PCR104

Family Impact of Adult Angelman Syndrome: Caregiver Perspectives

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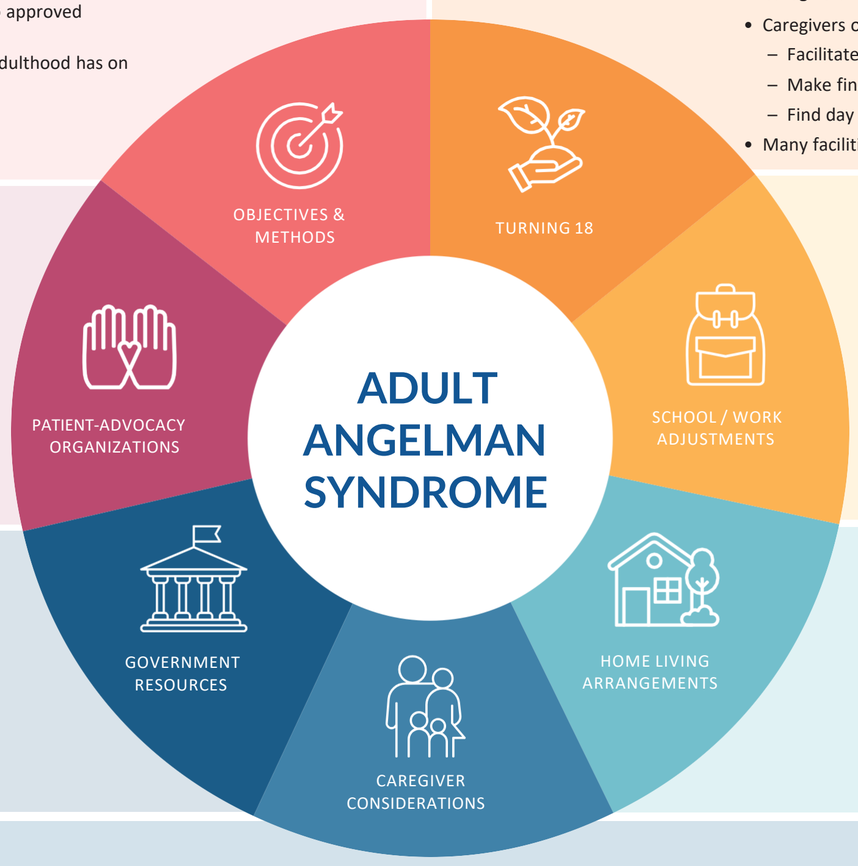
OBJECTIVES

Angelman syndrome is a rare neurodevelopmental disorder characterized by severe cognitive/ speech impairment, sleep disorders, motor dysfunction, and hyperactivity/noncompliance. There are no approved therapies for Angelman syndrome.

This study aimed to characterize the impact caring for a person with Angelman syndrome into adulthood has on caregivers and family members

METHODS

Seven current and future caregivers were recruited globally for individual, one-hour interviews



TURNING 18

- Caregivers reported that the adults with Angelman syndrome under their care were 18 to 37 years old
- Caregivers of adults with Angelman syndrome described the necessity to:
  - Facilitate transition from pediatric to adult healthcare providers
  - Make financial and medico-legal arrangements
  - Find day habilitation programs to replace school
- Many facilities for adults closed during the COVID-19 pandemic and never reopened, impacting nearly all caregivers

PATIENT-ADVOCACY ORGANIZATIONS

- Most caregivers indicated that they participate in annual or bi-annual meetings of the Angelman Syndrome Foundation (ASF), the Foundation for Angelman Syndrome Therapeutics (FAST), and/or Global Organizations under the Angelman Syndrome Alliance (ASA) to foster connection with other families and individuals with Angelman syndrome and to contribute to advocacy and therapy development efforts
- Some caregivers have been members of the boards of different patient advocacy organizations over the years

SCHOOL/WORK ADJUSTMENTS

- A majority of caregivers described leaving the workforce to care for their child with Angelman syndrome, limiting earning potential
- Most caregivers who discontinued gainful employment outside the home after their family received the Angelman syndrome diagnosis never returned to the workforce, though some caregivers reported maintaining productive careers
- Siblings or other family members described planning their school/work to account for potential future caregiving responsibilities

GOVERNMENT RESOURCES

- Most individuals with Angelman syndrome are covered under a complex combination of government- funded programs and private insurance that varied from state to state within the U.S. and from country-to-country ex-U.S.

HOME LIVING ARRANGEMENTS

- Caregivers reported that individuals with Angelman syndrome require constant supervision and support for basic activities of daily living
- Some caregivers reported having additional caregivers to provide assistance, either as live-in or on a daily basis
- A lack of quality facilities for adults with Angelman syndrome to live outside the home was reported by a number of caregivers

CAREGIVER CONSIDERATIONS

- As those with Angelman syndrome grow and age, sleep disturbances, communication issues, anxiety, and limited ambulation were noted as difficult to manage
- Caregivers of individuals with Angelman syndrome reported substantial and persistent caregiving burden that extends across the lifespan of an individual with Angelman syndrome and impacts all aspects of family life
- Caregivers differ in their approach to planning for the future when they can no longer serve as the primary caregiver for their person with Angelman syndrome

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