

Prepared for the
Aging and Autism Think Tank
October 28-29, 2017
Vancouver, British Columbia, Canada

Co- Hosted by



Autism Aging - The Odyssey

by

Scott D. Wright, PhD
Gerontology Interdisciplinary Program

University of Utah
Salt Lake City, Utah

Revised November 7, 2017

I. Introduction

The Odyssey, (and attributed to Homer), the main character Odysseus is on his way for a ten-year voyage home to Ithaca, and the story begins *in medias res* – *in the middle of things*. This ancient story has been an inspiration for me in how we will eventually return “home” despite the challenges, obstacles, barriers, and forces that seem beyond our control. For me, the concept of “home” is related to the reaching of our goals and our efforts to create a better understanding of autism in the context of aging, to the inclusion of those aging with autism as partners in research and outreach and outcomes, to the prospect of supporting quality of life and well-being for those with autism - *across the life course*. Are we there yet? No. But, in effect, it is similar to the discovery of new territory slowly being mapped and catalogued (Lawson, 2015; Wright, 2016; Wright, Brooks, D’Astous, & Grandin, 2014). We are on a ship sailing into new waters, but we are navigating and we are discovering – and soon will be home. Perhaps we are near a *mid-way point* – and that leads to another connection to the classic story of *The Odyssey*.

II. In Medias Res

The Odyssey started - *in medias res*- and I also believe that we (as attendees at this Aging and Autism Think Tank –Vancouver BC) who have an interest in autism issues in mid and later life (which I refer to as “autism aging”) are also in the “middle of things” on our own journey - to finally address autism issues in later life and complete the journey of the life course with scholarship and practical applications – and thus to return ‘home’. So I think of this long odyssey as at the mid-way point and I wish to share with you – *in medias res* – examples of what we know already and I refer to this knowledge as “Legacy Exemplary Literature” (LEL). And I will then share with you where are we are at now (n the present – *in medias res*) and refer to this as “Current Exemplary Literature” (CEL). As course, all of this together helps to provide a compass – and navigational maps, a lighthouse, for our journey ahead – to finally arrive *home*. But before I present the inventory of both the “LEL” and “CEL” domains of the literature, we have to consider that these domains represent the beginning of the scaffolding and structures for what I refer to as the “bridge-building” for autism issues across the life course. That is, the bridge of knowledge that we have (both the LEL and CEL) at this point (*in medias res*) is a good start, but thus far the bridge is incomplete, with major parts missing – and therefore, we are confronted with a significant “gap.”

III. Autism and Aging (Life Course): Bridge-Building and the “Gap”

One of the main points highlighted in the publication by Wright et al (2016), “Autism Aging” in the journal *Gerontology and Geriatrics Education*, was the significant *gap* in existing research (and thus a concomitant gap in the translational delivery of relevant services and programs) that addresses autism and aging issues. In that article, Wright et al (2016) conducted an extensive literature search via SCOPUS on the autism in the leading journals in these fields and with a few exceptions (e.g., see Pivens & Rabins, 2011), there is a glaring omission in gerontology and geriatrics publications, and in the literature *in general*. I refer to this as the “gap” and I have used the “bridge” metaphor frequently (publications and presentations) to describe

this gap effect, such that the potential is there to complete the bridge of knowledge across the life course (including mid and later years of life), but that in its current phase – *the bridge is incomplete*. Or rather some sections have been created and built, but the longer span sections of life course autism research is still missing – thus the gap.

The bridge metaphor can visually captured (in terms of my preference for a bridge) by images of the construction of the iconic Golden Gate Bridge. If you review and examine the historical images of the Golden Gate Bridge, the bridge building was done incrementally – and the process unfolded over time. The towers came first, then main cables, and then bridge sections for the actual road. When the towers were in place, there was still a “gap” over the bay waters. In my opinion, this is our situation; this is our status, with the literature with autism and aging. We still have a gap.

The existence of the current “gap” can be partially explained by the result of the research activity that is either limited by resources and incentives in universities or that the “priorities” within the funding organizations (e.g., government or NGOs) are skewed to specific topics, or targeted age groups, or directives of advisory boards or advocacy groups. We are beginning to see changes in funding priorities, but a balanced perspective for life course issues is still needed.

The other issue in explaining or at least creating the gap in autism aging is what I call the process of “epistemology following epidemiology.” This is related to the focused attention on age groups (or specific ages) where a diagnosis of autism is most likely to occur and is associated with the “school years” of K-12 where the federal law, called the Individuals with Disabilities Education Act (IDEA) requires that public schools create an IEP (Individualized Education Program) for every child (age 3 through high school graduation or a maximum age of 22) receiving special education services. In addition, there is additional attention generated through the Autism and Developmental Disabilities Monitoring (ADDM) Network and the CDC surveillance strategies with a focus gathering of data on 8 year-old children (and younger). As Gerhardt and Lanier (2011) have indicated, 70% of the currently identified individuals with ASD are younger than age 14 years. The end result is a process of “epistemology following the epidemiology” (in the broadest sense of the terms and including changes to nosology). In other words, the diagnostics, the developmental stage, the disability, and the demographics all combine to create the gravitational pull by which autism is seen, focused, understood, measured, analyzed, and translated into targeted services and programs that are typically associated with early stages of the life course. This “lens” of autism is then translated in the domain of pediatrics, and with an array of school programs and services associated with the K-12 school years. The intensity, frequency, and magnitude of research and education on autism issues, therefore, have also followed the “maturation of autism” as successive cohorts of youth diagnosed and identified with autism. So in effect, the “gap” is in large part (but not completely) the result of funding priorities skewed away from life course (and therefore aging issues) and also because of the way in

