

## Conceptualizing social support in families of children with special needs

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### Abstract

*Purpose:* Families usually try to organize the family environment and reach out to resources that can meet their child's needs. Successful resource utilization is important for families in dealing with the daily challenges and demands of caring for a child with special needs. In particular, social support influences the successful adaptation of these families. The concept of social support is increasingly being used to understand families and their functioning, and this research contributes to the evolving process of adaptation.

*Method:* This study used systematic literature review design. The article search was carried out from January- March 2022 for the literature on parenting styles for children with special needs.

*Result:* The results mentioned that one or all of the family members experienced adjustments in their work, i.e. shortened working hours, quit their job, or quit their job. The various adjustments that must be made often lead to various disturbances and stress for parents. The stress experienced by parents is also related to the heavy responsibilities of caring for and raising children. Parents' reactions vary. There are parents who cope realistically, resisting, feeling sorry for themselves. When facing significant stressors, families will go through certain processes that allow them to survive and adapt until they can become a harmonious family.

*Conclusion:* This social support can be emotional, assistance, or informational because it can have an effect on children with special needs so that they do not have to worry about their own weaknesses. Children with special needs that they do not feel different from normal children. This shows that one of the family functions is working very well.

**Keywords:** children disabilities; preschool; social support

### INTRODUCTION

Children's age is a golden age, so it is very important to pay attention to their development. Especially if there is a suspicion that his growth and development is different from children his age. Golden age is a very important time to pay close attention to the growth of children so that as early as possible can be detected in case of abnormalities. Children are the next generation of the nation, the quality of the development of toddlers in Indonesia need serious attention, namely getting good nutrition, stimulation that accommodates, and affordable by quality health services, detection, early intervention deviation in growth. The growth and development of children have increased rapidly at an early age, namely from 0-5 years. This period is often also referred to as the "Golden Age" Phase (Annaditha AC, 2017). Children who are in a period of growth and development have a great curiosity about their surroundings. This is indicated by the number of questions asked by them. This curiosity provides an opportunity for children to learn about something. The interaction of children with their environment, for example with peers or teachers, will make children learn to develop their social and emotional aspects. The problem of individual

development from birth, childhood, adolescence to adulthood is an interesting problem to look at. Some of the symptoms of children with special needs can be detected at toddler age because at the age of 1-3 years there is rapid development in children. We can find out by marking some inappropriate developments. According to the Law of the Republic of Indonesia Number 35 of 2014, children with disabilities are children who have physical, mental, intellectual or sensory limitations for a long time in interacting with the environment and the attitudes of society can encounter obstacles that make it difficult to participate fully and effectively on the basis of equality rights. According to Bahari (2019), a linguist from the Indonesian University of Education, disability is defined as an inability or deficiency (physical or mental) so that there are limitations to doing something. The term disability is used to invite the public to correct their views, which previously saw an abnormal condition or disability as an inability or lack of understanding of disability as a human being with a different physical condition. From the Inclusion of Persons with Disabilities data, the number of people with intellectual disabilities in Indonesia is 1,389,614 people (Rahmawati & Jagakarsa, 2018). However, early detection of abnormalities in children also influences many aspects of their growth and development. The high level of dependence of children in carrying out daily activities is a very big burden for parents, caregivers and health service providers (Munir & Virana, 2019). Families of children with special needs are known to experience excessive caretaking demands as well as extraordinary emotional stresses. Parents of a child with special needs often need to engage physically demanding care activities, constantly monitor the child's health status, and maintain multiple health, therapy and educational appointments. Emotionally, parents must learn to live with the child's condition and revise their earlier dreams and expectations, concurrently assessing and sometimes challenging professional recommendations and available services. Increasingly, early childhood programs include children with disabilities and children who are normally thriving. The purpose of this paper is to review the current empirical literature that underlies inclusion practices at the early childhood level to provide context for future research. We first explain the definition of children with special needs, class inclusion, and the demographics of children with special needs. Using Cohen's (1985) theory of social support systems as a conceptual framework, we review research related to classroom practice, children's social interactions, parental beliefs, teacher support and health professional collaboration. We conclude this review with an examination of research that illustrates the influence of the concept of social support on those with physical or mental disabilities that occur at different levels and recommend directions for future research.

