

PRIMARY PROVIDER EDUCATION REGARDING ADULTS WITH AUTISM SPECTRUM DISORDER (ASD)

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Background and Significance

- Transitioning from pediatric to the adult care system for the disabled was identified as an issue that needs to be addressed (Perrin & Hicks, 2008).
- Symptoms of ASD are barriers to accessing healthcare
- Without early intervention, adults with autism are likely to have chronic health conditions like diabetes, heart disease, heart failure, arthritis, and cancer.
- Adults with autism report that visits with their health care providers are impaired due to providers who were unable to accommodate communication, sensory integration, and executive functioning resulting in poor outcomes (Nicolaidis, Kripke, & Raymaker, 2014).
- Providers lack knowledge about ASD. Because of this knowledge deficit they incorrectly assume that they have the necessary skills or needs to work with this population.

Problem Statement

Autism Spectrum Disorder (ASD) is “a developmental disability that is caused by differences in how the brain functions. People with ASD may communicate, interact, behave, and learn in different ways” (Autism and Developmental Disabilities Monitoring Network [ADDM Network], 2016, p. 1).

1 in 59 persons are diagnosed with ASD currently in the United States (CDC, 2018).

Autism is associated with a reduced life expectancy of about 2-3 times lower than matched peers in the general population (Nicolaidis, Kripke, & Raymaker, 2014).

Nicolaidis, et al. (2014) found that adults with autism did not receive adequate health care, tend to use the emergency room as a source of primary care, do not use preventive care services, are generally dissatisfied with healthcare, do not perform self-care activities, and face significant challenges in accessing healthcare.

According to Sarris (2016), in a survey of adult care providers performed by Kaiser Permanente, 79% rate their knowledge and skills with autism as fair to poor.

PICOT Question

- Among primary care providers how does education on autism spectrum disorders in adults compared to no education affect knowledge, attitudes and beliefs in providing care to this population?

Search Strategy

- Databases Used
 - Cumulative Index of Nursing and My Allied Health Literature (CINAHL)
 - PubMed
 - PsycINFO
- Keywords Searched: *adult, autism spectrum disorder, autism spectrum disorders, autistic disorder, healthcare, nurse practitioners, primary care, provider, and physicians.*
- Initial Yield: The initial search of *autism, adult, and healthcare* yielded 41 results in CINAHL, 13 results in PsycINFO, and 12 results in PubMed.
- Exclusion Criteria
 - Not in English
 - Unpublished works
 - Published before 2012
- Ten were selected after appraising 41 articles

Evidence Synthesis

- Ten studies were selected for this review including:
 - one non-randomized control study
 - one systematic review
 - two exploratory retrospective reviews
 - two cross-sectional data surveys
 - one intervention/longitudinal study
 - three qualitative studies
- Levels of evidence range from three to six according to the *Rating System for the Hierarchy of Evidence for Intervention/Treatment Questions*

Evidence Synthesis Supporting this Project

Increased Complications

Increased Referrals

ASD training needed for Adult Primary care Providers

Greater medical needs with ASD

Greater mental health conditions with ASD

Greater ED Use

Purpose Statement

- This topic was selected because adults with ASD are a forgotten population.
- ASD is thought of as a pediatric issue however autism is not something that a person “grows” out of.
- Once teenagers and young adults with ASD age-out of healthcare as a pediatric patient, options are limited for finding an adult health care provider who is comfortable and confident in caring for them.
- The goal for this problem is to improve the overall health of adults with autism by increasing access to adult primary health care providers through provider education.