which autism research, public attention, and services and programs seem to incrementally “build out” and follow the demographics (large numbers of individuals with ASD diagnosis) of cohorts of individuals with autism as they “age out” and into the transition years of adulthood (which may also include the post-secondary and college years). Indeed, the area of the life course that has expanded most rapidly (if measured by number of research articles in the past few years) is associated with autism with the “transition years” into adulthood.

Of course, what we are observing is the lag effect and one might say, a natural shift as researchers and policy makers *follow* the demographic and the epidemiological focus of “autism aging” – and we are now seeing the beginning of a continuous and in-depth examination of autism into adulthood and beyond. Yet, questions and concerns remain. As example, the article by Wright et al, 2016, raises a few issues (out of many) that need to still be addressed (for any future endeavors) and related to, 1) conceptual and theoretical, and 2) methodological concerns.

I will review these concerns (and others) later in this paper for the Think Tank. But first, I think it is imperative that we briefly acknowledge and examine “where we have been” to see “where we are going.” Thus, I insert Newton’s famous line (but the expression goes back further than him): “*If I have seen a little further it is by standing on the shoulders of Giants.*” I can relate to this expression, not as a Newton-like person, rather, that as someone who takes a great deal of sense of duty – and honor – as an academic to appreciate the work already conducted, so that when I *review the literature*, I am able to identify words of wisdom from previous scholars on their experiences, their limitations, and most importantly their recommendations. All of this is the experience of “standing on the shoulders of giants.” We see further and we see more clearly. Are there “giants” in our interest area of later life and autism? Yes. Let’s briefly review my take on those shoulders that offered by the *giants* in our domain. And this is where we consider the not only the look forward, but also what has been accomplished thus far (where we are at now – *in medias res*). So these are the proposed domains of: **I. Legacy Exemplary Literature (LEL) and II. Current Exemplary Literature (CEL).**

Of course, one issue that begs clarification is this: At what point do we consider the exemplary literature as “legacy”? I have thought about this for some time. In my opinion, there was natural “break point” in the literature being produced, and with the timing of two books published. By “break point” I mean to say there was a steady stream of “legacy” type publications, but after 2016, I think the quantity and quality of publications began to grow in greater numbers. I also think that a major catalyst was the emergence of special sections and interest groups on *autism and aging* at IMFAR (now known as INSAR {International Society of Autism Research} annual meeting – e.g., INSAR 2018 at Rotterdam, Netherlands). Because these domains are something that I have conceived for this Think Tank in Vancouver, I indicate the proposed “break point” in the year 2016 (when the “Legacy” domain gives way to Current Exemplary Literature domain) with these two books as benchmarks to separate the legacy literature from the current literature:

1) one by Wenn Lawson (2015), and 2) the edited book by S. D. Wright (2016) for the conceptual “line” that captures the end point for Legacy Exemplary Literature (LEL) and thereafter initiates the “Current Exemplary Literature” domain. So what follows is a brief but substantive inventory of the Legacy Exemplary Literature (LEL) ranging from the year 2011 to the year 2016 in the larger domain of *Autism Aging*. I conceptually see this a “bridge-building” – toward a continuous range of scholarship and programs and services across the life span. But the “gap” remains – even as we see an increased expansion of robust scholarship in the Current Exemplary Literature (CEL). But the “Odyssey” continues – even if we see the next ten years – as where the bridge building will seek near completion and we arrive “home” with a better sense of experience of autism in the context of aging. This sense of “home” will be better understood with the inclusion of autistic individuals in the research process and the outreach to aging individuals with autism in the community – and perhaps, in other settings associated with the aging experience.

IV. Legacy Exemplary Literature – Autism Aging (2011 through 2016)

In my opinion, the legacy literature starts here with the article by Piven and Rabins (2011), which appeared in *JAGS*. This was the “call” and the benchmark examination of aging and autism issues. The recommendations and implications for any future research were robust and relevant. In addition to the Piven and Rabins (2011) benchmark paper, we must also acknowledge the team from The Netherlands van Niekerk, Groen, Vissers, Driel-deJong, Kan, & Vashaar (2011), and their paper, “Diagnosing autism spectrum disorders in elderly people.” Soon thereafter, is the landmark work of E. Mukaetova-Ladinska, E. Perry, M. Baron, and C. Povey, with “Ageing in people with autism spectrum disorder” (*International Journal of Geriatric Psychiatry*, 2012). The article by Howlin and Moss (2012), “Adults with Autism Spectrum Disorders” (*The Canadian Journal of Psychiatry*) is included here in the Legacy domain because of the reference to the lack of research on ASD issues and aging (specifically mid-life) and was part of section with a guest editorial by Eric Fombonne (May, 2012) on “Autism in Adult Life.” And then what followed, were several outstanding publications that continued the “call” for the investigation of more research into this domain of the life course. Geurts and Vissers (2012), *Elderly with Autism: Executive Functions and Memory* is worthy of the legacy status; and in addition with the excellent publication by Happe and Charlton (2012), *Aging in Autism Spectrum Disorders: A Mini-Review*, which presented a great overview of the issues and literature thus far...(as of 2012). And the article by Perkins and Berkman (2012), “Into the Unknown with Autism Spectrum Disorders”, which also highlighted the lack of research in the aging domain of autism. What was noteworthy was the focus on quality of life issues in this article as a balanced perspective to the traditional perspectives of comorbidities in previous research. In 2013, Wright et al published an extensive review of the literature on autism covering both adulthood and aging and offered recommendations for future research. And the publication by Howlin & Taylor (2015) helped to indicate the need for high quality research for autism and aging (and adulthood) issues. And here is an interesting study (2015) by F. Elichaoff, “What’s is Like Being You?”

