

SUMMARY REPORT

AGING AND AUTISM: A THINK TANK ROUND TABLE

Autism in Later Life: A Think Tank on the Effects of Aging on the Autism Spectrum.

VANCOUVER, CANADA
OCTOBER 28TH & 29TH, 2017



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FOREWORD AND FORWARD

The **AUTISM IN LATER LIFE THINK TANK** was the response and result of several organizations (*Autism Canada, the Pacific Autism Family Network, and the Autism Research Institute*) to address three prominent issues that have intersected and will continue to impact families, communities, and nations: 1) *the increased prevalence of autism*, 2) *the processes of autism and aging*, and 3) *the demographic change of aging societies*. Although we have a robust understanding of life course, gerontological and geriatric conditions for most aging individuals, little is known about aging with autism spectrum disorder (ASD).^{1,2,3}

Based on epidemiological studies, we do know that ASD is a lifelong condition,⁴ and it is estimated that adult care is the largest component of the lifetime societal costs of ASD, with 60% of medical costs accrued after age 21,⁵ thus research into prognosis, lived experience, outcomes, and useful interventions is essential to improve quality of life for older adults with ASD and to provide guidance for practitioners and caregivers.⁶ It has been indicated that aging with autism is an emerging public health phenomenon with potential challenges for autistic seniors,⁷ yet it has been shown that ASD is difficult to detect in old age,⁸ and it is still unknown if ASD characteristics change or are abated in later life. Notwithstanding such questions, it has been shown that ASD characteristics in adulthood are differently perceived across age, sex, and informants and this suggests that it

is important to repeatedly assess self-reported ASD characteristics during adulthood and later life.⁹

This relates to the need for more longitudinal studies to understand the many characteristics of ASD that may be associated with age change.¹⁰ This is particularly salient as we need to consider the array of cognitive issues (e.g., typical aging is often characterized by greater impairments in working memory, executive functioning, attention, episodic memory, concept formation, and processing speed) that may be differentially experienced by older adults with ASD.¹¹ But our **THINK TANK GROUP** also discussed the potential for the *positive* aspects of aging on the autism spectrum, such as the perspective of “aging well” with autism.¹²

All of these issues became the foundation for our **THINK TANK GROUP** to consider the priority issues to be discussed in a two-day period. We reached consensus on many issues, including the need for a viable *conceptual framework* to guide the various dimensions (the person and the dyadic, community, and social-political environments) of autism and aging¹³ and the critical need to include autistic adults in the research process and to help formulate and direct interventions and policy initiatives.¹⁴

The **AUTISM AND AGING THINK TANK** group focused on three themes: 1) *Understanding Aging on the Autism Spectrum*; 2) *Supporting Autistic Adults*; and 3) *Research Methodologies and Outcome Measures*. Relevant

“gaps” and research opportunities were identified for each theme and one important goal was to integrate the *life course focus* with autism issues, and yet to also understand that the heterogeneity of the aging process and of autism itself, collectively serve to create a challenge and a promise of strategic interventions, policy decisions, and targeted programs that may need to be quite different than that for younger adults.

The **AGING AND AUTISM THINK TANK** will continue to keep abreast of the most current literature and will seek to establish a clearinghouse of relevant and timely research and news items related to autism and aging. In addition, it will be critical for the **THINK TANK** to stay connected and in communication with various international and national organizations to share and receive the latest information on developments in aging and autism. Our **THINK TANK GROUP** will continue to advocate and support calls for ongoing funding for evidence-based research that examines autism across the life course, and with longitudinal studies that have direct application to relevant community based programs and services for aging adults on the autism spectrum. We look forward to the continued progression of this **THINK TANK GROUP** in the use of conceptual models and robust research findings, and most importantly, the application of evidence-based programs that work to increase the well-being and quality of life for aging adults on the autism spectrum.

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² Howlin, P. & Magiati, I. (2017). Autism spectrum disorder: outcomes in adulthood, *Current Opinion in Psychiatry*: March 2017 - Volume 30 - Issue 2 - p 69-76

³ Mukaetova-Ladinska, Elizabeta & Perry, E & Baron, M & Povey, Carol. (2012). Ageing in people with autistic spectrum disorder. *International journal of geriatric psychiatry*. 27. 109-18. [10.1002/gps.2711](https://doi.org/10.1002/gps.2711).

⁴ Brugha TS, et al. (2011)., Epidemiology of autism spectrum disorders in adults in the community in England. *Arch Gen Psychiatry*. 2011 May;68(5):459-65. [doi: 10.1001/archgenpsychiatry.2011.38](https://doi.org/10.1001/archgenpsychiatry.2011.38).

⁵ Ganz, M. L. 2007 The lifetime distribution of the in-

cremental societal costs of autism. *Arch Pediatr Adolesc Med*. 2007 Apr;161(4):343-9. PMID:17404130

⁶ Wise, E. A., Smith, M. D., & Rabins, P. V. (2017), Aging and Autism Spectrum Disorder: A Naturalistic, Longitudinal Study of the Comorbidities and Behavioral and Neuropsychiatric Symptoms in Adults with ASD. *J Autism Dev Disord* 47:1708-1715

DOI 10.1007/s10803-017-3095-3

⁷ Hategan, A., Bourgeois, J., & Goldberg, J. (2017). Aging with autism spectrum disorder: An emerging public health problem. *International Psychogeriatrics*, 29(4), 695-697. [doi:10.1017/S1041610216001599](https://doi.org/10.1017/S1041610216001599)

⁸ Heijnen-Kohl, S.M.J., Kok, R.M., Wilting, R.M.H.J. et al. *J Autism Dev Disord* (2017) 47: 2679. <https://doi.org/10.1007/s10803-017-3185-2>

⁹ Lever, A.G. & Geurts, H.M. *J Autism Dev Disord* (2018). <https://doi.org/10.1007/s10803-017-3444-2>

¹⁰ Megan Farley , Kristina J. Cottle, Deborah Bilder, Joseph Viskochil, Hilary Coon, and William McMahon (2018) Mid-Life Social Outcomes for a Population-Based Sample of Adults, *Autism Research*, 11, 142-152.

¹¹ Powell, P., S., Klinger, L. G., & Klinger, M. R. (2018). Patterns of Age-Related Cognitive Differences in Adults with Autism Spectrum Disorder. *J Autism Dev Disord*

DOI 10.1007/s10803-017-3238-6

¹² Hwang, Y., Foley, K., & Trollor, J. (2017). Aging well on the autism spectrum: The perspectives of autistic adults and carers. *International Psychogeriatrics*, 29(12), 2033-2046. [doi:10.1017/S1041610217001521](https://doi.org/10.1017/S1041610217001521)

¹³ Wright, S.D. Wright, C.A., D'Astous V. & Wadsworth A. (2016) Autism aging, *Gerontology & Geriatrics Education*, DOI: 10.1080/02701960.2016.1247073

¹⁴ Lawson W. (2015) *Older Adults and Autism Spectrum Conditions*. Jessica Kingsley Publishing. London.

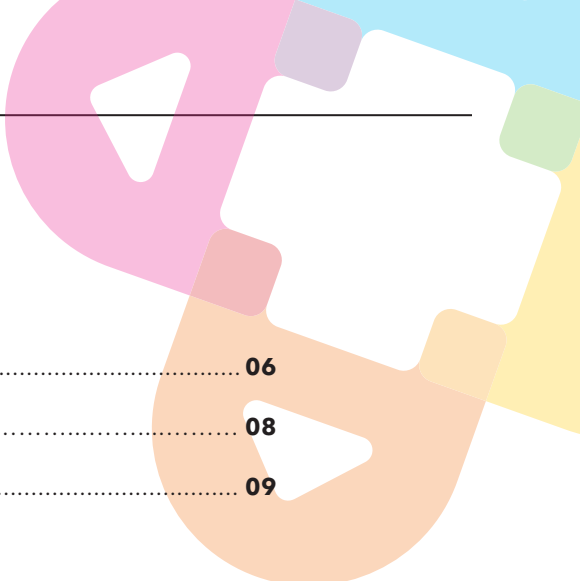


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EXECUTIVE SUMMARY

THE AUTISM SPECTRUM: First described in 1943, autism is generally a life-long condition involving different etiologies, clinical presentations and developmental trajectories. However, individuals also share commonalities including challenges in communication, social reciprocity and behaviour. The characteristics of autism vary widely across the spectrum, and there is no standard "type" or "typical" person. Many live with a multitude of co-occurring medical and mental health conditions that may severely impact their quality of life.