Evidence Based Practice Model

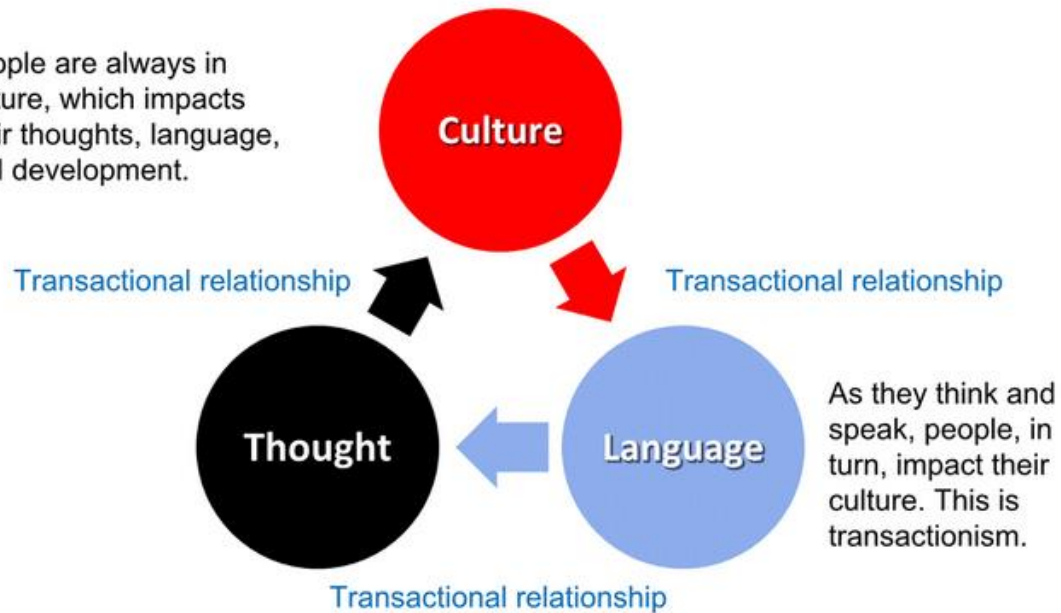


- Star Model of Knowledge Transformation
 1. *Discovery Research*
 2. *Evidence Summary*
 3. *Translation to Guidelines*
 4. *Practice Integration*
 5. *Process, Outcome Evaluation*

Vygotsky's Sociocultural Theory

Transactionism

People are always in culture, which impacts their thoughts, language, and development.



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CONCEPTUAL/THEORETICAL
MODEL –
SOCIOCULTURAL LEARNING
THEORY

Project Methods

- Protection of Human Subjects
 - ASU, IRB Approval
 - Mountain Park Health Center Approval
- Setting, Organizational Culture, and Participants
 - Large Metropolitan city in the SW United States
 - Multi-site Primary Clinic
 - Adult Primary Care Nurse Practitioners, Physicians, and Physician Assistants (N=45)

Project Methods (cont.)

■ Procedure

- Pre-test
- Education Session
- Post-test
- One month Post-test

■ Learning Objectives

1. Discuss the prevalence of autism and diagnostic criteria.
2. Identify at least four comorbidities associated with Autism Spectrum Disorder (ASD).
3. Determine at least four changes that can be implemented into your practice that would improve the experience for clients with ASD.
4. Identify one local and one national resource that can assist you to improve the health of your ASD patients.

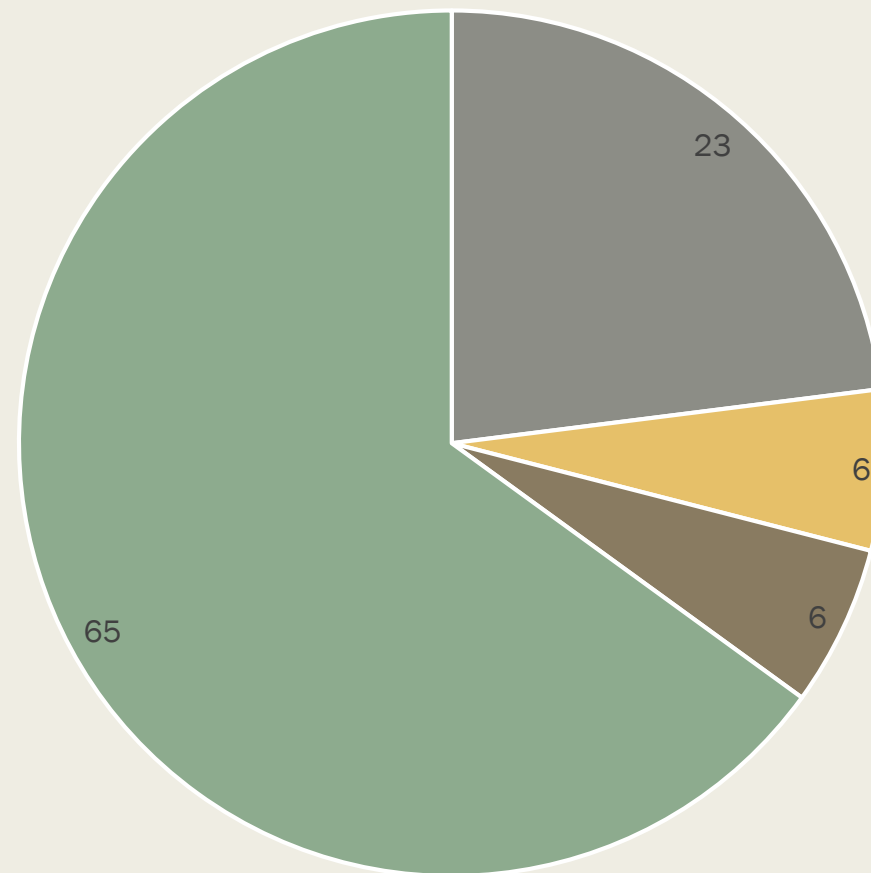
Project Methods (cont.)