Growing Old(er) with Autism: A Scoping Study” even though the sample size was nominal (N=4) the results offered pathways for future research. We then arrive at the proposed end point for the Legacy Exemplary Literature (LEL) with the publications of two books by Jessica Kingsley Publications: Wenn Lawson’s book (2015) and in January 2016, the edited book by S. Wright. Lawson’s book is a remarkable account of both personal and professional experiences with autism and aging issues. Wright’s book was an inter-professional, interdisciplinary and international perspective on aging and autism. Together they represent a significant benchmark in progress in scholarship, persona narratives, meaningful experiences, and practical solutions for the autism aging. But these publications also serve as catalyst, motivators, and needed inspiration to keep the momentum going in bridge building. The Odyssey continues.

So now we briefly examine the selected Current Exemplary Literature (CEL) in autism aging. Here we begin to the incremental development of robust methodologies and substantive findings to offer guidance and direction toward service and programs that are informed by gerontological and geriatric knowledge and practice.

V. Current Exemplary Literature – Autism Aging (2016 to present)

I begin with the publication of Sicherman et al (2016), “Grandma knows best: Family structure and age of diagnosis of autism spectrum disorder” in the journal *Autism* which highlights the intergenerational impact of grandmothers (specifically) as family watchdogs in that family structure and frequency of interactions were key in establishing a lower age for diagnosis in (grand)children. To me, this is a key feature to add to the landscape of autism and aging issues, such that we think of autism aging as also connecting to the family context (over time) and that aging individuals (grandparents) can provide an important dimension in the support network – *downstream*. While the focus may be on the aging individual (the person) with autism, here we recognize that autism also impacts multi-generations – and that grandparents may be an overlooked support system in the domain of autism issues.

As we focus on aging issues and autism, we speak of the associated lifelong conditions (autism across the life course) into mid and later life. But this publication by Hirvikoski et al (2016), *British Journal of Psychiatry*, was a reminder that co-occurring conditions across life course – can have a substantial impact (markedly increased) in premature mortality in ASD. This article delivered a ripple effect to the many in the autism community: *Individuals with ASD had a 2.56-fold increased odds of mortality compared with matched general population controls.*

And the implications of this study: *Adequate and coordinated medical care for individuals with ASD and research into the phenomenon should be a target for a considerably broader audience of medical specialties than psychiatry and neurology.* In effect, if we are talk about quality of life and well-being with autism aging – this publication is clarion call to consider this:

Our observation of excess cause-specific mortality in individuals with ASD may signify a

generally increased biological vulnerability in ASD, as well as insufficient awareness, diagnoses and treatment of comorbid diseases within the healthcare system.

I think this publication highlights the need for a systematic approach in autism aging, with a consideration of multiple systems – and contexts – to be understood – across the life course. And that as we consider autism as a lifelong condition - perhaps the fulfillment and potential for full life expectancy may be compromised by a multitude of medical conditions.

So even as we consider the impact of multiple medical conditions (MMCs) for individuals with autism, it is relevant that within the geriatric domain we also use the term “MCCs” to mean Multiple Chronic Conditions (MCCs) which is for many aging individuals (e.g., the old-old) a part of the frailty with those typically 75+. Obviously when we consider Hirvikoski’s work – we may be dealing with an array of medical conditions impacting quality of life and impacting ADLs and IADLs for those with autism conditions.

And this leads to the next exemplary publication, which was in effect a letter to the editor format, but the message of M. Bennett (2016) is still a powerful incentive for action and future direction for our think tank in Vancouver: “What is Life Like in the Twilight Years?” A Letter About the Scant Amount of Literature on the Elderly with Autism Spectrum Disorders”. In effect, Bennett called for more research in the area of aging and autism to the readers of *Journal of Autism and Developmental Disorders* and proposed the following: a) although the majority of the research funding for ASDs had been allocated to biomedical and clinical features, there is need for more research directed to the advancements of human health and projects exploring the impact of health care systems for people with ASDs; b) governments increase funding for projects evaluating health systems for elderly with ASD; c) to increase research on seniors with ASD and at all levels industry associations, community organizations, educational institutions to all engage in research on elderly with ASDs.

And in the same time period, Cos Michael, sets forth a powerful message in the journal *Autism*, with this title, “Why We Need Research About Autism and Ageing.” S. Patra (2016) wrote a nice overview of health care issues and challenges in the *Journal of Geriatric Care*, “Autism spectrum disorder in the elderly: a review of health care issues and challenges” and this is very relevant out think thank – for reference.