Until recently, attention has focused primarily on early diagnosis and interventions in young children on the spectrum. Relatively little is known about what happens during their adulthood, especially as they age into mid- and later-life. Over the past few years, individuals on the spectrum, professionals, and researchers have begun to focus their efforts on understanding the aging process in mid- to late-life, and such discussions, along with research findings, will have substantial implications regarding best practice as well as establishing public policy.

THINK TANK ON THE EFFECTS OF AGING ON THE AUTISM SPECTRUM: The two-day Think Tank, organized by Autism Canada, the Pacific Autism Family Network, and the Autism Research Institute, included 27 individuals from five countries with various expertise (Participant List, Appendix 1). The meeting was organized around a series of presentations representing the perspectives of adults on the spectrum, researchers, clinicians, service providers, and opinion leaders in the autism field. The goal was to discuss the current landscape in aging research with respect to autism, and set the stage for further discussions about building a collaborative agenda across international boundaries (Agenda, Appendix 2).

THINK TANK OUTCOMES: Participants identified three broad themes and several sub-themes in need of research or action regarding aging and autism (see Table 1). During the discussions, the importance of word choice and labels were highlighted, with an emphasis on the need to be sensitive to how these terms and phrases are interpreted by those in the autism community. The participants felt that fully including autistic adults across the entire spectrum and their family members should be a central pillar in all planning and

implementing of research. Taking a best practice perspective was also emphasized during the discussion. This perspective is captured by the phrase *nothing about us without us*.

It was clear from the presentations and plenary sessions that there is much to be learned in understanding the underlying mechanisms needed to explain the heterogeneity of symptoms and functionality across the autism spectrum. Similarly, much more multidisciplinary research is needed to better diagnose and treat many of the co-occurring medical and mental health conditions common among those on the spectrum. This integrative perspective includes biology, functionality, and behaviour. A prerequisite for this approach, however, lies in our ability to recruit a relatively large population of autistic adults of all ages. One solution is to work collaboratively with groups internationally who are already engaged in longitudinal studies and to leverage resources and expertise in multi-site, multi-disciplinary research programs. The participants at the Think Tank were very supportive of this approach, and several offers for partnership were extended.

In response to the aging population worldwide, the fields of gerontology and geriatrics have received much recent attention, and many studies and initiatives are underway that are geared towards gaining a better understanding of the aging process from the biological, social sciences and health services perspectives.

In general, there needs to be an increase in public awareness regarding understanding the perspective of those on the autism spectrum and implementing accommodations to optimize their quality of life. Examples include considering an individual's style of social communication and his/her sensory sensitivities. This is especially important for health care and allied professionals, including personnel in emergency services, primary and tertiary care centres, and residential and long-term care facilities. This also extends to educators and employers since there is a relatively large gap in training and employment opportunities for autistic adults.

TABLE 1: GAPS AND RESEARCH OPPORTUNITIES

THEMES	GAPS AND RESEARCH OPPORTUNITIES
Understanding Aging on the Autism Spectrum	<ul style="list-style-type: none"> • Finding and recruiting autistic adults • Diagnosing autism in mid- and later-life • Understanding heterogeneity and sub types across the spectrum • Bridging the gap between biology and functionality • Linking co-occurring medical conditions to behaviour • Exploring risk/protective factors for common conditions of aging • Understanding co-occurring mental health conditions • Probing responses to drug treatments and other interventions
Supporting Autistic Adults	<ul style="list-style-type: none"> • Increasing public awareness and understanding of autism • Providing autism training for health care and allied professionals • Developing appropriate tools to navigate the health care system • Creating post-secondary continuing education and other training opportunities • Improving employment access, engagement, and retention • Designing creative living solutions • Training staff in residential and long-term care facilities • Proactively addressing vulnerabilities
Research Methodologies and Outcome Measures	<ul style="list-style-type: none"> • Learning from other fields, e.g., gerontology, pediatrics • Longitudinal and intervention studies: ensuring opportunities for collaboration • Combining databases and standardizing experimental methods • Defining a common metric for assessment of symptoms and functionality • Designing appropriate quality of life measures across the spectrum

NEXT STEPS: The organizing committee will build on the momentum generated at the Think Tank and will widen the scope and breadth of the network. This involves the creation of a sustainable international collaborative group aimed at finding solutions to the challenges experienced by adults on the spectrum as they age.

BACKGROUND



THE AUTISM SPECTRUM: First described in the 1940s, the autism spectrum encompasses a group of highly neurodiverse conditions with different clinical presentations, yet they share many impactful characteristics, including challenges in communication, social reciprocity and symptomology. Behaviours common among them include deficits in communication and social interaction, repetitive behaviours, insistence on sameness, and sensory sensitivities. Today, those on the autism spectrum are usually diagnosed during childhood, with an estimated prevalence of 1:68 in North America. The symptoms and characteristics across the spectrum vary greatly and there is no prototypical description of a person with autism.

It is likely that there will be many causes of autism. There are now well over 100 genes that are known to increase the risk for autism. A number of environmental factors have also been implicated either alone or in conjunction with genetic factors. Individuals on the autism spectrum often have one or more

co-morbid conditions including intellectual disability, gastrointestinal problems, epilepsy and anxiety. There are currently numerous treatment options, with the most frequently employed being behavioural interventions and medications. The field is moving towards treating disabling features rather than autism as a whole.

THE KNOWLEDGE GAP: Historically, professionals and researchers have focused their attention to children on the autism spectrum. More recently they have expanded efforts to include individuals in their transition years, which are often referred to as “emerging adulthood.” The autism community has recently expanded its attention to individuals in their mid and senior years, with interest in their physical, social, and mental health needs. This is compounded by the realization that numerous adults, including seniors on the spectrum, are undiagnosed or misdiagnosed, and therefore receive little or no care and support, or may possibly be given inappropriate care.

AUTISM IN LATER LIFE: A THINK TANK ROUNDTABLE

THINK TANK PLANNING: To address the gap in our understanding of aging on the spectrum, Autism Canada, the Pacific Autism Family Network, and the Autism Research Institute organized a two-day international Think Tank to bring together experts and opinion leaders to start the process of identifying needs, gaps and opportunities to study senior adults, ages 50 years and older, who are on the autism spectrum. An expert organizing committee (see Table 2) met for several months by teleconference to identify Think Tank

participants from different subfields of study including adults on the spectrum, researchers, and clinicians. The committee determined the meeting objectives and an agenda that would deliver on these objectives. In total, 27 people participated in the Think Tank from five countries: Canada, the United States, the United Kingdom, the Netherlands, and Australia, including two who joined by technology-based connection (see Participant List-Appendix 1).

TABLE2: THINK TANK ORGANIZING COMMITTEE

MARGARET BAUMAN,
*Boston University School of
Medicine, Boston, MA, USA*

STEPHEN M. EDELSON,
*Autism Research Institute,
San Diego, CA, USA*

SUZANNE LEWIS,
*Pacific Autism Family Centre,
Richmond, BC, Canada*

LAURIE MAWLAM,
Autism Canada, Bothwell, ON, Canada

DAVID NICHOLAS,
University of Calgary, Calgary, AB, Canada

KEVIN STODDART,
The Redpath Centre, Toronto, ON, Canada

SCOTT WRIGHT,
University of Utah, Salt Lake City, UT, USA

In the weeks leading up to the Think Tank, 18 one-on-one interviews were conducted with Think Tank participants to gather personal insights and perspectives on key topics to be discussed at the meeting.

THINK TANK OBJECTIVES:

- To bring together individuals on the spectrum, researchers, clinicians and policy makers to identify individual and contextual factors facing aging individuals on the spectrum and their families;
- To promote a multi-role and inter-professional approach to identifying the unmet physical, medical, social and service needs experienced by aging individuals on the spectrum and their families; and
- To facilitate national/international networking and collaboration around common priorities to advance research, knowledge, and solutions for issues related to aging and autism.

THINK TANK FORMAT:

The two-day Think Tank was comprised of a series of presentations on various topics regarding aging and autism and was interspersed with several question and answer sessions and plenary discussions. This was followed by a two-hour plenary session, with the goal to identify needs, gaps and collaborative research opportunities (see Agenda-Appendix 2).

WORKSHOP PRESENTATIONS

The following is a summary of the key points from the Think Tank presentations.

THE INSIDER PERSPECTIVE

The Think Tank began with presentations from three adults on the autism spectrum who provided "real world" experiences of aging in autism.



GEORGES HUARD,
Adult on the spectrum

Georges, a 58-year-old man diagnosed with Asperger's Syndrome at age 36 years, is a computer technician at the Université du Québec à Montréal. Georges spoke of living in the present. He does not anticipate future challenges because they may distract him from his daily life and routines. He tends to misplace possessions, has short-term memory challenges, and has difficulty multi-tasking. Over the years, he has developed many coping strategies to overcome these challenges.

