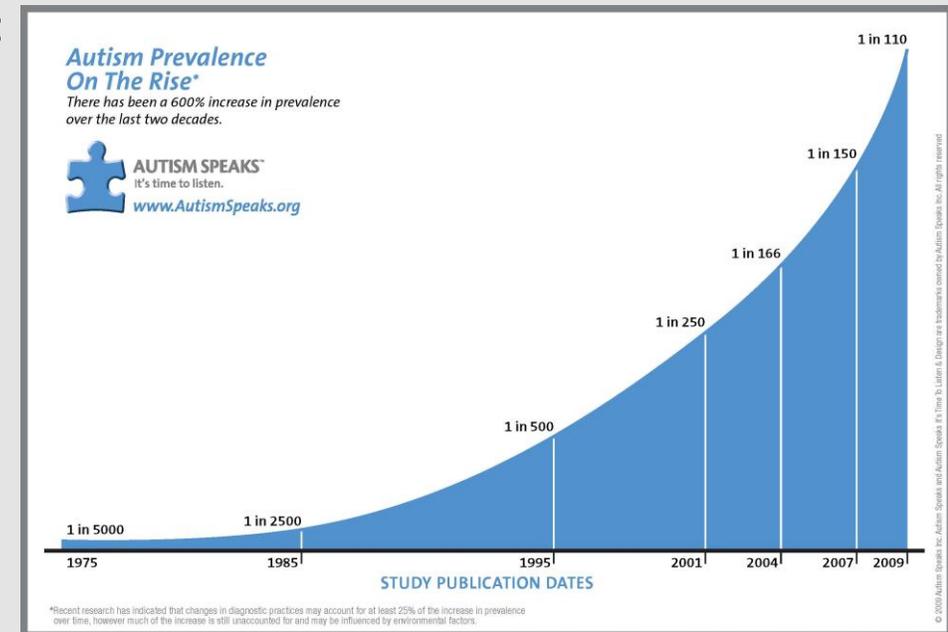

Autism Spectrum Disorder: Unique Challenges & Specific Demands

AMANDA L. DOERHOFF – ADVISED BY DR. SCOTT KOENEMAN
MIDAMERICA NAZARENE UNIVERSITY – HONORS PROGRAM –
OLATHE, KS

Research Concern

- Sharp increase in prevalence rates
- As that generation prepares for adulthood, the need for services increases
- The following study concentrates on three elements:
 - Developmental needs of adolescents with ASD
 - Demands placed on caregivers
 - Case study and personal reflection



<http://althealthworks.com/wp-content/uploads/2016/07/prevalence-graph1.jpg>

Key Terms

- **Autism Spectrum Disorder (ASD) – DSM-5**
- Neurodevelopmental disorder with three levels of severity
- Perceptions and socialization
- Two classifications of symptoms: persistent deficits in social communication and social interaction across multiple contexts and restricted, repetitive patterns of behavior, interests, or activities
- Symptoms present in the early developmental period
- Clinically significant social/occupational impairments or impact current functioning

Research Concern

- Autobiographical
- Helpers, Inc.
- The student worked as a DSW in the home of an individual with ASD
- For the purposes of this project, the client will be called **James**



<https://www.helpersinc.org/contact-us/>

Key Terms

- **Helpers, Inc.** is a **Financial Management Service (FMS)** in the state of Kansas that provides Medicaid billing services to individuals on the HCBS Waiver Program
- **Home and Community Based Services (HCBS)** provides oversight for community based supports and services for those in Kansas with disabilities
- The student was employed by Helpers, Inc. as a **Direct Support Worker (DSW)** who served to self-direct the individual's care. The work was centered around Activities of **Daily Living (ADLs)**

Research Procedure

- Qualitative research
- The student's goal for the project was to gain a more thorough understanding of a specific population through engagement
- Literature review with integrated informal case study

Research Questions

- 1. What are the unique challenges faced by adolescents with autism spectrum disorder as they transition into adulthood?**
- 2. What are the specific demands placed on caregivers who work with those who have ASD?**
- 3. How do the student's own experiences match the data?**

Literature Review

- Developmental needs
- Since autism exists on a spectrum and impacts the brain's development, those with ASD can experience mild to profound degrees of disability
- It can be difficult to analyze needs specific to the adolescent years because early intervention makes such an impact in the lives of those with autism spectrum disorder

Literature Review

- Some unique challenges faced by those with ASD include...

