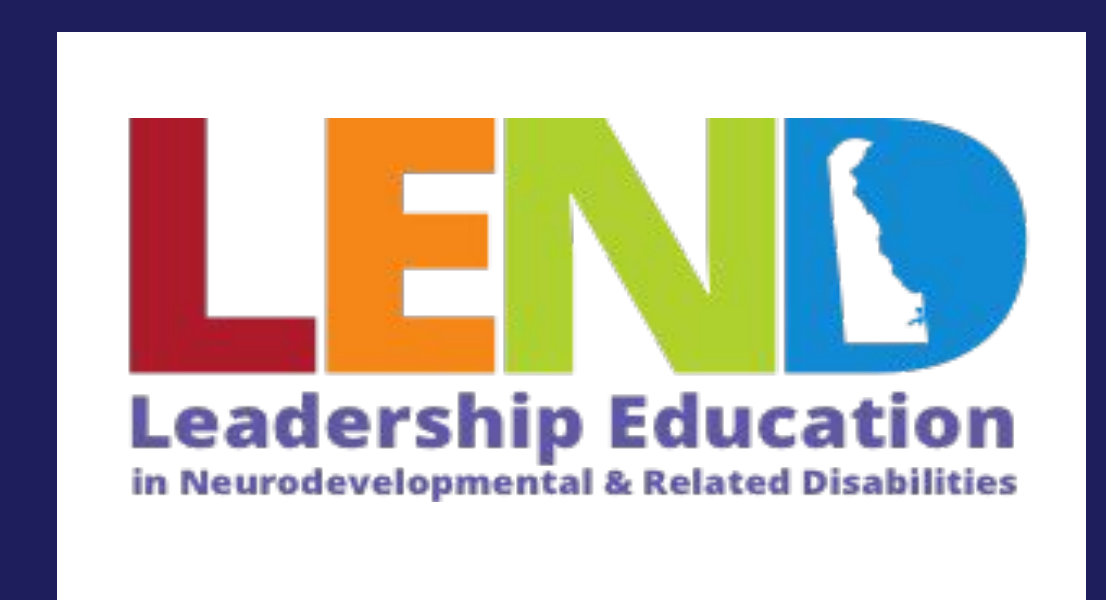


Family's Experiences Navigating Autism and the Transition Process



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Introduction

- Although ASD is typically diagnosed in early childhood, core symptoms affect development throughout the lifespan. Co-occurring medical, developmental, behavioral, or psychiatric conditions often persist into adulthood, and affect functioning and quality of life.
- Outcomes, such as employment, relationships, independence, quality of life, and life expectancy are poor for adults with ASD
- In both clinical work and research there is less emphasis on transition aged youth and adults. In the US, less than 2% of all autism funding goes to this target population (2016).
- Common difficulties include not an overall lack of information, inconsistent planning, poor community engagement/coordination, and the need for services for all levels of functioning. However, parents generally want their children to become independent and able to function on their own in some capacity. (Kou et al., 2017; Sosnowy et al., 2018).

LEND Project

Goal: To better understand the experiences of Nemours patients and their families as they prepare for the transition process.

Population: Parents of patients at Nemours Behavioral Health, aged 14 and older, with a diagnosis of ASD.

N = 5 Families; Ages 14 - 18

Methods

Families were invited to participate in a semi-structured interview to assess their experiences navigating the transition process. Families were asked about a) their experiences with the school and transition planning; b) transition planning and other professionals; c) their desires for the child's future; d) barriers and supports they have encountered; and e) what additional supports or services would be helpful.

Themes

Starting Conversation Earlier	No Clue Where To Turn	Barriers	Needs	Other Remarks
<ul style="list-style-type: none"> • Some observed that planning discussions happened earlier for TD youth • Younger participants (ages 14) had not begun discussing transition at all and some (15, 16) only briefly 	<ul style="list-style-type: none"> • "I have no idea" • "I do not know what resources are out there" • "I feel in a big loss with no one to talk to." • "I got lucky!" (Parent of 18 year old who reported success in starting the transition) 	<ul style="list-style-type: none"> • Lack of communication with school • Minimal teaching of practical life skills, leading to some anxiety about being independent • Parent's own stress • Difficulties when in homeschool 	<ul style="list-style-type: none"> • Help sorting through information, once it is gathered • Connect with other parents • Parent training for transition process • More services for older youth 	<ul style="list-style-type: none"> • The need for additional time for their child to mature • Parent of the 18 year old reported that life was better after school and better able to learn skills • For some parents, having their child able to drive was important

Discussion

All parents expressed frustration with how hard it was to not know where to turn for proper information. Multiple also mentioned that having a workshop, "certification," or other type of training would have been helpful. This may represent a good next step to expand services to transition aged ASD youth.

Next steps: Continue to interview more families and gather additional data.

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