Georges' concerns as he ages include being able to plan ahead to maintain his independent lifestyle, identifying when he has a health issue, seeking appropriate support when needed, and remembering to

take his medications. He is also concerned about adapting to new routines in the future, especially in an assisted living environment or retirement residence, where he is concerned that his unique needs might not be recognized. Georges' message to the group was to focus on aging on the spectrum in relation to non-autistic aging and to ensure that information is delivered in a way that encourages a healthy lifestyle, including good nutrition and physical activity. He also suggested that we avoid frightening predictions for their future because this may cause panic and distress among those on the spectrum.



LARS PERNER,
Adult on the spectrum

Lars is a 53-year-old man, who was diagnosed with Asperger's Syndrome at age 31 years. He is a professor at the University of Southern California (USC). Lars credits much of his success in life to his upbringing which provided access to excellent health care and few financial worries. He spoke of his experiences with anxiety, depression, spatial perception, and discomfort with change and surprises. Lars also described his ability to compensate for his challenges,

resulting in a successful university career. He expressed concern about his future as he ages, especially post-retirement and the loss of his network of colleagues. Although Lars has a supportive family, they are also aging, and he expressed concern about what will happen once his mother passes away. He intends to postpone retirement for as long as he can. He also wants to avoid becoming too dependent on social media for social interactions and his connectivity to others.



WENN LAWSON,
Adult on the spectrum

Wenn is a 65-year-old psychologist, teacher, public speaker and prolific writer on autism. He has been misdiagnosed twice - first at two years of age with an intellectual disability, and then at age 17 years with schizophrenia. He received an autism diagnosis at the age of 42. Wenn spoke of his long journey to discover who he was after having been misdiagnosed and being prescribed the wrong medications. He also spent much time figuring out what an autism diagnosis meant in "real time," and dealing with gender and sexuality issues in

later life. Wenn agreed with the previous speakers with respect to challenges with, (1) short-term memory issues and cognitive thinking, (2) managing certain aspects of everyday life, (3) adjusting to change, (4) balancing privacy and social interaction, and (5) making an effort to focus on a task in order to get it done. He encouraged the group to consider the impact of gender and sexuality issues, which are known to be quite common among individuals on the spectrum.

THE RESEARCHER PERSPECTIVE



SCOTT WRIGHT,
Gerontologist, University
of Utah, USA

A CONCEPTUAL MODEL FOR AUTISM: BRIDGING THE GAPS

The aging demographic of the world's population has driven a groundswell of international research activities in the fields of gerontology and geriatrics which are advancing our understanding of the aging process by initiating inter-disciplinary and inter-professional approaches that are needed to improve the quality of life for the elderly. In the last six years there has been a spike in the number of research publications, media stories, and books written by individuals on the spectrum that capture their personal perspectives of living as an

autistic adult. Gaps focus on the need for, (1) more social supports, especially for elderly parents with adult children on the spectrum, (2) more community-based residential solutions, (3) an increase in social advocacy to support individuals and guardians, (4) help and support with life-course decisions, (5) consideration of the extreme heterogeneity in aging trajectories across the spectrum, and (6) the critical importance of involving individuals on the spectrum into the design and methodological aspects of research. A conceptual bioecological model was proposed for consideration (see Appendix 3).



JEREMY PARR,
Clinician Scientist
in Pediatric
Neurodisability, UK

THE UK AUTISM SPECTRUM ADULTHOOD AND AGING RESEARCH PROGRAM

The autism research team at the United Kingdom's (UK) Newcastle University, in partnership with the UK charity, Autistica, has launched three unique longitudinal cohort studies (ASD-UK, Daslne, Adult Autism Spectrum Cohort- UK). This research involves children, adolescents and adults on the spectrum as well as their family members in research studies that span age as well as ability ranges; this work will include systematic follow-ups over decades. Currently, 1,400 autistic adults and 550 relatives have been recruited to the adult cohort, ranging in age from 16-88 years (median age: 36 years). It was emphasized that a commitment to working in partnership with the autism community, guided by individuals and families with lived experience, builds trust and mutual respect

in leading to more meaningful outcomes. The team has developed many best practice approaches on how to successfully engage individuals on the spectrum and their families in research projects, including ways to reach people on the entire spectrum through family members or innovative, tailor-made strategies. Key factors used to help establish meaningful participation in an integrated research program include, (1) relying on various communication methods (online vs. paper, visual vs. aural), (2) using different types of written materials (font size, spacing, colours, easy read formats), (3) tailoring meetings in autism-friendly environments (natural light, personalized meals, quiet space), and (4) making accommodations for autistic preferences and behaviour traits. An invitation to explore international collaborations was extended to Think Tank participants.



MARGARET BAUMAN,
Pediatric Neurologist, US

NEUROBIOLOGY OF AUTISM: EXAMINING THE HUMAN BRAIN

One of the challenges in studying the neurobiology of the autistic adult brain is obtaining a sufficient sample of quality postmortem brains and tissue samples to generate meaningful results. Progress in studying tissue has been impeded by the tremendous heterogeneity in etiologies, clinical presentations and developmental trajectories across the spectrum, and our lack of understanding about the relative subgroups. In addition, it is unclear how co-occurring medical conditions might impact

brain function. It has also been difficult to derive meaningful clinical/biological correlations with neuropathological findings in the absence of longitudinal and detailed medical, developmental, therapeutic and educational records, which are rarely available for autistic adults. A lack of appropriate age- and sex-matched controls presents a further challenge. A path forward could include longitudinal studies of the same population over time with some of the research subjects eventually providing brain tissue for study accompanied by the essential data needed to allow for meaningful clinical correlates.



DAVID AMARAL,
Neuroscientist, US

AUTISM BRAINNET AND THE AUTISM PHENOME PROJECT

Brain banking and longitudinal cohorts have been instrumental in advancing our understanding of the biology of Alzheimer's disease; similar resources are likely to be of value to the autism field. In 2014, Autism Speaks and the Simons Foundation provided the funding to launch *Autism BrainNet*, a US-based collaborative of four regional brain tissue banks, plus a node in Oxford UK. These tissue banks collect brain tissue for research on autism and related neurodevelopmental conditions, and to date, 103 tissue donations have been received and are available for distribution. Autism BrainNet is actively

seeking international collaborators in order to add additional nodes. *The Autism Phenome Project*, launched in 2006, is a longitudinal analysis of children on the autism spectrum and aged-matched controls, which includes brain scans (e.g., MRIs) and the collection of blood samples for immune and genetic analysis. Early results indicate that about 15% of boys have abnormally enlarged brains from about six months of age, which correlates to a lower IQ, a greater likelihood of a regressive course, and a more challenging prognosis. Differences have also been found in the immune system of children with autism, and different subsets of children have distinct patterns of metabolites in their blood.



DAVID NICHOLAS,
Social Scientist, Canada

EXAMINING EMPLOYMENT FOR OLDER ADULTS WITH AUTISM

Employment is often a pathway to social interaction, financial security and independence. For individuals on the autism spectrum, however, finding meaningful long-term employment can be difficult even for those with training and academic credentials. A recent Canadian study (2015) reports that only 22% of working age adults on the spectrum are employed. Too often employers are unable or unwilling to make accommodations for the diverse challenges experienced by many autistic adults. Individuals, who are fortunate to find employment, often find themselves moving from job to job in positions that can be menial relative to skill level and unrewarding. The

situation may be worse for women, especially with respect to risk for marginalization in the workplace.

Unemployment may result in depression and other mental health issues, including risk for suicidality, social isolation, and financial hardship. Recommendations include, (1) a longitudinal perspective of employment (i.e., engagement, retention and sustainability), (2) increased public awareness about the realities of living on the autism spectrum, (3) capacity building among employers, mentors and co-workers, (4) improved community partnerships, (5) greater engagement of self-advocates in the change processes, and (6) greater focus on quality of life issues. In addition, better metrics and methods of assessment are needed at individual, program and community levels.



SUZANNE LEWIS,
Clinician Scientist, Medical
Geneticist, Canada

iTARGET AUTISM

Lessons learned from the study of autistic children are likely to be of value in the study of autistic adults. Genomics research has identified rare forms of autism, and these results may someday provide answers to the genetic underpinning of part or all of the spectrum as well as the pathways causing co-occurring medical conditions. In addition, there are indications that phenotyping matched with whole genome sequencing might offer clues to best therapies and

outcomes. iTarget, an interdisciplinary collaboration based in British Columbia, Canada, focuses on genetic, neurological, and environmental biomedical factors. The goal of this collaboration is to better understand co-occurring medical conditions and develop accurate diagnostic and individualized therapeutic solutions (i.e., "best-fit" therapies). iTarget has already collected physical and genetic information from 100 individuals and is now focusing on investigating the impact of the microbiome.



