



Transition to Adulthood for Patients with PWS

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CONDENSED ABSTRACT

Early, collaborative planning is crucial for adults with PWS to achieve independent living, given their cognitive, social, and medical complexities. Education on transition planning along with collaborative planning is crucial to achieve transition readiness.

OBJECTIVES

- Educate family on the various steps in transition planning
- Help families develop a stairstepping approach to transition planning over time
- Track the patient's transition planning process within the context of the PWS clinical team

Patient 1

Adult Female with Deletion

- At Transition from Pediatric
 Multidisciplinary Clinic to Adult
 Multidisciplinary Clinic
 - ✓ Supported Decision Making and working on Guardianship
 - ✓ Texas Work Force
 - ✓ SSI
 - ✓ Utilizing local mental health agencies
 - ✓ Waiver list
 - ✓ Has a valid Texas ID
 - CommunityConnectionsPrograms
 - ✓ Adult Providers

Patient 2

Adult Female with Deletion
At Transition from Pediatric
Multidisciplinary Clinic to Adult
Multidisciplinary Clinic

- X No guardianship obtained
- X Adult providers not obtained
- X Texas Work Force not utilized
- X Not connectedwith local mentalhealth agencies
- ✓ Has valid TX ID
- ✓ SSI & Medicaid

RESULTS

Looking at individual patients showed that certain families require a more hands-on approach to transition goals and securing social supports. Implementing a formal process is critical to universally prepare families for adult care.

Transition Process Considerations

- Education: Develop an IEP transition plan addressing postsecondary goals
- Legal & Financial Planning: guardianship, conservatorship, power of attorney, supported decision-making
- Healthcare: Develop an emergency plan, understand health insurance options
- Housing: Explore living arrangements such as independent living (with or without support)
- Daily Life: Personal care, meal prep, household chores, money management