SESSION I
Working with Autistic Individuals Across the Lifespan: Current Perspectives

Catherine Lord, Ph.D.
June 11, 2020 // 12:00 pm EDT

Course Materials

The purpose of these materials is to help provide an introduction to the INSAR Institute session on understanding barriers and facilitators that influence autistic individuals' transition through different life stages. The materials were designed to prepare students and trainees who are unfamiliar with this research with the general background to get the most educational benefit from the session. Toward this objective, we have prepared the following: (1) learning objectives for this session, (2) key terms and concepts, (3) a selection of recommended resources. These materials are considered supplemental to the presentation.

In collaboration with Dr. Cathy Lord, these materials were developed by **Alana McVey, M.S.** (Clinical Psychology Intern in the Autism and Neurodevelopmental Disorders track at UCLA and Doctoral Candidate at Marquette University; amcvey@mednet.ucla.edu), **Marika Coffman, Ph.D.** (Postdoctoral Clinical Research fellow at Cincinnati Children's Hospital Medical Center;

marika.coffman@cchmc.org), and **Hillary Schiltz, M.S.** (Doctoral Candidate at Marquette University; hillary.schiltz@marquette.edu). Feel free to contact us with questions/comments. Register for this course and other sessions in this series at: https://www.autism-insar.org/page/SI2020.

Learning Objectives

The INSAR Institute for Autism Research was established in direct response to requests from students and trainees for multidisciplinary training opportunities. The INSAR Institute team is also working to engage stakeholders. The INSAR Institute priorities are to provide a (1) freely available, (2) multidisciplinary training platform for young scientists and others from various backgrounds that (3) allows for international participation. The overarching goal of the INSAR Institute is to expose junior scientists to topics they are not currently engaged in, with the hope that basic scientists and clinical scientists may learn from each other to ultimately advance the understanding of autism.

The current session, Working with Autistic Individuals Across the Lifespan: Current Perspectives, is led by Dr. Cathy Lord. A team of trainees who worked in tandem to prepare this handout and the web presentation. *At the conclusion of this session, participants will:*

1. **Understand** stable and changing aspects of autism across the lifespan
2. **Identify** symptoms of autism across development
3. **Discuss** barriers and enablers to quality of life in autism across the lifespan

Key Terms

Adaptive Behavior: Adaptive behavior is best understood as the degree to which people are able to function and maintain themselves independently and meet cultural expectations for personal and social responsibility at various ages. As such, adaptive behavior involves the person's physical skills, cognitive ability, affect, motivation, culture, socioeconomic status, family, and environment. Autistic people often demonstrate a discrepancy between intellectual potential and consistently-displayed adaptive skills.

Diagnostic Stability: Diagnostic stability is the degree to which a particular diagnosis remains consistent across multiple assessments over time.

Heterogeneity in Autism Spectrum Disorder: Autism spectrum disorder has been associated with many environmental and genetic risk factors (e.g., autism has been associated with more than 500 genetic risk factors). Similarly, there is a wide range of clinical phenotypes. Several researchers suggest that biomarker approaches that stratify the autism population into clinically and biologically meaningful subgroups may be helpful.

Intellectual Disability: *A neurodevelopmental disorder defined by limitations in cognitive abilities that affect both intellectual and adaptive functioning.* Ability to learn, problem solve, and

reason are all involved in intellectual functioning, which is generally quantified using an intelligence quotient (IQ) test. Intellectual disability is defined as an IQ ≤ 70 and reduced adaptive functioning. Adaptive functioning is typically measured using standardized questionnaires or interviews completed by caregivers and/or teachers. Skills that are necessary for day-to-day functioning, such as communication and practical skills, make up the adaptive functioning domain. At least one-third of autistic people have co-occurring intellectual disability.

IQ: Intelligence quotient (IQ) was originally the ratio of mental age to chronological age. The term "mental age," popularized by early tests of intelligence, referred to the age of the children in the standardization sample whose performance the testee matched. Most tests of intelligence no longer use this ratio, and IQ instead refers to a person's ability relative to available norms, which are usually age-based. By convention, IQ scores have a mean of 100 and a standard deviation of 15. Thus, about 95% of people fall within two standard deviations of the mean (i.e., 70–130). People with scores above 120 are generally considered of superior intelligence. When IQ falls below 70, it, in conjunction with adaptive behavior, is used to determine level of intellectual disability.