KEVIN STODDART,
*Clinician and
Researcher, Canada*

EMOTIONAL AND SOCIAL WELL-BEING OF OLDER ADULTS WITH AUTISM

A series of case studies on older adults with autism illustrated the importance of receiving an accurate diagnosis and community-based interventions. In addition, longitudinal tracking of medication use and their effectiveness are important issues. The more severely an individual is affected, the earlier he/she is likely to be diagnosed with autism, whereas those diagnosed in later life tend to have milder symptoms and greater functionality. Many of those with later diagnoses have learned to adapt to their physical and social environment. Unfortunately, there has been relatively little attention given to the social and emotional well-being of adults on the autism spectrum. Mental health professionals may not be aware that they are seeing autistic individuals in generic mental health practices, or when they are, unsure how to respond. Therefore, health care and allied professionals need to be trained on how to provide appropriate

diagnosis and treatment to address the unique needs of autistic adults. Furthermore, a common metric is needed to measure the various symptoms across the entire spectrum as well as proper assessment of the various levels of functioning in order to sufficiently characterize clinical and research samples. Unanswered questions include:

- What is the longitudinal experience of older adults with mental health care providers and mental health treatments?
- What are the needs for training of physicians and other mental health specialists?
- What are the risk and protective factors related to mental health over the lifespan?
- How does physical health status over the long-term affect mental health status?
- How might we extrapolate clinical/research methods/findings from children and adolescents on the spectrum, and from the non-autistic aging population, to autistic adults?



STEPHEN M. EDELSON,
Research Psychologist, US

CO-OCCURRING MEDICAL CONDITIONS

Many co-occurring medical conditions commonly reported in children on the autism spectrum are often reported in non-autistic seniors. This includes epilepsy, gastrointestinal and immune dysfunction, sensory processing challenges, sleep disturbances, bone density issues, and difficulties with memory retrieval and

executive functioning. There is mounting consensus that many of the characteristic behaviours in autistic individuals, such as self-injury and repetitive behaviors, may be attributed to underlying medical and sensory conditions. There is an urgent need for more research to explore the correlation between co-occurring medical conditions and autistic behaviours.



SCOTT WRIGHT,
*Gerontologist, University
of Utah, USA*

THE CASE FOR LONGITUDINAL STUDIES

The value of longitudinal studies was emphasized as a powerful tool in autism research so that we understand the changes within the aging process (changes over time) compared to cross-sectional studies which provide valuable information, but where we are typically examining the differences between age groups. It was noted that the definition of "old" has become a moving target, depending more on health and functionality than actual chronological age. In reality, aging is part of a seamless continuum, or bridge, across the lifespan, and there is much that can be learned about aging on the autism spectrum from the gerontology field. Medications, and drug interactions, for example, are already a huge issue in the elderly, and the Activities of Daily

Living (ADLs) and Instrumental Activities of Daily Living (IADLs) that determine an individual's dependency on others, may be useful in autism studies. There are also many new international initiatives in place that are focused on aging, including ways to make towns and cities more age-friendly. Universal Design aims to provide multi-generational and trans-generational housing alternatives, such as walkable/easy access to essential facilities, services and supports that are designed for the disabled community, the elderly, and those on the autism spectrum. Again, the importance of community based participatory research was stressed, including the need to involve individuals on the spectrum as the drivers of multidisciplinary team science. There should also be an agreement among researchers on measures and assessments to evaluate overall well-being and quality of life.

WORKSHOP PRESENTATIONS - DAY 2:

A RE-GROUNDING FROM THE INSIDER PERSPECTIVE: WENN LAWSON

Think Tank participants were reminded that few people welcome aging, and singling out autistic seniors may place undue emphasis on “autism” itself rather than the overall challenges of aging faced by the population at large. That being said, similar to their non-autistic peers, individuals on the autism spectrum change as they age, but many of these changes will be different from their peers. For example, they are more likely to read facial expressions (than autistic children), less likely to have memory issues (compared to those aging typically), and may have a greater self-awareness than when they were young. However, autistic seniors also tend to exhibit an increase in mental health issues, immune disorders, physical disorders and immobility. On the positive side, there is some evidence to suggest that brain plasticity decreases less in autistic seniors than in non-autistic adults, potentially conferring protection against dementia. Object permanence (i.e., knowing that something or someone still exists even if out of sight) can also be a challenge. This lack or poorly formed appreciation can be mistaken for poor theory of mind. As individuals on the spectrum usually think very literally, it is important that information is clearly communicated in a format that is tailored to individual preferences and learning styles, and that accommodations are made since they may have difficulties processing information as fast as their non-autistic counterparts. Individuals on the spectrum need to be motivated in order to seek out social connections and be physically active. They also need to understand the reasons for engaging in activities and/or seeking professional help, as well as why they may need help and where to go to find it. Just like everyone, autistic adults want to be “amongst the living” rather than segregated. As many autistic seniors live with sensory dysphoria and are easily over- or underwhelmed, increased understanding and accommodations among the non-autistic population would promote greater inclusivity for individuals on the spectrum.



HILDE GEURTS,
Neuropsychologist,
Netherlands

COGNITION, CO-OCCURRING CONDITIONS AND QUALITY OF LIFE ACROSS THE ADULT LIFESPAN

The presentation focused on some of the early outcomes of one of the few studies in the world focusing on autism and cognitive aging. Also, findings from one of the projects from the REACH-AUT research network were discussed. This network was launched in 2014 as collaboration between various stakeholders (from advocacy groups to clinics). Researchers in the network work closely with autistic adults to ensure that the outcomes of their translational research programs will be directly beneficial to older adults on the spectrum. The focus is primarily on executive functioning, inter- and intra-individual variability, subjective well-being, and interventions across the lifespan. Research outcomes to date suggest that:

- Cognition and structure and function of the brain change from childhood to adulthood;
- Autism symptomology and other co-occurring challenges change during adulthood, peaking at middle age;

- Many individuals on the spectrum feel that they are aging faster than their non-autistic peers, but there is no reliable evidence to support this based on experimental measures;
- Working memory is impaired in many autistic adults as compared to non-autistic controls, but there are no differences in verbal memory between the two groups, and visual memory is actually better than controls; and
- There are potentially autism subgroups with different future outcomes.

Challenges identified include, (1) recruiting sufficient numbers of older adults on the spectrum who represent all levels of function and ability, (2) defining subgroups that may be at risk for accelerated aging or have protective factors/strategies, (3) developing more appropriate measure for quality of life, and (4) building on lessons learned and best practices in other fields, especially gerontology.



MARGARET BAUMAN,
Pediatric Neurologist, US

AUTISTIC ADULTS: DIAGNOSIS AND ACCESSING MEDICAL CARE

The presentation highlighted the challenges in locating older adults on the spectrum, especially those who are non-verbal, severely affected, or living in residential facilities where they may have been misdiagnosed. Most autistic adults were identified as children by their pediatrician, and those diagnosed in adulthood may have been identified by their primary medical physician, by self-identification, or by a referral to a specialist by a family member or caregiver.

Research studies need to include individuals across the entire functional/ability range of the spectrum rather than predominantly focusing on the high functioning adults who are able to complete standard questionnaires. It is challenging for an individual to be diagnosed with autism as an adult, especially since there are currently no validated diagnostic measures designed specifically to identify autistic adults. An accurate diagnosis is important because it will likely provide access to appropriate services and thus, improve quality of life as well as increase individual

self-awareness. Increased recognition and appreciation of the special challenges as well as the sometimes exceptional abilities of people on the autism spectrum is needed across society, especially among health care and allied professionals, including students and early career practitioners. The health care system is currently ill-prepared to address the communication and sensory challenges of autistic adults who may have no one to help them to navigate the complex health care environment. Individuals on the autism spectrum with healthcare needs may not present with the signs and symptoms of illness typically recognized by primary care and specialty providers. Too often, the focus of health care management has been on behavioural issues without the recognition that, in many cases, disruptive and/or atypical behaviors may be related to pain and discomfort associated with underlying medical conditions. Thus, there is an urgent need for professionals, parents, advocates and self-advocates to work together to broaden the understanding of this disorder and to change policy.

INTERNATIONAL SUCCESS STORIES

ONTARIO WORKING GROUP ON MENTAL HEALTH AND ADULTS WITH ASD (WWW.ADULTASD.CA)

A group of psychiatrists, general practitioners and autism experts came together to develop autism policies and a strategic plan for increasing awareness of the mental health needs of autistic adults among physicians. Funds were raised by emphasizing the association between autism and mental health, a substantive area with existing traction in the community. Two major conferences have occurred in Toronto. Policy initiatives are in process to address the problem of individuals on the spectrum who are housed long-term in hospitals, when there is a lack of appropriate housing options.