- Outcome Measures and Data Collection
 - Demographic information collected.
 - Modified Knowledge, Attitudes and Beliefs Instrument
 - Pre and Post-tests (26 questions)
 - 1 month Post-test had additional follow up questions.
- Budget

Demographics

- 30 participated with 17 completing all parts of the project
- Age: 29-50 years
- Years in Practice: less than one year to 40 years
- Gender: nine males and eight females

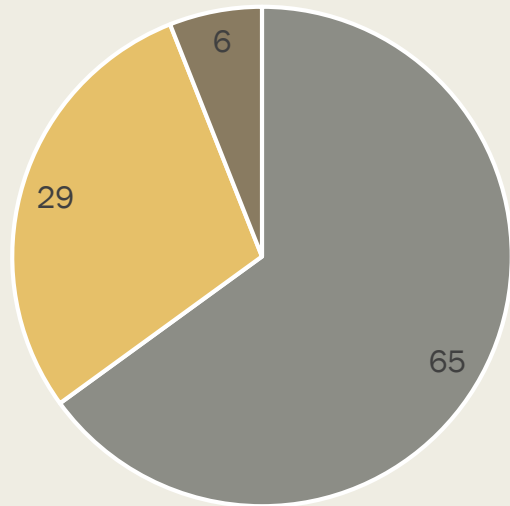
Race/Ethnicity



■ Asian/Pacific Islander (4) ■ Black/African American (1)
■ Hispanic/Latino (1) ■ Non-Hispanic White (11)

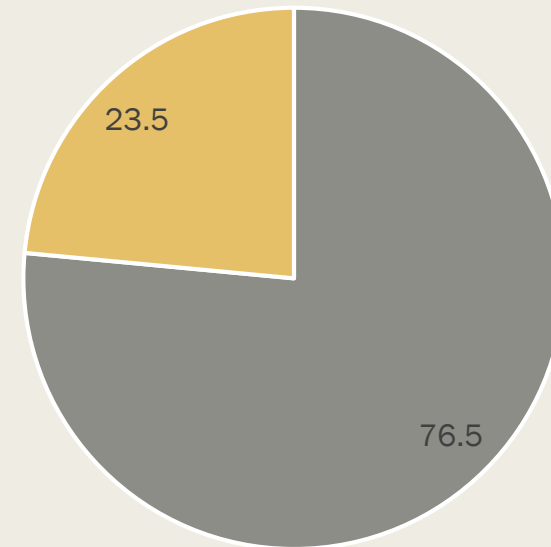
Demographics

Provider Type



- Physician (11)
- Nurse Practitioner (5)
- Physician Assistant (1)

