

Stakeholder Perspective on Transition Planning for Youth with ASD

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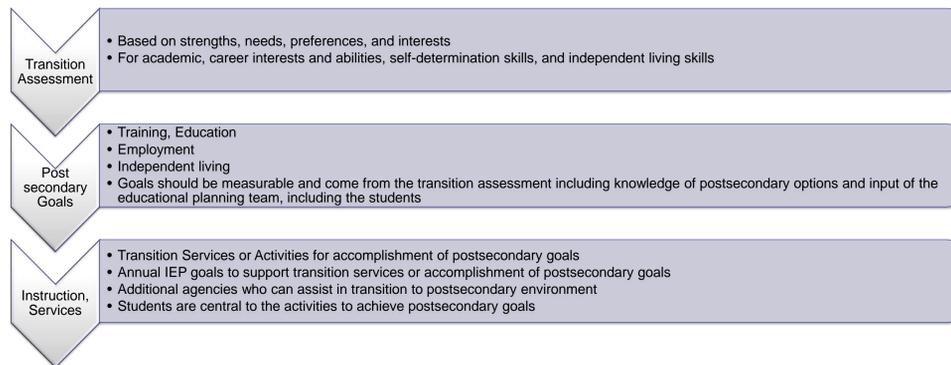
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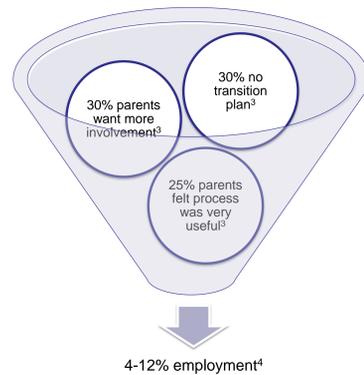
BACKGROUND

The Individuals with Disabilities Education Act (IDEA) mandates that public schools provide youth with disabilities with transition services to facilitate the move from school to post-school services or activities.¹

- Transition services are defined as a coordinated set of activities for the student which promotes movement from school to post-school activities which can include post-secondary education, supported employment, and adult services that should begin at 14.²



Research on transition planning and implementation indicates we are falling short for students with autism spectrum disorder (ASD).



When compared to adults with other disabilities (e.g., speech/language, learning, and intellectual disabilities), individuals with ASD had:

- the lowest participation rate for employment and the highest rate of no activities.⁵
- the second lowest (12%)⁶ to lowest percentage⁷ of living independently or
- the lowest percentage of friendships (48%) compared to the other 11 disability categories⁶
- were more likely to be living with parents⁷

Transition planning is poorly understood including the issues surrounding transition.

Little is known about how transition is actually perceived and experienced directly from the perspective of stakeholders.

OBJECTIVES

Describe stakeholder perspectives on existing state/local policies, procedures, services, and resources and the changes needed to support effective transition and integration with other adult services such as housing, social security, health insurance, and transportation.

METHODS

Participants

- A total of 42 stakeholders participated in 10 focus groups. Participants included parents, college students with ASD, school service providers, school administrators, adult service providers, and state policy makers from the Kentucky offices of Vocational Rehabilitation, Special Education, Medicaid, and Developmental Disabilities (see Table 1).

Table 1. Focus Group Description

Focus Group Name	Gender	Race
1. State Autism Committee	2 males; 8 females	100% White
2. Policymakers Group 1	1 male; 1 female	100% White
3. Parent Group 1	4 females	100% White
4. Policymakers Group 2	1 male; 3 females	75% White; 25% Latino
5. School Providers	4 females	100% White
6. Parent Group 2	1 male; 3 females	100% White
7. School Administrators	4 females	100% White
8. Adult Service Providers	3 females	100% White
9. Individuals with ASD	3 males; 1 female	75% White; 25% Latino
10. Parent Group 3	3 females	67% Black; 33% White

Focus Group

- The focus groups lasted about 1hr. Each session was recorded and transcribed.
- The research team performed qualitative content analysis. An initial codebook was created from themes derived from the literature on transition. All codes were cross-checked against themes appearing in a preliminary reading of all transcripts.
- Content codes /themes were derived from the focus group transcripts.
- Codes were discussed and refined within the team to finalize the codebook.
- Team members worked in pairs to test and apply codes; all codes were tested until reaching at least 80% agreement in inter-rater reliability.
- Finally, each pair of coders applied codes line by line to all transcripts.

RESULTS

Fifteen main themes emerged from the focus groups.

Table 2. Focus Group Themes

Focus Group Themes	
1. Key Players	9. Educational Outcomes & Skills
2. Key Services	10. Timing
3. Navigator/Coordinator	11. Goal Setting
4. Employment	12. Transition
5. Vocational Rehabilitation	13. Communication
6. Student, parent, and family	14. Monitoring & Assessment
7. Public Benefits	15. Specific Training on ASD
8. Continuum of Autism	

Major concerns centered around three areas: transition planning, entering the post-high school world and employment

1. Transition Planning:

- Key players are not at the table to help navigate key services.
- Understanding services, how to qualify and obtain them is complicated and parents are expected to negotiate all of these activities.
- Benefit planning / education is limited and parents don't understand SSI, etc. and how to plan accordingly and avoid making decisions based on incorrect information..
- Educational outcomes are not measureable and educational goals are not clearly linked to postsecondary goals.
- Timing of transition is too late, often the last semester of school.
- Monitoring of progress toward educational goals is limited and not done regularly.
- Challenges for higher functioning students include lack of training in social skills
- Challenges for lower functioning students include lack of expectations and meaningful community-based or employment options.

RESULTS (cont.)

- Vocational rehabilitation is not at the table; when they are, it is not clear what their role is and if they have training in autism.
- Services should be planned around vocational rehabilitation, not solely Medicaid waivers.
- Parents would benefit from a navigator to help access services.
- Language used by school personnel makes meaningful engagement by students and families difficult.

2. Like a Precipice": Entering the World Beyond School

- Parents have to start over learning a new system.
- Services are not guaranteed and long waiting lists for services are encountered.
- No one is available to guide parents through options.
- Adults service providers won't "hold" a spot for someone.
- Families delayed applying for waiver programs, causing further service delay.
- Lack of accountability for providing services to adults (vs children).
- Agencies could deny services because of a lack of workers; no forms of redress.
- Providers lack training in ASD.
- More community investment needed to ensure individual with ASD had meaningful role.
- No social life to involve person with ASD in.
- Transition outcomes should include, in addition to employment and independent living, personal growth and decrease of crises and behavior support.
- Vocational rehabilitation is one key to eliminating the gap.

3. Employment

- Transition planning needs to include more extensive preparation for employment.
- While vocational rehabilitation funds supported employment, they can also obstruct employment based on own assumptions and experience with ASD – by underestimating and overestimating abilities.
- Need for training for specific work contexts.
- Individuals' interests could be used before transition to identify work and vocational experiences.
- Need for more pre-employment training.
- Need for ongoing assessment of individuals' needs over the long-term.
- Community is not prepared for individuals and employers need more understanding of ASD.

CONCLUSIONS

Stakeholders' perspectives provided information on explanations for the poor employment and quality of life outcomes. Information on transition planning, life after school, and employment offer several areas for guidance for improvement in transition outcomes for youth with ASD.

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