Partnership and Progress: Maryland Regional Focus Groups for Parents of Transition-age Young Adults with Autism Spectrum Disorder

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Background/Introduction

The prevalence of autism spectrum disorder (ASD) has increased and influenced policy, program development, and service delivery. To provide quality care, it is crucial to look at how communities, school systems, and government agencies allocate resources to meet the needs of transition-age young adults with developmental disabilities, and their families (Westbrook et al., 2015). Furthermore, input and knowledge from the people most affected is fundamental in understanding how to be the positive force in changing policies, program development, and service delivery (Hagner, Kurtz, May, and Cloutier, 2014; Holmes, Himle, and Strassberg, 2016; Thomas, Parish, and Williams, 2014).

To learn more about this topic the Maryland Center for Developmental Disabilities (MCDD) partnered with Pathfinders for Autism (Pathfinders), Maryland's largest ASD non-profit. The MCDD is one of a national network of University Centers for Excellence in Developmental Disabilities (UCEDD) funded by the Administration on Intellectual and Developmental Disabilities. Together, they facilitated five regional parent focus groups on the needs of transition-age young adults with ASD throughout Maryland (MD).

Methods

The MCDD and Pathfinders developed a mixed-method approach incorporating focus groups, demographic data collection, and a satisfaction survey. The overarching question was "What are the transition issues most important to parents, and their transition-age young adults, in MD?" Specifically, "What is going well in transition-age young adult services?" "What is not going well in transition-age young adult services?" and "How can transition-age young adult services improve?" The focus groups were composed of parents of transition-age young adults with ASD and based on three broad themes: school-based transition, health-care transition, and adult services. The partners selected themes based on an analysis of the three most common transition-related inquiries through the Pathfinders resource center.

The structure of the focus groups was conducive to open discussion, as group size was limited to between six and 10 participants. Pathfinders staff facilitated the discussion and MCDD staff documented the input from the focus groups, summarizing key points. After an introduction and a short discussion of the topics, the participants chose which topics were the most pertinent to them and held the focus group on the top three topics. Participants completed satisfaction surveys yielding quantitative and qualitative data after each focus group.

Table 1 – Demographics

Location	Number of participants	Number of transition-age young adults	Gender		In school?		Race/Ethnicity	Age range	Counties
			M	F	Y	N			
Eastern Shore	9	8	6	2	6	2	White, Non-Hispanic/Latino	14-21	Wicomico, Worcester
Southern	9	10	6	4	9	1	White, Non-Hispanic/Latino, African American/Black	14-24	Charles, St. Mary's
Western	8	8	6	2	7	1	White, Non-Hispanic/Latino, African American/Black	14-21	Allegany, Frederick, Washington
Capital	7	8	7	1	8	0	White, Non-Hispanic/Latino, Bi-Racial, Non-Hispanic/Latino	13-19	Anne Arundel, Frederick, Montgomery, Prince George's
Central	8	7	6	1	7	0	White, Non-Hispanic/Latino, Bi-Racial	14-19	Anne Arundel, Baltimore, Baltimore City, Harford, Howard
Total	41	41	31	10	37	4	White, Non-Hispanic/Latino, African American/Black, Non-Hispanic/Latino, Bi-Racial, Non-Hispanic/Latino	13-24	Allegany, Anne Arundel, Baltimore, Baltimore City, Charles, Harford, Howard, Montgomery, Prince George's, St. Mary's, Washington, Wicomico, Worcester

Table 2 – Summary of Maryland Transition–Age Young Adult Services

What is going well in transition-age young adult services?	What is not going well in transition-age young adult services?	How can transition-age young adult services improve?
• Select education, employment, and post-secondary programs meet transitioning youths' needs • Some resources available for parents in regard to Supplemental Security Income (SSI), Medicaid, and state developmental disability services	• The programs are limited in capacity • The programs are limited in serving all transitioning youth on the certificate and diploma track • Some programs have not been sustainable (e.g., secondary education programs) • There is not a streamlined approach to applying for SSI, Medicaid, and state developmental disability services	• Research/develop/modify programs to meet more of transition-age young adults' needs • More school involvement in career readiness, individualized education program (IEP) implementation, and transition planning • Proactive involvement with teachers in meeting the students' individual needs • More training for developmental disability service providers to better meet the needs of transitioning youth and their families • More parent education on transition planning, and knowledgeable staff to provide guidance on key transition issues (housing, post-secondary employment/education, independent living skills, sexuality, relationships, transportation, benefits) • More inclusive programs

Discussion

While each session was unique in its discussion, overarching themes were congruent with current literature on needs of transition-age young adults, such as the need for improved information dissemination. The focus groups also served the latent function of being a supportive activity where parents were able to voice and process their concerns for their transition-age young adults with other local peers and professionals in a proactive, rather than a reactive, manner.

Feedback from participating family members was overwhelmingly positive. Many felt there were not a lot of answers, or programs, for their specific needs. They requested additional forum-style conversations, because parents felt that "you don't know what you don't know," and the collective conversations offered ideas and information about the availability of community programs not widely known within the community.

The MCDD is one of a national network of University Centers for Excellence in Developmental Disabilities (UCEDD) funded by the Administration on Intellectual and Developmental Disabilities. The MCDD is using data from this project to inform current and future UCEDD priorities, and is part of the needs assessment for the five-year UCEDD renewal process. Pathfinders is continuing to enhance its provider database by identifying healthcare providers who support adults with ASD throughout Maryland. Pathfinders is also working with local partners throughout Maryland to offer transition-specific workshops for parents, a need identified through the forums, and is co-hosting a conference featuring an expert on transition to adulthood and independence for individuals with ASD.

Conclusion

The regional focus of this project demonstrated the interdependence and mutual reliance, within the contexts of the communities, of the parents and their transition-age young adults. For example, the focus groups' findings suggest communities' capacities are closely linked to the availability of resources and programs, with high regional variability.

The series of focus groups highlighted the ongoing need for individual and family-centered care. A region's resources could then be presented in inaccessible and cumbersome ways, which increased parent frustration and difficulty accessing resources for their transition-age young adults.

Recommendations

Allocating resources, flexible venue requirements, partnership development with parent groups and/or organizations, and integrating multiple perspectives

The MCDD prioritized funding for this project to ensure there was adequate financial support. As a result of the focus group structure, the focus groups were able to be held in a variety of settings (two restaurants, a library, a church, and a school), which contributes to the replicability of this project. A team of staff with both technical expertise and diverse experience developed and executed this project. Pathfinders was founded, and is staffed, by family members of people with disabilities. The organization employs an individual with ASD, and is a vocational training site for young adults with developmental disabilities. The MCDD project lead is a woman with a developmental disability who has personal experience with making the transition from childhood and adolescence to adulthood; and is a former Leadership Education in Neurodevelopmental and Related Disabilities (LEND) trainee. The MCDD also included a trainee and a faculty member with expertise in needs assessments and information dissemination. A diverse team benefited the project design, as it allowed for an inclusive design development.

Acknowledgments

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