## **METHOD**

Initial behavioral and diagnostic information regarding children was collected from the state agency during the referral process. Additional child and family information was obtained from parents and existing agency records. As additional data, researchers prepared a questionnaire that was distributed to several special needs school institutions and must be filled in by parents of students. the aim is to get more accurate results other than literature reviews sourced from books, scientific papers, articles, theses and others. To protect participants anonymity, answer sheets were sealed in a plain envelope, identified with a predetermined code number, and secured in locked files.

**Study Design:** A systematic review method was adopted from Cohen's theory of issues in the study and application of social support for research, using the principles and methods of systematic literature review.

Data sources: A systematic search was carried out from January- March 2022 in the following databases: literature on parenting styles for children with special needs (online libraries, nursing journals, PsychINFO, social support literature, nursing psychology literature). Comprehensive search for combined term sets including and related to parental and institutional involvement (government, teachers, schools, infrastructure) type of involvement (participation, collaboration, interaction, consultation). In addition, References of all relevant articles were reviewed for studies that might have been missed during the initial search. A study or report was included in this review if it met the following criteria: target population is children at preschool for diagnosed with slow learner, developmental delay, emotional disturbance study is conducted in Indonesia, study describes approaches that target service providers like theachers or families and study reports outcomes related to early detection.

## RESULT

Play as well as learning, are natural components of children every lives. Providing children the freedom to select their own play activities is an aspect of developmentally appropriate practices that may have an important influence on children’s development. Hauser-Cram, Bronson and Upshur (1993) conducted a naturalistic study of 153 children with disabilities enrolled in community-based preschool programs. In classrooms where teachers offered more choice of activities, children with disabilities engaged in “more and higher levels of peer interaction and appeared to be less distracted and more persistent when involved in mastering tasks”. Similarly, found more positive interactions between children with and without hearing impairments when teachers provided consistent opportunities for children to work together in the same small groups.

The following table shows the characteristics of children with special needs, namely:

**Table 1**  
*Characteristics of Children with Special Needs*

Characteristics	Explanation	Causes
Slow learner (Reddy,1997; Chauhan, 2011; Borah, 2013)	The condition of someone who has retardation in every subject, limited achievement, does not stand out and is different from their peers because their cognitive abilities are below average so that extra effort is needed to meet the demands of learning in class	<ul style="list-style-type: none"> <li>● Poverty</li> <li>● Intelligence of Family Members</li> <li>● Emotional factors</li> <li>● Personal factors</li> </ul>
Emotional disturbance (Bower, 1982)	This term means a condition that exhibits one or more of the following characteristics over a long period of time, time and to some degree, which adversely affects educational performance: (a) learning disabilities that cannot be explained by intellectual, sensory, or health factors; (b) inability to establish or maintain satisfactory interpersonal relationships with peers and teachers; (c) a type of behavior or feeling that would be inappropriate under normal circumstances.	<ul style="list-style-type: none"> <li>● Biological Factors</li> <li>● Psychological/personal factors</li> <li>● Social factors</li> </ul>
Physical	Physical disability can be interpreted as a motor	<ul style="list-style-type: none"> <li>● Genetic Factor</li> </ul>

