



Social Support for Parents of Disabilities Children: A Scoping Review

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ABSTRACT

Raising children with disabilities can be a heavy burden for families which ultimately has a negative impact on the child. Many studies recommend the need for social support for parents. Although the need for social support has been widely reported, the impact of social support for parents with disabilities children in the literature is very diverse. Therefore, a scoping review was conducted to identify the impact of social support for parents of children with special needs in international studies. Four databases were systematically searched. Boolean operators were used to search multiple online databases. Ten studies were included in the review, from which positive impacts of social support for parents with disability children were identified on parents themselves, families, and children. The positive impacts of social support on parents were increasing resilience, coping skill, parenting efficacy, parenting mental health literacy and decreasing psychological distress and depression-anxiety symptoms. The impacts for parents are also buffering effect on parenteral stress-depression, parenteral stress-efficacy and parents' satisfaction, positive affect, and depression. The positive impacts on the family increasing family psychological health and family quality of life, and decreasing family burden. Social support is also buffering the effect on family burden-psychological health and resilience. The positive impacts on children are decreasing the emotional and behavioural problem. Social support for parents of children with disabilities has many positive impacts on the parents themselves, the family, and the child. Through identifying the benefits of social support, direction can be provided for interventions by enabling professionals to detect and address available social support. Recommendations for future research are made.

Keywords: children, disability, parents, social support

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BACKGROUND

Disability in children is a global problem that needs attention. Based on the Convention on the Rights of Persons with Disabilities (CRPD) 2006, children aged 18 years or younger who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others are defined as children with disabilities (A. delle Nazioni Unite, 2006). Globally, the United Nations Children's Fund (UNICEF) estimates that 28.9 million (4.3%) children aged 0–4 years, 207.4 million (12.5%) children aged 5–17 years, and 236.4 million



(10.1%) children aged 0–17 years have moderate to severe disabilities, while the Global Burden of Disease (GBD) study in 2019 estimated that 49.8 million (7.5%) children aged under 5 years, 241.5 million (12.6%) children aged 5–19 years, and 291.3 million (11.3%) children under 20 years have mild to severe disabilities (Olusanya, B. O. *at al*, 2022). The severity of the disability can affect a child's interactions with their environment. More than half of children with disabilities are in Sub-Saharan Africa and South Asia (Olusanya, B. O. *at al*, 2022).

Raising a child with a disability can have negative impacts on parents. Parents may face mental and health challenges related to their child's disability (Hadjicharalambous, Demetris, 2021 & Shahali, S. *at al*, 2024) because children with disabilities have special needs (Lygnegård, F. *at al*, 2013). Raising a child with special needs or disabilities is associated with several negative impacts including parenteral stress, depression, fatigue, musculoskeletal pain, sleep disturbances, financial difficulties, and stigma (Shahali, S. *at al*, 2024; Falk, N. H. *at al*, 2014 & Yamaoka, Y. *at al*, 2016). Approximately 41.2% of parents in Malawi reported extreme psychological distress compounded by difficulties in managing their children's behaviour and increased perceived burden (Masulani-Mwale, C. *at al*, 2018). Another study in Germany found that 55% of parents reported stress related to behavioural, sleep, or eating problems related to their child's disability (Scheibner, C. *at al*, 2024). 85% of parents also reported experiencing social isolation and partnership conflict. Parental stress has also been associated with adverse outcomes for parents, children, and their families later in life (Fang, Y. *at al*, 2024).

Social support is a vital need for parents of children with disabilities to cope with mental and health challenges (Idrageset, J., 2021 & Amini, S. *at al*, 2023). Support for parents of children with disabilities can be further enhanced by being sensitive to the age-specific support needs of children (Lahaije, S. T. A. *at al*, 2024). Social support is a form of social interaction between parents and others and shows serious interest. Social support functions to help individuals cope with stressful events, fulfil human needs for psychological safety, reduce their psychological suffering, and ultimately can increase their resilience to frustration and help them achieve psychological comfort, positive compatibility, and personal growth (F. I. A. Q. Al-Nawasrah and N. A. Wahsheh, (2024). Sources of support can come from family, significant others, parents, health professionals, both in groups and individuals (Bray, L. *at al*, 2017 & Jackson, J. B. *at al*, 2018).

