

Family Visioning for Their Adolescent and Adult Children with Autism: Mapping Current Regional Services and Identifying Gaps between Vision and Reality



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Introduction

Individuals with Autism Spectrum Disorder (ASD) have significant difficulty making a successful transition into adulthood.^{2,5,7} In their post-secondary years, ninety-percent of youth with ASD are unable to live independently in their communities, with most living at home.³ Only a quarter of adults with ASD are employed and more than half are working in sheltered workshops or day activity centers.^{4,6} Individuals with ASD face numerous barriers for making their life visions a reality. Currently, the available services and supports for successful transition are inconsistent with the visions the families and the individuals with ASD have for their future.

Purpose

- The aims of this study are:
- To learn about the visions that families of adolescents and adults with ASD have for their loved-ones' futures.
 - To learn about the visions that adults with ASD have for their own futures.
 - To learn about services currently available to adults with ASD and transition services in the southwest Ohio region.

Methods

- Focus Group:**
- Participant responses from 4 adults with ASD were transcribed following IRB approval and consent.
 - Data qualitatively examined using Grounded Theory.¹ Frequency distributions were utilized to analyze the data and identify key themes.
- Pre-existing Data:**
- Pre-existing data regarding current transition and adult ASD services in the southwest region of Ohio were analyzed using basic frequency distributions.
 - The pre-existing data were then compared to the key themes which emerged from the focus group data to identify gaps between vision and reality.

Themes

- Education**
 - Educational achievement
 - Need for educational alternatives
 - Negative education experiences
- Social/Relationships**
 - Negative social realities
 - Positive social experiences
 - Social motivation and ambivalence
 - Stress and "shutdowns" in social situations
 - Desire for romantic relationships
 - Family influences and support
- Services**
 - Received paid services

- Employment**
 - Career aspirations
 - Difficulties obtaining employment
 - Job retention issues
 - Desire to fill caregiver or helper role
- Housing**
 - Satisfaction with living situation
 - Dissatisfaction with current living situation
 - Varied current living situations
 - Impact of finances on housing
- Self-Reflection**
 - Reflections on positive aspects of life
 - Awareness of needed supports
 - Negative self-attribution
 - I'm different
 - Positive impacts of having a diagnosis

Discussion

- Post-secondary services and employment resources are lacking. The data obtained from the adults with ASD identified barriers with employment and post-secondary education.
- Key themes regarding the desire to have social opportunities and relationships were noted, and limited available resources pertaining to social events or support groups exist locally.
- The current available resources were identified as being for transportation and residential needs, which were not acknowledged as key themes by the adults with ASD.
- The need for social relationships and stable employment were recurrent themes throughout the focus group and were noted to impact many of the other key themes.
- When reviewing pre-existing data, employment, recreation, vocational, and post-secondary services were the least represented areas of services.

Conclusion

Our findings correspond and support the current research, suggesting a lack of consistency between the vision of adults with ASD and the available resources. Results from this study may assist in community planning and action to support the individuals' visions.

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Current Data on Local Resources

County	Total # of available ASD resources	Employment Services	Recreation	Family Support	Transportation Services	Residential Services	Vocational Services	Post-secondary	In home Support
Hamilton	34	24%	24%	24%	38%	41%	12%	0%	47%
Clermont	13	15%	23%	15%	23%	38%	8%	0%	62%
Butler	21	24%	29%	24%	38%	43%	24%	0%	62%
Warren	16	19%	12%	19%	38%	44%	6%	0%	63%
Northern Kentucky	5	20%	20%	20%	20%	0%	20%	0%	0%
Average Percentages	17.8	20%	22%	20%	31%	33%	14%	0%	47%