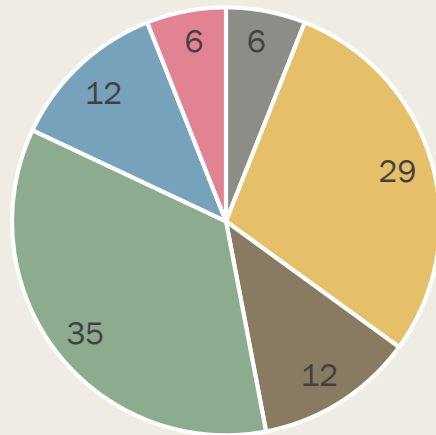
Previous Autism Education



- Yes
- No

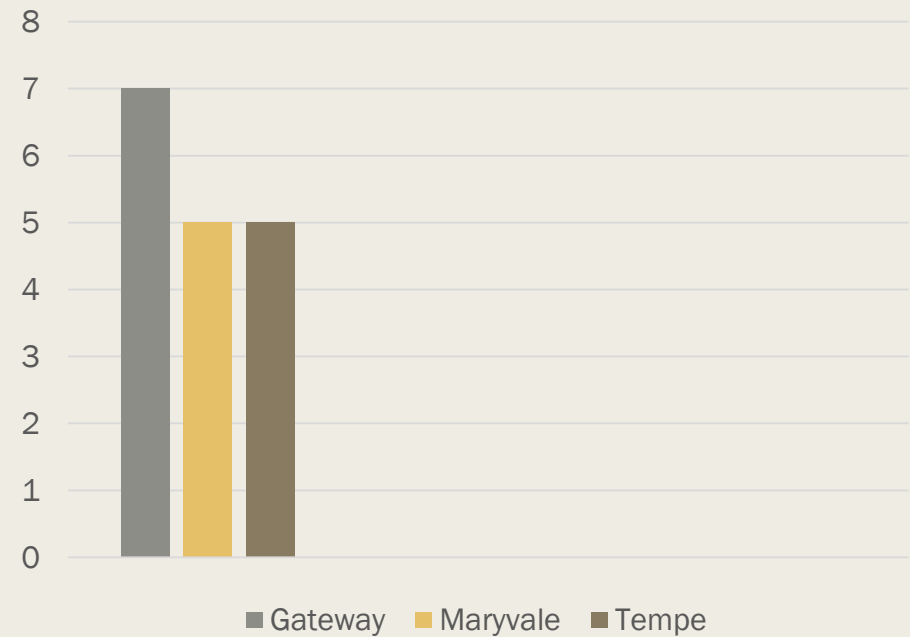
Demographics (cont.)

ASD Visits

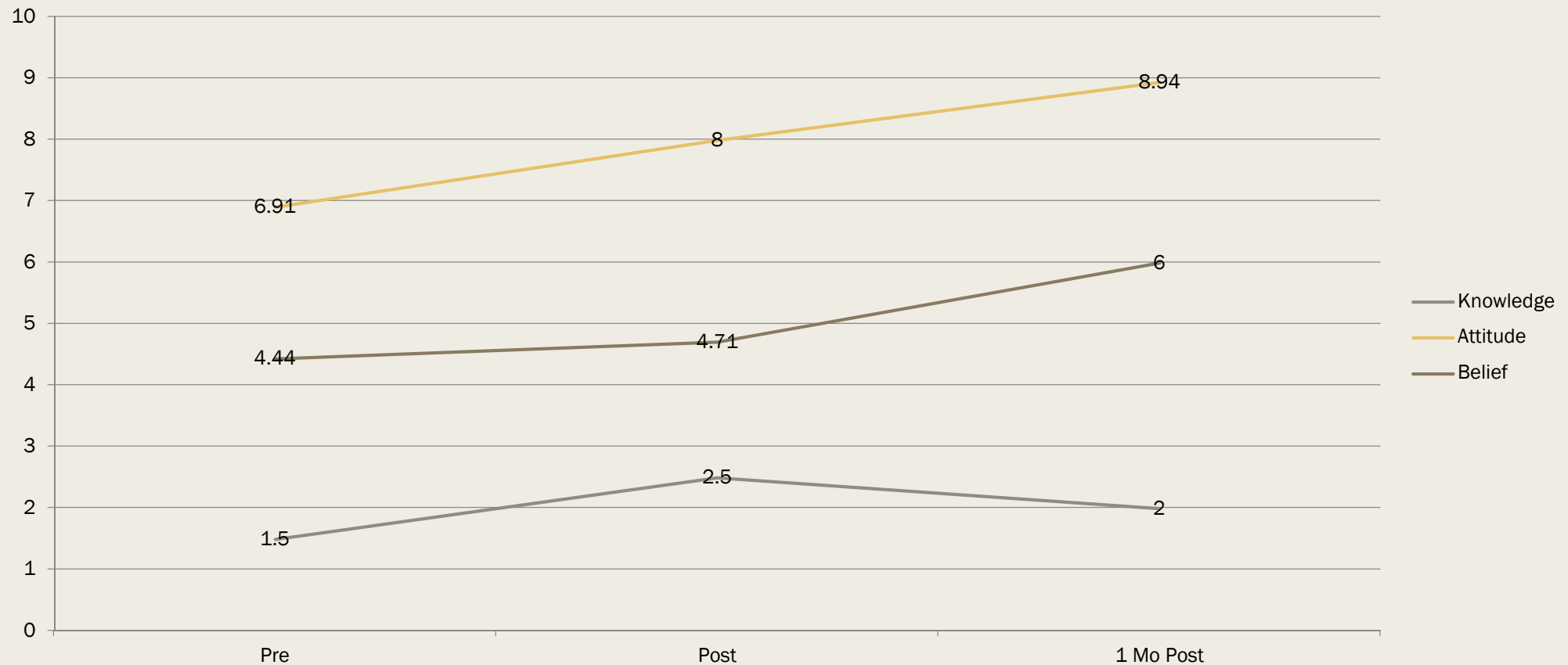


■ Weekly (1) ■ Monthly (5) ■ 2-3 Months (2)
■ 4-6 Months (6) ■ Yearly (2) ■ Never (1)

Clinic



How did adult primary care provider's knowledge, attitudes and beliefs about ASD change over time?