Scoping studies have not been conducted to clarify the positive impact of social support for parents of children with disabilities. Identifying the effects of social support for parents of children with disabilities provides a strong foundation for health professionals in providing social support. The purpose of this review is to identify the effects of social support for parents of children with disabilities on the parents themselves, their families and their children.

METHODS

This study is a scoping review of the positive effect of social support for parents with disabilities children based on the JBI Scoping Review Methodology Group's methodological guidance (Peters, *at al*, 2020) and the Prisma extension for scoping review (PRISMA-ScR) (Tricco, A. C. *at al*, 2018). PubMed, Taylor and Francis, Wiley Online library, and Google Scholar databases were searched from July 2014 to August 2024 for English peer-reviewed articles that were relevant to the research question using qualitative or quantitative, or mixed methods approaches. However, we did not include various other types of publications, such as research protocols, commentaries, editorials, book chapters, conference abstracts, and other gray literatures. Articles that only addressed the effect of social support for disabled children were considered as exclusion criteria.

In order to explore the research question “What are the positive effect of social support for parents with disabilities children?”, the PECOT (Population, Exposure, Comparisons, Outcome and Time/type of study) method was utilized: Population: Parents of children with disabilities. Exposure: social support. Comparisons: no social support. Outcomes: positive effect of social support on parents (e.g., resilience, parenting efficacy, depression, anxiety, health, coping skill), on family (family burden, quality of life), child (e.g., emotional, behavioral). Time: July 2014 to August 2024. Type of Study: Quantitative, qualitative, and mixed methods studies and review articles. Based on the PECOT elements, these search terms were used: Population (P): parent* (parents, mothers, fathers*) Or child* (children) Or disability* (disability, disabilities) Or special need. Exposure (E): social support. Outcome (O): resilience, coping skill, parenting efficacy, depression, anxiety, health, quality of life*. The study used Boolean operators (AND, OR, NOT) to combine our search terms effectively. Following the JBI Scoping Review Methodology, these terms were intentionally broad to ensure that a wide range of relevant articles were included and to ensure that the research team captured a wider range of findings. All articles were screened based on the inclusion/exclusion criteria using the article title, and abstract. Concerns about eligibility for inclusion were addressed by reviewing the full texts in accordance with the methodological approach.

The researcher independently reviewed the articles for relevance and quality. In case of disagreement, the articles were reviewed by another researcher. The final selection was ten articles out of a total of 423 articles (Fig. 1). The title, authors, design, objectives, description of participants and results were extracted from the included studies. (Table 1) Due to the diversity in study design, interventions, and outcome measures, the researchers analyzed the data narratively. The narrative synthesis method was employed to address the review question, evaluating various review papers, quantitative studies, and qualitative investigations.

