Autism, aging, and dementia: A consensus report of the Autism Work Group of the 2nd International Summit on Intellectual Disabilities and Dementia

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Executive Summary

The aim of this summative report is to synthesize what is known about the nature of autism (or 'autism spectrum disorder') and inherent later-age neuropathologies, particularly dementia, and to explore potential genetic, neurobiological, and environmental factors associated with dementia and their effects on the lifespan and lived experience of older adults with autism. This work stems from discussions undertaken during and after the 2nd International Summit on Intellectual Disabilities and Dementia, held in Toronto, Canada, on October 24-25, 2023. Drawing from the research and clinical literature, the summative report examines what is currently known about the intersection of autism and dementia, and those relevant factors that may contribute to the risk for dementia. The complexities of assessing dementia in older adults with autism, particularly when they have co-occurring intellectual disability are noted, along with the best practices for intervention and support among older adults with autism with conjoint age-associated cognitive impairment. The findings of the Summit's Autism/Dementia Work Group include:

*(1) There is limited information available regarding the **demographics** and other factors associated with older age among autistic adults. The available data primarily consist of prevalence studies focusing on cognitive decline. Estimates of the aging population vary, primarily extending from epidemiological studies conducted on individuals in early age or school age populations.*

*(2) Our **understanding of autism** is evolving, challenging the conventional view of it as a static, inherited neurodevelopmental disorder. Recent research is delving into the intricate relationship between genetic predisposition and environmental influences, suggesting a dynamic system of metabolic and immune abnormalities affecting various organ systems, including the brain, which may impact cognitive function later in life. Gastrointestinal factors, such as antibiotic exposure, hospitalization history, and distinct intestinal bacterial populations, are also under scrutiny, although the precise nature of their relationship to autism remains unclear.*

*(3) Previous efforts to **examine aging issues**, including neuropathologies like dementia, in autism have faced significant challenges. Previous work has not provided a definitive understanding of aging and autism or laid the groundwork for studying emergent neuropathologies in older autistic individuals. Challenges include sparse case identification, limited representation of older autistic adults in research, and a lack of emphasis on aging within the autism research community.*

*(4) The **diagnostic** landscape for autistic adults poses numerous challenges and complexities. While classic symptoms may not persist into adulthood, autistic adults commonly face difficulties in social interaction, communication, repetitive behaviors, sensory processing, and executive function, which may evolve with age. Two major sets of diagnostic criteria, outlined in the DSM-5 and ICD-11, are generally used to assess symptoms and their impact on individuals' lives. However, guidelines for diagnosing adults vary, with some recommending multidisciplinary*

assessments, while others suggest relying on a singular experienced healthcare professional.

(5) Assessment of autism shows significant ***sex-based differences****, with the condition less frequently diagnosed in females. Genetic and hormonal factors contribute to this disparity, leading to variations in how symptoms present in girls and women. The commonly cited adult sex ratio of 4:1 is influenced by intelligence levels, with males overrepresented among high-functioning adults.*

(6) The association between autism and ***co-occurring neurodevelopmental disorders*** *unveils a spectrum of genetic or genomic conditions like fragile X syndrome, tuberous sclerosis complex, and Down syndrome, often stemming from DNA mutations or chromosomal abnormalities. Intellectual disability frequently accompanies autism, while epilepsy rates are notably elevated in those with an intellectual disability. Down syndrome presents a variable co-occurrence rate of 2% in the general U.S. population, with an increased risk of dementia attributed to amyloid-beta protein accumulation. These links suggest shared genetic factors and neuropathological changes, highlighting the intricate web of conditions seen alongside autism.*

(7) Research into ***comorbidities*** *among autistic adults reveals a wide range of associated health issues, including seizures, gastrointestinal disorders, psychiatric conditions, infections, skin ailments, and hearing impairments, highlighting the intricate neurological and physiological nature of autism. Genetic and familial factors contribute to later-life outcomes, potentially exacerbating progressive health challenges and cognitive decline. Mental health conditions are prevalent among older autistic adults, alongside age-related health conditions more commonly observed in the general elderly population.*

