

Title: Mothers' Perspectives on the Future of their Young Adults with and without Developmental Disabilities

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Introduction: The literature on outcomes for young adults with intellectual and developmental disabilities (IDD) paints a bleak picture, as demonstrated by low rates of participation in the employment, education, and social arenas (Howlin et al., 2004, 2013; Kraemer et al., 2003; Shattuck et al., 2012). Little is known about how these outcomes relate to parents' goals for their young adults across diagnostic groups (Rehm et al., 2012). As a group, parents often play a crucial role in the transition to adulthood for young adults with IDD, offering financial and/or emotional support, helping access services, and identifying employment, educational, and social opportunities. Thus, understanding the perspectives of parents is critical for improving transition outcomes. We assessed mothers' goals for their young adults with autism spectrum disorder (ASD) and/or intellectual disability (ID), with a comparison group of mothers of typically developing (TD) young adults.

Method: Participants include a subsample of families participating in the Collaborative Family Study (CFS), a 17-year longitudinal study investigating the developmental trajectories of youth with ID, ASD, or TD. As part of an ongoing follow-up study, 75 semi-structured interviews were completed with mothers of young adults ages 20-23 with and without disabilities (see Table 1), exploring their experiences during their child's transition to adulthood. Two raters independently analyzed and consensus coded interviews for themes related to mothers' expressed goals for their young adults. In addition, young adults completed questionnaires regarding their transition outcomes, and specific questions were selected to examine whether mothers' goals align with young adult transition outcomes.

Results: Mothers' most commonly reported goals across both groups (i.e., IDD and TD) fell into four categories: employment (61% of mothers), social (51%), independence (36%), and educational (35%) goals (see Table 2). However, the types of goals reported within these categories differed by diagnostic group. Within the employment category, mothers of TD young adults more often indicated the subcategory of "meaningful career", while mothers of IDD young adults more often indicated "finding a job". In the social goals category, mothers of IDD young adults more often indicated the subcategory of "friendships", while mothers of TD young adults more often indicated "marriage/relationships" or "having a family/kids" (see Table 3). Additionally, 59% of IDD mothers indicated independence goals, compared to only 14% of TD mothers. Young adult transition outcomes related to these goal categories were as follows: 58% had a paid job (IDD=47%, TD=69%); 39% were living independently from their parents (IDD=14%, TD=66%); and 63% rated their overall happiness with their friendships as a 6 or 7 on a 7-point Likert scale (IDD=57%, TD=69%).

Discussion: Mothers' most commonly reported goals for their young adults were employment, social goals, independence, and education. In contrast to parental desires, young adults overall reported low rates of employment and independent living; IDD young adults in particular, reported significantly lower rates of both. In this sample, mothers reported similar types of goals for their young adults, regardless of TD or IDD status. However, mothers of TD youth were more likely to emphasize the goals of their young adult finding a meaningful career, getting married, and having a family, while mothers of IDD youth hoped that their young adults would find a job and have friends. Understanding the nuances of parents' goals for their young adults will generate more meaningful intervention targets for transition planning.

References:

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Table 1.

Participant Demographic Information (N=75) [Mean (SD)]

	Typically Developing (TD; n=36)	Autism Spectrum Disorder only (ASD; n=16)	Intellectual Disability only (ID; n=11)	ASD+ID (n=12)
Full Scale IQ – WISC at age 13	110.94 (10.51)	110.27 (12.76)	63.25 (13.52)	62.83 (13.20)
Adaptive Behavior Composite – Vineland at age 13	97.75 (9.08)	77.47 (7.42)	74.13 (7.79)	68.58 (8.19)
Sex (% male)	55.6	100	72.7	66.7
Ethnicity (% Caucasian)	61.1	62.5	63.6	66.7

Note. ID group and ASD+ID group include participants with borderline intellectual functioning (IQ<85). ASD only group includes participants with IQ>85.

Table 2.

Most Common Goals

	Employment	Social	Independence	Education
Total	61%	51%	36%	35%
TD	67%	53%	14%	36%
IDD	59%	51%	59%	36%

Note. % of mothers who indicated goals in in each arena, by diagnostic status.

Table 3.

Differences in Employment and Social Goals by Diagnostic Group

	Employment Goals – 61%		Social Goals – 51%		
	Meaningful Career	Finding a Job	Marriage/Relationship	Friendship	Family/Kids
Total	64%	37%	49%	36%	12%
TD	63%	29%	58%	21%	78%
IDD	37%	71%	42%	79%	22%

Note. 61% of mothers had employment goals, and 51% had social goals. This table indicates the percentage of mothers who emphasized the specific subcategory within the broad area of employment or social goals, by diagnostic status.