Longitudinal Research: Longitudinal research refers to the analysis of data collected at multiple points in time.

Nonverbal IQ (NVIQ): NVIQ is the use of thinking and problem-solving skills in a way that does not require language. This type of intelligence involves manipulating or problem solving about visual information (i.e., nonverbal abilities) and may vary in the amount of internalized, abstract, or conceptual reasoning and motor skills that are required to complete a task.

Phenotype: A phenotype is a characteristic of an organism or individual that can be observed. In psychiatry, the term is often used to refer to a set of behaviors that constitute a categorical diagnosis.

Repetitive Behaviors: Repetitive behaviors occur over and over or are stereotyped. They can involve motor movements, use of objects, or speech.

Social Communication: Social communication is a broad term that describes verbal and nonverbal behaviors used to interact with others. Examples include, but are not limited to, speech, prosody, gestures, and facial expressions. These behaviors can be used to initiate or respond to joint attention, to share emotion with others, or to signal when one person wants the attention of another person, and many other uses. Difficulties with social communication are a diagnostic characteristic of autism.

Verbal Intelligence: A person's verbal intelligence is assessed through performance on one or more specific tests involving receptive and/or expressive spoken language (i.e., verbal abilities). While these tests assess a limited range of specific verbal abilities, they are also intended to estimate, or to contribute to an estimation of, a person's general intelligence.

Recommended Readings & Resources

Anderson, D. K., Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A., … Pickles, A. (2007). Patterns of growth in verbal abilities among children with autism spectrum disorder. *Journal of Consulting and Clinical Psychology*, *75*(4), 594–604. https://doi.org/10.1037/0022-006X.75.4.594

Anderson, D. K., Oti, R. S., Lord, C., & Welch, K. (2009). Patterns of growth in adaptive social abilities among children with autism spectrum disorders. *Journal of Abnormal Child Psychology*, *37*(7), 1019–1034. https://doi.org/10.1007/s10802-009-9326-0

Bal, V. H., Fok, M., Lord, C., Smith, I. M., Mirenda, P., Szatmari, P., ... & Zaidman-Zait Zaidman-Zait(2019). Predictors of longer-term development of expressive language in two independent longitudinal cohorts of language-delayed preschoolers with Autism Spectrum Disorder. *Journal of Child Psychology and Psychiatry*.

Bal, V.H., Kim, S.-H., Fok, M., & Lord, C. (2019). Autism spectrum disorder symptoms from ages 2 to 19 years: Implications for diagnosing adolescents and young adults. *Autism Research: Official Journal of the International Society for Autism Research*, *12*(1), 89–99. https://doi.org/10.1002/aur.2004

Gotham, K., Pickles, A., & Lord, C. (2012). Trajectories of autism severity in children using standardized ADOS scores. *Pediatrics*, *130*(5), e1278-1284. https://doi.org/10.1542/peds.2011-3668

Lord, C., Bishop, S., & Anderson, D. (2015). Developmental Trajectories as Autism Phenotypes. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, *169*(2), 198–208. https://doi.org/10.1002/ajmg.c.31440

Lord C., McCauley J.M, Pepa L.A., Huerta M., Pickles A. (2020) Work, living and the pursuit of happiness: Vocational and psychosocial outcomes for young adults with autism, Autism, 2020, https://doi.org/10.1177/1362361320919246

Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism From 2 to 9 Years of Age. *Archives of General Psychiatry*, *63*(6), 694–701. https://doi.org/10.1001/archpsyc.63.6.694

Pickles A., McCauley J.B., Pepa L.A., Huerta M. & Lord C. (2020) The adult outcome of children referred for autism: typology and prediction from childhood, Journal of Child Psychology and Psychiatry, 2020, https://doi.org/10.111/jcpp.13180

Richler, J., Huerta, M., Bishop, S. L., & Lord, C. (2010). Developmental Trajectories of Restricted and Repetitive Behaviors and Interests in Children with Autism Spectrum Disorders. *Development and Psychopathology*, *22*(1), 55–69. https://doi.org/10.1017/S0954579409990265

Thurm, A., Lord, C., Lee, L.-C., & Newschaffer, C. (2007). Predictors of Language Acquisition in Preschool Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *37*(9), 1721–1734. https://doi.org/10.1007/s10803-006-03001