And this article, by Wallace et al (2016), Aging and Autism Spectrum Disorder: Evidence From the Broad Autism Phenotype in *Autism Research* 9: 1294–1303, suggest that the BAP in older adulthood imparts additional risks to areas of functioning that are known to be crucial to aging-related outcomes in the context of typical development. These results might in turn inform aging in autism spectrum disorder, which has been largely unexplored to date.

The publication by Murphy et al (2016) is another exemplary publication to add to the current inventory for consideration by the think tank. Even though the title indicates autism and adulthood, “Autism Spectrum disorder in adults: diagnosis, management, and health services development” in the journal, *Neuropsychiatric Disease and Treatment*, the implications of aging are well represented as the authors consider a wide range of issues (many of which by now sound familiar) including health care needs, diagnosis and management of conditions. But again the greatest need and challenge is to understand the health care needs for aging individuals and this is seen as the greatest and most urgent need.

The next article by Wright et al (2016), “Autism Aging”, appeared in *Gerontology and Geriatrics Education* (online) in October 2016 and represented a follow-up to the edited book by Wright (JKP). This article sought to focus the educational aspects of autism and aging such that it was noted that little was published in the textbooks or any educational materials for gerontologists and geriatricians in (and) for the their training as professionals. This article is seen as complement to the edited book by also highlighting how the field of gerontology and geriatrics can contribute to the understanding of aging issues and autism by working with experts and specialists in autism, and with aging individuals with autism, to create an interdisciplinary perspective on autism aging.

The article by Happe et al, 2016 (and see also Charlton), “Demographic and Cognitive Profile of Individuals seeking a Diagnosis of Autism Spectrum Disorder in Adulthood” (in *JADD*), is a keystone publication in this inventory as the authors note important changes over time (with aging) that capture the dynamics of autism as a life course experience. The authors noted that while aging (per se) may not reduce autism traits, the cumulative style of coping mechanisms and general cognitive ability *might* help to mitigate their effects. This represents the kind of robust research that is needed to establish a foundation for a scholarship “compass” in autism aging.

Before we move into the year 2017 and other exemplary research to note for this think tank, I think it is critical for our planning committee and the think tank participants to recognize the pioneering work of the National Autistic Society (London, UK) in the domain of ageing and autism, and in particular their publications (“Ageing with Autism”) and resource links at this web site: <http://www.autism.org.uk/about/adult-life/ageing.aspx>

And this link in particular to a 2012 conference on autism and ageing issues: <http://network.autism.org.uk/knowledge/insight-opinion/who-cares-supporting-older-people-autism-effectively>

VI. The Year 2017 – Exemplary Literature...

In the year 2017, we start with what I think is a remarkable publication that meets many of the expectations for a high quality and robust study for aging and autism issues. The title of the article, “Aging and Autism Spectrum Disorder: A Naturalistic, Longitudinal Study of the Comorbidities and Behavioral and Neuropsychiatric Symptoms in Adults with ASD” by Elizabeth Wise, Marcia Smith, and Peter Rabins (March 2017) in *JADD*. If you will recall, Peter Rabins was the co-author of the legacy exemplar publication (back in 2011) (with J. Piven) in *JAGS*, “Autism Spectrum Disorders in Older Adults: Toward Defining a Research Agenda.” This article begins with this first sentence in the abstract: “Little is known about Autism Spectrum Disorder in persons over age 50.”

While we agree, and this certainly enforces our notion of “the gap” in the literature, as you have already noted in this “odyssey” paper for the think tank, there are positive signs that the “gap” is being addressed – although we still have away to go – to reach “home.” What is substantial in this study is the longitudinal design and wider range of measurement tools to assess a variety of medical conditions and the changes over time.

The authors noted significant decreases in behavioral and neuropsychiatric symptoms in adults with ASD, and yet the authors noted that *high level of support* needed across the life course in order to sustain a degree of stability in the cohorts studied. The authors noted that future studies should examine if significant life transitions for older individuals with autism in later life such as retirement from supported employment or the death of aging parents or siblings (as support systems).

Note the similar publication (timing and content) in the journal, *The American Journal of Geriatric Psychiatry*, (Wise, Rabins, & Smith, 2017), “Aging and Autism Spectrum Disorder.”

Hickey, Crabtree, and Stott (2017) published a qualitative research paper, “Suddenly the first fifty years of my life made sense’: Experiences of older people with Autism” in *Autism*, and they included 13 people with autism over the age of 50 years and they proposed three emergent themes: *difference, life review and longing for connection*. These relevant themes were sustained across the life course...and point to an interesting discovery that isolation and loneliness and supposed hallmarks of adulthood and identity such as (un)employment affect a disruptive profile on the life transitions typical of older age. Autism support groups were highly valued and needed.

Judy Endow, who wrote a very informative chapter in the edited book by Wright, also contributes blog postings, and this one caught my eye is deserving of sharing with the think tank participants on “autistic burnout and aging.”

And it is good to see a continuation of books to be published in the domain of autism and aging with this title: “Understanding Autism in Adults and Aging Adults: Improving Diagnosis and Quality of Life” by Theresa Regan (2017).