THE REDPATH CENTRE (WWW.REDPATHCENTRE.CA)

A private mental health organization specializing in autism and other neurodevelopmental conditions, across the lifespan. In addition to providing a range of clinical services, they carry out research, educate stakeholders, and advocate for systems change. The Redpath Centre was highlighted as a model for integrated specialist care. As well as having clinicians in Toronto, the Centre provides support and endorsement to reputable clinicians across the province.

FIRST PLACE ARIZONA (WWW.FIRSTPLACEAZ.ORG)

First Place Arizona will offer supportive housing, a residential transition program, and opportunities for education, training and creativity to individuals with neuro-diverse conditions, including autism. Based on nurturing a spirit of independence and interdependence within a supportive and caring environment, First Place will also provide the necessary tools and resources to help residents develop a lifestyle that is meaningful, productive, connected and fulfilling. First Place is as an example of similar ventures in other cities in the United States, such as Louisville, Kentucky.

MICROBOARDS, THE STAR RAFT PROJECT, AND INCLUSIVE HOUSING COOPERATIVES

The community-based Microboard system provides life-long continuity of support to individuals who need care, acceptance and understanding, balanced with a need to determine their own life course. They manage individualized funding and direct supports for the person at the centre as well as advocate for their needs within the wider community. There

are now more than 1,100 such Microboards in British Columbia, as well as in other Canadian provinces and in the US. The Star Raft model is a government-independent tool to help individuals who live with disabilities and their families build and sustain their own individual support networks that are person-centered, family-friendly, and anchored in natural community connections. This field-tested model incorporates a set of step-by-step actions for, (1) identifying people who can help, (2) mapping their connections, capacities, workplaces and the community spaces in which they have 'standing,' and (3) mobilizing their individual networks. The model systematically identifies the focus person's gifts, interests and capacities and moves in the direction of connection, companionship and contribution. Inclusive housing cooperatives and co-housing projects can develop small clusters of homes in one community, in which the person needing support and their live-in companion/caregivers are at the centre and enveloped by a circle of caring and committed neighbours, family and friends that remains strong over time.

THE MASSACHUSETTS SELF DETERMINATION PROJECT

Launched 20 years ago, this project empowered families in ethnic communities in Greater Boston to identify and implement local, culturally appropriate supports for their loved ones with developmental disabilities. Implementation began with a major grant from the Robert Wood Johnson Foundation (RWJF) to organize local governing boards in each of several minority ethnic communities, comprised of people with developmental disabilities, their families, and members of the local community. These governing boards were given control of the flexible funding dollars awarded to each client from the Department of Developmental Services (at that time the Department of Mental Retardation). Governing boards could then allocate these monies for services for the individuals inside their own ethnic communities. For example, in the Chinese community, a group of families with adult loved ones on the autism spectrum pooled their funds to hire Chinese-speaking staff in a group home. Even after the RWJF funding ended, families continued to meet and work together on behalf of their loved ones; the Chinese governing board is currently advocating for a second Chinese-speaking group home. This community-based approach brings families together and empowers them to establish culturally relevant supports for their loved ones with developmental disabilities.

KEY MESSAGES FROM THE THINK TANK: NEEDS, GAPS AND OPPORTUNITIES

The participants acknowledged that many voices were missing from the Think Tank, including representation from the entire spectrum. With this caveat in mind, knowledge gaps identified in the presentations were organized into three broad themes, (1) understanding aging on the autism spectrum, (2) supporting individuals on the autism spectrum in mid- and later-life, and (3) research methodologies and outcome measures (each described below). In addition, the following two overarching themes were highlighted to guide future actions.

TERMINOLOGY:

Think Tank participants recognized that there are many valid perspectives regarding preferred terminology to describe autism, and a passionate debate ensued between proponents of person-first language (e.g., "adult with autism") vs identity-first language (e.g., "autistic adult"). Given a growing literature on the dislike, amongst a majority of individuals on the spectrum, of person-first language, and in deference to the wishes of the autistic Think Tank participants, the group agreed to use either identity-first language or the more neutral phrase, "adult on the spectrum". Furthermore, in concordance with the decision to use a socio-ecologic model, rather than a medical model, the group decided to avoid language that pathologizes autism. For example, the group decided to use the term "co-occurring conditions," rather than "comorbidities," as the latter implies that autism is a morbid condition or disease. Participants were reminded to focus on the strengths and abilities of individuals on the spectrum, and to view challenges as socially constructed, as opposed to framing them as personal deficiencies. Finally, the group clarified that the term autism community will be used when families and the extended community are included, and the term autistic community will refer to the community of individuals on the spectrum.

NOTHING ABOUT US WITHOUT US:

The phrase "nothing about us without us" captures the concept of a participatory, person-centered approach in which the group of interest plays a central role in the design and methodological aspects of research. Engaging individuals on the spectrum and their families as the drivers of a multidisciplinary team ensures that the outcomes of translational research programs will likely be of direct benefit to them. It is important that team members or advisors on research projects are people with lived experience who represent the full diversity within the spectrum, and incorporate a balance of gender and ethnic backgrounds. This entails reaching those with communication and/or behavioural challenges through family members or directly through innovative and creative means, such as connecting to personal interests and using technology and video. The physical environment should also be structured in ways that meet the diverse needs of all individuals on the spectrum, and information must be clearly communicated in a format that is tailored to individual preferences and learning styles. This includes accommodation for the time needed to process information in a way that is not threatening or overwhelming to the individual. Although this approach may add to the time, resources, and planning needed, studies have shown that such efforts lead to more relevant outcomes, and will likely change the way people on the spectrum and their families think about research, thus generating more positive perceptions and engagement.

THEME 1: UNDERSTANDING AGING ON THE AUTISM SPECTRUM

DIAGNOSIS IN MID- TO LATER-LIFE: As autism was not described until 1943, and only entered the Diagnostic and Statistical Manual in 1980, the cohort of diagnosed autistic adults over the age of 50 years is still relatively small with many remaining undiagnosed or misdiagnosed. Women, in particular, seem to be under-diagnosed although the reasons for this are not clear. Misdiagnosis can result in poor outcomes, such as receiving inappropriate support and therapeutic interventions. To better understand the aging process in autistic adults, we first need to locate them. Some of these individuals may not wish to have a diagnosis or may not be able to access the system in order to receive a diagnosis. Some may be in diverse or precarious circumstances (e.g., homeless, residing in long-term care institutions, incarcerated). Currently, the only way to diagnose individuals with autism is by relying on behavioural measures.

UNDERSTANDING HETEROGENEITY: The heterogeneity across the spectrum indicates that autism may actually consist of many different conditions that appear, at the outset, very similar but are more distinguishable over time, with different prognostic trajectories. There is some evidence to suggest that different genomic signatures and biological pathways correlate with different subtypes, but more basic and applied research is needed to fully understand and differentiate the various subtypes as well as to bridge the gap between biology and functionality.

CO-OCCURRING MEDICAL CONDITIONS:

Autistic individuals often suffer from a host of co-occurring medical conditions. Their response to pain and discomfort is highly variable as is their ability to communicate what is wrong and where it hurts. Consequently, pain and discomfort can lead to behaviour challenges in ways that we do not fully understand. More research is needed on how co-occurring medical conditions contribute to behaviour and experiences, and how this changes with age, thus shifting the focus from behaviour

management to the biological causes of behaviour. More research is also needed on the impact of diet on the human microbiome. We also need to learn more about specific health conditions associated with aging, such as arthritis, cancer, hypertension, diabetes, obesity, stroke, and dementia, and how they manifest in autistic individuals, and how those individuals respond to standard therapies.

CO-OCCURRING MENTAL HEALTH CONDITIONS:

Research is needed to better understand co-occurring mental health conditions (e.g., anxiety, depression, cognitive and executive functioning, catatonia), and how they change over the life course. In addition, we need to understand how commonly prescribed medications, such as anti-depressants, anti-anxiety medication, and anti-psychotics, affect this population, both positively and negatively. This is also the case for cognitive-behaviour therapy and mindfulness training. Furthermore, there is a need for improved training of mental health care professionals in these areas.

