

PARENTING CHILDREN WITH DISABILITIES

This month, Allegheny Children's Initiative's Elena Renze, MA, MEd, LBS put together a great review of publications to help us understand how to better help families navigate parenting children with disabilities. You can find the sources at the end of this presentation.

A 2015 study^[1] examined the psychological well-being and coping mechanisms of parents with children who have autism spectrum disorder (ASD) compared to parents of typically developing children. It found that parents of children with ASD experienced higher levels of parenting stress, depression symptoms, and more frequent use of Active Avoidance coping strategies. These parents also reported more negative self-views, lower satisfaction with the parent-child bond, and difficulty managing challenging child behaviors. However, there were no significant differences in well-being and coping across parents based on the child's specific ASD diagnosis. The study emphasizes the importance of addressing the well-being and coping needs of parents of children with ASD.

[1] Lai, W. W. (2015). Psychological well-being and coping in parents of children with ASD and parents of typically developing children. *Journal of Autism and Developmental Disorders*, 45(8), 2582–2593.



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Key Findings:

1. **Higher Parenting Stress:** Parents of children with ASD reported more stress in areas like negative self-perception, dissatisfaction with parent-child relationships and difficulties in handling challenging child behaviors.
2. **Increased Depression and Anxiety:** These parents also reported higher levels of depression compared to those with typically developing children.
3. **Coping Strategies:** Parents of children with ASD were more likely to engage in Active Avoidance coping strategies (i.e., avoidance behaviors in response to stress).
4. **No Significant Difference Across ASD Diagnoses:** No notable differences were observed in psychological well-being and coping based on the child's specific ASD diagnosis.

A **family-centered approach**^[2] refers to an intervention or strategy that recognizes the importance of families in the caregiving process and emphasizes collaboration between professionals and families. This approach is widely used in various fields such as healthcare, education, social services, and especially in special education and early intervention programs for children with developmental disabilities, such as autism spectrum disorder (ASD). It focuses on empowering families, respecting their knowledge and expertise about their child, and involving them in the decision-making process.

An article by Powell-Smith & Vaughn outlines **specific ways clinicians can help** while utilizing family centered approaches.^[3]

^[2] [Family-centered approach to helping parents | Raising Children Network](#)

^[3] [Powell-Smith.pdf](#)



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1. Empowering Families

- **What It Means:** Empowerment refers to giving parents the tools, confidence, and support they need to manage their child's needs effectively. This can include access to information, training, and resources.
- **How It Helps:** By feeling more capable and informed, parents can take a more active role in their child's development, reducing feelings of helplessness and stress. Empowered parents are better equipped to make informed decisions about their child's care, leading to improved outcomes for both child and family.

2. Developing Rapport and Effective Communication

- **What It Means:** Building a positive, trusting relationship with families through open, empathetic communication is essential. This can be between parents and professionals (e.g., teachers, doctors, therapists), as well as between family members.
- **How It Helps:** When parents feel heard and understood, they are more likely to share their concerns and ask for help, reducing feelings of isolation. Effective communication ensures that all parties are on the same page regarding goals, expectations, and strategies, which can alleviate stress and improve outcomes for children with ASD.

3. Involving Families with Schools

- **What It Means:** Collaboration between parents and schools is key to providing a consistent, supportive environment for the child. This includes regular meetings, updates, and a collaborative approach to addressing the child's academic, social, and emotional needs.
- **How It Helps:** When schools and parents work together, it ensures the child's needs are met in both the home and educational settings. This holistic approach helps parents feel more supported and less stressed, knowing there is a team effort in place to address the child's challenges.



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4. Attending to Cultural and Different Lifestyles

- **What It Means:** It's important to understand and respect the diverse cultural backgrounds, beliefs, and values that shape parenting styles. Culturally sensitive practices are key in offering relevant support to families.
- **How It Helps:** Acknowledging cultural differences ensures that interventions and supports are relevant and respectful. When parents feel that their cultural values are respected, they are more likely to engage with and benefit from services, reducing stress and fostering trust.

5. Preparing Parents to Work with Other Agencies and Supports

- **What It Means:** Parents need guidance on how to navigate various systems, such as healthcare, social services, or educational agencies. This includes knowing their rights, understanding available services, and how to access them.
- **How It Helps:** By providing training and resources, parents can feel more confident in advocating for their child, reducing frustration and stress that often come with bureaucracy. This preparation leads to more efficient service utilization and stronger support networks.

6. Transition Planning

- **What It Means:** Transition planning involves preparing both parents and children for major life changes, such as moving from preschool to school, or transitioning to adulthood. This planning includes identifying goals, services, and supports needed for the transition.
- **How It Helps:** Well-structured transition plans reduce uncertainty and anxiety for both parents and children. When families are prepared for transitions, they can manage changes more effectively and feel less overwhelmed by new challenges.



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7. Achieving Self-Determination

- **What It Means:** Self-determination refers to the ability of parents (and children) to make informed choices about their child's care and future. This involves fostering a sense of autonomy, advocating for the child's rights, and being involved in decision-making processes.
- **How It Helps:** When parents are empowered to make decisions, they feel more in control and less stressed. Self-determination also promotes a sense of independence for the child, which can reduce the caregiver's long-term stress and improve the family's quality of life.

Why are family-centered approaches important?

The article "A Review of Processes and Outcomes in Family-Centered Services for Children with a Disability" by Ian Dempsey and Deb Keen^[4] focuses on the effectiveness and complexity of family-centered services provided to children with disabilities and their families.

The article emphasized the significance of family-centered services in supporting children with disabilities. It highlights that services should not only address the needs of the child but also consider the family, including the parents and other family members. This broader focus aims to enhance the overall well-being of the family unit and improve outcomes for the child with a disability.

The authors based their review on family systems theory, which views families as interconnected systems, where each member's well-being impacts the others. This theory supports the idea that services should consider the family, rather than isolating the needs of the child with the disability alone.



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A crucial aspect of family-centered practice is the help-giving relationship between professionals and families. This relationship, characterized by mutual respect and trust, should involve collaborative decision-making and shared goal setting. This partnership is believed to positively affect child and family outcomes, but the relationship is complex and not fully understood, as the article points out.

The authors argue for the importance of evidence-based practice in family-centered services. They suggest that more empirical studies are required to provide practitioners with actionable insights and frameworks that can be easily applied in real-world settings. This will help ensure that services are delivered effectively and that they result in meaningful improvements in the quality of life for both children with disabilities and their families.

[4] **Article:** [TECSE316699.qxd](#) Dempsey, I., & Keen, D. (2008). A review of processes and outcomes in family-centered services for children with a disability. *Topics in Early Childhood Special Education*, 28(1), 42–52. <https://doi.org/10.1177/0271121408316699>