In my opinion, a landmark event (a significant indicator of progress in filling “the gap”) was the establishment of the 2017 IMFAR Special Interest Group (SIG) led by Dr. Hilde Geurts (University of Amsterdam, Netherlands) and Co-Leader, Amanda Roestorf (both of which contributed chapters to the edited book – Wright).

The special interest group discussed background measures and cognitive functioning, ASD Symptomatology, and Well-Being. The strength of this SIG was the determined focus on the assessment of older adult adults with ASD. I think this development is critical to the future of filling “the gap” because there is the focus on the collective efforts of the many researchers to be aware of robust measurement tools and sue of effective methodologies. Finally, please note the review of measures on “well-being” with older aged individuals with autism: this is significant and substantial!

As an example of the continued efforts to examine and review the use of appropriate measurement tools in the older adults with autism, we must include the publication by S.M.J. Heijnen-Kohl et al (2017) {also contributors to the edited book by Wright}, “Screening of Autism Spectrum Disorders in Geriatric Psychiatry” in *JADD*. The authors note a lack of validated ASD assessment tools in geriatric psychiatry and they review and discuss their Dutch informant personality questionnaire (HAP) and use for older adults in different settings. The authors propose that the HAP can be used as a screening instrument for ASD in older adults in a mental health setting.

In the July, 2017 publication by Powell et al in *JADD*, the authors noted that their study was one of the few systematic investigations of cognitive aging in younger and older adults with ASD, and the first to provide evidence that *age may disproportionately affect certain cognitive functions* (e.g., cognitive flexibility) in adults with ASD compared to adults with typical development. The authors suggest that much more research is needed on how environmental factors (thus, see Wright and use of ecological model for autism aging) account for individual patterns of age-related differences.

Before I complete this inventory of Current Exemplary Literature (CEL), I think it is important to note the recent event at City, University of London (July, 2017) (hosted by the Autism Research Group) which examined the topic of ageing and autism. The following individuals (many of which were contributors to the edited book – Wright) participated: Dermot Bowler, Michael Baron, Hilde Geurts, and Amanda Roestorf (see Hilde Geurts and Amanda Roestorf connected with IMFAR/INSAR meeting in San Francisco, CA, 2017). Patricia Howlin also spoke at this event. I think this represents a positive momentum for autism and aging topics and issues and this link is provided here: <https://www.city.ac.uk/news/2017/september/ageing-and-autism>

And finally this: In July 2017, there was an important “letter to the editor” (Hategan, Bourgeois, & Goldberg, 2017) in the journal, *International Psychogeriatrics* (see pp.

695-697), titled, “Aging with autism spectrum disorder: An emerging public health program.” The authors noted the importance of the imminent wave of “graying ASD” and they highlight the important “what we do not know” {yet} issues related to autism aging (e.g., “whether ASD patients develop compensatory cognitive mechanism throughout life and/or experience progressive cognitive deterioration remains to be elucidated.” The authors also focus on the impact, the role, and dynamics of neurocognitive disorders (NCDs) {formerly dementia} [or neurodegenerative diseases] and ASD in the aging context. The authors call for an increased role of “geriatric” ASD, but I also like the encompassing nature of their title (“the letter”) that is at the level of “public health.” This indicates to me the scope and wide ranging impact and resulting needs that should be examined in a systematic way – from the individual to the social/cultural level (or scale) of study, treatment, and policy implications.

And the call above from Hategan, Bourgeois, & Goldberg (2017) was responded to (perhaps even as overlap!), as this publication soon appeared (just recently September, 2017) in *International Psychogeriatrics*, “Aging well on the autism spectrum: The perspectives of autistic adults and carers” by Hwang, Foley, & Troller (research team from Australia) where the concept of “aging well” (which by the way is a provocative - and to some – a controversial concept) is examined with those with autism and with the care providers (both). I think this is an important scale or measurement to add in the array of variables to examine in the aging and autism experience. What emerged as an important perspective is the person-environment dynamic when understanding the autism experience in the context of aging. I would agree and I think the ecological model is a robust conceptual model to consider when we venture forth to work together on the array of issues for autism in mid and later life. <https://doi.org/10.1017/S1041610217001521>

VIII. Autism and Aging (Life Course): Bridge-Building and the “Gap”- Revisited

So we are closer to “home” on the journey, but we are not there yet. We are still building the bridge – the Odyssey continues – but we can see the shoreline in the distance.

I realize I have several metaphors and labels and terms going on here in this document: Odyssey, Bridge, Gaps, Journey, Legacy, Current, Exemplary (and so on), but the main point is the topic of “autism aging” is still emergent – in flux – evolving.