(8) The link between ***dementia and autism*** *is intricate, with limited research exploring this relationship, especially in older adults, where dementia prevalence is often influenced by co-occurring intellectual disability or Down syndrome. Some autistic adults, especially males, may face an elevated risk of developing dementia compared to the general population. Some studies suggest potential protection against age-related cognitive decline in autistic adults, others indicate associations between dementia and autism symptoms. Key indicators of dementia suspicion in autistic adults include frontotemporal functioning decline, severity of behavioral and psychological symptoms, increased stereotypical behaviors, and heightened compulsivity. Understanding this complex dynamic is hindered by overlapping symptoms, communication deficits, limited verbal expression, and atypical presentation of dementia-related symptoms.*

(9) The association between ***autism and certain types of dementia*** *remains complex and largely unexplored. While autistic adults under 65 show a 2.6 times higher likelihood of early-onset dementia, no direct link with Alzheimer's disease has been established. These early-onset findings may encompass various forms of dementia. Speculation on a potential bio-neurological relationship stems from shared brain changes in both dementia and autism, with autism exhibiting structural differences and dementia causing brain damage affecting memory and communication. Some studies suggest a genetic connection, while others explore lifestyle factors like diet and exercise as potential influences.*

(10) ***Mortality patterns*** *among autistic adults reveal nuance. While mean age at death closely mirrors that of the general population, exceptions exist for those adults with significant comorbidities. Mortality rates vary based on functioning level, with higher rates among those with both autism and intellectual disability. Sex differences are notable, with females typically outliving males, yet males with autism show a higher likelihood of dementia on death certificates. Autistic adults are less prone to Alzheimer's disease or dementia as a cause of death, although sex-specific disparities persist. Epilepsy emerges as a prevalent cause of death in severe autism, contrasting with circulatory diseases in milder cases. Lifestyle and social factors, rather than genetic elements, are implicated in the higher mortality rates observed in autism.*

(11) ***Risk factors*** *across social, individual, environmental, and biological domains significantly influence health outcomes, with their intersectionality critical in addressing health disparities. Research frameworks for health disparities emphasize both biological (like allostatic load and inflammatory*

response) and sociocultural factors (such as stigma and bias). Allostatic load, a response to chronic stress, may play a role in physiological dysregulation and accelerated aging in autistic adults, akin to the 'weathering hypothesis'. The interplay of these factors illuminates health challenges in autistic adults, including accelerated aging and immune system dysregulation. A holistic understanding of chronic health challenges in aging autistic adults necessitates considering both biological and sociocultural factors.

(12) The relationship between ***intellectual disability and dementia*** *in autistic older adults presents a complex and underexplored area of research. Studies highlight a higher prevalence of cardiovascular risk factors among autistic individuals, especially those with co-occurring intellectual disability, such as obesity, diabetes, and hyperlipidemia. Research also suggests increased odds of neurological disorders, including dementia, in autistic adults with intellectual disability, possibly influenced by comorbidities rather than a direct outcome of autism itself. While the link between autism and dementia is less evident in cases without intellectual disability, shared genetic and neurobiological factors, particularly in forms like frontotemporal dementia, are indicated by research.*

(13) Studies indicate that approximately 16–18% of individuals with ***Down syndrome*** *are also diagnosed with autism, with this population exhibiting a higher likelihood of various dementia-associated issues, like epilepsy. Despite known neuropathological changes linked to Alzheimer's disease in adults with Down syndrome by age 40, there is a lack of dedicated research on dementia in this mixed population. Overall, while the coexistence of Down syndrome and autism is acknowledged, any increased risk for Alzheimer's in adults with both conditions is primarily attributed to co-occurring Down syndrome rather than autism.*