Statistical Significance

■	<u>Test Statistics - Friedman Test</u>	
■	N	17
■	Chi-Square	130.483
■	df	8
■	<u>Asymp. Sig.</u>	<u>.000</u>

Discussion

- Knowledge, attitudes and beliefs improved after ASD education
- Most of the providers (76.5%) had never participated in ASD education prior to this educational intervention.
- Evidence suggests that further education would be beneficial.
 - Medical, Nurse Practitioner, Physician Assistant schooling
 - Continuing Education
- Strengths
 - Multiple types of providers
 - Voluntary participation
- Limitations
 - Location specific
 - Education session was brief
- Further Study Opportunities
 - Replicate the project in another geographic location
 - Include all members of the health care team
 - Implement and evaluate environmental modifications in the healthcare setting

Dissemination

- DNP, Inc. – Accepted for a poster presentation at the National Conference in Palm Springs in September, 2018
- Mountain Park Health Center
- Autastic: A Comedienne's Guide to Autism - podcast

Conclusion

- Education about ASD has the potential to make significant positive improvement in the health care experiences of adults with ASD.
- Assessing and addressing medical and mental health comorbidities in this population has the potential to improve quality of life and a longer life expectancy.
- Care coordination led by primary care providers can result in a more cohesive healthcare experience for adults with ASD.
- Adults with autism need to be afforded the same opportunity to have access to quality health care.
- Better overall health for this population will also offer peace of mind for families.

Thank You!

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References

- Ailey, S. H., Johnson, T. J., Fogg, L., & Friese, T. R. (2015). Factors related to complications among adult patients with intellectual disabilities hospitalized at an academic medical center. *Intellectual & Developmental Disabilities*, 53(2), 114-119. doi:10.1352/1934-9556-53.2.114
- American Academy of Pediatrics. (1992). The medical home. *Pediatrics*, 90,774.
- Andersson, S., & Andersson, I. (2005). Authentic Learning in a Sociocultural Framework: A case study on non-formal learning. *Scandinavian Journal of Educational Research*, 49(4), 419-436. doi:10.1080/00313830500203015
- Autism and Developmental Disabilities Monitoring Network. (2016). *Community report on autism*. Center for Disease Control. Retrieved from <https://www-cdc.gov.ezproxy1.lib.asu.edu/ncbddd/autism/documents/comm-report-autism-full-report.pdf>
- Billings, D. M., & Halstead, J. A. (2016). *Teaching in nursing: a guide for faculty* (5th ed.). St. Louis, MO: Elsevier.
- Bordini, D., Lowenthal, R., Gadelha, A., Araujo Filho, G. M. d., Mari, J. d. J., & Paula, C. S. (2015). Impact of training in autism for primary care providers: A pilot study. *Revista Brasileira De Psiquiatria*, 37(1), 63-66. doi: <http://dx.doi.org.ezproxy1.lib.asu.edu/10.1590/1516-4446-2014-1367>

References (cont.)

- Bruder, M., Kerins, G., Mazarella, C., Sims, J., & Stein, N. (2012). Brief report: The medical care of adults with autism spectrum disorders: Identifying the needs. *Journal of Autism & Developmental Disorders*, 42(11), 2498-2504. doi:10.1007/s10803-012-1496-x
- Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism*, 19(7), 814-823. doi: <http://dx.doi.org.ezproxy1.lib.asu.edu/10.1177/1362361315577517>
- Data and statistics, center for disease control. (2018). Retrieved from <http://www.cdc.gov.ezproxy1.lib.asu.edu/ncbddd/autism/data.html>
- IBM Corp. Released 2015. IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp.
- Johnson, M. K., & Carter, M. R. (2011). Autism spectrum disorders: A review of the literature for health educators. *American Journal of Health Education*, 42(5), 311-318.
- Kellar, S.P. & Kelvin, E.A. (2013). *Munro's statistical methods for health care research* (6th ed). Philadelphia, PA: Wolters Kluwer Health/Lippincott Williams & Wilkins.

References (cont.)