If we continue with the metaphors, and with the visual imagery of the “bridge-being-built” (still under construction), and the imagery of arriving to “Home” – what does Home look like? That is, what does the destination look like? (From our vantage point here in October 2017 at the Think Tank). What would the bridge look like? What is the blueprint for the “bridge” completed? I have a few suggestions based on the Legacy and Current Exemplary Literature and personal observations and communications with colleagues and aging individuals with autism. As a

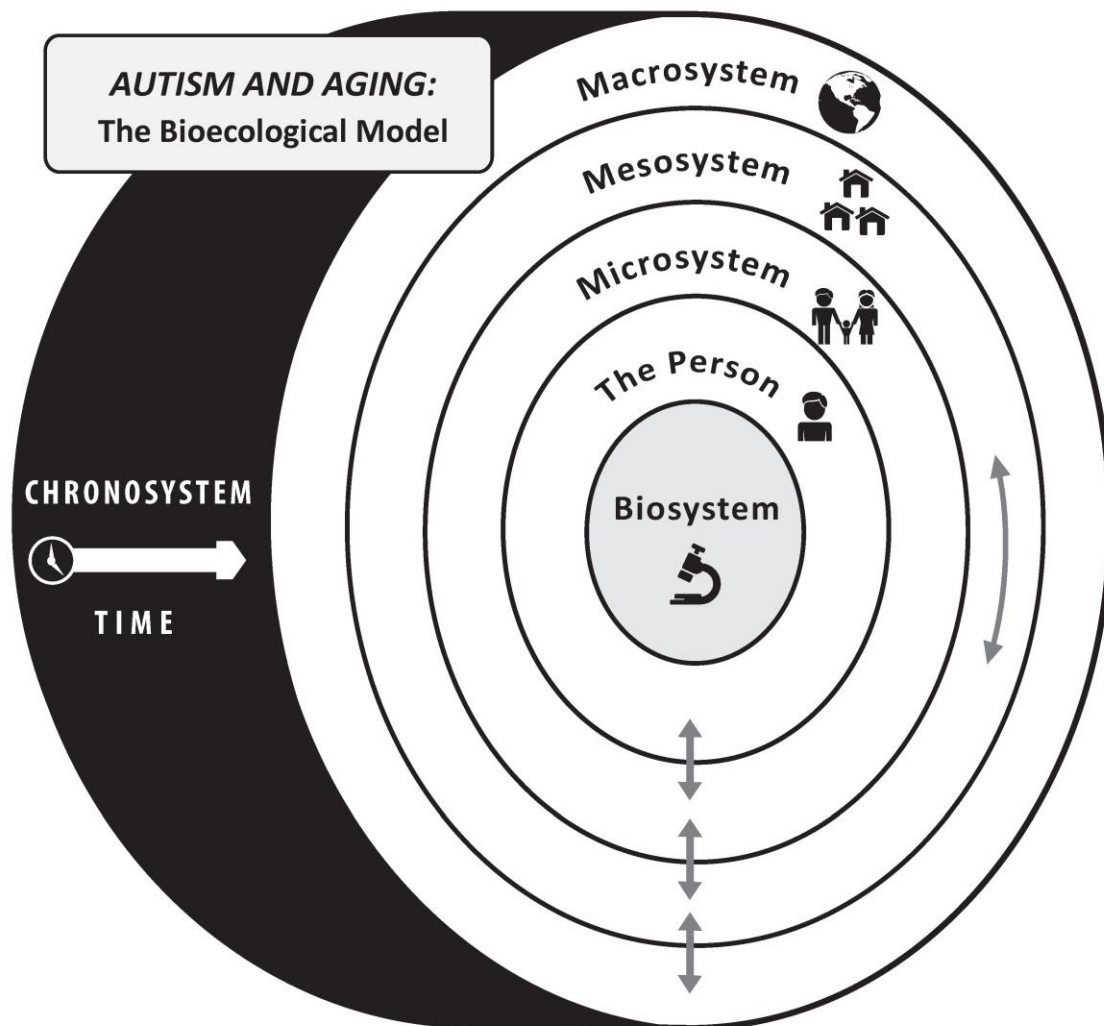
gerontologist, I envision *autism aging* with several key features, guideposts, structural factors, and compass points – *as we look forward to the future*.

A. Conceptual Models to Guide our Scholarship, Practice, and Policy

In the scholarship domain, conceptual models are powerful guides and frameworks to organize and visually coordinate the many dimensions of autism across the life course. It is my experience that both the use of conceptual models and theory for autism across the life course is lacking or limited in scope. While some see conceptual models and theory as unnecessary or too abstract or devoid of clinical significance, to me I could not imagine to understand the myriad of factors of autism aging – or autism as a life course topic – without the use of a conceptual model.

In the edited book (Wright) not only did I propose a conceptual model for consideration in our efforts for the future, but also I used to frame the entire edited book! As a gerontologist, I was trained in the developmental psychology tradition, but much more than that: Our understanding of aging encompasses many facets the aging experience including both the *person and the environment*. We have as a starting point the very basic formula of $A = f(p, e^s)^t$ which is based on Kurt Levin's model from many years ago. In this case A (aging) is a function of the person and their environments (plural) – over (t) time. Thus there is a premium of studying both the person in the context of their changing environments over time. The conceptual model that I think captures the necessary dynamics of autism aging is Urie Bronfenbrenner's Bio-ecological model – which is elaborated in the edited book. The multiple layers of autism aging are included: the biosystem, the person, the family, the community, and the larger social/cultural sphere of influence. All of these factors are important to visualize and embrace as influential (and bi-directional) on the other interconnected systems.

In the edited book, I modified the model in the context of autism and aging:



I think this conceptual model embraces other related perspectives such as the “Person-Environment Fit Perspective” and thus see the relevant new publication by Park, Han, Kim & Dunkle (2017) on “Aging in place of vulnerable older adults: Person-Environment Fit Perspective” in the *Journal of Applied Gerontology*.