(14) Studies highlight the intricate relationship between autism, ***cognitive health, and cognitive decline*** *in adulthood. Diagnosing dementia in autistic adults is challenging due to overlapping symptoms with psychiatric or neurological conditions. There's a significant association between autism symptoms and late-life degenerative dementia, especially in early-onset cases. Adults with mental disorders, including some with autism, face an increased risk of subsequent dementia. Elevated rates of cognitive decline are observed in middle and older age autistic adults without intellectual disability, suggesting a potential neuropathological link between autism and cognitive deterioration. Overall, older adults with elevated autistic traits may encounter greater mental health challenges, with difficulties persisting and potentially worsening over time.*

(15) Autistic individuals often experience heightened levels of social isolation and ***mental health issues****, leading to comorbid mood and anxiety disorders. However, the manifestation of behavioral and psychological symptoms of dementia in autistic adults remains unclear. The co-occurrence of Down syndrome, which increases the risk for Alzheimer's disease, further complicates the situation. Changes in anxiety, sleep disturbances, apathy, and depressive symptoms in individuals with Down syndrome may indicate the onset of Alzheimer's disease and conversion to dementia, often accompanied by increased aggression or destructive behavior. In autistic adults with Down syndrome, heightened verbal or physical aggression may serve as additional indicators of mild cognitive impairment or early Alzheimer's disease.*

(16) Research suggests a notable connection between ***autism and frontotemporal dementia*** *(FTD), though causality is not established. Some studies indicate potential overlap between behavioral variant FTD (bvFTD) and autism, with similarities in symptoms. Neuropathological evaluations reveal increased tau and neurofibrillary pathology in the frontal lobes of those showing autism-like behaviors in late-onset dementia. Despite challenges in bvFTD diagnosis, biomarkers may offer diagnostic clarity in the future.*

(17) Data do not indicate a clear increased ***risk of Alzheimer's disease*** *in individuals with autism, but some studies suggest a higher prevalence of other forms of dementia, such as behavioral variant frontotemporal dementia. Understanding the risk factors for dementia in autistic adults is still developing, with genetic, neurobiological, and environmental factors playing complex roles. Further research is needed to better comprehend the precise mechanisms underlying these associations and to elucidate the intricate relationships among these factors.*

*(18) Certain **medications** used for Alzheimer's treatment have shown promise in addressing dementia-related symptoms in autistic adults, particularly behavioral symptoms like irritability. However, further research on treatments targeting Alzheimer's disease is needed due to the lack of approved autism-specific medications. Caution is advised when considering use of emerging anti-amyloid drugs for autistic adults with mild cognitive impairment or early-stage Alzheimer's dementia, especially in those with Down syndrome, due to potential adverse effects and lack of specific safety studies.*

*(19) **Diagnosing dementia** in older autistic adults, particularly those with intellectual disabilities, poses significant clinical challenges due to the complex interplay of cognitive, communicative, and behavioral factors inherent to these conditions. Diagnosis is complicated by the overlapping symptoms of autism with other mental health disorders, further complicating the assessment process. Standard dementia assessment tools may not be suitable, necessitating comprehensive evaluations that consider sensory sensitivities, anxiety, and unconventional communication methods. Tailored approaches are needed to address communication difficulties and behavioral obscurities, requiring a multidisciplinary approach and input from various sources. Longitudinal assessments and frequent monitoring are essential for identifying subtle changes indicating the onset or progression of dementia in autistic adults. Advances in blood biomarkers and neuroimaging will be even more critical for this population and reasonable accommodations should be implemented to support individuals engaged in these investigations.*

*(20) **Caregiving** for older autistic adults with dementia presents diverse support needs, ranging from minimal assistance to extensive care, either at home or in supervised housing. Caregivers encounter various challenges, including difficulties in finding primary care providers, navigating patient-provider communication, managing anxiety, addressing stigma, and considering cultural and ethnic dimensions of dementia care. The mental health impact on caregivers is considerable, with higher levels of stress, anxiety, and depressive disorders compared to caregivers without autism-related responsibilities. Recognizing the importance of respite care, which offers crucial temporary relief for caregivers facing the physical and emotional strains of caring for individuals with complex needs, is essential.*