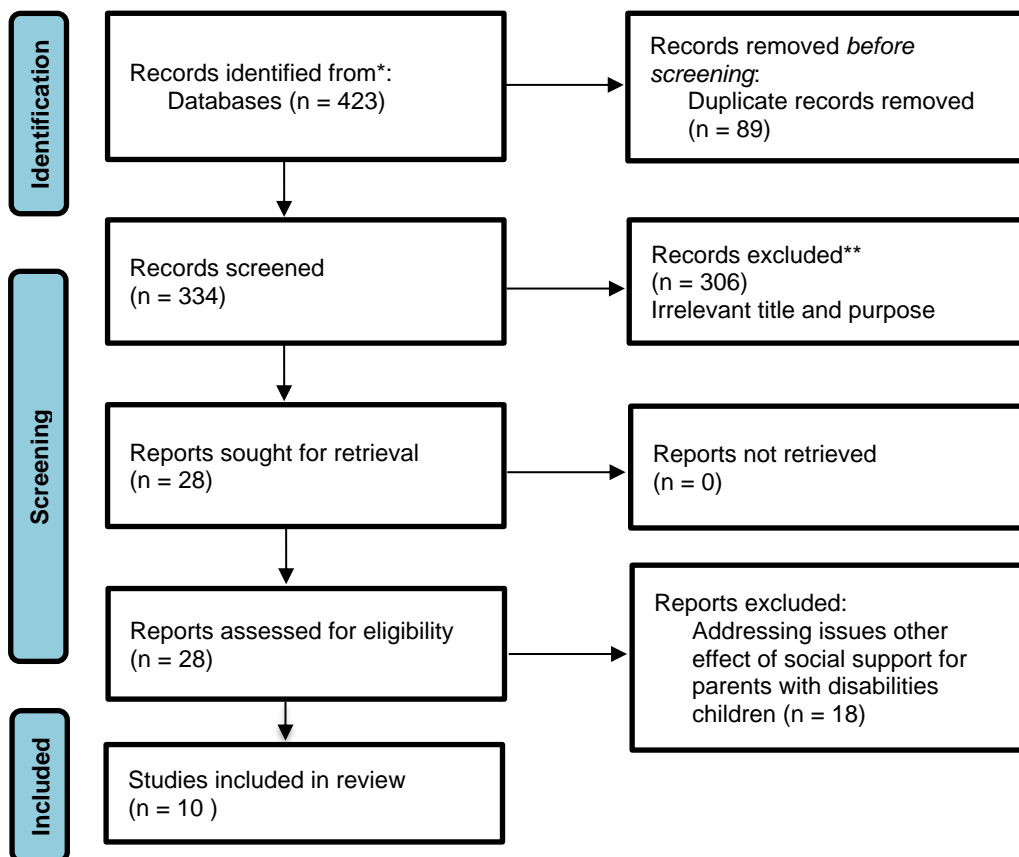


Fig 1. PRISMA-SCR flow diagram



RESULTS

Description of studies

The database search identified a total of 423 potentially relevant articles. After screening titles and abstracts, 28 potentially relevant articles were identified. All 28 articles were assessed at full-text level, resulting in 10 relevant articles for analysis. The most articles that met the inclusion criteria were carried out in China. Seven articles were quantitative studies. Two articles utilized a mixed methods approach. Only two articles described the social support source and one article described the social support type (Table 1). Analysis of the study results were categorized into three main groups: the positive effect on parents themselves, the positive effect on family, and the positive effect on children (Fig. 2).

Table 1. Relevant studies summary

| Code | Researcher, year of publication | Title | Country and study design | Research population/sample size | Findings |
|------|---|---|-----------------------------|--|--|
| 1 | Nutifafa Eugene Yaw Dey, Benjamin Ampomah (2020) | Sources of perceived social support on resilience amongst parents raising children with special needs in Ghana | Ghana Cross-sectional study | 107 parents with all disability children in Accra, Ghana | Social support from significant others increasing resilience |
| 2 | Wangqian Fu, Rui Li, Yaqian Zhang, and Ke Huang (2023) | Parenting Stress and Parenting Efficacy of Parents Having Children with Disabilities in China: The Role of Social Support | China Cross-sectional study | 373 parents having children with disabilities | Social support played a mediating role between parenting stress and parenting efficacy. |
| 3 | <u>Elsayed E A Hassanein, Taha R Adawi, Evelyn S Johnson</u> (2021) | Social support, resilience, and quality of life for families with children with intellectual disabilities | Qatar Cross-sectional study | 83 mothers of children with intellectual disabilities | giving and receiving social support (emotional and instrumental) accounted for significant increasing family quality of life |