THEME 2: SUPPORTING INDIVIDUALS ON THE AUTISM SPECTRUM IN MID- AND LATER-LIFE

INCREASING AWARENESS AND UNDERSTANDING:

With no prototypical person on the spectrum, day-to-day challenges are uniquely individual, ranging from modest accommodations to 24/7 care. One common feature, though, is the need for greater understanding and awareness among society, especially within the health care system. Although there is slow and steady progress, greater efforts are required to educate the public as well as sufficiently train health care practitioners and allied professionals on how to effectively and sensitively accommodate the diverse needs and idiosyncrasies of individuals on the spectrum across the lifespan. Similar to their non-autistic peers, autistic seniors often need to be motivated to be physically active and seek out social connections. They also need to understand when it is necessary to ask others for help, especially with respect to navigating the community and health care system. Finally, autistic seniors may be more vulnerable to fraud and abuse/neglect; hence, protective safeguards need to be in place.

EDUCATION: Although support for children and adolescents on the autism spectrum is improving, there remains a huge void following the transition from high school or college to employment. For all people, the capacity for learning does not end at 18 years of age. Many adults on the spectrum, regardless of age, may benefit from continued education. Further, there is an urgent need for policy advancement in this area; for examples, publicly funded post-secondary education and professional training are warranted for adults across the spectrum.

EMPLOYMENT: In terms of employment opportunities, policy, attitudinal and practice advancement are needed to create accessible jobs. Capacity-building is needed among employers in order to improve employment access and sustainability. Family and community partnerships play an important role in this sphere, as many success stories are reported to reflect employment opportunities

created by family and community members who appreciate the need to accommodate the special interests of individual adults by tailoring the environment to unique functional needs. Change practices can be applied at a systems level to drive long-term positive change. In nurturing meaningful career generation, public and private sectors need to be attuned to, and proactively address, a longitudinal approach to employment that is responsive to individuals' functional abilities and career aspirations. Better metrics and methods of assessment at individual, program and community levels are needed to evaluate progress.

COMMUNITY-BASED SUPPORT:

More community-based solutions and interventions are needed to avoid or overcome social isolation, promote inclusivity, and provide support for autistic adults and their families. This is particularly true for autistic adults who cannot live independently. One of the greatest worries for many parents is what will happen to their son/daughter when they are no longer able to care for them. The long-term care situation for the non-autistic population is far from ideal, but this situation is considered much worse for those with autism and other developmental disabilities. Furthermore, caregivers at retirement homes and other long-term care facilities may be ill-prepared to accommodate the needs of many, if not most, autistic individuals no matter where they are on the spectrum. Thus, there is a need for specialized training programs for staff in residential care facilities and for the development of alternatives to facility-based care. While research on short- and long-term care facilities, especially those who are seniors with autism, are in its infancy, creative residential solutions need to include qualitative evaluations of both formal and informal services. Much can be learned from existing initiatives on inclusive multi-generational and trans-generational housing alternatives.

THEME 3: RESEARCH METHODOLOGIES AND OUTCOME MEASURES

LEARNING FROM OTHER POPULATIONS:

Studies on aging should reflect a seamless continuum across the lifespan, bridging what we know from the early years, with what we are discovering in later life. Rather than simply start new programs focused on older adults, one possibility is to expand and work from existing types of programs. Driven by the aging demographic of world populations, there is already a wealth of knowledge on the aging process in non-autistic individuals, and this can guide studies on the aging process in autism. Similarly, there is a rich literature on autistic children as well as other groups with neurodiverse conditions. These studies can help steer research on aging in autism and vice-versa.

LONGITUDINAL COHORT STUDIES:

Think Tank participants were supportive of longitudinal research designs to thoroughly understand the aging process in adults on the autism spectrum. The advantage of a large-scale longitudinal study in autism would be to systematically follow a cohort over many decades while evaluating various factors on a regular basis, such as mental health, physical health, quality of life, and much more. This would also include obtaining biological samples and eventually brain tissue. Unfortunately, such studies are difficult to sustain and costly, but longitudinal research can also inform and add to the robust implementation and evaluation of interventions, programs and services.

Another option is to evaluate individuals using a cross-sectional research design, in which a cross section of the autism population is sampled, beginning in early childhood and followed throughout their entire lifetime. The disadvantage of this methodology is that it is disconnected from specific life experiences (e.g., during childhood) that may play a significant role later in life. In general, the

participants in the Think Tank felt that there is a crisis “now,” and the autism field cannot afford to wait for solutions. That is, research studies are urgently needed to develop and evaluate interventions to help autistic adults live healthy and fulfilling lives. An opportunity exists to collaborate with the UK cohort, and there was considerable interest among the group to explore this issue further and to establish an international cohort in which each country funds its own node or area of expertise.

OUTCOME MEASURES: There was a consensus that standardized metrics are needed to address unique symptoms both within and across the many different subtypes of autism as well as determine better ways to assess and articulate levels of functioning. The surveys and measurement tools developed in the gerontology field may potentially be adapted for autism. Importantly, quality of life measures are needed to assess overall well-being. Current quality of life measures are based on criteria identified for the non-autistic population, and these parameters may not be the same for those on the autism spectrum. For example, it was posted that an individual on the spectrum might indicate a low quality of life score despite feeling that he/she has a very good life.

With respect to data collection, given the relatively small number of autistic adults over 50 years of age, it is recommended that research groups combine their data to increase the overall sample size and to work together to identify appropriate comparison controls.

NEXT STEPS



Think Tank participants hope that this report will contribute to future networking and collaboration within North America and throughout the world. It is further hoped that the momentum generated at this meeting can be maintained and additional participants will join this network in order to expand its scope and reach. This may include autistic adults across the entire spectrum, family members, clinicians, researchers, funders, policy makers and other relevant stakeholders. In the near future, the organizing committee will oversee future activities which may include the formation of working groups on specific topics, an internet discussion group, regular conference calls to address key issues, and one or more Think Tanks in 2018 as well as the sharing of relevant articles and funding opportunities.

APPENDIX 1: PARTICIPANT LIST



DAVID AMARAL

Beneto Foundation Chair and Director of Research, MIND Institute, University of California; Distinguished Professor, Department of Psychiatry and Behavioral Sciences and Center for Neuroscience, School of Medicine; Core Investigator, California National Primate Research Center

AREAS OF INTEREST:

- Neurobiology of primate social behavior and the development and neuroanatomical organization of the primate and human amygdala and hippocampal formation.

- Postmortem studies of the autistic brain and magnetic resonance imaging studies of children with autism spectrum disorders.
- Animal models of autism and the potential immune basis of certain forms of autism.
- Analysis of children with autism called the Autism Phenome Projects defining biomedical characteristics of different types of autism.



EVDOKIA ANAGNOSTOU

Senior Clinician Scientist

*Co-Lead Autism Research Centre, Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Associate professor Department of pediatrics, University of Toronto
Canada Research Chair: Therapeutics*

AREAS OF INTEREST:

- How genes affect brain structure/function, behaviour, cognition and health in children and adults with neurodevelopmental disorders.
- Translating research outcomes into new ways and effective treatments.
- Lead of the Province of Ontario Neurodevelopmental Disorders (POND) Network.
- Co-lead of the Autism Treatment Network (Toronto).



MARGARET BAUMAN

Pediatric Neurologist

Integrated Center for Child Development; Associate Professor of Anatomy and Laboratory Medicine

Department of Anatomy and Neurobiology, Boston University School of Medicine

AREAS OF INTEREST:

- Early identification and interventions for ASD.
- Diagnosis and treatment of autism and various neurological disorders in children, adolescents, and adults to

include learning and developmental disabilities, seizures, cerebral palsy, and neurogenetic disorders.

- Founding director of the LURIE CENTER, formally called LADDERS (Learning and Developmental Disabilities Evaluation and Rehabilitation Services).
- Established The Autism Research Foundation, The Autism Research Consortium, and The Autism Treatment Network.



DAVID BLACK

Pediatric Neuropsychologist; Director, Center for Assessment And Treatment, NIH

AREAS OF INTEREST:

- Factors that contribute to the best outcomes among children and adolescents with autism spectrum disorders.
- Neurocognitive and psychological underpinnings for effective navigation of the social world.

- Transition to adulthood and unique challenges inherent in that transition, as well as the role of stress and anxiety in autism and interventions that may reduce its impact.
- Comprehensive neuropsychological evaluations of children, adolescents, and young adults for autism, learning disabilities, attention disorders, and other medical conditions.



SERGIO COCCHIA

CEO, Board Chair, Pacific Autism Family Network

AREAS OF INTEREST:

- Father of an adult son on the spectrum.
- Co-founder of PAFN, Hub and Spoke centre excellence of ASD and related disorders.
- Business man and philanthropist.



STEPHEN M. EDELSON

Executive Director, Autism Research Institute, San Diego, California

AREAS OF INTEREST:

- Research Psychologist.
- Research on medical, behavior, sensory issues, and cognition.
- Editor of the Autism Research Review International.



