of independence and self-acceptance put forward by Ryff (1989). This was expressed by the participant as follows:

*"We take care of them together. When I work, it means that my husband takes care of them, and vice versa. Their grandparents, opa and oma, also help by taking turns looking after them."* (MS)

#### **b. Community environment**

Based on the theory of psychological well-being dimensions from Ryff (1989), participants already have good environmental mastery values because participants have a sense of mastery and are competent in managing the environment. This was expressed by the participants as follows:

*“Alhamdulillah, the neighbors did not mock or make fun of us; instead, they provided positive support.” (A)*

*“Our environment always responds positively to us. In fact, our non-Muslim neighbors are very harmonious with us.” (A)*

*“If the neighbors around accept his presence well, because he often goes around in a wheelchair with me.” (YK)*

*“As for the negative stigma, I don’t think there’s any from the neighbors. In fact, when they see him, they even give advice, like suggesting where to go for treatment, here or there, to (F).” (IR)*

*“Until now, there hasn’t been any, in fact, every time we pass by with (N), they always praise her and give her motivation.” (MR)*

*“Even like when I post her story on WhatsApp, the comments are all positive, they say she looks even more beautiful, basically, all positive comments.” (NK)*

### **c. School environment**

Social support at school is related to the theory of dimensions of psychological well-being according to Ryff (1989), namely positive relationships with other people, parents have warm and trusting relationships through good communication with teachers, allowing parents to have low levels of anxiety, because they already have trust in teachers at school.

*“The children are close to the teachers, so close that as a parent, I feel my child is safe at school, even with the child’s physical limitations. (F)” (IR)*

## **Discussion**

This acceptance process refers to the attitude of not accepting the child's condition, understanding, and finally accepting the condition of the child with special needs and physical disabilities. Participants expressed that accepting and

letting go of their child's existence did not take years, because participants had learned to live and be grateful as time went by.

This acceptance process also reflects the dimensions of self-acceptance and personal development based on the theory of developing dimensions of psychological well-being according to (Ryff, 2013), which involves the ability of parents to see and accept all aspects of themselves and their children's physical limitations including good and bad qualities of life in the past and present.

Participants have the view that being a parent with a child with special needs and physical disabilities is a tragic situation when you first find out. Tragic circumstances refer to the sad situation for participants who have children with special needs, namely physical disabilities.

Participants viewed that feelings of gratitude were felt when they saw their children had developed and this sense of gratitude was also obtained over time by remaining patient and accepting things as they are because everything is a gift from God. Prasa (2012) stated that parents who have children with special needs with high gratitude are able to realize that everything that happens in their lives is a gift from God. Participants also revealed that caring for children with special needs will drain a lot of energy and time, therefore parents really need something called having a positive relationship with other people, be it from family members and friends, it can be in the form of emotional support or practical support.

The challenges faced by parents of children with special needs are very diverse, it can be from within the family itself or from the outside environment. Participants revealed that having a child with special needs has great challenges and hassles because they have to give a lot of time to take care of their children which makes children continue to depend on their parents because they have limited abilities so that it greatly affects the physical aspects of the participants which results in fatigue for the participants. In addition, challenges in the form of social aspects such as negative stigma and discrimination were also felt by one of the participants. Brydges & Mkandawire (2018) revealed that the difficulties and

challenges faced by parents of children with special needs are the amount of time that must be spent, so that it will hinder parents from developing their potential, working, earning income, or activities needed for the welfare of the parents themselves. This is also in line with the dimensions of the theory owned by Ryff (1989), namely the dimensions of independence and personal growth. The difficulties and challenges faced by parents who have children with special needs make parents more vulnerable to disruption of their psychological well-being, one of the factors is experiencing stress.

Participants expressed that the stress they experienced caused participants to always think and become tired and participants also had pressure in the form of anxiety about the future of their children which made it difficult to interpret future life goals for their children. Ahern & Senatore (2004) define parenting stress as being seen from excessive anxiety related to the interaction and role of parents with their children. Based on the participants' answers, there is a dimension that is primarily related to the theory of psychological well-being developed by Ryff (2013) in the dimension of life goals, namely someone who does not have a sense of meaning in life in the future or does not have confidence in the future, has a low score in the dimension of life goals in the theory of psychological well-being.

Based on the literature research conducted by the author, the results were found to explain that parents of children with special needs experience pressure in accepting the condition of children with special needs in the care process. This is different from the results of the research findings which explain that one participant did not feel pressure when he found out about the condition of the child with special needs because the participant already had good acceptance. The acceptance was obtained by the participant because he already had a high sense of gratitude and social support from the family, also from the beginning knowing that his child had physical limitations. There were several obstacles experienced during the research, namely the difficulty of arranging interview schedules because each participant had different working hours.

### **Conclusion**

Overall, this research shows that the psychological well-being of parents who have children with special needs who are disabled is influenced by the parents' ability to accept the child's condition, develop effective parenting strategies, and receive adequate social support. Through a process of acceptance, nurturing, and social support, parents can achieve better psychological well-being despite facing various challenges.

### *Suggestion*

The advice that can be given is through the process of acceptance, care, and social support, parents can achieve better psychological well-being despite facing various challenges, and parents are expected to strengthen gratitude and do activities together such as doing hobbies together with children and Usually every small development in children by giving positive affirmations to themselves and those closest to them. For school institutions, it is expected to increase active communication with parents of all students with special needs, not only physically disabled. So that it helps reduce parental anxiety about the condition of children at school. Participants are also advised to manage stress and anxiety through spiritual coping techniques such as praying and praying together to increase emotional closeness with children.

Further researchers suggest that research be conducted on the topic of the influence of spiritual care on the psychological well-being of parents who have children with special needs.

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