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| 4 | Gyeong-A Park and Oan Na Le (2022) | The Moderating Effect of Social Support on Parental Stress and Depression in Mothers of Children with Disabilities | Korea Cross-sectional study | 160 mothers with disabilities children | Social support showed the buffering effect on the relationship between parental stress and depression among mothers of children with disabilities. These findings indicate that mothers who perceive a high level of social support are less likely to experience depression. |
| 5 | <u>Xue Du, Qi Dong, Le Sun, Xiaoyi Chen, Jun Jiang</u> (2024) | The Effect of Social Support on the Mental Health Literacy of Parents Who Have Children with Special Needs: A Moderated Mediating Effect | China Cross-sectional survey | 165 parents of children with special needs | Social support positively predicted the mental health literacy and positive coping style. In addition, positive coping style played a mediating role between support and mental |



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| | | | | | health literacy. |
| 6 | <u>Salih Rakap, Mer yem Vural-Batik</u> (2024) | Mitigating the impact of family burden on psychological health in parents of children with special needs: Buffering effects of resilience and social support | Turkey Cross-sectional study | 256 parents of children with moderate to severe disability (intellectual disabilities, diagnosed with autism, and multiple disabilities) | Revealed negative associations between social support and depression-anxiety symptoms and family burden. Social support buffered the negative association between family burden and psychological health, alongside psychological resilience. |
| 7 | <u>Mariam Namasaba, Neo Kazembe, Georgina Seera, Ali Ayub Baguwemu</u> (2022) | Broadening the scope of social support, coping skills and resilience among caretakers of children with disabilities in Uganda: a sequential explanatory mixed-methods study | Uganda mixed-methods study | 621 caretakers of children with physical impairments, intellectual or developmental disabilities such as attention deficit hyperactivity disorder or down's syndrome, and multiple | Quantitative and qualitative findings converged that caretakers who received social support used adaptive coping skills and had higher resilience. The caretakers who |



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| | | | | | disabilities such as cerebral palsy w | received formal social support perceived it as a safer mode of care than informal social support. |
| 8 | Minghui Lu, Jiawei Chen, Wanting He, Feifan Pang, Yuqin Zou (2021) | Association between perceived social support of parents and emotional/behavioral problems in children with ASD: A chain mediation model | China Cross-sectional study | 289 parents of children with Austism spectrum disorder | Parents' perceived social support, parental resilience, and parenting self-efficacy were significantly associated with emotional/behavioral problems in children with ASD; (2) parental resilience and parenting self-efficacy were found to play a chain-mediating role in the association between perceived social support of parents and emotional/behavioural | |



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|----|---|---|--------------------------------|--|---|
| | | | | | problems in children with ASD |
| 9 | Lucy Bray, Bernie Carter, Caroline Sanders, Lucy Blake, Kimberley Keegan (2017) | Parent-to-parent peer support for parents of children with a disability: A mixed method study | Scotland Mixed method study | 70 parents of children with disabilities | Parent-to-parent peer support has a positive influence on parents' levels of psychological distress and their ability to cope with being a parent of a child with a disability. |
| 10 | Elizabeth J. Halstead, Gemma M. Griffith, Richard P. Hastings (2017) | Social support, coping, and positive perceptions as potential protective factors for the well-being of mothers of children with intellectual and developmental disabilities | UK Cross-sectional study | 138 mothers of children with intellectual and developmental disabilities | Perceived social support functioned as a protective factor affecting the relationship between child behavioural and emotional problems and maternal depression, life satisfaction, and positive affect. |