Inability to change perspectives

Difficulty regulating emotions

Disruptive behaviors

Physical aggression

Self-harming behaviors

Self-calming behaviors

Gastrointestinal issues

Sleep problems

Difficulty understanding danger

Speech delays

Seizures

Sensory processing issues

Literature Review

There are also specific demands placed on caregivers:

- Greater levels of perceived stress
- More depressive symptoms
- Poorer mental health
- Higher risk for developing mental health disorders

Literature Review

In comparison to parents of typically developing children, parents of individuals with ASD report...

More limited financial resources
Greater caregiving burden
More somatic symptoms

Higher divorce rates
Negative characteristics associated with family members

- However, family members also demonstrate high levels of passion, drive, and focus
 - Inspire change, increase awareness, and create organizations

Data

Overall, the student's own data is congruent with the literature:

- James is nonverbal, echolalia, iPad used to assist with communication
- Not usually interested in what others are doing
- Tantrums
- Change is difficult
- Routine drives and movies/shows

Data

Continued...

- Self-calming behaviors
 - Tapping and rocking
- Hypersensitive and hyposensitive in various contexts
- Can be a picky eater
- Sleep patterns
- Inability to understand dangerous situations
 - Stove, parking lots, pool
- Poor eye contact

Data

Points of Disconnect:

- No gastrointestinal issues
- No seizures
- Does not try to eat non-food objects
- Not unfriendly
 - Familiar vs. Unfamiliar People

Data

More applicable to James' parents since they are with him more frequently

- Stress
- Depressive symptoms
- Grieving process after the diagnosis
- Financial hardships
- Impact on family life
- Dad was president of The Autism Society
- Frustration when people are unwilling to understand

Limitations

- Lack of personal documentation
 - James' progress
 - Physical/emotional impact on the researcher as a caregiver
- One caregiver's experience with one client
- The researcher's relationship with the client is not a parent-child relationship
- Ten hours per week

Limitations

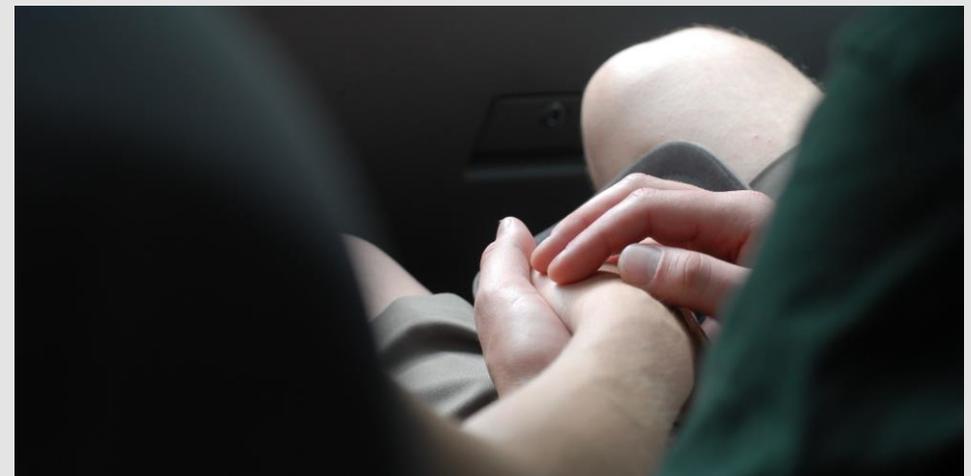
- Each case of ASD is unique
 - Student's experience has limited applicability
- James' pattern of development applies only to his case
- Intervention strategies that have been successful for James may not work as well for another adolescent with ASD