HILDE GEURTS

Professor, Department of Psychology University of Amsterdam & Autism Clinic 'Dr Leo Kannerhuis'

AREAS OF INTEREST:

- Neuropsychology of autism and ADHD across the life span (childhood to old age).
- Focus on cognitive functioning (executive functions, attention,

- memory), mental and physical comorbidity, and quality of life.
- Fundamental experimental cognitive studies as well as more applied intervention studies.
- Head of the research network autism (reach-aut) that supports translational research directly beneficial for people with autism.

APPENDIX 1: PARTICIPANT LIST



JUNE GRODEN

Co-founder, Chairman of the Board, and Past CEO of the Groden Network of Programs, Providence, Rhode Island.

AREAS OF INTEREST:

- Active in the field for over 40 years.
- Masters in Education and Ph.D. in Psychology.
- Formerly adjunct faculty of Brown

University, University of Rhode Island, and Salve Regina.

- Specialty area: Stress, and coping with stress in autism.
- Developed stress reduction procedures in relaxation and cognitive behavior therapies, adapted for persons with autism.



GEORGES HUARD

Computer technician

Université du Québec à Montréal

AREAS OF INTEREST:

- Diagnosed with Aspergers at 36 years of age by Dr Laurent Mottron, in Montréal.
- Works full time in IT support at UQAM, since 1997.
- Member of Autism Society Canada and its ASD Advisory Committee.
- Gives talks on aspects of living with Asperger's, since 1995.
- Has a sibling with classic autism, living in a group home setting.



CAROLINE JOSE

Research Associate

University of Moncton, New Brunswick

AREAS OF INTEREST:

- Complex care approaches by a multidisciplinary team of care providers: breaking barriers to better health and well-being.

- Patient-Oriented research working collaboratively with right stakeholders.
- Leads the CONTiNuity of care and support for the autism spECTrum disorder (CONNECT) Project.



WENN LAWSON

MAPsTutor/lecturer, University of Birmingham School of Education,

Autism Studies - Edgbaston Campus Birmingham, Victoria, Australia

AREAS OF INTEREST:

- Autism: Impact on daily living, due to brain disposition of being single focused (difficulties with multi-tasking, unless motivated by interest).
- Autism: 'Nothing about us without us'; co-production in research, from research conception to dissemination.



SUZANNE LEWIS

Clinical Professor, Department of Medical Genetics, UBC; Senior Clinician Scientist, BC Children's and Women's Hospital and Research Institute

AREAS OF INTEREST:

- Genetic, genomic and comprehensive phenotyping studies for the autism spectrum disorders, idiopathic intellectual disabilities and other complex neurodevelopmental disorders.
- Pan-omic applications of precision medicine and genetic counselling for autism spectrum and related conditions.



LAURIE MAWLAM

Executive Director, Autism Canada Bothwell, Ontario

AREAS OF INTEREST:

- Works passionately to facilitate the exchange and sharing of information and best practices and advocate for the rights of autistic individuals and their families.

- Participated in Senate and House of Commons Committee hearings.
- Sits on the National Autism Surveillance System (NASS) Advisory Committee.



DAWN MCKENNA

Executive Director, Pacific Autism Family Network, Richmond, BC

AREAS OF INTEREST:

- Passionate about supporting individuals with autism and other disorders through programs, services, research and knowledge translation.
- Over 30 years' experience with broad business background in finance, human resources and both business and non-profit management.



RAE MORRIS

Individual, Couple and Family Therapist Vancouver, BC

AREAS OF INTEREST:

- Specialization: Dual diagnosis, mental health, crisis intervention, behaviour support, family therapy, individual practice with children, adolescents, and young adults with ASD as well as parents and siblings of individuals with ASD, and qualitative research.

APPENDIX 1: PARTICIPANT LIST



**CHRISTINA
NICOLAIDIS**

Professor, School of Social Work, Portland State University; Co-Director, Academic Autism Spectrum Partnership in Research and Education (AASPIRE); Editor in Chief, Autism in Adulthood

AREAS OF INTEREST:

- Community based participatory research with autistic adults.
- Healthcare services for autistic adults.
- Other issues related to the health and wellbeing of autistic adults (e.g., employment, violence).



DAVID NICHOLAS

Associate Professor, Faculty of Social Work, University of Calgary

AREAS OF INTEREST:

- Approaches related to employment opportunities, training curriculum for employment support personnel,
- and community service for those with autism and other developmental disabilities (DDs).
- National and international practices to create inclusive work spaces and opportunities for persons with DDs.



JEREMY PARR

Clinical Senior Lecturer/Hon Consultant, Sir Kames Spence Institute, Royal Victoria Infirmary, Newcastle Upon Tyne, UK

AREAS OF INTEREST:

- Paediatric neurodisability.
- Investigating the neurobiological basis of disabilities, carrying out intervention studies to ameliorate disability, and undertaking research into clinical service delivery.
- Multidisciplinary assessments of children with ASD.



LARS PERNER

Assistant Professor of Clinical Marketing at University of Southern California, Los Angeles; Director on the Board of Autism Society of America and PSA Chair

AREAS OF INTEREST:

- Specializes in consumer behavior, international marketing, and electronic commerce. He holds a Ph.D. in marketing and an MBA and B.A. in political science and psychology.
- His main research interests center on consumer behavior, nonprofit fundraising, "win-win" deals, and autism subtypes.
- Lars became interested in the autism spectrum after being diagnosed with Asperger's syndrome in 1996.



KEVIN STODDART

Founding Director, The Redpath Centre; Adjunct Professor, Factor-Inwentash Faculty of Social Work, University of Toronto

AREAS OF INTEREST:

- ASD and other developmental disabilities in children, youth and adults, especially those with Asperger Syndrome.
- Clinical and psychological needs, co-morbid social and mental health problems, identification of ASD in high-functioning adults, aging and adults, families affected by ASD, cross-sector knowledge exchange, clinical services, social inclusion, policy change, criminal behaviours, sexual behaviours & gender identity.



**SUE VANDELDELDE-
COKE**

President and CEO, Kerry's Place Autism Services, Toronto

AREAS OF INTEREST:

- Care for the aging adult with autism, e.g., the effects of long term medication use and exploring the reasons for increased frailty in adults who have been in residence for 30-40 years.
- Ways to improve services/ programs for young adults who are seeking employment, educational opportunities.
- Exploring new methods of housing e.g., similar to US or Europe.



**DAVID AND FAYE
WETHEROW**

Parksville, BC

AREAS OF INTEREST:

- Innovative service development, evaluation, facilitation and training in the field of community living. Invented the Star Raft model for building enduring citizen-based circles of support.
- Created the very first Microboards and developed Prairie Housing Cooperative (inclusive cooperative housing), L'Avenir Cooperative (a family- and consumer-governed service co-op), and the Open Access Resource Centre (a lending library).



SCOTT WRIGHT

Gerontology Interdisciplinary Program, Con Nursing; Adjunct Associate Professor, Family And Consumer Studies;

Associate Professor, College Of Nursing, University of Utah

AREAS OF INTEREST:

- Innovative and impact zones that intersect the aging experience in an aging society. Examples: technology and aging and autism spectrum disorders in adulthood and later life.
- Autism spectrum disorders in adulthood and aging.
- Roles of technology in an aging society.



**ELIZABETH (BETH)
ZWICK**

Director of Community Relations and Program Officer, Nancy Lurie Marks Family Foundation, Boston

AREAS OF INTEREST:

- Improving our understanding of unmet needs of older adults with autism and their families.
- Identifying effective family support and future planning models for this population.
- Identifying accurate autism prevalence rates for individuals over age 40.
- Creating recreational opportunities for older adults with autism and their families.
- Understanding the role of religious organizations in promoting community inclusion.