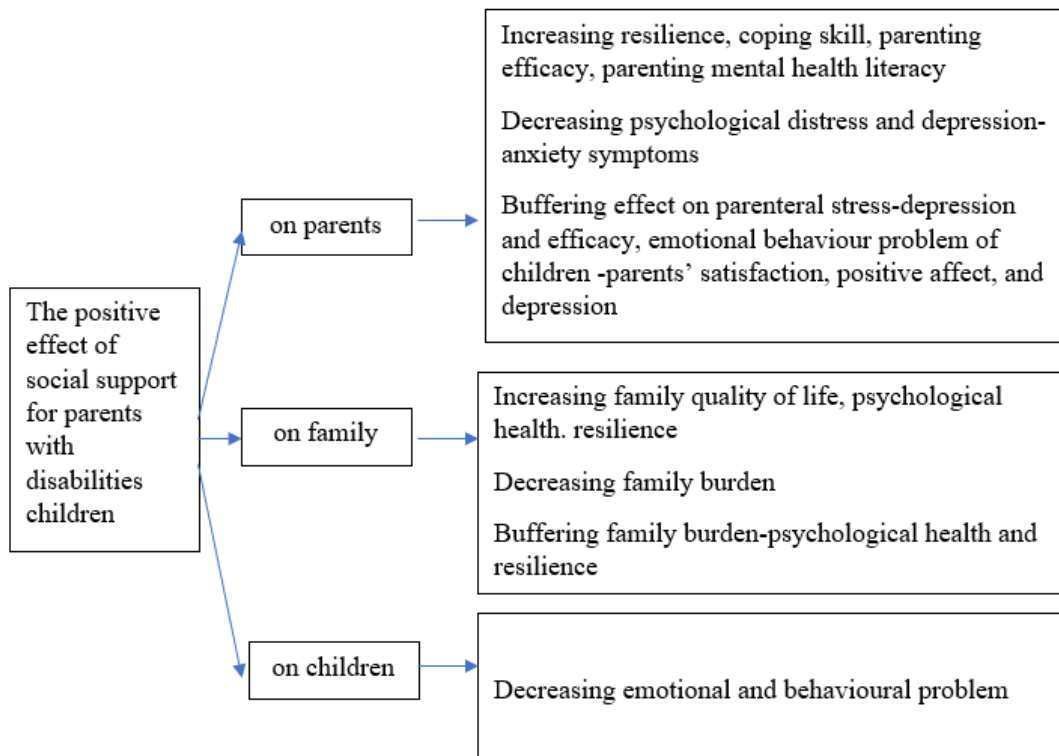


Fig 2. Finding based on narrative synthesis

The positive effect of social support for parents with disabilities children on parents themselves

This theme is about positive effect of social support for parents with disabilities children on parents themselves. Among the 10 studies reviewed, 9 highlighted the positive effect on parents after they had social support. Parents raising children with disabilities have reported that they have good resilience if they perceive good social support (N. E. Y. Dey and B. Amponsah, 2020), (Namasaba, M. *at al*, 2022), (Lu, M., Chen, J. *at al*, 2021). They also have adaptive coping skill while raising their children (Bray, L. *at al*, 2017), (Namasaba, M. *at al*, 2022) and parenting mental health literacy (Du, X. *at al*, 2024). Positive coping style played a mediating role between support and mental health literacy (Du, X. *at al*, 2024). Social support can increase parenting efficacy (Lu, M., Chen, J. *at al*, 2021) and social support played a mediating role between parenting stress and parenting efficacy (Fu, W., Li, R. *at al*, 2023) and also between emotional behaviour problem of children and parents' depression, life satisfaction, positive affect (Halstead, E. J. *at al*, 2017). Parents have reported that their levels of psychological distress (Bray, L. *at al*, 2017) and depression-anxiety symptoms were decrease after accepted social support (Rakap, S. *at al*, 2024). Social support showed the buffering effect on the relationship between parental stress and depression among mothers of children with disabilities (Park, G. A. *at al*, 2022).

The positive effect of social support for parents with disabilities children on their family

This theme is about positive effect of social support for parents with disabilities children on their family. Among the 10 studies reviewed, 2 highlighted the positive effect on their family after they had social support. Parents have reported that family psychological health increase (Rakap, S. *at al*, 2024) and decrease family burden (Rakap, S. *at al*, 2024). Social support



buffer the negative association between family burden and psychological health alongside family resilience (Rakap, S. *at al*, 2024). Social support can control the family burden so that the psychological health of the family is good. Parents also reported that social support can significantly increasing family quality of life (Hassanein, E. E. A. *at al*, 2021).

