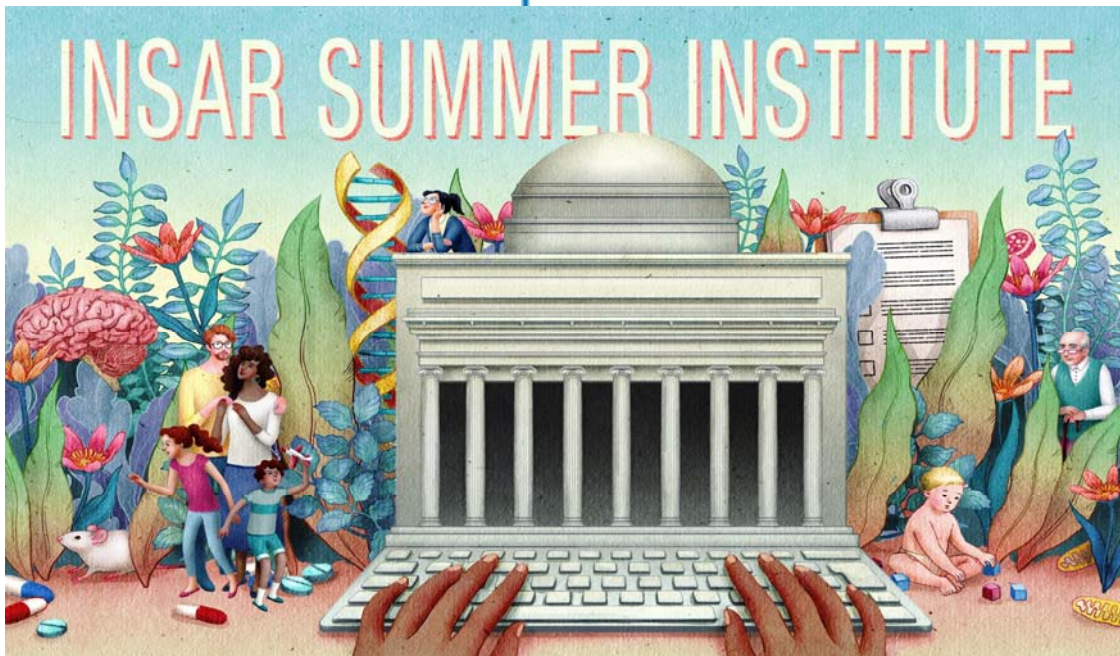


INSAR

International Society
for Autism Research



INSAR 2016 Summer Institute Session V: ASD in Adulthood

Patricia Howlin

Emeritus Professor of Clinical Child Psychology,
King's College, London
Professor of Developmental Disorders
Sydney University

July 21, 2016

July 21, 2016

7:00 pm EDT

Course Materials

The purpose of these materials is to provide an introduction to the Summer Institute Session on ASD in Adulthood. These materials were designed to prepare trainees who are unfamiliar with research on adult outcomes to receive the most educational benefit from Dr. Howlin's presentation. Toward this objective, we have prepared the following: (1) learning objectives for this session; (2) key terms and concepts related to methods and concepts in ASD adult outcomes research; and (3) review and research articles as recommended reading. These materials could be considered "prerequisites" in preparing for Dr. Howlin's presentation.

In collaboration with Dr. Howlin, these materials were developed by Michelle Hoogenhout (psychology doctoral student at the University of Cape Town; rbbmic002@myuct.ac.za), Iulia Mihaila (human development and family studies doctoral student at the University of Wisconsin-Madison; mihaila@wisc.edu), Jessica Ringshaw (psychology postgraduate student at the University of Cape Town; rngjes001@myuct.ac.za), and Tzu-Wei (Amy) Tsai (prev. psychology postgraduate student at University of Cape Town; tsailicious@gmail.com). Feel free to contact us with questions/comments.