APPENDIX 2: AGENDA - DAY 1 (OCTOBER 28, 2017)

TIME	AGENDA ITEM	PRESENTER/ MODERATOR
8:15 - Continental Breakfast		
8:45	<ul style="list-style-type: none"> Welcome Workshop logistics and objectives Pre-Workshop Interviews: What I heard 	Sergio Cocchia, Laurie Mawlam, Stephen Edelson, Judy Bray
9:30	<ul style="list-style-type: none"> The "Insider" perspective: Moving into senior years as an adult on the spectrum. Presentations: 10 mins each / Plenary Discussion: 15 mins 	Georges Huard, Lars Perner, Wenn Lawson
10:15	<ul style="list-style-type: none"> Current research and ideas for future research into the health and well-being of autistic adults. <ul style="list-style-type: none"> Presentation: 30 minute presentation / Plenary Discussion: 30 mins 	Jeremy Parr (Webex)
11:15 - Networking Health Break		
11:30	<ul style="list-style-type: none"> Tackling the issues in an organized, systematic and thoughtful way. Conceptual model: Bridging research and clinical practice, and community-based programs. <ul style="list-style-type: none"> Presentation: 30 mins / Plenary Discussion: 15 mins 	Scott Wright
12:15	<ul style="list-style-type: none"> Neurology - Structural and functional imaging, brain tissue banks <ul style="list-style-type: none"> Presentations: 10 mins each / Identifying priorities: 15 mins 	Margaret Bauman, David Amaral
13:00 - Networking Lunch and Guided Tour of PAFN		
14:15	<ul style="list-style-type: none"> Co-occurring (comorbidities) Medical Disorders <ul style="list-style-type: none"> Presentations: 20 mins / Identifying priorities: 10 mins 	Suzanne Lewis, Stephen Edelson
14:45	<ul style="list-style-type: none"> Social, Emotional and Mental Health Needs <ul style="list-style-type: none"> Presentation: 20 mins / Identifying priorities: 10 mins 	Kevin Stoddart
15:15	<ul style="list-style-type: none"> Employment and Vocational Issues: Challenges and solutions <ul style="list-style-type: none"> Presentation: 20 mins / Identifying priorities: 10 mins 	David Nicholas
15:45 - Networking Health Break		
16:00	<ul style="list-style-type: none"> The need for longitudinal research in memory, executive function and quality of life. <ul style="list-style-type: none"> Presentation: 20 mins / Identifying priorities: 10 mins 	Scott Wright
16:30	<ul style="list-style-type: none"> Wrap up of day 1 	Judy Bray
17:00 - Meeting Adjourned		
<p>Networking Dinner Century Plaza Hotel, 1015 Burrard Street (transportation will be provided and leaves hotel at 18:00)</p>		

APPENDIX 2: AGENDA - DAY 2 (OCTOBER 29, 2017)

TIME	AGENDA ITEM	PRESENTER/ MODERATOR
8:30 - Continental Breakfast		
9:00	<ul style="list-style-type: none"> Introduction to Day 2 - <i>Recap of Day 1, objectives, logistics</i> 	Judy Bray
9:15	<ul style="list-style-type: none"> Moving forward from the perspective of an individual on the spectrum <ul style="list-style-type: none"> Presentation: 30 mins / Plenary discussion: 15 mins 	Wenn Lawson
10:00	<ul style="list-style-type: none"> Cognition, comorbidity, and quality of life across the adult lifespan <ul style="list-style-type: none"> Presentation: 30 mins / Identifying priorities: 30 mins 	Hilde Guerts (Webex - will be 7.00pm in the Netherlands)
11:00 - Networking Health Break		
11:15	<ul style="list-style-type: none"> Diagnosis instruments for screening and in-depth assessment for older adults. How is it working in the clinical setting? <ul style="list-style-type: none"> Presentation: 30 mins / Identifying priorities: 15 mins 	Margaret Bauman
12:00	<ul style="list-style-type: none"> What's working? Examples of national and international success stories (10 mins each) <ul style="list-style-type: none"> First Place, Arizona Microboards The Red Path Centre 	Scott Wright, David Wetherow, Kevin Stoddart
13.00 - Networking Lunch		
14:00	<ul style="list-style-type: none"> Partnerships and collaborations around identified priorities: <ul style="list-style-type: none"> Where are the most promising opportunities for value-added national and international collaboration? What are the critical steps needed to move the field forward in a significant way? What potential funding sources are available? Engaging with the new journal Autism and Adulthood 	Plenary discussion
16:00 - Meeting Adjourned		

OCTOBER 28 -29, 2017

Pacific Autism Family Network, Vancouver

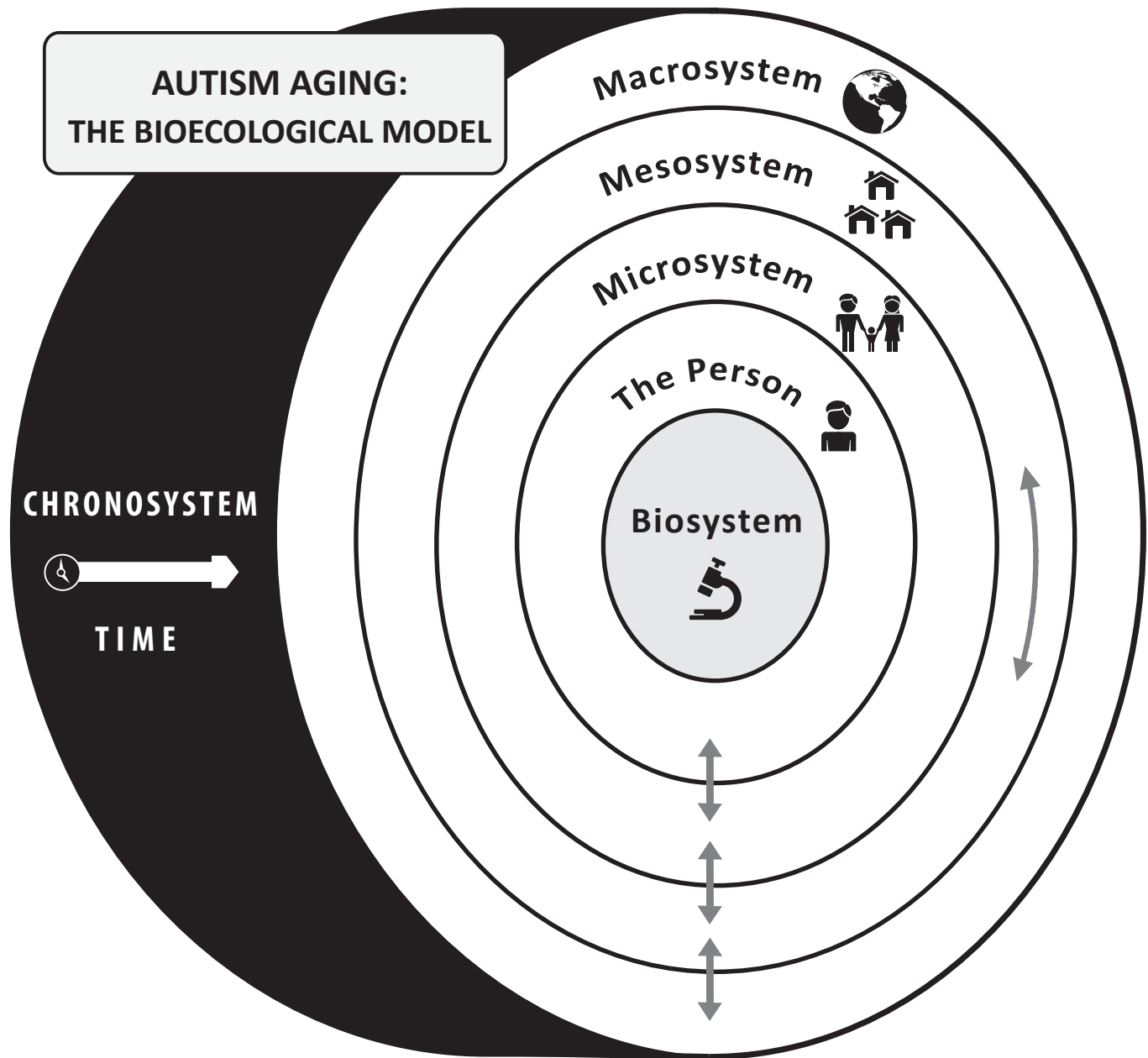
WORKSHOP ORGANIZERS

Autism Canada, Autism Research Institute, Pacific Autism Family Network

WORKSHOP OBJECTIVES:

- Bring together researchers, clinicians, and policy makers to generate interest and identify individual and contextual factors facing aging individuals on the spectrum and their families;
- Promote a multidisciplinary and inter-professional approach to identifying the unmet physical, medical, social and service needs experienced by aging individuals on the spectrum and their families; and
- Facilitate national and international networking and collaboration around common priorities to advance research, knowledge, and solutions for issues related to aging and autism.

APPENDIX 3: A CONCEPTUAL BIOECOLOGICAL MODEL



ACKNOWLEDGMENTS

We wish to acknowledge the generous donation from the Russell Agricultural Society's Ladies' Night event in 2017 in support of advancing the autism research agenda.

We wish to send a special thanks to Sergio Cocchia for his wonderful hospitality and a great dinner.

We would also like to acknowledge and thank all our sponsors.





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PHONE: (519) 695-5858 | FAX: (519) 695-5757

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