Characteristics	Explanation	Causes
disability (Nisa et al., 2018)	disorder. A disabled child is a child who has impaired movement function caused by problems with the motion organs in the body. Physically disabled children experience disturbances in their limbs, but in general disabled children do not experience problems with intelligence abilities. In general, disabled children experience normal development like other children. Children with physical disabilities grow up with problematic body conditions, of course this will more or less affect their social-emotional development.	<ul style="list-style-type: none"> <li>• Chromosomal problems</li> <li>• Lifestyle and environment</li> <li>• Infection</li> <li>• Smoke</li> <li>Alcoholic Beverages</li> </ul>
Down syndrome (Epstein, 1989)	Down syndrome is the set of physical, mental, and functional abnormalities. The physical abnormalities that together give rise to the distinctive facial appearance associated with this condition include upslanting palpebral fissures with inner epicanthic folds, flatness of the bridge of the nose, midfacial hypoplasia, and a tendency to protrude the tongue.	<ul style="list-style-type: none"> <li>• Chromosomal abnormalities</li> <li>• Malnutrition</li> <li>• Chemical exposure</li> </ul>
Visually Impaired (Sasraningrat, 1984)	A visually impaired child is a child who for some reason has a vision condition that does not function properly. This condition is caused by damage to the eye, optic nerve and or parts of the brain that process visual stimuli.	<ul style="list-style-type: none"> <li>• Glaucoma</li> <li>• Diabetes</li> <li>• Cataract</li> <li>• Trachoma</li> </ul>
Total		

### **Stages of Child Development**

According to Hurlock (1950) child development is divided into 5 periods, namely:

- a. Prenatal period that starts from the time of growth until birth. In this period there is a very rapid physiological development, namely the growth of all parts of the body as a whole.
- b. The neonatal period is the period of the newborn. This period is calculated from 0 to 14 days. During this period, the baby adapts to its new environment in the mother's womb.
- c. Infancy is the period when the baby is 2 weeks old to 2 years old. At this time the baby learns to control his own muscles until the baby has a desire to be independent.
- d. Childhood consists of 2 parts, namely early childhood and late childhood. Early childhood is the period of children aged 2 to 6 years, where this period is also called the pre-school period, namely the period when children adjust socially. The end of childhood is the age of 6 to 13 years, commonly referred to as school age.
- e. Puberty is the time when children are 11 to 16 years old. This period includes an overlapping period because it is the 2 years of late childhood and 2 years of early adolescence. Physically, the child's body in this period gradually changes into an adult's body.

**Characteristics of growth and psycho-physical development of children**

There are several characteristics of growth and psycho-physical development of children according to Kartini Kartono (1990), namely:

- a. Age 1-6 years: moral skills develop, activity and space for movement become active, games are individual, already understand space and time, are spontaneous and curious, colors have an influence on children, like to listen to fairy tales.
- b. Age 6-8 years: psychomotor condition is developing, games are in groups, not too dependent on parents, contact with the outside environment is getting more mature, aware of the presence of nature around them, shapes are more influential than colors, a sense of responsibility begins to grow, the peak of fun playing was at the age of 8 years.
- c. Age 8-12 years: psycho-motor coordination is getting better, group games, organized, disciplined, playing activities are activities after learning, showing interest in certain things, curious, trial and error, investigating, active, can separate perception from actions that use logic, can understand the rules.

Malnutrition can affect the brain development of toddlers. Malnutrition in toddlers in Indonesia is increasing every year. The four most important forms of malnutrition worldwide (protein-energy malnutrition, iron deficiency and anemia (IDA), vitamin A deficiency (VAD), and iodine deficiency disorder (IDD) are examined below in terms of global and regional prevalence, age and gender, groups, those most affected, their clinical and public health consequences, and especially, recent advances in country and regional quantitation and control. Refers to Hurlock's opinion about the Stages of Child Development in the Prenatal period which starts from the growth period to birth. At this time there is a very rapid physiological development, namely the growth of all parts of the body as a whole. At this time a balanced nutrition is needed to avoid malnutrition which can be fatal to the growth and development of the fetus while in the womb. There are a number of food safety issues that apply to women before and during pregnancy. It is advisable to pay particular attention to food hygiene during pregnancy, and to avoid certain foods in order to reduce the risk of exposure to potentially harmful food pathogens. Toddler nutrition status is the important fact that should be concerned by each parents. Malnutrition in this golden periods are irreversible (cannot be recovered). Nutrition plays a vital role in the community. Increasingly, early intervention services including nutrition are provided at the community level. Visible growth disorders are weight and height that are less than normal. While developmental disorders can be in the form of psychomotor development disorders, intelligence disorders, and mental disorders. Nutrition is an important factor in supporting the growth and development of children with special needs. The problem of nutrition for children is very complex, and it certainly requires the involvement of an interdisciplinary team to reduce risks and increase positive outcomes for each child.

