

Fostering Resilience and Empowerment Through Family-Centered Care in the Early Diagnosis of Autism Spectrum Disorder: Suggestions for Professionals

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Background

While family-centered care is a well-known and widely-used term today, families of young children recently diagnosed with Autism Spectrum Disorder (ASD) frequently report dissatisfaction during the diagnostic process. This is especially concerning since the experience of the diagnosis itself will likely contribute to the way that families make sense of and come to terms with their child's diagnosis. An executive summary was developed that covers the psychosocial and situational factors that affect parents and siblings surrounding the diagnosis of ASD. Findings led to the creation of suggestions that are intended to equip professionals with strategies for implementing family-centered care in the diagnosis of young children with ASD so that they can provide education, build support, and foster resilience to empower families.

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Method

A literature review was conducted to inform the development of the executive summary. Searches explored accessibility and readability of information about ASD, coping strategies in parents and neurotypical siblings of children with ASD, interviews of families' experiences of the diagnostic process, interviews of professionals' experiences of the diagnostic process, family-centered care, health literacy, parent-professional relationships, parents' expectations for their children with ASD, and strengths-based approaches. A total of 53 resources and peer-reviewed articles were selected and utilized. A set of strategies was created based on the findings of the executive summary.

Time was also spent with a team from the Delaware Network for Excellence in Autism (DNEA) developing a set of early childhood ASD resources for families. Work completed for this project assisted in completion of the executive summary and list of suggestions, particularly in outlining family and professional experiences during diagnosis.

Final Product

The executive summary outlines the following sections: tenets of family-centered care, challenges to providing family-centered care, impact of ASD on family members, coping strategies in parents and siblings of children with ASD, parents' expectations for their children, families' experiences during diagnosis, parent-professional relationship, and suggestions for professionals to provide family-centered care for this population.

The suggestions for professionals focus on three main themes: what to keep in mind, how to establish rapport, and what to provide to parents. These suggestions are shown to the right.

Other Findings

The findings as outlined in the executive summary and resulting list of suggestions emphasize the importance of effective communication, positive relationships, and social support in providing family-centered care. Parents have expressed that rapport with professionals is the single most important aspect to improving the diagnostic experience, and parents also rate other families of children with ASD as the most helpful resource both during and after diagnosis.

One of the most challenging aspects to providing family-centered care to this population is the accessibility of provided information, both in terms of readability and health literacy. Professionals can overuse clinical jargon because of how frequently they use it on a daily basis, and this makes it difficult to step back from the fact that widely-used terms in the world of ASD are not necessarily familiar or known to family members who have just been introduced to ASD.

Next Steps

This project can be furthered by trialing the list of suggestions with professionals who deliver medical diagnoses or educational classifications of ASD. While the suggestions were based on research about family and professional experiences during diagnosis, additional interviews can be conducted with professionals about strategies that have worked for them in the past with families.

In addition, similar suggestions can be created for professionals that focus on strategies that foster family-centered care in early intervention of ASD. While these suggestions focus specifically on the time of diagnosis, future suggestions for professionals can focus on other periods in these families' lives. For example, similar lists of suggestion can be created for fostering family-centered care in early intervention, school-based intervention, and intervention as individuals with ASD transition into adulthood.

Lastly, because effective communication, social support and positive relationships emerged as the most important aspects of providing family-centered care, workshops focusing on communication skills may be particularly valuable for these professionals. While professionals are trained extensively in their particular fields, communication skills are rarely an explicit part of their curriculum. Perhaps workshops could include testimonials from family members of children with ASD as well as opportunities for professionals to share ideas for how to improve communication skills in ways that support family-centered care.

Reflection

This leadership project is particularly applicable to my field of speech-language pathology (SLP). SLPs are among the first professionals contacted after a diagnosis of ASD is received to assist in the development of communication skills ranging from semantics (i.e., vocabulary) to pragmatics (i.e., social communication skills) to augmentative and alternative communication (AAC). Because SLPs are some of the initial professionals with whom families will interact, it is important for me to know the challenges that families may have faced so far in their experience with ASD as well as ways that I can promote healthy coping and resilience.