Another theoretical model for the Think Tank to consider when addressing autism and aging issues could be the SOC Model which is explained here in greater detail by <http://medicine.jrank.org/pages/1549/Selection-Optimization-Compensation-model-selection-optimization-compensation.html> by A.M. Freund and also endorsed by such legacy scholars in aging as Erdman B. Palmore who prefers the term optimal aging. What is the SOC model? According to the SOC model, successful aging encompasses *selection* of functional domains on which to focus one’s resources,

optimizing developmental potential (maximization of gains) and *compensating* for losses—thus ensuring the maintenance of functioning and a minimization of losses. I am familiar with several support groups for aging adults with autism in the SLC area and one of which is “Optimizing Autism” and it strikes me that Optimal Aging and Optimizing Autism have a lot of common ground. The bioecological model in the broadest sense, and person-environment fit, and the SOC model all capture the goals and activities found within the optimizing experiences of autism and with aging – thus *autism aging*.

B. Attention to Methodology Issues

We (Wright et al) have found that much of the research on autism and aging issues has not explicitly discussing the implications and consequences of using cross-sectional designs versus longitudinal designs in published research. When examining issues of autism aging in multiple dimensions of person and environment *over time* it is imperative to understand and evaluate the various methodological intricacies associated with age, cohort, and time effects and how to discern and interpret the influences of various forces on the autism experience over the life course. In addition, increasing numbers of individuals diagnosed with autism who grow older in greater numbers together as cohort groups will dictate and determine changing priorities in interventions, services, and programs because of “where” the cohort group is at that particular point along the life course. We think cross-sectional research is important to building the knowledge on autism and aging issues, and we know that pursuing longitudinal research may have its challenges (e.g., attrition of participants; financial costs; and a longer time period to present results in publications or presentations), but we have an interest in robust findings that can lead to “evidence-based or evidence supported” programs and services that will reflect quality and efficiency in implementation for communities.

One day in the near future – we may see this may happen:

The Integrative Analysis of Longitudinal Studies of Autism and Aging (IALSAA) ¹ network, which facilitates interdisciplinary, cross-national research on determinants and dynamics of within-person aging related changes in cognitive and physical capabilities, health, personality and well-being. A key feature of this network is the organization and evaluation of the reproducibility through a coordinated analysis approach based on comparable statistical models and measurements (* see below Aitken, 2018). Our network activities encourage the examination of cross-cultural and cross-cohort effects and provide a strong basis for synthesizing evidence from longitudinal studies. Our network supports both quantitative and qualitative methods for the collection of data (across time periods). Our network supports the activities of participatory research (CBPR) partnerships with autistic adults in the organization and design of scholarship goals and implementation programs and service delivery.*

¹ inspired by *Innovation in Aging*, Volume 1, Issue suppl_1, 1 July 2017, Pages 1275, <https://doi.org/10.1093/geroni/igx004.4652>

And see Gillespie-Lynch et al, (2017) for endorsing the inclusion of autistic adults as critical autism experts. And of measurements, the recent work by Aitken (2018) looks to a nice addition to your professional library as we seek to fill the gap and engage in bridge building with evidence-based assessment. It is refreshing to see and read scholarship on this domain.

Aitken (2018) raises an important point in our quest for understanding autism spectrum disorder (ASD) as process of discovery: Yes – there is the respect for individuality and the uniqueness of each person (“When you met one person with ASD, you have met one person with ASD”) – and yet,

“There are enough similarities across people with ASD that work that has been done can help us today. If this wasn’t true, it would be impossible to learn from previous work.”

Aitken offers a strong critique of methodologies used in autism research and this book offers a way forward with bridge building and filling the gap for autism across the life course. For example, Aitken notes that there are many tools to assess someone *for* ASD (to tell whether or not they have it) and some test for ASD severity. Aitken focuses on measurements available to assess someone *with* ASD. It is important to measure and assess the co-occurring conditions (or co-morbidities) with the Person (P) and the Environments (E) and process over Time (t).

- C. Youth, Emergent Adulthood, Adulthood, Aging, Mid-Life, Later Life, Elderly, Senior, Young-old, Old-Old ?????
What do we mean?

Based on our (Wright et al) examination of the literature in journals publishing on autism and aging, there is a need for better chronological differentiation when indicating the sample characteristics. For example, there is a lack of clarity when using terms such as “young adulthood,” “adult,” “adulthood,” “older age groups,” and “elderly.” One of the limitations of a child-centric “lens” on autism is that research including participants older than age 18 are then designated simply as “adult” without much clarification on the significance (or consequences) of creating a “kitchen sink” sample description. Reported age ranges can be quite vast, the mean and standard deviation clearly points to a typical skewed sample of (mainly) twenty years olds—as representing their “adult” sample. Thus, the labels adults with autism or autistic adults or adulthood may be too broad, lack specificity, and potentially discounts the heterogeneity and distinct life-course transitions for the span of adulthood and aging. Increased specificity in what constitutes the age groups will also provide a better foundation for targeted (age-appropriate) services and programs for aging individuals with autism and help to avoid a “one-program-size-fits-all-ages” perspective.