Based on data Indonesia's population projection conducted by UNICEF (2020) the total population of Indonesia in 2020 is 261,890,900 people. From the BPS projection data, it can be estimated that the number of persons with disabilities in Indonesia is 31,819,744 people. Of the 12.15% number of persons with disabilities, it can be divided into 10.29% including the moderate category and 1.87% including the severe category (Cahyati, A. D., & Choirunnisa, N. M., 2022). Meanwhile, the World Bank and ILO know that 15% of the world's population or around one billion people are persons with disabilities (Yogi, 2018). Seeing the large number of persons with disabilities is a challenge in itself, especially for parents who have children/family members with unusual symptoms (disorders). Parental involvement / support in parenting is very helpful for the

development of children with disabilities, such as taking the time to do activities with children, such as playing while talking, pouring out all thoughts, feelings, providing supervision, prayer, positive energy in the form of verbal and non-verbal to children. In line with research (Amelasasih, 2016) the resilience of parents who have children with special needs is needed, so that they can deal with the pressures faced during the care period and accompany the growth and development of children. Resilience is an individual's ability to adapt well even when faced with difficult circumstances. This is very important to support children in carrying out all activities both academically and non-academically.

**Tabel 2**

*Mother Characteristic*

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Mother Education	we know that parents have an important role in providing care to children. If the parents' mindset is embedded that children with special needs cannot make themselves valuable, this will affect the care given by parents to children. Caregiving can be implemented with the main functions of the family such as providing affection by creating a warm family atmosphere and providing genuine affection to children. There is security and acceptance by maintaining physical needs and accepting individuals as full family members by not saying that children are a "disgrace" to the family and providing a sense of security to children. Another important thing is identity and satisfaction where parents are agents of change as well as those who facilitate children to be able to develop their talents and interests. The importance of parent education in caring for children with special needs is of particular value. This can avoid parents from anxiety that can lead to mother stress.
Mother Stress	Parenting a child with a developmental disability has been shown to be particularly stressful for parents as they respond to the unique challenges presented by their child's disability. Numerous studies have suggested that severe disability in children has adverse effects on their families. The daily care of the child often depletes parent's energies and time, causing withdrawal from social and cultural activities. Besides, have also that parents experience financial problems, worries about the future of disabled child, and feelings of guilt and isolation. There is also evidence of increased marital tensions and parent-child conflicts.
Perceived Social Support	functional impairment could lead to deficits in social support because restrictions in mobility and difficulty in managing independent daily life impede engagement in social relationships and fulfillment of social roles. It suggests that people with disabilities with poor physical functioning experience restrictions in valued social activities. Social support is very influential on children with special needs in making these children not differentiated from other children their age. Support, motivation, encouragement and appreciation for them are very important.

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**DISCUSSION**

Factors related to maternal stress were considered together to predict the level of stress experience by mothers. Parenting a child with a developmental disability has been shown to be particularly stressful for parents as they respond to the unique challenges presented by their child's disability.



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Literature indicates that parents of children with a disability report greater levels of stress than do parents of typically developing children. These results are consistent with other literature establishing associations between the severity of behavior problems and level of parental distress for parents of children with developmental disabilities (Abbeduto et al., 2004; Baker et al., 2002). Mothers' success in parenting children with disabilities is affected by the emotional burden they experience due to stigma. Previous studies have shown a significant correlation between parenting stress and mothers' independence in parenting children with disabilities (Chinmi et al., 2020; Hong & Liu, 2021; Kabiyea & Manor-Binyamini, 2019). A person's perception of their ability to assume caregiving responsibilities is called self-efficacy (Coleman & Karraker, 2000; Kabiyea & Manor-Binyamini, 2019). The process of evaluating self-ability involves the thinking process, so self-efficacy becomes the cognitive basis for parents' adaptability in carrying out parenting functions (Meyer & Wissemann, 2020). Ultimately, parental self-efficacy is the basis for the effectiveness of parenting practices.