The topic of this project is also relevant to my personal growth as a future clinician. I have always had a passion for working with individuals with ASD, and this project gave me the opportunity to give back to the families of this population and those professionals who work with them. In addition, my first clinical placement will be in a school-based early intervention program for infants and toddlers with ASD. The research and results of this project have increased my familiarity with this population as well as the confidence I have in collaborating with their families to ensure provision of family-centered care.

The main tenets of the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program are cultural competency, interdisciplinary practice, and family-centered care, and this project connects to these themes. First, cultural competency is necessary in order to build rapport and establish an honest, respectful relationship between professionals and families. Professionals must ensure that children with ASD are receiving the best possible care, but they also must be sensitive to and respectful of parents' and caregivers' needs and desires for their families due to their culture's beliefs and attitudes. Second, there is rarely only one professional who works with a child with ASD. Instead, it takes a team of professionals that can include SLP, physical therapy (PT), occupational therapy (OT), social workers, behavior analysts, special educators, paraprofessionals, physicians, and more. These professionals must all work together to provide comprehensive, collaborative care for children with ASD and their families. Lastly, this project is focused on implementing family-centered care. Family-centered care fosters collaboration, communication, transparency, empowerment, and informed decision-making between professionals and families, and it is crucial for families of young children with ASD.

Acknowledgements

Thank you to Beth Mineo, Brittany Powers, and Kellene Copeland for their generous support and patient education that supported the development of this leadership project as well as my growth as a future clinician.

1 Keep in mind that...



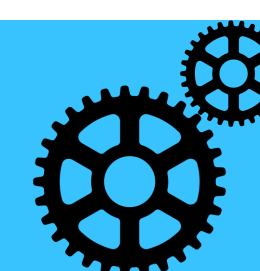
- On average, a family will see 4 to 5 professionals before their child receives a diagnosis of ASD. This may result in parents having preexisting frustration before you even walk in the door. While you can't change their past experiences, you can meet them where they are and respect their emotions.
- When you communicate with a family that their child has ASD, they're likely experiencing overload—both emotion overload and information overload. This may impact their ability to absorb new information or process their own thoughts and emotions.
- Families are likely unfamiliar with many terms that are used in the world of ASD. Although it's difficult to avoid using this language, try to be mindful of the clinical jargon that may be confusing for families.

2 Establish rapport through...



- Validating families. Many families have been told by friends, family members, and professionals to "not worry" or "wait and see" in response to their concerns. You have the opportunity to validate that they did the right thing by bringing their child in for evaluation.
- Showing interest in the entire family. Parents of more than one child express regret that they don't focus on their other children as much as their child with ASD. Showing genuine interest in the whole family, including any siblings, goes a long way.
- Being warm, open, and personal. Some professionals try to maintain objectivity in order to keep their own emotions controlled. However, many families have expressed that this perceived rigidity breaks down trust and rapport.
- Being mindful of cultural beliefs and attitudes. These may affect parents' needs and desires for their families. If you're unsure, ask!
- Focusing on strengths. Emphasizing the strengths of a child with ASD fosters hope and results in parents speaking more positively about their child.
- Being realistic yet optimistic. Acknowledge that ASD can be challenging, but there is reason to be hopeful about their child's future. ASD is a spectrum, and each child is uniquely individual. This also helps a family set healthy expectations for their child.

3 Provide parents with...



- Written information. You can guide them to accurate answers through written information that they can access when they're ready to absorb new information. Keep in mind that the suggested reading level to maximize understanding and informed decision-making is 5th to 6th grade.
- Connections to parents like them. Parents rate other families of children with ASD as the most helpful resource as they navigate life during and after the diagnosis.
- Answers to commonly asked questions. A family likely won't know what to ask in the moment. Some common questions that parents report wishing they'd asked during diagnosis included which therapies might help, with whom they should share the report, which community resources are available, and whether there will be a follow-up.
- Referrals to psychologists, psychiatrists, or related therapists as appropriate. This is a stressful and emotional time, and family members may benefit from therapy themselves.