Learning Objectives

The Summer Institute was established in direct response to requests from early career researchers (graduate students, postdocs, etc.), who asked INSAR for greater training opportunities in multidisciplinary topics. In designing the Summer Institute, the priorities were: (1) to provide a multidisciplinary training platform for young scientists from various backgrounds; (2) allow international participation; and (3) make it freely available. Thus, the second Summer Institute covers broad topics (which are geared to researchers outside the respective topic areas), is offered over a free web platform, and allows researchers from around the world to connect with the presenter. The overarching goal of the Summer Institute is to expose junior scientists to topics they are not currently engaged in, with the hope that basic scientists and clinical scientists can learn from each other to ultimately advance the understanding of autism spectrum disorder. The current session, ASD in Adulthood, is led by Dr. Patricia Howlin and a team of trainees who worked in tandem to prepare these materials and the web presentation. The aim of this seminar is to develop participants' understanding of adult outcomes in ASD. Specifically, it aims to help participants to gain a broad overview of:

- The latest research on transitions to adulthood.
- The factors that contribute to social and behavioral outcomes in adulthood.
- The effectiveness of interventions in adulthood.
- Recommendations for improving quality of life for adults with ASD.
- Recommendations for improving quality of adult ASD research.

Glossary of Terms

- **2011 Strategic Plan for Autism Spectrum Disorder Research:** The purpose of the strategic plan was to “focus, coordinate, and accelerate high-quality research and scientific discovery, in partnership with stakeholders, to answer the urgent questions and needs of people on the autism spectrum and their families”. Specifically, the 2011 Strategic Plan sought to provide information and seek further answers to 7 questions: 1) when should I be concerned, 2) how can I understand what is happening, 3) what caused this to happen and can it be prevented, 4) which treatments and interventions will help, 5) where can I turn for services, 6) what does the future hold, particularly for adults, and 7) what other infrastructure and surveillance needs must be met?
- **Adaptive functioning level:** Adaptive functioning level refers to the ability of an individual to manage daily life skills, as compared to other individuals of similar age and background. Adaptive functioning is composed of three skill sets: 1) conceptual (e.g., reading, numbers, time, communication), 2) social, and 3) practical (e.g., feeding, bathing, navigational).
- **Akaike information criterion (AIC):** A measure of the relative quality of statistical models for a given set of data; a smaller value indicates a better model.
- **Attrition rate:** Percentage of participants who drop out or leave a study over a specified period of time.
- **Augmentative and alternative communication:** Augmentative communication is any form of communication that people use if they are unable or unwilling to use standard forms of communication such as speech. Augmentative communication may be unaided, in which case it relies purely on signing and gestures without the use of special equipment. Aided augmentative communication strategies make use of additional materials such as charts, pictures, books or computers to assist in promoting effective communication. The Picture Exchange Communication System (PECS) is a widely used example of an augmentative and alternative communication system.
- **Autism Diagnostic Interview (ADI) & Autism Diagnostic Interview – Revised (ADI-R):** A standardized and structured parent interview for the assessment of current and previous behavior associated with ASD. The ADI serves as a clinical tool for the diagnosis of ASD severity and is based

on algorithm scores for communication, reciprocal social interaction, and restricted, repetitive and stereotyped behavior.