Conclusions

- Individuals with ASD face unique developmental challenges
- Difficult to make a generalization and say the same issues are present for all adolescents
- Caregivers experience variation in their work, but fairly consistent is the idea that the job is stressful
 - Impacts depend on the amount of time the caregiver and client or child spend together

Conclusions

- More positive than the literature presented
- Variance likely explained by the student's role as a part-time caregiver
- Though organizations such as Helpers, Inc. have lots to offer, social support and family involvement in care make the biggest difference



Hands Image: <http://i.huffpost.com/gen/2911546/images/o-HOLDING-HANDS-facebook.jpg>

Contact Information

Researcher: Amanda L. Doerhoff,
Undergraduate Student, Honors Program

Department and Institution: Behavioral
Sciences, MidAmerica Nazarene
University

Address: 2030 E. College Way Olathe, KS
66062

Email: adoerhoff@mnu.edu and
sgkoeneman@mnu.edu



Photo of client used with permission

References

American Psychological Association. (2017). Mental health of caregivers. Retrieved March 14, 2017, from <http://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/mental-health-caregivers.aspx>

Autistic disorder. (2000). In A. E. Kazdin (Ed.), *Encyclopedia of psychology* (Vol. 1, pp. 344-346). Washington, D.C.: American Psychological Association.

Barlow, D. H., & Durand, V. M. (2015). Neurodevelopmental disorders. In *Abnormal psychology: An integrative approach* (7th ed., pp. 511-541). Stamford, CT: Cengage Learning.

Christensen, L. B., Johnson, R. B., & Turner, L. (2011). Qualitative and mixed methods research. In *Research methods, design, and analysis* (Eleventh ed.). Boston, MA: Allyn & Bacon.

Glazer, S. (2014, August 1). Understanding autism. *CQ Researcher*, 24, 649-672. Retrieved from <http://cmps-ezproxy.mnu.edu:2144/>

Gouin, J., Estrela, C., Desmarais, K., & Barker, E. T. (2016). The impact of formal and informal support on health in the context of caregiving stress. *Family relations: An*

Interdisciplinary Journal Of Applied Family Studies, 65(1), 191-206. doi:10.1111/fare.12183

Harte, M., & Helpers, Inc. (2017). Helpers, Inc. - About us. Retrieved January 15, 2017, from <http://www.helpersinc.org/>

Hoefman, R., Payakachat, N., Exel, J. V., Kuhlthau, K., Kovacs, E., Pyne, J., & Tilford, J. M. (2014). Caring for a child with autism spectrum disorder and parents quality of life: Application of the CarerQol. *Journal of Autism and Developmental Disorders*. doi:10.1007/s10803-014-2066-1

The homestead. (2012). Family members of those who have autism. Retrieved March 18, 2017, from <http://www.thehomestead.org/learning/a-special-word-to-parents-grandparents/>

Kelly, A. M., JD, LLM. (2015). Caring for patients with ASD and their caregivers: Federal and state autism-specific insurance reform. *AMA Journal of Ethics*, 17(4), 328-341. doi:10.1001/journalofethics.2015.17.4.hlaw1-1504

Love without boundaries. (2017). Developmental needs. Retrieved March 19, 2017, from <http://www.adoptspecialneeds.org/special-needs/developmental-needs/>

Merriam-Webster, Incorporated. (2017). Case study. Retrieved February 21, 2017, from <https://www.merriam-webster.com/dictionary/case%20study>

Resources for Human Development. (2016). What we do. Retrieved March 6, 2017, from <http://www.rhd.org/>

State of Kansas - Office of Information Technology Services. (2017). Home and community based services (HCBS). Retrieved January 30, 2017, from [https://www.kdads.ks.gov/commissions/home-community-based-services-\(hcbs\)](https://www.kdads.ks.gov/commissions/home-community-based-services-(hcbs))

What is autism? (2016). Retrieved April 10, 2016, from <https://www.autismspeaks.org/what-autism>