*(21) While home caregiving remains an option, alternative living arrangements such as dementia-capable apartments or **group homes** offer supervised support and specialized care for some autistic adults with dementia. Adapting group homes for dementia should involve addressing sensory issues. Individualized dementia care planning is crucial, necessitating tailored care plans, as well as providing supports and staff training. Longitudinal studies are recommended to improve understanding and identify effective living setting accommodations.*

*(22) Autistic individuals commonly face **sensory sensitivities** that significantly affect their well-being. Tailoring sensory modulation techniques and creating sensory-friendly environments can enhance their quality of life. Dementia care settings can be adapted, focusing on minimizing triggers like strong smells, bright lights, and noise. Providing ample personal space, visual supports, calming colors, and reduced noise levels are crucial accommodations.*

*(23) Autistic adults need **structures and routines** and in the context of living with a dual diagnosis of dementia and autism it is often particularly challenging for the individual to hold onto structure/routine and sharing living space with others can be particularly challenging. Environments need to respond to this need and education/training of staff/family caregivers needs to consider this cumulative complexity.*

*(24) **End-of-life planning** is crucial for ensuring comfort and dignity, particularly in the later stages of dementia and what guidance for advanced dementia exists applies equally to older autistic adults. For autistic individuals, comprehensive end-of-life care should include palliative and hospice care.*

*(25) In essence, **global initiatives** like the WHO resolutions and NICE guidelines to enhance autism support are noteworthy. These should lead to coordinated efforts to address gaps in early detection, care, and treatment. These include government commitments to aid autistic adults with dementia, strengthening the workforce, and creating inclusive environments. Key aims for post-diagnostic dementia supports stress timely identification and emotional*

wellbeing, as well as access to medical/health care, non-institutional residential supports, and adaptive environments.

*(26) It is recognized that many **gaps in research** persist, particularly regarding the impact of autism on aging and dementia, underscoring the need for broader investigations tailored to autistic individuals' unique characteristics.*

The intersection of intellectual disability, autism, and dementia presents a complex array of challenges influenced by genetic, neurobiological, and environmental factors. A holistic, person-centered approach is essential for providing optimal care tailored to individual needs. Prospective, longitudinal studies are needed to understand aging in autism comprehensively and evaluate interventions for diverse sub-groups of older autistic adults. Research gaps include understanding social isolation, living arrangements, and dementia epidemiology, as well as educating healthcare providers and developing health programs for autistic individuals. Additionally, exploring neuropathology, cognitive aging trajectories, and the relationship between autism and dementia mechanisms are crucial areas for further investigation. Further research should also address methodological expansion, including varied research designs and larger sample sizes, to enhance our understanding and improve outcomes for this vulnerable population.

Statement on Autism and Dementia

The prevailing viewpoint, derived from current research, is that there is no overarching basis or foundation supporting a notable increased risk for any specific form of dementia in individuals with autism. As individuals with autism age, akin to the general population, some may undergo assessments and receive dementia diagnoses; however, such cases do not seem inherently predisposed to any specific brain disease genetically or otherwise. It is worth noting that adults with co-occurring conditions, such as Down syndrome and some intellectual disabilities, exhibit elevated risk markers, potentially leading to higher rates of clinical dementia in older age. In acknowledging this, the 2nd International Summit on Intellectual Disability and Dementia underscores the impact of social determinants of health, adverse life experiences, and stressors in compromising cognitive health during later stages of life, potentially influencing cognitive decline and premature mortality. However, the research is still incipient and inconclusive regarding whether such factors determine early, faster, or worse dementia outcomes in autistic adults in comparison to the general population. The Summit supports evidence-based practices to enhance social competencies, commitment to healthy lifestyles, and provide living supports that enhance personal capabilities, whenever consent and choices are sought, minimizing exposure to unsafe environments and risk-heightening behaviors, and encouraging adherence to life practices that promote mental and physical health wellness.

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