- **Autism Spectrum Disorder (ASD):** A neurodevelopmental disorder characterized by deficits in social communication and interaction as well as repetitive, stereotyped or restricted patterns of behavior and/or interests. For a diagnosis to be made, symptoms have to be evident in both domains and can be expressed along a spectrum ranging from mild to severe. The onset of ASD is in childhood, though symptoms may only become apparent later in life.
- **Bayesian information criterion (BIC):** A measure of the relative quality of statistical models for a given set of data; a smaller value indicates a better model. The BIC penalizes free parameters more heavily than the AIC does.
- **Cohort:** a group of people used in a study who have something (such as age or social class) in common.
- **Cognitive Behavioral Therapy (CBT):** CBT is a psychosocial treatment that seeks to treat mood disorders such as depression by changing negative thought patterns and behaviors. CBT combines behavior therapy (which focuses on behavior and how the environment impacts behavior) and cognitive therapy (which suggests that beliefs facilitate emotional and behavioral responses).
- **Competitive employment:** Employment opportunities that occur in the general labor market, such that the fraction of workers with disabilities (developmental, intellectual, and physical) is not greater than the proportion typically found within the surrounding community. Wages in competitive employments are consistent with, if not greater than, minimum wage. Support, in the form of a job coach or support staff person, may or may not be provided depending on the needs of the individual with the disability.
- **Co-occurring/ co-morbid mental health and medical issues:** The presence of one or more additional conditions that co-occur with the primary diagnosis. These simultaneously existing diseases or disorders may be medical, behavioral or psychiatric. For example, individuals with ASD frequently have other medical problems (e.g., epilepsy), demonstrate challenging behaviors towards themselves or others, or have psychiatric conditions including anxiety, depression and bipolar disorder.
- **Diagnostic and Statistical Manual of Mental Disorders (DSM):** The American Psychiatric Association's (APA) classification and diagnostic tool for neurodevelopmental, psychiatric and mental disorders. Currently, the DSM-5 is the latest edition in use. The previous version, the DSM-IV-TR was the fourth, text revised edition.
- **Emotional disturbance:** A condition that persists over a lengthy period of time and adversely impacts a child's performance in the classroom, and is characterized by one or more of the following features: a) inability to learn, which is not explained by intellectual, sensory, or health factors, b) inability to build or maintain interpersonal relationships with peers and teachers, c) inappropriate behaviors or feelings in typical situations, d) pervasive mood of unhappiness or depression, and e) a tendency to develop physical symptoms or fears associated with personal/school problems.
- **Executive function:** An umbrella term referring to several high-level cognitive processes that organize and order behavior, including inhibition, task switching, monitoring, attentional control, working memory, generativity and problem solving.
- **Facilitated communication:** A form of alternative and augmentative communication in which someone physically supports the person with autism and helps him or her to point at pictures or words. The theory behind facilitated communication is that many people with autism or severe intellectual disability actually possess normal levels of intelligence, and have difficulties with motor control rather than communication. Facilitated communication as a method of alternative communication has been discredited.

- **Functional skills:** The skills necessary for an individual to be able to live and work independently.
- **Intellectual ability:** The level of an individual's critical thinking, problem-solving, and reasoning skills.
- **Interagency Autism Coordinating Committee (IACC):** A federal advisory committee that is charged with the coordination of the efforts of the Department of Health and Human Services related to ASD. The mission of the IACC is to provide advice to federal agencies regarding ASD, as well as to facilitate and coordinate the exchange of information related to ASD programs, services, research, and policies.
- **International Classification of Diseases (ICD):** The standard international diagnostic tool used for clinical and epidemiological purposes. The ICD categories Childhood Autism, Asperger's Syndrome and Atypical Autism/Other Pervasive Developmental Disorders are roughly equivalent to the categories Autistic Disorder, Asperger's Syndrome and Pervasive Developmental Disorder - not otherwise specified (PDD-NOS) in the 4th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).
- **Inter-rater reliability, or independent rater agreement:** The consistency with which different examiners are able to produce similar ratings when judging a given ability or characteristic of a selected target person or object. A score of 1 indicates perfect agreement, while a score of -1 indicates total disagreement. Ideally, independent rater agreement should be above 80% (0.8).
- **Intra-class coefficient (ICC):** The ICC indicates the degree to which items within the same domain resemble one another.
- **Latent class analysis (LCA):** A statistical technique that identifies unobservable subgroups, called latent classes, within a population. Members of a subgroup are identified by their similarity or dissimilarity to other members on several measurable variables. For example, LCA can be used to find distinct diagnostic categories given the presence or absence of several symptoms.
- **Learning disability:** A disorder in which an individual has difficulty in processing and acquiring knowledge and skills (learning) in a manner that is similar to and reaches the same level as expected of their same-age peers.
- **Longitudinal Study:** A study that is designed to take place over a prolonged period of time whereby the same participants are observed or tested at multiple points. This enables researchers to detect changes in the characteristics of their target population.
- **Manifest variable:** A variable which is directly observed (in contrast to a latent variable, which cannot be directly measured).
- **Mental retardation:** Mental retardation, now referred to as intellectual disability, is characterized by impairments in intellectual and adaptive functioning. Typically, individuals with intellectual disability have an IQ score lower than 70 and limitations in two or more adaptive behaviors.
- **Metacognition:** The ability to be aware of and understand one's own cognitive processes.
- **Multinomial logistic regression model:** A statistical classification method used to predict discrete (categorical) outcomes.
- **Normative outcome:** Outcome compared to a "typical" peer group.
- **Polytomous:** The act or process of dividing into more than three parts.
- **Postsecondary:** Postsecondary refers to the stage after high school. For example, postsecondary education refers to any education received after high school, such as college.