- Kuhlthau, K. A., Warfield, M. E., Hurson, J., Delahaye, J., & Crossman, M. K. (2015). Pediatric provider's perspectives on the transition to adult health care for youth with autism spectrum disorder: Current strategies and promising new directions. *Autism: The International Journal of Research and Practice*, 19(3), 262-271. doi:10.1177/1362361313518125 [doi]
- Liu, G., Pearl, A., Kong, L., Leslie, D., & Murray, M. (2017). A profile on emergency department utilization in adolescents and young adults with autism spectrum disorders. *Journal of Autism & Developmental Disorders*, 47(2), 347-358. doi:10.1007/s10803-0162953-8.
- Melnyk, B. M., & Fineout-Overholt, E. (2015). *Evidence-based practice in nursing & healthcare: A guide to best practice* (Third ed.). Philadelphia, PA: Wolters Kluwer.
- Nicolaidis, C., Kripke, C. C., & Raymaker, D. (2014). Primary care for adults on the autism spectrum. *Medical Clinics of North America*, 98(5), 1169-1191. doi:10.1016/j.mcna.2014.06.011
- Nicolaidis, C., Raymaker, D. M., McDonald K. E., Baggs, A. E., Dern, S., Kapp, S.K., Weiner, M., Boisclair, C., & Ashkenazy, E. (2015). "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism: The International Journal of Research & Practice*, 19(7), 824-831. doi:10.1177/1362361315576221
- Nicolaidis, C., Raymaker, D., McDonald, K., Kapp, S., Weiner, M., Ashkenazy, E., Gerrity, M., Kripke, C., Platt, L., & Baggs, A. (2016). The development and evaluation of an online healthcare toolkit for autistic adults and their primary care providers. *JGIM: Journal of General Internal Medicine*, 31(10), 1180-1189. doi:10.1007/s11606-016-3763-6

References (cont.)

- Perrin, J. M., & Hicks, P. J. (2008). The future of disability in america: Review of the institute of medicine report. *Ambulatory Pediatrics*, 8(2), 71-72.
- Portland State University (2017). AASPIRE Healthcare [Toolkit](#) for [Healthcare Providers](#). Retrieved April 27, 2017, from <http://www.autismandhealth.org/?a=pv&p=main&theme=itlc&size=small>
- Rogers, K., & Zeni, M. B. (2015). Systematic review of medical home models to promote transitions to primary adult health care for adolescents living with autism spectrum disorder. *Worldviews on Evidence-Based Nursing*, 12(2), 98-107. doi:10.1111/wvn.12085 [doi]
- Saqr, Y., Braun, E., Porter, K., Barnette, D., & Hanks, C. (2018). Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting. *Autism: The International Journal Of Research & Practice*, 22(1), 51-61. doi:10.1177/1362361317709970
- Sarris, M. (2016, April 8). The Challenge: Finding Health Care Providers for Adults with Autism. Retrieved November 18, 2016, from <https://iancommunity.org/ssc/finding-health-care-providers-adults-autism>
- Stevens, K. R. (2015, February 25). Star Model. Retrieved April 8, 2017, from <http://nursing.uthscsa.edu/onrs/starmodel/star-model.asp>

References (cont.)

- Tyler, C. V., Schramm, S. C., Karafa, M., Tang, A. S., & Jain, A. K. (2011). Chronic disease risks in young adults with autism spectrum disorder: Forewarned is forearmed. *American Journal on Intellectual and Developmental Disabilities*, 116(5), 371-380. doi:<http://dx.doi.org.ezproxy1.lib.asu.edu/10.1352/1944-7558-116.5.371>
- Vygotsky, L., (1986/1962). *Thought and language*. Cambridge, MA: MIT Press.
- Vohra, R., Madhavan, S., & Sambamoorthi, U. (2017). Comorbidity prevalence, healthcare utilization, and expenditures of Medicaid enrolled adults with autism spectrum disorders. *Autism: The International Journal Of Research & Practice*, 21(8), 995-1009. doi:10.1177/1362361316665222
- Warfield, M. E., Crossman, M. K., Delahaye, J., Der Weerd, E., & Kuhlthau, K. A. (2015). Physician perspectives on providing primary medical care to adults with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders*, 45(7), 2209-2217. doi:<http://dx.doi.org.ezproxy1.lib.asu.edu/10.1007/s10803-015-2386-9>
- Webb, J., & Stanton, M. (2009). Working with primary care practices to improve service delivery for people with learning disabilities – a pilot study. *British Journal of Learning Disabilities*, 37(3), 221-227.