Parents' direct involvement in childcare increases parental independence. When parents see the developmental progress of children with disabilities, their feelings of satisfaction can increase parental efficacy (Boruszak-Kiziukiewicz & Kmita, 2020). In parenting, there are five dimensions of parental self-efficacy: (1) providing parental support for children's school performance; (2) helping children participate in recreational and social activities; (3) building habits for children's independence; (4) providing guidance on children's emotional development; and (5) maintaining children's physical health (Coleman & Karraker, 2004). Social support is positively correlated with caregiver independence and caregiving stress. In contrast, social support was negatively correlated with caregiver independence (Hong & Liu, 2021). This means that parents who can get support from others can be more confident in parenting a child with a disability and reduce the stress brought about by caregiving. The mother's ability to try to lower the stress level of caregiving is also a component that supports parenting self-efficacy (Asiyadi & Jannah, 2021; Maryam, 2017).

Mothers found the significance of having a child with a disability to be a faith- and character-building experience that strengthened their relationship with their partner. Awareness of spirituality influenced mothers' independence. Spirituality supports mothers' readiness to care for their child with genuine love without regretting their child's limitations. The expression of mental health functioning of caregivers and people with disabilities is known as spirituality (Ardali et al., 2019; Hodge & Reynolds, 2019). There is a relationship between spirituality and reduced stress levels experienced by mothers when caring for children with disabilities (Noviyanti et al., 2020). Individuals who have a close relationship with God experience mental health and calmness in living their lives, while individuals who move away from God experience stress and insecurity when facing difficulties (Kihe, 2019). One of the effects of awareness and obedience to God's will is the mother's ability to positively interpret the experience of having a child with a disability. Spirituality helps mothers of children with autism spectrum disorder avoid stress and hopelessness (Karaca & Şener, 2019). Parents' engagement and understanding of religious teachings, tawakkal, gratitude, and patience support parents' responses to their children's circumstances and their belief in taking care of their children (Abdussamad et al., 2022).

## **CONCLUSION**

The present investigation advances the literature by addressing several methodological limitations indicated in previous research. Children are the next generation of the nation, the quality of the

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development of toddlers in Indonesia need serious attention, namely getting good nutrition, stimulation that accommodates, and affordable by quality health services, detection, early intervention deviation in growth. The growth and development of children have increased rapidly at an early age, namely from 0-5 years. Toddler nutrition status is the important fact that should be concerned by each parents. Malnutrition in this golden periode are irreversible (cannot be recovered).

1. Nutrition plays a vital role in the community. Increasingly, early intervention services including nutrition are provided at the community level. Visible growth disorders are weight and height that are less than normal. While developmental disorders can be in the form of psychomotor development disorders, intelligence disorders, and mental disorders. Nutrition is an important factor in supporting the growth and development of children with special needs. The problem of nutrition for children is very complex, and it certainly requires the involvement of an interdisciplinary team to reduce risks and increase positive outcomes for each child. Age 1-6 years: moral skills develop, activity and space for movement become active, games are individual, already understand space and time, are spontaneous and curious, colors have an influence on children, like to listen to fairy tales. Families, especially parents, make a solution to the stigma against their children by providing full support, giving trust and providing motivation that their children with special needs can carry out normal activities like other normal children even though their children with special needs have few shortcomings.
2. Parents must believe that their children with special needs can carry out activities and achieve like other normal children. This social support can be emotional, assistance, or informational because it can have an effect on children with special needs so that they do not have to worry about their own weaknesses. Children with special needs that they do not feel different from normal children. This shows that one of the family functions is working very well. This is because parents try their best to take care of their children very well. In addition, support from close people such as family, relatives, friends, the environment, society, especially parents can give confidence to children with special needs to learn new knowledge and try new things. Each parent can become a pair of role models for their children in providing all the attention, love and affection that is more attention, love and affection to their children. Finally, research examining social support issues for parents of children with special needs could be used to inform the development of individually tailored social support intervention approaches designed to reduce parental concerns about children's futures. in which case, if successful, it could serve to reduce symptoms that may make the child even less confident.

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