The positive effect of social support for parents with disabilities children on children

This theme is about positive effect of social support for parents with disabilities children on children. Among the 10 studies reviewed, only 1 highlighted the positive effect on children after parents had social support. Parents perceived social support were significantly associated with emotional/behavioural problems in children with ASD (Lu, M., Chen, J. *at al*, 2021). However, parental resilience and parenting self-efficacy were found to play a chain-mediating role in the association between social support of parents and emotional/behavioural problems in children (Lu, M., Chen, J. *at al*, 2021).

DISCUSSION

Social support for parents with disabled children may have many positive effects or benefit. This scoping review has shed light on the positive impact of social support given to parents with disabilities children on parents themselves, family, and children. By synthesizing findings from 10 studies, we identified a significant positive effect on parents, family, and children with disabilities. The review included parents of children with a broad spectrum of disabilities and all source of social support.

The study findings are consistent with the social support concept and theory (Lakey, B., & Cohen, S. 2000), (Drageset, J. 2021) which explain the main and buffering effect of social support. The findings highlight the positive effects of social support for parents caring for children with disabilities on parents themselves, family, and children. The study found the main effects on health of parents, family, and children but the buffering effect only on family and parents. This study findings are also consistent with existing research that high social support level perceived by parent raising disabilities children have positive impact on health (Yan, Z. *at al*, 2024 & Muñoz-Bermejo, L. *at al*, 2020).

Based on the theoretical perspective on thriving through relationships, the positive effects that occur in parents with disabilities children are due to the close relationship between the two parties that can improve a person's development from now to the future (Feeney, B. C., & Collins, N. L. (2015). This explains that parents with disabilities who receive social support and support providers have good interactions or relationships that can support the development of the parents themselves. The relationship between parents who care for children with disabilities with other parties such as other parents, friends, health workers, and people who are considered important results in the development of parenting efficacy, resilience, adaptive coping, and mental health literacy. However, not all of the studies used in the review showed a second party who was in contact with the parents as a source of support and also did not show the form of support given so that it could not explain the relationship or social support further. The development found in these parents potentially supports them to develop further in the future and become a buffer in dealing with bad situations or stressful events such as parenteral stress and emotional and behavioural problems of children with disabilities. This can be seen from the results of the study that social support can be a buffer in stress event. The existence of previous positive thriving that are owned, allows parents to be ready to deal with children's emotions and behaviour so that parents remain satisfied with their lives, are not depressed, and have positive affect and positive efficacy in caring for children. Studies related to positive effects on parents, it turns out that they also found something broader where adaptive coping is a mediator between social support and mental health literacy in parents. Further research is needed related to this mediator.



The positive effect of providing social support to parents with disabilities children is also found in families. In accordance with previous research (Amini, S. *at al*, 2023), it shows that providing social support can improve family health, where a positive perception of social support increases family psychological health and family quality of life. Social support also acts as a buffer for family psychological disorders due to family burdens obtained by having children with disabilities. The positive effect on parents with the provision of social support to parents seems to be able to explain this because parents are part of the family.

The positive effect of providing support to parents was found to improve the emotional and behavioural conditions of children with disabilities, where parental self-efficacy mediates social support with children's emotional and behavioural conditions. Consistent with the previous study that parents' ability to mobilize social support for themselves and on behalf of their children was assumed to impact their children's mental health, and future ability to mobilize social support (Bauer A, *et al*, 2021). Mobilizing social support for disabilities children can be a complex process that requires careful planning.

It is crucial to support parents of children with disabilities. The role of health professional is very important. Positive and proactive approaches include resources, strategies, and evidence-based practices that support parents, educators, and families in meeting requirements and enhancing their health.

CONCLUSION

This scoping review highlights the effect of social support for parents with disabilities children. The findings highlight many positive effects on parents themselves, their family, and their children after parents accepted social support both in main or buffer effect. By promoting a collaborative approach involving health care interprofessional can create available social support more that empowers parents, family, and children with disabilities.

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