

Gaps in Parent Support During the Transition to Adulthood for Individuals with I/DD

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Introduction

- Transition to adulthood is complex for individual with I/DD (including ASD)
- Families face major system changes after high school
- Parents play a central role in supporting independence
- Parents/Caregivers often receive limited structured support within the transition period

Purpose

- Review existing literature on parent experiences during their child's transition to adulthood
- Identify gaps in parent-focused support services
- Focus Population: Individuals with I/DD, including ASD, ages 18-26 and their caregivers

Key Issue

- Transition = Stressful and fragmented
- Adult services are limited compared to school-based supports
- Parents often become primary coordinators of care
- Lack of preparation and guidance for caregivers

Parent Anxiety and Stress

- High levels of emotional strain and anxiety reported
- Parents feel overwhelmed and uncertain about their child's future
- Concerns about future caregiving and independence

(Lee et al., 2023; Cribb et al., 2019; Smout et al., 2020)

Barriers to Independence

- Difficulties in employment access
- Limited independent living skills supports
- Lack of inclusive job opportunities
- Parents unsure of readiness for adulthood

(Sosnowy et al., 2017; Curtiss et al., 2021)

Service System Gaps

- Services decrease after high school
- Fragmented adult support systems
- Families left to navigate systems alone
- Lack of clear transition guidance

(Lee et al., 2023; Cribb et al., 2019)

Key Finding

- Major Gap: *Lack of structured parent-focused support*
- Parents are essential to transition success, yet are not systematically supported

Important Shift in Perspective

- Move from “independence only” to *interdependence* too
- Ongoing family support is often necessary
- Transition should include both emerging adult AND caregiver
- Interdependence emphasizes balancing autonomy with ongoing support
- Should be an emphasis on independence *and* interdependence

(Moser et al., 2024)

Implications for Future Professionals

- Future professionals play an essential role in improving transition outcomes
- Emphasize family-centered care
- Support families in understanding systems, building skills, and reducing transition-related stress (Lee et al., 2023; Curtis et al., 2021)
- Strengthen collaboration between schools, community agencies, and adult service systems to create continuity of care

Future Directions

- Development of parent coaching interventions
- Integrate caregiver support into school transition planning
- Expand research beyond autism-specific samples
- Strengthen agency and family collaboration

References

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