- **Prognosis:** The predicted course, duration, and outcome of a disease or disorder.
- **Psychotropic:** Affecting mental activity, behavior, or perception; a mood-altering drug.
- **Randomised Control Trial (RCT):** A randomised control trial is a specific type of scientific experiment that randomly allocates participants to either the experimental group or the control group. This design aims to reduce selection bias and is considered the gold standard for clinical trials. Within this context, participants have a 50% chance of receiving the intervention or treatment and a 50% chance of not getting the intended intervention or receiving a placebo.
- **Savant skills:** Savant skills are extraordinarily developed skills, or 'island of genius' that are exhibited at an exceptional level and occur within the context of mental disability. For example, "hyperlexia" pertains to an individual's ability to read well beyond what is expected of their age, despite often demonstrating poor comprehension and even profound nonverbal learning disability. Approximately 1 in 10 people with autism spectrum disorder have savant skills in one or more domains. These skills are outstanding, both in comparison to the person's general level of ability, as well as that of the broader population's ability. Savant skills most often fall into the categories of impressive performance in mathematical calculations, music, art or memory.
- **Secondary school:** Secondary school typically refers to a high school, and provides education after primary school, and before postsecondary school (i.e., higher education, such as college). In certain situations, middle school may also fall into the category of secondary school.
- **Sheltered workshop:** Workplaces in which work activities are easy to perform, tasks are typically repetitive, and the pay is below minimum wage. Common activities in sheltered workshops include assembling, packing, and woodworking. All individuals working in a sheltered workshop typically have a disability.
- **Special education:** Education for children with a disability that is provided in a school and is designed to meet the unique needs of the child. Instruction is specialized, and adaptations are made to content, methodology, and/or delivery, such that the child is able to be successful and have their specific needs met.
- **Speech/language impairment:** A communication disorder that adversely impacts a child's performance in the classroom. A speech/language impairment may be characterized by stuttering, difficulty articulating sounds, difficulty understanding words or expressing oneself, or difficulty voicing words.
- **Society for Adolescent Medicine:** An organization dedicated to improving the physical health and psychosocial well-being of adolescents through interdisciplinary work in advocacy, clinical care, health promotion and service delivery, and research.
- **Survey weighting:** A statistical method that adjusts data collected from surveyed individuals in order to represent the population from which the sample of individuals was drawn.
- **Symptomatology:** The combination of signs, markers or indications of a disease or disorder.
- **Systematic Review:** A critical analysis of multiple existing research papers that are collected and identified in alignment with a defined research question and in accordance with explicit inclusion and exclusion criteria.
- **Transition planning:** Within this context, transition planning refers to the strategies and steps set in place to assist individuals with ASD in their shift out of high school and into employment, college, and other post-high school steps.

- **U. S. Vocational Rehabilitation system:** A system in the United States which helps individuals with disabilities find and retain employment opportunities. Services offered include, but are not limited to, job skills training, job counseling, and job placement.
- **Vocation:** A vocation refers to an individual's work, occupation, or employment. Vocational training is related to the development of specific skills sets necessary for a particular type of employment.
- **Quality of life (QoL):** The degree of satisfaction an individual has regarding a particular style of life.

Recommended Background Reading

Magiati, I., Tay, X. W., & Howlin, P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*, 34(1), 73-86. doi: 10.1016/j.cpr.2013.11.002
<http://www.interactingwithautism.com/pdf/treating/31Magiati2014.pdf>

Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child and Adolescent Psychiatry*, 52(6), 572-581. doi: e1. 10.1016/j.jaac.2013.02.017
<http://www.ncbi.nlm.nih.gov/pubmed/23702446>

Roux, A. M., Shattuck, P. T., Cooper, B. P., Anderson, K. A., Wagner, M., & Narendorf, S. C. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 52 (9), 931-939. doi: 10.1016/j.jaac.2013.05.019
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3753691/pdf/nihms-492240.pdf>

Bishop-Fitzpatrick, L., Hong, J., Smith, L. E., Makuch, R. A., Greenberg, J. S., & Mailick, M. R. (2016). Characterizing Objective Quality of Life and Normative Outcomes in Adults with Autism Spectrum Disorder: An Exploratory Latent Class Analysis. *Journal of autism and developmental disorders*, 1-13.
<http://www.ncbi.nlm.nih.gov/pubmed/27207091>