Examples: Emergent Adulthood (which is still controversial) is proposed to capture the new phase of development between adolescence and adulthood – thus capturing age group of 18 to 25. And then Young Adulthood as 25 +

Middle Adulthood 45 to 64? Perhaps. The life course is richly divergent with many pathways and chronological age is often a *too convenient* (e.g., arbitrary) way to indicate life stages – when (and if) we recognize the ecological model as indicating dynamics changes in both the person and the environments to where what was the “received view” (the tradition) is no longer applicable due the rapid changes in the social-cultural milieu, community resources and services, and family dynamics. A heuristic in gerontology goes something like this: whatever we thought aging was supposed, “to be like” at a certain age number (e.g., 55 or 66 or 70) – one may consider adding a ten (10) increment – which in the vernacular – we often hear as “60 is the new 50” – but perhaps we are moving to other reference points for the aging experience?

But then we have (typically) social/institutional benchmarks for the designation of elderly or senior or older adult (and so on) tied to retirement, Social Security, Medicare etc. but all of which are changing too with increasing age points! In this context it may be especially useful to consider old age as involving not one but several life phases and to ask whether these life phases exhibit Different qualities. Proposals have been made, for example, to distinguish between the young old, the old, and the oldest old, and between the Third Age and Fourth Age (Smith, 2000). For example, most demographers and social scientists see age 85 as a distinct benchmark for the Fourth Age and the “old-old” due to observation of significant changes in functioning in aging individuals. What is the “Fourth Age” ? Conceptually it raises an interesting profile as follows: According to Shmotkin et al 2013, it is a theory of *the incomplete architecture of human ontology*. This theory asserts that, “... human development is not programmed to function optimally at the fourth age (about age 85 and older) because the individual’s psychosocial resources (e.g., knowledge, skills, coping strategies), which are acquired and regulated in cultural contexts, become inefficient at this age to fulfill their life-long role of compensating for the natural constraints and omissions of biological functioning.” (p. 719).

The point is the there will be a noticeable and growing need to differentiate and know of the distinct age groupings in mid and later life that reflect the awareness of greater heterogeneity and differences across the life course versus the “kitchen sink effect” of lumping all aging individuals into arbitrary categories such as elderly as everyone over 65 years old. In contrast, the gerontological literature is considering the nuances of aging as highly differentiated within the traditional brackets of aging.

In the flagship journal, *The Gerontologist* - Shmotkin et al 2013 discovered that the ‘Fourth Age’ is fraught with multiple challenges in decline “it may be inferred that the capability of old-old individuals to preserve subjective self-coherence may be jeopardized by unpredictable changes in their destabilized adaptation systems.” (p.

720) – and subjective well-being (SWB) may be placed in jeopardy due to increasing frailty.

As we venture forth and examine more closely the aspects of autism and the aging process, we realize the horizon ahead is closer – to home – but the bridge building and the gap is still under construction. We need to embrace conceptual models and robust theoretical models for the autism and aging that are not child-centric or simply extensions of the first 25 years of life. We need to consider the dynamics of person and environment factors that influence autism aging – within the person, the family, the community, and society-at-large. If we have an interest in age change (not just age differences), then our methodological choices must consider the value of longitudinal studies.

D. Inclusion of Autism advocates in the research process

We must consider the voices of autistic individuals who are aging to be included in the research activities that we engage in --- not just as participants (the sample) responding to the interview or survey, but also as an integral part of “team science” (where possible) in the discovery process (e.g., authors and co-authors) and advisory boards (e.g., community programs) and policy groups. This reflects Wenn Lawson’s connection to “Nothing about us without us” – and to the participatory research work of Christina Nicolaidis.

E. Listen to Gerontology and Geriatrics

As we begin the voyage of discovery of autism issues into the later years, I think it will be critical from a cross-fertilization of gerontological and geriatric fields to be fully engaged with those whose expertise is autism across the life course. There is much to be gained from the insights of aging experts who can share decades of scholarship and practice techniques that related to the challenge and promise of “aging well” or optimal aging with those of us here in the think tank with interest in autism and aging. I will provide two brief examples for our benefit:

Aging with Disability for Midlife and Older Adults, which indicates the progression of persistent disabilities into later life (comparing age 51 and 65) and the all-important “currency” of health status – the ADLs and IADLs – in the gerontological and geriatric domains. My point here: The landscape of aging studies is concerned with the impact of limitations in ADLs and IADLs and the impact on quality of life and well-being – to me this represents a major point of intersection with autism spectrum disorder. There is much in the literature associated with gerontology and geriatrics where those who have an interest in aging and autism – can be begin now – even if we know that the samples in these studies may not include those with autism.

The final example is: “Aging in Place in Every Community: Social Exclusion Experiences of Parents of Adult Children with Autism Spectrum Disorder.” This

article highlights the dynamic issues of autism that expands into the family system (taking into account the bio-ecological model) with the caregiving role into mid and later life. The care recipient is the “adult child” (sometimes gerontology struggles with the right label here in a intergenerational system) and yet the impact on the health and social status of the caregivers can be significant. Policy issues need to review the systemic effects that are both downstream and upstream in a caring relationship – in addition to support for the informal support network.

To build the bridge, fill the gaps – and to set sail so that we can arrive home from our Odyssey – together. This will take team science and team work. Let the bridge-building begin!